Bi-Racial? Disabled? Blended? Acceptance Of Children "Not Like Us" But Who are "Part" of Us

“There is no hope unmingled with fear, and no fear unmingled with..."
"Only that thing is free which exists by the necessities of its own nature, and is determined in its actions by itself alone." -- Spinoza
Diversity training has begun on the popular airwaves. CNN’s Black in America, with Soledad O’Brien, aims to express the many sides of living as a black or bi-racial person in North America. Watching it, I see a similar theme that may be helpful for parents with autistic children. It is the comparison of being black and having a white child or vica versa. It is the experience of a parent without any disability or experience of it, who has a disabled child. If our children are "not like us," then who are they? To which community do they belong?

I believe it is one of the major sources of tension out there -- why the "recovery" movement is so strong, why acceptance is so difficult. While not accepting the status quo is great in terms of pushing for acceptance and inclusion of disabled individuals, it is not that helpful when the movement takes a turn to fundamentally change the individual's genetic make-up -- to say, in essence, there's something ill, or wrong with you. You are sick and we have to fix and heal you. If we don't, your life will be hard. We've heard it many times -- there is a strong movement against calling disabled people ill. The medical model doesn't fit the human model. While medicine can help us feel better, it can't take human difference away. If it tries, it can't be successful. I'm one who believes that any "progress" in science will see its regression too. In other words, not only will there be ethical problems, but with every seeming "advance," there is also an antithesis. With the advent of our lives being extended, for instance, we have more disability -- this is not to say that disability is wrong, however, with the extension of our lives, it is natural. If you are religious or believe in God, one might say that only God knows why he creates
what he does. If you are secular, you might believe that there is meaning, value and importance in the grand scheme of things, and that is still, perhaps like God, ineffable.

I believe that some of my family members have strong autistic traits. My father did not speak until he was six years old, for instance. He became an engineer and has exceptional eye for technological detail to the point of losing others when he talks about it. It is his obsession (sorry dad, but I think you are a brilliant). I crave alone-time and privacy and am much less social than my husband to the point that I think others may not understand me (I prefer to communicate more in writing and am not as reserved when I do so). As a child I used to play alone for hours and would twirl until I passed out (Adam does not twirl). I found idle chatter highly uncomfortable yet as I’ve become older, I’ve become better at persevering small talk. Like Adam, my obsessions have been words and letters. I invest in art with words in them or art that looks like it has been written upon. I am a big fan of Cy Twombly. I collect scrabble letters and typewriters. Because of Adam, my interests and habits have become more obvious to me.

So, I guess Adam, who is autistic in a non autistic family, really does belong. We share the same physical features. We even share personality attributes. Yet, he has a label and I don’t (which may suggest the nature of labeling and why so many people cringe with labels -- they can help AND hinder). He is "autistic," while the rest of his family "is not autistic." He has a community that organizes conferences for and by autistic people. I cherish that for him. Maybe in a way, I even envy him. For the communities who must really stand and stay together become the strongest. I do not fully belong save for being his strongest ally.

Some people get offended when they hear "autistic person." Some prefer "I am a person with autism." Without re-hashing this debate too much about person-first language, I don't think it matters how we put it. It's the manner in which we put it -- the tone of our voice, and the way that that tone reflects how we feel about people, the words we put alongside autism. It matters that we all recognize that we are all the same despite our differences. We are all equal, even though our contribution and output may manifest differently. We all have the same rights, even if one person is less independent than another. It doesn't all fit into a nice
As such, I like the comment made on the CNN blog about pride. Autistic pride, gay pride, we all know why those movements have had to spring into action: because there has been too much medicalization and stigma of both, and a need for society to become familiar with the paradox of difference and same-ness. There is no "other." There are only variations of ourselves. So I found the hundreds of comments on this series really interesting in the context of diversity, pride, but most of all this sense of which culture do we become loyal to or do we identify with? In my view, why can't we belong to more than one?:

Lynn Whitfield
Actress

My daughter Grace and I watched the premier of CNN's groundbreaking “Black in America.” I thought we would have lively discussions around many of the themes concerning black women in this country. However, when she saw the segments on interracial marriage and the children of those relationships, she had a visceral response.

I saw an activist being born.

Grace seemed ready to adapt James Brown’s black anthem to her cause: “Say it loud, I'm blended and proud!” I saw my daughter stand up for the equality of blended people like herself in all her olive-complexioned, big curly afro-like glory. She went immediately to the computer with dignity, passion and everything but a fist in the air...

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As a parent of biracial children, it feels really good to read such an article. That's exactly the way I want my children to be about their heritage: proud of both!

It is definitely unfortunate that you have to make a choice between different races. There are still a lot of administrative papers which do not have an “Other” section. Very confusing for the parents and children.

But after all, aren't we all from Africa anyway?
I am proud of having a child with autism/an autistic child. I believe that being autistic forms an important part of his experience with the world around him -- both from a sensory point of view as well as how he will be treated and regarded by others. He will grow a natural sensitivity to this and his ideas will be shaped by it. It is why I say that he is an autistic person. Jenny McCarthy, because she thinks autism is a disease, and is afraid of it like cancer, is appalled at the notion of calling a child autistic. I see her view as a denial of our children’s right to be who they are and accepted for that. I personally think it is wrong for a parent to think disability, or autism, is a bad word. I think the disability community, much like race, do not identify with the cancer comparison in the sense of being ill, however, it is interesting to me, after being through a stage one cancer experience myself this year, that people with cancer will identify themselves as being "cancer survivors" in order to explain who they are by virtue of their experience with cancer. Going through cancer, as my mother and I can attest, indeed shifts something within you. The experience forms who you are. And I don't see the problem with that.

I want Adam to be proud of himself as he is. He is part of a family who shares very many of his traits --inward and outward -- yet he also appears different in the way he expresses himself and moves. Autism may be similar to the experience of being bi-racial or "blended," if you will. Autism is a part of all of us.

Yesterday, Adam sat through the entire movie, E.T. Watching with him made me either believe Steven Spielberg is really autistic, or that the man really gets it. Usually, Adam can get into 30 minutes of a movie, and he's off doing something else. Yesterday, he would watch, then giggle, then roll around the couch, then snuggle with me -- enough antics to make many adults think that he couldn't have been really paying attention, but I could tell he was. There were also moments when he would repeat the lines. He would watch the screen and be still. Therapists tend to use the same stories over and over again to assess an autistic person’s comprehension of a story. And yet, when Adam sees something new, or more complex than people thinks he will understand, he really gets the gist of things. This typed conversation I had with him yesterday illustrates this:
Me: "Adam, I really enjoyed watching the movie with you today.
Adam: i like toad.
Me: what was the alien's name?
Adam: et
Me: E.T. had lots of feeling and a very big heart. E.T. had lots of love for others.
Adam: Et was the guy yes
Me: E.T. could hardly speak. In a way, E.T. is like you. He understands but finds it hard to talk.
Adam: E.T. was question
Me: Do you think you and E.T. are similar?
Adam: E.T. was the want
Me: What is want?
Adam: E.T. was the want to speak.
Me: E.T. wanted to be able to communicate. What else did E.T. want?
Adam: et wanted to go away.
Me: Where did he want to go?
Adam: home.
Me: yes, we all want to be home and be with people who are like us.
Adam: i people."

Indeed he is people, a person. Adam is Adam and he is all of us.

PERMALINK POSTED BY ESTEE KLAR-WOLFOND AT 7/27/2008 12:02:00 PM
12 COMMENTS LINKS TO THIS POST

SATURDAY, JULY 26, 2008

A Note About Crying to Michael Savage

I was very disturbed and concerned last week, as most of our community was, when I heard of Michael Savage's remarks on radio. As you can read in yesterday's post below, he suggested that autistic people are faking it, that the kids are crying as a bad behaviour instead of recongizing what that behaviour might be communicating.

Today, I have an example of something Adam has written and how I must try and understand what he is trying to tell me. I can do so by watching him and I usually think I can understand, but also,
because he can, we practice his typing. Of course, when autistic people are distressed, communication is more difficult. Nevertheless, I gently prod Adam to try and tell me what he means. For weeks now in the summer he has been typing "red jar." Because he's been using it over and over again, I was trying to learn its meaning. I found out today:

Me: Why are you crying?
Adam: I am crying read in red on red
Me: That is difficult for me to understand. I wonder if you can explain what red means when you write it?
Adam: red means to cry yes.
Me: What were you crying about?
Adam: in red jar
Me: So do jar and red mean to cry or be upset?
Adam: feel too hot.
Me: Oh yes! It is very hot and humid outside today. Were you very hot on our walk with Kiki?
Adam: yes
Me: Would you like anything to eat or drink before mommy takes you out?
Adam: is ready a party
Me: Mommy is taking you out for lunch.
Adam: to ears is eat.

So, I learned that all summer Adam's use of red jar means likely his feeling hot. The air is humid, so maybe he links that with the jar. I have to inquire more. Also, I liked the way he said "to ears is eat." I took that to mean (and the receiver must always acknowledge their own way of knowing and understanding meaning), it sounds like we're going to eat.

Savage said autistic kids are just brats. Imagine Adam being viewed, as he tries SO hard to communicate his needs and desires, being treated like a brat! I really think the brat is Michael Savage for accusing autistic children of this. He makes our lives more difficult.
Beyond Surviving The "Savage" Hurricane Season

It feels like we are in the eye of the storm. While I might say I hit a personal one with cancer earlier this year, at least that part is over and Adam and family are having the best summer on record. But we are really too close for comfort. As you can see from the images above that I took from Florida, tornados and hurricanes are close at hand.
Michael Savages out there or not, there is something about sustaining advocacy, and being able to rise above despicable remarks. It's like any other prejudice out there be it racism, anti-semitism and that continues to oppress others and segregate -- we know ignorant people will exist, that they do exist. We know someone has always wanted to get rid of Jewish people and we know facism still marches to its own drum long after Hitler's "reign" of terror. Yet, we must put the SAVAGES in the spotlight lest we ever forget how easily we can give over our own freedom and power. It is why groups exist to ensure that we never forget.

Today, ASAN and other organizations including The Autism Acceptance Project released Outrage over Michael Savage's Remarks Grow: ASA, UCP and The Arc and many others join the disability community's joint statement:

We, organizations representing people with disabilities, family members, professionals and other concerned citizens, are calling upon you to withdraw support for Talk Radio Networks in response to the outrageous comments by TRN personality Michael Alan Weiner, also known as Michael Savage.

On July 16th, Weiner announced: "Now you want me to tell you my opinion on autism since I'm not talking about autism? A fraud, a racket...You know what autism is? I'll tell you what autism is. In 99 per cent of the cases, it's a brat who hasn't been told to cut the act out. That's what autism is. What do you mean they scream and they're silent? They don't have a father around to tell them 'Don't act like a moron. You'll get nowhere in life. Stop acting like a putz. Straigten up. Act like a man. Don't sit there crying and screaming, idiot."

These comments represent dangerous misinformation. The refusal by Talk Radio Networks to condemn the comments or undertake any steps in response to them, as well as Michael Savage's refusal to apologize, is absolutely unacceptable. The autism spectrum is a very real developmental disability affecting millions of Americans [and Canadians]. It includes a series of impairments in social interaction and communication, executive functioning, sensory processing, and motor
Adults and children on the autism spectrum often require substantial supports and services and education across the lifespan.

Comments like those on the Savage Nation do real damage to autistic people by increasing public ignorance and misinformation about autism, thereby putting at risk vital education supports and services. Contrary to the remarks by Mr. Weiner, there is no evidence whatsoever to suggest that autism is over-diagnosed -- in face, research suggests that there is substantial under-identification of the autism spectrum, resulting in lack of vitally needed services and education. In addition, these remarks revive outdated and damaging misconceptions about the source of autism, recalling the "refridgerator mother" myth in which parents were blamed for having autistic children.

Talk Radio Network's sponsors must consider whether or not to associate with the hateful and offensive comments spoken by Michael Weiner. Because TRN has taken no action, we urge you to communicate the need for Mr. Weiner's immediate removal by withdrawing sponsorship for TRN's programming. There are over 50 million people with disabilities in the United States representing approximately $200 billion disposable income. We represent a market that cannot be ignored. By disassociating your businesses from the ignorant and hateful remarks made this past week and taking practical steps to help educate the public about the true nature of the autism spectrum with other disabilities, we can move forward towards creating a world that will recognize the rights of all people to respect, dignity, support and inclusion.

Ari Ne'eman
President
The Autistic Self Advocacy Network
www.autisticadvocacy.org

While an advocating Adam and family enjoy a first real quite a summer, he has also enjoyed camp every day. It's not an autism camp -- just a camp he goes to with other kids...talk about social skills.
skills! Adam is the most popular kid of the juniors! Imagine that for a child who can barely speak. Imagine the children who are evolved enough to understand him.

All the kids want to be with him, and as a mom, I am stupefied in sort of a proud and delirious way. Adam arrives home and swaggers with confidence -- the kind I want to bottle up and give to him for the rest of his life. Have I contributed to that in any way? Or has Adam given me the joy and strength I am experiencing? One thing I know for sure is there is one message I want to give him -- life is too short to waste on people who don't care about you. I hope he can have that confidence which is the kind that can make one a strong self-advocate. I also want to bottle the essence of child-like acceptance and give it to every person he encounters throughout his school years. So, I am working towards that -- I am about to announce an major inclusion initiative we are undertaking with another agency here in Toronto.

While keeping you on edge for a little while longer, though, Adam came home this week with his first-ever award. He was given **The Best Effort Award**.

I tend to think those are the best awards. You can win easily, or win with tons of effort. The person who has put in the tons of effort is the one we ought to celebrate.

Adam also returns home with a printed piece of paper with his certificate that reads, "Adam is always smiling and laughing during the camp day. His attitude is so positive towards campers and staff members. He loves to go to arts and crafts so that he can show off his wonderful creative side, and make wonderful pieces of art!" And aside from this his swim instructor wrote, "Adam's confident and easy-going attitude has made him a pleasure to teach...Adam is a lively, happy swimmer in our swim class..."
Mr. Weiner's remarks, as many of you have said, indeed lived up to the Savage name. Savage is primitive -- lacking in evolved intellect and robust with an ignorance that suggests he has never met the Adam's of the world, our autistic children, who need our love and support. Yet, as you see Adam below learning how to build with his grandfather, autistic people are able people too. The savage storms swirl, and yet, here we are. Adam for one, is the gift who keeps on giving.
Hi everyone,

Aside from working on a major project which will be announced, Adam and I have been having too much summer fun to write. However, I do wish to advise that our TAAProject website (www.taaproject.com) is temporarily and accidentally down. We don't know if we will be able to fix it quickly. Please be patient. We may have to rebuild it.

The Autism Acceptance Project Website

Fits and Starts

Yes, that's how I feel my recuperation has been. After a wonderful week in San Diego with Dad of Cameron, Autism Diva, One Dad's Opinion and Asperger Square 8, and the folks at University of San Diego, I came home, picked up Adam and we headed to a hot and sticky Florida to be awestruck by the possibility of Bertha hitting Miami. Then, we left. Adam has been having a terrific time at camp. He is the best swimmer of his class, and he is the favorite friend. So I hereby state that it's totally possible that kids can be "social" even without language!!

I am loving watching Adam get on the school bus, or strut back off after his first long days at camp (they used to be half days but now they go 9-5). He is totally happy. His friends also think that he's "very smart." Fancy that for a kid who can't respond typically.

So, while I got caught back in bed with threatening pneumonia again (which is why I don't write much), I want to share the "phenomena" with those out there who don't believe that non verbal autistic children are social or intelligent.

I am catching it all too -- on tape. And once I can figure out how to...
Despicable

To whomever wrote to Adam on his blog, you are the reason why I chose to privatize it. I thought that so far, everyone has been so kind to him, but I was waiting for the day that someone like you would show up...sad but true.

How dare you call my son's words "gibberish" and if I ever find out who you are, I will hunt you down. And yet, cowardice hides behind the veil of anonymity -- so should I waste my effort or shine a spotlight on you -- no better than the dirty, scurrying cockroach? As such, you are a coward to pick on a little boy's words.

Such comments from adults to children are NOT acceptable, and it such doubt of autistic individuals that confront them every day. It is not fair to children like Adam who work so incredibly hard to communicate.

If you have something to say to me, I am fully armed to take it. He, however, is not. An autistic child is still a child. No more, no less.

For our loyal and supportive readers, be not discouraged. I have to do what I have to do as Adam’s mother. However, we can invite people who choose to email us and reveal something of themselves, to read his wonderful blog. The whole point of course, is to share and celebrate our successes with one another -- to touch and encourage each other. In the end, to value what we all do offer. Who knows, it may go public again once my rage dissipates.
Laughter at the Airport

I am sitting in the San Diego airport waiting to go home and see my family that I miss. As I take a look at what happened over the past week, I stumble over San Diego Fox News, where I burst out laughing at what I see -- photo of me in my worst possible state after major surgery in the hospital with Adam this past May.

I can’t wait to tell you more when I return home about the fabulous Autism Hub bloggers I met down here and the wonderful folks in San Diego.

At least I'm laughing and happy. I caught my cancer early, I will survive, I made it to the conference, and I have a happy and healthy son.

Ah, the laughter... the joy.

San Diego

I'm in San Diego -- the Work With Me, Not On Me -- and I must say that I'm really enjoying meeting many other Autism Hub Bloggers here: Autism Diva, Asperger Square 8, One Dad's Opinion and Dad of Cameron.

We've all been busy presenting, and Steve and Bev have been on the radio which you can here hear by clicking on this link.

Today, Adam graduated Senior Kindergarten (Pomp and Circumstance and all), and my family has been sending me so many photos. I hated to miss it, but while I'm here, I know I'm also speaking for Adam's future. I delivered my Mismeasure of Autism: The Current Basis of Autism "Advocacy" presentation which is being published this July in Wendy Lawson's Concepts of Normalcy: The Autistic And Typical Spectrum. The
audience has been really interested, asking great questions and I must say that the reception at the autism conferences lately has been very refreshing.

In the meantime, Adam and I are sending SMS messages to each other. As he doesn't like the phone, we've found a new way to communicate. We found yet another way to adapt.

FRI DAY, JUNE 20, 2008

He Did It!

"We Jews, we dance," said Elie Wiesel in a speech he gave in Toronto just over a year ago now. I had the honour and privilege of meeting him in person. He was talking about how exactly BECAUSE of tough times, is reason to celebrate good ones. This is a philosophy I don't take for granted. Adam has just graduated from Senior Kindergarten and will be going into Grade One in September.

"It has been a tremendous joy to work with Adam this term, and to be a part of his progress. Adam has exploded into independence...the greatest achievements Adam has seen in language this term have been in the area of self-expression. The work he is doing in and out of the classroom with his device has built his confidence and allowed him a very important and impactful release," says his report card. Adam goes to an inclusive school -- not special ed, not an autism school, not a contained classroom or a partially integrated setting. Adam is also "classically" autistic.

The tough times for us seem to have been society's view of Adam, and schools adopting that exclusive, medical perspective of autism. Adam's challenges came from early pre-schools that didn't understand him and thought he had to develop just like other children. That was frustrating and emotionally debilitating for us all. Yet, we kept seeking loftier goals. We never believed in "NORMAL," and resisted many temptations to work "on" Adam to make him such. It never would have happened anyway. When we tried (in our early intervention days), Adam cried a lot.
In his book *Enforcing Normalcy*, Lennard Davis said, "before the early-to-mid nineteenth-century, Western society lacked a concept of normalcy. Indeed the word *normal* appeared in English only about 150 years ago, and in French fifty years before that. Before the rise of the concept of normalcy, there appears not to have been a concept of the normal; instead the regnant paradigm was once revolving around the word *ideal*. If people have a concept of the *ideal*, then all human beings fall far below that standard and so exist in varying degrees of imperfection. The key point is that in a culture of the ideal, physical imperfections are seen as not as absolute but part of a descending continuum from top to bottom. No one, for example, can have an ideal body, and therefore no one has to have an ideal body..." (pp. 100-101)

And so, we dance, we celebrate Adam's being, his achievements. We congratulate everyone who has assisted us in enabling him and his own personal success. I cannot imagine the world without Adam as he is. Our world has oversimplified the state of being human and to support this, I would like to direct you now to listen to Harriet McBryde Johnson who talks about disability and the notion of "the cure." Harriet McBryde Johnson brought a disability rights perspective to bear on issues raised by the Museum's Deadly Medicine exhibition. This podcast comes from United States Memorial Holocaust Museum.

**Reference:**


Proud Mom

School is almost over and camp is soon to begin. In closing the school year, Adam did a timeline of his life which you can view on Adam's own blog here.
I am swelling with pride for all the hard work he has done and I am that he's had a wonderful year at a truly inclusive school. Every day Adam always looked forward to seeing his friends there and started initiating "peer interaction." (I don't like using over-used terms, as they come to reflect what is otherwise known as "appropriate peer interaction" as opposed to simply peer interaction that may appear atypical -- or of peer interest that may appear atypical to onlookers).

I also verified this year that Adam's verbal communication cannot reflect what he thinks and how sophisticated he is. For instance, if I have a family albumn, he may say "dog" for daddy, deferring to an easier "d" word he knows. However, if he labels them with the written form, he can match names to his family members easily.

It's just an important point I want to make. Speech is not always as reliable as text.

What Can We Learn From "Jerry's Kids?"

What can we learn from Jerry's Kids? A lot, I'd say. How often do we hear relentlessly over and over again that so-called "high functioning" people do not have a right to talk for all autistic people as if they are "taking away services" rather than adding to better the quality of life for everyone?

Here are some myths that need dispelling yet again:

1. A non verbal person can often read. These are people often called "low-functioning," but they can often learn to communicate via augmentative communication methods. Very often, these possibilities are not tapped because behavioural interventions are sought first -- the typical response is sought instead of enabling the autistic response;

2. Some parents call their children low functioning when they are higher functioning than my son Adam. I've heard parents in the beginning of our journey who said they would "institutionalize"
their child who could talk more than Adam could. Some call their children non verbal even though they speak fluently, because they may have trouble with following directions. This is mis-labeling, so we cannot trust the use of labels used by many advocates;

3. We should not assume that "richer" people have more access to services and therefore can "cure" their children easier. Yes, one can hire private shadow support, and other therapies, but do not assume that a person who has more resources does not want to advocate for full inclusion and support of autistic people, and make this accessible as a right for all. At the same time, "richer" people have also wasted a lot of money on "therapies" that have not enabled their children to the fullest extent;

4. Biomed autism advocates like Jenny McCarthy's TACA group need and use "higher-functioning" autistic people in their statistics to try to prove there is an "epidemic" on the one hand, while stating on the other that they are not "severe" enough to speak for autistic people.

Okay, I could go on with the hypocrisy, but it's better to show than to tell. Visit the website http://www.thekidsareallright.org/, for a little history lesson on "Jerry's Kids." Watch how some disability rights advocates are blamed. Sound familiar to autism???

The movie trailer can be watched here. When you watch it, you'll understand why I don't walk for Autism Speaks.
don't listen to autistic people. I am continually surprised that an
African-American woman reporter, who might remember a time
when the Black Civil Rights Movement was considered extreme,
would call autistic people "ill" even though she interviewed them. I
was equally surprised when Diane Sawyer of ABC, asked
rhetorically, "isn't it [acceptance] a beautiful way of expressing
heartbreak?"

Well, no. I can't say that I am heartbroken in the least as a mother
of a truly, classically autistic child -- a child who struggles with
sensory issues and anxiety, but who is otherwise fully capable of
learning. If I were heartbroken, our lives would truly be miserable,
wouldn't it? I mean, what part do we parents play in feeding into
stereotypes and how must we become so hypersensitive to these
stereotypes so that we can give our children better opportunities
than they have today?

What part does the medical profession play in pathologizing
disability to such an extent that we are faced with the challenge of
making real systemic change -- because our systems are based in
the medical model, not the social model of disability? In other
words, when will the public begin to listen to autistic people and
not cast them aside as a minority group in this present
environment of heavy oppression that weighs upon autistics, and
on my mind, like the thick humid air of a Toronto summer?

ABC may be hearing, but it ain't listening. That kind of report that
I saw in the clip was akin to saying that well, "you're Black...you
really don't want to be White? We just can't understand why you
wouldn't want to be White! You must feel terrible. You must be
suffering because you are Black and not like us." Sigh. I guess they
just find it so terribly hard to believe, intrinsic in those who like to
admire their image in the crystal-clear water.

I have been interviewed lately (to be announced) and I am struck
by the repetition of the questions regarding "the cure," and the
relative comparison to the severity of disability and challenge,
which tells me that there is a conceptual gap that hasn't yet been
filled. In large part, the public can't get there so long as the medical
model of disability reigns supreme and the social model is ignored,
or is falsely perceived to be lead by a small band of "extreme"
disability activists, or people who are, as Thomas Insel called us, "a
nuisance." I mean come on! There are eighty million disabled
people in North America, and our scientific discoveries, while making us live longer, will likely have many of us becoming disabled in our lifetimes.

In an era when an African American man has finally received an opportunity to become President of the United States, we really should all be shocked that justice for the disabled remains elusive; that in the wake of acceptance of diversity as an overall ideology, 'neurodiversity' is scoffed at and ignored as trite; or that our educational systems remain as segregated today as were water fountains, schools and buses were for the "Negroes" or "Colored People."

No, today we live in a world where paradox reigns supreme, where everyone is a unique hypocrite, and where no one really listens to each other to really SEE that we do all want pretty much the same things in this life. However, equality does not mean that we keep paying the gatekeepers.

No one wants to be isolated, and yet, autistic people are some of the most isolated individuals today. Not because they do NOT want to be social, but rather, because "this isolation is indicative of existing social barriers experienced by adults with autism. Kudlick traces some of the different definitions of autism throughout the medical history. In the end, this article "casts disability as not just another 'Other,' it reveals and constructs notions of citizenship, human difference, social values, sexuality and the complex relationship between biological and social worlds." (Kudlick, 2001.) The idea that disabled people are viewed as different alone, can further emphasize inequality and segregation and discrimination that goes against social justice.

There might be no greater paradox than the public school system itself. Schools are a major social system of society. If there were any just policy shift, there would be no barriers to inclusion. Jenkinson argues that, "inclusive education is founded on the premise that all children, regardless of disability, are capable of learning and should be given the same opportunities to achieve, through learning, to the best of their ability." (Jenkinson, 1997) UNESCO, which the Ontario Board of Education is attending to, in the Salamanca Statement, says "regular schools with this inclusive orientation are the most effective means of combating discriminatory attitudes, creating welcoming communities,
building an inclusive society and achieving education for all." (UNESCO, 1994). Yet, the IEP, and the IPRC process here in Ontario, (*The Identification, Placement and Review Committee Process for Students with Autism*), leaves much to be desired in the process to such equality and inclusion. Instead, children are placed in contained classrooms or are partially integrated. The entire process is solely based on the medical model of disability, as parents wait and rely on prejudiced therapists and clinicians who maintain these barriers. Let us not forget to mention as I have numerous times, that NO policy board on autism in our school system has ONE autistic person on it. These are the barriers that inclusion would do without. Teachers would not graduate teacher’s college without knowing how to accommodate and include every student. Policy committees on inclusion or autism would not proceed without many autistic voices on them.

"Dempsey and Foreman examine five types of educational therapies available to autistic students. They conclude that early and intensive educational support is the best method to treat autistic students. Once these treatments are successful, it is surmised that students can then follow a regular curriculum. Essentially, Dempsey and Foreman describe a deficit-based approach which places the problem with the individual. This follows the medical model of disability." (Sandra Broekhof in her thesis to York University: *What’s In It For Us?: A Social Justice Approach to Educational Services For Students With Autism.*)

Sandra investigated the Ontario Ministry of Education to conclude, "it is clear that policy is based on the medical model of disability. As noted earlier, the policies have set up certain barriers that do not allow students with autism to be fully included members of the classroom or society. Policy leads to a certain way of viewing and dealing with learners with autism, as well as other learners." (p.16)

Hodge, of on *Reflections on diagnosing autism spectrum disorders*, an article in *Disability and Society*, says "he became increasingly uncomfortable with the extent to which giving diagnostic labels reinforces a system of provision that is about the potency of professionals and the impotency of parents in the lives of vulnerable children." (2005) Might I add, *in the lives of autistic children and adults too?* This over-reliance on the DSM IV-R is present in every aspect of education policy to the way society views autistic and other individuals with many aspects of human
The paradox continues: "Inclusive education is more than a method or a strategy; it is a way of life that is tied directly to the belief system that values diversity. Inclusive education is also a philosophical and practical educational approach which strives to respond to individual needs, and is intended to ensure equal access for all students to educational programs offered in regular classroom settings." (A Directive and Guidelines on Special Needs Education in the Northwest Territories). We often hear in our province that "everyone learns differently," and we are taught to respect that and make room for that. It sounds pretty nice. The Special Education Model, says Sandra Broekhof, "utilizes a philosophy that students with disabilities learn differently. In terms of students with autism, some of the services include music therapy and Intensive Behaviour Interventions. By utilizing the specific services available, the students can hope to be cured and can eventually enter the classroom. As well as using specific services, very often students with disabilities use a different curriculum than their peers. In this sense there is more segregation because the students learn different things. The assumption behind the Special Education Model is 'that every individual is unique but the services are not unique.' **By focusing on services, and not individual needs, students with autism are classified and individual needs are not being met."** [p.10] [bold mine]. This is the reason I do not support the ABA/IBI lobby in Ontario or in Canada. There is no one-size-fits-all therapy for any autistic person, and it should not be mandated that our children follow it.

"In order for individual Boards of Education to shift to a social justice educational model, there needs to be a shift in educational policies towards inclusion." (Broekhof) And yet, there are barriers. Ainscow and Cesar argue against the special education system as reflecting "assumptions, values and power relations." (2006). All of the services for autistic children and adults are aimed at curing and fixing. It is not until the child is fixed that they are accepted and/or allowed into mainstream settings. Consider as well, the autistic adult, who after the age of twenty-one, is presumed to have learned all they can, and are placed into group homes where the learning discontinues, and "quality of life" only goes as far as daily feeding and care. "People with autism are denied primacy and even agency." (Waltz, 2005) I know quite a few autistic adults
now, and I can say that the learning never ends, the contributions to humankind, immense.

I am drifting further and further away from centres that seek to support all kinds of people with disabilities based on inequitable treatment. Instead of clinician-client relations, we need a system of support where self-determination is a given, where this responsibility and agency is taken for granted. I recently attended an event for a centre here in Toronto that sought funds to support it. Still, kids and adults are segregated and I was struck how the video's testimonials were only of the parents, not of one disabled person who used the services of the centre. Not even one on the stage! The MC kept calling users of the centre, "clients," but who is the client, really? They are not always the people going there. They are, once again, the parents.

In my view as a parent, I feel it would have been fine to interview me, but not without my son in the foreground. I feel that Adam always has to be with me when I talk about autism. This will be his fight, you see. He will have to face the same asinine questions about why he doesn't want to be cured and how his case as never as severe as the next person's. Adam can clearly write now that he wants to be able to talk, but I do not believe that he would want to change the person he is. Could anyone guarantee that a cure would not take away one's essence, one's way of being in the world, having been like that from the time of birth? Does he feel that he's really missing a piece of himself, or is it society that makes him feel that way -- or will attempt to? I do not believe a blind person feels they are missing a part, or really feel envious of sighted people when they have never experienced sight! In contrast, I am sometimes envious of the voluptuous senses that the brain cultivates in the absence of the proverbial five.

We parents still have a big role to play. My role as I see it is to include Adam, to advocate for him and get him what he needs while also teaching him that has to advocate for himself. Yet, I think we can be doing more as parents by moving towards options for families. More aides and shadows, and a move towards real inclusion as opposed to integration which takes the kids OUT of the regular setting and away from their peers. I would tutor Adam on our own time, but I wouldn't want him to miss out on any aspect of school, or have a special curriculum made up just for him. Other parents do need some respite time and that should be part
of our community aide system. Adam enjoys the curriculum at his school and requires *a means of responding* in a manner that he *can* so he is enabled to participate. Special education, while it sounds good and may be peppered with the lovely language of "inclusion" and "acceptance," is still segregated and exclusive. It is the paradox of special ed and many of our centres and programs for the disabled today. They are still based in the medical model of disability which pathologizes autistic people, rather than views autism as an atypicality of humanity. Thus, we must consider putting more emphasis on environments and social structures as the real disabling and hurtful aspects of disability itself. We can no longer disguise insufficient services, systems and therapies with the language of acceptance. Acceptance is what acceptance does.

But out-dated, preconceived, tragic views of autism reign. Biomedical intervenors prey on frightened, ill-informed parents (see footnote) and a fearful public by using the medical model while ignoring the social model completely... and Diane Sawyer thinks I'm heartbroken.

I'm not heartbroken. I lovingly accept and celebrate Adam and all that makes him, *him*. I want for him a better world, and it is the autistic and other disabled adults who are paving the way.

*My Footnote:*

I said "ill-informed parents." In many respects, all of us are ill-informed. Many of us are over-informed which doesn't mean we are right, or something (like biomed) is scientifically proven to be effective for all autistic individuals, but rather, may be specific to the individual, whether they are autistic or not. Thus, over-informed may be akin to falsly informed -- information that is profuse but nonetheless false or not yet proven to be true. However, when I wrote "ill-informed," initially, I was referring to frightened, new parents to autism who are usually given access to biomedical interventions and behavioural interventions first, all based in the medical model of disability. I was once such a parent and admit to being a parent on a journey to learning, but committed to social justice for Adam and people like him.

*Special Thanks:*

**Other Sources Cited:**


Monday, May 26, 2008

The Autistic Rights Movement - NY Magazine

A photo of Ari Ne'eman, of The Autistic Self-Advocacy Network from the magazine.

An interesting article on The Autism Rights Movement here in New York Magazine. The only trouble is how the writer generalizes that the "movement" does not see autism as disability.

As I'm not feeling too well, I can't write much but Kristina did write about the piece in her blog Autism Vox.

Saturday, May 24, 2008

Autistic Kindergarten Student Gets "Voted Out" of Class

PORT ST. LUCIE — Melissa Barton said she is considering legal action after her son's kindergarten teacher led his classmates to vote him out of class.
After each classmate was allowed to say what they didn't like about Barton's 5-year-old son, Alex, his Morningside Elementary teacher Wendy Portillo said they were going to take a vote, Barton said.

By a 14 to 2 margin, the students voted Alex — who is in the process of being diagnosed with autism — out of the class. To view full article click here.

When I read this I became outraged. The Autism Acceptance Project is working towards an Inclusion Initiative here in Toronto to ensure that this does not happen, and that aides, and services be included IN the schools, instead of taking autistic children out of them. This initiative should be announced in a couple of months.

For my fellow parents here in Toronto, being included in schools is the number one issue for families. Yet, many of us are turned away at the word "autism," without even a first introduction to our children. They are called "disruptive," (I could name a number of schools geared towards special learners that even turn away autistic children here in Toronto), even though many of them who manage to get in, benefit by being with accepting, flexible teachers, with aides, and with other children. I know of another family here in Toronto raising money so that families can afford to hire aides for their children and that is a very worthy cause.

In the case of Adam, his peers love him in his "regular" school. And we are working towards adapting his classes and schedule to his needs while he is still in the classroom.

Yet the label "autism" inspires fear of either the child or the cost of that child in large part due to the nature of former ABA lobbying. I hope we can all work together to ensure that our autistic children, by law, will never be turned away. I hope we can work together to show teachers that we learn to do by doing and we learn to include by including. I hope we work together to change attitudes towards disability and autism, and that Inclusion is understood -- services be brought to the schools, not via integration (which means partially taking kids out of classes)or mainstreaming (which simply means throwing the autistic kid in the class with no accommodation -- a kind of sink or swim method) but by full
I hope that we can bring in people to give our teachers the tools they need in order to understand how to adapt a curriculum.

Inclusion benefits everyone, for everyone belongs. We are witnessing this in Adam's school, and today, he is at another one of his classmate's birthday parties. Parents often come up to me to say that their children talk about Adam a lot and they are grateful that their children will live in a world where a person with special needs is not seen as alien or an aberration. We are lucky and I want everyone to be as lucky.

I do not wish to suggest that having all one's senses intact makes one a better human. No. Humans have a remarkable ability to adapt and all humans indeed FEEL.

"One of the greatest sensuists of all time -- not Cleopatra, Marilyn Monroe, Proust, or any of the other obvious voluptuaries -- was a handicapped woman with several senses gone. Blind, deaf, mute, Helen Keller's remaining senses were so finely attuned that when she put her hands on the radio to enjoy music, she could tell the difference between the cornets and the strings. She listened to colorful, down-home stories of life surging along the Mississippi from the lips of her friend Mark Twain. She wrote at length about the whelm of life's aromas, tastes, touches, feelings, which she explored with the voluptuousness of a courtesan. Despite her handicaps, she was more robustly alive than many people of her generation." From Dianne Ackerman's *A Natural History of the Senses*, introduction.

I wish I knew how to make movies. I don't have good tools and am in the midst of imagining what I could do for Adam in terms of inclusion.
Images of Disability -- Whose Making Them And For What Purpose?

In a presentation given by student Dylan Walters, MA Candidate of Critical Disability Studies at York University, he focuses on the images of disability from the Afghanistan and Iraq Wars. I have many times announced how happy I am that Adam has a unique tool -- technology -- through which he is now able to communicate, and soon, make friends and accomplish many things. The rise of online communities is known to us all -- some one million YouTube videos are uploaded every day from around the world. The average YouTube user is twenty-six-years-old. As Dylan noted, "in a mere three years, YouTube has become a fixture in politics, business, education and entertainment." CNN debates and politics are a common feature and Amanda Bagg's video In My Language has reached hundreds of thousands of people. A good question, he asks, is if YouTube archives will be available in the future for historical research. Think of viewing them one hundred years from now. If so, we can continue to investigate how YouTube might have shaped our views -- from war to disability.

Below, Dylan showed (one of many -- I've only put one up here on this blog) shameless pro-war ads to inspire interest via the tragic myth of the disabled. Disability in many of the RAWA ads is the object of ridicule and bodies are rendered less valuable. Dylan says "injured soldiers in the media perpetuate the tragic/courageous myth peddled by many charities through media," and he cites a comment on YouTube: "LOL talking shit on YouTube is like competing in the special Olympics...even if you win your still retarded."

He asks "should there be an accountability on YouTube?" And then I questioned the same for blogs that proclaim their hate of autism or autistic people or the "neurodiversity movement," or some bloggers who mis-characterize autistic rights advocates
because they don’t inspire enough pity for autistic people. Should parents be banned from showing their children stimming in order to show the "worst" of autism (or any aspect of one’s Person that should remain private, particularly if permission to publish has not been received) -- of course "stimming" as something terrible is a matter of opinion. Remember, every picture has its frame. Should Autism Speak’s video *Autism Every Day* -- that frames autism as horrible for the purposes of raising millions of dollars -- similarly be banned? I mean, not one autistic person was interviewed and of course the point of view is terribly biased. No one questions that a parent might become depressed, but it is only a small piece of the picture being provided for public consumption. And folks, it has cornered the market.

These are very difficult questions, but ones that need to be asked because it means censorship. Yet, we do censor lots of other racist and hate-inspired material on the Internet. Why not when it comes to disability?

The bottom line here is that the use of people with disabilities for gaining support for war -- or for charities -- explicitly without their consent is a matter of "use." No person should be used for any type of profit, for the whole purpose of BEING is self-determination. Every person has this right.

Below, I have posted the Afghanistan video, then a video by a group *OUTSIDE OF THE BOX*, who does the same kind of thing that *The Autism Acceptance Project* promised it would do -- let autistic people do the work and make the films. Next time you see a clip, a report, or a YouTube video, maybe these are the kinds of questions we need to be asking.
I Am Love

Lately, Adam is really interested in collecting objects, touching them, looking at them closely, adding them to his collection -- rocks, teddy bears (which he talks to and names), dolls, pretty things, trophies belonging to the older children of our house. So of course, I'm at a stage where like any other parent, I have to teach Adam that he can't have everything he sees -- that some things do not belong to him but to other people. Other things have to be paid for and we can't have everything we want. Also, some things are just so plain delicate, that you can't touch them, but look at them only.

Of course, this has begun when I feel that I can parent him less than I want as I am recuperating in bed. As other family members seem to struggle in watching him or enabling him with his device (I recognize that for me it is natural and for others, they have to learn by doing -- which they are quite successfully), I am frustrated. And then it happens, curiosity has broken glass.

Smash.

It happens once. A small glass sculpture by Montreal artist Susan Edgerly lay in pieces on the floor.

"No Adam," I say. "You cannot touch the glass."

He goes and does something else and a half hour later, another splattering of glass tinkling like bells on my limestone floor brings me downstairs again.

"No, Adam." I say a little more firmly.

"Don't yell at him," says my mother-in-law. But I do not yell. I am as firm as I would be with any other child except that I bring Adam gently upstairs and pull out his device.

I write, "You cannot touch and break the glass. Why did you do that?"

"because touch is interesting," writes Adam. Indeed, he's been more curious than ever -- touching everything and soaking it all in
"Okay," I write, "it is interesting and glass is very pretty. But you cannot play with glass and break it. You cannot break it."

"You are hot," he writes.

"Does hot mean mad?"

"yes"

"I am mad because mommy told you once not to touch the glass and you did not listen to mommy."

"I silly joke on you."

He begins to feel bad and pouts.

"Why do you want to make a silly joke on mommy?"

"because I silly," he begins to whimper.

I write, "I love you and I want you to learn from mommy. So when mommy asks you not to touch something, I want you to listen to mommy."

He turns his head towards me and looks straight into my eyes and then writes "I am love."

Now what do you do with that?

(The glass has now been put away).
It does not sound like progress is being made at **IMFAR** in London, UK, from the comments from my post made on autism research yesterday (see yesterday's post below). Non autistic researchers, profiting from parental fear --societal fear, even -- about autism does not wish to hear the autistic person -- be it aspie or non verbal autistic typing out a sentence. I wish I was at IMFAR because as a parent I am angry and I am using that anger, as Lorde suggests we do as she refers to the divide between white and black women:

"The angers between women will not kill us if we can articulate them with precision, if we listen to the content of what is said with at least as much intensity as we defend ourselves against the manner of saying. When we turn from anger we turn from insight, saying we will accept only the designs already known, deadly and safely familiar."

Autistic people, when they speak up about oppression are accused of being "too high functioning," and "not like other severely autistic children." Some parent will always stand up and say how their plight is worse than the person standing in front of them. And for what purpose? In order to squelch the words of autistic people who only want better for every autistic person everywhere. What do parents fear? This lack of services? This lack of respite? That won't happen if we truly support autistic people everywhere and include them in society.

Is the fear of one's own failure for having a child that you don't really want to have? One with "problems?"If so, whose problem is it, really?

What fear do the scientists have by being challenged by autistic people about ethics and standards? Do they fear their tenure, their jobs, their reputation, their paycheques?
Would it not service us all to talk about it openly and out loud so that this useless research -- much of it supported by Autism Speaks -- actually gets funneled into assisting and dignifying the rights of autistic people living today! Let's call it an excavation of honesty, as Lorde put it once.

"Any discussion about among women about racism must include the recognition and the use of anger. This discussion must be direct and creative because it is crucial. We cannot allow our fear of anger to deflect us nor seduce us into settling for anything less than the hard work of excavating honesty; we must be quite serious about the choice of this topic and the angers entwined within it because, rest assured, our opponents are quite serious about their hatred of us and of what we are trying to do here."

I wish I was at IMFAR because the autistic people standing up and speaking out are speaking for my son and his future and I stand beside them in their struggle.

Here is a recent picture of me two days after surgery in the hospital with my autistic son, Adam. I look as anyone would after major surgery. Look at the concern on his face. And I can imagine all the "experts" at IMFAR calling people like him "not aware" or "incapable of empathy."

They do not live and experience the likes of him outside their labs everyday. Some of them might even call him "severely autistic." Some might say "moderate." Some of you even have the nerve to write that your child is somehow worse off than mine and doomed.
to an institution, yet, when I meet those kids, they are even more verbal than my own son!! I watch ablest videos (I am compiling a post of videos that some parents and governments make to reflect the "worst" of their child -- stimming --- and this is the most horrible thing I can imagine a parent doing for a child in the name of "helping" them).

Yet, I am hopeful that the autistic individuals at IMFAR march one step closer to actually being heard. I am hopeful that it is not wasted energy, even though it feels so often to be the case.

I end with a movie you can watch this weekend: *Music Within*. The struggle has gone on for a very long time.

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**Does Autism Research Support Humanity or Human Deviance?**

**Does Autism Research Support Humanity or Human Deviance for Profit?**

McMaster University is doing autism research. Autism Speaks raises a lot of money and some of that goes to our researchers based in Toronto and in Hamilton. Much of the money goes towards research to detect autism early or towards preventing or curing autism. The purpose of early detection is for early intervention. The concept of early intervention is derived from a medical model where the earlier diseases like cancer are detected, the better the chances of living. As a person recently diagnosed with early ovarian cancer, I can attest that in the case of mortality, I am thankful for early detection. However, in autism, the premise of early intervention isn’t that much different than the cancer
model – children begin to undergo a rigorous process of “becoming normal,” and are taken out of regular daily life, because they are not deemed “regular.” They are viewed as sick.

So it is with skepticism and interest for me to read of the recent research done at McMaster University of eye tracking as seen in The Globe and Mail today. The idea is that at nine months of age, we might be able to detect autism because it is assumed that autistic babies do not follow changes in eye direction. The early diagnosis is to find those children at “high risk” for autism.

I didn’t know my son Adam was such a risk. A risk to whom? I have to assume he must be seen as a risk to society, even though our friends enjoy him and he is living quite well. If living well means to receive an aide to assist and a teacher who understands so an autistic person can learn, then I feel that that is where the money should be spent. I also can’t say that he would have passed or failed that eye-tracking test and it’s my guess that with the ranges of autistic people out there, the test will not be very reliable because there is not one general assumption in autism that is universal for every autistic person. Adam’s eye contact seemed okay, maybe a little inconsistent. It was his play and interests that were different – the ones that also gave him an exceptional ability to read and correct his classmate’s work because of his ability to SEE the things they cannot.

Further, “the probability of a baby developing autism,” as stated in the article, would not apply to us. While individuals may develop autistic-like behaviours, it’s not necessarily autism. I can attest that dear Adam has been autistic since birth and probably in vitro. His wide almond eyes were curious and clever from the moment he was born. His surroundings were already an assault on his senses.

So where does this leave us? All this money being spent on finding earlier interventions to make our children less autistic? All this money being spent on tests that do nothing afterwards – they do not advance inclusion or eradicate fear of human difference so that our children receive fair and equal education and opportunity. No one is really working to understand and respect how autistic people learn so that our kids can become part of the world. No, early detection is still eerily angled at eradicating human difference.
In her essay *Age, Race, Class and Sex: Women Redefining Difference*, Audre Lorde writes:

“Much or Western European history conditions us to see human differences in simplistic opposition to each other: dominant/subordinate, good/bad, up/down, superior/inferior. In a society where the good is defined in terms of profit rather than in terms of human need, there must always be some group of people who, through systematized oppression, can be made to feel surplus, to occupy the place of the dehumanized inferior. Within this society, that group is made up of Black and Third World people, working class people, [autistic and other disabled people], older people, and women.” [Brackets mine]

She notes how it is the underclass, or oppressed groups, which autistic individuals have described themselves, that are expected to bridge the gap, change, be cured, act normal, rather than society who also makes a concerted effort to understand, accommodate and accept difference:

“As a forty-nine-year-old Back lesbian feminist socialist mother of two, including one boy, and a member of an interracial couple, I usually find myself part of some group defined as other, deviant, inferior, or just plain wrong. Traditionally, in American society, it is the members of the oppressed, objectified groups who are expected to stretch out and bridge the gap between the actualities of our lives and the consciousness of our oppressor. For in order to survive, those of us for whom oppression is as American as apple pie have always had to be watchers, to become familiar with the language and manners of the oppressor, even sometimes adopting them for some illusion of protection. Whenever the need for some pretense of communication arises, those who profit from our oppression call upon us to share our knowledge with them. In other words, it is the responsibility of the oppressed to teach the oppressors their mistakes. I am responsible for educating teachers who dismiss my children’s culture in school. Black and Third World people [and autistic people] are expected to educate white people as to our humanity. Women are expected to educate men. Lesbians and gay men are expected to educate the heterosexual world. The oppressors maintain their position and evade responsibility for their own actions. There is a constant drain of energy which
I know of so many autistic individuals who fight the good fight every day -- who have to justify their existence and intelligence and disability as autistic people. Moreover, the idea of "pretending to be normal," a title of a famous autism book, is echoed in Lorde's statement -- that the onus is on the oppressed group to change and no effort should be made on the part of the non-oppressed group. That is the entire premise upon which most autism therapies are based and built.

Rather than focusing research on eradicating difference (in this case autism), it should serve to examine the way we include autistic people in participating in research and on boards of directors and on the way we use autistic strengths to educate and include autistic children in the classroom. (Must I mention AGAIN that no school board here in Ontario has an autistic person on it??)

The Globe and Mail article on eye detection tests for early detection of autism does not make clear how it will better and enhance the lives of autistic people. It does not mention how to tap into autistic learning style and strength. It seems more clear that the onus will still be on the autistic child to change -- to appear and become less autistic, even if it's all just pretense.

"Too often, we pour the energy needed for recognizing and exploring difference into pretending those differences are insurmountable barriers, or that they do not exist at all. This results in false and treacherous connections. Either way, we do not develop tools for using human difference as a springboard for creative change within our lives. We speak not of human difference, but of human deviance." (p.p. 115-116)

We must not refuse to see the challenges that autistic individuals face, and I find it surprising that people still think that disability is a bad word, or that accepting autism means we don't educate autistic people. We must begin to re-imagine disability and autism. We spend so much of our energy mourning, eradicating, detecting and in the meantime, our children get locked out of schools, even “special ed” schools, or they can’t go to camps with shadows and become excluded from so many programs and from life in general.
Kids also generally get locked into categories -- special ed, normal ed, or gifted ed. But what of Adam who is both gifted and disabled? Believe me, there is no clear cut line when it comes to intelligence and disability. Autistic and other disabled people are not allowed to go to school with aide dogs or devices. They are viewed as a "disruption" to the classroom and are often turned away before even a first meeting. Many parents have called us up at The Autism Acceptance Project, disgruntled and upset with a system that simply excludes the autistic child or that separates them from their siblings. Furthermore, an ABA supported program which removes the child from the classroom is simply another form of institutionalization and segregation. It is also sadly a method which seeks to have a child respond normally, which is a kind of pretense as well, as opposed to enabling autistic response. It will not work to benefit autistic people in the long-run.

The barriers that exist do not lie within the autistic individual, although they do face many challenges. Most of the barriers lie in attitude towards disability. We spend so much money to affirm over and over again that autistic people are less valuable and deviant. Autism Canada has mimicked the Autism Speak’s style commercial to make autism appear like a horrible epidemic. They shamefully have objectified the autistic individual in order to raise money for the questionable research I have mentioned here. Adam and every other autistic individual need not/must not be objectified in order to be viewed as society’s surplus, or an object for research funds. So far, I’ve found little research that has actually shaped the lives of autistic individuals for the better.

Adam is the best. He works hard, he is smart, and he can type now. He is human. He is different AND equal. Once our autism research is developed on that premise of "different and equal" maybe, just maybe, our children will no longer be used for profit as the “surplus members of society,” or media entertainment, but rather, come to be viewed as valuable members of our community and thus, better able to contribute to it.

Reference:

Emboldened By Many Silences

I had my second surgery a little sooner than expected due to a lot of pain. Here I am last mother's day in the hospital. I am at home, tired now. Groggy as I write.

Audre Lorde said, "what I most regretted was my silences." She wrote about feminism and her breast cancer, and I too believe that staying silent is NOT useful when we have so much we have to learn and share with one another. "What are the words you do not yet have? What do you need to say? What are the tyrannies that swallow you day by day and attempt to make your own, until you sicken and die of them, still in silence?"

I try to test my silence and put it on the loud speaker.

Today I write:

The leaves of spring begin to glitter  
the warm sun across my face  
I try to heal under it  
my womanhood taken  
fear forsaken

I am more a woman today  
than I was with a womb  
more a woman today
with delicate crepe lines
weaving my hands that still work
more passionate today
than when I screwed to be loved

The sun bakes me and I rise
to learn
to heal
all the wounds
of a young woman

I rise to walk bravely
towards the power of this newer, older one.

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And now for a little ditty:

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In The Wake of ...

doubt, fear, criticism, I become stronger. I need to write and verbalize in order to move through experience, find joy, and learn.

Today, I borrow the words of Audre Lorde, for she speaks for me right now. Some people have explained that to be silent through their experience or their fear -- be it having an autistic child or a cancer, should be kept private. But this doesn't work for me. I have spent time considering this, and if I am wrong to make public what is so private for others. But what are we if we the village do not share, because we can make each other strong.

In "The Transformation of Silence into Language and Action," Lorde writes:

"I have come to believe over and over again that what is most important to me must be spoken, made verbal and shared, even at the risk of having it bruised or misunderstood. That the speaking profits me, beyond any other effect...for it is not
difference that immobolizes us, but silence."

And for those who have had such a difficult time understanding the Joy of Autism, (which I don’t really care because it seems those people only have political interests, not emotional ones):

"And most of all, how do I fight the despair born of fear and anger and powerlessness which is my greatest internal enemy?

I have found that battling despair does not mean closing my eyes to the enormity of the tasks of effecting change, nor ignoring the strength and the barbarity of the forces aligned against us. It means teaching, surviving, and fighting with the most important resource I have, myself, and taking joy in that battle. I means, for me, recognizing the enemy outside, and the enemy within, and knowing that this work did not begin with my birth nor will it end with my death. And it means knowing that within this continuum, my life and my love and my work has particular power and meaning relative to others."

I guess that's why I have been writing for books and this blog on autism for 3 years now. Of course, she is talking about her breast cancer, not autism, and I deal with a different kind of cancer. And I'm certainly NOT comparing autism to cancer, but it does seem relevant to compare her strength and will to find joy in her breast cancer and experience. It seems a shame that there are people who want to make autism comparable to cancer or a tragedy for political gain, not the benefit of autistic people, for our kids (and autistic adults) are full of such life. It is so important to move through despair.

PERMALINK POSTED BY ESTEE KLAR-WOLFOND AT 5/06/2008 08:53:00 AM 8 COMMENTS LINKS TO THIS POST

SATURDAY, MAY 03, 2008

Brief Thoughts on the Body
Lorde gives voice to her "feelings and thoughts about the travesty of prosthesis, the pain of amputation, the function of cancer in a profit economy, confrontation with mortality, the strength of women loving, and the power and rewards of self-conscious living." Lorde powerfully weaves together the three literary forms, allowing her to leap from raw expressions of pain to her inimitably astute social observations.

Guess what I'm reading? Sure, I'm a little scarred, but like Lorde's, and after attending some of lectures today for the graduate program I am beginning in Critical Disability Studies, I do believe that cancer is just as much an industry as autism (moreso, actually) and the way we conceptualize the body as "doing and being done to." I'm not saying that industries and economies are inherently bad, but we can't just move through this blindly without realizing what influences the way we think and feel and HOW it does that. In this sense, I refuse to be yet another "victim." You likely won't find me running for the cure, but instead, talking honestly about experience.

This is just a beginning. I am thinking about the body, the social body, the "transgressive" body and how we choose to encounter it and how disability exists as an interpretation between bodies.

As for me, I have been amputated once and will be amputated again soon. I will be either temporarily or permanently disabled in some way. So, I also struggle to view disability/ability in a "corporeal normalcy binary" (Eliza Chandler, "Transgressive and Transformative Bodies: A Proposal for Evoking New
Imaginations of Disabled Bodies for Disabled Youths”) because we are never constantly one or the other. We are all sometimes disabled, and sometimes abled.

It's time aggressively destabilize current notions of disability. Contrary to what Harold Doherty wrote about me in a recent post about Reverent Wright and his speech Difference is Not Deficiency, for which I mistakenly wrote "deviance," disability writer Tom Shakespeare notes that normalcy reinforces deviance, so I extend this to ideas of abnormality, illness (as autism is often described) and so forth.

Instead, there exists diverse embodiment in our world. We are always shifting, and never resting in the binary.

I can say so myself. I can say so for Adam.

Things Are Going to Change

As I put my Adam to bed last night, I hated to imagine that I couldn't smell his skin -- still young-smelling -- or feel his soft hair against my face one day. I lay there as he slept, listening to his breath, thinking that I would give anything for him. My love for him is so gigantic that without him, it feels almost meaningless. I would hate to miss is not being around to feel it and see it anymore.

Things are changing so fast, that it feels surreal. It feels a little like when we parents get that first autism diagnosis, but also different because now I don't know what's going to happen to me. With our children, we learn to live with uncertainty, for we MUST find the joy in everyday. And I really, really want to do that now, even if my situation becomes worse. I am one who likes to prepare for everything, even though I am an optimist nevertheless.

Things will change fast, they always do. We can't stop the flow of time. I dedicate this song today to my family. I used to be a musician and a singer in my day. I used to sing in bands, play the
piano and I sang and played this song. It is called WINTER and it meant so much to me when I was young, and now its meaning has taken on a slightly different note:

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**THURSDAY, MAY 01, 2008**

**Blogging Against Disablism Day**

I'm not going to do it because when it has already been done so exceptionally well, then I should direct you instead. Read Ballastexistenz today.

Also read Club 166 blog "Eugenics with a Smile."

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**WEDNESDAY, APRIL 30, 2008**

**Listen**

Now it is no secret that I am going through something – borderline ovarian cancer. I consider myself very lucky. If I had waited and not followed-up with some symptoms last fall, I may have ended up in some Stage 3 or 4 situation, and my chances of living would be poor. Like all parents, my fear is that Adam would not have his mother and that I would miss all of the magnificent milestones he continues to have.
Here’s an excerpt from Michael Bernard Loggins, a man with developmental disabilities who wrote *Fears of Your Life*:

*Fear #33:*

“Fear of you never known you were gonna lost your mother is very sad and scary experience you have to face and learn from and you wonder why she has to die I love her – and I had loved her once while she were alive. Especially if she was the mother that raised you and the others through birth and you only wish that you could have done all you can to help save her life. It gonna be worse times and hard times for Michael Bernard Loggins and his sisters and brothers too. Especially when mother’s day comes.”

But my chances seem very good. Except for the unknown – what my next surgery may reveal, I have excellent chances of being totally cured for good. In fact, my first serous tumour was already taken out, and because of the high risk, I must have everything taken out. It’s no secret. Millions of people go through it every day, and they go on living. I know I am supposed to be emotional and mourn some kind of loss, and it may be premature for me to express any of it now, but I’ve had my wonderful child, I have four stepchildren who support him and who I have come to love deeply. While I can’t speak for how I will feel after my surgery, I can say that the most important priority I have is living for Adam and my family.

This post is about listening to your intuition. My intuition is something that I tend to listen to quite closely, and what kept me away from “experts” who really could have done more harm than
good for Adam. I intuit people quite well – even though I may want to deny what I feel and “be nice” to people. That’s the way I was brought up -- to be nice. Sometimes I intuit things that frighten me because it sometimes means facing something difficult. I have even taught myself to ignore my intuition at times where people are concerned, only to have learned my lesson.

It’s the same now with ovarian cancer. “Listen to the whispers” is what ovarian campaigns tell women. What a wise line! The symptoms of ovarian cancer are so subtle that women usually do not discover them until they become severe. But I had some. They were small and quiet and they could have been anything. I began with ultrasounds – “it’s nothing,” said the doctors. “Pull out any woman your age from the street and they all have some kind of cyst.” But I wasn’t sure and I didn’t feel they were right about me, yet I had doubts -- was I being paranoid? Yet, right from the time I had the first symptom and ultrasound, I had a feeling. I got to see my CT Scan. “You have double spine,” they said. “Look at that!” they were fascinated, pointing to the image, showing me. “Only one per cent of the population have a double spine!”

“But what about my cyst?” I implored, as it appeared dark and with some kind of mass beside it.

“Don’t get hysterical” said a secretary sitting in for the regular one at my gynecologist’s office. I wasn’t getting hysterical. I was asking prudent questions. Why my CA125 kept going up; why I was getting uncertain results from my CT Scan. “You’ll be fine,” she said with a doctor’s assurance. She is not a doctor.

When I first visited the gynecologist in January, after the initial tests and after my wonderful GP seemed to "feel" something too, the doctor took a look at my healthy face and asked me questions. I have a lot of cancer in my family. But she said she wasn’t concerned. She did another CA125 and scheduled my MRI. “It’s probably just an endometrioma,” she said assuredly. CA125’s are unreliable in women my age. The test can rise with endometriosis, PMS, or benign cysts among other things. But mine kept rising.

Then, after the MRI, where I closed my eyes and imagined myself lying on the beach with a soft breeze for over an hour, I fell through the cracks for about another eight weeks. I heard nothing. I thought no news was good news…right? But in March, it was
gnawing at me. I called my doctor. They had not received any results. I cringed at the thought of calling that secretary who called me hysterical simply for asking questions, and for making me justify not only my intelligence, but also making me feel guilty for taking up her time.

Immediately following my call, however, I was squeezed in to see the gyneoncologist again. “I was wrong,” she said, and Henry’s jaw dropped – he thought everything would be easy and okay. “It’s not an endometrioma. I am very suspicious.” So I had my first surgery scheduled the following week.

“It looks good,” she said after I was barely awake from the anesthetic, shaking until they bundled me in five blankets and administered morphine. Then, she was gone.

As I was (and am still recovering), I thought that my April 29th appointment for my pathology report would show up benign. Everything was supposed to be fine. Everything in the process of medicine goes so very quickly. Everything can fall through the cracks if you don’t follow up with our own health. It of course showed up borderline, as I mentioned yesterday. This time, she expressed her concern again, and recommended that I have another surgery to take out everything.

The entire time I felt it, even though everyone pressed me to doubt it. Maybe they were just afraid and wanted everything to be okay. Since that time, many of my girlfriends are getting themselves tested, but what I want to express to women is just listen to your own body. While everyone, including some of the finest doctors told me not to worry, and that I would be fine, there has been an issue with each subsequent visit. When my mother was sick for two years with pus running out of her eye, doctors told her it was nothing, until finally she was diagnosed with renal cancer. The point is, people are busy, most cases ARE benign, but it’s prudent to continue to pursue the feelings in your gut.

You have to listen to the whispers, be they physical or something deep inside telling you something. You even have to listen to all your fears and move through them, I think. For my health, listening may have just saved my life. For my son, listening to my own instincts may have, in many ways, saved his, for he is doing really well without popular “interventions.” (Early interventions,
folks, are for serious, life-threatening diseases, not for people with disabilities like autism who deserve assistance and an education. The process of studying and educating him has been following him and trusting myself -- not listening exclusively to other people, but gathering the information and becoming selective as to who can assist us. No matter who tells you how crazy or hysterical you are for not doing something that is popular, weigh it all in carefully, study, and then listen to yourself and your child. There may be fear, but we must all use it wisely, not let it use us up. Fear is harming too many autistic children as it is.

As for any fears I have at the moment, here they are so written and to be used usefully, I hope, by anyone who cares to listen.

**All Truth Passes Through 3 Stages:**

*First: It is ridiculous*
*Second: It is violently opposed*
*Third: It is accepted as being self-evident*

--Shopenhauer
(and continue to want) to be with him.

I learned who really supported me, even when we had BIG disagreements.
I am still recovering from my first surgery (with the happy face pendant) and I never knew that a photo with Lance Armstrong could symbolize for me, what lay on the horizon.

Yes, that's right, I'm a writer so I won't hide it, and I don't want pity. I have to have another surgery as I have borderline ovarian cancer. The next surgery will ensure I will live to ninety.

You can bet on it.

And you can bet I will not let anyone complain or compare autism to cancer or a "death sentence," either.

'When I dare to be powerful - to use my strength in the service of my vision, then it becomes less and less important whether I am afraid.' -- cancer survivor.
"Difference is not deficiency" was his message as it related to race and religion. The man had me actually sitting upright in my seat, listening, laughing and enjoying every word and antic. I kept wondering why on earth so many people can't understand disability in the EXACT SAME WAY -- autism is a difference, not an illness, an abnormality or a deviance. Those people unfamiliar with my son's excited hand-flapping may not understand it, and may be so inclined to stare at it, and maybe even further inclined, by virtue of the crap they DO watch on Autism The Musical (I took issue with how some of the parents described their children as "ill." Otherwise, I absolutely LOVED the kids and found them so able and talented), or on CNN or whatever, that autism is a disease so that Adam's excited hand-flapping may seem like a pitiful thing to them, just as much as black skin was viewed back in the day.

Yet, as we were flying home from Florida yesterday, and he was watching a video of FRACTIONS (yes, fractions -- and he's just turned six years old), and he flapped his hands, I really thought nothing of it. In fact, I was joyful as it was something he was learning from (the video). And when he's happy, I'm REALLY happy. It's his difference. When he's happy and excited, this is how he will react to his environment. Now who on earth would want to "extinguish" that and why would that goal be so utterly important in those so-called early "intervention" programs? What are we "intervening" in? Aren't we supposed to accept and assist? Please get rid of that term "intervention" – it's so entirely insulting.

So it was such an irony this morning, when the big headline was "Hope For the Blind."(why I am turning this CNN on, I'm not so certain except to say I want to know what everyone is being "fed" in the realm of popular media)

Ted Turner -- please hear this: DIFFERENCE IS NOT DEFICIENCY. YOU CAN HAVE AUTISTIC NEWS REPORTERS, GUESTS -- YOU DON'T HAVE TO HAVE THE PRETTIEST PEOPLE. WE WILL ACTUALLY ENJOY WATCHING THE NEWS MUCH MORE IF YOU PUT REAL PEOPLE ON CNN.

Okay, sorry for that rant -- back to “Hope For The Blind.” I hope they get a new headline writer on CNN. Why not just say "new gene therapy offers possible sight for the blind?” They responsibly reported that the therapy is very risky, and only tried on 3 people successfully, and had actually harmed others in the past. Through
the therapy, blind individuals cannot see fully just like cochlear implants don't enable deaf people to hear like hearing people do. Apparently, there are sounds, but not perfect hearing and in this case some light but not full sight. And still, not all blind people want to see. As Oliver Sacks has written and spoken about numerous times, many blind individuals don't understand why they would want to change a way they have been their entire lives!!! What a possibly frightening experience to have to relearn everything just because someone else thinks it's better to see than to be blind?

Is this “intervention” and “therapies” for the benefit of others? Is choice a good thing here? That is, giving people the choice to have implants or not? Gene therapy or not? Or is this an expectation and a mandate under the guise of “choice?” In other words, there is really no choice at all. As long as we view the world as a homogeneous place where stronger and faster and the ability to compete is better (on the same playing field), then there is little choice, isn’t there?

As we move forward in our scientific discoveries, I don’t see the ethics getting any easier. But there’s one guide I do follow – it’s the one where when a “cure” is being preached because people think it’s better not to be disabled, or autistic, then it becomes grotesque. It feels Mengele, Nazi, and it frightens me that CNN as a channel has the power it does to dictate people’s lives and the way they think about everything. This is not “Hope for the Blind,” this is gene therapy being offered – and it could be the utter “Hell for the Blind” too.

When will our world understand that there are millions of people who live differently than many of us do? And not everyone wants to live like an American (or Canadian or whatever in the "first-world")? If we really want to know how the rest of the world lives and feels, then we have to watch their channels and read their books and...
I am happy to announce that I am a new graduate student of Critical Disability Studies at York University. I hope to continue discussing the differences in disability as they cross section with our discussions about race and religion, in much greater detail in the near future. Thanks to all of you who supported me through this.

The Autism Acceptance Project Update

Many people are emailing me asking to read Adam's blog as it will soon go private. This is wonderful and I thank you for revealing yourselves because Adam's safety is very important. If you are interested, please email me at estee@taaproject.com.

Aside from this, many of you may not know that The Autism Acceptance Project (TAAProject) sends out monthly newsletters and regular Newsflashes. Our e-mailing list is growing quite a lot and there's a lot of information in those newsletters that may not be in the blog or on the TAAProject website (www.taaproject.com).

If you are interested in receiving newsletters, please email me, being specific in the subject line (RE: NEWSLETTER) and we will put you on the list (estee@taaproject.com)

Precious Growth

As many of you know, Adam is really taking to typing. In two months, the typing has also instigated more talking in full sentences. It's as if I've offered him a window and now the floodgates are opening.
Let me begin by also saying that last week, Adam grabbed his own device in school and for the first time ever, asked for his father -- "daddy," he typed. He was asked again if he wanted daddy, and he typed that he did.

His magnificent shadow -- a young woman who has been with us for four years now -- told him that daddy could not be there and he was at work. She suggested that he instead draw a picture for daddy. Adam has drawn pictures before. Sometimes he writes mommy on them (well, he did once anyway), and he has definitely asked and typed for mommy a few times, but he has never drawn a picture for me without the bidding of some teacher's project.

Adam has never asked for daddy before and I wonder if it’s because I've been in bed recuperating, and dad has had to step in with Adam a little more, that Adam has truly relished it. So, completely unaided, Adam did the drawing below for daddy -- he wrote his name, daddy's name, car, and drew his rendition of a car.

Needless to say, this picture is being treated delicately like an old Leonardo da Vinci drawing -- so light and delicate is Adam's hand that you can see his struggle for control -- which is why we’re grateful for typing devices. If you saw him write letters by hand, you would also see his steely determination with the gargantuan challenge. This work of art will be well preserved, framed and displayed in an area for all to see in our home.

So a few things are happening in my mind these days about Adam,
typing, communication and expression, and I wonder if many parents of non verbal children, or whose child's expression is delayed in various ways, feel it too.

First, there is a burst of language in sentences coming out of Adam as a result of starting our typing together. It's still not always clear, mind you, but he's talking more. It seems to have sparked something in Adam -- something that was already there, but perhaps didn't have the courage or know-how to come out, and it simply needed the little push. Think of it like opening a window in a room swirling with words, letters and thoughts, growing by the minute. That's how I like to think of it and the rate at which Adam learns.

Second, his drive to do that picture for his father completely on his own, I believe, also has to do with this window-opening as well as his need for relationship with his father, and just turning six and saying some very interesting boy-things, he needs a male role-model in his life.

And third, as a result of this new form of expression for us in this family, there are questions I have of myself as his mother -- the mother of a son first, a child second, and an autistic child, third.

This very intelligent little boy, with so many thoughts and conceptions of himself in the world, and IN RELATION TO THE WORLD, while I knew were always there without spoken language, has suddenly manifested in so many typed views of himself. It's not quite like having a child who is natural with spoken language -- the precocious little talker who always asks "why?" At least a parent gets a sense early on of the depth of responsibility in holding a child's ego like an egg in one's hand. Maybe (I can't say as I am the mother of one child and a step-mother to four whose own mother served them well), a parent just gets sort of immune to the child's ego. Maybe they learn ignore some of the precocious talking. Maybe they know when something serious is being said, and when something said is just an experiment.

For Adam, I believe that the same thing has happened and has always been happening, even before the typing. In some ways, it bothers me because Adam's ego and his thoughts and his way of thinking of himself in the world has always been there. All of those things I just mentioned, have always been there. His sense and
ability to see people and know them -- like the child in the *Emperor Has No Clothes* -- has always been there. Yet, like many autistic people, he has been treated by many people (not all, thankfully, but many) that he never had the ability or capacity for such thought, such depth, such relationships.

My Adam, who notices how boys "should" behave and how he is "different", well -- tell me please -- how do you hold that precious little ego as it grows by leaps and bounds in your hand?

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**Out From Under**

The Royal Ontario Museum in Toronto presents exhibition on Canadian disability history

The Royal Ontario Museum (ROM) is proud to present *Out from Under: Disability, History and Things to Remember*, a powerful exhibit exploring Canadian disability history. A display of 13 diverse objects reveals a rich and nuanced history that pays tribute to the resilience, creativity, and the civic and cultural contributions of Canadians with disabilities. The first of its kind in Canada, Out from Under was produced in collaboration with students, scholars and alumni from Ryerson University and will be on display on Level 3 of the ROM's historic building from Thursday, April 17, 2008 to July 13, 2008.
My son's gonna love this book. Gregory Blackstock, dubbed "an autistic savant" by Darold Treffert, is also called "an everyday anthropologist."

*At age fifty-eight, [he] began a new and exciting chapter in his life. The retired pot washer walked into Seattle’s Garde Rail Gallery to attend the opening of a solo exhibition of the drawings he had made over the past eighteen years, the results of a consuming pastime relatively few people knew about. Beaming with accomplishment and self-esteem, he introduced himself to complete strangers, escorted them to the pieces of his work, and urged them to read a newspaper review of the show posted on the wall beside his biography. -- Karen Light-Pina*
Adam loves encyclopedias and dictionaries and he examines every bug, every stuffed animal. The book arrived this week as I recover from surgery and I have a sneaking suspicion it might be one of his favorite books of all as he studies each meticulously drawn category -- of birds, tools, musical instruments and more.
I feel as if I've come upon a treasure of a book as if it were tucked away in a small Parisian bookshop -- where collectibles are as much valued as is Versailles, Monet, baguettes and cafe au lait -- each shop displaying historical relics to be resold over and over again, and hopefully to never lose their significance as marks of both man and time.

It's the same feeling I get when I look at Joseph Cornell's Shadow Boxes -- that collectible spirit made into art. Cornell is another artist speculated to have been autistic. Collecting is a kind of spirit, or at least a spiritual act. I'm in the spirit to collect these days. I've not normally been a collecting kind of person. I admire the level of interest in detail and passion a collector has to have. I've been watching Adam collect rocks recently, and plastic animals and airplanes. I've turned my head to honouring his and perhaps my own collections as much as the thought process and sheer passion that goes into them, with particular displays and presentations -- artful in and of themselves. We give objects significance when we place them carefully in the architecture of our lives.
As I still lie in bed (second week now) recuperating and working from here, I've been bidding on antique typewriter letters on eBay for Adam, and a few old and electric typewriters, thinking of how he may love the clicking sound, and considering making his new bookshelf embedded with typewriter letters. I'm sure my husband will shake his head wondering where I'm going to put all of these typewriters -- but I have my ideas. I am also thinking I may be punished for throwing out all of Henry's old wine bottle corks -- so I hear cork is becoming 'extinct.' There they sat taking up precious basement space in large plastic bags, if not a testament to the wine, at least one to Henry's love of it. He said of them just lying there, I can make cork boards. Wouldn't that be a fun project? That was about ten years ago. He has has since taken up golf.

Adam's fascination has opened up new worlds for me and I want to spend time, well...collecting not only myself, but the things that make our lives meaningful. For things are only things until we give them a place in our lives - for better or for worse. I think the things that we love should be our relics. We should give them places of honour. They do, after all, mark our time here upon this earth. They say, I WAS HERE. I EXISTED. MAYBE I EVEN MATTERED. AT LEAST THESE THINGS MATTERED TO ME.
You can begin reading Adam's own words here:
http://www.adamwolfond.blogspot.com/
This blog is open for the time being, but will be made private (invitation only) very soon to protect him. If you are interested in reading his blog, please email me at estee@taaproject.com as soon as possible.

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"Play With The Cards We're Dealt"

To all those parents who complain about their autistic children (or how difficult life is), a few lessons from a dying man:

Note: I had previously titled this post "I'm dying and I'm having fun" which is a direct quote from the video. Alyric said I had frightened her so I realized I had better change the title pronto. Sorry folks!!
As We Are

This baby born in India with two faces, says *The Globe and Mail*, "is doing well and being worshipped as the reincarnation of a Hindu Goddess."

"My daughter is fine, like any other child," said her father. "She is leading a normal life with no breathing difficulties," said Dr. Ali, who saw no need for surgery.

The ignorance in the way we express our familial difficulties in having autistic children is boring and tiresome. It is systemic -- we live in a culture that overspends, overworks and over-competes and these qualities together are supposed to comprise our identities. We complain on air how "difficult" autistic children are on parents and teachers instead of espousing them. Who cares about difficulty? I mean, our entire lives are meant to be difficult! But it need not be as difficult if we can change the way we view things, which in turn effects the way we treat and accept people.

I am very disturbed at how trite our talk about autism and disability has become. I've said it before and I'll say it again, accepting autism does not mean preventing autism. It does not necessarily mean curing it, either. I am not going to speak for my son when he gets older -- I expect he will speak for himself. But I certainly do not wish to waste his precious time fighting for him to become something he is not when he can be successful as he is. Why does being "happy" with or without autism, not have to
How else would we feel one without the other? How do not other "normal" (hate that word as you know, but I use it facetiously) children and families go through strife? And yet, look at little baby Lali above.

I suppose my happiness comes from my critique of our existence and how we look at things. I’m going through a phase of disgust with the media -- as we all know it’s one big money making entertainment machine. I mean, do you really trust the newspapers you read? I hope we are all reading more than our national newspapers and CNN headlines!

As Elizabeth Gilbert said in *Eat Pray Love*, "people tend to think that happiness is a stroke of luck, something that will maybe descent upon you like fine weather if you're fortunate enough. But that's not how happiness works. Happiness is the consequence of personal effort. You fight for it, you strive for it, insist upon it, and sometimes even travel around the world looking for it. You have to participate relentlessly in the manifestations of your own blessings. And once you have achieved a state of happiness, you must never become lax about maintaining it, you must make a mighty effort to keep swimming upward into that happiness forever, to stay afloat on top of it. If you don’t, you will leak away your innate contentment... the search for contentment is, therefore, not merely a self-preserving and self-benefiting act, but also a generous gift to the world."

I started reading Gilbert’s book just before I went into surgery. Adam said I was reading "sad" books (his interpretation of my furrowed brow), so I said screw it, I’m going to read something light. When I read that paragraph of hers, it’s melody sounded like a jazz line that could tie in with my Joy of Autism mantra above, at any point in the jam.
In a way, that's how I see disability studies and art. It's about being happy when we can touch our sadness, our selves and connect with what unites us. It's a way of digging deeper and hopefully shoving out those kitsch and trite notions we espouse on the air and in too many self help and autism "acceptance" books. What about digging a little deeper not into what it FEELS like just for a parent of an autistic child, but take a look into the lives and creations of ordinary people -- disabled people. For if we are all human, I am disabled too.

In honour of Petra Kuppers and her work and her website, I found this poem by Neil Marcus:

**The Nude**

*by Neil Marcus*

Nude we are
As sunbeams
As light
As moonlight
In darkness

There is a slow burn in the nude
A passion
An expression
That only a nude can tell
An opening into another dimension

soft flesh, hard muscle, gentle hair, speaks quantities
Elegant
Needs no explanation
Or justification
Just is
Can only be
What we cannot say with words

We are cripples
We are exquisite creations
Is there a shame to resolve?
Freaks of nature or Precious Beings of another kind of second sight
Look again
Think twice

I wish to speak the unspeakable
The hidden
The secrets I have hidden
Insatiable DESIRE
Longing intimacy
Fierce intimacy
Ravenous touch
Total exposure
I wish to expose
My Gender. My
Sex. My Love. My
Passion
These words are
not just hollow
affirmation
I dare speak
clearly only in silence

They are my form
My disability
Naked to the world

Spasm to the world.

Don't we all want to be seen?
I know that Adam does. And he won't want to be seen through the
veil of misery, but just as he is.

Something Cute (to ease the tension)

Ah yes, Passover is coming. Our young ones are being exposed to
their first field trips to the matzah factory.

Here is Adam’s take on matzah that left me in stitches so bad, my
newly cut abdominal muscles nearly split open again:

Me: I heard you made matzah at the factory today. How was it?

Adam: read it was pool.

Me: why was the matzah factory like the pool?
Adam: because it papa you to interesting eat it eat ugly

Me: is matzah ugly?

Adam: yes factory yes

Me: does matzah taste good or bad?

Adam: bad it tastes like poo like eat

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Well, I can't blame him for being honest, no matter how far back his ancestral recipes for matzah brei may go. To Adam, you just can't dress up a plain-tasting cracker.

In Support of Kathleen Seidel And Her Work

For her outstanding research, our dear friend Kathleen Seidel is being subpoenaed because of her exposure of the nonsensical vaccine controversy which you can also read at Respectful Insolence.

Subpoenaed · Apr 3, 08:45 AM

A week ago yesterday, I was served a subpoena commanding me to appear for deposition and document production in Rev. Lisa Sykes and Seth Sykes’ $20,000,000 personal injury lawsuit, Sykes v. Bayer (Case No. 3:07-CV-660, Eastern District of Virginia, Richmond Division). On Monday, March 31, I filed the following Motion to Quash pro se in the United States District Court for the District of New Hampshire. The motion has been assigned to Magistrate Judge James R. Muirhead for consideration; the issuing attorney, Mr. Clifford Shoemaker, has two weeks in which to respond.

I urge readers to read her motion to quash the subpoena here.
Kathleen is a fastidious researcher, and it is truly frightening how far certain parties are willing to go to prove that vaccines cause autism, which science has proven otherwise.

I also appreciate this video by Stop Think Autism: "I am also Kathleen":

Which leads me to a point that Jenny McCarthy raised on Larry King when she held up her "vaccination chart." She held up a sign of what appeared to be a list of twenty vaccines our kids supposedly receive as young toddlers. But hey, Adam didn't receive all those vaccines. He may have received maybe four of them. And recently, he got his polio shot as he turns six. Similarly, as I wrote in my essay, The Mismeasure of Autism: The Basis of Autism Advocacy, I would like to remind readers of the hundreds of unproven "therapies" and holistic and medical potions administered to many autistic kids today in order to "detox" our apparently "environmentally toxic" kids. I wonder how "safe" they are?? If it weren't for Kathleen and the other reputable scientists working on behalf of protecting our children's health and their fundamental right to be autistic and treated with respect, I would not know where Adam would end up except in the hands of people who might literally torture him with their inhumane methods.

All I can say is the rot is rising and it sure stinks.
until I finish my book, so you’ll have to wait. So excuse me for being a little emotional as I recuperate, watching re-runs from “World Autism Day,” on CNN. I was thinking about this as I as being prepped, thankful in a way that I would not be watching the TV that day -- sorry, almost, that I felt compelled to watch it afterwards, holding my wounds, the words of some of its reporters pretending to “do good” almost cutting me deeper.

"We have to do something about this ugly, ugly, ugly disease,” Lou Dobbs said emphatically, talking to Dr. Thomas Insel. That’s when my tears flowed. I imagined my Adam listening to his words flowing in between his denture-like smile, self-righteously saying that autism, my son’s way of being in the world, is ugly. Mr. Dobbs has obviously never met Adam or any other autistic adult. He cannot even fathom the joy we experience everyday when we are together (Adam and I, that is), and the utter sadness when people like Lou Dobbs goes on air to talk to millions of viewers of what he knows absolutely nothing about. Autism is so “terrible” everyone is saying, that I felt so terribly sad for all the parents out there fighting for services, for their children’s right to be valued and accepted, to be educated, and to contribute to the world. That’s our fight. It is what unites me with everyone who also loves their child and just wants them to have the best in life. It’s what unites me with all the autistic adults who say the same things and are constantly ignored in favour of the parents! No, our fight is to change the education system to include all children of all kinds of learning abilities, because it is representative of the world we live in. Our fight is not to eliminate autism, because that then threatens the lives of so many people who are born with different disabilities (or who may age with them), and who cannot become a part of our world. So, I think Mr. Dobbs and CNN owe millions of us parents and autistic adults alike, an apology because,

Lou Dobbs has never seen Adam laugh so fantastically that it would make the entire world glow.

Lou Dobbs has never felt Adam’s arms wrapped around him so that everything in the world would make utter sense to him – even immigration policy.

Lou Dobbs has never received a kiss from Adam against his cheek that would make him stand up for Adam’s human right to be and live a full life as an autistic person, in an instant.
Lou Dobbs has never seen Adam laugh with his friends – something it took him a while to do, and something that one never ceases to appreciate when it happens – the true value of real friends.

Lou Dobbs has never seen Adam read Henry VIII at the age of a year old.

Lou Dobbs has never observed the interesting games that Adam is capable of creating on his own.

Lou Dobbs has never seen Adam begin to type sentences with such meaning that Lou would understand the depth of understanding of humanity that a five-year-old autistic boy can possess.

Lou Dobbs has never witnessed Adam pulling his mother and father's hands together when they are fighting.

Lou Dobbs has never seen Adam work so hard in a world that doesn't spend time to understand him, and who can also learn many things so easily in his own autistic way.

Lou Dobbs has never seen a child who wants to be so social, but who lives in a world with little patience. If Mr. Dobbs would make some time to spend with Adam, I know he would understand.

Lou Dobbs has never spoken with autistic adults who struggled against the stigma of “horror” and “ugliness” that the much of the world believes autism and disability is, and who today, can tell us all about it.

Lou Dobbs does not seem to understand the difference between challenge, struggle, sadness and joy and how we can never separate all of those human feelings. We can never make life more perfect than it already is. We can never separate the vastness of all these feelings for we would be a risk of being numb – smiling with whitened teeth without really knowing happiness at all. (Okay, I’m picking on your white teeth, Mr. Dobbs, but you have to take a little tit for tat because you hurt us so much, even if unknowingly).

No matter where you stand on spectrum of autism politics, I cannot imagine that not one parent or autistic person listening to Lou Dobbs has never seen Adam laugh with his friends –
Lou Dobbs would not want an apology. Adam has passed the television set a few times listening to these horrific reports. I’ve muted the volume. I never want him to hear anyone say that he’s ugly, or that his autism is. It is only Adam’s right to express what his autism means to him – not a non-autistic person’s. It is NOT OUR RIGHT TO JUDGE WHAT AUTISM IS OR MEANS TO AN AUTISTIC PERSON. We may relay what it means to us as parents, but that is only less than half the story. It’s time CNN put some autistic anchors on their shows about autism. It’s almost too late. CNN has made a lot of people perhaps so depressed. And it is not depressing to live with autism.

Our agenda, and the agenda of CNN (if they want to help) is diversity and inclusion. My child will give the world many gifts as many autistic adults do today – from software developers, to writers and artists --- these are things, folks, that are not trite – they are to be utterly valued as a part of who we are.

I don’t want whitened teeth and a fake smile and I’m fed up with pretty anchors on CNN. I want to see more disabled anchors -- truly representative of our world. I want to know happiness and I know it’s wrapped up in all of those complicated emotions that we all feel every day. From pain and suffering that makes the quietest joy like the faint sound of a flute playing in the dark of night. We look for those tiny lights that illuminate the meaning of life, that give us air.

I want Lou Dobbs to meet Adam. I even want to shake his hand and say thanks for the effort if he makes it at all. I want Mr. Dobbs to find out what the meaning of life is, through Adam the way I think I’ve found it with Adam and many others like him. I want CNN, if they want to “help,” to work towards a world of inclusion as the amount of disabled people, as our population survives longer and longer, will inevitably grow.
2005. He is my inspiration in life. How a child so small give gifts so large, well, I am always amazed. I guess it's why we become, and are overwhelmed, to be parents.

Adam is turning six this year. For me, it's rather significant in the autism-stream, because six was to mark that turning point that the doctors told us about -- if he didn't talk by six, he would always be autistic, prognosis wouldn't be good...etc., etc. Six was the cut-off year for the ABA that we never ended up using. Six was the age you were supposed to be cured of autism so you could enter school. So, for many parents, that number 6 is ominous. Too many parents work and struggle to beat the clock. We drive ourselves (and our kids) nuts, losing precious time during those toddler years, because, hey, our toddler's are not "normal," and we are irresponsible if we do not change the course.

Even the strong of heart feel the pressure sometimes, and if we are confident enough as parents to NOT care what the medical profession proclaims about autism, we still know very well the struggles of being accepted and obtaining the best education possible for our children.

Well, six has now arrived. We were told by ABA advocates "he may be a cute little picsher now, but just you wait... that hand-flapping won't be so cute when he gets older." I know, I've been hard on you ABA folks. It's just that I think you've been very hard on our kids. Who the heck cares about hand-flapping when we should all care about having our kids included in our communities? I think we all have a much more important agenda to be working on.

Six is coming and going, and for many of you, it has come and gone. I have shown a few birthdays in the following video. Just like many of you, we have struggled with ideas, perhaps struggled more so in ignoring the fear and trying to let it go for Adam's sake. We worked so that not every toddler year was wasted with worry. Six is arriving on April 11. I may not be able to write for a while due to some other reasons which I won't go into now, so I thought just in case I couldn't write this blog post, I would write it today.

Happy birthday to my dearest dearest Adam -- my son, my "boo-boo-bear," and my reason for being (peshaw Elizabeth Gilbert of Eat Pray Love -- my reason for being is my son AND I am
educated and have traveled and lived abroad-- I read your book because my son said I was reading too many sad ones, and it did make me happy, by the way).

I think our little autistic people have so much to teach us. Adam is talking a little more now, he is typing and there is more to come. There is great life beyond the age of six and we've had some great years before it too.

THURSDAY, MARCH 20, 2008

A Year Of "Upper A's"

Age 3.

Saturday, it's my birthday. All I want is:

Sunshine
A light warm summer breeze
A hammock
A willow tree
An inspiring book to ignite

A fresh outlook
Some needed dancing (it tickles my insides)
A few cooking lessons (for the sensuality of it)
More friendship and gatherings (to put life in perspective)

Maybe it's just winter has made me feel the doldrums of routine to such an excruciating extreme and a need to shed the weight of being (not to some "unbearable lightness," mind you, but some shedding is in order 'round here), for Adam said to me yesterday when I asked:

"What do you think mommy does all day?"

To which he replied, "read sad books."
Age 5. To think Adam is turning six next month!

Huh. This mom likes to be told by my child all my weaknesses. Isn't that what in large part, children are for? Maybe it's that serious furrow that's got him thinking that mommy might be sad. It's time to lighten up with the likes of spring.

The old perm days -- me at thirteen.

High School Graduation.

I hate to think that my forties has brought that seriousness that I used to see in other middle-aged people! Yet, it's a part of life -- we have children, we worry about many things, we are really busy, we are really tired. Still, a part of me never understands why some people want to be eighteen again.

Age 24

Being young was really difficult for me. Sure, I had good times, but my youth lacked a purpose that I acquired later in life.

I watch Adam grow up fast and I also learned this week that my cousin had her first grandchild -- her daughter, I recall, who seemed to be born just yesterday. That's more than twenty years gone by in just a snap!
So Happy Birthday to me, dag nammit! I hope this year will be, to use Adam’s words, "upper A!". The children in our lives are taking over the world, and they remind us just how fast time goes by.

Notes On "Hell"
Adam wrote, which we displayed in yesterday’s video "think hell forgets boy," which really intrigued my dad, who sent me a myriad of hell-ish definitions and references to Thomas Mann, Plato and Socrates (index in above illustration).

What Adam knows or understands of "hell" or what he has learned of it, is very interesting and inspired my father to think about Adam’s way of thinking in new ways.

We find Adam reading dictionaries a lot. He might put it on the edge of his bed, stick his head right in, lean in with his hands while using his arms to jump up and down. Others might say he is not reading at all because he has to move a lot when he does so -- but he can do this for hours. People ask me, "how did he know that word?" -- as he seems to know many sophisticated ones. Maybe this is one explanation.

I imagine he reads and learns many new words, but he is also a really good listener, even though people think that autistic children are not paying at all attention, as they seem to shift their gaze out to some kind of oblivion. I think about all the times when I used the word "hell" to describe how other autistic people feel when they are sent into special ed classes (quotes I gleaned from some of Paula Kluth’s books) where often, their intelligence is "underestimated," (another word that Adam has now used). Other
words, he comes up with all on his own, and it surprises me how he thinks about them. Better beware of what we say in front of our children!

Since posting yesterday's video, I also realized that "monsters" are probably Elmo, Cookie Monster and Zoe from Sesame Street, and it occurred to me today as we watched them before leaving for school as they continued to chatter away. He absolutely LOVES them, but they ARE talkative! I imagine Adam may have been comparing the monsters to the children he knows. So maybe monsters are endearing little creatures after all.

Omaasc was likely an attempt at spelling "home and school." It takes a while to condition one's eye to a child's attempt at spelling something. As this is new, it is taking me a while to think in these terms. And that's it, isn't it -- it is the ability to condition ourselves and recognize the communication that is happening every day!

And for those who don't believe that autistic children can learn or understand phonics -- Adam reads HBO as ch-bo. Boy does autism research ever have to catch up!! Absolutely everything out there is just about wrong.

Yesterday, I chanced upon a Socrates quote, "hell is other people," which was the inspiration for my father's research (a lover of philosophy). While it might be true that other people may seem like "hell" to many of us some days, I must say, the amount of people who have embraced Adam's words, and are sending him emails, well, I tend to think that we just want to be more bonded than separated. Maybe autism isn't the "hell" the media (and some people) make it out to be, but rather, the hell of a lot of heaven that we are, right now anyway, too busy to recognize.
Since Adam has started typing, it's hard for me to write on this blog. What do you say to a little boy who says upon my return from a night away:

"Glad you return."

"Why are you glad mommy has returned," I ask, wondering what he will say.

"because hell forgets boy."

What do you say to that -- a boy who understands what the world is for him, or perhaps makes of him.

What do you say to a boy, not yet six, who refers to his peers as "loquacious" or that "talking is oppressive."?

What can I say to all my theories about Adam when they no longer are theories but are real with each typed letter?

No longer do I have to speculate what letters mean to him -- the fact that he loves the letter A which makes him feel "euphoric," or of his affable nature that recently revealed that "jokes are a staple for the atmosphere." Thank goodness his sense of humour is
What do we make of "autistic behaviour" when Adam, who has explained that when he gets ill, the reason for his constant movement is because it "makes me feel normal," -- a word many of you know that I find relative, but which is his version of normal, meaning, not ill.

What do you say when your son tells you, his baby teeth just falling out behind those still cherub cheeks just beginning to thin, "i feel numbers," but to sit and wait for more?

You see, I am waiting now, which has slowed me down a bit. Adam has begun to email his half-siblings, telling them what he did in his day. He is beginning to use the computer to communicate with others, and as for sharing his words, I must obtain his consent. So, while he can type now, I question where we all have to draw the line. What is the difference between advocating for our children and what we can talk about in public? I liken it to talking about our children with utmost respect for their right to privacy -- that not everything they say and do is for public consumption. It is why I take issue with parents who talk about how their children "hit" them in public to display autism as something terrible. *(this is a special note to that certain Ontarian who ambushed me on CFRB during the Joy of Autism: Redefining Ability and Quality of Life event...how perfectly timed was that "hitting" for radio?)*

Now, I've tried to be careful in the past, but certainly I am thinking of this more now -- if I ever crossed that line and what a shame it is to only be waiting for verbal or written consent. I think I always have tried to represent Adam and autism with pride. That has been the point of this blog.

I know also that we parents talk like we would at kaffee clatches, reaching out and yearning for support as we figure out how to raise and accept the special literacy -- behaviour, idiosyncratic communication and all -- of our autistic children. We have gathered together for mutual support, but I think that consent piece, that piece where no one is too little to be respected, needs to be thought about again and again and again.

For as Horton says (Adam's favorite book of late), "a person's a person no matter how small." What about, a person's also a person greater than mine!
You see, autism is not on display here -- if you want that, tune into Larry King Live where Jenny McCarthy, Jerry Kartzinel and Toni Braxton go.

No, our pride for who we are is simply worn on our sleeve.

Small people, all people should be proud and I may ask Adam write a review on the Horton Hears a Who movie which comes out this weekend.

FRI DAY, MARCH 07, 2008

Vaccines and Autism: Can the Causal Link Be Proven in Law?

In my blog post yesterday, I talked about the difference between legal evidence and scientific evidence. It is disconcerting that a CNN poll revealed today that 71% of the public believes that vaccines cause autism, despite no scientific evidence to support the link. It seems that entertainment and sensationalism without fact still guide decisions and belief. I strongly urge Larry King to put on his program a number of autistic individuals from Autistic Self Advocacy Network, ANI, AutCom and The Autism Acceptance Project to balance the story and separate fact from fiction.

In keeping, I had my step-daughter, a first-year law student, prepare for you a synopsis of how something has to be proved in a private/civil law matter. I hope it helps further the discussion of the difference between scientific fact and legal "evidence," in the matter of vaccine injury:

Vaccines and Autism: Can the Causal Link be Proven in Law?

Serena Wolfond, L.L.B. Candidate 2010

In order to prove that the MMR vaccination causes autism it must be apparent: (a) that but for the
administration of the vaccination, autism would not be present, and (b) that (a) is true on a balance of probabilities (i.e. that it is more likely true than not true).

Part (a) is known as the “But For” test for causation and is the standard test for proving causation of harm in private or civil liability cases (as distinguished from criminal cases). Applied to the question of vaccines causing autism, the But For test requires the party alleging the link between the two to indicate that but for receiving the MMR vaccination, autistic individuals would not be autistic.

Of course it is arguable that multiple contributing factors either together or independently lead to a certain effect. Accordingly, if it is impossible (for reasons such as the lack of conclusive scientific data) to prove causation using the But For test, a more relaxed test for causation, referred to as the “Material Contribution” test, may be employed. The Material Contribution test maintains that if more than one factor materially contributes to some outcome, then both causes will be found legally accountable. This test would require proof that the vaccine at least significantly magnifies the probability of an individual becoming autistic.

Part (b) requires that any claim that the vaccine causes autism under part (a) is subject to the burden of proof. The standard of proof in private/civil law matters is placed upon the plaintiff (the party claiming connection). The standard of proof the plaintiff must meet is proof on a “balance of probabilities”. In practice, this means that the party alleging that the vaccine causes autism (according either to the But For or to the Material Contribution test) must demonstrate that this claim is more likely true than not true (literally, that the likelihood of it being true is at least 51%). This private/civil law standard of proof differs from that in criminal law, where proof is required “beyond a reasonable doubt”. However, it remains severely inadequate to claim that the vaccine may cause autism, or that there is
a mere correlation between the two.

To presume or infer that the vaccine is the cause of autism simply because there is a correlation between the time that the vaccine is administered and the onset of autistic behaviours is either to commit the legal error of shifting the evidentiary burden to the defendant (here, physicians or drug manufacturers) and calling upon them to prove that the vaccines do not cause autism. Or, to appeal to the doctrine of Res ipsa Loquitur, (a Latin phrase meaning “the thing speaks for itself”) which essentially carries the inference that some fact is true, though it must still be proven. Today this type of evidence is discarded by courts.

Problems with the Vaccine/Autism Hypothesis

Everyone is aware of the vaccine/autism court ruling in Atlanta. Autism Vox gives a good summary of the recent events here.

Tonight, Adam and I will be on Global National News to say a few words about the fallacy of normalcy and the vaccine hype -- that belief that one day one's child was developing just fine until blamo -- a vaccine was given and their child was "lost" to autism.

Ah hem. We are autistic in this family and proud of it. We are not "wrong" or "abnormal" and just because some organization (like TACA, Cure Autism Now, DAN! and the like) says you are, doesn’t make it so. Skills dissonance and inconsistency is very common in autism, and it can happen at any age.

Camille Clark made a wonderful comment on Kristina Chew's blog and I'm inclined to agree:

When Hannah was 6 months old, as the family came to grips with the likelihood that she was autistic, ...
But my question is, how much did their conversion to DAN!-ism in the months following Hannah’s apparent regression contaminate their memories of what she was like before and after the vaccines. Somewhere in the year after the set of vaccines in question, daddy began to consider becoming a DAN! doctor himself and both parents had attended DAN! conventions and they started exposing the girl to the typical quack and/or controversial treatments of that time, knowing full well, apparently that she had a mitochondrial disorder caused by a “point mutation” on a gene controlling mitochondrial function.

Then there are conflicting accounts about the timing and cause of Hannah’s diarrhea. I wonder if they tried to reconstruct a more serious sounding vaccine-implicating scenario after having contacted Shoemaker and after having been in touch with other DAN! parents for a few months. Considering that daddy was thinking about being a DAN! doctor they might have been considered celebs at DAN! conferences, etc way back in 2001.

Hannah might be as autistic as any other child, and maybe vaccines changed her by causing a fever, but her mother admits that it’s possible the same thing would have happened to Hannah without any vaccine, with exposure to virus.

And one has to wonder if mom is talking about taking the money to pay for quack DAN! therapies. If so that would be sad.

I would also be interested if we could discuss on these blogs, the difference between legal evidence -- the burden of proof, balance of probability -- versus scientific evidence. It seems that it in this court case at least, the lack of scientific evidence didn’t matter.

It’s about finding something to blame when you want to find something wrong. What about ditching that idea for a while and just keep growing, living and learning -- with autism?
in to The Autism Acceptance Project's office. Something was up with our voice mail that I was not aware of so I am just getting voice mails today -- some which are a few weeks old! The problem has now been rectified.

The Autism Acceptance Project is a volunteer-run organization. Please be patient and someone will get back to you as soon as possible. In the event that your voice mail did not make it through this quirk, please call us back.

**Autism Speaks (doesn't yet talk to me)**

Just to let people know, I recently discovered that The Autism Acceptance Project website and my blog are resource links on Autism Speaks' website. (If you have trouble go to www.autismspeaks.org, then to Community, then resources and then to blogs).

I want people to know that Autism Speaks never contacted me for such permission to link from their site to mine and in no way am I currently affiliated with them. To link to my sites is open to anyone and I will not deny access, but I do not wish the public to think that there is tacit cooperation between us at this time as they have made no effort to contact me personally for a discussion on why I, along with many others, take offense to the way they politic and market autism.

I am open to having a discussion with Autism Speaks on their politics and the problems with it, with other autistic folks. I believe everyone has a lot to learn from each other, but that autistic people have to be at the forefront of this dialogue, and I stand beside them and every effort to make this happen.

I am happy that people from Autism Speaks' site will be traveling here, but in no way am I endorsing their mixed message, as recently seen on Larry King Live as an example of tying in acceptance with a cure for autism. Many autistic individuals and myself have real problems in applauding people "who become
normal," or "who overcome their disability," or "independence" as
the Holy Grail. There is a difference between that expectation and
celebrating milestones. There is also a difference between the
burden of low expectation and the expectation that someone is to
look and become as normal as possible.

The difference is that we accept autism as a valuable way of being
and contributing to society. We accept that autistic people learn at
their own pace and in their own way. We do not hail independendce, although it doesn't stop us from also celebrating
those milestones that may take a person there. In other words, we
celebrate everyone and acknowledge the real challenges not as a
form of pity, but in order to enable and assist others to reach their
fullest potential. I think that those who directly experience such
challenges are far better able to express the dynamics better than
I, but as a mother who strives to understand the challenges my
son faces, and who is beginning to express those frustrations with
others and his limitations in his own typing, this is how I've, so far,
made sense of it all.

I invite Autism Speaks and Larry King to invite me on their show
to discuss the issues and implications of why their message of tying
"hope, cure and recovery" are so problematic and dangerous, and
how we can work as allies to stand beside the autistic adults who
are really paving the way for our autistic children.

On a better note, here is David Wolman's Wired article (The Truth
About Autism -- link on PDF above video) for which he
interviewed me for an hour, but TAAProject received no mention.

PERMALINK POSTED BY ESTEE KLAR-WOLFOND AT 2/29/2008 08:54:00 AM
12 COMMENTS LINKS TO THIS POST

MONDAY, FEBRUARY 11, 2008

Adam Speaks

I have no words yet for this...they are trivial. So I made a video
instead:

PLEASE NOTE: This video was made with the knowledge of
Adam, who has been very happy, by the way, at everyone’s responses and congratulations. From hereonin, he will address HIS readers, directly.

Friday, February 08, 2008

Petition -- Hospital Ignores Family Wishes

Many of you subscribe to The Autism Acceptance Project’s monthly newsletter. In my blog AND in our last issue, Barb Farlow, a mother with a child with Trisomy 13, wrote a piece on how a Toronto hospital issued a DNR without her consent. She has been an active advocate ever since for the rights of disabled individuals everywhere.

Barb directed me to this petition, where Grace Hospital in Winnipeg ignored a family's wishes and issued a DNR without their consent.

Why is this important to discuss and what relevance does it have for autistic people? It has to do with human value and worth and how others ascribe or take away that value. Do hospitals truly understand the great lives we lead with disability in the family? What happens when hospitals get to decide human worth when our non verbal children become ill? Will they think that our kids are "tragedies" and make consequent decisions based on that false assumption? Please consider what it means to sign that petition for our children.

Wednesday, February 06, 2008

Reasons to Smile
As I wrote already, Adam lost his first tooth last week. I had to travel for a couple of days, and the reports from school were that he went to all his friends to continue boasting how he lost a tooth.

"Tooth fell out," as he pointed with his finger. "Tooth fell out!"

Like all kids whose teeth fall out, he is really fascinated by this so much so, he is interacting and telling his peers, I think, more than ever. Yet, Adam can quietly work alongside them, even WITH them -- currently he is learning the map of Canada and already interested in the provinces. He knows were Nunavut is. I do not (except that is far North somewhere). As Adam's classmates come to know him, they accept that he doesn't talk much, and they jest me that I come too early and peer at him. Adam, who has only been at this school for a year now, likes to push me away from recess and doesn't like me to come and get him before his classmates also have to leave. For us, that is really something.

Adam has also started his first REAL piano lessons. We loved music therapy, but I thought now is the time (since he is interested) to learn to really play.

Here he is with Grandma (grandparents are wonderful and patient teachers) as he has to learn to count and move and study his fingers. He already knows how to count and move his fingers, but this is a piano exercise. I'd say he's already got it down pat.
So, there are many reasons for us to smile as we continue to grow and learn.
Adam swimming without life jacket end of 2007.

What have you learned in a year? What has happened in a year?

It's what I come to think of when I look at recent photos of Adam and realize that nearly 6 years have gone by since his birth, a little more than four since he was diagnosed with autism.

I have had a lot to learn and a lot to say since then. It's exciting to feel as at home and at peace with life as we know it, and I often think about those early days (maybe some of you are experiencing them right now), when we possessed a lot of fear and our days were obsessed with trying to make Adam less autistic.

Long gone are those days useless days of fear as he succeeds as an autistic person. I can't say I'm a proud autistic person, but I'm certainly the proud mom of one.

Anyone want to write about what a difference a year has made for you?

Doctors Speak Out Against ABC Autism Program (but ABC refuses to listen)

Tomorrow night, this program will air on ABC. Today, our Toronto news media have spoken out also against the airing of the show,
stating that "ABC will have the deaths of thousands of children on their hands." Entertainment or not, ABC should be held responsible for the perpetuation of fear and inaccurate information that vaccines cause autism, which for a long time now has been disproven by science.

But many of us know, that empirical evidence means nothing to marketeers who have so much to financially gain from "alternative medicine."

Of course, as an individual who speaks publically about how the media does damage to autistic people, perhaps we can all send an email to ABC stating whether under the guise of "entertainment" or not, the proliferation of inaccurate information is damaging to millions of individuals. Email ABC here to post a comment on their message board.

"I wish to propose for the reader's favourable consideration a doctrine which may, I fear, appear wildly paradoxical and subversive. The doctrine in question is this: that it is undesirable to believe a proposition when there is no ground whatever for supposing it true."

-- Bertrand Russell, 1935, *On The Value of Skepticism*

SUNDAY, JANUARY 27, 2008

**Another Milestone**

Adam lost his first tooth today while eating his chocolate ice-cream bar for dessert. Were it not for his wisdom in passing it to me -- this hard thing the size of a kernel of corn that I thought was a foreign object in the ice-cream, I would have never been able to store it in the silver-case-for-first-teeth someone gave me when Adam was born. I keep every first -- first pair of walking shoes, first outfit, first lock of cut hair and now, first tooth. Of course, I was excited as Adam lolled his tongue around the empty spot, then his finger -- the feeling so foreign. I showed him his lost tooth in the mirror and he smiled. We wrote a story about it and that...
tooth fairy that leaves money under the pillow to buy candy (so he can lose more teeth), in the morning. Then, I pulled out the Brother label maker and we had a little bedtime conversation I wish to share. While Adam's verbal ability increases little by little, he has a difficult time with conversation and full sentences.

"Adam," I proceeded to ask, "what happened today?"

He typed, "I lost my tooth."

"How does mommy feel about that?" I asked.

"Mommy is proud," he wrote -- all on his own.

He then typed out some other "feelings" he has been learning on the computer such as sad, angry, ecstatic. I realized these were the feelings he is learning from this particular program to which I said, "that's right, we were talking about mommy's feelings and those are feelings too."

Adam had spent the day playing at his friend's house -- with Daniel and his brother Brandon. He had spent nearly five hours there and I had left him there to play. He did not wish to come home (nor did I blame him after four days being cooped up at home with the flu). So, of course I had to ask,

"How do you feel about Daniel?" to which he replied, "I like duno." I guess names are a little more difficult to spell.

I've been watching Adam play on his computer, read books since he has been nine months old, copy words from reading to paper (even though his hand-writing is still difficult to decipher). And all it has taken is a little concerted effort, some directed questions, a Brother label maker, and a child's electronic dictionary. Okay, and a literacy program, and a good inclusive school, and some great people who work with us every day.

For this mom anyway, having conversations no matter what the form, is just as exciting as the lost first tooth.
By Design

Tomorrow, Henry and I are hosting a conversation dinner on the buildings we admire with the purposes of how we wish to develop our city. It is something I used to be passionate about as an art curator with an avid interest in public spaces. Living in Canada was always gray in the winter, with mediocre architecture. North American design has often been about about economy, efficiency and utility, while beauty has been considered a frill. Only our houses of art and music that have been sponsored by wealthy families have been the most inspired -- like old cathedrals. Perhaps our universities have brushed us lightly with a molding of history here, an arched doorway there. Canada does not have a lot of history.

So I had to think about my favorite building and what I came up with was a myriad of public spaces -- many of them in Europe that I encountered while living such as the Freiburg market where I used to buy my seven-dollar broccoli on a student budget. These markets are always near the city halls and cathedrals. Cathedrals were places where the public slept, commiserated, socialized and exchanged goods. When I was alone in Europe, the Freiburg cathedral was a quiet place to think in the evening. During the day, the market hummed with voices and the smell of coffee invited breaks at umbrella-tables outlining the cobblestone square. It was a place where people gathered everyday, and where the brautwurst-stand provided a student with a cheap meal. It was this culmination of everything -- grandiosity, history, beauty, commerce and community that continues to make it a successful public design.

Whenever I am out these days, I always look for accessibility that reflects our values and our community. I look for curb-cuts, easy access for people in wheelchairs, or for moms with strollers. I always look for nature, for beauty and that which soothes us. I pay attention to the piercing noise at malls -- as I feel assaulted with beaping vehicles, music blaring from within and without stores, and the scents of many things -- all indoors. I am painfully aware of the lack of access to malls on foot, to many of our food stores.
Sometimes, it's just too hazardous to walk, and in Toronto, the pedestrian no longer has the right of way, even though it is still a law.

We have built villages for cars -- not for people. When I see people think about design, I really appreciate it. From well-planned classrooms to an outdoor market, I feel a sense of relief. When I see a well-designed (barrier free) environment that soothes, rather than built with steel-like utility, I feel that the person for whom it was built was respected.

I wonder if the lack of access and thought about aesthetics not only reflects our thinking about the disabled, but also about humanity, as it doesn't seem that we truly respect ourselves and our need for each other. We certainly are not building for it.

"How is a village a village? By including young and old, white and black [disabled and non-disabled], rich and poor." -- Anonymous (brackets mine).

PERMALINK POSTED BY ESTEE KLAR-WOLFOND AT 1/23/2008 03:41:00 PM 1 COMMENTS LINKS TO THIS POST

TUESDAY, JANUARY 15, 2008

The Burden of Proof

Adam and I have been busy. He's typing out more sentences and we're talking a lot about how he feels about things (as opposed to the barrage of questions about what he knows which is a very ABA way of questioning children). Even though I know Adam has a lot to say, there is always more than what I think I know, which is why parenting is humbling experience. Adam likes Van Gogh's "spots" (referring to pointillism) he said to me yesterday. Then, in writing on a keyboard later he said, "I like the ocein," when I asked him what he liked about Florida. Even though a parent can intuitively KNOW one's non verbal or quasi verbal child is intelligent, I think we can't really know what lies within anyone until it is expressed. I am not saying do not assume a person is intelligent or that they are not communicating without words - we know that communication is more than words. It's just that words and symbols are very powerful.
These moments of clarity, punctuate my belief that to really know one's child is an act of guidance and then ultimately in letting-go. We just *do not know*, therefore we must be very aware of our own limits in thinking about things. It is why we have the phrase "make the least dangerous assumption." It is why I believe that our children are so incredibly awesome. It is, if I were to talk esoterically about knowledge, the difference between creating changeable frameworks that we apply to all kinds of things for our own understanding, versus realizing that nature and humanity cannot be framed. Every time we try, the picture shifts. So imagine the most amazing things!

So now I am going to explain how I felt when I took Adam to a popular horse-back riding program here in Toronto for kids with special needs (not the subsidized one so I'll keep you guessing). Adam, who is averse right now to putting on things around his ears, had a riding helmet thrown on his head as soon as we arrived in a big barn on a cold day. A big strange guy came up (we're talking on his first day), and threw him onto a white horse, without even introducing himself. Whoa! I expected them to introduce Adam to the horse, let me come along for the walk, get used to the helmet. I did not even expect that Adam would be on the horse the first day!!

"We know what we're doing," the big-guy said to me, trying to reassure me. "Don't worry," his partner joined him from the side as Adam was swiped away from me high on the horse's back. "We work with autistic kids every day." *That* was a red flag. I felt my innards tense. Anyone who says that "they know what they're doing"...be forewarned. It is the reason I am writing this post. *None* of us knows a child that well.

Adam cried and cried and cried. "I want to go...I don't want to!" he bellowed as they said "touch your legs." And he did -- in the midst of crying, his little round face all red, his eyes tired of not being listened to, yet responding to them obediently in hopes that they would finally listen to him.

"Say, 'move on Snowman,'" they asked. He would have said anything to get them to let him off the horse. His little voice was becoming raw, and still so small and fragile. "Move on Snowman," he said between gasps of mucous-filled air.
Now I'm getting pissed (with myself and the situation), while hoping that maybe he might calm down and begin to enjoy himself. I am putting on a fake smile, waving at him, trying to reassure him that I'm right there at the end of the long barn. I am feeling pressured from our old ABA days that I'll be judged for wanting Adam off the horse, and am distressed at my uncertainty at this point of what to do. I hate those stares I get from instructors that I am just the mom and they are the "experts." There are some of you out there that I'm sure will know what I mean! How terribly arrogant those stares can become.

"Is your child high or low functioning?" asks one dad as he approaches me while I am absorbed with Adam and his safety. I feel like I'm on the wrong planet, in the wrong place. Is it worth it to go on a diatribe how there's really no such thing as I listen to his feet squishing towards me in the mud. Do I need to justify Adam's intelligence despite the fact he is autistic? I move away and end up responding with little interest, "I don't think of him that way," and leave it at that. The dad looks confused as I leave him in the muck infused with the scent of horse.

I mumble in hopes that the parents who tried to also reassure me: "Yes, we remember when our kids cried in ABA," would hear me as I said aloud to myself, "They don't respect him. He is saying he wants to go." Yes, I am doing it on purpose, but also because I am feeling under attack. I move away and focus on my Adam some more, sucking in the air between my teeth, pondering my next move, feeling their eyes on me, then back to their own children. I watch the other kids as they obediently follow directions. Yet, I don't want Adam to just follow directions. I am proud, actually, that he remains upset and tells them that "he doesn't want to." I am not happy he is upset, but at least it is human. His will has not yet been broken.

"Can I get him off, please?" I ask the two 'instructors,' not realizing that this was an ABA horseback riding program. At least it wasn't stated on their website. They look at me as if my intervention will blow their break-the-kid's-will-and-they-will-begin-to-enjoy-it-approach to obedience. I pull Adam off the horse and also take the helmet off that has been visibly bothering him through the entire ride. His pants were bothering him and the instructors didn't help him out or even acknowledge his discomfort. "Walk on Snowman," and "touch your legs," seemed top of their agenda. Adam's
responses pleased the instructors. After all, isn't much of the purpose of intervention to please the adults who do it? (Pause for self-reflection).

"Calm down Adam." I crouch to his level and pat stroke his head, being very quiet. He stops crying immediately. "Let's look at Snowman together." I pat Snowman, I wear the helmet. Adam is watching me. "Do you think you can try again?" He pulls away, but I ask him to give it another try. We are not the giving-up kind of folk. He tires of crying as he whimpers, still very unhappy. We finish quickly after that.

"Many of our kids cry like that and eventually they get so tired of crying they begin to enjoy it," says the big-guy who has decided to follow us to the car. Adam's hands feel like ice and I am anxious to get him warm again. I am trying to give the "go away," body language. "Uh huh," I say un-enthused. I want to attend to Adam whose eyes are still red and watery.

It just may be that the kids learn to enjoy it -- the big-guy might be right. In fact, I don't doubt it. Yet, if Adam had been given time and patience, he may have gotten on that horse willingly as I have put him on ponies many times before. Adam loves so many things and he is usually not averse to new experiences.

But when I was EXACTLY Adam's age, my dad also put me on a great big horse and I freaked out. BECAUSE I COULD SPEAK AND WASN'T LABELED AUTISTIC, he took me right off and respected my desire to have nothing to do with horses for a while. I may have gotten used to it if someone forced me. But forcing wasn't the point. Forcing Adam has never worked for him (or me for that matter). Patient introduction and persuasion helps us get through the fear-factor. With myself as a child, I eventually wanted to do it on my own. I have a healthy respect for horses and don't ride them often.

You see, I wanted Adam also to enjoy himself. We get sick and tired of therapy. Everything for disabled and autistic kids is "therapy." You can't find ONE program -- be it a music teacher or anything unless it is labeled as "therapy" therefore "making the child better" [than they are]. We are not looking for therapy anymore and I hope there are clinicians and professionals reading this in order to be hired as teachers, not therapists -- people who
can open up new worlds and help with filling in gaps where we need extra help, and hopefully who have fun engaging with Adam. We are looking for equal opportunity to learn and be a part of many programs. We are looking for a chance to learn new things. Adam wants to be with other kids. We are looking for people with patience and maybe some understanding of the nature of autism and an understanding of how Adam might be good at learning these new things.

Because he's autistic, and I have to assume this as I did not see evidence to the contrary, those instructors ignored his requests, they didn't give him a break until I intervened, nor did they understand Adam's NEED, be it because of autism or not, to be gently introduced to the idea of riding horses.

Finally, I am upset that ANY therapist has such control over us as parents -- that they make us feel unsure about our parenting. It is particularly so right now in our autism community. Those seeds of doubt must exist in every parent. Be it from teachers and other people in positions of authority telling us parents what our kids should be doing and how they should be doing it -- parents need to have greater confidence in the way they want to parent no matter what kind of child they have. This might be even more important for parents with special needs children to assert these needs and desires.

In autism, and I introduce this sentence as such because that's what I am on the journey with, there is a difference between teaching skills and letting a child know their value and enabling expression. One cannot exist in isolation of the other, yet too often the focus is always on teaching skills. So here I was, standing there, letting my gut wrench primarily because I didn't realize that the "we know what we're doing" people were practicing ABA. And if they didn't do it knowingly, they did it anyway. They assumed that Adam should comply with their requests, to prove and show what he knows. Some might call compliance a form of skill-teaching or a basis from which to learn new skills. This program wasn't about enjoyment. It was about obedience. Adam had to prove himself in an environment that expected little of him, with people who cared nothing of him, and who thought that they knew everything there was to know [probably] about autistic children. That is the world that we are creating for autistic people, folks -- a place where all of Adam's energy must be placed on proving his value and his
intelligence, not enabling and valuing his expression, or letting him move on in life without the burden of proof.

Needless to say, we won’t be back there. Who knows if they have truly created a horse-aversion for the rest of Adam’s life. Yet, we will try again another time, if Adam wants. Some experiences we try end up being terrific. We try regular programs, "special" programs -- some are good and others not. Yet, I have to say, I am grateful that Adam does not go to an autism school, at least here in Toronto. I would fear that he would always be so incredibly underestimated.

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**Resolutions and "Realities"**

"*The systematic denial on science's part of personality as a condition of events, this rigorous belief that in its own essential and innermost nature our world is a strictly impersonal world, may, conceivably, as the whirligig of time goes round, prove to be the very defect that our descendants will be most surprised at in our own boasted science, the omission that to their eyes will most tend to make it look perspectiveless and short.*" -- William James

The wind is blowing in Toronto today. Up to 100 kilometers per hour. Just the right kind of wind for me -- the strong wind that can clear the cobwebs and symbolize new beginnings.

And so I wish you all a Happy New Year. I started mine with a health scare (my brother-in-law welcomed me to the perils of "middle-age") which is why I haven’t written that much over the past month. Turns out I’m going to be okay. In the meantime, I spent the holidays so happy with my Adam. The way his hair swept in the breeze, the way he smiles and is so affectionate with us all. At the sudden possibility of my becoming very ill, I wasn’t scared about the "future of Adam" anymore. I know, it sounds strange. All our time as parents and we fret about who is going to "take care" of our children when we’re gone.
I had to spend the last four weeks wondering and preparing for just that. While I was certainly, upset, that people compare autism to cancer in my situation and the circumstances of my mother who has gone through cancer twice now, I was scarred at only having to possiblyMISS Adam's future and all of his remarkable and ordinary moments. And then, considering that there are things simply out of our control, I thought that the one most important obligation we have as parents, is to have faith and let go of our children -- no matter what their "needs." I don't mean to give them to institutions -- heaven's no. I mean to believe in them and let them grow without strangling them with our selfish worry.

I had to think of the possibility that I would become very ill over the next few months. I had to think of all the people I have faith in, and with who Adam has forged his own relationships with, and rely on those people and Adam to continue. I had to drum up the trust I have in Adam, even with his age and vulnerability -- that he would have to "speak" for himself in whatever manner he would.

While I waited for my tests, I spent time enjoying Adam, reading books with him, still teaching and guiding as parents do, but I was very relaxed with him. We had lots of fun and he began to speak more. He wants to play with other children and I enjoyed watching him make his own kind of initiations. He played a terrific Simon Says. We snuggled on the Florida beach where my in-laws live, watched some thundering waves, and we were very content. I'm not saying that it was just my being relaxed that Adam "progressed" (in fact I'm tiring of that word because every human being evolves and the brain is malleable and fluid and everything always changes). I'm saying that we were relaxed and as a result, I probably could just SEE and appreciate more in and of him.

As part of my commitment to my son, I will finish my book this year and spend more time playing with him. Playing music, ball, Simon Says, and other marvelous games. Not to just "teach" him, but to be with him. I truly enjoy him. I think learning comes from being with and doing things together. When we spend too much time hypothesizing what autism is and why autistic people do what they do, we tend to miss everything. We imprison autistic people to our low expectations, often based in false or ever-evolving theories, and we so limit ourselves to the many possibilities and gifts that people -- all "kinds" of people -- bring us everyday.
You won't see me engaging in every autism news item this year. You won't see me publishing the derogatory comments that I sometimes receive from others on this blog, and you won't see me respond to questions on how to "treat" your autistic child, or acknowledge how you think I should raise my son. You see, I expect Adam may read this one day. I have personal difficulties in making any suggestions as to how someone else's child should be raised because the same choices in raising any other child also belongs to an autistic or any other disabled child. No government-mandated and segregated "autism program" or "surveillance list" will limit us or our options, and Canadians might wish to rethink the backwards direction such "programs" may be taking us. If anything, I will celebrate our children with you, share in the challenges created by obstacles unnecessarily placed on front of our kids and the adults today who are paving their way.

This blog speaks for itself and for the way our family lives and the choices we've made. The last thing we all need is another "expert" in the overwhelmingly vast sea of false ones. God knows it is those "experts" that compelled me to write a blog and a book in the first place. I will work with others who wish to improve the quality of service, education and inclusion for their children -- which, in my opinion, should be based on the inherent and natural being of the autistic person. That, dear friends, is called FREEDOM. Freedom to be, to roam, to have the education one deserves. I believe in working steadily and diligently in bettering opportunities and changing attitudes, but not worrying in order to "make things better," or "to get more services."

We will hear different interpretations of life with disabled children and they will collide with the interpretations of many other autistic and disabled individuals. One person may ardently claim for "scientifically proven treatment" based on their "reality." Another may claim their right to freedom -- the freedom to be disabled or or the freedom to have options for their children and for them to be included in schools and society. Wallace Stevens said "reality is the product of the most august imagination." We assume there is only one reality, one code, one cause, one "scientifically proven treatment." We have believed that one day, science will solve everything, says Jonah Lehrer (his last names ironically means "teacher" in German) in his book Proust Was a Neuroscientist. Yet, life as in art, is what we make of it. It is
how we paint, weave and write it. And from such constructions, science attempts to deconstruct life -- from how we experience it. Lerher points out that artists like Walt Whitman and George Eliot "witnessed the birth of modern science...[they] contemplated Darwin, Proust [and] Woolf admired Einstein -- they never stopped believing in the necessity of art. As scientists were beginning to separate thoughts into their anatomical parts, these artists wanted to understand consciousness from the inside. Our truth, they said, must begin with us, with what reality feels like."

The challenge of the year as I see it, begins not only with scientific deconstruction, but with listening to experience, particularly the experiences of autistic people. Their art, their writing, their political activism are not pretty little pieces or trite ramblings we can consume on the margins and forget about while the scientists do the "big" work and enjoy our research dollars. Both art and human experience must inform science, not the other way around. It is perhaps this trend to view medicine and science as the explanation for all things human, the faith in "scientifically proven" and the marketing and the money that gets poured into such promises, that disturbs me most of all. For there is no code that is written that can truly illustrate or explain every human soul.

"Science needs art to frame the mystery, but art needs science so that not everything is a mystery. Neither truth alone is our solution, for our reality exists in plural." (Lehrer)
Latimer, Judge Rotenberg Center (the article in the New York Times that seems to justify, again, its existence because kids are "too tough" to handle), and today's rather interesting but also perturbing article in the NYT (sorry, I can't link to articles on this computer so search for December 28th's paper), on variations of DNA. All of it would make you think there are serious epidemics going on rather than science beginning to find the distinctions between us. Will it really help us to assist our children? Will the barrage of labels really serve to understand various individuals with disabilities?

I haven't uttered "autism" once here, because it won't make any difference. Adam plays, he swims, he tried to kiss his first girl (other than his mother and grandmothers), and more. No one is passing judgement on him here, even if he can't speak that much (or is afraid to because he may also be so aware that it is more difficult for him). I don't feel the need to justify him or his way of moving and being in the world. As my mother-in-law can attest, he is "magnificent."

My friend with two disabled children is here too. She said to me last night, "it makes me so sad to think that there won't be any more people with Down Syndrome in twenty years." I think she has summed it up for many of us parents with genetically different kids. We don't see the problem, here. (Well, I can think of a couple of bloggers who think there are major problems, and as they are parents themselves, I cannot relate to them whatsoever). It is only the medical profession and the media which profits from such a gaze -- the medical gaze, if you will.

If you decide to read today's article in the New York Times, you might be thinking something like me: I can imagine a day when our kids are sitting in a bar, having grown up in a generation of label fanatics, thinking of themselves as quirky, maybe even deficient and living to tell about it. Hopefully they will have rationalized it and come to define themselves on their own -- without their labels. Adam may ask to buy a girl a drink and say, "Hey baby, what's your DNA."

But with the undulating wave of gloom that persists -- be it the Planet in Peril, the wave of health epidemics for which we must DO something, I can only hope for such wonderful sarcasm and such a strong sense of self.
Ransom Notes Campaign is over (but negative media and representations are relentless as I accidentally catch Dr. Phil)

Our petition worked. Thanks to everyone who came aboard to sign the petition against this campaign. The Ransom Notes Campaign is over. Here is their public statement.

However, as I write this, I am watching another "horror" show about autism on Dr. Phil, which demonizes an autistic boy. One mom talks about how the "divorce rate is so high" with autistic children (which is unproven), and how she wishes her child would die before her so that she wouldn't have to worry about what might happen to him when he dies. Sounds eerily familiar to Allison Tepper Singer's wish to drive over the George Washington Bridge with her autistic child, and which she said with her autistic child in the room.

Dr. Sears is on talking about recovery. The video of the autistic kid who has "fully recovered" scoring the touchdown is on. That mum is proud. Again, best if your kid can be a champ, as Dr. Phil insinuates -- better if all autistic kids can become normal. I'm giving you a play-by-play here. Now parents talking about how autistic kids can be abused by teachers -- yes that unfortunately can happen by people who think autism is just a set of behaviours or who are impatient. I wish we could focus on understanding autism in a show, rather than the horror. Where are the autistic adults?? Why weren't they interviewed on Dr. Phil??

I just want to remind people how the Autism Speaks video said many of these things -- the divorce rate stuff, the murder, how hard it is. I want to repeat how when one thing is said, it is repeated in the media (especially by sensationalists like Dr. Phil). It gets repeated by parents. It gets obsessed about. People believe that autism is just a nightmare. It gets repeated so much that people cannot fathom not believing it. So, it must be true.
So much so, need we remind you of the abuses and copycat murders that transpired after Autism Everyday was aired. As a friend mentioned recently, we never hear about Katie McCaron through Autism Speaks. They just don't acknowledge her.

I propose that we all send a letter, once again to Dr. Phil, to thank him for "trying to help," but to at least provide a more balanced view of autism and help us also celebrate the achievements and lives of autistic people, while we also address our challenges. Next time he does a show, it should be full of autistic adults and those of us who are also happy, and coping, with our autistic children.

Autism isn't holding us for ransom here

Thanks, Dinah Murray, for illustrating the hideous marketing from NYU Child Study Center in the video below.

Thank goodness I've got my son, and not them and not whatever they claim to have "kidnapped" him, cause it sure doesn't look like the Autism we know. You see, autism around here looks normal to us. It looks friendly, it still learns and grows, and it makes our family happy when it smiles. It's learning to type, it's learning to swim, it goes to school with other children and it seems quite happy there. It likes to travel and tends to speak more when relaxed and seeing new things. It likes to jump and likes to run and is just learning to ride a two-wheel bike. It likes to play musical instruments and likes to coordinate its beat with its music teacher. It reads signs well and is learning about dangerous things. It sure doesn't look like it's holding anyone for ransom here. Our son knows he's different, even if he doesn't know who your Autism is, and it's only what you make of it that he will be fully aware of. You can choose. You can tell my son that Autism is holding him for ransom or you can tell him that he's free to choose what he wants and he's alive, and beautiful and we are all here to help him succeed.
Please sign the petition Dinah makes reference to here.

Please read yesterday's post Pity: It's 100% Curable just previous to this post to contrast videos and campaigns.

SUNDAY, DECEMBER 16, 2007

Pity -- It's 100% Curable

Talking about fear-marketing at various conferences throughout 2007 and it seems that the work is never over (I will be speaking at the University of San Diego in January for those who wish to attend). As the year closes, I’d like to focus in 2008 on not just what is so destructive for individuals by marketing fear and how that leads to MORE stigma, but to focus on what disabled people do so well and what they DO contribute to society.

This will be my 2008 theme -- making such comparisons and critical investigations. My current studies and papers include a look into disabled art and performance and how it has criticized the "normalized gaze," and our popular notions of cure. I will also continue to look at how organizations "market" autism and disability -- be it overly positive as to glaze over the issues disabled people face and so make the so-called "typical" society feel better, to "acceptance" campaigns that don't really accept, to campaigns and films like Ransom Notes or Autism Speaks' Autism Everyday Film and the overly negative and generalized media attention it derives. I hope that all of us can look to ourselves, how we grew up, and challenge our conceptions of disability and "normalcy." I like to use myself as an example -- a neurotypical girl who grew up with virtually no disabled people around me; who ignored the mentally challenged boy from down the street as a child because of peer pressure (and fear); I consider myself an example of how to challenge and hold oneself up to criticism everyday FOR THE SAKE OF MY SON, and others like him. I credit Adam for at least starting my journey in changing my world view.
Thanks to a couple of friends of mine who pointed me to the Gillette Hospital Foundation’s Cure Pity Campaign. Here is what the copy says on their website:

Most of our patients have medical conditions for which there are no cures.

But through breakthrough surgeries and innovative medical treatments and therapies, we are able to help them overcome some of the barriers they face so they can lead more normal, joy-filled lives.

That’s what we’re trying to communicate with this campaign. That Gillette does provide a cure for one of the most insidious human conditions of all—pity.

We ask you to look beyond the disabilities and see the spirit, resiliency, and determination these children embody.

In these videos, you will see children of various disabilities who are showing us what they can do. No hype, no fear...only what is possible. In the wake of the Ransom Notes Campaign and Autism Speaks' relentless fear-marketing, there are a few of us who would like to suggest that every time you see some fear tactic, that you make a donation to the Cure Pity Campaign of The Canadian Down Syndrome Society of Canada -- the latter which has major billboards up here in Toronto that say "Celebrate Being." Self-reflection is really important. Listening to communities who are effected by such negative campaigning is even more so and our Canadian organizations can no longer act as if the voice and concerns do not exist and are not valid. With one in seven Canadians recently reported with having some kind of disability, such campaigning may effect most of us in our lifetimes. It may effect our ability to be treated fairly and with respect. It may effect someone's view of us, as they may ignore us altogether BECAUSE we are viewed as incompetent as a result of disability.

Take a look at this story from the UK Telegraph:

Myles Fitzpatrick, a 10-year-old autistic boy who saved his mother's life after she suffered a near-fatal asthma attack, was among those honoured at the star-studded service in Westminster Abbey, London.
Despite severe autism, which means he is unable to carry out even simple instructions, Myles dialed 999 and directed paramedics to his home after finding his mother fighting for breath.

As a good friend said, fear is good when you want to make people STOP something, like drunk driving. Fear immobilizes. **Hope mobilizes.** If you feel hopeless from all this negative campaigning, go to these sites and keep perpetuating LIFE and something tangible for our children's future. **Send a strong message.**

Thank you Ari Ne'eman

Thank you Ari of The Autistic Self Advocacy Network (ASAN) and others who supported the petition drafted by his organization. Ari's work to demand the withdrawal of the New York Child Study Center's Ransom Notes Campaign has been run in the New York Times, The Wall Street Journal's Health Blog, and the New York Daily News.

I once again call upon you out there to sign this petition. This campaign is not okay. It does not consult the very people it claims to "help," and it continues to perpetuate the fear and stigma it so
Is ANY publicity "good" publicity?

I am sorry I haven't been around to write about the New York Child Study Center "Ransom Notes" Campaign until today. Here is some more reference to it. The Autism Acceptance Project has signed in support against this campaign with The Autistic Self Advocacy Network. The Gimp Parade, Not Dead Yet, Whose Planet Is It Anyway, Susan Senator, Autism Vox, Alex Bain, and others have written on this and I urge you to read, if you have not already, or click on Autism Hub to read more from other excellent bloggers.

I was even more stunned when one of our friends, upon stating her disappointment over the campaign received this letter from its board of directors:

Dean Robert Grossman, Michael Recanati, and Ira Statfeld forwarded your email to me, and I am responding on their behalf.

The NYU Child Study Center's "Ransom Notes" public service campaign is designed as a provocative wake up to create awareness and spark dialogue about childhood psychiatric disorders, one of America's last remaining silent public health epidemics. Twelve million American children and adolescents face daily battles with psychiatric disorders. Untreated, these children are at risk for academic failure, school dropout, substance abuse, suicide, unemployment, and imprisonment. Children who do receive appropriate treatment, however, can
"Ransom Notes" may be shocking to some, but so are the statistics: suicide is the third leading cause of death among young people ages 15 to 24, and serious emotional problems affect one out of 10 young people, most of whom do not get help. The strong response to this campaign is evidence that our approach is working. We acknowledge the challenges faced by individuals with these disorders and their families. We hope to both generate a national dialogue that will end the stigma surrounding childhood psychiatric disorders and advance the science, giving children the help they need and deserve. We want this campaign to be a wake up call. Please join the dialogue.

Harold S. Koplewicz, M.D.
Director, NYU Child Study Center;
Arnold and Debbie Simon Professor and Chair,
Department of Child and Adolescent Psychiatry;
Sr. Vice President and Vice Dean for External Affairs,

As the ASAN letter says,

While the “Ransom Notes” campaign was no doubt a well-intentioned effort to increase awareness and thus support for the disabilities it describes, the means through which it attempts this have the opposite effect. When a child with ADHD is described as “a detriment to himself and those around him,” it hurts the efforts of individuals, parents and families to ensure inclusion and equal access throughout society for people with disabilities. When individuals with diagnoses of autism and Asperger’s Syndrome are told that their capacities for social interaction and independent living are completely destroyed, it hurts their efforts for respect, inclusion, and necessary supports by spreading misleading and inaccurate information about these neurologies. While it is true that there are many difficulties associated with the disabilities you describe, individuals with those diagnostic categories do succeed – not necessarily by becoming indistinguishable from their non-disabled peers – but by finding ways to maximize their unique abilities and potential on their
Individuals with disabilities are not replacements for normal children that are stolen away by the disability in question. They are whole people, deserving of the same rights, respect, and dignity afforded their peers. Too often, the idea that children with disabilities are less than human lies at the heart of horrific crimes committed against them.

I urge everyone to sign the petition against this very dangerous campaign. Not all publicity is good publicity. All we have to remember are the recent mall, church and university shootings to know that. I also think that most of us agree when the rampage of negative campaigning does not reduce stigma -- it only increases ignorance and fear.

YOU CAN ALSO COMMENT HERE AT TODAY'S NYT ARTICLE

PERMALINK POSTED BY ESTEE KLAR-WOLFOND AT 12/13/2007 04:29:00 PM
5 COMMENTS LINKS TO THIS POST

FRIDAY, DECEMBER 07, 2007

Happy Holidays from our Board

Let me introduce to you The Autism Acceptance Project’s Board of Directors: Bottom Row from left to right is,
Andrew Brown, Ellen Yack, our new President of the Board in centre, Michael Moon (who was recently featured in The Ottawa Citizen which got cut-off in this online version), my son and honourary board member, Adam Wolfond, Mira Davis-Kelly (part-time assistant and designer of our online newsletter), and myself, Estee Klar-Wolfond.

Top row from left to right is,

Brian Henson, Martine Stonehouse, Jamie Gold (active advisor), Mark Persaud and David Hill.

We look forward to continuing to lecture at schools and universities in our community and abroad, to conducting support groups, and educating governments with regard to the various needs of autistic individuals and to enhance understanding. We also look forward to further developing a very active membership of autistic Canadians at this governance level.

The Board of Directors wishes everyone a peaceful holiday season.

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**Monday, December 03, 2007**

**Live Strong**

I was just in NYC this past weekend for the Michael J. Fox's Foundation Gala. Henry insisted I get this photo with Lance Armstrong. So, in keeping with the "Live Strong" theme, I'm going to express it in the name of autism.

Also, I didn't have a chance to post Roger Collier's article from the Ottawa Citizen until today -- Autism Reconsidered. I also post it here within this theme.

I really like the article, compared to how other journalists have mostly written about autism to-date, almost always over--
simplifying a very complex matter. Most of all, I like the ambition and intention of non-autistic people who strive to understand the views of disabled and autistic individuals.

When I say in the article that Adam "regressed" because of the ABA that was conducted early in his home before he was two, he did. He has progressed without the use of it, exclusively. What I mean is, the "breaking some tasks into small parts" bit of teaching is something we do often here in our home. Yet with many instructors, ABA or otherwise, he lost some of the skills that he came to acquire on his own. He learned mostly with play therapy, music, exposure to new things, videos, computers and more. I found many therapists did not understand his learning style. I found that they tried to squeeze him into a box in which he did not fit, and those who used the method, or who had low expectations, made him anxious. I found that some therapists did not respect our family values (one told me that nursing Adam still at two was wrong).

Often when you hire someone to assist you or members of your family, they see their role as having to fix things. I wonder how much of this is an encumbrance on them as clinicians? I also wonder how much of this expectation from families shape a clinicians approach to autism? I will admit, there were a few who came into our home -- at the time of our early expectations of eradicating autism -- who said that we had to "accept" Adam and "enjoy" him. In those days when the fight seemed the more honorable route, I got angry with people who didn't want to battle his autism with me because it felt like giving up. At the same time, people who say "accept" should not beleaguer us with their low expectations. Here's one more definition of acceptance: it means that Adam is just as entitled as anyone else -- no less valuable and no less human.

What if we didn't construct a system for autistics that focuses just on fixing them or extinguishing autism? What if we focussed on their innate ability to learn? The wholeness of the child (for lack of a better word but I use it since our kids are conversely often referred to as broken). I want parents, like me, to have choices. We don't want to be fixed. We want to learn, grow, live and be included. Acceptance has propelled us forward and Adam is included in a "regular" school, with an aide. Acceptance has not forced us into isolation.
We did not pull Adam out of all therapy, so if you hear from others that I advocate "doing nothing" for autistic individuals, they are misconstruing the message. In Adam's case, we had to modify the approach to his therapy, and those modifications are always occurring as he changes and grows. I am all for one-to-one assistance. Also, those who want to claim that I am against ABA are mis-characterizing me and the role of The Autism Acceptance Project. There are many people who traverse this path and who love their kids, and I know many families who have little else to acquire here in Canada, so they are working with their teams in the best way they can. Yet, I haven't met one fully satisfied parent. The real fact is, in Ontario, there is little choice in what families can acquire in the name of support, and the overriding view of autism is that it's a horrible thing, which of course, I don't believe. I believe that view is extremely damaging to our children. I know there are challenges - some of which are rooted in perception, others which are real, perhaps exacerbated by lack of understanding and support.

If ABA (which ABA instructors are beginning to say in their classrooms does not work for all autistic people, and who are already expanding their methods outside of the ABA box), works for a family then they should get that assistance (and perhaps the ABA community might feel some solace in knowing that their child's right to assistance need not depend on devastation rhetoric). I am ready to acknowledge that ABA has evolved and it is not pure ABA anymore anyway. What needs changing is an evolution of our understanding of autism from autistic people as well as research that helps us learn the best way to assist autistic people -- from family attitudes to medical approaches to educational methods. We may also need to accept that our community will be diverse within itself. As in the deaf community, there will be branches of belief systems and some of these viewpoints will be influenced by whether or not parents share the disability, or at least share in a sensitivity to "difference."

Back to services, if I need an AAC device and training for my son, then I should be able to get that for Adam without having to travel to the U.S. to find that expertise. If I want my son to be included in the school system, and I want to hire an aide who will assure his safety and learning, then schools should accept that as much as a seeing-eye dog should be accepted. If we are all committed to
finding the best ways of assisting our children as well as the adults living autistically, then it can be positive. What I fear is a kind of re-institutionized-like policy for autistic people -- that all autistic kids must be surveilled and go to segregated schools. If the program of surveillance is to simply re-assess a child's need (a child diagnosed early may have been misdiagnosed), and the methods are more expansive -- from play, music therapies and more options suitable for the specific child -- then I'm in support. For Adam's sake, I want to work with others if they are willing to work with us in order that we keep moving forward and say a farewell to days past. We cannot do this, however, without autistic people helping us through the process, or at the exclusion of them. And no movement should feel threatened by including autistic people. If a method is good and really strives to understand autism, it will not wither with the inclusion of autistic people who can communicate.

The truth is, the reality in our home is different than in someone else's. While one parent may wish to wave the magic wand of never having brought a child with autism in the world, there are others, like us, who sigh and wonder what we would have never learned or gained if Adam were different than he currently is. Do I want to take away some of these struggles? Absolutely. But it is a very fine line we tread in not only preserving his self-esteem, but in recognizing that his challenges may be the very things that enable his gifts and may have formed much of his unique personality.

What is a mis-characterization of TAAProject's advocacy is a view that there is only one way to do things. We we wish to transmit the message that the huge GAP is society's understanding and attention to the way disabled and autistic people feel about themselves. We need to listen to the the kinds of assistance that they feel was helpful to them as children in order that we may learn (as well as what they need as adults), and we need to listen to how they want to be treated by others in society. We are still stuck in a recent mind-set of institutionalization of cognitively and physically disabled individuals, and in the wake of a disabled civil rights movement (started in the 1960's) we have irreconcilable images and views of disability. This is what we are seeking to change.

If we have different views about curing autism, then that is
current truth. That truth may be in part because of our recent history -- discordant with our view of the disabled-person-as-child, with the presumption that they have no means to self-advocate. There is risk to shifting perception and expectations, and to allowing our children to make mistakes, or even letting them move and exist in the world atypically. As parents, we may have to let go a bit and let our children take some of those risks.

We have decided to live our life fully and to be proud of who we are. I do not lessen my expectations of Adam, although clearly see that his path to success may meander. I still expect him to attend university. I expect anxiety, sadness and joys. I do not expect life to be easy, but I do not lessen my expectations that he, like my other step-children currently studying law, could one day be a lawyer for disabled people. A mom can dream inasmuch a disabled person can dream of freedom, for those of us who persevere may make dreams a reality. If you are naive, you position, quite incorrectly, the "Joy of Autism" blog and person behind it, as ignoring all the obstacles that exist. Instead, we live in spite of society's view of us as Tragedy. [capital intended]

This is why the Klar-Wolfond family merges with other autistic people who feel that living "the dream" also comes from a compromise by society -- accept us and let us roam and be included without so much fuss, without grim faces, without so many serious questions, without so many barriers -- many of which are perceptual which lead to passivity, or the belief that it's "too hard" or "too expensive." When we have to keep perky and bright for the sake of another's grim face upon our arrival, that is a stigma we face everyday that is exhausting to us. Wouldn't it be nice if we could walk into a new room that smiled at us? Adam is a bright and beautiful little boy. He does not deserve to be peered at for the sake of it. He deserves to be celebrated -- so says his mother.

While there are devastating moments in everyone's life, being autistic does not need to be characterized as a devastating condition. At the same time, it is okay to speak about devastating moments. Yet, we need to qualify them. What is a tragedy is characterizing an entire life within a thirty-second frame, sound-bite or headline for the sake of fear-marketing. That ignores nearly forty years of lobbying by disabled people that sought the benefits our children have today, as well as the expectation I have...
now that my son has a right to be a contributing member of society. There was a day when a parent couldn't even have that expectation.

I decided to put Adam's picture in the paper because we are not ashamed of who he is. We are so utterly proud of him. His picture smiling at you says, he and all autistic people DESERVE BETTER - - they deserve to be in our communities, to be included in our schools, and to receive the basic accommodations to enable that to happen.

WE DO NOT NEED PITY. WE NEED UNDERSTANDING. WE ARE HERE AND WE LIVE STRONG.

Why CBS Has Got Autism Wrong

I was forwarded a report on adults with autism on CBS (in the autistic realm, many people prefer to be called autistic adults -- but the preference differs among individuals).

Why does this CBS report have autism pegged all wrong? What does it show in the way society lacks understanding about disability?

I feel like going back a bit in history. In 1987, Reagan on George Bush's recommendation named Evan Kemp Jr. a commissioner to the Equal Employment Opportunity Commission. The US federal C. Boyden Gray, says Joseph Shapiro in his book *No Pity: People With Disabilities Forging a New Civil Rights Movement*, had opened Bush's eyes -- noting that disabled people were seeking self-empowerment. Gray was not disabled but "he had an instinctive understanding of the fight for self-worth..." Gray was a southerner who attended Harvard, and "he found that his northern classmates automatically assumed he and all Southerners were bigots, rednecks and stupid....'The stereotype was that you spoke with a Southern accent, so you've got to be dumb.' Gray empathized with the desires of disabled people to overcome low expectations and their distaste for being stereotyped...
During the negotiations over Section 504, David Stockman's Office of Management and Budget drafted a new White House position that applied a cost-benefit analysis to proposed disability benefits. To the bean counters at OMB, it seemed sensible. The less a disabled person -- and presumably the more likely that person was to work and live independently -- the more help and rights he or she got. The more disabled someone was, the less he or she was guaranteed. When Kemp [himself a paraplegic] confronted Gray with a leaked copy of the OMB memo, Gray agonized. Kemp, after all, was severely disabled. And Gray knew he could not justify a position that would put a price tag or a cost effectiveness formula on his friend's worth. The proposal was killed." (pp.123-4).

It was perhaps this that lead Gray to understand the meaning of a civil rights bill for people with disabilities. "He [referring to Kemp] reached out to explain the experience of disability, not to scream at me."

"Kemp took the Bush campaign. Three months later, Bush pledged 'I'm going to do whatever it takes to make sure the disabled are included in the mainstream.' Those simple seventeen words, spoken during Bush's image-turning acceptance speech at the Republican National Convention, marked the first time that an American Presidential nominee had acknowledged disabled people as a political force... for several years Bush pollster Robert Teeter presciently had advised his political clients that disabled people and their families were growing into an untapped community...

Later, at the polling firm of Louis Harris and Associates, Louis Genevie, was proving [this] instinct correct. [He] was tracking the voting preferences of disabled voters." They swung markedly to Bush. "Genevie wrote to Bush that disabled voters who had switched to bush had constituted up to one-half of the four million difference of popular votes between Bush and Dukakis. This made up one to three percentage points of bush's seven-point margin of victory....his polling did not even count family members who could be equally strong activists."

"A candidate ignores the issues of disabled people at his own peril," Genevie would later say.

Now let me see, it is said that there are between 40-50 million
disabled people in the US today. That is not counting people who become disabled as a result of disease -- many with Parkinsons and Cancer reporting the added stigma in society and the workplace as a result of their diagnosis. If we included that number, Shapiro estimates back in 1991, that that would have accounted for 120 million disabled Americans.

What has happened? Few people are aware of these events, despite their significance for millions of disabled people. Non disabled citizens ignore them. Disabled people, while they have protested on Capitol Hill, cannot do so in large numbers, despite the large numbers of disabled people out there, so it doesn’t make headline news. Together, blind, deaf, epileptic, autistic and other disabled people have come together for one cause -- access as a civil right, and to foster a greater understanding and acceptance of disability as an norm of humanity.

So what is wrong with the CBS report? Many things. It perpetuates crisis and fear -- the oncoming "burden" of the many children currently diagnosed with autism.

While it suggests that many adult autistic people CAN contribute to society, it still fosters the fear of autistic people -- their financial burden on the rest of us without viewing their contributions. It sits like a bounty over the heads of autistic individuals.

"To what extent do we have a duty to accommodate?" I often get asked. To me that’s like saying to what extent must we allow African Americans into our society? Without speaking to the people where the issues reside, we can never grasp the meaning of exclusion, and will only fear what we have to give up. Of course that fear is often unfounded and based on a false perception.

What is especially traumatic is that despite the headway made in our history by millions of people, Allison Tepper Singer still gets the soapbox -- and makes others worry along with her -- thereby continuing to create fear and despair. The same issues are present in my family, and in many families that come our way. Adam's siblings may have to watch out for him one day. Instead of it being a burden, we try to foster it as just a way of life -- a way of life that in our history would have been obligatory and not seen as a burden in this era of egocentric individualism.
Isn't it also disturbing that the young man folding towels was not being paid anything at all, for all work should be compensated -- even for work in training. What is most fearful is the creation and continuation of a caste system based on disability -- or the presumption that ALL our autistic kids will be able to do is fold towels and stock shelves. Of course, we know that that isn't always the case, and while there is nothing wrong with sweeping the floors, let us not limit the opportunities and possibilities for many autistic children who will soon become adults.

And speaking of work, how can disabled people get to work if they are not equipped to at least begin to pay for public transit? How can they get to their first job interviews without financial support to launch them? And what happened to a truly inclusive society with the special transit that must be booked well in advance and does not always allow non disabled people to travel with them on special transit?

Our attitudes are the burden for autistic people that keeps them at bay.

The only way to really understand what autistic people are confronted with everyday is to talk to them -- those who have to spell out a sentence letter by letter, slowly. Or those who rarely talk or get to talk at all as well as to those who also have never talked as young children but can talk today. CBS didn't talk to autistic people. They only spoke to an Autism Speaks spokesperson who likes to spread fear instead of qualifying concerns and reframing lives in order to empower caregivers. The mother knew her son could contribute -- I, for one, would have liked to have heard a bit more from her. Yet, it's not just the service system that needs improving, it's our attitudes. As in the history of disability rights, autistic people must help run the systems that seek to assist the autistic children who will one day become the adults.

George Bush said, "Let the shameful wall of exclusion finally come tumbling down." He put his pen to the bill. Then Bush turned to Evan Kemp, who was sitting next to him on the podium overlooking the Washington Monument, and gave him an affectionate kiss on the head.

Bush's administration would promptly issue regulations for the
ADA. There would be no four-year fight like that over Section 504. The law took effect in 1992. Many companies, particularly large ones, complied eagerly and reaped the rewards -- new customers, new workers, and good publicity. Passage of the ADA was an earthshaking event for disabled people. It signaled radical transformation in the way they saw themselves -- as a minority that now had rights to challenge its exclusion. But it was an odd victory; as radical as the ADA's passage would be for disabled people, non disabled Americans still had little understanding that this group now demanded rights, not pity." (Shapiro, pp. 140-141).

If there is any crisis that CBS reports, it should note the crisis of misunderstanding, intolerance and continued stereotyping. As Susan Goodman, President of CSAAC noted, "Because people with autism are the most difficult to serve, they are the first to be written off." (Shapiro, p. 144). She suggests that because of this, the autistic are the most segregated of all.

Presidential nominees might also take into account the numbers of disabled and autistic adults living in our society today -- valid, valuable and lo and behold -- voters.
Kay Olson's The Gimp Parade. Check out this poster "Good access is good business." Click on the picture to enlarge.

Absolutely.

Also check out The Perorations of Lady Bracknell:
"We exist in every culture; every race; every class; every creed; every nationality; every political party. We have arrived here as a result of accident, injury, illness or simple genetic glitch. We are adults and we are children; we are men and we are women; we are straight, we are gay, and we are bisexual. We are too frail to leave the house and we are strong enough to yomp across continents. We are desperately ill and we are at the peak of physical fitness. We die young and we live to a ripe old age. We are accepted in our communities and we are locked away in institutions. We have been this way since birth, and we have been this way since yesterday. We are the premature baby and the great-grandparent. We are the criminal underclass and the pillar of society. We are the warmonger and the pacifist. We are the teacher and the student.

We are, without a shadow of a doubt, the most diverse minority group on the planet. We are everywhere you look, and yet you do not see us. We are one in seven."

PERMALINK POSTED BY ESTEE KLAR-WOLFOND AT 11/22/2007 12:57:00 PM
5 COMMENTS LINKS TO THIS POST

WEDNESDAY, NOVEMBER 21, 2007

The Media Does Not Convey The Whole Message

As many of you know, Amanda Baggs and many people at the AutCom conference in Edmonton which was held in October, will be on CNN this Friday night on Anderson Cooper 360. The shortened version aired Monday night and you can read the transcript here. I am interested in the way people construe meaning. TAAProject has heard from more autistic people as a result of the broadcast. It has also received calls from people who want to "heal" those they saw on the broadcast (which of course
would be offensive to those very people who were on CNN). It is the nature of the media beast, of expression and art itself: what one sees and hears is a result of one's own experience and the challenge is to study and stretch beyond ourselves (the proverbial "comfort zone"). Please read Amanda's post on her feelings about the broadcast.

I am concerned for autistic people who really put themselves out there for the purposes of getting out the message. It's a Catch-22 situation. If you are visibly disabled, you are discriminated against or receive the insult of low-expectation. If you are "functional" or invisibly disabled, you are questioned or treated with disdain and do not receive the understanding you need in order to be able to contribute. People have a hard time understanding autism in the way of dissonance of skills -- be it in "doing something" inconsistently, or even verbalizing.

Despite all this, I want to say that I am really am grateful, because I am beginning to understand how frustrating it really is. Communication is already challenging for many of us, never mind jumping over such strong stereotypes that are deeply embedded in our society. While television can be important to get messages out, the work behind autistic civil rights (in the way of the writings and contributions of autistic people) is even more so. The media cuts and edits dialogue, extracts meaning, and it gets filtered or interpreted in ways not always intended by the person being interviewed. The purpose of many reports is to produce a general message for public consumption. Sometimes it is meant to sell papers and acquire viewers through sensationalism. We know that the messages that come out can be whitewashed. There is nothing simple about human or autistic experience, and the media tries to distill it for the simplest message, which is not always fair.

We've all heard that the grade level required to read the average newspaper is quite low. I found this blog "Common Sense Technology" that suggests that newspapers are written to the 3rd grade reading level. Adam will soon out read us all (he has been reading since 11 months of age and he is only 5 1/2). Seriously, just think about how simple the arguments have to be! It is important to read outside of the newspapers and what gets portrayed on television and it behooves us to "question everything." For instance, I let others know that the piece would be on on Monday night. I received emails back asking, "is this an accurate report?"
Still, while activism doesn't happen as frequently on Capitol Hill or Parliament Hill, it has ended up on the Internet, and the media does a great deal to send out messages to a larger public. That said, the media and the public are still learning (some might disagree saying that many reporters never learn -- Margaret Wente's report this past year in the Globe and Mail on autism was most definitely an ill-informed piece of journalism and did not "show two sides of the story." Sadly, it is not an individual case of sloppy journalism). As a parent, I keep learning about the community to which my son belongs, and I want to stand beside him. That means I want to stand beside all autistic people, for they continue to teach me so much and I also stand with parents who are open to learning from and assisting their children.

There ARE journalists who are really getting interested in the more complex story. I wish to encourage a Pulitzer Prize-winning one! Why not? Do autistic people not deserve it?! What about an article to discuss disability rights and culture and perhaps autism as the newest disability to be confronted with extreme bias that is at the ever-confusing ethical crossroads with bioengineering and Neuroscience -- that parallels with questions of how much a society should enhance itself? It should be written by an autistic journalist, but can be attempted by a non autistic one if the perspective (and inherent bias) are qualified.

For certain, opening up one's life is really difficult. So much vulnerability and the discrimination is ever more apparent when it gets met with such hostility, disrespect and utter naivete from some people. I look at it this way, if one is open to listening and learning, and keeps being open to confronting their own bias in order to understand before just discounting the perspective of the autistic person, then the learning has just launched.

I keep thinking of how much gratitude I have for the people who continue to go out there in the face of such adversity, because I really can't come up with any other way than to open up in the face of it. Adam's opportunities have been built on the backs of autistic people today and who before them came people like The Rolling Quads at Berkeley, and many other people in our disability rights history. Ed Roberts, a quadriplegic who ended up becoming the chief of The Center for Independent Living -- an agency that "a
decade and a half earlier had deemed it 'infeasible' that he would ever hold a job." He had a son, Lee, and later "underscored the silliness of a system that tried to write off people based on the severity of their disability." (Shapiro: *No Pity: People With Disabilities Forging A New Civil Rights Movement*, p. 54-55). The events at Gallaudet University and the protests that lead to the appointment of its first deaf president I. King Jordan, were significant that lead to the Americans with Disabilities Act just two months later. There are tremendous acts of courage and perseverance, in addition to these events, by many other disabled individuals of all "functioning" levels and "severities."

Many people do not even realize that the opportunities they have for their autistic children today exist because people with disabilities fought, through adversity, for the very rights we are beginning enjoy. Yes, we still have a long way to go, but at least we have a path to go there and I do not want it gated. Organizations forged by parents typically "[aroused] the public's fear of the handicap itself" (Shapiro). In the case of the Muscular Dystrophy Association's telethons, for instance, "the telethon makes viewers more afraid of handicapped people" (Shapiro, pp. 21-22.). We witness the same "marketing of fear" today in our own autism organizations lead by non autistic people, who put autistic children as "poster kids" in order to call for the prevention of autism while ignoring the adults. I hope for a day that non autistic people work with autistic people without talking and advocating over them. I write this because don't you know the saying that we teach others what we most need to learn? Michael Moon will soon become our new TAAProject's (The Autism Acceptance Project) President for this very reason. Brian Henson and Martine Stonehouse have been activists in their own right prior to the incorporation of The Autism Acceptance Project and we are lucky to have them on our board.

Some parents currently attack our autistic members of society as being "not autistic" or not "having the right to speak" because they are "higher functioning" than the children they have. And yet, people with all kinds of disabilities, and severities of them, have fought for many years so that our children do not end up in institutions, or can go to community schools, and have access to special services and accommodations.

Perhaps this is what we might keep in mind when the next show will be aired, the next newspaper report published. The media is
watching and listening *and learning*. I encourage all autistic people to hang in there and continue so that no one speaks on behalf of you, for no one should and no one really can.

Labels: autistic civil rights, media
But a military-like discipline was not my style. I was a quieter, poetic type who preferred to explore my creativity through other pathways (reading books under my covers with a flashlight was common). I never became that concert pianist, although I want to play again as I struggle to read my notations (I was always better at playing by ear). I never became a visual artist, despite my appreciation. Now at forty-two, I try to work on the craft of writing, recognizing that I will spend the next thirty more years of my life, if I am lucky, attempting to develop it. What of this do we pass on to my child? While he may appreciate music he may not like to play it, or even be able to. He may be the consummate listener.

The most awesome savants work endlessly at their craft -- the sheer obsession and focus that nurtures the end product. While a gift is clearly present, I am not convinced that even savants do not work tirelessly to become "savants," for it is the intense focus, or "obsession" as some call it, that creates the beauty and the ability. I am disturbed when "plain old" autistic people, for the mere fact that the "do" art, are called "savants." This happened when I curated The Joy of Autism: Redefining Ability and Quality of Life exhibition. This cheapens their Personhood, and the propensity to artistic endeavour for all human beings -- for art is nourishment. No, not all autistic artists and musicians are savants for the mere fact that they are artistic, or have some ability and enjoyment in the making of it.

Adam enjoys music. He likes to sing, though talking is much more difficult. As I learn that song is deeply embedded in our brains and can be "extracted," if you will, in even the most seriously brain injured, I believe that art and music are a part of human mystery -- the human "spirit." Despite all attempts to map it and observe it on FMRI's and TMS's (Transcranial Magnetic Stimulation), I wonder if we will truly transcend what has fascinated philosophers for all time. Isn't it part of being human to question what makes us
so? What will happen if that mystery disappears? Will we still be human? Will science decode the very nature of humanity -- the deeply embedded stuff of consciousness? While art informs us of cognition, it also equalizes and unites us. At least it should.

Neuroaesthetics is fascinating to me, and I’m in the process of studying it. It is thrilling to see this confluence of ideas -- of art, philosophy, music, and the sciences. My father used to hate the fact that universities begin to "teach trades," if you will. An engineer turned businessman out of necessity, his worldly entrapments abated on Sunday mornings as he engaged me in discussions about Roman History, Linguistics, Emmanual Kant, Baruch Spinoza -- and then the perils of the MBA. Perhaps he was a purist in thinking that universities should provide a "universal education." I have inherited such a belief (although I struggle to attain the same level of focus as he in my studies). In art history, how intrigued were my professors when I brought in musical pieces and examples from other genres to illustrate a period. I owe it to my father -- the man behind the camera, by the way, in many of the photos I post here to my blog.

Last night, Oliver Sacks came to speak in Toronto. He has popularized the merging of such ideas -- of art and science in his new book Musicophilia. I quite enjoy listening to anyone discussing art, cognition and the tacit suggestion that what we don’t know makes us fully human -- of the unbidden, the underpinnings of the brain, which we can also understand through injury, and the capacity of the brain to compensate and adapt. While I am fascinated how science can observe the functioning of the brain in action, I question if science, through its "simple art of observation" as Sacks says in his book, "may be lost, that clinical description may become perfunctory, and the richness of human context ignored." Isn’t this missing from our current scientific studies in disability and autism? The human context? The human experience? Afterall, when science de-constructs, what might it take away from human experience?

I will hopefully be writing more on this myself in the coming months, as the arts are my true passion. I revel in Adam’s own unique experiences, and I try to document the things he loves and the context in which he places them in order to try to make a sense out of them. He enjoys the number 4 today, and usually, 7 soothes him. When he repeats the number 11, I know he is very
distressed. And what of his art that embeds letters underneath his staccato (okay he is still only five and a half), brush strokes, or his innate musical ability (which as Sacks notes, tends to be innate in all of us, but is subsequently pruned)?

So I find it ironic that my son traverses the path of his Grandparents and of his mother at the university's Philosopher's Walk. We never know what will become of it, of us -- the matter of it all. You see, not everything can be distilled. There are some things that are just plain ineffable -- music and the human spirit perhaps just two of them.

M O N D A Y, N O V E M B E R  1 2, 2 0 0 7

Our Best Friend

This is Kiki. This photo was shot about an hour before I got dressed up for an event. She turned a year-old this week and is a mild-tempered, sweet girl. She loyally follows Adam around the house and lies at his feet. She wants to be everywhere he is -- and this is not something I had to train her to do. She just loves him unconditionally.

Some people note that their autistic kids don’t take much interest in dogs -- opposite to cats and more "like humans" the way they socially "get in your face," they may receive the same atypical response as people get (at least people who demand eye contact and typical social responses) -- which is something I’ve read from other autistic people. But Kiki is not just a pet, she is a presence. What I thought was an adorable nuisance when we acquired her has turned just this month for me anyway, into true love. I don’t know if any of you have experienced that sudden bond? Maybe it even happens to people when they give birth. Sometimes bonds
don't happen immediately -- they just suddenly click. How did it happen for me? Was it how she stayed by my side the night we had a dinner at our home with a bunch of strangers, or how she seems to be following Adam around the house when he's home -- her loyalty stronger to him than to me? She doesn't read his supposed "non response" as disinterest. She is just there, always by his side, often under my feet when I work at my desk when Adam is at school...waiting.

At first, I wondered if Adam would take to a dog. I got her because like me, Adam is an only child. Granted, his has four half-siblings, but they are all so much older. I grew up with dogs, and I wanted Adam to have something cuddly or "just around" like I did. I watch other kids with Kiki and they are more animated around her, wanting to pet her or feed her. Adam goes on playing and his way of being around her is much more subtle. Some days, she pisses him off when she cuts in front of him with excitement. Other days, she lies on her back, paws hanging and teeth showing like a mischievous grin -- in some dog-induced bliss of anticipating that tummy-rub. Adam thinks it's hilarious, and he may even go to pet her.

Adam is really changing again these days -- he is moving on to six years of age soon and I can't believe it. He put himself to bed on his own last night and was really clear he didn't want me in the room - - his desire to be more independent and in control is very apparent to me these days and I don't take it personally, but see it as a positive thing. He can do so many things for himself and when he does he is so proud. His communication was of upset with me for wanting to comfort him, but he didn't want it. He was over-tired and wanted to be by himself, and good 'ol mom thought she could solve it for him. I am acutely aware of how not listening to this communication would have lead to aggression, as he was already kicking me away (not actually kicking me, but the air that shifted in my direction with each thrust).

Tomorrow, we start a concentrated AAC program with a device. We have been working on literacy and it's been going very well for him. He is so proud when he writes things down, or can read to me a few words from a story book. His awareness is catapulting and I know he is aware already of his difference. I so want to support him emotionally with is growing self-awareness and awareness of how the world works and perceives him. And in the meantime,
I had a wonderful time last night at a Barmitzvah. I talk to a lot of mums who feel so burdened by all kinds of responsibilities. We forget to offload, to just be ourselves, and come back to our daily lives with refreshed views. Clenched in the vice of duty and worry, we could, if we don't go out and live, forget who we truly are. I always think about this -- how we are supposed to be so devoted to the point of forgetting to enjoy life! Long before I knew anything about disability, I would have thought that parents with disabled children make the ultimate sacrifices, including a ditching of their very sexuality, which in essence, makes up who we are! Not only are disabled individuals perceived as asexual beings, I think a lot of parents fear that this is how they'll be viewed if they have a disabled child -- that "life is over," attitude. I urge people to check out the exhibitions the Abilities Festival put on in Toronto this fall -- couples (both with Down syndrome) with a child, beautiful photography of disabled bodies. Man, there was nothing asexual about it!

We are perceived as some kind of "heroes" who give up our time, who make extraordinary sacrifices. While it is challenging and we all have are own unique "crosses to bear," I really don't like when people paint me out to be a hero of any kind. I thank their kind words, for perhaps it is I who don't take to compliments gracefully enough, but I see devotion as something that just is -- not a full sacrifice of myself.
When Adam was first diagnosed, I fretted. I still give most of my time and days to him and his development. I have also learned to let go a little over time. I don’t think it’s something a parent can just do upon a diagnosis. It’s something that has to be learned. One has to give themselves permission.

They say you have to put on the oxygen mask in an emergency on yourself before you put it onto your child. When I feel the pull of being a mom versus doing the things I need to do -- that purgatory of guilt -- I tell myself that I owe it to Adam. I owe him my passions, my failures, my humanity as a model for his own. I feel I would cheat him if I didn’t dance the night away, fall flat on my face some days, show him who I really am. Making room for who I am perhaps allows me to make more room for him to be who he is.

Dance to the Autism Beat

Adam is drumming to his own beat, and I am tapping my feet to the beat of these people:

Message from the You Tube poster: This band was formed by autistics since 1991. They are living in Taiwan and had won many awards. Please kindly give your comments to encourage them. Thank you.

Person-Centred Planning
There are many options to approach the ongoing development of an autistic child. Talk to many a family with an autistic child here in Ontario, however, few are aware of any options in planning, AAC, and facilitation of teams. Add to that limiting services by suggesting there is only ONE type of therapy to assist the autistic child, and we have an urgent situation where there are few services available here in Ontario that are actually subsidized. Typically in Ontario, we have to do it this way:

1. Get on a wait list for ABA services with TPAS;
2. Wait for an "approved" supervisor (a psychologist with BCBA accreditation) to run the child's ABA team;
3. Find ABA therapists (usually young women, but not exclusively -- often students interested in pursuing further study in ABA or seeking out part-time employment;
4. Add an SLP and an OT to the team, which is not subsidized to the same extent by government (there are some programs but the wait lists are pretty long -- Geneva Centre for Autism in Toronto is an example of some such services -- a full-time OT was just hired). These service providers often become part of the overall team and goal-setting process. Some kids are lucky if schools bring such clinicians to consult in their settings. Training for SLP's is limited -- very few are trained in how to use technologies to assist learning.

From there, a team moves together, but within the ABA framework (which is changing in shape and form -- so we cannot call it ABA anymore).

New parents to the process may not realize that there are options that may include a myriad of professionals as well as other team players that can assist the autistic child in their development.

I thought families might be interested in this tool: "Little Ones Have Big Dreams Too." By visiting the Insitute on Disability at the
University of New Hampshire, you might find some ideas to assist your current team or help direct change within that very team. It takes a community to raise a child, so the saying goes. I think the struggle for all parents is to ensure that we bring people into our family folds whom we trust, who share our values and respect our goals for our children. In the booklet, there are questions to assist us in facilitating our teams, and for mapping a plan of action that is child-centred:

1. What makes your child want to communicate and connect with you?
2. What makes him/her sparkle and smile?
3. What creates social connectedness to others?
4. What makes him/her withdraw?
5. When is s/he least likely to communicate?

Our friends in the US are way ahead of us in providing supports and subsidies beyond the ABA model, but they are still struggling in many states. I know my friends in ABA studies are also interested in moving beyond the ABA model, telling their students that "there is more than one way for each child." Thankfully, we are moving beyond a strict paradigm. Many of us really need to take the "behaviourism" out of the teaching approaches to describe education and assistance.

Interestingly, those questions that were outlined in the booklet were the questions that I asked myself intuitively, long before we learned that person-centred planning existed. Instead, I resisted and resented pencils scratching on lined paper, carefully marking out graphs typical in ABA programs, and therapists arbitrarily making decisions about what Adam SHOULD be learning according to them, without considering his own path and pace at all. While it does take a "village" as they say to raise a child, let's make sure that the village we bring into our homes and into the lives of our children are ones who don't work contrary to our children and our values.
The Autism Acceptance Project Blog

We are opening up the blog for other writers. Kathy Grant just wrote a post on what TAAProject means to her. Please visit The Autism Acceptance Project blog for more articles from our TAAProject community and write us if you are interested in becoming a regular contributor.

Registered Disability Savings Plan

“Helping Canadians with disabilities means giving them the means to plan for their financial future,” said Minister Solberg. “With this proposed legislation, Canada’s New Government is taking an active role in making sure the people who need it most are getting the long-term financial support they require.”

Interested parties are invited to provide comments in writing on the draft legislative proposals. Comments can be sent jointly to the Tax Policy Branch, Department of Finance and the Office of Disability Issues, Human Resources and Social Development Canada at 140 O’Connor Street, Ottawa, ON, K1A 0G5 on or before October 23, 2007.

Shifting Direction

I thought that posting Madeline Kahn's I'm Tired video might not be fully appropriate, but I can't get it out of my head. So, when I get a little tired of debates that shift the direction away from Adam, I turn back to him. He is my solace and my direction when debates rage and others try to convince us that our children are "hopeless," or reporters cheapen the discourse by "parsing complex realities into [simple] divisions of two." -- Stephen Jay Gould
There is nothing simple about Adam, or his humanity and existence as an autistic person. So I am back to celebrating (not that I ever stop when it comes to my child). Readers may notice my blog always sways from disturbing trends in society back to the joy of being.

"To appreciate children as gifts is to accept them as they come, not as objects of our design, or products of our will, or instruments of our ambition. Parental love is not contingent on talents and attributes the child happens to have. We choose our friends and spouses at least partly on the basis of qualities we find attractive. But we do not choose our children. Their qualities are unpredictable, and even conscientious parents cannot be held wholly responsible for the kind of child they have. That is why parenthood, more than other human relationships, teaches what the theologian William F. May calls an 'openness to the unbidden.'"

-- *The Case Against Perfection*, Michael J. Sandel.

It's rather cool to watch Adam, and consider my role in his life as his rock and maybe his guide, perhaps for a time, but also capable of achieving and growing on his own:

![Adam drawing](image)

**Autistics 'We Don't Want A Cure'**

Today in the Globe and Mail, Andrea Bradford-Lambert and her
son Griffin are interviewed with others regarding the philosophy of acceptance.

There is one thing I would like to correct Mr. Doherty on: we are NEVER "ashamed of" our more severely effected disabled members of our society. As much as I respect Mr. Doherty's right to seek the assistance he needs to attain for his child, I do not agree with this mischaracterization of the neurodiversity or acceptance movement.

I also do not agree that autism is just a "difference." It IS a disability. The "difference" analogy comes from the notion that there is no normal -- that normal is subjective and concepts of normalcy can change over time. Therefore, we are all "different." We are concerned that pejorative referencing alone (extreme characterizations of autism as "a living nightmare" and the like) will increase the stigma, prejudice and LACK of support. The latter may be replaced with government-mandated normalization campaigns which suggest that if you are NOT like others, you are less valued and, yes let's take this jump, do not deserve to exist. One might say that you are doomed if you do not fully "recover" from your disability.

It is not to say that disability is not challenging for families. On all levels - with these positive or negative sketches of autistic existence -- we have to recognize the result of gross generalizations and how they come to characterize autism or any disability over time. I feel strongly that we have to hold the media accountable for the manner in which they report about these issues.

The point of the whole "movement" is that it is okay to be disabled (for quick references check out TVO Agenda on "The Right to Be Disabled" as well as website Disability is Natural to start. Society has an obligation and must recognize an individual's right to be disabled and the access required that is currently denied. In other words, once we value disabled individuals for their inherent strengths and abilities, as well as accepting and accommodating the disability, we begin to dismantle prejudice and overwhelming assumptions that disability is a "fate worse than death" or whatever. We also begin to value inclusion as we humanize the disabled and what they already contribute to society. These values should seem natural in a society that claims to celebrate diversity
on all levels. Yet it still seems to be quite a conceptual "jump" for many people, which is reflective how locked into our bias and preconceptions we may actually be.

Let us all work together to find the supports that ALL autistic individuals require to ASSIST them to reach their fullest potential. The argument here is that assistance is an acknowledgment of this right -- not a mission to "normalize," because our assumptions of both what is normal and what is not are constructed on historical bias and abstract conceptions, as we learn from many disability communities.

Also, we all have to recognize that not everyone will agree on what they want for themselves as autistic individuals. While there is currently no cure for autism, other autistic individuals may seek out ways to assist themselves in this complex world. Note the key word is "assist." This may come in forms which we may not even conceive of at the moment, but are still do-able right now by learning from autistic individuals first what it is they need in order to contribute to society as autistic people.

What this Globe and Mail article shows in an attempt at balance, is the complexity and diversity of the autistic community itself, and the fact that there are individuals who do not want to be whitewashed under the autism as "illness" description. Perhaps for this aspect alone, I accept the article as a shift in the right direction. If we can embrace all needs, much like what happened to the deaf community after its virulent debates, we have taken a step forward. Yet, I'm afraid that the Globe article still misses some very important points, which I've already attempted to mention.

There are still bigger steps to take. The biggest is this understanding that the millions of North American citizens who are disabled have a right to be understood and this includes autistic individuals. Autistic individuals continue to generously express their experiences for which they are largely ignored. We all have to learn from their views on what they need to thrive, and their life-experience benefits children because we as educators, clinicians and parents develop empathy and understanding in order to provide more appropriate methods of assistance. Autistic individuals need to participate and be included in society -- and valued for their way of being -- not forced into becoming some
normal-seeming simulacrum. Disability need not be "catastrophized." By suggesting the latter, disabled individuals have been subject to human rights abuses exemplified throughout human history. Perhaps we need to keep illustrating those so we "never forget."

Valuing people for who they are will lead to better services and access that all families and individuals require. Some of this may require the right to medical treatment (we do know that because of disability, many individuals are denied the same "treatment" as other citizens in our society), even though disability need not be characterized in the medical context. As a human race, we are all subject to medical conditions that require medical support throughout our lives. A medical construct for discussing autism, as well as other disabilities, does not fully characterize or adequately describe the experience of being disabled. One might not describe one's experience of "being human" in the strictest medical sense.

I do have an optimistic outlook for Adam's future -- my son who still cannot speak at nearly six years of age. As we work for more understanding of autism and acceptance of the way he manifests his communication, I see possibilities of the access and accommodation he may need as he seeks higher education and employment. He may need an aide to help him navigate the outside world, he may need a device in order to help others understand what he is thinking. There is nothing wrong with interdependency in order to attain these goals. He certainly is worthy, wonderful and deserves these modifications by us as society so that he can reach them, and share his life with others. It makes me a little angry when I see money being funneled into "gifted educational programs" -- because these children are "our future," while we view autistic children as our future burden on society. I could go into the giftedness of many a disabled person, even those with "severe disabilities," not to mention the severe anxiety issues of many a "gifted" child. Adam has an equal right to prove that he can contribute and be educated in a manner that suits his learning style and ability to manifest his understanding of the world. A respect for dissonance is what needs to be cultivated by further explanation. For myself, I have better skills in some areas than others. This dissonance may be more extreme in some areas for some individuals. It warrants no less sensitivity and acceptance.
One explanation of this "dissonance" that speaks louder than words is by witnessing an individual who has been taught to communicate using a device. It demolishes assumptions that "just because you can't speak doesn't mean you don't have anything to say." Perhaps that is the best example we need in order to heed our words and monitor our attitudes towards every disabled individual who might otherwise be assumed "unaware," and thus subject to various "treatments" that we as parents and a society feel is in their "best interest."

I also look forward to more discussion about autistic individuals and what they contribute to the Canadian economy -- both in the work force and through their unpaid volunteer and creative work (Bruce Mau in the exhibition Massive Change, estimated volunteerism and unpaid workers to be the billion dollar engine of today's economy). Right now, we only hear about how much autistic people cost, which yet again adds to the stigma they face. I challenge others to valuate their enormous contributions.

So thanks at the attempt, Erin Anderseen of The Globe and Mail. This article was a refreshing change that many of us need in order to move forward, but it's still not the full story reflecting accurately the needs and issues confronting the autistic individuals right now. The article is reduced to the black and white dialogue that the media tends to default to on a regular basis (cure versus no cure) that sadly clouds the real issues and real needs of our community.

See this article in Mother Jones:
"The harsh reality is we're doing this to innocent children in Canton, Massachusetts," [says Senator Brian A. Joyce]. "If this treatment were used on terrorist prisoners in Guantanamo Bay, there would be worldwide outrage."
Mr. Israel continues to defend his use of aversives and electric shock in my blog today under "The Legacy of B.F. Skinner and Behaviour Modification." You can comment there or here.

Eye Contact

An interesting look into "eye contact" by Christschool:

The Legacy of B.F. Skinner and "Behaviour Modification"

There's something rotten afoot. It's at the Judge Rotenberg Center and it's electric shock and other aversive "therapies" for the "treatment" of autistic and other developmentally disabled individuals. B.F. Skinner still floats in our hallowed halls -- be it schools or of "child-rearing" -- in our systems of rewards and punishments for autistic and other children. Consider the legacy of behaviourism:

Please read this article released in Mother Jones.

If people feel strongly about ending this torture, please contact the American Psychological Association at the address below.

Lynn F. Bufka PhD
Assistant Executive Director
Practice Research & Policy
American Psychological Association
750 First St. NE
Washington D.C. 20002
The More Important Legal Battle

In the New York Times yesterday: Disabled Pupils, Private Schools, Public Money, David and Kim LaPierre enrolled their son Jack into private school for children without disabilities in addition to their in home therapy. They feared that Jack would backslide in a public classroom with disabled children and are suing the schools to recover their expenses.

"It makes no sense to us as parents that we would have to put our son in a place that we knew wasn't right for him, just so we could qualify for the school's services or funding to help us....

Cases like these have increasingly become a flash point in special education, pitting parents against school systems that say they cannot afford to pay to privately educate disabled children whose parents unilaterally reject their proposed placements."

While the courts seem to take a stance that people will abuse the receipt of reimbursements, "others say that if public schools did a better job educating students, private school placements would be unnecessary."

In the article, the LaPierre's did not digress into therapy treatments or talk about their son as "doomed without..." What they have done is positioned their argument, in my opinion to something that we all, as parents of disabled children, can relate to: our children are worthy of access and support. They deserve a good education in a setting where they can learn -- not with a classroom packed with thirty children or in a setting that teaches them only self-help skills. More often is the case that our children have strengths in one or more areas, and need support in other aspects of their development. What I would like to see extend the argument is that other children will benefit by getting to know and learn with our disabled children.

I would support a lobby in Canada for public educators as well as
private, to take a long hard look at how we educate disabled children whilst VALUING them -- preparing them to contribute to society because we know they will, and supporting them into adulthood so that those who cannot be completely independent, can. The levels of support will certainly vary, and we have to work for everyone's benefit. While we are doing it, we have a great deal to learn from the disabled students who have already traversed, nay survived "the system."

I was actually surprised to read something in the paper that effects all parents, that we can all universally relate to. I hope it puts pressure on public educators to change "the system," and society in general to shift perceptions about the nature and value of disabled people.

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Stay Awhile

Stay awhile and listen. Lord knows we aren't doing much of it.

Henry T. Greenly, from "Knowing Sin: Making Sure Good Science Doesn't Go Bad," From Cerebrum, 2007:

"'Despite the vision and the farseeing wisdom of our wartime heads of state, the physicists felt a peculiarly intimate responsibility for suggesting, for supporting, and in the end, in large measure, for achieving, the realization of atomic weapons. Nor can we forget that these weapons, as they were in fact used, dramatized so mercifully the inhumanity and evil of modern war. In some sort of crude sense which no vulgarity, no humor, no overstatement can quite extinguish, the physicists have known sin; and this is a knowledge which they cannot lose.' -- J. Robert Oppenheimer (1947)

Like All Tools, scientific advances may be used for good or for ill. As our knowledge about the human brain increases, we will certainly use that knowledge to relieve human suffering in profound and wonderful ways. But the vast promise of the science should not blind us to the possibilities of its misuse. I believe those
involved in human neuroscience need to pay attention to the risks that come with the science and to accept the duty to minimize the harm it could cause....to what extent should people be 'cured' of what they consider to be their personality traits? Should parents be able to use neuroscience to 'adjust' their children, something critics think is already happening with prescription drugs but that new techniques might make more powerful? As a parent of two teenagers, I can imagine the attraction of pills to 'help them' clean their rooms or do their homework before the last minute. On the other hand, should the state be allowed to interfere in how parents choose to raise their children? What of the government, near or far, that might use neuroscience to make dissent disappear -- not through the bread, sex, and some of Brave New World, or the propaganda and torture of 1984, but with a little blue pill? These are not new issues or new fears, nor do they have clear answers, but the rush of progress in neuroscience gives new importance to finding workable and ethical answers to them...The potential benefits from neuroscience are breathtaking, but so are some of the potential harms...

It reminds me of the old saying: "God is in the details, but so is the devil."

There is a lot to talk about, and as I continue to repeat, this needs to happen with autistic individuals at the forefront. What right do we have to determine the value or state of one's life without asking the very individuals in question, first? Is the sin already committed, with the worst of it soon to come?

This video, by Christschool, for those not closely involved with the autism community, juxtaposes award winner Vernon Smith, an autistic man, next to the cure slide, and Hillary Clinton who states that we have to "prevent and cure anything along the autism spectrum." All of the slides within deal with many issues surrounding disability which includes autism:

Listen to Naomi Wolfe (thanks to Amanda Baggs who made me aware of this through her blog). She addresses abuses of power and the propulgation of fear which is something I address in my keynote in the way we promote autism and in this paper The
Mismeasure of Autism: The Basis for Current Autism 'Advocacy.'

Stay awhile can consider her words and how it applies to autistic individuals and their suppression today -- for simply seeking their civil rights and speaking out against more powerful organizations. I hope it doesn't deter individuals from seeking their civil rights despite the dark scenario she illustrates. In fact, she reinforces Hillel's statement -- *if not NOW, WHEN?*
longer and autism may not even be considered a "developmental
disability" in some cases in order to qualify. Even those involved in
ABA will eventually agree, that IT and communication boards are
vitally important. In many cases, a child will not be able to
physically communicate with speech. Some days it will come, other
days it will be impossible to come by. It is the nature of the
disability. Why can't we agree that it is utterly important that we
are trained to support our kids when they're young, with AAC
(sign language, or other IT or augmentative systems)? Kids should
be learning literacy skills, live daily in a text-rich environment.
While language isn't all about speaking, it is about understanding,
reciprocity, and learning how to express not just wants (that is
easy for many autistic people who cannot speak fluently), but an
expression of SELF.

Can we agree to a variety and/also of approaches to get our kids
what they need????

But as long as we paint autism out as something we can get rid of,
the scenario may never change -- as long as there's the
POSSIBILITY that one child can be "cured" or "recovered," then
too bad for the others -- they're the "victims." I think that's a
lousy way to brand ABA or any autism "service" or charity --
some of which I outlined in my paper "The Mismeasure of Autism:
The Basis for Current Autism "Advocacy." We know autism is a
life-long disability and we need to support our kids now. Too often,
many kids wait fifteen or more years until parents realize that this
enablement with communication tools, is so vitally important, if
not an entitlement of all disabled individuals.

Looking through Different Roads to Learning catalogue today, I
see lots of neat things to help autistic kids learn. Lots of new
devices, but still old books on old ABA methods, Lovaas, and not
enough books from autistic people who can help the parent and
clinician understand and teach the autistic child. The ABA
community is looking into methods outside of its original
framework, which is a tacit acceptance that there are many tools
that can help the autistic child and adult -- and that is a good start.

I hope this community will, however, discontinue its solely
negative referencing of autism as something horrible. It is
challenging for all of us, no matter what the resources available,
and indeed, if there are fewer resources, all the more challenging.
At the same time, I know that Adam gives me so much joy and I feel he deserves so much more than what Canada offers to autistics today. He deserves to be viewed as a valuable person. He deserves access to programs and schools. He deserves to have a shadow who understands and empathizes with his way of learning and seeing the world. He needs early access to literacy programs and AAC and IT. He deserves early programs (we call them intervention, but I'm not keen on that word for various reasons and implications), that engage young infants in play, not table-teaching and aggressive "look-at-me" programs, that clearly do not understand autism as a disability. Even autistic infants deserve that play, even if it's more deliberate. At the same time, autistic kids should be allowed their down-time, not bombarded with interventions that deliver the message (you're no good the way you are, you're doing that wrong so let's engage you 24/7).

Balance, dear friends. Family should fee a little more freed to spend time to just "be together," than constantly engaged to "fight" autism. If I have to retrace our steps when Adam really began to learn (it was not like he wasn't learning before but it's just that the autism diagnosis made us THINK he wasn't really learning or that what he was learning on his own like the alphabet, colours, numbers and words, was not really learning per se, but 'rote learning,' or what Dr. Laurent Mottron has coined this perception as 'dead-end intelligence'), it was when we let go a bit.

It took us time to feel confident enough to let go of stricter ABA therapists and supervisors and VB programs. I liked some ABA therapists more than others -- particularly those who were reaching for something greater, who, while they were still ABA therapists, saw that there was still more to understand out there. I could also feel who really valued Adam for Adam, while others smiled a lot and "really wanted to work with autistic kids." As nice as that sounded, alarm-bells went off. Like, why just the autistic child? Why not ANY child? Was Adam their...pity project??

While my innards were telling me that Adam was happier, learning and had much more social interaction with us when we played with him and swung him in the blanket, we were still teaching him by following the ABLLS. I acknowledge that everyone has to come to terms with their child and be confident with their own choices and themselves over time. There is no other way I can suggest it. When I get calls from parents who have newly diagnosed children,
I tell them how I think Adam is terrific, but they will have to find their own way through all the information and tugs out there. I remember when someone said to me when Adam was diagnosed that I would have to accept him, I didn't understand. I thought that was a cop-out and I had to do more work with him. Four years later, I clearly understand what people were saying to me.

We have so much choice. We have play, we have more AND/ALSO options that Canadians must advocate for. As I push for Adam's entitlements, I keep thinking of all the other families I know on waiting lists, struggling in over-crowded public schools. We must keep asking and we must do it NOW. May we do it by keeping the dignity and value of our children, and the autistic people who came before them, in mind.

PERMALINK POSTED BY ESTEE KLAR-WOLFOND AT 10/25/2007 09:36:00 AM
15 COMMENTS LINKS TO THIS POST

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WEDNESDAY, OCTOBER 24, 2007

Judge Rotenberg Center

No matter how disabled our autistic children, I would like to think that most parents would not want them to be maltreated. I hope all of our children can change the world, and we can all cooperate to make a better and safer place for our children to become adults and to lead good lives.

To contact Derrick Jeffries and Nancy Weiss click and read letter here and lend your support.

PERMALINK POSTED BY ESTEE KLAR-WOLFOND AT 10/24/2007 09:47:00 AM
1 COMMENTS LINKS TO THIS POST

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TUESDAY, OCTOBER 23, 2007

Think Differently About Autism
I thought everyone should know that The National Autistic Society has launched a "Think Differently About Autism Campaign," with Emma Noble as its spokesperson. It is refreshing to see a National society run such a campaign.

In Canada, we've had "Redefining Autism" as front page news in The National Post, but nothing to compare to the UK campaign as of yet.

Our next steps? Well, take a look at the Canadian Down Syndrome Society and how they "vibrantly" promote the possibilities and futures of people with Down Syndrome for some ideas. These parent packages that are positive in nature (while not ignoring the challenges) and can be an example of the types of packages, information and programs that our Canadian autism community can endeavour to produce.

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**SATURDAY, OCTOBER 20, 2007**

**The Mismeasure of Autism: The Basis of Current Autism "Advocacy"**

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**THURSDAY, OCTOBER 18, 2007**

**Autistic Civil Rights**

A reminder for us all:
Stand Tall

I have been away in Edmonton. I was a keynote speaker at AutCom. I will be making that paper available here later this week.

I have just learned that Kevin Leitch of the enormously important blog Left Brain/Right Brain has decided to shut it down due to John Best Jr.’s "Hating Autism" blog. John Best has written scathing, rude, inaccurate things about everyone he lists, including myself. I agree with Kristina Chew -- I just don't see how Mr. Best has done anything to advance the help autistic people need. In fact, he has done so much damage to their basic human rights.

That said, I used the title of journalist Patricia E. Bauer from her keynote speech on Down Syndrome. She wrote,

"a couple of years ago, a newspaper running a piece I'd written asked for a family photo, including Margaret. I gulped, feeling exposed, and called my husband to ask his thoughts. He said, 'Stand tall; run the picture.' We did.

That is my message. Stand tall; get out the message. People will listen. We can do it."

So many times, I've questioned using Adam's picture for fear he would be threatened or his photo would be abused -- much like what has been experienced by Kev. Not one of us can be intimidated by the likes of a man who hates autistic people as much as John Best has publically purported he does -- and as suggested by the title of his very blog. John Best, using pictures of children or writing dehumanizing articles about human beings who must struggle with the bias and discrimination in society MUST NOT BE EXCUSED BY ANY OF US. It is simply unethical to use anyone's picture, especially that of a child, and use it to target the parent with whom that person disagrees. It is the lowest anyone can go. (In the meantime, I heard that "Mr." Best has taken those photos down from his blog).

I fully understand Kev's decision. He has not "slithered away," as
Mr. Best stated. He wishes to protect the dignity of his child. When a child's rights and dignity are violated, it's just plain crossing the line. It's not to say that name-calling autistic adults isn't, it's just that children simply don't have the resources to defend themselves. John Best violates the human dignity of every autistic person.

If Mr. Best was truly interested in a debate, then he would engage in one without resorting to name-calling and public dehumanizing. But let's lay down the rules: do not violate children. Do not threaten them. Are you even capable or accuracy and neutral language, Mr. Best? Or are your arguments so impotent that you have to resort to name-calling, and libel?

Friends, we have an obligation to protect our most vulnerable citizens, here.

So in the words of Particia E. Bauer, **stand tall**. We are proud of who we are, with our disabled/autistic or whatever "kind" of child we have. This mom, anyway, is interested in advancing a dignified discussion in the ways we can help autistic people throughout the course of their lives.

That said, here is the edited version I did of my video "Autism in the Media" which I understand people want a copy of. I do not charge for it. Just contact me for copy at estee@taaproject.com.

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**Oh Dear**

Adam has become a competent You Tube user...on his own I might add....without vitamins, detox and chelation therapy, even. Imagine that.

I will have all kinds of reasons to worry that he's watching you tube videos at the age of five. I dread him watching many of the autism ones telling him that he is ill, for instance.
As I re-enter his room after leaving for a bit, I notice he's back on.
He's not watching Sesame Street. He's watching "How to Impress a Woman."

I wonder what this will do to his social skills.

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**A Rejection of the "Soul-less" Theory of Autistic People**

Please watch this video from Kev of Left Brain/Right Brain. Then, if you haven't already yet done so, watch the next video "Praise only for the cured" in the post that follows.

Thanks for listening.

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**Praise Only for the Cured: A Comment on Jenny McCarthy, and How The Media and Society View Disability**

My commentary on recent media events:

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**Life is a Circus**
Adam went to the circus. Cirque du Soleil, that is. **Kooza** – a story of the innocent, “a naïve but charming clown striving to find his own place in the world. Between strength, fragility, laughter and chills, and turmoil and harmony, the show explores the themes of fear, identity, recognition and power.” I read the program afterwards. I am a big fan of Cirque du Soleil and relish the chance when Henry wants to go to Vegas just so I can catch the latest show. The last time I saw O, I knew this was for and all about Adam. For Cirque is about capturing the greatest human attributes of all – imagination and spirit.

Adam was glued to Kooza, which is currently showing in Toronto. Music, optics and contortionists all mesmerized him so much so, he was throwing objects in the air when he came home as if he was trying to juggle, just like a fellow did on stage.

But more than that, all of our human struggles are encapsulated in this marriage of art, multi-media, music and movement – good versus evil, the nature of being human and in Kooza, of innocence. The clown begins flying his kite. I have a picture I cherish of Adam watching a kite fly on the beach, a symbol of our dreams and the scope of our imagination. Adam peers at it flying high above him in the sky – an emblem that we all have something we look up to and aspire towards.

As I reflect two years after I started blogging and even calling this blog the Joy of Autism, I am content, because it is about capturing, or at least trying to capture this innocence, this spirit that is within all of us. As parents, we understand the possibilities that abound for our children despite their innocence and limitations. Our creativity and imagination can render the possibilities, boundless.
In talking about imagination, I am reminded of the Grimm fairy tale, *The Story of a Boy Who Went Forth to Learn Fear*. The father abolishes the young “stupid” one, saying “there is no hope for you.” All the boy wants to learn is how to shudder, as he does not understand fear, while the father tries to teach him more practical things. Since, according to his father, the boy cannot learn, he is expelled from his family home. The boy vows he will make a living from learning how to shudder. He comes across a man who challenges him to go the haunted castle where he could learn how to shudder if he would just keep watch there for three nights. The king promises that whoever would dare do this could have his daughter in marriage and would have the treasure that is guarded by the evil spirits. Many men had entered, but no one had come out of the castle.

It is a macabre story, as the boy bowls with skeletons and exhibits empathy by trying to keep his dead cousin warm. He confronts evil and defeats it, thus winning the treasure and the king’s daughter. But he still complains that he has not yet learned how to shudder. Ironically, the wife pours a bucketful of minnows on the boy during his sleep and he wakes up crying out, “Oh, what is making me shudder, dear wife? Yes I know how to shudder.”

When I read this story, I not only marvel in the bravery of the boy, but also in how the father underestimates him. It is also notable that the boy is also a literal learner, that he only learns how to shudder in the most simple and kinesthetic way (perhaps what is obvious is not what is the first thing we teach). It is laughable that he learns fear only through his wife (this is the interpretation I’ve read), but to me the point of the story is in how the boy was written-off by his family, and later succeeded by his seemingly purposeless and unprofitable quest, from which he ultimately profits in the end. I am not a fairy tale or Grimm expert, but I would love to hear of any other interpretations of the story.

My interpretation is that it is about what we can imagine. Limitations can still prove to be limitless. I just hope I can be the kind of parent that can continue to nurture Adam’s uniqueness and imagination, despite my own limitations. For all of life is a circus, a stage, and we all have a special role within it.
Another Autism "Story" -- Jenny McCarthy

I am in the grocery store line, and yes, I heard that Jenny went on Oprah to talk about how diet and biomed "cured" her autistic child (who still flaps by the way). "Fighting for her Autistic Son," says the People Magazine headline. My stomach clenches. Oh no, I should be used to this by now, I think. Another "devastating" article that talks about autism as a disease -- that can be cured with medications and therapies. I sigh. I reluctantly buy it -- like a compulsion. I would prefer to ignore it. I can't.

The story starts off the same. Every parent is shocked, worried, faces fear. The beginnings of our stories are almost always universal, and there is nothing wrong in stating how something effects us. But, in the article, it doesn't really stop. We see the loving pictures -- son and mum look happy. Is this to show that you can love your child and still hate autism? Or is this to show that her son is "cured?" I am cringing while reading the saga, and the way its told -- could be People Magazine's fault in part. It is a gossip magazine, after all.

But here's where it really got to me. The interviewer asks about her relationship with Jim Carrey: "What about having children together?" To which she replies:

"[Exhaling] Let me take a drink of water on this. I'm done having children. I always thought I'd have at least four or five. But I got my a-- kicked."

Well I'm sorry, Jenny. You really lost me there. What do you think all the autistic adults think about that statement? Did you consider how you made an entire group of people FEEL? How would you
As a mom with five children, and four of them step children, they are a blessing. Adam is a gift and everyone of his brothers and sisters will agree. You can read Max's take on Adam in an essay he wrote nearly two years ago now: From Adam's World To Mine. Max is now a one-to-one for older autistic children at camp.

Adam has made our lives richer by showing us that we can, without difference and disability, often be living in our own little worlds, our boxes, our arrogance. Our willingness to open up to possibilities, and to learn from Adam and other like him, enables him to succeed and us to become larger. Adam is beginning to speak sentences, even though he does not speak much, and other days can't speak at all. He can spell, he is aware, and he is --God forbid -- autistic. Jenny's child is the same age as Adam. Adam could not do many of the things his same-aged peers did when he was two. But yes, even autistic kids grow and learn with love and support. Adam has had lots of support, but not always the typical kind we hear about. We struggled to find ways that specifically HE would benefit from -- and we had to weed through various therapies and therapists to make it work. Today, his teachers are commenting that he can do many things that the other kids cannot! While I agree with support, I also know that autistic kids learn which is why, at five, we might be hearing that kids are "cured," when they really are still autistic and learning.

As I said, I have no issues with parents who want to relay difficulties and challenges and be honest with how they feel. I do have difficulty in preaching unfounded methods, insulting a community of people by stating autism is "horrible," without qualifying that "horror" -- is it really within the person who says it? Perhaps this reflects a need for more self-reflection instead of blame.

I am also uncomfortable with separating autism from the person -- because while there are challenges in being any kind of minority, in this case a person with a disability, we should not undermine individuals just because they have a disability. We have to acknowledge that human experience is, in part, defined by who and what we are. I see parents who always want to separate that -- autism is just a label. Of course we are more than our "label." Yet it's more complex than this. The architecture of our lives is
effected by both our environments and the way we were born. So why are people really saying this? Because they believe autism is awful? Because they are afraid of the stigma? I am always curious why people think they can separate autism completely from the person. We can't take deafness away from the deaf person and the way deafness influences their experience the world. We can't do it for blindness, physical or any other disability.

Now, let me conclude that I wonder if Jenny would still have children if she saw this video: Neurotypicalism Every Day by Christschool. Of course, it is a response to Autism Every Day, the unfortunate and poorly thought-out Autism Speaks' video. It just goes to show that if you put a certain kind of lens on something, you can yield a certain kind of result. Typical children look "horrible" to me here. They have melt-downs and geez -- parents get divorced over them. If I saw this video, I would NEVER want to have a neurotypical child:

Labels: Autism Speaks, celebrities, devastation rhetoric, media

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FRI DAY, SEPTEMBER 21, 2007

Call for Submissions

The Autism Acceptance Project is seeking to showcase the work of autistic people everywhere. If you are poet, an essayist, a fiction writer, an artist or musician of any type, we would like to show your work and direct our audience back to you.

If you are interested, please contact me at estee@taaproject.com.
Do Disability Organizations Presume Competence?

I have quoted Kathy Snow from Disability is Natural before and value her point of view. I highly recommend that everyone read her recent paper Do Disability Organizations Presume Competence?

The answer is no. Not autism ones, especially. When acceptance is entwined with ideas of recovery, when autism organizations want to recover, prevent, cure and praise autistic children only for typical responses, it is neither acceptance nor a presumption of competence.

"The service system (early intervention, special education, adult services, vocational-rehabilitation, therapies and interventions, etc.) seems to be built on the presumption that people with disabilities are incompetent," she says. "The result? Two unequal class of people ("providers" and "consumers")....the newsletters of organizations often tell the tale. A headline screams, 'Join the End the Waiting List campaign.' Advocates are exhorted to attend the rally...yes we need to effect systems change. But is ensuring government assistance our highest hope for people with disabilities? Doesn't this reflect an underlying PRESUMPTION OF INCOMPETENCE?

Wouldn't greater outcomes be generated if an organization rallied its troops (and its board members) to spend their time and energy helping individuals with disabilities find real work for real pay?"

Virtual Learning Options in Ontario

While my own son is only five, and attends a regular school with a shadow, I anxiously anticipate high school...already. Many autistic teenagers I know are having a rough time in high school. It's a time
when peer pressure is at its highest, and one's difference and lack of sensitivity and understanding about autism can really pack a punch. We often see a rise of "behaviours" as a result of high school, and quite frankly, with the inhospitable integration we currently have set up in our schools, high school just ain't fair for our autistic youth. Still, the onus sits upon the autistic to "change" and "be normal," while the rest glide by with insensitivity.

While we all know we need to change that, people need options. I don’t know how many will be available in the future and I think of many autistic youth today -- who could achieve at high school, given the right patience and accommodations.

People tend to think of homeschooling as a cop-out or as a failure. I beg to differ. Take a look and subscribe to Life Learners magazine to see how homeschoolers are succeeding in higher education and in society.

Also, there are virtual options that may be quite suitable for many autistic learners. The social piece may seem to be missing, but what's so great about the social piece if no one cares to understand autism and one's autistic child is not thriving in the environment? I would rather Adam go to many other wonderful supportive "social" environments that exist and that accept him. So, if you are looking for options, share them here and take a look at The Virtual Learning Centre, which partners with the Ministry of Education for more options in getting through high school.

The Autism Acceptance Project Announces A New Partnership

We all know how stigma influences the hiring of autistic people. A lack of understanding about the nature of autism limits opportunities. This is an interesting article on how the way society thinks about autism, can be an obstacle. It is titled Letters: Autism Shouldn't Be A Roadblock to the Working World.
LinkUP is an employment service in Toronto for persons with disabilities. They have autistic clientele. TAAProject and LinkUP will work together to help employers come to understand and value autistic people in the workplace.

Our autistic speaker’s bureau is growing and we are getting calls now to have autistic individuals speak to various organizations and schools. Now is the time to book your speaker. Keep checking the TAAProject website for a growing list of speakers. Our newest additions are Matthew Schuster from Queen’s University and John Gelmon, a friend of TAAProject and our new copy editor. If you are autistic and you are interested in joining our Bureau, please contact us at 416-487-3600 or at www.taaproject.com.

We are also working on many other partnerships which will soon be announced.

The Zen of Chocolate

Adam loves chocolate. He will sing for cake, remembering the Happy Birthday songs of parties-past. There is a true art to eating chocolate, and Adam has mastered it. So, instead of worrying about weight-gain, I imagine lolling in bed with a box of bon bons. He simply and truly makes it one of the most pleasurable things to watch that you just gotta try it...guilt-free.

Adam will wake up in the morning, a look of determination washing over his face. His eyes will then furrow as he forms his mouth to say "Choc-oh," looking into my eyes. He musters up the energy to say it just so, the "c -oh" punctuated, his mouth
extending the shape of an O a few seconds after the word has been said, so that it's as if the milky stuff floats in the air.

I blame Quaker, not myself. They make good chocolate chip granola bars for breakfast. Back in my day, my mother blamed Captain Crunch.

Okay, I let Adam have a chocolate chip granola bar before his healthier breakfast. He will ask for the finest of African Dark in the afternoons, and when the cake comes out, I can't leave a party quickly.

So, I sit back and take a long look of delight that passes Adam's face when he gets his piece of cake. May they all eat cake.

Labels: Joy

FRIDAY, SEPTEMBER 14, 2007

Why Friendship Can Be Difficult -- A Parent's Point of View

I am the kind of person that has a couple of really close friends. Unlike my husband, I will not likely have the big parties and reunions, although I enjoy them when I'm in the mood. I'm just not that good at keeping an array of friends like a financial portfolio, and I cannot spread my emotional self out too thin. No, I have one friend who I can really talk to and be myself. I have others who I can dig down deep with -- usually those "artsy" types. Others have come to me by virtue of marriage, and my other ones, by virtue of the work I do now -- in writing and in autism. I am like many of the friends I have -- not purposely snobbish or selective -- but simply wanting to enjoy myself, be myself, and sometimes, dig down deep. I am quiet and private, and in many ways upon reflection, think I am somewhat reserved like my son Adam -- carefully evaluating people to see if they are safe. After all, our lives are different, and one has to be careful not to expend too much energy on those who we have to continually explain "autism" and disability to. I mean, one doesn't want to have to keep explaining to one's closest of friends. The years pass and we just want to go on living, thank you. While I do enjoy explaining when
people want to listen, there are times we just want to be, without explanation.

Maybe this is why I am extremely sensitive to the language people use to describe autism. Some days I can let it roll of my back. I imagine most parents feel it -- days when we feel invincible and days when subtle bias -- spoken nonchalantly -- really gets to us. It is like when someone refers to their hyper-active child jokingly as "miswired" and then says it is "just like autism." This happened during a conversation I had last weekend, which was all about bias and how society views the disabled. Then suddenly, voila! Out of nowhere came an anesthetized remark, intended to close a conversation pleasantly, and not at all intended to insult.

It puzzles me further how some autistic people refer to themselves as "miswired." I mean, where do the references come from if not from non autistic people and the scientists who theorize about autism? How much does the way our medical community influence the way some autistic people view themselves and theorize about their own autism? It makes me incredibly uncomfortable as I envision Adam listening to such references at future family functions, Barmitzvahs and weddings to come -- the terms that media and medical professionals erroneously and carelessly use to describe the nature of autism, which then becomes the way that others come to think of Adam. These can either be subtle or blatantly insulting references that, if you are autistic and you don’t work to build your self-esteem, might just undercut you.

It is really time to address the use of language in every situation. It is something I am committed to doing, no matter how tiresome, except it is important for others to know that it can be. It is easy for me to exemplify it in my community -- I can use examples like, what if someone was having a nice conversation and just dropped in something like 'all Jews are good with money?'

Instantaneously, if you are Jewish, you feel the bias. You feel that everything that was positive and equal between you, has evaporated. While you could stand by and "educate" the person who has just said something insulting, you consider what you might gain or lose from it. In other words, is it worthwhile or just going to zap you of your energy? Or, will this person understand the point that is trying to be made? Finally, how can you say it so that it doesn't make the other person feel they are under attack, despite the way the comment just made you feel? These are the
down-and-dirty details (and hazards) of everyday activism.

Fortunately, my "circle of friends" has come along the journey with me, and I am richer because of it. And despite my reservedness, I think I have made more dis-abled friends who have taught me to accept my need to be (at least in public) reserved.

For some interesting lists on politically correct language visit http://www.sideroad.com/Business_Communication/politically-correct-language.html. Here’s an argument against the use of politically correct language, as the author suggests that to just use the language only in order to not appear ignorant, is also missing the point.

I tend to lean in the direction that if it's insulting to the group of people the term refers to, then the term is inappropriate.

THURSDAY, SEPTEMBER 13, 2007

Explaining....

Watch this excellent video by Amanda Baggs. It speaks for itself:

MONDAY, SEPTEMBER 10, 2007

Dancing

These videos from The Autistic Pride Dancers really made me smile today.

Maybe it's because my little Adam, who is humming classical music now everyday (perfectly to Mozart, Bach and a little bit of Berlioz, I might add), has also taken up dancing, swaying his arms and trying to move his body to the beat. Maybe it's because art does not deliquesce autistic people to "abnormal genes" but rather,
Measures of Time

The beginning of school. Most parents scramble to get their kids ready -- maybe new clothes, a new knapsack and for some of us, some story books on transitioning back to school. Maybe as children reach past the toddler age, time fuses a little, maybe the post Labour Day routine so ingrained. Maybe not.

For us, this first day of school is a stark measure of time passing by. Adam’s cherub cheeks have gone now, his body has grown taller, making him look skinny even though he eats all day long. This summer, we saw a real joy in camp -- Adam allowing his friends to kiss him, to hug him and Adam, sweet Adam, relishing it with giggles -- a stark contrast to Adam's earlier years when he didn't like people coming too close -- let alone noisy children. We traveled to Alaska where Adam endured six hour tours with grace and began to use his first four-word sentences. We saw a sudden maturity at the doctor this summer -- Adam entering the office and instead of distressed cries, grabbed the doc's hands leading them to the device to check the ears and saying "ear, ear" clearly. We went back to the hospital for ear cleaning procedures from swimmer's ear and Adam cooperated. Adam taught himself how to swim underwater. He taught himself to leap, to hop -- with a little help from his friends.

So while I reflect on all the things that Adam did this summer, even celebrate his growth, there is nothing more unclad than the sudden rush of the first school morning, and the first school bus to whisk him away from me.

"Bye, Adam, bye," I say frantically as the door begins to close, my hands waving, my face masked with a huge smile until he pulls out...
of my view. There is no other fuss. The bus driver has no idea in her quest to be on time.

So I guess yesterday was another measure of time, as Adam stripped himself of his clothes and made up for his ban on swimming by playing with the hose and then jumping on his trampoline.

The last day of summer, the final days of his baby years. His naked innocence peaking, and the relentless march of time.
Between Interruptions -- My First Review

Yesterday, my mother (yes my mom -- she is more vigilant than I am about finding these things), found my first book review for Between Interruptions where my contribution was also reviewed.

"Estee Klar-Wolfond writes eloquently about her autistic son, Adam, in The Perfect Child. 'There is no other normal but the normal we create for ourselves,' she says -- and we believe her."

While The Perfect Child reflects how I feel about Adam and how we have come to find our own perfection, I hope to continue to convey our journey honestly, and perhaps a little provocatively, as I write on. A journey is made up of bumps, falls and epiphanies after all, and maybe, just maybe, it might mean something to someone else at the end of the day.

You can purchase Between Interruptions from Amazon.com.

"Stigma Hurts!: Do We Only Have It Half Right?"

I have to admit that oftentimes, I wonder what's not to "get" about de-stigmatizing autism. I mean, it's something that we seem to "get" in many other disabilities and mental "illness." We hear the word de-stigmatize a lot these days in terms of depression, bipolar disorder and today in the Globe and Mail, about mental illness. But the rhetorical landscape remains confusing.

Even with "illness," I am compelled to put it into quotation marks because mental illness might be relative, maybe sometimes subjective. Who deems another "mentally ill," after all? Was Vincent Van Gogh "mentally ill?" Or was he an individual who lived with schizophrenia, who heard voices in his ear so that he cut it off? Or was he just Vincent, living with the egomaniac Gauguin and after their fight, cut off the mere tip of his ear to get the argument out of his head? A shocking gesture, perhaps, and not
unlike some other eccentric artists I have come across who have mutilated themselves (I am not going to judge here) -- for life, as some say, can imitate or even BE art. Still, Van Gogh, because he was so very eccentric, also thought himself mad and checked himself into a mental hospital towards the end of his life. Would he have if others had accepted him as he was? And yet, such intensity also came with his gift, his contribution to society in the way of his art. Art, like no other during his time. Art, that changed the way others viewed the world by way of his evolutionary brush strokes.

Quality of life is impacted when one lives with stigma and exclusion. The stigma lends itself to exclusion -- from jobs, from schools, from communities. The disabled say that their ability or dis-ability is effected by the way society understands and accommodates the disability. So it is wise to tread carefully as attributions of "mentally ill" might be social ones -- others might accuse us of being sick” or "ill" or "not normal" or "genetic abnormalities," like many do of autistic individuals, and the individual is neither delusional nor ill at all. So, as I applaud the fact that many Canadians are on the path to de-stigmatizing depression, schizophrenia and the like, I pause. Have we only got it half right? Are we still de-stigmatizing with one caveat: sure, we’ll not stigmatize you as long as you get yourself recovered. Because as long as we truly keep ourselves in the dark, as long as we refuse to try and understand, we will continue to marginalize and make assumptions about others who are different.

Margaret Trudeau now advocates for the de-stigmatization of Mood Disorders. On their website, the homepage reads "Stigma Hurts!." It reads:

"Stigma has been defined as: Prejudice based on stereotypes, resulting in discrimination (Corrigan & Lundin, 2001). While public attitude towards some mental illnesses seems to be softening surveys also reveal that people with serious mental illness and addictions are seen to: lack intelligence, are lazy, morally reprehensible, violent and dangerous, have nothing to contribute to society and are unable to recover. People are routinely denied employment, access to health care, housing, insurance and mortgages. Discrimination denies full citizenship and equal rights.

It is this diminished view which allows individuals, communities,
institutions and government to accept a reduced social and
economic status for people with these conditions than we would
accept for oneself. As a consequence stigma and discrimination
towards people with mental illness, neurological conditions and
addictions is under researched and poorly understood. There are
no systems of surveillance in place to monitor the levels or
changes in the degree of stigma and discrimination experienced
within the general population.[i] We know that stigma is not
experienced equally across all cultures, by all consumers or
consistently across one’s progress towards recovery.

A component of recovery includes rejecting self-stigma, and
combating the negative attitudes and discriminatory practices
through public education and advocacy. Studies of the
magnitude and nature of stigma need to account for both the
disease-specific and culture-specific aspects of stigma. However,
little research has been done to identify those factors which
protect people from the harmful effect of stigma or that promote
a healthy progression toward acceptance.

Now off to the Mental Health Commission lead by former senator
Michael Kirby. On that homepage, Kirby states:

"I look forward to the day when we can say that we live in a
country that has put an end to the stigmatization of mental
illness and has eliminated discrimination against people living
with mental illness; to the day when we can say that we have
put in place a truly seamless continuum of care across the
lifespan that allows people living with mental illness to find their
individual road to recovery."

Not all individuals feel they have anything to recover from when it
comes to disability and I am also referring to autism when I am
referring to disability. It is not a denial of the obstacles one can
face with a particular disability. It is about where the pressure lies
in terms of conforming. What and who "needs to change?" When
de-stigmatizing something, we have to believe that there is
nothing to recover from. In place of this notion, we might need
to consider replacing "recovery" with "accepting and
accomodating." We may have to put the type of assistance and
education into the hands of the individual -- "self-determination"
as it is often referred to. Further, one’s quality of life is based on an
individual’s acceptance by others in their community, and this
acceptance can lead to self-acceptance. It means that we treat others with equality and with sensitivity to their individual needs. It means that we learn to understand the issue or disability in order to learn how to educate autistic individuals and others with special needs in our schools.

The idea of acceptance is fundamental. Realizing what is reality for many individuals who have had to live in denial or suppression of their "way of being" has been, and continues to be, much more damaging.

We have to learn how to learn about autism rather than how we tend to ascribe it the other way around. We often say that autistic people need to "learn how to learn." Yet, we have to recognize what we mean by that. It means that "they have to learn how WE learn," while ignoring the fact that autistics learn in an autistic way. Autistic people learn. How can we learn how to teach them? Where is the two way street in special ed?

After speaking with many in the world of disability, a world that seems to be quickly becoming my own as I traverse it with Adam, the word "assistance" when it comes to autism seems much more appropriate -- "merging help with respect," say Norman Kunc and Emma Van Der Klift in their outstanding paper Hell Bent on Helping.

With so much money going into genetics research rather than research that seeks to understand autism and help autistics live rich lives with autism, we do not know how to teach, employ and interact or accommodate because our minds are on the goal of preventing, curing and recovering (can we say "saving") autistic people, literally, from themselves. Do we have this right? Or is our responsibility to learn and merge that teaching with respect for how autistics learn so that we learn to function in society with disabled people contributing to it?

We know that some individuals have more challenges than others and the levels of assistance differ. But as I continue to read the rhetoric, even if it seems positive and the goal is to achieve a world that de-stigmatizes the individual with either autism, another disability or mental illness, I scratch my head and wonder how the rhetoric will be used: to provide more fuel to the people who want to "recover" others, and change individuals so that they are
"normal," or to provide the supports and assistance to enable people to live freely and comfortably in society as they are? In other words, do we value the individual who lives with the mental illness or disability, or do we value them ONLY when they recover or come as close to "recovery" as they can get?

As the Down Syndrome Society includes in its site this article from The Chronicle Herald:

**Down syndrome: rights doomed by the media**

**By RENATE LINDEMAN**

"Canada’s signing of the UN convention on the rights of people with disabilities on March 31, 2007, marked another milestone in advancing the rights of people with disabilities. It appears we have come a long way. People with Down syndrome are included in their schools and communities, they get married, enjoy equal-opportunity employment. But beneath all this outward appearance of progress, a different message can be heard....

In Canada, this is not a heartening time to have Down syndrome....

The "value" of people with Down syndrome was being questioned over and over, as they were accused of being unproductive and a drain on resources. "Value" for society was only measured in terms of the ability to make money, and no value was placed on care, respect, acceptance or love. If society views people with Down syndrome as a "burden" in these times of abundance, what will happen if we face an economical recession? We cannot allow people with Down syndrome to be the scapegoat."

It comes down to value. It strikes me as odd, in a world that values "diversity," that people can sometimes stare at Adam strangely, which shows that he is not valued (or understood as understanding leads to valuing) that much by others. Instead, if they have heard anything about autism, they may stare at him with fascination and label him under their breath. It is with a strong resolve that I choose to ignore those scrutinizing glances, even if I notice it, for Adam's sake. It is with the same resolve that I question society's use of rhetoric so that his value is never undermined.
"Caroline had listened intently, her heart lifting with every word. They left for the library and went for coffee. Caroline would never forget those hours, the excitement she’d felt, as if she were walking from a long, slow dream. What would happen, they conjectured, if they simply went on assuming their children would do everything. Perhaps not quickly. Perhaps not by the book. But what if they simply erased those growth and development charts, with the precise constricting points and curves? What if they kept their expectations but erased the time line? What harm could it do? Why not try?" (Excerpt from *The Memory Keeper's Daughter*, Kim Edwards, p.98.).

Caroline is the nurse character who takes Phoebe, a newborn with Down Syndrome to care for. The father, a doctor who had lost a sister to disease, delivers his own twins. The second is Phoebe. He tells Caroline, his nurse, to take her to the institution, but neglects to tell his wife. He thinks he is sparing her from pain. Instead, he tells Norah, that their second child is stillborn. He ends up mourning longer than his wife, as he receives news of Phoebe doing just fine -- Caroline refuses to leave Phoebe in the institution she visits.

He must live with his guilt. The scene above is Caroline engaged in a weekly play date with another mother and Down’s child. She agonizes that Phoebe, at over a year in age, has still not rolled over. The other little boy, at three, is just beginning to stack blocks. They let them play, but the play is also targeted. Phoebe has not yet grabbed the dangling keys that Caroline keeps putting just within her reach. Her efforts seem futile as she attempts the...
"Phoebe was making soft sounds reaching. Her hands were brushing against Al's neck, his collarbone, his dark plaid shirt. At first it didn't register with Caroline, what was happening; then, suddenly, it did... Phoebe was reaching for the medallion. Not batting at air, as she had this morning, but using Al's chest for resistance, her small fingers scraping and scraping the medallion into her palm until she could close her fist around it. Rapt with success, she yanked the medallion hard on its string, making Al raise his hand to the chafing.

Caroline touched her own neck too, feeling the quick burn of joy.

Oh yes, she thought. Grab it my darling. Grab the world."(pp.104-105)

Perhaps what constitutes "successful parenting of an autistic child" as discussed recently on the blogs, is the innate knowing that there is no harm in waiting. As we push to help our children achieve the developmental milestones, we realize that much of our efforts our futile -- the forced effort, that is. Somehow, the milestones come, be it from a combination of teaching and environment, or because it comes naturally over time, with that confluence of experience, ability and desire. That's not to be mourned. It certainly need not be catastrophized. The points and the curves don't mean much. No harm will be done if our kids take a little longer to reach one of those precious milestones, or if they even come to it differently.

Recently, a friend pointed me to this blog by journalist Patricia E. Bauer: Stand Tall or her other website http://www.patiokiaebauer.com/--- bureau chief of The Washington Post, senior editor of Los Angeles Times Magazine and writer for The New Yorker. I highly recommend that all of us in the autism community reference her disability writing. I too like to keep talking about how autism is referenced in the media and will do so again this October at the Autcom Conference in Edmonton. You can also view my presentation on how autism is referenced at the MIT lecture I gave last May.

Patricia gives us many good reasons why we must continue to remain vigilant about the way autism is referred to. Here is an excerpt from her keynote speech about prenatal screening:
"Let’s start with what we can do as individuals. As I’ve gone around the conference, I’ve heard about some great things that people are doing in their own communities. Things like:

– Helping to educate the doctors and genetic counselors in their area by visiting their classes or professional meetings.

– Building relationships with hospitals, and talking with families who have a fresh diagnosis.

– Monitoring their local news media, and holding them accountable for their coverage and their use of language about people with disabilities.

These are great steps, but let’s not stop there. Let’s dream even bigger.

It’s time for us to insist that our organizations advocate forcefully on behalf of people with Down syndrome in ways that are targeted to reach decision-makers, to reach medical professionals, and of course to reach the general public. Here are some of the things we need to do.

1. We need to provide disability awareness training and accurate information directly to obstetricians, to gynecologists, and to the professionals who assist them. They need to hear the nuanced, compassionate message that is at the core of diversity and human rights: all people have value and dignity and are worthy of celebration. We’ve told them this nicely. Now perhaps it’s time to turn up the volume.

2. We need to put out lots and lots of well-designed materials that will teach doctors how to discuss prenatal screening and diagnoses with their patients. Senators Kennedy and Brownback have recently reintroduced their bill on this topic. Whether it’s this bill or another one, we need to find a way for doctors to get the materials they need.

3. We need to improve medical school curriculums, which include almost nothing about children with disabilities.

4. We need to hold publishers accountable for the editorial
content of their pregnancy handbooks. Take a look in your local bookstore, and notice what those books say about our young people. If they carry anything at all, it’s more than likely a cold, clinical list of symptoms and diagnoses, guaranteed to strike fear in the heart of any pregnant woman. We must change this.

5. We need to use technology to convey our message. Where does your average 20-or 30-something look for medical information? Right. The Internet. If we truly want to help people make informed decisions, we need to get involved in the Internet in a big way, both in print and in video. Our content needs to be useful and modern.

6. We need to enable prospective parents to see that people with disabilities live good lives, and that they have warm, sustaining relationships with their families and friends. Presently, that information is only coming to them anecdotally, if at all. Imagine how different things would be if people could be referred to a website that allowed them to click on videos that would show them footage of people with Down syndrome, of all ages and ability levels, going through their daily lives. America’s teenagers are communicating actively through Youtube – why shouldn’t we?

7. We need to speak up to challenge the old stereotypes about our family members and ourselves. We’re not victims. We’re not heroes. We’re just ordinary people sharing slightly extraordinary lives with people we love and who love us."

As I watch Adam’s exuberance, his joy, his desire, his beauty, his innocence, I consider that perhaps the world needs to think and pause for his sake;

Adam -- who doesn't judge anyone, who, just wants to grab his own piece of the world.
Experience and Literacy

Disabled individuals, says June E. Downing, in her book *Teaching Literacy to Students with Significant Disabilities*, are often given little experience. As many non-verbal or presumed "inattentive" disabled individuals are denied experience, this can significantly delay literacy skills. Downing says that people think that disabled people won't "get" anything from the experience, so the average person thinks, "why bother.... why take a blind person to the zoo? What would they gain from that experience?"

"Literacy builds on our life experiences, which is why it is imperative to provide children with multiple experiences to support their learning. Children with severe physical impairments may lack experiential learning due to the difficulty they have walking and physically exploring their environments (Blishcak, 1995). When children have significant disabilities that may involve the multiple impact of physical, cognitive, and sensory impairments, the ability to explore and learn from this exploration may be even more hampered. To compound the problem, experiences can become limited as care providers question the value of these experiences. Instead of supporting the child's involvement in varied experiences on an ongoing basis, the decision may be made to keep the child at home, where he or she is most comfortable. Unfortunately, such a decision further handicaps the child, making it more difficult to acquire and understand basic concepts." (Downing, pp. 9-10).

She suggests that the compounding of reading, exposure, experience and varied teaching is the path to literacy. Sadly, at school, many students with significant disabilities seem to be overlooked (Downing) when it comes to such opportunities.

I see it in autism. I see an over-generalization, and a plea for money that rightfully belongs to all people of disabilities and I would hate to see funding get taken away for educational opportunities for others. The more I begin to study the other disabilities alongside autism, I see that autism is not all that dissimilar. There may be differences in some areas for autistic
individuals for sure, and we need to build the understanding and sensitivity around those issues. However, we've made "autism education" and "autism funding" much too daunting. Few want to teach an autistic student. The path to acceptance, in my experience and many of my friends with autistic children, is empowering the teacher -- the "try this" approach that lets the teacher experience success. The teacher then feels that the teaching of an autistic individual doesn't have to be as daunting as it sounds.

In much of "discrete trial" teaching or ABA or whatever you want to call it, I see a lot of table-teaching of very young people (age two years). Sure, there is NET teaching too (Natural Environment Teaching), when the therapist believes it is time for the child to "generalize" his/her skills. It is a subjective choice by the therapist or supervisor, often based on the child's ability to respond to questions in a typical way, or do a task the way that is expected. In the meantime, hours, days and months pass by and the child loses experience because the therapist doesn't believe that the child can garner anything from experience without learning the skills at the table, first. If they child is on an outing, they are again expected to respond, to act typically, to talk in at least declaratives, instead of being allowed to experience in a way that may be unique to them. The emphasis in today's "autism education" is too heavily weighted in letter naming, letter-sound association "before accessing meaningful literacy," says Downing. She calls it a linear sequence of isolated skills.

We all need time to filter -- to let experience penetrate all of our senses. We need time to process, to get used to new things without being pressured or judged.

Teaching and experience must go hand and hand. A teacher has to believe in the innate garnering and registering of experience of the person they are seeking to teach.

Once in a while, a family member of mine would say when demanding "hey Adam look at this," or "do this," or "touch your nose," to appease his desire for Adam's normalcy, I suppose. When Adam didn't do it quickly enough or at all, this person would say "oh, he doesn't care." I don't think it was judgmental in a bad way, but it is certainly indicative of how most people view autistic people -- something we've all talked about so much on our blogs,
so I don't need to repeat it here. And we all know that an atypical response or what we perceive as non response is **NOT** no response, or a lack of understanding. It is an inability to respond in a way that the rest of us have learned so we do not understand it.

That said, I believe in experience. No matter how hard it is -- when a child has a meltdown and you feel like melting away as a parent -- we have to get up and keep trying. Dinners out, the zoo, the movies even if for only ten minutes at a time -- we've got to keep exposing our children to the world that also belongs to them. Experience also requires time away from the table.

As for the blind person who "wouldn't get anything from going to the zoo," read about the **blind person who shot a hole in one**.

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**The Zen of Dog Sledding**

This photo was taken a couple of weeks ago on our family trip to Alaska. On my knee sits Adam, laughing hysterically. In the back rides Henry, wearing the pink gloves I bought last minute because we learned it was going to be cold up there. As the dogs mushed, the jerk of the sled sudden by these mighty little dogs, Adam was thrilled.

"We could hear him all the way back at base camp," said a young woman wrapped in winter clothes in the middle of August. She is young and decides to give me two photos taken of us instead of one, "because he is so adorable," she says.

Should I mention that Adam took a helicopter to a glacier, had to wear earphones (he has always hated wearing those), and did not
flinch at the hundreds of dogs barking, yelping and leaping even more frenetically as we approached because they knew they were about to go for a run, we were told by Molly, our dog-sled guide.

"I live alone further North," she said. "Just me and my dogs and no electricity." She says this just after we meet all ten dogs who will pull us along, each with their own distinct personality -- the one closest to my view who keeps looking back to check with Molly, as if trying to please her.

"Being up here all summer with twenty-five others is claustrophobic," she says to us as if she is confiding. "In can get a little crowded up here," she chuckles heartily, I think, knowing that to city folk like us, twenty five people is probably a kafe klatch. Yet I suppose being with twenty-five people stuck high up on a glacier, anything can happen. I guess I too feel a little confined when my home door is revolving -- maintenance workers, people for Adam, our large family, the events we have at our home, our friends. I wouldn't trade it in, mind you, but it makes me feel, well, anti-social -- striving for moments when I can be alone, writing like this. When a book is in progress, when there's much work to be done as with The Autism Acceptance Project, I want to find those long stretches of time to think, to work. The rhythm of my life is fast, and the moments with Adam, like dog sledding, are suspended in time. I relish them as much as I do the moments alone to write meandering posts like this. I relish the moments as I watch Adam's almond eyes struggle to remain open at bedtime, and he finally surrenders to sleep, his soft breath warm against my face. I savour the memories of each trip, each sleep, each ordinary day by recounting them as I do here. If all this is a homage, a memory of Adam’s great impact on my life, then so be it. If it's about autism and thinking about it a little differently, then that's fine too.

I love this photograph. I love its joy. I love how Adam seems to drink in life, his precious and ordinary moments.
Wanted: Perfection

You can find this article about "getting rid" of Down Syndrome people as quickly as possible. I decided to post this as Adam is playing today with his friend down the street, who is "Downs." The other friend has another neurological issue. They are really wonderful kids, all of them just returned from different camps and find themselves in need of play on this hot summer day.

I find it disturbing that we have this trend, no less in "The Economist," where I suppose, the financial factor is critical to assessing human value -- the 'who costs more' issue. If you're special needs, you're in for trouble:

**Pre-natal testing**

**Wanted: perfection**

**Jul 5th 2007 | PHOENIX**

*From The Economist print edition*

**Doctors try not to be sued over Down's syndrome babies**

*BUSINESS is brisk at Phoenix Perinatal Associates, a practice for high-risk pregnancies in Arizona. “We are solidly booked for months,” the receptionist sighs. Part of the rush comes from new guidelines published on January 2nd by the American College of Obstetricians and Gynaecologists (ACOG). These urge that all pregnant women, regardless of age, should be screened for babies with Down Syndrome.*

*Only women over 35 have a high risk of producing a Down Syndrome child. They have been screened through blood tests and ultrasound scans, then with amniocentesis or chorionic villus sampling (CVS), in which cells are taken from the developing embryo. Younger mums have been screened too, but in their second trimesters and only with blood tests. The new recommendation is that all women be screened at the 20th week, using the same tests; and many women are being pushed to have them earlier.*
Many like the idea. The tests will be more accurate (amniocentesis has a 99% accuracy rate), and will give women more time to decide what to do. It makes sense to test under-35s: 80% of Down's syndrome babies are born to younger women, because their fertility rates are higher. But others find the changes unsettling, and with reason. Both amniocentesis and CVS tests carry a slight risk of miscarriage. And roughly 80% of women testing positive for Down's have abortions.

The new guidelines may also be triggered by the surge in lawsuits. In November an ACOG survey found that 65% of obstetrician-gynaecologists had reduced their practices for fear of liability claims. Clinic workers confirm that women who have imperfect babies tend to blame doctors. One nurse says her clinic can't afford the insurance to ward off the suits. “If more tests reduce our risks, then so be it.”

To advocates of the 350,000 Americans with Down's syndrome, all this sounds disturbing. Jon Colman, the chief operating officer at the National Down's syndrome Society (NDSS), notes that although many of them are born susceptible to heart problems, hearing loss and respiratory problems as well as mental retardation, most contribute to their families and communities and all are entitled to lead productive, independent lives. Down's children, many parents say, are delightful to bring up. And most do not die in their 20s, as Americans tend to assume, but can hope to live into their mid-50s.

Back in February, the NDSS challenged ACOG and others to make common cause with Down's syndrome organisations to give parents better information. They also urged doctors not to push expectant parents into prenatal testing, or towards abortion. But monitoring a more restrained approach might be tough. Many obstetricians are clearly overworked, with no time to offer more than suggestions and results. And although the guidelines describe these tests as options, many pregnant women are feeling badgered. Some are being asked six times or more whether they want an amniocentesis.

Asked what his goal was, one genetic counsellor in Phoenix replies: “To catch as many Down's babies” as he can. But with such eagerness, much could go wrong. Academic research suggests that around one in 100 40-year-olds produce Down's
syndrome babies, but many Arizona clinics cite a figure as high as one in four. “There must be a regulated message,” says one 40-year-old new mum in Chandler. “And even then I would question it.”

I would love for every genetic counsellor to reassess "perfection" by reading my short story "The Perfect Child" in the book, Between Interruptions. Perfection and imperfection, are in the eyes of the beholder. I never had an amniocentesis, even though I was of the age to get one when I was carrying Adam. I chose not to. I chose to take whatever I got. I believe in the right to choose. I also believe in the dire need for education in terms of what joys, mixed in with those challenges we hear about much more often, can come with having special needs children. I can't imagine, as Krista Flint of The Canadian Down Syndrome Society has reported many times "a world without a Down syndrome person [or autistic person, or cerebral palsy person or whatever] in it."

I would love for our Autism Society of Ontario and Autism Society of Canada Executive Directors say the same thing for autistic people. As confidently. As boldly.

The Branding of Joy?

I got a bit of a kick out of this when I fell upon this site selling Joy of Autism T-shirts. as well as "Autism: it's not what you think" T-shirts. Looks like the sellers are based in Hamburg, Germany.

Ah well... as long as everyone looks upon all human beings as a joy, right?
Viva La Difference!

It's perhaps slowly becoming known that there is an alternative view that autistics are different, not aberrant. It is more than apparent, after meeting any autistic person, no matter how "profoundly disabled or autistic" one person subjectively decides them to be are, well, just human. Difference does not define who we are and how we should be treated (often as ill or deficient), but rather, differences might be viewed as what makes up humanity. Valuing difference can also lay a path in providing the services required to also equalize the "human field" while respecting and protecting the difference, the heritage, the being. The pitfall of social stigma of human difference -- race, gender, sexual orientation and disability -- might be eradicated with this emerging awareness of the over-homogenization of human appearance and behaviour.

In this Association for Psychological Science Presidential Symposium, Dr. Morton Ann Gernsbacher chairs, "Stigma from Science: Group Differences, Not Group Deficits" Viva La Difference, (not La Deficit). Joining her on the discussion of stigma in science, are Susan T. Fiske, APS Fellow Douglas L. Medin, APS Fellow James Jones and APS Fellow and Charter Member Gregory M. Herek:

"I'm not saying that people are politically biased and that their science is suspect," Fiske explained. "I'm saying that people pursue what they find interesting, and what people find interesting is informed by their values and their identities." Group differences, when used unjudiciously, "have the tendency to divide us and oversimplify," Fiske said. For one thing, differences
assumed to exist between groups can become self-fulfilling (as in the phenomenon of "stereotype threat") and prescriptive. Even positive attributes can be damaging when assigned to a whole group. -- Fiske.

"A big problem in research is you start with what you know, in your own culture." As a result, he said, it is easy to export our own presumptions to other cultures and other ethnicities and to minimize the differences within cultural/ethnic groups." -- Medin.

"If you allege that groups are inferior, and then you develop opportunities for them consistent with that inferiority, then of course they behave in ways you predict so you have a sort of scientific self-fulfilling prophecy." -- Jones.

"On the subject of homosexuality, Sigmund Freud was ahead of his time, Herek said. Although he maintained that homosexuality reflected a less-than-optimal object choice, he did not consider it a sickness. But despite following the psychoanalytic paradigm through the first half of the century, the American psychiatric establishment departed from Freud on this matter and classified homosexuality as an illness. It was a classification based on assumptions and not on sound empirical data.

"The logical response was to cure it," Herek said, and numerous techniques were tried to alter people's sexual orientation -- all unsuccessful, some tragic." -- Herek.

Thanks to APS for putting on this presentation and The Autism Acceptance Project hopes to follow suit in 2008.
Our Walkabouts

Adam went to the doctor today -- calm and saying "ear, ear," leading the doctor's hand to the ears that seem to still bother him. We went there for a visit before our trip to Alaska as he contracted "swimmer's ear" with a blazing fever. The round of antibiotics had little effect -- his ears still bother him.

Usually, Adam has been terrified of getting his ears checked. Just approaching the doctor's office has usually sent Adam into tears. Yet, since being integrated into his quiet school and since being integrated at a camp, he is becoming more social, more aware -- being VERY aware of how others act around him. Obviously, he's an observational learner.

He's not the social butterfly of the group, but has what it takes to earn the nickname "Romeo" at camp as the girls have been fighting for his kisses, hugs and attention. Adam doesn't seem to mind. No, he's been beaming, in fact. Where close proximity and a swarm of people around him kissing him would have made him once meltdown, he is smiling and giggling away. He hung around the boys who came to visit us from Israel the other day, even though he can't find the words, "play with me." But "play with me," he is saying -- as clear as day.

Right, I was talking about his ears. I remember swimmer's ear. Adam comes by it honestly. He is the son of two former competitive swimmers and has come to love the water, advancing four levels at camp swim lessons. Shown once, maybe twice, he then launches on his own, dunking and jumping underwater and
trying the "starfish" on his back. Adam wants to conquer the pool. I say this as I remember the days of pushing and prodding him as "expert" ABA therapists told me that he has to "learn how to learn" and that we had to reinforce everything because an autistic person had no intrinsic motivation. We never had to externally reinforce Adam, even though the therapists insisted that he had to be. No, it was when we said goodbye to ABA that Adam began to find his way, and I followed his lead and found the support he needed with Occupational Therapists, shadows and Speech Language Therapists. Adam had to be shown. He also needs to feel, experience -- experience through all the senses so that he can feel and learn, because learning has to have some meaning. Too often, if a child is presumed to be inattentive, they are denied the experiences. Lessons are confined to a table. For a child whose senses are alive, table-learning is non experiential. Table learning is usually based on an ability to perform and respond -- it has little to do with learning. It leaves big gaps in fact, as one needs meaning in order to become literate.

Yes, all that dunking in the water has its price, though. All that fun. I remember my own many swimmer's ear infections, and I hate to say that Adam needs the pus manually extracted. No more swimming for him -- at least not for a while and not without plugs.

So we play in our yard, we've had very little "therapy" but lots of activity. I once said, as the Canadian ABA'ers faulted me for doing so, that "a child has to be happy in order to learn." I remember educators saying that "learning isn't always fun." It sounded reasonable because learning was often made miserable for me. I was not good at math and was never given the time or belief that I would ever be good at it. For sure, the message was that I would always bad at it, the expectation was low, and it has stayed with me forever. There is absolutely no way that Adam could have learned as much as he has by following a pedantic ABA program -- one that would still have him reciting the names of animals because he can not necessarily "respond" in a typical way. It is true that learning is not always easy, but learning should never be married with the low expectation that is typically associated with autistic intelligence and "performance."

Adam blossoms and I look forward to the liberty of a non-ABA school -- a school that simply accepts Adam and happens to be the right setting for him at the moment. He is picking up math books,
wants to write better (he has difficulty with his fine motor control), and he wants to gain those literacy skills as he enjoys lessons with mommy on categories and then go on jaunts to the grocery store to learn about "food." Or when we read and write stories about different kinds of "animals," after grandpa has taken dozens of photos from their trip to the zoo.

At the same time, Adam explores his yard, moving systematically from one bush to another, saying something to each, rustling our long ornamental grasses with his hands, getting his face really close. He walks to the pool and says something to it as well. He moves towards his image reflected in our glass door and takes steps backwards as if he's measuring the space.

"...repetitive, obsessive movement and interests," I remember being told. "They are dysfuntional. We have to make it functional." Again the famous last words of our ABA supervisors.

And yet, functional the behaviour is. Like a poetic mapping of his environment and a greeting of his familiar spaces. It reminds me of Dawn Prince Hughes' greeting of all the familiar trees and rooms in her house.

"I would silently acknowledge landmarks as the route unwound, whether they were the buildings or the hills or the flowers and trees. I had memorized everything. To me, each flower, tree, building and hill was a person, a being with its own personality and sense of agency. It I did not see it, it missed me and felt abandoned." (p. 19 of Songs of the Gorilla Nation).

Knowing her prose and meeting Dawn this year, I expect Adam is similar as we returned from Alaska and Adam greeting all our backyard plants. You call it odd? I call it an aesthetic: an ability to have one’s surroundings pulsate with life within you so that you care for its very existence; an ability to know what it is to LIVE in our house, our neighbourhood. As I listened to This American Life on Mapping (Click here for This American Life), Adam's "repetitive movements" in his backyard are like a cartographical poetry. The interview asks rather pragmatically, "What do the patterns of leaf light tell you?" He asks as if the act is a meaningless waste of time. I would say that this kind of mapping is to know, to intimately know. To even know and understand the relationship of things in the environment to each other. What does
it mean, in other words, to live?

Is *that* dysfunctional?

Is the Walbiri tribe in Australia? They "sing" their world into existence -- every stone and every tree. Or consider the Dream-tracking of the honey-ant, one of the totems of the Popanji:

"It was the Eternal Home, he explained, of the Honey-ant Ancestor at Tatata. And suddenly it was as though we could set the row on row of honey-ants, their bodies striped and gleaming, bursting with nectar in their cells beneath the roots of the mulga tree. We saw the ring of flame-red earth around the entrance to their nest, and the routes of their migration as they spread to other places.

'The circles,' Mrs. Lacey added helpfully, 'are honey-ant ceremonial centres. The "tubes", as you call them, are Dreaming-tracks.'

The American man was captivated. 'And we can go and look for these Dreaming-tracks? Out there, I mean? Like at Ayers Rock? Some place like that?'

'They can,' she said. 'You can't.'

'You mean they're invisible?'

'To you. Not to them.'

'Then where are they?'

'Everywhere,' she said. 'For all I know there's a Dreaming-track running right through the middle of my shop.'

'Spooky,' the wife giggled.

'And only *they* can see it?'

'Or sing it,' Mrs. Lacey said. 'You can't have a track without a song.'

'And these tracks run every place?' the man asked. 'All over Australia?'
'Yes,' said Mrs. Lacey, sighing with satisfaction at having found a catchy phrase. "The song and the land are one." (from Bruce Chatwin's, The Songlines, pp. 27-28)

Adam sings as he meanders through a yard on these hot summer days. He mumbles words to them like a mutual secret. He does this several times until he moves on to something else, butterflies fluttering above his head.

Perhaps the "pragmatists" of our world need some lessons in the behaviours of various cultures. Pragmatism kills art. It kills creativity and perhaps even the lifeblood of "different" kinds of people or species. It lives for some ubiquitous "functionality," and even characterizes "autism acceptance" as a kind of "denial" of any intrinsic difficulty or disability. One must measure, however, how much of the difficulty or the disability arises from a majority that does not see the Dreaming-tracks, or the poetry of the environment -- that otherwise rushes from one task to another ever so "pragmatically" so to never, or rarely, see or feel or value little, if anything, at all.

Hillary Clinton: Autism "Prevention" and Political Opportunism

Don't get me wrong. I rather like Hillary Clinton. I am in favour of a female or a African-American President. What I am not in favour of is using autism "prevention" -- aka another "war on autism" as a political platform in order to get votes. Chirstschool's videos are provocative -- as they should be. Below, is another good version of his ability to illustrate the problems with using "epidemic" to get votes, money or anything of the like. If I lived in America, Hillary would lose my vote for her poorly researched stance on autism. Indeed, we are not united with Autism Speaks. We are not united with those who support factless facts on a non-existent epidemic. Adam is not a misery or an epidemic, even if there are others who insist he must be. No, he is a wonderful, joyful, exuberant little boy...
who is now growing and coming into his own.

So, no thanks, Hillary. We don't need another autism vigilante.

MONDAY, AUGUST 06, 2007

Lazy Days for Language

Adam is back with his parents from his trip to Alaska. We visited Glacier Bay and College Fjords and more. We saw Humpback and Orca Whales jump out of the water, bald eagles perched atop of trees watching us carefully, sea otters trailing sea paths, their heads occasionally poking out of the water. Glaciers plunged large chunks of ice into the jade colour sea, pieces scattering the water landscape so that Al Gore's global warming theories seemed more real than ever. We travelled on the goldrush tram across the treacherous sides of moutains -- railway builders said a railroad could never be built there. The impossible made possible only by someone who knew railroad construction and the terrain.

Adam was a trooper and I am told by Henry that even on the worst travelling day at the end of our Alaskan cruise -- a twelve hour jaunt that began at five in the morning after a bad night's sleep, Adam was still better than the rest of his other kids. Adam ate in the dining room, he played in the play room with other children, he ate well and as I always predict now in these wonderful lazy days of summer that I now have began to treasure rather than fret (that no work is being done), he began to talk a whole lot more. He said things like, "I'm at the airport," when we were waiting in line to check in our luggage. He said "go away!" when he was frustrated with me on the airplane. He said, "I like this one," as clear as day when his friend B, (we were travelling with another family), handed him one of those balls that expand and contract. He demanded "breakfast" upon waking and specific foods. He yelled "I want to go!" at the top of his lungs on that twelve hour travel day near the end of our jaunt.

Now, anyone who doesn't know Adam would have thought him to
be a typical four or five-year-old, and maybe would be a little puzzled when he didn’t answer their questions quickly enough. Even though I don’t want anyone to think that talking is the be-all and end-all for disabled kids, I must say that it is exciting for me to experience. It would be just as exciting to see my child use sign language, use a device -- anything that would deliberately communicate with me. In fact, when Adam grabs my hand and leads me to what he wants when he can’t find the words, it is just as exciting. He is a strong-willed little boy who wants control over his life. He is growing up. If I do too much for him now, he gets ticked off with me. He is at the age when he wants to try many things on his own, and little enough to want to come to mommy when he really wants me to take care of him.

So today I am just a mom who is once again beaming with pride at her son. I am proud that he tries so hard, that he is a real trooper when he travels -- enduring four hour tours without complaint now busily occupying himself with games when he becomes bored.

There was a day when everyone said this wouldn’t really happen -- that autistic people always melt down, have real trouble with transitions, who, if they didn’t talk by three, would never talk at all, and who, well, just wouldn't be able to cope or understand the world around them. It’s not to say that it doesn’t happen for many autistic people. When travelling with Adam, I don’t see the disparity, just a few little differences as he grows. I also think that disparity is in the eyes of the beholder. I don’t know what the future will hold, and it’s no point worrying too much about it. The joy we find is letting the days unfold, watching Adam develop and become the person he is meant to be, and taking time out of the everyday to see that language develops when our kids are allowed to relax.
As you read in my last post, we've been really ill around here -- just emerging this week from virus' and Adam's swimmer's ear, the latter which brought about pain and a high fever.

Other than that, I feel a little removed from autism these days. Camp is so wonderful -- a "regular" camp where Adam attends with a shadow -- something I believe all families should be entitled to have and am considering raising funds for. We are all relaxed and Adam is talking a whole lot more. I look forward to his school this September, where he was so happy -- the atmosphere so quiet and suitable to him. It feels so strangely in place these days and I said to Henry last night:

"There was a day when Adam was first diagnosed that I worried all the time -- when I worried about his not talking and such. When he was first diagnosed, it was hard for the first year not to think about what he would be like without autism, for that's what the world would have you believe is possible. Today, I don't care. I don't think twice about it, except when I make a point of it on my blog. I accept Adam for who he is and I like who he is as an autistic person. He is the best boy in the world and I wouldn't change a thing."

Yes, our kids get ill. Yes, Adam can be anxious. Yes, we have to modify some things. But it's the world as we know it and we have gotten to the point where we don't think about it as much any more.

I am booking Adam's fall music and sports programs now, and we are welcome with open arms. I like to commend all the people we meet who have accepted us and who are so flexible in order to let Adam be part of the life to which he is entitled.

So I guess it's why I'm not responding so much to all the Google Alerts I get on autism. All the new news about the cause of autism du jour. It's like we've finally gotten to the point where we float
Middle-Aged Scare

It was last Saturday, a balmy hundred degrees along South Carolina's flat beach that I felt it come on -- an ache every time I tried to take a deep breath.

"It must be the massage I had," I said to my friends. "I think I had Helga's hands." I attempted to take in another breath against the thunderous sound of the ocean.

By Monday when I returned home, breathing became more difficult. That night I couldn't sleep on either side, my lungs aching. By morning, I was in the hospital. I thought it was pneumonia, but I wasn't coughing like the last time I had it. My x-rays came up normal.

I looked at my husband and gasped. If it wasn't pneumonia, then what was it?

"You need a CAT scan for a blood clot," said the emergency room doctor.

I began to weep when he closed the curtain. I could tell Henry was worried. He usually tries to be very calm, but he began to do that deep breathing when people try to brace themselves. I suddenly began to ream off where everything was, and what he needed to know about Adam.

Everything was about Adam -- what I wanted for him, who, I thought, he could trust. I discussed everything right up into Adam's adulthood. Faced with uncertainty, it was the first time I urgently articulated the general "plan" I had for Adam's future. Every parent thinks about the future. Even for all the plans and worries, life will still deliver the unexpected.
"I'll be watching," I said to Henry, half-laughing, tears streaming down my face and slightly insistent that if he screwed up, I would deliver some kind of punitive lightening bolt. He accepted it today. He accepted my over-protectiveness when it comes to Adam, faced with a new uncertainty. Behind the curtain of my emergency room niche, the lights turned off because I had a migraine, he may have even laughed a little behind the sighs and the stroking of my arm punctured with an intravenous needled put in such a painful spot that I could barely move my arm.

A few minutes later, I was able to gather myself. Blood clots can be controlled with medications. I could stop flying for a while. "Be brave" I thought to myself. "One's life can also be measured by how gracefully we leave."

I sucked in my last worried breath and laid back awaiting my CAT scan. Adam would be fine. He has a large family of four half brothers and sisters, and a whole pile of cousins. Henry would stay home for a while if anything happened to me. Life will go on.

Besides which, I began to say to Henry, "I plan on being around until I'm ninety-five." I laughed at the ridiculousness of planning my own life-span, at how everything is so out of our control.

Whatever I plan, it'll all be okay. I didn't have the blood clot, but the mystery illness zapped a week's worth of energy. Adam now has a fever as well and my weak body is helping him get through it now.

We can't help thinking about tomorrow, but we try very hard to live for today. And while we are not that well this week, maybe next we'll be mightier.
Autistic Planet is a children's book written by Jennifer Elder, book publisher and mother and wife of Paul Collin's author of Not Even Wrong: Adventures In Autism. Not only did I love Paul's book (I have been quoting from it for the past four-and-a-half years), but I am raving about Jennifer's. When have I been able to sit down with a book that REALLY captured Adam’s attention, particularly at this part:

"We don't do something one time, when...
...We can do it over and over again!"

and this part:

"Our love of music is so strong
That when we hear a great new song
We memorize each word we hear
Go home and play it back by ear."

and this part, Adam's eyes brightening:

"There's nothing hot in 'aut' cuisine
Lumpy, gooey, brown or green,
The only food to pass our lips
Are popcorn and potato chips."

Yes that one really caught Adam's attention. I can't recall if that one topped the bit on watching the weather reports.

I will take this book to Adam's camp and Adam's school. I will buy copies for his teachers if I have to and highly recommend that every teacher reads it in class. The book is lovely and affirming -- not your typical kids book about accepting that "poor" disabled kid they see in their school, or some that even proclaim acceptance entangled with raising money for a cure (thereby implying that autism is a bad thing). No, this one makes you want to live on the autistic planet for,

"...at the end of every day,
We flap our wings and fly away."

When do autistic kids get to read wonderful things about themselves that they can share with their peers to say how GREAT it is to be them -- to leave others perhaps even wanting to be them? Thanks to Jennifer, she made it happen and as a parent, I am grateful for her book. Every night, Adam and I will read Autistic Planet and talk about how great his world is, and how lucky we both are.

Everyone is welcome on "Autistic Planet" and if you haven't paid a visit yet, I highly recommend you do.

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**Between Interuptions**

This is the anthology I participated in. You can order it here. My excerpt is "The Perfect Child." What is perfection if not in the eyes of the beholder?

We are all imperfect despite our perfection.

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**Summer Adventures with Autism**

Summer turns out to be the busiest of months. Adam is at a "regular" day camp with his shadow and is beginning to do his "I've got this place under my thumb" strut. He goes on the bus, I
pick him up at 3 -- it’s a long day for my little guy. He has taught himself to swim under water (gulp -- I watch him like a hawk of course), and is learning to jump off higher and higher ledges (another gulp -- my guy who never climbed and had troubles with jumping is now leaping from higher bounds). He is growing, he is losing his cherub cheeks...he is becoming a little boy.

Sigh.

Henry and I were interviewed for a magazine yesterday (will post when ready). The interviewer was astonished when I said spontaneously in the context of discussing disability and autism, "Adam has taught me how to live." He is showing me vistas I would have never seen without autism and I have come to a point where I can’t imagine life any differently. Adam continues to teach me what it means to be human. He teaches me to expand and to know what supporting another person really means.

As we prepare to travel to Alaska -- I can't wait to see Adam's face -- and just enjoy our summer, I look forward to sharing more of our adventures. In the meantime, keep checking out the TAAProject website as we are receiving more essays and others are editing the content. Support groups are still running throughout the summer and keep your eyes out for our next lecture series.

The Right to be Disabled

Watch this from The Agenda, a TVO Program on genetic screening and disability and decide if your participation in autism genetics studies and sibling studies are helping autistics contribute to society as autistic people. Ask if our autism researchers are truly respectful of autism as a disability to be respected in the way Deafness and Downs Syndrome should be.

The CBC Quirks and Quarks interview that comes after the TVO one talks to Michelle Dawson and Laurent Mottron and publicized The Joy of Autism: Redefining Ability and Quality of Life that The
Are We Listening?

The audience waved their hands in the air – the deaf sign for waving. There were others who rocked back and forth, some other adults who gracefully flapped their hands. Drake sat in the front and squealed in acknowledgment when the speaker said, “just because you don’t cry, doesn’t mean you are not sad,” in acknowledgment to how many autistics take time to process their emotions. The squeal was a “yes yes!” to the speaker’s comments, and in any other setting, this highly intelligent, non verbal autistic eleven-year-old may have been asked to leave, or others might have stared, thinking that he didn’t think of anything at all. Yet Drake kept doing this. He sat longer than any other eleven-year-old I’ve ever met and made his noises in acknowledgment of the important points.

“I am fortified by being here,” he wrote on his Lightwriter.

I sat in the room and wished Adam was with me, his soft five-year-old hair brushing my jaw, snuggling up to me as he always does, and then taking breaks to jump up and down. Yet, I felt comforted in knowing that he would be there next year, and the year after that. I felt comforted that all of these people are him years from now, and how privileged I felt that they were paving the way, for it is a tough way, like swimming up a rapid flowing stream.
It is rare to sit in a room with so many other autistic people, some walking back and forth in the lunch room humming to themselves in a heightened perhaps even ecstatic state, where I can only imagine in other less accepting settings, would be frowned upon. When I came to squeeze into the small space where this young man hummed to deposit my lunch tray, he politely moved away to make room for me, extremely aware despite the fact that others would believe otherwise.

When I saw him next time in the leisure area, he was asking others to play a board game with him. Other autistic kids were hanging out together, and sprawled themselves out on couches in front of the TV, not unlike other teenagers. Around the grounds, people wore badges that indicated if they wanted to talk, if they would only talk to people they knew, or if they did not wish to talk at all. There were many times I wanted to flip my own badge that indicated the latter – as I am a person who likes to absorb and observe, yet have been taught to socialize and be diplomatic and suffer from a compulsion to keep that impression going. Although it’s a skill I’ve acquired, I still find it exhausting. I wished that those badges existed at the many functions I have attended, where most people pretend to be something that their not, or interested in things that others say that they actually have no interest in at all. I consider all the wasted time I’ve had to spend doing "small talk." and all the time I spend in explaining life as we know it to people who don’t have the time to understand.

The heat was oppressive this time of year. Yet, we were shaded by trees. My hair unkempt and my skin moist from the humidity, I unraveled. I could do what I needed to, to think. We were free to lie down during lectures, or roll up and be comfortable on the otherwise uncomfortable frayed wool couches -- remnants from the 1970’s. No lights were on in the summer heat, the hard-working garbled hum of old air conditioners tilting precariously in the windows of the lecture room.

The atmosphere was as honest as the discussions were. We tried to figure out how to manage all the issues confronting autistic people today, how to give another message to parents that there are more options than they are aware of – because they don’t hear it when all they hear about is ABA (in Canada specifically). The atmosphere was welcoming, where fear and confrontation were strangely absent. Strange because it is a sad reality of autism
politics these days – where some non autistic people never get exposed to disabled people to hear the real views and issues. It was strange as it was relieving. This was autism, and it was comfortable. I didn’t have to be appropriate, I could say when I had to leave without a guilty fuss. No one will judge me here. And no one will be judged.

It’s called Autreat. It’s a place I’ve never felt or experienced before, and I will want Adam to come again so he too can be fortified. Adam’s fortification is what’s tantamount here, as I try to raise him so that he knows who he is with autism, amidst a world that doesn’t understand it or explains it inappropriately. It is important that he understand himself as not a defect, but as a person. It is why we as parents cannot accept misery rhetoric, because no matter what level of “functioning” (that term means nothing as it has no bearing on either intelligence or awareness), no autistic child should have to grow up in an inhospitable environment that threatens their self-worth. Inhospitable and unsafe environments are those in which we seek to normalize and reward normal responses to tasks where the autistic response is never acknowledged, rewarded or accepted, thus valued. By never rewarding an autistic person for being autistic, we threaten their self-esteem and identity. Most will grow up being confused because every well-intentioned therapist was so “nice” to them.

We have to train our therapists and clinicians to understand autism – because most of them currently do not. They do not yet understand how an autistic person learns. They turn to operationalized methods that all seek at this time to make the child not autistic, without valuing the autism. DRI and RDI are also designed to “create a mind,” or have a child "play normally" to which the autistic audience gasped in disgust. What are those "gurus" implying? That the autistic people who could sit and listen, and contribute, either verbally or in writing need to re-create their minds in a fashion that suits the rest of the so-called "normal" population?

I surmised that many parents are and are reluctant to give up ABA because they may not understand that there ARE so many options and so many opportunities to educate and for a great quality of life. The latter is what hopefully unites us. What disunites us is the definition of what that quality of life entails – a life with or without autism. I seek the former because I have seen
that we can live a good life, thank you very much.

Quality of life is not determined by whether or not you drive a car, but rather, what you make of your life, and your attitude. Autistic people are capable, and how can we express to parents who only see -- particularly those whose children who are more profoundly affected by the disabling aspects of autism – sensory issues, anxiety, no spoken communication – that their children are there and aware.

How can we express that the most important thing – our children’s right – is to be who they are, but to provide AC (augmentative communication) in the absence of speech, instead of trying to force them to talk when they cannot.

How can we express that it is the teachers and clinicians who must learn how an autistic person learns, and not expect a typical response that can render an autistic person a robot. (All an autistic person ends up learning is to respond the way the instructor wants so that they can get the hell out of there).

How can we express the dangers of therapies that try to teach in a way that is not natural – for our benefit so WE can feel satisfied that the child has responded – that the child may in the future as a result of such approaches, not understand who they are?

This is the most important aspect. **Know who you are. Accept your autistic child for who they are** because this will allow them to know themselves. Pave the way for acceptance and yes, teach. But learn first. Learn how an autistic person learns and keep trying to adapt until you find the method that clicks with your child. That will constantly change.

Be a parent, not a therapist. Do not treat your child as a project, but rather, treat them and raise them as a child. Model actions so that a child can learn. Do not expect typical answers to “what is this?” and other typical questions. Find out ways to pull out what the autistic child does know. Do they know and answer better on the computer? Then use that. Accept all forms of communication, for they are valid and real. We are all obligated as parents to find the AC that works best for our children. That is their right to have over and above all those other therapies and monies wasted on “behavioural therapies.”
Allow breaks for autistic children to re-focus. Truly seek to understand their sensory needs. Do not offer artificial reinforcements, like “good talking!” They are fake and the child will know it. Accept echolalia as sometimes the only language a child can retrieve, particularly in moments when they are overwhelmed, and then listen to what their body language and faces are telling you.

Most parents want the best their our children. The difference is in how we regard autism – a medical disease, which it is not, or a disability with social implications, in other words, we have to deal with the societal barriers that obstruct the opportunities for our children. We cannot accept the latter. We must accept autism and move on with the real barriers – the attitudes that will continue to proliferate segregation.

We need to be advocating for inclusion in the school system and for the accommodations that need to be made to acquire that. We need to educate others as to the value of doing this – for all children, not just the disabled ones – in cultivating sensitivity and understanding. We need to teach our children how to advocate for themselves – yes, even the non verbal ones. And for those who are more profoundly affected by the more disabling aspects of autism, we can seek the help of other autistic individuals to be mentors and to advocate for the services that do not degrade and oppress others.

The one thing we must do is to make other parents aware that there are so many options about which they hear little or are belittled by an ABA movement that continues to espouse inaccurate facts about ABA under the guise of false scientific “proof.”

We need to stop participating in genetic research studies which determines only “prenatal risk” and threatens the existence of autistic people. This research is done under the guise of providing “better and earlier interventions,” which are non existent. What babies need is love, support and engagement like any other baby. The only purpose of this research is to determine genetic risk factors. We do not hear about research that seeks to help autistic people be the best autistic people they can be.
We need to redirect our attention to merging help (with the more disabling aspects of autism) with respect (respecting the autistic person’s right to exist) and realize that there is life beyond an over-simplified “cure.” Further, helping the more disabling aspects of autism (anxiety, sensory issues) can exist outside of a "cure" for autism.

I urge every parent (but for those who visit this blog, I bet I’m preaching to the choir), to actively seek out the alternatives and become proactive in not accepting strategies that change your child to “appear normal” because they will ultimately be very damaging to their self-image as teenagers and adults, and we will have greater problems to contend with later. There are options outside of ABA which takes time from you to actively watch and listen and respect your child.

Above all, as Anne Donnellan said in 1984, “make the least dangerous assumptions” about your child. Or as Douglas Biklen said, “presume competence.”

“The least dangerous assumption states that in the absence of absolute evidence, it is essential to make the assumption that , if proven to be false, would be the least dangerous to the individual.” (Zach Rosetti and Carol Tashie from the Communicator, Autism National Committee Newsletter, Inclusive Education edition.)

The constant banter that autistic or non verbal people who do not look you in the eye are “not there” or “not aware,” or “cannot speak for themselves” is an extremely dangerous assumption. All people can speak for themselves in many different ways.

Are we listening?
There is a robin that keeps banging into our window. For nearly a month now, it must be, but I’ve really noticed it lately. I thought the robin would be gone by now, failing to get into the house. Perhaps, I thought, he sees something he wants to get to in here, or more eerily, as Margaret Laurence once said in her novels “a bird in the house means death in the house.” Is some kind of death knocking at our door?

I heed "hidden" messages.

I am beginning to get worried about the bird. He seems no less affected by his beak-banging. I considered that something might be “wrong” with the bird. But knowing better, I turned to google to look up the meaning of the behaviour.

Birds, particularly robins, repeatedly bang into windows because they see their reflection. They are trying to fight the “other” bird for the territory. It’s perfectly understandable given the bird’s perspective. And then, I came to think about the irony of my interpretation: of fighting against our own shadows and came across the term egophrenia as I found written by Paul Levy: [It is the ] ‘ME disorder,’ for short. If ME disorder goes unrecognized and is not contained, it can be very destructive, particularly if the person is in a position of power." (Please note that I do not agree with how he makes references to "illnesses" in his article, but the over-riding idea of it is interesting in the context I have quoted here).

Apparently President Bush is egophrenic. I would venture a guess that he is somewhat delusional, and a collective manifestation of the way North Americans have come to think about their place in the world. We see it in everything, including autism advocacy. We have come to live the big lie, chasing the perceived enemy, that which lies outside of ourselves because we no longer want to take...
responsibility for what we do and how we contribute to injustice and the world in which we live. Autism Speaks is egophrenic and not self-reflective in the least at the moment. It is but one example.

We fight what we create. We fight ourselves, as the robin does its own reflection. If a polemic gets created, it does so with the creation of an “us” and a “them.” Fighting autism, fighting in the name of getting children services by creating an evil which is the other— the evil which is our own true reflection.

The robin reminds me of pushing myself constantly to avoid kitsch and rhetoric -- to consider myself as contributing to the polemic. The robin reminds me that what is out there is me. It is us.

Now what do I have to do to change it? What about all of us?

Labels: Autism Advocacy, kitsch, society

Joys of autism expressed by other parents

You know, I don't get to everything as quickly as I should, so I was quite surprised when I came across this today on About.com by Lisa Jo-Rudy: The Joy of Autism: A Mother's Day Gift. I hope it encourages everyone every day.

After reading it, read the post just beneath on happiness.

Have an enlightened day.

The Assumptions About "Happiness"

The days in Toronto are bright and we received Adam's glowing report card yesterday. He belongs now to a very inclusive school -- a special and rare place from what we've experienced and heard about schools. Adam and I went for a picnic in the afternoon, and
generally enjoying a little more time together as we wait for camp to begin. This child of mine observed by science as the child with "faulty wiring" who in fact, has many abilities.

As I appreciate the moment, despite the little sleep I've been getting this week, I stumble onto the stoop to pick up The Globe and Mail while drinking instant coffee because my coffee maker broke at 6 a.m., I turn to "Are you Happy? And does it really matter?" by Leah McLaren. I am not happy that I can't get my cup of java at six because I had to let the dog out and I otherwise would have slept in. In Leah's way -- her healthy dose of pessimism -- I would say no, happiness doesn't matter. As quickly as the days ebb and flow, our moods and circumstances can change. One day, we receive the glowing report card, the next, someone may put up barriers to Adam's access into another program. It's not all fun and games. It's just life. What we have today, we lose tomorrow, I once heard, and I try to remember that everyday.

"Joy of Autism" is meant to be a statement about our need accept what comes our way. Autism is neither good nor bad. It is just the way it is like life just is. So, if you've come looking for self help, you've come to the wrong place. The Joy of Autism is a place to work out how we can live and surpass the barriers that confront my son and individuals like him. My son is where joy does reside for me. Quietly as it should. The blog title is just a simple statement that I love Adam as he is, because in doing so, we can live a little more peacefully. Because in doing so, he can live a little more freely -- at least within the confines of his home. Because when we're together, its hugs and smiles and yes, struggles at times. And we try not to fret too much over them. It is a statement that we accept people and listen to how they feel about their oppression with whatever race, religion or disability community they belong. And it is a strong counter statement to those who engage in fear mongering.

With that joy and acceptance there is also anger. Anger that others ignore autistic people and the value of my son in other settings. Anger that it is so easy for people to let roll of their tongues that he is as if he's "in his own world," without a second thought. Lack of thought exists everywhere. It exists every time we never question a statistic, or a rhetorical line or even consider another point of view. Different cultures will correct us with our thoughtless use of
prejudicial phrases and assumptions. Autistic people are correcting all of us all the time -- and yet, there is a public and even parents who think that because they are trying to help their children, the use of such language is okay, without critically thinking of the how it effects an entire community. Even worse, they think they are more correct than the autistic adults our children will one day become.

As Phil Schwarz said in his essay, "Building Alliances: Community Identity and the Role of Allies in Autistic Self Advocacy" from the book Ask and Tell: Self Advocacy and Disclosure for People on the Autism Spectrum, a book I highly recommend, he talks about aspects of Personhood, or identity are shaped by autism. Being an autistic person himself with an autistic child, he says that these aspects,

"are not intrinsically disordered. They may be atypical. They may require significantly different teaching and child-rearing approaches. They may even put us at an ergonomic, economic or social disadvantage in conventional society. But they are not all intrinsically defective. Often it is society's intolerance or lack of accommodation, rather than anything intrinsic to the autistic characteristic itself, that renders the characteristic disabling."

He also characterizes autism not just about atypical individuality, but acknowledges that many autistic people experience characteristics of autism that "are intrinsically disabling, sometimes profoundly so," and cites lack of oral or written communication and lack of self-help skills and effective judgments about safety issues as examples. Sensory distress and impulse-driven behaviour are other characteristics. But this is how is defines the problem of reconciling the identity aspects of autism to the disabling characteristics in the way that society handles it right now:

"It is difficult for parents and family of autistic individuals who are profoundly disabled in such critical respects to see autism as anything BUT those critical disabilities. This is particularly true of parents of children who appear to be developing normally up to a certain age and then begin to lose those skills. It sure sounds and feels and is lived like something that is 100% bad and, therefore, worthwhile attempt instead to eradicate 100%.
However, even autistic individuals who are profoundly disabled eventually gain the ability to communicate effectively, and to learn, and to reason about their behaviour and about effective ways to exercise control over their environment, their unique individual aspects of autism that go beyond the physiology of autism and the source of the profound intrinsic disabilities will come to light. These aspects of autism involve how they think, how they feel, how they express their sensory preferences and aesthetic sensibilities, and how they experience the world around them. Those aspects of individuality must be accorded the same degree of respect and the same validity of meaning as they would be in a non autistic individual rather than be written off, as they all too often are, as the meaningless products of a monolithically bad affliction."

Based on these extremes -- the disabling factors and atypical individuality, Phil says, they are more so disabling because society devalues the atypical aspects and fails to accommodate the disabling ones.

That my friends, is what we are working towards -- a place where the group we seek to "help," we listen to. We do not get offended when we are corrected by the group. We are the parents. We have a duty to listen because one day, our children may be the same people correcting others tomorrow.

In closing, about assumptions, I post the article written by Ann MacDonald a few days ago in the Seattle Post Intelligencer:

By ANNE MCDONALD
GUEST COLUMNIST

Three years ago, a 6-year-old Seattle girl called Ashley, who had severe disabilities, was, at her parents' request, given a medical treatment called "growth attenuation" to prevent her growing. She had her uterus removed, had surgery on her breasts so they would not develop and was given hormone treatment. She is now known by the nickname her parents gave her -- Pillow Angel.

The case of Ashley hit the media in January after publication of an article in a medical journal about her treatment. It reappeared in the news recently because of the admission by...
Children’s Hospital and Regional Medical Center that the procedures its doctors had performed to stop Ashley from growing and reaching sexual maturity violated state law. In Canada (as in Australia), a child can be sterilized only with the consent of a court.

At the time of the initial publicity about growth attenuation, Ashley’s parents wrote on their blog: "In our opinion only parents of special needs children are in a position to fully relate to this topic. Unless you are living the experience, you are speculating and you have no clue what it is like to be the bedridden child or their caregivers."

I did live the experience. I lived it not as a parent or caregiver but as a bed-ridden growth-attenuated child. My life story is the reverse of Ashley’s.

Like Ashley, I, too, have a static encephalopathy. Mine was caused by brain damage at the time of my breech birth. Like Ashley, I can’t walk, talk, feed or care for myself. My motor skills are those of a 3-month-old. When I was 3, a doctor assessed me as severely retarded (that is, as having an IQ of less than 35) and I was admitted to a state institution called St. Nicholas Hospital in Melbourne, Australia. As the hospital didn’t provide me with a wheelchair, I lay in bed or on the floor for most of the next 14 years. At the age of 12, I was relabeled as profoundly retarded (IQ less than 20) because I still hadn’t learned to walk or talk.

Like Ashley, I have experienced growth attenuation. I may be the only person on Earth who can say, "Been there. Done that. Didn’t like it. Preferred to grow."

Unlike Ashley, my growth was "attenuated" not by medical intervention but by medical neglect. My growth stopped because I was starved. St. Nicholas offered little food and little time to eat it -- each staff member had 10 children with severe disabilities to feed in an hour. That was the roster set by the state and accepted by the medical profession. Consequently my growth stopped shortly after admission. When I turned 18, I weighed only 35 pounds. I hadn't developed breasts or menstruated. I was 42 inches tall.

My life changed when I was offered a means of communication.
At the age of 16, I was taught to spell by pointing to letters on an alphabet board. Two years later, I used spelling to instruct the lawyers who fought the habeas corpus action that enabled me to leave the institution in which I’d lived for 14 years.

In the ultimate Catch-22, the hospital doctors told the Supreme Court that my small stature was evidence of my profound mental retardation. I’ve learned the hard way that not everything doctors say should be taken at face value.

After I left the institution, an X-ray showed that I had a bone age of about 6, a growth delay almost unheard of in an 18-year-old in the developed world.

I was not only tiny but lacked any secondary sexual characteristics (a significant difference from people with naturally small stature). I was a legal adult, but I couldn’t see over a bar, much less convince anyone to serve me a drink. I didn’t see small stature as desirable.

My new doctors said that presumably I had the growth potential of a 6-year-old, so my new caregivers and I worked on increasing my size. My contribution was to eat everything I was offered. It worked. I started growing immediately, reaching a final height of 5 feet and weight of 120 pounds. That is, I grew 18 inches after the age of 18. Along the way I lost my milk teeth and reached puberty.

At the age of 19, I attended school for the first time, eventually graduating from university with majors in philosophy of science and fine arts. "Annie's Coming Out," the book about my experiences that I wrote with my teacher, was made into a movie (Best Film, Australian Film Institute Awards, 1984.)

Unlike Ashley, I’m now an ordinary height and weight -- but I don’t get left out, nonetheless. Though I still can’t walk, talk or feed myself, I’m an enthusiastic traveler. My size has never got in the way, though my hip flask of Bundy rum often causes alarm at airport security. I love New York for its galleries, its shops and its theaters; hearing Placido Domingo at the Met was one of the highlights of my life. Interestingly, Ashley is also reported as enjoying opera -- maybe it goes with the turf.
Many otherwise reasonable people think that growth attenuation was an appropriate treatment for Ashley. In an Op-Ed piece in The New York Times, for example, moral philosopher Peter Singer wrote: "... there is the issue of treating Ashley with dignity. ... But why should dignity always go together with species membership, no matter what the characteristics of the individual may be? ... Lofty talk about human dignity should not stand in the way of children like her getting the treatment that is best both for them and their families."

Ironically, I'm a friend of Peter's, and I've discussed ethics and disability with him previously. Despite this, he obviously didn't call me to mind when he wrote about Ashley.

This may be because Ashley is described as having static encephalopathy, a rather uncommon name for a rather common condition. Static encephalopathy just means "brain damage which isn't going to get worse." It's occasionally used as a euphemism for brain damage caused by maternal intoxication, but the most common form of the condition is cerebral palsy unrelated to maternal intoxication. Ashley and I both have cerebral palsy. Ashley's doctors may have used the term static encephalopathy to avoid the outcry that would have followed if people realized that it was being suggested that girls with cerebral palsy should have surgery to stunt their growth and prevent puberty.

When Singer wrote that, "Ashley is 9, but her mental age has never progressed beyond that of a 3-month-old. She cannot walk, talk, hold a toy or change her position in bed. Her parents are not sure she recognizes them. She is expected to have a normal lifespan, but her mental condition will never improve," he has accepted the doctors' eyeball assessment of Ashley without asking the obvious questions. What was their assessment based on? Has Ashley ever been offered a way of showing that she knows more than a 3-month-old baby? Only someone like me who has lain in a cot year after year hoping that someone would give her a chance can know the horror of being treated as if you were totally without conscious thought.

Given that Ashley's surgery is irreversible, I can only offer sympathy to her and her parents. For her sake, I hope she does
not understand what has happened to her; but I'm afraid she probably does. As one who knows what it's like to be infantilized because I was the size of a 4-year-old at age 18, I don't recommend it.

My ongoing concern is the readiness with which Ashley's parents, doctors and most commentators assumed they could make an accurate estimation of the understanding of a child without speech who has severely restricted movement. Any assessment of intelligence that relies on speech and motor skills cannot conceivably be accurate because the child doesn't have any of the skills required to undertake testing. To equate intelligence with motor skills is as absurd as equating it with height.

The only possible way to find out how much a child who cannot talk actually understands is to develop an alternative means of communication for that child. An entire new discipline of non-speech communication has developed since I was born in 1961, and there are now literally hundreds of non-speech communication strategies available. Once communication is established, education and assessment can follow, in the usual way.

No child should be presumed to be profoundly retarded because she can't talk. All children who can't talk should be given access to communication therapy before any judgments are made about their intelligence.

Ashley's condemned to be a Peter Pan and never grow, but it's not too late for her to learn to communicate. It's profoundly unethical to leave her on that pillow without making every effort to give her a voice of her own.

Anne McDonald is a writer and activist for the disabled
I am disturbed every time I pick up a copy of an autism society magazine and read the comments by our "leading" autism researchers. I've just got to be honest here. I want to work with others in order that we create better opportunities and a world of respect and acceptance for autistic people, and I know this post may seem undiplomatic. But it's got to be said. We have to up the ante in our Canadian efforts to understand autism.

As the founder of The Autism Acceptance Project, I receive emails from parents who find The Toronto District School Board, unaccepting -- not accommodating autistic children on playgrounds and not providing family-appointed shadows (right now, an EA is ascribed to a child). Shadows are simple solutions -- if the family feels comfortable and has a good personal rapport. Shadows can be a child's best advocate. They can ensure our children's safety from abuse where many of our children are non verbal. Many of our kids are academically strong and should be in safe schools -- this does not mean segregated ones. It means schools that appreciate the special need of the child and that value diversity and inclusion. What we have is a drive to conformity -- as school teachers cannot handle the numbers of students in the classroom, or may lack an enthusiasm for teaching under crowded conditions.

And I don't hear anyone fighting for our kids. I hear a lot about ABA -- a goal to make the child conform and dangerously perceived by politicians to be a quick fix to make children normal so they don’t have to support or pay for them later. Yet, people with disabilities can and do contribute to society and sometimes needs support well into adulthood. These issues never get addressed in the same fashion.

I hear about finding the location of the gene(s) for autism and preventing it. What is disturbing is this trend to ignore the culture of autistic people, and a failure to recognize the real issues facing our disabled population and how they feel they should be provided access and what would be helpful to them -- as they see it.

I am reading Autism Society of Ontario's Spring 2007 edition of Autism Matters. There are too few interviews of autistic people and how they feel about the policies being made by non autistic people. The magazine also contains an article titled "Unraveling the Mystery" on the research of Peter Szatmari and Stephen
Scherer. Now, Autism Society of Ontario wants to be a "non partisan organization." I was asked to speak at their recent "acceptance" conference because of that position. Yet as I consider the politics of autism and this so-called non partisanship, there is something very missing -- the largesse of opinion and articles by autistic people, the absence of which makes the magazine, partisan. I am asking ASO and like organizations to raise these issues, as they are the prevailing issues in autism today. It should defend the rights of autistic people first and posit those issues in a dignified way. While we as parents have a voice, it must stand alongside the population to which our children belong. Not everyone will agree, but we should never discount the opinions of autistic people just because it doesn’t serve our cause, feels uncomfortable or because someone tells us we've got it wrong. Rather, we might be asking ourselves the question, what might we learn and what can we do better for our children by including autistic people now.

Also missing is the dialogue about the research and how autistic people interpret it. Here is a quote from the article I found particularly "partisan" and disturbing:

"Glutamate increases neuronal activity and plays an important role in wiring up the brain during early development. It provides further proof that autism is caused by faulty wiring in the brain, and pinpoints this pivotal neurotransmitter system as a prime suspect."

"Prime suspect?" Are genes criminal? Proof of "faulty wiring?" Have our Canadian scientists read this article? More importantly, if they have, do they even care? Will my speech at the ASO be a drop in the pond of prevailing ignorance and drowned out by a non autistic faction who does not want to address these issues at all? Or can we work together to merge help with respect -- to encourage autistic people to participate without the threat of "being treated?" or being considered too "articulate" via computer or otherwise to "be autistic?" Can we provide safe environments for autistic people to participate without being chastised (many of them today are unfortunately attacked by some parents).

Let's take a look at the ultimate goal of research as found in the CAIRN newsletter:
“Preliminary findings have zeroed in on Chromosome 7 as one hot spot for continued research. But while results are promising, there remains much work to be done. Researchers hope eventually to enable clinicians to biologically diagnose autism, allowing children to be diagnosed earlier than ever and leading to more effective treatments and better outcomes for them and their families. Knowing what causes autism may even allow us, one day, to **prevent it.**"

Without paying any attention whatsoever to how autistic people feel about "being prevented," instead of helping and respecting them, do we march towards our Brave New World? I risk writing anything because to speak about this is like taking away a right and a freedom to choose. While I can't say I want to stop "progress" (right, like I even *could*), I want to BEGIN discussions that include autistic people here in my backyard and I hope others will do the same. I want to be heard as one of the many parents who actually wants to see my child respected and not stigmatized by *faulty* rhetoric and biased science. I want Adam to feel at home anywhere and possibly relate to others who have similar experiences.

Consider the startling difference from Szatmari’s team in approaching genetics research for the purposes of understanding autism by Dr. Laurent Mottron et al:

"**There are no available convincing data that autism with vs. without overt peaks of ability, with vs. without overt speech or overall autism vs. Asperger Syndrome, differs at a genetic level. Even language abilities cannot be used to distinguish autism from Asperger Syndrome, as written language experts are as representative of autism as oral language experts are representative of Aspergers.**"

Perhaps, having read the latter, we can consider what science can do in helping autistic people contribute to society as autistic people. Can you help with sensory issues and anxiety whilst keeping personhood intact or does genetics research seek to throw the baby out with the bathwater?

The Autism Acceptance Project hears from more parents every day who are disgruntled with this. This is not about preventing, it
is about celebrating and accommodating. It is not about determining what is "faulty" any more than I can say that being freckled is faulty. I hope to make it a little more obvious of the subjectivity of science -- that it can exist.

If a researcher tells me "I've seen families who have been beaten black and blue by their children," (a quote by Wendy Roberts in the National Post article "Redefining Autism") to justify the prevention of autistic people from being born, er, okay...genetic research, I want to visit that family to see what's really happening there. Many times, parents need a lot of support to understand their children and to live with what is instead of expecting what will never be. By doing so, we can appreciate what is possible and what is achieved. Many times, I've seen single parents with autistic children become very frustrated because there is already a lot of stress and the child not only feels that stress, and enacts it, but may also be under pressure to do things that they cannot instead of working with strengths to achieve what can be. The latter isn't about becoming normal, it is about becoming the best we can become. And it's about our attitude.

Ask any member of the disabled community and I think they'd agree. It's not about becoming like someone else, it's about being yourself without others telling you what you should be.

"Disability inspiration is a form of propaganda that glosses over oppression while simultaneously reassuring normals about the superiority of their ways." John B. Kelly found in Amanda Bagg's bag of quotes. Let us also be careful of sentimentalizing disability.

THURSDAY, JUNE 21, 2007

Donna Williams

Those of you who have read my blog for a long time know that I used to quote Donna Williams a lot. I have to thank her because she was really the first autie I ever read who began to change my perceptions about autism. Not only that, she is a marvellous writer and as you will see here, an artist. Enjoy this video made by her. I like the picture of her as a baby twirling a twig. Looks just like my
I wonder if most people don’t get it. I don’t believe that all parents with autistic children get it. I know this is an unpopular way to speak these days in autism. I’m supposed to feel compassion about how hard it is and all. I’m supposed to talk about the financial burden on everyone. Autism Speaks drives the agenda for how we think and talk about autism these days so much so that I’m afraid to use the word to describe Adam in public places. I prefer to say he has trouble talking. Because if I say autism, people will look dire, talk about his mutated proteins or that he watches too much tv, and presume things about him. The stats come out and it’s the same old party-line.

I don’t like parties much. Not the ones where I have to conform, where I feel uncomfortable being me. I’m getting too old not to be me. And it’s not really like me not to get in there and want to answer people's questions about autism. I really do like honest questions. I must admit, however, that there are some days that I just don’t think it’s worth it in certain situations. With Autism Speaks the new “Goliath” and autistic people a small David (but we all know how it turns out), autistics represent such a small community, and it is difficult to be heard with such, as irony goes, NOISE.
But you see, it's not that I don't have empathy or compassion. It's just that I try to direct it wisely. A good place to start searching where to direct "help" in autism is by turning to the disability community-at-large and disability studies departments at universities world-wide. Let's take a look at my home-town university [Ryerson's website](https://www.ryerson.ca) to read the following paragraph on the School of Disability Studies project:

"More traditional approaches to disability focus on ways to rehabilitate or 'fix' people with disabilities. In Disability Studies, we focus on society's definition and response to disability."

The school talks about social models of disability rather than the medical model and this is where we need to go. Autism Speaks and like organizations do not go there. The Autism Acceptance Project does. It did when it sought to "redefine autism" with "The Joy of Autism: Redefining Ability and Quality of Life" event last October. Autistic people are always going there. But not many people are listening because they are being drowned out.

Many parents (we have five hundred members now at TAAProject in less than a year), seem to believe this is important.

Why? It is so because many people (we know many of them) will try and make the rights of autistic people seem ridiculous because, as they will too often tell you in fact sheets and press releases, that living with autism is really horrible. They will make the "acceptance movement" or "autism rights movement" seem like it is non existent and made up by a faction of non autistic parents or, as we hear much too often, by autistics who are not really autistic because they can think and type on a computer. They sound convincing. They talk about going bankrupt because they have to do a therapy to make their kids not autistic anymore for to not do that therapy will send them all into the autistic "abyss."

Autistics will argue they are going bankrupt because they have chosen to try and turn their kids into something they are not instead of fighting for inclusion and an empathetic society where our kids receive a good education, no matter what the disability. Our parent advocates here in Canada will frighten others that to not pay for this therapy -- autistic kids will have to live in institutions, they say -- instead of working towards a society that
has just and decent living arrangements for those who will need extra assistance, and focussing on what individuals can contribute. We need to fight for a quality of life in many different types of living situations, that people with disabilities have a right to beyond daily care.

Our parent autism advocates ignore a vast array of academia, advocacy by the people who are disabled, and history. David Revielle writes in Abilities Magazine that disabled individuals have been part of changing the way we view "madness." He was part of the group that developed the documentary film Working Like Crazy in 1999. (See this link here for National Film Board link.) He teaches a course at Ryerson called "A History of Madness" with Jim Ward. He says in his article: "Jim and I are walking a trail blazed by Geoffrey Reaume. Following the publication of his book, Remeberance of Patients Past: Patient Life at the Toronto Hospital for the Insane 1870-1940, Dr. Reaume taught "Mad People's History."

Reville talks about the courses' increased popularity and how the agenda has evolved to changing the subject of disabiltiy -- to the social response. They bring in psychiatric survivors creating community by addressig their needs for employment and a decent income.

We have these resources in autism, but few people are listening. Autistics.org has posted many important articles. Michelle Dawson writes in her blog Autism Crisis and No Autistics Allowed. Joel writes in his blog, NT's Are Weird. And of course, Amanda Baggs, who is consistently accused of not being autistic. And there are many more autistic individuals who belong to self-advocacy organizations. The list is longer than I am providing here of autistic people who write books, blogs, do artwork or participate in these groups in some fashion. I do not hear of one autism society anywhere who acknowledges any of them.

It strikes me everytime that people write their bias on the page with pride. From hating something to pretending to advocate on behalf of others because "they can't speak for themsevles," prejudice against the disabled is intolerably tolerated.

I would recommend that any doubtful person turn to the many disability studies departments at their universities -- the hub
where change really happens. Or, you can attend the talk Doing Disability At Work: A Symposium on July 5, 2007 which discusses how disabled people fare as learners in mainstream workplaces. Contact Ryerson for more information.

Labels: disability rights, disability studies

MONDAY, JUNE 18, 2007

Happy Autistic Pride Day

Autistic Pride Day is celebrated on June 18 each year. It is a day of celebration of people on the Autistic spectrum.

Many families around the world celebrate in a simple way, but there are also numerous public events. There are also gatherings of autistics so that many can communicate together in real time via their computers.

Autistic Pride day is an initiative by Aspies For Freedom. This autism rights group aims to educate the general public with such initiatives to end ignorance of the issues involved within the autistic community.

We are proud in the Wolfond household of our son, Adam. We are overjoyed to celebrate this community and everyone's diversity any day.

THE IMPLOSION AT AUTISM SPEAKS

We all know the recent debacle between Katie Wright and her parents. Not only do I present on negative portrayals of autism for the purposes of raising money, but now we have to ask another question about responsibility.
Today, in the New York Times, "Debates in Autism Strain A Family and Its Charity" make the debate public. As it should be. Every charity must be scrutinized for responsibility from its public. The way money is spent, what the real directives are and so forth. In the case of Autism Speaks, it has been apparent from the time of its inception and their involvement with Diedre Imus, that the family believes in environmental and mercury causation and will continue its relentless search for these causes.

It's not that I'm against science. It's there to prove or disprove theories. But I'm having a problem with how we focus on an issue and where the money is being spent. I have a problem only searching for genetic causes because it seems like a scientist's masturbation. I mean, knowing the genetics of autism will do nothing to really change my son's life. It will prevent autistic babies from being born, and we know that 80-90% of Downs Syndrome fetus' in Canada are currently aborted. We know we have a high abortion rate for children with a cleft lip! Choosing life and death is becoming a little too easy, perhaps. But will genetic research help determine what medications are safe and life enhancing for an autistic individual who has anxiety issues, or other health issues? How can we ensure that autistic people live a full life with autism?

Looking for environmental causes may be a prudent way to cross it off the list of speculative assumptions, but it is creepily becoming more consumerist than responsible. Believe me, I've got nothing against protecting our environment. I've lived in Europe and recycling and public transportation existed for years before it did in North America. Yet, there is something eerie and kitsch when "saving" the environment sells products and becomes the CAUSE of everything.

We know that environment doesn't CAUSE Downs Syndrome or deafness. Perhaps if we investigate this for autism, we ought to start looking for every other disability out there too and I wonder how many in those communities might start laughing. Yet, Autism Speaks, after its gala with Toni Braxton and Bill Cosby, announced that the money raised would be funneled to the search for environmental causes. Apparently, the audience was aghast. They did not approve of where their money would be spent. The Wrights get to dictate the agenda of a public 60 million dollar charity. But that's not all, NAAR and Cure Autism Now are fighting
I think a little bit of temperance on the vaccine and environmental front needs to be applied here -- because if we don't we get to hear things like this. And this deserves scrutiny:

"The boy did not respond to behavioural therapies [who really does?] the Wrights said, leading to their daughter's desperate search for anything that might help. 'When you have the sense of hopelessness, and don't see results, you do things that other people think is too risky.' Mr Wright said. 'The doctors say, 'Wait for the science.' But you don't have time to wait for the science.'"


If I were to read into that quote knowing what I know now about autism, is that hopelessness is an epidemic in the autism community, leading parents to do some dangerous and desperate things like Chelation therapy and behavioural therapies -- all for the purposes of making the child not autistic anymore. (Behaviourists might disagree, but you just can't make ABA more palatable considering where it comes from). To the public, curing autism sounds reasonable, for to be autistic or disabled is regarded as one of the worst plights of human existence.

Instead of valuing and seeing the child who is right in front of us, we fight autism and waste our days. We waste all the important living and learning days of our children. The one thing I know for sure, is when we stopped fighting and started living, Adam began to change because he became happier. He is autistic and he can learn. Yes, I have to do a little more and yes, are lives are not exactly the same as families who do not live with a disability, but it's okay. We have a good life because of our attitude. We LIVE despite these debates.

Now back to responsibility. What of the autistic population who never gets interviewed in articles about autism in the New York Times? Why are they never interviewed about the very organizations that seek to represent them, but don't? When I read articles like the one today, there is something/someone so painfully missing and it is those real voices of autism -- these people who have to live with organizations like Autism Speaks that tell the public that autistic people are "not really there," or incapable of expressing their views or that if they are able, they too.
are not really autistic. The media ignores the fact that our autism community is another community belonging to a larger disability community -- the largest minority in the US today. Most people living with disability are described as incapable or "having the intelligence of a ____ year old." Is that right?

Yesterday, a relative said "did you hear about the study their doing about protein mutations?" I held my breath. I should have said,

"How would you feel if someone referred to you or your proteins as a mutation?"

And I don't see any journalist talking about this. About social responsibility. About helping to eliminate discrimination and bias. About living happily with autism despite the ignorance.

Here's Action for Autism’s take on the issue. as well as a more lucid discussion about science and perception by Dr. Gernsbacher. I do believe in doing science. But I believe we have to do it responsibly, meaning that we acknowledge the personhood, humanity of autistic people and as Dr. Gernsbacher so eloquently said, replace the language used in scientific papers with humanistic language to represent autism. If we were to put ourselves in the place of "mutated" language, we would be offended. What is the science that is life enhancing for autistic people? What will we learn that will help autistic contribute to society as autistic people?

[Postscript: When I say that Adam changed it does not mean that he didn't "come out" of his autism. He was always a happy child. It means that he became happier and less anxious when we didn't subject him to therapies that sought to change him fundamentally and when we focussed on letting him learn as opposed to correcting him. As the years pass, my decisions in this regard are confirmed. Adam has learned to also teach himself and I watch him spell words now and use phonics to decode. He plays games with me that he makes up. He does so many things. He does not always say hello to people and needs time to be alone in crowds. But I have learned never to underestimate him or to worry about the way he does "behave." My biggest priority is teaching him how to communicate in ways that he can. So for us, this means using the computer.]
SATURDAY, JUNE 16, 2007

More Literature ABA Advocates Prefer You Not Read

Yesterday, I presented at another conference: Autism Society of Ontario's "Building a Community of Acceptance." I am there to show that there is another side to all of this debate, and what is always most striking to me that people are not very aware of the dialogues going on by autistic individuals -- for years. They are not even aware that there is a disability rights movement. They are not aware of the information available. We must not believe in fact sheets point blank. We listen to some loud voices and the news, and shy away. But the information MUST be available and it must be read. So, for my readers anyway, I urge you to begin to read for yourselves and make up your own minds. Today, I'm including two other sources of information. The first is by Amanda Baggs, written in 2004 below the synopsis I embedded into video:

"The people on the Internet are still there, and many of them are still saying the same things. Here is what one of them said recently:

'Without intensive intervention, many individuals diagnosed with autism will eventually wind up in institutions, unable to even feed or toilet themselves independently. To avoid providing this intervention, all the while assuring the individual that we are doing this in his/her own best interests, "respecting dignity and individuality," strikes me as a bit hollow.' Read the rest of her article HERE titled Past, Present, Future.

And read this paper "A Tale of Two ABA studies."
A Response ABA Parents Don't Want You To Hear

Ralph Savarese, author of Reasonable People: A Memoir of Autism and Adoption, recently wrote this to our "autism advocate" in New Brunswick, Harold Doherty. It was in response to this post about Dr. Morton Ann Gernsbacher. Mr. Doherty decided not to print it. I guess it doesn't "fit" his cause. This is a problem if ABA parents will not listen to what autism really is, and of course, not listen to autistic people at all. In fact, I remember talking with Brenda Deskin who refused to read Donna William's books because she said that "Donna Williams isn't really autistic." Government officials and the public NEVER get an accurate view of autism from these parents alone because they refuse to discuss, acknowledge and listen.

Mr. Savarese wrote to Doherty:

I invite the father who insists on varying degrees of competence in autistic people (and who clings to labels such as "high functioning" and "low functioning) to review this new study on mental retardation in autism.

Here's the link:
http://www.willamette.edu/dept/comm/reprint/edelson/

The study is VERY provocative because it underscores the historical presumption of retardation in autism and the almost complete lack of empirical data supporting such a claim. New research by Laurent Mottron (Dawson's partner) has found, by changing the testing vehicle, intelligence in even the most apparently disabled. As the father of a boy with classical autism, I can tell you how easy it is to be fooled by autistic behavior, to extrapolate from it all sorts of things: retardation, a lack of empathy, etc. By teaching our son how to be literate and how to type on a computer, we have found a rich, complicated human being all too eager to connect with us and others--a boy, in fact, who is now a straight "A" student at our local middle school. If you saw him, you'd say he was "low functioning," but he's not. He could easily--with a computer--contribute to a scientific study. If the science on mental retardation in autism is weak,
why not practice what progressive educators call the "presumption of competence" or "the least dangerous assumption"? Then, we might really find out who is incapable of doing the things Professor Gernsbacher and Michelle Dawson talk about. Hope is a dangerous thing, especially with all of the quack cures out there trying to deceive desperate parents. But hope seems justified--hope and lots of hard work: TEACH LITERACY!--precisely because the science on autism has been so bad historically.

Sincerely,

Ralph James Savarese, PhD
Grinnell College
Author (with my son) of Reasonable People: A Memoir of Autism and Adoption

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**THURSDAY, JUNE 14, 2007**

**Being an Unperson in Canada's Autism Advocacy**

May I direct people back to Amanda's insightful posts and videos on "Being An Unperson" as parent advocates and Mr. Eugene Levy march on without autistic people at all:

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**Labels:** Autism Advocacy, Exclusion

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Autism: A Call for A National Funding Strategy

Today in the Globe and Mail, Brenda Deskin's son Michael, autistic, is a cousin to Eugene Levy. Levy, who has, according to the article, "only met Michael for the first time yesterday," decided that "this is a good fight here." He is holding a press conference in Toronto today to plea the government for ABA to be funded under medicare. He says in the article, "it's breaking families -- the emotional trauma and expense alone." Is this sounding tired and familiar?

Dr. Wendy Roberts is in support of this ABA movement and is quoted as saying "she has seen grandparents lost their homes and spend $80,000 a year for treatment." Not sure where Dr. Roberts stands these days since I had my last meeting with her. On the one hand, she wants to celebrate autism with art shows, on the other, she wants to treat autism with a treatment offensive to autistics. This desire to please everyone isn't accomplishing a thing. What we need FIRST AND FOREMOST to be just society, is to include autistic people in this dialogue. There are so many and we have them at TAAProject.

The article also starts with the line that autism "is no laughing matter," relentlessly and unethically making comparisons of autism to cancer. Hayley Mick, the reporter begins the article thus:

"When Canadian comedian Eugene Levy things about autism he pictures a scrawny kid. The kid is dwafed by other kids, who have names like cancer and diabetes and are protected by weathy foundations. And when they need treatment, those kids are swept into the loving arms of Canada's health care system."

Adam...scrawny? Dwarfed? Afflicted with a disease akin to cancer? HOW DARE YOU IMPOSE YOUR SORRY "ADVOCACY" and metaphors to paint a pathetic picture of my beautiful child! How dare you create such a scary picture that it becomes increasingly difficult for our children to be treated as children and not someone's "client" or "project." And if they get included at all, it seems like a miracle.

Once again, Deskin and her partners completely ignore what the
autistic community has to say -- namely autistics and the many parents of adult autistic children who are tired and offended by her constant referencing of autism as nightmare. If we are living a nightmare, she is perpetuating it through a basic violation of excluding autistics from her brand of autism advocacy.

She does not include any autistics -- at all. It is clear that she thinks that they have no right to be in "her fight." She does this for herself, not for autistic people.

She does not include other parents who do not want ABA for their children as the sole choice of education for their children. Deskin is trying to legislate what is right for others when we do not feel it is right for us.

She ignores the fact that Lovaas, to which she lovingly aligns herself in reference to ABA treatment, never apologized for his use of aversives. She ignores how that infamous 47% "success rate" was actually achieved. She is factless for her own convenience. For quick references that will lead you to more reading, read: http://autismcrisis.blogspot.com/ No Autistics Allowed and Dr. Gernsbacher's paper: "Is One Style of Behavioural Treatment `Scientifically Proven?'"

She ignores an immense disability rights movement, to which autistics belong and the fact that the disability community in North America makes up the largest minority group who are TELLING US ALL what it is like to live with a disability, and what they need.

So, does she serve the greater community? Does she take into account that we want our children to be included, to have lives filled with joy, to not be confronted by stigma and stress that she continues to perpetuate, to have access, to live in safe environments, free from maltreatment that ABA has been at fault for? There is no such thing as "good ABA and bad ABA." It is time to stop using the term as a shorthand for a multitude of services, and acknowledge that there is a toolbox out there with many different tools that we dip into that is unique to each child. Above all, we need to acknowledge that autistic people are people first. They deserve help with our utmost respect -- not sensationalized propoganda that draws on heartstrings and elicits pity.

Families deserve to be supported, they deserve to be empowered
to make their own choices for therapy and education. They deserve access. We need a strategy that encompasses all of our needs. And if Brenda Deskin wants her ABA therapy, let her have it. Just don't make us have to take it. Let's build a tool box that we construct by:

1) including autistic people in helping us understand and build appropriate education and self-help skills programs by revealing their early experiences;
2) build on what was successful for them;
3) build an anti-ableism strategy so that autistics and other disabled individuals have access and acceptance;
4) include all parents to work alongside autistics to develop generally accepted multi-model methods that honour each individual’s learning style (this could be OT, SLP, Play, and one-to-one education/assistance as well as family appointed shadows and/or service dogs, assistive technologies, vocational training, autistic mentors, humane and supportive community living environments, and more)

Overall, let us work together to state that YES, our kids deserve more and we need to focus on our to support autistic people and their families. Our kids are great and have lots of potential given the patience of others and a change of attitude in terms of the fact that disability is part of human experience.

In other words, we need to get away from this manner of advocating -- that excludes the very people it seeks to "support" -- and talk about what autistic people really want and need by including them.

Deskin, et al -- are you ready for a reality check? It's not all about you. Most of us are coming out of the dark ages. Will you decide to stay there? If you do, please don't drag the public back into those days where the disabled weren't treated as human at all. Having said that, I do hope to include everyone in much healthier strategy that includes autistic people in developing.

I'm sorry, Mr. Levy, that you have been dragged into this "living nightmare" of Deskin's "advocacy." I'm certain had you really done "your homework" beyond Deskin's propaganda, you would see that many autistic people and families find this method of "advocacy" and this one-size-fits-all approach, drenched in human
Is It Just Me?

Or is the summertime aware of being tired? Does it beckon our being mindful of it?

The leaves flutter silver in the soft breeze -- I want a hammock to watch them.

The warm breeze feels like silk against my arms -- I want to lie and let it cover me.

I want to breathe the ease.

I want to take a break.

I want to dance under the stars.

I want to take lazy walks.

Adam hugs me and lies with me in the yard. We fall asleep. YES! this is summer. It is sweeter when he lies with me, his head leaning in the crook of my arm.

It's what it's all about. Taking time, sometimes -- taking care of ourselves. Letting our children also experience this break from having to "do" just like we do most of the year. It's a relief to stop and see the life all around me. Hopefully we'll all be able to do some of the same.

Happy Summer. (31 degrees celcius and sunny in Toronto)
A Nice Transition

We have found a school that respects Adam. He is self-motivated, interested in what others do. He cannot talk to his peers yet, but he is respected by them. They say hello Adam in the morning, and talk to him normally. His teacher noticed today that Adam was interested in a math activity using beads. She said "Adam, it looks like you are interested in this so let me show you." She showed him how to do the activity, but today, Adam was interested in the materials. She noticed this and allowed him to explore and then simplified the activity so he had a starting point. She did not say that Adam was doing it "wrong" or that it had to be done her way. She was guiding him in what he wanted to do himself. Adam, since he began this school in February, is eating foods I've never seen him eat at home -- carrots and cucumbers being two of them. He watches his friends and wants to try too.

Before Adam went into class, he was a little upset today. We sat on the stair and I held his hand without saying anything, hoping that my calm would calm him. It did. I did not push him into class. I did not escape the situation thinking that I had to toughen him up by pushing him into class. I waited to see what he wanted to do. Five minutes later, he got up and walked into his classroom and proceeded to have, apparently, a great day.

I tell this little story of our morning because Adam's shadow and I were remembering the day when Adam was only twenty months old: she came from an ABA background and we also had a verbal behaviour goal of 80 mands a day. She withheld reinforcers like temptations -- "the promise" as it is known in ABA-speak. I look back at video footage of some of these sessions and cringe at myself, my husband and everyone who was so patronizing and demanding. As I watch Adam paint with a therapist, he is talking, saying some words I can now understand, imitating, and doing things really well. But back then, we didn't think it was good enough at all and we pressured him for more. We thought that he had to do things a certain way. He was just a baby.

Our shadow for Adam has been with us for nearly four years now. She says she has learned so much along the way. I was reflecting this past weekend at how she and Adam really understand one...
another, and how he trusts her. They are like real buddies.

I do have some regrets but it was not that I did not do enough to ameliorate his autism -- the regret I have is that I listened to too many other voices and ignored the child who was in front of me, doing beautiful things that I just did not recognize because he was not "like other children."

It's a nice transition, this ability to SEE what's in front of us, not lost in the sea of opinion.

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**SUNDAY, JUNE 10, 2007**

**Everyday Kitsch -- it happens in autism too**

Kitsch was a term used in late nineteenth to early twentieth century Germany to define bad art – art that sentimentalized everyday experience or “that appeals to beliefs and emotions encouraging vanity, prejudices, or unjustified fears and dubious successes.” Literally, kitsch “implies an artistic creation ‘that makes use of refuse taken bodily from the rubbish dump.’” (Catherine Lagg – From Kitsch: From Education to Public Policy).

We hear the term kitsch applied to the art of the Nazi era, if in fact Hitler's own pastoral art. Visiting my ancestral home (that is the home of my grandparents who had adopted my father just before the war from Poland or Sweden – we do not know exactly wherefrom. Thus, I can here extract myself in a way from the uncomfortable notion that I actually belonged or came from German culture, while understanding it deeply), I was surrounded by kitsch. Be it the pictures of the mountains hanging on their walls, to even the typical smell of Kuchen coming out of the kitchen, to the idiotic dirndl Oma made me wear on Easter morning, I was personally inundated with kitsch, if not a living, breathing example fetching coloured eggs and repeating Danke Schoen too many times to appease the generosity bestowed on me by a grandmother who needed constant praise.

Taking it further, Hitler destroyed or expelled any artists that provoked the status quo. Perhaps this is when the term was best
known. As Dadaists challenged society, Hitler himself was threatened. Only art that resurrected Greek mythologies or pastoral settings that celebrated German “cultural” life, that is, the Deutsches Volkes, was permitted in Hitler’s Germany. In fact, a good German home hung the picture of the Führer himself. Imagine eating dinner with a nice painting of Hitler watching over you – iconoclized for your adoration.

Kitsch is kitsch because it is simple and predictable. Art, however, is political. Almost always. It is so because, as Lagg so adeptly describes: “artists build on and play with their audience’s sense of history, culture and reality...art portrays relationships that exist among individuals, groups an inanimate objects....Art invades a person’s sense of self to literally play with their mind. Weaving through a person’s consciousness, art occasionally teases, reaffirms, jolts, disturbs, challenges, and pulls threads of deeply held convictions and beliefs.”

Most importantly, as I reminisce about what art is and what its purpose is, I reflect on the autism “debates” and consider that we are all at risk of becoming kitsch in the autism world.

The easy use of symbolism says Lagg, “gives Kitsch immense political utility. Kitsch can simultaneously provide psychological comfort and reinforce a host of national mythologies. It has immediacy that art must avoid.”

Autism organizations use many symbols and historic methods of raising money (that old cure word comes to mind as a type of easy access to heartstrings), that work extraordinarily well. One-liners that are supposed to summarize and encapsulate this so-called “struggle,” are kitsch and so too, I am wary that an organization that promotes autism “acceptance” is similarly at risk.

Jargon like “mercury moms,” or “curebies,” is also becoming dangerously close to generalizing categories that parents come to refer to as “camps” in the autism arena. In any subject, where we see a condensation of the “good guys” versus the “bad,” we are creating a simple narrative rather than addressing its real dimensions and complexities.

Acceptance of autism is such a loaded concept, that most people aren’t sure how to accept it. The term gets lost into some idealized
notion of a pacifist or perfect world. Idealized, it assumes that we are all going to just get along, holding hands to achieve our dream of accepting diversity. (I am pointing at myself for using symbols of hands and holding with the caveat that I do like hands as a symbol of creating things – and equally, they are capable of destroying). It’s a nice dream, but this idea of living in a world that never questions, where we happily skip across the field to the sunset together is just well, kitsch.

It is why I will not aggressively expand The Autism Acceptance Project into yet another autism charity, for I do not yet know how it will unfold. It is the reason why I called it a project, because I am aware of how easy it is to fall into the traps that charities always seem to fall into – having to appease a corporate funder, or a group of people who believe in one ideology. Instead, TAAProject was established to continue the dialogue -- in different forms be it through art, film, lectures and other creative ways. It is not an easy one-step to success organization. It is an organization that hopes to raise, provoke and discuss.

We will always have disagreements and we should. We should always question each other. We should feel uncomfortable and alerted when we begin to oversimplify the world, no matter what “side” we believe we are on – be it the line “we must fight the autism epidemic” to “nothing about us without us.” I like the last line in principle because it means that autistic people must be the people who lead the autism dialogue. But even that term might be too exclusive. Once we start believing too heartily in something, we end up being ignorant of the many other truths out there. While the Nothing Without Us line may provoke, as it should, I can also see the way it is used not completely applicable to the real complexion of the autism community.

“Kitsch differs from art by being a powerful political construction designed to colonize the receiver’s consciousness. As such, kitsch is the beautiful lie. It reassures and comforts the receiver through the exploitation of cultural myths and readily understood symbolism. But Kitsch neither challenges nor subverts the larger social order because it must pacify, not provoke.”

No question that we need to do more of the latter. We need to
consider that diversity means also accepting that there are many different realities within which autistic people live. By forming The Autism Acceptance Project, I have at least, met many more autistic individuals with differing views. It means that I seek the real truth from a bulk of autistic individuals and not a few. It means I do not listen to non autistics as the source of autism information and experience, but I do acknowledge that parents are the prime caregivers of their children and have a real stake in how they manage the lives of their children. It means I acknowledge that some parents and even autistic adults are having a harder time than others. One autistic adult once jested me when I wrote the post “The Learning Curve To Acceptance.” She said, “acceptance is not a learning curve.” I waffle on that one. I agree, to accept just is. It is free of debates, and ponderings of “how to accept.” And yet, society is on the learning curve of opening their minds to what acceptance really means in autism. It is no different than learning to accept women in the workplace. It is no different than accepting the black community not as inferior, but as equal. Acceptance did take activism and education.

The acceptance of autistic people must not be subverted to kitsch. It should not depend on “easily invoked symbols to address political dilemmas” and limit our thinking.

If I edited everything I received The Autism Acceptance Project would be ridiculous – another camp with self-made belief systems, and we’ve unfortunately experienced this with the ABA movement here in Canada. A women with Aspergers sent me a long letter. She gave me permission to print it here, but I will only give a few lines of it. She said:

Not all individuals with autism-aspergers speak for me either.

I am tired of people who are excelling at levels way beyond me proclaiming to be MY VOICE. They bask in the glory of their autism and that is fine for them. I am still fighting for my system to give me the HELP I NEED. This makes me sound judgy but...

AM I THE ONLY PERSON WITH ASPERGERS WHO WANTS HELP WITH ROADBLOCKS THAT MY AUTISM CAUSES ME???
I do believe in all of you and many share but where are the autistics advocating for help? I mean the right kind of help. I know it does not exist but it never will if we don't fight for it and then again its the ones in the middle who may wish for it but cannot fight for it like others because we are not at that level of functioning to be able to consistently advocate as some others are able to do...

Note that I do not think functioning levels are all that important as some can excel in different ways throughout the spectrum. I guess I mean that some of us just don't do as well as others and that is just a reality. We may be more severe in the fact that day to day life is tougher. Something like that. I am not exactly sure how to use the right words there...

I will not write a blog that only discusses autism rights WITHOUT including MY RIGHTS for help with things I need help with.

For those aspies who do not need that help and seem to think we are all the same, I feel they hurt those like me who wish to get help. I mean the good kind of help not the curebie kind.

I see 2 things with people with ASD who are doing well:

1: They either had a major support system and lots of help for sensory issues, social skills, etc or...

2: They are possibly higher functioning in a way that has not left them unable to maintain a quality of life that works for them. They can excel in a field etc. I cannot focus well enough to do that. Maybe with the proper help I could but that is not the reality in my life and probably not in others lives as well...

I have learned more about my autism from the parents out there because they cover the issues their children face and that helps me. It helps me more than some people with ASD simply hanging out and saying "respect me" etc. Yes that matters but I have only met a few with ASD who have actually given me information that I could use to learn to build a better life for myself or better understanding of my ASD. I do not mean in a cure way. I am sure you know what I mean when I talk of help. No I don't want ABA’d...
I saw in your previous blog that you ask them to join the Board of TAAP and they say no. I get that. To them the task is too hard - too overwhelming. The organization and sequencing skills needed and the focus needed may be an issue for them. Maybe with a little help a little bit at a time some of them can learn to take it on. Not all at once but one little step at a time. I hold back when I feel I am expected to know ALL of something at once. If given a chance to be on a Board such as TAAP, I would be honored (if I lived in Canada) but would only do so if given the "help": needed. Yes I have autism and I can not do it alone. Isn’t that what inclusion is all about? To include to me is to love one as they are to educate yourself on their disability but also to be real and to give them the necessary help when needed and let them go when they do not need help and if they grow in some areas where help used to be needed they may not need it any longer. They may excel after they learn to do their job. It’s the patience to assist them in the beginning that can really be the factor in where they are later on. This varies for all of course.

I want today’s adults and our little Adams of the world to be included. I want Adam to get what he needs now and in the future. If he needs help, I hope and pray he gets it and does not get ignored as so many of us are. I hope he does well but I am a realist and if he needs assistance we need a world that is willing to give it in the best possible way for all of our Adam’s.

I read how bad it is in Canada. Not better here Estee. In my town I just was told they want to diagnose an ASD boy schizophrenic. FOR CONVIENCE. They will not even asses for ASD. Why? It’s because they would need to learn something new and they are too lazy to do that. Do they care about this boy? NO that is obvious.

I go for a SSI review in 2 weeks. I am about to get reviewed by someone who knows nothing of ASD. Go figure. You see the war is offline and it sucks. I can not then get online and say that it is ALL OK. It is not All OK. I am so happy in some ways and yes I love the title of your blog. But it is not joy all the time. I cry daily at the lack of help out there for those of us who want it. Then again "The Joy Of Autism" is my only blog I read daily. It has become a part of my very strict routine.

Thank you so much and maybe someday I will join you all in my
What is striking to me time and time again, is how many different autistic voices there really are out there, and that we need this time to listen and digest. Autism cannot be conveniently packaged into puzzle pieces or colourful ribbons, although I would much prefer if I had to, to wear the latter, more positive symbol. It cannot be “treated” in one way or another. Like an individual, it is complicated. It is diverse. It cannot be tamed to behave in a way we want so that we can completely understand. If we wait or try, it may even be too late.

Truth is uncomfortable. There are many truths based on an individual's experience. Truth about autism must acknowledge the greater community -- even the one that we may find offensive -- and seeks to settle somewhere in the middle as a means of living together. While women and black people may have rights, they are not totally "accepted." That is an unfortunate truth. At the risk of sounding kitsch, let's stick together and work towards a more accepting world, for the work never seems to have an end.

On Schools And Services

You are not disabled enough.

Joey's Mom inspired this post today.

No services for you!

Here is an article that denies services to a person with High Functioning Autism.

Mary Ann Chambers, MPP of Ministry of Children and Youth Services was on CBC Radio when she announced additional funding
She said that ABA "was more for the lower functioning autistics." I went on air after her but didn't get a chance to say this.

Who is low functioning? Who gets to decide who must be "treated" with a government endorsed therapy? While I understand that there is some effort into providing more multi-faceted supports beyond the ABA model, and that yes, I don't mind if people personally decide that ABA is something they want to do (as the ABA today is a mix of various therapies in most cases and is no longer purely ABA and thus should be called by a different name), I do have a problem with the government telling autistic people how they SHOULD be treated. Knowing the history of "treatment" of people with cognitive disabilities, we must address the issues with such "treatments" as it has affected autistic people themselves. Michael Moon, one of TAAProject’s board members, recounts the "treatments" attempted on him when he was young and non verbal and how he describes very autistic, despite his ability to articulate today.

We are learning that designations of HFA and LFA are not accurate enough, do not describe autism sufficiently. Amanda Baggs, a "low functioning" autistic woman knows how to communicate using a keyboard. This whole dialogue we are hearing over and over again, so old and out-dated, that individuals with less ability to function are not intelligent, are not aware, is really getting tiresome. An inaccurate understanding of autism leads to maltreatment and a bad education using the model I describe often here. Here is what the University of Montreal has to say about so-called "low functioning autism."

"There are no available convincing data that autism with vs. without overt peaks of ability, with vs. without overt speech, or overall autism vs. Asperger syndrome, differs at a genetic level. Even language abilities cannot be used to distinguish autism from Asperger syndrome, as written language experts are as representative of autism as oral language experts are representative of Asperger's." — Laurent Mottron et al.

We are beginning to understand that high and low functioning does not have a bearing on intelligence. HFA or LFA also has little bearing on functioning too. Adam cannot talk well. This doesn't
have any bearing on his abilities. Some people’s autism is more of a
difficulty for them to "function" every day -- sensory issues, anxiety. But autistic people, as I have come to understand it thus far, are no different than anyone except that there are additional challenges, some more extraordinary than others. Those challenges vary from person to person and oftentimes there are co-morbidity issues. We do not belittle those challenges, but consider how we can accommodate them and provide access.

What is exceptionally dangerous is that parents are using this "low functioning" term to justify ABA services to "lower functioning" autistic children, while the rest of autistic children get left behind. In other words, we get more myth building in order to get the money and services without really addressing the real issues. While some people believe that getting something is better than getting nothing, I caution against this thinking as what arises is misunderstandings about what autism is, incomplete and often inhumane ways of "treating" autism, a very poor quality of service, and discrimination and dehumanization of autistic people.

Adam can function in a "regular classroom" (his classroom is genteel) with support (and I uphold that almost every child can if the attitude of inclusion exists -- it does not mean throwing a disabled kid into an inhospitable environment. It means that the environment can and must be modified). So, if only a person now with a LFA dx gets attention, does this mean that Adam does not qualify for any one-to-one education, or legislation that entitles him to a family-appointed shadow in an inclusive classroom (I believe that the family has a right to appoint someone they trust instead of being assigned an Educational Assistant who works on behalf of the school board. I say this because Adam’s shadows are my eyes and ears. As he cannot tell me if he’s being maltreated or bullied, it is important to me to hear from someone I trust).

Does this stratification of competence mean that teachers get to sit on their laurels and blame Adam and other children for not being like the other kids because they don't have to DO anything? I fear that prescriptions for medications are going up in primary school students because the onus is always on the child to act accordingly and to fit into the school's model or structure, without ever really delving deeper into the child him or herself (how can they, their classrooms are WAY too big!) So long as you do your work, show up on time, follow the rules, you will be okay. School, the more I
think of it, has little to do with the acquisition and love of knowledge, it is more about discipline and preparation for employment -- yet another structure we must learn to work within. Of course, there are always the teachers we remember who surpass the system to actually instill this love of learning, or who made us feel good about ourselves again. Dawn Prince Hughes describes school as the beginning of when all the walls went up. Everyone in her home, she recounts, was pretty much the same. In the telling of her story at a conference in Toronto recently, she tells us of how her quirks were accepted and supported. When she got to school, everything changed. More walls went up, she said. Eventually, she dropped out when she was sixteen. She became homeless. And of course, for those who know her story, she bonded with the Silverbacks and became a professor of primate anthropology. So, how much do we also have to reconsider the school system as an effective teaching mechanism? How many kids fall through the cracks? When I saw Amanda Baggs in Boston, someone asked her about school. She recounted all the schools she attended -- a long list -- and finally said, "but I didn't learn anything." I know my parents had to get me out of the public system or I would have been one of them.

So the Toronto District School Board, despite the issues I have raised which are overwhelmingly problematic, must include autistic people on the autism reference committee. It currently does not. We need autistic adults testifying about autism regarding the Senate Committee Report. We need autistic adults to state the kinds of help that would actually benefit them. It benefits us to understand their childhood experiences so we can set up the environments properly. Does it take our effort? Of course it does.

And why should we do it? Because we have kids with all kinds of learning and sensory issues who do not have autism too. I am troubled at seeing kids who need extra help, not get any because they do not have the diagnosis du jour.
As many of you already know, there has been a heated debate about leadership in the autism community. As the founder of The Autism Acceptance Project, I am obligated to this community to say something about what I believe.

I do believe wholeheartedly that autistic people must speak for themselves and lead the way in terms of autism "awareness," and "rights." I put rhetoric in quotes because we all know that the same rhetoric can be used by individuals who really do not support autistic people. I take the posts by Joel and Larry very seriously and I've been thinking about them the past few days. (When I get out of this Starbucks where I write while my son is in school, I'll find the link button to his blog which has disappeared for some reason here).

You can hear how TAAProject came about on interviews and at the talk I gave at MIT. For the purposes of those who do not know the story, I will tell it again. I was the corporate chair of NAAR. I became disenchanted with the way that they promoted autism and that there were never any autistic people speaking on their stages. I became disturbed at the rhetoric of Autism Speaks and this apparent avoidance in engaging autistic people. TAAProject became incorporated on the heels of the first Jonathan Lerman exhibition in 2005. Then, came the Joy of Autism: Redefining Ability and Quality of Life lectures and a second exhibition of more autistic artists, and many other autistic invidiuals who came to the lectures and opening night. It achieved some attention. My thinking is that anything that gets the attention of others to focus on the greater dialogue happening within the disability community itself was and is necessary. It was the reasoning for TAAProject.

I began the organization because I had the will and the wherewithall. Organizing anything takes time, money and effort. I asked autistic indidivuals to have a greater role. Some became board members, some "advisors," and others declined because of the fact that many organizations after a period of time, lose their purpose and integrity. There are many autistic individuals who are wary of that and for good reason. Other autistic individuals declined because they said that they couldn't organize something like TAAProject. While I've organized this, I can't do it alone. I won't. I am a determined little gal, that's for sure. But I think the discussions of late have made me think about where the "autism movement" needs to go.
This is also the reason why TAAProject has moved forward carefully. Any organization must set its goals and attempt to achieve them. That requires some consensus. Sometimes, as we've seen in some organizations, there is so much in-fighting that consensus is not achieved. So let me ask this entire community: what is the goal here? As we talk, we must extrapolate one and work towards achieving it together.

I do not wish to be the Executive Director of TAAProject forever, believe me. I would like to remain involved. I want to finish a book, I want to raise my son and I have other boards I sit on. I would LOVE to hand this project over to an autistic individual to lead or even co-lead, and even if it's not TAAProject, it must be done (it is in some self-advocacy organizations). TAAProject will support the work of autistic self-advocates. To me, the goal of the project is achieved at when the public begins to listen, when there are so many self-advocates that we are happily redundant, when we begin to see REAL CHANGE in autism "services," beyond JUST the ABA model, and I hear public dialogue about how it is important to cultivate an inclusive society (in schools and beyond).

What I have experienced with TAAProject is an outreach. Right now, I can say that in receiving this gift because of founding TAAProject, I am very grateful. As a parent, I’ve been able to learn from autistic people, and hopefully provide a forum on the website and at future events, to have autistic adults heard. I live in Toronto. Believe me, there is a huge shortage of understanding and a large patronizing of autistic adults in our neck of the woods. At the conferences I’ve spoken at so far in Toronto, NO ONE HAS HEARD OF AUTISM HUB OR ANY AUTISTIC SELF-ADVOCATES outside of Michelle Dawson -- and even so, not everyone even knows about her unless they are politically inclined. The reality is, the ABA advocates and Autism Speaks have cornered the "autism awareness" market so far.

There are few schools that accept autistic children -- many parents experience a funneling to autism-specific schools. Most ABA providers who must fulfill Toronto Preschool Language Service (TPAS) requirements are such poor providers of ABA, as we have experienced, that I feel many autistic children are needlessly held back because of it. Imagine only meeting your "supervisor" once a month for a mere hour on your child's
progress and programming -- I know that Adam's learning fluctuates weekly and no supervisor could ever keep up with his progress or his ever-changing needs. Most therapists have a periphery knowledge of autism through the big charities and outdated theories. No therapist I've met are even aware that this dialogue is going on. Most have some little ABA certificate they earned at a local college or some seminar. The Board Certified Behaviour Analysts I've met are so rooted in technique that they literally ignore the child right in front of them. There is gross overgeneralization of "autism education" under the ABA model, and one's child is often subject to a check list of skills that the child must learn at $25-$30 an hour for a junior therapist -- some kid. In other words, there is no real thinking behind why they are doing what they are in most cases. The child is just seen as being in need of remedial 'therapy,' and the child's individualism is ignored. A child's behaviour JUST BECAUSE THEY ARE AUTISTIC is viewed as bad or abnormal. Imagine the autistic child who wants a cookie and whines, cries or even has a meltdown because they cannot get that cookie, and is treated for his or her autism instead of just being viewed as well, a child in a battle of wills. Believe me folks, it has happened in my home by therapists who have come and gone. Of course, I will also say, there is always an exception to the rule. While I am not a big supporter of ABA, there are other parents I know who do it. ABA in and of itself is as someone put it a "shorthand term" for Occupational Therapy, Speech Language Therapy and one-to-one teaching in many cases, so in the true sense of the term, it is not really ABA, but is called so for funding purposes at the moment. So, let us focus on the more fluid approaches to education that service the autistic child by looking at challenges and innate abilities and learning styles. We may all dig into the same tool box at times, but I can never subscribe to a "way" of educating each and every autistic child. I think that parents from both perspectives can agree that our children deserve better and that there needs to be an awakening of the real abilities and NEEDS of autistic children, as well their right to be with others.

I also think that to disagree on these very issues also facilitates the changes we all need. While Sue Rubin may want a cure for autism, other autistics will not and to discuss the complications and ethics of the idea is important. Does Autism Speaks ever have these dialogues about what autistic people want -- what they agree and even disagree about?
Dialogue is what is painfully missing here. The public thinks that autistic people who talk and think DON'T EXIST or are AN EXCEPTION TO THE RULE. This is so dangerous. And why might they think this? Because they need support, and the talking autistic person doesn't fit the raison d'être for the funding plea -- and I do think there is consensus that the way in which funds have been requested has been degrading to not just autistic people, but to all people belonging to any disabled community. The idea that if you can't talk or "function normally" you are not aware or sentient is offensive to everyone belonging to this community.

The public is unaware of the very issues that face all disability communities today. While the deaf community cannot agree about implants so too the autism community may never agree about ABA or cures. And that, my friends, is the way that a society progresses -- through this dialogue. What I want? For the dialogue to change the way people talk to, provide opportunities for, make friends with, provide access to, provide quality services for, and hopefully one day employment to...Adam.

Autistic adults in Toronto and surrounding communities also have real issues with respect, understanding and employment. These are some of the issues that TAAProject has not yet addressed. Yet, our autistic board members are talking about it.

If TAAProject does not serve the needs of autistic individuals, then it will cease to exist. Period. I can advocate for my son and for what he needs as an individual. I’m not sure if would be as effective as doing it together, if only for this purpose of learning together, because there is so much learning (on my part anyway) that still needs to be done. Or, if TAAProject can exist as an organization that supports autistic individuals by raising these issues as parents, we MUST support autistic self-advocates as THE LEADERS in this understanding about autism.

I can think of other non autistic supporters who have built mechanisms by which many parents have come to learn more about autism from autistic individuals. Autism Hub is one of them. I do want to see more autistic people participate more rigorously. I do want to hear suggestions of what TAAProject might be doing or doing better. What is very use-able, is our website. This community can use it in different ways. We have nearly 500
members by virtue of being on the web for just under a year now. For any organization, that is significant, believe me. That means, members receive monthly newsletters. That means, we have government officials who receive them. Autism Hub gets readers. It seems to me that autistic people do have to pick this up rigorously. We have the tools, we've built them. How does this community want to see them used? How can we take advantage of all the skills and tools we already have?

And to be honest, I wonder if we would be having this wonderful discussion at all without the coming-together of parents, allies, and of course, autistic people at all. This working together must never cease, even if Autism Hub or TAAProject no longer exist.

Are these what we call "growing pains?"

Testament

Where have we been and what can we become? It's a basic question I've been asking myself the past several days listening to viewpoints and watching debates:

Empowering Allies

Phil Schwarz wrote this great piece titled "Identifying, Educating and Empowering Allies" which was posted on autistics.org from the 2004 Autreat session. Here is a paragraph:

Characteristics of Good Allies
Again, the gay community's model points the way here: the number of parallels between characteristics of good straight allies to gay people, and characteristics of good non-autistic allies to autistic people, is striking and significant.

But the gay community is not the only one with relevant models and experience here. In fact the following list was adapted from a women's rights organization's manual for male allies. (NY State Office for the Prevention of Domestic Violence Bulletin, What Makes a Good Male Ally?):

* They are able to take direction and leadership in work as an ally from autistic people.

* They understand that autistic people's empowerment is not a threat, but rather an additional strength.

* They listen to autistic people and have a willingness to "call out" other non-autistic people on autistic people's issues.

* They do not try to define the problems that autistic people share with them.

* They are willing to take a stand on issues of discrimination and exclusion by being vocal about them.

* They advance their perception of autism and autistic people by listening and talking to us and by challenging "conventional wisdom" & stereotypes about us.

* They model behavior for their friends and other non-autistic people by letting others see their example.

* They work to help unburden other non-autistic people of the misconception that autistic self-advocacy is about "attacking parents"

* They are willing to hear autistic people's reality "full out", with the realization that there are aspects of this reality that will be foreign to them.
* They are not struggling with their own identity and self-esteem, and do not need to prove that they are "normal".

* They are nonjudgmental — which implies equality and respect.

* They understand that autistic people know that all non-autistic people are not "the enemy".

* They are working to change the culture of mainstream autism organizations so that other non-autistic people can publicly voice their support for autistic self-advocacy.

* They don't assume that high-profile people in the "autism establishment" are automatically allied with us because of their credentials or positions of organizational leadership.

* They have done their personal work to become aware of their own issues relating to the issues autistic people face.

* They listen, but don't try to "fix" the problem by themselves.

Considering the discussion of yesterday, Phil recommended that we all take some time to read that piece once again. Thank goodness we have people who want to stand together and parents and supporters who want to learn.
Autism for tagging me for the Thinking Bloggers Award.

These are the official rules for participation:

1. If, and only if, you get tagged, write a post with links to 5 blogs that make you think,
2. Link to "this" post so that people can easily find the exact origin of the meme,
3. Optional: Proudly display the "Thinking Blogger Award" with a link to the post that you wrote.

Since Kyra of This Mom mentioned me last, I've been thinking about which bloggers have made a difference in our lives. Be it thinking or FEELING, autism blogging for me, is about instigating a change of attitude -- a change in the way we view and treat autistic people so that our children can lead full lives in society.

My thinking most definitely comes from the way I feel about Adam and the way we have experienced autism through clinicians, doctors, therapists. I have gone through self-doubt and confusion and then a growing acceptance of how we WANT to live the rest of our lives, despite the disennt and chatter in the autism world. In the end, I also come to see that, many of us simply want the same things: we want every opportunity for our autistic children and we want to be happy. The difference lies in how we go about that change: in changing the person or the environment. And, is there a compromise? Do we all try to mold ourselves to some degree and when do we feel ready to say that fitting in just doesn't matter as much as we think it does? We have a social issues that we need to keep talking about which is: is changing a person to "fit in," right? Is it just?

I got this the other day when Dawn Prince Hughes just said "f-ck it" on stage during her conference speech. She had to say it in regards to how others have viewed her or wanted her "to behave" in order to live HER life. When we let others pressure us too much, we give pieces of ourselves away until there is nothing left. I don't believe that any of us want our children to feel this way.

So, with this "meme" you make me think about thinking. While I would like to be a better thinker, I think it shows when you think over experience. A marriage of the two is what I hope to achieve.
one day -- an unmasking of my Self in order to connect with others to achieve a more empathetic society -- in this case regarding disability. I like what Stephen Covey had to say about thinking:

_I'm convinced that we can write and live our own scripts more than most people will acknowledge. I also know the price that must be paid. It's a real struggle to do it. It requires visualization and affirmation. It involves living a life of integrity, starting with making and keeping promises, until the whole human personality -- the senses, the thinking, the feeling, and the intuition -- are ultimately integrated and harmonized._

Wow. I don't think I've managed to get that far yet, but I'm committed to trying.

Now it's my turn to meme." Here goes, but like this video I just made, I don't think I could EVER make a thorough enough list of all you people and bloggers I have come to admire so much:

**Autism Diva** -- She may not remember, but before I ever became a blogger, I emailed her. Autism Diva is the most informative, entertaining and thorough blog about autism out there. She is thinking, feeling and unabashedly wry.

**Autism Vox** Can anyone keep up with Kristina Chew? I enjoy her essays and her daily thoughts on the latest autism news. I feel an affinity with Kristina (also one of the first autism blogs I ever encountered back in 2005), with her love of literature. I always need to check in with Kristina to read her take on autism lit or art as we often end up writing reviews on top of one another!!

Kathleen Seidel of [Neurodiversity.com](http://www.neurodiversity.com). There is never a shortage of information on Kathleen's site. She is a woman with the incredible brain. I still don't think I've gotten through all of her material on that site. She is a pillar of the autism acceptance/rights movement, in my opinion.

**Kevin Leitch** I don't know if most people know about this other pillar of the autism acceptance movement. Kevin, savvy in many areas, blows me away with his research, knowledge, love and generously. He is, as we say in the Jewish community, a real
Mensch. He has helped The Autism Acceptance Project in so many ways and I just can't proclaim my gratitude often enough.

This Mom I've never met Kyra (yet), but there are days when I just wanna hug her. There is never a moment when I don't belly laugh at her butt jokes, or am in awe of her ability to unmask herself. Unmasking is what makes writing great, and I expect we will see a book written by Kyra (I hope) one day. She is not only funny, but a poetic writer right along with her son "Fluffy."

But it's not fair that I have to stop there. I love all of the Autism Hub bloggers and I would give the award if I could to everyone on there. Thank you all for inspiring me so much. What a great community we are growing!!

“A man is but the product of his thoughts -- what he thinks, he becomes.” --Mahatma Gandhi

Labels: Thinking Bloggers

I Believe

There is something that I've been made aware of lately: at the conference I spoke at last week, a gentleman with brain damage noted after my presentation that I am proud. He meant it in the sense that he too is proud and that what shines when I talk about Adam and autism is not shame, but pride. He is right. There is nothing I'm NOT proud about when it comes to him. It's that heart-swelling thing I've got, and I hope it's contagious. I look at pictures and despite the fact that I am far from perfect and that there has been a lot of pain in my life, like there is in most of our lives, there is just so much to be happy about. Perhaps it is just sheer will on my part -- not out of some depression or delusion (I am not associating one with the other by the way) -- but this determination that has enabled me to well, BELIEVE in him:
TUESDAY, MAY 29, 2007

RESPECT: A Homage

If only I could put everyone in this little homage. The people I've met so far in Canada, do not know who you are:

What Kind Of World Do We Want

My video response to whatkindofworlddoyouwant.com

Credits to Asperger Square 8, autistics.org, Autism Speaks: Don't Speak for Me Petition and Jonathan Lerman.

SATURDAY, MAY 26, 2007

Not Everyone Wants to Be Cured

In Snowcake, Weaver's recent movie where she plays an autistic woman, she comments on finding her "inner autism." In the following article from San Diego, she is interviewed and Neurodiversity.com, Left Brain/Right Brain, Autism Diva and our very own The
Autism Acceptance Project, www.taaproject.com are mentioned in the article as important sites in support of autism acceptance. Weaver did the above public service announcement with GRASP.

Last night, I spend time with Dawn Prince Hughes who also presented at The Come To Your Senses Conference in Toronto where I presented the talk you can also see on video from MIT. She thanked me for presenting there, but what was so apparent was the ease of connection between us. This is a person, very much like myself, who understands the frenzy of how we behave socially, with masks and walls, and we both have an incredible need to slow down and really connect. When you are with Dawn, that's what you are feel (if you are willing).

I am really glad to see a celebrity align themselves not with an idea, a cure as it were, but with the people this means so much to. This is, after all, about living.

By James Hebert
UNION-TRIBUNE ARTS WRITER
May 25, 2007

She set out to learn about life with autism, and after a year spent with people across the vast spectrum of that condition, Sigourney Weaver found she hardly needed to step out of her own two shoes.

“What I ended up doing, in retrospect, was finding the autistic person in myself,” says the actress, who plays a middle-aged mom with autism in the new movie “Snow Cake.”

“God knows it’s there,” Weaver adds with a deep, warm laugh. “I mean, that’s one thing you see very quickly, is we’re all on the spectrum. We all have different ways of stabilizing ourselves.”

“Snow Cake,” which opens today at Landmark's Hillcrest Cinemas, arrives at a time of exploding awareness about autism spectrum disorders, the catch-all term for a range of conditions that share (to varying degrees) difficulties in the areas of speech, social interaction and repetitive behaviors.

It also comes as advocates for the autistic – including some
autistic people themselves – are raising their voices in a plea for respect and acceptance.

Their message is similar to the point Weaver makes: that autism is part of the continuum of human neurology, not some separate category of existence. That it is, in essence, a difference rather than a disease, although its consequences for those affected and their families can be profound.

It can be a hard point to get across when so many mysteries swirl around the subject, and when the main message the public hears about autism is how common its diagnosis has become. The incidence of autism spectrum disorders among U.S. children is thought to be as high as 1 in 150 now; the ratio has risen in recent years as understanding of what constitutes autism has broadened.

Weaver, whose memorable film roles over the years range from brave space warrior (the “Alien” series) to crusading naturalist (“Gorillas in the Mist”) to monstrous boss (“Working Girl”), says spending time with autistic people in researching “Snow Cake” was eye-opening in ways she couldn’t have imagined.

“I thought I knew a lot, but really, I knew less than nothing,” she says. “And I felt so humbled, both by the people I met on the spectrum, and the people who devote themselves to bringing out their talents and successes, and improving their quality of life – parents, friends, teachers.”

One of the most startling things she learned was how variable the condition is; there are as many expressions of autism as there are autistic people, which means there’s no single way to address it – therapeutically or artistically.

“Some people have said, ‘Well, my relative with autism doesn’t have any of these capabilities,’ ” Weaver acknowledges, speaking of those who have seen the film. “But this movie is not about autism, and we were not trying to present the (prototypical) autistic person.

“This is about a man who’s thrown together with these two different women, and Linda (Weaver’s character) happens to be autistic. And he learns from her, as she does from him. I think
interaction – for people who don't want interaction – is one of the messages of the film. Which is: It's good for us to mix it up with each other.”

In the film, Linda is able to live on her own and hold a job stocking store shelves. She speaks capably – a struggle for many with autism – but has trouble deciphering the moods and motives of the people around her.

She winds up playing reluctant host to Alex (Alan Rickman), a stranger in whose car Linda's daughter died during a traffic accident. Alex also forms a bond with Maggie, a loner who is Linda's neighbor.

Angela Pell, the British writer who scripted “Snow Cake,” was inspired by her own autistic son, though his story is far different from Linda's.

Nine-year-old Johnny is “at the other extreme of the spectrum,” Pell says. “He doesn’t have a huge amount of language. If I went to see 'Snow Cake,' I’d probably come out and say, 'Well, actually, that's nothing like my son.'

“But what I was trying to do is just give a general feel of what it’s like to learn to live with and love somebody who's rather extraordinary, really. And there are a few other themes in there, just generally about acceptance, really.”

Pell recalls that when Johnny was first diagnosed, “we had all these leaflets and books showing pictures of children on their own, with tears in their eyes. All these very negative images.”

“And although it was quite challenging with our son to start with, it’s not our experience that it’s been totally negative. Our son is one of the happiest people I’ve ever met, and he brings a lot of joy to a lot of people.”

Advocating for acceptance of those who are different might not seem particularly controversial, but “it's quite a minefield, actually,” says Pell. And some of those mines are inscribed with the word “cure.”

Those in what's loosely known as the neurodiversity movement...
say talk of a cure is insulting and demeaning because it suggests autistic people are broken or damaged or otherwise need to be “fixed.” They also argue that autism is an inextricable part of who the person is and cannot be removed like a bad tooth.

(The movement has a strong Web presence at such sites as Neurodiversity.com, Left Brain/Right Brain, Autism Diva and The Autism Acceptance Project, www.taaproject.com.)

Some also voice concerns that dangling the promise of a cure can make desperate families susceptible to questionable therapies.

Groups that have sprung up to fund research into a possible cure counter that it's cruel not to try to help those with autism – although nothing in the neurodiversity approach argues against taking steps to improve quality of life.

Quite apart from that debate, though, Weaver sees a more simple and basic need for understanding and respect.

“I don't like being in a world where I don't see people with different problems,” she says. “I think it enriches our world, and it hopefully will enrich their world, to be able to come and go without our shrinking in fear and ignorance. Which is all it is.”

THURSDAY, MAY 24, 2007

MY MIT TALK NOW FOR VIEWING

You can view my talk at MIT HERE.

I gave this same talk at the Come To Your Senses today. It was full unlike at MIT where they were in the middle of exame week. I also met Dawn Prince Hughes who gave me a big hug. She said, "imagine where I would be if someone decided to cure me."
New Minds, New Bodies, New Identities

You can now watch the h2O conference at MIT here. Consider Oliver Sack's comment on the blind man who was given sight, and thus became "more disabled."

Autistic Teachers, Scientists, Consultants Every Day

As many of you know, Amanda Baggs has been working with MIT on their assistive devices for autism. Michelle Dawson is a researcher at the University of Montreal. Dr. Morton Ann Gernsbacher so eloquently wrote about the meaning of participation in this article, The True Meaning of Research Participation. But autistic and Aspergers teachers? Policy makers? Board members and leaders? Introducing, Carole Ann MacDonald who is a teacher with Aspergers Syndrome in Brampton. The National Post:

It is the middle of a lesson in the classroom at Greenbriar Public School in Brampton, and the boys, aged 12 to 14, take turns jumping on the trampoline in between listening to their teacher.

"It releases tension," teacher Carole Ann MacDonald says matter-of-factly, as she surveys a classroom that also includes terrariums, a beanbag chair, a sectional couch and, most importantly, three teaching assistants and a teacher for just nine students.

Ms. MacDonald knows, perhaps more than most, the need for an autistic child to have a release from the structure of a school day.

When she was a bit younger than these students, she was labelled "retarded" and severely disabled, and required a team of private tutors to get her through school. It was not until her final
year of teacher's college, three years ago, that she was diagnosed with Asperger's, a form of autism.

I am excited about reading as Adam is still young and his prospects of being taught by people who might really understand him are becoming a reality. I was a little disturbed by this next judgmental paragraph, as I certainly wouldn't mind hand-flapping or "autistic behaviours" from any of his teachers, so long as they knew how to teach:

Ms. MacDonald is considered by autism experts such as Dr. Kevin Stoddart to be among the highest functioning cases of Asperger's. She does not shake hands obsessively or have any noticeable physical tics. Her unusualness manifests itself in a way that is difficult to pinpoint.

In the classroom, where other teachers might give harsh words when students misbehave -- the boys on this particular day were eating, pacing the room and talking out of turn -- Ms. MacDonald laughs.

The Autism Acceptance Project support group, lead by four autistic adults (so far -- more are welcome!), has adults with autism, Aspergers and are all so very unique as individuals as are their experiences.

The possibilities abound.

Labels: autistic people
This will be a rambling post. Contrary to the title, it is not "thinking" about much, really. It is not an essay with a point. It is a post reflecting the state of the world as we feel it today.

I want to thank This Mom for mentioning me in her post today. I've recently noticed this Thinking Blogger nomination memes going on, and I happened upon Kyra's post today.

As Kyra noted, there are too many wonderful bloggers out there and so much to read. I don't think I have the time to read everyone I would like to, particularly how I am trying to write a lot more these days on other topics elsewhere.

Yesterday, I spoke a little about Adam and how well I think he's doing. I have been thinking about all the fretting we have done, and how at peace we are these days. Is it spring? Sunshine? Summer quickly approaching? The great school we now attend where Adam is integrated and happy? The new approach we take at home in respecting Adam, his innate intelligence and building learning programs that really address his learning style?

I reflect that it has taken us nearly four years to get to this point -- dealing with therapists coming from ABA backgrounds and keeping the ones who really want to learn how to teach -- nearly fighting with some of them about Adam's needs and HOW to teach him respectfully. We need this combination of background and flexibility when teaching kids. And then, at Adam's school, there is no background but the right method for his needs. (I will not disclose his school for safety and privacy reasons).

Yes I Can! nursery school lost their funding for summer camps yesterday. I am very sad about that as Adam used to attend that camp when he was a very little guy. Adam attended Yes I Can! for preschool and camp. While he outgrew their teaching style, it was a warm welcoming place when he was very little. This was where he learned how to paint, where he wore his first Halloween costume.
Janet MacDougall really cared about our Adam. Many camps have had funding cuts -- the funding goes towards camp counselors -- special needs camps were not specifically cut. And Yes I Can! was not just for special needs kids. It was for all kinds of kids. This is why we loved it there too -- a marriage between understanding the special needs child and inclusion. The Toronto Star reported that the government said that Yes I Can! scored poorly on quality of service. I don't know if anything has changed because it has been three years since we've attended Yes I Can! But our early memories are positive, and then we had to move on.

Apparently, the government wishes to direct funds to counselors with disabilities. The Toronto Star reported:

Program funding gives priority to organizations in high unemployment areas as well as those that hire students "with disabilities, aboriginal students, and students who are visible minorities," Lesley Harmer said in an email. "It is unfortunate that every year there are always more applications for funding than money available," she said.

There is nothing wrong with that goal. The places I want for Adam include:

- access and inclusion;
- camps that take shadows or can provide them;
- affordability (some families should receive financial support);
- understanding autism outside of the behavioural box;

There is no reason why camps should limit access to kids with special needs, or not have special needs counselors.

Anyway, as I meander down the contented path the past few weeks, I will sit down and write my book, a couple of essays. We look forward to camp, to some lazy summer days, and just, well...rambling along.

Labels: autism, funding cuts, special needs, summer, summer camp, teaching
TAAProject’s First Support Group

Last night, TAAProject hosted the first support group for non autistics, lead by four autistic adults -- all very different -- from Aspergers diagnosis to autism diagnosis. The group went so well that it wants to convene every two weeks instead of every month for two hours at a time. There is one thing I want to share that speaks to comments on "early intervention."

All of the members were recipients of many "treatments," and physical or verbal abuse from their parents, and general exclusion and misunderstanding by society at large. Michael Moon said one thing that was very important, I think. He was diagnosed with autism: "What was considered my weakness turned into my strengths. My love of playing with sand turned into photography. My need to make noise turned into playing music. My need to move turned into dance." To see for yourself, check out the gallery at The Autism Acceptance Project website (www.taaproject.com) or link at the left side bar.

An overwhelming response from all autistic members of the group noted how important it is to focus on strengths -- that constant focusing on "appropriateness" is so damaging to self-esteem.

As the years pass, it becomes less difficult to break away from the limiting boxes that many interventionists put us and our kids into. Instead, the people who work with us are learning about the importance of following Adam's lead and respecting him. Adam works everyday, but we don't focus on the negative or what he isn't. We focus on what he is. And you know what, we are beginning to fly at a rate that we never did before. I believe that there is room for working with autistic kids for sure, but in a way that we do not typically think about which is valuing our kids and the way they learn.

Labels: art, autistic strengths, early intervention, quality of life, weakness
A belated mother's day wish to all:

MONDAY, MAY 14, 2007

My New Book

Well, it's my first piece published by Key Porter Books. You can pre-order here at Amazon, edited by Cori Howard and titled: *Between Interruptions: Thirty Women Tell the Truth About Motherhood*

The other contributors (all Canadians) are Lisa Bendall, Randi Chapnik Myers, Christy Ann Conlin, Leanne Delap, Monika Deol, Debleka Guin, Marina Jimenez, Alison Kelly, Chantal Kreviazuk, Joy Kogawa, Deidre Kogawa-Canute, Jen Lawrence, Mary Lynk, Rachel Mate, Chandra Mayor, Ami McKay, Carrie-Anne Moss, Susan Olding, Sheree-Lee Olson, Katrina Onstad, Elizabeth Renzetti, Harmony Rice, Rachel Rose, Denise Ryan, Cristina Sampang, Carol Shaben, Joanna Streetly, Dorothy Woodend, and Jamie Zeppa.

My other book is in the making.

SUNDAY, MAY 13, 2007

Are We Blind?
I have a little something I’m working on for all the “autism moms” today, but it’s not quite ready – the reason I haven’t been blogging this week is largely because I have to figure out how to use a new MAC computer which I got for the purposes of making easier movies and presentations. Huh. I knew the salesperson made it look too easy. Anything that looks or seems easy, is never easy. My father was right.

What an interesting week it has been: I spoke at MIT this week and they will be loading my presentation into You Tube. I met Amanda Baggs there and Amanda is at MIT all week now. I commend Rosalind Picard and Rana Kaliouby for understanding the importance of adding autistics to their research teams. Rana said to me “knowing what we know now, we would teach this course differently.” In other words, with a growing understanding of the social and ethical issues surrounding autism (rather than the medicalized accounts of autism we are hearing much too often), they would not teach autism and technology out of the proverbial text books. What a breath of fresh air. Some people who actually care what autistics think. I asked other scientists in the room to consider the same, and to talk to Autism Speaks and like organizations about their marketing tactics that steam roll over the real issues, in other words, how autistic people (and parents like myself), feel about manipulating fear and despair for research funds.

And then my other mother’s day surprises: two articles in the New York Times today that are must-reads: Genetic Testing + Abortion = ???. And then in Sunday Styles an article on the disability community called Clearly, Frankly, Unabashedly Disabled: “This is who I am. If you have a problem with it, that’s your problem.” Are we finally entering an era (in the US anyway, as Canadian press are very lame so far in addressing the issues) of discussing prenatal screening and, uh, ethics? Consider Sarahlynn Lester’s comment, a thirty-two-year-old supporter of abortion rights, “I thought it would be morally wrong
to have an abortion for a child that had a genetic disability.” In other words, it used to be “easy” to stand on the side of the pro-choice movement. But now that technologies have made the stakes higher, our knowledge and control over life greater, the choice is not so easy. Do we have the right to choose between certain kinds of children?

“How much choice do you really want to give?” asks Arthur Caplan in the article who is chairman of the department of medical ethics at the University of Pennsylvania School of Medicine. “That’s the challenge of prenatal testing to pro-choicers.”

I’ve written about this many times. I went into that genetic counselor’s office when I was pregnant with Adam. I heard statistics and was confused. There was no way of knowing what life would be like if I had a child with a disability until I lived with it. And the fault is society – us. People with disabilities are the statistically highest minority group in the US today. Unlike other disabilities, however, autistics still do not receive the same consideration. While people may be listening somewhat to the Downs and other communities, we have a real problem in hearing out those with autism, largely due to ignorance about disability to begin with and then how that has proliferated organizations like Autism Speaks which spread fear and despair about autism, despite what people with autism have to say about their own disability.

The New York Times article on disability today says:

“The public image of people with disabilities has often hinged on the heroic or the tragic. But Mr. Blue [who has CP], 28, represents the broader portrait of disability now infusing television and film. This new, sometimes confrontational stance reflects the higher expectations among many members of the disabled population that they be treated as people who happen to have disability, rather than as people defined by disability.”

At the MIT lecture, a young man said that he could understand what it would be like to lose an arm, be deaf, be blind, but he couldn’t understand what it would be like to be autistic – that he
I couldn’t wrap his head around it. I think what most of us are lacking, in this autism debate, clearly, is a theory-of-mind. Indeed, it is not the autistic who are “mind-blind,” but rather, the rest of us who are blind to the community, the words, and the real lives of those who tell us everyday, what it is like to be autistic in our society.

SUNDAY, MAY 06, 2007

Life is not a Preparation

This Tuesday, I’m speaking at MIT. I’m talking about all the fear and fascination we see and hear about autism and what respect means. I’m talking about a fair way of talking about autism. I’m so heartened to hear others who talk the same way. It strikes me that our autistic children are put under unfair and impossible microscopes -- every behaviour scrutinized, pondered, with therapists often wanting to change it. Is this really fair? Do we put other five year olds who tantrum and are being stubborn, or who do not want to do something under the same microscopes? Have we set the bar a lot higher for children with special needs?

This focus on changing behaviour that isn’t harming anyone strikes me as a waste of time when Adam needs to focus on learning and living, but not always preparing for the future. That really does happen naturally. We have decided that it’s also important to spend time enjoying life and being together. I think today I’ll take him out for lunch, walk the dog, and we’ll do what we want -- it’s Sunday. I don’t book anything on Sundays so we can discover what’s out there, discover ourselves, and who knows what else. What we want is some quality in our lives, and we are happier when we don’t have to worry every single day of what may be or what may become of Adam. Life is about living. Yes, it’s also about working. But we want to live today, not worry about tomorrow. Here’s a great post by Aspie Home Education. In order to learn and to discover ourselves, autistic or not, we need some time and space to experience.
Ralph Savarese's Book in Newsweek:

Home Is Where The Heart Is
The Savarese family thought they were autism experts—and then they adopted DJ.

May 4, 2007 - We’re told to pick our battles if we want to make a difference in the world. Activist and writer Ralph James Savarese thought he and his wife, Emily, had done just that. For her it meant working with a Florida center for disabled and autistic children. For him it meant writing and teaching college students about responsibility and social obligation. But in the late '90s they found themselves forgoing these larger causes for the smaller one staring them right in the face: an abused, autistic toddler named DJ. Click here to read more.

TUESDAY, MAY 01, 2007

Blogging Against Dis-Ablism Day

Today is blogging against dis-ableism day --the purpose of which is “to write about disability and rail against the discrimination that disabled people continue to face.”

Yesterday, Orato Media published "I am the Happy Mother of an Autistic Child." I think that will be my contribution to today’s theme. It is about accomodating autism versus remediating it, and understanding the Hue in Hu-Manity.

Speaking of hues, I also want to point you to Elliot, an autistic five-year-old artist who was in the New York Times today (thanks to
Kristina of Autism Vox for pointing me in his direction). Elliot’s cards are available for sale here.

In the Wolfond household, we are about what can be done as opposed to the cannots. Our lives are about creating the lives we want to live and trying to make it happen no matter what tries to obstruct us.

Labels: ability, art, disableism, possibilities

Monday, April 30, 2007

Reasons, Rationale and Representation

Yesterday, I attended a function for the arts. Not a minute too soon, either. When the well runs a little dry, one has to replenish. For me, its art and literature that inspires.

A few parents discuss how they do not write about their child, or reveal anything about their own autism, their past. This is utterly fine -- not everyone is comfortable in revealing truths about themselves, their relationships, their families and all that complicated stuff that goes with it. Some autistic individuals fear that information will be used against them, and already so susceptible to scrutiny and hate, I don't blame them. It's really a
personal choice about how much one person can take. "Exposure anxiety," is an issue when raising awareness about autism -- while Autism Speaks may have huge walks and people come together, it is much more difficult to physically coordinate an event of solidarity among autistic people and their supporters, for many of these reasons. That is why we must work together to find solutions of accessibility. Online solidarity has certainly changed the face of civil action and we have to keep working.

I have deliberated over Adam’s privacy issues over and over again. I try to be careful in how I express myself in order to keep his dignity in mind, but I also try to communicate that we too have our challenges. I never know when I may change my mind about how I write here or elsewhere. Yet, for now, I always come up with the same conclusion: Adam makes me so proud. Adam is autistic. Adam shows me (and hopefully others) that being autistic is really no big deal -- that despite the fact that he needs a little extra assistance here and there, he really is a great kid, with so many possibilities. We owe him, and others, the accommodations that he needs so that he may have a chance. We would ask no less for any other child.

After listening to the concerns of parents with older autistic kids on the Revolution Health conference call, in person and on many of your blogs, I am excited about the future. Here in Canada, we have college courses that are adapted for many disabled individuals. Organizations like D.A.N.I, won’t take NO for an answer and are working towards creating employment opportunities for many autistic and other disabled individuals. Overall, the pulse is changing. I find that more and more people are open to accepting autism and including autistic people. I believe that the increase of autism diagnosis is steering us towards an inclusive society, more than any other time in our history. Do I believe this because my attention is focussed on autism? Perhaps. But have you seen many people diagnosed with mental retardation these days? I see more and more kids being diagnosed with autism and parents who want their children to be a part of society. That is the engine I’m talking about here. It should not be an unrealistic expection of making autistic kids, "normal," per se, but rather, helping autistic kids to achieve their potential. Let us never underestimate that!

Many people who have never understood autism are reading fiction about autism. While those of us who are involved in autism...
everyday have many criticisms about how autism is represented, must remember that some novels have begun to change (for better or worse) some naive public perceptions -- many people who read this stuff come up to me and reveal "I never knew that people with autism are intelligent," for instance. This mainly from books like The Curious Incident of the Dog in The Night-Time and The Speed of Dark. Now I could scoff at the fact that others think that autistic individuals are "less than human," "not that intelligent," or come to terms with the fact that this is the first step in changing a perception -- so many people are never exposed to people with disabilities because we are not yet a fully integrated society. There are many hurdles to overcome in autism perception and representation, and our collective diligence in demanding more and better will only help to continue to shape this perception in a positive way.

Ralph Savarese's book Reasonable People is another example of a parent who has embarked with his child, D.J. in changing public perceptions. They have opened their lives, their challenges, and their family so that the rest of us may learn. This is why we share, write, create. This is why art is so important to humanity. Reasonable People is now finally available for purchase.

So, at the end of the day, Adam is my pride and joy. He is autistic. When I tell people he is autistic and their faces drop because they don't know anything, or don't know what to say, I talk about how terrific he is. I smile -- because he really does make me smile everyday I think of him. I remember a time when I knew nothing about autism. I never rubbed shoulders with a disabled individual in my school. Thanks to Adam, I’ve had to learn and the world has opened up for us. I can also tell you, smiles are contagious and open up the world for others as well.
Last night, I saw this dance troupe (Complexions Inc.) and two of the dancers from NYC came to our home. One of the dancers moved his body like I've never seen. I want to call him "rubber man." But his performance was more beautiful than that. It was as if his body was carving space -- I could see the archs of light that followed the movement of his arms and legs. Just like many shows I've seen, I think -- wow, Adam would love this. Many autistic individuals would love these performances. So, I'm going to start writing letters to the Toronto Symphony Orchestra, theatre troupes and dance companies to have special days where autistics can come, enjoy, whoop and flap. I'm calling it PLEASE DO DISTURB. Since I know from first-hand experience that art can change lives, I feel so strongly that Adam should have access to many performances in his life -- it inspires, enhances, and helps us create our own performance, this art form called life.

Labels: art, literature, representation

When What Seems Broken Is Perfect

WHEN WHAT SEEMS BROKEN IS PERFECT is a guest post by Barb Farlow. I got to know Barb after I wrote a letter which was published in The Globe and Mail on "prevention." The article was written in February 2007 and titled: "Expand Prenatal Gene Tests, MDs Urge."

Barb called me to discuss her daughter who was diagnosed with Trisomy 13. Barb is a professional engineer and mother of five children at home. She is married "to the greatest guy in the world." After an incredible amount of effort and a lot of help from ethicists, health care providers and patient safety...
advocates in Canada and the US, she was able to obtain change at a prestigious hospital here in Toronto. The hospital invited them to tell the story of their daughter -- Annie -- to the Grand Rounds to which she says "we are certain that it will have a positive effect for the care for all special children." Annie's story will also be told at medical schools, a genetics and ethics conference in Calgary and an International Ethics Conference.

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The graph is still taped to the inside of my kitchen cupboard, pencil on a string dangling down beside it. It depicts the progression of my newborn daughter's weight, most days showing a moderate increase and thus reflects a thriving child. It ends abruptly at 80 days.

How can the value and purpose of a life be determined? Can these be measured by longevity, intelligence or the productive contribution of an individual to the economic base of society? Even more important, who has the right or ability to make this judgment?

My husband and I were recently faced with a very difficult situation. We are in our 40's, educated and financially stable. We have 5 children at home and we love sports and travel. The kids do well at school, are athletic, and all are healthy as horses. Life was good to us. We were pleasantly surprised when we discovered that we were expecting a new life to love and nurture.

We first heard of our unborn daughter's genetic condition long before she was diagnosed. It was considered a lethal condition, an extra 13th chromosome. Most babies don't make it to birth and those that do live a few years and are severely disabled. I thought, "Well, what is the point of that life?"

When the geneticist uttered the dreaded words, "your daughter has trisomy 13" and it was a diagnosis about my baby and not someone else's, the reality was entirely different. With the ferocity of a lioness, I wanted to love and protect this little girl, and do all that I could for her. If her existence was only to be a few more months of kicks and flutters in utero, then I wanted her to have that life for the sake of both of us. We named her Annie.
After the diagnosis, the research began. It was frantic, and went long into the night for months. We researched medical details and personal stories. We communicated with parents all over the world who had a child with this very rare condition. We discovered that the babies can live longer, but they may need a lot of medical treatment. The most amazing discovery was that the parents continually stated that they treasured and delighted in every day of their child’s life. They knew with certainty, that the gift of that life was not theirs to keep. The children, called “survivors” were blissfully happy and progressed developmentally, albeit slowly. It became increasing clear to us, that unless the medical intervention to provide life was excessive, Annie was better off alive than dead.

We were not sure how we could do it. I was the kind of mom who usually forgot to pack a diaper bag. I would often be impatient when one of my children couldn’t master the math skills in their homework. Could I ever develop the patience for a child who may not be able to sit on her own for a year? How could we fit Annie’s care and needs into our busy schedule? We had 5 soccer teams in the summer! We were more frightened than we had ever had been in our lives. Love for Annie compelled us forward.

Annie was born full term, crying. She was mildly afflicted, as the syndrome goes. She needed a very small amount of oxygen and had hypoglycemia. Annie could not take all of her nutrition orally and so she had an NG tube (nasal gastric tube), which was a tube that went in through her nose down into her stomach. I became skilled at its reinsertion, every 3 days. We fed her expressed breast milk. Somehow, we dealt with all of the issues. We knew that with time, Annie would take more feedings orally and her need for oxygen would lessen, and likely be eliminated completely.

We were aware that the first year would be rough. Everyone pitched in. Our 12 year old son took over the lawn maintenance and his older sisters took on Annie’s developmental progress and bought “mind stimulating” music and ordered her a “Bumbo seat” to help develop strength.

The whole family came together in ways that I never dreamed possible. We discovered how true our friends and family were by their support and encouragement. Somehow, the homework got done and the gang made it to their soccer games.
At age 75 days, Annie smiled at us for the first time. Even now, a year later, the memory of that first and only smile causes me to cry.

Annie experienced respiratory distress at age 80 days and was transferred by ambulance to the Children’s hospital. The physicians told us she had pneumonia. Our beloved baby died less than 24 hours later.

There are two ironies to this story.

The first is that we thought we had a choice of life for Annie but the reality is that we did not. The medical records, which we instinctively felt compelled to obtain and have had reviewed, reveal no signs of pneumonia. An effective “Do not resuscitate” was ordered without our knowledge or consent. The final computerized medication report from the intensive care of an excellent hospital is inexplicably missing.

The hospital issued a letter of apology stating that sometimes “communication does not occur in as clear and consistent a fashion as we would wish. For that, we are very sorry.” Recent developments in medical science can be used to diagnose and terminate certain lives but the choice to use medicine to prolong these lives doesn’t seem to be an option.

During her 80 days, our little Annie taught us our greatest lessons in life. Through her life, we experience the deepest sorrow and the most intense love. She taught us the true meaning and purpose of life and we are forever changed as a family. Our children have learned that if they are ever in need, their family will love them, protect them and do anything to support them just like we did for Annie. They developed an incredible empathy for the disabled and the vulnerable.

The ultimate irony is that this little girl who seemed so broken, flawed and seemingly without purpose or value, was in fact, perfect after all.

Labels: Disability, Ethics, Medicine, Prenatal Screening, Treatment
Revolution Health Conference Call

I participated in absentia in this. Unfortunately I had another function but here it is for the rest of you to listen: Revolution Health.

Thanks to Dr. Michael Weiss, a developmental psychologist in Connecticut; Dr. Robin Chernoff, a pediatric developmental specialist in Maryland; blogger Autism Diva; Kathleen Seidel of Neurodiversity; and Jan B of Just a Mom, That’s More Than Enough and Madeline McEwen-Asker of Whitterer on Autism and Kristina Chew of Autism Vox. What a great way to pull people and this dialogue together. Special thanks to Cynthia Samuels for bringing everyone together.

Joy Is Not An Outcome

“We grow up believing that what counts most in our lives is that which will occur in the future.” Mihaly Csikszentmihalyi, Author of Flow.

“I never think of the future. It comes soon enough.” Albert Einstein

“Worry never robs tomorrow of its sorrow, it only saps today of its joy.” Leo Buscaglia

“Our future is not predictable. Our future is the result of the choices we made.” Garth Brooks
In the “autism debates,” how much of this is true – that the crux of what we seek lies in a desired outcome? Whatever therapy that is debated to be “right” for autistic children, this is the foundation upon which it has been built – that the outcome should be that the child should function, should be as normal as possible, should live as much of an independent life as possible. It seems that we are so focused on these outcomes, that we’ve forgotten about today. For me, I know that there are hard days. Frustrated days. Even worrisome days – worry is about tomorrow, about an expectation, about a desired outcome. For me, my frustration gets directed outwards on a society that doesn’t seem to understand autism, doesn’t know how to accept Adam fully as he is.

I forcibly took some time away from all of this. I recommend it for everyone – to live your life, go out (find that babysitter if you must), and do something you enjoy. Moving out of autism, you begin to realize what quality of life really means: it’s not living for tomorrow but for today. It’s enjoying your life and your child. It’s about creating your life and your reality. It’s not that you give up educating or on your child. It’s just that you don’t worry so much. How many times are we really putting our children under an impossible magnification? It seems that once your child is diagnosed autistic, the bar is raised higher for our kids than for others. Every tantrum, every bit of anxiety all goes scrutinized as the “fault” of autism. It’s simply ridiculous. No one can live a life like that without snapping.

There are many people coming and going and we’ve been doing a multi-disciplinary “therapy” (I prefer to call it tutoring or education or just one to one assistance) for three and a half years now. For all these years, all we’ve been focused on Adam’s “progression.” Reading all of your blogs, I would say we’re all pretty much focused on that. One assumes that progression must lead to someplace – a fantasy of a child who talks, who goes to school, maybe even university. In the meantime, we if think about the worst-case scenario (that our child will never become anything), our bodies are in constant fight or flight mode, a state of panic for what does not yet exist, and we’ve come to learn that being in “fight” mode all of the time is a contributor to chronic stress – we are putting our bodies in the thing that we are actually thinking about. Perhaps we’ve even attached our sense of self to
Think of an elastic band for a moment. You’ve got that band in your hand and are pushing and pulling it back and forth. What do you notice about the rubber band? It seems malleable and it moves back and forth – we are pushing and pulling the band to get that motion. Then what? If we pull too hard, the band may break, or worse, the band may hit someone else and hurt them. But where does this rubber band go? While it is moving constantly through our push and pull motion, it still ends up going nowhere. So although I’ve used the word struggle many times, and felt like talking, dealing, and confronting autism can be a “struggle,” a constant push-pull action that seems to be going nowhere, I would now like to change that word to STRIVE. What happens when we strive? We begin to move forward with what is.

We have come to believe that a struggle is noble. We believe that if we don’t struggle, then the undertaking is unimportant. I think I’ve had it wrong. Struggle is not what I want. I just want to move forward with what is. I want some flow. I want to spend more time with my son, who has just turned five and whose life is traveling at a speed that I never could have imagined. While we must strike a balance between teaching and living, we must always remember that our children are only children for a very short time. We need to cherish the moments.

In *Flourishing*, edited by psychologists Corey Keyes and Jonathan Haidt from Emory University and the University of Virginia respectively, Martine E.P. Seligman of the University of Pennsylvania writes in the chapter titled “The Past and Future of Positive Psychology.” I found the following quote very revealing:

“Prevention was a theme of the 1998 meeting in San Francisco. We asked how we can prevent problems such as depression, substance abuse, and schizophrenia in young people who are genetically vulnerable or who live in worlds that predispose them to these problems. We asked how we can prevent murderous school yard violence by children with access to weapons, with poor parental supervision, and with, perhaps, a mean streak. The answer does not lie in the disease model (Catalano, Berglund, Ryan, Lonczak & Hawkins).
What we have learned over 50 years is that the disease model does not move us closer to prevention of these serious problems. Indeed the major strides in prevention have resulted from a perspective focused on systematically building competency, not correcting weakness. Positive psychologists have discovered that human strengths act as buffers against mental illness (Keyes & Lopez, 2002.) Much of the task of prevention in the 21st century will be to continue this fruitful line of work and create a science of human strength, the mission of which will be to understand how to foster these virtues in young people. (Bornstein, Davidson, Keyes & Moore, in press).

By learning optimism, not out of naivete, “we do not repair damage, but instead teach skills.” Optimism also moves us forward. It is creative and empowering and keeps us in a productive mode.

It’s been an interesting week just thinking about where we are. I’ve had to think about how long we’ve been on this path and about the quality of our lives together and what I want that to feel like. I want more time with my little guy before he grows up. I want to teach him myself some days because I have the patience and love for him that no one else will ever have, and I do find those precious connections we share that enable him to learn. I do become frustrated some days. But it’s not because of Adam, it’s because I haven’t listened or don’t have the time to listen. It does take time. We have been so happy together this week, and he really wants to learn from me, his parent. Being with therapists all the time is no way to live. In the beginning, we were told we HAD to do therapy for 40 hours a week – we all pretty much hear that one. Our children are not happy exclusively with therapists. Our children need us.

There may never be a eureka moment in autism science. We may never know everything there is to know. As Isaac Asimov said “The most exciting phrase to hear in science, the one that heralds new discoveries, is not the ‘Eureka!’ (I found it!), but ‘hmm, that’s funny.’” In other words, we may learn not what we seek, but rather something entirely unexpected. So there is no sense in waiting for something that may never occur. It only makes sense to continue with what we have right in front of us, and what that asks of us.
“Imagination is more important than knowledge. Knowledge is limited. Imagination encircles the world.

We should take care not to make the intellect our god; it has, of course, powerful muscles, but no personality.

We cannot solve problems by using the same kind of thinking we used when we created them.” --- Albert Einstein

Joy is not what Adam will become. My joy comes from living with him, from possibilities that I don’t invest in too heavily. Joy comes from being with Adam, and what he reveals to me every day.

Happy Birthday Adam

It is Adam's 5th birthday today. We had a little party on Saturday and the parties will continue -- in our house they are nice quiet parties.

I am so proud of my little guy. He woke up all smiles, still cooing the way he did years ago. He is trying so hard to talk, but it’s not
really coming yet. I'm looking at Dynavox and other systems -- he sure likes the lightwriter we are playing with right now.

Problem is, here in Toronto, there is a wait list to get these devices because many "therapists" don't think they work for people with autism. At costs of $6,500-$10,000 Canadian, the average family can not afford to buy them. Bloorview Macmillan here in Toronto can "prescribe" them as they are the government's designated "prescriber." Yet, who can afford to wait two years, let alone swallow that price tag?!

Adam needs devices, computer programs and more. He needs these things to be subsidized and accepted in the classrooms. We need to press our government officials and make them understand what accomodation means.

Today, on his 5th birthday, I do not mourn the child I do not have, I celebrate the Adam I do have, to whom I responsible, and to whom I owe a great amount of fortitude and joy. His life is full of possibilities, and he will never disappoint me.
My recent viewing of LUCY – a play at CANSTAGE at the Berkeley Street Theatre in Toronto inspired some real feelings with regards to how our lives are viewed by others. LUCY is not alone at fault for raising arms-length fascinations of autism – movies like Rainman, and others that deal with peripheral views of disability as opposed to films like The Sound and the Fury and My Flesh and Blood which deal with in-your-face, real issues confronting those with dis-abilities. Autism Speaks and their recent parading of autism as horrible fate-worse-than-death scenarios on Larry King and Oprah don’t help. Oh but wait, “my life is better because of my autistic child” recent statements by the advocates who earlier stated how terrible their children were, is making the issues confusing (quite frankly I see no point in being politically correct when you are trying to beat the autism out of the child rather than dealing with the issues and enjoying the child you have). All of it effects our lives deeply:

We go into a store and two women who watch Adam hop to a row of books at the bookstore feel it is their right to stare at him and say “autism,” like we can’t hear them. Friends (with all the right “intentions) feel it’s okay to call out of the blue to proclaim they saw Michael Waldman proclaim that television causes autism, so gosh, it must be true and I better do something quick because I must be a bad mother for plopping my son in front of the telly (like by golly, that’s all we do all day). People feel it is okay to watch every single move Adam makes and talk about autism in front of him, rather than engaging with him. I do consider the media and representations of autism very much a contributor to the way we treat and regard autistic individuals.

There is a real difference between people calling asking “what do you think about such and such,” and authentically trying to understand. But it’s not fair to stare or to assume that all we want to do is talk about autism all day long. We don’t. I may say I don’t feel like talking about it. We don’t feel like being stared at all the time. All Adam and I want is to walk out into the world and to live
our lives freely. We want to work, to go to school and live as we want and are able. While one might argue that all the fuss is raising awareness about autism, and arguably, make us able to accommodate autism better, we must also be aware of the dangers are in making people “fascinating” like “pathologies” for our consumption or entertainment, rather than really getting to know us. There are days that I feel like the political chess game called autism is becoming quite boring, and yet ironically dangerous for us not to participate in. It may be a game without conclusion and yet, a game Adam can’t afford to lose.

A Review of LUCY

At CanStage in Toronto is the play LUCY, written by Damien Atkins who, in consultation with Autism Speaks, The Geneva Centre and the University of Toronto’s Department of Anthropology, starring Philippa Domiville as Julia, Tony Munch as Gavin (Lucy’s father), Seana McKenna as Vivian (Lucy’s mother), and Brendan Murray as therapist and head of Lucy’s school, and last but not least, Meg Roe as Lucy.
Named after the well-known fossil known as Lucy, she is one of the oldest and best-preserved skeletons of a hominid (two-footed, humanlike primate). Lucy was of the species Australopithecus afarensis. Her remains were found in Hadar, Ethiopia, in 1974 by American anthropologist Donald Johanson and his student, Tom Gray. During her life, Lucy stood about 3.5 feet tall and weighed close to 65 pounds. The shape of her leg bones, pelvis, and spine indicate that she walked upright. She is estimated to have been between 25 and 30 years old when she died of an unknown cause. Compared with humans, Lucy had a small skull, long arms, and short legs.

It’s interesting to hear a play begin with Lucy, an autistic thirteen-year-old talking, reflecting about the mother she peers on from above. When the spotlight shines on Lucy, she is lucid and not autistic at all, perhaps intended to suggest an ability to self-reflect, to think. The play begins with Gavin, Lucy’s father divorced from Vivian, her mother, to request that Vivian, an anthropologist, take Lucy for one year so he can connect with his new bride. “I’m exhausted,” he proclaims. “I didn’t think I could have life again.” Vivian, who left Lucy as a baby, eerily reminiscent of refrigerator mother theory, reluctantly usurps her traveling life to welcome this “stranger” into her home. Gavin arrives, schedules in hand. Lucy repeatedly rings the doorbell and once inside, settles into drawing on the floor. “She needs a lot of structure,” says Gavin, telling Vivian to do the same things, buy the same things lest Lucy devolve into a set of tantrums. Lucy also gets accepted into a new autism school after being on a wait list for three years and, “where they can do a lot for her,” he says.

Vivian gets acquainted with her daughter – Lucy turns on the television and takes off her pants. “Put your pants on,” says Vivian, “put them on or no TV.” A battle of wills ensues, Lucy retreats to the bathroom, we hear a few bangs, and comes out with feces on her hands.

“Did you do anything out of her schedule?” asks the brilliant therapist.
“I told her that if she didn’t put on her pants there would be no TV.”

“Her pants are made of corduroy,” he says, “it’s called sensory integration dysfunction. Her pants were painful to her and she was communicating to you that she didn’t want to wear them.”

Is this sounding like an autism 101 class yet? The first act certainly felt that way. Anyone living with an autistic person may have been cringing during this first part of the play. In fact, writer Atkins obviously was so fascinated with all the theories in autism that he had to get them all in there as quickly as possible to the point that the true meat and potatoes of the play – the idea that autism is a form of human evolution – a way for humans to survive in this over-populated, closely knit world – was not really explored. The play chugs along making quick stops at all the autism theories we hear about in the news today. We witness the devoted but exhausted father who “does everything” for his child by enrolling Lucy in endless therapies. We learn that Vivian is “autistic” as she prefers digging fossils in Africa over engaging in social repartee. The play shows Lucy overwhelmed by the therapists in and out of her life with an interesting auditory and visual montage of the voices in her life – of “do this, do that” and “use your words,” echoing painfully in her head.

Vivian becomes the mother obsessed with vaccines and mercury theory – unable to view herself as the genetic material that made up Lucy -- and moves all to quickly to an accepting mother, appreciating the gifts of her daughter. They become the coup d’etat against the outside world of theory and intervention. They bond, they read books together, and Lucy is allowed to express herself in her art. Vivian cuts off all therapy and decides to move to Africa with her daughter to finish her book, and let Lucy be herself. “Don’t you see?” Vivian says to Julia, her assistant. “We are not meant to live this way.” She begins to talk about how civilization is wrapped up in doom and gloom, how people use technology more and more in order NOT to socialize.
and engage in confrontation. Her theory, based on survival of the fittest, is not that autism is an aberration, but rather, that autistics ARE the future. To Vivian, autistic people are a genetic evolution of human survival – humans that are more pragmatic, who prefer to be alone, who do not get wrapped up in emotional webs that are not working. Contrary to disability, Vivian views Lucy as perfect. “No one will stand with you on this,” says her assistant, Julia.

In an interview in NOW magazine, director Atkins says, "I guess the point of the play is the validity of putting people in categories, boxes that distance you from others and don't allow for real understanding or compassion."

"I feel strongly that Lucy's not aware of her difficulties," says Meg Roe, who plays the young autistic woman. "For that reason I didn't want to know too much about the clinical aspects of autism but rather to draw on behaviours that came from me, from how I am in the world. Creating Lucy was more a matter of exacerbating my own habits, bringing out my own traits in a more intense way. In earlier versions of the script, Lucy screamed a lot; now she's finding different ways to communicate."

I was actually interested that Roe did not talk to autistic individuals before rendering the traits of an autistic young woman. She said in a Canadian television interview that she didn’t want any one autistic person to shape her character. It shows. While Roe may have exacerbated her own traits, she doesn't quite pull autism off.

"It's hard to know whether what I'm doing is working, because I can't see how I'm affecting the other actors," she notes. "Lucy rarely looks at the others and makes little eye contact. I just have to trust that Damien's text, director Eda Holmes and my own instincts will lead me in the right direction."

The instincts are off. The play is nothing more than a string of stereotypes glued together -- a collage of autism politics and theory.

Where is this all going? The play doesn’t give us a greater insight into the autistic experience than we can already derive from autistic art, or books and experience written by autistic people. It is a difficult task, this attempt of trying to relay autism theory
against an interpretation of autistic experience. We get the sense too, as Atkins ties up the play in haste. In the end, the therapists and the ex-husband come to take Lucy back to her therapy, because “she needs to get better.” The mother doesn’t fight for her, but says to Lucy “I’m sorry.” There was a point when Lucy is on the floor reacting to all the dissension, the yelling between Vivian’s assistant who inappropriately intervenes with the ex husband and the therapist. When Julia said “this isn’t survival,” as Lucy wreathes upon the floor I wanted to say “oh yeah?” With the suggestion that the government wishes to employ a National Autism Surveillance Strategy in Canada, the idea of intervention and the invasion upon others telling our family and autistics how to live their lives feels all too real. So I felt her wreathing is survival. It is communication.

I can’t help thinking as I write this of Munch’s The Scream: shut up and leave us alone already. The rest of live the consequences of theories and speculations and interventions every day. We get calls every time some quack wishes to publicize their latest theory, or gasp with excitement when autism is on someone’s famous television show again. What people don’t know is that this is life as we know it. Stop peering at us and let us live it.

While the play wishes to suggest many things, namely how we relate to one another, there are too many themes and director Atkins bites off more than he can chew. He may leave our heads swirling, but eventually we don’t end up in any place different than where we already are – except that maybe we’ll receive yet one more telephone call: did you see Lucy lately?
Just like in *The Music Man*,
March came in like a lion.
April approaches with
trepidation, as snow has
fallen on what should be the
eyear has begun with
trepidation, as snow has
fallen on what should be the
eyear has begun with
challenges. Mother’s health, my knee surgery, anxiety and I
wonder how it all effects my little guy, who is so attune to the
environment and moods around him. I can’t say that my own
immune system isn’t effected when the house in under duress. I
too, like Adam, am very much effected by moods, and
environment. I consider at times that the best remedy is to go
escape to the country and get the heck out of the punitive
demands of the city. There is something of a pulse here in Toronto
– programs to run to, schedules to adhere to, and obligations to
attend to. It is endemic to the way we are supposed to live here in
the city, I suppose. I don’t always like the way we are forced to
live, and I don’t think it’s all that healthy for Adam who is so
touched by all the stress. The world stops for no one, as they say.

The other factor is our doom and gloom society – be it through
terror and “war on whatever” campaigns – it is exhausting. There
is very little happiness in society these days, which makes it all the
more important that we focus on creating it. Forget about the
doom and gloom campaigns that are intended to scare you and get
you to act and throw money. Create a world that you want to live
in by starting at home. When I become overwhelmed, I just try to
remember what is important and focus on that. I wonder how
important these primary years are – those milestones as it were –
to Adam’s life. I wonder about just learning, being happy,
experiencing and living life.

I have four step-children in addition to Adam. Two are out of town
at university now. One of my step-sons came to me yesterday and
asked for my advice. He rarely does this, so I took it very
seriously. He said at Kings College in Halifax, his psychology
professor told them of various therapies for autistic people and
that ABA was “necessary.” Joe, my step-son, asked why Adam
wasn’t “better yet,” with all the programs he has at home. I would
like to meet that professor who gave Joe the idea that Adam should “get better,” as opposed to simply learning the best way he can. So I went into my spiel about helping Adam to learn and be the best he can be. I don’t know if Joe understood this yet – he was the one son that went to an all boys school that demands that you “be someone,” – that successful doctor, lawyer or businessman. Joe went on to describe how he had an Aspergers boy at his camp where Joe was his counselor. The boy had “behavioural” problems, Joe said, and “was not allowed to return to camp.” “We judged him as we would have anyone without a disability,” he said, but he said it as if he were questioning himself, and trying to understand.

It is here that I find that people have the wrong idea about inclusion – as if it takes no extra effort or training, and that the onus is on the person with the disability to “fit in,” as was clearly the case at this camp. It is clear that no matter how “nice” people are, that if they don’t understand autism and don’t have the toolbox, so to speak, they can do little for the autistic individual. Inclusion isn’t just including, it is learning HOW to include, to listen, to accommodate and to understand. An autistic person cannot be included without such understanding and provision, whatever that provision may be because it may be different for each autistic individual.

So now the camp loses, the Asperger’s teen loses. He is not allowed to come back on the basis that he does not fit in among the group of “nice” people. I asked Joe to consider when that may happen to our dear little Adam.

PERMALINK POSTED BY ESTEE KLAR-WOLFOND AT 4/05/2007 08:19:00 AM

COMMENTS LINKS TO THIS POST

WEDNESDAY, APRIL 04, 2007

The Autism Acceptance Project

On google, you are finding the old home page. The Autism Acceptance Project has a new website and forum.
Brian Henson's Response to Senate Committee Report

I have provided my blog to The Autism Acceptance Project's autistic board members to comment on the recent Senate Committee Report: *Pay Now or Pay Later: Autism Families in Crisis*. Below is Brian Henson's response to the report first. The second half is his comment on why The Autism Acceptance Project did not participate, nor was invited, to these hearings. We are working on doing so in the future:

One of the centre comments of the Senate Committee on Autism in its report "Pay Now or Pay Later" is the following statement (from Item H, in Part III: Action Needed by the Federal Government):

"...the [Senate] Committee supports the symposium announced by the government and recommends that: Health Canada invite autistic individuals to attend the symposium and be given the opportunity to contribute as equal partners in an exchange with other participants and Health Canada ensure that the symposium is conducted with a clear set of goals and defined outcomes and is based on consensus building."

This statement is, albeit, a first step, but the requirements (or conditions of inclusion) of the symposium, as outlined above, are just not precise enough. What is the definition of "equal" in the first recommendation? Would anyone care to say that it could mean equal representation for each participant in the symposium for those who are autistic individuals and those who are not? This is highly unlikely, given the per-capita rate of autism today and the number of non-autistic persons and organizations wanting to be represented at such a symposium.

Also, there is no mention in the statement that autistic individuals be represented "as equal partners" in any future symposium orchestrated by the federal government (or a branch of the government, including a crown corporation). This leaves the statement of equal partnership as just an olive branch to get...
autistic individuals to feel as though they are having some say in the development of governmental resources, when the case might be just the opposite--they might be used just as "pawns" to show how autism needs to be treated, because the individuals, themselves, do not "behave" as a "normal" person would behave, and anything these autistic individuals, regardless of the number, had to say at such a symposium, would "go in one ear and out the other", as far as parents, professionals, and government policy makers.

In the second part of the statement, it mentions "a clear set of goals and defined outcomes", but does not indicate (except by "consensus building") what these goals are oriented towards. Also, what is consensus building? Is it just taking what the majority of people at such a symposium want, and ignoring what the minority are saying? If, for every hundred non-autistic persons at such an event, there was just one autistic individual, how would one establish both the concept of equal partnership with autistic individuals, while, at the same time, building consensus?

These issues are not new, as far as symposiums (and the myriad of other forms of human interaction), but still require a better outline, available to the public, before the symposium itself, on how these issues are going to be handled at such a symposium or conference. That way, each person participating in such a conference, whether as an individual, or a representative of an organization, will understand what to expect beforehand, and prepare accordingly. For example, will there be provision at such a symposium for persons who used other means of communication (such as facilitated communication) to be able to present their views and priorities on autism? Will written briefs sent by those not present be considered just as important as the presentations by those attending the symposium? Will it be open just to persons in Canada, or will persons (professional or otherwise) from outside Canada be able to attend and present at the symposium? Will issues affecting human rights, aboriginal issues, and other issues, beyond autism (medical or otherwise) be open or restricted at such a symposium? These are just a few of the questions that need to be answered in outline form, open to the public, before any such symposium is ever scheduled. Without such issues being addressed ahead of time, there will just be more confusion and conflict wrought out of such a symposium.
Of course, if the outline of the symposium, itself, is far too restrictive, in any way, there might be more protests than input at such a symposium. Therefore, those preparing for such an outline of the forthcoming symposium need the assistance of various persons experienced in the principles of negotiation, and how to avoid conflict (and confusion), in yet another attempt at human interaction as a basis for policy making at the government level.

**This is Brian Henson's response as to why The Autism Acceptance Project has not yet participated in such hearings:**

The question seems to arise, as to TAAP not being involved in the recent Senate Committee Hearings.

That question is whether inclusion can be demanded or built. It seems to be a question of time. Those who see it as a demand (and without such a demand, no inclusion can be conceived) are ready to point a finger at anyone who does not demand inclusion (as they do, at that moment). However, those who see inclusion as something built in the form of diplomatic initiatives, see it as a test of solid but persevering patience.

If one is ready to confront those who are against inclusion, then the diplomatic moves will flow; but if one is not ready for such a confrontation, then the demands will be seen as purely rhetorical, and of no subsistence.

TAAP, at the time of the Senate Committee Hearings, was not ready, due to various factors, none of which was apathetic in nature; and these factors, including the fact that TAAP was not invited to participate in these hearings, must be taken into account. To suggest, in any way, that because TAAP did not participate in the Senate Committee Hearings it was being supportive of those organizations who deride autistic individuals in any way (because such organizations were present and forceful at the Hearings) is just not applicable.

If you do not defend a neighbour at every moment does not indicate, however slightly, that you are spreading hatred towards that neighbour. Perhaps you were just not there, at that moment, when the neighbour needed defending, or were limited as to the type of defence you could enable.
Like a hockey team player who has less energy than a week ago, and slips once or twice during a game where that player's team is defeated, it is not the onus on that player to prove that he was the one who lost the game (due to that player's decreased energy); there were just too many mitigating circumstances as to why the team lost. However, and this is important beyond the score: the team cannot be self-reproaching over one loss; it must move on to the next game, whether that game is tomorrow or next year.

Likewise, it is not a matter of portraying TAAP as being at fault for not attending the Senate Committee Hearings, and causing those opposed to inclusion to be seen as the victors at the Hearings. There will be more chances ahead for TAAP to be included, and often when the slower approach is taken towards political issues, the stronger the basis will be over time. When solid connections are made, however long that might take, the bonding is far more permanent, and the results go far deeper than just one set of hearings or one symposium. These results will be a much stronger stand in support of inclusion of autistic individuals in their own needs and support systems, whether by private interests or governmental interventions.

Therefore, TAAP has pursued the role of bringing autism awareness to the public not by trying to portray itself as a front runner, ready to persuade by popularity, but by trying to portray itself as the group with the most solid foundation as a basis of its stand that autistic individuals, themselves, must be full party to any discourse about the needs and supports of each autistic individual. While other organizations, more bent on the current situations, will fall over time, due to a lack of a solid foundation, The Autism Acceptance Project will, with its solid foundation, withstand the pressures over time to withdraw or to decrease its stand on the full potential of autistic individuals.

Please note that these are individual comments made by TAAP project board members. Stay tuned for more comments from The Autism Acceptance Project board members, autistic and non autistic, alike. To reach Brian Henson, please email ryley@taaproject.com.
Friday, March 30, 2007

Proud Pictures

Here’s my little guy just minutes ago playing with a girl next door. It’s warming up here in Toronto.
THURSDAY, MARCH 29, 2007

Love Makes Me Stay

Many thanks to Aspiegirl who sent me these videos this morning. Indeed, what makes us stay no matter what? Love.

Adam must be sensing my change of mood. He is having another happy day. How much do we as parents and teachers have to look at ourselves??
When the going gets tough

...the tough get planning.

Some of you emailed me about Adam's anxiety...thank you. Yes, there has been a lot going on in our lives the past couple of months and being as sensitive as he is, he does absorb everything.

One thing that works for me is to recalibrate and plan again. Get everyone on board, and ask for support.

By the way...I believe some comments are not getting through on this blog. Is anyone else having difficulty with this? Some people have emailed me saying they tried to comment but... I really haven't received these comments, so please keep trying.

Finding the Joy in Autism

This is my mother with Dani -- an autistic young man (21) whose name is celebrated by his mother, Kathy Laszlo in an organization called D.A.N.I. (Developing and Nurturing Independence) to get people with disabilities working in our community. I was honoured to be given an award at this gala. I spoke with many parents who have worked with their children through the years, who find the need to continue to celebrate despite the challenges.

I have hesitated renaming my blog. It was intended to make others think about finding challenges and celebrating lives despite them. There are people who do not understand autism, who speak
about it in unfair terms, who abuse our most vulnerable, and so forth. Many of you have understood the idea – the rebalancing of views as it were and protecting human spirit. Many of you have not and have taken offense to the title. I am sorry you feel that way and hopefully you can come to see why celebration is important in autism as it is with any disability and even in illness itself -- because we believe in life. I am not sitting in one “camp” or the other. I think there is merit to both "sides" and we have to begin to define what unites us. This is a moderate approach – not falling into the hype of hysteria and not languishing in self-delusion. I am really empathetic to the struggles that each family faces. A lot of what I do is self-reflection and listening to other voices. How can you not? As we learn and share, we evolve overall. Being married to an ideology is dangerous in and of itself.

Amidst all of the doom and gloom messages about autism and disability, as a parent, I became so frustrated that others could never look beyond the challenges that confront Adam daily and instead focus also on his strengths so he could receive an education that is beyond remediation and correction – the latter which increases Adam’s anxiety. While we still must deal with the challenges of autism in our own family, we must find the strength to run Adam’s team, deal with sleepless nights, and lately, anxiety. Would I want to alleviate Adam’s anxiety? You’re damn right I would. I don’t care if Adam flaps his hands in happiness, or looks different, but when a child is distressed, it takes even more work to not only find out why and deal with the source of anxiety. I’m certain that all parents experience this day in and day out sleuthing and trying new things. One can try a medication, but it may not work, it may not deal with the source, or it may cause serious side-effects. Or in the best case, it may work. Dealing with this is a process of elimination of all the things that could possibly be causing the stress – or the confluence of events and environment and physiology that makes one answer nearly impossible to find. In the meantime, as it is happening to me, I become more distressed and sad and I keep remembering for all the struggles that we’ve gone through together, we somehow find that joy again. It’s what we live for. It’s what we must live for and protect unless we become Nihilists. In autism, we need that. We don’t ignore the struggle, but we protect the joys.

Would I like to live my life so that family members and friends really understand the complexity of our lives – trying to “live” it
like others while not really living a “normal” life at all. Trying to fit into any category of normal isn’t a reality, and I find, very stressful. Is it comforting when a family member questions why I don’t answer the cure-all question with absolute certainty? No, because it doesn’t understand the complexity of autism and our reality. If autism could be cured, in our reality, people with autism might not be treated with the respect they deserve. Then again, if it is like Downs Syndrome – a way of being without a cure - how will all of negative referencing come to affect autistic individuals in the future? While many are busy finding a cure, others are complacent in waiting for it and we are not getting into schools, not getting enough supports, not getting enough accommodations. We simply are not accepting what is real right now: that there is human difference in our world. In the end, one can sometimes feel very isolated in the sea of misunderstandings, complexities and grey area. Grey area is what makes most of us up, and definitely makes up the landscape of autism, which is to say humanity itself.

I still believe that attitude is important and asking for support in schools and society will succeed with constructive dialogue, and in trying to understand autism better. I still do not agree with the hysteria we see in the media. I agree with a more strategic and respectful approach to achieving services for our kids while also supporting science that strives to be unbiased in this regard. After all, we are dealing with important people here – our children. They deserve to be treated as people, not half people and not in snappy little sound bites that manipulate heart strings. The last thing we need, or can endure, is disregard and misunderstandings among the other members of our communities.

I also wish to say that we need a multitude of supports and services for our kids that truly respects all that they can give to society. Adam can give. He can receive. He can learn. I want to find out what is happening to him that is causing his distress as any other parent would. It sometimes makes me feel helpless and want to cry. Many of you are right, you do not always FEEL the joy in autism, but we must wait for it, strive for it, and find out how our children can be the best autistic people they can be. For me, it comes down to happiness. When Adam smiles, all is right with the world again.

Finding the joy in autism – what it means to me – is a commitment to Adam. He needs me to be positive and strong. When I am down
I know how easy it is to wallow about something that is not part of our reality. But I notice it doesn’t help Adam at all. What would help him is a coming together of all autism families to achieve our mutual goals together. We need to celebrate our diversity as parents, the diversity of our autistic children, and a diversity of approaches to helping our children under an umbrella of ethical debates with regards to those approaches, because we are capable of constructive debates. Aren’t we? Despite other’s attempts to factionalize me, this blog seeks to debate how autism is represented because it concerns my autistic son. If titling this blog *The Joy of Autism*, or the event last October, *The Joy of Autism: Redefining Ability and Quality of Life* was the only way to get people talking in Toronto or online, then it was a good thing. We are waiting much too long for the services, accommodations and for the respect our children so rightly deserve. We should represent Adam and others with dignity because they are vulnerable and sensitive. I can’t imagine that other parents, no matter how they’ve interpreted the “joy of autism,” would not want the same for their children. It is my dream – and as the little boy says in the Goodnight Moon video: “Dreams are very important.” May we all work together, question everything in a constructive way, and be able to share our joys and struggles.

**The Right To Choose**

No matter what you do or what you write, there are some in the blogosphere who make up the facts or try to persuade people that to do anything other than an ABA program is akin to driving your child over a cliff. They are persuasive, I know. I know because I was at a place for two years where although I became angry at the poor quality of ABA service here in Toronto, it was still hard to let go because there is little else provided. To this day there are people who came from behaviourist backgrounds on Adam’s team because in autism’s recent history ABA has been the only funded service for autism. Many ABA therapists, however, still know little in how to employ a real literacy program, an assistive device program and more. An early ABA program is fairly rigid. If it’s play-based and incorporating other strategies, it is no longer an
exclusively ABA program. So perhaps we need to rename our advocacy to address an **autism program** – one that is devised specifically to each autistic individual with the goals and means that befit them. Of course, I’ll never say this without also adding that we need to continue to understand autism primarily from the people who are autistic.

As parents, we will always have doubt – one is not human without it. It is like an embedded checks and balance system. Still, we must ultimately trust ourselves and our autistic children. Too often, many put little faith in autistic kids. Yet, to inspire the greatest fear – that it is necessary to employ 40-60 hours of "treatment" or everything is doomed -- is cruel to the parent and the child. Most of the advocates who speak like this (who say that this kind of therapy time is necessary) have older children who still require accommodations and service. The message: panic doesn't pay (at least emotionally). Some children will grow up "looking less autistic" than others by virtue of who they are and yes, the environment they live in to some extent (I can't answer that nature/nurture argument and, it seems, neither can science). Therefore, finding ways to accommodate all autistic people throughout their lives cannot happen with fear as its engine. It will not help us think logically. It will only provoke us to react in emotional ways that may ultimately harm the autistic person.

ABA is not our first choice in this household. I have seen programs, however that call themselves ABA that are not quite ABA anymore. In addition, the scope of autism is so diverse, that one type of therapy suited for one child may not be suitable for another. The ABA advocates, about to March at Queens Park and in Ottawa don’t want us to have a choice. They don’t want speech therapy to be funded, or occupational therapy, or assistive technologies, or play therapies. They want every child to receive ABA “treatment” that many parents in Canada do not want exclusively or not at all. Others may think that if they choose this one treatment now, that either,

1. they will at least get a service -- the "better than nothing" philosophy;
2. or the autism strategy will evolve after ABA has been legislated.

Many of us want our autistic children to receive a variety of services and an ability to choose what we feel is best for our
children. We want groups for our children to belong to, camps to go to, programs to participate in that are not all ABA driven, but sensitive to the needs of our children. "Regulating" programs (one has to consider the measures we use to regulate) in the schools will only create a one-size-fits-all service that will not meet the needs of everyone. I recognize that the "right to choose" has real ethical implications and the treatment of autistic individuals can be compromised, and every discussion about education for autism must take place under this umbrella.

Even though we see the tide turning for a greater variety of services for autistic individuals in Ontario, the ABA advocates can't endorse it because it wouldn't support their claim that ABA is “the only scientifically proven therapy” for autism. Yet, we all know better. We all know that we need a greater understanding of autism than we already have, that we need to work harder, and that this is not the end of the line. Autistic individuals deserve more than the premise that ABA bases itself upon (to make autistics "normal"), and a better quality of accomodations and service.

A friend of mine came to me and said, “but isn’t scaring people the only way to get the government to do something?” Does Autism Speaks' tactics – claiming that we have an epidemic (when we don’t have the science to substantiate that claim), in order to get more research and services -- the best way? Is calling autism a disease akin to cancer a panic button to get politicians to listen? Perhaps. No one said that government officials listen readily, with so many others vying for dollars.

But does the end justify the means? Does advocating for ABA help obtain more services, or does it take away the opportunity for a better quality of service such as inclusive education, and a diversity of options for an equally diverse population? With so many parents using social skills groups, OT, SLP, and other play-based strategies, shadows, life skills training, and more, should we not be including all of this in our advocacy efforts? In so doing, should we not make the government aware that there is a greater problem here that strikes the entire disabled community: the right to be accepted, accommodated and included? The ABA advocates completely disregard what the disabled and autistic communities (in this case, people who are autistic) have to say about all of this which should shed some light on the bigger problem here.
It strikes me as suspicious when a group attempts eradicate any other voice when we only have so much more to gain for the greater autism community by opening this up. We all have autistic children, we have autistic self-advocates in our country, and we all need a place at this table.

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**Life, Language and Lessons**

*lan·guage (lǎng'gwij)*

*n.*

*Communication of thoughts and feelings through a system of arbitrary signals, such as voice sounds, gestures, or written symbols.*

*Such a system including its rules for combining its components, such as words.*

*Such a system as used by a nation, people, or other distinct community; often contrasted with dialect.*

*A system of signs, symbols, gestures, or rules used in communicating: the language of algebra.*

*Computer Science. A system of symbols and rules used for communication with or between computers.*

*Body language; kinesics.*

*The special vocabulary and usages of a scientific, professional, or other group: “his total mastery of screen language—camera placement, editing—and his handling of actors” (Jack Kroll).*

*A characteristic style of speech or writing: Shakespearean language.*

*A particular manner of expression: profane language; persuasive language.*

*The manner or means of communication between living creatures other than humans: the language of dolphins.*

*Verbal communication as a subject of study.*

*The wording of a legal document or statute as distinct from the spirit.*
As usual, I'm thinking about language and literacy these days and we continue our efforts to assist with Adam's computing and literacy in order that he be able to type more proficiently (or talk) when he's older. Looking at that definition above, Adam does share a language with myself and others, even though he's not yet fully verbal. There are indeed many legitimate ways to communicate -- all we have to do is watch and listen.

I've been asked to lecture at MIT this May for the Autism and Technology course. For certain, Adam's expression of understanding so many things is often first manifested on the computer. A multi-dimensional environment works best for him: text, visuals, computers, real-time experience in a variety of formats. This is how comprehension comes together. It's delightful watching that "a ha" moment in Adam, like I've seen this before and I know what it's about kind of interest. I can see him beam with pride -- and he doesn't need me to say "good job," either. It's a pride that is self-derived. I need not contrive an external reinforcement because he knows when he's done something he takes pride in -- he understands accomplishment. (I do, however, tell him everyday that I'm very proud of him).

Adam began to talk more this week. He has been trying to say sentences that come out like Baby Mo--ar-a-ar-a-ar. That means Mozart. He is referring to the Baby Mozart video he likes to watch. Or "I wa chic-a-bewm-bewm," with such determination. That means Chica Chica Boom Boom, by the way. Everything is coming out in two and three string syllabic sounds. I find his language development wonderful to experience. Every time I try to teach him too fast too soon, I can tell I'm teaching as I would a typical child. I need to break stories down. First the words with the picture, then building simple sentences. I have tried asking questions on sheet of paper like this:

My name is Adam. I am a ____________________.

Boy----------------------------- Girl

I give him a pen and he crosses off the correct answer. I'm trying with more complicated questions than this too.
I also am finding that if I'm teaching him pre-academic skills, they are better taught first on the computer. He has learned to sequence, match, match words to pictures and so much more on the computer first. Now I'm beginning with stories and comprehension there. Then, it becomes easier to transfer that skill onto the "floor." We are still playing around with conversations on the computer. He happily participates by sitting on my lap, but I must facilitate the answers on his behalf, as the art of this kind of typical conversation is a skill that requires time. It is rather nice to be trying this together on the computer.

The more I can get for the computer that I can transfer off, it seems, the better. I found stories that read and show the lines as it goes at a library site. I use the hyperlexia kit for building sentences, and that seems to be working well too. He's having a good time using Cheaptalk 8 -- he can already say the word (request) but I find it useful for recording whole sentences. The visual, the act of pressing the button and my encouraging him to try saying the whole sentence is a means he seems to enjoy. He can say the whole sentence when I ask him to try most of the time.

We've been busy as usual around here, but it's always exciting to see Adam develop on his own. He challenges me to try new ways to teach (and his learning is always evolving), play and interact with him. He plays great games like "under the blanket" where he likes to hole up with me (and others) and smile at you in the dark while he wriggles his body with joy.

This morning, Adam and I took a little break and spent Saturday morning lounging in on an early spring morning adorned with showers. Thanks to my friends who support us, and who remind me to take a little time. It's something that every parent needs to do once in a while, because we all try to do so much. I can't wait for the spring flowers and to walk barefoot in the grass. It is important to remember to do it with our kids.
Thanks also to Christschool for this, who seems to be thinking about the same things and speaking the same language:

It's my birthday again. I'm about to go out with my friends because Henry is out of town -- the first time in ten years -- with Max. Since I've been very young, I've been taking photos of myself every once in a while -- the kind that look a little severe and really close up. Sometimes I just take a part of my face, and often I keep my face blank and write about that time in my life. It ends up looking a little like a collage with writing all around. So, {sigh} this is what forty-two looks like close-up with makeup on.

It started to rain today. But the air was so mild -- like spring wanted to peek in on me and say a quick hello. It spat, it poured,
and now the sun has come out. I guess it's kind of like life -- ever changing. I used to do the typical birthday stuff. For the first time, I found that I don't really care about MY day. I care about what I can do so that others can enjoy "my" day and at the end of the day, that is what has made my day.

Today I:

1. Gave an old gentleman burrowing through the garbage something to eat and had a lovely conversation with him. I don't think I will ever forget his grace and his warm smiling eyes. He showed me how life can turn on a dime and deserves no less respect;
2. Gave Adam a birthday present -- a lollipop -- one of his favorite things, and he showed me how much joy he finds in simple things. Life is still pure and uncomplicated at age five;
3. Am buying dinner. I want to continue to share my life with my friends and family because life can get too busy and we can forget to spend time with them.
4. Wish all people I know and those I don't well, because we really do belong to each other. We share this life, this community and we are more united than we are divided.

Labels: Autism Community
If you caught Larry King Live tonight, you’ll be battening down the hatches: watch out, beware, autism is a big big scare. If you believe in fairy tales and the big bad witch, autism is going to come and take your precious sons.

There is was again, a bumbling Bill Cosby stumbling over his words, “a point that was missed is that there is no eye contact,” he explained, “like they’re not even in the room.”

Toni Braxton shed her tears for her five year old son, the same age as my Adam. “Autism Speaks reached out to me,” she said. “I’m so grateful that they did.” Honey, don’t you know that Autism Speaks is reaching out to every glitterati they know who has an autistic member of the family? Don’t you know that you mean big profile and bucks for them? It sounds like Toni needs some real support. Her son is truly gorgeous, smiling in his picture.

And hey, weren’t all the kids smiling, by the way -- these tragic, pitiful examples of humanity stolen by autism? Please.

And where were these wonderful kids? Where were the autistic adults? Hmm. Isn’t it curious that Autism Speaks speaks without autistic people present?

And then there were those increased “incidence” figures again. That epidemic rise in autism numbers that even the CDC had to explain that the incidence of autism hasn’t increased.

And then there was that 40-60 hour a week “prescription” for our kids – that this is the only way to beat the autism out of the child. No wonder they are crying. Who wants to live like that? No child needs this kind of "intervention." It’s not proven and it’s torture.

And yet, any progress that an autistic child displays is BECAUSE, they wish to claim, because of their interventions without acknowledging that kids develop, all kids develop, even autistic
kids develop, no matter what.

Tailored programs, loving programs is what we need -- a humane understanding of autism as part of a person. Our kids require assistance, for sure, but they also need to be appreciated as autistic people. Our kids are not possessed. Autistic kids display eye contact at times, and sometimes they cannot because it is painful, not because “they are not even there.” They certainly have empathy and plenty of it. Adam may not come and say "mommy what's wrong," but he sure knows when something’s wrong. Just because he doesn't give me the typical response, does not mean that I assume he has no empathy! The day he tells me, or types it out and he may reveal more than I ever imagined about his ability to perceive and understand many things.

Please stop demonizing autistic people. They are real people. When we went to the bookstore the other day, and Adam wanted to hop over to a set of books, two women stopped and stared and whispered “autism,” like it was a dirty word. Is this what Adam has to look forward by the continued work of Autism Speaks? Does Adam get to look forward to a world that thinks he is not there, that they can say or do things because they think he doesn’t know and understand? Does he really deserve the poor quality of services he will end up receiving because of such horrible stereotypes? This is what selling autism does to autistic people. It destroys not "the autism," but the very person they believe isn’t quite human, or not "with" us. It destroys the human spirit.

It’s time to end the hysteria and begin the work. It’s harder to accommodate than to kill autism or shall we say, the autistic person.

Autism Speaks does not speak for us.

You can also listen to a podcast where I raise the considerations in how we represent autism on Autism Podcast.

Labels: Autism Speaks, Human Spirit, Personhood
New TAAProject Website

The new Autism Acceptance Project website is now up: http://www.taaproject.com/. The gallery will be expanded for more art exhibitions that are curated by myself and other guest curators. There is also a new discussion forum there where we can discuss latest news and events. The Autism Acceptance Project is starting is support group soon in Toronto, lead by autistic adults for parents to ask all of their important questions and discuss their fears. Our autistic leaders are there to reveal a little more about what its like to be autistic and growing up with autism so that parents can get an idea of what it will be like for their children and family.

There will be more. Please re-check The Autism Acceptance Project website for updates on upcoming programs and events.

Many thanks to Kevin Leitch of Autism Hub for helping to reconfigure our website and for the TAAProject advisory who made comments on the site before we went live. Kev has done a great deal in keeping our community together online.

Jonathan Lerman and Elijah Wapner on MTV

Please check out Living With Autism: The Teenage View on MTV tonight at Sunday night at 9 Eastern.
Rebuilding the Autism Foundation

Many readers of my blog will understand that I am committed to finding acceptance for autistic people and a deeper understanding of autism that achieves education and accommodations for children and opportunities for autistic adults. I hope that we can build the bridges that support autistic people everywhere.

While I strongly believe we should celebrate autism in many ways, it is also necessary to discuss why something is inherently wrong. There is such a thing as right and wrong here, and we have to uncover it. By attempting to make something like a treatment “savory” or workable because it seems okay in some ways, may not necessarily make it ethical. Margaret Somerville, ethics and law professor at McGill University and author of *The Ethical Imagination*, acknowledges a type of situational ethics, where she notes that epigenics – the study of the interaction between genes and the environment, may modify each other. So while it is becoming difficult with that in mind to “draw the line,” she says, “what is or is not natural is not simply the matter of an end result, but involves how that end result came about – in particular, whether there was human intervention that gave rise to it, and whether the intent of that intervention was to achieve
In sum - with the negative marketing of autism as a fate worse than cancer, even though autism is a disability not an illness, discussing our children in pejorative terms in public, or for the purposes of obtaining public funding, and with interventions to render the child “indistinguishable” from others – does the end justify the means? Even if one has the best intentions to “accept autism,” as is now the becoming the case in the rhetoric of autism organizations, does the means of “correcting,” “curing” or “remediating” autistics, ethical? Perhaps we need to use Somerville’s ethical analysis as our guide in autism; that by determining our intent in autism, we come to a conclusion of how to regard and treat autistic individuals in science and in society.

In many instances, I like to illustrate the many manifestations of autistic discrimination – from treatment, attitude and access, to marketing by some autism charities. If we don’t begin to understand the many facets of discrimination, we can’t do anything about it. We cannot improve upon the education our children deserve. A commitment to celebrate difference, to call autistic people a joy, is a peaceful means to express how much our autistic members of society, our children, mean to us. In the midst of adversity, we continue to “sing,” as it were. Elie Wiesel, Nobel Laureate, Holocaust survivor, author, human rights activist, and recently knighted, alluded to “singing” and being “joyful” in the midst of adversity in order to maintain one’s sense of self, and community. In short, we celebrate life, all life, because it is so very fragile. He said in a speech in Toronto, “we Jews... we dance.” That has a lot of meaning in the Jewish community which is constantly surrounded by intolerance.

The purpose of calling this blog *The Joy of Autism* is the same. It is a means to uphold and protect the human spirit, namely, the spirit of autistic individuals as valuable members of society. If, as Hubert Humphrey said, that the measure of a society is how it treats its most vulnerable citizens, can we honestly say that we treat our disabled members with the same honour and dignity we would ourselves? Many find inherent problems in Humphrey’s statement, as it suggests that the handicapped live in the “shadows of life,” but there is some wisdom in the statement itself, aside from the man’s beliefs or convictions. How might we extend our understanding of acting morally and ethically in light of the autistic and other disabled communities who are involved in self-advocacy?
A couple of years ago, my husband and I built a new house. I took over the project until Adam was diagnosed with autism between eighteen and nineteen months of age. By February 2004, while we started “treatments” for autism because that’s what we were told to do when we were first introduced to this community. At the same time, I visited the building site. I noticed honeycombs in the walls and cracks in the foundation everywhere. The air was freezing – an inhospitable environment to building in the first place. At the time I thought this was a bitter irony, like my life, and now my house, were both “falling apart.” I was concerned about the foundation despite my builder assuring me that everything would be okay, so I hired a inspector. Sure enough, the foundation was irreparable and had to be torn down, so I’m glad I trusted what I could SEE rather than what I was TOLD by a building “expert.” We had to start building all over again. In retrospect, it wasn’t so bad, even though it seemed like a catastrophe at the time. It set us back a mere six months. We replaced our builder, and now we have a stable home. I was really glad I caught the problems so we could build properly and live in a structure that isn’t wrought with problems that require constant fixing. That would be upsetting, exhausting, and costly.

The reason why I have to talk about ABA and certain remediations or “treatments,” is because they are built on a premise that we have come to recognize as discriminatory. Perhaps we did not recognize it at the time, when we weren’t as publicly aware of autism, but the issues have persisted for a long time in the area of all disabilities – this idea of “treating” as opposed to “accommodating.” Since we have become very aware of autism since the early 1990’s, we have come to learn that autism was built upon a foundation of wabbly assumptions and we have erected the walls and supports that were based on them. Now that the “house” is nearly complete, while in the meantime we have come to learn about autistic dignity, intelligence and Personhood. We can now discuss the ethics of “treating” people and how that reflects in the way we regard autism and autistic individuals. Autism “rights” is built upon another strong disability rights movement gaining momentum in universities around the world: disability studies departments are viewing disability and autism from various cultural and ethical frameworks. Based on what we continue to learn from autistic self-advocates and other disabled individuals who speak out against the behavioural and medical “treatments”
Some insist on building upon these existing shaky foundations. We want to decorate nicely and put in the windows and an expensive roof, despite the fact that we have crooked walls. We keep hearing about some new “trend” in autism treatment, some new operationalized method. As such, we keep failing – there is a falling wall here, a leaky ceiling there. In order to stop the patchwork at the cost of continually having to repair, we have to consider the foundations that we've built our assumptions about autism, and the ways we have come to “treat” it. We may have to consider tearing down the house and rebuilding. It may seem exhausting, but it’s necessary. Is this merely another painstaking step in our evolution of understanding disability? Is it an evolutionary progression to viewing and assisting the disAbled, and autism as part of the larger disability community, with their assistance?

Re-reading many of the early books on autism, I am able to recognize bias in science and the diagnostic manual itself. This might be considered the primary basis for the manifestation of discrimination in autism – a foundation where individuals with a certain difference were then generalized and classified in terms of deficits by Hans Asperger and Leo Kanner in 1943.

Ralph Savarese, author of *Reasonable People: A Memoir of Autism and Adoption* captures the problem in the introduction to his book. He notes that "in the 1970’s Beate Hermeline and Neil O’Connor, both cognitive psychologists, focused on the mental structure of autism in a systematic way. Along with Lorna Wing, they note the “core problem” being the triad of “impairments”: the impairment of social interaction, impairment of verbal and non verbal communication, and impairment of play and imaginative activities." (Savarese)

Savarese, in the following paragraph, proceeds with introducing the American Psychiatric Association’s current definition of autism in the DSM IV, which follows and expands on the lists of “impairments.” He says, “it isn’t difficult to see how this definition derives from the portrait that Wing and others have sketched – over and over, I might add, as if themselves autistic. In short, the reigning view posts a devastating global disorder that robs people with autism of their very humanity. Moreover, it offers little hope of treatment but for modest behaviour modification.
No wonder parents of autistic children panic when receiving a diagnosis.” (Savarese)

No wonder. Yet it need not be so. It is possible to view autism more fairly, taking the view from autistic and other disabled individuals into account. It is possible to value disabled individuals and protect their right to accommodations, and to protect their dignity.

**An Autism Apartheid**

What makes autism “advocacy” so problematic is that we have inversions of truth. These inversions are pernicious as they stake claim for “equal rights” for autistics in these “treatments’ based on impairments and deviance from the “norm.” We have organizations that “fight for autism” but under further investigation and in the context of the larger autism community – in other words, autistic individuals and parents who represent their children’s right to be autistic– we can see that “equal rights” for one group does not automatically equal an ethical response to the treatment of autistic individuals they are “advocating” for. President Ahmadinejad of Iran is calling for the destruction of Israel under the same rhetorical premise. Does this make Iran ethical or right? We witness such inversions of truth or of rhetoric all the time for nefarious causes.

When one specific treatment is promoted for autism, which continues to segregate and identify children in terms of their deficits, when we do this to the non autistic population, we are witnessing an apartheid. In fact, we are witnessing it more in autism today than many other disabilities. When it is suggested that special needs children be screened before being allowed into schools because they are viewed as potentially dangerous, as stated in *The Boston Globe last month in the article: A Clash of Rights in Education*, we are witnessing an apartheid. No other society which represents its “people” advocate for the fundamental change to personhood or autistic-hood. Conversely, the *Downs Syndrome Society of Canada celebrates and promotes the dignity of the Downs community.* They advocate for their rights, in employment and acceptance of them in society overall. Sadly, despite such advocacy, we have a ways to go as over 80% of Downs Syndrome fetus’ are aborted in Canada. It reflects that society still understands very little about living with disability. The
People with the difference are often born to families without the difference. This can be seen in deaf children born to hearing parents and the complications that arise. View *The Sound and The Fury* for an example of the virulent debates in this community. It should be stated, however, that with current research in genetics, the familial link to autism is strong. I have autistic members in my own family, although we didn’t know what autism was at the time. Further checking into family members can help in developing a greater empathy towards the newly diagnosed child. Many Aspergers/Autistic parents are especially understanding and supportive of their autistic children, and much more able to understand behaviours and needs. Such observations have lead me to believe that we need many more autistic individuals who are willing, to teach other autistic children in integrative settings.

Many organizations and individuals have recognized the fundamental problems of referring to a people as a deviance from the “norm” as opposed to assisting individuals in society who have a fundamental difference. Such referencing is akin to political apartheid because it begins to single out a group of people and apply a different set of standards to them. Here, the difference between accommodations versus subjecting autistics to treatments is an example of a prejudiced standard, as Professor Emeritus Bernard Lewis of Princeton University noted in the PBS documentary “*Anti Semitism in the 21st Century.*” He was referring to how prejudice is “tolerated.” I argue that prejudice towards our disabled communities is tolerated because we still do not value and understand disability as much as we could. At most levels of government, advocacy, reference groups, and autism societies around the world, this kind of singling out and segregation is rampant. ABA politics has “hijacked the autism agenda,” as stated in an Autism Society of Ontario paper written by Doug Reynolds -- no other voice or opinion contrary to them is allowed to be heard. But is this an ethical way to discuss the issues surrounding autism treatment and autistic people – without opening the table to a diverse group of autistics and other individuals like myself involved in autism? Is there a way to repair the damage to autistic individuals in addition to assisting the parents who currently “struggle” with their very own autistic children because they continue to walk under the umbrella of such
Autism advocacy groups for ABA specifically have unanimously decided that autistics do not have a place at the table of autism advocacy, because it doesn’t further their cause for funding supports. They want ABA to be funded an nothing else. Autistic individuals have indeed complicated the process for obtaining funding for ABA services, but for good reason as it has ethical problems and further does not provide the accommodations necessary for a diverse population of autistic individuals. There are parents like myself who want a better world for our children, want them to be able to go to school with a family-appointed aide if required, receive funding for assistive devices and human support, vocational training, and more. Yet we do not have a place at the autism table because it is not aligned with this one type of approach. When autistic individuals are specifically targeted as “not even aware,” or conversely “not autistic” because they can use a keyboard, or can talk, they are excluded from the autism dialogue. There needs to be funding and provisions for autistic individuals and families based on a foundation of value for autistic persons, a preservation of their dignity, and their inclusion. There are Occupational Therapy and Speech Language services that do more for the dignity of autistic individuals than many other operationalized “treatments” and “strategies” out there. There are assistive devices used all the time, and they are the communication bridge that is so needed by this community. All parents use them, but we hear very little about any government support for such services for autism, and little provision for adaptive and assistive technologies in the schools for all disAbled individuals.

The Operationalization of Autism “Treatment”

Any “blanket” or operationalized method has two faults: First, because it presumes that that autistics “don’t” have this skill that must be manifested "typically" which determines the success outcome of the method. For instance, rather than looking how an autistic individual acquires the skill naturally, it suggested that we need to “intervene” in the natural learning process of autistics and impose our method, or what is called a “typical” way of acquiring and manifesting this “joint attention.” Secondly, I am wary of operationalized methods because the autistic population is so diverse that one size does not fit all in autism education. The label
of autism has stripped individuals of their uniqueness on the one hand, yet made society much more aware of autism on the other, for better or worse.

When I refer to teaching with Adam, I have come to refer to it like a bridge: I consider Adam can be on one side, I on the other, and we most often meet in the middle. I have learned to come over to his side as society demands so much that he and others like him, join the them on their side.

Such bridges are seen in the way Helen Keller learned about water – the confluence of learning a new language, which was taught to her, against her experience of water at the well. The culmination of learning the language and then having the experience resulted in a light-bulb moment, where she learned to communicate with Ann Sullivan, her teacher. She developed a bridge to come to our side. As a side note, it is interesting to me that the ABA community has staked its claim to Helen Keller’s learning as behaviourism. In fact, the community does this in all aspects of teaching, thus calling into question the entire basis of ABA as a valid method of teaching rather than just calling it teaching. Reversely, might we just take the good aspects of teaching in general and learn to understand autism in order to build bridges rather than transform people. In another example, there was an exhibition titled "Seeing in the Dark." People with sight enter a dark room with all kinds of sounds and sensations. Other blind people are in the room to escort the sighted people through the exhibit. At the end, they come out together and the sighted people begin to engage in a conversation with the blind people. A report I heard is that the exhibit is "life-changing," and indeed it is a fine example of crossing over to the other side.

Stephen Hawking writes about the importance of assistive technologies that enable him to communicate in a way that he can. Providing bridges, rather than remediation, is a large part of this compromise – respecting autism and autistic learning and recognizing a need to communicate with others who are not autistic. We need both education and the bridges to communication. Dr. Morton Ann Gernsbacher’s paper “Towards a Behaviour of Reciprocity” in my view, is one of the most important papers in recognizing the need to learn the autistic language as a valid one. Neither type of “language” is superior of the other here. Is learning the autistic language difficult in a world that largely
doesn’t “speak” it? Most definitely. Yet, it is no less important and we might consider just being open to the possibilities of listening. By doing so, we can assist the difficulties of autism in addition to accommodating the implicit abilities.

Adam learned joint attention by having fun. Lots of swinging in the blanket (I bet many of you succeeded with this), and OT made a lot of difference for its movement made Adam very happy and willing to engage. OT seems playful and less invasive than many other therapies. It is respectful to the child’s needs. For many reasons, I am very much in favour of Occupational Therapy and Play therapies with therapists who respect autism. The therapist has to work hard to find the preferences of the child, the games they enjoy and builds from that framework. I will admit that I started Adam’s therapy from this basis of thinking that he had to respond in a typical way. I often wonder about the foundation I built for him back then. Since that time, I have been working painstakingly on rebuilding the foundations that others insisted were stable.

**The dangerous premise**

In contrast, ABA builds from a framework of making the child “normal.” This is why I have strong feelings about it. It is not that I am against ABA parents per se, and their desire to obtain financial aid. I have no wish to become part of the political debate which seeks to insist that one method is superior over the other. I am against, however, any treatment that is built on a damaging premise. Today, since the court cases which has brought ABA into the public foray, its advocates continue to shape-shift. It claims every successful teaching method as its own. It turns claims from “medically necessary treatment” in autism into “necessary educational tool.” I warn readers, that the nature of it is still the same, and the quality of ABA therapists in Canada, with very limited knowledge of autism, is extremely poor. ABA may be shape-shifting to become more acceptable in the public eye and to parents at large, but as long as autistic individuals are held up to the impossible comparison of “becoming normal,” it is unachievable and as such, we must continously question the ethics of it as the only educational option. Margaret Somerville, whom I quoted earlier states:

“In general, when we are in doubt about whether an intervention
or its outcome falls within the definition of the natural, we should apply a precautionary principle: we should assume that they do not do so until the contrary is shown, and therefore undertaking that intervention and its outcome must be justified....in the past when our powers to change the natural were extremely limited, we allowed intervention until it was shown to be harmful. I believe that the new powers science and technology have given us make this no longer acceptable...I argue that we should have a presumption in favour of respecting the natural, which means that unless we can show that we are justified in intervening or altering it, we should refrain from doing so... The burden of proof of justification lies with the person claiming that there should be an exception. Consequently, in situations of equal doubt, the position of the person who is favoured by the basic presumption prevails. This difference in burden of proof can be extremely important in determining what we may do, and what we must no do if serious, or possibly serious but unknown or unknowable, risk is present.”  

(p107)

Why, with such a recognition, would you keep up a therapy that is intrinsically painful and potentially demoralizing to the child? We know from autistic individuals that the “look at me” program and means to obtain “joint attention” can be downright painful. Autistic children continuously refer to themselves as “bad” children and “freaks,” suggesting that the good children are those who are not autistic. As parents who want to protect the self-worth of our children, and want them to be as independent as possible, or to fulfill their dreams with the assistance and support they may need, should we be looking towards building a new foundation together? Might we consider moving beyond looking for the “cure” the one remedy and begin again by looking at the complexity of not only autism, but of how we value human beings? Can we work to protect the dignity and spirit of our amazing autistic children?

By creating acceptance and diversity as the “enemy” to autism, as if all that exists here are a bunch of granola eating hacks, or “dilettantes” they are creating a divide that is damaging to the future of autistic individuals. In sum, the end does not justify the means.

**Steps to Rebuilding**

It mightgo without saying that we need to build a new house.
Maybe the entire floorplan needs to be changed. Can we save one room? Perhaps one beam from the old framework? Or perhaps just a nail? Or has the entire ABA community claimed some plain old teaching methods as their own to be “acceptable?” Dump the terminology. That would be one step out of the boxes that entrench us as being invested in a "method."

We can’t rebuild unless we acknowledge that the achievement of normalcy isn’t the goal. The achievement of a fulfilled autistic person is. The creation of safe and nurturing environments. Perhaps that may mean that one autistic individual will need supports throughout their lifetime, but can otherwise achieve other pursuits with those supports. It often means that some autistics may not be toilet trained. Do we withhold entry into schools, these children who are often so intelligent, because of something so minor? Does it matter if your child can use a stove, or make a sandwich and use a microwave, if they can later write books or pursue poetry? What does it mean to be a fulfilled individual? Why is it so contingent on being independent? Afterall, we live in a society that is so interdependent.

My concern is finding the assistive technologies that help Adam to communicate now and dealing with anxiety. I recognize his intelligence and observe his innate way of learning. I try very hard to provide him with tools. I want teaching to be a creative, fluid process, because no one has the answers here, the way ABA advocates suggest it has. I want parents to have a choice in the way they can teach their kids. I want them to have a choice in the way they are taught in the schools.

ABA methodology suggests that without certain fundamental skills that need to be learned first, a child cannot move on. It sequences learning in a way that fits a “typical” developmental process, which we know is not typical in autism. Rather, my son might recognize and read words beyond his grade level. He knows how to count by 5’s and 10’s on his own. Because he does not yet communicate with me in a way I can completely understand, I cannot presume to know his learning process and thereby, cannot assume that he needs this sequenced teaching because I need him to respond typically. I appreciate all kinds of ways of teaching Adam to find the way that he responds to. Yet I am horrified at the notion that he may be subject to a government driven program that states autistic people only learn through one method. I am horrified.
because we have been subjugated to four years of people and the 
behaviourists never understand Adam fully. They apply strategies 
and talk about them in front of him and I know he understands 
what they say about him. They treat him like he’s not even there. 
I have also met good therapists who come from this background, 
as I’ve stated many times in this blog. But please, open up the 
funding to support autistic people and families – consider the 
accommodation required with assistive devices, human support, 
inclusion in schools, lectures to understand autism. Consider the 
choice that parents want in supporting their children with 
Occupational Therapy, Speech Therapy, keyboarding skills and 
other augmentative communication, and more. Consider that I 
want autistic adults in the schools also a part of teaching my son 
because in order to understand how to educate autism, we need to 
figure out who, among the autistic adult community, is willing to 
pitch in here.

The Autism Acceptance Project is bringing such projects, support 
groups for parents lead by autistic individuals, lectures and more. 
We are here to support people, to talk, and to learn. We have 
people who use ABA, and people who do not. While we do not 
support its premise and demand more quality and understanding 
from educators and therapists, we have no wish to exclude anyone 
from creating a better world for our autistic children. I consider 
that my son Adam is worth the toil. He is worth my researching, 
learning, traveling, meeting other autistic adults, and continual 
learning about autism. He is worth making our mistakes, as long as 
we learn from them and move on.

Above all, I want to respect my son for who he is and how he 
learns. It can be difficult and frustrating at times. Yet, I consider 
myself his guide, his mirror upon which he will self-reflect and 
derive a part of his identity. I want to support him in every way 
possible so he can be as self supporting and productive as possible. 
At the end of the day, parenting an autistic child is not much 
different than parenting any other child, except that our kids are 
truly, wonderfully exceptional.
Some days, like everyone, I get frustrated. I must admit I have a little more on my plate these days – my mother’s recent surgery and now more bad news. Facing a parent’s mortality is just sad. I don’t want to go into details here to honour her privacy. Everyone in my family is away, except my mom, Adam and I.

Adam is frustrated. The winter is now too long. The ice on the streets too prohibitive. We await the melting streams of spring.

I used to be a singer. I tried to be a dancer when I was a younger woman. I forget how liberating that can feel. I decided to blast out the music in my kitchen, my dog, my son both needing me, but not really. It was more of a wanting than a needing. Maybe it’s just this mom who feels every call like I interpret the telephone ringing too often – like panic alarms. As I danced and sang like a lunatic in my kitchen, Adam came down stairs with a great big smile on his face. Kiki, the dog, watched with her head cocked to the side. Adam jumped into my arms, and we danced together, melting away our tension. We laughed. He ate breakfast. Life back to normal, but with a lighter heart.

The autism community is filled with so much hurt right now. There are important dialogues happening, but sometimes this can add to the weight of caring for your autistic child. So dance, sing and smile. Celebrate with your child and let it all fall away. Adam loves it.

Song of the morning: "My Heart Will Go On" -- one of Adam's favourites:

MY HEART WILL GO ON

Once more, you opened the door,
And you're here in my heart,
And my heart will go on and on.
You're here, there's nothing I fear,
And I know that my heart will go on.
We'll stay, forever this way,
You are safe in my heart
And my heart will go on and on.

Teaching Versus Remediating

I'm about to give two examples I've observed which illustrates the seemingly minor, but hugely important differences in treating children with autism. Often when I say I don’t do ABA in my home, people think that the alternative is doing “nothing,” – as Brenda Deskin loved to misrepresent me on CFRB, “it’s okay that she let’s her son stay up until 2 in the morning.” Well, this is just silly. After speaking with some parents who did visit Dr. Lovaas with their children in California, I am actually astounded at how much they let their kids, now teenagers, get away with. Maybe that therapy is just too hard to keep up at home -- so exhausting to try to get a leopard to change its spots.

Parenting is parenting. We establish rules and boundaries for all our children, it is no different for autistic kids. The difference is in how we treat our children – to respect their will because they are trying so hard to communicate (or have us understand their communication). Adam may be hankering for a video for instance, but that does not mean he will still get it, if we need to do something else.

Let me illustrate the difference I’ve observed:

Adam is crying. He hasn’t slept. I run up the stairs to see what has
“No, no, Adam. Stop crying and then you can watch the video,” says his new therapist waving the video box, who comes from a behaviourist background and is brand new to our home.

Adam cries harder, his eyes are fixed on that video box. I watch for a bit and intervene.

“Adam, we know you want the video,” I say. Adam stops crying immediately. “Let’s just calm down a bit and then you can watch it.” Adam calms down for a moment, a little residual upset bubbles. “It’s okay. We know you want the video.” He calms down immediately again. The video goes on. Now the therapist didn’t want to "reinforce" his crying, and certainly for any child who acts like a brat, I would say yeah to that. But, Adam was tired and hadn’t slept all night so there was a reason for his tears. For a child who can’t use words to talk, he sure is communicating. And he was really tired. Any four year old would make a fuss when they’re tired, and Adam makes much less than most I’ve seen. Adam, who can’t talk should be dealt a little more respect because it is so much harder to communicate. I’m not so sure if the goal of not having him cry was useful here, as Adam may not trust this therapist for not having understood his exhaustion. But this is a learning curve for many therapists, so I am patient. [By the way, Adam loves this new teacher and this teacher watched the taped program of Amanda Baggs with me and left a certain centre because of DTT methods. The teacher is listening to my comments and is very receptive. This sort of dialogue and working together -- including my receptivity to others’ suggestions is one of the things that makes a good teaching situation for Adam -- because it questions everything. I’ve also maintained a relationship with another teacher who comes to my home for three years who came from an ABA background and we’ve been continually learning together and she is a gem. Also, after I initially wrote this post, Adam saw this teacher and was ecstatic to see him, so there was certainly no harm done.]

It is the ability to self-reflect as a teacher that is vitally important here too. As long as autistic children are viewed like belligerent "brats" when all they are trying to do is communicate, as exemplified in this instance, they will be subject to this kind of discrimination. Certainly, if Adam continues to act up and think he
I'm not saying that I know much about parenting, but I do know something about parenting my son, Adam. I am suggesting that we can all do our part to really observe behaviours and ask ourselves whose purpose we are serving when we are making certain demands. These may seem like minor adjustments, but they are major to the child. They are major in stating “I understand what you want, or that you’re upset.” It is major because it is the difference between accommodation and correction or remediation.

I have another example. I took issue with a behaviourist who came to the park with me where Adam enjoys picking up the sand and letting it run through his hands. Instead of saying no or making a fuss (it’s a behaviour that no non autistic person can understand, but uses a subjective judgment to determine that it is aberrant), I just say to Adam “let’s go on the slide.” It’s not that I care about the behaviour per se, but I am there also to play with him, so we do a bit of everything – sand play, slides, climbing, see saw and so forth. I simply invite Adam to join me, and he usually does. I always let him enjoy his sand, though.

The behaviourist came with us once, grabbed Adam’s hands and stopped his “stimming” in front of everyone. In fact, she grabbed his hands aggressively to stop him and moved him on by pushing him. She wanted to do it over and over again, and it seemed like Adam also wanted his sand more than usual when she did it. Instead of arguing with her there, I said “let’s go home,” to end this “session” as soon as possible. Afterwards I told her that that I was uncomfortable with what she had done and I could see that we weren’t seeing eye to eye so we agree to disagree. (She doesn’t teach Adam anymore, but she certainly "cares" in her ABA way, a way that doesn’t match my idea of caring. So the lines get really fuzzy.)

Yet, here is a child who has such a hard time being viewed as a whole human being, and this person wanted to “correct” him in public, thereby stigmatizing him more in front of people we knew. It’s like trying to beat the Adam out of Adam, or as some refer to as remediating his autism as if it is separate from him. I guess I
should ask if you can beat the blindness out of the blind? Even the idea that autism is separate from the child's being and experience, is to suggest that autistics should not be taught the way other children are taught. It doesn't respect the disability and does not ask us to question ourselves or make a better effort to learning about autism and how we can best teach our autistic children or accommodate their learning style.

Further, all one has to do is to look at Michael Moon's photographs to see what the rest of us cannot – for playing with dripping objects, sand, water, is an enthralling activity, visually. Michael's artwork gives us a glimpse into that outstanding world. And who knows what other learning is going on that is atypical, but certainly not less valuable or even fantastic.

It is a fact of life that the therapists out there in autism all come from this behaviourist background. It was the confluence of increased autism diagnosis around 1992 and Dr. Lovaas. The good teachers, however, keep an open mind about autism and evolve their teaching to what we continually learn about autism and about autistic people and how they want to be viewed and treated. The bad ones will always try to correct instead of teach, which calls into question this whole notion of ABA as an "educational tool." Many of the ABA people are simply doing play therapy embedded with teaching skills. So what we have here is a lot of confusion. Let's go back to the drawing board to integrate many of our skills, and question the goals of our teaching.
autistics not viewing themselves as a "puzzle," as represented in so many charitable campaigns today.

Last night, Adam didn't sleep until 5 a.m. Once in a while we have the episodes. They seem to coincide with too much stimulation in the evenings, or if we forget and let him run and jump around. He sure is a happy little guy, so it wasn’t a distressing evening. He simply didn't want to go to sleep. Believe me, we've had many of those nights in the past. About three years solid from the time he was born. I have to admit, I got to a point where I was so sleep deprived, I was in tears some days. Luckily, we moved beyond it and sleep soundly most nights, so this is now an exception.

While I was awake, I was thinking about Brian, Martine and Michael, our autistic board members (and we want to expand our autistic membership), and other members of the TAAProject advisory. Recently, we had a visioning meeting. It was wonderfully stimulating, as we discussed all the issues about autism these days. We have a forum where we can do that at TAAProject with the one goal to keep it positive and guided by our autistic members. Us "non autistics" have a lot of opinions about autism. Our board has clinicians on it, a lawyer who for us, represents "public perception" about autism, some parents and of course, autistic people. What I notice is that the autistic members are quiet. They let us non autistic people go on and they don't aggressively edge into the conversation -- largely because they can't and often because they won't. I often had to stop the conversation in order that they could "have the floor." Afterall, this is who we are doing it for, so we put the weight of our decisions there. It made me think how safe environments for autistic individuals to participate is steamrolled over by most of us. It made me consider when I began moderating comments on this blog when an autistic person from the US called us at TAAProject and said "thank you, I didn't feel safe to comment before."

Michael, Brian and Martine can come to meetings. Some autistic people cannot. Last year, when I considered putting on a panel discussion to debate the ethical issues with Wendy Roberts (a genetics researcher), heads of charities here in Canada, and other autistic people, the overwhelming consensus was that it would be difficult to process in that type of setting for the autistic members of the panel.
All of this has made me consider what it is we have to do at TAAProject to make it work so that autistic people CAN participate -- how do we provide access? How do we enable "panel discussions" to work be it through live feed, be it providing questions and have people write answers in advance of presentations? Afterall, Dr. Roberts and the like get the floor often enough, and autistic people do not. How do we make autistic people who currently feel unsafe, safe to discuss the important issues that face them every day? How do we honour certain sensitivities for individuals who want to participate, with light, noise and unrelenting stares? How do we use technology and forums to further allow autistics to participapte world wide?

These are the considerations that will hopefully turn to action on our part. Asking autistic people what they need and observing how one can sucessfully accomodate, is the first step to inclusion.

"You learn to read by reading.
You learn to write by writing.
You learn to include by including" -- Paula Kluth

Animal In Translation

Our dog’s name is vagina. Oh my yes it’s true. We found out out a couple of months ago while eating my in-laws place in Florida. They have a fellow who helps them out from the Philippines. He broke the whole roasted chicken with his hands before he cut it into pieces, his hands glistening with fat. My brother-in-law asked what we were going to name our new puppy.

“Kiki,” said Henry.

Holding his wet fingers in front of him so as not to get anything marked with the fat, Berardo, the man from the Philippines, could barely contain himself, not wanting to interrupt the family conversation.

My brother-in-law noticed.“What’s so funny,” he asked.
Berardo hesitated in between his giggles, not sure if he should say what was on his mind. We began to laugh with him, ignorant, but curious as to what was so funny.

“In my language, Kiki means vagina,” he giggled shyly.

Well that was plenty of fodder for my two brothers-in-law -- this perilous world of language, translations and meaning. It makes me wish I'd research the name a little more, 'cause now it is forever on my mind. But it doesn't change her -- the fact that she is still an innocent, beautiful dog.

“It would be like if you came to my country and called your dog, pussy,” Berardo elaborated.

Ah well. It's still a cute name for a dog. But it gives a whole new meaning now when I say “Kiki come!”

Joy from John

The other evening, I managed to watch a few minutes of TV. I love the show The Actor's Studio when I can watch it. John Travolta was on the other night and this is what he has to say about joy and sorrow taken from a written interview following the show:

"In 1992, on a trip to Maine with Preston and their infant son, Travolta had an inspiration. He wanted to write a story about a bright, sensitive young boy who loved airplanes and all the romance and dreams they symbolized. Through that little boy, Travolta wanted to express his own feelings about life and to share those feelings with the people he"
loved. The result was Propeller One-Way Night Coach, a delightful fable that was published in 1997 by Warner Books. The story, with drawings by Travolta, runs only 42 pages, but Travolta says it contains the essence of his philosophy of life:

**Always focus on the positive.** [bold mine] *Never give in to negativity and darkness. Count your blessings, not your laments.* [bold mine] Stay as warm and open and receptive as a child. Dare to go your own way, dare to be free. And in good times or bad, never be afraid to lead with your heart.

"In the little book, the kid really does that," says Travolta. "**He looks sorrow right in the eye.** [bold mine] He sees the front-page story of an airline crash and thinks, 'That must be awful. But I can't think about that now.' He doesn't ignore that, he acknowledges it, realizes it's awful, but in order to survive, **he moves on to something that's going to get him through.** [bold mine] I think I've done that my whole life. I've tried to make my life an ascent, as opposed to a descent. [bold mine] The character in the book is real, but he always looks on the bright side of life. [bold mine] He looks at the glass as half full.

"If we can't think of life as something potentially joyful, life isn't worth living.** [bold mine] That's why when actors speak of wallowing in the darkness, I think there is enough darkness, there's enough tragedy. [bold mine] If you look around you, there's a war in Bosnia. There are people being murdered. There are enough crashes. There's man's inhumanity to man. There's abuses. It's all there, very evident. It's much more difficult to look at the brighter side of it. [bold mine] I would almost like to see people challenge young artists to look on the brighter side, rather than indulge in the evident. Because right there you've got all the darkness and sadness you'd ever want. At a moment's glance. **So the real challenge in life is to look for ways to handle the upset--and to always look forward towards something to live for."* [bold mine]

Listening to this over and over again from philosophers, thinkers, and now from John gives a whole new meaning to the term applied to autistics like Adam -- when he jumps and flaps his hands -- "happy dance." (If you've never tried it, you should. It is quite
Acceptance, Appropriateness and The Whole Damn Thing

When I did that Podcast interview, I just found out that my mother had to go in for urgent surgery. She is recovering at home now and things look okay. I also work on a committee for the Jewish Board of Education here in Toronto (remember I am a convert, having gone through the public and the Catholic systems). This committee has a university course at York University to train willing teachers to work with all kinds of special needs children. We are also working to get more inclusion happening within the day school system here. When I said on Podcast that “at the end of the day, we do a lot of things for Adam,” we do. We, like many parents, have tried a few things at the beginning and continue to look at how we teach in addition to what we teach based on Adam’s needs: what issues are arising for him, what he is learning or needing to learn at school. I have never found a great “method” for Adam – a “one true thing.” I have found that for Adam, knowledge of as much as possible allows one to extract the best of the many approaches to autism out there. Adam is my guide. I have to work very hard (and I mean VERY hard), to find the right accommodations for him. Sometimes, I feel like a failure – that I am only human, have only so much time, and he needs me to work faster to find those accommodations. Other times, I know that as I plug away each day and study and learn more from autistic people,
As Adam approaches five, I feel we are at the edge of what we thought was going to be the end of “autism treatment.” When he was diagnosed early at eighteen months, other parents of autistic kids seemed envious, as if Adam had a higher chance of “recovering” from autism because of “early intervention.” Adam is hyperlexic. At nearly five, Adam cannot converse, although he can whiz through a computer learning program and has superior reading skills. So this is our scenario, in a very little nutshell. As Adam grows, his anxiety (the same anxiety he had on the day of his birth when he came into the world and did not sleep for thirty-six hours), still exists. But it is not all Adam. He is affable, extremely affectionate, charming, humorous, curious, active, and wants to be social even though this can be very tough to execute.

Our issues come from the anxiety and from other children who now can see that Adam is very different from them and who don’t know HOW to interact with him, because this too needs to be taught to "typical" children. Last night, we went to our dear friends for Friday night dinner. They also have five children (I have four step-children and one of my own). Their children are all still young and live at home. The youngest, a girl, is Adam’s age. She is gregarious and LOUD. At least loud for a sensitive mom with an autistic son who feels his pain. I did not prepare Adam. He had a long day and when he entered everyone said “hi Adam,” with patience, but still overwhelming him. They love him. They have no intention to hurt him -- they were just being friendly in the "typical" way -- with "typical" language, which Amanda made note is invasive for an autistic person. Then, their HUGE dog approached, frightening Adam a little more. Adam cried and wouldn’t let go of me. I tried to console him. He began to say “go!” and “away!” I took him upstairs to find an ABC book in a quiet room, but he still would not let go of me. He kept saying “away!” and I think he even said a sentence “I want to go!” The little girl came in the room, and because she is little and acts the way she should, still makes enough noise to frighten Adam. Henry came in, took him to the TV and Adam settled a bit. He made these throaty, quiet wails as he tried to settle himself.

As a parent who just arrived as a guest to our friend’s house, there are a few feelings I had. The first, because this doesn’t happen very often, but is certainly beginning to, I felt frustrated because this is the best anyone can do.
everyone feels bad for Adam. They jump through hoops trying to be quiet so that he can settle down. I also feel bad for Adam, as he is clearly communicating with me that this is just too much for him -- he is saying with words “go,” and “away.” He is trying to get me to help him, while I try and persuade him to stay with potato chips and ABC books, none of which worked. So caught in between to worlds, I feel so terrible. Luckily, with television, Adam calmed down. When it approached eight-thirty, and he had to go to the bathroom but didn’t want to go in their bathroom (we have developed a little fright of bathrooms out of our house -- not autistic per se, but just a part of being a kid who has to get used to it). Henry had to take him home just down the street. When he got into his familiar surroundings, he was as happy as a "clam." (Are clams really happy?)

Perhaps it is this part of the autism disability that parents find difficult – having to do things because they are part of your lifestyle, and the other, because they are obligations. I didn’t make Adam sit at the dinner table, even though I wish he could sit beside me because I love him and want him there. I wanted him to feel good about being there – sometimes this needs a little more time. Why push him when he found his comfort zone for a couple of hours? I also know that with Adam, everything takes a little more time, a slightly different path. While our journey may be zigzagged, I can also say that Adam achieves more than I imagine some days – like tolerating a loud echoic gym to play Sportball on Saturdays. The instructor came to me and told me how proud of Adam he was – because in the beginning, Adam would cry as the noise was way too loud. Now, he has no problems with it and is so happy at Sportball. So, this is about hanging in. This is about developing a tougher skin as a parent when others do stare. But it is also about accepting the zigzag journey and discovering things you would have never otherwise discovered along the way.

Adam is a busy and pretty social guy especially in settings that he knows. He goes to OT, has SLP, and does some 1:1 therapy here at home, derived from play therapy. We teach skills within a text-rich environment with instructors even though he is able do many of those skills so beautifully on the computer. I want him to try and learn how to answer a question, as much as I want to learn how to understand Adam. As Amanda Baggs put it, I think speaking bilingually is a necessary skill for autistics, even if it is the unfortunate result of non-acceptance of others, or a
misunderstanding of what autism is by society. My expectations of Adam's ability here, are I hope, still adaptive to Adam's style.

He goes to school now and I’m sending him to a school next year for SK with all kinds of kids with a shadow -- it isn’t a special needs school in particular and it took a bit of coercion to get him in. This summer, I’m looking further into FC and technology and will try to learn to scaffold Adam’s communication on the computer, as he may need a lapboard. I think, once he learns to read and write, he may become independent on the computer. I am trying to watch his skill-set and find ways of accommodating it.

All of this learning should be called **autism learning** for anyone who wishes to teach autistic people. It should be learning with autistic people, not learning how to teach in rooms without them. Learning how to teach in autism is dangerous when we use a medical model as a basis for teaching versus having to try harder to understand autism with autistic people, and marrying that with our skill set as teachers to what is already available -- a kind of filtering as it were. This kind of periphery knowledge of autism, or a "pathological" understanding of autism as a deviance from the norm doesn't help. Teaching is not about making someone they are not. Teaching is about helping someone and hopefully lessening their anxiety. It is about recognizing differences and challenges that must be dealt with while finding the abilities to work with. It is not about taking away the “stereotypy,” but focusing on these innate abilities indigenous to every autistic person so they can learn and grow into competent autistic adults. I am not holding up the bar of normalcy to measure this success. I really do believe that the gift of being human, and all the things all kinds of people can teach us, is immense if we work to listen.

Autism acceptance may be a little different for everyone -- some parents have more to deal with than others, and we need to find ways to both support autistic people and the parents who care for them. If an autistic person needs a medication for anxiety, it doesn’t mean you’re not accepting autism. If you use a tool to teach so that your autistic child can learn skills to communicate, that doesn’t mean you are not accepting autism. The difference between acceptance and non acceptance is rooted in a desire to fundamentally change the person who was born to you in ways that they cannot be changed. Persons with CP were approached behaviourally in the 1970’s with a “treatment” called Patterning.
It held with it a belief that the person with CP had to crawl before they walked as this was thought to be an “appropriate” developmental milestone. This was very popular therapy back then, touted in similar ways as ABA is for autistic children today as needing to learn “appropriate” ways of behaving and learning as “developmental milestones,” – this concept that one’s learning course needs to be sequenced accordingly for success against the "normal" course of development. With many neurological and other disabilities, however, this fails. A child with a neurological disability like autism, downs, CP, cannot necessarily attain these “appropriate” developmental steps. Usually, I hear from some well-known researcher here in Toronto, that Adam does certain things now because he is at a two-year old level emotionally. I don’t buy it. He is a five year old autistic boy. He is an autistic boy who is part of my world, the way my family functions and has learned to adapt and interact in an autistic way – a valuable way. He has superior intelligence to other children his age. Yet, because of his innate autistic way of being, one school wanted to hold him back a year because he isn’t acting “emotionally” appropriate for his age. It may seem logical to parents while children are little. One year doesn’t seem like much. But the years pass, our children remain autistic, and the judgments don’t get any easier.

The other day at JK, I spoke to a grandmother of one of Adam’s friends, K, who has Aspergers. Apparently, they are forging a friendship of putting their faces close together during gym and they are very happy together. The grandmother told me that K came home and said “I’m a bad boy, but the other kids are good.” She said she was shocked – he was equating his worth with that of the other kids – the “good” kids who were not autistic. He saw himself, by comparison, as “bad.” If that doesn’t make every parent of an autistic child out there furious, it should. As long as we hold up this holy grail of being “indistinguishable” from others, our children will continue to feel bad about themselves, as the world thinks being autistic is inherently wrong.

It never ceases to blow my mind
It does it to me everytime
Standing here looking at you
It makes me wonder what he was up to
Was he thinking about me
When he thought about you -- Keith Urban from Album Love, Pain and The Whole Crazy Thing
Autism Podcast

First, I want to thank Anderson Cooper of CNN last night for having Amanda Baggs and Dr. Morton Ann Gernsbacher on his show with Sanjay Gupta. It was a positive a fair TV program about autism, which we don't see very often.

Here is the Autism Podcast show I also did recently. I am only speaking this quickly because I found out my mother had to go into urgent surgery about the same time. All is well now.

You'll Never Think The Same Way About Autism

Amanda Baggs will be on CNN's Anderson Cooper tonight at 10 p.m. "You'll never think the same way about autism again" was the byline for the upcoming show. View the CNN story here.

Many thanks to Amanda for stepping out and doing this difficult thing.

Good Practice in Representing Autism

I just gave my presentation in Montreal at Giant Steps. It was
called "The Selling of Autism: how the marketing of fear manipulates the way we treat autistic people." It came on the heels of the 60 minutes piece and of course, the piece in The Globe and Mail, with the advent of prenatal screening not that far off.

I couldn't do too much this week, as my mother went for urgent surgery yesterday. With two rounds of cancer already, and now this surgery, I can tell everyone with certainty that autism is certainly NOT like cancer. Autism is another patch on the quilt of humanity. It is not always easy, but nothing in life is easy.

When I visited Thomas Henderson at Giant Steps in Montreal, a beautiful school for autistic children up to age eighteen and met the kids, I felt at home. The kids were wonderful, all very happy, smiling at me or working. I had the pleasure of meeting another Adam there -- who presented at the ASD Perspectives Lecture Series, autistic and nine years of age. NINE! He presented for one hour. How many other nine year olds would be able to make an hour-long presentation? Adam came up to me and told me he was on CTV. He was quite excited about that. He asked if I had a website, as he so desperately wants one. I said I did. He kept begging his mother: "I want a website too!" and I felt I got the mom into a bit of trouble. Adam, apparently, has found his way into university chat rooms, and like any parent of a young child, she is very concerned about the potential danger. I then met Hugo who also made a presentation, who told me how he enjoyed letters and numbers -- certainly like my Adam -- and how he likes the number six, but not the five because the five looks like it could eat you. I heard kids whooping like my Adam does, and for a moment, I thought it was him. There was artwork everywhere, Smart Boards (very cool white boards that kids can use wireless keyboards to do classes, but that you can also write on), pees, kids doing sign language, and OT room and more. But what struck me, as how at home I felt there among the children and teenagers. I felt like I wanted to stay there. I realized, that this was a real telling -- that despite what we write about something, ideals do not always reflect the way we truly feel when we are immersed with dis-abled people -- that we know when we are no longer prejudiced, in this case towards autistic people, until we are swathed within a community of autistics. In my case, I felt warm. I felt I belonged. I wished that my Adam was there with me.
There really is so much to say in how the piece in the Globe was written, how it showed no other balanced side to those who really love their dis-abled children as they are, who find the joy that is inherent in their children mixed in with all those challenges. It doesn't reflect how those with dis-abled children, like the Downs Community of the Canadian Downs Syndrome Society, feel about those wanting to prevent autistic or Downs babies from being born (notice how they celebrate Downs). It doesn't reflect how wonderful my Adam is, who is like the many of the other autistic kids and that the "remediation advocates" use to complain about autism, despite the fact that they like to diagnose Adam without meeting him in order to state that their plight is worse.

When Brenda Deskin announced on CFRB Radio: "Autism is a living nightmare: my son Michael hit me today," I felt really bad for Michael, as autistic people are criminalized all the time, and that is inherently wrong. We need not unfairly represent in order to receive accommodations for our children, or support as parents. One does not need to advocate this way at the expense of a person's dignity. It calls into question about whose life is at stake here, whose career, whose reputation, whose pocketbook, as it seems people are more concerned about all of this rather than really seeking to assist and educate people with autism.

Further, considering how the dis-abled were referenced in history (Nazi Germany), we might need to call into question the legality of making references to the costs of being human. Deskin's fact sheet, co-written with Andrew Kavchak and written in 2005, suggests that not only should special education classes be delivering ABA therapy (ergo you have no choice in how you wish your autistic child to be educated), it also states: that "autism is a lifelong
affliction [bold mine] that will result in 90% of afflicted individuals being placed in institutions and residential facilities."
The "fact sheet" says it just like the Nazi's did.

It calls into question, when a reporter suggests that all special needs kids should be screened (Boston Globe Editorial: A Clash of Rights in Education) before being allowed to enter schools and programs because someone has over-generalized and criminalized autism,

what prejudice is and why the same screening does not exist for non autistic people who can be more aggressive and violent. Prejudice IS a different set of standards that we apply to one set of people over another, noted Professor Emeritus, Bernard Lewis from Princeton, and it is alive an well in autism. All children can be a challenge for their parents. Parents and society still have a responsibility to protect their children from a world that will apply prejudical standards. Therefore, the way we talk about our children and represent autism, is so important here. In our society, representation matters.

Today, with Canada's Fetal Alert Network, the stats show that in Southern Toronto, almost all women who have a confirmed amnio for a genetic defect will terminate -- even late term abortions for children with a cleft lip.

There is some urgency here. We have a huge lack of information and education about living with a disability from those who are disabled and the families who love them. Instead, the media prefer to write about disagreements, challenges, and drama and prejudice is rampant. I was so sad that the article with Szatmari did not contain a balanced view, or a view from an autistic person. Autistics from The Autism Acceptance Project board wrote in after the article, but their letters were not published. We do not get to hear that often from autistic people in the media in order to have ethical discussions about what screening means for autistic people. I wrote in a letter that also went unpublished and of course, only a
letter supporting the prenatal screening steamroller was published. I find it continually astonishing that reporters call parents first regarding opinions (including me) and never autistic individuals. Science is big drama these days -- big breakthroughs into understanding our genetic makeup. But we are more than our genes. We are a composite of genes and spirit -- an ineffable makeup of the mystery of the imagination and human spirit. In light of what we know and can do with human life, how much must we now begin to discuss our responsibilities to protect life, to protect that part of being human that we do not know, and perhaps must not "know," for it is what makes us who we are.

On the advice of Margaret Somerville, where I derived this idea of protecting human spirit from her books: The Ethical Canary and The Ethical Imagination, and who is an ethicist and professor of law at McGill University, I suggest we begin by finding what we share as parents and autistic people -- what we value. If I can send out an idea for others to blog about, is not always what divides us (but it is necessary in order to identify bias and prejudice), but also, what unites us. I ask that people expand this list of what it means to implement a "Good Practice in Representing Autism". I have begun a list:

1. Inclusion of autistic people and their voices in fairly talking about autism, at all levels of policy making regarding autism;
2. Reflect autism as a diverse condition that has strengths and challenges;
3. Autism not as defeat in relation to “norm,” but a different way of thinking and learning;
4. Inclusive language instead of exclusive
5. Humanitarian references (not dehumanizing ones)
6. Ethical discussions at all levels: media, autism organizations and societies;
7. Discuss how we protect the “mystery” of being human: What is LIFE?
Reasonable People

Ralph Savarese's book *Reasonable People: A Memoir of Autism and Adoption* is a heart-wrenching memoir of autistic abuse, abandonment, adoption and durable love. Ralph, who is an English Professor at Grinnell College in Iowa writes about his family's arduous journey to adopting DJ who has been separated from his "neurotypical" sister, Ellie. Their biological mother, Rhonda, a substance abuser, is in and out of their lives and later creates obstacles in the process of adoption. During Rhonda's absences, Ellie was left to assume care of DJ until she was taken to move in with her biological father. The father, who is self-described as "an unemployed former drug user," marries an HIV positive woman who takes in Ellie, in order to rebuild a "normal" life – a life without DJ. DJ, in turn, is subjugated to the perilous world of foster care. The split between biological siblings is the constant source of pain for both throughout, and we view it through DJ's transcripts and Ralph's re-telling of events.

Emily, Ralph's wife, is an expert on inclusion and had been working with DJ. One evening she brings DJ their home. In a charming early encounter, we watch as Ralph falls in love with DJ when they lock foreheads and stare at each other -- this is their first "connection." Soon after, Ralph begins to engage DJ in a tickle game which becomes their early pathway to life and love together.

As the story opens, Ralph foreshadows the stress to come by illustrating the brief reunion of DJ and his biological sister, Ellie, and how the shadow of sorrow follows their temporal happiness:

"With great difficulty Ellie pulled DJ uphill. At six, her birth brother, whom she hadn't seen in nearly three years, understood..."
rollerblading to be a matter exclusively of somebody else’s exertion. While you labored, he’d stand with his legs a bit too close together, his chest a bit too rigidly upright, his eyes more than a bit too captivated by whatever birds were darting overhead or leaves were rustling in the wind....With amazement, we watched the girl effortlessly reassume the role of facilitator as she directed DJ around the park....Even more significant, she refused to be saddened by what her brother couldn’t give her after their long separation – what he couldn’t say or do. But then he had given her something. In fact he’d stunned her, stunned all of us, when just before we were to meet in the city, he’d spotted his sister a full block away, run up to her, and like a character in a French movie, placed his hands on her shoulders and kissed her on both cheeks...The girl seemed to ride the gesture right into the afternoon, as if it were pulling her.”

It pulls us too. We can’t help but root for the reconnection of DJ and Ellie throughout the book. The anguish that DJ experiences as a result of separation is increasingly evident as he begins to acquire language through Facilitated Communication which Ralph notes, “I’m with Margaret Bauman, a neurologist at Harvard who appears in *Autism Is A World* and who is quoted in the *Washington Post* article as saying that FC was “oversold in the beginning” and then, like the proverbial baby, “thrown out with the bathwater.” Ralph shows the belabored task of teaching literacy to DJ and it how it opened up a whole new world of psychological stress and awakening. “Language meant anxiety,” said Ralph:

“Language meant fear....Put provocatively, language is the group home of life. By the time an infant recognizes his separation from his mother and can speak of her as a discrete object, he is already racing toward the lonely singularity of adulthood.” And,

“Ellie became the name he’d track like a bounty hunter through the swamps of longing...”

As DJ’s literacy unfolds, we begin to witness increased aggression and violence at home and at school, and we learn more of his own abuse in foster care. Ralph refers to DJ’s mind in these references to abuse like a “Mission Impossible communiqué, combusting immediately after it’s read.”
Savarese’s parlance about DJ, and the recapturing of a traumatic past through FC, continues to suggest that we need to look longer and harder at cognitive disability and all disabilities. The violence and aggression, alongside Emily and Ralph’s perseverance to help DJ - through the post-traumatic-stress, through trials of medications, through the rocky road of mainstream schools and inclusion (even though inclusion worked to DJ’s and his classmate's benefit because of the Savarese’s) - all communicate the challenge of autistic behaviors while suggesting that we must always consider that there is more to our autistic children than meets the eye; that autism does not render a person unaware. In fact, we sense where this autism journey might take us early on when Ralph states in reference to raising DJ, “To us there was no such thing as unbridgeably distant.”

There may be no such thing as a bridge that can’t be crossed but Ralph illustrates there are many broken bridges. His radar for prejudice is acutely sensitive throughout the book, and this is illustrated in the way the public viewed DJ’s behaviors on an airplane, to schools, and sadly, to a visitation with Ellie and the biological father when the latter says, ‘Does he take their tests? What’s the point of this inclusion stuff, to make the parents feel better about having a retard for a son?’ The man actually used the word ‘retard.’ I don’t know if he’d discerned that he was in trouble with his daughter, had exaggerated DJ’s disability, or whether he suddenly felt that he was in trouble with himself....I don’t know if he was merely like so many other people who know nothing about disability and advance a case of prejudice.”

Ralph succeeds by making DJ not only the main character, but gives him his own voice by relaying their computer “conversations” to us, which are recorded meticulously.

“At part of what we were doing was compensating for the autism, but mostly for DJ’s belated emergence. In fact, DJ would end up becoming a great professor of feeling, understanding in its innumerable cultural inflections – all of this a rejoinder to the autism experts and their ‘devastating’ theories.”

In Ralph’s book, we bear witness to this difficult process of adoption, autism, stress, epilepsy, trauma and the struggle to
connect and create a family against many odds. One can’t stop thinking of the challenges that adoptive parents take on willingly while others may complain endlessly about the plight of their family because of autism. But Ralph will have none of that. While there is pain, there is never talk of a cure, or of wanting DJ to be anyone other than who he is, except to alleviate the struggle. Like most parents, Emily and Ralph want to help DJ with communication, and to have him happy or at least content despite a life of loss, to hopefully replace it with a life of gain.

For all of his autistic behaviors and inability to talk, DJ is bathed in Ralph and Emily’s considerate light, where all of his actions are interpreted as real communication and thus DJ is returned from a level of subterranean species back to humanity: “Only her goodbyes would provoke the emotional scurrying of a frightened animal or the hiding-in-plain-light routine we’d come to think of as the mind in brilliant camouflage.” Here, Ralph makes reference to DJ’s encounter with his biological mother.

Perhaps Ralph is predisposed to taking care of DJ: “Can one be too serious? Can one still live, as Thoreau once put it, ‘deliberately?’” With all of his self-deprecation and reflection throughout the book, I am convinced that Ralph and Emily’s act to adopt DJ was not to be benevolent for the sake of it, or to bestow pity on DJ, although they truly had strong feelings for what he had been through. It is their persistence and work with DJ that carries the narrative. There is a sense of what’s right and wrong, and justice due to DJ. There is so much pain throughout, and despite all, the triumph is one not only of will, it is one where we watch a child, otherwise lost and forgotten in the world of foster-care, now remembered, celebrated and succeeding as an autistic individual -- and respected no matter what.

The last chapter was left for DJ to write. As a parent of an autistic child, its message struck me as serious, considering the lessons we are learning about autism, and how autistic people best learn:

“Dad has written a book about my fresh start. I’ve written the last chapter. Please read it because in it I write about how years of early lessons were wasted. Why weren’t you teaching me to talk, to read, and to write? All you had to do was awesomely encourage me as smart and really kind, and fresh start really could have begun sooner. Your breathing would make me
nervous. People weren’t assuring me as sweet, inspiring me to work at dreaming of typing to responsibility act like everyone deserving respect...Quite pleased that you are respecting and reading this tested-as-smart, growing up boy’s resentment. I live in constant fear that respect will be taken away, and I will have to return to easy years of doing nothing....Reasonable people should each see what they can do to free people who can really understand.”

This is not necessarily a story with a proverbial happy ending which some people come to expect: a miracle cure for autism as it were, or DJ’s journey to “normalcy.” Sadly, DJ and many others like him, will continue to be subject to discrimination, and the anxiety may never really be over. As a daughter of an adopted child, I am also more than aware of the painful, incomplete legacy that lives on inside the adopted one, and how that can even carry on in continuing generations. This is, however, a story about what life is all about: trial, error, perseverance, and faith in people. Faith in love. Ralph, Emily and DJ give us that, and much more.

PERMALINK POSTED BY ESTEE KLAR-WOLFOND AT 2/11/2007 01:59:00 PM 9 COMMENTS LINKS TO THIS POST

SATURDAY, FEBRUARY 10, 2007

The Reason: The Joy of Adam

PERMALINK POSTED BY ESTEE KLAR-WOLFOND AT 2/10/2007 09:42:00 PM 7 COMMENTS LINKS TO THIS POST

For Adults with Special Needs

Congratulations to Kathy and Danny Laszlo, organizer of DANI "Developing and Nurturing Independence." I hope the Toronto community will come out and support this fundraiser to nurture the independence of adults with Special Needs. I am priviledged to be honoured at this event with also Rabbi Joseph Kelman, co-founder of Reena, Carol Goldman, principal of Zareinu Educational Centre and Dr. Gerald Friedman, chief of pediatrics at York Central Hospital. Please view this article for more information on the upcoming GALA EVENT.
Son Caged in Class

As I become more sensitive to perspectives and language, I caught this article today in The Globe and Mail: "Son Caged in Class, Parent's Say."

"'Just imagine. My son would come back from school and he always appeared troubled. He had tried to tell us what was going on, but we couldn't understand what he meant. It wasn't until we asked him and his twin brother, who is in the same class, to draw us a picture of this enclosure that we realized what it was...'

Ms. Sinotte insists that Felix is a normal intelligent child and said there was no reason for this treatment."

SCREEEEEEETCH. What does this mean? That it's okay for other children who are "not normal" or let's posit for a moment, autistic, to be caged?

"The school board called a news conference yesterday, explaining that it is normal practice to place turbulent children in an isolation area for about an hour throughout the course of the day 'so they can rest and clam down.'"

Hmmm. I can think of better rooms, like snoezellen rooms, for instance, that provide that calm and are not cages.

What era are we living in?
Prenatal Screening and Ethics

In the Globe and Mail today, you will find a series of letters, and one paragraph of one I sent in, published regarding yesterday's article "Expand Prenatal Gene Tests, MDs Urge."

Two pages later, one of my favourite ethicists was quoted on The Ashley Treatment, Margaret Somerville, who is author of many wonderful books (The Ethical Imagination: Journies of the Human Spirit, The Ethical Canary) and founding director of the Centre for Medicine, Ethics and Law at McGill University.

She also targets NYT writer Peter Singer for his latest support of The Ashley Treatment and writes:

"He believes in extrinsic human dignity -- that is, dignity is conferred on us by others; we have dignity if they see us as deserving it and that depends on how well we function mentally and physically. Below a certain level, we don't merit dignity and the protections it affords. And because dignity is conferred, not innate, we can, as Mr. Singer proposes, confer on animals the same kind of dignity we do on humans. Humans are not special in any relevant sense and thus not deserving of respect different from that owed to other animals. So if you can redesign your dog, why not your disabled child?

Mr Singer says the surgery is ethically justified on a wide definition of 'best interests' and uses a utilitarian ethics analysis. That analysis does not involve an inquiry into whether something is inherently wrong. What is and isn't wrong depends on circumstances.

I suggest we need to inquire into inherent wrongness (a prinicple based on ethics analysis). The arguments that the intervention on Ashley is inherently wrong would include that we're doing something to this girl we would never do to a non-disabled child; that it's not 'the least restrictive, least invasive way' to achieve a necessary benefit (an ethical requirement for 'wounding' interventions such as surger) because we could provide assistance to the parents; that it's only peripherally therapeutic..."
and cannot be justified on that basis (although a medical cloak makes us feel better); and that Ashley is being treated as an object to be 'designed,' not a natural person to be respected whatever her state -- which after all is 'her...''

Once we leave ethical analysis at the individual level, the case has very disturbing features at the level of societal values. May we redesign disabled people to make them easier to care for? They used to take out all the teeth of the mentally ill people so they couldn't bite their caregivers, but we are rightly appalled by that now. And what about the precedent it sets for our society with respect to how we value and treat disabled people in general?

In deciding the rights and wrongs of the Ashley case, we should keep in mind that the 'ethical tone' of society is not set by how it treats its most powerful, strong and independent citizens but how it treats those who are weakest, most vulnerable and most in need. It's hard to imagine anyone better fitting the latter description than Ashley.

On February 19th, I'm presenting a talk at Giant Steps in Montreal which I've now re-titled: The Selling of Autism: How the Marketing of Fear Manipulates The Way We Deal with Autistic People. In it, I will be talking about my experiences as a parent, as someone who initially knew nothing about autism faced with dire messages from parent groups, doctors, and of course, the media.

Articles and doctors who promote prenatal gene tests as 'mandatory,' or necessary, only heighten the fear, the urgency. The article on screening yesterday states that it will enable better, earlier interventions in the context of disabilities and Down's Syndrome. We've heard that before in autism. But I ask better than what? If, as we are beginning to understand, autistic people do learn naturally, in an autistic way from their environment (a way underappreciated by the larger population so much so that we are seeking to ameliorate autism and autistic learning altogether as 'inappropriate'), what better intervention can their really be? ABA studies with children under the age of two have been useless, as the children could not "respond" under that age.

I suppose you are thinking like I'm thinking that "in your face,"
therapy might be the way in autism, but how much more "in your face," can you be to a six month old baby than we all likely already are?

I am skeptical and concerned that prenatal testing for disabilities, under auspices of finding "better interventions" will be used as a cost-effective measure to get rid of any person with a physical and neurological difference, instead of accommodating people. We saw the costs of the "mentally ill" written in German posters and ads to justify their extermination under Hitler. Juxtapose this financial "analysis" against our modern politics and lobby efforts: "it will cost taxpayers," or "autism will be a burden on society if..." and we can see that we have not come very far.

MONDAY, FEBRUARY 05, 2007

Just Super

There are days when I'm just pooped -- surgery, new puppy and life in general. Minus thirty with the windchill and a low pressure system that makes my head want to explode, it feels like all I need is a dose of springtime, fast! Adam and I headed to the movies yesterday, something he has begun to enjoy these past several months for the first time. So far, he's seen Flushed Away, Happy Feet, Charlotte's Web and yesterday, a boring flick called A Night At the Museum. We headed back to the car and a gust of wind nearly blew Adam out of my arms and wouldn't allow the door of my Honda Odyssey to close. My fingers were frigid with pain. I vowed not to go out for the rest of the day, so we hovered over the fire and dipped strawberries in chocolate sauce.

I forgot it was Superbowl Sunday, because I just don't care. Well, not until it started. A friend and his son, a year older than Adam came over to watch it with Henry and Max. After his bath, Adam went downstairs to join the "boys," noshed on pizza and ate a few potato chips. He was positively giddy and silly, obviously enjoying the gang, and intrigued with the patterning of the football players and the numbers on the field, for a few minutes anyway. Snuggling in between everyone was much more fun. Later, he played a bit of ball with the five, soon to be six-year-old visitor, something we
don't see often without prodding. He was jumping, laughing and all
red in the face.

I took him to bed at eight -- it took a while to settle down. All I
could remember is how giddy and silly and red in the face I used to
get at his age when people were together, having fun, eating chips
and pizza and free to play in the basement.

The apple doesn't fall far from the tree.

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**On Not Being Human**

Dr. Morton Ann Gernsbacher just released this article in her
Presidential Column *On Not Being Human*

Also read Susan Senator's post *today* and her reaction to this piece -- another way of
criminalizing the disabled (remember Captain Hook as a
narrative figure as an example of
how the disabled have been
represented) and therefore finding reason to either exterminate or
segregate them. Read the Boston Globe article she posted *today*
here.

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**The First Step in Dehumanization**

*A Credo For Support (People 1st version)*
In April, I am going to Auschwitz and Treblinka. It will be a difficult trip as I have another story to tell outside of autism, but that’s for another time. For many reasons, I am profoundly affected by prejudice and labelling that dehumanizes people. In Europe, the first step to dehumanization was to make the Jewish people wear the Yellow Star of David on their clothing. The second step was to take away their ownership. The next, to ghettoize them -- you see, people were not ready to accept instant extermination of the Jews. It had to be a process. It was the process of dehumanization that is disturbing me greatly, and this post is intended to make us all think critically, of how we may be naively doing the same thing to disabled and autistic people.

It may seem benevolent to seek a cure for autism, if you believe autistic people are ill, if you believe that you are helping them through research by "solving a puzzle." But ask yourselves this: when you refer to humans as a puzzle, are you also stripping away of piece of their humanity -- suggesting that with autistic people, a piece of them is missing? This is not a healthy way to represent autism. Humans are never a puzzle and we have to consider how attitudes are shaped by representation. If you think language and symbols are trivial, and not that important, think again.

I think if you want to do something right, if you need a logo, use the rainbow, the circle, any symbol that accepts diversity, that denotes that we all belong and we are all equal.
responses to the way Autism Speaks conducts its marketing. Just click on each number to begin reviewing:

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There are many more people who are disturbed by the marketing and goals of Autism Speaks. I'll leave it up to you to search for more.

Compassion

I envision a group. A gay friend of mine came up with this idea today -- it may sound "granola head" :) but it was an interesting idea: He said that he was asked, by his Reform Synagogue, to lead a group of parents who couldn't cope with their child's homosexuality. Parents were even embarrassed to be seen in the group as they did not wish to be stigmatized. My friend had to listen patiently to all of the bias and prejudicial comments of these fearful parents in order to build a bridge to acceptance. My friend received this comment: "If my son was successful as you..." Someone else always had the tougher plight. Someone else's
homosexual child, was always better off than another's.

So, he brought other gay people in (my friend is conversative, not the stereotype a gay person -- or at least the stereotypes these parents had). He is successful. Some of these others were like a "spectrum of gay people" -- successful business people, lawyers, judges, women who looked like men, pretty women who didn't "look gay," to unemployed people with nose rings and blue hair. These people attended the subsequent meetings and also listened patiently to fearful parents, angry parents, prejudical parents who wanted to cure their children of their homosexuality. Many of these people were also subject to behaviour modification training to look "normal," while other parents sought to cure their child of homosexuality altogether.

There was a rule to this group, however: There was to be no talk of causes or cures. This was thought to be a barrier to true acceptance.

Everyone was allowed to express their thoughts and feelings, and at the end of the exercise, the parents didn't see anything wrong with homosexuality -- that it was just another kind of "normal." Siblings born of these parents later attended (the gay children were not part of the group in order that the parents be allowed to express themselves freely). It was discovered that in the years of the parent's "mourning," and obsessing over their sick or abnormal gay child, the other siblings felt neglected.

While I do express many views based on basic human rights in this blog, I do feel that groups can be brought together in autism, and I really liked this example my friend told me about today. Autistics must lead these groups. While some are not able to lead them, there are others who can and who are likely willing. Autistic people came to speak at the Joy of Autism: Redefining Ability and Quality of Life event in October -- and we discovered how Susan Senator sends her son to an ABA school because "they love him there," and of course if people accept autism, that is really all that matters. We learned that Elijah does stand-up comedy. We learned from Jim Sinclair that his need to move his hand up and down was not a stim or inappropriate behaviour, but a way to find and feel his hand so he could direct it, or that his wheelchair represents for him not confinement, but liberation -- a piece of equipment that allows him to move around without falling down.
We learned from Phil Schwarz about his Aspergers and then of his son's autism; we learned from Michael Moon that what a non-verbal autistic child truly does change over time, and from Michelle Dawson that autistics deserve better than speculation, assumption and "lousy science." Martine Stonehouse talked about her journey with autism and read her poetry and Brian Henson also talked about discrimination in front of his photographs.

I know that when we feel a certain way about something, of feel blamed and confronted, it is easy to become defensive. But what if parents had a safe place to talk about autism, with autistic people? I know there are some groups that do this, but I am not sure if people go in those meetings with the same rules (no talk of therapies, cures, remedies or causation) and goals of acceptance. People try so hard to understand this little quirk and that, that maybe we are all missing the forest for the trees -- there is a difference between fascination with autism and genuine understanding. At the end of the day, true acceptance doesn't really require any knowledge of autism at all. But that may be too big of a jump in thinking for today.

"To hate is to refuse to accept another person as a human being, to diminish him, to limit your own horizon by narrowing his, to look at him - and also at yourself - not as a subject of pride but as an object of disdain and of fear..."
- Excerpt from The Oslo Declaration
This picture was taken last year when Henry hosted Elie Wiesel in Toronto. We are seen here at a book signing at Indigo Books in Toronto. I didn’t "advertise" this photo for all sorts of personal reasons, however, I feel it is time to discuss the tougher hills people have climbed in their lives, and how that relates to autism.

Autism is referred to all too often as a war, a fight, a combat. The war is waged largely between ABA parents and those who do not solely advocate for this one type of therapy. There are large factions of us in between, who want to acknowledge and receive support for an education and accomodation that befits our unique child and the ABA "fight" doesn't do this. There are many who understand that if there is a tougher hill to climb than putting the onus on children to change, it is this hill of prejudice that effects our children.

In my opinion, Elie Wiesel has climbed it. With a recognition that prejudice abounds, and may always, people like Elie don't give up the quest for peace, justice and the dignity for all.

Mr. Harold Doherty (Autism Reality NB) and some others want to create divides, where there should be none. Your toughest ABA advocates who I know personally, have called me to find out about other approaches (you know who you are), because all they want to do is to help and accomodate their children: the ultimate acknowledgement that their are other ways to broach autism education other than ABA.

Mr. Doherty calls autistic people who can communicate "not autistic." He creates divides between levels of functioning to justify services and money -- as if the "neurodiverse" movement is doing an injustice. Yet, all autistic people require accomodations throughout their lifetime. There should be no prejudice towards autistic people in terms of the assistance that they require, no matter what level of functioning. People like Mr. Doherty like to put the blame on someone for not getting ABA therapy funded as a sole "treatment" for autism. So it will be people like me, like Michelle Dawson, like any one who wants something better and let's face it, a lot more complicated.

I am advocating for more services, not less. I am advocating for the basic human right of the disabled person to be regarded as a full member of society. I am advocating for a new standard of...
ethics to be applied as it would be for any of us, towards disabled people. I am advocating that autistic people should be on the Ministry of Education's reference committee on autism, and any other committee or policy that concerns autism. I am advocating for parents to receive support and compassion with the challenges they face in raising special needs children, so that they will also experience the joy of their child. I am advocating for bias and harmful language to be removed from autistic organizations and scientific research, for the purpose of creating hype for money, and which end up perpetuating prejudice and continued segregation. I am advocating for the parent's right to participate in educational and service decisions for their children while also drawing the ethical line of how far those decisions can go. I am advocating for inclusion of all disabled members in society at all levels -- which may be the hardest objective of all -- as prejudice starts young and runs deep. Yes, inclusion can be cruel if a disabled member is not fully accepted and accommodated. But inclusion should be the ultimate goal. Real inclusion. I extend my hand to you, Mr. Doherty, and any others who wish to work together for the sake of our children, to find that middle ground that will help them be the best autistic people they can be. If autism "awareness" was built on the backs of people like you (and not), then we have to ask ourselves now, with the advent of the disability rights movement, with the voices of autistic people yearning to be heard which can benefit the way our children are viewed by society, where we are going? Between your reality and mine, there lies a place where we can achieve our goals.

I don't think the onus should be on our children to just "fit in," or "become normal," and ABA has functioned on this premise of making children "indistinguishable from their peers," with questionable methods. I believe that the onus is on the rest of us to discover all people -- their intrinsic value, beauty and worth.

It may take a very long time, for prejudice is the toughest hill to climb.
What's on my mind: As usual, beauty (as in human spirit), justice, dissention and this recent reponse to The Ashley Treatment by Peter Singer, ethicist from Princeton University:

What matters in Ashley’s life is that she should not suffer, and that she should be able to enjoy whatever she is capable of enjoying....In any case, the “best interest” principle is the right test to use, and there is no reason that other parents of children with intellectual disabilities as profound as Ashley's should not have access to similar treatments, if they will also be in the interest of their children. If there is a slippery slope here, the much more widespread use of drugs in “problem” children who are diagnosed as having attention deficit hyperactivity disorder poses a far greater risk than attenuating growth in a small number of profoundly disabled children." (NY Times Op. Ed, Peter Singer, January 26, 2007).

Imposing assumptions on the state of mind of others is a value judgment (one with bias). Assumptions that another person does not understand what is happening to them is prejudice. Valuing one type of life more than another is also prejudice. Remember: prejudice is a different set of standards which we apply to one set of people over another. Throughout history, "behavioural phenotypes," have given rise to bias about people who display different behaviours:

"A behaviour phenotype is a characteristic pattern of motor, cognitive, linguistic and social abnormalities which is consistently associated with a biological disorder. In some cases, the behavioural phenotype may constitute a psychiatric disorder, in others, behaviours which are not usually regarded as symptoms of psychiatric disorders may occur." (Flint and Yule, 1994)

Throughout the Journal of Applied Behavioral Analysis is an abundance of biased language: aberrant, stereotypy, and more. If we scrutinize every pattern of behaviour and classify it, we run the risk of creating aberrance, where there is none.

But I thank God for one thing: the freedom of us all to discuss all of these issues, the drive of parents to accept nothing but the best for their children -- there was a day when society really didn't accept
any disabled person, when parents had little hope. Today, parents
will not accept that. They expect their children to attend schools,
receive an education, and obtain accommodations. Despite virulent
disagreements over the ethics of "treatment" versus
accommodations for autistic children, I still have faith that we’re
moving forward, with one caveat: always keep your eyes open...

Here is some dialogue from the movie Sophie Scholl: The Last
Days. She and her brother were the leaders of the White Rose
movement which was a resistance movement in Nazi Germany.
The setting is in the interrogator's office discussing her ideals
against his Nazi ones:

**Sophie:** “The other children asked where they were going.
‘They’re going to heaven,’ said the nurse. So the children got on
the truck singing. You think I wasn’t raised right, because I feel
pity for them?”

**Interrogator:** “These are unworthy lives. You trained to be a
nurse. You saw people who were mentally ill.”

**Sophie:** “Yes. That’s why I know. No one,
regardless of circumstances can pass divine
judgement. No one knows what goes on in
the minds of the mentally ill. No one knows
how much wisdom can come from suffering.
Every life is precious.” [bold mine]

Perhaps we need to revisit history, our older concepts of ethics to
find a new shared ethics that befit the unprecedented ethical
issues of our time. What are our shared values that unite us in
humanity and responsibility for others. Perhaps we need not only
go back to history, but our songs, our stories, our art -- that which
truly makes us human.

At the basis of the Ashley argument, we cannot assume that
Ashley is "suffering." This is a big problem with disabiility itself --
that because a person is disabled, the rest of society views that as
a terrible state -- that the disabled person in question must be
suffering. Even if, what does it mean to suffer? Isn’t suffering part
of existence? We can learn by listening to the disabled community
and their response on this. And, it is our obligation to do so.
I argued in my last post, that in the absence of truly knowing or understanding, we must presume sentience. A recent visit to a Montessori school, and I reviewed Maria Montessori’s mantra: "Every child is born intelligent but learns at a different pace."

Click here to listen to "The Riddle" (the video ain’t great, but it’s better than having the song on autoplay everytime you click into this blog, which is what was happening.)

The Ashley Treatment

“The Ashley Treatment”
Assumptions About Suffering, Disability and Quality of Life

The Ashley Treatment is our most recent example of society’s relentless quest for consensus on the ethics of medical decisions cited as “treatments” made on behalf of dis-abled individuals who are unable to give consent. In effect, to improve Ashley’s “quality of life,” and alleviate the potential “suffering” from her inherent vulnerability (there were a few cited), Ashley, who is today only nine-years-old with “profound multiple impairments,” was given “grown attenuation therapy.” It was instigated and promoted by her parents where she has been given high does of estrogen to bring about permanent attenuation in her size. Ashley also underwent a hysterectomy and the removal of both her breast buds to “improve her quality of life,” so that she could remain
under the care of her parents at home. By reducing her size, her parents claim, they are able to lift her.

Unquestionably, the so-called “treatment” has raised significant questions on the legal protections and rights for the dis-abled, society’s assumptions about what dis-ability means in terms of cognition and sentience, limitations on the family over “treatments” for their child, the subjectivity of definitions over “quality of life” entwined in overall assumptions about dis-ability, society’s prejudice towards dis-abled individuals, and the issues surrounding the meaning of suffering against the medicalization of dis-abilities.

This essay argues that The Ashley Treatment was a prejudicial medical “treatment” for the benefit of the parents, not for Ashley. This recent “treatment” was performed against our recent history of sterilization and involuntary institutionalization of the dis-abled.

It barreled forth despite the fact that the case possessed no urgency as Ashley is only six years of age. The health risks continue to be high, and Ashley’s outcome remains too soon to predict, both with and without so-called “treatment.”

In short, The Ashley Treatment favoured the parents and assumed that her dis-ability rendered her unable to “register” her world and what was being done to her. We have so much to learn from those who are dis-abled. We ignore their words, we are witnessing an exclusion of their involvement on American’s biggest autism charity, Autism Speaks, which will be one day be acknowledged as one of America’s biggest embarrassments. As Hollywood glitterati parade their puzzle ribbons fashionably at The Golden Globe Awards like the red AIDS ribbons once were (AIDS was life threatening as opposed to Autism, and the “puzzle” campaign is largely rejected by the very autistics they believe they are supporting), I fear they do not fully realize the prejudice and subordination they are in fact endorsing, which suggests a gross ignorance in society about dis-ability overall.
I have stated many times on this blog, using the words of other scientists, that “we do not understand autism.” Yes, we don’t understand the all the genes involved, or the possible environmental influences. We are undergoing a scientific process to either prove or disprove these speculations. What is more important to bear in mind as we fund the science, is engine that drives the process itself: us. Do we view autistic people as a diseased in need of a cure, or, do we view them as people first -- full-fledged members of our society who deserve to be treated with respect and who deserve to be treated as any other non-disabled person would want to be treated. Part of me rejects completely this notion of difference, as we are all human and in my mind, deserving of the same rights and privileges. If I were to become dis-abled, I would expect to be accommodated for my dis-ability and accepted with it. (Although I did experience a different view when I was in a wheelchair at a restaurant last week as a result of slipping after knee surgery – another blog entry entirely, but I noticed the looks and some referenced the chair as “troubling” and “horrifying”). Further, we must not practice economic prejudice for making cases based on financial burden (this is rampant for all of the vulnerable), rather, identify needs before resources. Only with such practice, and such observance of basic human dignity for others, can we begin to think out of the proverbial box. So, if we do not understand autism, if we do not fully understand what is like to BE Ashley, or Adam for that matter, we cannot assume her lack of cognition, and we cannot treat her as an UNPERSON. This applies to any person with a disability.

Therefore, in the absence of knowing truly what dis-ability is, or knowing the OTHER, as philosopher Emmanuel Levinas has argued, we must presume sentience:

“If precognitive experience, that is, human sensibility, can be characterized conceptually, then it must be described in what is most characteristic to it: a continuum of sensibility and affectivity, in other words, sentience and emotion in their interconnection.” (Stanford Encyclopedia of Philosophy quoting Levinas)

We simply do not yet understand the complexities of the human mind, and therefore we must take a humanistic and pluralistic approach. Anything less is prejudice, and I would like to use the
definition of prejudice by Professor Emeritus Bernard Lewis, Near Eastern Studies, from Princeton in reference to anti-Semitism in the PBS documentary “Anti-Semitism in the 21st Century.” He states that in history, Jewish “inferiority” was accepted and tolerated – that while they were free to practice their religion, they did not enjoy equal rights, were subordinate in the Muslim world, and had to pay higher taxes than Muslims and were sometimes subjected to violence. Today, Professor Lewis defines prejudice as a different standard from which to judge anyone else in the world. Let us ask ourselves: how do we judge dis-abled persons differently?

The Ashley Treatment, similar to those historical and modern references to prejudice just cited, applies a different set of standards to the dis-abled person because of the assumptions that,

a) Ashley will not progress;
b) Ashley is not aware, therefore not sentient;
c) that “the treatment” will improve Ashley’s “quality of life,” without understanding what quality of life means for those who are dis-abled.

In the position paper, Unjustifiable Non-Therapy: A Response to Gunther, Diekema (2006) to the issue of growth attenuation for young people on the basis of disability, written by The Board of Directors of the American Association on Intellectual and Developmental Disabilities, the board states,

“The ultimate and worthy goal in this case was to ensure a higher quality of life for Ashley through the avoidance of an eventual placement outside of her family home. As individuals and as an organization, we endorse policies and actions that help families to rear their children with intellectual and other developmental disabilities at home, nurturing their capabilities as well as coping with their impairments. We applaud the efforts of many caring professionals who are engaged in providing extraordinary care to children with intensive and pervasive support needs and who continue to meet those physicians as they weigh with families the benefits versus costs of various treatment options and struggle with the complex ethical concerns that can arise. Gunther and Diekema, as well as Brosco and Fuedtner, discuss some of these issues in the context of
growth-attenuation therapy and seek responses from the field to inform future practice. As the American Association on Intellectual and Developmental Disabilities, we view growth attenuation as a totally unacceptable option.” (p.2)

The paper negates the reasons why Diekema supported the parents in administering the “therapy” in question. In summary,

1) They argued against Diekema’s view that Ashley’s mental capacity “will always remain that of a young child.” The AAIDD argues that there is “abundant evidence that all children are able to learn and that the cognitive abilities of children with severe motor impairments can be grossly underestimated -- that the extant case histories of people with cerebral palsy incorrectly diagnosed as having profound mental retardation should be recognized and discussed;

2) The AAIDD argues that there is no guarantee that growth attenuation and hysterectomy will effectively delay out-of-home placement and the future development of any six-year-old child will depend on many factors – that the medical, social and programmatic needs of the adult Ashley cannot be anticipated with certainty;

3) Brosco and Feudtner noted that risks of harm from this “heavy handed” manipulation are unknown for this population, and this is an issue that begs for further amplification, citing the documented physical risks inherent in The Ashley Treatment;

4) The AAIDD question the idea that growth attenuation is in fact a type of “therapy;”

5) Lastly, The AAIDD questions the legal questions involved in the case:

“Because there was no urgency in this case, a very substantial burden of proof of benefit should have been imposed before moving forward. We see no such evidence of benefit, and despite description of a committee review process (apparently for future cases), there was no mention of including an independent legal advocate for the child or any other professional with explicit expertise in disability rights and autonomy, nor was it apparent that anyone participating in the process would be knowledgeable
about the ever-expanding options for in-home supports and services. The lives of parents of children with severe disability are profoundly affected, and these individuals are asked to shoulder exceptional responsibilities for care-giving. They should be supported as they strive to meet the extraordinary needs of their children, and we as a society must acknowledge and value their efforts. We must provide them with the supports and services they need to succeed in what Brosco and Feudtner rightly refer to as their ‘most admirable of undertakings.’ However, growth attenuation of their children should not be included as an option. Under our law, parents are vested with the responsibility for making health care decisions for their minor children, but parental prerogatives are not absolute. Children have their own distinct rights and protections afforded them as individuals established in ethical principles and legal statutes. These rights should be of central relevance in the current situation, yet they did not seem to receive the attention they deserved....With a damning combination of uncertain benefits and unknown risks, growth attenuation as described by Gunther and Diekema is bad medicine, but this practice has even more troubling implications...It seems painfully obvious that medical practice for an individual can rapidly degenerate if the anxieties of the parents regarding as yet unclear future issues replace the medical best interest of the child as the primary focus, even with the noblest of intentions of all parties involved. We see an enormous potential for abuse here.” (p.3)

The Ashley Treatment has enormous implications for the autism community. Chelation, vitamin, oxygen, and behavioural therapy among many other “types” of speculative therapies based on insubstantial “beliefs” about autism, as opposed to accurate science, ring with the same “good intentions,” with disastrous results. To what extent, we must ask ourselves, are we imposing the same prejudices that Ashley has endured, to autistic people who cannot communicate for themselves? To what extent can we support the family who cares for an autistic person without exploiting the vulnerability of the person who does not speak? To what extent are we ignoring the scientific evidence that states clearly that all autistic children progress without treatment?

People assume that the autistic person is “suffering” because of autism. Perhaps we do not consider enough, that the source suffering comes from frustration, lack of accommodation, and
being treated as less than a full-member of our society, instead of persons with the same rights to access, and the right to be protected from such “treatments” under the law. Canadian governments are supporting a type of therapy based on one randomized study and anecdotal evidence from parents, forgetting that the fraud, Bruno Bettelheim also once had a long-waiting list of clients. While parents have “the noblest intentions” (I will include myself in this reference as I am a parent who believes I am doing the best for my son without fully understanding autism -- using trial and error approaches in order to teach him), we are left with the decisions to raise our children with little guidance and on the other side, little support and protection of people with disabilities under the law. A framework of prejudice shrouds our children, influencing the way perhaps we, and others, look at them, deal with them, and teach them. What if we could practice a letting go of all our assumptions?

For the parent who believes that their child is suffering, or that the “burden” of raising a child with autism is overbearing, the debate is based on a fundamental question: what constitutes quality of life? Based on differing belief systems and assumptions about disability which, in my opinion, turn into prejudices about disabled people, the question is answered differently. If we evaluate the dis-abled as “unhealthy” and as such using the World Health Organization’s definition of Health Related Quality of Life against them, then it will be assumed that every dis-abled individual has a poor quality of life. We know that society en masse, does believe that as a truism as evidenced by overwhelming public support of The Ashley Treatment as seen on Larry King Live on January 12, 2007:

*LARRY KING:* The parents consented to some questions submitted in advance which I submitted to them today.

*We'll show them on a screen and give you some of their answers.*

*I asked them, "What made you take her to the doctor the first time? Were you surprised by the diagnosis?"

*They said: "Long story. Some other time."*

*I asked them if they consulted with family members and the answer was "Ditto."*
I then asked what kind of criticism they have received from people who have learned about this through the Web site.

And they said, "We have received 3,600 plus private messages. They continue to flow at the rate of 200 a day. Ninety percent plus in support of Ashley's treatment. Today, we posted on the Web site some of the 10 percent or so that we've been able to read. Many of the support messages are from families who have direct past or present experience with disabled children. Their testimonies are a real life illustration of the substantial benefits this treatment will bring Ashley and hopefully others."

In contrast, as reported by those with disabilities:

“...people who lose functioning as a result of disease or accident typically report, despite initial disruption and feelings of loss, increasing satisfaction and proficiency with the passage of time, whether or not they receive a particular health intervention....The lives of people with disabilities are assumed to be of low quality, whatever environmental factors mediate the impact of their impairments, and their own testimony to the contrary is seen as inherently unreliable.”

– from Quality of Life and Human Difference, (Wasserman, Bickenbach and Wachbroit)

Until we can eliminate prejudice and assumption, we cannot define “quality of life,” based on health as we assume it is related to disability. Simply, if we do not understand disability, and in particular, sentience in an individual who is unable to communicate, we will never understand the way they experience and see the world. The best way to get an inkling of understanding is to include the voices of the dis-abled in these dialogues. Joni Tada, a quadriplegic herself, unfortunately made an incorrect reference to autism on Larry King Live, (an autistic who flaps his/her arms is no different than a deaf person who cannot hear, therefore, is hardly "undignified" because of it) so I understand some have corrected her inaccurate understanding. However, she was included in the discussion:

JONI TADA: I think you need to remember that society, if it can find a way to cut costs by removing proper care for people with disabilities and instead place it with these surgical removal of
body parts, society will do it. Given the opportunity, society will always move in the direction of convenience for the masses at the expense of people with disabilities.

We have heard the discussion about human rights here. And I have heard one expert observe that -- well, Ashley has no cognitive ability. She does not experience human dignity. Well, then let the Alzheimer's patient run around naked. Let the boy with autism flap his arms with no intervention. Let the mentally handicapped eat off the floor. We need to treat people with disabilities with respect, even if they do not have the cognitive ability to understand or feel what that dignity is all about.

Steven Rosnbaum is a disability rights attorney also interviewed by Larry King with a son with the same dis-ability as Ashley:

**STEVEN ROSENBAUM, DISABILITY RIGHTS ATTORNEY:** You saw pictures of my son earlier flashed in the background, that's David. Where I stand is I reject Dr. Diekema's notion completely as does the disability rights movement, the ADA, Americans with Disabilities Act tells us and Alan now says United Nations treaty that it's about humanity, it's about dignity, it's about quality of life, with whatever supports or accommodations are needed. It's not about Joni -- I'm glad Joni's living the life she is but Joni's message is right, we have to look at all people regardless of the severity of disability and give them the opportunity to develop the best they can.

**DR. DIEKEMA:** I think what's dignified, what is humane and what's quality of life will depend on where you sit...

There are always people who will claim we're playing god. We -- we can't help but play god in this world and in medicine. Every time we intervene in the course of patient's care, we're playing god. When we put a child with Attention Deficit Disorder on medication we're playing god. When we choose to treat pneumonia, to a certain extent, we're playing god.

My personal opinion, as somebody who has strong religious beliefs is that god's intention is that we use the tools we have to do what we think is best for other individuals. And in this case, that meant asking ourselves whether these three things that the parents were asking for would benefit their daughter and benefit
their daughter in a way that justified any potential harm.

Where is the line drawn? Why the compulsion to eliminate all “suffering” when it is so difficult to determine in that which we do not understand?

I will end with some quotes in the New York Times Letters last week regarding the article “Screen All Pregnancies for Down Syndrome, Doctor’s Say,” on January 9th, 2007:

“I was appalled at Dr. James Goldberg’s statement that to some couples, losing a “normal” pregnancy is not as problematic as the birth of a Down syndrome child. The issue at hand is not a political one, but rather the fact that all children have the potential to provide joy to their parents’ lives. While I’m sure it is distressing to discover that your baby has any kind of “abnormality.” The idea that a miscarriage of a healthy pregnancy is a better “option” than giving birth to a child with special needs reeks of ignorance.” – Lynn Ryan, White Plains, N.Y. and;

“Of course, younger women should have the option of having prenatal tests for Down syndrome and other abnormalities. But as the mother of a lively, lovely 16-year-old daughter with Down syndrome, I’d like to hope that doctors won’t just present the “down” side of having a child with special needs. Yes, there are heartaches and worries, but how is that so different from parents with typical children? Our daughter and her friends are quirky, funny, opinionated teenagers who are learning job skills and dreaming of having apartments of their own. Your article doesn’t mention the bottom line: that most women choose to terminate a pregnancy that reveals the possibility of a Down syndrome baby. I have nothing but deep compassion for women struggling to make this choice, but I’d like them to know there is a lot of joy mixed in with the challenges of raising “special” kids.” -- Jan Farrington, Forth Worth, Tex.

I’ll second that.
January Has Gone to The...

The beginning of 2007 has been the most delirious of new year beginnings. I believed I mentioned a lovely family holiday -- all twenty of our family down south -- and Adam enjoying his cousins. As soon as we returned, I underwent knee surgery the following day. Three days later, we acquired our awaited puppy, Kiki, when the unusual warm and dry streets of Toronto, because of the knee surgery of course, turned to ice. So I fell, irritated my knee and was down two more days. Then, I acquired the stomach flu this past week, and yesterday, Adam underwent the same. This is why I will endearly refer to January 2007, the RIDICULOUS month.

Yet, I have the perfect antedote for any ailment: get a puppy. There are no excuses, no possibility of sitting too long. Kiki arrived in her eighth week. A goldendoodle, she has a great temperament and is easily trainable. We are training her to be a "companion dog," for Adam. She arrived teething, nipping and of course, jumping all over us. Thanks to Henry, who read all the puppy training books there may be on the market (he made up for all the Penelope Leach books he didn't read), he was ready. Kiki doesn't have a chance to chew on our furniture, jump up on the couch, or...
jump on our visitors. Henry took hours training her, "behaviourally" of course. Sit, off, lie down, wait...all are part of her everyday repertoire now because of him -- and we've only had her for two weeks.

"This is operant conditioning, you know," he says to me with a wry smile, Kiki sitting obediently at his feet, looking up at him. "She's a good dog," he says with a look of dumb puppy love. "I have to say," he sighs, "it is pretty gross."

"What is?"

"To think of teaching a person this way."

I shrug. He knows my feelings so there is not much more I can say. I am too tired, my knee up on the couch with two pillows. The obedience trainer has enlightened me to the dog's world -- how the Alpha Dog let's the pack know who's boss, and how to teach a dog who's Alpha in the home, and what is expected. The means of training a dog is not unfamiliar to what they already experience within their pack. When the trainer comes and I express my trepidation of being too harsh, I watch a video of "puppy training" on the couch. The dogs are shown in their natural environment. A firm but gentle nudge to show whose boss is enough to have a good puppy.

Anyway, it's all about the dog, the knee and the stomach flu this month. I look forward to smoother sailing ahead.
When I was curating the exhibition this year, I considered doing a type of virtual reality room, with autistic people designing sensory types of areas so the "language" of autism could be experienced by those who do "not speak" autistic. I still think it could be an interesting project, with contributions like the one below.

When I saw this video recently, I thought it was brilliantly executed -- bridging that ever imaginary divide between what we believe autism to be and what is. In My Language is not only intelligent, it is beautiful to watch.

In My Language

Disability By Design?

As I sit an recuperate from my knee, using the latest in technological advances, I imagine all of us I-Pod, Blackberry people as the new Borg, hooked up from head to toe. For those who are autistic or disabled, the phenomenon may be no different. Ladies and gentleman, let me introduce ESP: The Emotional-Social Prostheses for autistic people.

The advent of virtual reality, computer devices and software, has made a world difference for many people with autism and many other developmental disabilities. From online high schools, where individuals are not judged for how they appear, and who can excel from such an “environment,” from the very software programs that my own son Adam uses to exemplify that he understands what is being asked of him -- that he can answer more in that forum than he can from a “real” person in the
moment -- our environments are definitely changing.

When I first heard of the ESP device, I scoffed. I considered that my intuition might take on numerous physiological responses to a situation, not just the reading of a face. Be it the proverbial “gut reaction,” or “second sense,” I can’t imagine that ESP will be able to replace those senses while “face reading,” let alone mind-reading.

In our home, we have used the face-reading programs that Simon Baron-Cohen has already developed at Cambridge, and while I’m convinced anyone can study faces like dictionaries and rote learning can be a segue to real understanding, I am unconvinced that autistic people have difficulty understanding emotions and human interactions. In exchange for this popular view, I am more convinced that autistic people understand emotions quite fine. While unable, perhaps, to express an “appropriate” or expected “social” response, or "real-time" response, it seems apparent that autistics can register and understand human interaction, if simply different in responding or conveying the processing of that information in a typical way. What perhaps might be expected of an autistic person is a more deliberate way of teaching meaning for the expected social response (if the autistic adult chooses this). In return, society can do its part to understand autism so that this is a true compromise, and autistic people are not judged because of an atypical social response. This would make for an authentic empathy lesson.

I am thinking the ESP device might be an excellent tool for me to use, as long as it comes in a variety of cool colours, and can fit into my evening bag. I mean, I can decode faces just fine, thank you, but some assistance with mind-reading would be welcome!! Imagine being able to “decode” Mary Sue’s “I’m so happy to see you schmoogy schmoogy kiss” to its real meaning (oh God, there’s Estee and I have to say hello, let’s make this quick!). Seriously, I’m not sure if we all want to know what many of our friends and associates are really thinking, do we?

The ESP device, being developed by Rana el Kalibouby and Rosalind Picard, might be affixed to a baseball cap of a pair of...
sunglasses, writes, Jennifer Schuessler in the New York Times Magazine (December 10, 2006): “It consists of a small camera mounted on a cap of glasses that monitors a conversations partner’s facial expressions and feeds the data into a hand-held computer. Software tracks the movement of facial features and classifies them using a coding system developed by the psychologist Paul Ekman, which is then correlated with a second taxonomy of emotional states created by the Cambridge autism researcher (and Ali G cousin) Simon Baron-Cohen. Almost instantaneously, the computer crunches each raised eyebrow and pucker of the lips, giving a whispered verdict about how the person is feeling….

El Kaliouby’s system, which is currently being tested on teenagers with high-functioning autism and Asperger’s syndrome, has an accuracy rate of 85 per cent when reading the emotional state of trained actors, though it drops to just 65 per cent for ordinary people. While the technology has a way to go before it is ready for the market, el Kaliouby is already thinking of ways it could be using in helping everyone ‘move up the spectrum’ defined by severe autism at the one end and off-the-chart emotional intelligence at the other. Cocktail party bores and dinner-table droners beware: el Kaliouby envisions a ‘Bore-o-Meter’ that might, say, cause your cellphone to vibrate when software senses that your conversation partner’s eyes are a glazing over….

Anything that creates this bridge to understanding or getting any kind of edge in this world, is welcome in my home. I am grateful for the many technological advances from which Adam can benefit. I’m also very interested in technological advances aimed at assisting Adam, but with the understanding of autism, or at least the quest to a greater understanding of autism, that backs it. Until I see ESP in action, and based on the computer program Adam has already used, ESP may be DOA. But I’ll be fair. I’ll wait to see it in
ESP may also lead to greater ideas, initiated by autistic people, if they are truly to be workable and meaningful accommodations that benefit autistic people as opposed to non autistic people. I am all for greater access for all disabled individuals. I am very interested in the “Wheelchair Car,” otherwise named the Kenguru, which looks something like the Smartcar where a wheelchair can roll right in and start driving. It offers the long-awaited accessibility for many disabled people in wheelchairs. At $12,500 and environment friendly (it’s electric), the government should think about subsidizing at least part of the cost.

In the meantime, I think we are doing just fine without ESP:

*History has repeatedly demonstrated that empires seldom seem to retain sufficient cultural self-awareness to prevent them from overreaching and overgrasping.*
They have neglected to recognize that the true power of a successful culture resides in its example. To take it successfully, a society must be self-aware." (Jane Jacobs, Dark Age Ahead, p. 176).

Nature Has It "Own Sweet Reasons"

Atop The Gorge

For all the yearnings, all the hope,
The brook still moves the flow
From up atop the rocky cliff
To down the gorge below...

The roar of water as it falls,
Is heard above the mist,
And this just goes to show how much
That nature does exist.

The trees grow out of rocks and cracks,
With tiny bits of earth,
And seeds then blow atop the gorge,
To give some new trees birth.

The cycle goes through many years,
Through many storms and seasons,
But nature does not tell us why--
It has its own sweet reasons.

-Brian Henson is an autistic member of The Autism Acceptance Project
Statement

The past decade has witnessed an accelerated tempo of NIH funded research into the causes and character of autism. However, without exception, NIH funded research has approached autism from a perspective of pathology: Autism is envisioned as a disease to be cured and autistic citizens are characterized solely by their deficits and impairments.

Consider a contrasting and highly successful model for scientific inquiry:

"Twenty years ago, most scientists associated old age with decline and disability... Today, the concept of aging has been transformed... An important root of this shift in thinking can be traced to 1984, when the MacArthur Foundation brought together a group of scientists from widely disparate fields - physicians, psychologists, sociologists, cell biologists, and others - to mount an intensive, ten-year study of aging. This group, the MacArthur Network on Successful Aging, took a simple but radical approach to its research. Rather than focus on the problems of disease and disability associated with aging, which was the accepted approach of gerontological research at the time, the network chose to study people who age well."1

We believe that the scientific study of autism needs to be radically reoriented, just as researchers in the MacArthur Network on Successful Aging radically reoriented the scientific study of aging. Rather than continuing to conceptualize autism as a disease, we believe that NIH must begin to conceptualize autism in the same human rights perspective as it conceptualizes sexual orientation (which up to 30 years ago was, as autism is now, considered a severe psychiatric disorder). Rather than continuing to support studies aimed only at investigating autistic deficits, we believe that NIH must begin to support research that investigates autistics' unique strengths. And rather than pathologizing the biological and behavioral differences between autistic and non-autistic citizens (many of which are no greater than those between males and females), we believe that NIH must begin to embrace the diversity that autistic citizens embody.
We admonish NIH to meet these goals for future autism research:

to understand autism as a neurological difference that results in atypical modes of perceiving, thinking, and acting;
to identify empirically the strengths and competencies that autistic individuals possess; and
to provide the scientific answer to how autistic individuals can develop and live successfully – as autistic individuals.

There can be little doubt that such a re-conceptualization will result in autistics leading more fulfilling and respected lives and non-autistics living more harmoniously among autistics.

Please sign by clicking here.

SATURDAY, JANUARY 06, 2007

Celebrating Autistic Children Every Day

For all the parents who work so hard to provide the best opportunities for their children, who love them, who have undergone confusion and fear, who choose to live with joy and pride, who want a world of tolerance and acceptance where our children can be educated and contribute to society, and whose children may need further accommodations in adulthood, I propose we talk honestly while protecting our children’s best interests and self-esteem.

"Joy doesn’t come without struggle," I wrote when I chose The Joy of Autism. Joy is a choice, and the joy my child continues to bring me is the engine behind everything. These pictures reflect our journey with autism every day. Adam trying to kick a soccer ball after repeating over and over again (and thank goodness for Kevin of Sportball who convinced us to stay when I was about to leave the first day when all the kids were staring at him. He encouraged me, said Adam was doing great and even if he had to stay and watch on the sidelines that would be a good thing. Well, it was, and Adam began to learn soccer), his love of books and reading, his joy of watching the sand drip through his fingers, his innate curiosity, his fourth birthday celebration last April, his joy of dance at his cousin's Batmitzvah. His smile, his soul...is everything. Thank God
for him. I do not share the sentiments in The Autism Every Day video as its director Thierry suggests. I had my moments, early on with autism when I didn't understand it as much as I do today, when I was angry and confused, but I never thought of taking Adam's life because of autism. Adam is my life, my world, my everything -- *my autism every day.*

Even if you have a bad day, there are a multitude of others that make us content and happy. What are your joyful moments? For all the worry and work you do, name those stupendous, maybe subtle moments that elate you, for the achievements of our children are momentous occasions!! What price do we, and our children, pay by not celebrating them?
Friday, January 05, 2007

What Are They Thinking?

Autism EveryDay and Autism Speaks -- Stop Speaking for Autistics Now!

Let me go on the record right here and right now: I protest this screening of the Autism Every Day video at the 2007 Sundance Film Festival. While I believe it is a parent’s natural reaction to experience a period of mourning, and that some parents find it harder to cope with difference and disability than others, I do not agree to stage this film as the real representation of autism as it is harmful to autistic people, does not include their voice, and as such, does not fairly represent them.

I hereby stand to protect my son from the harm that this video is causing by creating a devastating message about autism that then gets reported by the media. I believe Christschool has produced a video that we should all watch. I also urge all of you to add your comments to me by email or herein that I will gather to send to Sundance.
So I am recovering from knee surgery. I had a terrible reaction to the anaesthetic which has now thankfully let up.

The day before yesterday (surgery day), our flight was delayed for two hours. We left my in-laws Miami condo at nine in the morning to return to Toronto a mere eight hours later -- what should have been a four hour trip all 'round. Adam was fanatastic. We walked around the airport, we watched the airplanes take off, we played games and ate Adam's favourite: potato chips. On the plane, Adam initiated a game with me. He beamed and asked "Make a face!" So I crossed my eyes and stuck out my tongue. He found it hilarious (and thank goodness no one saw me because I was acting ridiculous!). He kept asking me "make a face...make a face!" I kept making them. So I told him, "Your turn. Make a face!" He tentatively stuck out his tongue a little way out. I was elated. My son had made his first face intended for my laughter! He was laughing with me.

I decided on this trip to show Adam how to draw objects. I have so far, taught him to draw a happy face, a snowman and a house, using a triangle, square and rectangle for a door, reading somewhere sometime ago, that using shapes and putting them together to make a cohesive whole might make more sense for Adam. Sure enough, Adam has begun to imitate such drawings. However, I decided in the airport to ask him to draw objects I have not taught him how to draw: a boat, a tree and a butterfly. He could draw them. Sure, his mast was a triangle that didn't quite meet up with the bottom of the boat, but I don't care! My son's world is expanding!!

Adam spent his nearly two week vacation with all of his cousins and his half-siblings. He played with all of them, and they got to experience his affection, his happiness. Adam really does make everyone around him smile. These wonderful moments, along with the same tough days(arginually)that we experience with all growing, little children, is the autism we experience EVERYDAY.
Let Sundance See The Dignification of Autistic People and the Videos produced By Autistic People

Other Autism Reality Shows can be found on PosAutive. I strongly suggest Sundance take a look at the hundreds of videos that try so hard to achieve the respect and dignity for autistics that children and adults deserve.

Let Sundance See the Dignification of Autism in the Media:

This recent article on an autistic 5th grader, or

and this article that I recently appeared in January 2007 issue of The Village Post.

And this homespun autism awareness video among many others:

Autism Awareness video 2

Or the recent wonderful book by Ralph Savarese

The "real autism" is the face of life itself -- with ups and downs, sorrows and triumphs. Autistic people are not tragedies. The real tragedy is that there are people who continue to represent them as such.

Disease: The New "Normal?"

I have been in Miami this past week -- Adam enjoying the sun and beach. He listens, expresses himself just fine. I watch in this atmosphere with a sense of relief at how relaxed we all are. It is a far cry from those early first months of initial diagnosis.

Yet, there is something else here amongst the crowd of retired snow birds: it is a little pain here, a little pill there. Or perhaps, it is a story I hear, among many, a grandchild with some kind of
diagnosis -- from autism to ADHD and many other childhood "disorders." I know there is a great deal of contention over this issue: is autism just better diagnosis (or more liberal diagnosis in order to get some kind of subsidized service), or is it a combination of environmental and genetic factors?

While we continue to turn to science to find the answers to our hovering questions, I have to ask, where do studies in social evolution come into play in our discussions in how we influence science? From bias, to flat-out prejudice, to financial opportunity, how much do WE influence the understanding about not only autism, but about what it means to be human? For those of you who read my blog, you know my view is that we influence everything that has to do with our views of autism and the direction of scientific research.

I have a healthy skepticism about our medical system: I do with the information what I want and I don't trust doctors very much. You go in with a complaint and expect to be medicated, or at least offered a prescription. So it was interesting for me to read this article in the New York Times this morning: What's Making Us Sick Is An Epidemic of Diagnosis:

"Americans are living longer than ever, yet more of us are told we are sick. How can this be? One reason is that we devote more resources to medical care than any other country. Some of this investment is productive, curing disease and alleviating suffering. But it also leads to more diagnosis, a trend that has become an epidemic.

This epidemic is a threat to your health. It has two distinct sources. One is the medicalization of everyday life. Most of us experience physical or emotional sensations we don't like, and in the past, this was considered part of life. Increasingly, however, such sensations are considered symptoms of disease. Everyday experiences like insomnia, sadness, twitchy legs, and impaired sex drive now become diagnosis: sleep disorder, depression, restless leg syndrome, and sexual dysfunction.

Perhaps most worrisome is the medicalization of childhood. If children cough after exercising, they have asthma; if they have trouble reading, they are dyslexic; if they are unhappy, they are depressed; and if they alternate between unhappiness and
The other source is the drive to find disease early....

Most of us assume that all this additional diagnosis can only be beneficial. And some of it is. But at the extreme, the logic of early detection is absurd. If more than half of us are sick, what does it mean to be normal? Many more of us harbour "pre-disease" than will ever get disease, and all of us are "at risk." The medicalization of everyday life is no less problematic. Exactly what are we doing to our children when 40 per cent of summer campers are on one or more chronic prescription medications?

No one should take the process of making people into patients lightly. There are real drawbacks. Simply labeling people as diseased can make them feel anxious and vulnerable -- particularly children.

But the real problem with the epidemic of diagnosis is that it leads to an epidemic of treatments. Not all treatments have important benefits, but almost all can have harms. Sometimes the harms are known, but often the harms of new therapies take years to emerge -- after many have been exposed. For the severely ill, these harms generally pale relative to the potential benefits. But for those experiencing mild symptoms, the harms become much more relevant. And for the many labeled as having predisease, or as being "at risk" but destined to remain healthy, treatment can only cause harm.

The epidemic of diagnosis has many causes. More diagnoses mean more money for drug manufacturers, hospitals, physicians and disease advocacy groups. Researchers, and even the disease-based organization of the National Institutes of Health, secure their stature (and financing) by promoting the detection of "their" disease. Medico-legal concerns also drive the epidemic. While failing to make a diagnosis can result in lawsuits, there are no corresponding penalties for overdiagnosis. Thus, the path of least resistance for clinicians is to diagnose liberally -- even when we wonder if doing so really helps our patients." (Essay by H. Gilbert Welch, Lisa Schwartz and Steven Woloshin, NYT, Health &
We know we have an epidemic of autism diagnosis. I am wondering if, with the help of others, we might calculate the income of this "autism economy" to see just how much others are profiting from pathologizing our children. I look back and consider the autism diagnosis, how it made me look at every one of Adam's behaviours as being the result of autism, and today, I laugh. Adam is a healthy 4 1/2 year old who is still not fully verbal, but otherwise a normal kid. When he gets upset, it is because maybe he wants something, maybe he's naturally upset or sad, maybe he's learning to cope with all of those big emotions in his tiny body that we learn to manage (or not) with maturity, or maybe he's just plain tired and has reached his limit. Surely, autism has its set of challenges for both a parent and a child, and each of us as parents, are dealing with a slightly different set of challenges for each of our children. Surely, we mustn't ignore what it takes to accommodate our children to enable them to communicate, learn to socialize, or whatever needs to be addressed. The bulk of the responsibility to accommodate, seems to lie with parents and educators, for I have not seen or experienced any medical professional yet who has done anything to de-stigmatize or accommodate our kids. I can teach Adam to communicate using a computer. He can show me how much he knows (and I am continually floored at how much he knows and understands when he using educational programs) on the computer. He can learn how to use a program, a new mouse, faster than many an adult. As his parent, I can figure out how he learns with fill-in-the-blank sentences. I can "backward chain" a sentence until he says it fully by himself. It is a process of learning that I can figure out with him. It takes my time, my patience, and my utter faith in his intelligence and ability.

Two nights ago, Adam said on his own "I love you mommy," (more like I wa you mummy). Quickly after, he went back to splashing water in the tub with his throaty little bird sounds. Among the many other sentences he works so hard to utter independently, it goes to show that the teaching, the exposure to many words and sentences, the reading, the computer programs the "text-rich environment" that we provide for him, may be working.

I am about to go into knee surgery on Thursday. Apparently I "have arthritis" in my knee that I’ve suffered four dance and ski injuries. I’ve gained some weight because I haven't been running
this year (I've lost some since those news clips you might have seen). For years, I've been avoiding surgery to correct my patella that initially popped out for the first time dancing at age fourteen. On the eve of my 42nd birthday, coming up in March, I decided that the constant swelling and limitation in my physical activities warranted surgery. My first surgery. My first general anaesthesia. My first "letting-go" to a medical professional. May he be good to me!

Sometimes we need to let go, but not without a fight when it comes to decisions about health and our own well-being. We need to resist all attempts to limit life, to categorize it, and ultimately in autism, to limit the many opportunities that all our children rightfully deserve.

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**You'll Be In My Heart**

Thanks "Aspie" for this charming video, inspiring enough to begin the year anew. Children light up our lives, our days, and for me anyway, are the engine that drives me on my most difficult days.

May it be a good 2007 for all parents and children everywhere.

**Kids**
What do you say?

More often, I receive a call from a parent with a newly diagnosed autistic child. I remember my first weekend, when I first heard the word "autism" outside of Hollywood context. All I could picture was the doom, the life now "limited" to "dealing" with disability. The weight of the perceived "restricted" life felt so heavy I could barely breathe. I know that every parent reading this remembers the day when the word autism was actually uttered like remembering where you were and what you were doing at the time of 9/11; the moment when time stands still and we catch a glimpse of mortality.

Now three years later, I am far enough removed from that place that I can look back objectively and consider the journey we've taken, but not so far that the pain is far from memory, or the tears of worry still don't occasionally trickle out of an eye. In the world of dis-ability, the shape of pain changes.

So what do I say? I first ask what they understand about autism. I ask what they've heard, and what they have done thus far. I then begin to tell them that autism is different for many people, and like any family, decisions about care, education and therapies will be individual. I like to refer them to other autistic writers and advocates, because they are the real experts in autism and teach me so much. I talk about our personal experiences (some of which you can read in this blog). I urge parents to explore what works
So why the tear I mentioned earlier? Do I wish Adam was not autistic? Do I wish for what I don’t have, what he is not? Or do I focus on what is and what I can do and rather than what isn’t our reality. Even more than that, what I feel I can’t seem to express well enough here tonight, is that there are gifts in the very things that we originally think are not gifts at all. There is beauty. There is joy.

In finding all of that good and sweetness in the child that I do have, I care strongly about the way people view him without knowing him, without taking the time to look and see beyond the "category," and the way people put the onus on this little child to fit in, instead of thinking about what he needs and how he needs to be accommodated in order to be a successful little boy. Most importantly, I want him to feel good about his life and, ironically, that he be provided the accommodations so that he can fit in if he so chooses, and in his own "size." At four and a half, I have been able to provide the supports that seem to be given to the little children more readily than when they become older. Soon, as he enters an integrated primary school, the blows will come. No parent can protect a child from everything. That fine balance between advocacy, protection, and accepting our children's right to be individuals and figure it all out...well let's just say I don't expect to be the perfect parent.

So what can I say to a parent of a newly diagnosed child with autism? It's an uncomfortable place to be, actually, because I do not like to appear as all-knowing as many "experts" like to appear. I still await more years, more experience, more scars and of course, many more successes. All I can offer is the information that we, as a society, do know, state the issues, list the therapies. All I can state is my own messy journey in autism, as messy as any family's and as trial-and-error based as parenting can get. And
then I want to say...carry on! Life with autism can indeed carry on, even joyfully. Indeed, it could carry on much more easily if we lived in a more tolerant and accepting world.

On that note, it is heartwrenching to watch a society march heartlessly on with messages that do nothing but spend precious human lives to justify their own incompetencies, their research, or their need for pity. As happy as I am with my son who is autistic, we live in a world that is not very easy for autistic people -- for those whose disability appears so visibly on the outside to the person whose disabilitiy is "invisible" so that a family or society does not think enough about accomodation.

Also, while it is perfectly okay to work through feelings of confusion, grief and worry as parents, it is simply not okay for people to go out in public and talk about autistic people as if they are nothing, have nothing inside, know nothing, or have nothing to contribute and that if they do, they are anomalies, or "not autistic," in order to receive pity or support. I consider all the worry and tears I shed in my first days, when I realized that Adam was autistic but didn't really understand what that meant. All of those messages are incredibly pervasive -- they infiltrate the media, they propogate research projects that get publicized by the media and get funded by some charities, they get purported by some families in order to receive funding for their preferred type of therapy, they go to Hollywood and then presto -- they enter mainstream consciousness, or ignorance, about autism.

The popular image of autism is dark and "mysterious." The image of autism is dehamanizing to the point that those very parents who want to get that funding, who want desperately to BE RIGHT, will say that a person is not autistic if they can speak or read or write. No -- those people MUST be savants!! If they are not dysfunctional enough, they are even less human than autistics because they do fit into the "devastation criteria." If they are not savants, (and those who read and write are not savants, btw), they fall into an abyss. They are the supreme nothing, unworthy of this pitiful pity, and then publically besmirched. We are witnessing the most horrific arguments about humanity ever -- these dangerous attempts to categorize humanity and worth, all while these same groups will use the statistics which lump these very "categories" of human in order to bolster their epidemic numbers.
The real autism is diverse. It feels, it speaks, it has a voice and an opinion...it is like all of us -- so utterly human -- the same, while different, indeed what being human is all about.

Christchurch made another poignant video, about the effects of what the devastating messages about autism create.

THE CONSEQUENCES OF DEVASTATION RHETORIC

You can read a news report about the Gravelle case here.

To all my fellow bloggers and readers, have a very Happy Holiday.
This is The Autism Acceptance Project's Card to you:
May we all appreciate the life we have, and never disregard the dignity of others. In appreciation, I direct you to Lisa Jo Rudy’s What Do You Love Best About The Autistic Person In Your Life, now at 88 comments last I checked. It is a wonderful way to celebrate our autistic family members, and appreciate the lives we have with them.

Also, in appreciation, if you want to feel uplifted, visit PosAutive for more inspiring autism stories.

TUESDAY, DECEMBER 19, 2006

TAAPrject in the Media

Here are some of the clips I could get from the Joy of Autism: Redefining Ability and Quality of Life event and The Autism Acceptance Project. What’s missing here is Gill Deacon’s beautiful introduction of me prior to this interview, in which she uses the story by Emily Pearl Kingsly: Welcome to Holland. It was a lovely introduction and did put a tear in my eye. You might also want to read this story Farewell to Holland, a response by another parent to that story, which is also terrific.
Also missing is the ten minute interview on CP24 with Anne Rohmer.

The Autism Acceptance Project on CBC

The Autism Acceptance Project on CTV

The Autism Acceptance Project on CityTV

What is "Good Practice?"

I am borrowing the title of this blog from Dr. Rita Jordan and Stuard Powell, from their book *Autism and Learning: A Guide to Good Practice*. I hear it used in references to teaching methods that still remain unproven as "effective autism" teaching methodologies -- preached like gospel. Repeated over and over again, the term has become a meaningless cliche. So if we are going to use it, how do we define it, as we continue to know little about autism? It seems we all want good practice, but in advocacy and "fact sheets" the term is used abitrarily and no one can truly define what it is with regards to teaching autistic pupils. As Jordan and Powell note, however, it is governments that want to hear it. I appreciate this book and how it gives some practical and sensible answers to re-evaluating ourselves in how we approach and think about autism, and respects the learning style of the person.

I have summarized some of the first chapters for those who have not yet read the book, in hopes that educators will pick it up:

"With increased public awareness of autism and the proliferation of one day courses and seminars, many teachers are developing at
least a cursory knowledge of autism and its implications. This is a positive step, if it leads to an awareness of the complexity of the condition and a recognition that there is more to be known both in terms of understanding the condition, and ways of meeting the needs that arise from it. It is less positive if, as is sometimes the case, just the difficulties are emphasized, so that the teacher is left feeling that intervention is pointless or needs to be left to the 'specialists.'...teachers need the knowledge and the support to know when and how to intervene and how to make that intervention effective....there are still numerous examples of where teachers, especially perhaps in the mainstream, either do not fully appreciate the nature and extent of the child's difficulties or are unwilling (or perhaps unable) to alter their own approach to teaching to accommodate those difficulties. Parents of children with autism are still often told by mainstream teachers, even when the child is academically able, that, if his or her problems are that severe they do not 'belong' in a mainstream school. Ironically, it may be the very wish not to separate and segregate children that leads to educationists refusing to 'label' a child or to see the value of a diagnostic category such as autism, which in turn leads to interpretation of behaviour as wilful and the subsequent expulsion when the child fails to conform. We would suggest, therefore, that recognition of autism as a condition with important educational consequences is a first step to creating good practice. There has to be some understanding of the kinds of difficulties that [that autistic people experience] so that behaviour is not misinterpreted and the children's difficulties and strengths in particular contexts (their special education needs) are understood. Yet it is here that there must be an INTERFACE with good teaching. Without the skills of observation, the capacity to motivate and involve, the knowledge about autism will not translate into good practice. The art and science of teaching has to be informed by the knowledge of autism, but also has to exist in its own right. Without it, practitioners are reduced to following set routines and recipes and some home treatment programmes are indeed based on this, so that they can be performed by paraprofessionals and parents. Such programmes have some value (and indeed extensive claims are made for their success), if only that they offer intensive early positive intervention, but they are also limited. 'Good practice' should involve professional judgement and the capacity to adjust the programme to meet the changing needs of the child and the situation." (pp.16-17)...

"Some of those involved in developing the process of accreditation began to have doubts about its validity on the grounds that 'good practice' could not be defined. Indeed, early attempts to reduce the task of the peer reviewers to the ticking of checklists of certain behaviours, did prove abortive as these quantitative assessments seemed to bear little relation to perceived quality. What they did do, however, is highlight the fact that professional and experienced judgements are just that, and their subjective basis cannot be disguised by attempts to provide quantitative ticklists. The objectivity must reside in the selection and training of those making the judgements and the value of the judgements resides in the quality of those making them. In effect, while it may not be possible to define good practice, it is possible to recognize it and it is the experience and knowledge of the observers that determines the validity of that recognition." (pp.18-19).

**The Lure of the Recipe**

"We have already mentioned the dangers that may arise from knowledge of autism that stops with a knowledge of the characteristic difficulties and we have shown that good practice must incorporate both knowledge of autism and good teaching techniques. We would like to mention here another source of danger in the way that some teachers and some authorities adopt training in one particular approach as the training for autism. The particular training packages that are marketed in this way are of variable quality, but our worries do not stem from the adoption of any particular approach, but from the notion that training in any one method will be adequate for developing expertise in working with people with autism." (p. 19)

"Thus, we would want to eschew adherence to any one approach, especially when followed as a set recipe. We recognize that teachers would sometimes wish to know exactly what to do with Johnnie on Monday morning, but we also know that most teachers recognize this as an unsatisfactory solution to their difficulties. An outsider may be able to offer something useful to resolve a particular situation with a particular child (and there will be times when all of us get stuck in our approach to a problem and it helps to talk it over with others and gain fresh insights and suggestions) but most teachers do not want the sense of being de-skilled, which comes from having to follow someone else's package without being
able to adapt or extend it. In our experience, what teachers want is to know what strategies there are available and to understand both the potentialities and the limitations of their use. They want the time and resources to enable them to observe and make their own evaluations of the child and the situation, and they want sufficient flexibility within their work situations to enable them to apply the strategies and approaches their professional judgement dictates.

Many teachers, then, describe the approach they use as 'eclectic' and will go on to elaborate to the effect that they 'take the best from a range of different approaches.' This could represent as teachers suggest, the best of all worlds, or it could be chaotic with the benefits of one approach being negated or unrealized because another approach has a directly contrary effect. It may also mean that no one approach is given a chance and that the teacher does not really understand the rationale for each approach, but only uses some technique that has a difference meaning and value divorced from its proper context....[For example: Option and Lovaas style] On the one hand, they [the children] are being encouraged to make spontaneous moves towards interactive play with an adult and to enjoy rather than fear the experience. On they other, they are being made to conform in a very set way, there is stress in having to identify and produce the one correct response on cue and the adult may dispense spoonfuls of jam but may also dispense sharp reprimands which may even be shouted (from witnessing some Lovaas style programmes). It may seem as if we are suggesting that one of these approaches is better than the other; it is true that Option is more easily accommodated without our approach than Lovaas, but that is not the point we are trying to make. The point is, that to employ both approaches would be confusing and the aims of neither programme are likely to be fulfilled." (pp. 21-22)

"It is not only important, therefore, that what is done fits together into a coherent whole and that each part of the curriculum contributes to the overall aims for the child, but also that there is a principled rationale for teacher one thing rather than another or in one way rather than another. These principles should reflect what is known of autism, what is known of the child, and the overall educational philosophy of the school. They should respect and incorporate where possible, the views of the parents and of the child. This may involve elements that come originally from an
eclectic trawl of different approaches, but the dangers of this are avoided by the principles guiding their inclusion and the way in which they fit together to serve the overall educational aims for that child." (p.22)

I have taken the liberty of summarizing Jordan's and Powell's "Curriculum for Autism," on pages 24-27. "A curriculum for pupils with autism, therefore, may or may not incorporate the National Curriculum, but it should have the following features:

1. It's content should be determined by the needs of the child rather than cultural values in respect to academic subjects adn so it needs to be pupil centred and not subject centred;

2. It will need to give priority to communication and interpersonal areas including the specific teaching of cultural norms and meanings;

3. Functional life skills should be involved from the start (there is no reason why the child should not be sorting knives from forks or socks from pants, rather than plastic bunnies from plastic Christmas trees), although we would be wary of having too low expectations and teaching children of 12 to clean toilets (as happens in some curricula) on the grounds that they will be expert by the time they are ready to take a job;

4. We would also take an eclectic leaf from the Higashi approach (Quill et al., 1989), as well as from British primary school survival tactics and include a period each day of sustained physical activity;

5. a) All centres should look at ways of encouraging integration and teaching the child with autism skills that will help to make this successful;

5. b) There will need to be education for integration into the community and reverse integration where mainstream pupils go to the specialist setting [this] should at least be a possibiltiy;

5. c) There will need to be training in imitation and observational skills, and then a way of providing access to normally developing peers to practise skills, and to have them prompted and drawn to the child's attention in real life contexts;
6. There needs to be some form of structure to minimize stress and promote learning and, in most cases, this is most appropriately provided through visual structure, as in the TEACCH programme;

7. In accordance with our own views of the fundamental difficulties in autism, the teaching approach should be one that provides opportunities for learning to learn. This will involve addressing each of the areas of difficulty and providing direct teaching in areas where intuitive understanding is lacking. **[please note, that there are autistic people who do not agree with the principle of having to "learn how to learn" and this should be understood as there is research going on with regards to autistic cognitive ability and differences in learning styles/intelligence. So I suspect, as we continue to learn about autism, we will become more sophisticated in accommodating autistic learning styles]**

8. Most children will need some access to 1:1 teaching, although there are some who cannot tolerate this kind of confrontational contact (especially if the teacher sits across from the table from the child) and will respond better in small groups. Note that we merely access to 1:1 teaching so that in some cases, the time allocation can be used by the teacher to observe rather than teach. Although children with autism will have particular difficulties in learning in and from groups, this does not mean that they should be shielded entirely from group teaching...**difficulties need to be seen as a challenge and an opportunity, rather than an indication that this aspect of curriculum work should be denied.** [bold mine]

9. It is important that schooling for children with autism does not become a succession of activities devised to address their difficulties; their strengths also need to be developed and encouraged so that we can maximize potential in all areas of development. In the same way, difficulties should not be a barrier to experiences, but rather the teacher should ask of a desired goal 'What support will this child need in order to participate in this activity?';

10. Teachers should try and engender an atmosphere of trust and high expectations, with the trust including an understanding of the
child’s real difficulties rather than a misperception of them as resulting from laziness or aggression, or whatever. Parents are important partners throughout education, but this is even more the case in autism where there needs to be consistency across all settings if the child is to progress, and where communicative and early interactive skills are often best fostered in a home setting;

11. [It is important] that teachers [know] about autism and the kinds of differences in thinking and learning that can be expected as a result, the curriculum should include policies of staff development in understanding autism;

12. We would make a plea for education, not containment or training. We have already stressed how much there is for the pupil with autism to learn and how dependent such pupils are on being taught explicitly. They cannot afford to spend time on occupation tasks, unless there is a specific educational goal of teaching the child to perform the task in a social group independently or faster than before. We have sometimes seen classes arranged and resourced so that the child as 1:1 time with an adult, only to find that it is wasted by the adult not quite knowing how to use this time. The teacher may get the child to perform a task they can already do (mere occupation) or may interfere with the child's spontaneous behaviour, not to extend the play or teach a new procedure, but seemingly because this is the time allotted for 1:1 work. Teaching 1:1 should not be assumed to be like group teaching only easier; it is not! Teachers will need training themselves on how to observe and interpret what the child is doing and, as we point out later in the book, when to intervene and when to hold back.

None of it is easy.....BUT IT IS REWARDING [CAPS MINE], especially if we sometimes manage to 'get it right.'" (Jordan and Powell)

I would love to talk about IQ and overall testing in light of the above. Consider this conclusion to an article in the November issues of GeneWatch, Intelligence and Genetic Determinism, A Brief by the Council For Responsible Genetics:

"Based on findings from current research, further study on brain plasticity and neural development, improvements in learning environments and teaching techniques, and policies which
emphasize support for disadvantaged populations [in reference to ethnicity here] are likely to yield more positive outcomes in school achievement. Contrary to what authors of *The Bell Curve* suggest, key social policies have demonstrated strong positive effects on IQ scores, particularly for disadvantaged groups. Unfortunately, however, a new educational climate is forming. Increases in all kinds of academic testing have overtaken more balanced approaches to learning. Possibly the largest shift occurred in 2001 with the "No Child Left Behind" Act implemented by the Bush Administration. Research has shown that self-esteem directly affects motivation to learn. We will continue to see that performance on IQ and other standardized tests has an effect on the way students are treated and on their self-esteem. Low scores affect the attitudes of teachers and other adults as well, so that this approach may ensure that students who struggle with testing will end up in classrooms and categories in which they won't be expected to improve. In this way, performance on tests, rather than helping children to learn and improve, can become self-fulfilling prophecies or failure for both the children and the adults who are expected to teach them."

We know that there are plethora of tests out there unsuitable for the autistic learning style (Mottron, Dawson), which is why we must continue this drive to support autism and insist on a dignified response and approach to teaching and accommodating autistic people.

I'll end with some videos by "Christschool". They remind us that no autistic person should be deemed "a financial burden on society," and to get on with accepting autism, working to carefully understand it, and by listing a person's needs before resources and before politics. We can accommodate everyone if we break the barriers of bias, misrepresentation and misunderstanding.

Here is the first video which cannot be embedded. You can view it by clicking here. And then this one:

**Modern Day Eugenics**
Tis the Season to be Joyful

Tis the season to be joyful and thankful for the many people I've come to meet over the past year and the achievements made in promoting, with the help of so many others, a better understanding of autism.

The Autism Acceptance Project is currently renovating its website.

After an extremely successful Joy of Autism: Redefining Ability and Quality of Life event, we are already into planning for next year. In addition to three conferences where I will speak --

Giant Steps in Montreal: ASD Perspectives Conference (February)
Come to Your Senses, Toronto (May) and,
The Autism Society of Ontario's "Acceptance" conference (June) --we are also planning a series of events in redefining autism education, and providing a free service to schools to bring in autistic people, their friends and families to speak about autism and to answer the practical questions. Stay tuned for some exciting activities in 2007.

In October, we were so excited to have the following people deliver lectures at the Al Green Theatre in Toronto:

Dr. Morton Ann Gernsbacher
Michelle Dawson
Dr. Laurent Mottron
Dr. Nehama Baum
Ellen Yack
Susan Senator
Valerie Paradiz and her son Elijah Wapner
Phil Schwarz
and Jim Sinclair

And Artists at The Lonsdale Gallery in Toronto:

Jonathan Lerman
Larry Bissonnette
Brian Henson
Mukibaum artists
Autspoken Writers

We enjoyed a concert by autistic musician Michael Moon and enjoyed a month long exhibit and critical analysis of how autistics are represented and viewed by society. Kevin Leitch of Autism Hub was so helpful to me personally in streaming in video from YouTube about Autism advocacy so it could be broadcast to the Toronto Community. Thanks to Dinah Murray, Kevin Leitch and Dr. Darold Treffert for writing endorsements for the project that were posted at the exhibit.

The Autism Acceptance Project is publicizing PosAutive. You can find the press release by clicking here. We also have our video on the PosAutive Project’s YouTube Site:

**The Autism Acceptance Project**

**Redefining Autism** became part of a the media’s theme in covering *The Joy of Autism: Redefining Ability and Quality of Life event*. We received national coverage in the following:

Front Page Feature Story in The National Post: "Redefining Autism" by Joseph Brean on October 7th

CBC's Quirks and Quarks with Laurent Mottron and Michelle Dawson

The National Post Counterpoint "Accepting Autism" on October 13th

CTV's report on the myth of vaccinations causing autism on October 4th

CTV's nightly report on the opening of The Joy of Autism
exhibition with Larry Bissonnette, Jonathan Lerman, Mukibaum Treatment Centres and Brian Henson on October 5th

CP24's interview with Anne Rohmer, October 4th

City TV's Pause for the Cause on October 10th

Canadian Jewish News

Canadian Chinese Television (Fairchild TV) December 31st.

CBC's The Gill Deacon Show on November 28th

The Village Post, January 2007

and more -- there were smaller radio interviews and coverage by Erica Ehm and others. Some of these clippings and video footage will soon be available at http://www.taaproject.com/

Thanks to Ralph Savarese and Roy Grinker for two wonderful books that have recently come to market and to Ralph, for supporting the project as well as Autism Diva, and the many wonderful bloggers I have listed at the side bar of my blog that I read regularly.

Okay...my list of gratitude is longer than you'll want to read, so I'll stop there. I could thank Henry, my family, but they know how grateful I am for their support...I think! I thank all the bloggers, writers, and researchers out there who have done so much to promote a greater understanding of the complexities of autism, but who also believe in accepting autistic people -- conducting research by including autistic people and doing so with respect. Those who participate with a spirit of cooperation have inspired me to do more with The Autism Acceptance Project and our list of supporters is growing. Even when parents and autistic people disagree, it is vitally important to discuss issues with a sensitivity to Personhood. If you want to register for news and information, go to http://www.taaproject.com/and "Get Involved."

Which leads me to the season's greatest blessings of all: my son
Adam:

I endearingly call this photo "Adam and the Nutcrackers." This is a recent photo and soon, Adam will be five.

An older photo of Adam when he was nearly three.

It is lovely to have Adam in my life. There have been challenges, yes, but without Adam, I would never have garnered the positive outlook I currently have. I’ve come to learn that being positive comes in the strangest packages. Without Adam, I would have been stuck in my old box of meaningless expectations and a frenzied life. Adam has lead me to a life that is blessed with appreciation, and purpose. He has taught me to consider other’s perspectives, and he is teaching me more about empathy for
I've been thinking about writing a post about an agreement about what not to say about autism. Because there is so much disagreement, lack of scientific evidence and understanding about autism, I am always struck with the "assurance" of some people on how they can speak about autism. Be in so-called "Fact Sheets" created by parent groups, or some professionals who speak about autism as a disease or condition, with lack of substantial understanding, we have to agree at least about what NOT to say about autism, until we know otherwise. Based on what we do know, I suggest we begin by creating a list that we can all reference when speaking about autism and further, put pressure on the Ministry of Education and others to impose an anti-ableism policy as much as we enforce anti-racism. While the drive towards inclusion is there in words (in the Ministry of Education's Special Education Transformation document submitted on May 6, 2006) we can't enforce autism acceptance, it seems, without an enforceable policy, and a means by which teachers and schools cannot turn away any child, no matter what the disability. Turning away children with autism is happening far too often in both public and private settings. "We don't take autistic children," or "we don't want to look like a speical needs school," is something I hear almost daily. Or "we are far too verbal a school. Your child may have difficulty here." Or my favourite: "we don't have enough space in our school for shadows." While there is intent to accept, there is still a great amount of hesitancy.

Words are not enough. Bad words are even harmful. Semantics plays a role in how people are viewed. So, I've started a list of what we might agree on as a society in how we reference autism, that I thought everyone could contribute to, so this is just a stab at it. It's a draft about what we might agree on, which may lead to a list of others. He is teaching me that there is never one answer, or one way of doing something, but instead, a life of possibilities. As Jonathan Lerman says "there's no such word as can't," and I know that Adam would agree.
what NOT to say in light of lack of evidence, about autism:

1. Agree that murdering an autistic child is not excusable simply because the child is autistic. Therefore, although living with challenged kids is just that, "a challenge," let us not excuse violent acts in our reference to autism;

2. Agree to refer to autism as a disability that requires accommodation;

3. Agree to refer to autism as an ability as education needs to cater to the unique learning needs and abilities of autistic children who are as learning "different" as any child;

4 Agree to reference autistic people as people, not people "afflicted" with a disease or illness;

5. Refrain from referring to autistic people in pejorative terms: "autism is a living nightmare," horror, etc. as it does not connote any respect for the living autistic person;

6. Agree to invest in Understanding Autism and become less fragmented in terms of investigating appropriate teaching methodologies for autistic children;

7. Refrain from using "Autism Treatment" to "Autism Accomodations and Education" in order to respect the fact that we do not yet fully understand autism and the manner in which autistic people learn;

No parent should find it necessary to speak about their children in pejorative terms in order to receive effective accomodations which should be backed up by accurate science. There is a way of acknowledging struggle without spotlighting children in a miserable way. I will quote here from Peter Szatmari, from his testimony to the Senate Committee on Social Affairs, Science and Technology on November 22, 2006, in which Eric Fombonne and Michelle Dawson also testified:

Szatmari: "The first thing is we do not know enough. [bold mine] As Ms. Dawson pointed out, there is only a single randomized control trial of the efficacy of early intensive behavioural intervention. There are not many programs in this
country that have such a large investment that are based on only a single randomized control trial. It works. However, there is a lot of misinformation. I would argue that the 40 per cent cure rate that is often quoted is not really consistent with the data. It is not based on the best-quality study that is available. There is no question that some children with autism spectrum disorder do need intensive early behavioural intervention. It is very expensive. However, not everybody needs it. There are other forms of ABA, if we think of it in the sort of broadest sense of the term, that are less expensive, less intensive, can be delivered in a more naturalistic setting and which are very effective for those children. There are some children who will not respond to any form of intensive behavioural intervention no matter how much you give them for how long a period. They need another form of intervention, and they deserve the right to have that intervention. The key is that we have to match the type of intervention to the type of child.”

Dr. Eric Fombonne: "there are techniques that can be very harmful to the child. Children have died from correction therapy based on the notion that mercury poisoning is causing autism, which is completely untrue. Therefore, we need to provide evidence-based information to Canadian families in order to inform them of what works and what does not...."one approach has been the TEAACH method [showing slide]. This is a patient of mine who is nonverbal, Jacob, but he has been using these pictograms so he can communicate. He does not have any words but he communicates in his family using these pictures. This has been around for many years. The evidence for the efficacy for this method has not been as good as we like, but we have techniques like this that work....What are the factors that will explain the response of a child to a particular treatment approach? ...There are different approaches which may work for some children; others work better for other children. However, we do not know that much yet. [bold mine]

8. Agree that we "learn to do by doing," meaning, that you won’t know how to accept an autistic child into the classroom until you bring him/her in. We don’t have to wait to accept people with evidence;

9. Agree that there are many ways to teach an autistic person;
10. Agree not to use CURE in reference to autism. Agree to invest in **Understanding and Accomodating Autism**, and indeed celebrating the lives of autistic people as a means to humanizing instead of dehumanizing people; (we cannot use the word CURE for many reasons: first being that many autistic people are taking offense and the idea of a CURE does not lead to Acceptance of people. It connotes aberration. Second, like Cerebral Palsy and Deafness as only two examples, autism may not likely "curable.") Look up the history the history of "behavioural treatments" used to "cure" cerebral palsy, which we understand today to be uncurable. Use history as a guide to how we regard people and use our powerful language to support people while we continue to study to understand autism;

11. Change the name of the "Combating Autism" act to "Understanding Autism" act and the language therein;

12. Agree that all parents handle disability differently and that parents require more support as we continue to understand autism;

13. Agree that "being different" is as unique as being human.

I invite more people to add to this list. I intend to make it longer and more detailed. If you want to contribute via your blogs, it might just be a positive step into appropriate representations of autism, and might also be worthy of a press release.

Finally, I want to share a anecdote with you. I was watching the news for a brief ten minutes last night, and there was a commercial, I wasn't paying attention for what, with kids playing karate. In that commercial, there were a number of children kicking and doing their "karate chops," and the camera flashed to a girl with Down's Syndrome. I didn't notice it in the beginning. She was just there with the other kids and I truly didn't think anything of it until about two minutes after the commercial. I thought to myself, "I didn't even notice that she was different," but the moment I realized how unremarkable it was, how she truly belonged in those scenes I thought that this is the place where we all need to be. When we realize that disability is not such a big deal, and that providing accomodations is much easier than we think, we will be a lot further ahead. We only just yap much too long about it.
Imus and his racist rants

Yesterday, I linked a You Tube video showing Imus criticising CBS's "Jewish Management." About an hour after I posted that video with subsequent anti-semitic supportive comments (supportive of Imus' own anti-semitism), the video and comments were taken down.

Here is a link to Imusblog where some other commenters noted his racism. He is accusing "Jewish Management" of boycotting a The Blind Boys of Alabama on his show.

Does this make any sense? Accusing the Jewish people by virtue of stereotyping them and by accusing them of intolerance of disability? It doesn’t make any sense to me. Firstly, two wrongs do not make a right. You can’t stereotype a people and say you support tolerance of people with disabilities. Secondly, it doesn’t make any sense that a people subjugated to hatred themselves would forbid another group of people who do not receive equal rights and tolerance in the world. Certainly, this is only one side of the whole story and Imus seems to have control of the mike.

Imus: Autism's Hero????

I was recently disgusted when I heard this comment about CBS:

Imus Talks About CBS
I am more terrified at the comments that are on regarding hatred of the Jewish people that you can read below that video: click here to read. We all know where stereotyping leads and has lead.

Is this the kind of hero and advocate that autism needs? Someone who hates Jews? Someone who one might deduce, "hates" autistic people? Is this the right way to promote tolerance of our children?

We should all be skeptical about who is talking for whom.

What have we learned about tolerance in allowing such intolerance?

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**UPDATE:**

**In the last hour, the comments I referred to above (the antisemitic comments and video) have suddenly disappeared.** I saved the following comment sent directly to me from my email box from someone named "fullstemahead." This was one of the many antisemitic comments on the YouTube comments section under the Imus video where Imus was targetting CBS's "Jewish Management." Here is the one comment I saved directed at me:

*This coming from a semite. You proud of yourself? Anti-semitism is a moral imperative. Semitic-supremacism must be challenged at every corner. Semite-supremacism will not stand when good people speak up. Thankyou, Mr. Imus for taking a stand for the world. You're one of those fake conservative Harper kooks, likely, like our neocons, insanely pandering to jewish-supremacist cells. How do you like your Adlers, your western standards and your global TV, run by jews, and that spew more hatred for every gentile on the planet. Those semites who have turned the once beloved Canada into a globally ostracized hatefest. Who are you to talk about "hate"? Hate is what were stopping...You Nazi...Shame. Shame!*
Unremarkable Autism

Autism: A "Horrible epidemic" for which we must quickly find a cure? Or rather is autism more unremarkable than what we first thought -- a pandemic proliferated by the conflation of circumstance, interpretation and dare I say it, BIG AUTISM BUSINESS, as charities, and autism cottage industries boon throughout North America, all promising to recover and cure the autistic person?

We have known for some time that autism is a modernist construct, the term invented in 1911 by Eugen Bleuler and then adopted by Hans Asperger and Leo Kanner who both observed their first "autistic" clients in their psychotherapy clinics.

Now we have Roy Grinker's Unstrange Minds, which is an anthropological view of autism. I received a copy of the manuscript a couple of weeks ago and am nearly finished it. Grinker introduces the "new" autism phenomenon this way:

"Between 2003 and 2004 the number of grant applications to the National Alliance for Autism Research, the leading private foundation for autism research, doubled. Through the Internet, people in remote areas of the world read news stories about the epidemic. Media reports consistently refer to autism with phrases like 'hidden epidemic' and the 'mysterious outbreak,' citing the 'exploding number' of autism cases, leading to fears that causal factors such as vaccinations, mercury poisoning, or other environmental exposures (a subject I do not discuss at length in this book) might be contributing to the rise in cases of autism....But is there really more autism, or are we just seeing it more? There are lots of theories around to explain the rise in diagnoses, none of them proven. Some scientists think that the 'increase' is due to more aggressive epidemiological methods that make it easier for researchers to count the right number of cases. Others think that the broadening of diagnostic criteria over the past two decades to include more symptoms, and bigger range of severity of symptoms, has made it easier for physicians and psychologists to fit their clients into the framework of autism...." (p.9)
Grinker's book is about how culture affects the way we view autism. His book is an interesting study of how cultures around the world view autism and how it affects parents, children and politics.

Recently, The Wall Street Journal published **How Many Kids Have Autism?** I need not write it again, as Autism Diva has done so nicely here in her post "Nobody's Fool." Although others have taken the time to dissect the numbers and their sources, it was done particularly nicely in this article.

Then, as parents want to exclude "higher functioning" autistic people from the autism "crisis" debate, it is this very group that can be accountable for their numbers that they use in their arguments to proclaim an "epidemic" of autism. They are brazen at including this group in their numbers on the one hand, and then having them and their parents excluded from the autism discussion altogether.

As for the severity of autism, I've met those who would be classified under such a label. It is not a black and white label either. Recently, Amanda Baggs has been accused by the parents advocating for a cure, or to have the rest of us excluded from participating in the autism discussion, as not really being autistic. You see, if you can communicate at all, despite your disabilities, you aren't autistic according to these folks. It's all quite silly, you see. It's all quite a sensation. As long as fear continues to be promulgated; as long as those who are not affected by autism continue to listen to parents who say autism is a horror, autism will continue to be a "terrible mystery," with dire consequences for our children and autistic adults.
I've met many people on the "spectrum" of autism as a result of The Autism Acceptance Project, and there is something that ties us all together -- that is our humanity. Autistic people are no different than non autistic people. They are no more or less diverse, desirous, aware. You see, the more you look at autism, the more unremarkable it is. It is filled with challenges, yes, as the case can be with any child. It is filled with disability and ability. The worst of it all, though, is the stereotyping, the stigma and potential danger that autistic people face as schools close their doors to our children because of the very so-called "advocacy" that dehumanizes the autistic person, and as parents do not allow autistic adults to participate in discussions about autism. I've heard parents suggest that certain autistic adults "are horrible to look at." I think it is a horror that these very parents suggest that another autistic person, like their very own child, is terrible to look at. I just can't say anymore how disgusting I think that is, because I like to stay positive, and I would like to invite all parents and autistic people into a new discussion about autism and how we want our children and autistic adults to be accepted and included by society-at-large.

So today, as Adam still fights his terrible cough, I found some more unremarkable, lovely, special, autistic children. I thought how wonderful to celebrate them, their differences, the joys. Autism is just another kind of normal. Everything is "normal."

**The face of autism**

**My Autistic Child**

This celebration of difference is also featured in the kids movie *Happy Feet* (Warner Bros.) What a wonderful movie to take all children to as the holidays approach. Maybe a few adults too.
Autistic Adam

When Adam is sick my already protective mode goes into overdrive. His first ear infections, fevers...I never leave his side and I mean NEVER. Early fevers were accompanied with wails in the middle of the night. Stomach flus also in the quiet darkness of three in the morning, were consoled only with the soft moving shapes – triangles and squares dancing to Beethoven and Brahms on a computer generated video. Ear infections turned to his first surgery and general anesthesia for tubular implants. The surgery was a mere fifteen minutes, but I’ll never forget how the insensitive hospital staff would not let me in until he woke up. He hadn’t yet turned three. As I entered the recovery floor, I could hear his wails from down the hall – I knew my son was wondering where he was and where I was. When I arrived, I still could not console him. We had to wait thirty more minutes to leave until his vital statistics were satisfactory. Finally, when I said we were going home, he stopped crying instantly.

So often, parents of very young autistic children assume that they don’t know what’s going on around them – that they are confused. Surely, a disorienting procedure and environment would have one believe that this would be more so when Adam was in the recovery room. But I’ll never forget how he calmed down as soon as I said we were going home. Grandma was waiting in the hallway with a balloon which he gladly took.

When we brought him home, I put him in our king-sized bed so I could lie with him, and I did all day. I would not leave my son for an instant while any anesthetic was still wandering through his bloodstream. Seeing my little guy otherwise so lively and endlessly moving, now still and quiet, was scary. When eight hours had passed, and he wanted to eat, when his eyes became alive again, I was relieved. Adam and his autism were back. The world was right again.

Then, he needed dental surgery for overly soft teeth that were
already decaying despite all the attempts to clean them. Nothing stopped me from doing the exact same thing, except this time, I spent days before calling the hospital to advocate for him and to get me into recovery before he woke up. I asked for a sedative before anesthesia so he wouldn’t have a melt-down (he now was wary of hospital staff doing anything to him). I asked well in advance that I administer the sedative myself (otherwise he would not have received a sedative at all). I knew just the right way to get him to swallow it without spitting it up, without fighting. I advocated to get suited up to accompany him to surgery and to hold him while he was given anesthesia. And, this time, I was there when he woke up. I knew just what songs to sing when he woke, how to orient him enough to let him know that I was there and everything was going to be okay. This time, he got a private room to recover in. He didn’t cry. I know that Adam trusts me. He will run to me first whenever he is scarred or ill.

This is a rite of passage for a parent of an autistic child: learning how to advocate in a way that does not discriminate the child, but instead advocates for the child’s need in a way that others can understand and respect. I don’t just say Adam is autistic as it tends to mean nothing, or leads to a perception where doctors will raise their voices and treat him as a behaviour rather than with sensitivity. I explain the particulars, our experiences and our successes. I can tell you with certainty, it is extremely worthwhile.

I’ve decided to write this section because it occurred to me that doctors, illness has been a major part of our lives since Adam was born – when he was a year old, he had his first terrible ear infection in Florida and went on intravenous. This was my first horrible experience – Adam was so ill for days with a huge fever. Adam was sleeping day in and day out and family was telling me not to worry until I finally put my foot down and said that I was heading for the hospital, and it was a good thing I did. Coming from a family where there are ten grandchildren, people in my family thought they knew everything about parenting and taking care of children, for good reason. But I quickly learned that they did not know about Adam, about his idiosyncrasies, and my instinct was always right on.

I think this first experience for Adam was the beginning in traumatic sensory overloads and just general fear: bright lights, hospital staff holding him down while I tried to console him by
singing in his ear. I cringe as I write this...there is nothing you can do when your very young child needs intravenous or blood tests. I can still feel so helpless and all I can do is offer my presence, my voice, and my hugs. As we grow up together, Adam and I, we are getting a little smarter about the advocacy part.

The last two days, I have been by Adam’s side as he fights the croup again. It happened last year – another first experience with it -- he couldn’t breathe once we got to the doctor’s office so they had to give him an oxygen mask. He was terrified at that mask. With the hands or myself, my mother, the nurse, we all got Adam to sit still enough to take the mask. When we reach the doctor’s office, he hates it and wants to turn around. Today was no different. I said the “doctor will make you better.” He cooperated but not without Henry’s assistance as his ears had to be checked again. But I did notice for the first time today, he began to calm down during examination, where he used to fight a whole lot more. He is growing up, my guy. He is learning that the ear examination will not hurt. It wasn’t something anyone else in the room noticed but me.

So he suffers again today as he watches *Elmo in Grouchland*, only half-there, nearly ready to drift off to sleep, so his little body can fight some more. He probably hates the movie, but he doesn’t care. A healthy autistic Adam would fight for another video – he would open the drawer, grab the one he wants and give it to me. Or, he might say ABC, meaning that he wants an ABC video. You see, when Adam is sick, I always want my autistic Adam back. He is alive, full of vigor, curiosity. How anyone can say autism is like cancer baffles me, if not angers me. How can ANYONE compare autism to cancer?!! As Adam lies beside me as I write this and struggles for air, I bet any parent who is on the brink of losing a child would trade it in for **autism any day**.

I couldn’t be prouder of my son, more in love with any child. It is always natural to wonder what could have been without autism. But autism is here and I don’t mind a bit. I mind the stigma. That part of autism and disability is the heart-breaking part. Here is Adam recently (on the left) with his facilitated play group in my home, baking muffins...in a healthier state. This is what life is supposed to be like, right? I guess autism isn’t that remarkable afterall.
"Having failed to distinguish thoughts from things, we then fail to distinguish words from thoughts. We think that if we can label a thing we have understood it."

-Maha Sthavira Sangharakshita

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**CBC Television**

Just to give Canadian readers the heads up, I will be on the Gill Deacon show tomorrow at 11 a.m. and 2 p.m. EST on CBC.

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**Mourning Ulysses**

As I said in my last post, I returned to Toronto to more disturbing news reports, primarily the one by Margaret Wente in the Globe and Mail and how she portrayed the autistic person -- a person doomed to a life-sentence of head-banging and screaming. Every time someone's face frowns at my son when I mention autism, when someone says "I'm sorry" when I tell them that Adam is autistic, I blame news reporters like Wente who neglect to do their research and have never met the likes of my son Adam, or do not make the attempt to speak to the many adult autistics living in Canada today.
I am horrified that nearly every couple of months, there is another story, another murder. And what do we hear in the media of it? Will the media cover the connection between pejorative commentary about autistic people, the constant disrespectful misrepresentation of the autistic person and these murders? If epidemic innuendo could stop, if parents, autistic people, scientists could work together without prejudice, if we could respect every autistic person....if only....

I went on a little R & R this past week to return to disturbing news reports. I came home to my happy little cherub, Adam, and every time I go away I am reminded of how big he is suddenly getting...how independent he wants to be, and is becoming, and yes, all without an intensive ABA program, but a diligent program of OT, SLP, JK, facilitated playgroups and one-to-one teaching and lots of visual schedules, books, choice boards and computer learning.

He still doesn’t say “mommy, mommy,” when I walked excitedly to his room. Instead, I asked him to sit in my lap as he watched TV after a long day of his own, as he got used to me being back, wrapping my arm around his tummy. A few minutes later, he could look at me and smile. I guess it was just before bedtime, there was commotion and he needed a few moments to take it all in.

I love Adam so much it brings tears to my eyes. I try to have compassion for all these parents who are fighting for their ABA services, when they say that their children give them “joy despite the autism.” I scratch my head at that one, because autism isn’t curable, and it is a part of their child. I also know that down here in the trenches, it’s a little different than what the advocates say or what the media might compel you to believe. It really all is pretty gemischt down here.

It is perhaps for this reason I have compassion for real feelings of
loss – myself watching intently an adorable little baby pointing and interacting with practically the entire air cabin this evening, with a bit of a pang in my stomach on the one hand for all the things I didn’t see in my infant Adam and curiosity for what this baby was doing in terms of "development." Then I think and wonder why these little pangs still come and I know – it is not the Adam that I didn’t have, it is the world that may never understand him – the parents and reporters who would have you believe that autism is a life-sentence without ABA, that autistic people will forever bite you and bang their heads without it. It is the fear I feel for Adam’s future that he may always have to hide his label or else be sugjugated to quick judgement. How will my little guy, so tender at nearly five now, be able to handle it all? A mother’s perogative to worry, I suppose, so long as the worry doesn't transfer or debilitate.

So, to some extent, I have compassion for how parents feel, and I consider that there is a hairline that keeps all of this apart. At least that’s what I would like to keep thinking.

But when I read parents with this special agenda to take all other services and special education away from our children EXCEPT ABA – who suggest that our children – my child – should be institutionalized without ABA treatment, then my tears or worry flow a little faster. I consider escaping to a small town, to homeschool – absolutely anything that might protect Adam’s dignity and ability as an autistic person – and of course, to protect him from the non-autistic people, parents and some media, who insist on speaking pejoratively about autistic people – their own children in fact – as non-sentient beings. I have compassion for parents who want to find the safest, most welcoming environments for their children, even if it happens to be an ABA school. But the world needs to know that many of us parents who have tried ABA programs, have been appalled at the poor quality of service, and lack of overall knowledge about autism in so-called “therapists,” and the arrogance and lack of understanding in some of the “psychologists” and other professionals. As I’ve said, I’m not against all behaviourism per se (although if you want to know the roots and perils of it in pedagogy, read Alice Miller’s work) – it’s employed for changing all of our behaviour – exercise, diet, relationships – all behaviour can be altered. We also live in a world where in order to function, some conformity is required. But is autism just a behaviour to be altered? Is normal the gold standard
of autism "treatment"? And if an autistic child never becomes “normal” (and they won’t), they are only suitable for institutionalization? I cry and fear for Adam because of this. And so should all of you.

What if we gave permission to these parents to mourn, but to also accept autism? What if we said, okay – all parents deserve to be supported, to be able to choose the educational method they feel most suitable for their child while we continue to conduct the science that seeks to understand autism better, and to respect and educate autistic people more effectively? What if we could allow autistics in this discussion to tell us what works without feeling like we might be accused of being bad parents for doing one thing or another? It seems to me that we need to bring all of these voices to the table to discuss what we have learned over the last fifty and even the latest fifteen years, and what needs improving. We can’t do that if this ABA advocacy group marginalizes everyone who does not agree with their agenda. Parents at the Joy of Autism conference came up to me and said “we needed you thirty years ago.” Why? Why do parents and autistics continue to feel so bullied by these parents? And that’s the word that they consistently use: bullied.

Any party that does not allow another party to come to the table and have a voice, namely, letting autistics speak for themselves and participate productively in advancing autism education, is wrong. Will Margaret Wente understand that aspect to this issue after her unbalanced autism column?

I approached Margaret Wente to cover The Autism Acceptance Project. We sent her our video. We invited her to come and listen to actual autistic people speak about autism. She responded with silence. She certainly had my number.

Margaret Wente didn’t do any fact finding. She didn’t interview one autistic person. She didn’t call the thousands of parents who do not subscribe to the perjorative so-called “autism advocacy.” I was glad to read that Michelle Dawson had blogged about the story when I returned to Toronto today. I am going on CBC tomorrow. Airtime to be announced. In the meantime, you can write a letter to the editor regarding balanced autism reporting and the lack of autistic people contacted at: egreenspon@globeandmail.com.
It saddens me everyday to see that the ABA “advocates” want to make this a zero-sum game: either you’re an absolute ABA supporter or you “swim with the dolphins.” It should be extremely frightening to society at large to hear parents call their children useless, or to think that ABA and institutions are the only options for autistic people. It is even sadder when a Globe and Mail reporter doesn’t do her research to either get her facts right, or to get the very important other side of the story from autistic people and the many parents like me who just wants my son to go to school and be allowed to receive the accommodations he requires – whatever they may be at different points throughout his life.

PERMALINK POSTED BY ESTEE KLAR-WOLFOND AT 11/22/2006 11:33:00 PM
7 COMMENTS LINKS TO THIS POST

WEDNESDAY, NOVEMBER 15, 2006

More Positive Autism

I'm about to go away for a few days and may not post to my blog. I find I'm at a loss for words these days, which is a sure sign I need to retreat, be alone, collect my thoughts.

In the meantime, for Toronto viewers, I’ve posted a little more "positive autism," and I hope that people will figure out that no matter what level of "functioning" we can surely all learn from each other. It's like what Jonathan Lerman says, a man who at ten was still completely mute, who is learning to speak more and more today, going on nineteen years of age: "There's no such word as can't." And you don't have to be a Nobel Laureate either!

Vernon Smith, Nobel Prize Winner & Autistic,

PERMALINK POSTED BY ESTEE KLAR-WOLFOND AT 11/15/2006 12:11:00 PM
6 COMMENTS LINKS TO THIS POST

THURSDAY, NOVEMBER 09, 2006

Young Blogger Asks Age Old Question
To cure or not to cure, that is the question. This is a post by a 20 year old David, who decided to take a year off college to pursue this project in his blog titled Growing Up With a Disability. He is recording both personal stories and stories of others with disabilities. Here is an excerpt from his post, which is applicable to autism:

My first interviewee, “Ashley,” discussed her perspective on a cure for her learning disability. Ashley said she would only accept a cure if it were on her terms. What society calls rigidity and stubbornness, Ashley calls discipline and focus. From her challenges, Ashley has learned patience and perseverance. She feels aspects of her learning disability have helped her become skilled at math, science, martial arts, and fitness. Ashley wonders if a one-size-fits-all cure of her learning disability could rid her of some of her very best qualities.

Many people who have made valuable contributions in society are thought to have had learning disabilities. Would Leonardo da Vinci, Pablo Picasso, Albert Einstein, and Winston Churchill have wished there had been a cure? What about Jay Leno and Robin Williams? Would these and other people with learning disabilities share the same concerns about a cure as Ashley? Would the unique talents and gifts of these scientific and creative individuals be lost if their disabilities were cured?

I wonder how Franklin Delano Roosevelt would have been a different leader had he not had the perspective and skills learned from dealing with polio. How would Stevie Wonder and Ray Charles be different musicians if they were sighted? How would Beethoven’s 9th Symphony be different if he had not lost his hearing?

These are interesting questions to think about. We, as a society, are quick to point out the negatives of a person’s disability; with a little effort, strengths can be seen too. Disability is a natural part of human diversity and should be respected and treasured.

Thanks, David!
Meet Kiki, our new puppy...born today...the breeder just sent us a photo of her. Finally, Henry has bitten the bullet and allowed us to get one for Adam. As an only-child myself, I am ecstatic for Adam. I grew up with three dogs (at different points of my life) in my grandparent's home. I took care of them whole summers, saw them every weekend. While I know I will have a new "baby" to take care for the next thirteen years, I cannot be happier.

This makes me think of all that Adam has given me, including the courage to get a dog of our own. I think now of the lines my recent favourite children's book, *You Are My I Love You*, by Maryann Cusimano:

"I am your favorite book
you are my new lines
I am your night-light
you are my starshine

I am your lullaby
you are my peekaboo

I am your goodnight kiss
you are my I love you."
An Excerpt of a story written by a father of a Down's Syndrome girl:

[at the birth of their child]"The masked pediatrician finished his sentence. Abruptly, he turned and left the room. Two nurses began to sob. I looked at Jonna. She looked at me.

Thus began our wrenching, happy, challenging, humanizing, angry, crusading, broadening, rejoicing, proud adventure in parenting a child with a developmental disability. Over the past then years, we have learned that there is very little wrong with our daughter. but a great deal wrong with the culture into which she was born.

As for so many other families of children with disabilities, our first experience was in 'medical' environment. It took us a while to realize that the 'medical' environment thinks about children with disabilities using a 'medical' model -- a model that teaches parents to think of their child as sick. Subtle and not-so-subtle messages tell parents to do everything they can to make their child more 'normal.'

Several years ago, on the advice of a medical professional, we went to see a specialist who dealt with issues of growth. We were concerned that Elenor was too small, and we wanted to know what we could do to make her taller. In other words we wanted to subject her to growth hormones in an effort to make her look more 'normal.'

What we learned was that she is in the fiftieth percentile for girls her age with Down Syndrome. How much more normal could she be?" --From The Perfect Daughter, by Michael T. Baily, from anthology: You Will Dream New Dreams: Inspiring Personal Stories by Parents of Children with Disabilities.

Autism has been around for hundreds of years. Only since 1943, and then again, not until 1980, did we pay attention to this "new" diagnosis, which is really just a better awareness. Luckily, as more
children and adults become identified, we CAN produce better opportunities that understand the learning potential and abilities of every autistic person. Horribly, society and parents who continue to insist their children are terribly ill, can continue to prop up the fate that was once bestowed upon people with disabilities in the past: stigma, segregation and stereotyping and worse.

If Dr. Wendy Roberts, the very person some of you stake your cures on says, "we will never find a cure for autism," then we should listen. There is no cure for many differences of the human condition. We must cure society of its naivete and help our children get the supports and opportunities they deserve. We must invest in learning to understand autism even better than we do today, and we must consider how much society can drive science to appease our desperation.

What Preys on Personhoods

The press incite panic
Pejorative parlance professes improper pedigrees and peadiatric pandemic of percentages and preseverations propogates parental paralysis of proper analysis and instead posits piteous epidemics that prey on personhoods.
Every few years, a press release touts a breakthrough in autism research or treatment. The list of these discredited causes or treatments of autism includes secretin infusion, the MMR vaccine, chelation therapy and facilitated communication. Each of them has given parents false hope, or worse, false guilt. The researchers behind these press releases suffer from the most ethical of motivations: they sincerely believe that their conclusions are sound, they perceive a prejudice of the scientific establishment against these conclusions, and they sense an urgency to communicate their findings to the broadest possible audience of scholars and, more significantly, parents, so as to prevent autism’s ongoing tragedy. This well-motivated urgency often results in circumvention of peer review, the careful process by which scientific findings are vetted and judged worthy of presentation to the broader community. Despite its many faults and delays, peer review remains essential to maintaining public trust in science. Read FULL ARTICLE HERE

Matthew Belmonte is an assistant professor at the Department of Human Development at Cornell University. He can be contacted at mkb4@cornell.edu. Guest Room appears periodically.

Morton Ann Gernsbacher from her article REACHING FOR RELEVANCE:

As we all know, times have changed. Psychological scientists feel the crunch of funding cuts, the burden of congressional accountability, the threat of prioritizing applied over basic research. Therefore, psychological scientists are now reaching for relevance — often, it appears, to the point of gratuity. Nowhere is this more apparent than in recent press releases issued to promote publication of basic scientific research. Consider the following three examples.

Admittedly, I have a dog in this fight – a dog that could well be apparent through all my presidential columns. I am mother to an incredibly wonderful, light-of-my-life, engaging and eccentric autistic son. I am actively involved in several federally funded projects empirically investigating various aspects of autism.
also believe strongly that whenever we, as researchers, write about autistics or Jews or women, we must be cognizant that we are discussing and describing members of our society.

Indeed, I submit that whenever we write for the public, we must be more not less circumspect. We can't depend on stereotype, a Hollywood movie, or a casual conversation with a colleague to provide us with knowledge of the phenotypes that NIH cares about. Instead, we must research the implication of our findings with the same rigor that we research our basic phenomena. Relevance is a prized commodity these days, but let's not buy relevance at the cost of scientific inaccuracy and societal stigma.

Here is some of the effects of the stereotyping and stigma that arises from so-called "FACT SHEETS" released by some parents, research news released by press, and unproven and even non peer-reviewed studies by some scientists:

**Being an Unperson**

And then there is a new blog by a mother, *Autism Voice*. Ms. Sinclair says this:

>In either case, society is telling us how we should feel- happy or unhappy. But in reality, no one else can dictate your feelings, unless you allow it. You truly decide how you feel from moment to moment. You decide if you're going to buy someone else's idea about how you should feel. And yes, you can decide to be happy or unhappy, despite what everyone has told you. You can decide to be happy now, without waiting till your child is recovered. I'm not talking about denial, where you're pushing down feelings and pretending they're not there. I'm actually talking about making the decision to be truly happy.

>That doesn't mean that you give up on hoping and trying for more. If you can hope and work for your child's best outcome without making your happiness dependent upon it, and if you fully accept your child as he is now, even with his autism, then your child will feel that acceptance and positive expectation, and will respond by believing in himself.
I don't need to write today. It's been said. When will it sink in?

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THURSDAY, NOVEMBER 02, 2006

Joy of Autism Event Opening Photos

As promised, here are a few of the photos from October 5th opening at Lonsdale Gallery of The Joy of Autism: Redefining Ability and Quality of Life. I have yet to get you good installation shots.

Larry Bissonnette among incoming crowd.

Jonathan and Alan Lerman and Estee Klar-Wolfond

Crowd begins to fill The Lonsdale Gallery.
More Guests.

Guests.

Master of Ceremonies: CTV News' Ken Shaw.

President of TAA Project Board, Dr. Nehama Baum.
Guests listening to my speech -- notice only my mother is smiling. :)

Of course, Jonathan is smiling too -- just before he yelled, "SELF ESTEEM!"
Larry "speaks" to the crowd. You do not see the screen upon which his words could also be viewed as they were written.

Martine Stonehouse speaks. An autistic board member "in waiting."

Michael Moon speaks. He is also an autistic member of the TAAProject Board.
Brian Henson speaks. Brian is also an autistic member of the TAAProject Board.

Ellen Yack, TAAProject Board Member.

Brian among some of his photos.

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6 COMMENTS LINKS TO THIS POST

WEDNESDAY, NOVEMBER 01, 2006

The Plastic Pumpkin and the Candy Factory
Halloween Update

Someone suggested that Halloween is an attempt to normalize an autistic child. I agree and don't agree. If you expect your child to
be something they don't want to be, then obviously that isn't right. If the expectation is to enjoy each other, to do one's own version of a something, to make "our own Halloween" -- an adapted version, and the child seems to enjoy it, (and as parents and educators we have to constantly evaluate our interpretations of what we even think our children enjoy because it can also be an imposed state), then we can use the opportunity to build an experience. It can be a valuable learning experience for everyone.

Adam enjoyed painting faces on pumpkins -- especially the triangle eyes. He particularly enjoyed these mini pumpkins on sticks and we painted a face on one that he's been carrying around for three days now. He loved his alphabet costume (the alphabet part anyway) as he tried to pluck the letters off his shirt. He enjoyed a couple of little kids coming to our door, and he greeted them with a big smile. He certainly loved his lollipop and then a stroll down the street to watch the rotating ghosts in blown up plastic pumpkins and strobe lights at some of the houses.

It was our Halloween and if Adam didn't want to participate at all, that would be fine. I always think a little sharing is what's important here -- a non autistic mom and her autistic son sharing, compromising. It's what Morton Ann Gernsbacher calls "Reciprocity." He comes out for a walk to view the lights, and I enjoy what he takes in, watch his face and try to learn from him as well. It was an opportunity to do something together.

I don't need him to go door to door for candy. It's just not the point. The point was how we shared the sewing of the letters on his shirt, how we called it a costume, and that he learned about this silly night called Halloween when kids get candy. I like to expose Adam to lots of things. He decides in the end what he likes and doesn't like. It is not normalization. It is just sharing, learning and compromising. The best part for us was not the actual eve, but the night before, when we made something together.
Tonight is Halloween. When Adam was two, his grandmother made him a little bunny costume and we went out trick-o-treating. Those were the days when Adam was learning “open door,” and during the crisp Halloween eve, he thought that every door that opened obliged him to walk through.

“No, Adam, you take the candy, see?”

He would reply with a whine. He just didn’t understand why he couldn’t visit every house that opened their doors to him. Candy was also something he hadn’t yet discovered.

The second year, I decided not to make a big deal out of Halloween. He would wear the bottom part of his bunny suit from the previous year, and answer the door to hand out candy. This was a hit. Adam was beginning to learn how to give and take, and he took delight in the children coming to our door in their costumes, and placing his tiny hands full of candy into their pillow cases. Later, it was a pleasant enough evening to walk over to our friends place to experience the “receiving” of candy, but at age three, he still wasn’t that keen.

This year, at age four, I am building on what I’ve learned. Adam is not yet that excited about Halloween. Instead of making him Spider Man or some character we both don’t really know, I sat down yesterday and stitched letters and numbers to old clothes. He will be ALPHABET BOY. My hyperlexic little guy was delighted. He watched me stitch the letters to his clothes with great focus.

“This is the needle and this is the thread.”

“Thread,” he’d repeat, watching me holding it tautly in the air.

“This is your costume.”

“Costume.”

“You wear a costume on Halloween.”

“Halloween.”

“You get candy on Halloween.”
“Candy,” he perked. Since last year, he has learned all to well the pleasures of candy.

I bought some pumpkins and we drew faces on them. We wrote a little story of how he will get into his alphabet costume and give out candy to the children at our door.

It was really nice to do this for Adam. It was wonderful for me to see him watching me sew the letters on his clothes and be a little interested in Halloween – or at least his mother’s sewing.

As I sit in the rocking chair I once nursed him in, stitching letters and numbers, feeling matronly once again, I consider with a great warmth inside that this is as good as it gets. -- this bond, this love, this peace. Adam may not be the man who leaps tall buildings, but he is my super hero, my avenger, my...Alphabet Boy.

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SUNDAY, OCTOBER 29, 2006

Amanda Speaks

Reply to Autism Speaks and GRASP Articles of Understanding

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SATURDAY, OCTOBER 28, 2006

Sadness and Joy

Last night, The Autism Acceptance Project drew closer to its end with a concert by Michael Moon. People were “sad” they said, because the month-long events are drawing to a close.

There is some sadness in me too. One thing I came to learn: when there is a safe environment for autistic people to come out, they do. I met more autistic people here in Toronto than I knew before.
I felt last night that we had a mini Autreat going on and at the end of Michael’s concert he had us all singing Alleluia. I’m not a religious person, nor was this sung in a religious context, but surely this is what it was all about: Thank God we are all here, together, and we believe in each other. Humanity oozed in the room. Difference was transcended. We were all equal with the music. As the battles are fought outside, much needed peace swathed us inside.

I have two potential new autistic board members – one who is non-verbal and uses a keyboard. It’s all about accommodation and how people can participate and not about how they cannot.

As the year continues, we will continue our talks with government; we will get autistic people into the schools as we plan our series of talks on the inside – familiarizing students and teachers with autism from the source.

As well, I will be talking at a few conferences across Canada next year.

We have a growing membership and our website will soon change to keep people up-to-date on the news and our efforts to increase opportunities and better education and services for all autistic people and their families.

Next fall, we are focusing a lot on education and science in autism. We have been asked to produce a magazine as well...TAAProject is hardly over even though the event is drawing to a close.

Thanks to all who participated in the event this year – coming a little closer to promoting a healthy dialogue about autism, even among the fury, perhaps coming closer to viewing autistic people, well, just human. Thanks to all the parents who brought their older autistic kids out (21 and above) who really want vocational opportunities for them. While TAAProject can’t do everything all at once, we understand the need to integrate everyone.

I was thinking about the Combat Autism Bill today, the name which is very unsettling for me, as a mother. I squirm at the thought of my son asking me about why he has to be combatted when there are real issues to contend with, like bullying in the school yard, isolation from being different. Real issues that we
COULD transcend if we promoted tolerance and educated others about how to accept autism. I was thinking how we need to form a group of scientists without stigma, how we must reword our scientific questions: Research FOR Autism and the like. Lord knows we don’t want to combat our kids who are intrinsically autistic. We want to help them, enable them.

I wanted a perfect ending... Now, I've learned, the hard way, that some poems don't rhyme, and some stories don't have a clear beginning, middle, and end. Life is about not knowing, having to change, taking the moment, and making the best of it, without knowing what's going to happen next. Delicious ambiguity.  
--Gilda Radner

What We Gain

Valuable Autism

Thanks Dinah and Ralph and all those who have contributed to research in autistic ability.

Building Bridges

If you believe the impossible, the incredible can come true.
As the Joy of Autism: Redefining Ability and Quality of Life draws to a close on November 5th, it is far from over.

The experience, as a parent, has been incredible, if not speckled with very few vitriolic comments from some parents. Most comments are filled with similar determination of parents seeking acceptance for their children.

Nonetheless, The Joy of Autism concept rose to the surface some of the angry divides that still impede the progress of all our children – through the belief that autistic people do not know themselves, or have no right to discuss autism if they are verbal, or have written communication abilities. It is a divide that continues to puzzle me as I believe that by working together with autistic people, we could do so much more for our children. Instead, by putting autistic voices first, some parents even go so far as putting their children so far down, “my child can’t do anything.” Having met many autistic adults over the course of the last two years, I haven’t met any disabled individual, autistic or not, severe or not, who can’t do anything. People can always do something and it is this something that continues to drive this discussion about just what a quality of life is – for people with disabilities and their families. In this blog post, I’ve searched for some messages that we can learn from other disabled communities:

**Disability awareness**

In an Articles of Understanding, between GRASP and Autism Speaks, Alison Singer, Senior Vice President of Autism Speaks states that perhaps Aspergers Syndrome should not be classified as ASD. She states, “…the differing abilities of persons with Asperger Syndrome are nothing like my daughter’s autism. When we at Autism Speaks use the word cure, we are most often focused on the people at the lower end of the spectrum.”

This is the most misunderstood aspect of autism and perhaps the spectrum idea has to be further clarified and less generalized. Every parent who will contest my use of JOY with autism will use that argument saying that my son is high-functioning and theirs is
“much more severe.” The whole concept of high functioning and low functioning has muddied the autism waters. As my son grows, I know he is intelligent. However, at nearly five years of age and with many approaches, he still does not speak. He is quasi verbal. He still flaps his hands when he’s excited (a beautiful sight as it is an expression of extreme happiness for him). He still has motor difficulties. This from a child who was diagnosed “early” – at eighteen months of age (a note to all those on the "early intervention" bandwagon). Yet, he still learns and he will continue to learn throughout his lifetime.

In order to clarify understanding, autism, as Jim Sinclair adeptly put it at the Joy of Autism lecture series, is a dissonance of skills. While one person may be verbal, they may still possess autistic behaviours. Another, who may be non verbal, may have less autistic behaviours. Or consider the person who has learned to "behave" like others, but is still autistic. It is so difficult to categorize autism into shelves of intelligence with high and low functioning distinctions. Amanda Baggs is a perfect example of a woman whose intelligence is so laser-focussed, I have to admit she makes me think twice about my own preconceptions and beliefs almost daily. She needs daily assistance and is completely non verbal, using a keyboard to type. For more information on Amanda, go to Getting The Truth Out. In the same city lives Larry Bissonnette, who is in the exhibition part of Joy of Autism: Redefining Ability and Quality of Life. People who don’t bother to come to visit the show, have assumed he is “high-functioning.” But that means nothing. Larry can’t talk, and he uses a device to speak, through typing. He still draws lines in the air with his fingers and repeats words. He is aware of his repetitive speech and the way he looks to others, despite the fact that some may think he is incapable of deep thought. Yet, he is. He is a philosopher as well as an artist. And there are more. Consider those f who were taught to use a typing device, like Andrew Bloomfield here in Ontario who submitted a poem for Autspoken -- despite his “silence,” he shows that autistics do "speak." What they say has a lot to do with how we view our children, how we view autism, and how we value human life.

Segregation of high and low functioning autistic people is problematic. We should not allow this categorization to decide which human life has greater value, simply because one person may be more obviously in need of assistance. The argument to
cure low-functioning autistics because they cannot do as much as a high-functioning autistics is an obvious categorization of human worth. Who gets to decide? Perhaps one’s “severe” is another’s “moderate”? For the parent who says their child “can’t do anything,” they need some exposure to many more autistic adults – of all areas of skill "dissonance." When we marry people with people, sometimes the fear just slips away. This is why it makes no sense to exclude every autistic person in discussions about autism.

Here is the catastrophe of the zero-sum game that a cure implies: either seek to cure your child or do nothing. Autism isn’t a zero-sum game. We also know that parents who accept their autistic children don't sit idle and do nothing for their children. We still educate, use various therapies that do not seek to normalize the autistic person but enable them. We still sometimes require medications for anxiety, epilepsy, depression, for instance. Yet, we must be careful with medications too – anti psychotic medications are again being prescribed for autism, reminiscent of what happened to many autistics when they were once institutionalized. Autistics will tell you up front what those medications did to them, and we need to hear it again. If people just allowed others to be autistic, recognize strengths and abilities in all people, no matter how severely disabled, we could enable every individual to contribute to society to the best of our ability.

We need to set up facilitated places of business to employ disabled people -- non disabled and disabled people working together. We need more employment outreach services that can place those in companies who can be placed. We need creative opportunities for those who need more accomodations. No one should be left behind. Every community should include each member of our society. Instead of throwing money at a cure, the corporate community could contribute to the real values of community, and could enable and empower people. Let's say you still hope for a cure? What if it takes another fifty years or more? That’s an entire lifetime for our children. Switching our hyper focus from cures to enablement -- education, vocational training, social skills training, inclusion, and more -- could actually create the real hope parents are after.

Michael John Carley, Executive Director of GRASP also wrote an Articles of Understanding.
“If the autism spectrum runs from A to Z; and if Albert Einstein is an A, and that non verbal individual a Z (using ability to succeed in the world as our spectrum), then where is the Autism/Asperger cutoff? Is the line in the sand drawn at M or at N?

Although GRASP does not have non verbal folks participating in our support groups, the problem for is is that, in addition to the M’s and the N’s, we see plenty of G’s and T’s along the functionality spectrum. And we see no dividing mark. We see a gradient. We see a gradual progression of abilities and challenges that flow into each other quite naturally. Also, if there was a dividing line between M and N, what if N was able to improve enough to cross over to M? Again the diagnosis can’t change, but the affected individuals almost always do, and often quite dramatically.”

We can’t sensationalize autism and present it like cancer. It isn’t a terminal condition and it is not completely debilitating. The door doesn’t shut at age six. Autistic people continue to learn throughout their lifetime. What you see at age five, twelve, eighteen, is not the same autistic person you will see at thirty, and fifty. While some autistic people will require more daily assistance than others, it is their right to obtain it while also having the right to focus on their areas of interest – to improve their quality of life. If an autistic person isn’t toilet trained – move on, says Camille Clark in an autism podcast this past summer. Perhaps it will happen or never happen, but the point is that there are always other skills that an autistic person has that can be nurtured so that they feel competent and valuable to society and to themselves. How can we move beyond the divides and accomodate the disability to utlize the ability for the benefit of us all?

Autistic people are not vegetables. Despite the way they may manifest a behaviour, or not, they are aware of what goes on around them. It frightens me when parents believe that there is “nothing” there. It frightens me when I hear parents caging their children in their bedrooms at night “to keep them safe.” Treat an autistic person like an animal, you will get an animal in return. It is the parent’s responsibility to keep them safe, but to also protect the dignity of their child. If an autistic child may wander, get an alarm system, put hidden inside locks on the doors, but don’t cage him in.
If a parent is depressed or overwrought, get help. There should be more supports set up for understanding autism as well as respite for parents who still need to take care of themselves and feel safe to express their feelings with these challenges. Go to a support group with autistic people in it. Autistic people are very understanding if you are open.

But don’t divide autistic people, and don’t divide us as parents. We have so much to share and learn from each other, from autistic people who have taught me more about autism and how to parent my son than any scientist or clinician. It is called humanity. Look it in the eye. Don’t boycott it so that the autistic person becomes further dehumanized by society. Don’t as a parent, continue to use pejorative language regarding your child who does understand how you feel and what you say about them. Don’t wish me or anyone else “an autistic child,” as a curse. (Someone did this to me once, which I had to laugh, since they did not know I had an autistic child. It was also very perverse to talk about autistic people in this regard).

If you are fighting to cure your child, know that it may be futile. We have been trying to “cure” autism for forty-odd years. Well-regarded scientists everywhere are stating that they don’t think autism “will ever be cured.” Yet it continues to be central to this debate when we must begin focussing on the real issues at hand: how do we get our kids educated, included, accepted, and integrated into society as best we can? How do we do this by respecting them as autistic people, without trying to change their very being?

Many scientists are making their livelihood on trying to bring a cure, to no avail. People will accuse me of not wanting to cure Adam. But as I said in an earlier post, to answer that question quickly is scarrier than the question itself. What about answering the questions that arise from the very possibility like who gets to decide? What do we have to lose? Who would we lose if there were no more autism in the world? Can we separate finding a means for a non verbal person to become verbal versus curing the autism? Can we keep the autism abilities while curing the disabilities? These are questions that can leave our heads spinning, but spin they must.
Some autism charities use the fear tactic to get you to give more money to find a cure for autism. Some families use “life-saving cure,” language to get the government to offer more money for specific services. It is wrong to use incorrect facts and fear tactics to market for money to cure autism without regard for how the autistic person feels about it, and at the prospect that many well-respected scientists will admit that a cure is still improbable.

Do autistics need help? Yes, they do, but not this way. Not at the expense of their personhood and dignity. Not with pity parties dressed in diamonds. They need real help, real acceptance. They need us to learn and roll up our sleeves.

I had to chuckle the other day. A couple of people got angry at the Joy of Autism title, but it is not a foreign concept even for life-threatening diseases. The Toronto Sun last weekend had an article called “The Gift of Cancer.” Ellen Schwartz, whose young boy has Canavan’s disease and is not expected to live very long, wrote about the joy of having a boy with Canavan’s disease. Joy and Gift is often associated with adversity. Often, in the face of dire circumstances and the unexpected, we have found more purpose and joy in life by appreciating it all the more. Disabled communities “celebrate disability.” So what this tells us that we are at a very young stage in understanding autism, that the debates that occur today, were the same that occurred with the deaf community, with the homosexual community (the latter were thought to be severely mentally ill). I will continue to celebrate and cherish autism because of all the autistic people that I know. I will celebrate autistic people as I learn to accept what is and what can be achieved faced with such adversity. By looking to other disabled communities, I feel we can inform ourselves about our preconceptions about what disability is and how we tend to regard it. Ask yourself, what can we learn from people with other disabilities?

Wonder

By believing in autistic people, we can obtain the services and education that is their civil right. By complaining about autistic people as being “a burden on society,” and more, we cease to acquire services and accommodations and dangerously head towards a sophisticated eugenics model that begins to assume that
As a parent of a moderately autistic child, I take issue with anyone who will market autism in a negative way in order to obtain money, or parents and organizations that exclude autistics from a dialogue where everyone has to benefit from each other. I take issue with scientific bias. I take issue with every single press release being reported in the media to the point that parents are on this frenzied ride to “cure” their child’s autism:

Let’s take a look at the last month alone:

Last month older dads caused autism
Then, about a week later, high cholesterol did.
Then, about two weeks later, excessive TV watching caused autism

Get the picture? I could go on. Scientists need to take more responsibility for what they are reporting, as reports cause frenzy. The public needs to understand that some scientists also possess prejudice against autistics. If they don’t believe that autistic people are people first, then what direction do you think the science is headed? Parents have to really stay abreast of who is behind the science, and get off the recovery train that leads to nowhere, that only lessens a family’s quality of life by the sheer exhaustion of this never-ending "recovery" journey.

It’s a real struggle to get an autistic child an education. It is a real struggle to go into public and have to explain autism to just about everyone who wants to know. It’s a real pain when someone comes up to me and says “Your child is autistic? Oh, I’m sorry.” It takes a lot of guts to stand up and say “What for?” Most of us are still very naïve about disability with its assumptions that disabled people are “unfortunate,” and less human and entitled than the non disabled person.

I am proud of my autistic son. I am proud of his joy, his efforts to learn amidst those who have already tried to pathologize him and his tenacity. As his mother, I am quick to sift people out. It has become easy to see who really believes in Adam, who just loves him for who he is, and who can see his potential. If this is autism, yes it is a challenge, but not the autism as much as the stigma of
I love being Adam’s mother and what he and autism have taught me. Adam is a joy, and he humbles me with his pure child-like wisdom that the only thing that’s really important in life is happiness. Perhaps it is innocence still unscathed. I look ahead to his teens and beyond. I see the bumpy road ahead. It is there but I won’t complain. We’ll keep moving forward. I will always be proud of my autistic son, Adam.

From Ellen’s book -- an excerpt by Emily Perl Kingsley:

*The stewardness comes in and says, "Welcome to Holland."* 

"Holland?!?" you say. "What do you mean Holland? I signed up for Italy! I’m supposed to be in Italy! All my life I’ve dreamed of going to Italy."

But there’s been a change to the flight plan. They’ve landed in Holland and there you must stay. So you must go out and buy new guide books. And you must learn a whole new language. And you will meet a whole new group of people you would never have met.

But...if you spend your life mourning for the fact that you didn’t get to Italy, you may never be free to enjoy the very special, the very lovely things...about Holland.

**Imagine...**

This one is for Carol Motts of CFRB Radio who suggested that all parents of autistic children *should* make them as "normal" as possible, as if it is a parental duty, and for anyone who carelessly suggests that "Autism is a Living Nightmare." I can’t imagine that any autistic person would have felt safe to participate in that
phone-in discussion and as I tried to make my point on CFRB the other day about sharing, respect and value, the Motts hung up the phone on me. I was raising those points because The Motts were discussing "good behaviour" of students in a preceding program. Carol began to pontificate that the show of respect was marked by a student saying "please," "thank you," and delivering "eye-contact." I thought these were some good points to go on in discussing how to respect autism in the absence of those capabilities. (Note: I was also told that this wasn't going to be a phone-in and I was the only person being interviewed about The Joy of Autism: Redefining Ability and Quality of Life event).

My next post will be about the responsibility of the media to recognize the polemic discussion of autism without creating more and more divides. It will be about the need to create safe environments and healthy dialogue where autistic people can participate with parents, as well as how parents can express the challenges of severe autism without making an autism spectacle that the media feeds upon, and at the peril of all our children.

**When The Moon Come Up**

**Euthanasia Blues**

PERMALINK POSTED BY ESTEE KLAB-WOLFOND AT 10/19/2006 06:32:00 AM
4 COMMENTS LINKS TO THIS POST

WEDNESDAY, OCTOBER 18, 2006

**CJN article**

Art, lecture project part of Autism Awareness Month. Click HERE to view.

PERMALINK POSTED BY ESTEE KLAB-WOLFOND AT 10/18/2006 11:39:00 AM
0 COMMENTS LINKS TO THIS POST

SUNDAY, OCTOBER 15, 2006

**Autistic People "Speak"**
The following is a quote from Mike Stanton: Autistic People are human beings with human rights that are not predicated upon whether or not they or their parents are seeking to normalize their condition and trying to eradicate all traces of their autism. These rights include the provision of accommodations that are necessary to maximize their ability to benefit from participation in society.

Listen to Autistic People "speak" HERE Jim Sinclair, one of the autistics interviewed here, will speak at the Al Green Theatre in Toronto at the Bloor Jewish Community Centre at Bloor and Spadina at 7 p.m.

There should be no question that autistic people, whether keyboarding or speaking, have a right to participate in all discussions concerning them at every level. They can help us understand the issues at stake, how to understand autism, how to accommodate and educate our children. We have nothing but to benefit in every way from them -- for our children, our families and our society.

Listen.

Redefining Disability

I like the way this article Redefines Disability that we can all easily supplant to autism. While a disability should be a passport to services, it should not dictate the way you are treated and regarded by your friends and family.

Read on: Redefining Disability: Revolutionary Common Sense by Kathie Snow.
COUNTERPOINT -- Today in The National Post
Accepting autism
Estee and HENRY WOLFOND

The article in last Saturday's Post headlined Redefining Autism grossly mischaracterized the mission of The Autism Acceptance Project and misrepresented the role that we take in raising our autistic son. The premise that acceptance of our son's autistic condition equates to acquiescence or denial is totally misleading. Autism is a challenge. Our son works many hours with us, with speech language therapists, with occupational therapists and with his school teachers to learn and thrive in the world. We do everything we can to ensure him the brightest future possible— a future that will include autism.

Autism is a disability that needs to be accepted and accommodated in society in the same way that ramps are provided for the wheelchair-bound and braille is put on signs for the blind. We view it as a human rights issue. The focus of The Autism Acceptance Project is promoting the objectives of gaining deeper scientific understanding of autism and exploring methodologies to enhance autistic potential through reciprocal education of both the autistic and nonautistic populations. It is imperative that autistic individuals participate in this dialogue. We advocate that more funding be applied to research the inherent strengths and weaknesses of autistic people. Services and government financial support should be provided to accommodate autistic people. All policies must respect the dignity and intelligence of the autistic individual and their special needs.
While the title of The Autism Acceptance Project’s exhibit and conference, “The Joy of Autism: may be provocative, it is organizations that attack autism as a disease to be beaten, the ones that focus on the "misery of autism" (Autism Speaks, Defeat Autism Now, etc.), that undermine the opportunities for autistic children to lead happy, productive lives. The message that war must be waged on autism leads to prejudice against autistics. Despite their peculiar behaviour, autistic people have intelligence, sensitivity and many other empirically documented strengths. So long as we persist with the view that normalizing our children is the ultimate goal, autistic people will continuously face stigma and discrimination. Misery proponents lead parents to believe that autism is attacking our children and needs to be eradicated. Parents are channeled in to a therapy that aims to normalize behaviour - to make their children "in distinguishable from their neurotypical peers." There is no accommodation for a parent who accepts that his child may at times behave autistically, but who still wants to focus on developing inherent intellectual strengths.

If there is anything that could ravage our son Adam of which we are most fearful, it is this attitude that he is somehow diseased, insufficient or incomplete. As we evolve, let us all find a common language that supports parents and families so that our autistic children can be the best autistic children they can be. We work to achieve every possibility for our son. Adam works very hard to reciprocate, to become part of this world that judges him so harshly. To witness such an affectionate, charming child be viewed by society as less than human - in fact, "not human at all" - that is the tragedy.

National Post
estee@taaproject.com
I Estee and Henry Wolfond are founders of The Autism Acceptance Project.
WEDNESDAY, OCTOBER 11, 2006

A Human Rights Crisis

After The National Post article, I have mixed emotions.

Adam brings me great joy. Adam is autistic and that it's okay TO BE AUTISTIC. Autism is entwined with many abilities as well as challenges. I am resolute that we MUST as a society begin to pay equal respect to autistic people who do not see their lives as a tragedy, or that THEY are not like US, as such, inflicted with a disease. Indeed, this idea is imposed upon autistic people by non-autistic people, and continues to marginalize and stigmatize the many autistic children AND adults living in Canada today. I am resolute that I have a responsibility to defend my son's right to accurate science about autism and that he not be assumed or deemed a "burden on society." If we said that about our blind and deaf communities, that would be discriminatory. Yet, it is sanctioned in autism. I am resolute that we must continue our arduous work at the level of human rights and science, to understand autism in the face of such pejorative use of language and interpretation of autism and its respective "behaviours," viewed from an abstract notion of what "normal" may or may not be.

I read the first lines of the article: "Four year old Adam Wolfond is comforted by shadows. Jumping on his backyard trampoline, with his arms at his side and his face turned to the sun, he wiggles his hands furiously so that, in the lower periphery of his vision, he sees the sunlight flicker through his tiny fingers...his shadow play is properly [bold mine] called self-stimulatory behaviour [bold mine], like his habit of spinning around and around and strangely never losing his balance."

I was immediately struck by this interpretation of autistic behaviour. Again, looking at him from a non-autistic perspective, and without knowledge of what autism is, or asking the question of what that behaviour means for an autistic person (the article did not interview many autistic adults in the room at Lonsdale Gallery last Thursday night), there was a language use that lacks a
fundamental rigorous and respectful investigation of the autistic perspective. This lack spotlights a false-belief that autistics don't understand themselves or their own behaviour, or are even aware of it, or that they understand how they are viewed by non-autistics. Indeed, if you speak to any autistic individual (even the "low-functioning" one who may use a computer to communicate), one begins to garner an appreciation for the line formation of ice on the ground that may twinkle in the sunlight. The behaviour of the autistic person entranced by such a vision, may to us non-autistics who may not appreciate the intricacies of such grand designs, be interpreted as "weird" or "abnormal." Indeed, many an assessor, who viewed my son at the time of diagnosis, often wears these prejudiced glasses -- the outsider "interpreting" behaviour that s/he does not understand -- and hardly does the work TO UNDERSTAND. As a result, you will get such a skewed, unempathetic, unknowable, nay biased, interpretation of what autism is for the non-autistic person, thus, a comparison between what is and isn't "normal."

And then of course, Dr. Wendy Robert's, confusing "conclusion" that while she feels autism is "on the continuum of normal," she "would [still] be injecting." And of course the notorious comment used by most genetic researchers to justify prenatal testing for autism: "many parents have been beaten black and blue by their autistic children," as if the diseased, sick, [their implication, not mine] child is at fault for this and ALL AUTISM MUST BE ERADICATED -- strikingly reminiscent of a FINAL SOLUTION. It sounds like other genetics researchers, whose funding depends on such flagrant statements, and like Dr. Joseph Buxbaum, whose parental supporters "will never be an Albert Einstein." I've stated many times in past posts, that the most frightening thing for me is the rash and quick conclusion that a cure for autism is required, without understanding autism in the least or for any consideration of the ethics involved with regards to implication and consequence. No consideration is paid to the damage this may be doing to autistic people, living and thriving in our communities today. Michelle Dawson said correctly in her CBC Quriks and Quarks interview: "even if it helps one person, it may do an equal or greater amount of harm." Does ANYONE consider the harm such talk inflicts upon the autistic person??

It's time to say ENOUGH IS ENOUGH.
While my Adam may never be an Albert Einstein, I refuse to impose an assumption that he is incapable of being one, or at least, the best ADAM he can be. To believe that our children are incapable to fulfill their potential as autistic people, is to believe that Stephen Hawking is not possible. I refuse to state that just because he is autistic, he is an incapable vegetable. Simply, it is just not the case. It strikes me as sensationalist of these scientists to continuously use such depreciative examples of situations or children -- whose circumstances may be so complex -- to just write it all off as the predicament of ALL AUTISM, for the purposes of aggrandizing their research. As we still do not understand what autism is, it strikes me as horrific for a researcher to proclaim in the national press, that she "would be injecting" a cure for autism. Just like that. It strikes me as terrifying that such researchers exist, who do not at all pay attention to what harm they are doing to the very people -- the autistic adults and children -- who hear from such espoused autism "experts" that they feel autism is something terrible that needs to be cured. Just like that. It angers me to think of the lack of consideration they pay to the likes of my son Adam, who will be utterly offended and effected by such "expert" views of him. Indeed the laziness of society to accept such "expert" advice on autism also frightens me. If we believe all of those epidemic statistics that are currently espoused by our so-called "respected" autism organizations, we will all be autistic in about twenty years time. I can assure you, I will never take my son to the likes of such "experts," who espouse so-called "facts" about autism -- either disproved or out-dated. We know we do not have an epidemic on our hands, as refuted by the science, and it's time we stop saying so for the purposes of raising money.

I will invest in understanding autism.

I sat back the past several days, and considered the effects of all this on Adam. I would now like to quote a response I typically get from parents, which was written in the letters to the editor in the National Post today: "With all due respect for Ms. Klar-Wolfond, her son is only four years old. It is presumptuous for her to think that she can speak on behalf of parents of children with autism before she has watched her son endure the ravages of puberty and the challenges as he becomes more self aware."

Perhaps it was this comment that struck me as I take a view to...
It seems odd that such parents believe, in their whole hearts, that autism is *attacking* our children, like cancer, and needs to be eradicated. And yet, the science proves that there is no epidemic; that autism has existed for generations; that there has been no increase in autism; and by all accounts from science and autistic people, autism IS a different species of human, as noted in the recent words of Dr. Laurent Mottron, and appreciated by Leo Kanner as far back as 1943. If there is anything that could ravage my son Adam, of which I am most fearful, it is this attitude that he is somehow diseased, insufficient, not normal or incomplete. I, like many parents, work to achieve every possibility for my son. Adam, works very hard to reciprocate, to become part of this world that judges him so harshly. That, above all else, is heartbreaking. To witness such an affectionate, charming child, otherwise viewed by society has less than human, in fact, "not human at all..." that is the tragedy.

If there is anything I feel I need to do more than ever, is protect Adam and to endow him with the confidence to stand up against all of these pejorative comments about him as an autistic person. I am baffled at how parents find it justifiable to comment on every negative, or challenging trait of their child, without at all doing the work and research into understanding what autism is. One day, when their child becomes more "aware" of themselves, they will understand their parent's disappointing view of them. I know Adam, at four, is already aware that he is different and *this* speaks to me as a crisis to contend with -- not a crisis of autism, but a crisis of inaccurate stereotyping of autistic people. Not a crisis of an autism epidemic, but a crisis of prejudice and lack of understanding. Indeed, an epidemic of laziness and sanctioned discrimination. Autistic children and adults are suffering, but as they say, not from their autism, but from society and parents who do not accept them and spotlight EVERY challenge, EVERY negative as the sole purpose to get rid of autism.

I am always struck by the dignity and grace with which autistic people continuously handle such attitudes and perjorative language, and I choose to stand with them -- because my son Adam is one of "them."

Our society is full of inaccurate science to which parents pay no attention. Society shoves the evidence aside because in autism, it
doesn't matter. Instead, inaccurate information is espoused by our leading autism organizations who say that autism is a crisis, an epidemic and our children are a "tragedy" and will be a "burden on society." They choose to ignore the science that states overwhelmingly that we neither have an autism epidemic on our hands or that "ABA IS THE ONLY LIFE-SAVING WAY TO CURE AUTISM." We now know from every control and random study, that ABA does not help the child to become independent adults BECAUSE of it. In fact, ABA may have done a great deal of damage. We know that so-called early intervention candidates as young as two had to be removed from these so-called "effective" therapies. Ivar Lovaas himself said "ABA is not a cure for autism...it is only an educational method." So let's not then overstate things. If you want to extract methodologies, recognize them as such. Do not hyperbolize a therapy as a life-saving cure. Further, understand the formerly aversive nature of ABA. I see changes in the therapists today, recognizing and extracting from many different methodologies that help autistic children. But do not state that it is "evidence-based." We are, still at this point since we do not fully understand autism, extrapolating.

Here is a parent who actually reveals the so-called "effectiveness" of ABA:

"Because of that, he was able to get started early in his life on an effective behavioural treatment therapy, called Applied Behavioural Analysis. He has been benefiting greatly from it ever since....

I see no joy in watching my child repeatedly bash his fist to his face or in cleaning up feces-smeared carpets and walls at 3 a.m. My wife and I will continue to do everything in our power to stop autism from ravaging our lives and, more importantly, the life of our much-loved son, Michael."

With all due respect to their child, I do not equate the benefits of ABA in this statement. We know that autism is forever. It is not life-threatening like cancer. ABA will not eradicate autism. Various methods to teach autistic children, if taught with respect and understand of autism itself, can help the autistic person be the "best" autistic person they can be.

The fact is, ABA is not a proven therapy for autism, despite what
parents say and it's time people stop ravaging our children for the sake of trying to prove it. Further, the science just does not support it. Yet, we continue to espouse it as absolute -- in government fact sheets, among autism organizations. As Dawson says, "Don't autistic children deserve better than assumption and speculation?" The least we can do is invest in understanding autism, and respect our children.

All children need to be understood and accepted by their parents, not constantly reminded what a disappointment they are, and how much grief and financial burden they have caused their parents. All children deserve to be respected and provided every opportunity in life, and be regarded as whole people instead of broken ones.

While I do not want to alienate parents (even though some continue to alienate the autistic in these discussion about them), I do mean to suggest that it is obvious some have spent more time mourning over the "ravages" of autism rather than meeting the hundreds of autistic adults living in the Province of Ontario, and learning from them. There is more time spent grieving over the child who is alive and who needs us as parents to believe in them. I believe that if we can build that bridge by providing more forums for autistic people to speak, to participate on our scientific research teams, to teach in our schools, to sit on the boards of autism organizations, we will better understand the enormous challenges as well as the fundamental value of autistic people in our society. Parents also need to be supported in understanding the many aspects of autism. No one is denying that autism can be a challenge, that perhaps some autistic people who can't speak, may wish to, for instance. I am also baffled that parents do not find intrinsic joy in their children, no matter what the disability.

Autistic people have much to teach us. My son has taught me so much already, even, at four. He has guided me to many autistic people in North America who have taught me more about autism than any non-autistic "expert." But I guess if you feel that autistic people don't even understand themselves, you might continue to alienate autistics from the very discussions concerning them. This does not happen in any other disabled community today. Yet, it's sanctioned in autism.

It bewilders me that parents do not share the same goal for their
children whom they love. It strikes me as odd that they do not want them, really, to be the best people they can be, but instead, have committed to hopelessness, placing all of their time on ineffable cures. It seems to me, that our children need all of our strength and commitment AS PARENTS to BELIEVE in them. But you won't believe this if you constantly believe that your child has a disease like cancer. And we do KNOW from the science, that no external cause has been identified with autism to suggest that it is like cancer. Overwhelmingly, autistics say that despite their many challenges, they still would not cure their autism. This sounds familiar, as the blind describe their blindness as a way of being. Something that becomes part of them. Do we define blind people as diseased? No. We define them as handicapped in a world where the majority SEES. Yet, we know that the blind have many abilities and strengths without sight as a result of the brain's ability to adapt.

Instead, these are the questions I ask myself with every action I take as we grow with autism:

Doesn't Adam deserve to be understood?
Doesn't he deserve to be treated with respect?
Doesn't he deserve to be protected against pejorative comments that destroy personhood?
Doesn't he deserve to be regarded as a whole person instead of an impaired one?
Doesn't he deserve to be included in discussion about him as an autistic person?
Doesn't he deserve the right to a good education?
Doesn't he deserve the right to be accommodated with services that is proven by peer-reviewed science?
Doesn't he deserve the same quality of life that we all have?
Doesn't he deserve to be respected by me, as his parent; to treat him as a delightful and equally entitled individual?
Doesn't he deserve the right to be legally protected against discrimination on every level of science, education, employment, accomodation and services?

I think he does. It doesn't mean denying autism. It does not mean that I am in denial. It means that I accept autism. I accept the challenges, and indeed we all have our own, as families, as individuals. I respect the challenges that all parent’s cite. They are real. They should be supported, but not at the exclusion of autistic.
people and inaccurate facts. Also, we must all acknowledge that opinions may differ. One person's tragedy is another person's challenge. We can meet life head-on, viewing the cup half-full, or choose to live with it half-empty.

Yet, I strongly disagree with regarding autistic people as incapable of understanding themselves, and at the exclusion of an autistic person's right to accurate science, and with the complete and utter disregard for how words effect them. We must consider autistic people as whole people, with the right to speak for themselves and participate in these discussions.

Acceptance also means I disagree with spotlighting the challenges of our children for the sole purpose of being right in the face of incorrect facts about autism that are glaring today. This is why I will not discuss many things about Adam -- and many people make a lot of assumptions about him and our family. It's a weak argument -- whose better or worse off, who is higher and lower functioning, whose child is most self-injurious, who has more money to "treat" autism. These arguments achieve nothing, reveal nothing. I've met many parents with little who do not complain as much, who face the same struggles, and who have come up with creative, accepting environments for their children. And you know what? It's still all autism.

The strategy of creating a disease model in autism is not even working. On the one hand, while we broaden our knowledge about autism, we are also increasing fear, and this is resulting in the exclusion of autistic children in many of our schools. We need more services and education -- not to remediate autism, but to teach the autistic person in a way that befits them. We need to respect and accommodate autistic people as much as we accommodate the blind with Braille.

Above all, we need as parents, professionals, society and autistic people, to find a common language, perhaps only forced upon us by the evidence, to support parents and accommodate the autistic members of our society. I believe we can do it.

With all my heart and soul, I believe in Adam, and his basic human entitlements. I believe that by the time he reaches puberty, he needs to know that he is loved and accepted by me, his mother. He has taught me all of these lessons. All thanks to his world, his
Is It Artism or Autism?

Instead of using the speech he prepared for opening night below, Larry typed in his words on his computer, on the spot. Here is the prepared speech he was thinking of using, but didn’t. It asks the perennial question: *Is it Artism or Autism?*

*Larry Bissonnette asks the question, am I artist potentially because of mental and neurological traits of autism or possibly am I an artist because of obvious natural talent?*

*All it comes around to is awesome perspective that an artist can get on world’s sights, sounds, and smells. Wearing an old shirt and grabbing a paintbrush is like letting go of closed in feelings and applying lavish amounts of attention on pure creative impulses.*

*Sawing wood for frames also lets relatively simple task of hands working with tools assume status of artistic worth because paintings are represented by their images and the lifegiving frames around them.*

*I waltz into Toronto enjoying lots of international travel so I hope it’s the same crossing borders experience for all of you."

*Larry Bissonnette’s work is on display at The Lonsdale Gallery at 410 Spadina Road, Toronto.*
Hi Estee,

Larry and I had some time between flights on our way home on Friday and we had a chance to look over the TAAP magazine and read your story about your visits to see Larry and Jonathan. We have been to many events together and I could tell he really enjoyed this one. He wrote some words to you:

“Kinship with people either classically autistic or mildly lit up by less obsessive peculiarities of autism is really wonderful. Looking at my artwork presented with such elegance let me proudly get goosebumps in my heart. Most liked doing speech on loud microphone. Maybe will FC speech and read it out loud in the future. Thank you again.”

Let there be more autistic voices that rise, more forums in which they can be heard, no matter what the medium. You can view Larry's work at The Lonsdale Gallery at 410 Spadina Road, Wednesdays-Sundays 12-5 p.m. It is part of the Joy of Autism: Redefining Ability and Quality of Life EVENT

CBC Quirks and Quarks

Listen to interview with Michelle Dawson and Laurent Mottron here: CBC RADIO ONE "Rethinking Autism."

Michelle Dawson, Dr. Mottron and Dr. Gernsbacher can be seen at the Al Green Theatre, Bloor Jewish Community Centre (at Bloor and Spadina) on Tuesday, October 10th, at 7 p.m. Tickets are also available at the...
And The Last Word On Autism Goes To...

People without autism are more often than not, given last word on autism. The problem with the article, is that it doesn't interview one autistic person living in Canada today. I am glad that autism is finally being discussed -- that the concept of neurodiversity has been given some attention.

Today, you can read the front page story in The National Post here.

Here was my reponse today to the editor and the writer:

Dear Mr. Brean and Editor of The National Post:

While I thank you for doing the article on Redefining Autism, and understand the need to “balance” the argument by garnering many opinions from parents and professionals, I must point out that it remains imbalanced because it lacks one fundamental group: autistic people.

You did not interview any of the autistic people at the show at Lonsdale Gallery on Thursday night. Larry Bissonnette, considered “low functioning” has said by using his keyboard, “people who think your disability is an illness need to be cured of their ignorant attitudes.” You did not call the many autistic individuals living in Canada today, or our leading researchers in autistic cognitive ability – Laurent Mottron and Michelle Dawson (also an autistic person).

The Autism Acceptance Project’s purpose and The Joy of Autism: Redefining Ability and Quality of Life event is unabashed by this article because it once again shows that the media does not put the voices of autistic people front and centre of issues regarding them. Instead, we
continue to get skewed views from non-autistic people and autism academics (also many autistics are part of this academia), about ideas of normalcy. This does nothing more than continue to stigmatize autistic people as aberrant in a way that degrades them and misunderstands them. Don’t you think it might be a good idea to ask an autistic adult what those behaviours mean for them? When you interpret the “boy jumping on his trampoline so that he can see the sunlight flicker through his hands,” one always has to consider that you may not understand what that boy sees – because you are not autistic. Your observations would have been much more fascinating had you contacted an autistic person who could have given you yet another perspective – the autistic perspective.

It was interesting that you did not talk to the many disabled members in the audience as well at Lonsdale Gallery on Thursday night. We had a remarkable attendance of people from many disabled communities – the idea of representing disability with the voices of the disabled is nothing new, and it was certainly not started by me. We had a few unexpected autistic guests as well. I’m sure they will be once again be effected by a de-humanizing, nay medicalized, portrayal of autism. As usual, people without autism are always given the last word.

I guess I should have mentioned that Adam gets speech therapy, occupational therapy, one to one therapy every single day, and that acceptance does not mean ignoring these things.

All of you (and I hope many responses come from autistics themselves), can respond to the writer and the editor by emailing to these addresses:

jbrean@nationalpost.com
letters@nationalpost.com

Also, today, Saturday, Laurent Mottron and Michelle Dawson can be heard on CBC Radio One 99.1 at 12:00 NOON.
The Launch

The Launch of The Joy of Autism: Redefining Ability and Quality of Life last night was a dream.

Five autistic guests who spoke at the microphone, and a gallery full of people, willing to accept. Parents thankful and aware of our need to accept the joy our children bring us, despite the challenges. People untouched by autism approaching me who said “I didn’t understand autism, and now I understand a little more.”

And then, as I finished my speech which had no mention of the following words, Jonathan Lerman yelled: “SELF ESTEEM!”

Larry Bissonnette wrote on his computer: “Larry looks good on Estee’s film.”

Brian Henson said “we are not all the same,” and gave reference to how autistic people are stereotyped.

Martine Stonehouse talked about autistic ability despite the many challenges she has face throughout her life, and her wish to be appreciated for her ability.

Then Alan Lerman said, "The title Joy of Autism seemed provocative. I read some of the comments on Estee’s blog where one parent said 'I'm tired of all the doom and gloom.' The Lerman family is in that corner."

We were well attended by educators, autistic people, scientists, parents and many people from other disabled communities.

I am grateful that my life has been touched by these incredible people. And all because of one child who has given me more than I could ever give back in return: my Adam.
It's No Joke

A snigger for the chattering classes

BY SOPHIE COLES

(This article was passed around by Kevin Leitch. It is from The Times, U.K.)

MY 11-YEAR-OLD son is funny and clever, kind and happy. He is also autistic. He doesn’t compulsively collect bus tickets, nor does he rock gently in the corner. But his condition will affect him for the rest of his life.

And the most scary and unpredictable time is the approaching teenage years when children learn about their condition and often tip into depression or even suicide. I think about the possibility of that every day, and what my husband and I can do to help him through it. And it comes down to self-esteem. Simon has the brains to have a fully independent place in the adult world — but only if he feels he is worth something.

Soon we will have to explain to him what he is, why he is different, why he needs support — and in a way that makes him believe in himself. Simon has no idea yet that he is different — and so far, his eccentricities appear to the children around him to be just that. Years have already gone into helping him to cope in the world, helping him to make friends and understand other people, managing his social relationships.

We are now at the critical next stage. It starts with saying that we are all different — certainly on the outside, and sometimes on the inside too. So far, so good. But the next phase is to explain the ways in which he is different. Finally, a name is put to it — autistic. The theory is, in a year’s time he will understand why he thinks and acts differently and, crucially, see it as something that, if not positive, at least isn’t negative.

In the past few months, it has become fashionable among smart metropolitans to use the term autistic as a catch-all to denigrate
any but the most socially adept men. And it’s always accompanied by a snigger. It’s in the media, it’s at dinner parties, now it’s at a party conference. Somehow it’s acceptable and clever — though those same smart metropolitans would never refer to someone physically maladroit as spastic.

My son cannot help who he is, what he was born with. The most I can do is make him feel good about himself. But how can that ever be possible if, when the time has come, he’s already heard the term autism used by people who should know better as a cruel joke. It is fodder for the playground bully. And it will eat away at the self-esteem of any autistic child or teenager able enough to understand that it is an insult.

*The author is writing under a pseudonym*

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**TUESDAY, SEPTEMBER 26, 2006**

**Take Joy In Every Step**

This morning I awoke to the same rhythm – get up and right to the computer and keep working before the opening of *The Joy of Autism: Redefining Ability and Quality of Life*. We open with the exhibition on October 5th.

Over an extra-large cup of coffee with milk and too much sugar, Adam quietly ate his eggs – he prefers them sunny side up with salt. I cut them – the task of poking them with the fork still a little too difficult for him. Max, his older half-brother, came downstairs and Adam’s face lit up. He grabbed a ball and persistently tried to engage Max to play with him.

Now, for those people reading this who don’t know much about autism, this was a pretty huge thing. Two years ago – a year ago, even – Adam would not engage anyone in play. If he saw a group of kids, he would head in the opposite direction. Today, he was persistent, laughing, throwing the ball to Max, kicking it. “Play!” he said a couple of times, in between expectant jumps, and giggles – and Max got a lot of hugs in-between.
This afternoon, the children in his JK class began playing with the ball in a triangle formation. Adam looked on. He edged his way in. And further in, still.

“Last year he was really tentative about joining in and this year I really see he’s trying to play with the others,” said his headteacher, in that sweet, sing-songy preschool voice that I know will end all too soon as Adam gets older.

So I know that my patience is important with Adam. We never forced him to play with others. We tried facilitated groups, we practiced, but we never forced him. We just exposed him. I certainly worried. But the moment I stopped letting worry rule our lives, was the moment that life began to happen.

How can I not feel joyful for him? How can a parent not feel joy in every baby step? Is this not the purpose of our lives?

When my grandfather died in 1984 from a severe allergic reaction, I was devastated. I was his only grandchild and we had a very close relationship. In one week, his body caved in on itself. I entered intensive care, finishing my Grade Thirteen exams -- the ones that get you into university or not -- to see his body shrivel in upon itself. I told him I loved him. He couldn’t say it back, but I knew it was on his lips as it was one of the rare times his body moved after I’d said it. When he died I chose for his epitaph:

**The purpose of life is life itself.** (Goethe)

This is the only life we have, folks. Take the joy.

PERMALINK POSTED BY ESTEE KLAR-WOLFOND AT 9/26/2006 04:05:00 PM 3 COMMENTS LINKS TO THIS POST

SATURDAY, SEPTEMBER 23, 2006

**Understanding Autism**

**This article is from Action Network in the UK. Kev Leitch was interviewed:**

‘My daughter, Megan, was three when she was diagnosed with autism. She was classified as ‘low functioning’ or ‘Kanner’s’
or 'classic' autism. At the time we were devastated. We knew nothing about autism and all of a sudden we had to become experts and yet at first we seemed frozen in what we came to recognise as grief.

There are five stages of grieving. We traversed them all. We went through stage one quickly. Denial is a way of trying to stay in blissful ignorance. But we quickly accepted that this wasn’t good enough. It was real, it was happening. Anger was next. We lashed out, trying to find something to blame. We settled on vaccines, mainly as Megan did have an atypical reaction to her DTP. It was easy to make that connection. And once we’d settled on vaccines we went straight to stage three. Bargaining is an easy trap to fall into once you agree to blame an external 'something'. Please God, if you cure my daughter then I’ll never have another vaccine given to her again. Take away her autism and I’ll convert to Christianity. But nothing changes and it’s easy to fall into stage four. Depression is the worst stage. You worry about money, about health, about family and it never seems to stop eating at you. Every day. Every look you get from your boss when you come in late. It all contributes. And then, it lessens. You start to look at things afresh. Or we did anyway. We took a deliberate decision to stop fighting autism and learn about it from people who were like our daughter – autistic. What we found amazed us.

One of the first pieces of writing I came across was that of Jim Sinclair, an autistic man. He’d written an outstanding essay entitled ‘Don’t Mourn For Us’. In this essay, Sinclair says: “Some amount of grief is natural as parents adjust to the fact that an event and a relationship they’ve been looking forward to isn’t going to materialize.”

Grief

And then he goes on to say: “But this grief over a fantasized normal child needs to be separated from the parents’ perceptions of the child they do have: the autistic child who needs the support of adult caretakers and who can form very meaningful relationships with those caretakers if given the opportunity. Continuing focus on the child’s autism as a source of grief is damaging for both the parents and the child, and precludes the development of an accepting and authentic relationship between them.”
And it hit me that that’s exactly what I’d been doing. I’d spent so long fighting and bargaining that I’d forgotten about the needs of my little girl. From that point on, our outlook changed. We relaxed and read as much as we could from autistic adults so we could try and see the things that might matter to our daughter about her life rather than what might matter to us about her life.

And we also started to look objectively and rigorously at the science of autism. We found out how wrong we were about vaccines for example and I discovered a whole subsection of quackery on the internet made up of people claiming to be doctors offering bizarre, untested therapies for hundreds, sometimes thousands of pounds.

As Megan grew and we became more and more relaxed, she became more and more relaxed too. Soon she was exhibiting learnt skills such as using a computer fluently. She did this as we become increasingly prepared to come into her world. If she was rocking in front of the TV, so would we. If she was singing at the top of her voice in Sainsbury’s then so did we. Suddenly, we weren’t fighting; we were sharing and living as a family. I eventually discovered that this approach had a name and a concept: Neurodiversity. This is the idea that autistic people do not need a cure but do deserve respect and recognition for who they are.

This is not the same as doing nothing. Megan still undergoes speech and language therapy for example but it means not ‘fighting autism’, rather accepting it and working with your autistic child in a way that they get the most out of. It’s essentially meeting your child halfway.

Megan at age six is not the same child as Megan at age three. She’s more confident, happier, more settled and progression is marked. Thankfully, we were able to listen to her in a way she felt comfortable with.’

Kevin Leitch’s company Left Brain/Right Brain is about two things – autism and web design. Sometimes the two combine but mostly they’re distinct. Here in his own words Kevin, as father of autistic daughter Megan, candidly reveals his belief that autism is not a life sentence.
worse than death or an epidemic. Megan is now a confident little girl.

Thanks, Kev.

SATURDAY, SEPTEMBER 16, 2006

Connie Said It!!

Let's give her more airwaves. Thanks to Autism Diva who put her on the blog. I'm borrowing for our Toronto audience once they click from the TAAProject website to here.

Point to be taken: Nothing about autistics, without autistics:

AFTER VIEWING EACH VIDEO, CLICK THE BACK BUTTON TO REACH THE REST OF THE VIDEOS IN THIS POST.

VIEW CONNIE ON VIDEO BY CLICKING HERE

Also watch The Empowerment Conference VIDEO CLIPS FROM FINLAND HERE

Watch Kev's VIDEO "POISON" HERE for those who don't empower, but take all fact and spirit away....

And then his spirit soaring video BEAUTIFUL AUTISM (an inspiration for The Autism Acceptance Project Video)

and Dinah’s positive and boundless energy with the PosAutive project

and Janet and VIDEO ON ALEX’s RUN ACROSS PEI.

More fact than fiction, joy is a choice, it is boundless, it is....human.
A law cannot guarantee what a culture will not give

That quote in the title is from Make Them Go Away: Clint Eastwood, Christopher Reeve and the Case Against Disability Rights. I often wonder if legislation is just a prelude to a forced change in the direction society needs to think about the disabled. But it is true that the law can only take us so far, and if society won't give our children equal access, it will always be difficult for our children.

Adam did his first Sportball program in a loud, echoic gym today. At first, he seemed a little frightened of the noise. His shadow let him run around a little, until he felt comfortable in the setting. We want him to enjoy Sportball, not find it unpleasant. He ran into her arms and began laughing. He watched his peers. He felt the materials. Then, he picked up the hockey stick and made a score.

The coach said he is going to call me tonight. I have to say that this is the only thing that puts a pit in my stomach -- when a teacher or coach says they have to "call" me. I'm hoping that my paranoia is unfounded. I hope he won't tell me to take Adam out of his program.

You see, Adam needs to learn this way until he becomes comfortable in this new and loud environment. He needs to be able to adjust to his setting, run around a bit, get used to things, observe his peers, and then eventually, he can do it. He was the only kid to sit in the coaches' lap at the end of the program today. One thing Adam has down pat: affection.

I want him to stay in that program. I could see he got used to it and that despite the bumpy beginning, enjoyed it in the end.

But the coach, or any teacher for that matter, may have his way of doing things that doesn't include Adam and kids like him. Rules might be too rigid. My joy is in Adam's success - because I understand that his success comes from a place where he has to work so much harder than others. But my sorrow lies always in other's non acceptance.
I heard that we have to earn joy in this world. It doesn’t always land in our lap just like that. When it does, it is golden, like Adam. But mostly, joy is what we make of things. I will await the call, and do what we all have to do: advocate for Adam so that he is accepted in the program (if they are so willing and open-hearted), and empower his teachers with information about Adam’s learning style and success today... Make the teacher proud!

PERMALINK POSTED BY ESTEE KLAR-WOLFOND AT 9/16/2006 02:43:00 PM 1 COMMENTS LINKS TO THIS POST

FRIDAY, SEPTEMBER 15, 2006

If You Could Make Your Autistic Child "Normal", Would You?

We as parents of autistic children have so much to learn from other disabled "communities." I am considering showing this film, The Sound and The Fury at The Joy of Autism: Redefining Ability and Quality of Life event this October with a follow-up discussion.

The film is over the debate about implants to make deaf people hear. We see the debate concerning isseus of identity, community and how those in the hearing community view the deaf and how deaf people feel with these views. I’m not going to say much else here, other than this film is important to watch in the context of the autism debate: to cure, to normalize or to accept autism, and what acceptance means for each of us. I look forward to your comments.

CLICK HERE TO WATCH CLIPS FROM THE SOUND AND THE FURY

PERMALINK POSTED BY ESTEE KLAR-WOLFOND AT 9/15/2006 03:53:00 PM 29 COMMENTS LINKS TO THIS POST

TUSSDAY, SEPTEMBER 12, 2006

You're Not Me!

“You’re not meee...you’re not meee,” says Adam in a sort of boyish...
I chuckle at his wisdom. “That’s right Adam -- I’m not you!” I’m not sure where he got this phrase -- I certainly don’t use it. It sort of reminds me of my step-daughter’s four-year-old willfulness when she said, “You’re not the boss of me!” Is this Adam’s version of self-assertion? Self-definition? Self-awareness?

Sometimes we think our autistic kids adopt phrases and don’t quite know the meaning of them -- at least not immediately. This might be the case, but he always has a sense as to where those phrases should go.

“Adam come here.”

“You’re not meee.”

“Adam, it’s time to brush your teeth.”

“You’re not meeee.”

It baffles me. He doesn’t look at me intentionally as he says it -- not like my step-daughter Maddie used to, with crossed eyes, and hands on her hips, just short a stuck-out tongue. Her posture hollared, “Defiance!” Instead, Adam just says it automatically. It sounds more rote. But I can’t assume it has no meaning. No, not my willful little guy. He does share some of the same genes as his half-sister, after all.

After I brush his teeth, I turn on a video before bed that is visually stimulating. I haven’t put this one on for a while now -- computer generated dancing shapes to Mozart’s Eine Kleine Nachtmusik. His hands go above his head as he makes a type of pirouette. His feet are moving quickly -- rat a tat tat -- to the music and he does a little turn. His cherub cheeks are jiggling with each step.

“Hey Adam, you’re dancing!” I say delightedly.

“You’re not meee,” he exclaims.
What do we mean by Inclusive Education?
Some Comments from Others

Excerpt from “Parental Models Go To School,” from An Unexpected Joy:

How you think you should behave as a parent and how you think your child should be taught come of the same deep place inside. Schooling is a very emotional topic. We all know stories of horrible things going on in classrooms, and there is much righteous fodder for the educational reform movement. But rigid thinking about a school’s structure erupts from the same dark source as rigid thinking about a successful family.

It gets even more emotional when you throw in disability. With the abandonment of the developmentally disabled by the medial system, the societal responsibility has been shifted to the school systems. A lot of good has come of this. Special services can most conveniently and effectively be served up in this setting. What an experienced special education teacher or occupational therapist or autism specialist has to say about a problem is much more likely to be helpful than what your physician has to say. There is no disputing the advantages to our kids from the ADA and the development of services and accessibility that has resulted from this legislation.

I am always shocked when I run into resentment toward special needs kids and the amount of money spent on their education. I am not aware of people resenting speech rehab services for their elderly stroke relatives or post-closed head injury rehab for young adults after their skiing, diving or auto accidents. The public is quite naïve about medical insurance. Many people in my state are so used to extraordinary coverage that they think of their insurance cards like a charge card, with the bill going to someone else. The notion of insurance money being a pooled, collective resource is lost on them.

A more visible form of pooled money is the public-school dollar. This is probably because of the election of local school boards and public voting on school millage issues. Parents feel they have
more control over this money and are therefore more vigilant stewards. So they resent the extra dollars it takes to educate disabled kids. They see it as money not being spent on their kids. They are unaware of the shift of this responsibility out of the medical dollar – which they view unrealistically – into the more visible public-school dollar. The idea that these dependent individuals will otherwise end up on welfare, another pooled money pot, is lost on many of them. Basically, the biggest bang for the buck is the money spent on schooling these kids. It will result in less money being spent from other pots.

The passage of the ADA resulted from years of persistent, effective lobbying by disabled individuals and their families. Part of that early activist movement was the radical notion of inclusion. The concept of least restrictive environment was introduced and determined to be an important goal in meeting the needs of special education students.

This was good. It brought many problems out of the closet. All kids benefit enormously from effective inclusion programs. Both the special-needs child and the typical child benefit, as they do from anything that increases healthy diversity in the classroom. ...Ineffective inclusion programs are another matter altogether. When they’re bad, everyone loses. But in too many schools, the trend is to push everyone into the mainstream. When that happens, an individual assessment of the child’s needs isn’t considered, and inclusion is hyped as a goal for all special-needs children.

Nic didn’t benefit from inclusion. The worst year of his school career was the year he spent in the mainstream classroom. And this was with the cards stacked in his favor. He had a marvelous teacher, whom he knew from his PPT (pre-primary impaired) classroom. He had a loving and experience parapro. The parents of the other kids in his class bent over backward to include him. It was simply too much for Nic. There was too much noise, activity, and visual stimulation. All that enrichment was right for the regular kids, but it was toxic for him.

I have two concerns about mainstreaming. The first is what I call malicious mainstreaming. Parents who are still in denial about their child’s prognosis commit this. They insist on mainstreaming because they mistake the process of role
modeling provided by the other students for a normalizing process. When a year goes by and there is no change in their child, they think the teacher has done something wrong or someone is to blame.

My other concern has to do with the basic nature of humans. My son has known he was different from the get-go. He has communicated this to me in many ways, most of them nonverbal. When you put a child who is profoundly different in with a bunch of fully equipped kids, everyone knows what’s going on. If the children have been brought up well, they are polite and practice acts of inclusion as they are able to. Many are very kind. If they have not been brought up well, they can be cruel. Neither of these is an ideal environment because both preclude the development of a real peer group.

...I believe a critical mass of time spent with real peers allows true friendships to grow. This is as good as it gets. We found this in Nic’s contained classroom.

A good teacher uses these real relationships to teach. Renee, Nic’s current teacher, is the gold standard in my book. My son knows about “showing heart” and “giving zingers” because these behaviours are illustrated and discussed in his classroom every day. Renee is able to make these principles concrete.

The continuity we have been blessed with has allowed a real classroom culture to develop. This in turn benefits the younger kids who come into the room. For my son to be a role model for a seven-year-old is huge. He sees himself as competent and feels pride. This is true growth. It helps interrupt the cycle of constant dependence that so many of these kids suffer from. When they’re around the regular kids, they are never fast enough or smart enough or acceptable enough. This is an exhausting way to live. If we didn’t have a contained classroom, I don’t believe these trusting relationships could have developed.

The children in Nic’s class are remarkable. They show pure and simple tolerance of diversity. They are sib-like with each other, which means they can be joyful with each other and then turn around and give each other a hard time. The kids gloves are off, and they’re on as even a playing field as they’ll ever get. This is a much more balanced environment for them to grow in.
Mainstreaming cannot provide this kind of intimacy.

...One of the specialists we saw was a woman who has studied the educational needs of autistic people for more than twenty years. She gave me a wonderful gift. As we were going over the summary of the recommendations they were making, which was all in educational and psychological language I didn’t understand, she paused. She looked up, right at me, and said “Basically, people with autism never stop learning. I’ve seen people learn to read at eighteen. I’ve seen people learn to live independently early in their thirties. They aren’t restricted by these developmental stages like regular learners seem to be.”

She opened a door for us. She gave Nic a future. I don’t even know if it’s accurate, but the notion that Nic will continue to grow and benefit from enrichment changed the way the horizon looks to us. It feels a lot different than the smaller and smaller world we envisioned for him at the worst grip of our fear.”

(From *An Unexpected Joy* by Mary Sharp, M.D., pp 102-108.

Here in Toronto, the gap is too wide. It’s either an “autism school” that provides ABA, or trying to get Adam into the mainstream, with accommodation. Sometimes I feel the most flexible teachers and administrators will help us get through. But ultimately, it is the real acceptance of diversity that will change the education paradigm. Other times, I worry that if we don’t do inclusion well enough, autistic kids will still lose.

Most autistic adults hated mainstream schools because they were never accommodated. The goal here is not normalization, the goal is education. The best-ever for autistic kids, that not just manage behaviours, but educates to their fullest potential. Further, we have to consider what disabled children have to offer non disabled ones. Learning goes two ways. These can be done within existing schools or privately, but we have much work to do to define that large gap that currently exists between segregating the disabled, inclusion and the right education. That is why a continued drive towards acceptance is urgent.

Consider the world wide movements and actual practice of inclusion around the world:

**Inclusive education - a worldwide movement**
Inclusive education is gaining ground. Throughout the world, teachers and others involved in education are working to develop positive educational experiences that all children and young people can enjoy and benefit from, together. For disabled children and those experiencing difficulties in learning, this means inclusion in mainstream schools and classrooms alongside their non-disabled peers. For all children - and adults - it means a more enriching and rewarding educational experience.

Internationally, the drive towards inclusion is fuelled by a number of initiatives and treaties, including the UN Convention on the Rights of the Child (1989), the UN Standard Rules on the Equalisation of Opportunities for Persons with Disabilities (1993) and the UNESCO Salamanca Statement (1994). Together, these documents recognise the human right of all children to education which is inclusive. 193 countries have signed the Convention on the Rights of the Child, with Somalia being the most recent in May 2002. All but two countries (Somalia and the United States) have also agreed to be bound by the Convention by ratifying it.

Some countries have made significant advances towards promoting inclusive education in their national legislation. Examples include Canada, Cyprus, Denmark, Iceland, India, Luxembourg, Malta, the Netherlands, Norway, South Africa, Spain, Sweden, Uganda, the United Kingdom and the United States. Italian law has supported inclusive education since the 1970s.

As the 1999 report by the Organisation for Economic Co-operation and Development (OECD), Inclusive Education at Work: Students with Disabilities in Mainstream Schools, states: "The rights of students with disabilities to be educated in their local mainstream school is becoming more and more accepted in most countries, and many reforms are being put in place to achieve this goal. Further, there is no reason to segregate disabled students in public education systems. Instead, education systems need to be reconsidered to meet the needs of all students."
This drive towards inclusion is not only rhetoric. Rather, the reality of inclusive education is transforming the lives of millions of children - and teachers - in countries across the world. According to the OECD report, there is a decline in the proportion of students in 'special' schools in most countries. CSIE's *Index for Inclusion*, which helps ordinary schools break down barriers to learning and participation, is being taken up in a range of countries around the world (see page 16).

Diversity in the mainstream is increasing in many countries. The vast majority of disabled children and young people in Iceland attend their local schools. In Italy, more than 99.9% of all children in the state sector are educated in ordinary schools. In the province of New Brunswick, in Canada, there are no 'special' schools - all children are educated in local mainstream schools.

A national study on inclusion in the United States in 1995, carried out by the National Center on Educational Restructuring and Inclusion, reported a huge growth in inclusive education for students with all levels of disability. A report from the Ontario School District in Oregon stated: 'The only criteria for a student to attend any of our six elementary schools, our middle school or our high school is they must be breathing.'

In Uganda, the human rights of disabled people are enshrined in the Constitution and sign language is recognised as an official language. Deaf children now attend their local schools, with appropriate support to enable them to learn. One observer noted: 'Instead of sitting silently and unnoticed in their classrooms, they now have sign language interpreters provided.'

In the district of Douentza, in Mali, West Africa - one of the 'poorest' areas of the world - villagers worked together with outside agencies to set up a much needed local school, which disabled boys and girls attend together with every other child. One of the teachers said: 'To begin with we had the commitment to include disabled children, but we did not really believe that they could be in school. Now we have seen for ourselves, and we have moved from commitment to conviction.'

These are but a few of many examples.

**No room for complacency**
Despite these significant advances, however, large numbers of disabled children and young people throughout the world - including in the United Kingdom - continue to be subjected to negative, deficit-based language and exclusion from good quality mainstream education.

Some countries - such as Italy, Uganda and Norway - clearly see inclusion as meaning all children and young people learning together in mainstream provision. But all retain a dual system of 'special' and ordinary education.

The existence of legislation supporting inclusive education does not necessarily mean that inclusion is happening in the everyday lives of children and young people. For example, there is a strong Government commitment to the philosophy and goals of inclusion in India, but this is not yet fully reflected in practice. German national policy and legislation support inclusive education but high proportions of students are placed in 'special' schools. The Norwegian policy of not providing 'special' schools is undermined by the practice of parents sending their children to 'alternative centres'. In Denmark, a pioneering country in terms of inclusive education, the number of children placed in 'special' classes has been markedly rising.

**Not about money**

It is not simply a question of funding. It is a common assertion that 'full' inclusion - all children and young people learning together, including all disabled children - would be too expensive. Yet the example from Mali demonstrates that inclusion can happen whatever resources are available.

International work by both the World Bank and OECD has shown that it is far more expensive to operate dual systems of ordinary and 'special' education than it is to operate a single inclusive system. In Reykjavik, Iceland, local authority staff calculated that the cost of educating a child requiring the most intensive support in a mainstream school was no greater than the average cost of sending students to 'special' schools.

The real problem lies with the historical investment in separate, segregated systems of 'special' schools, the lack of political will to
make inclusive education available to all, and the uncertainties of some parents that inclusion will benefit their children. But throughout the world, people are seeing the benefits of inclusion for themselves. Everywhere, those who have experienced inclusive education - including providers and disabled and non-disabled students - are convinced that inclusion is the way forward.

**From strength to strength**

These experiences must be built on. The urgent task is to change hearts and minds, encouraging openness to the values and aims of inclusive education and a commitment to the human rights of all children and young people. Non-government organisations and individuals must also continue to lobby Governments, and raise awareness among teachers and parents of the advantages of inclusion. People directly involved in inclusive education need to share their knowledge and experiences with those just starting out.

Progress needs to happen on all fronts, from Governments passing legislation and formulating policy to people in schools working inclusively with real students. As one school director in Swaziland said: 'I had thought the problem of integration of children with difficulties was difficult to solve, and a problem of the state. But all my conversations have now confirmed my opinion that someone had to start, to break the mould, and fight against the isolation of children with special needs.'

Exchanging information about examples of good practice in the restructuring of mainstream schools in the UK and overseas is an essential step towards ending discrimination in education. In persisting with these efforts to secure a worldwide move from ordinary and 'special' education to inclusive education, we can press on towards the goal of making inclusion an everyday reality for all children and young people.

**INCLUSION from University Of Western Ontario’s Centre for Inclusive Education**

Dr. Jacqueline Specht

You learn to talk by talking
You learn to read by reading
You learn to write by writing
What does inclusive education mean in Canadian society?

Prior to the 1970s, it was very rare to see children with exceptionalities educated in their home schools along with their siblings and neighbours. Typically, they were bussed to schools that had separate classrooms where children with special needs were grouped together for learning. In the 1970s, a movement began to bring children with special needs into the regular classrooms. These children may still have been bussed from other areas, but for certain times in the day, they were "mainstreamed". While the term mainstreaming seemed to imply that children were placed in the regular classroom, this was not really the case. Children with special needs were considered more like visitors to the class rather than full members of the classroom.

Why is inclusive education important?

Inclusion assumes that children with special needs are part of the regular stream and should be treated as such. Inclusion is based on Wolfensberger’s principle of normalization (i.e., all persons regardless of ability should live and learn in environments as close to normal as possible). The basic idea behind normalization is that people with special needs should be viewed in the ways in which they are the same as other people rather than in the ways in which they are different. School can be seen as a microcosm of the larger society. As Canadian society has moved toward a more inclusive view of all individuals, so too have schools moved toward inclusion.

What are the controversies?

Inclusion is not without its controversies. As the movement has evolved, the distinction between regular education and special education has become blurred. More and more regular classroom teachers have been expected to program for the children with special needs. This has caused a lot of problems because many of the teachers have not been trained in special education. Even current teacher education programs do not provide a significant amount of instruction in special education. Another issue of concern relates to the education of the children without special
Some parents of these children feel that their children's education has been weakened due to inclusion. **Research has shown that this is not the case.** The educational attainment of children in classes where there are children with special needs is not significantly less than in classes without children with special needs. **One may even argue that children in inclusive classrooms learn more as they begin to understand and accept diversity.**

**What are the characteristics of an inclusive school?**

All children can succeed in an inclusive environment. Research tells us that effective inclusive schools have the following characteristics:

*Supportive Environment*

A school's culture and climate refer to the school's atmosphere, values, and policies. These lead to particular expectations and behaviors on the part of staff members and students. An effective school is one that has high expectations for its staff members and students, provides caring support for students and staff, and provides opportunities for their participation in the classroom and broader school setting. Feelings of acceptance are promoted by a welcoming school atmosphere and a school culture that accepts different kinds of behaviors in the classroom and does not make assumptions about children's abilities.

*Positive Relationships*

Teachers encourage the development of relationships through their decisions about where to seat children in the class. More formal actions include exposing children to role models and setting up buddy relationships. Many strategies can be used to promote the social inclusion of all children.

*Feelings of Competence*

Children need to believe that they are competent at something and that others believe that they can succeed. Children can develop a strong self-concept in many different areas. Children can feel competent in areas related to their social, athletic, moral, and...
creative abilities and qualities, as well as their ability to learn. By understanding their areas of strength, children come to value themselves and develop a strong sense of self-worth or self-esteem.

**Opportunities to Participate**

All children require opportunities to participate in activities that allow them to understand societal expectations. They can then acquire the physical and social competencies needed to function in their school, home, and larger community. As well, they gain an understanding of their strengths and their interrelationships with others. When children are valued, listened to, encouraged, understood, and believed in; they will be successful.

**It's Not Always About What We Can Do For Autism, But What Autistic People Can Do For Us**

"If you take him out of this school, you might as well take his life away from him." Line from the Movie "Radio."

Many of you might have already seen this inspirational movie with Cuba Gooding Jr. and Ed Harris, but I only recently saw it. It goes to show that sometimes, Hollywood does some good, and sends a message loud and clear to a wider audience: if we accept, so much can be accomplished. This movie is based on a true story.

If you haven't watched the movie, watch it. Here's the trailer you can view: [CLICK HERE].

Adam with his autism, has given me more than I may ever give back in return.
Larry Bissonnette, Jonathan Lerman and the Profound Joy of Autism

I have rewritten this post from an earlier one.

ability
1 a : the quality or state of being able; esp : physical, mental, or legal power to perform
b : competence in doing : SKILL
2 : natural aptitude or acquired proficiency

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It is this notion of ability versus disability that has come to mind after meeting with Larry Bissonnette and Jonathan Lerman in Burlington, Vermont and then Vestal, New York. I visited Larry and Jonathan in order to curate their artwork for the exhibition and upcoming event in October: The Joy of Autism: Redefining Ability and Quality of Life.

I climb the narrow stairs of a barn-like structure housing other workshops. It is hot and sticky; the air is thick with dust. Larry watches me approach and I smile excitedly. He leans in to me with his forearm, and returns the smile -- his version of a handshake.

I am so happy to meet him in person, finally -- an admirer of his awesome insight and poetic way of describing things. After reading about a person for so long, they become a kind of celebrity -- I feel so familiar in his presence, yet am a complete stranger to him. It is an invasion of sorts, being here, meeting him, looking through the hundreds of paintings so neatly organized in his studio. This is Larry's private space, both his inner and outer worlds.

I am tentative and try to be delicate and gracious within his space. There is a cameraman with me. Larry, I’m told, likes to be on camera, but we are all quiet, introducing ourselves slowly, meeting his assistants, letting the minutes determine what is to be said, and how much.

Larry is standing near the door, drawing arcane lines with his finger through the air, like the conductor of an orchestra. "Baby
“Does that have a meaning?” I ask Pascal Crevedi-Cheng, Larry’s Facilitated Communication assistant since 1992.

“They are repetitious phrases, a breakdown in communication. They don’t have any specific meaning,” he tells me. I think about the times when my own son Adam, now four, is scripting -- when he places a phrase into a space or a moment, how it can make sense even though it is repetitive, like he is enraptured with the sound and the melody of the words.

I ask Larry “What is happening for you when you loop your language – when you say Baby Blue Door, for instance. Does it have meaning for you?”

Larry looks at me, and I can tell he acknowledges every word, leaning in and listening closely. “Ah!” he says, and promptly begins to type on a portable laptop that Pascal pulls out for him. “Pale imitation of real feelings,” he writes.

At the studio, and after the introductions, I begin to feel comfortable enough to look through Larry’s work. He is watching me, arms folded, smiling. I ask him if it’s okay to look, even though this is what I came here to do. Craig, the cameraman turns the camera on, the dialogues at this first meeting among the artifacts of Larry, of autism, and this attempt to promote awareness about autism ability.

After two hours, I pick the work for the show, we grab lunch and return to the Howard Centre, a few miles away from Larry’s studio, where the interview continues. We are next to the University and Burlington still bustles with summer students. Larry is listening to us talk while we eat, and I ask him what his favorite food is.

“Macdonald’s cheese burgers,” he says, and I chuckle. He shines a big smile and Ryley, my assistant grabs two coupons for Macdonald’s burgers from her purse and hands them over. Larry reaches for them hastily.

“Do you have a girlfriend?” I ask him. Larry cowers and blushes. I
joke around. “Ah!” I say. “I made you blush!” He grins.

The laptop computer comes out again, the camera is ready. Larry is using a computer program called Write Out Loud, which says the words and sentences he writes. Pascal’s index finger and thumb squeezes his shoulder gently to remind Larry to keep his fingers moving along the keyboard. I have not yet asked him a question and he begins to type, “Least little force of my typing isn’t making sense. Estée ask me your awesome questions.” He is a gracious man.

I have seen many symbols in his work – houses, cars, and crosses. So I ask “What do cars mean for you?”

“Problem knowledge of goings on with interpreting images as symbols is Larry doesn’t paint ever vesting deliberate symbols. It’s all intuition.” I understand intuition.

It amazes me that popular science has purported so many myths about autism to the point that the public doesn’t believe that empathy, emotion, imagination and intuition are a major part of an autistic person’s life. Larry is one of the many autistic adults I’ve met and spoken with over the past two years of travelling who refute many of these ideas – “the shell of a person that is autistic.” We have learned that autism is very much a part of the person. We have learned, through the research of Dr. Laurent Mottron and Michelle Dawson from University of Montreal and Dr. Morton Ann Gernsbacher from University of Wisconsin-Madison, for instance, that there are cognitive abilities in autism that seem recondite but valuable, and using the metaphor of Camille Clark in a recent Autism Podcast, may be akin to "learning upside-down."

“How can you begin to know how to teach an autistic child unless you understand how we learn?” says Michelle to me in a lengthy telephone conversation. Her research with Dr. Mottron is helping us understand this. “It is untrue that autistics need to learn how to learn,” she laughs. “We learn!” I can see that of my son, how he acquires reading skills, among many things, on his own. It may not take the shape I’m used to, but I know he is learning.

“Whose to say that our senses are disintegrated?” she scoffs. This is the premise for sensory integration theories, but Michelle and Laurent both make the point that there is no disintegration, just a
difference. I feel that Adam’s sensory system is so precise, attune and very intact if not overly astute to the point of intuitive. Michelle helps me think about how boxed in I feel with popular theories that have been interpreted as absolute truths about autism. She doesn’t say this to me, but what she does say is more congruous to my experiences with Adam than any one else’s words or theories of autism as a set of deficits and inabilities.

She suggests that there is a false-belief that once we know the cause of autism, we’ll understand everything. Instead of jumping from causation to behaviour as a means to supposedly "understanding autism," we are finally looking at cognition and abilities – one might say, the meat and potatoes of it all.

Larry is what you call classic autistic. So I ask him outright, “Do you want to be cured of your autism?”

“People who think your disability is a sickness need to be cured of their ignorant attitudes.” I smile, he smiles, we high-five. We have a moment of understanding and his sense of humor becomes so apparent.

“What do you want people to know about you?” I ask.

“Larry loves McDonalds like people once they stop dieting and only when work that I spend my time on is seen as personally motivated and not derived from autism will I be satisfied.”

I tell him that people will be interested in his art for itself, and because of his autism. His art and the titles he ascribes to them, are inseparable. Larry is like a poet, revealing profound truth about his experiences in institutions and his views about life in a mere phrase.

“Yes,” he continues, knowing how people will view him, most likely, better than I.

Ralph Savarese, a professor of English at Grinnell College in Iowa and a father of an adopted autistic son, wrote to me about Larry’s language:

“There’s something profoundly relational (analogical) in the way that non-speaking people with autism communicate. Perhaps
being forced to map the world visually encouraged an over-reliance on metonymy (or the principle of relational contiguity); whatever the case, their way of communicating and the ethics it implies (not individualism but community, connection) seems a lovely rejoinder to much that is sadly neuro-typical. In a footnote about Larry, I suggest that he seems to produce spontaneously the wonderful analogical dislocations of the great modernist poets.”

“What do you want parents to know about their autistic children?”

“I am in life until the total realization about the power of communication happens so parent occupied with over-coming problems of disability needs to focus on abilities that are not easily seen.”

So on the note of ability, I have to ask, “What is your greatest strength?”

“Am slacker by nature. Am the personification of practice makes perfect.”

Perfect. Indeed he is.

“You are a wonderful writer,” I tell him. He smiles. “Would you ever write a book?”

“Yes,” he says enthusiastically and begins to type, “not pictured in People magazine yet maybe publishing a book would put in on People’s reporter’s plain but cool list.”

Larry is tired. I’ve been with him for four hours, looking through work, talking on film which is being made into a video for The Autism Acceptance Project. He shakes his tired hand from typing – a long and deliberate task for him as he types slowly with one finger. And we have a plane to catch. Larry will come to Toronto in October and speak to others at the gallery on October 5th, which will be open to the public.

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We fly to Vestal, New York. It is raining again like the last time I was here. This time, Jonathan will be with Alan, his father. I
haven’t seen him since last December. They greet us and Jonathan looks as excited as he did when I picked them up for the opening of his exhibition at Lonsdale Gallery last year -- he is almost breathless.

I bring him a book from the gallery – illustrations by an artist – a book-long comic strip. Jonathan seems to enjoy it as he reads it in the car on the way to his studio – a building attached to a church which is owned by Joe, his art-teacher who has known Jonathan since he was seven years old. It is an old musty building and we are lead to the basement where a series of studios, including a clay one, are housed. Jonathan has his own studio way around the corner and at the end of the long narrow hall.

“I want to start a sculpture,” he declares. Joe was hoping he would draw or finish the one in front of him. Osama Bin Laden stares at us in the doorway. Jonathan’s room and the clay studio are filled with other political figures too. Today, he wants to do George Bush. Again, the camera sets up and he begins sculpting. “There’s no such word as can’t,” he declares, molding Bush’s nose.

I enter the adjacent room flipping through hundreds of Jonathan’s incredible drawings. I pick drawings from Jonathan’s various stages of interest – people he knows, rock musicians, busy collages of faces -- while talking with Joe and Alan, intermittently.

“How often does Jonathan come here?” I ask Joe.

“He’s here almost every day.”

“No wonder the prolific work,” I comment.

Joe works with other students in his after-school arts program. He has been helping Jonathan for over ten years, making suggestions, exposing Jonathan to different mediums. I am impressed how Jonathan’s sculpture is becoming more sophisticated, and the speed at which he works.

“One day I finally got Jon to do a self-portrait in clay,” Joe says while I’m flipping through artwork. “He has done so many heads, and there hasn’t been a problem with any of them when they’ve been fired. But the day he does his own head, it blows up in the kiln.” I pause. We stare at each other at the apparent irony. “Isn’t
that bizarre? Not one other head blows apart except for Jonathan’s.”

Later, I see that head proudly sitting on the window ledge of his drawing studio. It is not blown apart as much as it is fractured. The outer skull on the left side has fallen off but sits deliberately next to the remaining head. The inner clay is still round and clean, like looking through the skull to the brain-intact. It reminds me of not so much an incomplete or fractured brain as much as an invasion of one – man’s curiosity to find out what makes us tick.

It is getting late – nearly eight o’clock in the evening and we’ve been going non-stop since nine in the morning. We’ve been with Jon for about three hours. He is getting hungry and tired, the bright camera light becoming too much for him to bear. He is showing signs of agitation and begins to cry.

“I’m tired. I want to go home.” Alan goes in to soothe him. Jonathan wants to hug his father and there is a sweetness that surrounds them like a cocoon. We all watch in the crowded studio, feeling invasive, and this is not the first time I’ve witnessed the tenderness between them -- Alan is completely devoted to his son. Alan is sad to see his son upset, his tall frame enveloping Jon, comforting him. I want to tie this up. I want Jonathan to be with his father and go eat.

While wrapping up, Joe goes to calm Jonathan while Alan takes photos of the works I’ve picked for exhibition. I show Joe the picture I’ve used in The Joy of Autism ads and ask him where the piece is. Nobody knows. There are still so many works still to be exhibited, catalogued. I think, Jonathan’s work is his artifact and must never be lost. To distract Jonathan for a few more minutes, Joe asks if he can replicate that drawing. Jonathan does. He is calmer.

We are back in the car, Alan’s Magellan is talking us back to the airport in the otherwise quiet SUV.

“What do you want to eat?” Alan asks Jon, trying to let him know that dinner is coming soon.

“Italian.” We are all salivating in the back at the talk of food. It’s been a long day and we too are hungry.
“I want Fettuccine Alfredo,” says Jon. I have noticed a remarkable increase in Jonathan’s language compared to a few months ago. Alan holds Jonathan’s hand to keep him relaxed. Jonathan is rocking his body a little, like he’s holding on to himself. It is clear that Alan is his steady source of calm.

“Jonathan has been talking of going to college,” Alan says, taking a deep breath, turning his head to talk to me a little more. I am thinking it’s entirely possible, if not probable. Jonathan is surrounded by the love of his parents, and after meeting Larry, will likely manage his anxiety at some point. Jonathan has a girlfriend, just went to his high-school prom in a limo.

We run out and say a quick goodbye; Jonathan shakes everyone’s hands and runs back to the car.

“Go feed him!” I laugh, and Alan runs after him.

I am delighted to see Jonathan, hoping that food and going home will ease his stress. I think of what Larry might have been like at Jonathan’s age, when his sister took him out of the institution he talks sourly about today. I think of Barbara Moran, the autistic woman, age fifty-five from Topeka, Kansas, who wrote to me of how her sensitivity to noise has made it virtually impossible for her to be around people, and how she says that being on medications and being institutionalized made “her autism worse.” I think about ability, about the title The Joy of Autism, about sadness and struggle, but how every autistic person I’ve met and spoken with enjoys being as they are despite their challenges, which even to me some days, is difficult to comprehend. I think about the responsibility of talking about the provocative title The Joy of Autism amidst all of these challenges – how some parents might call their children a joy, but “not the autism.” Yet, every parent of an autistic child knows that our beautiful children demand from us a commitment to joy. Joy is struggle’s antithesis. We can not experience one without the other.

I hope that the positive messages from autistic people who face these many challenges, will reign. I think about how we define ability and how we must search for uniqueness, potential and dignity in every individual – how we must find our little ounces of joy in the many moments of our lives.
The Joy of Autism: Redefining Ability and Quality of Life, October 5-November 5, 2006. A lecture series at the Miles Nadal Bloor JCC and concerts and exhibitions and presentations at Lonsdale Gallery, Toronto all by autistic people, parents and researchers in support of acceptance.

For more information contact
http://www.taaproject.com/
Or 416-487-3600
Click Here for VIDEO

TUESDAY, AUGUST 29, 2006

Another Kind of Video

Click here to view The Autism Acceptance Project Video

MONDAY, AUGUST 28, 2006

The Perils of Representation and Communication

The exhibition of autistic artists at The Lonsdale Gallery in Toronto as part of The Autism Acceptance Project will begin in a month. The exhibition serves many purposes:

1. To demystify many myths about autism, as art is communication and speaks for itself;
2. To celebrate autistic artists and people instead of instilling fear and doom;

Is this putting art on a pedestal thereby seeking to sensationalize autism? If we sensationalize autism, or the work of autistic artists in a spotlighted way, are we at risk of perpetuating another myth:
Last year, Jonathan Lerman was portrayed by certain media people as a “genius.” It bothered me on the one hand – Jonathan, this wonderful young man, understood and perhaps accepted by others only for his “genius.” While I was ecstatic that Jonathan was reviewed and revered, I felt that something was taken away from his personhood in the process. There are hazards in representing others, and communicating about autism. I recognize these perils and not only take responsibility for them, but also keep aspiring to communicate in a way that continues to achieve understanding and respect. Communication is an art – it is difficult for most of us at the best of times. However, with the divide as huge as it currently is, that is, between parents, society and autistic people, I consider the goal an important challenge.

Some people say discourse is a process. Others believe that acceptance is not a discourse. In my post The Learning Curve of Acceptance I said that acceptance is a process, as unfortunate as that is, and that as we learn about autism, listen to autistic people, our assimilation of knowledge about autism takes time, mostly because there is so much assumption and inaccurate information about autism. I think many of us have realized that acceptance doesn’t exist to the full extent that we need it to, and communicating about autism is ambiguous, paradoxical and difficult in the midst of the doom messages that are popular. The work of Michelle Dawson, Jim Sinclair, Amanda Baggs, Kathleen Seidel and others has been integral to intelligently understanding autism and the issues that abound when non-autistics begin discussing autistic people.

How we present the work of autistic artists is important as is discussing their work. Do we regard the work of autistic artists with awe because they are autistic, or do we regard the work for itself? When we consider the work in the latter context, we can then regard the person behind the work with respect. There seems to be some confusion in granting respect and equality to autistic people. Equality simply means that despite race, creed or disability we all deserve to be regarded equally while acknowledging challenges and differences.

The work involved in creating something is arduous. To believe that it comes just from some autistic stream of consciousness –
that it just flows because of the autism -- is part true and untrue. There is always the work, the hours spent creating and perfecting it. I consider the hours that Jonathan spends at his art studio and the hundreds of paintings awaiting my attention at Larry’s. Their work is prolific. Jonathan’s work appears lucid, full of emotion. Larry’s, on the surface, looks more like folk art. What makes Larry’s work fascinating and important are the titles he ascribes his work, as important as the work itself and as inseparable as Siamese twins. His titles read like metaphors, poems. I am in awe of his use of language that rings with profound meaning. While the way in which he writes may come in part from autism, it is also indigenous to Larry. He has the ability to describe the world like a poet who can pinpoint the complexity of truth in a mere phrase.

In this respect, Larry and Jonathan have worked to SEE. Seeing, observing, understanding, assimilating in a way that touches us in a mere moment – the toilsome work of perceiving and understanding the world and manifesting that in a work of art, or literature, or poetry for that matter – this is a process that demands the artist to actively participate in the world.

Kamram Nazeer, an autistic policy advisor at Whitehall and writer, addresses our banal understanding of genius in his book *Send in the Idiots*. He notes that when we designate an autistic artist or writer a “genius,” we are taking away their dignity because we are in essence saying that there is no effort behind the work. When we believe this, we have once again diminished not only the work, but also the person behind it:

**GENIUS:**

“The term obscures; it provides an area of grace. The problem with the term ‘genius,’ however, is that we do not only use it for the purposes of bereavement. We use it commonly. And we use words and attitudes that are similar in effect.”

The work by autistic people deserves the “full and proper rigor to the life of the ordinary, though very clever, subject but not to the life of the genius.... If the task of criticism is to somehow explain, or make guesses, or lead interesting speculations as to how works come to be or how they do what they do, the use of the term ‘genius’ must be eschewed. It reveals nothing, it gives no insight into the creative process; by using it, we get no further.”
**Genius** has to work hard too. Our conception of privileges of genius is a false one.

**Genius** has to engage with tradition.

Perhaps the greatest achievement and finest use of the term ‘genius’ is that it makes us feel safe. By using it to identify a group of individuals who are different from us, and we refuse to engage with how it is that these individuals do what they do. We accept that their achievements do not depend on anything but the special quality of genius itself.

**Genius** doesn’t rely on us.

**Genius** just is. Hence, the overall effect is that we completely rid ourselves of any responsibility for progress. We don’t have to understand what they do. We don’t have to aspire to do it ourselves. In return, we give geniuses certain special privileges. We cannot hold them to ordinary standards of behavior, for example. And in the end, we are able to remove ourselves from the great game. This is incredibly liberating. We can now enjoy our private lives. We need never feel anxious about our “contribution.” (excerpts from pages 79-88)

Genius is creative activity with hard work. It is true for all of us. Are these works of genius at The Lonsdale Gallery? Maybe yes for some, and no for others. But let us not put these artists on pedestals because of their autism. Let us regard the work for itself, and then we can also come to understand the person behind the work. If art is also communication, let us actively seek out what it is trying to communicate. Art, like all communication, is a two-way process.

The TAAProject video which will be released this week, is set to celebrate autistic people and to provide a positive view among society-at-large so that we can begin shifting paradigms. It is not perfect. I consider the video a work in progress, reflecting how views are in the midst of changing. It is a beginning for the general public to have access to something different about autism. The next video will begin to address the complexity of our beliefs about autism, even those beliefs that suggest that autism is a special ability. It is and isn’t any of this. Autism just is.
How do we explain autism to the general public, if not one step at a time? This is our very first step. I believe it is for the better.

**Autism Podcast**

Thanks so much to Autism Diva and Autism Podcast for this wonderful show. I hope all of our Toronto readers will listen:

click on this: Autism Podcast

I am in Haliburton, sitting in an Internet Cafe while listening to this. Across from me sits "The Rails End Gallery" with a sign that reads: **ART IS TRIUMPH OVER CHAOS.**

The autistic artists who will be exhibited certainly are triumphant, showing an ability to take the abstract and make it into an interpreted, cohesive whole. Hopefully, with every word and deed, the same can occur for views about autism. Thanks again, Diva!

**The Pill to Cure The Autism Divide**

I’ve received positive and negative responses to The Autism Acceptance Project’s title “The Joy of Autism.” As expected, not everyone sees the joy in autism, at least not immediately. Many find autism a challenge and the joy of autism, elusive.

Yet, there is a tie that binds all parents, those of us who want services, education, and opportunities for our children. There is little difference between the devotion many of us feel towards our children, the daily commitment toward them in ensuring their
The difference lies in our attitude towards our autistic children. Is success defined within the frame of “normal,” or is it defined individually, without preconceptions? The idea of normal baffles me. In trying to define normal, I only come up with more absurdities.

When we believe that something is extrinsic of us, then we can blame something outside of ourselves, our children. For some parents of autistic children, it might be easier, although there is no scientific evidence to prove this, to believe that autism is a mask that shields the true child within, or that autism is a disease akin to cancer, waiting for a cure. To acknowledge that autism is as much a part of the child as congenital blindness or deafness, may be akin to telling a parent that their autistic child is dead. To acknowledge autism as part of the child may seem hopeless, but this project is here to show others that it is not. The devastation a parent might feel in light of these ideas, that their child will “never” do something that was expected, can be crippling, and may even lead to hatred, some of which will be directed towards this project that wishes only to preserve the dignity and opportunity for not only our autistic children, but also for adults who are speaking up. These adults are saying “autism is part of who I am.”

As a parent who has gone through the very same experiences of other parents, who has seen the devastating messages and videos, I asked myself, “how is all of this going to help my son Adam or my family? How will this effect his self-esteem, and the challenges of being accepted into the mainstream community? Ralph Savarese, a professor from Grinnell College, who has written a memoir titled Reasonable People: A Memoir of Autism and Adoption, stated,

“As a father of an Autist, I can tell you that feeling good about oneself is a big problem with autism. What do you say to an eleven-year-old who so understands the world’s intolerance of difference when he starts announcing on his computer at night, ‘freak is ready for bed’? Like other people with disabilities, some with autism have found that identity politics offer a vehicle for fighting discrimination and improving self-esteem. It locates the problem with difference where it should be: outside the self, in a world of ignorance and fear.” (p.13)
In other words, placing judgment of others outside of ourselves, is an important way to preserve self-esteem. This is why The Joy of Autism event is hosting the work and presentations of autistic people.

Judgment was the first negative experience we faced when going through the diagnostic and early intervention process. There are people who judged Adam from the outset, peering at him as a pathology. They became more focused on what he couldn’t do rather than what he could do. I wouldn’t say those are good teachers. A good teacher is one who can see the child for who they are, to find a entry point, to teach where a child’s interest lies, to understand the challenges and address them without using them to define the child. One seasoned teacher told me last night, “I became a good teacher when I realized that the content of what I was teaching wasn’t important, it was the child who was important.” Read that sentence carefully and find the profound wisdom in it.

Michael Moon, who seems in many ways non autistic today on the exterior, claims that he was very challenged as a young autistic child, and continues to find challenges as an adult despite his higher functioning. As a teenager he suffered chronic fatigue syndrome from trying to “fit in,” not yet understanding that he was autistic. “When I found out I was autistic, it was a relief,” he said. “I knew I fit in somewhere.” He says that at the age of twenty, when he found out about his diagnosis, the world shifted, and he was more able to become part of it.

“School didn’t help me,” he said. “Schools were more interested in how you followed rules rather than teaching.”

Brian Henson, an Asperger’s adult from Brantford, Ontario also relays similar pain from his school years. “Teachers only wanted me to read the text book. I couldn’t ask questions. When I wanted to explore something, they told me to just read the text or I would get an F.”

“We’re only teaching your child how to respond,” said Jim Partington to me over the phone, a few days before I considered flying him to Toronto. Adam was only two years old. He was not relating to us well, and consistently ran back and forth. I thought,
that teaching Adam to respond was not the means to an end. I wanted to teach him how to relate to me, and to be happy. We succeeded with lots of play. Adam is extremely intelligent, showing his knowledge in variant ways, one being the computer. He can do all of the skills suited to his age, and then some. He has more difficulty responding in a typical way. While we teach him now that he is older, happy and with respect for him (not using normalization of him as a goal – semantics are important here), I feel that we are building bridges between his world and ours.

When Adam was at camp, his head counselor asked his shadow, “what is it?” in terms of his limited speech, to which his shadow wisely replied, “he’s a child.” What difference would it have made for this young person to know that he was autistic? Would it have furthered her understanding of Adam as a whole child, or simply categorized him as an incapable one? I continue to ask the question: does the autism label help or hinder? If it serves to support autistic people and have them regarded as whole people as well, then I can support its use. If it is used to paint a horrific, disease-identity, where an autistic person is refused by teachers, therapists, and others, then it is wrong.

Paula Kluth, Ph.D., formerly from Syracuse University, and an expert in inclusive education and US legislation cites a quote by an autistic person:

“All my life I was enrolled in classes for the profoundly retarded. The pain of that isolation, I can’t describe. Some classes consisted of putting together flashlights together and then they would be taken apart for the next day’s project. I never spoke or made eye contact. I hummed and self-stimulated. No wonder they though I was hopeless. I was always treated well but my intellectual needs were never addressed because nobody knew I had any intellect at all. Sad to say, many like me remain in that same hellish situation.” (Kluth, You’re Going to Love this Kid: Teaching Students with Autism in the Classroom, p.23)

If there is any social injustice in the world that does a disservice to autistic children, it is those organizations and individuals who continue to paint autism as a horrible way of living and being. These are the same organizations that could help with what is: the reality that there are autistic people living in the world, who need education, and that there are families who need to feel inspired
and empowered, not constantly pounded with the message that their child is insufficient. This is the disease mind-set that is negatively effecting so many people. If autistic people suffer, it is not from their autism. It is from society who judges them.

Jim Sinclair acknowledges the process of parental grief stating basically, that although it is understandable, it is not right to take one’s grief out on the child. He offers some advice, being an autistic person himself:

“After you’ve started letting go, come back and look at your autistic child again, and say to yourself: “This is not my child that I expected and planned for. This is an alien child who landed in my life by accident. I don’t know who this child is or what it will become. But I know it’s a child, stranded in an alien world, without parents of its own kind to care for it. It needs someone to care for it, to teach it, to interpret and to advocate for it. And because this alien child happened to drop into my life, that job is mine if I want it. If that prospect excites you, then come join us, in strength and determination, in hope and in joy. The adventure of a lifetime is ahead of you.” (from his essay, Don’t Mourn for Us)

I have to say that the turning point for me was when I began to read the books and essays written by autistic people and autistic artists who have found a language outside the written word: Lucy Blackthorn, Richard Attfield, Donna Williams, and so many others. Some of who can’t talk, and who have dealt with challenges, and society’s stigmatization of them for a lifetime. This stigma effects the entire disabled community, who despite their disability, want to be accepted and want the same things as you and I. The vast majority believe that disability means incapable. The idea that there is actually a sentient being behind the exterior of disability is intolerable to many, but precisely the opposite is true and must be dealt with head-on.

Over the past three years, and especially the past year, I have made an effort to travel to meet many autistic adults all over North America – some with “severe” autism, “Kanner’s Autism,” Asperger’s Syndrome. I have met adults who were mainstreamed into schools when schools didn’t know the word autism to the extent we do today. I have met others who were institutionalized in the 1950’s when it was considered shameful for families to have children with any disability. Some of these people, now adults in
their late fifties and early sixties, said they were put on psychotic drugs and were treated poorly. One woman I met from just outside of Toronto was diagnosed with “Kanner’s Autism” has worked for thirty years since leaving a psychiatric hospital. As a child, she was placed in a facility for children with emotional disturbances. She managed to get married, drive, work and live her life as we all do.

Barbara Moran, from Topeka, Kansas (I am careful whose names I will use – I have received permission from some but not others as of yet), stated that she too was institutionalized. She says "just think of all children who were autistic placed in institutions back then, who we never hear from." Now in her fifties, she is extremely sensitive to noise and cannot work. She says she could have done better if she was accepted and allowed to go to regular school “where I could have been desensitized,” she notes. She says that the drugs she was placed on nullified her, and she hated being on them.

Larry Bissonnette, who uses a keyboard to communicate full sentences said to me “people who think your disability is an illness need to be cured of their ignorant attitudes.” Larry was also institutionalized until his sister saw how he was treated. She pulled him out and now lives with her, making art, traveling around the world on occasion. I met him and experienced his humour, his human-ness. Despite the challenges in communication, he is profoundly intelligent. It breaks my heart to receive emails from parents who cannot find the daily joy in their children, in these people who can teach us everything about autism.

Science has not yet provided any answers about autism, only more questions. Some science is unveiling the abilities innate to autism, thankfully, as it garners respect for a human condition, creating the needed bridge between so-called “different worlds,” to reveal that our worlds are not that far apart. As a parent who has sought answers from a variety of autistic adults, after hearing them tell me of their experiences, what worked for them and what didn’t, and the overriding message of each of them wanting to enjoy life, to be tolerated, understood and accepted by society, I had to ask myself what the point was in attempting to “normalize” Adam. For to do so would have meant that I did not value him as he was, or was unhappy with him.
No, autism is a challenge for the rest of us because we only see through one lens. We have to ask ourselves – is it the only lens? Is it the only way to look at autism? What of the autistic perspective? Is there a right way to be and a wrong way to be?

I’ve met parents who have revealed to me that “of all my children, my autistic child brings me the most joy.” This comes from two families I have encountered personally. Many others write about it: Paul Collins, Susan Senator, Valerie Paradiz, are some. It is something I strongly relate to, as Adam is my first and only child, my life, my reason for being, my utmost joy. Reframing my expectations of him has brought me daily surprises. I no longer expect myself in my pencil skirt and hat sitting at his Harvard graduation, but I also can’t say it won’t happen, or that I might not be sitting at his high-school graduation beaming at his success. As parents, we all know that the milestones our children do achieve give us monumental joy.

My husband likes to play devil’s advocate. I like that because I never think that there is one conclusion. Autism has revealed that to be human is living in paradox. He asks me, “So what if there was a pill to cure Adam? How are you gonna answer that?”

I can’t say that is an easy question to answer. Do I want Adam to suffer the stigmatization that a judgmental society will bring upon him? No, of course I don’t. I’m not sure if a pill could ever cure external judgment of him or of me for that matter.

Is autism curable? There isn’t one scientist that has proclaimed that it can be. In fact, the landscape of autism is so diverse, that one magic pill might not do the trick for everyone.

And if there was a pill? I just don’t know. To answer that question quickly is scarier than the question itself. Autistic people say that autism is a challenge, but still, they don’t want to be cured. Oliver Sacks once noted that we need to appreciate diversity in all its forms and called the brain “remarkable [in its] plasticity, its capacity for the most striking adaptations” as the “creative potential” of disease itself. People who have been medicated to the hilt, nullified of their experiences with neurobiological disorders, have suffered a marked decline of their creative abilities. I have to listen to this. We all do. If there was that pill, I would want Adam to decide, but even that answer is much too simple.
So do I deal with the reality of what is? Absolutely.

So now, I will reveal some of the responses, calling The Autism Acceptance Project “a political fringe,” to which I do not sigh, but perhaps acknowledge because eventually, a fringe becomes a mainstream. At least I hope that tolerance and acceptance will become mainstream. This project is about celebrating human dignity, potential and seeks to perpetuate respect so that we can ask for a variety of services and education to governments and teachers who just might see the individual potential of an autistic person. Waiting for a cure will not help us obtain services, support, vocational training. Governments will simply wait for those cures as a cost-saving measure.

Jonathan Lerman in Vestal, New York, is experiencing something akin to an team that enables his self-determination and empowerment, with support. It is a government-funded program. I cannot attest to how it is working, but the concept is interesting and might be considered. Jonathan basically states what he wants to do, and his team of people that support him, including his parents, ensure that his wishes and goals are realized. I believe that teenagers should continue to be supported with their peers, with self-image, that adults should receive vocational training, placement and support. I believe that inclusive education is a right, and that special education is also a right. Autistic people need access to a variety of approaches and educational opportunities. Above all, autistic people need self-determination.

How do the following statements encourage or hinder these needed services? To paint autism as a horrific disease waiting for a cure? Or an ability, a way of being, that deserves respect and opportunity to reach its potential? I am not revealing these responses out of disrespect for those who wrote them, or to create more divisions, but rather, as an opportunity for us to see the difference between empowerment/disempowerment in hopes that some may choose to find the same kind of joy and inspiration that my son has brought to our family.

**Response #1:**

I have to say; shocked is a mild word for my reaction.
As a parent of a child with autism, I applaud any effort to help the world understand this mysterious condition and the enormous strain it puts on those it afflicts and their families. However, to destigmatize autism with a sugar coating does this challenge a major disservice. Many of us actively advocate for those suffering with autism and accurate public education is critical. Making autism seem like “a happy place” doesn’t help our cause.

Response #2

While I am sure we all appreciate the benefits that accrue to children who are involved in artistic self-expression (and I am particularly sympathetic to this as a professional musician), this is an issue quite separate from the matter in hand - which is the choice of or tacit approval of the title "The Joy of Autism". This will not produce controversy, it will elicit fury. Parents who are trying to access funds and services, who are managing children with trying behaviours and who are fighting for educational equality do not want to have to deal with its implications.

What is next? Happy and Leukemic? Cancer is Cool? Incest is just another kind of love? I really hope you will not only appreciate the full horror of this gaffe, but do something public to acknowledge it! The good the event is certain to achieve will doubtless be diluted by the negative reaction from the autism community.

Response #3 (I apologize for the awkward spacing as this was taken from an email to me from Kevin Leitch of Autism Hub):

As parent to an autistic child considered to be 'classically' autistic (other terminology includes low functioning/Kanners) one of the most troubling aspects of the international autism community (by which I mean the self appointed organizations of largely non-autistic people) as oppose to the autistic community (by which I mean the organizations comprised of a mixture of autistic and non-autistic people, or solely autistic people) is the way in which a lot of people are opposed to
any attempt to present a non-tragic face to autism.

There is no denial that raising a child who has special needs is difficult but it worries me that people want to compare an attempt to look at a less negative aspect of autism to incest and cancer.

It seems to me that there is a large element of pre-judging occurring here. Both in terms of what the event itself is and in terms of what autism 'must be' for all people.

To me it is not only possible, but *vital* to separate the issues concerned. Yes, a battle for services is important but it is of equal importance to see that autistic people of any and all ages are as capable and as entitled to joy as anybody else. I don't see this event as an attempt to sugarcoat anything or to misrepresent anyone. If it was I would not want to be associated with it.

Recently in the US, the organization Autism Speaks released a short film entitled 'Autism Every Day'. During the course of this film the only side of autism that was presented was an unremittingly negative one. Children were badgered into meltdowns and situations, by the admission of the Director, were manipulated to show autism in the worst possible light. One segment showed a mother telling how she considered killing herself and her autistic daughter to escape the misery of autism. She related this incident whilst her daughter was in the room with her.

Consider the differences between this film and the Joy of Autism event. The film was made for an organization called Autism Speaks - the organization wishes to push themselves as the voice of autism, that they are they authority on the subject. This event is organized by an organization called The Autism Acceptance Project - referring to a project to promote acceptance.
The film is entitled 'Autism Every Day'. The filmmakers wish to present the idea that the unremittingly negative subject matter is the sole reality of 'autism every day'. By contrast TAAP's Joy of Autism, by its very title, indicates focusing on one aspect of autism. It doesn't seek to eliminate the negative, merely to accentuate the positive.

I can't see anything wrong with that aim. It puzzles me that anyone can.

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If I want a cure for anything, it would be for these divides: misery versus joy; normal versus abnormal; acceptance versus intolerance for autism itself.
I've been looking for a photograph for the piece that will be published next year. It is a piece about Adam, autism, family life. I called it "The Perfect Child." I like this photograph. It was taken in the throes of worry, when Adam was newly diagnosed; when clinicians and psychologists consumed us in their leather couches, saying *um hum*, and scratching their pens against lined paper, peering at Adam from behind dark rimmed glasses. I remember feeling angry at them. How dare they view my first and only beautiful child as a pathology? I remember hiring and firing so many therapists and clinicians who came into our home -- our door might as well been revolving.

This photo brings me back to this time when I was worried, angry, confused. It reminds me of all the terrifying things I saw, the films of autistic people screaming, being tugged by therapists. Yes, there are many movies like those.

Soon, The Autism Acceptance Project will release its video. It was made to give people dignity, others hope. In a world where there is little, where people put all their stakes in cures, pills and perfection, we need to remind ourselves that in the end, hope is not vested in cures, it is vested in humanity.
Toddlers in Black

I picked up Adam at camp today when his head counselor announced, “Tomorrow is Olympic Day. The teddies [his group name] have to come wearing black.”

The mothers stood bewildered.

“Black? My child doesn’t own anything in black,” one said in disgust.

Another just rolled her eyes.

“Who makes these decisions?” asked another “Why don’t you know anything about children?” I don’t think anyone in the group owns a black anything. Not at this age.

Instead of colourful toddlers strolling about the camp tomorrow, they will be dressed in dark black under the sun. I can picture it now, a line up of toddlers marching to their event, these dark shadows, perhaps in black sunglasses -- a set of oblivious spy kids, cranky under the raging heat of the sun. It’s a rather morbid scene in my head. These red-faced and sweaty toddlers, following in a
row like walking a funeral march. Not at all a sight I would expect, these bundles of joy who should be dressed in every colour of the rainbow, but not in black.

“Perhaps we can just cut out black circles and tape them to their backs,” suggested Adam’s shadow.

“Sure,” I said. “It’s better than dressing in black. Now they’ll all look like a bunch of walking targets.”

**SATURDAY, JULY 29, 2006**

**Just Breathe**

I just finished a piece for publication next fall by Key Porter Books, edited by Cori Howard – a woman’s anthology: *Between Interruptions: Mothers Write About Guilt, Anxiety, Ambition and More*. I guess my piece classifies for the “more” part.

My hands hurt like I’ve got arthritis, yet my compulsion is to come downstairs and write some more before we leave for the cottage again – a rented one, an exercise in determining how much we enjoy, or not, the weekend schlep into cottage country.

TAAProject is going well. The video is almost complete, the magazine, the Autspoken submissions, the exhibition I have curated and am still organizing. Adam still goes to camp but I enjoy spending these weekends alone with him, relaxed for a change. The water has a way of just letting you take a deep breath.

Like many cities, Toronto is hot in the summer. The heat rises with the smog. The trees and the water of cottage country calls our bodies to just say ahhhh.

There isn’t a moment when I don’t think about our busy-ness, and how it effects our children. Our work, their programs, driving, driving, driving in between. At the cottage, we have nothing to do. We can only be. Adam always seems to talk more when we are up at the cottage with Henry and I. No therapist can bottle that and
There is a part of me thinking, why the heck am I going up there with the October event around the corner? My pain in my hands remind me that I've been busy. I've been writing, and working all the time, so much correspondence now by emails. Many of us share the same quandary – the compulsion to keep working. Perhaps we do not spend enough time observing and being with those we love. We value output instead of input.

The trees will speak to me, the water will beckon and refresh me, and Adam, Henry and I will just breathe.

Gossamer Dreams

I've been to the cottage. I've gathered with about fifteen other mothers, drinking wine, making exquisite food, and playing games in the darkness of the cabin, while moths beat their wings chaotically against the windows, the light lulling them like sirens. We don't let them in.

Our children are at home and the games reveal us -- unravel our everyday mother-armour, our hard practical sides to the soft sticky stuff that composes our mucky lives. I don't reveal to much too soon. When I do, I am always disappointed. I talk about Adam, of course. I talk about how wonderful he is, how I've come to appreciate what he brings to me, how he expands me in every way.

She happens to be a speech-language-pathologist, and as I talk my
joyful talk, a look of subtle skepticism crosses her face. I've seen that look before. The kind where I feel like I have to talk wiser, faster, smarter. I've seen it in the eyes of Adam's psychometrist, when Adam was first diagnosed, eyes peering at me from behind dark-rimmed glasses like I was a mother in denial of her doomed child. I've seen it in the developmental pediatricians' eyes when she looks at me as if I don't know what I'm talking about. It is a subtle look, even if unintended, a glance like a drop of poison that could seep in slowly, killing everything.

"I don't admit to know anything about autism," she says. "But unfortunately, the majority rules." She is talking about how we interact. How we are judged and what we have to do to "fit in."

*The majority rules.*

I can't respond. I have to absorb what she says for a while because I don't want her to think I agree. Thankfully, she is called away while I stay on the lounge chair -- the wind picks up and it's just me and the lapping waves swelling near my feet.

It hits me as the group of women gather on the porch and I stay back with my books and writing notebooks gathered around me, my silence swathing me like silk against the drone of voices in the distant background.

A majority is a perception. That "normal" is just a version of ourselves -- what is *normal* must be like us. It is a narrow-minded way to look at the world that is comprised of so many different kinds of people. A majority is comprised of tribes and they form larger communities that simmer in melting pots. What is the majority today always shifts the next -- the gay and black communities being poignant examples of a world made better with the acceptance of difference.

I am in town and I buy a magazine to zone out, *Town and Country*, and find an article about autism, just when I want to think about other things. It is not a good article, but one featuring *Autism Speaks*, the tragedy of autism, the stories reminiscent of the *Autism Every Day* video -- of desperate parents pulling on their children's hair..."hard" because they "have to." There it reads in the glamourous gloss of a high-society magazine, directed at an audience that will give their money to any heart-felt cause. It's not
that it isn't heart-felt to them, but it is nevertheless destroying the spirit of many autistic people and infuriating me as my own friends will approach me about that "devastating article" with perhaps a pitiful glance at my beautiful son. Adam deserves so much better than this.

The hors d’oeuvres come out on the picnic table as chilled wine is being poured. Perhaps I’m not the "majority" in this crowd who are talking about the many people I don’t know, and the ability to talk without end. I enjoy listening. I seem to be welcomed enough for it. I prefer to sit alone next to the trees whispering their sweet messages, the expanse of water soothing away the noise of the city. But the voices call me to partake, to play games, to reveal, to share, to learn, perhaps to burn but to always, always start again.

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I am a moth and she my candled flame
By her flickering light I guide the journey
By her guttering glow I view it all
And painted by her light, the world is glorious
And to her I am drawn

I am a moth and she my doom
Fluttering towards her I am flying
Deeper into her pool of joyous light
Ever closer to her killing flame
And by the heat of her presence
I ignite

Gossamer wings burn and seemingly evaporate
Incandescent pain lances throughout my self
I drop to the earth burned and battered
But miraculously alive
And I rail at my foolish ways
I could fly, and where did I go?
To pain, to anguish, to her
I wait to die

But I do not end upon the days next dawning
And upon my burned and scarred back
Are several strange nodules forming
Wings regrowing and a second chance
And by the evenings' cool embrace
flight have I again attained
And as I launch into the dimness
I see a soft light

Its her, her light undiminished for having consumed me
And I approach again
And...

As the next day rises, my new wings just forming
My again burned body rests now
A strange sight I see
Its her I somehow know, but different in form

In the light of day I see her for what she truly is.
Not a candle's flame, but a moth in her own right
And upon her burned back grow
A new set of wings...

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If You Hate the Roots

You can't hate the roots of the tree and not hate the tree -- Malcom X

No one had a greater impact on the cultural consciousness of African-Americans during the second half of the 20th century than Malcolm X. More than anyone else he revolutionized the black mind, transforming docile Negroes and
self-effacing colored people into proud blacks and self-confident African-Americans. Civil rights activists became Black Power militants and declared, "It's nation time." Preachers and religious scholars created a black theology and proclaimed God as liberator and Jesus Christ as black. College and university students demanded and won black studies. Poets, playwrights, musicians, painters and other artists created a new black aesthetics and ardently proclaimed that "black is beautiful."

No area of the African-American community escaped Malcolm's influence. The mainstream black leaders who dismissed him as a rabble-rouser today embrace his cultural philosophy and urge blacks to love themselves first before they even think about loving others. No one loved blacks more than Malcolm nor taught us more about ourselves. Before Malcolm most blacks wanted nothing to do with Africa. But he taught us that "you can't hate the roots of the tree and not hate the tree; you can't hate your origin and not end up hating yourself; you can't hate Africa and not hate yourself." A simple, profound truth; one that blacks needed (and still need) to hear. And no one said it as effectively as Malcolm X. (By James M. Cone)

As I referred to in The Learning Curve of Acceptance, there are different voices in the autism advocacy movement. I think Malcom X's statement about roots sums it up for the autism rights movement as well. In this X equals Y statement, you "hate" your child if you hate autism. I know many parents are really struggling with this concept. Many parents struggle with the disconnect between autism as illness, and autism as a way of being. Parents struggle with figuring out autism, and coming to accepting it. I empathize with their struggle. But I also empathize with autistic people who feel the same way as many blacks did. Just like the black rights movement, there are mainstream activists and militant ones. Yet, what strikes me most is the reverberant voices of the Malcom X's of the world, and just how potent their messages are, even they are hard pills to swallow.

As I said before, parents aren't always at fault. Yet, parents and organizations have to be responsible in how we talk about and present autism. Further, this negative talk effects the way autistic people may view themselves. We are fed bad information by media sources. These messages do not talk about the joy of autism, only the struggle.
Let the voices rise. Let time pass and tell us, we are different, but so very much the same.

FRIDAY, JULY 14, 2006

**An Example of Insensitivity**

Yesterday, Adam had a play-date with a non-autistic friend from camp. Adam is enjoying camp. In the morning he watches and waits for the bus, and as it approaches, he jumps happily up and down, “There’s the bus! There’s the bus!” There is a wonderful melodic tone to his speech and the repetition, and I love to make songs out of the things he says and jump around with him.

He has made another best friend, it seems at camp, “M,” — a little three-and-a-half-year-old girl who has motor planning difficulty, making language challenging at the moment. Adam and M sit beside each other during every circle. M won’t go in the pool unless she is with Adam. M began tickling Adam and he giggled and tickled her back until they were entrenched in their own private giggle-fest. She touched Adam’s nose, and he touched hers, she touched his head, and he touched hers. This was the report I received from his counselors.

Adam is in a “regular” camp with a “shadow,” who stands back as Adam becomes independent. Adam needs little assistance now from her and during the school year -- we faded the shadow back to one day a week. It’s just that at camp, the teenage counselors do not know how to teach appropriately to any of the three and four year olds, and I’ve discovered that his shadow’s positive advocacy of Adam and all of his abilities, and meaning of toddler-speak in general, is teaching the counselors how to actually interact with him, and the others, in a positive way. I don’t think I expected Adam to enjoy camp this much. He has formed attachments with one counselor and his swim instructor, and of course, little “M.”

I could have been angry with the camp. Yesterday, the head counselor, also a “teacher,” came out and said that Adam was “crying for most of the day and she didn’t know why.” I felt
singled-out and that the look on her face was that he was crying because he was autistic, a sweeping feeling that crossed me, and all the parents stared at me. When Adam’s shadow explained what had happened -- Adam had apparently bitten his tongue and was upset about it -- I marched back up to the “teacher” to say also in front of the lineup of parents, “Did you know that Adam bit his tongue which is why he was crying?” She indicated that she hadn’t been paying attention. “You shouldn’t made a statement that gets me worried without investigating the cause,” I said politely, but firmly.

The mother of “J”, who has the non-autistic child who came to play late yesterday afternoon initiated a discussion that her son “hates camp,” and that that same “teacher” did the same to her in the lineup of parents. The mother also felt stigmatized.

So, it isn’t an argument of prejudice against an autistic person, although I might have interpreted it that way. It was sheer insensitivity and lack of professionalism on the part of that head counselor. I have discovered that she knows little of this age-group of kids, doesn’t know appropriate activities for them, and is so busy being “head” that she doesn’t have time to interact with the kids.

In the meantime, my shadow is in there with a group of teenage counselors teaching them what kids want and need, autistic or not, it sounds much the same to me. Looking at all kids positively, with respect and dignity as little people with reasons and needs seems to be sorely lacking here, and perhaps is the problem with some teachers and institutions in the first place.

Assuming prejudice may be too easy. Accusing people of prejudice may even be deconstructive. We have to look at the context, teach the ignorant (ignorant as unknowing and insensitive), and act positively to achieve the goal of teaching and raising the self-esteem in all children.
The Learning Curve of Acceptance

The Joy of Autism: Redefining Ability and Quality of Life
is an event that will take place during the month of October and
organized by The Autism Acceptance Project. The event is
organized around a group exhibition of international autistic
artists, Larry Bissonnette and Jonathan Lerman, and Toronto
artists, Michael Moon and students from the MukiBaum
Treatment Centres. In addition, lectures around the issues of
autistic ability and what constitutes quality of life will be explored
by scientists vested in research focused on autism ability,
clinicians, autistic people, and parent authors – the latter who will
relay their journeys to acceptance of autism.

The exhibition not only seeks to confront popular and
misconstrued ideas regarding what it means to be autistic, but
also, will ask “what is art?” The elite art world is replete with
categories and genres. As such, it has classified the work of autistic
artists as “Outsider Art,” “Naïve Art,” “Art Brut,” or “Raw Art.” In
fact, the terms are referred to as self-taught art, not belonging to,
or informed by, another genre. Tom Sherman of Canadian Art
Magazine, states that the obligation of artists is “to find the
differences they need to distinguish themselves in an era when
similarities rule...The artist has a role to play in our society and
that role is to remind people of the value of difference.” He was not
specifically talking about art executed by differently-abled people.
He was discussing art in the context of a society that “craves
conformity and order.” He also makes the “what is art?” question a
little more difficult when he states, “There are artists, and there
are artists. Creating the appearance of art is easier than making
art.” How does the art of self-taught artists who achieve
Sherman’s obligation of reminding people of the value of difference
– intentionally or innately – fit in? Is this the sole premise –
intention to make art – upon which art is rendered valid? What
about compulsion? This will be investigated in the exhibition as
well as seeking to understand differently-abled people in the name
of de-stigmatization, and acceptance through understanding art as
human artifact. The event doesn’t seek to draw conclusions, but to
raise more questions.

Through art and a lecture series, we can try to define acceptance.
Acceptance doesn’t mean acquiescence. It doesn’t mean that we do
not foster skills in our children that increase competency and rest
on our laurels as parents. On the contrary to passivity, acceptance is a very active process. It means accepting autism as a way of being, and not conducting therapies that seek to “normalize” an autistic person. This is the fundamental difference in the politicized autism discourse – to conduct therapies in order to “normalize” the autistic person, or to teach and impart skills.

Acceptance means accepting the abilities that can enable an autistic person to succeed in the world as an autistic person. It means seeking ways to educate an autistic person and to help each child fulfill his or her potential. It means creating inclusive opportunities in schools and in the workplace that actively adapts education to meet the learning needs of the child. It means supporting autistic people in areas that they want and need extra support. Many of the autistic adults who have written to me and who I know personally -- who cannot live without assistance -- state that they would not cure their autism despite the challenges that autism, or being different, brings. As a society, we have to listen carefully to these messages and what it means when we study causation and advocate for cures.

The term acceptance is co-opted by many organizations that continue to purport therapies that seek to normalize the autistic person as the final goal. Many organizations still state that autism is an illness and a condition to be cured. This is not acceptance or part of the autism rights movement. As a society, we must continue to be rigorous in what messages get mixed in with acceptance. We must stay aware as to which organizations are lead largely by non-autistic people, who may be presenting autistics as token figures rather than as active participants. Some autistic people have referenced treatment of autistics akin to how the Canadian native community has been treated – with decisions being made for them by non-native Canadians. As the founder of a new autism organization, a non autistic person myself, I’ve had some recent share of scrutiny regarding board and advisory members and the way TAAProject presents itself in addition to the speakers it invites to participate. As it is still a new organization, the board will continue to grow and it will actively seek autistic members, speakers, contributors, advisors, audiences and artists.

It is important to acknowledge that acceptance is also a learning curve. I feel that the learning should never end for all of us. As a mother of an autistic son, I feel that working together – both...
autistics and non-autistics - is an effective way to change the stigma attached to all “disabled” people. After all, if we believe that we as humans are to all be accepted and supported for our differences, and we wish to create an inclusive and diverse world, we have to debate this, learn to cooperate, and build the important bridges.

That said, it is also important to disagree with the aim to find areas that we can all find in common, with our differences. It is not fine for one part of the population to consider autistic people ill, a tragedy or to impose cures that they do not want. There are also autistic people who disagree among each other about “treatments” and education, about the nature of autism, about challenges. The community is as diverse as any other. Some are militant in their advocacy approach; others are more genteel and persuasive. It’s all communication style, and all of these voices are part of the discourse.

Therefore, there are many autistics who are representatives of the autism community, a community that will forever remain as diverse as the world-at-large. The autism discourse is privy to a variety of perspectives about what it means to be autistic. So long as we respect one’s right to exist as they are, is there not value in many different contributions to the autism community? All of us must take an active role in the process and acceptance of autism/autistic people through the means I am attempting to describe here.

Will science conclude the ever-lasting question about the cause of autism? Can science completely level the equality field? Can it also destroy it? Or can it simply help us understand autism in a way that ironically, society might be finding out for itself through ethical questions. Are we paying enough attention to the ethical issues in the context of science? In the end, even in science, there are no absolutes. Only more questions.

Many arguments are made in the name of “autism acceptance.” It may look and sound like acceptance, but that doesn’t mean that it is autism acceptance. For this reason, rigor is required by all of us. Are large organizations that espouse a cure for autism, who still continue to taut autism as an epidemic, who present scientists without a credible background, being real or honest when they in turn say they “accept” autistic people? If organizations do not...
enter this active and sometimes exhaustive process, do they have a right to advocate for acceptance? Conversely, can we consider the adaptation of the term the first seeds to a conversion of real acceptance? Further, is it the honest intention of some of these large organizations to really achieve it? Can autistic people have an affect on this process? So, the inherent complications in using the word should be evident. If we advocate simply for acceptance without accepting criticism, are we honest advocates? Are we going to stumble and make mistakes? Most likely. But let us take responsibility for them and own up to our words and deeds and act to change our aims. It won’t happen overnight. It can happen over time.

Conversely, both non-autistics and autistics must be careful in how we regard each other as human beings. That must be the platform upon which autism rights and acceptance must be debated. Let us not engage in character assassinations that will not change minds. We must presume human decency in all people as much as we need to presume competence in autistic people. When actions, words, or intentions do not express that decency, then we have a right to speak up.

Perhaps ideally, I desire a de-segregation of the autism arguments which create greater divides among humans. I will continue to hope for common ground. At the same time the divides are paradoxically important and inevitable. The pendulum swings from one extreme to another, and proverbially speaking, acceptance and de-stigmatization will hopefully enter into mainstream consciousness. I am also against discrediting all parents as “wrongdoers” as it turns away those who are ready to accept the autism rights movement, and the learning process, without acknowledging the different points they may be along the path to acceptance (presuming human decency). Parents who engage in behavioural therapies may not yet fully understand that autism is not a behaviour and behaviour does not define a person. That said, autistic people must understand that there are many parts of many teaching methodologies that work, maintaining the focus on imparting skills, not in correcting or normalizing behaviour.

So, the messages are politicized, and many parents who are struggling with acceptance, also need to be accepted, morally supported, and must continue to find ways to teach their children.
We do not wish to drive these parents away with misunderstandings. Parents are the anchors in an autistic child’s life as they are in any child’s. We want to empower parents with strength, information, choices and opportunities for their children.

The Autism Acceptance Project acknowledges the difficulties of the autism rights movement and the philosophical divides. It does however; believe that the divides are inevitable and important. Research is important. This ethical discussion among all of us is critical right now. TAAProject believes that it is important for many voices to be heard so that the bridges to rigorous acceptance – not token acceptance – can finally be built. It above all believes in equality of all individuals and that all of us, no matter how different, deserve to be regarded as able individuals, with the right to be educated and to contribute to society. Governments and educational institutions need to take responsibility to support children and families, and to provide inclusive opportunities for all autistic and “disabled” people. We must also acknowledge specialized schools where inclusion is not possible at various points in a person’s development. There is an opportunity to foster tolerance in all future generations – start now and start young. All autistic people deserve no less, and autistic families deserve support.

In experiencing this difficult process by organizing The Autism Acceptance Project, I still believe in the Joy of Autism because I believe that there is good in humanity, and that acceptance, support, and understanding can be achieved. As a parent and a curator of art, I studied the works of autistic artists. I came to understand the one thing knew innately about my son and about autism itself: that what the “experts” were saying about what autism was, wasn’t necessarily true. That innately, I knew that my son was capable and indeed a gift. There is ability, there is brilliance, there is depth, there is emotion, there is grace, there is humour, there is sensitivity, there is love, and there is incredible perception and understanding in many autistic people. Autistic people are not the sum of their behaviours. Behaviour is a communication, it is part of perception. The exterior often fails the interior world of most of us. For most people, autistic and non-autistic, effective communication is very tricky.

Most of what I have come to know as autism, I have learned from my beautiful son Adam. Then, through the art that stands alone --
with or without autism -- I wanted to show the rest of the Toronto community what exists and what is possible.

This event celebrates autism and autistic people. It is a living, breathing, thinking event that is growing alongside us all.

For more information see [http://www.taaproject.com/](http://www.taaproject.com/)

TUESDAY, JULY 04, 2006

**Separation Anxiety... For Whom?**

Remember my weekend post on separation anxiety? Well, it's me, not Adam who has it bad.

Today was the first day of camp. The first day of getting on a school bus without mom. We previewed camp yesterday and last week. I drew pictures of a school bus, bought him a toy bus and spoke about busses ad nauseum.

The school bus was late, being the first day I guess this is normal. Adam was clingy. I was getting nervous, even though I TRY to hide it, but it seems that Adam picks up on all of my hidden emotions.

Four busses went by. They were not HIS bus. It was like a big tease. I was getting more agitated.

Making the School Bus connection a few minutes before camp.

But then the bus came, I scurried Adam in to the bus and his camp shadow followed.
Getting on the School Bus for the very first time.

Before I knew it, Adam was sitting on the bus, looking out the window, wondering why I wasn't coming. His eyes showed initial signs of distress. Then, the bus took off and I saw Adam's neck bend to watch me out of one eye for as long as he could.

My eyes teared as I walked into the house, as I laughed while I cried. I called Morgan on her cell.

"How's he doing?"

"Oh, he's fine. His friends are telling him about when they started at camp. He's having a ball."

The camp just called. My heart dropped as I thought I would have to pick him up early -- that something has happened.

"We're just calling to say that Adam is having a great first day at camp."

Ha. Go figure. It's always the parent who is the mess. This parent, anyway.
cold stone floors, I hear the pitter patter of Adam’s feet following me ardently.

Adam, just at the end of his school year, decided to begin his separation anxiety phase. Wherever I go, he will follow like my shadow – to the kitchen, up the stairs, to my office...to the bathroom. He is my loyal little lover-boy, enamoured with me, it seems. If I am ill and in bed for two hours, he will sit dutifully beside me. But if I go to get something upstairs and leave him behind for a minute, there is bedlam – whimpers turn to tears which turn to inconsolable wails.

He will no longer go to his long-time playmate/nanny, Flor – the very same woman who consoled him under the fluttering leaves of our hundred-year-old maple tree which seemed to covet them both when he couldn’t stop crying; the same woman who tried alongside me to put him to bed, which often took up to three hours; the very mate who taught him how to climb his first climbing wall just when I thought he might be so motor-challenged, and it might take him much longer.

Yet, Adam will go to Grandma and easily abandon me. But he will run away at the sight of Flor’s face. Flor, a single, forty-something Pilipino woman, a Jehovah’s Witness, who it seems, has devoted her entire life to praying to God and to the raising of Henry’s five children. She is in tears, “I love him so much,” she said to me yesterday as I tried to console her. “He doesn’t like me anymore.” Flor is a child-spirit in a woman’s body --jolly and playful. She does not yield to tears often.

It used to be after five minutes of leaving the house, Adam would be okay with Flor and happily resume playing under the covers, “peek-a-boo,” or greedily keep requesting a “squeeeish” from her under a pillow.

So, the problem-solver I like to peg myself out to be, I have Flor and one of Adam’s tutors working together with him. I am also scheduling more time for Flor to be with him. She needs to re-bond, reconnect. They both need to find their mutual playful sides again. They really are best friends.

At four, mommy is the centre of the universe, I’ve discovered. With no other children as a point of reference, I have to recall my
own four-year-old memories – being terrified when my mother got out of the cab before me in fear that the driver would skid off with me cowering in the backseat. My mother recalls the many stories of her own exhaustion tempered by her love for me as I followed her, as well, to every bathroom visit. I remember my mother’s devotion, her friendly, sweet voice and the many nights we spent alone together when my father was off on business trips. Yet, how thrilled was I to see him every time he came home with a little something just for me! At four, my dad was fun, full of smiles and caved in when I begged to be taken to a drive-in movie, even though he knew without fail, I would fall asleep in the back. It wasn’t as if he didn’t make me feel secure. It was just that my mom was always there.

I come from a short-line of only children and do not know my father’s biological parents because he was adopted. He was taken away from a family and put into a German one at the beginning of WW2. He was part of a long list of children who were stolen from families in Poland and Sweden for their Aryan features. German families adopted them – and it is for certain that my “adopted” grandmother couldn’t have any children herself. By the time he was fifteen and living in Canada, my father left his “parents” because he felt he didn’t belong to them, and because of what the Germans did. Fifteen. A boy with an unknown background, with no place to call home. At eighteen, he joined the Canadian navy and got himself educated. He did end up resuming a complicated relationship with his adopted parents, for the rest of their lives. Much of those mysteries and complications, I have inherited to mull over, investigate and discover, perhaps, the meaning of it all.

Being separated from one’s roots, now that I have my own child, another “only” child, and married to a man whose roots are firmly planted, perhaps has made separation, togetherness, loneliness and the temporary nature of all relationships, so much more apparent. Perhaps being an only-child instilled this innate sense of independence and impermanence. In many ways, it is quite liberating. One learns how to create family with all the people in one's life. On other days, there is a shadow of existential starkness to it all.

As an only child, I wasn’t spoiled. In fact, my dad was tough on me, I know now because of his knowing about one's need to be resilient, and to create one's own happiness. My mother was
attached to me. In fact, I think my parents were very “attached” to me, and my leaving was tough on them. I married to leave the nest right after university, and that marriage didn’t last long. My mother got sick right at the same time, and I attribute a lot of it to her separation anxiety. I understand it now, especially these days when I am tired and want to complain about how much energy Adam can take out of me. I think of when he will be in his twenties, ready to leave me for his own greener pastures. I think of how autism has pulled us so closely together, how our destinies are entwined, and perhaps how much more involved I may be in his life when he gets a little older, although I have no doubts that he will be that proverbial “success.” We can never predict the shape of our lives, but can figure it out a little, by the time we reach our forties. Adam certainly has taken a large lump of the clay of my life and given it great form. It's simple for me to say that I don't know what I'd do without him.

So now, at four, when he is trekking behind me with the putter of little feet on our limestone floors, I have to smile. He will get used to Flor again quickly, I imagine. All things recounted and considered, his phases are pretty short-lived. Weaning him took 3 ½ years, and now it seems like a million years ago. He has just turned four. He is about to go on a school bus to a half-day camp on Tuesday. I hear him crying in the background – he is looking for mommy as he learns to cope with separation.

I imagine I will have many sleepless nights when Adam decides it is time for him to leave home, Henry is away, and I am again, that only child.

POSTSCRIPT: The bonding time worked a great deal. I walked in the hot sticky afternoon, leaving Adam to bond with Flor. Perhaps the quiet streets abandoned by Canada Day cottage-goers has made me think about solitude. There is no work to be done, no store to distract myself with errands.

Adam saw me later and made a fuss. I told Flor to "take charge" and give him a bath. It took only five minutes for him to calm down. She came to say goodnight to Adam and he did not run, did not cry, but smiled. "Ah," she said with her usual giggle. "We’ve made up!" Now my four-year-old Adam and I have two days by ourselves in quiet Toronto to enjoy some Canada Day Weekend hoopla, some time which will be spent with Grandma.
It is this notion of ability versus disability that has come to mind after meeting with Larry Bissonnette and Jonathan Lerman yesterday in Burlington, Vermont and then Vestal, New York.

I entered Larry’s studio where he was waiting for me – his head cocked a little to one side, as if he was watching me and my camera crew from a better eye. I was so happy to meet him in person, finally, an admirer of his awesome insight and poetic way to describe things. After reading about a person for so long, they become a kind of celebrity – I feel so familiar in his presence, yet am a complete stranger to him. It is an invasion of sorts, being here, meeting him, looking through the hundreds of paintings so neatly organized in his studio. This is Larry’s private space, both his inner and outer worlds.

I climb the narrow stairs of a barn-like structure housing other workshops. It is hot and sticky; the air is thick with dust. As he watched me approach me, I smiled with delight – he leaned in with his forearm, and returned the smile -- his version of a handshake.

I am tentative and try to be delicate and gracious within his space. There is a cameraman with me – Larry likes to be on camera, but we are all quiet, introducing ourselves, meeting Larry’s assistants, letting the minutes determine what is to be said, and how much.
I receive some direction on how the works of art are stored and I ask permission to go through them, Larry standing near the door, drawing arcane lines with his finger through the air, almost like the conductor of an orchestra. “Baby blue door,” he says pointing to the door next to him. “Baby blue door.”

“Does that have a meaning?” I ask Pascal Crevedi-Cheng, Larry’s Facilitated Communication assistant since 1991.

“They are repetitious phrases, a breakdown in communication. They don’t have any specific meaning,” he tells me. I think about the times when my own Adam is scripting, when he puts a phrase into a space or a moment, how it can make sense and then repetitive, like he is enraptured with the sound and the melody of words.

I ask Larry “What is happening for you when you loop your language – when you say Baby Blue Door, for instance. Does it have meaning for you?”

Larry looks at me, and I can tell he acknowledges every word. “Ah!” he says and promptly begins typing, Pascal’s index finger and thumb squeezing his shoulder to remind him to keep typing.

“Pale imitation of real feelings,” he writes.

At the studio, and after the introductions, I begin to feel comfortable enough to look through Larry’s work. He is watching me. I ask him if it’s okay to look here and there. Craig, the cameraman turns the camera on watching me, watching Larry, the dialogues that happen at this first meeting among the artifacts of Larry’s mind.

I pick the work for the show, we grab lunch and return to the office where the interview continues. Larry is listening to us talk while we eat, and I ask him what his favorite food is.

“Macdonald’s cheese burgers,” he says, and I chuckle. He shines a big smile and Ryley, my assistant grabs two coupons she happens to have with her for Macdonald’s burgers. Larry reaches for them with delight.
“Do you have a girlfriend?” I ask him.

Larry cowers and blushes. I joke around. “Ah!” I say. “I made you blush!”

He grins.

The laptop computer comes out, the camera is ready. Larry is using a computer program called Write Out Loud, which says the words and sentences he writes. I have not yet asked him a question and he begins to type:

“Least little force of my typing isn’t making sense. Estée ask me your awesome questions.” He is a gracious man.

I have seen many symbols in his work – houses, cars, and crosses. So I ask “What do cars mean for you?”

“Problem knowledge of goings on with interpreting images as symbols is Larry doesn’t paint ever vesting deliberate symbols. It’s all intuition.”

I leave the art. I understand intuition.

Larry is what you call classic autistic. So I ask him outright, “Do you want to be cured of your autism?”

“People who think your disability is a sickness need to be cured of their ignorant attitudes.”

I smile, he smiles, we high-five. We have a moment of understanding and his sense of humor becomes so apparent.

“What do you want people to know about you?” I ask.

“Larry loves McDonalds like people once they stop dieting and only when work that I spend my time on is seen as personally motivated and not derived from autism will I be satisfied.”

I tell him that people will be interested in his art as it is and because of his autism. I am clear and he acknowledges this. “Yes,” he says.
“What do you want parents to know about their autistic children?”

“I am in life until the total realization about the power of communication happens so parent occupied with over-coming problems of disability needs to focus on abilities that are not easily seen.”

So on the note of ability, I have to ask, “What is your greatest strength?”

“Am slacker by nature. Am the personification of practice makes perfect.”

Perfect. Indeed he is.

“You are a wonderful writer, I tell him.” He smiles. “Would you ever write a book?”

“Yes,” he says enthusiastically and begins to type, “not pictured in People magazine yet maybe publishing a book would put in on People’s reporter’s plain but cool list.”

Larry is tired. We’ve been with him for four hours, looking through work, talking on film which is being made into a video for The Autism Acceptance Project. He shakes his tired hand from typing – a long and deliberate task. And we have a plane to catch. Larry will come to Toronto in October and speak to others at the gallery on October 5th. It’s a conversation I would love to continue with this delightful, warm man.

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We fly to Vestal, New York. It is raining again like the last time I was here. This time, Jonathan will be with Alan, his father. I haven’t seen him since last December. They greet us, Jonathan looks as excited as he did when I picked them up for the opening of his exhibition at Lonsdale, and he is almost breathless.

I bring him a book from the gallery – illustrations by an artist – a book-long comic strip. Jonathan seems to enjoy it as he reads it in the car on the way to his studio – a building attached to a church which is owned by Joe, his art-teacher/mentor who has known Jonathan since he was seven years old. It is an old musty building
and we are lead to the basement where a series of studios, including a clay one, are housed. Jonathan has his own studio way around the corner of the long narrow hall, at the very end.

“I want to start a sculpture,” he declares. Joe was hoping he would draw or finish the one in front of him. Jonathan’s room and the clay studio are filled with political figures. Today, he wants to do George Bush. Again, the camera gets set up and I enter the adjacent room flipping through hundreds of Jonathan’s incredible drawings. I pick drawings from Jonathan’s various stages of interest while talking with Joe and Alan, intermittently.

“How often does Jonathan come here?” I ask Joe.

“He’s here almost every day.”

“No wonder the prolific work,” I comment.

Joe works with other students in his after-school arts program. He has been helping Jonathan for over ten years, making suggestions, exposing Jonathan to different media. I am impressed how Jonathan’s sculpture is becoming more sophisticated, and the speed at which he works. There is a head of Bin Laden sitting on the table, scatterings of other heads throughout the building.

“One day I finally got Jon to do a self-portrait in clay,” Joe says to me while I’m flipping through artwork. “He has done so many heads, and there hasn’t been a problem with any of them when they’ve been fired. But the day he does his own head, it blows up in the kiln.”

I pause. There is irony in this story, but Joe says it, not I.

“Isn’t that bizarre? Not one other head blows apart except for Jonathan’s.”

Later, I see that head as it is proudly sitting on the window ledge of his basement studio. It is not blown apart as much as it is fractured. The outer skull on the left side has fallen off but sits askew next to the remaining head. The inner clay is still round and clean, like looking through the skull to the brain-intact. It reminds me of not so much an incomplete or fractured brain as much as an invasion of one – man’s curiosity to find out the basic functioning
It is getting late – nearly eight o’clock in the evening and we’ve been going non-stop since nine in the morning. We’ve been with Jon for about three hours. He is getting hungry and tired, the bright camera light is becoming too much for him to bear. He is showing signs of agitation and begins to cry.

“I’m tired. I want to go home.” Alan goes in to soothe him. Father and son are bonded. Jonathan wants to hug his father and there is a sweetness that surrounds them like a cocoon. We all watch. This is not the first time I’ve witnessed the tenderness between them, Alan’s complete devotion to his son. I can tell Alan is a little sad to see his son upset. I can tell, I think, because I understand the sensitivity of a parent towards their child.

I want to tie this up. I want Jonathan to be with his father and go eat.

While wrapping up, Joe goes to calm Jonathan while Alan takes photos of the works I’ve picked for exhibition. I show Joe the picture I’ve used in the Joy of Autism ads and ask him where the piece is. Nobody knows. There are still so many works still to be exhibited, catalogued. Jonathan’s work is his artifact and must never be lost.

To distract Jonathan for a few more minutes, Joe asks if he can replicate that drawing. Jonathan does. He is calmer.

We head to the car to return to the airport. We are returning to Toronto.

“What do you want to eat?” asks Alan to Jon.

“Italian.”

We are all salivating in the back at the talk of food. It’s been a long day and we too are hungry.

“I want Fettuccine Alfredo,” says Jon.

Alan holds Jonathan’s hand to keep him calm. Jonathan is indeed experiencing some anxiety issues. It is clear that Alan is a steady
“Jonathan has been talking of going to college,” Alan says earlier. I am thinking it’s entirely possible, if not probable. Jonathan is surrounded by the love of his parents, and after meeting Larry, will likely manage his anxiety at some point. Jonathan has a girlfriend, just went to his high-school prom in a limo, and I’ve noticed a language burst since I last saw him.

We say a quick goodbye; Jonathan shakes everyone’s hands and runs back to the car.

“Go feed him!” I laugh and Alan runs after him.

I am delighted to see Jonathan too, but indeed saddened by his sadness, hoping that food and going home will ease his stress. I think of what Larry might have been like at Jonathan’s age. I think of Barbara Moran, the autistic woman, age fifty-five from Topeka, Kansas, who wrote to me of how her sensitivity to noise has made it virtually impossible for her to be around people, and how she says that being on medications and being institutionalized made “her autism worse.” I think about ability, about the title Joy of Autism, about sadness and struggle, but how every autistic person I’ve met and spoken with enjoys being as they are despite their challenges, which even to me some days, is difficult to comprehend. I think about the responsibility of talking about the provocative title Joy of Autism amidst all of these challenges – how some parents might call their children a joy, but “not the autism.” Yet, I hope that the positive messages from autistic people who face these many challenges, will reign. I think about how we define ability and how we must search for it in every individual – and how we must find our little ounces of joy in the many moments of our lives.
This project was inspired by an autistic woman, from Topeka, Kansas, Barbara Moran, who sent in her life story and some photographs which will be exhibited at Lonsdale Gallery. She submitted photographs and tiny drawings that give meaning to her story.

Submissions can be of poems, or short stories, or your personal story about autism in mailable or email-able format. Please do not send any artwork, unless they are your drawings or photos fitting an 8 1/2 X 11 inch page, and are specific to your writing.

"Winning" entries (simply meaning we only have so much room to print and/or exhibit your work) will be rewarded a token fee of $50.00 (CDN) and will be displayed at The Lonsdale Gallery in Toronto during the month of October 2006. All entries will remain the property of The Autism Acceptance Project unless you specify that you want the work returned to you. The Autism Acceptance Project will keep your work on it's website in the AutSpoken section. It may also reproduce your writing in gallery materials.

Please include a return address and telephone number in your package.

Mail to:

The Autism Acceptance Project
P.O. Box 23030
Toronto, Ontario
CANADA
M5N 3A8

or email at estee@taaproject.com

Happy Autistic Pride Day
In Search of a Democratic Education

How often do we hear that teachers or principals of schools cannot make changes in the classroom “just for one student?” Education has been on my mind a lot lately. As I struggle to find a school, not an “autism school,” but just a great school for Adam, I am floored by the static, undemocratic set up of schools today. Endemic to this autism trend: autism as a disruptive behaviour instead of a perceptual and cognitive difference that effects behaviour – much like the deaf community and their perceived “aberrant” behaviour thirty and more years ago, Adam and other autistic kids like him are getting unjustifiably turned away.

If a school is interested in him, it seems to be with trepidation – Adam must fit into the school’s culture, completely forgetting that at least of Canadian culture, it is one of purported tolerance and multiculturalism. Adapting programs seems to be rather difficult – some schools try to define “adaptive” within an already rigid curricula and format. Of course, other than nursery school and soon Junior Kindergarten at the lovely inclusive Play and Learn in Toronto run by Nancy Searle and Karen Ward of Bloorview MacMillan, I find little truly inclusive philosophy or practice akin to Nancy’s. Nancy will speak about the system currently set up where parents can advocate and get the needs met for their children in Canada in October in Toronto. I urge parents to mark in on their calendars.

I am studying successful models in education for autistic people. Both inclusive and autism-specific models. I’m trying to be very selective in what we choose for the Resource Page in The Autism Acceptance Project website, but when I find interesting school models, like the Creative Growth Project in Nottingham – where even mathematics is taught through art and sensory explorations – believe me I’ll find out more and put it on this blog.
Michelle Dawson has made an important point with me as well: “how can you know how to educate,” she said to me in a phone conversation, “if you don’t understand the cognitive ability in autism?” It is a rhetorical question that we all better think about. This is why this research by people such as Michelle, Laurent Mottron and Morton Ann Gernsbacher are vitally important in this process.

As we learn about ability in autism, we are learning how to teach. Of course, I hope I need not have to re-mention that if we look at autism as deficit, we won’t be teaching successfully. Just in case, I said it again.

Paula Kluth mentions democracy in the classroom and that has got me thinking just how little it exists in all of our schools and teaching methodologies today. Democracy means turning the teaching, the curriculum design over to the students. It means using students as teachers, and teachers as guides. It also means that students can teach teachers. Kluth begins to define the rigorous exercise of inclusive education:

“In a study conducted by Udvari-Solner and Keyes, administrators who were identified as leaders of inclusive education claimed that they needed to have courage to “relentlessly pose the difficult, the contrary, the controversial, and the seemingly unanswerable questions.” (p. 24 Kluth). “In addition, these principals and central office administrators stressed the importance of expressing their own personal values.” (ibid).

Kluth quotes principal Sue Abplanalp about openness and honesty in forming an inclusive school community:

“I guess the most important thing I can do is to be an advocate by voicing my opinion, modeling, and letting teachers know about best practices, by continuing to ask the same question when I’m not sure about what to do: is this in the best interest of the child.” I have a desire to be an advocate, for equality, regardless of age, disability, race, religion, sexual orientation, ability, gender and anything else I forgot. It’s part of my vision for justice.” (Kluth, p. 25)

Dawson, however, states that opinion in autism is not enough. Her
quest, because of this fractionalized autism community of autism “interpreters” [my word] – parents, educators, politicians, is to unveil cognitive ability in autism through accurate science. Accuracy, in terms of semantic representation of this community, by people who have defined themselves, as well as in science – much of which out there is inaccurate, supported by special interests, and not peer-reviewed – is of utmost importance when understanding autistic people.

In terms of education, as a mother, I believe that the democratic process is the missing link. Democracy means accepting everyone. It means adapting curricula. It also means, that when all children stay together when they’re young, they will understand and support one another in adulthood. Fostering a tolerant society begins early.

Also, the term “therapy” is dangerous. It implies remediation and is a popular psychological and clinical term. It does not necessarily honour the different perceptual learning that autistic people not only view often as a challenge, but more often than not, their strength. And what are we doing? Quashing the very strength that defines our autistic children? I do one-to-one instruction with Adam. I call it instruction, tutoring, education. I no longer refer to him as an “inappropriate behavior” and do not spend the hours teaching him how to “behave appropriately.” I used to be uncomfortable with that idea, torn between old-world ABA thinking and my current practices. I am so comfortable with this today as Adam continues to learn and grow.

Nearly three years now and I’ve finally learned, with the help of many autistic adults who I continue to interview and befriend, that teaching Adam, like many autistic kids, has been a paradox for ME. It is a daily quest to strike a balance between boundary making, and following his obsessions and passions. It is a quest to put myself in check, to be his parent, to teach him, but to also learn about him, respect his learning style and to find the ways in which he learns. It is a quest to not just turn his unique way of accessing language to “make it functional,” but to find a way that is functional for him. In a way, it is a meeting of his world and my world, the world-at-large, and to live together within it.

Through this autism paradox, I have learned the delight of life itself – the delight of having to think, to find, to never accept the
black and the white, and to never accept the status quo. It is an effort for sure, but it is one that is expansive and most definitely worthwhile.

Congratulations!! You’ve given birth to an awesome autistic child. Do you know how lucky you are?

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MONDAY, JUNE 12, 2006

Living Library

Harpers recently wrote a little snippet about a Living Library to destigmatize people. Here’s a short hotlist of people who are often stereotyped. It’s a good exercise to think what comes to mind when you read this list:

African American
Environmentalist
Feminist
Gay
Disabled
Asian
Jewish
Autistic

Would you like to add to the list in the comments section?

The Living Library is a concept by which members of these groups come in to talk about themselves. I was thinking that The Autism Acceptance Project is very much like a Living Library -- with autistic people coming to talk about themselves and the issues that surround autism. I love the concept and hope others will consider doing something similar in their own towns.

The Autism Acceptance Project -- Exhibition is Free.
Tickets for lectures on sale now.
Bear With Us

Tickets have gone on sale for the Joy of Autism: Redefining Ability and Quality of Life lectures today (click on side). Thanks for your patience on the website which we are still fixing and loading.

I hope many of you will attend this forum for critical thinking about autism.

The Purpose of Life

"Cultivate more joy by arranging your life so that more joy will be likely."
--Georgia Witkin, American Professor of Psychiatry

What causes us to be human? Genes? Spirit? The ability to ask “why?” Human beings tend to define themselves in social, spiritual and biological terms. So no, it ain’t all in the genes.

There are many who are intent on finding the cause and cure for autism. They don’t need my energy, money or help. A cause may be found, even if only because man’s ego is at stake if he doesn’t. He will find an answer, even if it is wrong. It is the desire to ask, and to answer the “why?” A desire for order, mechanisms, understanding, and control, even if the mind itself is to forever remain, in all its complexities, an eternal puzzle, perhaps rigged to remain elusive to man. So, a cure may one day be purported, even though the many autistic adults I talk to say they don’t care about the cure for autism – that they wouldn’t take that little “pill.” Like life, this is their challenge. They also say that it is their strength, even those who would be classified as more “severe.”

If people with autism can speak for themselves, if they say they don’t want to be cured, we have to listen. If they are denied the right to speak for themselves or advocate or direct research by big
organizations that fund research, then they are denied their basic human rights. For those who can’t advocate for themselves, we still have to listen to the autistic community to guide us in our actions and decisions that affect the well-being and quality of life which extends way beyond mere physical care.

Goethe said

“Der Zweck des lebens ist das lebens selbst.” (The purpose of life is life itself). Life is in the living, the challenge, and the choices we make. So in keeping,

Autism is not

A tragedy
An illness
An epidemic

Autism is
A way of being
A different perspective
A sensory difference
With strengths, abilities, intelligence and something to offer society.

I say that “something” is humanity. What is our responsibility to humanity, and in this context, to those who are autistic?

PERMALINK POSTED BY ESTEE KLAR-WOLFOND AT 6/03/2006 11:22:00 AM 5 COMMENTS LINKS TO THIS POST

SUNDAY, MAY 28, 2006

The Autism Acceptance Project

Backgrounder

The Autism Acceptance Project
Tapping into Human Potential and Dignity

§ The Autism Acceptance Project: Tapping into Human Potential and Dignity is a not-for-profit organization working toward achieving acceptance and tolerance of autism in society.
The Autism Acceptance Project was founded by Estée Klar-Wolfond, writer and curator. Estée’s young son Adam was diagnosed with autism at 20 months of age.

Through a series of annual events and exhibitions that support positive views about autism, the organization seeks to support parents and people with autism by advocating for educational support and a variety of services that enable identity, dignity and quality of life for both adults and children who are autistic.

Celebrating its second year, The Joy of Autism: Redefining Ability and Quality of Life is a gallery exhibition of international artists with autism at the Lonsdale Gallery from October 5 until November 5, 2006 and a lecture series by renowned academics, researchers and individuals with autism held on October 10th, 11th, 12th and 16th at the Al Greene Theatre at the Miles Nadal, Bloor JCC.

There are many autism fundraising organizations who solicit funds for autism cures. The autism community (autistic people) is dissatisfied and offended by such organizations touting autism as a tragic epidemic and illness. They believe that the relationship between illness and being autistic is a misnomer misleading the public and the media. By waiting for a cure, autistic people continue to be marginalized. The educational system, while improved since the seventies, still remains unprepared for the increasing number of autistic children.

The Autism Acceptance Project will present dialogues and exhibitions to understand autism further and debate the humanitarian issues surrounding it. Without the overriding moral obligation to treat every human being with value, respect and dignity, we cannot establish acceptance, tolerance and support within society.

The Autism Acceptance Project will expand its mandate to not only present annual lectures, exhibitions and concerts that bridge understanding, but also to assist schools and educators with programs that address each individual’s learning needs.

http://www.taaproject.com/
On Memory and Forgetting

Hillel of Greater Toronto brought Elie Wiesel two days ago. I had the privilege of meeting him personally, and listening to him talk at University of Toronto's Convocation Hall, a day before Oprah aired her visit with him to the Auschwitz death and labour camps.

The confluence of my recent meetings, travel to Jerusalem to witness many beliefs divided by walls, how co-existence is possible if tended and policed, and how violent fanaticism is the one of the most inhuman of human traits -- merging with the incorporation of The Autism Acceptance Project and its event this October called The Joy of Autism: Redefining Ability and Quality of Life, against this background of recent events: the abhorrent Autism Speaks video, and the murder of three year-old autistic girl Katie McCarron. All of this resounds deeply within me and should within us all.

Dr. Wiesel questioned this complicated time. "How is it that Auschwitz didn't rid our society anti-Semitism for good" he asked rhetorically. We all say, "never again." Most of us vow to stand up for the impoverished, the oppressed. Yet today, like then, when injustice rises up, people can't seem to bring themselves out of their silence. Lessons of propaganda - what it is and what it means - goes unnoticed and sadly endorsed by others. There is still a population that continues to support fanatical messages without
understanding what marketing, positioning means. "Good"
propaganda must always contain elements of truth -- it sways you
emotionally and in a one-sided way. I do not share the opinions of
these mothers (who were edited, by the way -- we did not get to
hear their complete sentences), and many of you do not share the
same views as myself. Yet, the cause, the purpose of the video is to
raise money for a cure. The motive is clear. I wish everything was
at least as transparent, even if in this incredibly naive way.

Autism Speaks did wrong. NAAR and Autism Speaks continue to
do wrong because they continue to exclude the autistic population
from its mandate and research. This is why, as former corporate
chair of NAAR Toronto, I withdrew my support and sponsorship.
Any organization that uses language against the desires of a
culture, race, or type of people who have identified themselves as a
culture, is immoral. We have learned to be careful about semantics
where race and religion are concerned. Why is there so much
problem in understanding the inhumanitarian treatment against
the autistic? At the utter agony of this population who struggle to
be accepted, and to avoid negative labeling, these organizations
continue to do so anyway. Many Europeans deemed the Jews
subhuman, undeserving of fair treatment. Many people today do
not feel that autistic people understand themselves and
purposefully exclude them from autism "dialogue," decisions about
research, and continue to take away their right to choose and
decide for themselves. Some mothers will claim they would rather
be dead than living with autism, while their autistic child plays in
the background, alive, but otherwise treated like furniture. Their
words about their children are selfish -- how it affects them -- and
they describe and talk about their children as objects rather than
humans. Other parents abuse, neglect and even murder their
autistic children because they believe their lives are too difficult
living with it. The lists are long in Ontario of autistic children who
are abused to get into Mukibaum. "Autism Every Day" is rampant
with parents pulling and tugging on their children (a set of
behaviours rather than people) amidst quickly edited excerpts. It
is a dark video inciting little hope. It disempowers parents so
maybe, just maybe, they feel life is no longer worth living with
autism. Afterall, the premise of the video is that life is too hard
with autism. It has actually enabled others to excuse the murder
of Katie because of this premise. I call on Autism Speaks to retract
the video and apologize for its offensive marketing of pity. It has
done not only a disservice to the autism community, but ironically,
to its very own cause. I’m sure many are suspect of this undignified attempt to market autism.

While neighbours stood silently during the Jewish genocide, there are parallels to many injustices today. How is it we can remain asleep? How is it that one of you may be thinking that the comparison between the Holocaust and Autism Marketing is extreme? Germany was financially suffering. Hitler found a whole race to blame for it. Then, that race ceased to be viewed as human. Then, that race was murdered because Germany thought they would be better off without not only the Jews, but Gypsies, the disabled, the "feeble-minded."

We must stay awake to past lessons in every community of race, ability or religion. We must continue to open ourselves to discussion and debate and accept many views. We must learn to respect a type of people, an autistic people, and listen and acknowledge the messages they give to the rest of us, even if we don’t always agree or fail to understand completely. The Autism Acceptance Project hopes to empower both parents and those who are autistic through balanced views, with the over-arching belief that all humans have value, deserving respect, support and dignity. You don’t have to agree with every one, but you have to accept those who have the same respect and tolerance for you and for others. Any marketing, message, or research that is underway or disseminated must be done with this value in mind. With all of life’s lessons in current and past human atrocities, this is our moral obligation.

But the problems of humanity and its inhumanity continue. Dr. Wiesel said this, and he wondered if we were, as humans, all of God’s great mistake. And yet, he believes in humanity. In my byline for The Joy of Autism above, I borrowed one of Wiesel’s lines: "Despite inhumane acts, I believe in humanity." This value must be our guide.

"We Jews," he said in his quiet voice, "sing. We sing when we’re happy, we sing when we’re sad." Life is filled with injustice from which we have an opportunity to grow and learn. There is joy and value in all human life. May all parents find this joy, no matter how hard the struggle; may we continue to raise our voices and words against the wrongdoings of NAAR and Autism Speaks and of those whose special interests are doing harm to those who are autistic.
We have the tendency to rest on our laurels and forget. May we be nudged to remember. May a life never live, or end, in vain.

Da Code, Da Belief, Da Danger

My recent trip to Israel on a United Jewish Federation Prime Minister’s mission was too short. A mere nine days, cut short because I didn’t want to leave Adam for the entire twelve, was filled with snapshots, images etched in my memory forever.

I think everyone should go to Israel and start in Jerusalem. I landed at the King David hotel, opened my French doors to overlook the walls of the Old City – a mere square mile inhabited by 35,000 Muslims, Jews, Christians and Armenians literally on top of one another.
The Old City

I started at the Dead Sea – a visit to the Masada where 965 Jewish settlers felt it was more important to die for one’s freedom than to surrender to the Romans. Then to Qumeran – the home of the Dead Sea Scrolls – where this cultish sect of Jews maintained the very Jewish traditions that are kept, more or less, today. The fine invisible thread of a people, in fact of all people, and this seabed of belief, lies here in the dry hot dessert.

After floating in the Dead Sea, I slept the rift in time away. The following day I went to the Old City, walking through slippery lime stone streets to the Church of the Holy Sepulchre and touched the ground where Christ was crucified. I walked about the Church, now divided into spaces owned by various Christian sects, walls built to illustrate regions of ownership within a formerly gothic style church – its flow entirely disrupted. The Greek Orthodox community owns most of the church now, but the keys to all the holiest Christian sites are held by a Muslim family – considered non-partisan enough to keep an equality and peace among the divided sects of Christians.

I walked through the Muslim market, to the Cardo (the Jewish market) and in one day, I visited Christ’s tomb and then prayed at the Western Wall. High above that is the Dome of the Rock -- the holiest place for the Muslims as it is thought to be where Mohammed ascended to heaven. That very evening, upon returning to the Kotel (wall) for Shabbat, watching the most religious (Hassidim) of Jews dancing and praying at the wall, I heard Church bells and Muslim prayers over speakerphone under the full moon -- a collision of smells and sounds in the cool evening air. If one listened carefully, the murmurings of history, the prayers -- the sentiments of faith could be heard.

I was here at a more peaceful time in Israel, knowing how dissention and violence can errupt at any moment, but for now, kept at bay by the seam line and the many police stationed around the the old Temple, where Palestinians sometimes throw stones at the Jews praying below. Coffee shops and restaurants are now guarded by security, so when I walk past the Hillel Cafe that was bombed just a short time ago, now rebuilt and filled with customers again, I can rest, a little, knowing that there are now people on the lookout for suspicious characters strapped with
I rode past the site near Gilo where a bus filled with children going to school was bombed -- the man thought to have spent the night in a neighbouring Arab home.

Jerusalem to me manifests human paradox – to co-exist and yet remain divided by this great ideological divide called belief. Religions claim ownership to holy sites, and other sites are deemed holy by those who want to believe (there is more than one burial site for Mary, for instance). People interpret scripture, and it too has been re-written. On the eve of the Da Vinci Code’s movie release and the idea of the quest for one truth, we must always remember that according to mankind, there is always more than one. Belief is the engine behind such quests and the etchings left by man the multiple truths of many beliefs. Israel epitomizes cultural and religious tolerance despite the violence. The violence epitomizes the dangerousness of belief -- the warbled footings of a human construct.

I have caught up with the news of the past days and the video distributed by Autism Speaks, "Autism Every Day." It is a repulsive video, a type of religious zeal taking away the dignity of a child, of many people with autism and example of how belief can ruthlessly expend human life, or the dignity of it. What is understandable is the "loss" in the sense that we all have to reframe our expectations in life. What is not, is the positioning of the video, the parents who choose to view people with autism as a loss. We can all choose to view and act positively or negatively in life. We all face the same challenges. I felt sorry for all the kids who had to hear their parents talk about them in that manner on the video. A child does live up to their parent’s expectations. These parents have very low ones.

Marketing "religion" as this video does, is unforgiveable -- this shameless act of marketing pity to make a buck requires a vigilant response from all of us. As innocent and heart-felt as this video may seem, and in because I'm talking about Israel I will say it here: a visit to Yad Vashem (Holocaust Memorial) made me remember how innocuous belief appeared on the surface of all European citizenry. It was a belief that the Jewish people were at fault for lowering their economic status, and were subhuman. In the case of these parents, there is no excuse to talk about one's
child in the way they have here, or to mention that the only reason you didn’t drive off the Washington Bridge (in front of your child) is because of your other neurotypical child waiting for you at home. The positioning of this video is classic propaganda.

In the fractionalized community of autism believers, this religious phenomenon of belief is no different. The complexity of human functioning is like the cracking of a code. Some scientists and autism organizations continue to perpetuate the idea of a “mystery” that requires de-coding. New codes are cracked about genetics and neurology and sects are created. And, as we come closer to "knowing," we begin to have an enormous responsibility to protect and covet all human life.

I prefer to believe that all life is incredibly awesome. At the end of all these paths, do I really need to know what causes autism? Does it really make a difference to know why Adam does the things he does? Or is it our exploitive curiosity? To what end do we study autism to the extent that we do? To help? At whose request -- the mother who might take the life of her autistic child because her life is too "hard?"

With knowledge, may be all beget wisdom.

Oops, try again.

“What is Buddy Bear reading?” Adam points the mouse to the right answer. “A book. Buddy Bear is reading a book. Good job.” In the time it took me to fly and return home from Israel, Adam has “mastered” (sorry for the autism teaching jargon – some of this never leaves one’s repertoire after so many years of hearing it...yet another reason why semantics are so incredibly important). If Adam is learning a new concept in the Buddy Bear programs like “categories,” and clicks the mouse in trial and error to find the right answer, the child-narrator says “Oops, try again.” He does, he gets it. Even if rotely, Adam is building his own bridges to understanding the meaning of language. It is up to us, and his environment to put together the rest.
Adam figured out a mouse program that I couldn’t. He learned in a week to pick the “different” icons in order to move forward in the game, how to maneuver the mouse, how to exit the program. Various instructors have had a hard time in some instances getting Adam to pick “the one that’s different” in an “array” of whatever. An instructor will sit with Adam and say the words “pick different,” “find the one that’s different.” Adam may or may not respond. Maybe it depends upon his mood. Sometimes he’s just not understanding what the expectation is if it’s a new task. I mean, I am over exaggerating a little – he’s great at matching, but it seems more so if there are NO SPOKEN WORDS.

It has been a hard time since I got back from Israel. We arrived early in the morning the day before yesterday. Adam heard us come in and sat at the top of the gated staircase and smiled when he saw me. For the rest of the day, he clung like it was life or death – a natural response since his mommy was away for nine days. Perhaps it was a mistake to take him to school and drop him off there. He was miserable because mommy came back and then was gone again. For me, it’s a push to keep life as regular as possible. I am very happy that he is responding in this way. All I am is a little jet-lagged.

We go to shabbos dinner at my mother-in-law’s yesterday and Adam doesn’t want to stay very long. They’re home is tall and a little cavernous – typical of newly built homes. The floors are hard marble and reflect sound all over the house from top to bottom. For Adam, when he’s not in the mood for crowds, it’s a dose of misery – the children’s voices pinging all over the house making it difficult to hear oneself think. Adam flicks his hands, he cries, he’s heading out the door without me. He is very stressed out and when he is, I know the rest of the family is thinking THIS IS AUTISM. Adam’s lack of words, his anxiety and it becomes difficult for others to see what lives and breathes within him. He goes up to the computer and he flies. My little four year old is becoming a whiz – packing in loads of information I can hardly imagine and I keep having to find new computer programs now. (If any of you have any suggestions, send them my way).

A friend and fellow mother at school arrives with dewy eyes to pick up her son yesterday. We lean against the hallway wall, and she confides in me.
“You know what it’s like, Estée. I’m having one of those weeks when I’m realizing what acceptance means. I mean, our lives have changed forever. Is this how we have to live the rest of it? What if [our son] can’t work? Who will take care of him? I just read that only seven percent of autistic people get jobs.” Her eyes begin to well some more.

“I don’t listen to those statistics anymore.” I say strongly, trying to inspire hope, partly frustrated by them. “I’ve heard them all too. I’ve been frightened by them. That’s why we as parents have to keep advocating for school supports, for our children. You don’t expect a person who has difficulty walking up stairs do so without a banister, do you? Why do we expect that of our children? If Adam doesn’t get to university until a little later, who cares? Whose timeline are we on anyway?”

Adam begins to tantrum. He wants to get out of my in-laws house. The noise level rising, he managed to still get through dinner and a little swim. He is right at the door and I decide that I’ve made him wait long enough. I haven’t had much time to say hello to anyone, talk about my recent trip to Israel, and I am tired and can’t win this “battle.” I drive home, really frustrated, and like many other times, wanting also to cry. I open the door and Adam begins to grin from ear to ear. This is what he wanted. He just wanted to be home. It may or may not be his autism. It may or may not have been the noise level. It may have just been a need to have mommy all to himself in our quiet place – a bath, a snuggle and time to ourselves.

Like good ‘ol Buddy Bear, life is full of trial and error. Last night was just a little “Oops, try again.” And we do – we try and try again and somehow we just figure it out.

ODE TO JOY

If I could only live a hundred years
because of you
and when considering this world, only because of you

Adam fell asleep tonight, his little head on my heart. Tomorrow night he will not sleep there. I will not be putting him down to sleep. I will be missing him enroute to Israel.

A friend from Israel was over this evening – he worked with “severe” autistic children in his past. He took one look at Adam and kept saying “no, look at him, he’s fine,” his bright eyes glowing within brown Egyptian skin, his thick Hebrew accent melodic with broad hands gesticulating. Of course I know that Adam is “fine.” I accepted the good intentions with which language often betrays and let him continue. This friend relayed a story of an orthodox man he knew who had nine children, one of them autistic. This man told our friend that the one with autism gave him the most joy of all of them.

I understood instantly, I think. I believe it’s all about expectations. When you have a child with whom you don’t know what to expect, then everything can become a joy. Expectations, and failed ones, imprison us. A vicious cycle, I consider, ensues. Yet, even more than that, at least for me, Adam makes me appreciate life so much more than I ever have. Adam: each and every pain and triumph, his innocence, his brilliance, his happiness and yes, even those frustrations that he learns to overcome he is red hot life throbbing through my raison d’etre.

Frida Kahlo once said that she never wanted to live life after the one she had lived – there was so much pain in hers. I also see the agony of life often (is it that artist’s “angst” or a way of seeing?). It is Adam that has given worth, this life, my life, everything. I know there are many Adams in this world. We all need to take moments, to see, to give us this sense of joy and value in every human life.

Adam breathes life for us all to consider and all to bear.

ARUNDHATI ROY:

NOT ONLY IS ANOTHER WORLD POSSIBLE, HE IS ON HIS WAY. I CAN HEAR HIM BREATHING.
Coming Home

Sorry, readers. I’ve been busy organizing the October event: The Joy of Autism: Redefining Ability and Quality of Life, which is coming along nicely. You’ll be able to access a website by the end of May.

I’m also getting ready to go to Israel without my sweet Adam. It’s like he KNOWS. I likely eminate the “I’m anxious” vibe, or something sentimental. He looks into my eyes, gives me a kiss, snuggles against me. There is never a moment when I travel that I do not miss his sweet cherub cheeks beginning now to draw down.

The week has been full of smiles. The sun is shining everyday and it’s like summer here in T.O. – three weeks too early and making me a little nervous that we’re going to have a summer like Phoenix.

Adam has been talking in full sentences now and then, which I like to report after recent anxiety issues. If he gets frustrated, the words are still difficult. Some sentences are slurred, some are perfect. Even his slurs are becoming clearer, and I have to attribute that to maturity, since he’s had no SLP for a few months now. He is doing well in school so much so that his teacher has said that he no longer needs a facilitator -- he approaches teachers and friends more without one. I attend school fifteen minutes early every day to spy on him. I watch him playing alongside other children and while he still needs a little extra assistance and reminding, all I see is a really happy child. Maybe he’s a little happier since we purchased a twelve foot trampoline for our backyard last weekend. It’s like his own personal paradise.

So, I cherish these peaceful times when things seem to be steady. It wasn’t like that before. From the time Adam was conceived, I purchased every developmental book out there – I had to know how he was growing, week to week. When he was born, I referenced the same developmental books, making sure he was...
doing all those things on time. It wasn’t until his first birthday, and after little Adam began reading letters and numbers at eleven months, that we noticed he wasn’t very interested in people -- preferring to watch Maria sing to *The Sound of Music* as the barrage of invited guests tried to *couchi-coo* him.

Now, he is very interested in people. He is very social, for Adam. He smiles all the time. He wants to play with others -- I would say he prefers to play with people than to play alone. There is a real joy that I feel in him -- well worth the worry, work and the wait. Beyond that our joy has come from my acceptance of him as he is. It was an acceptance (and learning) that all of those timelines didn’t matter, and were in fact, detrimental to his individual development. It was an acceptance that our lifestyle had to be adapted, that Adam needs more time, more support. Regarded for who he is, we have achieved happiness wrapped in all the everyday challenges and realities. Today, instead of that "tragedy" we once thought of called autism, "masking" our son, or worse "stealing" him, today Adam is a smart, charming, wonderful little boy with the same potential belonging to any other child -- whose future I look forward to instead of brood about.

We are travelling without Adam, as you likely gathered. We've travelled without him before, but I don't travel as much as I used to. I can't stand being away for too long. Last year, returning home after a week in France, Adam heard my voice from the bathroom, smiled from ear to ear, and lunged into my arms. It was one of my happiest moments. It is true that the best part of going away is coming home. Maybe it's the same with autism. The diagnosis is the flight away, the worry is the journey in a foreign place, and your child, my sweet Adam, is home.

**The Irony of Outsider Art**

Soon to be on the web: *The Joy of Autism: Redefining Human Ability and Quality of Life*. Exhibitions October 5-November 5, Lonsdale Gallery, Toronto featuring:
Jonathan Lerman
Larry Bissonnette
Donna Williams
Michael Moon and
MukiBaum Centre for Complex Disabilities Students

and Lectures at the Al Greene Theatre, Toronto October 10-17 featuring (confirmed):

Michelle Dawson
Laurent Mottron
Nehama Baum
Ellen Yack
Susan Senator
Valerie Paradiz

Other tentative speakers and events yet to be announced.

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The purpose of this event is to bring a different view about autism to the public. There are many parents out there getting their messages from the media. The media makes autism a "mystery," "a puzzle," an "epidemic" of such wide-spread proportions, that parents feel hopeless and worse, transmit this message in the way they feel about their children. Instead of receiving support for education, we pay for expensive services and "therapies," and wait for cures that will never come (at least for the autism part, not the subset of "symptoms") because autism, as stated by those classified as autistic, is not a disease, it is a way of being.

Quality of life issues will be discussed at length. By adapting, viewing autism from this angle of competence and ability, requiring support in the schools and in places of employment, our individual and familial QOL can be enhanced significantly.

In discussing the art, as I did when I organized the Jonathan Lerman exhibit last December, I try to avoid sensationalizing it at all costs. It is not "good art" because it was created by an autistic artist so we coo at it. An autistic artist is not a savant just because s/he can create art. At a cost to humanity at large, classifications have hindered as well as helped us. It is much like receiving that
Labels can serve to guide us in how to support people, and hinder us by giving us a kind of "permission" to judge the person on their label alone. For me, labels, classifications are my expanding and contracting universe, this constant push-pull between regarding Adam for who he is, and helping me to understand that what makes him different is okay, something positive -- not an abnormality. As humans, we construct and deconstruct all the time. This process is important.

Someone alerted me about the sensationalizing aspect of art of by artists with autism. As there will be, in art-historical terms (or construction let us say), "levels" of art in the sense that some work, like writing, is more fluid and natural, others a little more "contrived," it is vital to note that all of the work is important. Some people, like Jonathan Lerman, whose talent comes naturally, we would view for the art itself -- it doesn't matter that he is autistic. But we are fascinated that he is because this knowledge can also open up a window to understanding that he, despite his limited language ability, or his different "behaviours," sees the world acutely. Other work, like the work from the MukiBaum Centre, where art is used in more "therapeutic" ways, allows people to self-actualize, communicate, relax and more. If we view a piece by a schizophrenic artist, who draws their hallucinations, then we can validate that person and those hallucinations -- a better view than to call a person "crazy." It respects a fundamental difference between "their" world and "ours," perhaps building bridges to understanding that we are, artists, musicians or not, all quite similar despite our differences.

I don't like exhibiting work just because it is "done by so and so." In the art world, there is as much work as I don't like as much as I do, but it is a part of an art-historical discourse, and many who are not in the art world think it's all elitest bologne, but it's not, it is, it is all of it. People have been trying to answer the "what is art?" question, at least since the "modern" movement began in the 1800's.

So, here I am coming from two backgrounds now (art historical and parent trying to change the perspective of autism in the sense of questioning and looking at human diversity as a strength as opposed to a weakness thereby attributing hierarchical value to human beings), trying to bring the discourse to the fore through
art -- NOT by sensationalizing it, but by being critical of the work itself as well as by ensuring that a form of communication is being valued here. As an art historian, we as a society regard the art as much as we do the person making the art. This is a fact. We are curious about the maker, their frame of reference. So, even though we often want the work to stand for itself, we as humans must know the author. Is that a bad thing? I don't think so.

I've always said that the challenge is to avoid the sensational -- did Jonathan receive media attention because he was a great artist, because he is autistic? Both? And when bringing attention to the artist and the art, on the other hand, do we not begin to pay attention to ability and begin to view others as competent, whole? There is still value in this (and I know we have, as a blogging community, debated this on a similar topic with Hollywood and basketball -- which is both dissimilar and similar).

Here are some good quotes I considered elaborating for my exhibition essay. We live in a world where the current classification of this art is "outsider." I agree that in an ideal world, all art will be "insider," but that is not the nature of the art world -- to declassify.

Here are the quotes. I am thinking of calling my exhibition essay, as I did this post, **The Irony of Outsider Art**:

Lyle Rexer, Alexander Marra, and others argue that this raw art, or Outsider Art, art by the untrained, is on the demise as cures, drugs and therapies have dulled the senses and "different" minds:

"The insane were, in the beginning of the 20th century, sadly locked away in asylums and treated with electric shocks and other horrible detrimental "treatments." Ironically though, they were also given loads of pencils, paints and other materials to occupy them, in hopes that this would keep them from violent behavior. With all the time on their hands, being locked up 24-7 - away from reality, the outside world, they found refuge in their art, where a newly created world of their own devise, had found a place to manifest itself. With this society of the insane dispersed and obliterated by drugs and more "humane" treatments, the society of the insane may have ultimately found its demise, at the hand of those who had once appreciated and cultivated it."

Lyle Rexer, an Outsider Art-historian also notes the same cynism of a culture that has barraged it's differently-abled citizens with drugs and therapies:

"Within and beyond institutional settings, the expanding armamentarium of drugs to manage psychiatric conditions appears to have diminished the output and intensity of artistic production. As a result, some theorists insist that the time of art brut is long since over. Given the complex circumstances of creativity... any alteration of the significant conditions of inner experience could make the form-giving impulse disappear. Art making requires reservoirs of energy and concentration as well as an inner tension and irresolution that powerful therapies can devitalize or suppress. Nevertheless, the impulse to form is so bound up with conditions such as schizophrenia and autism that art-making -- art brut, true outsider art - will not disappear until the sources of these conditions, not merely their unacceptable behaviors, are eradicated." (Rexer pp.167-68)

There is some irony in the possible end to Outsider Art and its seasonable acceptance among society and the art establishment at such exhibitions as the annual Outsider Art Fair in New York -- increasingly frequented by collectors and museum curators. It suggests a downward trend and a homogenization, and raises ethical issues about cures, therapies and human difference overall.
Letter from Van Gogh to Theo, 3 September 1888

"...suffering as I am, I cannot do without something greater than myself, something which is my life -- the power to create....And if, deprived of the physical power, one tries to create thoughts instead of children, one is still very much part of humanity. And in my pictures I want to say something consoling, as music does. I want to paint men and women with a touch of the eternal, whose symbol was once the halo, which we try to convey by the very radiance and vibrancy of our coloring."

There was a time when people who were “mentally ill” were institutionalized -- as Van Gogh was -- confined to desolate, sterile places likely made so because the people who lived within them were considered unworthy and barren.

Within the most putrid and lifeless places, the human mind has transcended barriers. Be it a prison for the criminal, or the cell for the so-called “insane,” many pieces of political manifesto, literary works, and visual art have been created. Now take the idea of prison to the human mind, or better said, the confines of physical or neurological impairment, or mental state --works of art can express lucid manifestations of those inner workings otherwise mysterious to an outside onlooker. To the person who creates art, the process is a breaking away, a freedom from those confines, either real or imagined. As Van Gogh alluded, art is like birthing an aspect of ourselves in order to become part of a larger whole. In the case of those with complex disabilities, art production is as much of a freedom to be, as it is a by-product of the Self. Many differently-abled individuals have found solace and esteem through art making. As Van Gogh said, art not only makes one a part of humanity, but it calls for the world’s interaction with both the art and the artist. For the disabled members of our community, many who have complex disabilities (a series of diagnosis’), art is enablement and a validation.
A Brief History of Outsider Art

People have been fascinated with “insane art” since the dawn of psychology as a legitimate field of study. Even Plato and Renaissance artists saw a connection between creativity and insanity, and the idea lay dormant until it resurfaced in the 19th century. As Freud was making breakthroughs as to the inner workings of the mind, in particular, the development of the conscious and subconscious, we have paid some credence to the inner workings of the “insane” mind in a romanticized fashion. As with the rise of modern, abstract art, which left conservative, academic styles behind, the personal style and psyche found its way into public acceptability.

The art of the insane garnered attention in the 1920’s when Dr. Walter Morgenthaler published his book, Ein Geisteskranker als Künstler (A Psychiatric Patient as Artist) on Adolf Wölfi, his psychotic mental patient. Wölfi took up drawing spontaneously and the activity seemed to calm him. An itinerant Swiss farm laborer, Wölfi was institutionalized in Bern when he began to molest young girls and erupt in violent fits of anger. He was prone to hallucinations. Yet, after some years of confinement, he began to draw with no training in the disciplines that came to enter his work: art, music, geography, theology, and science. His vast oeuvre – an epic forty-five volumes in which he narrates his own imaginary life story, 25000 pages, 1600 illustrations and 1500 collages “is an attempt to describe his alternative scheme of the universe and represents, the locus classicus of schizophrenic art.” (Rexer, How to Look at Outsider Art, p. 55)

“While the causes of schizophrenia are most likely developmental and physiological, its effects are psychic and behavioral. At least since the eighteenth century, the display of its symptoms has been considered unacceptable by Western society, and those suffering from it have been cordoned off as much as possible into psychiatric and criminal institutions. Schizophrenic art has generally come to us from such institutions, most recently through art therapy programs. In the past, this artistic production was usually destroyed as a symptom of disease or even as a contributing factor.” (Rexer, p.57).

Of course, this treatment of the work as refuse is akin to how our
society once regarded our differently-abled members. It is a clear indication of how we value humanity. Thankfully, the work of Outsiders is gaining respect and notoriety within public spheres, and the art market.

The French artist, Jean Dubuffet was particularly taken with the *Bildnerei der Geisteskranken* and began his collection of such art which he called *Art Brut, or Raw Art*. In 1848 he created the Compagnie de l’Art Brut along with André Breton. The collection came to be known as the Collection de l’Art Brut. It is now permanently housed in Lausanne.

Dubuffet characterized l’Art Brut as “those works created from solitude and from pure and authentic creative impulses – where the worries of competition, acclaim and social promotion do not interfere – are, because of these very facts, more precious than the productions of professions. After a certain familiarity with these flourishments of an exalted feverishness, live so fully and so intensely by their authors, we cannot avoid the feeling that in relation to these works, cultural art in its entirety appears to be the game of a futile society, a fallacious parade.” (from Dubuffet’s, *Place à l’incivisme*, Make Way for Incivism. *Art and Text* no.27 December 1987-Feb. 1988, p. 36).

**Redefining Human Value**

Dubuffet argued that society has asphyxiated genuine expression. The power of art, the heated core of one’s inner universe, cannot be filtered by “culture,” which has managed to assimilate every new development into an intellectual art discourse. Outsider Art-making then, quite the opposite of that executed by art “professionals,” becomes a shift from inscribing the “social codes of language...to action itself...desperate attempts to order the elements of personality.” (Rexer, p.57). Larry Bissonnette, an autistic artist who lives in Burlington, Vermont, finds solace in making art. It is a chance to fluidly express the world as he sees it, without correction. Fully aware that what he is making is art, it is clear that his motivation is the expression itself. This is how he describes one of his pieces:

“Larry leads an existence which promotes passion for colorfully patterned, open to attractions in environment like smokestacks.
Past life of institutionalized person lets in novel ideas. Outsiders to this life can’t go out and obtain it. It’s significant that my artistic styles let me express personal perspectives of autistic but intelligent old Vermonter.” (Larry Bissonnette on his own work from Douglas Biklen’s *Art and the Myth of the Person Alone*, p. 177.)

Clearly, Larry is intelligent. Yet, based on his movements, his outward appearance, acceptance by society is a little more difficult. Larry’s art is the way he can bridge this difficulty, not only to affirm his views and intelligence, but to also bridge preconceived notions about human difference.

Modern art has embraced individuals with mental illness and difference to a degree, and the “modern artist” has come to be equated, stereotypically, with some kind of angst. Mark Rothko, Egon Schiele, Diane Arbus, Vincent Van Gogh, Jackson Pollock, and Edward Munch are some who are notoriously associated with their psychiatric conditions. Perhaps because of artists like these, we have come closer to viewing art by individuals with differences as significant for the sheer humanity of it, if not just out of fascination. Possibly, the work serves to break down the invisible barriers that society has built to create an Us and a Them – the “normal” versus the “disabled.”

In contrast, Freud believed that art was evidence of a person’s *failure* to achieve maturity -- that a fully integrated personality was one that effectively reconciled internal and external demands. Art, for Freud, sublimated unresolved infantile conflicts and wishes into acceptable substitute forms of gratification. All art for Freud was considered pathological or deviant. Beginning in the 19th century, insane art was not only observed, it was promoted. While Freudians swarmed the art to learn about the abnormal mind, artists watched as therapists encouraged art as a way to relinquish stressors and also as a materialistic insight into the strange workings of their disturbed minds, in hopes of finding a cure.” (From Alexander Marra, *Outsider Art: The Art of the Insane*)

Perhaps this approach is a cause of the sensationalist view towards Outsider Art and artists – a gazing from the outside in without engaging or accepting the variety of human functioning, much like a human safely viewing a Gorilla in a cage.

Outsider Art is anything but outside. It can be viewed, if we
choose, as effortlessly as looking at human-kind heterogeneously, as “Insider Art,” and as a need for human expression beyond confines and definitions, even those of the art market which seeks to establish a value between “good” art and “bad.” Art is for most, a means to self-actualize and is, as humans are, priceless. Art can de-stigmatize and demystify the labels that otherwise encumber so many members of our society.

Over time, we have come to learn that unlike Freud’s view of absence instead of presence of mind, Outsider Art has indicated intelligence and an internal universe that need not be feared. Art, or other modes of individual expression (it has been said that the computer is for the autistic what sign language is to the deaf) is an equalizer of humans, showing desire, a need for acceptance, awareness, and a means to self-advocate.

Some people use art to understand themselves, others to communicate when no other source of communication is as effective -- (Donna Williams, Larry Bissonnette, Jonathan Lerman). These artists, as an example, are able to communicate that they are self-aware, intelligent and share their ideas on their autism and society at large. One might say that they help to bridge an understanding “between worlds” – “normal” versus “autistic.” For others still, we will never quite know if they had any idea that there was an audience for their prolific work. (Adolf Wölfi, Henry Darger).
The fact may be true that for some artists, the audience isn’t of high importance and does not influence production. For other differently-abled artists, outside acceptance is an affirmation that can transition an individual from hopeless to hopeful – an assertion that we can be valued for the work we do. Oliver Sacks calls it enablement of identity. All we need to cultivate is a society that will support that enablement. **Art Against Stigma**

**Jonathan Lerman**

In terms of enabling self-awareness and identity, expressive means to communicate can also be a form of self-healing, regulation and an engagement in the process of esteem building. “I paint, therefore I am,” is an assertion that as humans, all of our lives have significance and mark-making is part of being human, an urge as primitive as man’s first mark in the cave.
The beauty of Outsider Art, or art therapy for the differently-abled, is this “free-flow” approach, allowing spontaneous thoughts and action to collide. Jonathan Lerman began drawing suddenly at the age of ten. Allowed to draw freely, Jonathan’s fluid communication method is through charcoal and paper. Once instructed, Lerman’s work begins to look more contrived. This ability to self-teach, to be self-motivated, is in part, the awesome nature of his work. Unobstructed, Jonathan’s vision is not only articulate, it is profound.

Today, Michael Fitzgerald, author of *The Genesis of Artistic Creativity: Aspergers Syndrome and the Arts*, and others are beginning to acknowledge the fine line between genius, creativity and other mental “conditions.” Many gifts are associated with autism, however, to the point of being stereotyped. Yet, Seneca stated that “no great genius has ever existed without some touch of madness.” Shakespeare noted in a Midsummer Night’s Dream that “the lunatic and the lover, and the poet/Are of imagination all compact.” Temple Grandin once said that “it is likely that genius is an abnormality.” (Fitzgerald, p.14). Fitzgerald attempts to define genius into something discovered or executed in a way that fundamentally changes society. He notes that “genius” can occur in a neurotypical or in a disabled person, but within the confines of that paradigm. He believes that a person of “lower IQ” is incapable of genius, thereby providing a very narrow definition and understanding of test performance in people with differing abilities.

In contrast, Paul Collins, author of *Not Even Wrong: Adventures in Autism* says:

“A genius must assiduously ignore others in order to be guided by his own curiosity, by a desire to make sense of the world. And can’t the same be said of the light bulb painter? There is no way to know what an immense concentration and radically altered perspective will alight upon. To someone with great focus, the fascination is the point.” (p.214)

Recently, we hear more often of an acknowledgement of ability within so-called “disability.” We discuss genius burrowed within the most disturbed behavior. More importantly, we are learning to value people of all abilities, or differing ones, perhaps highly unusual ones. In so doing, we must not to contradict ourselves by
sensationalizing artists and then institutionalizing them as unintelligent, ignorant individuals – “idiot savants” -- requiring mere daily care as an acceptable means to one’s quality of life. We cannot put people on pedestals and then seek to cure them for their abnormality. We must instead alert ourselves to what so-called “outsiders” seek to teach us about the beauty of humanity, and necessity of preserving human difference.

"The only man who behaved sensibly was my tailor; he took my measurement anew every time he saw me, while all the rest went on with their old measurements and expected them to fit me." --George Bernard Shaw

**This essay was written for INspire, summer issue.**

My Talismans

I've been wondering what every one says to their God (or themselves if they see fit) what they think about their lives, their lives with their children? What do you really say (or think)? Do you wish your lives were different? How many of you are satisfied with the way things are? When the going gets tough, do wish it could be easier?

Why is there so much irony in everything?

Adam lashed out at me yesterday for the first real time. He has experienced frustration in the past, some “obsessive interests,” for sure. Yesterday, in the midst of excitement and then going to the potty, he just lunged at me and pulled my hair. I put him on the soft bed and said no. I said no about three times. He rolled around and cried, but looked at me the entire time. I sat on the bed and held him, telling him to calm down. He did after a while, but certainly, the “upset” stuck, and remembering it just set him off a little again – on and off for about an hour.

Again, this morning while making eggs, he grew impatient and grabbed my new and adored love handles (hey, I just started
training again). There was clear frustration on his face – all tensed up and red. I told him that I couldn’t cook them any faster, and held him as we counted to ten with some deep breathing. I’m hoping that maybe he will start counting to ten on his own one day, to help him self-regulate.

With the parallel experience of some profound advances in Adam, and some unbelievable skills, I am finding that his emotions don’t follow suit. My thoughts on the matter are this: I want to show him that I care, that I understand (or at least think I do) his frustrations, while teaching that aggression isn’t acceptable and by giving him tools to enable his success with all kinds of skills, including communication. If we can provide him with tools to be successful -- and I define success in an indigenous way, not always contingent on outside definitions, then perhaps I am filling a gap for him. I like to call it building bridges (a title of a book by O.T. Ellen Yack), that allows us to travel between both our worlds, sometimes allowing us to meet in the middle.

But for now, he is becoming so frustrated. He is having difficulty with unstructured time, which occurs at the end of the day. He wants so badly to communicate – he is typing every day on the computer – the animals he sees on the videos is one thing he does on it and together we are learning about the seasons on the computer as well as labelling actions. When I acknowledge what he writes with a song or some script, he is so delighted that I “get it.” In some ways, I hope that he understands his power and that I do “get it,” even if I feel clumsy in how I help in through this phase of his life. Perhaps that’s how we all feel as parents -- clumsy, uncertain and in need of support that not pities us at the expense of our children, but that educates us to at least feel we are helping them the best way we can -- to morally support us, and accept us as the blubbering dimwits we sometimes are. In terms of parenting, for me, the goal is to understand Adam during the chaos of a tantrum, or the obsessive wandering up and down the stairs. During these so-called "obsessive" episodes, is he Gutstein's confused child, or Tito's child in need of gravitational pull? Indeed, the most terrible feeling of all for a parent, is the feeling of helplessness. There are times, in autism, when a parent feels such a disconnect between making a child happy, teaching a child through the tougher phases of life, discipline which tends to get wrapped up in the terms "weakness" and "deficit." The tendency is to look at the latter without remembering that our little ones
need guidance just like any other child, but delivered differently.

So what do I ask the God I am still not certain exists, but seem to question a lot? I ask a lot of why questions, but most often I ask him how do I be the best parent for Adam? What should I do? How do I do it? (Please don’t write ABA in the comments section -- I'm for finding effective ways to educate and teach and ABA is a term that means many different things to different people).

Life’s questions seem to all boil down to Adam’s joy, his contentment, his ability to do the things he wants. It feels that so much is riding upon my shoulders and it is those days I need to take a deep breath and count to ten myself. Practise what you preach, right? It seems that Adam’s life is built on the decisions I make today, and in the autism world, those decisions can feel heavy. Trial, error, thought, personal research, and time seem to be my most effective talismans. With every hurdle, there is a joy. With every sunset there is a dawn.

Donor Fatigue Versus Food for Thought

I have been very involved in fundraising in my life, as I’ve mentioned in a few posts thus far. When I approached individuals and organizations for money, I sometimes received a sigh of fatigue. “Donor fatigue,” as one put it. It gets me thinking today at how charitable organizations are cottage industries turned big business – many, when investigating the percentage of administrative costs from funds raised, go to salaries. In Canada, a “responsible organization” should have no more than twenty percent of its raised revenue go towards these costs.

Nonetheless, charitable organizations are popping up everywhere like business, all vying for your donor dollar. There are many “good” causes out there in my opinion, but the responsibility to sift through the mire of organizations and their motives has become much more complicated. Sheer altruism, wanting to be a “good” person, is naïve, and the donor has to now engage in due diligence or truly believe in the supported cause.
I consider this as I am setting up the Canadian Autism Acceptance Network. I don’t plan on doing any aggressive fundraising – I just need enough to cover expenses for speakers and exhibitions. I do not plan to take a salary. The purpose is solely to bring information that is not yet available in Toronto -- information that demystifies autism, or at least brings a countering view to the ones presented by the high-priced, higher-salaried orgs out there. I want to continue to bring exhibitions so that people with autism can have a venue and be paid for their work. I want to show, and not always tell, through the work of autistic people – without sensationalizing them, but through regarding and respecting their work. It’s rather like presenting Art Against Stigma. As a parent, I do not see any other presentation, lecture or exhibition that offers an array of literary, academic and creative individuals as will be offered this October.

Tickets will be sold to the lectures to help cover expenses. Media is supporting some promotion. Speakers are being confirmed and I hope to give you the line-up in the next two weeks. I hope some readers will consider coming to Toronto to support this. This is about creating new paradigms, and making new viewpoints available to the public. I believe controversy is healthy and important. Please bring some to Toronto. I'm not about to espouse a cause to grab a dollar. This is about getting fed with information - - food for thought.

A website is being built with more information about the lineup and event and will be available soon.
Autism is classified as a neurodevelopmental disorder that manifests itself in markedly abnormal social interaction, communication ability, patterns of interests, and patterns of behaviour. Most notably, autism can make it very challenging for a person to converse in real-time, which can make face-to-face conversations and debates difficult.

Currently, in autism discourse, there are two distinct arguments occurring online between those who feel autism is an illness that must be cured — conducted largely by those without autism — and then those who are autistic and their allies, who believe that autism is a way of being and that autistics have a right to be respected and supported within society — an issue that deserves the same regard as race, colour or creed.

Thankfully, the blog is an equalizer of humans, serving the autism community well at this point in time. It is a universe, a “sphere” without rules, without barriers — faceless, sometimes nameless. It transcends some physical and attitudinal barriers and in this realm, one cannot judge another based on appearance or so-called levels of “functioning.”

In years past, self-advocacy by autistic persons could not be as prevalent as it is today. If it was, people with autism would have to be edited and published — by and large not a bad thing. Letters have been written, but without the dialogue and the breadth of interaction the blog invites. With current media “hype” over autism, people with autism take offense and can advocate in public, through the blog. In fact, the blog is a powerful medium for the autistic person because, as mentioned earlier, communication difficulties that arise from delayed processing make real-time
dialogue difficult for many, impossible for even more. With allowed
time and space to communicate, the autistic person can self-
advocate more effectively online. I direct you to Part Processing,
Whose Planet is it Anyway?, Ballastexistenz, and Michelle
Dawson’s website “No Autistics Allowed,” to name only a few (the
rest you can view on the right side-bar).

In an email exchange with Michelle Dawson, she told me that it
takes “extra time” to write emails. “Zilari” of Part Processing
makes a number of comments on her processing time with
colleagues at work:

“This is the main reason I prefer reading to listening. I like huge
blocks of text I can sift through and find the relevance in. I like
how text stays firm within time and does not melt away like
sound. I like how reading does not demand every 30 seconds
that one speaks to the text aloud and says, "Yes, I'm getting it,
carry on!..."

It takes different brain functionings to type, read and write than to
speak – some have pointed to Broca’s area and Wernicke’s area
(the left frontal cortex and the posterior part of the temporal lobe)
that have effected aphasia in some. It is widely known that
“written language is often much more convenient for processing
large amounts of linguistic data.” Verbal communication may be the
sine qua non of childhood development measures, and of
pragmatic communication (socialization) in this society, but with
the advent of the blog, many barriers for the autistic person just
mentioned have been destroyed, thus allowing others to discuss
issues with each other – not only between those with autism, but
with another population that didn’t have day to day access to this
population. Parents like myself can listen to autistic adults which
can then guide interactions with our own autistic children. Autistic
people, judged all too often for their exterior “behaviours” or
functional impairments, or romanticized because of their literary,
artistic or other exemplary work, can be viewed as intelligent,
“regular” beings deserving and desiring a quality of life beyond
cures, therapy or daily physical care. This even-playing field
enables people with autism to discuss what autism is, thereby
demystifying the so-called “disorder.”

When writing, an autistic person can experience inertia. Blogs
enable time to pass without further handicapping the autistic
“Some people find it difficult or impossible to summon certain ways of thinking on demand. For example, some people have a lot of trouble getting into an "essay-writing mode" - they'll get out the assignment, open up the word processor... and then sit there blank, unable to figure out how to begin. For another example, some people get easily caught in a given emotional state - frustration, say - and are unable to get out of it on their own... Lucy Blackman writes, in her excellent autobiography Lucy's Story: Autism and Other Adventures, that she has trouble getting her thoughts into the stream which effects what she actually does, unless she's had time to type it out before hand.”

(From Theory to Praxis)

Blogging and email communication are invisible, fluid highways to change the face of rights and acceptance of autistic people as thinking, vital human beings and further, raises issues about how we treat disabled members of society as a whole. Michelle Dawson, banned from Autism Society of Ontario’s listserv, and Jim Sinclair who writes the article Don’t Mourn for Us, among many others, have created a dialogue on such an equal footing that so-called altruist seems assaulted and on the defence, remaining stubbornly rooted in some false-belief that the autistics are wrong about themselves -- that autism is a tragedy despite what the autism community (people with autism) say. As I noted in a post titled The Economy of Pity: “altruism exists largely for oneself, not others.” People are unaware of the pity they disperse and the autistic community doesn’t want that pity. Pity suggests that there is one who is superior over another. Society is forced to contend with the likes of Dawson because of her ability to write, for example, and her arguments about autism research and treatment in society. Society, in turn, brushes her aside only to spotlight the discrimination even more. Other people with autism and their allies, are able to discuss news events and issues about autism and rally behind the likes of Dawson and the acceptance movement, thereby taking the revolution off the streets and into the information superhighway.

So, the autism discourse has become political – with demands for basic supports, respect, tolerance and inclusion to a society who largely hears from mainstream media that autism must be cured,
therefore assuming that autistic people have a lower quality of life because of their autism, and who see autistic people as inferior beings. Cures seem to come from camps wishing cost-effectualize the human race, inauspiciously reminiscent of the former eugenics movement in America. People with autism and parents like myself, are frustrated and outraged with the messages that mainstream media is purporting.

Bob Wright, Chairman of NBC, and his wife Susan, decided to take the hyped “epidemic” message and run campaigns over the media because of their recently diagnosed grandchild. This family, who personally believe that vaccines have caused the autism, are personally funding, and fundraising, for research to find out if thimerosal, the claimed offending preservative, is the cause of increased autism diagnosis. They began a charity called Autism Speaks and have coupled with The National Alliance for Autism Research (NAAR) in rallying for greater funding on this basis, even though the science has already disproven that vaccinations have been the culprit, or the cause of autism. Kevin Leitch, web designer of Autism Hub that has brought "the best of autism blogs" together, exposes Lenny Schafer's opposing views about mercury in vaccines. Many autism bloggers committed to uncovering rigorous, peer-reviewed science, dedicate their time to disproving these claimants, who unfortunately, have a large portion of the public ear, not to mention access to deeper pockets. These bloggers: Kathleen Seidel, Autism Diva, Kevin Leitch, Bartholomew Cubbins, Michelle Dawson, and many others, have spent countless hours on legal and scientific matters that are now shaping mainstream messages and court cases – the latter from parents suing based on thimerosal in vaccines.

The call for altruism to corporations and high-ranking political figures like Alan Greenspan and Laura Bush, are so misguided – as the funding and the goal is being disputed by autistics and is nonetheless disregarded, furthering ghettoizing the autistic population. This shows the special interests of the media and the lack of objectivity, just when the public turns to the media first for some kind of truth. It is the highest abuse of the media, and bloggers are largely motivated by conspiracies, special interests, and abuse within trusted institutions in general. As a former corporate chair of NAAR, I was shocked at the organizations' apparent disregard for autistic persons and their message when I suggested that people with autism should be directing the research
and the public messages – not researchers and parents. This obvious disregard is a slap in the face to the autistic population.

The blogging movement is thankfully more democratic showing a widespread public dissatisfaction with the media, politics, and many charitable organizations. David Kline, who writes in *Toward a More Political Democracy* – an excerpt from the book *Blog* with Dan Burnstein says, “Any serious discussion on political blogging of course, must begin with an examination of how it has reshaped the way in which Americans get their political news and discuss the political controversies of the day. Because on that score, at least, political blogs really have become, in the words of *Time* magazine, ‘a genuine alternative to mainstream news outlets, a shadow media empire that is rivaling networks and newspapers in power and influence.” (p.5)

In this “citizen-created medium,” people with autism and parents can tell it like it really is. Blogs are devoid of editors and special interest groups who control mass messages about autism -- messages crafted by those who are not autistic. Some autism groups have garnered their energies as in *Aspies for Freedom*, using a critical mass of autistic people to ensure the message of acceptance of diversity is spread. Kline further states that, “This is not the first time citizens have created their own media...During the Renaissance, for example, ‘commonplace books’ helped educate citizens cope with the information overload of the newly emerged printing era...these commonplace books reflected personal experience and conscience of their authors.” (from *Blog!* P. 245).

Recent changes in the thimerosal argument by bloggers and the Schafer letter will hopefully kill the myth that vaccines cause autism, showing the power of online discourse. “The results are in. Without blogs, there wouldn’t have been a Drudge Report to help speech the impeachment of a sitting President. Trent Lott, hounded by bloggers for a racist remark originally ignored by big media, would still be Senate majority leader. Blogs played a critical part in the downfall of Howell Raines, former executive editor of the New York Times, in the Jayson Blair scandal.” (Blog! P.369) I’m sure the autism community will soon be able to make the same claim.

The quality of blogs will be scrutinized by their audience. Bloggers
I’ve heard murmurs of the autistic person being unable to participate in live video-feed discourse. Yet, for centuries, the written word has been a powerful force to change the world. With allies, both the keyboard and the spoken word will move toward cultivating a tolerant society. The blog is not just a nice little cathartic diary in the autism world. It is a major movement about disability and humanity that can no longer be ignored -- no matter how hard others try.
"Lay your sleeping head, my love. 
Human on my faithless arm;

Time and fevers burn away 
Individual beauty from 
Thoughtful children, and the grave 
Proves the child ephemeral:

But in my arms till the break of day 
Let the living creature lie, 
Mortal, guilty, but to me, 
The entirely beautiful...

...Let the winds of dawn that blow 
Softly round your dreaming head
Such a day of sweetness show
Eye and knocking heart may bless,
Find the mortal world enough;

Noons of dryness see you fed
By the involuntary powers,
Nights of insult let you pass
Watched by every human love.

---Excerpt from W.H. Auden's "Lullaby"

Rare Flowers

Quite a week...my first Passover Seder, Adam’s school party, his fourth birthday party out in the yard, spring’s first sunshine blessings. I have many stories in my head and I haven’t had a spare moment to write any of them down.

In the midst of my anxiety that everything be organized to perfection, I decided to add a little worry over Adam’s academic future. Family is hearing things about schools – autism schools.
Special needs schools. Here in Toronto, many of the LD (“learning different/disabled”) schools do not accept children with autism – “too disruptive,” one administrator commented once to me over the phone. Some others have hummed and haa-ed, but have “invited” me to send in a registration form with a hefty non-refundable deposit. There is the day school that may still agree to my plan to implement a supplementary IEP-type program. If this doesn’t pan out, there is the home-schooling option – an option says Businessweek’s Michelle Conlin, that a “many number of affluent parents [are implementing as they think] they can do better than any school.” (February 20, 2006)

Hand it to Bonnie Ventura, who commented on my post A Weekend Thought to Change the World. She has been “in this” a lot longer than I, and frequently directs me to an article already written on one of my thoughts or “epiphanies” on autism, acceptance or education. I specifically wish to direct everyone to Thomas Armstrong’s paper “Special Education and the Concept of Neurodiversity.” (See This Site for more ideas on education) As I said in my previous post, if we look at the issue of educating those with difference in the opposite direction, if we do not view people with deficits, but instead regard their strengths, we could affect education in a positive way. Despite the difficulties, still, in finding a suitable educational match for Adam, I realized from Armstrong that special education has come a very long way since the 1970’s. He blames the system, not the special educators, who have to “work within a system that requires that they treat their students as disabled. As many a parent or teacher has pointed out to me: how are they going to get special services in the first place unless we get them labeled with a disorder?” So this current disability discourse, this view, cannot set up people with differences for success.

In Canada, parents who sue the public school system, or fight for ABA services beyond the age of six, must fight within a system that will continually suppress special needs, if not oppress them. I once wrote last September, that I believed these ABA court cases were hindering the education process and success of our kids. I now will elaborate that these is more likely the case because the system continues to frame and define people with autism as disabled, unable to care for themselves, instead of providing support and education throughout an autistic child’s academic career. When we presume all people competent, with multiple
intelligences, with varying levels of ability on this tape measure called life, we enable people to become contributing members of society.

When Adam was diagnosed, the diagnosticians paid special attention to keeping Adam at a particular ADOS score “so he would be eligible for services.” I didn’t particularly know what that entailed at the beginning of the process, and I soon abandoned those government services. Current ABA programs offered by Toronto Preschool Autism Service, are lacking at best. Young people calling themselves “therapists” are setting up “behaviour shops” endorsed by this government agency. Desperate parents pay monthly fees for the agency supervisor, who meets with the parent only once a month, and send in their therapists who the parent has to pay additional hourly rates – thirty to fifty dollars an hour. Other services, like Floortime, RDI, incidental play, occupational therapy or speech language therapy, are not approved by the government as services that can be subsidized, even though they can benefit a child with autism. The agency here in Ontario paid for some “Direct Funding” so that some programs could be done in the child’s home. Such a program would have to have a psychologist – another hefty fee – oversee the program. This agency saw that they couldn’t control home-based programs, so they are beginning to withdraw the Direct Funding option and insist that families send their kids to their “approved centres,” reminding me of the Bettelheim days when parents were considered ineffective at parenting their autistic children, or blamed for their autism. In Bettelheim’s day, children were institutionalized.

When I look back and see how Adam is doing without this government directed program, how Adam can receive the unique one to one program at home that I have created with him, with the help of my personal team, within an integrated nursery school that works with my team as well, I can’t see how the government model can work, because it still strives to homogenize autistic education and training, when autistic people are all unique. The cost of running a home-based program is still hefty, and I am always afraid when the government wishes to become involved in Adam’s programs. I do not think “the system” is set up for independent training, or leaving Adam’s future in the parent’s hands. Yet, this is what has benefitted Adam the most. My involvement in his school will not be anything less.
In this example, I feel that Thomas Armstrong is right – that moving beyond this discourse, these models and institutions for autism would change our education system as a whole, and treat every individual as, in his words, a beautiful and rare flower. He posits reasons to reconsider to change our educational system:

“...Research has been coming out about newer disorders affecting larger groups of people. Harvard psychiatrist John Ratey, for example, has written about ‘shadow syndromes,’ which are milder forms of psychiatric disorders that afflict far more people than are currently identified. Other researchers have suggested that half of all individuals will experience mental illness sometime during their lives. It seems to me that while I’ve been attempting to focus on the positives in the lives of children and adults with special needs, research and culture have been moving in the opposite direction, finding more and more things wrong with more and more people...Recently I’ve discovered a new concept – neurodiversity – that I believe provides a means of reversing and moving beyond this expanding disability discourse. Neurodiversity is a term that was first used in the Aspergers/autistic community by an Australian disability activist named Judy Singer in that late 1990’s...This new term has great appeal because it includes both the difficulties that neurodiverse people face (including the lack of tolerance by others), as well as the positive dimensions of their lives, something that is generally missing in the disability discourse except in a token way...

Instead of wallowing in the current ‘disability discourse,’ both regular and special educators have an opportunity to step ‘out of the box’ and embrace an entirely new trend in thinking about human diversity. Rather than putting kids into separate disability categories and using outmoded tools and language to work with these students, a perspective based on neurodiversity invites educators to utilize tools and language from the ecology movement as a key to helping kids succeed in the classroom. If we apply the same kind of diversity model to children as we do to the flora of the world, then we should be in much better shape than we are now.

Consider the issue of inclusion in education. Regular classroom teachers are far more likely to want a ‘rare and beautiful flower’ or ‘an interesting and strange orchid’ included in their classroom...
In this model, in looking at our children requiring different ecological thriving factors, we can reach the goal of addressing our children’s need for optimal growth. This goal is in direct contrast to trying to “cure,” “fix,” or “repair” “remediate” a child’s disability, as Thomas notes. When I look at my four stepchildren, I also see an apparent need to cultivate each child differently – by imposing the same standard on each of them, they can become depressed and stressed about their futures.

Toni Morrison recently said in a Brick interview with Maya Jaggi that “the black people were the first modern people.” She views slavery as “a reign of terror in which the victims were stripped of the normal places for sustenance and had to invent and reinvent...” in that sense they were modern, “not clinging to tradition for the sake of it.”

I had to consider, as I’ve suggested in many previous posts, that autistic people have a unique opportunity to change disability discourse from hereforth – that this dialogue, these debates, this struggle for acceptance, equality and education, makes the autistic modern. The need to reinvent the system, to redefine ourselves as human beings, is of utmost importance at this critical juncture – a point where the media and certain organizations are loud and brash in their calls to cure a type of people.

Last week, I attended a gala organized by my new friend – Dr. Nehama Baum – “The Possible Dream Gala,” for the MukiBaum Centres. Tables were reserved for some of her students and I met her son Muki, who is forty-six, with cerebral palsy and who is deaf, for the first time. Others, with various differences, got up and spoke, danced. My husband and I purchased a painting at live auction – a collective effort by young children with complex disabilities who were believed to be hopeless and incapable of doing anything. For me, it is a symbol, a talisman, that everything in life is possible if we believe in people. This painting sits in Adam’s room where he does his one-to-one work. Forever, I will tell him the story about these children and what can be achieved if we work hard and believe in ourselves.

Yesterday was Adam’s fourth birthday party. I kept it small as I usually do now – I avoid the loud play gym rentals with a class of
twenty children running about wildly. Adam has taught me how simplicity is beauty. I put flowers on the table, a few toys outside, a lovely set up of food and sweets. I hired a percussion troupe which Adam enjoyed at the Sick Kids Enchanted Evening Gala last week. He sat enamoured with the various instruments the drummer pulled out.

Adam and the percussionist

Adam the musician

I invited six kids and their siblings – four of whom are also autistic – all different, rare and beautiful. The sprouting yellow daffodils surrounded us, but these rare flowers stood out in all their glory. They were a delight to behold.

A Perfect 10

It was Adam’s fourth birthday today. He began the day early at 4:30 a.m. and despite the fact I just want to lie down and rest, the day, the thoughts, moved on. Adam started his day by typing his first and last name on the computer. I wrote that he was four years old, that it was his birthday. We got dressed and sauntered down the steps and moved in our usual way toward breakfast. I
gave him a magnetic calendar for his first present – he knows all the months and I would like to use it functionally. I was excited to give him a gift, trying to make a connection between the word “birthday” and his day. He tore open the paper to my delight, picked each month and recited it, in between a few bites of egg, sunny-side-up. I rustled about the house as usual, getting ready for school. We packed up our knapsack and chocolate cake for his friends at snack time, and I bellowed “Adam school time, go get your shoes.” He headed for the door, but insisted on bringing the number 10 from the calendar. It was quite an issue – he wouldn’t let go of that number 10. I didn’t want him to lose it – the calendar wouldn’t be the same without it. I tried to trade him the number 10 from the calendar for a 10 of spades from a nearby deck of cards. He liked that, took it, but still wouldn’t give me that other 10, holding it with all his might in his tiny fist. I told him that he couldn’t take that 10 to school, and felt my temperature rising as he yelled and protested. I told him we were going to school and he could see that 10 when he came back home. Eventually, reluctantly, I got the 10 and stashed it away before stuffing ourselves into the car.

It’s hard to set boundaries with any child, not to mention one who has autism. It was his birthday, and I wanted him to be happy, not sad. I know he used to get stuck on numbers, but I also knew that I just gave him a new toy and any child would be a little obsessed with something new and not want to let it go.

On the drive, I opened the window for the cool spring breeze against my reddened face, the route always the same -- the only difference in the change of season, the winter that finally turned to spring, the new brand gleaming convertibles on the road, the rising gas price. I wanted to cry, I don’t know why for sure. The dull yet calming repetition or our day? Our upset? I thought how if I called someone to give me advice, perhaps they would treat Adam’s protest as a “behavior,” that if I mentioned the incident, he would be the targeted culprit and not the fact that I stupidly gave him a gift at a rushed breakfast right before school. The “behaviour” would be addressed with rigorous, unwarrented “procedures.” At the same time, as he continued to yelp in the car, on and off, I wondered who was there to support me. No answer would suffice this morning. As a parent, if you ask for help, you don’t always get what you want. If you don’t ask for help, you feel alone. I often don’t want to hear those answers that never quite fit the situation,
so I tend not to ask unless I’m in a more resilient mood. Often, if you ask a simple question, you receive a deluge of unsolicited parenting-of-autistic-child advice. Sometimes it’s just better to sit with all your mixed up feelings until the answer comes to you. Sometimes, it’s better to just be a temporarily confused parent -- feelings, guilt and all.

I have another birthday party for Adam on Saturday with four other autistic boys and a couple of other friends from the class and the neighbourhood, my first big Passover Seder to host tomorrow, art installations, and lots of other things on my plate, like us all. When Adam begins to protest, it’s usually when I’m too busy to be as patient and attentive as I would like. When I’m too busy, it is a sign to slow down and attend to Adam and the things that agitate me.

Adam and autism certainly leave me with lots of questions, problems to solve, people to manage, convince teachers and others about ability, programs to coordinate and more. The questions can be overwhelming at times, Adam’s will and protestations a little frustrating. Yet, weighed within the context of life itself, Adam, and our lives, are still a perfect 10.

(Oh.. and he loved his cake at school!)

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**Week-End Thought that Could Change the World**

Let’s end the week with a thought:

If we base our teaching methods on human deficit, whose intention are we serving? Conversely, if we teach based on a human’s ability, what is possible?

In recent ramblings about how to teach an autistic child, I’ve come to this conclusion. It is a shift in thinking, as it requires us to think about human difference and disability in the opposite direction.
Autism and other people with varying degrees of disability all have something. As human beings, we all have spirit. We all have inner lives. We all have desires. To assume that even the most disabled person does not have these feelings is to assume they are not human at all. And we all know this is false.

A doctor asked a clinician I know the other day, “do autistic people form attachments?” When she told me this, I gave my little laugh of disgust. It is alarming how pervasive these thoughts are about autistic children and adults.

I’ve been reading some research papers, which discredit Cohen’s mind-blindness theories that have done a lot more harm than good. Dr. Paul Mottron has discredited many notions about cognitive delays in autism, and deficits in face-processing ability. There is a lot to still discredit publicly. It is going to happen, I assure you.

In the meantime, as I prepare for school meetings and think constantly how best to teach my child the skills that he is good at, which he will be able to excel in, which will bridge the easier to the more difficult, I think about every human right to BE HUMAN which means, to dream, to express, to belong and to choose. Quality of life for people who are severely disabled means not just providing for daily physical care, it means coveting the human spirit and enabling it to express itself through whatever means possible.

I ask you: think about what is possible this weekend. Think about what is present in your child rather than what is missing. Think about struggle as a rite of passage in life itself.

Only good can come of it.
Anonymous, this one anyway, has no guts. Anonymous wants to promote intensive ABA therapy at ANY mention that a child with autism has had a bad day. It must be because that that child isn't doing ABA. Anonymous called me ignorant by dismissing ABA. I call anon ignorant in assuming that from one post Adam needs intensive ABA, assuming that we’ve never tried it. I also think it is ignorant not to acknowledge that there are many modalities of teaching that work for children with autism.

Hey, if it works for your child, do it, I say. I strongly disagree, however, that a child who is an apple must be turned into an orange. This is most often the premise under which ABA is used, unfortunately. In short, that attitude and attempt to alter a person, is a human rights violation.

I must also say that Adam is doing, despite some of our harder days, amazingly well. I do not need to compare him to other children to see how he is doing. I can look at Adam’s world and see it without this kind of context. If I had to compare, which is the way people with autism are evaluated all to often, he goes to an integrated school, he sits in circles, sings songs, participates in groups, plays "functionally" -- he is beginning to do so many things and I run the risk of belittling him if I ream off a list of what you want to hear. If I had to look or compare with other children of the same age, I witness the same wandering behaviours. At the age of four, I see many other kids tantrumming. It is utterly ridiculous to assume that autism is always to blame. It is naive to put autism under this kind of microscope. Some things will take a little longer for Adam, maybe, likely -- it doesn’t matter. I find it utterly horrible for people to come on sites, and comment that one’s child would be "doing better if..." You don't know us. You don't see my son. You, anonymous, are ignorant.

Parents who have not visited at least a hundred children with autism, as I’ve done over the course of two and a half years, who have tried "intensive" ABA therapy which didn't work for Adam, who spends hours researching options, combing through both rubbish and viable teaching ideas, might be subject to doubt with people like these. Afterall, isn’t it compelling to believe when one says you haven’t done something that it must be your fault?

This is the problem. People who are "selling," particularly the ones
who stay anonymous, seep into parental doubts. I know because I was there. I know because the call of diets, DAN!, mercury poisoning claims (don’t you know that the “feeble minded” of the 1800’s were also claimed to be contaminated by mercury?!! I mean, must be something to cause the difference, right? Argh.).

C’mon anonymous. Have some guts. Come out of hiding.

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Postscript:

On a lovelier note...in the middle of writing today, my friend -- the one I wrote about in earlier posts -- came by. It was emotional. It was EVERYTHING. You see, if you can be honest, things can happen. Beautiful things. I do have a friend who really cares. Without getting things out in the open, I may have never otherwise known. Life is too short and we need to KNOW who stands with us. Without friends, ones I can really talk with, this is too difficult. I think it took a lot of courage for my friend to do what she did and I really do have renewed faith in people.

Did I mention the sun is shining in Toronto today?

Human Rights Violation In Sudbury

Here is a story from TalkSudbury.com. Another reason why we have to keep advocating:

> Autism is classified as a neurodevelopmental disorder
> that manifests itself in markedly abnormal social interaction, communication ability, patterns of interests, and patterns of behavior.
> Shocked and disappointed was how we at TalkSudbury.com felt when one of our members sent us this TRUE story
I am an autistic adult living in Sudbury, and use a wheelchair.

Being autistic means that I have many sensory differences, as well as social skill difficulties. Thus, when I am out in public I wear headphones all the time, in order to deal with the busy world. Otherwise would not be able to leave the house at all.

Friday March 17th, 2006 after a long workout at the YMCA, decided to go to "BlackCatToo" where I have gone for YEARS to get magazines. In fact it has been the only place I ever buy magazines (autistics are creatures of habit). I buy Adbusters, Shambhala Sun, and some Yoga magazines once a month and when can afford them.

This time was actually also looking to see what kind of running/triathelon/marathon magazines they had, since am training for a marathon and during my training period, I have entered many local races to raise funds for several non-profit organizations locally. I will be pushing my wheelchair through four separate 5KM courses between May 2006 and July 2006 here in Sudbury to raise funds for our local charities..

I did NOT touch any magazines, I had NO TIME to, before the 'problem' started.

When went in there, turned to the left (where the buddhist and yoga magazines are) and sat in my wheelchair listening to my walkman (which is what I ALWAYS do, in EVERY store that have gone in alone... am terrified of having the workers at stores talk to...
me, so the walkman drowns them out, and they
> eventually notice the walkman and realize am
> listening
> to music and leave me alone).
>
> Well, very soon after entering (within one minute)
> the
> man behind the counter was yelling the following
> words
> at me:
>
> "I said HELLO to you and I EXPECT my customers to
> SHOW
> PROPER SOCIAL POLITENESS and say HELLO back".
>
> I started to cry. I said I have my walkman on
> because
> i want to drown out the voices of people, because I
> am
> autistic. Talking to strangers sends me into a panic
> and then I need to leave the store.
>
> The man continued and said - well HERE in OUR STORE
> we
> EXPECT people to BE SOCIA LLY POLITE and you have to
> say hello back.
>
> I said I am autistic and I have difficulty talking
> to
> strangers and that I fear this means I cannot shop
> here if I have to talk to strangers, all the while
> my
> anxiety increasing as I needed to try to explain
> this
> to the man behind the counter, with the hopes that
> if
> I was able to help him understand my disability, he
> would let me shop there.
>
> To which he replied:
>
> "FINE. GO BE AUTISTIC SOMEWHERE ELSE THEN!"
this incident happened at exactly 11:30 AM Friday March 17th, 2006 at the Black Cat Too store.

Now, I fear that I cannot get the magazines that I want, because to go to Chapters, I would need a separate Handi-Transit ride booked just for that, and it would add $4 to the cost of my magazines. The Black Cat Too was easily accessible from the YMCA where I am already 3 days a week.

Furthermore, have always believed in supporting local independent shops, rather than the big 'box stores' like Chapters.

This leaves me feeling very much like I could be making a complaint to the Human Rights Commission about the fact that the store will not serve autistics and tells us to "go be autistic somewhere else", (which IS a violation of the Human Rights Code under discrimination due to a disability).

Now I realize that my magazine purchasing days are over, and am going to have to settle for reading things online only.

Am very sad about this incident, considering I have been a loyal customer of Black Cat Too for a decade (since 1996) and this has never happened to me before. I do not understand why they changed their policy and expect those of us with communication and sensory disabilities such as autism to 'go be autistic somewhere else' merely because we do not know how to be socially polite enough to talk to strangers.

To learn more about Autism please go here and here.

TalkSudbury has communicated to our member that we
The Unsettled Path to Acceptance

This is a most unsettled state I’m in tonight. Adam is frustrated – trying to talk, not being understood (he slurs his sentences). Also, he’s turning four next week and I am finding a new desire for independence – a desire to do everything on his own, pretty much. He resists my care of him – brushing teeth, brushing hair, getting ready for school. In some ways, he reminds me so much of my youngest stepdaughter when she was four. I remember a lot of whining, tantrums, and lots of hitting. While I remember her being much more articulate than Adam, I do see similarities in behaviour. So that should make me feel okay, right?

But it doesn’t. Adam is growing up, and I find myself nervous. I want to teach him how to use the computer – he is already typing his own words, but in the same way that he labels things. My team of therapists suggest it is “too early” to teach Adam the computer for communication purposes, and that baffles me. If Adam has a skill that he’s inclined to use and benefit by, then why is it too early just because the other kids aren’t doing it?

At school, Adam’s teacher notes that despite his words going down, his skills are going up – again that time of acquisition, of processing and for me, of waiting. I wrote before that I find these transitional times difficult. Logically, I know that these periods are necessary, but I wonder if I’ll ever stop worrying.
I find extracurricular programs so difficult to find, as the music class I had enrolled him in became very “verbal,” entrenched in pretend play. Long diatribes of being a pirate on a ship bored him, and he eventually got up and wandered around the room. So many “teachers” really don’t know a thing about autism. Adam is expected to sit and respond.

There is a lot of talk about these ideas of acceptance and just wanting one’s child to “function” in the world and “have all doors open.” Today, I wanted to pack this all in, all this blogging, learning about science, this struggle with friends, my loneliness in this struggle as there seem to be no more friends out there who really care about me, or want to understand what this is all about. No parent thinks they will be engulfed in controversy about autism. No parent has any idea that they will have to advocate for their child every single day from schools, to the doctor’s office to a nice little music class. No parent realizes that all privacy is lost with therapists coming and going from the home every afternoon. No parent has a clue that there are people who want to tell you how to raise your autistic child at every turn – that they think they know better. No parent banks on getting involved in autism so deeply in order to improve their child’s future, that it becomes their new career.

But I know of many.

No, acceptance is not easy, friends. It is not standing idle.

It is about recreation. It is about creating new friends, and new communities who will teach and support us and our children. It is about creating a new awareness what difference, autistic difference means, and supporting it, and supporting success. It is about investigating our notions of well-being and happiness.

If this is rebirth, I think I’m in labour.
Because You're Worth It

I was at a function last week, honouring a CEO of a major Canadian bank. Amidst a room full of businessmen and women, and philanthropic leaders, the man was being honoured for his *Words And Deeds*. I listened intently to his speech, waiting for something I could cling to, some words that hit the heart of human rights issues for all people. I wasn’t surprised that despite some of the fine work by the man, the speech was a string of rhetoric meant for an audience largely invested in commodities. This CEO spoke of Canada as a tolerant and diverse nation. Tolerance, ethnic diversity, struck a chord with me, and I waited for an acknowledgement, a phrase that pooled human diversity and disability together. In contrast, diversity and tolerance were directly equated with global competition – the idea that we accept diversity, ethnic diversity specifically, as long as we can give it some economic value. Diversity, therefore, is acceptable only if it can contribute to society in the market economy. The hierarchy of tolerance, in my mind as I sipped a glass of sour conference centre wine, struck me. When, I asked myself, did we begin to equate tolerance, acceptance and diversity with global competition? Where do people who are physically or neurologically diverse fit into this economic universe? Where do people who cannot globally compete this way, stand in his view? This CEO conveniently left out the disabled because within this framework, they cannot exist. If you cannot compete in the global marketplace, then you do not have value. But is this what he really feels?

I prefer to believe that this CEO is not purposefully omitting the disabled -- the issue is so much more complex and his speech shows how the discussion cannot fit into current frameworks of altruism and market economics (see *Economy of Pity*). I consider that the current worldview about disability and the construct of competition are incompatible. As we can see from previous posts, the ability to compete, equated more often than not with physical strength and uniform appearance, is similar to Karl Marx’s ideal of the perfect worker. Those who are unaware or unaffected by disability have an obscured notion about it, so there remains huge need to address these very issues with our leaders.

This is commoditization of life. Commoditization of healthcare, of just about every aspect of our current existence is based on
markets. Parenting is a billion dollar industry. Getting frustrated with the endless frenetic calls to do something for our children, I inadvertently picked up a mothering book the other day called, 12 Simple Secrets Real Moms Know: Getting Back to Basics and Raising Happy Kids, by Michelle Borba, Ed.D. I don’t normally pick up self-help or parenting books of this kind very often. Yet, something in the title at this point of my journey in parenting Adam, was compelling. I have spoken a lot about how marketing calls us to do something for everything – how marketing leaves us as if we’re missing out on something and that we are not good enough as we are -- there is always something to "improve." Parents of NT kids are unhappy, kids are unhappy. Why? We are unhappy because we are learning that goods do not free us but indebt us, that happiness is intrinsic instead of extrinsic. These ideals have filtered to the autism community where society deems that our children and our parenting of them are not good enough, that if we buy someone’s intervention package, our children will learn how to fit into society. Question is, are we really satisfied the way we’re heading? Is learning to fit the right goal?

Consider these points of a generally exhausted society in the context of well-being or Quality of Life (QOL) which I will use interchangeably) taken from Borba’s book:

-Of the American moms surveyed, 70 per cent reported finding motherhood “incredibly stressful” (Ladies Home Journal, 2000)
-Depression affects 30 per cent of mothers of young children
-One-third of parents in one survey said that if they were to do it all over again, they would not start a family
-In the same survey, 53 percent admitted they felt significant resentment in making sacrifices as a parent
-In a Texas survey, 909 women said they found taking care of their kids about as much fun as cleaning their house, slightly less pleasurable than cooking, and a whole lot less enjoyable than watching TV
-Of the 1,306 moms in one survey, 95 percent said the experienced guilt feelings associated with parenting, and almost half said that the guild only increased as their kids grew older
-Two out of three adults say that parents are doing a worse job than twenty years ago (p.29)

Why? The author who posits these statistics from various US journals cites the following to blame for the frenzy:
-new knowledge about child development and how much nurture, the way we behave, affects who they will become;
-parents wanting their children to excel so they enroll them in umpteen programs;
-more entrepreneurs creating more to sell to kids, including programs;
-more media on parenting and motherhood;
-financial pressures to meet all these consumptive needs;
-guilt that we’re working too hard and not spending time with the kids and;
-parents wanting to be liked by their kids instead of saying no.

This idea does have a spillover effect once we receive that autism diagnosis. Psychologists need to diagnose, we hire expensive agencies and specialized schools to teach our kids, then hire lawyers to fight expensive suits to get additional life-long funding as a so-called “support” to autistic children, we buy books, travel to conferences, fund research, buy ribbons and more. Autism is now an industry unto itself with a lot of snake oil salesmen. Buyer beware.

So, when discussing Quality of Life (QOL) for people with disabilities and people with autism may be skewed because our very own is compromised with the commoditization of own lives. Ascribing value to life then, or to the very definition of QOL is mostly an extrinsic, objective exercise based on market ideals.

Assessing QOL with objective models is not a sufficient way to analyze the well being of people with autism. A subjective view of QOL is required from the person with the disability. We may, as RDI does, define quality of life as “to get married, have relationships and have a job,” and prescribe interventions that seek to change the person to fit these goals. However, those definitions of QOL may not be the same from person to person, not to mention for a person who is different. The issue with commodity, therefore, is an external one which alienates those with autism currently articulating what QOL means for them. If we impose an objective value of QOL, under the umbrella of belief that people with autism are incapable of understanding, or further, somehow deceive themselves into thinking they are happy as they are, then we are not accepting of people with autism. If we insist as parents, researchers and teachers, that interventions are
necessary to help people with autism learn, instead of looking to the environment as the source of handicap, then we are not creating a tolerant or supportive society. Further, we are not honouring the way in which autistic people can learn.

I strongly suggest, that as parents, we consider that we have to reconceptualize our view of disability, and autism specifically, by turning to those with autism first, for a start. I also suggest that our goals should not focus on interventions to change the person with autism, but rather, seek supports and changes in the environment to support the person with autism. “The extraordinary variety of ways in which people can flourish suggests a comparable variation in the impact of abnormal functioning, an impact that people with normal functioning, notably health professionals, are notoriously poor a gauging,” says Anita Silvers from San Francisco State University. “[She] contends that the distorting effects of treating health as an indispensable practical good will be greatly exacerbated by the growth of predictive genetic testing in the coming generation, exposing previously hidden health deficits in a large portion of the population. Silver urges that health be viewed not as a good with instrumental value for almost all forms of human flourishing, but as an intrinsic good, on that, like art, will have radically different values when assessed from different standpoints.” (From Quality of Life and Human Difference, p.17)

If society views people with disability as a financial burden, then society will not build the supports for the disabled, but instead will seek to cure them. Further, educational supports for children with autism will not be made in the schools or by society-at-large if society is waiting for that cure. Organizations and some researchers rather invest monies on cures and pills that can harm people with autism as a long-term cost-saving measure. With this current goal touted by many major autism charities, it takes the burden of responsibility to change and to support autistic persons off society. It also threatens to take away a support network of fellow autistics from current ones, comparable, in argument, to aborting all fetus’ of ethnic diversity, thereby robbing a future of variant culture, mores and tradition, leaving those currently in existence, alone. This, of course, is morally repugnant.

“Disability is not a condition or a property of an individual, but rather, an interaction,” state David Wasserman, Jerome
Bickenbach and Robert Wachbroit in the book cited above. Treating disability as a condition or property leads to commoditization of life, and the medicalization of disability then becomes a natural extension to this. In making a prenatal choice, another arguable extension of this notion, I mentioned in The Difficulty of Knowing, that genetics counselors and doctors do not provide enough information regarding quality of life, because they themselves lack a definition with any reference from families or disabled persons who can help qualify it. Instead, I was pummeled with a variety of genetic factoids about which I knew nothing. In a matter of a week, I was expected to make a choice whether or not to abort without knowing anything – just based on whether or not I wanted to raise a child with a potential disability. In a society that does not value this portion of our population to begin with, where disability is assumed to be of lower quality of life, one can understand why so many abortions may needlessly occur. My feelings about this experience upon reflection is supported by Tom Shakespeare who “finds that stereotypes, over-generalizations, and dubious assumptions about the impact of impairments on quality of life shape decisions about testing and termination. But he believes the more important bias occurs at the institutional level, and that the debate over prenatal testing tends to place too much emphasis on individual decision-making. Just because of the importance and difficulty of the choices that individuals must make, society has strong obligations to ensure that those choices are knowing and voluntary. In order to do so, it must provide adequate accommodation and support for children with disabilities, and balanced information about raising children with disabilities for parents making decisions about whether to test or to terminate. Reviewing the relevant social science literature, Shakespeare concludes that society fails dismally in all three areas.” (IBID pp.19-20.)

The authors of this book contend that the World Health Organization (WHO), “belie its avowed commitment to equality in several ways: by taking cost-effectiveness as its ultimate standard for rating health systems, by ignoring inequalities among ethnic and socioeconomic groups, and by assigning the extension of lives with impairments lower priority based on a flawed methodology for assessing the impairments, one that relies solely on the judgments of health professionals.” (IBID, p.20)

When debating rights issues we first have to investigate this notion
further and make note of the very prejudices that endow our current beliefs about disability and human difference. We need to begin to spell out the basics of how people with autism wish to be viewed and treated. We need to make corporations and leaders aware of the complexity and the fact that all people may not financially contribute, necessarily, to the global economy, and they still have a right to be supported. Worth, value and contribution to society can take many forms. Heck, the volunteers of the world make no financial contribution, and when quantified, would make for a trillion dollar industry (noted in Bruce Mau's exhibition). So conversely, we all have value and we all have something to add.

The dialogue about quality of life – the objective and subjective views cannot be answered quickly. A review, however, is essential to understanding the complexity and the richness of those lives, those which are disabled. We must do this because we are all..."worth" it.

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**Gone Golfing**

My husband thought it would be a good zen-like experience for me -- the worker-bee who never quits.

I may just go crazy, or maybe I'll have an epiphany through the arch of my swing, or the simple sweet chirp of a bird. Who knows. In the meantime, great dialogue happening over Open Arms post (see previous entry), everyone...thanks. So much to ponder over regarding support for parents in the mire of mixed messages and misinformation.

I also want to make an autism blogger-oath -- someone pointed out to me that Acceptance Therapy I spoke of in previous post is also controversial. So, whenever I mention something that I have not researched, I will say so, so that no-one suspects I am actually promoting it. If I do promote something, I will research it.

Fore!
Open Arms

Recently, I’ve been writing about how friends and family had treated us, with good or innocent intentions, however thoughtless, in an honest vein. I’ve been talking about acceptance to the point where advocacy pools us all into two camps: the curabies versus the neurodiversity types. Sounds like teams for a Harry Potter quidditch match.

The term acceptance is being interpreted as a do-nothing approach in a culture that needs to do something for just about everything. Depressed? Take a pill. ADD, take another pill. Epileptic? I’ll continue on that one in a moment. Pills are a matter of choice. I do believe that there are people who really need them. I also believe that we live in a culture that over-prescribes them. I’ve listened and respect people’s choice to take them temporarily, permanently, whatever. I ask you all, however, to consider the bigger picture for a moment.

All parents (I say this loosely – there are parents who abuse their children), want the best for their children. When confronted with the term autism, there is little chance for a parent to trust themselves and not be swathed in fear. There is an entire culture and history out there that has helped construct that, so I understand that it is extremely difficult for parents to steer away from wanting to “help” their children.

When Adam was first diagnosed, I was confronted by one type of “scientifically proven therapy.” I joined an organization that funded research in support of a cure because I believed, at first, that autism was an illness that masked my son’s true potential. At least that was how autism was presented to Henry and I. Once we enter the “stream of autism,” as parents, there is little choice to believe these messages as sole choices in a culture that does not accept acceptance for people who are different.

I hired therapists who viewed Adam as a pathology and that didn’t feel right. After two months of being in “the autism stream,” I
decided that something was horribly wrong with this view. It took a while to trust myself, after hundreds of hours of reading and attending conferences. I really believed that the answer to Adam’s autism, to his progress, was out there somewhere, extrinsic of me. I believed that we needed to impose forty hours of therapy and usurp our family life, and that the pay off would be an end to his autism, or at least make him “indistinguishable from his peers.”

It wasn’t until I read books by people with autism that I began to view autism differently. I agonized over all my choices and prejudices about autism. In this world that also doesn’t support parents very well, it is very difficult to stand on one’s own and not listen to all the things other parents are doing and think you are not doing the best for your child. A parent tends to worry about what they’re not doing.

The odds are really stacked against parents. Our idea of “normal” is an historical construct (see previous posts on this) beginning in the mid-1800’s with Charles Darwin’s survival of the fittest theories. Karl Marx supported ideas of the perfect man in outlining ideal physical attributes of the worker, which was the basis for socialism – an average. We began to construct hierarchies of preferred traits as history continued with its evil side culminating in the Holocaust. Today, these ideas carry over into a consumerist culture, with a billion dollar industry invested in ideas of human beauty and perfection, leaving us otherwise in debt and continually miserable. We fight fat, we fight disease, fight ourselves, and what? Fight disability? There is a lot of effort in fighting and it leaves parents empty and exhausted, not to mention consigns our children as innocent victims -- there is always an innocent victim in a war. How do you think this has effected our quality of life? Isn't it time -- and perhaps we are on many levels now -- to re-define what quality of life is not only for us all, but for people with disabilities?

The anonymous commenter of yesterday's post, who believes autism is the evil taking away her son, feels that acceptance is synonymous with doing nothing. She further makes a fundamental mistake in believing, as a result of a culture that supports her in this false-belief, that autism is the enemy. For the rest of their days, her child will feel that there is an enemy within, and both of them will be forever miserable. People will offer diets and pills, but the autism will still be there.
False-beliefs need to be corrected, and parents who feel this fear might just need our open arms. This is not an attack by any means. It is a comment that there is a prevailing attitude that is harmful to all people with disabilities. There is a marketing machine of research and pharmaceuticals that need to take more responsibility for their ethical mistakes.

This afternoon, I met with JoAnne Dahl from Uppsala University and Dr. Emanuel Shapiro, a psychotherapist from New York who has written books on relating to patients. JoAnne was giving a presentation in Toronto today about, **Acceptance and Commitment Therapy** (Stephen Hayes, Kelly G. Wilson, Kirk Strosahel) and I received a call to go and speak to these two scholars today. The idea (and I haven’t yet read the book), is that when we have to understand our preconceptions in the way we look and judge people, overcome them and accept others as they are. Once we accept ourselves and others, we make a commitment to support them. I learned from Joanne that some epileptic seizures can be controlled without medication, that children often have seizures because it is a way to avoid physical abuse, a way to stay home with their parents, or a means to feel good. Through acceptance, and working through the barriers to it, the seizures can be controlled by the epileptic person. If this is true, it is an interesting study about non-acceptance and frustration and anxiety. Please note that I am not supporting this theory before investigating it, but want to mention it as an interesting piece of information that was given to me today, and we can all investigate it further. I know little about epilepsy and in brief investigation, have come across papers about techniques for self-control of seizures. I invite others who know the science better, to comment.

I was asked at Adam’s school today by another parent who reads this blog, “How do you do it? How do you just not listen to all the diets and therapies out there?” Did I manage to look at things differently in my art-history classes when we turned paintings upside down to see what we otherwise couldn’t right side up? Or was it my philosopher-father who taught me that for every belief, there is an equally compelling other that taught me to question everything? Whatever the reason, this is not about keeping up with the Jones’ anymore. I really care about my son’s wellbeing. I read as much as I can, with whatever energy I can muster in between playing with Adam, and lately, teaching him on the
computer – something he has lead me to. I have chosen to view his so-called “behaviours,” as functional needs, his “obsessions,” as interests, and remember how Dawn Prince-Hughes had to repeat words of things so that she could absorb them, or how Zilari’s father fostered her interests by feeding them even more. Adam’s latest “obsession” with calendars has enabled him to type the months out on the computer, and soon, I’m sure I can teach him more about the calendar and how he can use it. If I had viewed all of these obsessive interests as dysfunctional, or strange, I could never nurture Adam’s potential.

If I have to rely on the DSM IV, I would otherwise view all of this “stereotypy” as dysfunctional because it seems foreign to me and what other children do. Aggressive behaviour is always a function of non-acceptance and often, frustration. When Adam becomes angry with me, it is usually over something that he can’t do when he really wants to – like writing when his hands are not mature enough to hold a pen well. If I choose, as I’ve learned from autistics like Dawn Prince-Hughes, Zilari or Donna Williams, to understand Adam’s learning style, his perceptual differences, his processing differences, and his sensory differences, and respect them, I come to learn how unique he is and this stuff doesn’t seem that odd at all anymore. Sometimes, we just have to go into someone else’s world to understand them. I try and do this with Adam every day and I believe it can be done in every world, one that seems even more foreign than Adam’s.

Acceptance is a commitment to your child. To love them forever, to find joy in them, to believe that they have every ability to learn. If we believe this, we can begin to build and provide the supports they need to achieve. Without it, our children will forever be subject to discrimination and closed doors. A pill won’t open them, I assure you. Autism is forever.

To walk in another man’s shoes always leads us down the road of compassion.
Awakenings

Adversity’s sweet milk, philosophy.
William Shakespeare

Awakening is process. Some people stay asleep their entire lives. Others have mini-awakenings and slip back into old habits and ways of being, simply because thinking outside of boxes seems impossible, and still others have major awakenings because of what life thrusts upon them. Whatever the cause, whatever the means, the point is to wake up.

This past week, I’ve had a series of conversations, with different people I know well, who have raised questions in me on how to advocate for autism, as it is most complex and challenges our everyday notions of how we live and raise our children. It also raises a personal issue in me about the meaning of friendship. A while ago, I wrote about advocation as the Sledgehammer and the Song, stating we need both styles in advocating for the rights of the disabled. Back then, I was taking a softer stance, trying to be the song, and others with autism challenged me in a positive way. My awakening can be read right here on this blog, in black and white. Awakening begins with an agitation that something is not good enough, and the process of action takes a little longer to develop.

I’ve been gentle with friends who have hurt me with what seemed like harmless comments. Afterall, there was a life before Adam, and that kind of talk didn’t bother me then. Isn’t the onus on me to maintain the friendship as is? I’ve had to think long and hard about that one before writing about events that have shaped our family journey with autism. By my 41st birthday last week, I decided that life is too short and that honesty and writing my story is an important process for me and for others. It is also important to figure out who will continue to stand by me in these important moments that have come to define, in large part, who I am. If I continue to call people “friends,” and I give my time and my heart to them, then I need to make sure they know for what I stand. I like to think that if you are honest with someone, the truest friendship can spring forth, if of course, the person wants to stand with you, and we are all willing to listen to each other. I suppose if I am honest with a friend about how I feel their comments and behaviour have effected me, it means that I believe that that friendship has a possibility to grow into something much more
profound. So too, I am open to hearing about all of my follies as much as another lovely friend lifted up her arm in mock breast examination mode and laughed, "Oh no! I've just found an emergent ideology!" It was funny and while I wouldn't call these ideas a cancer, I do claim they can often be more cumbersome than my monthly PMS.

"Trouble is part of your life, and if you don't share it, you don't give the person who loves you a chance to love you enough," said Dinah Shore. I like to think that autism isn't trouble, but it is a fundamental shift in the way I've come to live.

Time has a lot to do with shaping opinion. It is doing a lot to slowly change the attitudes of people towards disability. In a conversation with a family member this past weekend, it left me considering the reality that advocates and people with disabilities are facing.

At a party on Saturday night, I grabbed my crantini, enjoying the people and approached a familiar face. She asked me what I was up to, and to be safe, I said “a little bit of this, a little bit of that,” shrugging it off as mindless party babble. I mean, I don't want impose my "emerging ideologies" at every single social event. Even I need a reprieve! But she probed me a little further, and asked if I would be organizing another exhibition. She got me going about the Canadian Autism Acceptance Network, the organization I am in the process of establishing to organize lectures and events that will change the message that autism does not necessarily need to be cured, but rather, needs to be supported and accepted.

“Why wouldn’t you want to give Adam a pill to cure his autism?” she looks at me as if I am a crazy, irresponsible parent. “To me that seems ridiculous,” she scoffs, drink in one hand, her other hand dismissing me with a quick flick in the air.

“It is not for me to decide. It is up to the person with autism,” I say. “People with autism say they do not want to be cured, they want to be accepted as they are.”

“Well what about the people who can’t decide? I think it is up to the parents,” she sums up quickly. “The child should not be a burden on the rest of the family.” I am not making this up, folks.
I am taking a couple of big swigs of my crantini and turn to Henry who is signaling me to cool down, knowing how passionate I tend to get. “Get me another would you?”

Her face is becoming ascetic, and she is on the attack. “It’s fine for you, you have the means to help Adam,” accusing me of sufficient resources, which translates into more respite, I suppose. “Consider all those people who don’t have the money to help their children,” assuming that they even need the kind of “help” she is inferring.

Of course I have to assume this family member possesses the following presumptions: that I hand over Adam to others, and that raising him is not an active process for me and, that other parents who have less means are incapable of raising children who are not “normal,” or more appropriately stated, challenged, without listening to hundreds of countless stories from them and the daily work they do. Like many of us who do not have to actively engage, she is full of arm-chair opinions.

I slowly begin to draw my sword, as her words have wounded me and I’m not one to cower. “That is why we need to fundamentally change attitudes about difference, so we can get supports in schools, in places of employment,” I try to say calmly, failing miserably, as the pitch of my voice gets a little higher and more intense.

“She said to my face. I manage to compose myself enough to think of a respectful response despite the kick in the stomach she just gave me.

“That’s a problem,” and then I get nasty, “because my kid just might be smarter than your kids,” ouch, really low blow. “I’m sorry,” I backpaddle quickly. “It’s just a point, I’m not saying your kids aren’t smart, but I believe it is a right, and is a necessity to mix people of differences so that we can transcend that kind of attitude.” My face is visibly red. She is saying, in essence, that Adam needs a pill to be cured of his autism, that I am an irresponsible parent for not wanting to cure him, and that people with autism should be aborted. She further assumes, perhaps, that like her, I am a couch philosopher, whose opinions come out of nowhere, and I don’t spend countless hours researching and thinking about this.
“I think people should be able to abort if they learn of disability or autism,” she starts again. “I believe people should have a choice. There are families who fall apart over these things.”

“I agree, there are some families who fall apart -- with these things and many other things, and in our culture, it seems ludicrous to not say that choice is a right. But I don’t think there is enough information about what the choices are.” When I was shuffled into a genetic counsellor’s office, they told me the stats, but not anything about what quality of life I would have. I assume also that most people out there fearfully believe that one’s quality of life disappears after having a child with a difference. If I had been told autism when I was pregnant, I wouldn’t have known about the unique gifts and changes in my life that have resulted in Adam, and sadly, he may not be with us today. At this point, I would not change a thing accept the attitudes of people who will effect his life.

At another party, a friend asked me “Okay, people who are high-functioning say they don’t want to be cured, but what about those who are low-functioning?” This is a friend who always asks me frank questions, but I really want to correct her about the functioning issue. While in reality she is right, there are people with more and less handicaps in society, the issue has nothing to do with one’s personhood or inner life or level of intelligence. If we are going to define disability into spectrums, let us do so only in the name of providing supports.

“Some ‘low-functioning’ people are actually not what you think they are.” I am agitated with my own answer. It seems to be the only way I can segue into the tougher issues of simple acceptance, no matter what level of disability we're talking about. “If they find another means to communicate, like typing, you will discover that despite the challenges, they too do not want to be cured, but just accepted and supported for who they are. Also, a lot of issues you think are autism, aren’t autism. There are co-morbid issues like epilepsy.” But I haven’t gotten to the crux of the matter, and I do not know what it is like to be “severely” impaired, either. I only read the materials by those who are, and meet them, to learn what it might be like to be them.

In terms of advocating for autism, making way for the final point,
making autism more acceptable is how it manifests, and usually peters out there. “Einstein had autism,” is not intended to make Adam and people like him more acceptable to a society that has difficulty thinking outside the box. It is to say that there is so much human potential that remains untapped because people with disabilities are not presumed competent – they are judged for how they look, how they behave, and what they cannot do. If we continue to do this, we may be getting rid of all the Stephen Hawkings’ of the world. Likewise, those who are not like Hawking have a right to be here and have a right to find ways to enable their Identity and find personal fulfillment. I am a believer that just because one is severely disabled, doesn’t mean they do not deserve to have a full life. Certainly, the onus is on the society-at-large to ensure that they can have it. For the rest of us, the assumption that they, the severely disabled, feel nothing but pain or are unaware and therefore sub-human, is a terrible assumption to make.

Yet another friend this past week read my blog and accused me of self-pity, despite the posts “The Economy of Pity” and “Now What?” I found that accusation a little surprising, actually. This is not a move to seek vendetta for any previous comments that may have hurt me. Instead, this is a dialogue that means so much to me, my son and to others. The point is to have others consider their embedded views and assumptions about disability. I retaliated in an email stating that accusing me of self-pity is like saying the Jews victimize themselves when they raise their own human rights issues and anti-semitism, no different than women complaining about their equal rights, and not so unfamiliar in the example of African Americans fighting white oppression.

Most people would prefer to sit comfortably visiting exhibitions, to view ability, savantism – the sensationalized view of the autistic so that it is at least understandable, dare I say, palatable. They would prefer to be inspired by my words of ability instead of suggesting that we all have to look at ourselves, our collective history, and how this effects our thinking and way of living. The latter requires active engagement by people never wanting, or needing based on circumstance, to actively engage. When another party, the Jews, the blacks, the gays, impose their desires as a community who feel entitled to the same respect and civil rights, and it touches us in the sense that we will be effected in how we live our own lives, where our money goes, and the semantics we use, many of us jolt.
negatively. The former method of advocacy, the more passive approach, is an easier one where one has to do nothing and the onus is on the disabled to prove themselves worthy to co-exist in a society dominated by so-called "normal" people.

There are inherent dangers purporting this kind of safe message so we don’t offend others. Yet there are millions of people who are differently-abled, who deal with prejudice and sereptitious, or “unintended” discrimination and prejudice every single day.

So I’ve taken my “awakenings” public. I consider every single day in whose name I do this -- if it will positively or negatively effect Adam. I’ve come to the conclusion that an awakening is a call to act. It is a moral obligation. Instead of confined within the walls of academia, universities, we need take the issues to the street --the reformed eugenics movement, medical genetics, bioethics, and the idea of perfecting ourselves -- all of this needs to be considered in how our endeavours in the name of consumerism and progress are still aimed at perfecting the human race. (Joan Rothschild, The Dream of the Perfect Child):

“By mid-twentieth century, eugenic discourse had shed its racist rhetoric and supporting genetic justification, thanks in part of evolutionary biologists and the realities of a post-Holocaust world. The movement gained a new respectability and was recast in positive terms, as seeking to improve the entire gene pool and de-emphasizing the coercive measures central to the old eugenics. A reformed eugenics rediscovered the role of the environment, which was joined to biology to bring evolution back into perfectibility discourse. But perfectibility discourse, as redefined by the scientists and reformed eugeniscists, still sought to use genetics to control procreation, now extended to control cultural evolution. The new eugenic rhetoric, however, had little connection to medical practise. It was not until medical genetics developed as a clinical specialty in the late 1950’s, providing physicians with new tools to identify and help prevent disease, that the door opened to introduce eugenics into reproductive practice. But, by the 1960’s, a new generation of doctors did not have a eugenic agenda. The irony was that, just as even a reformed eugenics lost its following, reproductive medical practise gained the tools to mark and weed out the imperfect, according to medically defined criteria.” (The Dream of the Perfect Child, p.52).
Let me move to *Orange Life*, a magazine distributed by Canada’s national newspaper, *The Globe and Mail*. The magazine is about fashion and beauty and dedicates a few pages to un-cited statistics, splattered artistically over its pages. I read the stats, thinking about the ideas of late, and one in particular jumps out at me: “1 in 10 would abort a child if they knew it had a genetic tendency to be fat.” Then another, “80 to 90% of women dislike the size and shape of their bodies.” “Canadians spend $5.3 billion on cosmetics annually.” “Americans spent just under $12.5 billion dollars on cosmetic procedures in 2004.” “Young girls have indicated in surveys that they are more afraid of becoming fat than they are of cancer, nuclear war or losing their parents.” This list goes on, within these glossy magazine pages that spread out pages of thin, lanky models with perfect skin anyway.

In 1947, *The World Health Organization* defined “health” as coextensive with quality of life. Health was defined as “not merely the absence of disease, but a state of complete physical, mental and social well-being.... That definition which set no limits on the scope of health policy or health care, was widely criticized and, though it remains a piece of interagency political rhetoric, plays no scientific role even at that WHO.” (From *Quality of Life and Human Difference*, David Wasserman, Jerome Bicekenbach, Robert Wachbroit). The authors argue that this definition assumes that the lives of people with disabilities is of low-quality -- that the treatment [by WHO] of the personal and social challenges of people with disabilities and health problems creates a demeaning impression of the impact of impairment. It is the basis for the “pro-choice” movement, as people assume it is “cruel” to bring a child with difference into the world, and that their quality of life is significantly impaired. Ultimately, the source of genetic research and identifying human genes is to reduce the cost of supports for the disabled, in the environment, in the schools, in the workplace – and therefore, to create a perfect, selected race.

I can’t tell you how many parents, friends, have said just as matter-of-factly to me that they don’t see how children with disabilities can be integrated with supports in schools with *their* children. “It’s too expensive... it will require too many resources... teachers can’t handle it,” are common arguments I hear. In fact, as my family member said to me, most people believe that the disabled will pull their own children down. Yet, not everyone will
I argue that we will achieve a more compassionate race. I argue that these ideas of success and achievement are limited, and people need not fear people of difference. Fear is best killed by familiarity, I always say. I argue that we all need to reconsider, as parents and people with disabilities or not, what quality of life really means and how we want to re-define it for future generations.

Near the end of the party and my week of last, I thought of drinking my worries, and all this adversity away. Then, I had a conversation with a family friend who has a child with Cerebral Palsy and it was like meeting with an old friend bathed in sunshine. Once you have a child with a challenge or “handicap” (a handicap means that the source of the problem is in the environment, not the person. It means that if I have hurt my leg and it is a requirement that I climb a staircase without a rail, I am handicapped), there is an innate understanding between people, who accept and love their children for who they are amidst a society that doesn’t. Not all parents do this, but there are many I have met who do.

“How do people’s attitudes about disability affect you, has it effected your friendships?” I ask her.

“You get used to it,” she says. “Some friends will stick with you, others can’t handle it. You end up making new ones.”

“Hmmm,” I nod knowingly, cradling my last martini of the night.

“Last year P had a series of bladder infections because her teachers didn’t take her to the bathroom. We had to ask them to take her and now her infections are gone. They just assumed she didn’t have to go, but she won’t make a sound or verbalize unless you ask her. Advocacy becomes part of your everyday life.” She purses her lips and smiles. There is a little bitterness in the journey to acceptance as our intolerant society inflicts the exhaustion.

“She has such a sense of humour, P,” said the mother, "She’s wonderful."
I am not just a parent with an opinion. I am a parent listening to people with autism, listening to them to guide me in the process of raising Adam, and in the very messages that need to be heard about good and bad science, how to teach, how to parent a child who feels and perceives differently from me, and who are defining what quality of life means for them. I like to think I have an informed and evolving opinion.

I ask all of my friends, even those with countering opinions, just to come and listen. This is not an attack. We are all at different points of awakening. It’s a process. There is a community of differently-abled people who want their “label,” their handicap, their disability, to be as commonplace as saying someone is black or white. The only purpose of the label should be to acquire the supports one needs to function and be accepted as just another human being in this world.

“Are you Estée?” a woman with a warm face approaches me on the dancefloor.

“Yes.”

“I just want you to know that your name came up in my book club when we were reading *A Curious Incident of the Dog in the Nighttime* and someone suggested that we read your blog.”

“Really?” I am dumbfounded and a little tipsy from the three martinis I’ve downed with debates.

“I want you to know that I really enjoyed reading it. It is really important what you are saying.”

Now that, my friends, is the reason for all of this. Cheers and good-night.
bacteria that tooth brushing, flossing and flouride treatments just
couldn't beat. We arrived, and experience a little from last year's
ear tube implants, I must say the hospital staff accommodated us
beautifully. A little bit of advocating for Adam's special needs really
went a long way....

Adam has gained, quite justifiably, an incredible fear of doctors and
their gadgets. Forget the dentist. He won't have anything to do
with him anymore. Last week's visit to his pediatrician resulted in
screaming, tearing out my hair, and yelling to the doctor "go away"
repetitively. All of these events lead us to decide that it was better
to give Adam general anaesthesia to get a lot of needed work done,
than to subject him to a series of dental appointements.

To prepare, I called the anaesthesiologist a week in advance. I
asked to be in the O.R., and that Adam be given a light sedative so
that he wouldn't panic once he had to have the mask. I asked that
I be in recovery before he awoke so that he wouldn't panic and
scream like the last time -- I don't know how he perceives things
when he wakes up. At first, when I advocated for Adam, there was
some hesitancy. I needed to tell the woman that Adam was autistic
and recently developed a severe fear of doctors. Subsequent
questions proceeded -- was he "high or low functioning?" she
asked nicely.

I said he was autistic and there was no such thing as high or low
functioning -- I felt that I needed to stay with the facts that I
knew: that he could talk a little but in a circumstance like this may
not talk at all, that he would scream if they tried to pin him down,
that he would resist everything and would need extra time, and
require sedative before anesthesia. I asked that the crew talk softly
to Adam and not raise their voices if Adam resisted. I mentioned
that Adam panicked the last time he was in the recovery room and
that it would be best if he could see my face when he awoke.

"It's scary for all kids," she said.

"I'm sure it is, but we can't honestly say that we know how he
perceives the experience and if he is extra disoriented," I replied.
"I feel it is important to support him and make sure he gets the
accomodations he needs."

After half an hour of requesting, the very pleasant woman said she
would do everything she could and even came to the waiting rooms to meet us today. I had a chance to recap all of these with the head anaesthetist. All of our requests for Adam were honoured and respected, and as a result, this surgery, which took two hours, was much less traumatic than his last one. One might even say, smooth.

In contrast, I saw another autistic older boy today. He was non-verbal but made noises. He kept "regarding" lego pieces, his body hovered into a ball on the floor, after the pre-operative examination -- he moaned in terror and the legos calmed him. He tried to resist as they made him transition from this room to the O.R. waiting room. There were more legos to regard when I saw them there, but I wondered why the same accommodation wasn't made for this child who could not advocate for himself? At one point, his mother grabbed him aggressively by the arm and forced him to put the legos away. I was shocked. These were the obvious means by which he was soothing himself. She looked visibly annoyed with him, but I couldn't tell if she was just scarred herself. You know that feeling when you want to burst into tears, but instead you literally swallow them? Well...

Later, that same boy came out earlier than Adam from surgery, walking with his father, but moaning and making sounds like a wounded animal. The distress was clear enough communication for me. His moans became mixed with cries when they passed the doorway, I could see the son try to burrow his head in his father's chest. The father kept talking to him firmly, "shhhhh, shhhhh," moving his own body away from his desperate son's. Now, all of these observations and judgements are mine, I know. But I never felt so sad in my life for a child. There was a coldness there and I simply couldn't relate.

Adam slept most of the day today and when he woke up, came to
and later laughed a little, I was shocked. All of his back teeth -- upper and lower -- are silver capped. He looks like that guy from James Bond with all the silver sharp teeth!! I knew they were capped afterward -- the dentist told me. He also had two "baby" root canals. Apparently, his teeth are deteriorating quickly -- tightly jammed teeth and this lactobacillic bacteria that don't give his little teeth much of a chance. Thankfully, his front teeth are still white, but let me tell you, Adam's smile is very different when he laughs. I thank God that these are just baby teeth and they will fall out. The silver will likely dull with time and mastication. Yet, I know his smile will keep on shining, even if a little brighter than before.

Now what?

Now that we are all beginning to understand the impact of pity, and the interpretation of actions, what is the right thing to do? As a parent, what is it I'm asking for? It is enough to point out the erring ways of others, but what about the things that others can do for me, or for other parents with autistic children? Here are some things from my viewpoint, and I think other parents should add to the list so that we make a wish-list for our friends who otherwise don't know how, or feel the need to tippy-toe around the issue of autism:

1. Ask a lot of tough questions about autism to the parent who is dying to answer you. (Not every parent is the same, some are in denial about their children's autism). Tough questions, the ones that seem offensive, are actually not because you are asking them with an open heart.

2. Don't pretend the autism isn't there. Some people feel that dealing with something politely is to ignore it all together. This is really tough on the parent of an autistic child. The autism is there, our family lives are different.

3. Don't ignore the autistic child and play only with the other children. There is nothing more relieving for me than to see others
just hang out with Adam, not just talk about him in front of him. Even if the autistic child doesn't seem to be paying attention, the need of the autistic child is your quiet voice, taking their lead, and patience. And if all it is is sitting with the child, either watching them or playing side to side, but not engaging, so be it. Some autistic people explain that being autistic is like being a cat. They like to circle for a long time, and when they feel comfortable with you, they will pounce.

4. Don't talk "dumbspeak" to the child with autism. Don't talk loudly as if they cannot hear you. Just talk slowly, and if they don't respond, don't demand a response. A friend is not a therapist.

5. Autism is not a cold. Don't ask "is he better yet? or "is he making any progress?" The inference is that he is not good enough as he is. If you want to ask about school possibilities or what his capabilities are, then just be frank and ask.

6. If a friend learns their child is autistic, talk a lot about it. Like death, not all people who mourn need or want to be alone. Don't fall silent. It made me feel as if something was terribly wrong and that hurt a great deal and broke my trust to the extent that I clammed up around that person all the more.

7. Don't ever say to a parent "you are so strong to do this," or "the reason you have an autistic child is because God thought you were special to handle it," or "I'm so proud of you for handling this," kind of gibberish. Having a child with autism doesn't mean we are strong or special, it just is. Open, detailed talk is more important than empty praise.

8. Understand that most parents with autistic children live and breath this every day. It may be the only thing they can talk about for a long time. Most people do not want to be distracted from the autism. My distractions are books, travel, movies and academic discussions and debates. But hey, that's just me.

9. Don't suggest that Adam go on the GF/CF diet because you know someone with autism who improved. Don't assume that because you know someone with autism, you know everything there is to know. If you know one person with autism, you know ONE person with autism. Every autistic person is different. If you're going to go on about mercury poisoning, chelation therapy,
ABA, or tell me that you have a friend I should talk to to get more information, take a deep breath and PAUSE. Every parent of an autistic child likely knows more than the person or the therapy you are suggesting and may be philosophically opposed to what you are talking about. Better to ask a question about what a parent thinks about the subject at hand than to suggest it might "improve" the child.

10. Many parents, even the fighters, can become depressed. Depression is not a weakness, actually, it can be a great sign of strength. Many great inventors, composers, activists, writers and artists, have been depressed. It often means that the person can see a whole picture that others may not see. There is the depression of the person who cannot see, and the depression of the see-er. There is also joy in depression. They are entwined. What parents with autistic children face everyday is a lot of bias and discrimination in public places, in schools, even from doctors. We are faced with people who believe that children "get" autism like a disease and hear it in the media everyday. Parents can get confused with so many differing messages about how to help with hundreds or therapies and diets, myths about vaccine poisoning and more. There is no one expert or piece of information that a parent can rely on. Some parents are at a war of belief with each other within the community of autism, whether or not autism can be cured, or an autistic fetus should be aborted when the opportunity presents itself in the future. Others, like myself, believe that autism is a way of being and that these pervasive attitudes are a human rights issue. When our children are denied access to camps and schools, or supports within them, it is an issue of rights...I could go on. Anger abounds and many of us may sometimes come on too strong. Forgive us.

11. Understand that there is anger and then there is forgiveness. I have been angry about that event with the friend, but also acknowledge that to "err is human, to forgive is divine." Some friends can grow past debates and disputes, others cannot. I have made many friendships from disputes (you know who you are XX) to find that many of us are exactly the same.

Ah, the point at last.

I want to be able to help some of my friends with the tough questions, or who are just uncertain what to do with a parent who...
This story goes back to the weekend of November 28th, 2004, the weekend we suspected that Adam was autistic. We weren’t sure on a Friday that we should decline the previous dinner invitation from our friends down the street. We explained what we had just learned and why we were tentative. But these friends said “nonsense,” and insisted we come despite the news. My eyes were puffy, my heart pounding. The news, or discovery, just three hours old. My girlfriend did not try to mask the tension and instead embraced it, talking about the many learning differences of her five kids and some information she gleaned from a paper she did in school about autism many years before. Adam trotted back and forth in their home, exploring rooms and hallways with a nanny following behind – he was a mere nineteen months old. I will remember every aspect of that day from three o’clock on, and how relieving it was that these friends did not stare at Adam or try to mask the issue with fake empathy.

That weekend was really tough. I cried too much, yelled too much.
There was too much advice from friends pouring in like a deluge, and I wondered why I didn’t know about autism before. There was too much information on the Internet, which we scoured the entire weekend anyway. With this type of news, as with any crisis we are confronted with in life, my instinct was “to beat this thing.” Obviously, the early view was that Adam had something, and with therapy and diets, we could overcome it. Since then, I’ve come to learn that autism is not something you have, it is something you are.

Sunday rolled around. We were invited to other friends but by this time, I really wanted to cancel. We should have cancelled, but Henry convinced me that it was good to get out, as Friday’s experience was a positive one, and this would help get us out of the tunnel of despair. We arrived at our friends’ and a playpen was set up for Adam. I placed him in and turned on his favourite Baby Einstein videos. He jumped up and down reciting the alphabet and counted to twenty. Then there was silence. These friends stared at Adam for the longest time, sadness and fear crossing their faces as if they were looking for the defect. Now, perhaps they were thinking, everything was explained. I was enraged. I yelled at them. How dare they stare. How dare they feel sorry for us!

“Oh Estée,” said this girlfriend laced with a bucketful of pity, as if my anger represented my own fear and disappointment over Adam. No, I was angry at their staring, at their new fear of him. I pretended through dinner and cried all the way home. There is nothing more isolating than friends who stare, who believe there is an abnormal, who think it is kind to disperse pity on you. How do you continue to have a fluid relationship with people you can’t be honest with? To this day, I’ve wanted to tell these friends how angry I am with them for not listening, which I interpret as not really caring and I hope this story helps others who are friends of autistic parents understand how pity can be interpreted. I’ve tried to find the opportunity, but some people are just more open than others to these issues, perhaps. There are lots of people with "pity" who will pull out their wallets at the drop of a hat, who will support any charitable endeavour for autism. It is something they at least can understand. It is a tangible way to help. At least they are doing something for this “horrible disorder,” right? Alturism, however, exists largely for ones-self, not for the other. While I searched early on for organizations to support Adam, like NAAR, I’ve also come to learn how many people will not accept autism by
supporting this organization, thus viewing my son and people like him, as an aberration, an illness that must be cured.

The expectations I’ve had with doctors over the years has been fairly high. Since my girlfriend belongs to this profession, I expected more. Yet, even with Adam’s doctors, I’ve always expected that they will understand sensory defensiveness, and take their time with Adam. To my dismay, I am always shocked how they raise their voices like he’s dumb, actually making the whole experience of a doctor visit more terrifying for him, and how they expect Adam to behave the way they expect. I’ve had to educate the "professionals," something I did not expect when I was seeking support for our family.

Expectations. There are a whole lot out there about autism. There are a whole lot from me towards the people I love, which sets the bar perhaps a little too high. It is a problem because autism doesn’t fit any frame, so perhaps no one is right or wrong here. There are many expectations I’ve had to reframe in my own life and the way I look at Adam and the way I look at others. Knowing what I know now, the daily explaining I have to do about autism, I expect people who know me to listen and learn, not to feel sorry for me. I expect them, as this is the most important thing in my life, to help me disseminate positive messages about autism, as I am confronted day in and day out with people who don’t understand, who get their misguided messages from big organizations seeking to cure autism, from television. I expect them to ask me questions if they are confused. I like open, tough questions. I expect that, because they love me, they will understand that my tears don’t come from the fact that Adam has autism, but rather, from the fact that even those closest to me, still don’t entirely get it, or that I have to advocate for Adam every single day – and that can actually be very exhausting. It is exhausting for messages to largely fall on deaf ears, but it is utterly important to keep on trying.

Failed expectations can leave one feeling angry. I am still angry to a large degree because I haven’t been able to tell this person how I have interpreted her pity, or that weekend episode. I am angry that there is so much prejudice in society and I keep trying to dig deeper so that people might see it for themselves, and how views about normalacy and perfection are social constructs serving only to marginalize people like Adam. Failed expectations, however, are
also cathartic and freeing. It means that there are no boundaries and we can, if we choose, transcend all of this.

Don’t mourn for me. Don’t mourn for those with autism. Autism is a world – a netherworld, a place filled with paradox. We need understanding for autistic people as both different and the same; we need acceptance of autistic people as intelligent, but also handicapped in a world that thrives on language and other physical and social functions; we need to provide schools that intellectually challenge persons with autism while providing supports in the environment for sensory needs and different styles of learning; we need you to understand that autistic people see the world differently and may behave differently, but are not to be viewed as a set of behaviours or pathologies that should just “fit in” with the rest of society; we need you to understand that people with autism may appear disinterested but want to belong; we need you to acknowledge that autistic people may want to belong but also need time alone because processing the world is much more difficult; we need you to understand that people with autism want to contribute to society and the rest of us need to support education and occupational opportunities to enable self-esteem and identity; we need you to understand that as a family, the daily structure of our lives is different from yours, but we still want to be included. As a parent, I don’t want you to tell me that I need to go out more, no. I need you to support the work I am doing right now.

No dear friends, if I cry today on my birthday, it is because all Adam and I seek is your unconditional love. It is the only birthday present I want.

PERMALINK POSTED BY ESTEE KLAR-WOLFOND AT 3/22/2006 10:11:00 AM
20 COMMENTS LINKS TO THIS POST

TUESDAY, MARCH 21, 2006

The Archeology of Ideas, Writing and Censorship
Censorship is tough stuff. How much should one reveal or censor a private conversation in non-fiction, or reveal the line of a furrow so deep that my friends would recognize the person in fiction? I recall a course I once took with writers David Bezmojis, John Metcalfe and others talking about this very subject – about using friends and family and people we know in writing, to which the final conclusion was “don’t they know you’re a writer?” In other words, every experience, every conversation, every aspect of a writer’s being and perspective is... “material.” I need not ask permission to write and shape things as I see them. I have a right to see things the way I do. I may wrap someone in another "identity," in the context of an event or conversation to protect that person, but even if I changed the colour of someone's shoes, s/he would know about whom I was writing, even if others do not. The question always on my mind is, if the intent is to further an argument, to shape an argument bathed in descriptions of the experience, how much does one have to reveal? How much truth is there in fiction, how much fiction in the truth? John Metcalfe critiqued my draft book about my experiences and noted that even in a piece of non-fiction, the "artifact" is what's left. The craft of writing, the descriptions of people all have a purpose in writing, in an argument. In writing, both fiction and non, everything is shaped by the perspective of the writer. Further, there is not one fiction writer I've met so far, who does not "use" all the people in their lives to shape their characters.

This blog is about discussing human diversity within the context of acceptance. Once one begins to think about things, to go on the
archeological digs of "why" and "how" and "to what end," it is natural to consider how one lives as a reflection of belief. Every point I raise is something that is on my mind in this vein. Sometimes I reflect on the origins of our current ideas, as innocuous as they may seem, to question how pervasive our ideas of perfection are within this context. Everyday conversations are examples of ideologies, known or unknown. I can’t censor my thoughts or my words and no one should try. Explorations into how we feel, think, and what we do are essential in looking at the complexity of autism.

I’ve had hundreds, if not thousands of episodes and conversations yet to write about in the subject of autism, and hundreds of more personal past "mistakes" in the way I’ve lived which juxtapose my emergent ideologies. I’ve had friends who with the best of intentions, have left me feeling utterly isolated in the way they view autism and disability, the way they disperse "empathy", and the way they look at and behave around Adam -- I intend to write about these experiences in order to continue to promote awareness and understanding. This is important stuff to write about, the meat and potatoes of living with autism. Should I edit the conversations? Censor the characteristics that shaped the experience? The ones that evoked strong emotion in me as I write about my experiences will likely remain on the page.

I may be wrong and I may be right in my evolving opinions, and the importance is in the asking "what does this mean," and "what is the origin of that idea?" Here are some other good quotes on writing I thought some of you might enjoy:

*David Ben Gurion:*  
Anyone who believes you can’t change history has never tried to write his memoirs.

*Denise Levertov:*  
One of the obligations of the writer is to say or sing all that he or she can, to deal with as much of the world as becomes possible to him or her in language.

*Jessamyn West:*  
Writing is a solitary occupation. Family, friends, and society are the natural enemies of the writer. He must be alone,
uninterrupted, and slightly savage if he is to sustain and complete an undertaking.

Ralph Waldo Emerson:
Put the argument into a concrete shape, into an image, some hard phrase, round and solid as a ball, which they can see and handle and carry home with them, and the cause is half won.

Margaret Chase Smith:
Moral cowardice that keeps us from speaking our minds is as dangerous to this country as irresponsible talk. The right way is not always the popular and easy way. Standing for right when it is unpopular is a true test of moral character.

Martin Luther King, Jr.:
The ultimate measure of a man is not where he stands in moments of comfort and convenience, but where he stands at times of challenge and controversy.

As I learned from writer teachers and friends, the stuff of life, of conversation, is material. I do, however, believe in respect. It is difficult to draw the censorship lines in writing.

Epictetus:
First say to yourself what you would be; and then do what you have to do.

The Economy of Pity

My background is unique in discussing the economy of pity. I began my circuitous career as a curator of art, later a director of a large event, then a corporate fundraiser and marketer for two major health charities. I also summarized that art made me an effective beggar of money (not many love to fund art, to my chagrin). After Adam was diagnosed with autism and NAAR came to Toronto, and coming from Jewish family entrenched in the Hebrew ideal of tzedakah (helping those in need), it seemed natural for me to raise money for the cause that was dear to my
At the NAAR Kick-Off Luncheon, I was asked to speak about autism. I sat and waited for my turn as Corporate Chair, becoming agitated already with what I was hearing. I was listening to leaders talk about how they “lost” their child, how devastating it was for them, poems eliciting a tremendous amount of pathos from the audience. In my speech I instead spoke about research to help us understand our children with autism better. I did not talk about cures – I spoke about awareness. It was my hope that others would share the same optimism. I quoted Paul Collins:

“Autists are described by others – and by themselves – as aliens among humans. But there’s an irony to this, for precisely the opposite is true. They are us, and to understand them is to begin what it means to be human. Think of it: a disability is usually defined in terms of what is missing. A child tugs at his or her parents and whispers, “Where’s that man’s arm?” But autism is an ability and a disability; it is as much about what is abundant as what is missing, an overexpression of the very traits that make our species unique. Other animals are social, but only humans are capable of abstract logic. The autistic outhuman the humans, and we can scarcely recognize the result.” -- Paul Collins, Not Even Wrong.

I was approached afterward by educators and parents, who said they thought my speech was the best. While I am a very good speaker, I considered that my words about acceptance was the source inspiration as opposed to those mothers weeping at the “loss” of their children. It didn’t take long – a meeting with Glenn Tringali, a phone call with Alycia Halladay, appealed for my continued support to sit as Chair of NAAR. I remember sitting at The Four Season’s Hotel with Mr. Tringali, saying that if I joined, my mandate would be to raise awareness – the brand that I was selling. I addressed a consideration when Dr. Buxbaum made a quote about being able to prenatally test for autism, and to what end. A snarky email later, addressed to me by Joseph Buxbaum, and no return call from NAAR agreeing to my wish, I quickly realized that NAAR’s marketing appeals are not acceptable, if in fact inflexible. This is not to say I haven’t met scientific researchers funded by NAAR who are themselves questioning the marketing and the research, and in order to protect them I will not reveal their names. Believe it or not, there are scientists out there who have come to the same conclusion that I am revealing here.
Similar to the difficulty of pulling away from ABA to try other methods of teaching Adam, leaving the gods of research initially made me uneasy. After all, what might the research tell us? Who was I, not scientific in the least, to question the gods? Once looking carefully at the bulk of research, I realized that it will go on with or without my support. It doesn’t need me. There are people who will find the genes, who will sell the pills, who will abort the fetus. The only thing I can keep doing, we can keep doing, is to keep talking. Give speeches, make exhibitions, run media campaigns. Did you know that eighty per cent of fetuses with Down Syndrome are aborted? Isn’t that number shocking? I think of little B running down the hall of Adam’s integrated nursery school, a huge smile on her face, living life to its fullest and wondering what is wrong with my wiring that I’ve missed out her type of joy. Having children who are “different” is an unexpected experience, a positive one, and I keep trying to figure out how to impart a message of experience to others who have never had the challenge, and ergo, the ultimate benefit of one.

NAAR recently posted a book about accepting autism on their website. While it’s an attempt, I still appeal to them to change their fundamental error – to suggest that autism requires a cure at the utter dismay and disagreement of those with autism. I’ve asked NAAR to consider giving me an opportunity to voice these concerns, to change their semantics, and to conduct research only directed by autistic persons and to keep one ultimate goal in mind – the acceptance of and quality of life for families with autism as they are. Change, if it happens at all, will be slow. Now partnered with Autism Speaks, NAAR has an annual budget in excess of $30 million, with CIBC World Markets in the US trying to raise more “miracles,” and Home Depot is doing their part donating $25 million to the cause.

I certainly can’t offer a matching grant of that amount to get NAAR to listen to me, but I am a parent who “can speak up for my child,” and do so by listening to others with autism as well. I can’t compete on the same playing field with cause-marketing thrusts to make companies appeal, with their good intentions, to customers. What I suggest companies are missing is a due-diligence. Do they know what brand of pity they’re paying for? In War Against the Weak, Edwin Black writes about the first three decades of the 20th century when American corporate philanthropy “combined with prestigious academic fraud” created the pseudeoscience of...
eugenics that “institutionalized race politics as national policy. The goal: create a superior, white, Nordic race and obliterate the viability of everyone else....How? By identifying so-called ‘defective’ family trees and subjecting them to legislated segregation and sterilization programs. The victims: poor people, brown-haired white people, African Americans, immigrants, Indians, Eastern European Jews, the infirm and really anyone classified outside the superior genetic lines drawn up by American raceologists.” We always have to ask ourselves what is the end to this means of genetic research. Must we simply accept the good with the bad in the name of progress?

War Against the Weak By Edwin Black discusses how American corporate philanthropies launched a national campaign of ethnic cleansing in the US.

It seems to me, after having made hundreds of solicitations to corporations myself over the years, that no one thinks twice about the brand of pity they disperse. Pity is one and the same and it just makes us plain good. There is little discrimination going on the world about who is soliciting for what. So long as the message is filled with a little bit of logos and a whole barrel of pathos, the cause is whitewashed under the guise of “doing good.” It is a problem with altruism, actually. This is how Nietzsche felt about so-called ‘benevolence’:

*Is it virtuous when a cell transforms into the function of a stronger cell? It must do so. And is it wicked when the stronger one assimilates the other? It must do so likewise: it is necessary, for it has to have abundant indemnity and seeks to regenerate itself. One has therefore to distinguish the instinct of submission in benevolence, according as the stronger or the weaker feels benevolent. Gladness and covetousness are united in the stronger person, who wants to transform something to his function:*
gladness and desire-to-be-coveted in the weaker person, who would like to become a function. The former case is essentially pity, a pleasant excitation of the instinct of appropriation at the sight of the weak: it is to be remembered, however, that “strong” and “weak” are relative conceptions.”

Therefore, the whole idea of charity segregates people into strong and weak and forever keeps the “weaker” members of society at a disadvantage, serving only to marginalize them. On the other hand, where would the Stephen Hawkings of the world be without the help, the selfless behaviour, of others? Love from his caregivers was what kept him alive, and archeological digs have revealed the remains of people who evidently lived for long periods of time being crippled.

I will posit here, in this initial draft, that Autism is the one “disability” that may change the course of philanthropic history, that may be able to jolt citizens into giving with knowledge as well as with heart. Autism is neither a race nor a disability, it is a way of being. It may even be viewed as a course of human evolution, and most illustrative of all human difference. On the surface, it appears alien, and from within people with autism maintain huge capability and intellect, often able to communicate themselves through alternative means, if presumed competent, if given the chance, much like Stephen Hawking. Organizations that seek to fund this “difficult and mysterious disorder,” to "cure it," as a war waged against the autistic population, instead of listening to them, may become baffled at the ability of autism, despite its superficial dysfunctions. It is finding itself at an intellectual and philosophical divide with those they are seeking to cure. Parents are baffled, or angry. Afterall, aren’t they just good people trying to help others? Shouldn’t parents who struggle day in and day out, whose expectations have been taken from them, have pity bestowed upon them?

I say no. I say that as difficult as it is for many families, who experience a "spectrum” of challenges, this is life's test. "The best thing about the future," said Abraham Lincoln, "is that it comes one day at a time." We have time to reframe our expectations and to find joy in autism.

Corporations, innocent and unknowing of this divide and the abilities of those with autism are giving money – perhaps one day
to find themselves confronted with violations against human rights. I don’t think they are prepared. People with influence (those in control of the media), appear shiny and credible in the eyes of fellow CEO’s. Logos – the rational appeal of statistics and numbers manipulated for Pathos is the thrust of this economy. The most “underfunded disorder,” “1:166 children affected,” mixed with a little “epidemic” lingo is enough these days to convince a CEO to give. On top of that some media profile, signage and press releases for being a “responsible corporation” -- another rational and economically sound reason to give.

Autism requires donors to do their research. It requires others to talk to people with autism as the experts of it. It requires philanthropists to fully understand the motives of charities asking for money for the sake of a cure.

"Autism is finally speaking," says Suzanne Wright. "Now the world will listen...Be loud, be brash, be emotional, be angry," added Bob Wright.

"Don't accept it," Ms. Wright continues.

Yes, Mr. And Mrs. Wright. Autism is speaking. But not through you.

PERMALINK POSTED BY ESTEE KLAR-WOLFOND AT 3/19/2006 11:35:00 AM 26 COMMENTS LINKS TO THIS POST

SATURDAY, MARCH 18, 2006

New Identity?

In the name of quasi-anonymity, of standing up by hanging low, similar to registering for votes, but never talking about a stance with colleagues and friends, I belligerently make a comment about the need to hide ourselves in order to protect others. A reality perhaps, but a shame indeed.
Anonymous Critics

I have an anonymous critic. It's not that worry about different opinions. I have to wonder, however, about the validity of anonymity online. It has raised a whole lot of issues in my mind about debating on an even playing field.

I find this anonymity fascinating. I have to wonder who and why this person wishes to state their opinion without revealing themselves. Afterall, this a respectful dialogue. We fellow bloggers respectfully disagree with one another. Thank heavens for opinions, for the ability to learn from one another, and in the words of a blogger with whom I had a heated debate once, someone I came to admire, to have a opportunity to “stretch ourselves.” Inflexible opinions are not healthy – the ability to empathize with one another is our ultimate goal in the name of human rights.

I suspect this anonymous person has written me before, expressing some opinions about me in the past (if it’s not you anonymous, I’m sorry, but how can I know?). I asked the person, who spoke of me as if they knew me personally to “come out of the bushes of anonymity.”

Anonymity reminds me of the cowardice Nazi youth who slithered into Jewish graveyards to desecrate them in Toronto two years ago, to hide in the night to paint swastikas on the doors of Jewish homes. The Internet is also a scary place. People don’t have to be
true or real. They can put on personae, lie about their identity. I often wonder about this when I am blogging to personae instead of "people" and I think it's something we all ought to consider. If we don't set a precedent here, to reveal our identities in these important discussions about human rights, then is there a point to the Internet, to the Blog?

Consider another couple of quotes I pulled from the Internet:

"Looming as the new preferred method by those who seek to diminish the quality of life of Jewish Australians is harrassment through electronic mail. The Internet has made it easier for individuals to be anonymous, reach large audiences adn operate with very little expenditure..." From Sticks and Stones and Hate Mail, Australia/Israel Jewish Affairs Council, 1999.

I think of Anthrax, and the surreptitious acts of terrorist organizations that veil themselves in anonymity.

Here's another comment on Internet communication:

"All the same, I believe that the most tragic outcome of promoting sites like Keen.com is that it will only foster even more sterile and untruthful interactions between human beings...If people mistrust each other so much that they're afraid to reveal their email addresses and phone numbers, why in the world are they bothering to talk to each other in the first place?" From E Commerce News Internet Anonymity Promotes Cyber Cowardice.

"To be one's self, and unafraid whether right or wrong, is more admirable than the easy cowardice or surrender to conformity." -- Irving Wallace.

As Ghandi alluded, the point of sharing opinions is to see ourselves, the err of our ways, to see others, and to better mankind:

"It is good to see ourselves as others see us. Try as we may, we are never able to know ourselves fully as we are, especially the evil side of us. This we can do only if we are not angry with our critics but will take in good heart whatever they might have to say."

Still hope you, anonymous, will join us for all you are, in the comments section.
THURSDAY, MARCH 16, 2006

**Don't Get Too Cheeky**

Okay, you've all seen the inevitable materialize. Autistic basketball player goes to Hollywood. Don't get too cheeky, don't get too critical...we still need heros. I like the fact that he says that he is just who he is. The last line in the article says it all, doesn't it?

If he didn't get this publicity, (and yes, there is a lot more to his story than a two minute frame), the world might not be seeing the positive, way of being, aspects of autism. A Hollywood story isn't always that bad. The public really does have a TV attention span, you know.

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**What's in a Name?**

Well, it's happening. I've begun incorporation for Canadian Autism Acceptance Network -- C.A.A.N.

The organization will be the umbrella under which the exhibition and lectures this October will be organized -- for the purposes of raising awareness about the need for acceptance of autism. The organization will not advocate for a cure. It will support research only directed and requested by autistic persons. The primary goal of the organization will be event and media driven. Participants in this year's exhibition who are confirmed are:

- Donna Williams
- Michael Moon
- Dr. Nehama Baum
- MukiBaum Centre for Complex Disabilities
- Jonathan Lerman
- Caren and Alan Lerman
I also have a list of prominent unconfirmed participants, who should be confirmed shortly.

I am looking for Canadian autistic persons to consider joining the board. Please send letters of interest to:

**estee@wolfond.com**

**THE DIFFICULTY OF KNOWING**

There is an old adage: Ignorance is Bliss. In the case of liberal eugenics, human genome research and ethics, some people might think this as they read on. As we come closer to discovering what makes us physically human, we come closer to becoming god-like. In the name of progress we fly higher and seek control. Apollo had a son called Phaethon, who was human. Phaethon nagged at Apollo to let him borrow the sun chariot and fly across the sky. Finally Apollo agreed. Phaethon proudly drove the sun chariot up into the sky, but then he lost control of the horses. The sun chariot dived towards the earth, burning everything. Finally Jupiter had to stop him with a thunder bolt.

In the name of progress, human genetics, biotechnology and the economic engine that will profit dearly from it all, this movement will go on. To what end is yet to be determined. In the meantime, let’s keep talking about what this all means as my son hugs me from behind with his cherub smile this morning.

I’ve been pondering my first pregnancy with Adam. The expectation of him. Needless to say, after thirty-six years of waiting, I was ecstatic. I was in Barcelona when I found out, unknowing of the apparent irony of Gaudi’s warped buildings, Dali’s surrealism – beauty born from “juxtaposing unrelated systems and altered established visual order.”

When I came home to Canada was when my apparent joy was met with foreboding – my first ultrasound and nuchal screen and then shuffled in to a genetic counselor’s office to talk about the 1 in 244
chance of giving birth to a child with some kind of genetic defect. I think they told me what kinds of defects, but the discrepancy between them obviously meant nothing to me because I can't remember. That was like throwing a bucket of water on my flame. Not having children before, I had no idea I would be subjugated to a tiny office with a stranger giving me statistical factoids – whose supposed disengagement angered me. In fact, I remember feeling pressed, asking questions of what it all meant...I just remember that severe countenance giving me probabilities devoid of empathy.

I called my obstetrician and asked him what it all meant. Did he or did he not feel that from my test results I was going to give birth to a defective child? He tried to root himself in statistics, reserving himself to the facts instead of any judgment. I searched for a tone of voice that might allude to an opinion. I found myself in an unexpected ethical debate with myself – strewn into a situation of making prenatal decisions about my child that I was wholly unprepared for, and in fact, given a choice that I never asked to have.

I felt jilted out of my joy. The news of risk not sobering, just agitating. It was overwhelming information. I did not know what to do with it. If I wasn't so excited with having my first child, would I have listened to that counselor and aborted? I did not have the amniocentesis. Sheer excitement and determination was the force behind the birth of Adam.

Doctors, geneticists and genetic counselors are trying to remain in the neutral ethics zone. Remembering the false neutrality of that counselor, how I was shuffled into a genetics counseling office without given the choice, the warning of what that was going to be all about, I consider that the scales are tipped against this whole movement towards the rights of the disabled, and for that matter, the fetus. It is said that The Human Genome Project will identify over 100,000 genes and diseases without cures over the next ten years. I think it is obvious to state that ethically, we are not ready for this. What do we do with all that information, all that choice? There is difficulty in knowing.

I take these thoughts to daily life with friends. I know a dermatologist, working with people's desire to transcend time, people's vanity. I remember once how she considered to pin back
her son’s ears for fear that he might be ridiculed in school. Of course, readers who know me will understand how absurd I feel this procedure is in the context of human difference. Let him have his ears, I say! Let him exult in his uniqueness! Yet, I know she is trying to protect him, as all parents are inclined to do. What cost is her seemingly innocent motive to “protect” her son, to the rest of us who fight furtive discrimination every day? Discrimination is so deeply rooted within us, perhaps within human nature itself, that we must tear down concrete walls with bare hands.

There are many people who put their children on Ritalin because kids simply cannot not perform in school or complete their homework. The Ritalin “is amazing,” they all say. “Joe’s [made-up name] teachers have said he is doing so well.” The teachers are satisfied that little Joe doesn’t act out in class anymore, now uniform and compliant, I suspect. "Joe" can now focus on what he has to do, I'm not saying that in itself is a bad thing. Parents are often left with no other recourse. What I am saying is that it's a shame that the "system" won't accept him for who he is. A friend asked me once “what if there was a pill Adam could take...” Ah, that thought was for a moment, tempting. I could escape all my worries if Adam’s autism could be cured by a little pill, right? This is an excellent question. What if? Would I stop this rampage about discrimination and eugenics if Adam were, all of a sudden, normal? After all, what would I have left to fight for?

Little pills, escape from any kind of struggle or pain, is all too tempting, I might speculate, for all of us. What kind of absurd world might we have if we were all operating on even-keels, on pills? (I always tend to use Ritalin as an important part of this debate). I think of a Stepford Wives world here. Within the “normal,” rigid classroom, a child who acts, or thinks, outside of the box is rejected. I must admit that to undertake the alternative, to stand up against the school system is a difficult and time-consuming undertaking. My friends do not willingly choose the path of such resistance, nor are they in a position where they need to. They are extremely intelligent and hopefully will recognize the importance of this posited argument.

I have a big reason to be concerned. My father was a victim of the Lebensborn movement in Germany, and if not specifically bred for Nazi parents, he was stolen from a Polish or Scandinavian family and put into a German one in Breslau “for his Arian features.” As a
result, he had a difficult relationship with his parents and after coming to Canada in 1952, left his parents at fifteen, the pain of being any part of Nazi Eugenicism a complete repulsion to him at that young age. He tried to convert to Judaism. His daughter brought that realization full circle as he now has a Jewish grandson.

I am considering today how the Eugenics Movement has too much steam in its disguised innocuous research, and ideals that can be traced back to the universal worker of Karl Marx, who sought uniform and idealistic physical traits of workers, for the sake of the nation.

Just how much do we conduct science for the sake of mankind? Or is it the quest to be like the gods? What drives us in these quests? The greater good, or control? If we want a greater good, we always have to take the other, more unpleasant side or progress. We also have to understand that all words may sound the same, but have entirely different meanings.

I am certainly not saying that most people are evil or have evil intent by actively participating in cleaning up the human race. I am not accusing parents who give their children Ritalin or consider pinning back their ears for aesthetic reasons. I am suggesting, however, that the pressure to belong, to fit in this "normal box" is immense. I am also suggesting that wrapping up language and intention in palatable words, ones that seem to be harmless, or disguised for the greater good of humanity, may in fact be just the opposite. Hitler's propaganda promised a better Germany – more jobs, economic stability. You can wrap up intention in all kinds or good words, but it doesn't mean the same thing.

In looking deeper into my social responsibilities, in putting some intention and action behind my beliefs, I have to reconsider the rights of animals, the rights of minorities, the poor. I can't sit back and scratch myself debating this intellectually as I sit comfortably in my chair. I am considering how I can best participate. I am incorporating a Canadian organization which will deal with acceptance. Yet, I consider that as the years progress, this will evolve into an organization to undertake political action. It is unknown territory for me (any words of advice are welcome at this stage). Let me begin with incorporating and organizing the exhibitions and lectures this fall. (help me with the name please – I
We didn’t make it to Vail. Life intervened. This time, with a flu bug and a nasty fever. Henry and Max have gone ahead, leaving Adam and I alone this week to get better and perhaps discover the unexpected.

There are a few things going through my mind -- a luxury of unscheduled, impromptu time. I am going to be 41 next week. I have two frames of mind right now about growing older:

1. I’m not really ready (or am I?);
2. Let the wind blow where it may (this thought takes a little for effort).

Children punctuate time. Before Adam, I was husband-less and free, for a time. I met Henry with four children and that stopped this nomadic existence -- moving senselessly from here to there. I could forget about obligations when the kids were not with us -- we had them only part-time. I got married and had my first child...
at 37. The mind-clock began here. Time is always felt most dramatically in connection with birth and death. On Saturday, I chatted with Henry's 92 year-old grandmother. "Where does the time go?" she asks. Adam will be four in April. Where does the time go? It's been two years since his diagnosis. Where did that go? Perhaps it is good to remember that the grim reaper looms not too far off in the distance, that time is a huge train station clock hovering over our heads.

My favorite clock at Musee D'Orsay -- Henry, Joe and Max in the background.

We can measure it, forget it for a while, melt away within it, distort it, but time will keep on ticking. Time, it's the only thing we really have -- it cacoons my mother who has struggled with two bouts of cancer, carrying her fragile body, for now, with grace. It wisps around my father whose spirit remains timeless, but peppers his blond hair with grey, freckles his Nordic skin a little more each year. It has made its first sinister introduction to Henry in his aching hands, and me, while I don't remain unscathed, untouched by time, I hear it brushing against my door, scurrying busily about the neighbourhood. I watch as it nears my bell -- all too aware that it is coming close. If time is the only thing we really have, let it be full of events, people, places, moments, and joy (we can feel joy only in the presence of its counterpart: pain). I cannot fathom a life without time framing it, without beginning, middle and end. Henry does not like to think of the end and would take the immortality pill if it were ever available. I suppose I need clearer boundaries.

I've been re-reading comments on my blog. I enjoy re-reading well-thought out comments. In my post The Lonliness, The Struggle and the Profound Joy of Autism, Lisa Fischler said...

I highly recommend the book "The Spirit Catches You and You Fall Down" which is the story of a young girl with
epilepsy. The book deals with issues of how we define illness, quality of life, adequate treatment, etc. according to our cultural beliefs and practices. Many cultures don’t tolerate disability of any kind, but some consider it to be part of human nature and are able to see what is special and, more to the point, human about those in their midst who are a bit "different".

Maybe it’s because we are so obsessed with success that we have a hard time appreciating what is joyful and worthy in any life, even one that is painful. Westerners have an aversion to difficulty and pain, to the point where we can’t understand why someone would "want" to suffer - which is odd, considering that suffering was once taken to be noble and spiritually uplifting in Western religious traditions. I personally found a lot of value in a spiritual path that teaches that we don't have to "do" or "be" anything special in order to fulfill our life's work - that just sitting and breathing, or whatever you’re doing, is "enough". Being 100% engaged with life, whatever life might look like, is doing life's work. This perspective says that life is worthy when you’re imprisoned or oppressed, when you're ill or dying, when you're shunned or beloved or misunderstood.

And it has always struck me as foolish to write someone off as "damaged" when I’ve personally worked with kids who have defied the odds. I look at Helen Keller, Stephen Hawking, Temple Grandin, and other notable examples of folks with one difference or another who’ve been able to rise up, and the common thread I see is that these are people who fully engage with life and somewhere along the way had people believe in them at a critical time in their development. As long as our kids have that, who knows what could happen. Not that our kids need to be physicists or PhDs - they already are who they are. Just like the rest of us.

Considering my thoughts about another looming birthday, about the journey so far with Adam, and how I see he is growing before my eyes more quickly than I could have ever imagined, I have to let Lisa’s comment envelop me. I have to remember that my life, my time, is not defined by how hard I work and what I seek to achieve, but by simply being. Success and achievement serve one final function -- to remain immortal. Gilgamesh (see Epic of Gilgamesh) worked so hard to achieve immortality and it fashions the way we live today. It drives business people, authors and
artists to make art, write books, build buildings with their names on them. It is a difficult construction, this immortality business, this quest for Holy Grails, for Utopias, for Ideals. It provides steam under Eugenicist movements, while at the same time, inspiration that we all have something to offer in this world. Inspiration, Aspiration, Hope and Being also have their counterparts. It is up to us what we decide to build with our blocks of time.

I wonder if I can die content with the fact that I'll just be dust in the wind -- immortal only as long as Adam lives and remembers me. He is, however, my life's work. Time will certainly get me, but my legacy will live on, if only in him.

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FRIDAY, MARCH 10, 2006

**Bikini in my Baggage**

I am frantic, so why the hell am I sitting here and blogging today? In a few minutes I will return upstairs in the midst of sweaters and toys that will fly around the room as I pack for Vail. I will confirm the many reservations I have made to accommodate Adam and our family.

Blogging is a nice escape from the inevitable hectic journey ahead. I have closed my door and am drinking a nice LARGE cup of coffee. I really hate packing. I hate unpacking even more. I hate planning how many pairs of socks and underwear I will need. I labour over which outfit I need for the evening – what if I don't feel like wearing the one I chose come Tuesday night? How I yearn for those days when I could just pack a little bikini and head onto the plane – without making any plans. Okay, fine. I've never walked on a plane with just a bikini in my bag, but oh how I long to. Imagine if I can just walk into the middle of some strange place and let experience become me -- to let it unravel me, shape me, and become part of my memory forever. I came close many times. Living in Europe, when I had little money, it seemed I could breath in everything more fully, walk for hours, meet new people, taste the food sold on the street – flavours, locations, the people who with whom I ate -- still a colourful memory today.
I took reprieve in cathedrals on cold walking days, reading the story of stained glass windows, meditating and keeping warm amidst the low rumble and shuffle of visitors. I ate bratwurst with sauerkraut in the *Markt* between classes, watching German folk buy their fruits and vegetables at a price that choked me back then. I’ve walked the cobblestones of Strasbourg, close to where I studied and the fanciful boulevards of Paris from the outside looking in. I loitered along the solitary paths of the Black Forest Mountains after a snowfall, nary a cow or person in sight the higher up I went. I’ve traversed to carpet vendors in Turkey, and sipped Turkish coffee in stalls on hot summer days, stopping to listen to Muslim chanting over speakerphones, golden turrets above my head. I’ve visited *David* in Florence, and walked in the footpaths of great men. I’ve waltzed to grand Vienna and visited the singing hills of Salzburg, feeling Mozart not too far behind. I’ve entered the universities, the music schools to hear other student’s aspirations climbing *do re me* in cavernous halls, history listening. I remember the full taste of Schaumwein (Strawberry Wine), a three *Deutsche Mark* luxury to the pops and cracks of New Year’s Eve in Freiburg and recall the vision of gypsy huts behind treeless and grassless apartment buildings in the Slovak Republic, the decorative embroidery of table clothes and doilies trying to brighten the history of their Marxist oppressors. I’ve hitched rides to see jungles and monkeys on remote parts of islands – visited only by die-hard surfers searching for bigger waves. I’ve soaked in sunshine with the smell of warm beer and roasting chickens on the west side of the Atlantic, where African winds blew gentle kisses across my cheek.

I long to see the colourful markets of India punctuating the duller shades of a spent land. I hear the voices of Ethiopia call me to see with my own eyes, the suffering. I wait to visit Israel this May, to take a dip into Middle Eastern sand. Without walks, without journeys, without time, without freedom, we cannot discover. I’ve been on the outside looking in, and now with age and a little more money, been on the inside looking out. It is these poorer times that remain the most endearing and memorable, as well as the times when spontaneity had little use for money. The rich man’s vacation is sometimes very poor by comparison.

The family vacation: Hmm...structured, another home-away-from-home. Yes, Adam will indeed benefit from a new experience, and yes, he will likely enjoy all this novelty, and yes, it will be a lot
easier to have everything around me, easily accessible. Daycares, swimming pools, shops, movie theatres. The first-world has become a series of Disney locations – one-size-fits-all, with the conveniences of home.

There is something to be said, and welcomed in convenience, in being prepared. I will think about transitioning Adam onto the plane, making books for him to visualize the experience. I have yet to pack the DVD’s the books, the food, the toys, the crayons, the hats, mitts, ski pants...and of course there are my books and computer because I don’t ski anymore (knee injury). I’ll work out, go cross-country skiing and snowshoeing. One does need a lot of STUFF for a March Break ski trip.

Adam will wear skis for the first time on Monday. I’ve enrolled him in the Adaptive Ski Program. In the afternoon, we will mush with the dogs on our first dogsledding escapade. Of course, I do not know, nor can really predict how Adam will take to all of this. I suspect he will cry when ski boots are placed upon his feet – he won’t understand why they will move, or barely, like lead. He will hate wearing the helmet and will scream (he hates putting anything on his head or near is ears). I will hold it on and say “you have to wear this,” sweetly, lovingly, as I break out in a sweat, hoping for him to calm himself. I will watch him crying, becoming scarred going down the hill, the lovely people helping him – they will be dear, I suspect. Adam will get the hang of it, he will enjoy the movement, the feeling of gravity moving down the hill. The movements will be repeated and he will become a little more at ease every time.

To further prepare, I will take him to the ski shop tomorrow. We’ll try on boots, look at skis and then talk about it some more at home with pictures. While this may make the equipment look a little familiar, it will be the experience that will make the lasting impressions.

I remember my first trip away from home with my parents. I was as old as Adam is now. It was to Ottawa. The trip was made by car, and to me it felt like a very significant journey, with stops and a night over in Kingston. When we reached our destination, we visited the Parliament Buildings. I still have a picture of myself, standing against my father at the Eternal Flame, in my little green dress with a newly bought pair of sunglasses to match and fancy
white shoes. I marveled at those sunglasses, those rose-coloured lenses, and consider the memories that Adam will cherish forever from this trip, suitcases, DVD, Pringles and all. I will be looking through Adam’s lens and savour the unexpected joys of being his mom. I may still bring the bikini (there is a swimming pool), even if it comes with the rest of the baggage.

PERMALINK POSTED BY ESTEE KLAR-WOLFOND AT 3/10/2006 12:32:00 PM 0 COMMENTS LINKS TO THIS POST

THURSDAY, MARCH 09, 2006

There Are No Prodigies in Art

There are no prodigies in art -- Pablo Picasso

There is no art without the artist. For Jonathan Lerman [see gallery statement and video footage in my sidebar], as Lyle Rexer alludes, the self and the compulsion, not the subject or the talent, makes the art. Taking this view, as Picasso did -- "art came through the accumulation of experience, which kneads the unconscious and constantly reshapes it, thus making the prodigy self-less, the victim of whatever subject seizes him, victim of his own aptitude" -- gives Jonathan’s savant label a different meaning. If we take the view that art is part of him and his universe, the method by which he has come to express himself, then Jonathan is really, different and at the same time, like the rest of us.

I took a trip to Vestal, New York this morning to meet with Jonathan's parents and to look at more work by him. I brought back with me some of the colour charcoal drawings this time, some completed when he was as young as twelve years of age (he is now eighteen). For Jonathan, charcoal is a native tongue. It is more acute for me after I viewed his oil paintings -- a lot more contrived (apparently he has an art teacher now, so this may be part of the reason). His sculptures are interesting and look like folk art. Yet his drawings sing. For a young man who has great difficulty communicating verbally, his line is lucid, sparse at times, but speak volumes. It is a sophisticated language, this, as verbal language is hard pressed to describe multiple states in a single word.

In some of his later pieces, I am struck by the numerous faces [not pictured here] that surround some of Jonathan's favourite rock
musicians, or renderings of rock personae unknown. Caren, his mother, states that she suspects Jonathan is suffering from temporal lobe seizures which may be resulting in some aggressive behaviour, and visual hallucinations. Caren notes that he sees different faces, sticking out tongues, heads floating in air. Jonathan "wants them [the hallucinations] to go away," she says, and looks forward to the day when someone can help him.

It is apparent to me, that these drawings are Jonathan's world -- a definition of himself within it, and affirmation of "I" in the universe, as well as a continuing investigation of it -- as he sees it and as it comes to him. Alan, Jonathan's dad, said to me today that he is interested in doing "something real," meaning, Alan thinks, that he wants to continue to do portraiture.

Jonathan is also interested in religion, and often asks other people "if they are Jewish," says Alan. He is also aware of ethnic origin and draws people of different races and makes up endearing names for his made-up characters.
I will continue this investigation of art and autism, talent and savantism as I continue to head towards the "really big show" in October. Indeed, the tendency to classify all persons within and without of autism, seems to be the tether we can’t do without.

The Hotbed of Discrimination, Acceptance and Advocacy

Recently, I’ve seen two wonderful bloggers go “off the air.” This Mom and 29 Marbles have decided to take a reprieve from the consuming blogging universe. I am saddened by their departures, and consider the hotbed of issues being discussed can leave us all feeling dizzy.

Parents are trying to understand and raise their autistic children. When are children are initially diagnosed, our first entry point is to a world of medical professionals trained in describing abnormalities, illness, deviations from the “norm.” Other immediate entry points are the Internet and high-profile organizations raising money for autism research. I would imagine that it takes an extremely strong individual, or an experienced one, one who has been in a family with disability, to shove the apocalyptic voices aside. For most of us, it is a journey of understanding autism and coming to understand our children with autism.

For me, I quickly felt uncomfortable with professionals viewing my
only child as a pathology. I guess love did this, and that’s a good thing. Acceptance is the next word that comes to mind, but the journey to acceptance, for me, is still an arduous one – the pull of therapies, professionals versus listening to myself, then, the strong voices of the autistic community often condemning parents as abusers. These are really harsh voices, and I’ll be frank here – I do agree that there are therapies and parents that are harming their children – chelation, viewing autistic children as a set of bad behaviours, pathologies – it does take away the humanity of the autistic person. It is prejudice. Yet, there are parents still searching, trying to help their children function in the world without frustration, and those parents need supporting.

After acceptance comes a search into the history of disability, racism and human rights, the construction of normalcy, and the social construct of autism. These are weighty issues and my background is in fine art and literature, not philosophy, although I have an interest in it. As a parent, and a lover of knowledge, I am trying to go back to some of these roots in order to figure out where my belief systems come from.

I use myself as an example in yesterdays post regarding racism – a quick, seemingly innocuous, tapping of the keyboard that put two words together that are interpreted in a certain way, and I am reminded that semantics and words are indeed important. May we all learn from our mistakes, may those that cast the first stone not make the same mistake, harbour any furtive thoughts, of be self-righteous (“The greatest of all sins is self-righteousness”). I use myself as an example not to state that I am a racist – hardly – but rather, how stereotypes are firmly entrenched in our minds. This is a story about how our minds interpret the world.

On Philosophy.com, Jonathan Miller author of Beyond the Fringe states, “The job of philosophy is not to find out the meaning of life, or our relationship to the larger metaphysical principles of the universe; it is finding our relationship of the mind to the world. How the world is represented in the mind; how do we come to have knowledge; what do we mean by certainty. These are the only things about which you can ask questions. I am interested in problems for which you can foresee a solution; questions to which there is possibly an answer.”

As I consider this, I still have yet to find that light at the end of the
In *Intellectual Conservative Politics and Philosophy*, Wendy McElroy titles her article, “*Disability Must Be Defined Before Debated.*” It’s a good article about attitudes towards the spectrum of disabilities and I am reminded of the contention between various levels of functioning between autistic people. The story in essence, starts with Janeal Lee, Ms. Wheelchair Wisconsin who outraged others with muscular dystrophy because she could actually stand for ten or fifteen minutes on a good day. Judy Hoit, the treasurer of the organization stated, “you’ve got women who are in their wheelchairs all the time and they get offended if they see someone standing up.” This article is an example of people seeing themselves “as an oppressed minority, turning disability into a cultural and political identity...Thus, the now-deceased Christopher Reeve was severely criticized by some disabled advocates because he actively sought to ‘cure’ his paralysis rather than accept his disability.”

The article questions “what is disability?” and how we should react to it:

“Because my grandmother had German measles during her pregnancy, my mother was born with a malformed arm that ended in a claw-like appendage where most people have an elbow. At first, I didn’t know my mother was handicapped. She was just my mother: an attractive, smart woman who ultimately supported two young children after being widowed. It was the attitudes of other people [emphasis mine] that made me aware of her disability. Not that people expressed hostility or disgust; they were usually awkward, too helpful or furtive in their glances.”

McElroy summarizes: “By my definition, disability is a sliding scale. How people react to ‘the disabled’ hinges on where that person falls on the scale. An extreme disability often makes people uncomfortable because it connects to their own fears of infirmity.”

*Ayn Rand* states that the solution to racism is Individualism: “`Rationality is man’s basic virtue, and his three fundamental values are: reason, purpose, self-esteem. Man – every man – is an
end to himself, not a means to the ends of others; he must live for his own sake, neither sacrificing himself to others nor sacrificing others to himself; he must work for his rational self-interest, with the achievement of his own happiness as the highest moral purpose of his life.’ In this view, Objectivism rejects any form of altruism – the claim that morality consists in living for others or for society.”

It is here I have a difficulty in seeing myself as an “autism awareness advocate,” and understand the wisdom of 29 Marbles and This Mom for taking reprieve, in Brett’s case “trying to figure out what raising awareness means.” We all want to help -- philanthropy a kind-of business. By helping, do we assist our own conscience, or others need? The whole concept of religion is now at stake here, and I am thinking of Nietzsche’s anti-religious view – seeing altruism as a kind of farce, rooted in monotheistic religion. “As an esoteric moralist, Nietzsche aims at freeing higher human beings from their false consciousness about morality (their false belief that this morality is good for them), not at a transformation of society at large.”

You see, it’s an interesting exercise to determine where belief systems lie, to consider that none of us have any unique thoughts, and how altruism can be interpreted by those we are seeking to help and support.

I still like President Clinton’s summation which, for me today, is an easy way out of this labyrinth: we are just “people helping people.” I know I am trying to raise my son in a positive environment and accept him for who he is. I understand that I am a product of morals and ethics and build my actions on them, while studying the architecture of ideas. It is all I understand, for now, and the point from which this journey initiated.

LINK:

History of Racism
I seem to have offended someone using the “crusty Asian woman” phrase in my post about Adam’s haircut. I appreciate the person, although remaining anonymous, for speaking out. My intent was not meant to be racist at all, although the person raises an interesting point about labels.

Here I am talking about being careful about semantics, and whack, I used the word “Asian.” Now, I see that word as descriptive, for writing purposes – a set of physical attributes summed up in one word. If that person was German or Swedish (except that "they" are not visible minorities, I acknowledge) or whatever, I would have found a word to sum up a look in order to give this picture. I often describe people in terms of Black (a really general term considering the scope of the world where people are from), German, Jewish, British, Russian, Phillipino, Canadian, American, European. I try not to overgeneralize. Perhaps this is what makes any phrase slanted with racism. A label certainly doesn't describe a person. It only describes a set of features and physical traits. Instead of a sweeping brush stroke to provide a picture, I instead put a black line through an entire race of people?

Of course my intent was not meant to be racist, except that in fact, I did offend someone, so I suppose for that reason alone, it can be considered racist. For that, I am sorry. It’s a good question, actually (feel free to answer it) -- what is racist in the scope of writing, in being descriptive? (I think I've in part answered it). If someone who is not Jewish speaks about the Jewish people, it often comes across all wrong, perhaps even if the person didn’t intend it as such. Just prefacing a sentence "I met this Jewish guy," is like a loaded gun -- I find my hair standing on end, waiting for the next phrase, racist or not. Having converted into a Jewish family, my radar is a little more sensitive than it used to be, so I actually should have been more aware of this type of referencing. Yet, looking at the argument from the side of receiving supports for autism, what have we all come to that we can’t describe and state difference, and if we do, it appears to be discriminatory? How defensive are we that we must equate equality with homogeneity -- to whitewash description and difference entirely?

In my case, I do not intentionally use race to describe the human being. Except in my description, I placed together race and a description of the person “crusty” or abrasive, together. Any person of any race can indeed be unpleasant. Character traits
transcend race indeed. It also takes many encounters with a person, many paragraphs and descriptions to figure out if someone is a racist. Adolf Hitler’s *Mein Kampf* is clearly a collection of rabid racism.

When I describe a person in my writing, I try to paint a picture of the character, hopefully in all their richness. If that character has unpleasant flaws does it make the writer a racist -- the collection and context of words is important here. Perhaps the description in my last post was simply too brisk of a sweep. If I describe a person autistic as a “bitch,” (Autistic Bitch from Hell dubs herself, not me... and I think she is brilliant) does that make me bias against people with autism? Many parents can’t take Michelle Dawson (I like her for what she is doing and the voice she has risen, I will state for the record, even if she might very likely find many flaws in me) – does that make them prejudice? It strikes me that if we are going to talk on an even playing field here, then we all have to *presume ourselves equal*, with difference -- an oxymoron indeed. To debate with Michelle Dawson *presumes her competence* to fight for her beliefs. In my case, when I call a person “crusty,” it is because they damn well are, white or black or Jewish or Asian.

To me, this is what we are fighting for – perchance to transcend labels or to use them without prejudice, to acknowledge the beauty and the challenge of difference, and the freedom to say that someone stinks when they just, well, er... are. This is the heterogeneity of humanity. Let us be careful, however, how our words are interpreted and how we sweep our brush.

It’s a difficult issue -- to equate a person with a crusty old label, still as thick as rye, yet to crumble.

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*Inspiration from President Clinton*

*There is no happiness where there is no wisdom;*

*No wisdom but in submission to the gods.*

*Big words are always punished,*

*And proud men in old age learn to be wise.*
I went to see former President Bill Clinton speak at the *Friends of Simon Wiesenthal Center for Holocaust Studies* event last night. Clinton's long fingers typically rolled into that gestural fist with the thumb pointing out instead of his index finger to make a point. He is softer now, perhaps weakened by his surgery, a Dalai Lama of politics, if there can ever be one -- I think of Ghandi when I write this. He is soft and gracious when he speaks, his head often down thinking of every word. He is the epitome of a life-well-lived in my view -- of mistakes, of experience, of knowledge and smarts, boiling down to his essence...gracious and wise. I think he is a brilliant man.

You can see I had front row seats (ha!). In fact, the event was sold out and we got these seats at the last moment:

Here is my not so great photo of Clinton.

I couldn’t have cared less. Just being in the same room with him was a thrilling honour. President Clinton spoke about how interconnected our world is becoming, but in that interconnectedness, we have more discord than ever before. Perhaps we get too close to one another, in all our differences, and then we have to deal with it instead of building the walls that formerly kept us apart. This is the price of interconnectedness: from Palestine’s new government Hamas to Israel’s front door, from people with varied religions living together, to neurodiverse and disabled people living with abled ones, we’ve got difference smack dab in our face. We live in an incredibly priviledged economy and we have to deal with and be responsible to those living on less than two dollars a day. We have to be cognizant of what we are doing to our environment and become more responsible about that. In a priviledged society, we ought to think less of ourselves and what we can do for others.
There is no difference in my mind between these issues and those of human rights for the disabled. Across the board, there is prejudice and fanaticism that endangers all of us. He noted that those areas that support America today are Ache Province where the Tsunami hit, and Gujarat, India where the earthquake struck because Canadians, Americans helped people -- "people helping people," as he put it. Once we cross bridges and meet each other, it is always incredible how we are alike. Respecting differences -- from race, religion, culture, and ability can only enrich us all. Building walls can only lead to fear and hate.

If we truly live in a democratic society, then we have to continue to speak out against organizations that are seeking to do that which is against the wishes of the autistic community. We have to keep talking and talking, and wait for the gap when someone might just be listening -- or else we will never be heard. This is the inspiration I glean from a great President.
cookie with blueberries in-hand. Typically, I would just grab the latest book that caught Adam’s eye and let him flip through it as I placed him in a Thomas-The-Train seat. Usually, he would just flip happily through the book, letting Sherry, his regular hair-cutter, talk to him sweetly, cutting his hair gently and quickly. We discover that Sherry has unfortunately left *Melonheads* to pursue greener pastures. After I place Adam in the train seat, he wants nothing to do with *Curious George – a book of Opposites*. He is much more interested in the streams of other children coming in, the bins of toy cars ready for his plucking. It is a busy morning and instead of the usual attention, Adam waits a fairly long time until a crusty Asian woman with long scissors just starts going at Adam’s hair from behind. No introduction – no sweetness that one would expect of a children’s hair-cutting salon. Needless to say Adam leaps into my arms screaming bloody murder. Other parents stare and in a flash AUTISM is about to roll off my tongue ...but I manage to hold my breath.

“It’s okay,” I whisper calmly in Adam’s ear while he holds on to me tightly, trying to get out of the train, scissors still swiping off uneven clumps of hair. “You’re just getting your hair cut. You will be okay.”

What would AUTISM have meant to this gruff woman who didn’t seem to care except to get her next customer and tip? Besides, wouldn’t any child have reacted to a stranger putting them in a headlock with a razor next to their ear? Even if I’d said that he gets “scarred easily,” or is “sensitive,” would she have cared?

Adam manages to seat himself back in the chair, even though he continues to cry. In about five minutes, the ordeal is over and we grab a lemon lollipop from a clear bin by the cash.

I think all morning of when, how, and if to use the word autism at all – when it might stigmatize, marginalize, and remain meaningless except to possibly suggest that Adam is “not normal” -- something I do not wish to convey. I even struggle to use it now with persons in the know, who may be able to help him -- not because I am ashamed of the word or that Adam is autistic, but because it doesn’t mean the same thing to every person, and every person with autism is not the same.

As this thought agitates me, Adam carefully works on the same
lollipop I gave him at the salon for about thirty minutes as we drive to pick up shoes to match the new Strenesse suit I will wear when I shake President Clinton’s hand tomorrow night (my birthday is on the horizon so a new suit seemed in order). I shuffle him to music class, the French boutique an irresistible reprieve.

Music class is a challenge today. We arrive a little early from the efficacious shopping spree and Adam has a chance to move around while eating pizza Goldfish and drinking water. At the beginning of the class, Adam is visibly distraught. He is resisting control these days and doesn't like being pulled into circle by the music teacher. I decide this week to give him more choices over personal things like food, since he is also being toilet trained and has a couple of new therapists in his life. I figure he needs to also feel in control of his Personhood as I reflect on the week’s “No, No, No, NO’s!” that have bellowed out of him. Ah, I am grateful for those. I waited a long time for them. Nonetheless, I am a little beat from power struggles and decide that he needs my empathy and support. I step in, acting as Adam’s shadow. He has missed a few classes – a trip to Florida, sick with the croup the weekend before that. We missed instrument and boat-making, so in fact, we have missed a lot -- without my support today, and he is like a boat without a mast.

Today we sail on a pretend ship, looking at pretend things on the pretend ocean. Adam enjoys the pretend waves as we rock to and fro. This “pretending” is tough, needless to say, but by the end of the class, between some successes – of moving and imitating and listening attentively to various sounds – Adam ends the session with a smile.

Pretend. Ugh. How does one explain to another who doesn’t understand autism that it’s hard for him to understand what he cannot see? What’s the point? It’s just a weekend music class – we’ll practice at home. There are parts of the class that he truly enjoys and I don’t want him to miss out on that.

When Adam was first diagnosed, I was urged by another mother of an autistic adolescent to get a Disabled Parking Permit. She said she used hers all the time. I couldn’t do it. Adam is not physically disabled. He did not have meltdowns at the mall. Although I am entitled to get one, and was tempted by the ability to park anywhere I wanted, I didn’t want that on my conscience – there
Autism still means so many different things to different people. I sometimes have trouble using the word now because it doesn’t have any ONE true meaning for most people. Just like Adam’s pretend ocean – it is difficult to understand what you cannot see. Adam doesn’t really look any different, although he may sometimes act a little differently, and even that is difficult to discriminate. PreRainman Autism talks about things like this all the time, before the “age of autism,” before the time when everything has to be symptomatic of something.

I have been considering this week that the autistic community just might change the face of the disability rights altogether – for the better. There is a unique opportunity here for the vocal, articulate people with autism to communicate autistic experience in a society that barely tolerates difference. Then again, I wonder if we just might come full circle.

Collection of Moments

I sat on the edge of my hospital bed, a small box of Kellogg’s Corn Flakes and a tiny carton of milk for my effort – giving birth in eight hours, passing a kidney stone for four days before that. Adam was asleep in his clear plastic crib, swaddled tightly in blue hospital flannel. This is a moment I will never forget – how the air shifted, time punctuated.

Life is a collection of moments, memory the lingering perfume.

I am a collector of moments:

Adam rubbing his bare tummy against mine
Adam nursing and staring into my eyes
Adam weaned at 3 ½ years and how I could have continued
Adam’s gleaming smile
Adam’s starry eyes
Adam running to me while I work, giving me gentle kisses on my
Adam running to me and saying “here I come!”
Adam crawling under the covers, utterly relaxed
The way Adam looks straight into my eyes like he’s saying *I get you, I love you.*
Watching Adam interact with others
Watching Adam from afar, becoming more adept at everything
Watching Adam is like watching TIME with a pierced heart.

If this is autism, then it most certainly is God’s correction of “normal.”

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**THURSDAY, MARCH 02, 2006**

**A Sledgehammer or a Song?**

I’ve never hidden my views. I’ve also proclaimed that I do not know everything there is to know about autism and constantly turn to those people with it on how to teach, on perspective and so forth. I am not here to pontificate. I am here to learn and discover. Through the process I hope I can also become an "ally," as Amanda commented on Kevin’s blog. I hope I can challenge other people as well, but often the best way to reach the inflexible mind is slowly, with history, with familiarity, with true stories by those who are autistic -- perhaps my preference is through literature, art and the like. In my view, we need sledgehammer's and we need songs -- I think I’m the latter. Whatever our style, we have to "speak" in a language that suits us best. While it is utterly IMPORTANT to speak up and show the inhumanities against autistic people, there are some people who can't be reached. This is the tragedy. This is why the dialogue can never cease no matter how much it sometimes beats us down.

I’ve been hinting of the history of eugenics in America. I’m actually quite suprised how few people picked up on that or didn’t know what to say about it, or are fearful of "going there." I try and take a stand that shows rather than pontificates. If I say I believe something, another parent will accuse me of "speaking for" the autistic. I repeat: I am learning. The purpose of blogging for me is...
I am speaking to Amanda's comment as I mentioned, in Kevin's blog. She is strong in her response and for that reason, it speaks to me. She states:

"Basically, the autistic people most likely to be harmed by various "therapies" and "philosophies of autism," are not likely to be helped by the "let's respect the opinions of those who are doing this to me" thing. By all means respect people as people, but opinions are something different, and some opinions, some actions (and actions start with opinions), are just not excusable... Frankly when I see people talking about how all parents of autistic kids should have this kind of solidarity, it frightens me. It frightens me because I have seen the results of both parental hatred and parental well-meaning bad things directed towards autistic people, and this is so rarely acknowledged, that good intentions aren't good enough and that some parents do not love their children and that some parents who do love their children still horribly mistreat them.... Isn't it possible to both be an example of acceptance and celebration, and at the same time say "No, some things just are not okay?" Isn't it possible to be both loving and take a stand? When people believe that peace is the absence of apparent conflict (while meanwhile the conflict all continues under the surface and harms and kills people and so forth) bad things happen. And most autistic people can't escape those bad things without allies, and where are the allies if they're all going into "sweep it under the carpet mode," if nobody's willing to confront anyone because it wouldn't be polite or validating or parent-solidarity or whatever?"

Amanda, I am so glad you wrote that. I can't say it like you say it. It wouldn't be the same, in fact, coming from me. I don't speak for you, but I can listen, advocate, ally. I can present the work of autistic people in special events, art exhibitions and I feel I need to. I must admit that it is unnerving as a parent who wants the best for her son, to undergo such "confrontation" as you put it -- when one would think that all parents would want the same. Yet, even those sentiments, as you said, do not address the injustices against the autistic population. I can say I want "the best" for my son, and in fact, do what's best for me. This is the semantic issue. It is consistent with Ebohlman's comment, also on Kevin's post:
"`Sincere,' does not mean `correct.' The most passionately and deeply held beliefs are those of bigots, zealots, and fanatics, the people who have the least hold on the truth. Believing that you're right is not the same as being right."

As parents, I think many of us grapple with this all the time. What is the difference between what I want, what I think Adam needs, and what he needs or wants. At this young age, as a custodian of my son, these are difficult decisions for any parent, autistic or not. However, with a child with autism, the issue is more serious. There are too many pulls for insidious therapies, too many organizations that appear to befriend the "struggle" and appeal to parents on this basis that totally ignore the discrimination issues and the voices of those with autism.

So people like you need to keep speaking up for yourselves and people like me need to make way. The truth of the matter is you've just got to keep sending your message to the parents. They are the nucleus of everything for the autistic child -- they are the point at which all views about you in society can possibly be changed.

Kevin, Ebohlman and Amanda -- thank you for your posts, your strong words. They came at a time when I needed them most. I'm going to keep singing.
watch him open his eyes and smile at me, each day more shiny and new for him as it should be for all of us, and at night when he cradles himself in his bed in the crook of my arm and falls asleep -- a sweetness so joyous and a dialogue so painful, it is making me bawl.

Then, I turn on CBC Radio One and Ellen Schwartz of Jacob's Ladder is speaking. Ellen happens to be the sister-in-law to one of Adam's therapists, Bianca. Ellen's eight-year-old son Jacob has Canavan's disease and was never expected to live -- he is not expected to live past his tenth birthday. Their lives are challenging at best -- taking 45 minutes to leave the house for any family outing as Jacob requires medications, air tanks, and more. Ellen makes me bawl some more in the car as I am about to view my son's art show at school. I feel ridiculous -- eyes red and puffy, I have to wear my Jackie Kennedy sunglasses and take a time-out to grab a vanilla soy latte to warm myself in Toronto’s recent frigid air.

I get back in the car quickly to catch more of her interview. She and her husband have developed a screening program so that carriers of this disease can be informed before they make a choice to have a child. She says, "why would I want to bring a child into the world who I know will suffer and then die?" She acknowledges that the ethical issue is different for all people, but she wants them to have a choice. By the same token, through all of her family's suffering, she acknowledges how Jacob is a gift for her. She talks about how her heart will unexpectantly turn sad as she watches his cousins playing while he is confined to a cot. I erupt again thinking of Adam's ten cousins running around on socializing on Shabbat, his same-aged cousin Annie so swift and talkative -- he just can't keep up with her. While Ellen accepts and loves Jacob with all her heart, she acknowledges the struggle with the disease, the hard life of Jacob, of acceptance and sadness mixed with her profound love.

We all have opinions about what is best for our children. We all have different "religions" so to speak. I am not very tolerant of evangelism -- I must be honest with my bias' -- but I believe that everyone has a right to express themselves, to discover their views, to evolve. This, for me, is what blogging was in part about. It was intended, for me, to be an exploration of views, "lenses to try on" as I stated in my profile, to hopefully develop and grow.
Some people take these debates, points of view, so personally (a hazard of religion as it involves so much emotion), that I have discovered a very dark side of autism. I discovered that parents with autistic children are so divided that the support I was seeking is hard to find. Instead of a journey to discovery, it is starting to look more like a war out there. I want to agree with Susan's post today that we have to have a gentler approach. I am thinking about "celebrating difference" as I have through the art shows I've done so far, the lectures I've organized, the floating wall of quotes from people with autism that spoke more loudly than the words themselves.

So for me I suppose this is my best "reprieve," other than my own thoughts and words -- there is still no friend who truly understands, no fellow parent of an autistic child who doesn't have an alternate "politic." I struggle to find that middle ground -- that ground where parents can feel safe to state their struggle, to express their opinions, to be allowed to take care of themselves (I've gained about ten extra pounds of "armour" since Adam's diagnosis but am now allowing myself some time to work it off), to even be accepted by the autistic community for this evolutionary process. To be accepted as equals, sometimes we have to express empathy for others. I am left wondering if this is an ideal, if this type of repartee can be achieved.

In looking to history, we can learn about ourselves by understanding what is at the root of our beliefs. It deconstructs them, and I think that is a very healthy undertaking. When we think we believe something, we quickly learn that the belief does not really belong to us. We are not the authors of our own destinies, really. We are not free-thinkers, truthfully. We inherit so many ways of thinking -- we can not claim our thoughts as our own. When we take a look at our own beliefs in this way, I think we can grow more tolerance for each other.

Adam's OT reads my blog. She was mentioning how sensitive even "celebrating" autism is for some families -- she knows of an autistic girl who poked her eyes so many times that she has now blinded herself. For some families, she reminds me in my quest for acceptance and celebration of difference, this "enlightenment," this belief, is pretty difficult to muster. I am not sure how to address this, and by no means do I want to undermine the struggle of some families out there. It is not my right to shove "celebrate"
in front of their faces when they just do not feel like celebrating.

Ellen's dialogue today reminded me of something I've said to myself before: **joy does not come without struggle, it doesn't come for free.** I've found joy only through my journey with Adam. I too thank God for him every day. He has brought so much purpose to my life, and I am grateful for all that I am learning because of him. My joy and my sadness are always intertwined which is why Ellen's interview struck a chord with me today. In the struggle to find the black and the white, I find nothing. In the acknowledgement of the rainbow, there lives everything. As I cry a little more, the sun comes out. It is frigid out there, but at least the light brightens my outlook.

**Master of Our Own Destinies?**

For those of you interested in the History of the American Eugenics Movement, go see this interesting website: Image Archive of the American Eugenics Movement, further to my earlier post: **A Better Breed of American**

![Image](image_url)

Captain of my own destiny, keeper of my dreams.

Hard to believe that such a movement would state that my son be sterilized, marginalized, and worse, would not deserve to exist. The movement is all to recent to forget, and perhaps lurks around the corner again.

**Autism Diva** wrote a post on mercury today and I wrote a comment on her blog quoting from the site mentioned above: "By mid-19c most scientists believed bad environments caused
degenerate heredity. Benedict Morel's work extended the causes of degeneracy to some legitimate agents -- including poisoning by mercury. Richard Dugdale believed that good environments could transform degenerates into worthy citizens within three generations." The talk of mercury now, and the words from history, send shivers up my spine.

Must there be a "cause" for autism? Is it another attempt to "degenerate" the autistic?

All I can say today is, let us never forget.

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**Adam's World to Mine**

By: Max Wolfond

I was thirteen years old and preparing for my Bar Mitzvah (Jewish ceremony into manhood) at my desk when I heard yelling from the room down the hall. My heart began to pound, as it often does when I hear panic. Moments later I heard my step-mom Estee scream "My water broke!" At an instant my dumbfounded face turned immediately to a smile. She was rushed to the hospital by dad and a mere eight hours later, Adam was born. Unlike my clever response at age three when my sister was born, "I knew it was going to be a boy or a girl," when I first saw Adam I was speechless. I had never been so happy to see a baby cry in my entire life. I don't know if I realized it consciously or subconsciously, but at that moment, I knew my life would change forever.

About a year and a half later people began to notice things. Adam was not making eye-contact like most 18-month old babies, nor was he socialable as the other kids in his nursery. It became somewhat of a concern to the family and to Estee...
especially. I cam home from school one cold December afternoon to find Estee struggling to hold back tears. She told me that Adam had been diagnosed with autism. At the time I was not exactly sure just what autism was, although I had known somebody at camp who was autistic. I did my best to show sympathy for my dad and Estee by saying I was `sorry.' So life went on and Estee began to hire therapists to work with Adam. She hired two therapists who worked closely with him, on basic skills such as interaction as well as trying to strengthen his verbal and non-verbal communication skills. At about one, my brother Adam took a keen interest in letters. Soon, he could recite the whole alphabet and identify letters at random. He could also count to twenty.

Adam is now three and two-thirds old and is working with a therapist daily as well as attending Nursery School for half the day. He has a very busy life and no doubt keeps Estee and my dad's lives busy as well. Adam is now able at less than four years of age to read a number of words and write the letters of the alphabet. He is very compassionate and gives a hug to just about every friendly face he sees. Like any kid his age his favourite foods are pizza and chocolate. Something as simple as juggling can make him smile and laugh, and often cause him to burst into song. When he hurts himself (bumps his head or falls), it takes all of thirty seconds to put a smile back on his little face. He is the most loving and happy three-year-old I have met to-date.

I find "Adam's world" to be the most intriguing of anyone in our family or any of my friends. This is not to say I love him any more than the rest of my siblings or my parents, but his interaction with others is more fascinating than most people I have met without autism. The goals of the work Adam is doing with Estee and the therapists have changed since he started. Where as the initial goal of the therapists and our family was to "cure" Adam of autism, it is now quite the opposite. We believe that it is not Adam who needs to be cured, rather, our society who needs to be cured of its phobia of difference. Society needs to learn to accept people for who they are, not who they want them to be. Our new goal is to try to get a better understanding of Adam's way of thinking and how he sees the world, to better the way we can interact with him. I feel people around can learn from Adam and learn other things from other's with autism. A common misconception and assumption people make is that all
people with autism have the same problems and same strengths as one another. In truth just like all human beings, people with autism spectrum disorder are all extremely unique. Techniques we use to help Adam may be different than the ones to help "Sue," but the primary goal remains the same: Acceptance.

On April 11, 2002, the stork dropped off a helluva gift. My baby brother has given me so much love and happiness, and so much to learn. I am certain he will gain abilities that will take him on an endless path of success in his life and I pray people will be able to see past the word often put in front his name: Autism. The uniqueness he possesses will show the world that "they" are not all the same, and are wonderful people too. The initial tears on my step-mother's face the day she got the news have quickly turned to tears of joy. Adam is growing into a sensitive yet strong human being. He is to me a brother, a friend, and a teacher, and I am certain my life could never have been so great without my younger brother Adam.

Could a brother and an old step-mom be any luckier? Can a sixteen-year-old change the world?

A Better Breed of American


The book reveals how in 1904 biologist Charles Davenport established the Cold Spring Harbour Laboratory on Long Island as a national center for eugenics reseach and policy planning. Several years later Davenport created a Eugenics Record Office with Harry Laughlin at its head, "sending field workers across the country to indentify the `germ-plasm' of unfit family strains so it could be eradicated... Bruinius deftly plays up the contrast between the eugenicist's obsession with cold measurements of human value and their own messy lives, which were marked by
"Cold human measurements of human value," can be attributed all the way back to Gottfried Achenwall in 1749 who created the word *statistik* -- used as a political arithmetic, but that concept was later applied to the body in medical science. Bisset Hawkins defined medical statistics in 1829 as "the application of numbers to illustrate the natural history of health and disease." (Disability Studies Reader). It was the French, Adolphe Quetelet (1796-1847) who applied the most generalized sense of the normal. "He used the "law of error" by astronomers to locate a star by plotting all the sightings and then averaging the errors, [and noticed] it could be equally applied to the distribution of human features." (Disability Studies Reader, Edited by Lennard J. Davis, p.11) "He then took a further step of formulating the concept of *l'homme moyen*, the average man. As we can see, an ideology about a middle class was born from these early concepts.

"In America and elsewhere," *The New York Times Review* states, "enthusiasm for eugenics was broadly supported by elites. In Britain, people as varied as Winston Churchill and George Berthard Shaw embraced its goals, and there was lively debate about how much the state itself should control reproduction on individuals. Eugenic science especially appealed to Fabian socialists, who saw it as further justification for abolishing class -- after all. once the playing field was level the effect of heredity could finally express itself clearly and be studied....

Bruinius sees America's leading role in the eugenics movement as a reflection of its utopianism. `Seeing their country as a land of innocence, many Americans had long clung to the idea of self-purification, attempting to excise that which posed a danger to the social good...Bruinius describes how Hitler modeled Germany's sterilization policies on California's 1909 sterilization law. While reports of Nazi racial policies provoked a growing outcry among the American public, eugenicists themselves remained enthusiastic, with some traveling to Germany to study its program."

Some of us may already know that the so-called "mentally ill" and "developmentally disabled" in 33 states underwent the procedure of sterilization.
Perhaps this book and understanding the history of eugenics and the quest for perfection only hovers beneath the frightening surface of the Holocaust and awaits its day to seep out of the cracks of biotechnology and genetic engineering. It lives in marketing pulls for things as seemingly trite as botox, plastic surgery and the quest to stay "perfect" for as long as possible.

It is the American Dream gone way way awry.

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The Wind and the War

The migraine has passed and I spend some time reading on the beach print-outs from autistics on rights, Jim Sinclair's good piece "Don't Mourn for Us," the ongoing online debate between Michelle Dawson and Wade Rankin, and my Disability Studies Reader.

Adam runs up and down the beach, watches sea gulls and parasails on this windy day in Miami, happy, but...oblivious to the hundreds of man o war (sp?) that in the last few minutes, have swept up onto the beach. It is the first time I've seen so many man o war but I've heard of what they look like -- these blue balloon-looking creatures. I jump out of my chair and pull him away from the water quickly.

The wind and the war -- may the wind blow away the injustices and wash the war away.

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What I've Learned So Far

In my recent quest to ask some lingering questions about autism, I've learned that all parents love their children and the journey with autism is a complex and emotional one.
I think there is a point here for all activists, even to those who are autistic, in fighting for equality. The emotional journey this is for parents is significant and shouldn't be underestimated for the sake of philosophy. Sometimes, the fight becomes more important than the person, and when this happens, we have to reconsider the position from which we argue. I think parents deserve all the kudos in the world for doing everything they can for their kids with autism. As long as we all have an open mind and an open heart, our kids will thrive. Children thrive on love. (disclaimer: sometimes parents do things out of "love" for their kids that are medically dangerous -- I will never agree with parents on that).

In respecting parents, emotions, feelings, (I have my moments), when we have the energy, the arguments for equal rights for the disabled, I believe, are still vital ones in order to obtain the respect and concessions our kids will need. We may debate a great many issues, but let us never judge one another through a blog -- we can never know how people live, in what circumstances, and just as much as we have to respect the rights of people with autism, we have to respect the work of the people who parent them.

I've been debating what to write this past day or so -- what it means to write a blog (a self-gratutitous act, notes for my book, sharing with a community), and have come to the conclusion it is all of that. I may be wrong, I may be right, I may provoke to the point of annoyance, but in sharing all of our words, the point of this, for me, is to learn. And I must say, many of you are helping (read Zilari's response to my request to write on "How and What to Teach" -- thank you so much, Zilari!! (see PartProcessing in sidebar). As a parent, I am no expert on what it feels like to be autistic -- from a social discriminatory sense, from a sensory perspective, but I can be an advocate for my son and continue to try and work for his best interests. I AM, however, an expert in what this feels like for me, and how incredibly insensed I become at anything that smells of discrimination, or alludes that my son is less than human, normal, because he is autistic.

I will continue to have many questions -- I will debate and provoke standards, systems and popular thinking because it is important for ME on MY journey -- I'm very interested in the rights of the disabled, a movement which has only surfaced recently despite an enormous international disabled population.
The next questions I will have when I get home from Florida is the construction of "normalcy," a construct that is as recent as the mid-1800's. Also, I am interested in PreRainManAutism's (see sidebar for link) posts on anthropology and autism, which puts a lot of today's hype into focus.

So for what it's worth, as I suffer from a migraine and consider the burdens I often feel in the face of what may lie ahead for us, despite debates, my heart is with every fellow parent out there.

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**Deconstructing A View Continued: Autism as a Gift**

Kev of Left Brain/Right Brain made a comment about Sigourney Weaver's "autism is a gift" statement in reference to her newly released movie "Snow Cake" where she plays an autistic woman. Weaver talks about how she came to talk to autistic adults and observed a greater appreciation, in them, for the details of life -- a child-like view and a sense of wonderment as Einstein once stated. While I initially thought of Weaver's comment that "autistic people are gifted" a little naive because it is a generalization, I have to rethink this in terms of the pool of humanity -- each of us having inherent gifts within us.

In our society, which values homogenization -- a mediocratization of humanity and its manifestations, the idea of giftedness is translated into genius. The two are connected, but not the same. I prefer Michael Fitzgerald's definition of genius which states that a person with it must alter the way we view the world. Giftedness can be viewed as having a special ability or talent. In this wider definition, we can view everyone as gifted in one area or another. In short, it is a similar concept to "different intelligences."

Jasmine O'Neill, author of *Through the Eyes of Aliens: A Book About Autistic People*, and herself autistic, seems to also view autism as a gift:
"I believe there are intelligences that cannot be measured. I believe Autism is one of these. Autistic people must be discovered [Donna Williams' version of the "cat" mentioned earlier]. They must be coached to reach their full potential. They are worth much more than being subjected to idiotic therapies, which push them to repeat endless tiny tasks. Use tiny tasks as stepping-stones to mysteries beyond. Autistic people must be allowed to live their lives the way they please. They need to feel happy about themselves and be proud of who they are." (pp 56-57)

In this morning's post of mine Asking the Questions - Deconstructing a View that I wrote while packing my bags this morning, I ask the question of what we are teaching autistic people is right. Is acceptance about transforming autistic people to our way of responding to and acting in the world?

"Their [autistics] gifts are formidable assets. Even autistics who aren't savants have special gifts, which aren't present in non-autistics. Autistic people naturally are better at simply being themselves. They are not magicians. They should never be criticized or called stupid because of the way they live. People who are adept at focusing attention like a laser beam are people who can retain details. The tiniest details they notice escape other people's attention. Minute details are important too. They exist. Plus, they can build up one another to create big details.

Savant gifts are present from birth. They are honed, as the person grows older. A misconception is that only mentally slow autistics can be savants. I am a savant in music, writing poetry, drawing and some electronics. Savants are amazing, fascinating people. They may never be able to live independently. Some of them never grasp the complexities of regular human life enough to be able to drive a car, or look after a bank account by themselves. Yet, they have one or more very superior gifts which they can perform better than other people can. Also, there are those savants who do very well at many things; they have their specific savant abilities, combined with a knack for picking things up rapidly (one sign of the type of intelligence measurable in IQ tests), and they are whizzes at various things. They thirst for knowledge. They are insatiable.

Contrary to what a few teachers still believe, most autistics enjoy learning. There are many examples of this. If an autistic is
interested in learning, but is unable to get others to teach her, she will find a way to teach herself. Sometimes, communication skills aren’t developed enough to tell others what she wants to learn about. Other times, too many surrounding people don’t have faith in this ‘autistic cripple.’ If other people are condescending, and have no faith in the special child or adult, he will begin picking that up and have no faith in himself.” p.57

In my post called Sensing the World Into Existence, I entertained this notion of intuition and exceptional sensing by Adam. The way he hones into my emotions in a split second, the way he inherits them as his own and is so sensitive to people in general -- there are many times I believe that his sense about people is much more acute than mine (and I like to think I’m pretty intuitive). There is just as much, if not more value in this way of living, and like Weaver suggests, and the way Albert Einstein stated, our society no longer values the child-like perspective, the sense of wonder that gets lost in the face of the quest for the material, the quest to be like others, and hence, nothing.

I hope this extensive quote from Jasmine's book further suggests that autism is a gift, and further, how we may be misguided in our approach to teaching our autistic children. If we take this view, perhaps we can create learning environments that nurture inherent strengths and talents instead of focussing on the negative, on remediation (sorry, there's that word again), and on changing autistics to be like us.

(I'm in Florida now and can't yet figure out how to make links for you on this computer...bear with me!)

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Asking The Questions -- Deconstructing A View

In a world that I cannot fully understand how do I know how and what to teach? I’ve asked the question to Zilari who wrote a great post “Listening or Not Listening” about what is important to teach autistic children.

My main concern is that we are trying to teach “connections,” and
“appropriate responses” to people who see the world upside down, so to speak. I am doing just this – trying to interpret Adam’s perspective and finding the modes of teaching that will nurture his inherent strengths. Because we live in the environment we do, see the way we see, we do not know what else to teach. We set up classrooms in a particular way, we talk to respond to questions, write tests – it seems that autistic intelligence and perspective is completely different from our own and that perhaps we should not be the ones imposing teaching styles and methods upon our children. So, hopefully our friend Zilari (and the rest of you with autism, I hope), will continue to shed light on this as much as Larry Bissonnette, Sue Rubin, Lucy Blackthorn did in Biklen’s book *Autism and the Myth of the Person Alone*.

I also find words of wisdom from *Squaregirl*, who is autistic and teaches children with autism. Donna Williams who consults online has agreed to attend my festival this October. I have also discovered a great deal about Adam through correspondence with her. In trying to support people with autism, I really seek out their advice. It largely comes out in their writing, as it can be the easiest means in which to communicate.

Donna wrote me that typical teaching styles do not always befit the child. In the case of Adam, he is like a “cat,” she said, and when cats are ready, they will join in. I don’t think that RDI or ABA will be patient enough for cats. RDI claims that the autistic child is “confused” about the environment and we, as parents, have to be their guides. That sure makes sense to me. In this methodology, we are teaching children how to have a relationship with us, assuming that this could never develop on its own, in an autistic way, and perhaps that way is not acceptable to us as parents who long to hear the voice of their child, who crave a hug and affection. But does this show of affection and relationship mean the same thing to an autistic person who doesn’t see anything inherently wrong with the way they see things, but rather, struggle within a world that forces them to be like us, or may show affection in an utterly different fashion? Did Tito’s insistent mother convince him what was “good” for him? Did Stephen Shore, whose mother didn’t have any interventions, fare any worse? Acceptance and what that fully means is a fundamental question as I continue my struggle to understand.

As a parent, it feels wrong to sit and do nothing. There is an autism
culture out there pressing us to give our kids tons of remedies and therapy. Our culture is wrought with pressure to hire an expert, buy a drug, go on a diet...DO SOMETHING to fix things, because the way things are can never be right. There is always some marketer out there who says we can have more, do better. Then, in our kids we see improvements, so it must be right, right? Do we ever consider if “improvement,” whatever that means, could happen on its own, with an individual’s development of consiousness or SELF? Afterall, where would these kids be without remediation? Out of love for our kids, I too justify my actions – trying to help Adam “connect with the world” (do I presume he doesn’t in his own way?), respond, get by in school, keep him safe in an unsafe world. All seem to be worthy goals, and they are done out of sheer love, and fear, for our kids.

Mainstreaming seems to be a goal too – anything that helps our kids “blend in,” garner a group of peers so they won’t feel alone – this is one aspect of autism that shakes us parents to the bone, and one that kept me in shock the minute my husband uttered the word “autism” on November 28, 2004 at 3:30 in the afternoon. Picturing my son without friends, or with peers that look at him oddly, judgmentally, simply broke my heart.

Today, when I read people with autism, I feel more at ease about autism but now worry that what I am doing still does not honour Adam’s way of being fully. The intellectual debate is important because we are at a stage when we do not accept difference and disability entirely.

In a discussion with my husband about words, he stated that the word “remediation” is like “splitting hairs.” His eldest son, who went to an all boys academic school, did a math remediation course, he said. So, on the surface it seems harmless. And yes, it may be splitting hairs. But what of “remediation” classes for special needs kids in public schools? Is that the right word? It offends me because it assumes that all special needs kids are cognitively delayed ---that they need to be fixed.

“Too often, individuals with autism are asked to make accommodations, to use ‘typical behaviour,’ and to learn ‘appropriate social skills.’ Instead of asking students with autism to make all of the adjustments, teachers and students without identified disabilities can rethink their ideas about concepts such
as `typical,' and `appropriate’ and question whether conforming is always the best way to support students with autism. For instance, instead of asking the student with autism to study all of the social norms of attending a basketball game (e.g.; sitting on bleachers, cheering when the home team scores), all students and teachers in the school might expand their notions of what appropriate participation looks like." (From Paula Kluth Your'e Gonna Love This Kid: Teaching Kids with Autism in the Inclusive Classroom p.107).

Taken a step further, if we can accept differences in development, that development does not always occur on the same timeline for everyone, then we might be able to rephrase education as “individual.” Individual Education. It is a term that is used today but not to its fullest potential. Think of all the skills and talent we could develop if we really understood different ways of learning, seeing, understanding? I think there is a lot of possibility in that. For this reason, I turned to a lot of books on different intelligences and gifted learning to discover that most gifted people have a learning disorder. In the face of autism, that makes complete sense. It acknowledges that giftedness is inherent in so many of us, despite other areas of weakness. If we can view all of us as gifted in some way, in a more general sense, then we might be able to honour the person’s individuality, and difference.

To me this is the most important thing we can do as parents to help our children and ourselves in appreciating them. It is reframing our views, thinking about our actions, our words and what Being, Belonging and Becoming means in this question of what it means to be human.

We are off to Florida to visit Adam’s grandparents now. It is a time when I can stop and watch Adam run sand between his fingers and stand at the foot of the ocean, wondering how this world looks to him without always having to “re-direct” him. There is a kind of freedom in acceptance.
Stumbling Over Words

I anguish over how to put things. I find that expressing myself often comes out wrong in this heated dialogue about autism. I stumble over my own words, trying to say the politically correct thing, something that sums up a thought just so, a word to describe the formidable nature of autism and acceptance -- and turn to autistics for answers. I seem to never get it “right,” as being who I am is intrinsically wrought with problems from a set of experiences that inhabits the way I see things.

But the words must continue to flow, the effort must never cease.

I am confused as to why, when I say that we need to accept our children the way they are translates to some of you as a parent who idles – does nothing for one’s child. In some personal emails directed my way, I am under the impression that my use of that term “acceptance” means I sit back, marvel at Adam flicking his hands in the air and say everything is okay -- that somehow there is simple poetry in that and it should just be. (There is some poetry in it, by the way, but it can get in the way of learning). That baffles me. Accepting the autism does not mean giving up, it does not mean that children of all kinds do not need to learn. It does not mean that everything about autism is wonderful. It simply means I accept the autism in my son as his way of being, for better or worse. As he grows older, he will have a way of showing me the way he sees the world. I accept that he will not be like me. He will have obstacles and he needs my support and society’s acceptance the way he is in order to feel like a validated and contributing member of society, and to feel a part of it.

I am constantly anguishing over teaching styles and do not abandon a style of teaching simply because I hold these principles of accepting the autism. I just do not want anything to harm my child, or to squelch any of his sense of SELF. -- it is a myth that autistics are not intrinsically motivated by many things and must be constantly reinforced artificially. As I said in my previous entry, I simply try to cull from different teaching approaches to find what works for Adam. I have an “antibehaviour behaviourist” (her words, not mine) consultant on my team, who has learned to welcome many styles of teaching. We debate and follow Adam’s lead in what he wants to learn because I see that he has many interests. At this stage, Adam’s perfectionism sometimes prevents...
him from trying again, so lots of praise is important for him now. I want to encourage every attempt he makes. He is so intelligent, my little guy. I pains me to think that just because he doesn’t want to say hello to someone on cue that his entire mental faculty is judged in an instant.

I am incited by people who want to cure autism. This is clearly against the wishes of those with autism. Strict behavioural approaches also hurt people with autism. It’s not that I don’t think all behavioural tactics are horrible – we use them everyday with all kinds of children to motivate them from potty training “stickers,” to stars on a spelling test.

Whatever language you are using, “remediate,” “teach,” “help,” “help connect” -- many of us are simply trying to help our kids learn within the environment we live, and with the obstacles that are present. At the same time, other people who use those same words “accept” are doing just the opposite in the way they do things. Some people talk the talk, but they definitely don’t walk the walk. Meaning is subjective and words can be manipulative.

Accepting autism does not mean that we as parents do not want to help our children function and hopefully enjoy the world in which they live. We simply want to respect the viewpoint, the perspective so that the world will make a place for them, give them a voice, let them make choices for themselves. As I said in my post “What Is Quality of Life?” empowerment is about choice and it belongs to everyone with any kind of disability. If we do not continue to raise awareness and BELIEVE in autistic intelligence and competency, then society will not provide autistic people with any rights of self empowerment. This is why I think language is important – we always have to think about how the rest of society will decipher it when it comes to creating tolerance and opportunity for our children as they grow into adults.

I know I’ve started a debate about semantics and how I believe it reflects the way we think and feel and then how we act in society. It seems I too am making a lot of mistakes in my own semantics, and look to the community of autistics for help. Even that word “autistics” I discovered, is the more accepted word, where I thought referring as “people with autism,” was more respectful. I am wrong, however. In Why I Dislike First Person language, Jim Sinclair wrote in 1992:
But when I – and other autistic people – choose to refer to ourselves as autistic and express our preference for being referred to that way, and we are told that our opinions don’t count because non-autistic people have decided it’s better for us to be called something else, this shows absolute contempt for us as self-aware, communicatively competent people. The idea of putting the “person first” in language makes about as little semantic sense as saying “White Christmas” is racist...To put it bluntly, your prejudices are not our problem, and you should find ways to deal with your prejudices without trying to cut our nature off from our personhood. It is tremendously invalidating to say that people’s basic perceptual and mental processes are so inferior that they’re not compatible with personhood.

I apologize if I’ve offended anyone with autism. I am always stumbling over my words. Everyday, I seek to find the politically right way to state things. I encourage autistics to help me along the way, for I will never know what it means to be you and how you feel about the way I represent you in my writing.

The language debate takes its toll. Kit Weintraub likes to really twist language around to state that autistics who dispute her are “not really autistic at all,” and that the plight with her son is different, more serious. This is an example of a parent of an autistic child who is doing nothing to advance her child’s rights and opportunities and in fact is herself, discriminatory against autistics. This is just one example how parental community is ripe with prejudice:

In Support of Michelle Dawson and Her Work from autistics.org, Kit Weintraub “claims that she doesn’t want her children to be cookie-cutter people, but on the other hand says that if she could erase her son’s quirkiness, she would, because people don’t accept him for it. She describes medicating her daughter for her behaviour and hospitalizing her to use a ‘tough’ behavioural approach to get her to eat when she started having sensory aversions to food textures, and makes it sound as if this the only possible solution to these situations. Above all, Weintraub does the usual things that are done to dismiss the opinions of autistic people:

- She questions whether we are really autistic at all, showing the
skills we do have, particularly intellectual and writing skills;

- She simultaneously makes accusations about lack of empathy, insight, or compassion that are often leveled against autistic adults who disagree with the presumed parental status quo;

- She mistakenly equates the statements “We don’t want a cure,” “Autism is an integral part of who we are,” and “We don’t want ‘help’ that harms us” (which we do say) with the very different statements of “We don’t want help with anything,” “We have great lives,” and “We think all parts of autism are absolutely wonderful” (which we emphatically do not say).

- She brings out descriptions of her children that are intended to show how different her children are from us, without ever meeting us to know how we were at their age or even how we are now. As Dawson herself says, “How you can tell me when exactly it became good science to diagnose over the Internet.”

- She makes it sound as if problems (when they are actually problems) have an all-or-nothing solution – either her methods or nothing, and that means Dawson is advocating neglect.

- She blames her children’s difference for the cruelty that other people show to people who are different, thereby shifting the responsibility for their actions off intolerant people and onto autism.”

From Weintraub’s words to our ears, this example shows how semantics reflect the way she views her child and people with autism. It is very important that we all try to watch our words because others are listening and interpreting them. I don’t think dismissing it as “perilous territory,” is an excuse to give up on trying. The work on our part, will always be to clarify our meaning.

On a personal note, Adam found the right words today. A child was bullying him and Adam retaliated by pushing them away and saying "NO!" I say this because in the past he has always been passive to a bothersome tug. I have been hoping and praying for him to find the words and initiation to retaliate when people bother him. He is truly a little cherub, snuggling sweetly to me, hugging the dear people in his world. At times I’m afraid that he doesn’t discriminate enough -- not everyone will be his friend in life.

Yesterday, he developed some canker sores in his mouth and he looked to me for help, putting his hand to his mouth saying “mouth, ouch!” I was so happy to hear his little voice. It is afterall, what I need to understand his needs. I’m happy he is finding his voice so he can speak up for himself. It certainly doesn’t matter
how he communicates, it just matters to me that he can so that I, the alien in his world, can help him.

None of us know it all and it is vitally important that we open our ears to autistics. What drives us emotionally may not always be in the best interests in our children. The head and an open heart must work harmoniously. Autistics.org, is a great site that demystifies autism and speaks for the rights of autistics. I find the site is extremely helpful to me in raising Adam and helping me see him. Here is another quote from In Support of Michelle Dawson and Her Work article:

“Some of us assist parents in finding solutions of how to raise their children in a way that respects their uniqueness, including autism, and does not hurt them, but also helps them grow. We do not think of parents as the enemy, nor as refrigerator parents, but we have little patience for the particular parents who insist we are bad for discouraging harm to autistic children. We are not oblivious to the difficulties involved in raising autistic children, particularly in current societies, and we are not ignorant about possible solutions that don’t involve mistreating people. We simply don’t believe that being the parent of an autistic child, or even loving one, means that a person suddenly becomes incapable of harming that child.”

I like to think about how my son would feel if I told him he had to be “remediated,” which implies, rectified or fixed. Once I think of it that way, I can steer clear of those words and find other ones that reflect better my absolute love for him, and my efforts to learn about autism and accept him for who he is with it. It is important to think of these words because someday, science may just one day find a way to “fix” our kids and then there will be no more like them. Is that what we want?

Insidious harm can most definitely dwell in words.
It is wonderful how much time good people spend fighting the devil. If they would only expend the same amount of energy loving their fellow men, the devil would die in his own tracks of ennui. Helen Keller

There is such dissention among parents about autism. Parents “fight the battle against autism,” “remediate autism,” and use behavioural methods to make their kids more like them. Let’s stop beating around the bush and call a spade a spade.

I understand and empathize with the process of learning about autism and how difficult it is to just accept it -- the way we view the world is difficult to transcend. The important point is to transcend it.

I will reveal how I’ve come to this point on my journey, a journey like every other parent I’ve read, more or less. First, I noticed parents were in some kind of reticent competition to see whose child was “doing better.” I noticed this when my son was first diagnosed – some sort of strange comparison between parents as to whose child was going to “beat” autism first. It was thought that if one child was verbal, that child had an advantage over the other. We all wanted our children to be PDD-NOS or Aspergers, if we had to have a diagnosis at all – anything that eluded to normality, better functioning, and to being more acceptable to society. Catherine Maurice said she “cured” her kids of autism. We all believed her. So, we all wanted to try as many strategies as possible to “remediate” the autism, and most of us went to every conference and workshop imaginable (RDI, Floortime, ABA conferences...I traveled all over the US in search for a way to "cure" Adam as "quickly" as possible).

If I had to describe my journey in all of this, I can tell you right off that not one person could “cure” the autism out of Adam. I hired and brought to Canada every person I could. If I couldn't, I went to the US to visit them personally. The unexpected happened during the process -- another kind of transformation, and a more fundamental and important one at that.

When viewing how little “experts” understood my son, and viewed him as pathology, a set of “behaviours,” or as diseased, I knew that we had taken a wrong turn. When we practiced more social strategies (RDI was a turning point, I must say), Adam lighted up.
It was like he was happy to be acknowledged, to play. But the Connection Centre took our full fee and stopped servicing us because I needed to integrate their strategy with ours. Doing an obstacle course three times a day for fifteen minutes hardly seemed like enough. (We never got our money back, by the way). Just before I was to enter Adam in nursery school, Dr. Gutstein told me directly not to: “It doesn’t matter when he enters school,” he said to me firmly. While I agree, it hardly matters in the sense of time, it did in that Adam derives a great deal of satisfaction from being with peers and is a wonderful observational learner. I wouldn’t have discovered that if I hadn’t put Adam into school.

We still use many modals of teaching today, but in our own way that is successful for Adam. Everyday, we do the hard work of figuring out how best to teach Adam – and believe me we really have to find answers ourselves. I always appreciate a new strategy practised or researched by another to see how we can cull from it. Adam, if I must provide a progress report (seems to be wanted) is happy, he is in nursery school and he will be attending a “regular” primary school -- I am working with that school to obtain the accommodations he needs. I found a school that is flexible, private, and willing to work with us to teach Adam in a way he needs. None of this will be easy, but I find a positive attitude goes a long way with teachers.

Over time, in researching autism and running my son’s team as my full-time job, I stopped listening to the “experts” and turned to people with autism. It is through them that I am at a wonderful place on this journey – learning to absorb, live with, and continue to try and understand autism perspectives. I have come to view it as another marvelous way of being and I believe this benefits Adam and my entire family. Adam continues to learn as we respect his many needs. I believe he could have become aggressive, banged his head – and he might if he meets the wrong teacher. I know that it is because we acknowledge his frustrations and help him through them that he is a “well-adjusted” kid – he seems to be developing good sense of self and a healthy attachment to me. There were signs early on that this could have been quite a different scenario. Had I listened to the experts, we would not be at this point today.

Stephen Shore is autistic and obtained his doctoral degree in Special Education at Boston University. He noted that during his
day, there were no interventions for autism, with the exception of his mother who did "what she felt was right." (from Reflections of a Different Journey: What Adults with Disabilities Wish All Parent's Knew, p.57). "It is important to do what seems right for your child."

All in all, a parent really has to learn, study, and trust themselves and respect the point of the journey that they are on -- the journey never ends. I know this is hard to take in an era of gurus and genome research – and a view of science as a new God with supposed cures and answers for everything. At the heart of the matter, this all has to do with embedded stereotypes about disability.

Here are some points that I have come to learn and believe on my journey as a parent of a child with autism:

1. All autistic people deserve to be accepted for who they are with autism. They cannot change, and becoming “indistinguishable from one’s peers” should not be the ultimate goal in teaching them. In fact, it’s a horrible and sinister goal.

2. People with autism deserve a right to be treated and taught intelligently and be offered the supports that help them learn in the style that befits them. Not all autistic people learn in the same way; not all autistic people are created equally.

3. Autism cannot be remediated. Period. (Semantics reflects thought so watch your words!)

4. No parent should support any organization that seeks to cure autism. Any one person or organization that uses these terms is fundamentally against the lives of our children. To them, my child is an aberration, and the “enemy.”

5. My child deserves to have patient teachers -- ones that do everything in their power to find what drives him to learn.

6. My child has a right to learn the following: want, wonder, discovery and desire -- not simply learn “how to respond.” He has the right to choose and make decisions about his own life and to be presumed competent.
7. My child deserves and will likely go to university. A child most often (albeit not always) lives up to the expectations of their parents. It's all about what we believe. Further, various supports and accommodations at university can be made.

8. Achievement carries no timetable.

9. As a parent, I am my child’s one and only advocate. I do not expect an expert, a teacher, and an organization to do this for us.

10. No Jim Partington, Catherine Maurice, Steve Gutstein, Ron Leaf, Stanley Greenspan and the like is our saviour or will save my child from autism. Some people have talents in operationalizing teaching methods. These people have done just that. There are good things in many methodologies, but not one is “autism religion.”

I highly recommend autism cynics to start reading books written by autistic people. Also, read Reflections from a Different Journey. (See sidebar).

_no pessimist ever discovered the secret of the stars, or sailed to an uncharted land, or opened a new doorway for the human spirit._

_Helen Keller_
problem is that autistic intelligence is not measured accurately," Dr Mottron said..."In much of the autistic community -- support groups dominated by parents of autistic children ... is public enemy number one. They want autism to be a sickness that needs to be cured," she said. "They say horrible disgusting things so they can get more money for their lobby groups. They make me sick," Dawson said.

Bravo. Read the Globe and Mail link for full story above.

Autism R and D

Three points converge to a head.

**Point One--Awakening:** I turn on my blackberry to receive an email newsletter from NAAR stating that their merger with Autism Speaks is completed, and they will together “fight the battle against autism.” Like the war on drugs and the war on Iraq, they got the President Bush’s wife to join in. It’s all sympathetic to the triumphant war hero, and many like to be just that, even at doing so at the expense of others. Even Alan Greenspan has decided to get “bullish on autism.”

**Point Two -- Early A.M.:** Had breakfast and went to get an overdue pedicure before a short jaunt to see grandparents next week in Florida. Hubby bought me Jasmine Lee O’Neill’s book, *Through the Eyes of Aliens: A Book About Autistic People*. I read while my feet are immersed in soothing warm water. I consider buying it in bulk for the October show, for my family and friends as the Autism Reader 101. I am nearly in tears at her ode “For An Autistic Child:"

*To you in your world,*
*Locked inside yourself,*
*An island,*
*Isolated winds in your mind,*
*To you, locked inside beauty,*
*Inside anguish, inside joy,*
You live
Breathe
Die
Emotions
too profound to understand,
Little one curled up rocking,
Your floor your world,
Safe,
Just you,
Your little expressive hands,
Like tiny little birds,
talking in flutters,
your little angry snarls
repel a monstrous outside realm,
your beloved treasures:
Buttons
Diminutive faery animals
Smooth wooden beads
Dots of sunlight on your wall
Humming your songs
to calm your anxious hands,
Safe,
Just you,
At one with rhythm,
Your world
only bits of those others
who come and go like currents of air,
barely ruffling your forelock,
Your face a delicate empty mask
to those who see only with eyes,
Those who don’t understand,
your world,
To me,
watching you,
I see myself,
I sing songs for you,
little one, to tell you,
You don’t have to forsake your world to be free.

I hold back the tears behind my new reading glasses, hiding my face behind the book face:
Through the Eyes of Aliens by Jasmine Lee O'Neill...should be Autism 101 Reading.

“The autistic world isn’t a dark and horrid chamber. It perhaps sometimes appears that way to outsiders. Knowledge and understanding will lessen the fear. For, as an autistic fears new or unknown people, events, places, even foods, a non-autistic may also fear a world inside another that seems incomprehensible...” (p.18)

Fear is the ogre. It is the war-monger. It lives in Presidencies, in massive organizations, and in research that seeks to ameliorate people with autism.

**Point Three -- Lunchtime:** Picked up Adam and we go to music class -- we haven’t been in two weeks because of how ill he has been. On the positive side, he was watching his peers and especially the teacher – he seemed to be having a good time. On the other side, he preferred to lie down and watch the ceiling in circle, and he didn’t want to be “redirected.” I felt that he was being directed so much at one point, that he wasn’t allowed the time and space to be competent. He preferred to circle and watch like a cat, and when he was ready, he pounced in. The other children were watching him. It is all too noticeable, being a parent, trying so hard to appreciate him for himself, for his autism, to appear on the surface accepting and unaffected, and watching other eyes full of judgment and wonder -- in children as young as three.

“You should not seek to change what you are, or try to do it to another. I also don’t agree with the therapists who try to prevent an autistic child from seeking refuge in her inner world. There are extroverts and introverts. If an autistic person doesn’t
actively relate the way others do, so what?" (p. 21)

It all comes to a head -- P.M.: Begin writing and am feeling discombobulated --- Why or why do we have so much fear of people who are different in the world who can persuade the Laura Bush’s with words like “fight,” “battle,” and “war” and a multi-million dollar budget. I call for peace. Stop the fight against my son. Love him and accept him for all his wonderful traits. Let’s start a new Autism R&D project – Autism Respect and Dignity.

Drops in the Desert

One day a family drives to Haifa -- a son with cerebral palsy and a hearing aid. Thirty-six years ago, hearing aids were obvious – wires coming down from the ears and a box against the chest. Mother, father and son had to make a stop. Father got out and two young children, around the age of six, came out of a store and stared at the boy in the car with the hearing aid and mumbled something to themselves. Mother notices and says,

“Do you want to know what this is about?”

The children hesitated, unsure of what to expect.

“Come, let me show you,” she beckoned.

The children approached slowly while Mother took one of the earphones out of her son’s ear. The son couldn’t move, so Mother explained to the children why he couldn’t move and why he had the funny earphones with wires.

“Why did you do that?” asked an observer. “Do you think they will care?”

“It’s like a drop of water in the desert,” said the Mother. “Over time, there will be more drops and then something will grow.”

When it comes to creating tolerance and awareness in our society...
about disability, we are pouring drops in the desert. It seems like
we'll never get far, that our voices will never be heard, but over
time the drops will become more frequent and we may have
ourselves one fine oasis.

Dr. Nehama Baum has people with complex disabilities enter her
centre. Some are suicidal, homicidal, and incredibly aggressive
when they arrive. Most have come from complicated backgrounds,
some even abusive – from families who have tried so hard to
change them, and like putting a square peg into a round hole, we
all know this is impossible. When they enter MukiBaum and are
acknowledged for who they are, however, with schizophrenia,
autism, and a number of other complex issues, they are able to
calm down, learn and attain the quality of life I talked about in
yesterday's post. When one is talking about autism in this context,
I must also refer to other disabilities. I cannot interchange one for
another when it comes to conversations about acceptance.

"If one can acknowledge the other's voices in their heads and enter
their inner world," (referring to schizophrenia) says Nehama,
"they feel respected and become easier to reach." No matter what,
Nehama wants to enable Identity in some of the most severe cases
of disability you will ever hear about. Some continue to paint and
have become quite prolific while others have used art as a
therapeutic tool.

Jordan, from MukiBaum Centre for Complex Disabilities has 5
diagnosis'. One of them is schizophrenia.

So why am I going on about this? I do so to continue to raise
awareness and will be setting up an organization to do this. I am
organizing another big arts event this October -- so far featuring
Donna Williams, Michael Moon, Mukibaum patients, and Jonathan
Lerman. I will be seeking more -- email me if you’re interested.
We are all bricklayers – we need to build the bridge between the
world of disability and the rest of us. As Autistic Bitch from Hell
The neurodiversity movement is based on the belief that there is no such thing as normal when it comes to the human mental landscape. The neurotypical person simply does not exist. Together we display a wide variety of neurological behaviors and abilities...

Consider that for a moment so we can stop creating that lingual and conceptual divide between “us and them.”

And the drops in the desert story? It belongs to Dr. Nehama Baum.

What Is Quality of Life?

Front and centre of this dialogue about autism is inclusion. At the heart of the matter, understanding and acceptance that people with autism and other disabilities is needed, and as parents and people diagnosed with ASD, we need to keep up aggressive dialogue and awareness-raising so that equality can be achieved.

Too often, “mainstreaming” and “integration” are touted as goals for children with autism without recognizing the missing components that make this successful. As mentioned in recent posts by Autism Diva, and Elmindreada, “mainstreaming” currently leads to bullying because children are not taught to accept difference, and integration is mere lip-service as schools try to integrate by have little idea of how to successfully include and educate children with learning differences. As Adam and I prepare for entry into JK, I think long and hard about what we are in for in terms of prejudice, snubbing by his peers, and his need for a different mode of learning in order to achieve the quality of life I believe we are all referring to.

When we talk about quality of life for people with autism we
usually talk define it in subjective terms as “being happy,” “being fulfilled,” “having a job,” “getting married.” While these should still remain goals, we cannot reach them if we do not acknowledge the missing links in the system that result in endless obstacles.

In essence, we are talking about a paradigm shift in thinking – an evolution of how we view disability. While it has changed significantly over the years, we still run into a general concept that “quality of life” for people with disabilities is the physical care of them, while ignoring other spiritual needs -- as caregivers do not believe these needs are at all present or desired in people with disabilities.

So what is quality of life for persons with disabilities? Society, for the most part, still largely shoves its differently-abled members in places where it will not disturb and perturb them, where it will not agitate their homogeneous state. As I noted in my post Smack Dab in the Middle, a recount of my first visit to the MukiBaum Centre for Complex Disabilities in Toronto, my personal prejudices, despite my having a child with autism, were all too notable. In this recognition of my state, and how I arrived to it, I realized how hard we must work to include the heterogeneous members, the disabled members, into our communities more rigorously.

Nehama Baum, PhD and founder of MukiBaum, talks extensively about quality of life for people with disabilities, and the power of art education in embedding a sense of self and identity. In her paper, “Enhancing the Quality of Life of People with Dual Diagnosis: The Power of Art Education” (The Journal on Developmental Disabilities, December 1997), she notes through her research that “[people with disabilities] are seen [by their caregivers] as not being able to make decisions because of a lack of intellectual ability, and more simply, because they do not know how. The perception is that they cannot interact because they are acting out and they do not possess talents because people with developmental disabilities are not capable of creativity. As a result of these long-held beliefs, caregivers have felt that their role was predominantly to care for the physical needs of the people in their charge and to ensure that they comply with what the caregivers perceived to be the ‘best for them.’”

As I continue to evolve the way I myself view disability, autism, and my son, I consider in this last statement, all the therapies and
modes of autistic education that teach compliance because “it is best for them.” Is it? In doing this, are we truly accepting and understanding the difference? While I cannot entirely change my viewpoint (I have my limitations), I will still want Adam to pay attention when he is learning, or when I am speaking, but perhaps I will also be able to adapt and empathize that he comes about things differently.

Baum goes on to define quality of life encompassing these basic human needs:

Being = refers to one who is an individual
Belonging= refers to a person’s fit with his/her environment
Becoming=refers to the intentional activities a person becomes involved in when striving to achieve goals and actualize wishes

We must ask ourselves if the scientific communities and organizations like NAAR are enhancing these opportunities for personal power of those with autism in their use of phrases like “epidemic” and other negative semantics that paint a picture of people with autism as slightly less capable, a little less than human. In preparing marketing campaigns and slogans for the purposes of fundraising, what damage are they doing to the ongoing struggle to obtain “equal rights” and acceptance of people who are different?

“Reiss, Levitan and Syszko (1982) observed that, in many cases, when an individual has a developmental disability, other aspects of his/her life are not acknowledged. Reiss et al. called this phenomenon ‘overshadowing.’...Such perceptions influenced the development of services that were provided to these individuals over the years (Menolascino, 1994). Programs for people with dual diagnosis tended to emphasize teaching based on the perceived deficits of the individual, without taking into consideration areas other than practical skills for living and adaptive behavior. Such programs gave little attention to exploring and developing the potential of these individuals...Furthermore, this approach has also emphasized behavioral interventions with externally imposed standards of appropriate conduct. No acknowledgement was given to other possibilities. Therefore, programs that accentuated such areas of life as creativity, artistic talent, inner growth, cultural identity, economic self-sufficiency and community inclusion, were not developed.” (p.103)
Organizations like NAAR, Autism Speaks, Cure Autism Now, many behavior analysts (not the evolving ones), many peddlers of autism products, diets, cures, some scientists, even some parents ascribe to a reductionist view of the person with autism – a judgmental view regarding a person’s Being. (see yesterday’s post on Do Animals Have Feelings, Do Autists?). “For example,” states Nehama “if it is assumed by others in his or her environment, that an individual is manipulative, suspicion about the motives of all the person’s interactions may develop. Similarly, when an individual is evaluated as an ‘aggressive behavioral problem,’ the social environment might become more rigid in its expectations and more restrictive in its allowance of freedom and choice. In turn, this increased restrictiveness could affect the individual’s ability to intentionally choose goals, initiate activities, adapt to life changes, and develop as a person (i.e.; the Becoming area of life).”

When Dr. Joseph Buxbaum indicated the plight of parents, and I hear parents who want a cure for autism because their kids are banging their head against the wall, I consider that these components of enabling a sense of empowerment and self have been ignored in exchange for the ongoing struggle to make our children “like us.”

Nehama goes on to say that while quality of life is a complex concept, with subjective and objective evaluation of physical, material, social and emotional well-being, the holistic approach touches upon many aspects of a person’s life and incorporates both empowerment and choice. (p.99) As much as the objective realm is important (housing, employment, income), “the subjective realm (social support) is comprised of a general feeling of well-being, feelings of positive social involvement, and opportunities to fulfill one’s potential.” (p.102) I do believe that fulfilling potential is the utmost goal for Adam because I see so much potential. As a curator of art, this was also apparent in the work of Jonathan Lerman – how the spiritual side of him is still growing, exploring and is utterly intact (see my side-bar for video footage of the exhibition).

“In order to enhance quality of life of individuals with developmental disabilities...an added effort has to be put into developing opportunities in both the objective and subjective dimensions. In doing this, there needs to be an emphasis on creating a balance between them. This should be a process that is
person-centered and person-referenced, but that also takes into consideration environmental realities.” In her studies, art (painting, drama, movement and music) “are psychodynamic therapeutic modalities for the promotion of consciousness, emotional growth, and well-being of children, youth and adults with dual diagnosis.” (p. 103)

In my posts Sensing the World Into Existence, and On Becoming a Self, I also explore the need to enable self-fulfillment, actualization and awareness through sensing, art, and acceptance. As we learn to appreciate and accept people with autism, as we begin to think about and define what we mean by quality of life for people with differences, we will be able, as parents of children with autism and as adults with autism, advocate for the supports that will enable a sense of SELF. Even more important, we will offer people with autism empowerment and choice over their own destiny.

Do Animals Have Feelings....Do Autists?

A recent article in MIND (Scientific American February/March 2006 issue), discusses scientists who debate the issue about whether animals not only have emotions, but are aware of their emotions. It is this self-awareness and reflection that connotes an emotional sophistication akin to humans.

Charles Darwin was the first to devote an entire book on the topic, The Expression of the Emotions of Man and Animals and concluded “striking similarities between human and animal behavior.” Later, reductionists stated that “all animals are merely organisms that follow hardwired, instinctual behavior patterns. They are devoid of feelings.” (p. 26)

This statement resonates with similarities to our scientific community studying autism today. From Hans Asperger to Simon Baron Cohen’s mind-blindness theory (see Zilari’s post on the topic) to recently Joseph Buxbaum’s rather sinister personal response to my blog, the person with autism is reduced to a subset
of component parts. By looking in too closely, some scientists cease to see the forest for the trees.

Antonio Damasio who wrote *Looking for Spinoza*, cites the difference between social and instinctive emotions. He notes that feelings stem from self-reflection. “Primary emotions include fear, anger, disgust, surprise, sadness and joy, and Damasio ascribes them to many animals....To Damasio and many others, emotions are physical signals of the body responding to stimuli, and feelings are sensations that arise as the brain interprets those emotions...For social emotions, he lists sympathy, embarrassment, shame, guilt, pride, envy, jealousy, gratitude, admiration, contempt and indignation.” (p.27) Some scientists believe that these emotions are largely automatic and inborn – “routinized mechanisms to help them survive.”

Sound familiar?

Feelings, the article states, are born of awareness of the body’s response to emotions and an ability to self-reflect on those emotions. “Damasio theorizes that pygmy chimpanzees, for example, may be able to show the social emotion of pity for other animals but that they do not realize they are exhibiting pity.” (p.28) This sounds like current autism theory “children are unable to attribute the beliefs of others.” Or taken further, people who claim that people with autism are unable of feeling empathy.

In response to that theory, I think about Dawn Prince Hughes who has Aspergers, and her learning of herself through her Gorillas in *Songs of a Gorilla Nation*. Here she speaks of one Gorilla she names Nina:

“...*She stood up and with a flourish snapped the burlap from her neck, then let it billow out before her while she held two of its corners between her thumbs and fingers*...*She spread it out on the grass and smoothed out the wrinkles. When the material was perfectly flat, Nina eased herself down in the middle of her picnic blanket and looked up to the keeper after letting out a long sigh. She seemed suddenly self-conscious as she noticed the look on my face. It had been an incredibly involved set of steps, and we were awestruck.*” (p.126)

Hughes not only observed the Gorillas and decoded many of their
complex social and emotional nuances, but she came to learn about herself through them:

“Very cautiously, I tried to apply the things I’d learned from the gorillas in social situations. I tried to put people at ease by acknowledging them with quick sideways glances and smiles – which evolved from submissive primate grimaces and are intended to convey that no harm is meant.” (p.134)

Here is another example:

“...Eventually I showed him the contents of my lunch...He pointed to the bottle. Still feeling stupid, I shoved the bottle against the window and shrugged my shoulders – it wouldn’t fit through, I tried to say. He pointed to the wall where the keeper threw his treats. He knew the trail led to a secret area close to where I sat. He raised his eyebrows. `Walk up there and throw it down to me...what kind of stupid gorilla are you, anyway?’ he seemed to say.

I shook my head and pointed to my seat and notes, a feeble attempt to demonstrate my duties. He turned his body away from me and reached back to bank the window with his fist, pursed his lips, let out a raspberry, and then pointedly ignored me. Occasionally, he would turn to look over his shoulder and purse his lips in my direction. He didn’t need to say it in English; I knew what was going through his mind.

This was one of the first times I remember knowing for certain what another person was thinking and feeling, and that my actions were a direct cause of their subjective experience. Something about the directness of his communication, combined with the honesty of his body language and his emotions, painted a kind of consistent and forthright picture that allowed for a moment of communication that was, paradoxically, more intense and more subtle than that of a human person. It demanded that I stay engaged until the moment had resolved with both of us as participators. It is clear to me that not only do apes have a language that is complex and holistic, but by communicating with us, they illustrate that it may be we who are less skilled at the art of sharing true subjective experience.” (p.136)

This is obviously the problem of humankind – our arrogance and
The article in *MIND*, notes that feelings such as joy arise from the mind’s awareness in bodily emotions. Sumatran “orangutans swing from branches and splash their hands into pools of water for no apparent purpose than just for the fun of it.” (p. 29). Studies show that brain metabolism for animals is not very different from those in humans. In the end, it is still “not possible to prove whether an animal possesses conscious feelings [any more] than we can be sure about what another person is truly experiencing.” (p. 29)

Again, science has no slam-dunk answer. I posit that there are elusive things in life that simply aren’t measurable through fMRI’s, namely the complex process of imagination, perception, emotion and self-awareness. While we may see areas of the brain fired up in response to certain stimuli, the complex ingredients of being human can never entirely be distilled. For to distill them is to reduce humanity to component parts.

It could be said that we have Damasio approach to understanding autism – how people with autism think and feel to an extent that some scientists reduce the person to a mere organism, and an aberration of nature at that. The approach is disturbing when it splices characteristics of our children into little bits, and those little bits are INTERPRETED by the scientist, hence subjective and often wrong.

I will argue that there is no such thing as *empirical science* -- it has been argued before. Go on line and take a look at some of the research projects going on out there. Every abstract, every project is subject to the scientist’s bias, presentation of stimuli, environment…it is so difficult to obtain an unbiased view. At least an artist, a scientist of sorts, and in my view a better expert of what makes up the sea of mankind, admits to viewing the world through a set of inherited lenses.

Science is still filled with fallibility, subjectivity, and judgment. One theory in science and in art will always supercede another. We will forever be changing our view of the universe. May the arguments continue so that we can stay true.
Happy Valentine's Day

Happy Valentines Day Bubby, Zaida, Serena, Joseph, Max, Maddie, Grandma, Grandpa, and Daddy....I am feeling better as you might see from my jumping 🎈

Autism Kisses

Remember that nanny I was telling you about in my previous LOVE post? Well, she took off. Adam was sick yesterday with the croup and stopped breathing and she just LEFT. I couldn’t believe it. Good riddance, I guess. The good news is Adam is better today, taking Prednisone and breathing a lot easier. It was a scary day yesterday.

My heart breaks. It is because of Adam that she left. For him, my heart gets all ripped up. I don’t care about her. I care about him, and all the people who come in his life and those who don’t stay because they can’t handle “having to play” with him. I know, I know...what did I do keeping a girl like that? A favour to my other part-time, 15-year loyal nanny? Partly. Hope in a human being, always. I always think that people will “come around.”

I should have listened to my instinct. It’s always too damn right. Never fails. Every time I turn my back on instinct, I screw up. I was right. Should have listened to Blink.

Blink, written by Malcolm Gladwell, a University of Toronto history grad, quotes Simon Baron-Cohen’s Mind-Blindness theory in his arguments about intuition. He notes that people with autism
cannot “read” minds in the important first-impression stage and are at a disadvantage where intuition is concerned, thereby losing an edge the rest of us have to make split second, profitable decisions (yes, it’s all about BUZINESS -- at least business people seem to be the book’s primary audience). People with autism claim that “real-time” mind and body reading are difficult, but are hardly incapable of understanding others. I am always interested in how people with autism claim that they can think of their responses long after a conversation – how the processing takes longer. I suppose there are millisecond clues that are processed unknowingly by me...those clues we can’t break down into little bits, and call intuition. All I can do to perhaps come close to understanding that difficulty are those times when I am stumped by a person’s words – all those witty responses and come-backs I could have said long after the moment is over. Yet I hardly think that experience does the ACTUAL autistic experience justice.

Anyway, my heart will mend. No matter how hard I try to find the right people to encircle Adam, to be part of his world, I am guarded. I only want positive people around him, but I cannot always thwart off the negative, hurtful ones. I cannot always be around.

On the upside, I have written little about the people who do love him, from within and out of the family. Laura, his wonderful therapist who has gone on this journey with me and who is the most wonderful part of Adam’s expanding life; Morgan, Adam’s loving shadow at school who has unshattering belief in Adam’s abilities; Bianca, who is leaving us to have a baby, but who has stood by Adam and felt the hurt along with me; Ellen, Adam’s OT who has been more ‘right’ about Adam than any psychologist or doctor or “expert”; Stacy, who works with Adam once a week at OT with an unending white smile and more recently, Leslie, who has brought her lovely, calm and positive attitude into Adam’s life and is helping to shape his programs; to Flor, who stays by Adam and who plainly loves him; to Jaclyn who has taught Adam how to “bend his knees”; to Paula and Nancy, his teachers at Nursery School who always go the extra mile for Adam; to my friends who pass no intrinsic judgment and ask Adam to come over and play; to his music teachers who accept him for who he is; to the Snoezelen people who let him relax and just be; to grandparents who take this journey with Adam and I daily; and of course to my immediate family who deal with it all so lovingly. To all of you, a hearty thank
I talk too little of these people who make our lives wonderful and hopeful every single day. Without all of you, my optimism and strength would not be possible.

Tomorrow is Valentine’s Day. Hubby is skiing with daughter in Whistler. I am planning a sweet dinner (Pickle Barrel with candles?) with my other true love and reason for being. I didn’t budge all day from Adam’s side yesterday and in between his wheezes for air, I realized again how large love is and how my little heart can hardly contain it. Like today, Adam will surely lean into me tomorrow and give me his little kiss – for his "senses" or for love, I’ll take his “autism kisses” any day.

The Poetry of Autism

It is perhaps difficult to consider the poetry of autism as my son struggles for air, looking up at me searchingly – “what is happening to me?” He is sick and we are on pneumonia watch. He doesn’t have it yet, but he is very ill this weekend. I write in the darkness of his room as he sleeps, not letting my eyes off him.

I imagine the poetry of autism is similarly difficult to comprehend and a parent watches one’s child bang their head against a wall, or bite oneself in the frustration of not being understood. The following premise “the poetry of autism,” is not in any way to belittle or forget these moments. Rather, I consider that autism, it’s way of seeing and sensing the world, poetic. As I read Donna Williams, Susan Golubock, or Larry Bissonnette, their style of communication and use of written language is plump with metaphor and meaning. In fact, it takes me a few repetitious readings of a sentence or a paragraph at times, to fully appreciate the entire meaning. As in poetry, the language of autism sometimes requires unraveling. The language reads sometimes like stream-of-consciousness writing.
Here is what Donna Williams wrote me in response to Adam’s schedule;

“yes, grandparents are really important
Having other attachments
Being flexible about new discovery environments
That’s building WANT and wonder.”

I want him to have hands on ‘doing’ based, tactile, kinesthetic experiences with sound, form, line, light, movement, space so he WANTS to talk about, draw, build, compose as expression brewing from these things...if he chases the world, then the potential is great...so activities should inspire, be about DISCOVERY and wonder and one discovers and wonders when the answers aren’t already jumping out at you, then the understanding isn’t ‘theirs’ its ‘yours’ and that builds self and a relationship with the external world as ‘one’s own world.’ Without this, it is ‘their world.’”

Donna’s grammar is more intact than some. Her writing leads us from one image to another which leaves my head swimming – one has to dive in to her language to understand the rhythm of her world. It is in joining this rhythm that we perhaps catch a glimpse of the way she sees it.

Even more akin to “poetics” is the prose of artist with autism, Larry Bissonnette:

“Casting teepee posts of happiness in the ground of slaves to big accounts will never make your life better.” (Biklen, *Autism and the Myth of the Person Alone*, p.169)

Larry’s political views are apparent, as most artists struggle between the call of money versus the call for Truth, which is within our grasp, through art.

“Tapping well of silence with painting permitted songs of hurt to be meted with creativity.” (Biklen, p.170)

The phrases ‘well of silence,’ ‘songs of hurt,’ and ‘casting teepee posts of happiness, ‘in the ground of slaves,’ are all distinctly visual and metaphorical images. Silence is a well. Hurt is a song. Teepee posts of happiness can rise and fall. Slaves are often confined to the
If the president could tout the artist’s ability here, acknowledge the fluidity of thought and process, might we be able to change the notions of autism? If we shared the same ‘beam of belief,’ like the light of TRUTH, then it is possible.

“My pent-up time in tested for learning patterns of best behavior institution wasn’t entirely greys; it offered personal periods of great relationships with friends with disabilities.” (p.174)

Bissonnette was thought of as mentally retarded so he was institutionalized during his youth. “Tested for learning patterns of best behavior,” tells us that his life was full of tests, and he deciphered through patterns, what was expected of him. When Adam did ABA therapy, he was tested all the time. (I only did so-called ABA therapy for 2 months when we started this journey...thank God.). I could see as well, that Adam could learn the expectation at 20 months, very quickly. But it didn’t teach him anything about his world. James Partington told me once in a conversation over the phone: “all we’re trying to do is teach your child how to respond.” It was that statement that made me close the door to “pure” (whatever that really means) VB and ABA forever. I didn’t just want to teach Adam how to respond, I wanted to teach him how to learn for himself, enjoy the world, garner what he wanted from it, and I still believe and see through him that this is possible for all people with autism, and is happening for Adam.

“Past life of institutionalized person lets in novel ideas. Outsiders to this life can’t go out and obtain it. It’s significant that my artistic style lets me express personal perspectives of autistic but intelligent old Vermonter.” (p.177)

Indeed, Bissonnette is an intelligent “old-Vermont.”

“Producing art is like making puppets on strings because massive edges of inspiration in creating graspable figures get constricted by people’s patterned control of sticks put on strings. Not
allowing people with disabilities their patterns of inspiring art through total freedom of expression is like limiting creativity with censorship.

Artists like Larry urgently make situations of doing art into large statements; occupying worlds of public awareness; calling for justice for people without speech; praying for true freedom of splashing language over pricey spreads in people beautiful but superficial magazines; moving down stereotypes of disability and leaving people speechless over power of brushed on with wild, outside the mainstream ideas, steeped in the tradition of autistic compulsivity.” (p.179)

And,

“Look up early lessons in learning about my struggles to communicate and determination of others to make me learn to eat neatly and talk clearly was really most important factor in my rostering of skills. I am seriously past learning swimming in the shallow end of the pool of language but I am ever told `can do’ words by others like Aunt Theresa and that is the sled that pushes me to accept excellence over languishing in mediocrity.” (p.181)

Needless to say, we as parents should accept this kind of equality for all our children, no matter what type of disability obstructs. There is not one person with autism who hasn’t told me that there was someone believing and pushing them to succeed (and that success is different for everyone). It is the parent’s will to accept this equality of excellence, meaning that we all have a right to work towards and attain it, to accept and believe that everything is possible, even with children who have been diagnosed at the “severe” end of the spectrum.

“...I’m not asking that life’s expectations be changed for me. I seek only acceptance for the ways I choose to meet them. Remember what gives joy to you is often very uncomfortable for me. The way you would do something is often not the way that would enable me to best succeed.
Or more importantly
find pleasure of self-satisfaction
in what I might accomplish.
I don't experience loneliness
or have the same needs and wants that you do,
so don't pity me for not having what I don't miss or want.
I recognize that your life,
with all its complexities
has its own set of difficulties.
Your definition of accomplishments
and what you find encouraging
go beyond the simplicity
which defines me.
I'm only asking for the same rights
and freedoms you seek for yourself:
To be accepted for who you are,
To be the best you that you can be.
Don't assume that I want or think or experience
the way that you do.
As nice as you think it is to be you,
I only want to be me.”

----Susan Golubock from “Our Lives in the Universe of Autism,”
Women from Another Planet, pp. 70-71

That, my friends, is the sum of all these parts.

FRIDAY, FEBRUARY 10, 2006

Sensing The World Into Existence

What if Adam can sense the world? What if this sense, his intuitive
sense even, is more robust than his other senses? In my
conversations with Donna Williams, this seems plausible. I have
been so focused on visual-spatial skills, but not of Adam’s other
sensing mechanisms. As I was disorganized and literally sick to my
stomach at temporarily losing some of my vision at the eye-doctor
(see yesterday's post "Unfathomable Mind"), I realized how I have
come to over-rely on my vision and hearing, and under-rely on my
other kinesthetic and other sensing mechanisms. In essence, those
of us that share the same faculties have come to view the world
through a very narrow tunnel of vision – where other worlds can be experienced through different avenues of perception.

This led me to think about Bruce Chatwin’s *The Songlines*, which I read years ago. The main character, Arkady, spends time with the Walbiri Aborigines of Alice Springs. The Walbiri sing the “world into existence.” Without having traversed the country, the world doesn’t exist.

“He liked Aboriginals. He liked their grit and tenacity and their artful ways of dealing with the white man. He had learnt, or half-learnt, a couple of their languages and had come away astonished by their intellectual vigour, their feats of memory and their capacity and will to survive. Arkady learned of the labyrinth of invisible pathways which meander all over Australia and are known by the Europeans as ‘Dreaming Tracks,’ or Songlines to the Aboriginals as ‘The Footprints of Ancestors’ or ‘The Way of the Law.’ Aboriginal Creation Myths tell of the legendary totemic beings who had wandered over the continent in the Dreamtime, singing out the name of everything that crossed their path – birds, animals, plants, rocks, waterholes – and so singing the world into existence.” (Bruce Chatwin, *The Songlines*, p.2).

Does what we perceive really exist? If it exists does it exist in the same way for others? As I consider that a blind person perceives the world entirely different from the way I do, I can easily suggest that we each perceive the world differently. If we believe this, then we must believe that the way people with Autism perceive is differently from us, and even among themselves as a group labeled Autistic. If perception is different, then we must completely rethink the way we evaluate and teach people with Autism. ABA leaves little room for creativity, discovery, and kinesthetic exploration. We are dealing with a group of people who are simply human with a set of different sensing and perceptual mechanisms – entirely valuable, completely fascinating. As I consider this along with my own biases, perceptions and the layers of belief systems that I have inherited through an inflexible world, I am coming to appreciate Adam and his wonderful complexities.

Like the Walbiri tribe, I suggest that Adam is sensing his way into existence. His visual and touch senses, his intuition, his ability to feel rhythm and pattern may be his strategies for making sense of
I got my first pair of reading glasses. I call it the perils of turning 40. I went to the ophthalmologist and got two doses of eye drops – the yellow one that burns and then the ones that dilate the pupils.

I have always thought of myself extremely eye-sensitive. I remember as a toddler, my eyes were at the same height of the hooks that held various tools at the hardware store and I use to squirm and squint – the thought of me falling into them and poking out my eyes all too consuming.

Then came friends with contact lenses. I would watch their first trials of putting them in and being unable to take them out of their eyes, or worse, getting them stuck in their lids. Ugh. Just the thought makes my skin crawl. Needless to say, I will never be a candidate for contact lenses. I’ve had wonderful vision all of my life until about a month ago, I picked up a medicine bottle and couldn’t read the fine print like I used to. In desperation, I picked up those drug-store glasses, the magnifying ones, and I could read the fine print much better. One morning, I woke and couldn’t see the TV screen. Thankfully, this was short-lived. Soon after, I noticed that when I read, the words were jiggling on the page.

So I went to the eye doctor.

When she put those drops in, I couldn’t read a thing – not my watch, not my phone. My eyesight was so profoundly affected I couldn’t even dial the phone by myself. This alone, sent me into chaos – an unmanageable oblivion. I couldn’t see the contents of my handbag to pay, I couldn’t find my keys, I was dropping all my receipts from the day all over the floor and I couldn’t find my prescription for the glasses the doc just handed to me. Losing some
of my sight for a short time put me into a tailspin. I had a headache from straining to see. I felt sick. I couldn’t work or even watch TV. I had to lie down for the remainder of the afternoon.

My dependence on my sense of sight is all too profound. By losing part of my sight for this short period of three hours, I became disoriented, unable to coordinate the rest of my body, even. I realized how underutilized my other senses are, and this lead me to think about how we under-appreciate the use of other sensing mechanisms that people with ASD may use to compensate for the sensing on which I have come to over-rely. Dr. Oliver Sacks talks a lot about compensatory abilities in the deaf and the blind. So too, I feel that Adam intuits, senses people and his environment in order to manage. I am sight-centric as well as audio-centric. I process primarily through these avenues while avoiding or ignoring and underutilizing my other capacities. In a conversation I’ve been having with Donna Williams about my son, I have come to realize that he may be about 50% meaning deaf and he intuits the rest of meaning through pattern, theme and feel. Donna says regarding Adam: “BUT he’ll likely become such a master at this compensation he’ll do it better than most non-auties ever could...that’s enough to `get by’ receptively, but it’ll be a challenge when people expect their dialogue to be responded to more specifically, more precisely, their instructions followed more accurately.”

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The mind of man is the world’s true dimension
And knowledge is the measure of the mind;
As the mind in her vast comprehension
Contains more worlds than all the world can find,
So knowledge doth itself far more extend
Than all the minds of men can comprehend. ---- from A Treaty of Human Learning by Fulke Grenville (1554-1628)
“Thinking in Pictures,” is a phrase used long before Temple Grandin did for the title of her own book to describe the way she perceives the world. It is a phrase that is used by many people with various diagnosed learning disabilities, dyslexia, and autism spectrum disorder to describe the way they understand the world and how they think. In order to comfort parents, many artists, writers and scientists were able to achieve a great deal with some form of substantial learning disability: Hans Christian Anderson, Albert Einstein, Thomas Edison, Gustave Flaubert, Thomas Jefferson, Harvey Cusing, Auguste Rodin, Leonardo Da Vinci, George Patton, Ludwig Wittgenstein, William James, Woodrow Wilson, Nelson Rockefeeler, William Butler Yeats, Lewis Carroll and someone we hear little about, Michael Faraday, who Thomas West introduces in his Overview of *In the Mind’s Eye*.

In 1841, Michael Faraday was recognized as one of the leading scientific minds of Queen Victoria’s Britain (West). Faraday’s visual imagination, more akin to a poet than a scientist’s, his mind’s eye, is responsible “for many fundamental discoveries in chemistry and physics although he hated these specialist terms. He preferred to call himself a `philosopher.’” (West, p.29). His most known achievement was the concept of subtle electromagnetic “lines of force” as well as the concept of the nonvisible electromagnetic “field.” “So sensitive was Faraday to these `lines of force’ that for him they were `as real as matter.’ His powerful visual conception of these ideas provided the basis for James Clerk Maxwell’s famous mathematical equations which, in turn, provided the foundation for modern physics by defining the relationship between light, electricity and magnetism” (West, p.29). They were also the foundation for Einstein’s later theory of relativity. Faraday was horrible at mathematics and could not transcribe his intuitive, visual theories which are the basis for the way we live today – “Faraday perhaps the greatest electrical inventor of all, was completely innocent of mathematics, and he developed his notion of lines of force in a remarkably unsophisticated way, picturing almost like rubber bands (West). There was ambivalence towards Faraday in the scientific community – “showing their difficulty in taking seriously a scientist who was not a mathematician, no matter how original, productive or prescient the scientist may have been” (West, p.30).

By the 1860’s Maxwell, an admirer of Faraday, put his theories into mathematical analysis, which proved to be solid. “Maxwell
explicitly stated that the development of his own equations was merely a translation of Faraday’s ideas into conventional mathematical form.” (p.31).

In terms of thinking in pictures, Thomas West states, “One might wonder whether the time for this mode of thought has entirely passed, or whether there is much value to be gained by returning to it to deal with some difficult contemporary problems....A partial answer to this question might be obtained by reminding ourselves that ‘sensitivity’ to ‘lines of force,’ also seems partly to characterize the thought of Albert Einstein. Einstein’s ‘productive’ thought was intensely visual in nature...” (West, p.33)

It is interesting now to note that Faraday expressed a learning disability, Einstein, possibly dyslexia or ASD (I’m still not sure whose poster child Einstein really is) and a notable bunch of leading thinkers had tremendous difficulty in typical learning environments. In reading about dyslexia and learning disabilities in Thomas West’s In The Mind’s Eye, I am reminded how many a disability is really a trend, perhaps a fabrication of our day in the sense that we identify absent or weak skills in people while ignoring strengths on the basis of what we value.

In the late 1800’s, in a literary society, and until more recently, people with dyslexia were considered “stupid,” or cognitively delayed. While many dyslexics will attest that they expend an enormous amount of energy compensating for their deficit, in other words, disguising it, it is also well recognized that people with dyslexia have a number of significant or special abilities, primarily visual-spatial ones. In the 1980’s more prominent people began to reveal their dyslexia. “As dyslexia and learning disabilities have become more clearly identified with persons of high intelligence and ability, these conditions seem less frightening and people are less reluctant to admit the problem and seek appropriate help.” (p.46) Today, we would hardly consider dyslexia a major “disorder” requiring a “cure.” We have learned to appreciate the abilities and have come to learn to teach people with dyslexia so that we hardly think twice about it.

It is on this last point I will posit that Autism is the new Dyslexia. It is the New Trend in the disability realm -- being touted as an elusive disorder, a “behaviour,” and prescribed limiting modals of teaching, while a multi-modal approach would respect the unique
learning styles and perceptions of the Autistic. I also propose that Autism, like Dyslexia-Past, is a construction of our society -- our expectations of what is considered “typical” behaviour and performance, as defined by our economy and educational system. In our economy we value language – our world is filled with marketing symbols and verbal messages. Language is also the *sine qua non* of development if we take a look at modern development “scales” as one example. Classrooms are taught primarily with text books. For children who do not think literally, the education system is quite a challenge. Further, as West notes, “our educational system, in focusing on remediation of certain disabilities, may be dealing with only half a condition, and he least interesting half. Somehow, a way needs to be found to deal with a very broad range of skill levels to address both unusual abilities and special difficulties in the same individuals” (p.41). We often note the people in history who have succeeded despite their disability, when we should be noting that they succeeded *because* of it. The value of particular abilities is time specific. Today, we value a literal and literary society. We value a homogenized society at the expense of possibly losing a huge pool of gifted, but unusual people. It is because of the fact that the brain is “wired” differently, for the reason that some people with ASD sense the world or see in pictures, that many major achievements have been realized.

I have argued earlier in this blog, and West seems to agree, that computerization of current systemized professions like law and medicine, will change the face of our economy yet again. If we have a society that appreciates visual-spatial intelligence, and an economy that rewards it, this may change the face of autism all together.

Autism and its prevalence of diagnosis because of changes in the DSM IV in 1993, has become a new economy unto itself – full of interventions, tests that are akin to snake-oil salesmen preying on unknowing and terrified parents. As a parent, I would like to see less hype in the Autism communities, and more *work* being done in appreciating our kids for who they are while obtaining the support and strategies they require. I prefer that my child not be treated as an elusive specimen requiring reams of data.

“Einstein first played with images in the visual right hemisphere, the apparent source of new ideas or perceptions of order, possibly relatively independently of conventional thought, current scientific
understanding and education...Such observations as Einstein’s occur frequently in the literature of creativity. The concept of two modes of consciousness has been cropping up in the medial literature for at least a hundred years, particularly with reference to artists, musicians, and composers. What is new is that research on the two hemispheres of the brain has yielded such substantial evidence that serious investigators have been forced to reverse a major trend of scientific thought (behaviorism) and not only recognize once again, the concept of consciousness, but also entertain the concept that there are not one but two major modes of consciousness, each fundamentally different from the other – one that we know a little about, the other that we know almost nothing about.” (p.26). In observing and appreciating my son's perceptual abilities and trying to understand them, I believe I am coming closer to understanding autism than many a scientist.

I feel we have lost sight of the big picture. I believe that noting intelligence – those who have made remarkable achievements because of the special wiring of their brain, need to be mentioned for the sake of understanding autism and learning disabilities in general. By remembering these marvellous stories of success, people with autism may be able to gain access to education they require and deserve. It took society to realize that prominent people of their time had dyslexia for it to receive different teaching approaches and strategies. I believe the same has to happen with autism.

I also believe that we may be focusing in too closely on autism – putting it under a microscope – to the detriment of those who have been diagnosed with it. “Sometimes if you focus in too closely, too early, you run the risk of losing sight of a larger pattern, one that is only visible by stepping back a distance, to get a view of several variations on a theme, a view of the pattern of the larger whole.” (West, p.80). I think all parents can relate to viewing every little motion as something to do with an "autistic behaviour," rather than a typical course of development. It is also ironic that in doing so, we may be losing sight of the wonderful processing that is occurring but which we cannot see or understand.

I can hear the gasps as I write this. Yet, I think we all have a lot to learn from history. We all seem to acknowledge that Autism's landscape -- it’s shape, our perspectives on it and more specifically, our children -- is changing from day to day. Let us all
Will the real Autism please stand up? I'm not sure what colour Autism we're talking about. Often, I hear that the goal for people with Autism, goals prepared by people without Autism is to render the person with Autism "indistinguishable from their peers" -- in other words, to make people with Autism appear more "normal."

I suppose it's an easy trap because we live (as parents, educators and the like) in the colour typical (well, this too is debateable). At cocktail parties, social dinners, if I get an audience interested in Autism, I usually get hit with the same array of questions:

1. How's Adam doing? (Like he's got a cold -- just when will he get better?)
2. Will Adam go to a normal school?
3. Will he go to university?
4. Will he get married?

These are honest questions coming from people who want a picture of Autism. They are the questions that we parents think about every day, maybe even aspire to -- we want our kids to be fulfilled and that may include these milestones. I know that I hold pretty much the same expectation for my son as I did before he was diagnosed with Autism except the frame has changed. I hold this expectation because I can also see that, with support, he can achieve these goals. The framing of expectations means that I don't change them, I just change how I view the journey.

If we are not paying attention, however, we can fall into the trap of making Autism appear more acceptable by making it look the same as the rest of us. In other words, these are the benchmarks of success in the colour typical. If people with Autism talk, that is more acceptable. If they can go to a "regular" school, that is even more acceptable. If they go to university or we call all Autistics "geniuses" we do so at the peril of those with Autism who cannot keep an open mind for the benefit of our children.
or who are not so. We have to be careful what colour we are painting Autism and not be afraid to use a different hue.

I experienced this directly by visiting the MukiBaum Centre this week (see post titled "Smack Dab in the Middle") and by going to the Snoezelen Pool today. Watching other kids with Autism, teenagers, some kids with Cerebral Palsy, yelping with their teenage and toddler voices layered in glee, and my little Adam bouncing on Grandpa's lap, I saw the colour Autism...and it was beautiful.

Love

My husband comments, "wow, your last post is reeealy long."

I know. Pardon me, dear readers, I've had a stressful week -- Adam's emergency trip to the dentist, a scheduled dental surgery in March with general anaesthesia, and the flu, an emotional visit to MukiBaum (see last post)...I've come to know love.

Two of my four stepchildren lived with me for two weeks while their mother was in Israel. Every night, I reveled in making dinner, planning dishes, chit chatting about our day. Adam relished in their company -- he particularly likes to call out his brother's name "Max," with an emphasis on the X as he holds it until it sounds like an S. Max and Maddie, his half-siblings would play with him in his room and snuggle with him on the couch, juggle for him every time he said "juggle!" and Max even tried to put him on the potty. Even though my husband was out most of those evenings, I had the kids wrapping around our circular kitchen table keeping us warm.

Donna, a part-time nanny who has been with me since Adam was six months old, has left. Her last day was January 30th. She, like Flor my other nanny (hey, there are five kids in this household) who has been with the family for fifteen years, has seen Adam before and after his diagnosis. You go through times like these, you really get to know someone.
On Wednesday, they all left. The kids' mom came back and Donna left. Adam was searching the hallways to no avail. He searched Wednesday and Thursday and by Thursday evening, the dinner table quiet with just the two of us again watching Treehouse, the desolate quiet sent me into tears.

We called the kids at their mom's. We got the voice mail. "Adam, say Max I miss you," I said.

"Max, I mi you," he slurred.

"Say Maddie I miss you."

"Maddie I mi you," his voice as melodious as mine.

There are times when the running up and down of stairs, the slamming of doors and coming in at one in the morning can get on my nerves. There were times when Donna was oversensitive or over-protective of Adam when I needed her to challenge him a little more.

I wonder what Adam thinks now that Donna is gone, Max and Maddie's rooms, dark. They say you never know what you are going to miss until it's gone.

Smack Dab in the Middle

I remember seeing Nehama Baum introducing Dr. Oliver Sacks at The University of Toronto last fall. Her voice deep and soft with a Hebrew accent, red hair cascading her shoulders, I could barely see her eyes over the microphone as she strained to reach it. Yet despite her small frame, Ms. Baum in the world of disability is no bush leaguer. In fact, I am tempted to call her a goddess with those red locks -- a defender of sorts. A clinical psychologist and a lifelong advocate of the disabled, she is the mother of a now forty-two-year-old multi-handicapped son. Nehama founded The MukiBaum Centre for Complex Disabilities in Toronto twenty-five years ago. The Centre services children and adults with a dual
diagnosis (an intellectual disability and an emotional, behavioural
or psychiatric disorder). Her programs provide treatment,
education, sensory-motor therapy, music and art therapy,
vocational training, adult day programs and a residential program.
Some kids come to the day program from abusive backgrounds;
some have Schizophrenia, others Down syndrome, Landau-
Kleffner syndrome and some other rare disorders that we never
hear about.

On this grey day in January, unusually warm at nearly nine
degrees Celsius, I am invited to MukiBaum to visit the children’s
day program, and to consider curating a show of student and adult
work. I meet MukiBaum fundraiser and events coordinator,
Ashley Grant at the head office. Ashley introduces me to the art
show idea while I can’t help but notice the impressionable art on
the walls – art executed by the so-called “disabled.” Ashley speaks
compellingly about Nehama and the tireless projects she has
initiated, her voice swiftly switching from one related topic to
another. Right down to business, we take her Volkswagen Golf to
visit the day program which treats and educates people from five
to twenty-one years of age.

We drive across Dufferin Avenue to the boxy schoolhouse, stuck in
the middle of a Toronto-Italian neighbourhood, replete with arches
and embellished fences that surround post-war bungalows. As we
walk towards the main door, I noticed a garden obviously made by
the students smack dab in the middle of this otherwise
monotonous area.

As we sign in, busy yet cheerful staff greet us -- some students are
coming in for their medications. I have to admit, seeing these BIG
kids (BIG is anything over 10 to me) is a dose of reality, and I
always like to take a nice clean swig of that. Here I am, right in the
middle of more serious cases of Autism and other disabilities,
witnessing a world not solely through my cute little pischer Adam
waiting for me at home – a well-adjusted autistic four-year-old. As
I brace myself, we walk by a heavy set pre-teen as we look for
Michelle, head of the school. He scrutinizes us the entire time.

“Why did you come to visit us?” he asks curiously, his face ticking
and mouth stuttering trying to form his next sentence, or perhaps
recover from his last one. This is an obvious effort.
“We came for a tour today,” replies Ashley cheerfully. “This is Estée.”

“So you came to visit us?” he acknowledges happily, his neck snapping to the right.

“Yes! Nice to see you again,” Ashely shakes his hand.

“Nice to meet you,” I say, extending my hand next. He happily accepts it. I am ashamed to admit that for a few moments before this, I was uncertain of this child who was watching our every move upon entry. I had no idea if he would approach me aggressively. As he limply shook my hand, I recovered, but I was plainly reminded of what fear of the disabled felt like, and my own bias that I have carried all these years into this doorway, into this young man’s hand. Despite having a child with Autism myself, the struggle is notable.

Out of breath enters Michelle Manning - a slim young woman with her brown hair drawn back hastily into a ponytail, t-shirt ruffled from a day’s work. Her face is clear, her eyes are bright.

"Nice to meet you," she beams at me, hands clapping her lap like she’s ready to go. I can already tell she is determined in situations that might beat down the best of us.

As we enter the hallway, pictures of faces on the wall strike me. One half of the face is cut from a magazine, the other half is drawn in by the students in order to match and then recognize the emotion. I will take that idea home, I think.

“You can see how much this student has progressed,” says Michelle noticing my intrigue. She points to a picture of a happy face on the wall – the eyebrow, eye and mouth positioned a little too high, the face drawn too narrow. “Compare it with this one,” she moves to another picture by the same student. “See how much better he matches here and the face is rounder.” It is true. It is now a perfect match, but truth be told, I like the more abstract one purely for aesthetic reasons.

We move a few steps to the first classroom. The door is slightly ajar and I can peer inside.
"This class has some Aspergers, some Schizophrenia, some abused kids and Autism," she tells me. Without naming them, I can tell that she knows her students like the back of her hand perhaps by what she doesn’t say about them.

“The class was initially a little aggressive. I would be on the phone across the hall and some not-so-appropriate words would be spilling out of there… I would be like ‘no everything’s okay’ to the other person on the line.” She chuckles at this like it’s all in day’s work. “Today the class is doing so much better.” It sure looks like a good day to me. All the kids are facing the teacher and working studiously.

Michelle takes us down the hall from door to door. I take in the tired seventies Bauhaus hallway peppered with artwork. I notice a musty smell. The building is too old, I think. They need trees and lots more windows. I went to a school just like it -- spotted tile, plywood doors and brown grass. Yet, the school’s inner spirit counters the structure.

I gawk curiously at the music class. Three teenage boys “play percussion.” One stands twirling a bowl repetitively while looking out into the room, the other is playing "the spoons" on his lap as a teacher models silently, and yet another wanders our way towards the door. He comes close and then turns to an adjacent room until he is guided back to the group.

"He just got here two days ago," says Michelle. These same kids will be playing in some part of a MukiBaum theatre or band project in the future. One small step at a time.

Michelle works her way to the adjacent room where a teenage girl “Sally” (not her real name) swings. “Sally needs the swing several times a day.” MukiBaum incorporated Sensory Integration Therapy several years ago into it’s programming. Michelle notes in the school’s video that “sensory programming is built in every ten to fifteen minutes and within a year the kids can sit at their desks...at the beginning of the year, some kids are barely verbal and by the time they leave, they are completely verbal using words as a source of communication.”

Sally who is Autistic, clutches a stuffed animal and looks relaxed. Her hair is matted, her face spotted with a few freckles. She wears
grey sweatpants and a dark green sweatshirt. She smiles while hunching over the teddy bear. There are two squishy spiked balls and Michelle decides to throw them to her. She catches and returns them with fair ease, becoming excited, squealing each time she catches.

"Do you this one or this one?" Michelle asks her, holding each ball up at a time.

"This one or this one," Sally echoes, reaching clearly for the ball she wants.

It falls my way and I toss it back to Sally and then we have to say goodbye. She says goodbye, the smile still there. I don’t want to leave her just yet.

Michelle leads us to the gym where I peer through the tiny window -- the young men playing some sort of game with the teacher. They all look adept, running back and forth, the coach trying to tag them.

"I’m going to create a water room in here," Michelle says opposite me. But I want to watch the young men in the gym enjoying themselves. “A child can sit under a waterfall and feel that input while the water collects around them. There will also be a sprinkler."

"That will be great," I reply, now attentive. "The kids will really get off on that sprinkler," I joke, knowing how Adam loves to watch water or flick it with his hands to watch the droplets.

"Oh yeah," she acknowledges with a knowing snort.

We continue down the halls, as I listen to what goes on in each classroom, broken up by Michelle into an interesting array of progress, kinds of kids, and “issues” in each room. Some kids are verbal, others are not, some kids, just emerging with their words. Without naming any of the kids, I can tell Michelle knows them intimately and tracks every one of them from the time they enter the school until the day they leave. She is like a walking database and basin of endless devotion. It is akin to a mother’s knowing – every fall, every triumph, the history of every scar. I wonder if she does anything outside of her life at MukiBaum.
“We don’t see the diagnosis or the behaviour,” says Nehama in her video, “we see the person behind that.” Even though Michelle notes the labels for my sake, without names or by pointing individuals out, I can see the ease with which she handles the kids. There is an obvious equality here, not unlike any other school. These are just “the kids.”

Next, we visit various sensory rooms -- Snoezellen, the O.T. room, and the black-light room. The MukiBaum program is renowned for its individualized, multi-modal, and sensory-based programming. Through Sensory Integration Therapy, and the development of sensory “diets,” children learn to develop coping strategies, emotional regulation and self-expression.

As we enter the black-light room, two students are resting -- a young woman with earphones who can hear us coming from down the hall, and the other, a young Asian man rests on a vibration mat.

"Do you want it on?" asks Michelle as we enter. I feel intrusive, seeping light in to their restful space.

"No," he says, his hands covering his eyes from the open door. I don't think she hears him.

"Here, I'll put it on."

"No!" he says again, sits up and moves away from her.

"Okay, the button is here if you want it."

Michelle continues to show me her dollar-store finds that help with body awareness and visual tracking. She tosses a spider ball to me that glows in the dark. Another great idea, I think. I can get a black light and some glow in the dark toys and help with Adam's body awareness by tossing this stuff to him, or putting it on his body. The black light helps delete other visual distraction, thereby helping one to visually track a tossed ball, for instance.

“Sweetie, you have to get up soon, your bus will be here,” says Michelle to the girl with the earphones who is also Autistic.
“Want to feel better... Want to feel better,” she presses her fingers between her eyes.

“You would feel tired all the time too if you didn’t sleep all night,” Michelle says of the girl who never sleeps. I decide not to tell my feeble story of waking up with Adam every hour and a half for two years.

“Are you tired?” I ask. She sits up and looks right at me.

“Yes.”

“You have to go home now sweetie,” a rotund bus driver walks in. He sits down beside the girl so she can adjust to leaving. “You can go to sleep at home, star.” I want to burst into tears at his terms of endearment.

“Some drivers leave after three minutes of waiting,” Michelle notes.

“But this guy is great.”

“The others leave and the kids have to wait until seven till their parents come and get them.”

The lights of the black-light room come full on.

“Go!” says the young Asian man. And he is gone.

I am uneasy at my voyeurism, my curiosity of the Autistic because I have a son with Autism. I am gingerly walking the halls, trying to engage with some of these kids. Michelle, in her daily rigor, does it with absolute ease.

“Here the kids created a garden box and bench on AutoCAD. They have been cutting and preparing the wood. The project will take a year before it’s finished,” Michelle beams with pride, knowing the accomplishment despite the timeline.

“The weather doesn’t always permit them to complete it. So, it will be a year.” She shrugs happily. I am looking at the AutoCAD design posted on a bulletin board in awe. It might take me two years before I could finish the garden-box-bench-thing that the
students have designed. I notice a backroom and Michelle focuses her attention on it. There is a washbasin to the side.

"Our kids collected money this year from cans. They wrote letters in Italian and English (this is an Italian neighbourhood), and handed them out to all the homes. The neighbours were so great, they left out all their cans,” her eyes become moist for an instant. “The kids took wagons and collected the cans, washed them and recycled them for money. The first time, they used the money to go to Canada’s Wonderland. But the second time, they decided to donate the money to the Food Bank. You know, it’s amazing -- some of these parent’s already have to use the Food Bank, and here the kids are giving back to it."

I am listening and my heart is sinking. Food Banks? Cans for money? My version of the purposeful life changes like a lightening bolt. My definitions of success, obliterated in an instant. I have forgotten the purpose, the context, perhaps even with my own life, with Adam. These kids are being taught to be self-sufficient in the face of challenges I can barely imagine. They also know innately, the spirit of giving. This is humanity distilled to its purest, simplest essence – an ounce inspiration in the face of hopelessness. For these students, success may not include a university education and a corner office, or even a job as a letter carrier. But it will include a developing sense of self and pride.

"We teach the young people how to write resumes, how to interview, how to dress for the interview," Michelle continues as I peer into a vocational training class. The young men look adept and are talkative. One was writing purposefully at his desk. I learn that even a few of MukiBaum’s students have entered college. “We also help with vocational training after they leave the day program.”

The kids get on their buses and we say goodbye to Michelle so that I can meet Nehama back at head office. I think of Nehama saying “Inspiration comes day to day working with the students moment by moment.” If any person is an inspiration, it is Michelle and her team who work tirelessly here at the day program.

Nehama greets me warmly after speaking to her husband on the phone in Hebrew. Her voice is calm her eyes, experienced. She is retiring next year, I learn. She wants to open a research facility to
study quality of life for families with disabilities. The sound of that is like an open meadow to my ears – something as a parent I would welcome. MukiBaum’s mission is to “discover the human treasures within disability,” Nehama tells me as she points to the marketing materials that reiterate it. “I am not interested, dare I say it, Mickey Mouse art,” she says. “I want to show the treasure and talent inside these people.

She doesn’t have to say a word more.

“I’ll do it,” I say. “and I want to see more.”

Watch for us in October 2006. Lonsdale Gallery, Toronto.

Response from Dr. Joseph Buxbaum

Dr. Joseph Buxbaum, who I cited in this blog (see my post "Autism and Paradox") does genetic research funded by NAAR. He kindly wrote a response to me personally, and I would like to give this opportunity for him to be heard:

The first thing to remember is that unlike some other disorders, there is evidence that behavioral interventions work in autism, at least in some cases. In addition, although it has certainly not been proven, the general thought is that early and more intensive intervention will be more effective than later and less intensive intervention. So, in complete contrast to what you suggest, I am of the thought that prenatal, perinatal and postnatal testing will allow for appropriate behavioral interventions for children at risk.

Note that the question of testing and of recurrence risk is the question that I most often receive from parents. I think this reflects the deep concern of parents with one seriously affected child that desire to have another child. I think we can be sure that none of the parents who ask me about these issues are the parents of a Bill Gates or an Albert Einstein.
First, I would like to thank Dr. Buxbaum for his reply. As I've said in this and to NAAR directly, I believe it is important for open debate and dialogue. I still believe that the ethical question lingers with this research, even with Dr. Buxbaum's intent of earlier intervention. With the choice of whether or not to have another child with autism, there exists the likelihood that many a parent will choose not to. It is not that I don't believe in the right to choose. I do, however, believe in the GREAT need for autism awareness. Positive awareness. This is not about Bill Gates or Albert Einstein. This is about a human being -- many people with autism who appear "severe" have articulated in writing that they just don't understand why the world has so much trouble accepting them for their difference. I admit that before I had Adam, I may have chosen not to if I had been given the opportunity prenatally. However, after the fact, after I have learned so much because of Adam, I believe there is a greater need for putting the voices and people with disabilities at the forefront of this dialogue. Had I understood and been given the opportunity to KNOW people with disabilities when I was young, perhaps if they were integrated with me during my school years, I would not have grown up with preconceived prejudices about these members of our society. Too often, we hear the voices of parents and researchers. These are often bias voices. We need to hear from those with Autism and organizations like NAAR need to make way on their "stages."

This, Dr. Buxbaum, is where I think you've got it wrong. I believe these are complex issues that require years more of deliberation. Without having an opportunity to raise positive awareness about the "normal Joe" with autism, and making way for their point of view, the entire research goal is sorely incomplete, perhaps even misguided. In fact, I've asked NAAR why you as scientists are not asking those with autism what research they would like to see. Why are you deciding and why are the parents? This is my raison d'etre for raising awareness -- your semantics and that of NAAR's have political affect -- using words that express despair and a loss of hope(cures are for terminal illnesses, not for autism) are indeed closing many a school door for us RIGHT NOW. By suggesting that parents have "deep concerns" and arguing from this angle is not helping my child who is living, breathing and has a right to the same opportunities, education, and indeed additional supports as
needed within these environments. I am not saying that the job of
the parent with a child with autism is easy. I am such a parent. Yet
I deliberate every day at why obtaining a school placement with
concurrent supports and intellectual rigour for my son is so
difficult. Why is it that he cannot be integrated with his peers --
something from which he benefits? Why do schools that claim to
service the "Learning Different" hum and ha when I mention the
word AUTISM? Why is it that when schools claim that they are
integrated, leave the child with autism largely alone? Why are
IEP's so difficult to obtain and implement? Research and
fundraising vernacular, in my view, is serving to marginalize my
son, not advance his opportunities or understanding, and
acceptance in the world. This is where you and organizations like
NAAR can really help!! Help build understanding about autism
that leads to tolerance. It is fine to state that the means to an end
is "early intervention" and no one will argue with you. But I think
you have to consider the people who are living with autism, how
arguments are presented, who is truly guiding the research, and
how your semantics effect societal attitudes toward disability as a
whole.

Once again, I appreciate your response.

Link PERMALINK POSTED BY ESTEE KLAR-WOLFOND AT 2/01/2006 09:18:00
AM 7 COMMENTS LINKS TO THIS POST

MONDAY, JANUARY 30, 2006

On Becoming a SELF

"Wa wa..woo. Wa Wa...woo." Adam's hands open and close to his
own utterance of "quack quack..ribbet. Quack quack...ribbet," like
he's using his hand as a puppet. In fact, on a Baby Einstein video,
there is a little performance by a duck and a frog. You too might be
intimate with this little act if you've watched Baby Einstein as
much as we have in this house. I digress. The duck and the frog do
their little bit until ALL OF A SUDDEN, the duck ribbets, and the
frog quacks! Adam seems quite amused by this little interchange.
So much so, he has enacted the scene with his very own hands.

I have a little theory. (I have many about autism, but I'm not
autistic just a very close observer). Adam seems to be talking to
his hands at times. Sometimes his fingers do a little dance that wiggle in sync with *Mary Had A Little Lamb*, and other times, his hands open and close like those puppets to various dialogue. The obvious insight is that Adam has taken the scene and adopted it himself...the first stages of pretend play. But the real a ha for me is the realization that his hand is an extension of himself, let me press, could at times EVEN BE HIMSELF as he sees himself. "Body awareness" is difficult, it is said, for people with autism. Tito Mukhopadhyay says it took him years before he realized he had a body. He discusses that he wondered if he lived just in his thoughts rather than in the physical world. Adam can see his hands. It is easier for him to imitate with an object, for instance, than it is with his body alone. I see Adam's hands and simultaneous dialogue a little deeper than sheer stereotypy. I see it as his practising dialogue and speaking through his hands. If he can't SEE himself talk, perhaps it is easier for him to WATCH himself through his hands. I consider that like an actor, who projects a character that is not himself, does in fact REFLECT his own true character. The PROJECTED OTHER and the SELF are entwined.

Projection/reflection through puppets is a technique often used with abused and traumatized children. It is easier for such a child, perhaps, to enact a scene without having to identify one's true nature, or character. Children often draw scenes to communicate because it is often to do so verbally, especially painful experiences.

Adam is projecting, practising, through his "characters," the duck and the frog. He is practising language. I am wondering that to talk to his hands, if he feels more grounded, more aware that HE IS HERE.

This is abstract stuff. I have a wonderful new supervisor who is BCBA but also has a Ph.D in sensory issues. I find her very sensitive to Adam and useful in the sense that Adam really wants to learn new skills now and she is doing a marvellous job with him - just one of those really good, intuitive teachers who has a little extra knowledge. Originally, the type of ABA, and later, VB we received was distasteful to me. All these so-called "experts" treated Adam as a pathology. No one seemed to understand that at 20 months of age, he needed to be happy, to play and understand the value of relationship. After I fired a bunch of "supervisors" Adam still learned skills all along the way because I believe that through his joy and learned ability to relate, he
became able to express that he wanted to learn -- express his intrinsic motivation. Now, for things that are tougher and more demanding, I searched for a very skilled and sensitive person to join Laura (one of Adam's therapists) and the team to provide additional advice and training. Ms. Doc (I don't mean this is a derogatory way -- she is a lovely person but I don't want to disclose her name for her sake), has said to me many times "stereotypy is Adam's enemy." I don't necessarily like to coin it this way myself. In a way, I can definitely see how Adam stops learning if he engages in too much self-stimulation (I'm talking during learning time here, not when a person needs to wind down). However, I still feel strongly, that "STIMS" can serve important functions, which is why I watch him carefully and question. Is this something that Adam needs to explore or this an obsession? The lines are never clear, nay, always shifting.

Last night, five of us were sitting at the dinner table. Adam was tired and we were all chatting away to each other until he said loudly and clearly "Quiet please!" in a firm but polite tone. Indeed we all quieted down and ate our dinner. (!!!!!!!!!!!)

Neurotypical Syndrome

I'm not meaning to frighten you, but I think I have something going on and it might raise doubts...I don't know...I hope I don't raise something that you find wrong in yourself too...I haven't wanted to speak of it, well, not until all of this diagnostic stuff came out. Well here goes:

I seem to be putting on facades. I mean, everyone expects that I act and be a certain way. They expect me to say nice things even when I'm not thinking nice things. I guess this is called social etiquette, and it really exhausts me. Nevertheless, I lie. Yes, that's right. I tell someone I like their hair when I really hate it. Or I say "no your'e not fat!" when it's darn sure that the person I said that to has put on a few. Or "nice to see you" when I really couldn't care if I saw you a hundred years from now. Lying to people is a number one symptom of Neurotypical Syndrome (NT). I read all...
"Those with Neurtotypical Syndrome express a qualitative impairment in being alone as manifested by at least two of the following:

(a) lack of ability in spending time in the company of oneself for a long duration;
(b) preoccupation with being with others, and social events."

Here's another one: I think I am superior. Yes, that's right. To anyone who cannot do as I do. In fact, there's no one as good as me. I believe this is called arrogance in the diagnostic criteria for NTS:

"(c) preoccupation with oneself, one's career, one's material and physical image;
(d) preoccupation with one's social status, fame and income."

I do too many things and don't really focus on one. Instead of just focussing on one thing at a time, like I would like to do, I try to do too many things and it seems like I've got it all figured out, but I really don't. "Inability to focus intensively on one interest," is a definite symptom.

Judgement. I judge everyone. I judge based on whether you are like me or not like me. I expect everyone to blend together, to homogenize. If there is any difference, I become afraid and have to send that different person away. "Persistent intolerance of others," is another symptom.

I am highly impatient. I guess that's why I don't really think that hard about anything. It takes up too much time when I have to get my hair done. I thought about becoming a musician once, but eh, I just wanted to go to the clubs with my friends, instead. Not to mention impatient with others. I don't have time to listen to your bla bla!

I take things for granted. Um hum. Big time. I don't take time to "smell the flowers" or watch the rain fall... Who has time? I need to stand in line at Starbucks while I'm rushing to get to work!

It says in this manual I read today, that "the onset of Neurotypical
Disorder is prior to three years of age...there is also a strong fascination for social belonging to the point of chronic lying...In most cases, there is an associated diagnosis of depression, substance-related disorders, sedative dependence, and other behavioural symptoms including inability to listen carefully to others, difficulty with empathy, and a deep fear of heterogeneity."

There were more symptoms in this manual I read...I’m too upset to write them all down. You will have to look them up in the DSM. If you have more than three symptoms, I think that means you are lower functioning. If you have just one or two, there's more hope. I am in BIG trouble. I am not normal!!!
him from behind (This is the best way to teach independent skills. If the child sees you prompting from in front, it is an extra step because you are now associated with the action. If prompted from behind, I can fade myself and my physical prompts faster. Adam gets the feel, faster). I do this from putting on socks... 1st we put in the thumbs, 2nd we open the sock, 3rd we put the sock over our toes, and 4th we pull the sock on. I do a hand-over-hand prompt until the pull part. (He still has trouble opening a tight sock and putting it independently over his toes). I am "backward chaining" my teaching so that he gets each part of it on his own. His fine motor and bilateral skills are still a little weak, but coming along. Soon, I am sure he will show me just what he can do! But, if I just sat in front of Adam and recited instructions he would be peering out the window! In autism, the steps are broken down, but the tactile sense, the learning by doing, is the easiest way for him to "get it"... with lots of practise!

"Can't do it for myself. Can't do it as myself. Can't do it by myself." The words of Donna William's from her book Exposure Anxiety reverberate in my head pretty much all the time now. Everytime Adam walks away and observes from the periphery of an activity and needs to be nudged in, I think about how he needs the little push on his back to walk again. I think about the movie AWAKENINGS from Oliver Sack's novel, and remember the catatonic woman who rose from her chair because of the pattern on the floor. The pattern was the impetus, the fluidity, the guide to get her to the window. When the pattern stopped, so did she. When Adam stops in his tracks and watches like he is on his way to something, and then just stops for no apparent reason, I think of those similar examples. If prompting, a little nudge, gets him back into things, so be it. Hopefully, he will find his own way to nudge himself back into the world.

Today, Adam started a music class. There was no aide, no shadow, but a nice small group of five little children. There were some imaginative movements, and musical instruments. I was so proud of him and always want to keep him in some activities without an aide because I can see how he was watching the teacher, watching the children, joined in the circle independently, expressed some delayed imitation! (We can practise banging on the drum at the same time as everyone else at home -- coordinated activities also have to be practised). Most of all, he was gleaming again. When Adam gleams, everyone smiles. Adam is practising his skills on his
Between a Rock and a Hard Place

I run, with therapists, a facilitated playgroup at my home. It has been going very well -- a mix of kids with and without autism. But I have to admit, keeping the mix is getting harder.

Yesterday, a mom pulled her kid (autistic) without warning because there were other programs she enrolled him in -- she said. That really irked me -- not because people naturally move on, but because she did this without warning, so that the dynamic of the group is now affected.

I am also looking for a new therapist too...one of my leads is pregnant, and I'm finding it really hard finding a therapist with experience who is willing to work fifteen hours a week.

Running a home-based program, without agency support is rewarding, frustrating and terrifying some days, like all of Adam's progress and development is at stake because of what I do, or don't do for him. If I hire an agency here in Ontario, I don't receive adequate communication, (my team talks weekly, meets bi-weekly), and the therapists (the one's I've met), have been doing something that looks and talks like ABA, but it's not ABA.

I think most parents who use agencies, go to schools, or try to find play groups might also feel caught between a rock and a hard place. Speaking for myself, I feel we have to seep through the system, find a way to glide through the cracks, in order to get the services and education that Adam requires. Work with the system the best you can, I say to myself, and after that, do it yourself.

Today, tears well in my eyes about Adam's social world...he is just beginning to really observe and WANT to do what his peers are doing. This wouldn't have happened without our playgroup. And now, it seems to be falling apart. So I consider charging the
$250.00 that the other Facilitated Play Groups here in Ontario charge. But how on earth will that attract the parents of kids without Autism? The whole thing seems screwed up and no matter how hard we try, this will stigmatize Adam.

Adam got his passport photo taken the other day. He obeyed the photographer, taking a step on to the stool, standing still, facing him. He gleamed a smile. One of the store clerks insisted strongly that Adam close his mouth (it was hardly open).

"Close your mouth!" Adam wiggled, still smiling.

"Close your mouth! They won't accept the photo like that. Close your mouth!" The stout little man with no hair pursed his lips. His angular features punctuating his words, and effeminate voice beginning to feel like steel wool on my skin.

Finally, I blurted, "it's hard for him...he has Autism." My gut sank. For all of my wishes to not label Adam, I labeled him anyway. I suppose I could have just said, "it's difficult for him," without any further explanation. Yet, it was his utter lack of empathy, or observation, or assumption, that I found repulsive. This is the dilemma -- to not identify Adam in times of need (I'm not saying this was a time of need, but there will be other times), will not allow him any special accommodation or support he may need. To identify him (his label), will lock him out of other opportunities that may benefit him.

"Close your mouth!" shouted a number of times at Adam felt totally foreign, and I realized how difficult it will be for him for a while. Or maybe me.

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Starry Night

Adam loves Vincent Van Gogh's *Starry Night*. Since he was three. Morgan, his of his art "instructor" (we do art -- I'm a curator, what can I say), brings cards with various paintings and they talk about them. Adam loves to label even the more abstract ones, telling me
that he has a sense of representation (symbol recognition is another way to say that). Morgan thought it would be good to begin with the impressionists. But when she pulled out *Starry Night* on the floor, he twisted his body and peered at it from various angles -- something he did when he reamed off his letters and numbers that were on the floor at 11 months of age. I believe the sweeping, rough, and swirling short lines (thus adding to the feeling of movement) must actually move for Adam -- the undulating night sky quivers.

Then, I saw a preview for Little Einstein. Eureka! There it was...the Rocketship swooshes into Van Gogh's sky -- the swirling starry night. Needless to say, Adam stops dead in his tracks when that preview comes on. There is this aspect of Van Gogh's art that leads me to think that theories he was autistic might be true. He created areas of flat unbroken colour -- a revolutionary approach to art-making that was viewed as crude at the time. His stark figures are outlined with dark cloisonne line against flat backgrounds or busy patterned walls that nearly distract the eye from the subject. Or consider *The Night Cafe*, or *The Yellow Room*, with seemingly distorted (but logically true) perspective, and harsh disharmonies of colour. Van Gogh "could not be taught" and therefore, was a self-taught artist. Today, he would be classified in the "Outsider Art" genre. He was later plagued with seizures, unsettled relationships, and except for a short, tumultous stint with Gauguin, lived alone.

So I have to wonder: does Van Gogh's Starry Night appeal to my little Adam for the reason that they might share a similar perception? Adam has expanded (on his own) his repertoire of painting techniques -- studying the brush and using various sides of it, and lately, splaying the paint on the paper like Jackson Pollock. So I eagerly wait and see if he can represent his experiences on paper.

When my eyes get tired these days, the outer edges of objects begin to quiver (I’ve made an optometrist appointment). Instead of finding it annoying (which it can be), I stop and revel in another way of seeing things.
Decoding Perception

In my previous post, **Body and Mind**, I try to decode Adam's perceptions and experiences through the eyes of Tito Mukhopadhyay, autistic author of several books including **The Mind Tree**.

This is all about understanding autism and decoding perception -- someone else's. In Adam's early years I watch him curiously, learning from others how he might be experiencing his environment. But even these clues from Tito are not necessarily Adam's experiences.

Autism as "mystery" is at the heart of our fascination. Science thinks it can solve the "mysteries" of the brain. In 1977, Noam Chomsky was not optimistic about the future of brain research. He said: "It may very well be that, among the theories we are unable to attain by our biological endowment, there is included the theory of mind...it will appear that human beings have mystical, unintelligible properties because we, as biological organisms, will not have within our range the theory that would, in fact, explain it."

Each scientific community -- neurology, psychology and so on have so many of their own theories about the brain, and yet even today, all of it still remains pretty much a mystery. Autism can be viewed as the embodiment of this metaphor. We are fascinated by autism for what it shows us we can be (ability) for as much as what is different. The idiosyncratic language, the sensory issues (which seem to be an oversensitivity and heightened awareness of the environment), to non-verbal intelligence...our society is curious to know how we tick -- and autism is a part of this search. We are similarly interested in a stroke victim's ability to adapt -- using different parts of the brain to relearn speech is a good example. A real mystery is also that -- human adaptability. Perception is elusive. Yet, it is all we have -- seeing how an artist views the world can shed light on how we view it -- it can make our world, our perceptions more three-dimensional.

What is perception? Is it a visual world? Is it something that happens to us? Is it tactile? Certainly, perception is different for all of us... the blind perceive and experience the world differently
from those who are not. The way they describe their perceptions is not at all the way I might describe the same experience.
Perception is the biological as well as the psychological, and as much as biology takes a part in autistic perception, the psychological and environmental factors also take a role. In addition, there seems to be some universal perceptual consensus - for example, we all agree what "red" looks like so we, for the most part, have a universal perceptual language. Do we *feel* red the same way? The experience, and language is different for a blind person who has never seen red, but who may interpret red. That said, a colour-blind person also has no concept of that visual language. A full understanding of the mind is intangible. We may be able to plot physical and chemical events that an object triggers in the retina and in the perceptual centre of the brain, but will detailed knowledge of which nerves fire and the patterns of nerve activity ever adequately describe the *experience* of seeing the object?"

I consider Autism and human evolution -- a language distilled, that is, a different language, non-verbal, visual, musical, mathematical - a language without words. I've heard of speculations that human language will evolve from verbal language to a sort-of computer movement language -- highly visual. How have computers even altered the way we think and the way we communicate today? Perhaps that language is easier to comprehend for those with autism?

Adam went to the dentist a couple of days ago. It was not pretty. He's been pretty good so far, but for whatever reason, the dentist, before showing his face to Adam, went right into his mouth from behind, holding his head down with his arm while his purple-gloved hands pried Adam's mouth open. Adam was terrified, I think, because of this. It is like when Henry approaches him from the rear to put on a shirt with a narrow hole and Adam can't see for a couple of moments...not only could he not see Henry coming from behind, but all of a sudden, he is blinded and confined by the hole -- and again, he is terrified. Trying to put the pieces together, I am presuming that Adam is highly visual and anything that impairs this skill that he has come to over-rely on, is exceptionally scary. If all of a sudden I lost my sight, I would be afraid. If I lost the feeling of my legs, I would be terrified. We come to *rely* on our strengths. Adam's strength is his sight -- but what of his perception? This is what I'm always wondering about -- what does
Adam see that I cannot understand? Is this sense like looking through a thick lens -- blurred and images melded together? Or his sense so sharp and lucid -- that the sharpness of colour and line can be painful? I would like to look through this lens one day. The closest I've come is through art. For me, it is the universal non-verbal language. Or music. Right now, Adam does not verbally offer many clues, so what I do is decode his behaviour. Like the curator of art that I once was, I decode perception.

Body and Mind

I think about the times when I live just in my head -- I can sit for days and read, and write -- making unconscious trips to the kitchen for yet another coffee with too much sugar. A month or two of this can pass until I decide it might be a good idea to reconnect with my body in a yoga class or two. While goading my limbs to "enter a pose" just a little further between grunts I realize my body is trying to connect with my mind -- trying to just let go in blissful symbiosis. I am shocked at the huge disconnect between my body and mind and wonder where I've been.

I try to give this feeble analogy in an attempt to understand what it might feel like for those with autism -- where body awareness is not altogether intact. I struggle to understand a lack of body awareness that otherwise comes so naturally to me.

Tito Mukhopadhyay states that no one autistic person can follow a command if they are not aware that they have a body. In autism, this disconnect seems to be magnified -- of "not knowing where my knee is, if I even have a knee, when my instructor demands 'touch your knee.'" I considered his responses to Biklen's questions and reflected upon Adam's life:

"Am I made of thoughts or am I made of my body? I usually experience either, one at a time. I had to shut my eyes on the road because the whole road seemed to become so alive, although my logic told me that it could not be so. Only when my mother took me to some other lane, could I open my eyes... I had..."
to learn about my body, because I could not feel the pain, or realize it, till I was taught. So without knowing anything about the body, how could I apply parts to do different activities, which people do? So when someone asks you to do something manually, I get clumsy. You have to map yourself, map the part of the body you are going to use and time it up, because someone is waiting for you to complete the task. You know that your intelligence or stupidity would get measured by that performance of yours.” (p.122 Biklen)

I think of all the times Adam squints his eyes. I have always called him a "visual" child, he can read, decode, and his primary stims (self-stimulatory behaviour) are visual ones. But now I consider that he is also shutting his eyes to feel the world, for to see it is just too much information, thereby making the world too overwhelming to feel and comprehend. I also consider all those standarized testing situations that have evaluated Adam's performance without considering the difficulty of body awareness.

"Games can get awfully puzzling. Exercising can work better because you are sure what you are supposed to do. Limited boundaries of movement can save a lot of strain."

I think of all the activities that should be close-ended and structured so that Adam can learn to become competent, and later, more fluid in other settings. The speed of play in a children’s playground is still too much for Adam. He observes, I feel he is trying to join, but he doesn’t know HOW to join or what to do. If the game was close-ended and more structured, we could teach Adam how to join in play and he could feel more competent and happy with himself, thus enjoying the experience.

On the association of Mental Retardation and Autism:

"It is the most disgraceful label which the term Autism is associated with. Yes, some areas remain less developed because of a lack of associating the mind with the body and environment. I had been labeled as mentally retarded when I had my first encounter with the psychologist. I was three years old then. I was not able to apply my knowledge although I could understand perfectly what was being asked....I do not blame the psychologist. Seeing is believing [bold mine]. They should begin with the attitude that the client is understanding him and
not wonder where to start or what to start. Start with anything. And grow around that anything. Talk with an easy tone because the client is not hearing impaired. Trust that the client is capable of understanding. And then `Carry on.'"

I think of all the myths about autism as a parent I try to diffuse -- the myth that 2/3 of the autistic population is mentally retarded, the myth of low functioning autism and high functioning autism -- the view that LFA renders that person "less" human or intelligent or for that matter, capable. It really just is about the amount of obstacles we have to learning -- some have more, some have less.

"It took me many years to realize that I have a body. I think that is not because of my preoccupation with other thoughts. I was totally aware of sounds and colours, which my senses picked up for me...Even this day sometimes I feel that I am walking without legs...Many Autistic people need to be helped because of this reason. How can they perform a task using hands if they just cannot feel them? And without any feeling how should they have control over them?...as I grew up and started my mirror gazing, I became more aware of my looks and size. I had a favourite bed sheet which I loved to wrap around my body so that I could enjoy it....When I learnt that a swing was not anything which could kill you, I started using it a great deal. Half my school hours are spent on the swing. I enjoy climbing up a staircase also because the gravity acts on my body as I apply myself against it. Escalators are wonderful as I can be sure of getting the feeling of my body gradually. At home a little rocking and spinning also helps. Thank god mother doesn't stop me." (p.138)

This tells me the importance of Occupational Therapy in Adam's life -- his need to experience and feel his body as an essential component to completing the simplest tasks to problem solving. It tells us that spinning isn't a "behaviour" that needs to be "extinguished," but an essential need for the person autistic to KNOW themselves, to feel alive. Providing for this makes the world easier to understand and easier to join. The goal for Adam is...SELF AWARENESS.

"To think about it, I recall that I learnt every skill through touch method. I have a problem imitating any movement by looking at people performing or mapping my body accordingly to the instructions given to me...I am stressing on how to do and not
what to do because no one should have the impression that I did not know what to do. Different skills need different time to practise depending on the feeling of awareness of that part of the body. Sometimes I feel my legs better than the hands. But I needed my mother's help to learn the tricycle. She had to manually push my legs because I could not do the movement. It needed some practise before I could ride it independently."

(p.138)

I am always doing this with Adam. I am pushing and squeezing his legs so he can FEEL them -- in hopes that he will eventually correlate the feeling to the action in his own mind. He has peddled independently a few times now...but I expect it to be a few more months because it's not something we practise intensively. I also believe that we should teach in the easiest possible manner for the learner -- we want learning to be as fluid as possible. Adam is a kinesthetic learner -- learning by doing. If he needs me to nudge him from behind, some hand over hand -- whatever it takes to get him started and eventually independent, is the right way to teach.

"Life can become very boring for an Autistic person if he does not learn how to play -- touch is always a big help when an activity is new for me. Only through practise and gradual fading of the touch the activity can be done independently."

It's what I always tell people...Autism is not NOT KNOWING, it is not knowing HOW. We teach Adam HOW to do everything. A lot of times, he can generalize himself afterwards. He is lucky in this regard.

"I could not point at objects for many reasons. The most important reason is that I had very little sensation of my body. So the technique of moving my right handed needed control over the ball and socket joint of the shoulder and then hinge joint of my elbow and finally fold the other fingers and keep the point finger out...It is an essential skill because I can go to a shop [now] and point out exactly what I want. I can point to my forehead and show the doctor exactly where I had got the knock because he should not end up treating my nose." (p.133)

Although Adam is verbal, this is still an important skills for intention. "Show me" skills are important -- even if he can't find...
the word. He is okay at pointing to concrete objects close up. We
have to work on those things that are further away. I like how Tito
describes all the steps that one simple point requires. It
illuminates the laborious steps to be learned for an Autistic person.

"Exposure to variations be it clothes or food, place or timetable,
help us to, if not love, but to tolerate and understand our role in
situations better." (p. 141)

I’ve mentioned it before in this blog. If this is one thing we learned
early if even by default, is to expose Adam to EVERYTHING. His
life, aside from his special training at home, is no different than any
other child’s. He goes to regular school, he has a playgroup, he goes
to the Ice Capades, children’s performances, the art gallery, and
travels on planes. He is flexible and enjoys the novelty.

"Many Autistic people try to cut away the various inputs of
sounds by producing their own convenient sounds so that the
other sounds get to the background and the sound which he is
making gets all the attention and concentration. He should not
get away with that because it would lead him to nowhere other
than get entangled in its own intoxicating effect leading him to
get deeper trapped in the obsessive nature of that sound....That
can make his life miserable."

Adam babbles a lot. I use Tito’s suggestion intuitively -- of turning
on the radio, or changing the environment to bring Adam back to
the world. I have to be careful, though. His articulation is
sometimes off, and I try to recognize when he’s actually trying to
say a full sentence. If it’s repetitive, I can usually tell that its self-
preservation.

"Mother asked me what I would like to do next, or what I shall
like to have for dinner...Later in life I had faced similar questions
about my likes and preferences. I kept myself prepared by
finding a more honest answer before telling somebody that I
liked something. I have seen people asking other Autistic people,
showing two objects and inquiring whether they would have this
or that. And the Autistic person randomly replies this or that.
Nobody answers "both," although some may not mind having
both. When the prospect of an answer is so narrow and the
tendency to escape is more, how could the person grow and
organize his reasons? So although it is difficult to face an open
Here I think of the perils of Verbal Behaviour methods. We have stumbled into the same roadblocks with Adam, trying to introduce "choice" questions. Instructors (thankfully not mine -- Adam has a great therapist named Laura) can get so lost and wrapped up in their goal for the lesson (child to make a clear choice from two objects), that they can forget that the child may want neither or both and the lesson hasn't been set up for that possibility. It might be better to enable Adam by using textual and pictorial choice boards, so that he understands that he is free to express himself, rather than just meet an "expectation." We also have to be open to his own responses, the ones we don't expect.

"There are many approaches to a question. 'What is this?' is a very rudimentary approach to communication. When my speech therapist asked me 'What is this?' and tried to get an answer out of me by telling me more than half the answer that 'this is a ______' he forgot that I had already authored more than a hundred poems by then and two of them were already published. Naturally, I did not like this two-year-old treatment just because he had the advantage of speech. I could have started my answer when he was showing me a picture of the cat like this ---

Call me a cat
Or call me a feline
Call me any name
I shall haunt
Your doors at night
Now, then and again.

That would be an open-ended response to any question rather than restricting the wonderful prospect of answering with a sentence like 'this is a ____.' My ego is always important matter to me." (p.136)

Self-awareness, ego, self-mastery, competence. These are the ultimate goals for helping our children. This is the GRAIL. And it is attainable.
An eight year old boy wanders in the room with toys and then beelines towards *Cranium*.

"Would you like me to play that with you?" asks the therapist.

"I most certainly would," replies the boy unpacking the box on an opposite table to her. His hair is cut in a kind-of mohawk, sticking up at the crown like ostrich plume. His face is changing, even I can tell...he is slowly losing his cherub cheeks and soon he will look like a teenager. Our eyes meet for an instant. I sit furtively, pretending to read my book.

"First, we're going to talk about our engines."

"Okay...I'm with you," he replies sprightly.

"Can you please come over here and sit in the chair?" He sits on a tricycle next to the chair.

"I need you to sit here in the chair." After some shuffling, he sits.

"How are you feeling about *Cranium*?"

"Excited."

"Right, excited. And how fast is your engine running, too fast or too slow?"

"Too fast."

"But that's okay because you are excited."

"Right."

"Tell me something that makes you feel sad."

"CONNECTION ALERT!" he blurts.
"Can you show me something that makes you sad?" The therapist has the boy enact a number of scenarios that arouse different emotional states in him. When he doesn't quite know an answer (I am guessing here), when something doesn't make sense to him, or if something makes all too much sense -- perhaps too arousing to mention -- he blurts "CONNECTION ALERT!"

What a strategy! I am thinking of all the times that I get stumped, confused, over-emotional and I try to cover it up and be cool. How many of us do things we don't really want to do, particularly in the social realm, or act one way when we feel another? If I could yell "CONNECTION ALERT!" every time I stumbled inside, maybe people would understand me and leave well enough alone.

The therapist, for the purposes of teaching emotional/self regulation and emotion recognition in tandem with pretend scenarious (brilliantly taught, I might add), didn't acknowledge his connection alerts, but rather, kept probing him on how he was feeling in that moment to get him to recognize himself. By recognizing our emotional states, we can self-regulate. Further, we can become self-aware.

Emotional/self regulation is one of the challenges in autism. Michael Moon, a musician/composer/presenter/astrologist with autism, presented at The Muki Baum Centre last Thursday night in Toronto. Michael is 38 years old and notes that it wasn't until he learned he had autism that he could begin to become self-aware and in control of his future. For the purposes of not wanting to label him, his mother, who was present, eschewed the system (i.e.; believing that he could do anything) and didn't tell Michael of his autism. But he states that his learning about it enabled him to understand himself and overcome the obstacles that confronted him in life.

It seems to me that the people I've read and met with autism get really good at understanding what makes us all tick. If you had a challenge in an area and were compelled to learn everything about it, then you would likely become so proficient at it. This is how I'm feeling about everyone I've mentioned in my blog thus far. People with autism can, in fact, understand what it means to be human perhaps better than "the rest" of us.
**I Know What I Want and Want What I Know**

To know what we want, or think we know what we want is largely based on what we know. It isn't any different for someone with autism.

Adam asked for eggs for breakfast. "Eggs!" he blurted, checking out the kitchen counter. All by himself. He didn't see an egg, he asked for one. I made him one (he is into them sunny side up). He devoured it. He saw it a few times before and asked for it.

I am lucky that at the first sign of Adam's fussiness over food, I offered different types of food. He got used to various textures early on because I didn't give him any choice but to try different things. I admit it wasn't always easy. Today, Adam sometimes grows curious at what I am eating. A couple of months ago, he saw me eating an egg sunny-side up and he wanted a try....he ended up eating the whole egg! Pretty awesome for a guy who cringed at jiggly, slimy things.

Jonathan Lerman began to draw suddenly at the age of ten -- completely non-verbal at that time, no one understood or even realized that Jonathan had a rich "inner life." At an afterschool program, he had a serendipidous date with a piece of charcoal and paper and he began to draw -- not crude backgrounds and stick figures, but sophisticated renditions of faces. One major message his parents give to others is "expose your [autistic] child to everything because you never know what's going to happen."

There is a fundamental message here -- do not coop Adam up in special schools, do not isolate him because it might be hard [on me], and expose him to every opportunity because I MUST ASSUME THAT HE IS COMPETENT. Further, it is known that "learning by doing" as opposed to ONLY sitting at a table is really the most efficient and successful way to learn for many people labeled autistic (their account, not mine -- read Sue Rubin on kinesthetic learning). As a mom, I can see that Adam definitely benefits by generalizing skills as a first option to teaching, not after spending hours at a table. I know that every person must learn
differently, but if we stand by the belief that our children are competent, then we must approach teaching this way. Constantly practising skills makes Adam's learning more successful in a setting and yes, sometimes they have to be taught "in isolation" if a particular skill requires extra attention.

I don't think I know very much -- like most of us, I haven't experienced, yet, everything I've wanted to. In fact, I cringe at how little I know -- how there is so much more to read and so much more to learn from others. I am a product of my upbrining, my standard of living, and what I expose myself to daily. I went to a salsa lesson yesterday and saw a whole new world of people taking the night to enjoy a couple of hours of merengue with each other -- wow -- what am I missing?! There is a whole other subculture here. Anyway, my simple point is this: we are the sum of our experiences and it is imperative to provide our children with as many as we can offer.

Paul Collins in his book Not Even Wrong: Adventures in Autism (another great one I highly recommend), is where I first learned of "The Wild Boy," later named Peter. He begins his book with this story and as an historian mirrors his studies against the development of his own son with autism. He notes that Peter was first found as a creature in the Black Forest lurking on the riverbank in 1725. Among the forest "was the rarest of wild animals: a human." It is a story of this young boy, with autistic traits who had run away -- left to his own devices in the wilderness. When he was found, he was summoned to London, dressed to meet aristocracy. He was brought to civilization although he spent years learning to adapt like other animals, was taught new skills which he learned to a certain extent: "The wild boy who had been living in the trees just months before was to receive the finest education in the land... Many years later, Peter had run away and was picked up in Norwich:

"Who are you?"
"Wild man."
"Where are you found?"
"Hanover."
"Who is your father?"
"King George."
"What is your name?"
"Pe-ter."
A dog was pointed at.
"What is that?"
"Bow wow."
He was then asked to name the family horse.
"Cuckow."

He understand everything he hears, the mistress assured...And he could sing too: he loved songs and would rattle his collar tag in joy when music was played...when the song was over and the catechism of simple questions exhausted, the [now] old man would fall silent and would not say anything more. (Paul Collins pp. 44-45).

The wild boy couldn't be entirely taken out of Peter, but it is obvious that he was "tamed," or civilized to a certain extent that as an old man, he could answer these questions.

P.S. **Tabula Rasa**: A phrase (meaning blank writing tablet) from the Latin translation of Aristotle's *De anima*. It does not occur in Locke's *Essay* (1690), though it is present in Pierre Coste's French translation (1700). The *Essay*, in its statement of the empiricist these that there is nothing in the mind that was not previously in the senses, speaks rather of the mind at birth as `white paper' awaiting ideas from experience. (from Oxford Companion to Philosophy edited by Ted Honderich)

P.S.S. Thanks to everyone's intelligent and inquisitive comments and posts. It gets us all thinking!!

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**The Importance of Presuming Competence**

Biklen, from who I borrowed the title for this post, sums it up in that sentence -- how important it is for us to assume that ALL autistic people are competent and intelligent. I've written it before and I will keep writing it.

I believe that to coin autism in any negative sense is not our
perogative — it is the right of those with autism to tell us like it is, not for us to interpret their behaviour ("behavioural deficits") or presume that typical responses are the only or right responses. I believe that the decisions to be made on what should be done in the research and therapeutic fields should be determined by those with autism. Reading the stories of Richard Attfield, Sue Rubin, Donna Williams, Temple Grandin, Stephen Shore, Lucy Blackthorn and many others for the exhibit I put together of Jonathan Lerman (I prepared an exhibit upstairs titled "The Voices of Autism" with floating quotes from those labelled with autism), has only made my opinions more resolute.

As organizations, teachers, fundraisers and parents, we MUST make way for these accounts. We must provide supports (determined by those with autism who decide what supports they need) to enable people with autism live successful lives. As I presented in previous posts, the success of the person classified autistic lies in our supports, our school systems. If our organizations for autism only present in terms that make autism sound TERMINAL (cures should be sought for cancer, not necessarily for autism), this will effect the way people think about the people labeled with it -- without hope. I believe that the act of advocating the rights of our children is a priority in this "journey."

"In its simplest articulation, presuming competence means that the outsider regards the person labeled autistic as a thinking, feeling person. This is precisely the stance that every educator must take -- failing to adopt this posture, the teacher would forever doubt whether to try to educate at all, and would likely be quick to give up the effort. Aside from the optimisim it implies, another benefit of presuming competence framework over a deficit orientation -- where particular levels of incompetence (e.g., belief that the person is incapable of learning to read or lacks the ability to appreciate other people's perspectives) are presumed -- is that when a student does not reveal the competence a teacher expects, the teacher is required to turn inward and ask, "What other approach can I try?" (Biklen, p. 73)

Of all the stories I've read, it is interesting to note that so-called "behavioural deficits" have been often identified as the result of anger and frustration on the part of the person labeled autistic -- sometimes also being misunderstood by others who have preconceived notions of what it means to be normal, thereby
silently, or perhaps not so silently, passing judgement on them. Richard Attfield notes that he cannot perform for such people. I know that Adam will not perform for such people.

The people with autism who feel "successful" labeled "low-functioning" in their childhoods, were the ones whose parents believed in them and worked with them. Biklen was asked "What percentage of people with autism can be expected to achieve the communication abilities of Albert Frugone or Richard Attfield or Lucy Blackman has achieved?" He suggests "that the percentage is likely to be a reflection of context. How many have parents -- in the main this has been mothers -- who can contribute huge amounts of time and energy to their education? How many have access to academic school cirricula? How many enjoy access to communication training and hundreds of hours or practice? It is likely not insignificant that [the aforementioned -- Frugone and so on], all had mothers who devoted themselves to providing intense instruction and who interceded with schools to see that they received academic content even when social policy and prevailing professional and social doctrine and attitudes discouraged it." (p.67)

This is not a profitable stance nor does it relieve parental guilt of never feeling like we're doing enough for our children. But it seems to be true. I know many mothers who sacrifice their time and their work in order to study and teach for the sake of helping our kids. I'm not taking a Bettleheim stance here, but intensive practise and advocacy and working with curriculae is an everyday job of the parent with a child labeled autistic.

P.S. Will the scientific community ever buy the "nurture" argument?

PERMALINK POSTED BY ESTEE KLAR-WOLFOND AT 1/19/2006 01:58:00 PM 6 COMMENTS LINKS TO THIS POST

WEDNESDAY, JANUARY 18, 2006

Dr. Phil's "Extreme Disorders"

Please go to side and click on Autism Edges blog for a review of Dr. Phil's good ol' Hollywood style. Unfortunately, I didn't get to see the show, but am concerned about this sensationalist
Small Talk

Language, spoken that is, seems to be the *sine qua non* of early childhood development, THE benchmark of whether a child is developing "normally" or not. Perhaps we depend on it more than we realize, and without being able to express oneself verbally is clearly a disadvantage in a verbose society.

Today, I think about how urgently we are trying to get Adam to SPEAK. How we seem to only measure his comprehension and his acquisition through his verbal responses. It is clearly difficult for Adam to talk. He is encouraged moreso by cues -- if I start the sentence and he can fill in the word (intraverbal), if (when I must) sound out the first letter of the expected response. At other times and unexpected conditions, he talks completely on his own for things he sees or wants..."I see a bus!" or "I'm hungry!," among others. If I was a pessimisitic parent, I might grieve over the lack of reciprocal conversation at this early stage, when other children might be speaking in more complex sentences, and comprehending more of my spoken language.

Here's an example of how I talk to Adam right now, when I'm asking (expecting) a response:

Me: Where are we going Adam? We're going to ....school?
Adam: School
Me: Where are we going?
Adam: School
Me: That’s right.

Me: Adam when you make a poo poo we go to the ....bathroom?
Adam: Bathroom
Me: Where?
Adam: Bathroom
Me: Good job, when we make poo poo, we go to the bathroom.

Then, there are easier concepts:

Me: What do you want Adam?
Adam: Chips
Me: Okay...here's your chip.

Other fluent Adam-mands are:

Hungry! Snack!
Squish
Turn it on!
Open Door!
Happy!
Tired!
Sleepy!
Water!
On the Potty!
Come!

Lately, I've been teaching Adam to read full sentences out loud with great success. He picks the right cards that go with the right match, then he reads the full sentence while pointing to the words using his index finger.

"The bird is blue," and so on. I'm not sure if he's going to chunk colours with the is, but it's worth a try.

I guess one could say this is the ultimate small talk. Right now, Adam is not conversing with me about all kinds of things fluently. But here's something that happened last night:

I was on the bed reading for a while. Adam came over and pulled me to his magnadoodle. He said to me "draw!" so I wrote the word draw, as this is what he usually loves -- me writing the words he says. Then he told me to write down the following words on his own (i.e.; absolutely no prompting!)

Jump
As the proverbial interpreter, I was thinking he was telling me of the things he liked. Then, he grabbed the pen and began to draw. He starts his drawing the same way an airplane draws and airplane in the sky with its fumes (from one of his Baby Einstein videos). It's an exact replica until his hand doesn't know when to stop. When he was finished his drawing, he took my hand and said "Airplane!" So I assumed he drew an airplane, was telling me it was an airplane, so I wrote AIRPLANE down. When that was finished, he drew another picture. When it was finished, he took my hand again and said "Sailboat!" so I wrote it down. He did it again -- another new drawing -- "Motorboat!"...It stopped after that. Adam is learning about airplanes and boats in school right now. I found it interesting that he could draw a representation (his own) and tell me what it was supposed to represent and, that he was taking in what he was learning in school. Symbolic thought? I THINK SO! See -- so much is flawed with this mind-blindness theory.

Adam knows so much that he can't tell us. It is unfair to judge a person with autism as cognitively delayed. What is deficient is the typical way of responding. We do not know what Adam knows and comprehends unless he can show or tell us in some way. Here is a quote from Richard Attfield (autistic) taken from Biklen's book (I know - I'm still reading him...):

All my life I have been considered stupid. I understand that autistic people are intelligent and if you people admitted that you cannot understand us then perhaps we could try in a way to understand each other as fellow human beings. I get so frustrated in this useless body. If you just expressed some understanding and treated me as an intelligent person I could try to talk to you instead of feeling frightened to express and opinion. I know that I am intelligent...will you ever take what I say seriously? (p.58)

Lucy Blackman, author of Lucy's Story (also recounts her own story about being autistic), indicates like in the other stories, that there is profound awareness in the world "Most people need proof [of the student's competence]. How can the disabled meet such a gauntlet?" Isn't this what I, we, are after? Proof that Adam
knows? And if we impose standard ways of measuring that, aren't we setting him up for failure? Lucy notes that she is able to attend school because she is allowed to pace up and down the hall when she needs to assimilate information. As an aside, she also notes that *walking away from a conversation may reflect excitement or a desire to manage excitement, not an indifference to conversation.* (Biklen). We forget to realize that also, certain conditions affect whether an autistic person can respond or "perform." We have to figure out for our children the most fluid path to be able to respond to what we are trying to teach. This is SUPPORT. With support, we feel empowered, we can perform, we can feel worthy and HUMAN. What the autistic person needs is our TIME. They need time to process in order to respond...one of the major issues I am learning is that once they are able to respond, we have already long left.

I believe writing will be an avenue Adam will be able to take. Since he reads already...(still need to teach him what words mean) -- it is a strength he will likely use for the rest of his life. I have purchased a toddler keyboard and mouse, and will teach him how to use it. My only present concern is making activities structured and close-ended so that he will stick with it before he gets frustrated.

I think of watching one of Brigit Taylor's presentations at New Haven conference held here in Toronto about a year and a half ago. She was dealing with social scripting. I remember feeling appauled at watching kids look at a list of questions, then being taught how to use their fingers to remind themselves of question one, two and so forth without the paper. Today, I see how I teach Adam scripts all the time. We practise hello, bye-bye, play, and all kinds of things every day. I see the value of scripts today now that I understand that I am not teaching Adam to ACT human. He IS HUMAN, with the same feelings as you and I. He is only challenged in this area, at this point in time (I don't know what the future holds). I think it is this fact, however, that teachers and parents either may forget or ignore the capabilities of children with autism.

I do not particularly enjoy walking into a cocktail party making small talk -- the weather, the presentation, the drive, the holidays -- but I'm definitely learning the value that we, as social animals, place on it. For the person with autism, cocktail parties and crowds seem to be the number-one stressor. While it is unnerving for
many of us, it seems to be a hundred times more so for people like my son. Small talk is the entry point -- do I want to get to know this person or not? There is a lot at stake with small talk.

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Einstein Dreamed About Riding on a Beam of Light

This picture was taken when Adam was fourteen months old:

His little legs barely steady, he walks over to a toy truck, turns it over resolutely, and begins to spin the wheels with his index finger.

“He’s checking out the properties of things,” I imagine. “What a smart little guy.”

He plunks his diapered bottom to the ground and continues spinning one wheel religiously. “Vroom,” I say, scuttling to him on my knees. “The car goes vroom, like this.” Just when I take it to show him how to drive the car on the floor, he leans his hands to the floor before standing. He moves away from me to the corner of the L-shaped couch.

“Come play, Adam. Come play with the car,” I plead, holding it out and returning to my demonstration. Adam stares beyond me and resumes running back and forth, crashing into the couch.

“What about these Adam, look!” He continues to ignore me, running back and forth. “Oooo, look at this, so cool!” I try emphatically holding up blocks to invite him to build a tower. “Look how high it is.” It seems to grab his attention now so he comes over and bangs it down.

“Come build a T-O-W-E-R!” I model and begin again, stacking one block over the other slowly.

End of picture show.
Will Adam will be able to do something special with his life? I believe this is a secret wish of all parents. As he peers out the window with his transparent-coloured blocks, observing intensely at the age of 3 how the outside can be red, yellow or blue, or as he flips through the pages of his book of planets and reads Mars, Jupiter and Pluto, I begin to wonder what autism is, how Adam sees the world wrapped in autism-speculated legends of Mozart, Einstein, Wittgenstein, Mozart, Jefferson or even contemporary artists like Jonathan Lerman, who, with autism, began drawing suddenly at the age of ten. Just what do these stories have to lend to the average Joe with autism? What light might this shed on the autistic mind, and are the gifted just different from the rest of us, with autism or not?

I know that many are skeptical about diagnosing the dead. Michael Fitzgerald, Ph.D., Deidre Loveky, Ph.D., and others insist there is enough (reams, in fact) of biographical data to make reasonable assessments about historic figure and AS and HFA (Autism and High Functioning Autism – terms used commonly in this context so I will keep using them here for the sake of this argument). I have to speculate that diagnosing the dead is as perilous as diagnosing children today – we have the guidelines – but as the landscape of autism is constantly evolving for our kids as the years pass, as people grow and change, as standardized tests and assessments serve to label and perhaps create more conditions, well, I think, speaking from an art-historian’s point of view, we can make fair judgments based on historical data, albeit never conclusive. We can fairly determine the nature of a person and frame their image as good as any portraitist in a particular point in time, as well as any DSM (Diagnostic Statistical Manual of Mental Disorders)-- whatever edition. We know about Van Gogh’s life from his letters to Theo and Paul Gaugin and others. We can appreciate his art as much as for his way of making it as for his psychosis’ – now thought of to also be autism.

Fitzgerald argues that giftedness is anyone who changes the way we previously view things, who offers a change from the way we’ve studied, perceived something in the past. He believes that giftedness can only exist for AS or HFA people, and not LFA (low-functioning autism), and excludes precocious skills from giftedness – such as musical ability, for example. Simply put, an exceptional piano player wouldn’t fit the bill for giftedness in Fitzgerald’s definition. To fit it, this person would have to be an
exceptional composer. To him, there is a difference between ability and changing the world, or at least the way we view the world. He has set the standards high, and perhaps that's a good thing.

Einstein developed the theory of relativity at the tender age of sixteen but how long was he thinking about it before then? Did he spend his days watching the air move and dust particles dancing in the air at the tender ages of two and three? We know that his speech was profoundly delayed. We learn in his later childhood years of his lack of affect and socialability, intense focus, awkwardness, his poor performance on tests. But we can never see his earliest years, the years of toddlerhood, when we, at this point in time, place our children under the autism microscope.

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**Little Drummer Boy**

*If a man does not keep pace with his companions, perhaps it is because he hears a different drummer. Let him stop the music which he hears, however, measured far away. --- Henry David Thoreau, Walden, Conclusion.*

So my little drummer boy is still trying the potty -- he is a willful little one. I am thinking about all this motivation stuff -- extrinsic and intrinsisc motivations of the autistic person. I do believe we all need our trophies and ribbons, but in the case of Adam, his competency *seems* to be the Holy Grail (or is it mine?). External motivators, or reinforcers have to be used oh so carefully and faded as quickly as possible. I know Adam needs to be pushed now, at this stage. We can try. We can see.

I think of motivation and the person with autism. Maybe being with us, or what we do, or what we think is "normal," just isn't that interesting. So, just what is rewarding?

First Category, *Survival*:

1. Food
Second Category, *things that lead us to first category*:

1. That which comes easily;
2. That which feels good (pleasure which is sensory);
3. That which we get lauded for (fame);
4. That which buys us what we need or want (fortune);

In Adam's case, in an environment where much of the above is already provided for, what he finds motivating is:

1. Sensory Play
2. Food
3. Running Outside
4. Balloons and Bubbles
5. Swinging
6. Praise
7. Independence (competence -- ability to play and do things without having to ask for help)

It is the last point that I’m really noticing and for what I believe he will be willing to learn our way - no matter what else tries to pull him away. We can help him with those things by providing temporary ways to get his attention. On other days, the things he does on his own and that we try to interpret (his "behaviours") give him so much pleasure. We can look at that as negative by stating that these activities suck him away. Donna Williams seems to describe it as such. Yet, I will never forget the lines she wrote in *Somebody Somewhere*, when she rented a house and she was lying in the grass describing the environment -- the breeze, the trees, probably the way the air moved...she was lost in the world around her...THIS world, our world, perhaps her world, in a state of rapture.

I sit here in icy-cold Toronto. There is freezing rain beginning to come down, trapping me in the house this grey upon grey day...layered so thick now I hardly want to open my eyes. I rather dream about Donna’s world under the trees. I believe most of us dream about such moments of losing ourselves and becoming
Carry on, my little drummer boy. I consider this journey between you and me as somewhere between two worlds, both yours and mine.

Intuition Precedes Science

Reading about autism can both help and hinder me. Two years ago, when Adam was initially diagnosed with autism, I began reading the typical stuff -- Catherine Maurice and then moved on to so-called "experts" -- scientists, academics. I have a Masters Degree in Fine Art History -- I am a wannabe to a certain extent. Yet, when it comes to Adam, and I’m sure many parents will relate to this, I just KNOW. It’s not that I know what to know, but I feel and have always felt at odds with the many elusive theories out there about autism. And so, two years have gone by and I realize that it is not my son that wears me down on the days "the cup is half empty," but rather, all those "experts" out there whose egos come before our children, who must push their theories without ever having given birth to, or raised a so-called "autistic" child. Worse, autism as metaphor (Biklen) has permeated clinical and educational consciousness to such an extent, that our kids do not even have a fair start out the gates. They are doomed before they begin. Parents who are not inclined to trust themselves, to read, to question, who believe in clinicians and their assessments that set our kids up for failure at the get go, feel overwhelmed and depressed.

I’ve never had a great love of science. I believe science must be rigorous and I wish academic egos could go in the garbage where they belong. (Read The Behaviour Analyst journal for some of the most hilarious studies I’ve ever read like "How to introduce new foods to autistic children" -- gosh golly, ever asked a mother? And all of this gets funded, people!!). Foregoing the obvious fact that nothing is perfect and we still need science, then comes along a researcher or two that actually furthers our understanding about autism in a positive way. Please read Douglas Biklen's book...
The problem with autism now, NAAR, Autism Society, many clinicians, teachers, some behaviour analysts and other therapists (even RDI and Floortime ones), is the absolute belief in autism as "inside the person" as Biklen puts it. In fact, in my earlier days at NAAR, I also held the same belief that autism somehow "masked" my true son before I realized that autism is simply a way of being. There was good reason I held that previous belief and they were the theories of Mind-Blindness, Central Coherence theory and the theory of impaired Executive Function.

As time went on and I tried to hold up these theories against my son, it felt like trying to squish him into other identities. I didn't see that he had any problems with memory, affection, wanting to be social, linking concepts, shifting attention, eye contact, joint attention...he's got all of that. What I did recognize that he needed to be shown how to do a lot of things -- how to play with a toy, how to join a group. His biggest challenges to date is "stereotypy" or "stims" and attention which is affected because of them. On the whole, Adam is a child who wants to learn and be independent and takes pride with his competence. Adam's language is delayed -- he speaks but it may take him time to process, or it is still prompt-dependent. When he's not sure what the answer to a question is, he is echolalic. Yet, when I write the answers down for him, he reads them fluently. Written language seems to flow while processing verbal language is more difficult. But it is coming with lots of practise. Motivation is often identified as a challenge for him, and for many children with autism. But even "motivation" is too general a term when we learn from Biklen's synopsis of other science that what we thought as lack of motivation (again another small box that doesn't seem to fit my son), could be related to other factors:

"Bara, Bucciarelli and Colle hypothesize that a single rather narrow impairment such as attention difficulties could affect a range of other cognitive functions, thus causing a person to appear incompetent in higher-order thinking, when the problem is really more on performance (2001, p.219) under particular conditions." (p.42-3). In regards to theories on so-called impairment of Executive Function, Biklen states that the genetic view to autism is pessimisitic and does not consider the person who is classified autistic as elastic like the rest of us:
"The nature side of the argument holds that people are born smart or not, thus exonerating socially created inequities such as poverty and poor educational opportunity from culpability for stunting a person's development. Similarly, when a theory treats autism primarily or exclusively as an internal state or trait, it may, albeit possibly unintentionally, imply biological determinism. Save for the unlikely prospect that science could cure a person of the presumed internal flaw, such a theory is fundamentally a pessimistic stance. The theory defines the person as more or less bound in and made static by trait, with any chance of "improvement" (i.e., becoming more "normal") being modest or unlikely." (Biklen, p.45)

To say that an person classified as autistic is not at all influenced and nurtured by the environment is absurd. To hold the view that one's child will never develop and grow is not only bleak, but unfair and it is the fault of those scientists who push the deterministic views upon parents.

About a year ago, Adam, Henry and I took part in the baby sibs research project here in Toronto. Adam underwent a series of cognitive assessments by a former behaviourist student who was hired by this particular researcher. It was your typical assessment -- and she spoke what I call "dumbspeak" to Adam the whole time, you know, that deliberate higher pitched tone of voice. I swear to this day, here is a person who has no empathy and a set of presumptions about autism. She would look at me like I was in denial about Adam's abilities (no, disabilities in her view). She would peer at me from behind her black rimmed glasses. I am certain to this day that Adam could sense her lack of faith in him. I am certain that any child who has been given the diagnosis of autism knows who believes in them and who doesn't. To this day, I want to smack that girl. To this day, it baffles me when I hear parents say with such certainty that "my child will end up in an institution," or "my child will never do x,y or z." And it may just be so. Not because the child, or adult, cannot grow, but because they perhaps may not be growing in an environment that is nurturing. For all we do as parents, the one thing we must have is optimism and faith in ourselves and our children.

It is difficult to interpret the way Adam sees or experience the world. Interpretations of his behaviour are inherently dangerous,
so thanks to all those people who have expressed themselves who are autistic. I think my family and I try to interpret Adam every day. It in fact bothers me when someone says he wants something as presumption without any intentional or verbal communication from Adam. We are all learning to wait him out. If he needs time, it’s okay to give it to him. Autism needs time, and yes, more research. But listening to instinct is an underrated skill in science and yet, science has nothing to argue without it.

Through the Looking Glass

I watch Adam observing the dust particles spotlighted by the beam of sunlight through the window. Daddy tried to make him pee on the potty until I heard "mom, mom, mom...come!" He was happy to see me, obviously not wanting to sit to pee, but more interested in the dust particles happily dancing in front of his eyes. Yesterday, it was the reflection of water against the wall, again aided by the sun's reflection. He was swimming with grandpa in the pool of their condominium, and the water performed a dance like it was just for him.

I've heard other people with autism express how they can SEE the air moving. My Adam is intrigued when rain or snow is falling from the sky -- no small miracle in his eyes, I presume.

He is interested in putting on my sunglasses -- whoa -- the world must look interesting through those, or putting the coloured water blocks to his eyes and then to the window, to see how the outside looks all blue, yellow or red. These are quiet moments, totally entralling for Adam. His babbling stops and I want so badly to see what he sees like I am missing out on one great miracle, or secret, exclusive to his eyes, his world.

Other days I want to give him rose-coloured glasses - the kind that might make the world look like a jollier place. A mother's interest to protect her son.

Adam is busy today -- Sunday. He has O.T., P.T. meeting with his
new consultant with our lead therapist and I'm meeting a possible
new therapist. If I have time to write more today, it will be by the
graciousness of my husband....

Adam is in a session now with his new consultant and our lead
erapist, Laura. He is tired after O.T. and P.T. and barely eating
because of a stomach virus that's been plaguing us on and off all
week. But he always has such a happy disposition. This part of me
leaves me amazed and wanting to be like that -- although his
happiness must be, in part, genetic.

I feel like describing my days as cup half full or half empty ones --
perhaps I'll begin a daily barometer so you, the reader, can tell
from which side of the fence I will be talking about our lives and
autism. Today has been a waffling kind of day. The weekends are
tougher because I have less supports around. I began thinking
about freedom as standing in the Starbucks line with a bunch of
other adults. Ahh...and coffee -- definitely associated with Nescafe
moments.

Does Adam feel free? Is he affected by "the big black
nothingness" (Donna Williams), the sense of imprisonment? Will he
as he gets older? "Exposure Anxiety is a invisible cage and to those
who live with it, that invisible cage is either their prison warder-
monster-saboteur or their saviour, helping them to cut off,
shutdown and keep the world of overload at bay." (Williams, p.83)
Overall, freedom is based on perception -- entirely resting upon
our daily barometers. Freedom can exist in the mind even behind
bars, I've heard. How much is autism a prison within? And then
there is the prison outside of autism, those that the rest of society
constructs.

How much of looking at dust particles is Adam's prison, or personal
world, or escape? "It's like trying to remove a parasite which has
become finely intertwined with the person's own functioning; they
may respond to this 'help' as though it were an assault on
selfhood...the self of mind which may be free, and the self of will
which opposes the desires and needs of the mind..." (Williams,
p.83) When I read that I can't help but think about the box, the
way of looking at the world, depression, and all of that which suck
like parasites on all of us.

I have to move on, paradox keeps tripping me up!
Now to MacLeans Magazine: The Next 100 Years. One Child's Journey to 2105 - How She'll Live, Love and Never Really Die. By 2055, scientists state that there "will be a cure for everything." Yikes. Consider this want ad for a mate:

Tall Blonde. Attractive SWF 29 who is educated looking for SWM 25-35 who is of good moral fibre, monogamous, yet extremely loving and playful. DNA screened for all neurogenerative and metabolic diseases including diabetes, Alzheimers, [Autism] and Parkinsons. Carrier of longevity gene.

Not only will we live forever, but the species that we are attempting to create is perfect. What does that say about my son and his future? What does that say about society's true goals for supporting and enabling the "disabled," and of acceptance of difference? I certainly never wanted to live that long, not until I had Adam. Still, I do not want to live forever as I believe it will effect the quality of my life in the sense that if we have an endless supply of something, we cease to appreciate it.

Yesterday, I laid down on my couch and watched the air move. I watched the clouds drift by on that windy day, undulating swiftly. Sadly, I was missing the transparent coloured blocks.

My husband just told me that I sound like a pro-lifer in my last post. I’m certainly not the type to stand in front of an abortion clinic and make protest.

I am a mother in love with her son who happens to be autistic. In him, I see miracles everyday. I admit that prior to having a son with autism, I would have been fearful of autism, down syndrome...it is not a condition people would prefer to deal with because people have no idea what it involves without having had the experience. This is why we as parents have so much awareness-raising to do. Before I had my son, I feared anything that was "different." After the experience, I would have opted to
Everytime I have a resolute opinion about autism, a moment later, I feel I must offer an antithesis. The feelings conflict because autism is itself a paradox. Of knowing and unknowing, of ability and inability, of what is present and what is missing. Perhaps only as an outsider do I view it this way.

First, there is Donna William's description in her book Exposure Anxiety: "Can't do it for myself; Can't do it by myself; Can't do it as myself." And yet, a person with the diagnosis of autism, let's use my son as an example, does many things by himself, albeit not always under scrutiny or on demand. What appears like a missing piece or to a layperson, a cognitive delay or inability, is in fact ability obscured. Autism is indeed not what it appears, and the way we treat it is ultimately paradoxical -- trying to teach someone who knows inherently, like teaching emotion to an autistic person highly tuned in to it -- perhaps it's knowing and perceiving without knowing how to translate it into another language -- the language the rest of us understand? But then this is not so with writers and artists who are autistic, who have found a common ground with which to communicate. Going back to face recognition seems almost ridiculous when we begin to understand the complexity of perception and thought beneath the surface of autism's appearance. But in order to translate it to operating in our world, the common language, simply put, must be used?

The way I deal with autism in the way we teach Adam is in constant flux as a result of him -- it is trying to find a way to teach that challenges him while at the same time bringing him to respond at any time. I am trying some behavioural approaches without wanting to subscribe to behaviourism, solely because
learning is in large part based on pride, and marathons are won with ribbons. I like what Donna Williams says about work on behaviour: "for with Exposure Anxiety, more than any other condition I can imagine, compliance is not a long-term sustainable answer if our goal is independence in capable people who cannot handle awareness of the self." Or consider this quote about social-emotional development:

"The only things that could actually lend support rather than add to incapacity were things like objects, nature, reflection or the sense of myself in the third person as a form of company. Essentially, these "autistic" self-reassurances made it more possible to dare communication, expression, or involvement or a true self-expressive kind (as opposed to avoidant, diversion, and retaliation responses). It's important to realize here that what I was probably trying to get around was not an emotional development issue, but the interference of my own chemistry mechanisms which were triggered too easily. Many people think that getting through to people is the answer. When you are looking at underlying physiological problems and their impact, there may be very little the outside world can do to reassure. It maybe more a matter of doing what one can to help people chemically and understand how the behavioural approach may interact with that chemistry to the benefit or detriment of the person's cognitive, communication and socio-emotional development." *Exposure Anxiety, p.41*

Ok, I'll have to work out these raw thoughts. What I'm trying to allude to is the utter confusion between our way of looking at things, at how we should view the world, interact and communicate and all the nitty gritty in between that makes autism difficult for the rest of us to perceive and understand. We do everything in our power to change the autistic person. We do it under the premise of helping them "cope" and "adapt" (my own goals -- I still grapple with them), without actually knowing what it is a person with autism wants. It is so difficult when they cannot tell us themselves, or when children are so young, we try as parents interpret and make choices in their best interests.

I believe that this ethical grappling as a parent must be crucial -- always trying to understand and figure out the best we can do while honouring our children and who they are with autism.
I received a disturbing link today on Dr. Joseph Buxbaum's research on MSNBC -- NAAR supported:

"Dr. Joseph Buxbaum heads up the Autism Genome Project at the Mount Sinai School of Medicine. Buxbaum says he expects major progress in identifying the genes associated with autism in the next decade.

“I think within ten years we’ll have found the genes of major affect and most of the genes of minor affect,” said Buxbaum.
“That will then lead to reasonable targets for drug interventions. It will lead to much better diagnosis and certainly earlier diagnosis.”

Buxbaum says there could be a prenatal test within 10 years.

“If we get to the point where we have 10 genes that predict risk to some significant degree, then there is a prenatal test,” he said.

Once genes are identified, there will be targets for drug intervention.

What does this imply? Why do we have prenatal testing - to what end? I think the likelihood that abortion will be offered if an autistic fetus is identified. Does anyone think of the repercussions of all this research? Abortion of so-called "disabled" fetus' is akin to ethnic cleansing in my opinion. We are not ready to make these decisions, we have not had enough time to debate these important bioethical issues, these researchers and the organizations that support them are like bulldozers trying to pushing this along before we really talk about what's at stake. Whether you believe the following people are Aspergers or not(I acknowledge that there is uncertainty, but let's use as examples for the sake of this argument), "would the world consider aborting the next Bill Gates or Albert Einstein?" asks Arthur Kaplan at the Centre for Bioethics at the University of Pennsylvania. He states that the future of society depends on how we answer these questions, and I believe he is right.

I have HUGE problems with prenatal testing for autism and I urge all of you reading this to join me in this dialogue and raise your objections everywhere. If any of you are lobbyists, come aboard. This is a very disturbing trend that needs a whole lot of dialogue.
Autism as a Social Construct

Last summer, I read the story of Hugh Blair -- a son of landowners who was married off and inherited the estate. The only reason we know of him today is because of court records -- his brother sought to take the estate away from Hugh, who today we understand to have been autistic. In it, there are accounts of how he curiously lived his life -- and was described as mentally incapacitated, unable to live on his own. When reading these accounts of nearly two hundred years ago, Hugh, through the eyes of his contemporaries, appears like a caricature. Due to his "mental incapacitation," he was deemed by the courts as unable to look after himself, live freely and keep the estate his mother endowed to him.

So what role does our society play in viewing and thinking about those with autism? We have progressed so far in terms of our knowledge about autism from the days of Leo Kanner and Hans Asperger. Yet the words of history resonate to this day. When autism was first described by these men in 1943, the frame autism was placed in, although yellowing at the edges over 50 years later, remains in the same frame. It appears that the views of society wallow in the safety of history. But if we take apart the vernacular used back then, we can see clearly how history, society and personal bias takes a huge part in how we view autism today.

Let us start with Leo Kanner and pay attention to judgmental language. He described characteristics of autism as "a marked limitation of spontaneous activity," "stereotyped movements," "a child's inability to relate to themselves" and called autism "inborn autistic disturbance of affective contact." Hans Asperger describes autism thus: "The autist is only himself and is not an active member of a greater organism" which he is influenced by and which he influences constantly. The essential abnormality in autism is a disturbance of the lively
relationship with the whole environment." Abeit these are brief examples and perhaps not the best ones in their repertoire, but these descriptions do not describe the abilities of autism or even assume that the life of the autistic person is rich with perception, intelligence, thought or even prefers to be alone and quite content with that -- it assumes that what is not like the rest of us, is abnormal and "tragic." (Read Douglas Biklen, *Autism and the Myth of the Person Alone* for further reference to this).

This is the main thrust of behaviourist and many other operationalized principles: it is taking a view about autism that does not belong to one who has been diagnosed with the condition of autism, but rather, the rest of us who are not autistic have more authority in terms of labelling, diagnosing, assessing and interpreting autism and autistic behaviour. It assumes that:

1. Autism is a socially inappropriate way of behaving that must be corrected;
2. People with autism do not want to be social so we must teach them social skills or assumes that they want to be social and we must help them be so (do we ever really know the desires of others if not articulated to us?);
3. It accepts the behaviourist's or any other therapist's interpretation of the behaviour as the true meaning of that behaviour.

Simon Baron-Cohen, whose theories I believe are fundamentally wrong (assuming people with autism are mind-blind as he also states "knowing seems beyond most children with autism") is his judgement alone. I've met many a "low-functioning" (hate that term -- it means nothing), person who possess great intellectual ability, emotion and perception of others, despite their outward appearance or way of being. Further, does outward appearance and action reflect thought? Would we classify Stephen Hawking as "low-functioning?" (Biklen refers to Hawking in this context as did I in a paper last year).

It is important that we all understand that judgement and bias is innate in the "scientific" theories about autism -- we must account for the scientist's own personal bias, social influences, judgements and opinions and the history of disability, and how that has influenced our thoughts and opinions. However, we seem to be taking all of these accounts now as today's TRUTH about autism.
Parents and educators assume that these resonating words, unworthy as they are, are absolute truths. Parent's invest dollars in therapies that claim to be "scientifically proven," when they are not. I call these vapours -- and we stake children's lives upon them?

How do we evaluate success? What frame do we put that in as another absolute? How do we even evaluate progress in therapy for that matter? All this therapy, 40, 50 hours a week, and yet I've not yet met one person who is no longer "autistic." There is no proof. Is the goal of becoming "indistinguishable from one's peers," an honourable goal? Is it in the best interest of the child? Making one "indistinguishable" can be translated into "acceptable." And what does that say about us and how we view genetic diversity?

I will be writing more...I have to go pick up Adam from nursery school now...

Paying Attention to Autism Vernacular

In autism and dealing and describing our children, I believe that how we describe them reflects how we as parents VIEW them. The use of language in how we refer to autism directly relates to how we feel and relate to our children.

I admit that some days I feel confused. I use terms like "an autistic child" as opposed to "a child who happens to have autism." It is true that we are all more than our labels. Autism is a difference, not a disability. I find myself constantly correcting my language, or making mistakes. Yet, I think as parents especially, we ought to be cognizant and careful of how we use it.

**Wrong Ways of Stating Things:**

My child is autistic
My child is disabled
Autism is a disease
Autism is a disorder
My child is special needs
My child will be in an institution
ABA is the only LIFESAVING therapy for autism
Autism is an epidemic

Right Ways of Expressing Things
My child learns differently
My child is unique
My child has special requirements
My child has ability
My child will learn on his/her own timetable
My child can learn

There is more...anything that chips away at the unique identity of the child, the child as a whole person instead of "half" of one (normal versus abnormal), is wrong.

It is easy to pull out my hair with autism therapies too. ABA, RDI, Floortime, SI, whatever. At the end of the day, I still ascribe, with my whole heart, to a program that meets THE UNIQUE NEEDS OF EACH CHILD. The problem with programs, per se, is a dangerous lull to blanket approaches, thereby assuming that every autistic child has the same learning needs. In fact, there is nothing more difficult than to help our children and program for them because of adherences of certain teaching communities to one program or another. A parent really has to have some balls. A parent has to have faith amidst all the influences and seeds of doubt that many communities wish to impose upon us. It takes a lot of research and a lot of guts. I call every parent to acknowledge the doubt and exercise the time and patience it takes to learn everything you can get your hands on. Then, go back to watching your child and your intuition. Then and only then do I think we can do the best things for our children.

Here's an answer that I repeat to myself when this or that comes pounding in -- what is making Adam attentive and willing to learn? What makes him happy? What makes him able to adapt to the world around him? What are his abilities I can use as bridges to learning? If we can answer those questions, we are well on our way to building a program that works for him.

I used to be co-chair of NAAR here in Toronto (my title changed a couple of times from sponsorship chair to co-chair, so I'm not sure
What I was, actually...I raised some money...). NAAR uses vernacular I highly disapprove of, albeit I do appreciate all the research that they do support. It uses CURE to market itself and since there is no, and likely never will be, a cure for autism, I find this highly objectionable. I prefer to address the research in order to understand autism, teach better and create more awareness and understanding. I find the CURE for autism, highly controversial and takes the negative and disabling view towards our children. Instead of fostering a community of genetic diversity, and accepting that as parents and fundraisers, there is a community of people who hate people with autism and insist on CURING them. Think of it that way for a change. Maybe we will all view our children a little differently now.

Wisdom Comes Through Suffering

As I said earlier, optimism doesn't come for free. I look at all kinds of positive stories about those who are autistic, who "presented" similarly, or even worse than Adam in the early years. The purpose of looking at positive stories is the same as an athelete's visualization -- the goal has to be clear. I believe the same approach holds for my son Adam. For me, it is a marathon that never seems to end right now. For Adam, it is the marathon he doesn't quite yet understand. Some parents who write to me seem so low -- their child will "never" do this or that, instead of realizing that their marathon, no matter how old the autistic person is, is just not over yet. Development can occur at any age. I've heard of 42 year old autistic people just becoming independent, just acquiring a new stage with such joy and sense of accomplishment. So I read and talk to parents of autistic people, now in their twenties and thirties, who struggled just like us, but now study jazz guitar, or teach mathematics. Things that just didn't seem possible happen only with plain faith and constant chipping away. This is the journey of autism.

I would be lying to you if I didn't tell you the moments of worry and doubt. These moments keep wanting to press in and strangle me. It is a battle not to let them. Here was one last night: I dreamt...
that I died while taking care of Adam. I am most often alone here with him in the house -- my husband works long hours and I don't have any live-in help. I dreamt that Adam's nanny was also sick and didn't show up the next morning, my husband was out of town and I died. Adam was alone in the house, his diaper getting fuller so he took it off and the feces bothering him that he smeared it all over the upstairs in an attempt to clean himself. He kept coming to me and pulling my arm, crawled all over me for a "squish," oblivious to the fact that I died. He soon gave up and chattered to himself in his room, preserverating with toys, walking back and forth, playing with his hands. This goes on for a while. He pees, he gets hungry. The phone rings -- my parents think we just must be out. Adam gets hungrier. He cries. He tries to climb over the dangerous gate to go down the stairs to get some food. He tries to wriggle under it (there is a space). He gets stuck and screams. No one can help him....

Isn't that awful? Consuming thoughts like this happen once and a while. I have to fight them off. I take a deep breath as I write this down, my eyes tearing. Deep breath again. I must shake this.

Isn't this the worry of all parents with autistic children? Just how long can we live so we can take care of our children? Eighty years? Ninety? What if I get sick? I am already forty years old. He is just turning four this April. When he is twenty, I'll be fifty-seven. When he is forty, seventy-seven (my aunt just died at seventy-eight). I don't think there is one parent I've met who doesn't have the same thoughts run across their minds.

Adam's stims have gone way up these days. I see so much potential in him, but these are the biggest obstructors. I am installing a swing in the basement for vestibular feedback (he becomes so much more organized when we incorporate movement into his day). We need to teach him more functional play skills so that he can redirect himself. We will provide him with a visual box that he can have at prescribed times during the day to give him the feedback he needs, but teaching him that he has to do others things at other times of the day.

I have been teaching him reading. This is going well. He does have some issues at discriminating words -- words that I know he knows will get confused with same-letter words if he is distracted. But if I teach him this skill, I am convinced it will help him
communicate. I also notice that he is terrific with intraverbals, but I think he has learned to speak this way, so I am getting him to read complete simple sentences now in the hopes that he will understand them and use them. I am also fading back (backward chaining) my intraverbals in order to get him to say the last two words of a sentence instead of just the last word. I've just started doing that and it seems to be working. If I had to evaluate his progress against last year's, he really is speaking a lot more. He is transitioning well, he has been weaned effortlessly, and he is taking to potty training very well. He loves art-making, has begun to spell words (albeit with inconsistent interest in doing so), and is learning to read. He adores music and is singing more songs and is slowing learning to imitate actions, even if they are still delayed responses, he never did actions before. He has improved his motor skills -- can hold a pencil better, can draw, can climb, and is beginning to jump off higher surfaces. There is more, but I think that's enough to convey how much progress he has actually made. It is all these steps we have to remember every day.

Parents and Therapists - A Vulnerable Partnership

As some of you know from reading my blog, I run my own in-house therapy team. Here in Ontario, I have not yet found an agency flexible or sensitive enough to meet my son's needs or work with me to approach Adam as an individual as opposed to just another boy with autism -- with a generalized, blanket approach to his therapy.

I've hired my own therapists, psychologists, SLP's, OT's.... all have been exceptional. There is, however, perils to these relationships. Typically, the therapists we hire to work with our children on various ABA and Floortime or RDI therapies are young, in their twenties, having come to this via a university posting, an ad, to make a little bit of extra money. Some go on and continue to work in the field as they discover a love of working with autistic children. Others are simply good at it, but so young that visions of having
their own families supercede their loyalty.

This is just a harsh reality for families like ours. Right now, I am looking for another therapist as one of my excellent ones is pregnant and dreamily drifting through her days in happy anticipation. I don't hold it against her -- I understand it perfectly. But as a family with autism trying to work in these early years in preparation for full-time school, it leaves us feeling hostage. If you have a good therapist and she wants more money...guess what? You're going to pay it because your son's progress is dependent on her and there are so few good therapists out there. When you find someone you really like, you want to hang on to her. But I have to say that I feel abandoned and a little peeved at being left without their help in finding me a replacement. I've wanted to help them on in their career, paid them the money, and in the end, this is the harsh reality. People will come and go no matter how hard you try to keep them. Very few therapists that I've encountered are seeking their M.A.'s or Ph.D's in the field. They do not know yet if they want to stay committed to it.

This is my venting of the day. In the end, as parents, we are alone with this. There are days when I want to get peeved, but I can't. People will come and go -- in and out of Adam's life.

PERMALINK POSTED BY ESTEE KLR-WOLFOND AT 1/09/2006 09:19:00 AM 0 COMMENTS LINKS TO THIS POST

SUNDAY, JANUARY 08, 2006

Raindrops from God

Just when I am at my lower points, I receive raindrops from God. (Not even sure I believe in God, or fate, per se, but then moments like this make me wonder...).

Adam's stims have been way up these days. When I say that I mean that he flicks his hands in front of his eyes in a frenzy, he constantly babbles and talks to himself, as if leaving a silence would be torture, or he licks a window, a wall, a toy. It is then so hard to get his attention. My otherwise intelligent young boy who I've seen do so many things, here and there and all too inconsistently. He gives me flashes of his brilliance some days (like reading headlines of books -- like the headings in encyclopedias or...
reads the names of planets), just plain normal interactions on other
days. Yet on other days I need to constantly repeat myself, use
chips to have him sit down so I can teach him a skill, or he seems
to forget how to read the simplest words I've seen him spell with
his magnadoodle. Skills come and go and the fear is always if he
still has the skill he once so brilliantly displayed. I believe that
everything in his brain is stored and as more linkages are made
and concepts fuse, his skills will become more consistent.

Stims give me the most fear because he is then at his most
unreachable. They are like hurricanes -- much stronger than I am.
There is little use fighting them and I want to respect the need and
the reason behind them. Donna Williams writes a lot about the
senses in *Exposure Anxiety: An Exploration of Self
Protection Responses in the Autism Spectrum and
Beyond*. The doctor I will be working with, who has her BCBA as
well as a Ph.D. in Sensory Integration, suggests I delegate a visual
box 6 times a day for 10 minutes at a stretch. It is a behavioural
approach and I deeply wonder if this will help Adam -- I still want
to honour his way of seeing the world while building bridges so he
can interact with me and others. But when Adam isn't listening, I
find myself at odds with my own principles. I am afraid if an
approach will harm him and dishonour him in an effort to
"normalize" his behaviour. This is the paradox of autism. It is a
skill that is there one day, gone the next. It is a parent's optimism
and days of utter gloom. It is a battle within one's self to do what is
right for one's child -- honour them and their difference -- while
balancing a need to have them join us. Schools hardly help us with
this paradox -- they only seem to make the conflict worse.

So, when I am at this low point today (my husband is gone for
almost the entire week and then gone again this weekend with his
other children skiing while I stay home with Adam who is getting
sick -- his stims always get worse as he gets sick), Adam's lead
therapist brings the book *Autism and the Myth of the Person
Alone* by Douglas Bilken. He is the co-producer of the CNN
documentary *Autism is a World*. Everything he says supports
my philosophies of acceptance and integration. It is again an
affirmation that in my hours filled with doubt, there is someone
out there who does think the same way. Here are a few
paragraphs from a chapter "Framing Autism;":

...building understandings from autobiographical narratives may
prove challenging precisely because it requires a shift in perspective from the so-called normal body to other bodies, and from enforcing narrowly defined, dominant ideas of normal to embracing difference as normative. In general, the distinction of disability is fundamentally connected to the notion that there is a normal body. The person with the nondisabled body runs in a particular way, eats with utensils in a particular way, crosses the street, builds objects, dances, and speaks in sentences. The person classified as autistic, who might not do some of these things or who might do them in clearly different ways from the so-called norm, is in the position of being seen as awkward or inadequate, or even as an `individual failure.' Thompson (an autistic person), puts it this way:

`So powerful is the cultural imperative to structure experience with absolute categories that figures who seemingly defy classification-- such as mulattos, freaks, transvestites, bisexuals, and other hybrids -- elicit anxiety, hostility or pity and are always rigorously policed. The rigidity of social order testifies to the destabilizing threat of ambiguity.'

The policing of people classified as autistic may include, for example, desires to `cure' autism, forced segregation of people labeled autistic in special schooling and housing and insistence that the person perform within completely normative standards, rather than in ways that reflect how autism is experienced. The idea of being policed runs through the autobiographical accounts. Fortunately, the contributing authors also explain how they often resist regulation." pp. 71-2.

I even have disagreements about respecting autism with my very own husband, who loves Adam with all his heart. His doubts work overtime as well -- the lull of chelation therapy, diets, gurus and ABA all too strong. Family members who do not spend as much time as I do with Adam, find it difficult to embrace his differences and struggle to make him more "normal." I worry about my tendencies to do this as well, as I get different inputs from various doctors and therapists. They can leave you feeling dizzy at the end of the day. To find one with the level of empathy and respect that I wish to achieve with my son without the endless worry that seems to parallel it, is still slightly beyond arms-reach. I still have years of living with autism and I want to understand how Adam thinks so badly. But I can't reach this level of understanding without
acknowledging the things out there that try to pull us away from
our goal -- of accepting, understanding, loving and helping our son.
At the end of the day, Henry and I are both there for Adam and
we love him to the end of the earth.

I've had parents who have read my blog, sending me information
on diets I've tried with no success, or promoting ABA programs
which I do to some degree, but with other therapies as well. Their
suggestion is always that Adam would "do better with ABA." This
is an example of all the things that pull on a parent in this arena
every single day. When Adam begins to stim more, it is easy to
think that something else would work better. It is harder to trust
ourselves.

I believe a parent has to have eyes and ears open, acknowledge
self-doubt and listen to oneself with as much knowledge in hand as
possible. The expert on the child is the parent. Each autistic child
can benefit from different teaching strategies and those strategies
may change over time depending on the child's need.

I would also never advocate a therapy that is in direct
contradiction to autism -- against the best interest of autism and
the child who is autistic. Any strategy for autism must honour the
autism as part of the child, not attempt to conquer, heal or cure it.
To do so is to consider autism, and then your own child, the
enemy. And I believe a child can feel that.

Canada AM aired the piece on Jonathan Lerman today...I’ll try and
download it soon for access.

Potty training is going very well. Adam has made 5 pees on the
potty during training time.
We have begun potty training -- seriously this time. Before the holidays, I was designating a half hour -- 5 minutes off, 2 minutes on. I have written "I need to go potty" on a few index cards and have deposited them around the house. As part of the training, I take Adam to the card first, in hopes that this will one day help him articulate it. He is finally anticipating his pee now, holding his crotch, holding it in. He never did this before and I think it is in part because of the training. We can't necessarily wait for our kids to be "ready," because there are gaps. We have to train and teach things systematically first and then the concepts come together. Now that this has happened, holding his pee that is, we can begin more rigorous training. He is holding it in now though -- either insecurity or a control issue -- I'll let you know. Just like weaning, all of this requires a parent's energy and readiness as well. I am ready -- for kicking or screaming if need be. He is whining a bit, none of that aggressive stuff. Either it is sheer luck or my perseverance -- I won't take no guff, so to speak. He's going to transition, he's going to eat all kinds of foods, he's going to use his fork, and he's going to use the toilet dag nam it! And guess what? He does. Without much fuss too. Day in and day out, no matter how long it takes, practise, practise and more practise. It doesn't mean that I'm neither flexible nor empathetic. I certainly am!! But my dad taught me this perseverance and I reiterate the same thing to Adam that my father said to me all the time: "If at first you don't succeed, try and try again." Yes, it's tiring, yes, sometimes it breaks my heart. But I think what has carried me through all this is the view to the future. If I don't do this now, then when? And the older Adam gets, the harder it will be.

It effects me -- I have to lose 10 or 15 pounds that all of this work has brought upon me. I struggle to find the time to do the work I need to run his program, to do what I love (writing and lately, awareness-raising about autism), and then to take care of myself. There are always projects I want to do. So as we all do every New Year, I am taking time to re-evaluate my goals and time commitments. Soon, I will have to submit a part of my manuscript weekly to an author/editor -- a self-inflicted task, really -- an attempt to keep my book on course.

I received an email from a reader today -- indicating that it seems that Adam is high-functioning. I've been thinking a lot about high-functioning versus low-functioning and how it's all rather
arbitrary. We seem to take the view that lower-functioning people with autism have more cognitive challenges and are, in large part, non-verbal. Yet, I’ve seen many "low-functioning" people who have incredible insights. Jonathan Lerman is an example. And if one person who is like this indicates otherwise, then I MUST assume that all people can think this way. To think otherwise would be discriminatory. One person with autism may have the talents to express themselves and so we must assume that just because the other does not have the same talent, there is no sententiousness. Like you and I, an artist may have the ability to express in a way I can not but it doesn’t mean that I don’t feel, see, and interpret. Ergo, even these labels are problematic, another attempt to make one kind of autism a little more acceptable than the other kind. It’s unfair to those with so-called "low-functioning autism" because if you think doors are closed for kids like my son, imagine all the more doors closing for these other kids.

Adam's Hyperlexia

Well, what I’ve been writing about the past few days is working like a charm: Adam’s reading skills are so strong that I can write something down that is verbally more challenging, and Adam can follow the command. I’ve begun putting labels (textual only) all around the house. I’ve tried PECs but he just doesn’t get as turned on by those -- it’s not that I won’t use them, but if I can accelerate Adam’s language this way, I’m going to do it! I’ve been reading When Babies Read by Audra Jensen over the holidays and it inspired me. Although knows hundreds of site words and I have to move him a little further into the program, it is also showing me to move back a little so I am sure Adam can pair the object with the word. I know he knows, but sitting at the table, I wonder if he will respond appropriately. I also began carrying the small magna-doodle all around with us today -- I used it to explain the following:

My Questions: "Where are we going?"

Text Prompt and Adam’s response: "Store"
Me: "What do we buy at the store?"

Text Prompt and Adam's response: "Food"

I made sure to do it again in the store. So I do this a few times before we go somewhere and again when we are there.

Soon, I will write the question down, then the answer. The perhaps Adam will be able to fill in blanks, categorize and more. His site reading is very strong and he does sound out some words phoenetically on his own (no one has ever taught him to read). I am going to make him books too. The first one I make is about his family and the second one will be about school. It all has to be about Adam's life...FUNCTIONAL stuff.

We came home from Blue Balloon's facilitated playgroup (a group being conducted until school starts next week). Another autistic boy was there today and does a lot of high-pitched whooping. Adam does this occasionally too, but this child does it a little more often at the moment and has his own way of doing it. But, when Adam came home, he started whooping just like his friend. This tells me he is watching and listening to his friend! I don't know what causes our children to whoop. Has anyone ever come across research that discusses it?? I wonder if it has anything to do with a sensory need. Is it something like the babble?? Sometimes I know it is the sounds from Adam's Baby Einstein videos -- child-like sound effects. Some other times he does it when he's anxious.

Oh yeah... the babble that sounds like a real sentence, but has no meaning. I'll try and write an example...it sounds like poems sometimes (and have been repeated often), full diatribes at others. He was standing at my parents window today looking out at something and spoke a couple of beautiful sentences like he was speaking another language. We always stop and try to discern if there is any sense to them -- something, anything we can understand. Or this little diddy he likes to sing:

"Happy days
a way oh a
wha say you" -- with a distinct and consistent melody. He particularly enjoys singing it while jumping up and down when his older brother Max jungles balls. If Max drops the ball, Adam will...
stop dead in his tracks, like he's rewinding the song. When Max begins juggling, Adam resumes the song like pressing the *PLAY* button.

Speaking of songs -- ever notice how many of our kids never sing along -- but maybe after, or quite a while later? I look forward when Adam sings a song along with me...I know it will happen some day soon.

Adam began using his fork independently -- that took about a year. I don't say it to denigrate the achievement, in fact, I believe it is a significant one and Adam makes so many of them!!

So, I look forward to the year ahead as we get Adam ready for school. I saw the movie *Munich* over the holidays (my husband said that he loves to watch the previews to see how many movies we don't get to see), and came out wondering what the world is coming to. The movie poses the problem that Israel and the rest of us face -- the utter hatred towards us. The answer to the question is that there is no answer. Facing all of this, we must work for peace, for hope in all things. This is life. It does not run smoothly.

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SUNDAY, JANUARY 01, 2006

It's New Year's Day and we're headed back home today from Miami to Toronto. Not really looking forward to the dank and cold. I write this while Adam awaits to make his final visit to the beach with Bubby while I pack...he enjoys playing with the TV buttons, no matter how many times I say NO. I figure at least a million times, and maybe, just maybe, he'll comply. The compulsion to turn buttons on and off seems stronger than I am. Nonetheless, he does listen to me most times.

I've been looking at the Dan Marino Centre for Autism here in Miami. Next time I come down, I want to check it out. One thing I liked (just from viewing it online), was that the centre's therapists all collaborate, much like what I do with my own team. OT's, SLP's, and other therapists meet weekly to discuss what each child is learning. If a child is doing Mr. Potato Head (I saw this in their...
The OT will also develop motor skills by having that same child draw Mr. Potato Head. I've been doing this for two years. It's been so important to build comprehension about Adam's world. I still strive, with my team that is, to build more synchrony (I always thing that having someone who can really manage and who knows about how important curriculum development is, would be the ultimate for Adam -- he needs a program that keeps him interested and challenged while also working on areas where he is challenged). We struggle with curriculum building (none of us are educators per se). I have very high expectations and I think for the most part, Adam has an excellent team of people and I've been able to build likely a great team of people. The key is for the parent (especially in the absence of centres like the Dan Marino Centre) to be really involved. A parent has to be involved in that case too. Teaching occurs every day, every moment, in every setting. Yes, I feel bad when Adam cries. I want him to be happy. But he must respond when I ask him something. I must wait him out for him to tell me what he wants. Otherwise, he will be a frustrated man.

We are going home and all I think is what I have to do for Adam when we get back. The sense of urgency never leaves me. He is turning four in April. He was diagnosed at 19 months. The first book I ever read, like most parent's, was Catherine Maurice's *Let Me Hear Your Voice*. According to her, Adam should have been cured by now. So either she is very successful at making most parents feel utterly inadequate, or we all quickly learn that her version of the story isn't all that accurate. On the one hand, I feel I have implemented the best resources for Adam and on the other, I feel there is never enough time in the day to implement the things I want to try for him. I think right now of a mom I talked to in the beginning who implemented a 50-hour a week ABA program for her son, and how she said to me he was in a regular school but never wanted to talk about autism again. All of this puzzles me. Is her child really ok? Did he suddenly turn non-autistic? I don't believe that he turned typical, but instead he learned to function and become less confused about his environment. This is what it is all about, isn't it? Getting our children to function in the world. But is denying his autism respecting him? I really do have such a hard time with denial. Some children will learn to function in a "typical" environment, other's won't. We really have to listen to the autistic -- I am trying so hard to understand autism in order to help, and respect my son.
He has gone to the park first with Bubby. I luxuriate in a dark cup of coffee before I get busy again...something I wouldn't have considered a luxury before Adam. Here, in a different environment, I chase him down the hall, ask him to come back four, maybe five times, insist on mands, ask him questions, keep him from stimming on sand by using it in different ways so that he can still enjoy it, but build on it and understand what he can do with it, teach him how to pick up seashells and put them in the pail, bring them back, count them and stick them in the sand...

It is time to pack our bags and go home. It's a New Year and the goal for Adam this year will be to get him ready for JK and ultimately a regular school, in essence, attending. When Adam is attending, he is so ON. I also want to help him with his reading skills. With all of this, I believe he is capable. I hold high hopes for him. I expect him to have his Barmitzvah and I will be overjoyed. I expect that he will graduate high school and go to university -- all the typical benchmarks of success. I speculate at the other unexpected successes he will bring, and all the possible jobs he may be able to do in life. I will be with him every step of the way. I will find the people to support us who believe that this goal is achievable. And when these goals are achieved, whenever they are (timeframes are quite irrelevant, actually), I will know every memory, every step it took to attain them.

I am in Florida and have had no time to write down anything...until now. Adam has been keeping me busy here...he loves the waves of the ocean, running up and down the beach (with a huge grin I have to add), and enjoys throwing sand in the water when not letting it spill from his hands so he can enjoy the visual part of this. He still jumps up and down and flicks his hands in the air -- his visual self-stim. It really is the most interfering behaviour he has. Everything else is manageable -- he doesn't stim to self regulate, he is easy to transition, enjoys novelty. We are lucky -- but I wonder how much of the work that has been done with him has helped too. I remember when he was so stuck on his routes and if we took one
wrong turn away from the park, there was a major meltdown. So, we just kept breaking our routines to keep him flexible. One thing is for sure, as a parent, we have to endure the crying to move beyond the stickiness of autism -- the areas where our children find it either difficult to transition or can't disengage from something.

I have started reading When Babies Read: A Practical Guide to Helping Young Children With Hyperlexia, Asperger Syndrome and High-Functioning Autism, by Audra Jensen. She writes down everything as prompts for her child. Now that I'm getting into potty training with Adam, I'm going to try what she suggests -- putting index cards around the house "I need to go potty," and at scheduled times, go to the card, make him say it, then take him to the potty. It worked for her child to articulate that he needed to go -- the most challenging part of potty training for Adam and I right now. In an attempt to get Adam to speak, my therapists want to pull back to one-word mands because Adam is chunking his sentences (ie; confusing "come here Flor" for everyone instead of just "come here"). This says that Adam doesn't truly understand what he's saying (the difference between the command and Flor's name in this instance). Yet, everytime I write something down, Adam understands what to do. I know it is still a prompt, but who cares? I want my therapists to really understand his reading capability to prompt and teach him. I also want Adam to learn to read before it's too late (the window begins to close at 4, apparently). Adam can read and decode words, but he can't do it with all words. He needs to be taught phonetics. Once he has this tool, then it is easier to teach him so many things.

Of course, I feel I need to jump all of this today, as the sun rises in front of me above the ocean. Ahhh. But I think I'll hold back a bit and just use a card here and there this week. Adam is on his vacation and I only want to help him enjoy it.

Check this out:

It's Christmas Day and Adam has gone for a long walk with grandma. We are off to Florida tomorrow to see Bubby and Zaida. I know Adam will love it. Now that I've taken him off milk, I notice a difference in his language again. He is speaking more and is much more attentive and intentional in his communicative gestures. Either it's just a coincidence or it's the milk that aggravated him. I’m letting him relax this week -- enjoy the sounds and smells of the ocean, the feel of the sun. It is so grey and damp here in Toronto -- it also dampens the spirit.

I was up until 4 a.m. last night. My head keeps spinning. This time I was thinking about how much all of this therapy costs us a year, and all the other families who struggle to afford it. My girlfriend, whose child is recently diagnosed ADD, is going to put her son on Ritalin. After all her research, she determined that it was the best thing for him. She said to me, "imagine if Adam could take a pill in the morning..." I did imagine it. It did seem easier. I admit it. If it would make him less confused about his environment, then I imagine he would want it. I don't know. These issues, and the bioethical ones I've been thinking about, are not easy.

Our kids need the therapy. Our kids need the research. Autism is the most underfunded area of research, yet it effects so many children. While debating many of the issues, I never want to undermine the research -- it helps us understand the functions of the brain, autism, and if we are wise, we must always struggle with issues surrounding tolerance and disability, ability...

Adam is doing great again. He has figured out how to jump from high surfaces into the pool or into beanbags -- something he could not do before. He is speaking more and I am determined to help him to read more -- as he does it naturally and I believe this is a gateway to more learning for him.
In the dark hours of 2 a.m., my son asleep at his grandparent’s place, I twirl my hair obsessively whirling thoughts on my pillow instead of closing my eyes. It is yet another sleepless night when tomorrow morning I have to meet with a new school for Adam. Instead of just thinking, I kept the promise I made to myself many a sleepless night ago to just grab this computer and write the damn stuff down.

I entertain thoughts of the salsa lessons I always wanted to take, maybe a hip hop lesson or two -- to get connected to my body again -- this one that is sagging just a little more than it used to -- a far cry from my fitness instructor/modelling days of my twenties -- those jobs I juggled while going to school. Now, when I get work, my mind disconnects from the body and while it reels, I feel more tired and sluggish. It's all about time and paying attention to these things of health and vanity. Like Emmanual Kant, I consider the rituals of daily walking, at the very least, to stay connected to myself and other possibilities that surround me. Walking, for Kant, prepared him for his daily writing. I truly love being immersed in work, but I also long for a kind of freedom I once had -- smoking cigarettes on my window sill in Freiburg (I've long since quit and can't stand the stuff), luxuriously writing down poems, stories and diaries of worries that now seem sensual and sometimes, just plain trivial in the grand scheme of life as it is for me today. That is what youth is for -- all of those wonderful experiences that prepare us for the life ahead -- the life of giving another young person the same opportunities. Marriage for a woman should definitely be put on hold until at least 30. There is so much wonderful living to do before we have children. Then, at least when we have them, there is no real unknown or imagined life. Only the reminisced one.

I believe I also can't sleep because Adam isn't home. For all the work our children bring, we miss them so when they go out. Everyone I talk to seems to have the same experience. Love is truly built out of all the tough steps of life -- and sometimes, just sticking together. It amazes me, because remember I only have one child of my own, the infinite love I feel for Adam. I wish, sometimes, I could have more children, but Henry has 5 and he's done. I respect that and now that I’m getting older, I feel I am done too. Adam can get the benefit of all of me instead of a sibling. I was an only child too. It just is what it is. Is there any point living the imagined life?
THURSDAY, DECEMBER 22, 2005

As I've been calling schools -- and the ones who might take Adam (there are only 2 that integrate) -- I've come to the conclusion that I, and my therapists, must do more to prepare Adam for the basics: ability to sit and attend. Schools consider it a disruption to the class if children are wandering around. We really have to push him harder and I have to give him a little more "tough love." I suppose I am terrified at any other option and I feel that he has so much to offer it would be a shame if he couldn't get into one of the integrated schools.

Adam is downstairs now in his facilitated play group. Two other boys in the group are also autistic -- but they talk and attend more. It terrifies me. I wonder why Adam doesn't talk and interact as much as they do. I hear him crying. He does not want to be down there with those kids today. But he has to be. There is no other way through this barrier than to push him. When he begins to interact more with other kids, and talks to them, I will be so happy.

WEDNESDAY, DECEMBER 21, 2005

Helping or Hindering: ABA cases and it's role in discrimination of autistic children. That's the topic I will write on soon. Keep checking in for it.

I've called OISE at U of T. They too do not take kids with autism. Everywhere I ask, we get turned down. I keep asking myself why? With all the legislation to provide equal rights to education, why? I know we can't legislate prejudice away, but maybe it's a step in the right direction. Without legislation and advocacy, where will our children go?

I am disappointed with the ABA schools -- I called Montessorri School for Autism -- and although it's director is so very nice, and
she wants to integrate, she is new and her program only services half-days for kids with autism. So too, it is too specialized. The goal of integrating is not yet achieved here.

We need a small school to start the model for integrating autistic kids -- providing enriched programs and IEPs (Independent Education Plans) to service everyone from the gifted to the delayed, while keeping them together. In such a school, the neurotypical kids can build their self-esteem by learning to help and teach those that require extra assistance, thereby building a future model for tolerance in our society. In autism, where expression is largely different or difficult, I truly believe that exposure is also important. We must never underestimate the cognitive abilities of autistic people. Just because the manifestation or output is atypical, it doesn't mean that autistic people aren't absorbing everything that is presented. We need a school that honours this while providing supports so that people with autism feel empowered and can build their self-esteem. I am shocked how we are being turned away at every school. The alternative is that I do this myself -- and I already have people ready to jump aboard. It will have to start small, and as I said, the model will be built so that it can be supplanted to other schools. What I envision is a plan that will finally make Ontario legislation for inclusive schools possible, successful and efficient.

As for the piece I am preparing on ABA cases, I believe the plight of parents is the same as mine-- the struggle to educate our autistic kids. I don't believe in the slow-paced approach and isolation that ABA programs cultivate (most therapists won't expose kids to new things until the task is "mastered" -- thereby totally viewing the typical response as the means to the end). The main and big difference is the legal argument used -- constructed with semantics like disability, inability and dependence -- the view that in the end, strips away the dignity of autistic people as people who want to be independent, are abled, require special assistance, but also have equal rights. When I get frustrated with autism, it is my problem, not my son's. This frustration is built from years of my growing up NOT exposed to different people. Now that I've learned otherwise, I believe we must grow and nurture a youth that wills support and include our kids in society.
Yesterday, I was frustrated. So Adam demonstrated what he could do. Here’s a little note I wrote to all of Adam’s therapists this morning:

It is interesting to note that Adam does not stim at all during art activities. He is focussed and engaged. This tells me that he enjoys the visual stimulation of art and that he is desperate to learn. Morgan always plays classical music while he’s making art. Adam loves music too -- all of this is a great gateway to learning, language and socialization.

Here’s a little story of what happened last night: As you know, Adam's stims have been up this past week or so. His attention has been challenged (seemingly). I’ve been teaching him how to dress himself intensively this week. Last night, before bed, I took off his socks and threw them over the bed adn onto the floor. When Adam was playing on the bed a little later, he spotted one of his socks. He focussed on it, got off the bed, grabbed it, came back on the bed and laid on the pillow and began putting on his sock. He said, "sock on.....watch!" Every time I worry, he gives it to me. He lets me know he's paying attention, even though it doesn't look like it and he can frustrate me. There is no doubt that he has to learn what’s appropriate by learning to pay attention -- especially in the classroom or with other teachers. But then, Adam teaches me that even though he doesn't look attentive, he is paying attention. Sooo, I wonder if this is a fine balance of moving along with programs and EXPOSING him to lots of things even when you think he hasn't mastered it, even if done incidentally before formally. Because of lack of attentiveness, I believe that kids with autism could be held back needlessly because the rest of us think they aren't learning. I sure hope that Jonathan and Adam have demonstrated that this is not necessarily so.

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Adam always gives me these surprises, just so I know that he's with me.

Now, I have another good story after all the disappointing school calls I’ve been making: Eric from Crestwood Valley Day Camp. I
had a long conversation with him and have enrolled Adam in his camp for 3/4 days. He wants Adam and asked all the right questions and wants to keep him challenged while recognizing his needs. It was a relief to finally talk with someone who cares and gets autistic children. We talked about the challenges of finding schools and he suggested Willow-wood. I will have to check them out. Apparently they have done a nice job with integration, even though they started out as a more special needs school. So too, I will be meeting with Gail Baker of The Toronto Heschel School to see if she would be amenable to my starting a program there that would work for autistic kids. The goal really is to keep them integrated. I know Adam would do well there, and it is not fair for us to discriminate against him, and children like him, just because we think they are not paying attention. Not when he will actually get something from the experience, even if it looks different the way the rest of us acquire knowledge and learn. I think this just about sums it up. If we truly appreciate the way the kids learn differently, the way they need to be with other kids of all types, perhaps we and teachers will learn to appreciate their unique style of learning and being, and never underestimate them again.

So I am sorry I said I hated autism yesterday. Like us all, I have moments of frustration and self-doubt. It lasts about an hour, at worse, a day. I'm just trying to be honest here. Otherwise you might think I'm not real. And boy, this is REAL.

Consider these thoughts from Paula Kluth on Inclusive Education:

Some parents and teachers assume that some students with disabilities cannot be provided an inclusive education because their skills are not similar enough to those of students without disabilities. This is perhaps the most common misconception about the law that exists among families and teachers. Students with disabilities do not need to keep up with students without disabilities to be educated in inclusive classrooms; they do not need to engage in the curriculum in the same way as students without disabilities; and they do not need to practice the same
skills as students without disabilities. In sum, no prerequisites are needed for a learner to be able to participate in inclusive education. Students with disabilities can participate in general education without engaging in the same ways and without having the same skills and abilities others in the class may have. In addition, this example highlights ways in which students with disabilities can work on individual skills and goals within the context of general education lessons. It is also important to note that the supports and adaptations provided were designed by teachers and put in place to facilitate a [particular students’] success. [A special student] is not expected to have all of the skills and abilities possessed by other students in order to participate in the classroom. Instead teachers [can create] a context in which [a student] could "show up" as competent.”

Although understanding inclusive education, the laws related to it, and practical strategies are important, nothing is more helpful in learning about inclusive schooling than doing it. Teachers in today's schools must make a commitment to value the participation of all and to work toward good inclusive practices every day. It is my hope that readers will understand this chapter as a call to action, begin to see inclusive schooling as a verb, and help students with autism gain access to inclusive classrooms and educational experiences.

Perhaps the most important reason to pursue inclusive education, however, is to provide all students with an education that respects the diversities they bring to our schools. As one teacher commented, inclusive schooling is not for about students with disabilities, it is for and about all learners. 'I don't call it inclusive because of [my students with autism]. I call it inclusive because ...I am a teacher of all kids.' (Kasa-Hedirkson, 2002, p.145)"

By moving towards inclusive education I guess it is political. There is no way avoiding it, I have moved into action. Everyone I talk to doesn’t understand inclusive education or understand that special kids can integrate into the classroom. Money, resources, training, all come into dialogue. What it requires is a change of heart and mind - thinking out of a very narrow box.
To open a school or to create a type of Outreach Program to integrate one or two autistic kids in a regular classroom -- with well trained teachers and with a flexible and open school staff -- that is the question today. If I could do this in one school, then perhaps it could be used in others -- and the legislation that exists for inclusive education would be much more effective.

I am so concerned about schools. I am talking with my friends today who are experiencing the same plight as I am, but they are two years ahead of me -- schools who turn their autistic kids away, schools that turn us away without being blunt about it. There is no place for them, and now there are so many children with autism. How many more years is this going to take?? Even schools who teach the learning disabled don't want the autistic kids, because the social component is difficult to teach and deal with. Then there are the ABA schools, and there are lots of parents like me who do not want our kids there. I do not want exclusive ABA all day long for my child.

Where integration would help my son, with extra assistance, it remains elusive. Will continue this later...a ladder has to be put into my office library now...

For those of you who were looking for the segment on Canada A.M. yesterday, it has been postponed to air between Xmas and New Years.

In the meantime, I have refocused on Adam again. He is so cheerful these days. But I need to do more to make him talk and become more independent. Nannies and loving grandparents just put food in front of him and don't give him choices. In a rush to get to school, we don't give Adam enough time to dress himself. We are not giving him opportunities to discover, try and make mistakes. When he's pushed, he does so well, but it does take a
great deal of patience and budgeting of time. There is a price to doing exhibitions and writing books -- the price is less time for my Adam.

I went to The Alan Waldorf School yesterday, which is not the school for autistic kids. They claim to be co-educational, but after interviewing a couple of schools now, I can see how talking the talk and walking the walk are two completely different things. The principal said they would take him but I couldn’t talk to a "remedial" teacher (hate that word), until I paid the $100 deposit for registration! She went on and on about how the school "taps into the energy of the universe." Medieval penmanship is a requirement as well as drawing for every single subject -- the student notebooks look like artifacts but I wonder how much they are actually learning. I asked that principal if a child with motor difficulty could use computers. There was no flexibility -- the penmanship seemed more important than the content. We all know that it doesn't matter how we write, it matters that we UNDERSTAND. In this school, every teacher looked like a hippie -- one teacher may teach Sanskrit while yet another teachers about the Saints and yet another into gnomes (yes, it's true). So when it came right down to it, she said, while using her fingers as quotation marks, that "so called high-functioning autistic children" may not be able to move too far in the school, to which I wanted to reply - why would they?

Discrimination abounds. It is disguised which is the most disgusting kind. It is disguised by principals saying they are "open" to having children who are different, but really, they are not and push you away with rigid programming and lack of flexibility. It is disguised by friendly voices, and the hiring of "remedial staff" and "educational assistants," most of whom know nothing about autism. As parents, we are invited in for tours just so those schools can't be blamed for being prejudiced. As parents and autistic people, we are pushed to the margins so that others do not have to deal with us and our children.

What kind of society are we? THIS IS NOT GOOD ENOUGH. I want to expose all this ugliness and each and every school I encounter that does this to us. I want to tell you of all the good I find in the world as well, so that gets more exposure in the end than those ignorant people that run schools like The Alan Waldorf School, The Willow School, and The Mabin School -- all who have
turned us away with disguised discrimination. (The Mabin said to us that there is not enough room in the classrooms for shadows).

At least the Willow School -- who told us they have one autistic child as a favour to someone they know -- said straight up that they don't take autistic kids. In the end, ignorance about autism is no excuse and furtive discrimination for those with any special needs is akin to any other kind of racial or ethnic discrimination.

We have schools that are fractionalized, even an autistic community within itself, divided in what we believe is good for our children. There are more schools popping up for kids with Learning Differences. The Public School system tries to integrate and I still have to look at the ones that have been recommended. Discrimination abounds but it always takes me by surprise. I mean, my son is beautiful in every way. I am always shocked that he, and other innocent children like him, are subjected to such naivete.

I believe that we parents are given assignments. Every child requires *something*. There is a great irony when I hear another parent complain that their otherwise unscathed child is not developing the way s/he likes -- I marvel at the luxury of that complaint.

And yet everything about Adam is a gift. He has taught me to slow down, to appreciate every single step. He doesn't lie, he is not greedy like some other children. Buying him toys where other children would become spoiled does not effect Adam in the same way. Toys are his tools for learning -- much more so than non-autistic children. I see him playing with toys and exploring him in a way that a one year old does easily. Where other parents get caught up in which Ivy League School they would prefer their kids to go to, what cars to buy them (my husband does this with our other kids, so I see it in my own household!) I will receive simpler and what I think are richer gifts -- the gift to learn what it means to be human -- of patience, kindness, of frustration and triumph, the pain of isolation and the utter joy of when he will gain a friend, or even a girlfriend one day. When Adam celebrates his Barmitzvah, it will be a momentus occasion -- instead of getting caught up in the carnal hype of the party -- the party will be woven from the painstaking steps to get there -- and those are the best parties of all. Happiness really does come from the simple things that the rest of us take for granted. From talking and
reading other parent accounts, I am preparing myself for the future while also taking in the moments as they occur. Moments of bliss are constructed of painstaking work. I can't write naively about the joys of my son without discussing the pain and frustration which is part of the package.

So I do worry that Adam isn't speaking like his fellow autistic peers. I consider it my fault because he is capable and I'm still doing too much for him. So I do get tired sometimes, impatient too. I make mistakes. All one can do in life is keep trying.

The best has happened - the show now has a life of its own. The Toronto Star covered it to a point beyond my expectations. I was on CBC Metro Morning and Global TV and tomorrow we're on Canada A.M. And this is all to raise positive awareness about autism. There is a steady stream of visitors to the gallery making comments in the guestbook like "this is a very important exhibition." I think so. I believe that awareness does change the world one tiny step at a time.

I believe strongly in inclusive education and changing the way we view people with so-called "disabilites." I am currently researching models around the world of inclusive schools -- they don't take the resources and the money that we think they do. And they are so successful in other countries. For reference, take a look at Inclusive Education sites online and the UN Convention on The Rights of the Child, the UN Standard Rules on the Equalization of Opportunities for Persons with Disabilities and the UNESCO Slamanca Statement. These documents recognize the human right of all children to inclusive education. Also there is The Ontario Coalition For Inclusive Education.

I am pressed to get back to Adam's programs now. I am concerned that he is displaying some inconsistencies, which may tell me that we have to cut back on some of his programs in order to refocus on some missing component skills. I always feel that if I take my attention away for too long, this happens. It must be a parent's
inclination to feel like they are never doing enough. In particular, Adam is having difficulty with making choices. Instead of consistently saying what he wants from two items, he echos both items, or says the thing he doesn't really want (he gets the broccoli and he gags!). We try writing out the sentences (which he likes and can read), but it's not helping with the concept of making the choice. So his SLP at school will give him a blank item (piece of paper) and the item of choice, and repeat it until he grasps the concept. Laura is giving him just the two objects, and that still seems to be the best option yet.

Also, the Neoprene Vest seems to be helping at school. When Adam is motivated, he is so focussed and attentive, but when he's not, or if he's tired, he just keeps moving around. He is seeking out a lot of deep pressure these days -- crawling under pillows and asking for "squish." So the vest gives him some pressure and he seems to enjoy it.

His OT wants to try having a visual box -- a box consisting of visually stimulating toys that he can play with 5 times a day for a limited period. She wants to do this to fulfill his visual stimulation needs. She finds that the visual distracts him the most in the classroom. Although he is easy to redirect and focussed and attentive while doing something, if left to his own devices, most (not all) of the time, he would be looking around the room. I am wondering if the visual stimulation will over-arouse him or fulfill the need. Everything is a test.

He was so tired this afternoon, my Adam. This morning he was so affectionate and snuggled into my arm making the sweetest sounds of contentment. This afternoon, he nested his little head into the crook of my arm and fell asleep. Such a far cry from the days of nursing himself to sleep -- a far cry from the child weaned only two months ago. I tried weaning him for months (years, actually). I tried giving him a bottle from the time he was an infant. He would have nothing to do with it! Then, one day, I decided to try again -- this time with a glass of warm chocolate milk (just a pinch of cocoa for the taste). It worked because he was ready. It didn't work a year ago, or the year before that. One just has to keep trying. One worries so much about all of these steps. Then when they are accomplished, the struggle to get there is easily forgotten. That part amazes me. How we quickly forget the effort. This is the kind of effort an autistic child must make every
I am marvellously tired. The opening and autism awareness event went as good as I hoped -- everyone seemed touched by Jonathan and floored by his work. We had over 200, maybe 300 people attend the opening! It was on Global TV. Friends who believe in me, admitted they were not expecting work of this calibre. I can understand -- what one might expect when you talk about raising awareness for autism is a nice little exhibit of student calibre work -- wonderful expressions of the human spirit, but still, not necessarily excellent works of art. That's the other reason why I picked Jonathan for this exhibit. Just like you and I, autistic work can be good or average. Why I picked this work is not only for its intense emotional conveyance, but for its artistic excellence - simple strokes of line that, like a well-written sentence, becomes loaded with feeling and innuendo. By picking good art, writing, music, the message is clear. The message about what is possible for autistic people is clearer. Like the rest of us, we transcend the burdens of life in the works of Mozart, Van Gogh, Picasso, Hemingway...you get the idea. Most people intuitively know the difference between great and average, and we seek the former in order to see ourselves and all that we can be. We rather fly freely in the simple sweeping air, than become snarled in confusion. Jonathan's work is simply that: lucid.

The evening was crowded, filled with the music of Rosemary Galloway and the Norm Amadio trio. Wine poured while everyone marveled or quietly took in the panels I installed, "The Voices of Autism: In Their Own Words," and contemplated. People commented how overwhelmed they felt. I was overwhelmed that they were overwhelmed, and I said it. I was excited that the audience related so well to this show, and yet grounded in my passion to express my belief in the abilities of autistic people, of my son. These expressions, the work, is easy when it comes to one's child.

Dr. Roberts spoke eloquently and it was wonderful how she shared
the humour and the poetry of her autistic clients. Alan Lerman was incredible -- his dedication to his son was so apparent. Jonathan wore his headphones to muffle the sounds and greeted everyone with a hand-shake and asked lots of questions about the people he met -- names, where they were from. He asked my husband Henry, "why don't you have any eyebrows?" and Alan commented there would soon be a painting or drawing of him!

Jonathan insisted on staying until the end. He basked in the limelight and I was so excited for him. We stopped at Shopper's Drug Mart on the way back to their hotel (Jonathan's lense popped out of his glasses), and Alan ran in. I asked Jonathan, "Do you want some music?"

Pause. "Yes"

"Do you like classical music," I asked, twisting around to watch him.

Pause. "Noo!" An emphatic negative from a typical teenager in the backseat, in the dark.

"How about rock?"

Pause. "Yes." All was good now. I put on Q107 and on came The Doors.

"Do you like this?"

Pause. "Yes." He seemed calm. The flurry of the night ending as we rested on Cloud Nine. I thought I'd stop talking and let him relax, until he asked, "Are you sleeping?"

He was great. I could relate to some of this conversation with my son, as I teach him how to answer questions. He pauses as he needs more time to think about how he's going to answer, or what might be the right answer. I worried about speaking what I call "dumbspeak" to Jonathan -- that slower, more articulate way of speaking as if he can't understand if I go too fast. I worry I might be patronizing him, patronizing Adam. I can talk normally to Adam and now much of the time, he'll just do what I say, if it's a direction or I say we're going to do something. It's a hard call. Sometimes I
have to repeat myself to Adam, to give him more time to process, and other times, its just as fluid as can be.

In the car with his dad and I, Jonathan would make comments, but mostly ask questions, or answer them. Conversation is more difficult, disjointed. His hand and his art are his dialogue instead. When Jonathan was younger, he didn’t communicate. Now that he’s older, he’s communicating more. When he's older still, who knows? More still? Probably. People with autism often develop these skills later.

Caren, his mother, said to me today, that no parent should give up hope for their child. Autistic children need to be exposed to everything just like other kids, for you never know what they have inside them. She speculates that they would have never known that Jonathan had any artistic ability unless he had that serendipidous date with a piece of charcoal and paper at an after-school program.

I am glad that many people from the autism community came -- even the ones I may not agree with. I am terrible at politics and find it difficult to take extreme political stances in these court cases. I just can’t agree with ABA and how they -- and this is a new one -- call it "the only life-saving therapy for children with autism." You gotta like that life-saving bit. Really makes a point, doesn’t it? And yet there are so many parents I’ve met now who feel just like me. We see that therapies that focus social interaction skills help our kids significantly. Extracting from different approaches helps too -- I do a bit of behavioural conditioning in that we may use bubbles to get a response out of Adam that is more difficult to get -- but it’s natural -- like giving a kid a lollipop to learn how to toilet train. In cases where motivation may not be as apparent to learn something, this approach can be helpful. But as soon as a connection is made, we don’t rely on reinforcement, other than praise, for the sake of reinforcement. And we really don’t use this that often because we taught Adam the joy of relating early on -- and that in itself garners his attention - something you need in order to learn. At the end of the day, children with autism benefit significantly from good teachers. Patient, knowledgable, willing to adapt to the child and his/her needs. It is not the teacher’s agenda, but child’s we’re interested in. One can’t learn, or learn the joy of learning and then become independent, if one doesn’t feel the motivation from within. And to think that autistic
children do not intrinsically have that motivation, some, any motivation within them, is to say that they are not human. Finding that motivation is the key to unlocking the learning process and the joy of living in the world -- something all autistic people are entitled to.

Even if at odds philosophically, we parents love our children. I hope the autism community can de-politicize autism so that we can get on with the business of helping our children -- seeing them as whole beings, accepting them for who they are, and helping them in areas of need as well as finding their niche in life.

Beyond Words: The Drawings of Jonathan Lerman
- Insight into an autistic Mind -
By: Estée Klar-Wolfond, M.A., Curator

There are many myths about autism. Perhaps because there are so many pieces of the puzzle, so many areas of the brain that are affected and are still being studied, that it leaves room for too much speculation. As a result, we take the view that people with autism, and their behaviors, are a mystery to us. Like aliens or foreigners, we watch their behavior with bewilderment, and sometimes fear.

This view is a danger to people with autism because so many people are affected. Currently 1:166 children are diagnosed with autism in Canada and it is most diagnosed after mental retardation and cerebral palsy. The condition affects communication, socialization, perception and movement. Its symptoms can be mild or severe. Children with autism are treated all to often for their behaviors and not the core of autism, which then reduces their self-esteem. Too often, we hear that we are seeking to CURE autism, when many autistic people say they do not want to be cured. While one opinion may not reflect another, it does alert parents that we must be careful of whose interests we’re purporting.

Michelle Dawson, who was profiled in Canadian House and Home (2003) is a letter carrier in Montreal who has autism. “She laughs
easily, reads voraciously and takes pride in her perfect work record. She has language problems – she’s not sure if she really understands the words she uses or if she just memorized how to use them. She says, ‘I really like books, but mostly I like looking at the words. But having read the same stories over and over again, I have them in my head and use whole sentences from them.’ She says that because of her quirks, people may judge her to be weird – unfairly, she states, ‘because its much like judging a blind or a deaf person while not acknowledging that the person is blind or deaf.’ Michelle is adamant that people like her be judged for who they are and what they can do, and not some behavioral standards developed by so-called “normal” people. ‘What’s wrong with being autistic?’ she asks. ‘Why are we considered to be so disastrous? Why are we such a mystery? I think we should be allowed to be who we are. We work hard, we’re honest, and we contribute a lot without getting much back.’ Michelle wants people to understand that it’s not easy having autism in a non-autistic world. ‘I think people should recognize that the entire burden should not be on us to be like them, but rather, to acknowledge how hard it is for us.’”

Autism is not really a mystery. At the core, people with autism are like all of us – they need to be accepted for who they are, to be happy, to have fulfilling work and to be loved. As a mother of a 3 year old son with autism, I feel strongly that he, and others like him, be integrated in a regular classroom – as integration in the school sets up the foundation for a democratic society where no one person with special needs be marginalized. Consider this from a severely autistic adult:

*All my life I was enrolled in classes for the profoundly retarded. The pain of that isolation, I can’t describe. Some classes consisted of putting flashlights together and then they would be taken apart for the next day’s project. I never spoke or made eye contact. I hummed and self-stimulated. No wonder they thought I was hopeless. I was always treated well but my intellectual needs were never addressed because nobody knew I had any intellect at all. Sad to say, many like me remain in that same hellish situation.* (Treacy, 1996, as taken from Paula Kluth, *You’re Gonna Love this Kid: Integrating Autistic Kids in the Classroom*)

When Jonathan Lerman was 2 years old, his parents state, “he slowly began to slip away.” A formerly alert and cheerful infant, he
now wouldn’t respond when his parents called out his name. “The few words he once knew were gone,” they write. “He would tear his hair out in clumps when he was upset. And although we longed to comfort him, he resisted our attempts. It has long been widely believed that children with autism do not comprehend emotional states of others and, indeed, may be extremely limited in their ability to understand or experience their own emotional states. For many years, we assumed it was so for Jonathan.” Then, one day, when Jonathan was ten years old, his parents received a phone call from the school. Jonathan began drawing—“not stick figures and crude backgrounds,” as art historian Lyle Rexer states, “but parts of eyes, mouths, stylishly rendered. In a short time, he was drawing entire portraits, some from life but most from personal sources such as television and magazines. He worked rapidly and with uncanny expressiveness, capturing the essence of his subjects in sharp, sweeping lines and smudged shadows. He was a prodigy, a savant of the charcoal crayon” (Lyle Rexer, How to Look at Outsider Art, pp.64-5). That was written when Jonathan was twelve years old. Today, at eighteen, Jonathan has demonstrated that he, as reflected in his art, is growing through varying representations of people, their interactions and positioning. He also paints and sculpts. The Lermans write: “What does Jonathan’s talent mean in the larger scheme of things? We believe that Jonathan, through his work, teaches us that we must open our eyes to the world of people with autism. He is helping us expand our knowledge and transcend our beliefs about their perceived limitations….Jonathan may only be one person with autism, but we have no way of knowing that other people with autism do not experience a similar degree of emotional connection and simply lack the talents to express it.”

Jonathan’s work has been categorized into the Outsider Art genre— which refers to self-taught art. The critical art world has begun to take it seriously, people collect it, and its market is far-reaching—he is quickly becoming and “insider.” Perhaps Outsider Art has gained status in the art world because as in modern art, let’s use Jackson Pollock or even Vincent Van Gogh as examples, artists are regarded just as much for their psychoses as for their art. The human mind and its manifestations are intrinsically entwined. As I researched and studied creativity and autism, learning about Henry Darger, Joseph Connelly, as autistic artists, or other gifted minds such as writer Lewis Carroll, or philosopher Ludwig Wittgenstein, scientist Albert Einstein, or entrepreneur Bill Gates,
those whom I call autism celebrities, I was staggered when I came across Jonathan’s faces. To-date, I have found no other artist with autism like him, who perceives humanity with such profundity. It now becomes impossible for you to leave here today, carrying the myths in your mind that autistic people are rendering machines – only capable of quick calculations and are robotic in the way they live upon the earth. This is why I eagerly wanted to share Jonathan’s work with the Toronto community. Finally, we begin to see visually what is possible. We can see for ourselves that he registers and feels intense emotion, that he has an incredible intellect despite the way he functions. But perhaps, if we were to only consider the surface of him, we would be unaware of it. This is Jonathan’s way to let us into his world. It is his way to self-actualize. By looking at his work, we must then consider how every “disabled” person in the world may have a vibrant inner life. It can be a painful thought, as we who are abled find it difficult to consider a body without movement to be anything other than a quiescent being. The rest of us have not experienced the awesome malleability of the human brain and spirit -- the human ability to adapt to the environment no matter what area of functioning may be impaired.

We know from research by Dr. Patricia Czapinski that anatomical issues may be a factor in facial expression in some autistic people. We know that registration of intense emotions may make eye contact difficult for people with autism. Sad to say, that when we don’t see affect from some autistic people, the inference is that autistic people don’t have emotions. I hope you are now convinced that this is nonsense. What friends and family can do is to speak to an autistic person with respect, directly to them as if he or she is listening, with emotion towards them because they are human and need you. As a mother, I want you to understand that my son, and people with autism have physiological and neurological difficulties with things that the rest of us take for granted.

I don’t really want to bore the reader with the construct of our day. There are many parents of autistic children who live it the same way, more or less. But for those of you unfamiliar with this world, I might be remiss to leave out at least, its essence. Our day is filled with teaching, of learning HOW to use a toy, to put on a sock, to play with a friend, to answer a question, to feed a doll, trying to peddle a trike while steering, or clap hands to a song on cue. Once the how is learned, Adam begins to take off. But the
learning is deliberate – step-by-step - and a great deal of patience and understanding is required. Days are filled with therapists coming and going from our home, Occupational Therapists, Speech-Language Therapists, therapists who teach cognitive, social and self-help skills. Weeks are spent organizing of team meetings, programming, more research, advocacy, meeting with nursery teachers, and for us soon, meeting with elementary schools and trying to find the most flexible ones. Adam, and children like him, works hard to learn about their world and function within it, unlike other kids who learn naturally from their environment. Days are filled trying to understand and assist Adam’s sensory requirements as he flaps his hands above his head because he needs to, or wants to be squished underneath a pillow in order to relax. For other parents it may involve dealing with seizures and medications, or episodes of frustrated aggression. My days are spent with endless worry about the future (no matter how optimistic I try to be) – of whether my child will be accepted or bullied, and wanting to protect him from the pain and isolation that discrimination may bring.

No one child or insensitive person will be able to beat the autism out of Adam. Autism is a way of being and experiencing the world. I hope to teach him that no one person can beat his spirit. Autism is so pervasive that it affects the way one moves, feels, and sees. It affects all the senses. My husband once asked the question of “why do therapy if the goal is not to cure autism or make Adam appear less autistic?” to which I responded that the goal for Adam is to understand his world, to learn how to communicate his thoughts and desires, to self-advocate and self-actualize and in essence, to feel fulfilled. Adam is a partner in his own therapy as we learn to respect the way he sees the world while helping him to communicate his own thoughts. It is an unfortunate fact that we feel less valued if we can’t communicate and then get left behind. I uphold the belief that if we build supports to set children up for success, even the most affected can be fulfilled. Autism is as much a social construct in that we do not yet provide enough opportunities to enable self-esteem or identity.

Research, as done by Dr. Wendy Roberts and others around the world, helps us identify early markers so we employ interventions as early as six months of age. We can begin working on socialization and pragmatics earlier which has proven to be beneficial. Thanks to research, some of which becomes refuted or
improved by more research, helps us understand the inner workings of the autistic mind. It helps me as a parent understand and empathize with my son so that I can be a better parent. I call upon everyone to support research that enables us to provide better therapeutic interventions.

Upstairs, I have created a wall called the Voices of Autism. These are the people who can talk or write about what it feels like to be autistic. Like all of us in this room, we have different talents and capabilities. Some autistic people are artists, musicians, writers, computer programmers, scientists, bus drivers, professors, doctors, and others have a more difficult time, being in need of extra care.

I am only one parent of a young autistic child who wants to raise awareness so that my son can reach his potential with less discrimination in the world. I am adamant that he not be forced to live in the margins of society because people do not understand autism. But it is those with autism who must also step up to the plate and speak, or draw, communicate in some way on their own behalf, and our responsibility as parents, fundraisers, teachers and scientists to make way. Autism may sometimes be beyond words, but the voices, both reverberant and real, continue to fill my head. May the collective voices of the autistic community become loud enough for us to hear what it means to be human so we can build a more tolerant society.

Estée Klar-Wolfond, M.A.
http://joyofautism.blogspot.com
Curator of Beyond Words: The Drawings of Jonathan Lerman
December 1-22, 2005.
Lonsdale Gallery, Toronto.

A day in the life of Speech Language Therapy:
Estee,

I pressed Adam today as I increased my expectations (moving towards joint attention), and introduced some new activities into our repertoire (e.g. Elefun, pretend play with the picnic/food). Adam was not interested in the picture schedule I showed him. If I had to venture a guess as to why he moved the blue card away it would be because I chose all of the activities without asking for his input.

The first game was the Elefun game. Adam and I shared in the excitement of the ‘butterflies’ flying around and he watched me as I caught them with the net. With encouragement and direction, Adam helped me re-load the butterflies into the machine. He was determined to figure out the on/off button by himself. At one point he got up, walked around the toy house and then came back to try again, this time with success.

Next, we worked on a puzzle, a new puzzle. Adam was not interested in this at all! He inserted one of the four pieces I left for him and then refused to do any more. He walked away from the puzzle and headed for the spare bedroom. He stood there and said, “open door”, “I want open door”. I followed him to the door but hesitated before opening it for him. When he looked at me I opened it and told him, “It’s good to talk and look”. Once inside the spare room, we played our favorite Pillow Plop game for a bit of a break.

After that, I began to set the table for the stuffed bear and the toy person. I used a lot of self talk as I put the items on the table. Adam wandered about the room, occasionally looking towards me and what I was doing. Eventually he came close enough to the table to signal interest in the activity. I invited him to join in and he helped set the table and distribute food to the toys (e.g. “Bear needs a spoon. Give Bear a spoon” or “What does bear want to eat? Corn or spaghetti?”). Adam fed the Bear ‘pizza with peppers’ with a hand over hand prompt.

Finally, we played with bubbles. I used this activity to target joint attention and cued Adam to look at me after looking at the bubbles (I pointed back and forth between the bubbles and my eyes and
I'm hoping that many people will come to Jonathan's opening on December 1st at Lonsdale Gallery. He and his father are driving up from New York to be at the opening. TV will be there. I want everyone to come, afterall, this is a show to promote awareness about autism that is becoming so prevalent. I do not want my son to live on the margins of society, and no autistic person should have to.

I'm including an excerpt on Jonathan's work in the context of art-history:

Art And Autism

When Jonathan Lerman (b.1987) was barely three years old, his
parents noticed that instead of continuing to develop normal intellectual abilities, he began to withdraw from the world around him. His capacity to speak, play, experience emotion, and relate to others began to erode. Intensive therapy and special schools could not bring him back, and he slipped into a sort of arrested life. He was diagnosed with autism, a neurological disorder. Then, suddenly, at the age of ten, he began to draw. He did not compose stick figures and crude backgrounds, as children usually do, but parts of faces, eyes, mouths and noses stylishly rendered. In a short time, he was drawing entire portraits, some from life but most from impersonal sources such as television and magazines. He worked rapidly and with uncanny expressiveness, capturing the essence of his subjects in sharp, sweeping lines and smudged shadows. He was a prodigy, a savant of the charcoal crayon.

In clinical parlance, Lerman suffers from a severe form of autism known as Kanner’s autism. As less serious but more prevalent form is known as Asperger’s Syndrome. Kanner’s autism is often associated with prodigious achievements in a single narrow area – rendering, calculating, memorizing, or playing music, for instance. Autistic artists like Lerman live in a largely visual world, which they can render but not interpret symbolically, a world very different from the schizophrenic, whose constant task is interpretation. According to neurologist Oliver Sacks, these so-called savants lack the very basis of artistic expression, the capacity to transform what they see – imagination. They are rendering machines, and their work cannot be regarded as purposeful, symbolic communication. At a deeper level, according to Sacks, people with autism lack what imagination itself depends on, the ability to experience their own inner states or intuit them in others. In the words of the author Temple Grandin, who is herself autistic, such people confront other human beings like “an anthropologist on Mars.”

According to this description, the “art” of the people with autism springs full blown and can never develop, since they accumulate no intrinsic creative awareness of past work against which to measure current creations. Their productions are, in Sack’s telling phrase, “raw, pure expressions of the biological,” their lives, “a collection of moments,” vivid, isolated, devoid of any deeper continuity. As Picasso famously remarked, there are not prodigies in art. That is, art is the product of experience and reflection as much as it is the expression of raw rendering talent. Beneath the dizzying variety of
styles and abilities of artists with autism – styles as different as the precise multicoloured architectures of Jessica Park (b.1958), the rough-framed, google-eyed self-portraits of Larry Bissonnette (b.1957), the graphic industrial fascinations of Laan Irodjojo (b.1969), and the bold gestures of Lerman – lies an unreflective, unchanging void, a negative nirvana.

If Oliver Sacks is right that artists with autism never develop as acculturated, “real” artists do, then, like gods and monsters, they do not bear the burden of time and cannot tell us something essential about being human. They cannot inspire us with forms of celebration in the face of our progress toward oblivion. But this is misleading. Only modern art has explicitly assumed the tragic burden of isolated self-consciousness and a temporality that hurtles us forward into the unknown. Earlier art and most scared art sees the world as more static, and human consciousness as only one of its elements. The fact that the “vision” and technique of artists with autism do not seem to change or expand in range or depth means that their relationship to the world is not changing. Is that relationship incomplete? Certainly. Is the self behind it incomplete, limited? Perhaps, but the self as expressed in art is not some discrete thing but only the gestures that embody it, the traces it leaves behind. The repertoire of gestures can be rich and varied or narrow and repetitive, but the validity of any gesture cannot be dismissed without a loss to our sense of what it means to be human and the ways that created forms can testify to the diversity of that experience.

From Lyle Rexer’s, How to Look at Outsider Art

PERMALINK POSTED BY ESTEE KLAR-WOLFOND AT 11/21/2005 04:01:00 PM
0 COMMENTS LINKS TO THIS POST

SUNDAY, NOVEMBER 20, 2005

My mother's birthday yesterday and her eldest sister died. I couldn't sleep again all night thinking about life, death, what's important and what's not. How unremarkable a life seems at the point when it is all over...how most of us will be forgotten. I
thought about deathdays as opposed to birthdays -- and how significant they are. I remember the days my grandparent's died. When I walk around Mount Pleasant Cemetery, I study not only the life span but wonder about those deathdays...how I wish I knew mine, knew Adam's...how long do we have and what will the rest of our lives look like? I just can't help myself think like this. The mind reels over and over in the darkest hours of 3 a.m.

I think about Jonathan coming to Toronto and how excited he is about having his show here in Toronto and how he should be excited. Everything he's about is being validated. And it's not just for the sake of his autism that I'm doing this. He is also a strong artist. His mother, Caryn, told me how he's having a hard time these days -- some aggressive bouts, how he hates having them. Is it the hormones of adolescence? Seizures? The medication he has to take? Frustration with not being able to communicate so that others understand him? One or all of the above? That's the mystery of autism. For many, it has some tough sides. Yet, his mom says that 90% of the time, he's happy and social, enjoys the recognition of his art ... a "joy," she says. I sighed. I can relate to that word.

Going to a regular nursery school was the best choice I could have made for Adam at this time. For all the fretting I did at the beginning, he is talking and relating more and more all the time. All of us have noted the changes. He is more curious about his environment and he plays more functionally on his own than I've ever seen. He still can do repetitious things, but sometimes I let it go for a while, and one he's finished, he stops and moves on, on his own.

It is Sunday. We're going to O.T. soon. We do it 2x a week now. It's been the best thing for him. Learning how to use his body, how to sequence his actions to do a task, has done wonders for him exploring the environment on his own -- like typically developing children do without any help.

My O.T. said that the DSM is going to change to include Sensory Disorders -- it certainly makes me wonder how many diagnoses' will change yet again. Everyone is getting diagnosed with autism now, but as we continue to refine the specifics of each child, we'll be better able to tell if a child who has sensory issues is as autistic as the psychologists tell us. Certainly, these are all brands of
neurological differences in our children. But the more we know, the
more we can do in the way of therapies. I truly hope I will never
have to put Adam on any medication. I am so anti-meds -- I see
them as temporary solutions, not cures. I prefer to take the
therapeutic routes. Work and play and relate day in and day out.
People don’t realize my schedule or the schedules of other parents
with children with special needs... Wake up, teach how to dress,
teach how to eat with a fork (all of this takes a little longer), go to
school, meet with teachers, work on programs, find a smidgeon of
time to write, pick up Adam, have lunch -- teach to use that fork,
get ready for therapy, meet with therapists, take part in part of
therapy, put Adam for nap, relax with Adam (mommy time), get
ready for dinner, all the while teaching how to request for things,
to answer my questions, to discriminate between objects, make a
choice... it goes on all day long... then at night, we have a new sleep
ritual so that Adam can learn to self-regulate since his brain goes
non-stop and he could otherwise stay up all night.

He plays around me now and waits for me to do something with
him, circling my chair -- sweetie.

Max, Adam’s 16 year old half-brother plays with Adam everytime
he's here. It just comes naturally to Max...and last night at my
mom’s birthday dinner, we talked of Wills and who would take care
of Adam should something happen and Max just said, "I'll take
care of him." Just like that. No big deal. And I know he can and he
would. And I know that out of anyone in the family other than my
parents, he knows about Adam intuitively and he's seen what goes
on day to day in this house. I know that he get's it. So Adam is
truly lucky to have him. I am touched and even relieved to know
that there is a person like this in Adam's life. I don't have any
brothers and sisters, so this touches me to the core.

PERMALINK POSTED BY ESTEE KLAR-WOLFOND AT 11/20/2005 09:56:00 AM
0 COMMENTS LINKS TO THIS POST

WEDNESDAY, NOVEMBER 09, 2005

For many months Adam never took to teddy bears. He does not
cling to a blankie or a bear the way we see many other children do.
Other comfort objects have included books, and comfort tactics,
stroking his belly or my arm.
Yesterday, I pulled out the many stuffed animals we acquired from friends and family over the first few years. Adam hugged them and really took to Elmo and Cookie Monster. He loves Elmo and I realized that when he becomes distressed sometimes he says "baby Elmo!" almost as if he's asking Elmo to rescue him -- it has that same intonation.

He couldn't get enough of Elmo when I pulled him out last night. We sang "Elmo's Song" together (this Elmo is a puppet, so I used him as such). We sang over and over and over again -- he kept passing Elmo to me and asking "Elmo! Elmo's song!" He sings the last words of a sentence -- I've been using that intraverbal tactic for some time. We did the same for "C is for Cookie" song. I thought I was going to lose my voice, but hearing Adam's voice singing and all that eye contact and joy between us, I would have sung 'til I dropped.

So I put Elmo and Cookie Monster to bed with Adam last night. He gave Elmo "five", kissed him. I'm trying to use them for pretend play and the development of symbolic thought. He didn't seem to have any problem with any of it accept that it was repetitive. He did Elmo first, then Cookie Monster and we kept going like this. I then tried to vary it each time.

Every week, it seems the lights keep getting brighter in Adam. He still needs his time to do his letters (I let him line them up after a session or in the evening). He needs to do what he likes and what relaxes him like us all. But I find when we balance between having to keep working on his engagement and his skills, and letting him be obsessive for a little while, he is a happy, balanced kid. I'm not trying to extinguish Adam's "behaviours"...I'm trying to expand it without taking it away, for to do so might result in a behavior that is more difficult to cope with. I have seen little aggression in him. He gets a little angry with me if I don't do what he wants or one day, if I don't take him to bed and he's super-tired. I find that if I acknowledge that he's frustrated, he is grateful and calms right down. It all comes down to respecting your child and reading them correctly. If we feel acknowledged and loved, we all do better in life.

I'm trying to always figure out his sensory requirements. He is squinting a lot these days and I wonder if all the visual stimulation
(he is a visual learner), hurts his eyes, or if he’s just checking out the world -- what it looks like when he squints. He does love to hold up his arms and flick his hands (he has found that it makes shadows) and I am trying to just replace that with something else. I find if I start saying "hands down," it just makes the action more obvious to me, to him and to everyone else. It's like Tourettes and I see how neurologically there is a connection -- the body does things unvoluntarily. If you tell a Tourettes person to stop, they have to "do" their tics even more. So I try to replace it subtly by distracting Adam. Better to look at a book or play with something else. And at home, give him times to just do it. I find that all his "stims" just end up going away. Another one pops up -- they all come and go.

I've been optimistic these days. I said to another couple two days ago that I wouldn't change Adam. He is the boy I have and who I love. I still lay awake many nights thinking about all this, worried about other kids who have autism who do not have the resources to pay for therapies, schools -- people who can help them along in life so that they are less frustrated. I have a dream -- that awareness about autism can be raised to such a level where we can set up systems to enable them.

Beyond Words: the drawings of Jonathan Lerman
-- Insight into an autistic mind --

Londale Gallery
410 Spadina Road
December 1-20, 2005.
Exhibition Opening: December 1st 6-10 p.m.

Jonathan Lerman is an artist with autism. He is unable to speak so we cannot ask what inspires him or what triggered him to suddenly begin drawing at the age of ten. Today, at seventeen, Jonathan is prolific and shows no signs of slowing down. He has been featured in the New York Times, on The Today Show. He is in high demand because, as an artist with autism, he draws faces
with uncanny insight. Publicity is not something he’s keen about, says gallery owner Kerry Schuss, his representative in New York City who bravely took Jonathan on at the age of twelve – something his colleagues in the industry felt he was crazy for doing. “He has trouble with crowds and cannot stop moving around. When you see him, you might think he isn’t capable of anything.”

Lyle Rexer, who wrote a book about Jonathan and also How to Look at Outsider Art writes: “Looking at Jonathan’s work is an affirmation that he sees everything. Working with the assurance of Matisse and the speed of Picasso, and the humour born of a cartoonist, Lerman has created an unforgettable body of work. His drawings include portraits of actual figures as well as figures from his own imagination, and rendered with great acuity. These drawings overturn the stereotype of the so-called savant artists as an unchanging talent sprung to life fully-formed. Instead, Lerman shows the detail, the restless experimentation and rapid growth of an artistic sensibility.”

Lerman is first an artist, and second, a person with autism. His drawings refute theories that people with autism are “mind-blind”, in other words, cannot perceive emotions or understand that others have their own thoughts. It is unusual, in fact, to find an artist with autism who draws faces with the depth of perception that Jonathan does. It therefore shows that an autistic person can have enormous capacity for perception.

As art, Lerman’s drawings stand alone. They draw the viewer in like a good novel and make us ask for more. We witness a beginning, where Lerman’s body parts are dismembered and then watch them come together like a recognition of others and of himself. Associations are made (“The God is Wrong”) so that we wonder what meaning they have for Jonathan. Like the autistic artist Joseph Connelly who brings together multiple objects in his shadow-boxes, associations between objects holds great significance, again blowing the theory that autistic people have difficulty with symbolic thought.

Jonathan Lerman, like some other people with autism, is a person with a gift. Michael Fitzgerald, who writes about Autism, Aspergers entwined with creativity and genius writes: “Ever since the term autism entered the public mind, its perception has not
been linked with genius and creativity. Rather, in the minds of many people, autism is associated with a very significant learning disability. A genius is a person with high ability, with or without autism, who produces a work that changes our view of a subject.” Is Jonathan a genius or a person with a gift? At seventeen and still going, we have time to wait and see.

As a mother with a young son with autism, curator of the show, Estée Klar-Wolfond wanted to use art to raise awareness about autism. She wanted everyone to know that lack of speech and different types of behaviour do not indicate a lack of intelligence, but quite the opposite.

Through Jonathan Lerman’s work, we can begin to see that even the most affected people are capable of thought and a unique perception. We are viewing here a “different sort of person” and Estée hopes that by taking a view into Lerman’s world, we can begin de-pathologizing the phenomenon of autism and respect this community’s insights and abilities.

Proceeds from sales go to autism causes.

I have to write a press release for Jonathan Lerman's exhibit. Like most nights, I lay awake grappling with myself -- wondering how to communicate about him, and about autism, in a way that doesn’t belittle his work. He is first an artist, and second, a person with autism. The interest in the show is autism, for sure, but how do I resist the sensationalization of autism? I think just by stating that it is indeed a struggle to avoid talking about autism -- I mean, those of us without it, are innately fascinated by the brain's functioning, and any other perspectives, like autistic ones, that help us to understand the enormity of human capacity.

Can someone with autism please write to me?
There was an article in *The New York Times* a couple of weekends ago where a mother discusses the emergent sexuality of her teenage autistic son. She talks about how he is finding girls "hot" and asking even the "hottest" girls out on dates, unaware of the cliques and social niches that may influence other boys. She is concerned he'll have his heart broken, but then she notes that he doesn't seem to mind.

A response to this article that I read yesterday was by an enraged mother with another son with autism -- a child with lower functioning. She was upset how this mother was upset, or representing her son -- noting that not all autistic people are verbal and that all parents of autistic children work hard.

I am, quite frankly, upset by the politics of autism. The politics of which therapy is better, the court cases, whose doing a better job, which child is doing better -- the comparisons of one autistic child to another -- which is probably done by the best of us, but which is unfair to the child.

Has there ever been so much competition in the Deaf, Blind, Downs, Cerebral Palsy and other communities? What does all this dissention serve?

One mother may want to avoid me because Adam is "doing better" than her son. I may then turn around and sigh as I see another autistic child who is doing something that Adam cannot yet do. I know that comparisons that we make, even silently, are inevitable, but they are torture and in the end, are useless.

I see autism as a spectrum. Each child is on a different point on the spectrum. In other words, each child learns differently and has to jump different, and in some cases, more hurdles. But I believe the learning can happen. Does it really matter when it happens. Whose time line are we on anyway? So what if it takes someone until the age of 40 to become independent. I think we should be so glad for it and glad for that person.
Autism, the way I understand it, is a different brain construct. Instead of superhighways (those connections in the brain that make certain things for us a given), are as Dr. Gutstein puts it, "country roads in persons with autism." The processing takes a little longer, but with more and more use and practise, we can mold that maleable brain into making the connections more efficient.

Dr. Sacks talks frequently about the incredible pliability of the brain -- we certainly do know the abilities of stroke victims who are able to reconstruct speech and other areas of functioning using completely different areas of the brain -- different than the areas that those functions were orginially based.

Every person with autism can and will learn. I wish parents would stop the painful comparisons that torture them and begin looking at autism, even at its most challenging, with more hope.

SATURDAY, OCTOBER 29, 2005

My eyes are blurred. I've been up every night this week -- either from 3 a.m. on (Adam's sleep patterns are changing again and he wakes talking about the things he's seen the previous day), or, I've been out until 3 a.m. at fundraisers. Met some genome researchers last night from Toronto Western Hospital.

Then today, I took Adam to the Snoezellen Pool at Bloorview Macmillan Centre. The word snoezellen is actually taken from two Dutch words: "snufflen" meaning to seek out and explore and "doezelen" which means to relax in a wonderful place. The idea is to expose children with various issues to relax and in Adam's case, the visual stimulation and relaxation enables him to talk more and focus.

So I take Adam to the change room -- there is another mother needing the large flat changing table to change her child with cerebral palsy who must be around 7 years old. The girl is listless and her eyes are nearly closed, leaving the impression that she could be sleeping. The mother talks sweetly to her child, getting
her ready to enjoy the pool -- a shallow pool where the lights are dimmed so we can see changing-coloured fibre optics, lights and shapes on the walls, with soft music piping in.

Another child -- a young teenager cannot move around much. She is taken from her wheelchair and placed in the shallow water path that leads like the yellow brick road into the actual pool. I'm afraid she is going to drown as she sucks in some water and cannot move her head well.

A young boy -- not much older than Adam is also autistic. He is afraid of the water and screams as he's being placed in it while the bright lights are on. Soon, the lights are dimmed, and he calms down. His mother can gradually take him into the water as they watch the shapes move on the walls and he is relaxed and learning to enjoy the water. He cannot talk.

Adam is delighted (we taught him how to swim with a suit that keeps him afloat -- he was no longer as fearful and he learned how to doggy-paddle with a look of glee). He wants to jump in. He is yelling "water, water!...1,2,3 Rocketship!" as he pleases with me to throw him up in the air on the count of three. He is singing "twinkle, twinkle little star" when is sees the stars projected onto the walls. He swims to the lights, to the bubble tank. He lets me swish him around. He jumps up and down and sings with me in the shallow end. He says "splash, splash" as he kicks the water around.

I felt at odds, really. Adam was having a ball. He could move his body at will. The visual stimulation fulfills his sensory needs so he can talk more (although he is talking more in general at home too).

Here I am talking about CURES for diseases without considering the thoughts and desires of those who cannot move their bodies at will. While Dr. Sacks talks even of paraplegics who learn to adapt, I take a deep breath about my recent arguments and what they imply. I can talk only of the community I am directly in -- the community of autism, and from a parental perspective, not an autistic one. I honour the words written and spoken by autistic people and I encourage them to keep talking about themselves and their perspectives. I can only hope to facilitate some of this.

I cannot speak for the parents whose children are physically disabled, for instance, but I do know one mother of a child with CP
who talks with pride about the major achievements of her child -- milestones that are part of everyday life for the rest of us. These are the miracles that the "abled" world cannot partake in. They make us appreciate life, in all its forms.

Back to my musings about CURES. I suppose I should clarify why it is I have the perspective I do. After working as an art curator, I became a very adept fundraiser, so much so, I was hired to lead various arts festivals and later, became director of corporate development for some health charities here in Toronto. I am the developer and the mind behind one charities' click to give program, which was called "Click for the Cure." Alongside one other major charity, I was the first in Canada to get it online and generate corporate support for it.

So I know the leverage and power of that word from a marketing perspective. In order to have the needs of the charity met, the drive had to be goal driven. Being goal-driven gives a reason to support a cause. If not a cure, then why? Why give? To give for any other reason than a cure seems too evasive and uncertain.

Of course, within autism, I do hold a different perspective. I believe that research has enabled us to understand the complex framework of autism so that we can understand people with autism and offer them a better quality of life through such understanding, and providing better and more appropriate education.

It is not as if I am saying stop the research. I am not daring or confident enough halting hundreds of years of PROGRESS. I do ask questions, though. I believe we are all asking the questions about what progress actually means, at what costs do we achieve it, and, are we really progressing?

Through science, technology, economics, we have nearly deified ourselves. We have come to a point where we believe we can FIX anything. The environment has gone to pot? -- it's okay, we can fix
it when we need to. Getting old? -- don't worry, we can extend your age and cover it up with botox. Progress seems to be intrinsically entwined with having control, and with immortality. Remember Gilgamesh? We have become victims of our own hubris. Jane Jacobs states: "History has repeatedly demonstrated that empires seldom seem to retain sufficient cultural self-awareness to prevent them from overreaching and overgrasping. They have neglected to recognize that the true power of a successful culture resides in its example. To take it successfully, a society must be self-aware." (p. 176 Dark Age Ahead). In terms of a cure of autism, which will sometime be on the horizon, I ask that we continue to ask the questions that I mentioned in my previous entry.

Adam is talking more than ever these days. I've been insisting that he answers questions, I model the answer or I have prompted it -- he had a difficult time understanding what yes meant until I put it over and over into context. Now, he's telling me he's hungry, he answers me when I ask him if he wants something (Yes or No), he calls for me, or Flor, he answers all kinds of questions and he understands receptively. He can print his own letters, and do so many things that he couldn't do a year ago.

As in progress, it is better to measure it in years and months than in days or weeks. It is easier to see the huge and deliberate strides Adam has made within a year.

I talked earlier about the quest for the cure -- that Holy Grail if each and every disease and disorder (and I think we are creating more of them than ever).

Dr. Sacks spoke about the Deaf and the Blind. When he asked people who adapted -- adapted their brains, their senses after a period of having hearing or sight and then losing it, most of them claimed that they would not want to be cured. They stated that
On the radio program that I keep referring to, *The Infinite Mind*, AS panelists said they did not want to be cured -- that they didn't feel "broken." They felt that they were better off "than the neurotypicals."

I had this discussion with NAAR - The National Alliance for Autism Research -- as I was the sponsorship chair this past year. The word cure is part of their marketing and their raison d'être. The money gets dispersed to prominent researchers around the world to study autism. In my view, it is a greater understanding of autism that is enabling us to provide better therapies and making us better parents in dealing with autistic children. I believe in the research, but I'm not sure about the cure. Yet, I know there are some families who desperately want to find a cure. I asked NAAR, in honour of autistic people who are offended by the semantics of cure, disability, abnormal, eradicate autism, to be careful of those words and to exchange them for difference.

In my strong opinions about not abiding by one type of therapy, draconian approaches in some ABA programs, poor teachers and agencies who claim to be the experts in autism, and basically, those aiming to financially benefit from the plight of others, I am aware I run the risk of certain people being wary of me.

Like an autistic person, I feel misunderstood. Shouldn't we be asking the question about what is may mean if we find a cure for autism?? Should we not leave the decision to cure autism to those who are autistic? And if we do have cures, which part of autism will it address -- there are so many areas of co-morbid disorders in some people autism -- anxiety, self-injurious behaviours, and many more. Which parts can be addressed with "a cure?" If we find a cure, what aspects of autism -- the gifted parts -- can we maintain? Autistic people claim that autism is part of their personalities. Are we stripping away their being by taking away their autism? Are we saying that they, as autistic people, are not vital and important? Are we suggesting that they are...broken? By making people the same, are we therefore not running the risk of homogenizing society?

These are questions that we must ask ourselves now. We may be 50 years from some sort of "cure" and in the meantime, we should...
be debating this bioethical issue.

I hope I can make a dent in furthering awareness about autism. It will be autistic people who will ultimately have to keep advocating for themselves as they will have the strongest voice, and I'm so glad for their website, aspie.com, and the many books that are written by them including Donna Williams, Dawn Prince-Hughes, Stephen Shore, among the many others.

I attended a school meeting today. One father mentioned that he never understood the *culture of difference* until he had a son with an issue. I am learning that we "normal" people are closed to a wonderous world. There are cultures of different kinds of people out there that are truly fascinating and have every right to the same education and places we do. Deaf people have their own graceful dynamic language, autistic people curiously migrate to one another. There is a world out there that is bigger than we are.

When I was born, my mother used to tell me the story how she counted all my fingers and toes was grateful that I came out "normal." I think about that today, and consider how absurd a thought that was, now that I have a son with autism. We must ask ourselves what *is* normal? Normal seems to be one of those mythological vapours that have been passed down -- normal seems to be anything that does not act differently in any way than a neurotypical person. But considering how vast the population is of people who are not NT, perhaps we must reframe our way of thinking.

And so I come to autism as a social construct. We create difference and inequality in society by how we provide, or do not provide supports. Paula Kluth in her book about inclusive education for autistic children *You're Gonna Love this Kid* states:

"Many people with autism have experienced difficulties due to societal and cultural ideas of how people should look, interact, move and behave. Although most people with autism will tell you that "it" is real, that they do experience things in different ways, that their bodies are uncooperative, or that they have sensory or communication problems, it might also be suggested that autism is in some ways exacerbated by an inflexible society. That is, autism is a social construction; it is a phenomenon that is created and recreated through culture, interaction and social
circumstances. For instance, people may feel more or less disabled on any given day based on whether appropriate supports are provided for them or whether they are expected to communicate in a conventional way."

Jonathan McNabb, she writes, suggested that neurotypical individuals (people without autism), stop assuming that difference means deviance and start understanding the autistic experience from those who live with it. Consider a passage written by people with autism where they imagine a world where autism is the norm and being typical is a problem:

"Neurotypical syndrome is a neurobiological disorder characterized by preoccupation with social concerns, delusions of superiority, and obsession with conformity. Neurotypical individuals often assume that their experience of the world is either the only one, or the only correct one. NTs find it difficult to be alone. NTs are often intolerant of seemingly minor differences in others. When in groups NTs are socially and behaviourally rigid and frequently insist on the performance of dysfunctional, destructive and even impossible rituals as a way of maintaining group identity. NTs find it difficult to communicate directly, and have a much higher incidence of lying as compared with persons on the autistic spectrum. NT is believed to be genetic in origin. Autopsies have shown the brain of the NT is typically smaller than that of an autistic individual and may have overdeveloped areas related to social behaviour."

Bravo.

Researcher Uta Frith also notes how mental disorders "are largely defined by the social context of their time." More children now than ever are being diagnosed with autism. Is the result of nature, the environment or new diagnostic criteria (The DSM IV) that came out in 1993? Schools lack the resources to truly understand and service the autistic child. Emergent curriculum is extremely helpful, but most schools use the canned curriculum. Integrated schools with Emergent Curriculum could help foster in a broad sense, an equitable and democratic society, while addressing the specific learning needs of each child (the Independent Educational Plan). I am dreading the challenge of finding the ideal school for Adam and wonder if I should open my own. Did you know that most gifted children are learning disabled? Food for thought, dear
I am waiting for Adam to write words, now that he is writing letters. He has already spelled words with his magnetic letters. As a mother with a child with autism, I hold the same hopes and dreams as I would for any other child. I hope he will be able to recount these days for me (most autistic people have incredible memories because the same neural pruning that occurs in other children at 18 months of age doesn't happen -- many autistic people recount their own births, which I find fascinated [see Dawn Prince Hughes for reference on that]). One mother wrote a book of her interpretations of her son's behaviour and later, the autistic child was able to write why he behaved the way he did and recount his perspective.

Most of all, as a parents with children with autism, we can never lose faith and optimism. Yes, in reality there are worrisome days (what parent doesn't have them?), but something tells me to go out dancing and be happy. I have a beautiful son.

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Monday, October 24, 2005

I am organizing an exhibition of Jonathan Lerman's work at The Lonsdale Gallery in Toronto. Jonathan is a 17 year old autistic young man. It will run from December 1st-20th. What struck me about Jonathan's work are his faces. So far, in my study of art executed by autistics, the execution of faces isn't typical. Maybe doll-like faces like Henry Darger, but not the kind of faces that show such depth of perception of his subject's character. They may be primitive and Picasso-like, but the type of observation that is beneath the surface is evident. Simon Baron-Cohen, in his speculations about the absence of Theory of Mind in autistic people can now be debated. (Theory of Mind suggests that autistic people are not capable of empathy or recognizing expression because they are mind-blind, in other words, not aware that other people have their own point of view separate from the autistic person).

On some occasions, and even today, when a child cries in Adam's class, Adam will go to that child and hug them. He will get jealous...
when other kids pay attention to his shadows at school. If Adam is "incapable" of understanding others, then how is he capable of these actions? Obviously, the theory is somewhat flawed.

Other HFA/AS (High-Functioning Autistics/Aspergers) who have verbal skills, eloquently express that they can understand body language and have emotion, understand emotion, etc., but what makes social interaction difficult is understanding all of this in real time. Because body language is so fast and fluid and coincides with speech -- the processing of all of this at the same time can be difficult for some autistic people.

Just when others don't think an autistic person isn't paying attention, beware. I have a theory that their way of observing may not be entirely typical, but in fact, over sensitive in many cases. Either through peripheral vision, sensitive hearing, everything is getting in -- if even in an overwhelming way. I never doubt that Adam is exceptional in many ways. I never doubt that he is listening and understanding. I have learned that sometimes he just needs a little extra time to process things.

On the radio program called The Infinite Mind, well-known panelists such as Simon Baron-Cohen, Stephen Shore and others talk about an autistic expression of love -- that parents must reframe their experiences. Instead of a hug, an autistic person might pull hair as an expression of love -- the context must be observed.

Last night at University of Toronto, Dr. Oliver Sacks appeared warm and meticulous, posessing eyes that smiled with a humble defiance that comes with age. In fact, as the evening wore on, I realized that this was THE trait that the actor Robin Williams captured of him brilliantly in the movie Awakenings. Dr. Sacks was articulate yet hesitant in his speech and spoke about "different modes of being." Like the AS people who spoke on The Infinite Mind as well as those that write on aspie.com, he feels that society needs to rid the notions of normal and abnormal. Instead,
We must replace this notion with another semantic, and the word different kept popping up.

I write in my book that Adam’s ABA therapists pathologized him. This for me, a mother and an ardent observer of my son, was not only distasteful, but unbearable. How can a good therapist come into a home of a different sort of person, and begin to follow a list of skills and behaviours and suggest that we would want to make that child as they should be? Surely, when Adam was diagnosed, I thought that this indeed was the goal. But as our lives progressed, and progressed with these new people, therapists, consultants, supervisors and government representatives coming and going daily from our house, I began to feel uneasy. The ABA people came in with the promise of making him "functional," and spent little time observing him as a person but more as an aberration.

Luckily I fired all my ABA supervisors and agencies that I tried for Adam within the first four months of his therapy which began at age 20 months. I also pressed my husband to abandon TPAS (government) funding as they mandated us to do a minimum of 30 hours of ABA therapy a week -- an impossible demand of such a young child. It's difficult for me to hear the glee of parents in school hallways these days "we're so relieved we got TPAS funding yesterday..." (The government recently increased the age to receive this funding past the age of 6 and all of a sudden people seem to be getting funding everywhere). I know of parents who have fought court cases for this funding and have lost their homes and have had to move out of the city. The stress that this puts on a family is too high a cost for the return. Certainly, ABA is NOT the only scientifically proven therapy that works in autism. The myth that it is keeps getting regurgitated by so many -- parents use this in the papers, in our first phone calls when Adam was diagnosed. Parents are putting all their stakes on the vapours of this myth, and that's scary indeed. There are many therapies that work and ABA is the fashionable therapy of the day. Indeed Oliver Sacks also said that about every four years, the hip therapy of the day predominates. Funny how the government wouldn't look at ABA 10 years ago. Anyway, in my view, it has become all too political at a great cost to people with autism.

Once Henry asked the question, "if you believe Adam will always be autistic, why do therapy? Isn't your goal to make him more normal?" I struggled with this question for a while until I realized we must replace this notion with another semantic, and the word different kept popping up.
that the purpose of therapy was to make Adam a happier person -
to help him understand himself and his world, to increase self-
estee, to learn new skills that would enable all of this, and most
importantly, relate to people. I turned to therapies that felt more
suitable for Adam -- to work on sharing and relating, to help with
skills that would give him a sense of pride so he could continue
with them at will. We moved to approaches like RDI and Floortime
and just plain old "incidental teaching" if we want to use technical
words here (I ascribe to no one therapeutic approach -- but bits
and pieces of those techniques that reach a child). When we did, it
was like Adam had his own awakening -- he became so happy and
related to us in a way he never had before. He enjoyed playing
peek-a-boo, sleeping bunny, and other games and giggled all the
time. He became extraordinarily affectionate. My mother said it
well: "it was like we were alone in the room when we were with
him and now it's completely different."

So, after trial and error, some research and plain old instinct, I can
say a year and a half later that listening to Oliver Sacks last night
was a confirmation of what I came to believe on my own: that we
must honour Adam's autism as part of the person he is and we
must nurture his obsessions (or strengths) as well as challenge him
in areas that will make him feel competent and give him more self-
estee. I believe in challenging at the right time. There was a day
when he wouldn't be able to play with a certain toy because of
motor problems, but when he is ready, it is time -- and then he can
play on his own without assistance. This independence is critical in
life and to make us feel whole. I don't believe that even people with
the most severe of disabilities can't have some semblence of this
feeling, no matter what their limitation. Dr. Sacks mentioned we
must encourage activities that enable IDENTITY. Certainly we all
feel expanded when we engage in creative pursuits, sports,
cooking... It is what makes us human and frees us from the
heaviness of life and the limitations of SELF.

Dr. Sacks said "autism must be recognized as a different mode of
being and must be proud of itself." As a mother, I do still struggle.
The outside always wants to pound in, in such negative ways.
School is on the horizon with its rigid curriculae, notions of
normalcy, standardized testing. The world is not so empathetic,
although we are making strides. Adam is an only child with four
older half-siblings, two who are now in university. So I view him as
an only child in the sense that he doesn't have a sibling in his face -
- relating and demanding on a daily basis. I feel the onus is on me to keep the relating going -- from school, to facilitated play groups here in the house -- I feel a need to keep him exposed to other children in the absence of this sibling. When Henry is not home in the evenings, the onus is on me to play with him, to keep relating. It makes me tired some nights and when I am, I often feel guilty or angry that I’m tired. Logically, I know it is the way it is and I cannot be so hard on myself. I don’t have complete control and we all do adapt, and Adam will too. And for that matter, my control could also have a negative impact. It’s all a fine balance, I know. Then again, down time and just hanging with mom or dad, is just as important. Being with Grandma and Grandpa for a few hours on the weekends is a gift and a memory he will have forever when they are gone.

Life is pain and happiness and they are intrinsically connected. Without one, we couldn’t feel the other.

Regression in autistic child development is common, I hear. Adam will progress in many areas and at times, he appears so "normal" and I feel we are "scott free." And then it happens. For a week or two, he regresses into repetitive behaviours, in particular, visually scanning letters and numbers, lining them up, or getting a letter, in sequence, go jump on trampoline, get next letter and so forth. I thought I got used to these little regressions with the relief of knowing that he would still learn and that curve would keep going up, up, up...

I just experienced his longest regression and I became quite upset about it. He started a new integrated nursery school. It is a busier setting and more demands are being placed on him. There are two carpets in the room, one with letters, the other with numbers. Of course, his safe place, when he's uncertain, are letters and numbers, so everytime I peeked in, I would see him contort his body on the floor to look at each letter or number in sequence. At the beginning of week four, I’d had enough. "Push him," I urged the teachers and his shadows. "If he's not transitioned out of there..."
and taught how to play with others and other things, he will never feel competent."

I was so freaked out (it seems I am always pushing people where Adam is concerned), I cried in front of Adam. I think he understood, because that same afternoon, he "snapped" out of it. He began to use his words, he was so "on." I will have to find the psychiatrist's name of the phenomenon that I've heard about -- where parents and children mirror each other's emotions, but when the child feels understood, they feel they can move on. I'll get that reference later.

As far as letters go, I let him do them when he finishes other things. In fact, at age three, Adam is writing his own letters on his magnadoodle. I am so amazed at his determination. I've heard of other kids using keyboards, but not write, and not this young. Has anyone else encountered this? It's also amazing because Adam had fine motor problems, yet with focus and determination, I guess anything can happen. This is autism's gift. It enables focus of such high degree, that so much can be achieved in the niches that interest our children.

For fun, I've been teaching Adam the piano. He has begun to use two hands now, just having fun. It's great. That's how I became interested in the piano -- just hacking around. The only thing I do is play for him. I've also taught him do, re, me. He has begun to imitate me.

So, I've been thinking this week of how the scale tips so dramatically when Adam learns. He exceeds in one area and the other seems like it has gone away forever. But I believe that can't be. It seems to be stored somewhere until another connection is made. Then another concept is understood, a new skill emerges. Tiny building blocks are constructed each day, and his learning is so intricate and deliberate that I am fascinated some days and awe-inspired on others.

I'm going to listen to Oliver Sacks tonight at University of Toronto. He's speaking on sensory integration. Keep you posted.
Adam is at the park with Donna, his nanny. I'm trying to get him tired for a nap before going to his bubby's for Rosh Hoshana.

He was so happy today and at school. We are attempting to set up a facilitated play group here at the house with some of the kids at school - many of whom are non-verbal or have trouble with verbal expression. They have all gravitated to one another, this group, like they appreciate each other and they are still clear in their communication. They likely understand each other and appreciate the fact that someone isn't babbling their heads off so fast that they can't understand or keep up.

Henry and I spent some time together this weekend and we are both newly determined in eating better and losing some weight. This is refreshing, so I worked out for an hour and a half today, in my new attempt to lose 10 or more pounds.

Adam is back from the park, so it is time for me to put him for a nap. He is saying my name, mum, mum...It is time.

You can tell I'm better 'cause I haven't written here in a while. It's amazing how much one must catch up with after an illness. I'm watching Elmo with Adam while writing this...unless I won't have time...he went to Downey’s Farm with Henry and my father while my mother and I went to a smokey baby shower that my cousin was throwing for her daughter...I lasted 15 minutes there with my chest...I can't believe how incredibly negligent it was of my cousin to organize a shower in a smokey environment with her daughter who is pregnant, her mother, who is on an oxygen tank and my other aunt who is severely asthmatic.

Anyway, I left after 15 minutes and my mother stayed. My poor mother. I wanted to support her but I really have a hard time with the smoke.
I am moving around now and hoping to take Adam to school this morning. So much happens when you're not looking. I need to really know how Adam is doing at school this week. I didn't even know that the language group he partakes in has begun...no one told me when I called the school this week, and the shadows didn't tell me either.

I will try my damndest to find a school that fits him. I don't want him in the public schools where they will funnel him into the special needs classes. I will be looking for integrated schools. As difficult as those curriculuae can be to organize, I believe in integration, philosophically.

My team of therapists is great, but I still have to stay on top of paperwork, Adam's programs. No one cares as much as I do, and I'm always trying to up the ante, to find a new way of doing things, or use the most effective way. It's a constant quest on what and how to teach. Sometimes, I wish I had someone who could expedite the management of the team. I am always trying to stay on top of everything at home and school, and I take a large part in what is important to teach. Everyone has a different style of teaching, and he is doing well by them. So this is the most important thing. Yet, with my pneumonia, I do notice that letting go a little makes me feel uneasy. Just being part of taking him to and from school let's me know how he's doing because I get to see and hear for myself. When I'm lying in bed, I don't get to see a thing and I don't have a real handle on how his week went. It all sounds good, and he seems well, so I'm sure he is fine.

This is the obsessive part of being a mom with an autistic child. Maybe some moms don't do as much or trust more people... so called "experts," but I don't. His life is in my hands. I don't believe anyone will care about him more than I will. Adam is engaged for almost the entire day. His down time is spent with me. As he's engaged with therapists, I come and go. Adam is such an active
guy that if he wasn't engaged, he would have ended up in repetitive activities. This way, he learns and he is happier for it. He plays a lot and always wants to play with others.

I do notice his peers in the neighbourhood have surpassed him in play and verbal skills. They play together, group together...Adam tries to join in but can't keep up with all of them. It always appears as if he's a step behind. At school, there are enough varied kids, that he seems to do better there. There are other non verbal children as well as autistic ones. Some kids in Adam's neighbourhood group are quieter than others. I just hope he finds the crowd that he can interact with. Everyone has to find where they belong.

I can't say that I don't worry. Some days I do, but it depends on HOW I think. If I think of those other kids in the neighbourhood and the cafe klatches I'm missing because he can't keep up, I may feel down. If I think about how far he has come, that he actually does make some buddies at school, I feel fine. I can't expect him to be like everyone else overnight and there's a part of me that doesn't want him to be like everyone else. I do want him to feel socially competent, though. Enough to have a few friends.

He's three and a half. I don't have him toilet trained yet. It's another thing I have to work on when I'm better. I'm going to cancel all therapy and people in the house so that it's just Adam and I for a couple of days doing this. He's so good with me. And it's really something that should be done with mommy.

PERMALINK POSTED BY ESTEE KLAR-WOLFOND AT 9/25/2005 10:56:00 AM 1 COMMENTS LINKS TO THIS POST

SATURDAY, SEPTEMBER 24, 2005

I am able to move around more this morning and sit with Adam during breakfast while my mother and Henry help out around me. I'm so grateful for my mother being here.

So, Henry said our friend of ours suggested that we should look at the Montcrest School for him. I heard it's a good school. It is a school for children with learning disabilities but is integrated. I'm not sure how they teach or how they integrate yet, so that is a
number one factor. It’s not what the glossy marketing words suggest-- it all sounds good -- it's what they actually do and what their philosophy is.

Last week, I took Adam to a neighbourhood drama/music class hosted in a friend's house. This friend built a separate building attached to her home with a glass tunnel. The building is like a school house - amazing for kids -- so she hosts this class and invited Adam to attend. I said that he should have his shadow there (therapist), so she just told us to show up. I thought it would be lovely for him to be with his neighbourhood peers. Treasa, this crazy woman with skraggy, curly hair that was thicker at the crown than at the ends, striped Lululemon pants and bulging eyes. She spoke cacaphonously while rapidly moving from one activity to another. I didn’t expect that Adam could take her shrill voice let alone pace. But he was so happy to be with his peers. He followed them and pretended to be an elephant -- I’ve never seen him try this before. So he was clearly gaining something from the experience. Yet at the end, she didn’t want us to come back. Despite the fact that he was a doll, was not disruptive in any way and was the only kid who could name the Dreidel song, she didn’t want him back because he had a shadow, and I expect, because he is special. She said she would try with him later, but as I considered it at the pressing of my friends to return, I decided that it is better for Adam to be around teachers who really believe in him.

I expressed my dissatisfaction to the host. I told her that I found Treasa horrible for doing this. And now I may have made ourselves the target in their eyes -- a sensitive mom and a her disabled child. It's a terrible stigma, but I have to get over it. First, I feel I have to pick the best teachers for Adam. Second, I feel I have to speak up for him, but I wonder at what cost? If I speak up do I run the risk of stigmatize him more? Do I make him the centre of a negative kind of attention? Or does he get treated differently than the others. And is that bad? Here is the area that is new to me and I try to navigate. Now our friends are suggesting special schools for him. Do they do so out of kindness? Do they do so because they think Adam is not capable? I think he is capable of anything. In fact, I know he is smarter than the other children in some areas, and maybe even overall, but he can't express it all in the same manner yet. I refer to a quote from another autistic child from Paula Kluth's book, You're Gonna Love This Kid:
"All my life I was enrolled in classes for the profoundly retarded. The pain of that isolation, I can't describe. Some classes consisted of putting flashlights together and then they would be taken apart for the next day's project. I never spoke or made eye-contact. I hummed and self-stimulated. No wonder they thought I was hopeless. I was always treated well but my intellectual needs were never addressed because nobody knew I had any intellect at all. Sad to say, many like me remain in that same, hellish situation."

His area that needs work is the social area and that may come more and more once he feels confident about all the other areas of his life -- knowing how to play and being able to handle the materials. Also, learning how to pretend play -- symbolic thinking, is something we are working on now too. All this will lend itself to an easier time in the social arena. Eventually, it will happen for him.

So it is not a surprise that I isolate myself a little. People who try to help, really don't get it at all, even though I appreciate their kindness. And in their helping, they innocently and unknowingly, isolate me even more. How can people know autism if they are not living it? He is not mentally retarded, so he can't be treated like that. He is not socially functioning like his peers either, so he is at risk for being treated like he is not intelligent. As Paul Collins wrote in his novel, *Not Even Wrong*, "autism is as much an ability as a disability, it is as much of what is present as what is missing." I've memorized that quote. It's perfect.

Or my other loving friends often ask how Adam is like he's got a virus. It's like he's supposed to be better soon, like his autism will go away. In the heyday of the "cure" -- when all charities and diseases are raising money for that grail -- I understand why this is an everyday question. But he will always be autistic. He will always be different. But he will be different too, thank God. He will be unique, intelligent, and if nurtured, may be able to exhibit his intellectual gifts as his vocation.
By the way, the reason why I called this blog joyofautism is because I thought that no one else would put those words together (all the other titles I wanted were taken and I later found out that there are plenty of references to autism and the joy of having a child with it). Autism, which is part of who my son is, is a joy to me. He may not be a label inasmuch as those may treat him in a standardized and therefore, destructive way, but autism is part of who he is. He is as much an individual as any of us, but the autism also makes up part of how he moves within the world. He is wonderful to watch. His moves are not random or behaviourally quirky if you look closely. They are strategic and orchestrated -- curious and innocent. Watching him helps me learn to see things in a different way. Watching him reminds me of how important focus and concentration are to become really good at something. His smiles, affection and abilities bring endless days of joy and I thank God for him every day.

It's been a week now that I've had pneumonia, so I have time to write this. It amazes me how much the building of our new house and taking care of Adam has really taken its toll. More the house than Adam. Adam is a passion. The house is lovely and at times, fun, but this and that needs to be finished, workers always need to be prodded. I am thinking that my life should become simpler, that going back to the friends who actually care about me is what matters. I've had so little time for making connections, having coffee with people who mean something to me. Instead it's always about the to-do lists -- a disease that inflicts most of us and I believe affects our children, especially our children with autism. I am investigating now how autism is largely a social construct. Will talk more about this later on.

I saw a round table hosted by the Dalai Lama on the CBC with representatives from all religions, including Bishop Desmond Tutu. I didn't catch the whole program, but what struck me was their humanity, their humility. That's what I respect. I also respect those from all factions who can get together and talk only to find, that we are all pretty much the same.
I have converted to three religions in my life, and I’ve had enough religion to know that I’ll never be religious. But I’ll be inherently interested in the universal messages. For this reason, I am interested in philosophy.

I am sick and I haven’t seen Henry much all week...Last night he went to the hockey game with his buddy in from Montreal who is helping shoot a film here -- I prodded Henry to get the footage of his 93 year-old grandmother -- the story of her life. I wanted to book the film crew for his birthday and I’m glad he is finally taking the time out of his schedule to document her stories and memories -- it will be so important in the years to come. One life is so rich and active and before we know it, as Joan Didion says, "you sit down to dinner and life as you know it ends." Every life deserves to be documented and remembered. So, my parents are helping Adam and I out while Henry is doing this.

In the meantime, I must simplify my life for me and for the sake of Adam. He is such a happy, delightful little boy and when I feel remoedly down, I just think of his face. He is everything I live for. Life doesn't seem that full when it's all about acquiring things for the house, and organizing all day long. Life is more full when one is invested in things one is passionate about. Reading a good book, seeing a great play or movie, having a great hour with my son...all of those moments are infused with more meaning. Life is about experience. I’ve had so little of that.

Blog and Blaa sound much the same. This is what this sounds like, but hey, this ain’t literature I’m writing here. If you want to read it, so be it. If it’s crap, move on.

Still feeling terrible. Henry off early again and luckily my mother will help get Adam ready for school.

In his first week, Adam wasn’t as social as he was at Yes I CAN!. But he was there for only two mornings a week and now he is at
Play and Lean for five. He became very "social" at the other school, which was mainly comprised of girls, but interestingly, he began to lead another little autistic boy named M. M was non-verbal and very disconnected, but when I watched him, had exceptional skills, like drawing. When I saw M I commented on how much I loved his drawing and I know he heard me. When I said it, his therapist, who shadowed him at the school jumped in and said, "yeah look at this....M, draw a triangle." Her tone was patronizing. Sure enough, M complied and drew the triangle and then went right back to his own drawing.

Was this an ABA therapist's version of success -- the imitation of the triangle? The fact that he could comply with her lame command? In my view, his success was his love of drawing and the fact that when I commented on it, he did it more. Isn't self-motivation and will the point? This is only one of my examples, and there will be more, of the failure of behavioural teaching with autism. M is smart enough to know he has to listen to his teacher. But his true abilities are being ignored by his behavioural therapists.

When M couldn't talk for himself, he began to take Adam's lead. Adam was quite adept at winning the affections of his teachers with his own affection. M would take Adam's hand and Adam would lead him. They sat beside each other. Willingly. Did they have some innate understanding of one another?

Researcher Simon Baron-Cohen lead the research on mind-blindness in autism. What this means is that it is difficult for autistic people to understand that other people possess different thoughts. Some autistic people take many years before they come to this realization. Often, his theories get over-simplified and people say that autistics don't recognize emotion. But they do. They can recognize it in pictures, but they may not be able to read complex social cues in real time. In fact, Adam can seem to empathize and where researchers such as Baron-Cohen say autists cannot. If Adam sees another child crying, he will go to that child and play alongside him or give him something to play with. It's all non-verbal but communication can be without words. If Adam sees me crying, he doesn't come up to soothe me, but he seems to pick up on my emotions. If I am distressed, he may become distressed. I wonder if he feels I am distressed at him, or if he takes on my emotions as if I am an extension of him. But the
empathy he has shared with his peers is distinctive from the mirroring of my emotions.

Perhaps some people might say that Adam isn't autistic. Adam was diagnosed with autism, by three doctors, at nineteen months of age. He wasn't engaged, he involved himself in repetitive behaviours, he couldn't engage in typical or pretend play and he was obsessed with letters, numbers and was hyperlexic by the age of eleven months. At three, he can read. Some diagnosed him with moderate autism and others higher functioning autism. At the end of the day, the nuances of diagnosis don't mean a thing. Autism gave me a frame of reference from which to learn about Adam, and now I find myself having to view him as a unique being, with a learning style that is all his own, that may share some universal qualities with other categorized neurological phenomenon like ADHD, giftedness, Aspergers and even Parkinson's disease.

I watched Oliver Sack's movie version of his book, Awakenings, last night again. The movie is marvelous-- suggesting the human behind the being, behind the catatonic bodies that otherwise appear unresponsive and lifeless. I see so many autistic children. I've attended a year of conferences and visited many schools. When Adam was diagnosed, I wanted to learn everything I could. I started with ABA, with agencies here in Toronto, behavioural analysts from the US (I would fly them in), and fired them all. I attended all of Gutstein's RDI seminars and even took Adam to his office in Houston. I tried and dumped all the diets that didn't work. Vitamins too. Adam's success began when I began to have faith in him and my decisions for him. The turning point for me was when I was about to fly in Dr. Jim Partington. The behavioural analyst I was using, J. P., kept insisting I bring him to see Adam. She used to come into my home with lists from the Hawaiian Development Profile to see what Adam should be doing and based his teaching on that. She viewed Adam as a pathology. Every behaviour went under a microscope and had to be "extinguished." But there was never ever empathy, any view that he was exceptional in some way and he was spoken to in such a contrived tone and presented with external reinforcements like he was an animal. So, when Dr. Partington said to me "we are only teaching your child how to respond," I held by breath and wondered, is it? I am not just teaching Adam how to respond. I am teaching him how to understand, how to do things, develop a sense of self, be able to understand his needs, desires, limitations and much more. Adam
didn't need their approach. The turning point was RDI for us, but it still wasn't the end. Gutstein would have had me delay entering Adam into school and thank God I didn't listen because Adam craved social interaction, even if he didn't know how to interact. Gutstein would have had me keep him at home until he mastered Stage Three of his protocol. Yet, Adam learned with help, with RDI at home, and with exposure to school, with teaching him how to share, to play. If we followed RDI to a T, Adam wouldn't be where he is today, either. This was my mapped journey to understanding autism. I still wonder if any of these therapies are really necessary at all. I sometimes think that just good teaching and an understanding of the child and of autism, is essential to a person's success.

It was the combination of our intuition, the therapies that made sense, like RDI, Floortime, teaching skills to increase Adam's sense of competency and self-worth so that he felt confident in knowing HOW to play so that he could do so with his peers.

And so, Adam just went to school again today while I am stuck in bed. The process I have just described isn't easy. What I didn't understand and am also just learning is how long it takes for him. We parents want instant results. We want a CURE, a PILL, anything to bring our children back. I find the emotions complex. My husband said to me once, when I was arguing about semantics, "Isn't that what you're trying to do, Estee... aren't you trying to make Adam more like his peers?" I couldn't say yes or no. I couldn't imagine Adam any other way than what he is. I help him because he has to be taught like any child with a learning difference. I want him to understand, to communicate, to be able to play with his peers because he wants to. I want to give him the tools he needs so that he can do the things he wants to do. I can see he wants to. We are giving him the tools to put the steam behind his motives. The heartbreaking part for me is if he had the motivation but couldn't follow through, if he wanted friends, but didn't have them because he looked different or didn't know how to interact. If I fear anything, it is that.

I hope I am not a parent who is trying to change her child into someone I believe he should be. I am just trying to understand who he is, what he wants and hopefully, provide the teaching he needs so that he can do what he wants to do in life. It is not so simple to sit back and think this -- I struggle to understand the
complexities of autism and the mind -- or to at least appreciate them. I am not a scientist, but I try to read a lot of their work.

I found a wonderful book, by the way. I don't recommend a lot of books unless I find one that really sums up a lot of works in a useful way. Henry actually found it: *You're Going to Love This Kid:* Teaching Students with Autism in the Classroom by Paula Kluth. Good for parents and for teachers.

Funny. I'm struck down with pneumonia and I finally open the blog I've been thinking of for a while. I am a mother of a three year old boy with autism. His name is Adam. Since nineteen months, he has worked with therapists to help him play, communicate, socialize, understand how to do things that the rest of us found easier at his age. What I've come to realize over the past year and a bit is that Adam is not the aberration that the behavioural analysts used to try and make me believe (and boy they tried hard), but a wonderous addition to the world around him.

Okay, you might think only a starry-eyed mother could say that. I figure, from the many down-and-out moms I meet who also have children with autism, I need to speak like that because simply, I believe it. In fact, I find it really depressing looking at the other blogs out there on autism -- parents who believe their children are broken in some way. Words are permeating our consciousness and shaping our behaviour -- words like disabled, disorder, cure and epidemic -- words that as a parent, I have found at first scarry and later, scandalous and unjust to the thousands of people who are autistic.

I surely have had confrontations with teachers who know nothing about autism, mother's in school hallways who ask "is your kid normal, or is he special needs?" We have always had a need in society to discriminate, at the peril of hurting others. As Adam's mother, it's my job to be his advocate. First, I must talk about that word N-O-R-M-A-L. A strange word. I hear people use it in so many contexts, and it seems to haunt us --a lingering apparation.
in our minds that keeps us from doing many things for fear we may not appear normal. The word is strange and ineffable because there is no "normal." There is only difference. Yet we spend most of our lives anguishing to be like others.

Luckily, there are more teachers that are realizing the unique learning styles of many children, including those with autism. Not everyone is as unaware as those mothers in the hallway who believe they are harmless.

I'm stuck in my bed and I hear my little boy call my name "mum, mum, mum," the m's melding into one another. He wants to see me. He comes now with a big smile on his face, climbing up the bed. I pause. He wants to be on my body but I feel like I'm about to vomit. It pains me to ask my mother to pull him off. I ask him to be gentle, this little happy cherub, the simple happiness of being around mommy.

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