

# **The Mismeasure of Autism: The Basis for Current Autism “Advocacy”**

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## **Introduction**

We take for granted that women have the same rights as men. We have come to acknowledge that women can still be women in the workplace and not a male simulacrum. Women can be both different *and* equal.

A man named Protagoras (c 485-410 B.C.) may have best laid the grounds for many struggles for equality when he said,

“Man is the Measure of All Things.”

Against this exemplar, a woman can never measure up. If equality means to be exactly like one other than yourself, there is no equality. For example, if a woman attempts to be like a man, a woman’s true equality can never be achieved. In her book, **The Mismeasure of Woman**, Carol Tavris encapsulates the legal dilemma of sexual equality when she says,

*“As in medicine, the law regards the male as the legal standard of a human being. Therefore, women may be treated like men, in which case they are equal to them, or not like men, in which case they are deficient or special. But they are never treated specifically as women. There is no concept in the law of what is normal for women.”<sup>1</sup>*

Similarly, we have no concept in our current jurisprudence or our medicine, of what is normal for an autistic person. When we seek to educate and improve the quality of life for persons with disabilities such as autism, is this not the right question: **What kinds of help do autistics need in order to contribute to society as autistic people?**

It was in the mid-1800’s when French Statistician Adolph Quetelet (1796-1847),

*“contributed the most to a generalized notion of the normal as an imperative. He noticed, that the ‘law of error,’ used by astronomers to locate a star by plotting all the sightings and then averaging the errors, could be equally applied to the distribution of human features such as height and weight. He took it a further step of formulating the concept of ‘l’homme moyen’ or the average man. Quetelet maintained that this **abstract human** was the average of all human attributes in a given country. For the average man,*

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<sup>1</sup> Carol Tavris, [The Mismeasure of Woman](#), (New York: Simon and Schuster Publishing, 1992), p. 106.

*Quetelet wrote in 1835: ‘all things will occur in conformity with the mean results obtained for a society.’”<sup>2</sup> [bold mine in paragraph]*

Quetelet, a founder of statistics, may have laid the groundwork for larger intentions. What happens to those in our society who do not conform to abstract measures? Is there only one kind of normal? Of course, when we measure every type of human being against these statistical “norms,” many people will inevitably fall into the margins. The danger is, when we truly believe that there is only one kind of normal, others begin to be de-valued and become subject to submission. Christine Littleton, Professor of Law at UCLA says,

*“Efforts to achieve equality through precisely equal treatment, therefore, are doomed to fail, because men and women are not starting from the same place.”<sup>3</sup>*

So too, autistic people are not starting from the same place as the majority. Instead, our view of autistic individuals was recently exemplified in Jenny McCarthy’s characterization of her son’s autistic behaviours as “boo boos,” on **The View** and on **Larry King Live** -- an affectionate way of calling autistic behaviour **wrong**.

What do her characterizations of her child mean to those people who are autistic or have other disabilities? Do we value people only when they have overcome their disability, or as we now hear, “have recovered?” It seems Jenny is unaware of what autistic people have to say about what it really means to be disabled.

My thesis is that the struggle of autistic people, like what happened to women, is the result of this “mismeasurement” against subjective norms. The way we market autism – from advocacy, education, therapies and treatments -- stem from this mismeasure. Neither valued for their neurological difference, nor heard regarding their perspectives on the social implications of their disability, autistic people have been subject to treatment that seeks to normalize them, or as history has shown, institutionalize and segregate them. Using I.Q. tests and other measures that are constructed for non-autistic people,<sup>4</sup> thus seeking responses that are typical for the majority and not for them, autistic people are considered “wrong,” “abnormal,” “sick,” “victims,” and “hopeless,” and are therefore, continuously set up for failure.

Biology and culture are always entwined with experience, and these experiences are variable for every individual – not determined. That said, autism is not an aberrance, but a challenge AND a way to live and experience the world. This is not “wrong,” but atypical, unique, and referred to as a way of being. In other words, autistic people are

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<sup>2</sup> Lennard J. Davis, *The Disability Studies Reader*, (New York: Routledge Publishers, 1997), p. 11.

<sup>3</sup> *The Mismeasure of Woman*, p. 107.

<sup>4</sup> Binet, the inventor of the I.Q. test, did not intend it to be used to “stratify intelligence,” but rather, to identify those who needed extra help. “Binet declined to label the I.Q.,” notes Stephen Jay Gould, from his book *The Mismeasure of Man*, as “inborn intelligence.”

“normal” in their own right. Paul Collins, a father of an autistic child and author of the book, **Not Even Wrong: Adventures in Autism** wrote:

*“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 to understand 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 as much about what is abundant as what is missing, an over expression 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.”<sup>5</sup>*

Their common experiences and characteristics unite autistic people as a community in which to also discuss the social prejudices against them. Therefore, it is necessary and important to discuss what is “normal” for autistic people before we can begin to discuss ways in which to raise both awareness and support.

### **Misguided Advocacy**

*“The people can always be brought to the bidding of the leaders. That is easy. All you have to do is tell them they are being attacked and denounce the pacifists for lack of patriotism and exposing the country to danger. It works the same in any country.”*

*Hermann Goering,  
The Nuremburg Diary*

Fear is embedded into the names of some of our most visible autism organizations. Names like Generation Rescue, Cure Autism Now, Fighting Autism.org, and Safe Minds, make us all question -- just whose mind is considered to be *safe*?

Leaders in autism are called advocates. They are running schools, they are scientists (considered experts) and the heads of autism organizations, like Bob and Suzanne Wright of Autism Speaks, our largest autism charity. Last I looked this charity had a total annual budget of sixty million dollars, mostly dedicated to, as Hillary Clinton so clearly stated in her campaign speech for President, “preventing and curing ANYTHING along the autism spectrum.”<sup>6</sup>

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<sup>5</sup> Paul Collins, Not Even Wrong: Adventures in Autism, (New York: Bloomsbury, 2004), p. 161.

<sup>6</sup> Captured in video and used in Autism in the Media which can be used on [www.youtube.com](http://www.youtube.com) and search The Autism Acceptance Project. “Christschool”, the codename of autistic man and father of autistic son who produces many videos on You Tube executed Hillary’s clip capture.

We hear from our own Canadian ABA advocates that “autism is a living nightmare,” a “prison that locks the child within,” and recently in the *Ottawa Citizen* on September 29, 2007<sup>7</sup>, where Michelle Dawson and I were interviewed in all but too few paragraphs for the other side of the autism story, ABA advocates still insisted (I say “still” because after years of requests from autistic people and parents regarding the inappropriate use of alarmist and fallacious language in order to garner political support, this community still insists on using it), “autism is like a death in the family,” and it’s all “doom.”

Of course, doom is the path to nowhere – it leads to an overall perception that with autism, we live in a dark tunnel that we cannot escape. It’s leads us to desperation. With that model, there is only one hope: to cure autism as quickly as possible.

In Autism Speak’s *Autism Everyday* video, which was acclaimed at the Sundance Film Festival, Allison Tepper Singer, Senior Vice President of Autism Speaks, talks about wanting to drive off the George Washington Bridge with her autistic daughter, while her daughter is in the room. While many of us can relate to the frustration she feels in not finding an appropriate school, many autistic people and parents were shocked that she said this on a national fundraising film, moreover, with perhaps a belief that her daughter wouldn’t understand her, which is all too typical of how autistic people are referred to as “not aware,” or “like they’re not even in the room.” Need we remind people of the consequences of such beliefs with Ashley X (“The Pillow Angel”) or what people like Ann McDonald<sup>8</sup> has had to say from her own life experience?

Singer says that the only reason why she didn’t drive off the bridge is that she had another daughter at home (who, by the way, is not autistic). Her non-autistic daughter goes on to say that she wished she didn’t have an autistic sister and that she didn’t want anyone to see her, which eerily takes us back to the last century, where parents were made to feel ashamed for having disabled children and thus, sent them to institutions.

The video makes autism appear horrible and challenging beyond imagination. Not only is autism portrayed as dark—parents want to commit murder-suicide – and sadly, some do.<sup>9</sup>

Living in the land of “what-if’s” is not a denial. It’s a necessary step in creating new paradigms that are more appropriate for the realities that both autistic people and parents face. Autism Speaks has a major problem: they are raising money for a people who do not necessarily want to be cured and to whom they don’t listen. Autistic people face a

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<sup>7</sup> Roger Collier, *The Politics of Autism*, **The Ottawa Citizen**, September 29, 2007.

<sup>8</sup> Ann McDonald is a Disability Rights Activist and woman with CP. Rosemary Crossley introduced Ann to Facilitated Communication in 1977. Ann has a website called **The Right To Communicate**. Today, many autistics use communication devices with and without facilitation. The result of AAC and IT have enabled autistic individuals – ones that others would have deemed “unaware” or “severely disabled” -- to communicate to us their thoughts about their treatment and about disability.

<sup>9</sup> For more information on autistic abuse see: [http://community/livejournal.com/autistic\\_abuse](http://community/livejournal.com/autistic_abuse) and [www.neurodiversity.com](http://www.neurodiversity.com).

problem: they are the constant subjects of disrespect, hatred, dangerous treatments, and at risk of annihilation. Parents are at risk: they don't know what to do and where to turn, so that they risk harming themselves and their autistic children.

Based on the different and equal premise of autistic individuals in our society, what if:

- Allison didn't have to see dark videos (or hear the messages) like this, but was congratulated at the time of her daughter's diagnosis;
- A doctor smiled (instead of frowned)<sup>10</sup> and explained that many autistic people already contribute to society -- they are musicians, scientists, computer programmers, poets and writers, and there are other autistic people are contributing in different yet valuable ways;
- Doctors helped Allison see that autism is a part of the human condition;
- Allison was educated and supported about the challenges autistic people face in addition to the abilities, (so at the end of the day, we can see that all children will have challenges, get sick, bring us joys, and the outcome of any child is not fixed or predetermined);
- Allison had access to a good school where her autistic daughter was accepted, included, and autistic skills were honoured and built upon;
- Allison didn't feel so isolated and didn't have to answer questions about why her child was different every day, or subject to advice on how to fix her child;
- Allison's daughter was taught to use a communication device, so her daughter could be able to say, "I love you mommy?"

What if our autism organizations fought for this? I am sure that others can tweak or expand the list I've provided.

Potentially lethal is this combination of two dissociated concepts: acceptance with cure. Canadian autism societies are claiming that they have to be "non partisan," and thus support nearly everything despite a lack of empirical evidence, like biomedical intervention, Applied Behavioural and other therapies -- and they do so while advocating acceptance. In a month-long investigation, the Kennedy Krieger Institute found over 180 treatments and/or therapies being promoted which they said, "all require a checkbook and/or credit card."<sup>11</sup> How many times have we heard well-intentioned parents say things like *we have to try anything and everything?* Our autism societies are not properly filtering the information. Instead of supporting the people it claims to work on behalf of, our societies are still advocating for the cure and remediation of autistic people. They do so by suggesting that some of these "therapies" work by tacitly endorsing unproven

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<sup>10</sup> The reason for the frowns might not only be the fact that disability studies is not taught in medical school, but also because doctors are often sued by parents who have children with various disabilities, like Down syndrome, for instance.

<sup>11</sup> IAN – Interactive Autism Network website: [www.iancommunity.org](http://www.iancommunity.org).

treatments on their websites. As they are considered authorities to which people turn, we must hold them accountable.<sup>12</sup>

Helping people manage a disability, however, is not akin to saying they must become normal. While acceptance doesn't mean acquiescence, it is difficult to tie it in with "recovery." If autistic people are normal in their own right, then there is no need for recovery; there is only need for support.

What if, our organizational leaders, like Krista Flint of the Canadian Down Syndrome Society, said, *I can't imagine the world without an autistic person in it.*<sup>13</sup>

What if, our autism organizations renamed themselves perhaps like this:

-Instead of Generation Rescue, we could have Generation Respect;

-Instead of Safe Minds, we could have Unique Minds;

-Instead of Cure Autism Now, we could have Celebrate Autism Now;

-Instead of The Autism Autoimmunity Project, we could have The Autism Acceptance Project.<sup>14</sup>

If we renamed our organizations, what might the public, parents, scientists think and feel about autism and how might it guide our actions and attitudes towards autistic individuals?

## **Misfired Intentions**

We all know the saying : The road to hell was paved with good intentions, or as Robert Herrick said, "Hell is paved with good Samaritans." In response to my criticisms of Jenny McCarthy recently, people say, "well at least she's raising awareness." But is this the right kind of awareness? Does the marketing model for say, curing cancer, fit the needs

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<sup>12</sup> This pressure comes from parents. Autistic people are not considered and autism is still viewed as a tragedy, for which we must try anything to cure. If autistic people are accepted into charities, acceptance is sort of like a footnote, an adjunct perhaps in order to appease some of the new pressure they are facing from an autistic civil rights movement and parents who are frustrated with the prejudice against and lack of access and support for their autistic children.

<sup>13</sup> Ms. Flint said "I cannot imagine a world without a person with Down syndrome in it" in response to a **Globe and Mail** article on the prevention of Down syndrome births titled *Expand Prenatal Tests, MDs Urge*, February 6, 2007 by Carolyn Abraham. The website is [www.cdss.ca](http://www.cdss.ca).

<sup>14</sup> The Autism Acceptance Project was named after it learned of the The Autism Autoimmunity Project.

of autistic people in terms of their human rights and the accommodations and supports they need in order to contribute to society as they are?

Nietzsche didn't think highly of benevolence as he recognized it as an act in order to keep the benevolent person in a superior position. He said,

*“one has to therefore 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 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.”<sup>15</sup>*

To pity others is to put oneself into a superior position. It oppresses others which is why autistic people often identify with other social movements like the Gay Rights Movement or with the Black Civil Rights movement in America.<sup>16</sup>

Prejudice is best described as applying a different set of standards to one set of people over another. We have to consider that we would not like to be referred to in the way that charities have begun to encapsulate autistic existence through the puzzle image. The puzzle piece is a suggestion that autistic people are the mystery, again putting the burden on them to metamorphose into something that WE can understand. Instead of looking at ourselves and our own bias and working harder to accept autistic individuals, we are gung ho on curing them to make ourselves feel good, and relieve our burden.

We also have to ask the important question of why we seek to ameliorate autism or “recover” it. Are we seeking to obtain the “normal” child we thought we were supposed to have? Are we in search of the elusive “perfection?”

**OR:** Do we accept the child we do have? Do we **celebrate** that child, while trying to help them manage some of the more challenging aspects of their disability? Do we assist autistics to be the best they can be because we understand and value autistic people?

Perhaps the answer is in not throwing the baby out with the bathwater, but rather, in merging help with respect.<sup>17</sup>

Many autistic people have rallied against the puzzle image by stating, “I am not puzzle, I am a person,” and have petitioned against Autism Speaks in their campaign: **Autism**

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<sup>15</sup> From Nietzsche's The Gay Science.

<sup>16</sup> Autistic people have made these comparisons on their oppression. Authors Ralph and his autistic son, D.J. Savarese have also made many references to autism and oppression of other cultures.

<sup>17</sup> I have adopted this phrase “merging help with respect” from Norman Kunc and Emma Van Der Klift in their essay: **Hell Bent on Helping: Benevolence, Friendship and the Politics of Help**, 1994.

**Speaks: Don't Speak for Me.** Yet, the public never hears about this. Autistic people are still kept in the margins.

By examining the way autism is represented by our celebrities, charities, therapists, and some of our scientists, we can illustrate that bias and prejudice are not limited to race or religion, but also to people with disabilities, and it is the most tolerated form of prejudice today. We live in a society that glorifies celebrities who in turn support causes about which many of them understand little.<sup>18</sup> When philanthropy is the “new black,” we do not reflect enough on the consequences of what we support. In short, it is probably worthy of our consideration when the disabled community says en masse: “we do not need another Jerry Lewis.”

What if we changed the marketing model so that instead of eliciting pity, we focused on gathering respect?

To construct a new marketing model for autism charities, what if we:

- let autistic people speak and ensure that there are more autistic people running our autism society boards and that there are at least an equal number of autistic people at all our conferences as there are non-autistic ones?
- we regard their lives with honour and respect?
- we listen to their experiences in order to learn and become sensitive to their needs?
- we approach carefully and learn from autistics on how to educate and support them instead of imposing what we think they need and how we think they should be taught?
- we believed that they are truly different AND equal?

## **Misrepresenting Recovery**

As advocates and celebrities continue to spotlight autistic deficiencies in the name of better “treatments,” and refer to autistic people as “hopeless” without recovery, they not only acrimoniously exclude autistics from the dialogue, they are tacitly suggesting they are alien from the human race. Autistics who ask for accommodation are insulted and ignored, even hated. Parents on the **Evidence of Harm** discussion list, named after David Kirby’s book which blames vaccines for causing autism, and parents who advocate for ABA as the ONLY treatment to cure autism, have demonstrated their view of towards autistic individuals whom they have described as:

Hopeless  
Doomed without ABA

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<sup>18</sup> For more information on the fallacy of what celebrities support see [www.senseaboutscience.com](http://www.senseaboutscience.com).



Inappropriate  
Disruptive  
Weird  
Government mercury vaccine poisoned kids  
A Parent's Worst Nightmare Syndrome  
Equal Opportunity Disasters  
Walking Biohazards

Unfortunately, the list of pejorative references is much longer than I've written here.<sup>19</sup>

Autistic adults who speak out against autism charities and interventionists, are called “not autistic,” by those parents who wish to paint a dark picture of autism for funding purposes, because if autistic people can communicate, they do damage to the marketing model. G.K. Chesterson said, “Art is limitation; the essence of every picture is the frame.” Autistics don't fit into their frame. They do not conform to the pity paradigm. They are not hopeless enough.

Society cannot recognize, within this overwhelming autism-is-a-fate-worse-than-death framework, the innate value of the autistic person, and we do not understand the challenges of their, in many cases, “invisible disability.” People have a difficulty in understanding that there is no normal or abnormal in autism. There is only dissonance. There is, as Paul Collins said, ability and disability. With every disability, everyone is valuable and has potential. Society cannot wrap its collective head around the fact that some people are different *and* will require more support and accommodation throughout their lifetime in order to contribute. We tend to overrate independence and normalcy as worthy goals, whilst forgetting that we are all, in fact, interdependent. We do seem, however, to understand quite well the notion of the **handicap** in golf:

*“Since its inception USGA Handicap System has made it possible for golfers of differing abilities to enjoy fair competition.” --USGA website*

We use a handicap to equalize the playing field by identifying what one's handicap is and then accommodating that in the game. Yet in autism, if I may borrow the words of Stephen Gould, we “parse complex and continuous reality into divisions of two.”<sup>20</sup> We base everything on our need for proof of either competence or incompetence and if you are considered incompetent cannot participate a fair game. Yet, what about making room for both – accommodating the handicap in order to make room for the possibilities?

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<sup>19</sup> To read more of these pejorative references from the biomedical advocates, read Kathleen Seidel's **Open Letter to David Kirby, “Evidence Of Venom.”** It is also worthwhile to add here that many autistics who have spoken out against pejorative referencing and dangerous treatments, have been stalked, been the recipients of hate mail, and name-called on websites expressing their anger and dislike of autism and autistic people.

<sup>20</sup> Stephen Jay Gould, *The Mismeasure of Man*, (New York: WW Norton & Company, 1996), p.27.

Consider this anonymous quote from an autistic person on [www.autistics.org](http://www.autistics.org) when discussing the accommodation and greater understanding of autism, and the current lack thereof:

*“They see you talking; therefore, talking must be easy. They see you moving around; therefore, motion must be effortless. ...Maybe it's like being a duck-- you appear to be gliding smoothly across the water surface, but underneath the water where people can't see, you're busy paddling like hell....*

*...I finally got independent study "privileges" at the end of the year, after my parents, of all people, started pushing for it, but everyone was very adamant on the point that "in the future, you won't get this. You'll have to do it the same way as everyone else, with everyone else."*

*I don't think people get it. I expect nothing. I expect nothing to be given to me. I expect to be called a liar and manipulator and an excuse-maker and to be told that the system owes me nothing and that I can sink or swim. I expect to be forced to plead, beg and grovel in order to get any kind of accommodations at school, extended deadlines and the like, and to be seen as a manipulative liar if I still can't do it. ...”<sup>21</sup>*

We require an urgent shift of perception to view autistics as atypical, as opposed to “wrong,” and autism as a different and *valuable* way of being. Autistic people, much like women, have the right to be, therefore, different AND equal and worthy of accommodation. They do not have to change themselves into normal-seeming simulacrums. This is not the worthy goal in assisting autistic individuals.

In the wake of celebrities speaking as experts on autism, let’s step back a bit and consider AGAIN that autistic people are missing from our public dialogue – they are not seen on **Larry King Live**, **Oprah**, or **The View**, for example. Only recently was Amanda Baggs featured on CNN.<sup>22</sup> In no other charity for any other disease or disability do we view such an obvious absence of the people autism charities represent. We get to see autistic people only in extremes in the media -- once in a while as tag-alongs of parental lost-dreams, or as models of recovery -- all usually representing a charity or special biomedical treatment group. We rarely get to hear what autistic people really think about what’s going on or what’s happening to them in their lives.

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<sup>21</sup> From anonymous autistic person on [www.autistics.org](http://www.autistics.org).

<sup>22</sup> Amanda Baggs’s blog is called **Ballastexistenz** and her video from You Tube “In My Language” was featured on CNN in 2007.

Yet, there are a multitude of organizations and autistic self-advocates (and the list is thankfully growing) out there. I know that as a mother, I've learned a lot from them. But I wonder how many of you have heard of them:

Autistic Self-Advocacy Network	Temple Grandin
Autism Network International	Vernon Smith
Asperger's Association of New England	Abnormal Diversity
Autcom	Action for Autism
No Autistics Allowed/Michelle Dawson	Along The Spectrum
GRASP	Bartholomew Cubbins
Amanda Baggs	Autism Diva
Jim Sinclair	Aspies for Freedom
Ralph Smith	Autistic Adults Picture Project
Phil Schwarz	Autistic Advocacy (Frank Klein)
Larry Arnold	Oddizm
Brian Henson	PosAutive
Michael Moon	Pre Rainman Autism
Martine Stonehouse	Whose Planet Is it Anyway?
John Gelmon	Jane Meyerding
Matthew Schuster	Patty Clark
Kassiane Sibley	Laura Tisoncik
Alex Bain	Kathy Grant
Ari Newman	Barbara Moran
Joel Smith	Robert W. Cutler
Stephen Shore	Jamie Burke
Liane Holliday Willey	Sharisa Joy Kochmeister
Larry Bissonnette	Anne Carpenter
Lucy Blackman	Mike Hoover
Sue Rubin	David Goodman
Autistics.org	Jenn Seybert

I have limited space here, but there are many more individuals and self-advocates than I've listed.

We must seek their input!

Yet, without consulting them or considering the social implications just described, Eugene Levy will rally behind ABA/IBI as the only treatment or therapy to remediate autism here in Canada, while Jenny McCarthy has already begun her cries for curing autism through biomedical intervention and diet. She is the new spokesperson for TACA – Talk About Curing Autism Now.

What kind of authority do celebrities bring to autism, when, as Jenny McCarthy also admitted on **Larry King Live**, that she has never once met an autistic adult? Eugene Levy reportedly only met his young autistic cousin the day before the press announcement<sup>23</sup> that he was going to represent Canadian ABA advocates, and Bill Cosby bumbled, “it’s...it’s like he’s...” [referring to autistic child] “...not even in the room.”

<sup>23</sup> From Globe and Mail, *Autism Is No Laughing Matter*, by Hayley Mick, June 13, 2007.

These are all non-autistic people who seem to be missing the point because they are not engaging with a myriad of autistic people.

Celebrity endorsements, however, are powerful motivators – from getting you to buy jewelry on The Shopping Network, to giving your money for AIDS research -- celebrities can bring in the big bucks, not to mention a great deal of awareness and attention to a product or a cause. That said, autism awareness has a dark side.

Autism is not cancer or AIDS. Those diseases are life threatening, while autism is life-long. There is a real difference between marketing for cancer, AIDS, saving Darfur, and the marketing for an autism “cure.” As a former marketer for health charities, I am more than aware of the temptation and effectiveness of using the word “cure” for raising money. I was the developer for the first Click for the Cure Campaign for The Arthritis Society.<sup>24</sup> When charities only answer the call of non-autistic parents as the people who are “suffering,” – we can say this because it is only their voices we hear -- we have not an organization for autistic people, but for parents who cannot resist the siren call of a normal child, or are in fear that if they do not try anything, they are bad parents.

Further, as I already noted, autism is a disability, not a disease. Yet, some neurologists and other advocates still want to portray autism as a “whole body medical condition,” despite the lack of evidence to support that notion.<sup>25</sup> Consider also, that we are diagnosing anything and everything that comprises the human condition, rather than evaluating the circumstances around autistic experience – the good and the painful -- and asking what that means and feels like. We can and are pathologizing human experience, and we do so by adding in our bias -- our mismeasures.

Carol Tavis notes that we have done the same with women’s natural biology and cultural experience. She says,

*“Everywhere we look today, we see that the normal changes of menstruation and menopause are increasingly being regarded as diseases, problems and causes of women’s emotional woes and practical difficulties. In particular, biomedical researchers have taken a set of bodily changes and packaged them into ‘Premenstrual Syndrome,’ and sold them back to women as a disorder, a problem that needs treatment and attention.”<sup>26</sup>*

She notes that doctors have listed over 150 symptoms associated with PMS –many of which would apply to men! For these millions of sick women, myself included, there are a myriad of products we can buy -- prescription medications, over the counter remedies,

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<sup>24</sup> My work history is a curator of fine art who became an effective fundraiser for charities.

<sup>25</sup> Let us please not confuse the disability as a medical condition, but take a look at how we can assist the disability while dealing with some medical aspects that can result in any human being.

<sup>26</sup> Tavis, p. 133.

herbs, diets, and medical support groups -- and the same could be said of the autism industry that uses fear in its sales pitches.

“A physician writing in the Wall Street Journal estimated that the illness of PMS costs US industry 8% of its total wage bill.”<sup>27</sup> Similarly, we hear that autistics cost the Canadian economy \$3.5 billion<sup>28</sup> – so ominous is the number that it hangs like a bounty over the heads of autistic individuals.<sup>29</sup> Nothing can compete with the “financial burden of autistic people” or a “cost to industry” framework to sell a method, a product or a cure. It’s the strongest marketing tactic around.

Let’s compare. The media has reported PMS as:

“The Monthly Menace” – *Science News*

“The Internal Earthquake” – *The Orange County Register*

“In a tea factory in China, almost 80% of women suffered from PMS”

“Premenstrual syndrome remains as baffling to researchers as it is troublesome to women.” – *Psychology Today*<sup>30</sup>

Autism has been marketed and promoted as:

“a mysterious upsurge” – *The New York Times*

“a baffling outbreak” – *CBS News*

“cases are exploding in number” – *TIME*

“and no one knows why” – *USA Today*

“The nation is facing an autism epidemic”<sup>31</sup>

Yet, as Hill, Gernsbacher, Dawson and Goldsmith deduced in their paper *Three Reasons Not To Believe in An Autism Epidemic*, “Epidemics solicit causes; false epidemics solicit false causes.”<sup>32</sup> In order to understand this, let’s take a look briefly at epidemiology, the study into the causes of epidemics.

Epidemiology, says Gary Taubes of the New York Times Magazine, in his article *What Really Makes us Healthy*,<sup>33</sup> “is the here-today, gone-tomorrow nature of medical wisdom. There are after all, an infinite number of wrong hypothesis for every right one, so the odds are always against any particular hypothesis being true.”<sup>34</sup>

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<sup>27</sup> IBID.

<sup>28</sup> CBC News, “Add autism treatment to medicare, comedian Eugene Levy, parents urge fed,” June 13, 2007.

<sup>29</sup> I haven’t seen any numbers prepared by this ABA advocacy group of how much autistics contribute and add to the Canadian economy.

<sup>30</sup> Tavis, p. 135.

<sup>31</sup> This example was taken from Hill, Gernsbacher, Goldsmith and Dawson’s paper “**Three Reasons Why Not to Believe in the Autism Epidemic.**”

<sup>32</sup> This paper and Roy Grinker in his book *Unstrange Minds*, dispel the epidemic myth by analyzing “incidence” versus “prevalence.”

<sup>33</sup> Gary Taubes, *What Really Makes Us Healthy*, *New York Times Magazine*, September 16, 2007.

<sup>34</sup> IBID, p. 54

The media will publish a press release on any study, not yet proven, on autism. It might behoove us to remember a journalist's maxim: "Yesterday's paper wraps today's garbage."<sup>35</sup> Most of what we hear is speculation, not yet fact. Still, we sell products and build health policy on what the media reports. Little research is undertaken by many of our journalists into the real sides of the autism "story," regardless of the Journalist's Code of Ethics<sup>36</sup> which states under the heading **Seek Truth and Report It**: "tell the story of diversity and magnitude of the human experience boldly..." and, "avoid stereotyping by race, geography, sexual orientation, disability, physical appearance or social status."<sup>37</sup> Flare and doom sells and many reporters have become lazy. We have to be skeptical about what the media reports because as Taubes says, "after all, it's the first claim in any scientific endeavour that is most likely to be wrong."<sup>38</sup>

We must also remember that there are and were real life-threatening epidemics out there. Polio, AIDS are but two examples, and our scientists cannot conclude that we have an autism epidemic, but it's sure a scary word. Roy Grinker said,

*"Epidemic is a powerful concept. It implies danger and incites fear, calling up associations with plagues that can sweep through the streets, something contagious in the air you breathe or in the food you eat, threatening the ones you love. With autism the label 'epidemic' sounds both frightening and tragic."*<sup>39</sup>

Those who profit from the cultivation of despair broadcast catastrophic depictions, and the true meaning of epidemic has come to have little meaning. Yet, "epidemic" is a powerful reality. The loose use of the term cheapens it and minimizes the significance of true epidemics.

Though we know that autism is not a disease, claimants, like Jenny McCarthy and TACA, are proselytizing and marketing diets, supplements and therapies and suggest that with them, autism can now be "recovered" -- a rather tricky semantics exercise in stating that autistic people can't be cured but they can be "healed," but not in all cases, and oh, they will likely still have "boo boos." All said, because they are already "damaged" and "broken."<sup>40</sup>

In September 2007, the CBC reported that Canadian doctors warned not to give a child under the age of twelve a multivitamin. We've all received conflicting messages about

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<sup>35</sup> I have to credit Gould's book for the acquisition in this paper, some oldies but goodies.

<sup>36</sup> From The Society of Professional Journalists website.

<sup>37</sup> There are many goodies in this Code of Ethics which you can view online by Googling "Society of Professional Journalists: Code of Ethics."

<sup>38</sup> New York Times Magazine, p. 74.

<sup>39</sup> Roy Richard Grinker, Unstrange Minds: Remapping the World of Autism, (New York: Perseus Books, 2007), p.5.

<sup>40</sup> "Broken" is how Dr. Kartzinel referred to autistic people on **Larry King Live**.

what is going to make us live longer and healthier one day, to find that tomorrow, what we thought was good for us, just might make us sick. It's also the basis for a lot of latitude in the promotion of autism "remedies."<sup>41</sup>

To recover autism, autistic kids are to go to specific doctors, some under the DAN! Protocol, otherwise known as Defeat Autism Now, and use a variety of medicines, supplements and therapies to "heal" the child. The lists and "protocols" are ominous:

Calcium	Selenium	Zinc	Magnesium	Iron	Cysteine	Sulfate	Taurine	B-12	B-6
Lysine	Methionine	Essential Fatty Acids		Vitamin d	Vitamin e		Vitamin a		
enzymes		Vitamin c	Vitamin b-6	Zinc	Calcium/magnesium		Probiotics	Digestive	
Melatonin		Methyl-b-12		Folinic acid	N-acetyl-cysteine	Amino acids		TMG or DMG	
vitamin/mineral		Coenzyme Q-10	Transfer factor		Selenium	Iron	Chromium	Multiple	
Charcoal	N-acetyl-carnitine		DMAE		Silymarin	5-HTP	Active		
Creatine	Pantothenic acid	Phosphatidylcholine		Oral gamma globulin		Pycnogenol			
Qurecitin	Carnosine	SAME	Methyl-B-12	B-spectrum vitamins, including pantothenic acid					
Lauricidin		Curcumin	Oregano oil	Caprylic acid	Olive leaf extract		Garlic		
supplements		L-Glutamine	Quercetin	Pyenogenol	Magnezium	Cucumin	Niacin		
Anti-inflammatory nutrients and flavonoids, including quercetin, pycnogenol & others									
Lauricidin		Arabinogalactan	Acidophilus	Bifidus	Garlic	Saccharomyces boulardii			
primrose oil		Cobiotic companion	L-Glutimine	Lauricidin	Panthothenic acid	Gama Oryzanol			
permeability factors		Biotin		Omega-3 EFAs	LOTheanine				
GABA		Inositol	Fish oil	Larginine	Glutathione				
Detox phases 1,2,3,4		ALA	Silymarin	Dimercaptosuccinic acid					

The list is dauntingly longer than what I've provided.

Would we subject a neurotypical child to dozens or more of supplements, detoxification therapies, and "healing" medications, without scientific evidence to support that it is safe? I doubt it. Yet, for autistic kids, taking substantial risks seems to be okay. And to make them what -- better at math, quicker on the sports field, or well-mannered? Is this fair?

The consequence is that not only are autistic people are stigmatized as a result of gross generalizations that one thing can cause or remedy autism, the lives and health of many autistic children are in danger.

Still, the volume and weight of these messages that bamboozle and intimidate a confused public -- delivered by "doctors" and celebrities -- is compelling. More parents are choosing not to vaccinate their children, exposing them to the risk of life-threatening diseases. Some children, who have undergone chelation therapy in order to "recover" from autism, have died from it.<sup>42</sup> Why are we risking our children's health? Does the

<sup>41</sup> I am not ignorant to the fact that the same argument could be applied to vaccines. However, we have to date, no evidence to prove that vaccines cause autism after rigorous scientific research.

<sup>42</sup> Many references on this. Start with [www.autismdiva.blogspot.com](http://www.autismdiva.blogspot.com) -- "Death Raises Debate," The Pittsburg Tribune: "Death Raises Debate," and check out IAN and the CDC, "Deaths Associated with Hypocalcemia from Chelation Therapy, March 3, 2006.

benefit really outweigh the risk? There might be people who say, absolutely yes. There are ABA and biomedical advocates telling our politicians and public that “autism is a fate worse than death.”<sup>43</sup> If you really believed them, you might agree that anything, even a child’s life, is worth the cost.

While I do not wish to alienate families who are undergoing a struggle to accept, understand and raise their autistic child, I do believe that we can rally for more support by including autistic people. I do believe that all parents are concerned with the welfare of their children in terms of safety, rights and opportunities. I don’t believe that the doom scenarios are really helping parents cope, or assisting autistic people in living healthy and productive lives.

### **What Kind of World Do We Want to Live In?**

So, here’s the rub: if you believe in that statistical norm and that autism is “hopeless” without recovery, and the *actual* truth is that autistic people mature and progress **while still being autistic**, then autistic people will, under the “autism is hopeless” lens, “be recovered.” To put it sarcastically, if you believe that autism is hopeless, then autistic people are bound to recover ‘cause there’s no where to go but up. You’ve already put them at the bottom of the pile.

What if *what* we are witnessing and measuring is not recovery, per se, but just the nature and variability of autistic development? What if, with such awareness, the circumstances surrounding that development were positive, nurturing and valued the nature of autistic intelligence and ability, while we respect and accommodate the more disabling aspects of autism? The research by Mottron, Gernsbacher, Dawson and Soulieres from the University of Montreal on the **Nature of Autistic Intelligence**<sup>44</sup> is exciting to many of us because it is the first of its kind in autism, which takes this *different AND equal* premise into account. It does not base autistic ability as the reverse side of human pathology, and hopefully future studies will be conducted with the autistics-as-valuable measure.

Imagine what the world would look like if:

- autism ability was valued, not greeted with arms-length fascination, or perceived as weird genius;
- autism was viewed as natural;
- autism was okay;
- autism was understood in terms of a different way of being; knowing, learning and behaving;
- autistic behaviours were viewed as a different way of communicating rather than disruptive and problematic.

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<sup>43</sup> See Sabrina Freeman’s [Science for Sale in the Autism Wars](#). The reference has been used elsewhere in the press.

<sup>44</sup> Dawson, Gernsbacher, Mottron, Soulieres, *The Level and Nature of Autistic Intelligence*, **Psychological Science**, Volume 18, Issue 8, pp 657-662, August 2007.



What if we could develop support for:

- anxiety and physical issues that took into account the external issues and seeking to modify the environment rather than the behaviour?
- non autistics in sensitivity training and autistic people could do the teaching?
- Socialization-understanding versus becoming a normal-socializer?
- training and augmentative communication with AAC/IT?!
- autism education versus remediation?
- inclusion as a win-win situation for both non disabled and disabled citizens?

What if we defined the “mosaic” of support and education for autistic people with the premise that everyone progresses from their own starting point. Perhaps a mission for the way we educate could derive from this:

**Teaching autistic children, as opposed to wasting their time, may be the difference between teaching them to be normal as the sole goal, versus teaching them about the world and enabling them, with the appropriate tools, to communicate their feelings about it.**

I define teaching my own son by valuing his response while building bridges for him to communicate and navigate the world. I do not judge Adam by his behaviours, nor do I measure his intelligence through typical responses. His responses and behaviours are the valuable ways he communicates with me and from which we can build together.

There is nothing in our current autism advocacy or marketing campaigns that is set out to explicitly de-stigmatize autism, celebrate autistic existence, improve quality of life *with* autism<sup>45</sup>, advocate for a mosaic of support so that all autistic people can be served, that demands the highest standard of scientific research, and that includes autistics, with the exception of The Autism Acceptance Project here in Canada and other self-advocacy groups. The dialogue today, sadly, is increasingly exclusive and polemic and, the marketing-of-despair model seems to be set in stone, while a few of us gather to advocate for basic human rights. As there are many smaller groups and individuals working toward the same goal throughout the world, we need to consolidate so that people can SEE us and the real issues autistic people, of all ages, face. So-called “advocacy” groups that resort to bullying and exclusion must not intimidate us for our efforts.

### **“What if” in Research – MEASURE OF VALUE**

We are, however, bound to the concrete need for truth when the cards are so stacked against autistic people as different *and* equal. Currently, there is too much focus on research that seeks to prevent and cure many disabilities, not just autism, instead of

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<sup>45</sup> Some societies have positive aspects to their campaigns. Yet, most programs are shrouded by remedies and cures, rather than support for living good lives with autism. Mixed messages, as I describe, lessen the resolve and integrity of otherwise positive campaigns.

conducting more research into the nature of human intelligence. There is not enough research into how to improve the lives of autistic people, notwithstanding the many families who feel they have benefited from having autistic and other disabled children. We need to see and hear the positive stories parents can express, and persuade our scientists to conduct the research that will benefit disabled people living in society.

Patricia E. Bauer, a journalist and a mother of a daughter with Down syndrome said, “while people with Down syndrome enjoy an improved quality of life, there is a disconnect between how society views our children, versus the way we live with Downs...[yes, with ] some frustrations, but [with] possibility, love and joy.”<sup>46</sup>

King, Zwaigenbaum, Baxter, Rosenbaum and Bates, conducted a “Qualitative Investigation of changes in the Belief Systems of Families with Autism and Down Syndrome,”<sup>47</sup> which documents the positive life changes that families have experienced with their disabled children. Such accounts and studies are important if we seek to support and empower families, and improve the quality of life for people with disabilities.

With genetics research and preventative diagnostics, a thriving billion-dollar industry, we are, says Patricia Bauer, “developing better ways of spotting and eliminating these people before they are born.... doctors, [have] failed to notice that they have embarked upon the elimination of an entire class of people who have a history of oppression, discrimination and exclusion.”<sup>48</sup> While she is talking about Down syndrome, it really is no different for autism.

Many in our research community are already biased against autistic people – using language that dehumanizes and pathologizes them as “abnormal” and “mutated.” Recently, Kevin Leitch creator of the **Autism Hub** illustrated in a recent video, the thoughts of Dr. Jerry Kartzinel (who has “dedicated” his practice to recovering children with autism) who said,

*“Autism, as I see it, steals the soul from the child, and, if allowed, relentlessly sucks the marrow out of the family members one by one.”*

People like Dr. Kartzinel relentlessly suck OUR lifeblood with this horrible depiction of our autistic children and we must speak out because it is precisely these kinds of words that will ostracize them, and will do damage to their self-image, not to mention their safety, if we allow to continue.

We know that many scientists give little or no consideration to what autistic people say about their own autism or listen to the positive stories and love we feel for our children as

<sup>46</sup> Patricia E. Bauer “Stand Tall.” [www.patriciaebauer.com](http://www.patriciaebauer.com).

<sup>47</sup> King GA, Zwaigenbaum, King S, Baxter D, Rosenbaum P, Bates A, *A Qualitative Investigation of the Changes in the Belief Systems of Families of Children with Autism or Down syndrome*, **Child: Care, Health, Development**, Volume 32, Number 3, May 2006, pp353-369 (17).

<sup>48</sup> IBID.

they are. We have an over-medicalized, and one might even say after hearing Dr. Kartzinel, ruthless view of disability. Our celebrities who are “spokespeople” for such organizations, take it further and paint the doom and gloom picture of autism to a larger public that makes people fear it and want to get rid of it as quickly as possible. That’s why we have so much money dedicated to preventing autism.

So much for protecting our most vulnerable citizens.

Scientists, says Stephen Gould, “are good at analyzing data and critiquing conclusions of others...but rarely do they contemplate history in the sense of moral instruction.”<sup>49</sup> A true model of oppression, autistic people are kept at arm’s length as “patients” and “clients,” and are not welcome to participate in the overall scientific process. Autistic people are presumed to be incompetent, and therefore, not considered the true “experts” of themselves and autism. While one might argue that none of us are the true experts of our brains or DNA, we certainly have a lot to learn in the way we approach autism and autistic people.

To make our land of “what if’s” a reality, we must insist that our scientists and clinicians, at every level, engage the input and work of our autistic citizens and exercise some self-reflection into the bias that exists within all of us, for as Darwin said,

*“If the misery of our poor be caused not by the laws of nature, but by our institutions, great is our sin.”*

So to just make it clear, at the time of this writing in October 2007:

1. There is no scientific evidence that diets and biomedical treatments work to either “recover” or “cure” autism;
2. Science has tested the autism and vaccine theory, and there is no evidence to support that vaccines cause autism;
3. Finally, no credible scientists will say that there is autism “epidemic.”

### **Let Us Stand With, Not Speak “For”**

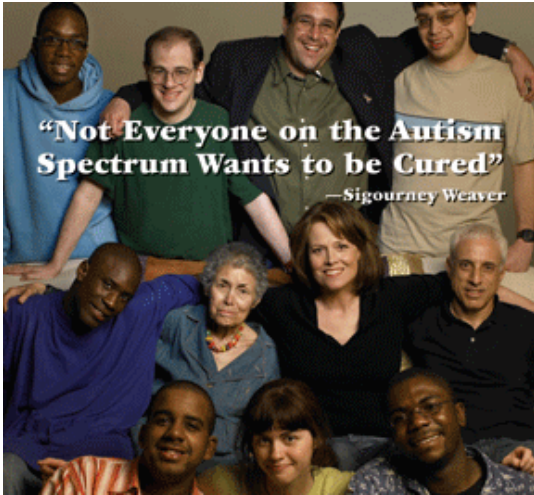
#### **Together,**

**We must rally for the accommodations, education and the supports autistics need while valuing them as autistic people. We must do so by including autistic individuals in the process and by engaging in language and with attitudes that reflect our respect for human dignity – embracing the difference AND equality of all persons in our society.**

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<sup>49</sup> The Mismeasure of Man, p.25.

As far as celebrity endorsement goes, I support Sigourney Weaver, who recently had her photo taken alongside autistic folks at GRASP in New York. The poster reads, “*Not everyone along the autism spectrum wants to be cured.*”



It is an example of what our leaders and celebrities *can* do: **instead of purporting to speak for autistic people, let us, as non-autistic people, stand beside and with them. Let us become allies.** As autistic self-advocate Phil Schwarz has alluded in his writings about autistic “allies,” there is room for many more of us.

As I envision Adam as an adult, I hope there will be many more of you who will stand with him, and value him. I am so grateful to the autistic adults and youth who stand up against adversity, for it is you who pave the way for my son’s future. He is, after all, my real star. I want him to live his life peacefully, without the constant bombardment that the sole purpose of his life is to only become like others. I watch his sweet smiling face in his new school, as he focuses on his work. I would hate for all his hard work to be funneled into “becoming normal.” It seems like such a waste of not only time, but of human potential.

***Estee Klar-Wolfond is the founder and executive director of The Autism Acceptance Project and a writer and public speaker. Most importantly, she is the mother of a wonderful son named Adam. This essay was part of a keynote address at AutCom in Edmonton, October 13, 2007. Please do not reprint this article without permission from the author: [estee@taaproject.com](mailto:estee@taaproject.com).***