

THREE CORE VALUES IN TEACHING AUTISTIC INDIVIDUALS: VALUE, SHARING, RESPECT

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Introduction

While autism is a neurological disability “has attracted many theories concerning its basic nature and numerous claims for therapies or teaching approaches that offer THE solution,” (Jordan, 1997)ⁱ, my thesis argues that we must take into an account the “autistic way of thinking” (Jordan, Mottron, Dawson, Gernsbacher et al)ⁱⁱ, that forces us to reconsider our notions first about what autism is, and then how autistics perceive information. By adhering to three core values in approaching the autistic learner: sharing, value and respect, we will be better equipped to reflect as parents and teachers to the efficacious pedagogies and overall treatment of autistic people as whole people, despite the level of disability. The goal should be to work effectively *with* autism and not against it, while understanding its constraints so that autistics can progress and contribute to society as *autistic* people. By **valuing** the autistic perspective, I argue we can do more for autistic people.

Initially searching for the “one” methodology to help “recover” my son's autism, I instead discovered that autism is his “way of being,” and by respecting the autistic style of learning, I could not only teach to Adam's abilities and interests, but also learn more about how he sees his world. This lesson in “reciprocity” (Gernsbacher, 2006)ⁱⁱⁱ, or **sharing**, improves our ability as non-autistics to assess ourselves and our preconceptions in relating to the autistic person, in addition to considering how we may impose our perceptions in our lesson plans. **Respecting** the autistic learning style and re-assessing and evaluating these preconceptions has clearly been the key to success in interacting with, and learning among, the autistic population. In short, the onus is on the non autistic teacher and parent to reciprocate by listening, learning and self-reflecting.

By culling existing methodologies without adhering to one; while learning to understand autism through cognitive ability research and sensory perception in autism, supported directly by experiential evidence from autistic adults, I have come to understand how Adam learns about himself and the world as he continues to progress and thrive.

There are attempts by all of us non autistic individuals to decipher the language of autism, and to employ “strategies” that “pull” the autistic individual “into our world.” The disability rights movement, alive and well online and in universities around the world despite little public knowledge of it, forces us to consider the ethical questions regarding the “treatment” of autistics. The movement suggests that we must work harder as non autistic individuals to include autistic members of our society as teachers in our classrooms, as scientists (see Michelle Dawson's work at University of Montreal)^{iv}, as people who are not just fascinating for us to watch or listen to, but to welcome fully into the fold of autism education. Currently in autism practice, this is not done to the extent that is needed. We do not listen to autistic individuals as *the* experts on themselves, but rather, keep deferring “expertise” to non autistic researchers and clinicians.

Do We Value Autistic Intelligence, Perception, Learning and Autistic Individuals?

Although I knew nothing about autism at the time of Adam's diagnosis, other than what was mentioned by popular media, I learned quickly that the space of autism today is largely negative and frightening. While I haven't escaped unscathed, I quickly regained the experience of joy with my son, perhaps because of all these experiences, and because he *is* a joy, a cherub, my long-awaited child. I gave birth at thirty-seven because Henry, my husband, already had four children who were young and needed attention prior to Adam's birth.

Adam was a sensitive child. When he was born, his eyes were wide open, darting around the room and he didn't fall asleep for nearly thirty-six hours after his entry into this world. He was happy, he could imitate me and at three months, could already say hello in a melodic way. He didn't sleep and we still occasionally have sleep issues. It took nearly three years before he could get through the night and he seemed to cry all the time. By nine months we noticed his fascination with moving images on the TV, with books. By eleven months, he knew his alphabet and his numbers up to ten. Henry thought he was "a genius." He said, "I've never seen anything like it before," he said, as he tested Adam's skills at identifying numbers and letters randomly, before Adam could even walk.

After we concluded Adam's first birthday party where he ignored the guests and preferred watching *The Sound of Music* throughout the festivities, and while Adam outlined the sharp shadows cast on our living room floor by the four o'clock sun with his hands, my husband's tone had changed: "I think there's something wrong," he said, to which I angrily replied, "there is nothing wrong with my child." Little did I know that, despite all the doubt since then, and sometimes even now, I would come to think the same about Adam today. He is now five.

It took us until Adam was 18 months of age before we obtained an autism diagnosis. It was the day that I will never forget. Some call it D-Day or "diagnosis day." The diagnosis changes the pace of time and the shape of dreams. Doctors, newspaper articles, all about autism were beginning to form an imposed identity for my child despite the fact that he had never changed. While it scarred and confused me at first, it also made me angry. All of this talk and urgency was distressing -- I was working against the joy I felt for my child, thinking that I had to work to beat his autism against the clock. This desperate "race" changes the nature of the interaction with your child. Further, as Adam and his autism were being described as a "burden on society," a "horror" and a "living nightmare," and our famed Canadian doctors and North American therapists viewed him as a pathological specimen, I became very unhappy so I turned to the work by autistic people. Then I began to write, curate exhibitions of autistic artists, and talk about the disconnect between how we view autistic people against, this language of devastation which is used regularly in representing autism at all levels of society. It is interesting that despite Adam's affection, his ability to learn without instruction which is common to many, that society still refers to autistics as "not aware," and "in a world of their own." Perhaps it is the other way around -- we are in our own non autistic box, and we are intolerant of difference.

Jim Sinclair, an autistic man who lectured last October at the *Joy of Autism: Redefining Ability and Quality of Life* event in October 2006 in Toronto calls autism a "dissonance of skills." No one questions that autism is a disability that requires accommodations and assistance. Paul Collins from the book [Not Even Wrong: Adventures in Autism](#), also notes this "dissonance" as he humanizes autism:

"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 is 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."^v

In autism and dis-Ability, representation and referencing matters. It changes the course of education and lives. It will result in either a periphery understanding of autism that will result in a poor quality of services or create a desire for an authentic understanding of autistic individuals -- where we simply include and listen to all members, no matter what level of ability into society. Valuing our autistic members does not mean we relegate human worth into high and low functioning.^{vi} The science is growing to support the abilities and enhanced perception in autism at The University of Montreal and University of Madison-Wisconsin.^{vi} There are autistic activists all over the world who have written a petition to Autism Speaks called **Autism Speaks: Don't Speak for Me**^{vii} and a petition to the **National Institute of Health**^x -- all seeking to redefine the terminology and description of autism with less reference to impairments and deficits and more to the diversity of autism, its abilities and difficulties. Soon, the concepts of high and low functioning and "spectrum" may be obsolete in referencing autism as the science is showing that difficulty with daily self-help skills, or the fact that one is non verbal, has no bearing on intelligence. Yet, the fact that some are non verbal rushes many to the assumption that many autistics have no cognitive ability. Studying the appropriate ways of measuring autistic intelligence has found that all kinds of autistic individuals have superior problem solving and cognitive skills:

These are the Raven's Progressive Matrices data...They draw attention to the fact that there should be a lot more caution than is currently the case, when making assumptions about what autistics can or can't do. Some serious rethinking is necessary, about intelligence in autism and possibly intelligence in general. Our data demonstrate that areas that have been presumed to be dysfunctional in autism (e.g., fluid intelligence, high-level abstract reasoning) are instead strengths. We have called into question the basis for dividing autism into presumed "high" and "low" functioning.^x (Dawson, Autism Crisis Blog)

Many people in our history have been speculated autistics. Albert Einstein, Isaac Newton, Ludwig Wittgenstein, Hugh Blair, Hans Christian Anderson, Béla Bartók, Glen Gould, Thomas Jefferson, James Joyce, Michelangelo, Alan Turing, Andy Warhol, are pretty much accepted historical autistic people, based on their biographical data and work. (Michael Fitzgerald). These people are accepted by the culture of autism (meaning autistic people) as being one of them. Phil Schwarz, an Asperger's father of an autistic son writes:

"Discovering and recognizing kinship with historical figures sharing traits, sensibilities, and struggles, is not just about finding role models -- it establishes a history, a community-through-time, and the reclamation of a shared cultural heritage...."

Is there such a thing as 'autistic culture?' I think there is, as much as Deaf culture or gay culture. There is a population of fellow-travelers who, despite often wide diversity, share experiences, values, sensibilities, struggles, a growing lexicon, and an emerging history."^{xi}

Amanda Baggs^{xii}, recently on CNN is a non verbal autistic woman who I know personally. She is diagnosed as a non verbal, low-functioning autistic woman who uses a lap board with

a voice synthesizer. I can barely keep up with her intellectual rigor. Stephen Hawking is an example of what exists beyond what we can see. He is an example of how we must work to find the right technological and other accommodations in order to provide communication outlets. However, by doing so, we are not de-valuing autistic language, we are simply building bridges. It is a sad fact, however, that much of our society still do not understand people like Amanda, or Larry Bissonette, or Jonathan Lerman and call them "savants."^{xiii} While it is true that there are some autistic savants out there, the ability to converse or type is not an indicator of savantism. Such categorizations may inhibit the likelihood of non verbal, "low-functioning" autistic individuals from receiving the training they require in augmentative and technological communication quickly enough. DJ Savarese a non verbal "low-functioning" autistic young man, in his father's book Reasonable People: A Memoir of Autism and Adoption, notes that time was wasted teaching him skills, when what he really needed was to be taught how to "talk, read and write."^{xiv}

Today, I continue to learn how autistic and disabled people feel about how they are referred to by the rest of society and how they have been treated in institutions, by doctors and social service providers. My Adam is a part of this autism culture. How can I stand aside and let others make disparaging remarks about him and his people, which is representative of all of us? The test of humanity is reflected in how we treat society's most vulnerable citizens. We have a responsibility to view the dis-abled as dignified and deserving citizens. If we take up the responsibility to serve them, then we must do the work to understand not only what exists, but what we cannot see.

Devaluing Autistic Individuals in Marketing and Media

Our current marketing strategies are not only harmful to autistic people but to the fate of all mankind -- from lobbying in a desperate way for specific autism "treatments," to speculations on the causation to autism, to our efforts to prenatally screen for autism in the name of "better interventions" -- the way in which autism is presented largely excludes autistic people and what they have to say about autism. I suggest that, even when it looks good, or benevolent, we *must* look deeper -- that we are facing an ethical crisis in the manner that we *regard* autistic people as not even human or a sub-species of human as a result of such indolent and adverse referencing. Instead of focusing on the human spirit and an inclusive community -- ways we can accommodate and assist as opposed to remediate and correct -- we have learned to legitimize marginalization as a cost-effective strategy, and we might need to reconsider the legality in referring to the costs of being human, especially when considering the disabled and how they were treated historically. As a mother of an autistic child, I believe we must work harder together, to discover how we can positively obtain the accommodations and services that autistic people need throughout their lifespan and across all levels of disability, in addition to achieving compassion and support that families require. One does not need to come at the expense of the other. This, if it is to respect the human spirit, must be done through a means that values and respects the dignity of autistic individuals as whole, and entitled members of society.

Walter Lippman, (d.1974) a New York journalist of German-Jewish descent, did not assume that news and truth were synonymous. He said,

"The subtlest and most pervasive of influences are those which create and maintain the repertory of stereotypes. We are told about the world before we see it. We imagine most things before we experience them. And those preconceptions, unless education has made us acutely aware, govern deeply the whole process of perception."^{xv}

Probably like most people, I had a preconception about autism from what I had seen in Hollywood, and the notions I held about disability in general from the media. I had no previous affiliations with this community except the boy Casey who lived down the street whom my group of peers ignored, or the brief time I was a camp counselor and was asked to look after the children in the segregated group with cognitive disabilities for a couple of hours (I was unknowledgeable and thus overwhelmed). So many times, disabled people were not around me. When they were, I can only recall these two instances in my childhood. The segregation of people with physical and mental disabilities does not help bridge our understanding, but instead, allows our perception of disability to be skewed if not totally inaccurate. The segregation and marginalization of these communities occur as a result of these shallow perceptions and arms-length media fascinations.

Our over-reliance on fast media messages and summarized factless fact sheets ^{xvi} prepared by special interest groups, is an example of how the public not only prefers condensed information, but also easy solutions, even if deadly ones as there is little public reflection about ethics. Where people and ideas can be reduced to mere symbols, and sound bites, we defer our ethical dialogues and our social responsibility to an elite group (be they researchers, academics, journalists, lawyers, and other professionals, some of who are bias about disability to begin with), at our peril. Consider, for instance, the puzzle piece as a fundraising symbol and “awareness” symbol for autism when autistic people say adamantly “I am not puzzle!”^{xvii}



How much, as parents, should we be working to understand disability and listen to the messages of a community to which our children belong, in the context of how it affects stereotypes and the lives of our children?

Society believes that disability is one of the worst plights of human existence. In response, society has come to fear dis-ability (or to become dis-abled), avoid it, pity it, “treat” it in order to normalize it, or tragically, euthanize it. In history, we have involuntarily institutionalized and sterilized disabled individuals in the name of “progress.” A February 2007 issues of *Genewatch*, as well as many writers, see this as no different than and expedition of a new, more sophisticated, eugenics movement.

These messages illustrate several things: first, we fear disability of any kind; second, we do not understand disability as the disabled community communicates it; third, we exclude the disabled communities, in this case, autistic people, from the policies and committees that affect them directly. All of this suggests that we do not truly value

disability or the autistic individual. We portray autism as a fate worse than death, despite how autistic people feel about such portrayals. One must ask how this effects then the way we not only view autism, but how it effects the way autistic individuals are taught through “therapies” and in the classroom.

Margaret Somerville makes note of this “determination of human worth” regarding New York Times writer Peter Singer, also an ethicist who was in favour of the Ashley Treatment. In contrast to Singer, she states that human worth should not be relegated to personal value judgments. Regarding an underlying principle that we must work for the common good in these discussions, John Ralston Saul says, “we seem to have lost the ability to agree that anything is inherently wrong, that is, wrong no matter how much good can come from doing it.”^{xviii} She also uses dignity as a guide to good ethics when she makes reference to Singer’s “bad ethics”:

“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 as we do on humans. Humans are not special in any relevant sense and thus not deserving of respect different from that owed to animals. So if you can redesign your dog, why not your disabled child?”^{xix}

Perhaps it is as simple as when Sophie Scholl, leader of the White Rose Resistance Movement in Nazi Germany, when she says, “every life is precious.” We might consider it as our guide in valuing all autistic individuals.

Sharing: A Lesson in Respect

Dr. Morton Ann Gernsbacher’s paper titled “How to Spot Bias in Research,”^{xx} indicates that by virtue of being non autistic, we have much bias in our research and this negatively effects how autistic individuals are treated. She suggests we put ourselves in the shoes of the subject to whom the terminology applies.

“We test our writing for bias by substituting our own group for the group we are discussing. If we feel offended, then our writing is biased. I recommend we test our interpretations for bias by peeling off the labels. If our interpretations make little sense, then our science is biased.”^{xxi}

This is in keeping with definitions of prejudice as defined by Professor Emeritus Bernard Lewis when he states that prejudice occurs when we apply a different set of standards to one set of people over another.^{xxii}

I believe we can use such notions to the practice of teaching autistic people. If we continue to consider that “being normal” is the goal to teaching, we are neither respecting or reciprocating. Rather, as Sinclair writes in his essay *Don’t Mourn for Us*: “Be still and listen and you will discover a world you could have never imagined.” Dr. Gernsbacher, in her presentation in Toronto titled “Towards a Behaviour of Reciprocity,” showed a video of a therapist who tried two methodologies: the first was to try and get the child to imitate and comply using typical behavioural strategies. The child did not respond “typically,” but instead continued to play with an object that he shook in front of his face. The therapist then fell silent. She sat beside the boy, picked up a similar object and mimicked the actions of the child. The child became interested in the therapist. They continued in this way for a while,

doing a variety of things lead by the child. The therapist concluded the session by going back to a couch and sitting silently with her body still, expressionless, and hands folded in her lap. The child approached the therapist, sat beside her and looked at her straight in the face. This communication was to obviously prolong the interaction. This example shows not the goal to make the child “normal” – to lure them into “our” world, as it were. Rather, the interaction shows us the value of reciprocity, of sharing the child’s experience and may serve as step in understanding autistic “language” and autistic socialization. The therapist crossed to the child’s side. Sometimes we ask the child to cross to our side, and most times we must meet in the middle. Perhaps this is the social compromise that we practice everyday but take for granted, and we certainly do not extend its graces with more deliberation in autism. We are so busy teaching with typical developmental tests and within milestones that do not necessarily fit the learning style and development of the autistic individual. As Michelle Dawson, an autistic woman and researcher at the University of Montreal states: you cannot perceive of an autistic individual as a person upon whom you stick on or take away abilities and deficits. You cannot view autism ability as the “other side of the coin of autism pathology” as Dr. Peter Szatmari has suggested.^{xxiii} In sum, Dr. Laurent Mottron in support with other autistics and non autistics, postulates that an autistic is another species of human – not alien. He says: “a dog is not a negative of a cat. If we thought of it as such, the dog in the cat world would be considered a genius at fetching slippers, but have deficits in climbing trees.”^{xxiv} Further, the scientific definitions of “delays” are relative to the assessment process – that if given the appropriate assessments to measure autistic intelligence instead of administering ones that measure autistics against the non autistic population, the referencing will be different.

The new knowledge and approach to autism will have profound effects on how we teach and understand it. It will ask us to listen and reciprocate more, in other words, to learn the autistic style of communicating and learning. We are learning that autistics, even if they are non verbal, are “there” and “aware.” Do we have the right to refer to them as a devastation? What are we trying to accomplish and what are the ethical questions we must be asking in light of a rampant movement for equal rights by the autistic community (meaning autistics) who say that their autism is part their identity. Most importantly, what part of the mystery of life do we preserve when we can now control it more than ever? The confluence of scientific knowledge plus the awareness of autism, is the ethical issue at hand. Our future ability to screen for autism raises all kinds of questions about what we may stand to lose. It asks if there is enough understanding about disability overall. In the little room with the genetics counselor, there little regard and discussion about quality of life with disability. We simply assume that there is none despite testimony from disabled individuals and many of their families that their lives are of no lower quality than others.^{xxv}

There are educators and researchers who can appreciate this autism culture, and the many dimensions of autism – where the goal is to educate the autistic person without seeking to ameliorate autism and while cultivating inclusion in schools and society. This is not to say that we don’t want to alleviate some of the stressors of autism – one must ask the question of whether intolerance, and an unaccommodating society is a contributor to the cause of anxiety. Professor Rita Jordan and Stuart Powell in their book, Autism and Learning: A Guide to Good Practice, say that knowledge of autism as a medical condition is insufficient to ensuring good practice in education. They say that “special needs should not be just reflected in delays or defeats in relation to ‘the norm,’ but in a radically different way of thinking and learning”:

We would suggest 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 so that behavior is not

misinterpreted and the children's difficulties and strengths in particular contexts (their special educational needs) are understood. Yet it is here that there must be an interface with 'good teaching.'^{xxvi}

I would like to extend this concept of 'good practice' to teaching in autism, to 'good practice' in representing and talking about autism, as a way of dealing with not only important educational consequences, but humanitarian ones. Is the way we represent autism in the media 'good practice'? Does it reflect autism as a diverse condition that is a challenge best described as an ability and disability or a dissonance in skills, rather than an aberration or human pathology? Does it support and respect parents AND autistic people? In short, to take the words again of Margaret Somerville, does it cherish human life and protect human spirit? Does it hold a fragile life gently, safely and protect its mystery?^{xxvii} If there is any 'evidence of harm' (a play on words from David Kirby's infamous book), it lies in our behavior as parents, researchers and clinicians in trying to remediate autism at any cost – steamrolling forward without a discussion about ethics.

Our behavior is influenced by non inclusive use of language, or biased language. Rosalie Maggio, author of The Bias Free Word Finder: A Dictionary of Non Discriminatory Language, says, "while many will disagree that language will change behavior, it might alleviate the pain that non inclusive language has on a person with a disability."^{xxviii} I would like to think that the way we use language in reference to people with autism has profound effects on how we deal with autism. When a word becomes an epithet, endowed with tainted meaning - 'I'm acting autistic today – or 'autism is devastating,' it represents how we think about something. In our society, representation matters.^{xxix}

Conclusion

Consider Peggy Lou Morgan's introduction to her new book, Parenting Your Complex Child,^{xxx} where she references life with a complex developmentally disabled child like a war with many battlefields, the first being dealing with the agitation and frustration of the child caused by inappropriate programs in school, schedule, or a child's confusion about what is expected of him. She illustrates the homefront being a deluge of frustrated, sometimes aggressive responses to school and other problems, and often manifests in sleep problems. Her "Battlefield Number Two" are the schools and agencies wherefrom parents not only try to obtain services, but where the bottom line dictates the quality of those services as well as the time the agency spends with the family and in understanding the child. The third "Battlefield" is going out where there is limited access, or when people stare and impose their unfair stereotypes. I don't think there is any parent, dis-abled individual, or autistic person, who has not encountered the same feelings -- that it all seems like an uphill climb. Not only is it imperative that we regard autistic individuals and the families who care for them with the utmost of respect, we must do it authentically and whole-heartedly. We can learn to create and adapt a life that works for our children and our families. We are entitled to the education and services that serves the uniqueness and individuality of a diverse autistic population. Advocacy must include an acceptance of such diversity, a need for understanding, inclusion, access, and a steering away from a "one-size-fits-all" approach to autism education.

In summary, I have included the points I believe should be part of the journey to good practice in teaching, treating and referencing autistic individuals:

- The inclusion of autistic people/voices;
- Reflect autism as a diverse condition that has strengths and challenges;

- Discuss and teach autism not as defeat in relation to “norm,” but a different way of thinking and learning;
- Put the onus on non autistic service providers to understand autism and learn its language;
- Use inclusive language in referencing autistics, instead of exclusive;
- Diligently use humanitarian references instead of dehumanizing ones;
- Conduct ethical discussions regularly at all levels of society and professional circles;
- Protect the “mystery” of being human: LIFE

If one child can teach a mother one of life’s biggest lessons, then surely, our autistic population can serve to teach us all what it means to be human.

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