

Estée Klar

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Upcoming Events

Filed Under ([EVENTS](#)) by Estee on 05-07-2014



I will be on the panel with the [De Veber Institute for Bioethics and Social Research on autism](#) this **Thursday, July 10th at 5:30 p.m. at 280 Bloor Street West in Toronto**. I hope autistic self-advocates will register early as well as those involved in Critical Disability Studies.

Also, stay tuned for more details on a screening of [Wretches and Jabberers](#) and a talk with the subjects of the film, Larry Bissonnette and Tracy Thresher; autistic self-advocates who type. This will be presented **at York University on October 24th** and also sponsored by [The Autism Acceptance Project](#). Stay tuned for another event in downtown Toronto on October 25th!!

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[The Hunt for Humanity? Some words for Ivan Semeniuk, Dr. Stephen Scherer and Dr. Mohammed Uddin](#)

Filed Under ([Discrimination](#), [Eugenics](#)) by Estee on 29-06-2014

I came by your article in Canada's **The Globe and Mail**, *The Hunt for Humanity*, printed on June 21st, 2014, a little late. To recap for readers, you suggest that your project, Brainspan Atlas research at Toronto's Sick Kids Hospital (Dr. Scherer works in Toronto and Brainspan Atlas is located in Seattle) explores the exons – the series of “segments” (including introns) that make up the human genome, are involved in human evolution. In this exploration, Dr. Uddin, a computational biologist and geneticist, sits to author the computer code comparing the relationship between “sequenced exons from thousands of apparently healthy individuals” (Semeniuk, Globe Article) and those with “mutations.” Dr. Uddin looked to Brainspan Atlas data on exons “that were rarely mutated but highly expressed during brain development” and “filtered out” to *distill* the genes suspected of having a connection to ASD candidates – finding some speculated connection between exons and these genes which both Uddin and Scherer now study.

Without delving into the “science” of their work, let us consider the premise, for few science writers will begin any article with a discussion of ethics and disability. Interesting because when we read articles in the Globe and other news sources, one can't write an article about autism or disability and ethics, without getting some remark from a neuroscientist or geneticist (I am leaving the rest of this sentence for the reader to fill). No...Dr. Scherer believes in [natural selection](#). He says, “natural selection has sculpted these genes by tweaking their expression in the brain” (Globe). Darwin's theory, adopted by Sir Francis Galton in 1883 laid the groundwork for an entire movement that institutionalized and segregated many from society and was the basis for the eugenics movement which separated people by their supposed “genetic soundness.” This was also the premise by which the Nazi's killed the sick, mentally handicapped, and the elderly (before the Jewish population). One need only a lesson in history, picking up original text from the period to compare the language used by Semeniuk, Scherer and Uddin to see that the people involved in this project may be treading too close to a history we must not repeat. Terms used throughout the article such as comparing autism as a mutation – using the binary of health versus mutation or worse not human (this was implied throughout) – are dangerous in that they sway, with their power of position, the general public to believe that autistic people are less than human. The entire article does more than insinuate that autistic people are not human.

Says another doctor cited in the article, Dr. Varki, “**...the children of a mating between humans and Neanderthals may have been physically healthy but ‘cognitively sterile.’ The disadvantage of losing the uniquely human genetic package, even to a small degree, would have conveyed a tremendous cost in terms of social interaction and reduced their chances of reproductive success**” (Globe article).

The language throughout the entire article (if you can get your hands on it as *The Globe and Mail* now has a subscription service online), it is rife with dangerous language. Autistic people are compared to “non human” species. But worse, as I find with many neurologists and “autism experts,” there is a gross lack of knowledge about autism from autistic people and the people who live every day with the label, and the challenges of being different than what is supposed to be “normal.” This was very apparent throughout and also at the end of the article when Semeniuk writes:

“For Dr. Uddin, who has grown increasingly aware of the burden carried by those with ASD since coming to Sick Kids, the payoff comes from watching his ideas and his number-crunching materialize into something that may improve lives...” These kids often don't talk to anyone, or have any way to express their concerns,” he says. ‘As a researcher, I want to help if I can. It's us, as a society that has to come up with our own understanding of how to approach this.’

Along the way, the bonus prize may be the ability to see what it is that compels us to connect – to get inside each other's heads – in a way that no other creatures seem to do” (Globe article).

I'll assume, Ivan Semeniuk, you are meaning that only humans communicate, and those who do not are not human? Have you met autistic people? Have you talked with them? Have you connected with any of them or have you avoided contact (or insisted that it only happen on your own terms)?

I'm asking questions here that must be asked of everyone involved in this field. I'm often surprised at how experts haven't met many autistic adults, or read their work. This seems to me to be a prerequisite if you state you are going to work in a field, that you get to everyone who has a stake in the outcomes of your work.

Can you see how my son is very social and just this past week, despite his struggle in forming words, has gone with his friends to the Science Centre, the farm, out to restaurants and has been happy in being with his mates? Have you seen an autistic person, Dr. Uddin, not be able to form words well, but can express themselves with alternate communication? Have you seen an autistic person type cogent sentences at the same time making supposed inarticulate utterances? Have you investigated the actual fact that the two occur simultaneously? How important is rhythm and support to the ability to communicate and what must we all do to appreciate the many ways of being human (certainly not a natural selection theory). Mr. Semeniuk, I'd love to talk with you about research and critical theory on linguistic theory and what I call the *language prejudice*. This prejudice assumes that if you can't speak, you don't think or don't understand, which of course is not true. It might provide a more well-rounded article on autism, ethics and the prejudice in society about autism that we all must avoid.

This, by the way, is a first draft, unedited. I am writing from my mind and most importantly, my heart as both a scholar in the field of critical disability studies and a mother. I look forward to dissecting genetic science (and your work) and the **premise of discrimination**.

If you want to read the article, [The Globe now makes you pay for it](#).

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[**A Better Autism Awareness Month?**](#)

Filed Under ([Ableism](#), [Acceptance](#), [Accessibility](#), [Activism](#), [Advocacy](#), [Autism and Employment](#), [Autism and Intelligence](#), [Autism and The Media](#), [Behaviours](#), [Contributions to Society](#), [Critical Disability Studies](#), [Diversity](#), [Inclusion](#), [Institutions](#), [Uncategorized](#)) by Estee on 08-04-2014

I've been sitting back and watching. While not all things are perfect, I have to recall what it was like in Ontario 12 years ago when I was first introduced to this social phenomenon called autism. CNN had numerous reports on the "epidemic" of autism; the MMR vaccine was blamed; there were numerous reports of questionable remedies that put autistic children in harms way; there were hate blogs written about autistic people and parents who wanted to love and support their children. The blogosphere was not yet syndicated and contained burgeoning home-made blogs by people labeled with autism and we learned a lot from autistics who wrote them – about activism, identity, the right to be who we are in every neurological way. Indeed, neurology is a term of the times which has redefined difference (neurodiversity). Although this is critiqued by many of those belonging to the disabled community as the new normalizing term (**Lennard Davis, *The End of Normal: Identity in a Biocultural Era*, 2013**) thereby losing its utility, I suppose I belong to a group who believes that we might not have gotten to this place of questioning, and beyond an institutional disabled identity (i.e. segregated and isolated), without this renaming and reconceptualization. To further highlight Davis' important question:

“If we are now living in an identity-culture *eshatron* in which people are asking whether we are ‘beyond identity,’ then could this development be related in some significant way to the demise of the concept of ‘normality? Is it possible that normal, in its largest sense, which has done such heavy lifting in the area of eugenics, scientific racism, ableism, gender bias, homophobia, and so on, is playing itself out and losing its utility as a driving force in culture in general and academic culture in particular? And if normal is being decommissioned as a discursive organizer, what replaces it?” (Davis, 1).

Davis argues that diversity has become the new normal. He also makes an important point that there are some people who do not have a choice of identity, which, in my words, may dampen the concept of diversity for our community. In particular, disabled identities are not chosen. Perhaps we now have to think beyond identity and challenge the concepts of acceptance and community in a world where these lines are always expanding and contracting.

That said, I remember what my introduction was to autism. Mothers and fathers before me remember institutionalization. Parents advocate for a world where autistic children are accepted, *even if* in a neoliberal paradigm (in other words, while we can see its shortcomings, we still do many unpleasant things to survive). It seems the “strengths” of autism at least are earning a place at the employment line, which then perhaps allows our children to get an education and better services. Perhaps our kids will be understood for their sensory, communication and social issues and not be reprimanded or judged for them. All these seem like good things. I would like to imagine a world where we *never forget* – where many of the younger generation of ABA therapists and teachers have no recollection of “different” kids in their neighborhood suddenly disappearing. There is work to be done to educate people working in the field on the history of disability and institutionalization and how close we always seem to be to doing that again. Must we continue to ask why this is happening despite the advocacy for autism acceptance?

And finally, in Davis’ words:

“There is a built-in contradiction to the idea of diversity in neoliberal ideology, which holds first and foremost each person to be a unique individual. Individualism does not meld easily into the idea of group identity. And yet for neoliberalism it is a must. In a diverse world, one must be part of a ‘different’ group – ethnic, gendered, raced, sexual. It is considered boring if not limiting, under the diversity aegis, to be part of the nondiverse (usually dominant) group. So diversity demands difference so it can claim sameness. In effect, the paradoxical logic is: we are all different; therefore we are all the same.

The problem with diversity is that it really needs two things in order to survive as a concept. It needs to imagine a utopia in which difference will disappear, while living in a present that is obsessed with difference. And it needs to suppress everything that confounds that vision. What is suppressed from the imaginary of diversity, a suppression that actually puts neoliberal diversity into play, are various forms of inequality, notably economic inequality, as the question of power. The power and wealth difference is nowhere to be found in this neoliberal view of diversity.... **Ultimately what I am arguing is that disability is an identity that is unlike all the others in that it resists change and cure...disability is the ultimate modifier of identity, holding identity to its original meaning of being one with oneself. Which after all is the foundation of difference.**” (Davis, 13-14).

While I acknowledge Davis, I find myself thrust into an acceptance paradigm that allows Adam to be in a classroom and in the community, however imperfect (requiring time, exhaustive and emotional effort, Adam’s emotional effort and his ‘trooper’ ability among it all) – and all of this based on proof of competence and ability as he counts money so fast that the adults in the room have to check to see if he’s right (he is). I think it is great if we can enable others to see autism as a way of being in the world – sensory difference as not behavioral belligerence; non-verbal disability as not an unwillingness to speak or non-intelligence. To go on: not looking at someone when they are speaking doesn’t mean that the autistic person doesn’t understand what is being said; not wanting or able to be social should not be isolating or a reason to segregate nor a reason to push one to be social

just like everyone else. (So what I'm saying is that as activists and/or advocates, we are still at this place). There are still so many misunderstandings in a moment with an autistic person, and one hopes that this marketing will help. I mean, we all have to survive, right? Adam's survival is no different than mine except that he is at a clear disadvantage despite "neurodiversity."

While recent autism advocacy is far better than I can remember 12 years ago, it remains services and employment based (and I am not at all suggesting we don't need to do this important work to discuss services and accommodations past the age of 21...but we need to discuss this also in a much larger context). A discussion of the inequalities about which Davis and others speak must also be a topic to discuss the bigger picture of what we mean when we talk about inequality. Another part of this discussion might be to discuss all the the proofs that an autistic person has to demonstrate before earning a place at the school desk and in the boardroom – and a discussion why these suggest human value. These may not acquire the immediate services that people need but they are important to our evolution. We can do this while continuing to mine the various meanings of purpose.

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[Beyond Mall Therapy](#)

[Filed Under \(ABA, Accessibility, Aides and Assistants, Anxiety, Autism Theories, Autistic Self Advocacy, Behaviours, Communication, Community, Inclusion, Intelligence, Language, Living, Obsessions, Parenting, Safety, seizures, Sensory Differences, Transitions, Travel, Wandering\) by Estee on 21-03-2014](#)

I think many parents will agree that one of the most challenging things for families with autistic children are outings. Adam's anxiety and repetitive activities increase over his perceived threats and fear of change; he will need to check out the bathroom in every restaurant; know where every door leads. This of course makes outings difficult, and it has a lot to do with impulse. At this point in our lives, Adam has been exceptionally tense – and I want to add that this coincides with his development, awareness and abilities too. This is a really important point to make up front in order not to treat behaviors by redirecting them in meaningless ways (such as touching your nose to replace a hair-raising scream...this will just piss Adam off). One of the dangers with partially-verbal or non-verbal people, as we know, is that when behaviors start, there is a propensity to exclude or treat the autistic person as if they are not aware of what they need, or what they are doing.

This is where adaptive communication has become very helpful for us since November. Adam has been typing for many years, but most ABA schools will not support supported typing – this is so problematic for folks with movement issues which Adam expresses – Tourettes tics, seizure-like episodes (and seizures are much more complex than one initially thinks), and “stuckness” which is catatonia. These are some of the reasons for speech impairments in many folks – similar to aphasia. It's not that they don't think or understand or even “hear” what we say but rather the word-finding and expressive capabilities through speech are not available. However with typing, Adam becomes more fluent in his speech. With support, he becomes, eventually, a more independent typist. In the meantime, he writes, “my body is like an engine that doesn't run continually,” and despite that he can type some things independently he has asked for our support. To not give it to him is seen by many as immoral...something to think about in terms of our own learning in how to support people to communicate in order to hopefully become more fluent and independent. (While I have issues with this latter notion as a neo-liberal concept, I acknowledge we are swimming against a tide here and in order to survive, Adam has to work hard to prove himself...something else to think about in terms of how we treat the disabled).

So, to go out when a person has frequent anxious or bolting episodes (the fight/flight response as we know it), now requires perseverance, patience and planning, and a respect for Adam's ability to participate in his daily planning. It also requires our time in letting him assemble himself if he begins to meltdown. For example, while on our March Break at the beach, Adam needed to go the bathroom. If there is a loud hand-drying in the bathroom, he will become anxious and turn right around. This anxiety lingered after the visit, and he began to flop his body on the beach. I told him to keep walking and tried to distract him, but at this point, it wasn't working. I asked Adam to sit down until he was ready again to walk. As we did, we began to feed the birds. This made Adam happy and then able, after 20 minutes, to walk again.

Similarly, a week before on the same beach boardwalk, something triggered Adam and he wanted to urgently turn around. I could not understand what Adam wanted or needed so I asked him to sit down and type with me. This was difficult and he wanted to get up and bolt. I said he could not get up until we knew what he wanted. As he began to type, he was able to say what he wanted faster - "hot air balloon." At that point, I realized that there was a water tower that looked like a hot-air balloon far down the beach, however, I miscalculated just how far. As we began to walk, it was occurring to me that we wouldn't get there on foot. But Adam was so happy and relieved to be understood, and skipped merrily alongside his grandfather and I. I began to say to Adam that I didn't think we would get there on foot, so at this point I was able to negotiate with him that we would go to dinner first and then drive by the "hot-air balloon." Adam was able to have a nice dinner and also get to see his hot-air balloon on the drive home.

Today, my team are helping Adam on his outings with lots of preparation and photos and are working with me to practice outings with Adam in many places so Adam himself can feel more competent and less anxious. Every day while we were away, I insisted on taking Adam out, with someone with me for safety, because I fear that isolation is deadly. This is where mall therapy begins but also has to end - so often, we only see autistic kids in places where therapists feels safe, and this sadly restricts the lives of many autistic folks. Some parents might be afraid to be stared at in public. This is when it's better to have a card to hand out to people indicating that your child is autistic and you are working on outings. Or, if someone is exceptionally helpful, as I've experienced lately, send a thank you note if you can to support inclusion. While we may begin with mall therapy, we must move on quickly. As I was preparing Adam to see the animals today in the park, he typed, "seeing animals is getting very tiring," and he asked to walk and take the subway instead. This part of negotiation is also key to success for outings as people like Adam have a hard time advocating for themselves (although they do communicate with their behavior, which is largely viewed as maladaptive, sadly). I also have asked Adam how to support him in moments of need or meltdown where he wrote, "please be calm..." and indicated that these moments are also very embarrassing for him. In addition to a bag of tools he has to help himself and cognitive behavioral therapy (which, by the way, is typically used on people who are verbal and are deemed "high functioning"... Adam's ability to learn the concepts and techniques quickly rules out theories on HFA and verbal ability and the ruling out of such therapy for non-verbal people...I hope a researcher who presents at IMFAR will pick up on this as most of the people *used* in research study tend to be from the HFA/verbal group due to cost and time constraints...something to think about in terms of who we service, who we value, and how we treat autistic people).

So the question is whether the mall is used to simply used to truly help autistic people be included in the world, a step towards many outings and environments, or if it excludes people from being in the world. Yes, it's a challenge for folks, and in the end, a person decides for themselves where they want to be. But if Adam doesn't learn now as well as being able to advocate his choices while learning to negotiate with others, our lives will remain behind closed doors. While I know this is hard for Adam, I also know that he doesn't want this.

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[Moving along...](#)

Filed Under ([Adam](#), [Advocacy](#), [Anxiety](#), [Communication](#), [Community](#), [Inclusion](#), [Intelligence](#), [Living](#), [Movement Disturbance](#), [Obsessions](#), [Sensory Differences](#), [Transitions](#), [Wandering](#)) by Estee on 17-03-2014

There are times when you have to just stop everything. Adam has required it...his school has required it. A focus on Adam's typing and adaptations in school have alas been paying him dividends. Despite his want for escape, screaming and bolting, Adam has been in cognitive behavioural therapy and we've been working on his accommodations in school so much so, he is literally whipping through his academics – I know this is the tip of the proverbial iceberg. Sensory breaks every 20 minutes enable Adam to focus and he has an array of self-help tools he can now choose for himself to calm – from stretchy therabands (his fave), to signals that he can verbalize “the body needs to move.” His penchant for routine and doors is akin to panic attacks. It is important to give Adam concrete options to move from one thing to the next. His will is strong as is his intelligence and everyone who knows Adam must try to help him by staying two steps ahead of him at all times in order to respond. Or, as I do now, I also ask him what he needs:

Me: Adam, what I can do to help you around when you have the impulse to go through doors?

Adam: You can help by staying calm.

Me: What do you need?

Adam: Hard to move forward. Really hard to tell.

So we will work on it and Adam is beginning to communicate his more complex needs. Here in Florida (for Adam's March Break), the building security guard came by and noted when he saw Adam in a moment going through doors with his “help,” he could recognize it as a panic attack right away because as a young person he too had panic attacks. This is what is like for Adam when it's happening. For now, I ask him to sit down and try hard to get him to focus by typing. When he is able to think and redirect his thoughts to communicate, we can better negotiate our next steps. It takes time, so when we have an agenda, it just won't work. We need to be prepared to spend an extra 20 or 30 minutes helping Adam to the next step because he could be literally “stuck” in his loop/OCD and tics, or needs that long to get his words out. But when he does, it's so glorious to see him gleam with pride. It's so wonderful to be able to negotiate now with my son! Our days are more rigid than they used to be; Adam needs his routine. And I am finding the balance, and keep asking him for knowledge on how to help him. It's a team effort.

And as for that building security guard? Well, not everything has stopped...I began the **thank you-note project** – a new form of advocacy for Adam and autism. Every time someone helps in a positive way – by standing back and letting us be, to a nice gesture or comment, and letting us be a part of the community despite challenges, they receive a thank you note from Adam and I. People need to know they are doing the right thing by letting us be a part of our communities and advocating for what we need. It may not be a big glitzy campaign, but it's something that we feel good about... reaching one person at a time.

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[Parent/Teacher](#)

Filed Under ([Adam](#), [Anxiety](#), [Behaviours](#), [Communication](#), [Estee](#), [Language](#), [Obsessions](#), [Parenting](#), [school](#), [Single Parenthood](#)) by Estee on 07-01-2014

We begin 2014 anew. I have applied for a leave of absence from my PhD study to focus entirely on Adam's program. In so doing, I recognize I need time to energize myself and have some free time; this is not possible as a single parent of an autistic child if I don't cut back. So, at the end of 2013, I made the empowering decision to become a communications specialist and educator of my son. I'm making field notes along the way. I don't do this alone of course; it takes others to assist us. But in Canada where there is a lack of trained specialists in supported communication, this is up to me now. Thankfully I have other supporters and success stories including our own.

With the ice storm, a sudden move to a hotel due to the massive power outages in Toronto, the holidays and general upset at the end of this year, I may have fallen into one of my darkest places. I hate to see my son so upset, so less able to handle transitions. I realize I hate holidays too – there was too much expectation despite the fact that I know that this a sure way to fail. No way, no how next year. One modest dinner and one present... that's enough and that's lovely.

Of course, much of this has to do with my own resilience and preparedness. Sometimes, Adam requires more preparation than usual – more social stories, lists, repetition of what we are going to do next. He can be the kind of kid that seems to be rolling along quite well and then he needs exceptional support. Let's just say this past December he needed way more than I provided. School had exhausted me as well which didn't help. Writing about the philosophy of language and disability takes a lot of of one when a child's scream replaces words; they are more commanding. As soon as I turned my attention to helping Adam, he calmed down. His school assisted with what we call "operation calm down" and his environment, demands and work were all reassessed. For Adam, he requires proactive breaks every twenty minutes to return to his desk. His school has been most accommodating in helping to provide these breaks. Eventually, kids who are accommodated are often able to increase their level and time of focus as they mature. If there's one thing I never stop learning is that changing expectations means that you always have to reassess them.

Adam then had a long break (albeit the first half was stressful with the storm). When he returned Sunday, we had another cold weather, namely the "polar vortex." Schools were cancelled so I planned the day: a walk before it got too cold to go outside, art, reading and typing (I made a program for that), sensory swing, and computer. In between such a good day, Adam decided he wanted some pretend play so we went with that (lots of language there). There was only one incident when his grandfather popped by and then Adam thought he was going to "gramma's house." Adam will tend to want to do things that are routinized and when he found out he wasn't going, he screamed. I left the room and asked him to read a book to calm down. He did so in less than five minutes, which I thought was pretty good. When he was quiet, I returned to ask if he was feeling better, ready for another scream. None came, but it might have. I told Adam I'd check on him again in a few minutes.

When I did, Adam went through his lists when he knew "gramma's house" wasn't an option: "Brunos"(which is a grocery store), "Hero Burger...Burger King...Shoppers Drug Mart..."

"Adam, mom needs a break. I'm going to have a cup of tea," I said. I decided that bargaining wasn't going to get me anywhere and I'm trying hard to build Adam's "no" muscle. I sat quietly on the couch drinking my tea, expecting the whole while that another scream was possible. None came. Soon, Adam made his way up the stairs from where he was in the rec room, and lay flat in the hallway. I said nothing and kept drinking my tea. Eventually, Adam brought a book to the couch and sat with me. We got to the point where I could ask him what he wanted for dinner. If he would scream, I would have sent him quietly to his room not as a punishment, but so

he learns about self-calm and what I expect from him. There, he has more books to read, which I feel is a positive way to self-regulate intense emotions and which seems to work for Adam.

“Teachable moments” like these make me feel like a competent parent and teacher, and I think we all need to feel that way. I had prepared, I have been studying to make Adam’s programs comprehensive, and I’m becoming more prepared and working on the more difficult behaviours such as bolting, opening doors, and the so-called willfulness of puberty while recognizing that Adam might be confused and sometimes fearful – helplessly resorting to routinous behaviour in order to self-regulate or find order. It is my job to help him. This is what makes my days feel gratifying rather than worried about him while I sink my head in Barthes and Derrida. While I’m not going to stop reading and writing, I just am going to use what I’ve learned in theory and turn it into a practice.

Yesterday and this morning, Adam was beaming. He was happy to go back to school this morning. Starting next week, I get to teach Adam more communication, typing and literacy, life and social skills. I have begun my leave to do this work. I hope we both have a wonderful 2014.

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2014

Filed Under ([Academia](#), [Acceptance](#), [Anxiety](#), [Behaviours](#), [Communication](#), [Community](#), [Critical Disability Studies](#), [Inclusion](#), [Inspiration](#), [Intelligence](#), [Joy](#), [Language](#), [school](#)) by Estee on 18-12-2013

There are days when I feel so grateful for the support Adam and I receive from the team, friends and family. My university is so supportive of our needs as well, allowing me a leave so I can lesson-plan for Adam and train him more in language and typing. With support since he was around five years old, Adam is now somewhat independent when conversations are not that open-ended and unclear. I can hand him a keyboard anytime and he can type his feelings or what he needs sometimes faster than he can speak the words. I also learned that animating words makes them meaningful and is better than rote vocabulary instruction.

Adam, as a hyperlexic individual since we could hear him speak at 11 months of age, loves letters and words. I am going to work with my son’s strengths. In so doing, I am training others in the process. Others watch how I do this with Adam and also learn to do it with him. I have no formal training other than personal study and my PhD work which focuses on semiotics and language and disability. This is my passion because of my son.

Adam is heading into puberty and has issues with anxiety, but seems most frustrated at not being able to say what he wants to say. When he gets the words out, he says them forcefully, looking into my eyes and saying the phrases again and again until I say it back. He knows I’ve understood him. I think it’s the way he’s been treated all of his life by us jabberers (dominant ordinary language users) in that we tend to repeat ourselves to autistic people who have trouble with ordinary language because we think they don’t understand us. Adam is doing what we have been doing to him. When I say the words back, echo him, he is satisfied that his message is understood. Phrases like, “I can’t wait anymore!” can be met by me with an acknowledgement and a timer which settles his need to know how much longer he must wait for his desired activity or item.

Also, *operation calm down* has worked. Adam is happier, the screaming tics abated. Following the stress and episode, Adam always emerges with more sentences (communication). I've yet to hear anything from the neurologists on it, but we keep trying just in case. This is not to "cure" the autism as much as it is to ensure that Adam's health is attended to well; that we are not missing something. The health of the autistic person must be attended to as much as the non-disabled person. (Another topic about how to regard the autistic person might be better sought from autistic people themselves).

It was as if Adam was saying "please listen to me!" and we have. Some of it was because he didn't enjoy a transition and the team and I will be working on this all year. That said, Adam is fairly flexible all things considered. We haul him on our travels, and I plan on taking him on many no matter what. I believe in respecting his difference and limitations while also helping him through without pushing too hard some days and knowing when to push because those days are so apparent. He loves to be with other people and to see new things. He loves being out in the world and engaged. It's in the manner we engage him that is important to expand his horizons. I want to thank my university for supporting us in making this the best year for Adam and I. Without the understanding of schools and universities, we might never be able to do this important work that does effect so many people with disabilities in that not every year can be a consistent, machine-like operation. Sometimes we need to step back and focus on our children, or our own disabilities. I am overwhelmed by my school's support. Thank you York University! I look forward to sharing my copious notes and experiences from the journey this year.

As for Adam this year, my mantra has nothing to do with compliance. It is about cooperation, engagement, respect, "muchness," connection and yes, joy. Adam's learning can't happen without these principles.

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[Emerging Tensions: Puberty, Autonomy and Safety](#)

Filed Under ([Aides and Assistants](#), [Anxiety](#), [Autism and Learning](#), [Behaviours](#), [Communication](#), [Development](#), [Family](#), [Identity](#), [Inclusion](#), [Intelligence](#), [Living](#), [Love](#), [Movement Disturbance](#), [Obsessions](#), [Safety](#), [school](#), [Sensory Differences](#), [Single Parenthood](#), [Transitions](#), [Travel](#)) by Estee on 13-12-2013

It's the end of the term...I need a long break and so does Adam. His anxiety went up as soon as the clocks turned back. The darkness brought about a new mood, Adam's ticking went off the charts and he started a new tick – a screaming tick. He wasn't happy – he couldn't stop it as the pressure mounted on him to stop. I felt pressure in trying to help him, because let's face it, screaming disturbs the peace. It's alarming. With it, Adam's flight-fight prompts him to bolt when he sees pathways and stairwells. These are all the signs that *Operation Calm Down* had to be put into effect. By virtue of naming it so, it's not the first time we have implemented it.

Dad took Adam on a short vacation and this allowed me to have one too. On my yoga vacay, I met another dad with an Asperger's son. He too mentioned that his son ticks and these anxiety attacks, let's call them for now, make it difficult to get back to schoolwork. His son's grades are going down, he said. So too, autistic autobiography reiterates the length of *time* it requires to self-regulate...sometimes days. Although I've been busy with PhD study, I realize the patterns of Adam's distress tends to be at regular intervals during the year, *and* after sickness. Now that his body is changing as well as his needs, I am considering a leave-of-absence to help him, but also to help myself in so doing.

In thinking of Adam's life and the very complex anxiety he has, his motor-planning difficulties, his frustration so apparent as he tries so hard to talk (the other day he got so frustrated, he picked up a pencil and in his chicken scratch wrote that he wanted to go to "gramma's house"), we can't always expect a learner like Adam to spend day-after-day exactly the same. The seasons change, there are new anxieties in life and we all need breaks. This is one of the most fundamental obstacle I can think of in how we teach children in general – in chairs for too long, in small rooms, with little outdoor exercise because of liability issues. It's not one person's fault, per se. It's how we've built our society. We live in cars, in buildings and we don't get out much. If Adam had an outdoor learning environment as a major part of his learning experience, I think he would be able to take in much more (outdoor education is decreasing but can be made accessible to people with disabilities). In the summer with lots of activity, for instance, he can talk more – and this is a feat for someone like Adam.

It is therefore very difficult to be talking grades, assessments, intelligence and so forth without recognizing that, living in the settings that are the way they are, that my autistic son will be delayed in his learning. The focus is far too much on intelligence (or ideas about intelligence) rather than somatic knowledge, difficulty and other ways that we can learn. I know this because when Adam is "on," and there are adaptations to his learning, he can learn. I am writing in these terms because when looking at sites or articles about autism, the terms and ways of thinking about intelligence and learning are so "matter-of-fact" or normalized that we forget about how other kinds of learning can take place. This makes so many people, the forgotten ones. In essence, I'm trying to move away from a linear model of development and learning which doesn't work for many people.

When the body has to spend so much time readjusting and becoming comfortable, the rest of the school work (at a desk in a chair...) has to be put aside. It would be wonderful for schools and educators to think about this a little more – to integrate movement into every aspect of the day including field trips and outdoor activities – even in inclement weather (my parents never protected me from it). I fear with our autistic children in Canada, that we are growing more back towards re-institutionalization in a different costume; we segregate and we isolate in order for our kids to be "safe." In this, I appreciated mother and author of the book *Spark*, on her autistic son, namely, her "philosophy of muchness." Never stop exposing (even with ticks, flaps and screaming) autistic children from many things – theatre, music, the outdoors, and accept the difficulties and make room for them.

We need to change the way we look at the length of education – since not all bodies cannot finish high school by the age of 18 (or 21). What other modes of education might we employ? Considering this is not as much an "intelligence" issue (I hesitate because I do not like to promote intellectualism which I find further separates people) as much as a somatic one.

Which leads me to some new revelations for me as a mom: that Adam's "voice" is a part of his growth. It's hard on me to watch him in a kind of pain from which he can't escape (sometimes the ticks are a loop he can't stop and sometimes they are willful – one "behaviour" can serve many different purposes) but also, I want so badly to give him the tools he needs so he can gain some latitude in his life. His life is so restricted with people always watching his every move – and this is, as I mentioned, for safety reasons. I often wonder, if given a great expanse of land to explore, could he feel better? What will his choices be for how he needs and wants to live his life? How can we support that? How do we stop protecting (or at least let up a little) in a dangerous world? I am certain some of Adam's stress comes from having very little autonomy, and although he is strong and willful (which I believe will bode him well), if you can't communicate fluently in our society, or you can't cross the street by yourself, your autonomy is limited. This, of course, is where the concept of supported-decision making and assistance comes in, but assistants (and parents) really need to understand this and how to be good listeners (for some reading, look to Val Williams' conversational analyses between caregivers and non-verbal individuals). Think of the life-skills training in addition to the education that our children also deserve. This takes more time than the allotment prescribed during the Industrial Revolution. I mean, it's time to move on.

Then there is the need to reconsider how we look at behaviour from the outside. This is a problematic approach because we cannot know how Adam feels on the inside, yet we have lots of autistic autobiography to help us. When we tried redirecting Adam with a behavioural approach, this enraged him – he smashed himself into the couch and crumpled the paper from his Zeotrope in his little fists and threw them to the ground. The basis of this was to get Adam to stop screaming, but it did not account for the fact that he perhaps could not stop. This is the

same for Tourettes (which I think Adam “has”) in that if you call more attention to the action, it will increase it. Instead, deflecting to relaxing activities seems to help more in addition to the sensory (deep pressure) that Adam needs.

An and calming approach worked much better than a behavioural one – this is what has to be done before we can teach any lessons – social and academic. Social stories and cognitive behavioural training are now a part of Adam’s week in addition to us seeking more adventure for him – rock climbing, circus arts and swimming. For CBT, another boy character is inserted into social stories to take the attention away from Adam. This way, Adam can relate to the character without feeling targeted. I gleaned this from reading Donna Williams’ *Exposure Anxiety*, which makes a lot of sense where Adam is concerned.

I fully believe after 12 years of being with Adam that seeking cooperation through engagement is our obligation, not his because he is still learning. He is a child who wants to learn, but we can’t do that by mere compliance. He complies when he is respected and engaged and also knows the rules (teaching boundaries respectfully will be our new challenge). I’ve started teaching three key concepts in various formats and in daily life to Adam – cooperation, patience and gratitude. In teaching Adam these concepts and ways to enact them in daily life, I also have to do so towards him. I’ll let you know how it goes.

Puberty will be challenging for Adam and for me. I am protective mother noticing the need and beginnings of separation. On the one hand it seems that Adam needs his structure and certain environments especially when he is feeling uncertain. On the other hand, he is truly becoming a teenager who is showing more signs of frustration and wanting to expand his world (this is different than bolting or escape but could be *sometimes* related). These may always be competing impulses in him, I don’t know. All I can tell is that they both exist within him. How do I give Adam boundaries and his own need for control over his own life now *and* ensure his safety? I’ll keep you posted on how this goes too.

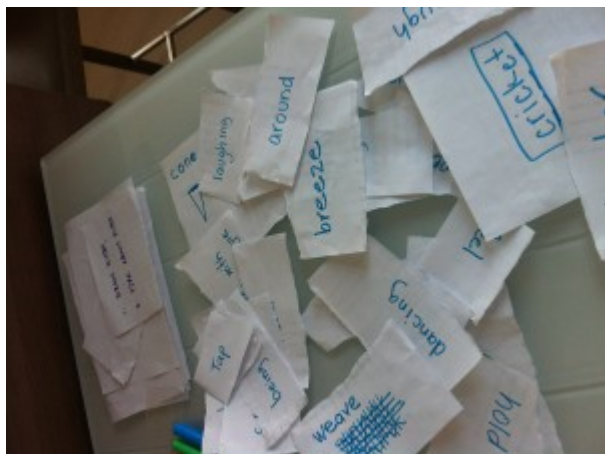
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[Breathing Life into Words](#)

Filed Under ([Communication](#), [Language](#)) by Estee on 03-12-2013



Adam has been reading words since he's been 11 months old. When he reads aloud, it sounds as if Adam has weaker reading skills, but his typing is always better than reading out loud. Yet there is a difference in how we come to language, and I suppose I'm more inclined these days to post-structuralism in the way words relate to other words when I think of relativism and how, as we hear about some autistic folks, that words can have an associational meaning. For many people, words relate to an event, a sound, an occurrence. They are associational; sometimes they are sensory where metaphor works best. The point is, language is just a system. It limits experience that can not always be translated into words. For Adam, words are very important. They can mean life and death since most people would not bother to understand Adam's language outside of "behavioural" contexts. As David Abram says, we are conditioned to speech. We miss the sensory properties and ways of knowing outside of speech and language; it is very hard for Adam and other people who come to language differently (if they can at all), to translate experience into words. Decoding and reading words can be different than feeling. I think that we have to view language more creatively and recognize that language does not denote intelligence – although we live in a society that still believes it does. Language is a half-formed tool, and in a political sense, it excludes many folks who do not come to the dominant, or ordinary, language as easily as some.

Adam and I were reading last night. I asked him to read out loud, but unless he uses words in the way he uses them (which is why typing is useful in many ways), it's difficult to know what he knows about a word. So, as we were reading, I quickly ripped off strips of paper and we not only spelled words (which he can do well), but we made them come alive. The word around when literally around Adam's head. The word "through" went through his fingers. "Wind" moved violently (fanned by me with a large book) and a pictorial leaf "spinned" and "tumbled" to the ground. "Whisper" came close to his ear and whispered "I love you," and the "breeze" gently moved the word on the strip of paper in the air. Adam wanted to read more. He grabbed book after book off the shelf as he read out loud, while we both made the words come alive for hours.

This is akin to when we hear parents labeling items all around the house which makes words "functional." Yet words are more than that. How can we make words sensory? How do we make them experiential? How can we role-reverse the word? God may have breathed the word into Adam, but he forgot that we have to also breathe life into words. And still, words are never enough.

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[“Weeds or Herbs?”: Eugenics Rhetoric Reinvoked](#)

Filed Under ([Activism](#), [Employment](#), [Eugenics](#), [Uncategorized](#)) by Estee on 26-11-2013



I am end of term, writing papers on technology and autism using critical theory and my interest is how we invoke these to obtain work, to socialize, but also in how these shape our existence. While technology is said to open up avenues for communication, we do not heed the critical theorists warnings of Adorno and others – that there can be “no true life possible in a false world.” The question is, how do virtual realities and mass culture, mechanization and so forth limit the acceptance of autistic bodies among us? It seems that work to befit the

body, not the body to work. This is also a feudal notion invoked by the company **Specialisterne** which is a software development company providing work opportunities for autistic people.

My job is to critique these structures and life is my lab. I am a mother to an autistic son as well as a single mother and I engage (and explore) in atypical forms knowledge production with my son – I attempt to resist the standard ways of producing knowledge that in fact are, to Adorno's critique (my interpretation), relativist – that speaks only unto itself within a frame. That is, science speaks to science and we've adopted its rhetoric. As such, it may shape the way we think about our lives by this framework.

We cannot examine a system if we don't try to work from without. So, when I go online to look at the company **Specialisterne**, which provides work opportunities for autistic bodies, it is imperative that we question how bodies may be vulnerable to exploitation in totalizing "autistic characteristics" as: "able to focus for long periods of time; superior ability to recognize patterns; superior visual perceptual ability" and so forth. While autistic people need to eat, and work provides important human connection (see "emotional labour"), we have to be cognizant that we are working within a system that reduces support, devalues disabled bodies and in fact, requires all of us to work longer and harder – in fact, like machines...automated...autistic. While these characteristics that may be present for some individuals, we have to be aware of how generalities about autistic characteristics may serve to oppress people.

That said, as I do my research, I was tuned in on the marketing of **Specialisterne** to ask if an autistic person is a "weed or herb?" (see **Specialisterne's** banner above). If we are to speak, to anchor ourselves in frames of reference for how we have come to be where we are and to think about autism, we are obliged to point out that the term came from a eugenics book [*Weeds in the Garden of Marriage \(1931\) by George Henry Lane Fox Pitt Rivers*](#). Using this object metaphor is also explored [in this paper by Gerald O'Brien in *Disability Studies Quarterly*](#).

It might be helpful for self-advocacy organizations to engage in media and marketing monitoring to ensure that dignity, respect and the history of oppression is recognized, so that we may never again re-invoke the rhetoric which belonged to the eugenics movement which rendered the segregation and sterilization of disabled people mandatory. It is curious that marketing firms would not research this thoroughly.

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[Autistic Teenager Tipped for Nobel Prize](#)

Filed Under ([Autism and Learning](#)) by Estee on 22-11-2013

It is important to remember what autistic people can do in light of my previous post this morning of autistic people being confined to the isolation rooms and separate schools. Imagine the emotional and intellectual starvation of most autistic children who live in isolation or in segregated schools which only educate the "lower skills." Not everyone is a Nobel Prize winner, and creativity can take many forms. Non-verbal, "behavioural" autistic people are always thinking, even when they "look" autistic (and looking autistic shouldn't be judged as negative!). This is important for every parent, educator and friend to remember – even if the skill isn't translated into normative language. This mom's *philosophy of muchness* is rich and beneficial and I agree with her 100%. Let's keep listening. Let's keep providing opportunities for autistic people:



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[What's Going on In Canada? Autistic Children in Isolation Rooms](#)

Filed Under ([Activism](#), [Human Rights](#), [Law](#)) by Estee on 22-11-2013

[The CBC news story on an autistic child being sent regularly to an isolation in a B.C. school was aired this morning.](#) The student, who is “mildly autistic” (she can speak), is sent regularly to a windowless room. In polling the other young students if she should go, they responded with a resounding yes.

So what's going on in Canada? Recently, the institutional “residents” of [Huronia](#) were awarded for their incarceration and imposed sterilization in Canada. Schools regularly remove students from classrooms. Despite the loss of the Auton case, ABA is the only “therapy” in Canada that attempts to normalize the autistic child. Negative reinforcement is still used in some of our government-funded autism centres. So while Auton didn't win, the ABA movement has. There is no choice for autistic children in Canada. The Harper government has an agenda of ridding autism from our country. Money is spent from our “top” charity Autism Speaks to cure autism and when those same ABA schools and communities apply for funding for a \$5,000 whiteboard, those grants are denied. As Ari Ne'eman writes in *Loud Hands Speaking*, the charity *Autism Speaks* does nothing to support autistic people and the communities that support them. Those same walks in our communities, with the parents who give thousands of dollars to it, get nothing from that charity in the way of supporting autistic well-being, lives and options. Despite deinstitutionalization, the rehab and medial model is supported to keep incarcerating people with disabilities. There is a human rights model, and those in the rehab and educational industries would be wise to start reading.

In the meantime, the B.C. school board seems defensive about its position. Policy-makers are deferring and the autistic girl is left in limbo and to the devices of a system that remains intolerant of her inclusion. There is an air of defense in this position. This, let us be reminded, however, that this is an infringement of the *Canadian Charter of Rights and Freedoms* and the *UN Enable on the Rights of Persons with Disabilities*. It is against the

law as more cases set the precedents (it is still an hermeneutical exercise it seems, but the principles apply); we have to keep working. The school system, which only cares about those who conform the best and get through the fastest (it's a business model of course that doesn't care about those who require support – it uses the cost-benefit/burden models), supports this marginalization. Most disturbing is the trend of adults who poll young children, or indeed condone this isolation of their autistic peers. These adults need to be questioned, their attitudes need to be changed, and in most cases, the only way to implement change is to bring this to the courts.

And where will our Autism charities be in incidents like in B.C.? Those who continue to support the amelioration of autistic people in the guise of acceptance and help? There is a predominant medical and libertarian model that we urgently need to discuss. It makes sense when government money supports economic solutions, that is, proposals to make children normal contributors to the market economy. Of course, these are just proposals. Work projects will only work when autistic people are respected, their rights upheld and dignity in place. As in other countries, all people (especially considering our economic privilege in this country) should receive a baseline of support in order to live good lives (but I'll leave that discussion for another post). These are modeled in other countries but we don't pay attention. There are too many people living in poverty and many other people are making lots of money in the false-marketing of cure and recovery, not assistance, support, rights, social supports, attitudes, and yes, employment – the latter which more often than not is also a means of emotional and social support. Such exclusion in policy and law speaks volumes. *Autism Speak's* leader in Toronto states that she “hates autism but not her child.” What message does that send to a public still in need of education about disability, it's history and human rights? How does that attitude improve the lives and acceptance of her child, and other people who will always be autistic? These are the challenges that are most difficult to face and that ask many families with any child who is different to lock up their doors and stay off the playground. If we don't talk now, we are risking a horrible reversion to institutionalization.

Instead, let us think about how we can work together to recognize that our country is sick, not autistic children and adults. We some of that change such as the recent settlement of former inmates of Huronia. We need to work with our communities to identify the attitudes and policies that lock us out and keep us in isolation.

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[Why is Seeing, Believing?](#)

Filed Under ([Adam](#), [Anxiety](#), [Behaviours](#), [Communication](#)) by Estee on 21-11-2013

I learned another lesson tonight. Adam has had a few difficult days. He was complaining last week that his ear hurt, and I thought maybe he had an ear infection. I took him to the doctor who suggested it could be his 12-year-old molars coming in. I was still worried; I thought the dentist told me they had already come in. A few days passed and Adam wasn't eating that much. His body began to twitch and spasm more. Yesterday, he placed his body under the cushions of the couch, wanted to watch a *Baby Einstein* video (as opposed to Shrek or Wall-E) and I knew he needed comfort. These are the things he will do to get it. I then suggested a bath and he headed for the stairs.

Once he got to the front door, however, things were out of place. Adam spent time picking up his coat, and placing his shoes just the way he wanted them and did it again and again. He was stuck in his loop. Then all of a sudden, he layed down on the floor on his goose-down coat and began to scream, biting the fabric of the sweater that was laying beside it. The blood-curdling scream broke my heart. I sat at the top of the stair, where I was waiting for him, calm and quiet. “It's okay, Adam. I'm right here.” Adam let out a few more screams, but they

didn't last too long. I called my father to come over as I didn't know what was going to happen next. Grandpa is one of Adam's favorite people and I thought it would help. But Before Grandpa arrived, I came down the stairs and sat at Adam's feet. "I'm right here. It's okay."

"Okay," he said in a distressed voice.

"Do you want to move to the couch?" Adam seemed uncertain, needing more of my help to get him there; he got up walked half way down the hall, then back, unsure of where he needed to land.

"Come to the couch," I repeated. Adam laid down and I sat at the edge of his feet with my hands on his legs. "I love you Adam. Everything's going to be okay," I said in my Zen-mother voice. My entire body wanting to absorb the knotted energy around him. I smiled at him lovingly and he smiled back.

"Hand is hurting," he said looking straight into my eyes.

"Oh, I'm sorry your hand is hurting!" He leaned back and then sat forward again.

"Hand is hurting," he repeated, holding it out for me.

"Yes your hand is hurting. Do you want me to kiss it or blow on it?"

At that point Grandpa arrived, also quiet and calm in Adam's presence. Adam lead him to the basement where they typically hang out together. Soon after he came back upstairs for a bath and went to sleep.

This morning on the way to school, Adam sat in the back seat in the car and declared, "tooth hurting," while pointing to his front tooth. When we arrived at school I checked but couldn't see anything wrong. Adam had a fine but reportedly cuddly morning with his assistant. She said he became increasingly twitchy. Adam had said "yellow" which is what he has learned from the *5-point scale* which symbolizes levels of distress. His assistant immediately took him to the sensory room. Adam began to tell her that his back, bottom, nose, were hurting and indeed he had a nosebleed at lunch time. When I heard he was pale and sweaty, I decided to fetch Adam early from school. Upon hearing about this, Adam assumed that he would not be able to go to circus arts where he is coached in the trampoline and began to scream. I texted (much of this conversation was happening by text) his assistant to say no, we were going no matter what because he had been asking for it all week long.

Adam did well the first half of the session and then let out a yelp. His coach put him in the silk swing until he yelped again. It was time to go home.

Nearly in tears for the way my own body responds to Adam's distress on the inside, Adam yelped again in my car.

"Adam, I need a word please. I don't understand screams." I was expecting protest but Adam was quiet. When we arrived home, he again had a meagre appetite, unusual after rigorous exercise. He again placed his body underneath the cushions of the couch. He then showered and then yelped in his room. I suggested we brush his teeth, and when we did I noticed that a tooth had broken through the skin.

"Oh Adam, poor you. You are in pain!" Adam smiled from ear-to-ear, probably relieved that I finally understood what he had been telling us all along. I hugged him.

"Tired," he declared as he climbed into bed. "Daddy hurt." I figured he wanted to tell his father that he was in pain.

"Do you want to call daddy now?"

"No"

"Do you want to see daddy tomorrow?"

“Daddy tomorrow.” That’s an affirmative.

So as I think this through, when Adam says he’s sick and many of us just think sometimes he says things that don’t mean anything, I consider how much MORE listening we all have to do. Why do we need proof? Why do we need to see a tooth is hurting to believe it? I’m not suggesting that people (or I) don’t listen to Adam, but that Adam seems to need a lot more time and affirmation to feel comfortable as he passes through pain. Even for all the words Adam mustered to communicate how he felt, to get help, we didn’t see it and we didn’t know quite what to do for him. It’s not that we didn’t try to be helpful, or that we didn’t go to the doctor, but we beat ourselves up about Adam and his “behaviour” almost to the point of wondering if it had any function at all. Another lesson learned: We don’t always need to see to believe and Adam did the job that we always tell him to do. He communicates like hell.

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[What Might Derrida Say About Autism and Language?](#)

Filed Under ([Activism](#), [autism](#), [Communication](#), [Community](#)) by Estee on 16-11-2013

Adam types, mostly independently, and also with various modes of assistance. Of late, he has developed his grammatically perfect sentences and I have to wonder about teaching the system of language. To most, this should be a heralded moment when Adam has joined us, society, in the shared system of social reciprocity. Yet I wonder about that term reciprocity. Is it reciprocal when we are a dominant group of language users? What of Adam’s own communication is considered valid? With learning our system of signs and signifiers, he will be able to join classrooms and other groups. I wonder about the validation of his body, his movements as asserting his being in society. I wonder if he will not lose his, for lack of a better way of putting it, metaphorical ways of speaking. This to me was representative of communicating a pattern of thought, perhaps translation, and perhaps a pattern of sensory experience; meagerly conveyed through our dominant language. In order to think this through, we have to consider how we limit experience by insisting on a form of contemporary autistic “oralism” (a term used for the Deaf/deaf, when they were force to speak instead of sign).

Adam also sometimes speaks. Sometimes he finds it hard to use words and “speaks” better through his body. This discontinuity, as it is often called, is referred to in the medical system as impairment or a problem. Speech in our society, we must remember, is also denotative of “rationality” which I continue to problematize. Derrida might not consider his speech discontinuous any less than language and rationality are (Simons, 88). Derrida says that without any gap between pages and letters, there would be no language or communication. So language is in itself discontinuous.

Adam’s meaning must be considered similarly. Without considering his whole being in the moment I could not weave a meaning. (And it should be noted that this should not be executed by only myself. I recognize I am a dominant language user/speaker and I have to ask for various clarifications in a translation process but also have to be patient and simply watch and listen). Meaning is co-constructed, but the most important part of this that I want to convey is that often parents ignore this complex aspect of communication and maintain a level of expectation that no one autistic person will ever accomplish without a feeling of self-loss. Inasmuch as people should be praised for achievements, they should be praised for who they are. I also consider how this interactive view contributes to the feelings of impairment; that is, every interaction with others, mostly those fluent in speech (and who may consider themselves superior or normal as a result of being a political majority of talkers),

contribute to feelings of impairment. There are a number of issues here, too long for a mere blog post, but let me continue.

If I follow Derrida's line of thinking about language, there is no easy translation. I consider Adam's typing a way of translating his thoughts into a system; I have to recognize that language limits the expanse of his thoughts, experiences and sensations. Like science, which is a system of thought and signs, we learn to frame a "problem." We understand science by learning its language and it is primarily an encapsulated system which speaks among itself. It is here that I will reiterate a need to move away from science as "truth" as there are other valid modes of inquiry, much of which is already produced by those who are non-speaking. I am concerned also when fellow allies and autistics revert to this form of absolutism which has only oppressed them for many years. There are ways to take back the research and inquiry and IMFAR (among other science orgs) needs to respond to them too. I am reticent, as much as I support, a specific "autistic" advocacy as we know that language and labels change with time. How do autistic people keep their needed culture while at the same time co-organize across the many disabilities who share the need for respect, acceptance and inclusion (the latter word needs clarification but I will not do so here)? Many people labeled with autism prior to 1993 were placarded with dementia praecox, schizophrenia, mental retardation, to name a few. Labels are socially constructed, temporal. They are as diachronic and responsive to society as much as the rehabilitative and treatment methods seek to "recover" them. Yet they do share one characteristic which is political and social exclusion. Here, language as a system has played a huge role in how we regard and treat autism.

To continue with Derrida, discourse and meanings are shared and malleable (my word). Meaning is assembled across spacing/timing and interactive contexts. A text is like a textile, "produced only in the transformation of another text" (Writing and Difference, 279-80). The problem occurs in the behavioural and the sciences, Derrida would argue, when "provisional meanings are taken for definitive ones" (Simons, p. 90). Isn't this what we've done? Isn't this the way we continue to respond to organizations like Autism Speaks? In a Saussurean sense, we react to the constructed meaning, signifier of autism and we continue to validate it. In other words, by reacting, we also support the dominant system. In a political sense, I think this is important to remember when we respond. It's not that we should not do so, but we must also think of ways of moving beyond this discourse as I fear we may only be continuing to support the current infrastructure that oppresses many people who do not fit the normal paradigm.

References:

Derrida, Jacques. (1978) Writing and Difference. Pp.279-80

Simons, Jon. Contemporary Critical Theorists from Lacan to Said. p. 90.

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[Where I left off..let me say a few words](#)

Filed Under ([Adam](#), [Communication](#), [Estee](#)) by Estee on 08-11-2013

Hmmm, let me see, where do I need to begin again? I am in the mood to just tell you where I last left this blog off, between finishing my MRP, changing Adam's school and off to the PhD races. I can already see where this will try to pull me in many directions but Adam keeps me focused. He types on his own, but he also increases his spoken words. He is not cured of autism just because he is gaining these skills. It simply represents (if I can use that word) that coming to words, no matter how many or few, is different for all of us. Progress is not linear and I'm skeptical of *progress*. In terms of the human body, it changes over time. That's about it.

Focusing on words, despite the fact that I write and defer to them all the time, remains tenuous – open to interpretation. Words are both important in this verbose culture, one where David Abram might say we are conditioned to speech (alas unaware of nature around us and our other senses) whereas Adam and others may be more attuned. If I say that, I am walking a tightrope – I wish to avoid *sensationalizing* “autistic” skill. Could it be there is a space in between words that we are ignoring more than ever before? Don’t we all tend to say that we live in a world where we feel more disconnected? How ironic the term automatic/automatism/autism; I get up, get in my car behind glass and these actions are automatic and required for work. People honk horns, illustrating a passive aggressive irritation – with other human beings – that may dissolve without the glass, behind computer screens. By stating my observation, I am speaking my hope. This doesn’t have to be, “just the way it is.” We can rethink the way we form relationships and community.

Words are what Adam learns in school, what we teach him through typing, reading. He is strongly attracted to words; he owns that **hyperLEXIC** label. We find it hard to find the right *lexicon* to describe our lives within a paradigm of normality, alas devoted to speech. We cannot see the forest for the trees; we are too busy building roads and computerized devices. We are busy proving our minds... and our reason.

Still, Adam is happier. He is being educated in a “real” school, and that only happens with those willing to accept that he still needs a person to help him navigate spaces, other bodies... a deluge of words coming at him in the forms of conversations and instructions. He is with other kids, and he gets to learn. This makes him happy. He directs when he needs to be with others and when he needs his space, and he learns to translate what he knows into the words we need for proof. And I, in a PhD program, must combine lots of words to put to this, in an attempt to move beyond them. In the meantime, I always feel full when Adam is around and there are few words between us. I seem to understand so much about his meaning, and he mine. Silence is full.

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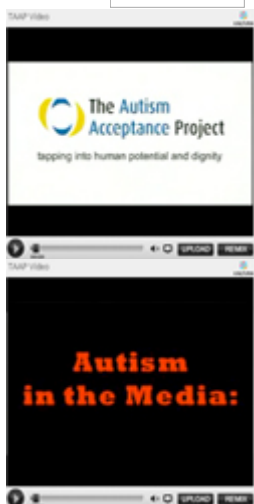
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About Me



ESTÉE KLAR

I'm a PhD candidate at York University, Critical Disability Studies, with a multi-disciplinary background in the arts as a curator and writer. I am the Founder of The Autism Acceptance Project (www.taaproject.com), and an enamoured mother of my only son who lives with the autism label. I like to write about our journey, critical issues regarding autism in the area of human rights, law, and social justice, as well as reflexive practices in (auto)ethnographic writing about autism.

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because finding joy doesn't come without struggle;
because the point is to find it;
because if an autistic person calls autism their way of being, not an illness, then it is;
because every human has value and is a joy;
because despite inhumane acts, I believe in humanity;
but most of all, because of my son Adam.

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