

Estée Klar

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Autism to Inclusion (with and without captions)

Filed Under ([Education](#), [Inclusion](#), [Movement Difference](#), [Uncategorized](#)) by Estee on 14-02-2017

A collaborative project made with Adam for Project Revision:

Without Captions:



Autism to Inclusion. Without captions

from [Estée Klar](#)

05:27 |



With Captions:



Autism to Inclusion. With Captions

from [Estée Klar](#)

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[Autism Strategy Masks Societal Exclusion of Autistic Ontarians: Ottawa Citizen](#)

Filed Under ([ABA](#)) by Estee on 20-04-2016



Dr. Anne McGuire, Dr. Patty Douglas and myself have written an [Op Ed piece today in The Ottawa Citizen](#). “It is dangerous to assume the problem is autism rather than society’s failure to recognize autism as a way of being which cannot simply be eliminated. The intense pressure placed on autistic people to not appear autistic is creating a world where those who do not, cannot, or choose not to behave like neurotypical people are left increasingly vulnerable to social exclusion or violence”

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Where are we?

Filed Under ([Adam](#), [Advocacy](#), [autism](#)) by Estee on 28-07-2015



“Entrance is funny because it reminds me of the love of people. It is easy to enter love through an open door.” – Adam Wolfond

As a part of my duoethnography project with Adam, we are on Facebook for now. For many reasons, this seems like the safe space he can communicate and Adam and I will be presenting at our first conference together this fall. We have also started our new school, which we are very excited to say more about later.

There are times when advocacy needs to take different forms, where the current form isn’t serving as well and where, I feel, certain binary arguments continue to perpetuate the cycle of exclusion we are experiencing today. I also feel there are so many autistic self-advocates that write important blogs, and these are important resources.

We will be back (soon) and are around in many creative ways that foster social justice and the kind of inclusion that doesn’t continue to force a mainstream will (or a curist approach to being remediated before being included, which we feel is unjust). Our project has much to do with how we communicate with each other, about how Adam feels about his disability, and how I explore the interactions and ethical dilemmas between parent-child interaction, relationship, support, interdependence and justice for folks with disabilities. I could not write an autoethnography about being a mother to an autistic child because in my view, we have an overabundance of research about the parents and *their* stress that expenses the lives of autistic people as “burdens.” The top-down approach to research has been cited numerous times as problematic and I take this to heart in my own doctoral research.

Adam and I are exploring this together in multiple ways (not just language-based ones) that will hopefully contribute to the way we think about community, school, inclusion and participatory research about autism. We will return to writing at this blog site and for now, we “exist” as mutual explorers on Facebook where Adam “speaks,” and where we draw and comment too. So this is just a short note to say we are alive and well and... we’ll be back.

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[What's the Problem Represented to Be? Autism, School and Policy Musing](#)

Filed Under ([Government Services](#), [Human Rights](#), [Inclusion](#), [Institutionalization](#), [Policy](#), [school](#), [Single Parenthood](#)) by Estee on 22-04-2015

As Adam school closes, we have our Plan B which does involve his acceptance into a high school language arts community in a school devoted to social justice. Adam is in grade seven but will jump a grade. Some might say this is Ironic, no, for a child who some therapists said couldn't understand, let alone speak fluently? But it won't all be in school. In thinking about the schools, policies and systems that are currently in place for autistic people in Canada, I came across the following:

“Heidegger says we are accustomed to having conditions given so that we can plan out definite results. We are used to being able to plan, to calculate, and when we cannot do so, we feel out of our depth...” I fell onto this while reading “Our Dissertations, Ourselves” (2014) but it has another meaning for me. I have promised Adam (and myself) that I would never put Adam into an institutionalized setting/school or group home. The IBI program that I strongly critique is anchored in calculations and definite results or outcomes, even when they are built on false promises because of false assumptions/premises. We want to depend on others to much of this for us... to solve a “problem.” [In this, I like what Carol Bacchi asks “What is the problem represented to be?”](#)

This is the core of how systems and autism policies are built.

I think of it this way, we really shouldn't launch into parent-hood without recognizing that no matter who the child will be, there will be challenges, systemic and otherwise. The neoliberal system also in which we all live works against children by suggesting that everyone can work (and this is also disguised as fulfillment and leisure which often creates a tension with domestic work). I admit I resent this tension. Parenthood requires all of me. It requires that I work outside of existing conditions neither serve Adam nor our values. It is not easy to work outside of systems, or meander in and out of them as we see fit. But right now, we feel it's necessary.

Reference:

Christine Sorrell Dinkins and Jeanne Merkle Sorrell (2014), *Our Dissertations, Ourselves: Shared Stories of Women's Dissertation Journeys*. Palgrave Macmillan

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[Save The Merle Levine Academy](#)

Filed Under ([school](#)) by Estee on 20-04-2015

I rarely write a piece to save my son's school, so hear me out:

Due to dwindling enrollment, the Merle Levine Academy (MLA) is shutting its doors – unless more students attend. For autism and other learning disabilities, MLA has graduated students and 90% have gone off to college and university. The school has allowed myself and Adam's super team to assist and support him where needed and Adam is also included into the classroom. In the past 2 years, Adam has become a speedy typist, communicates his feelings, writes essays, talks with his friends by typing, is above grade in language arts and studies grade-level academics. All he needed was this opportunity. These are some of the most important gifts that MLA has enabled. The other is the priceless smile and pride that Adam wears on his sleeve.

When math was tricky to learn to teach, his teacher stuck with it and now Adam finishes his own math sheets and learns practical math. MLA is not specifically an autism school – there are many different kinds of learners there. In fact, of the schools available for kids like my son who are non-speaking with lots of challenges, there are basically none except for the ABA (or IBI) autism school here in Ontario. When it comes to the public schools, Adam would have been relegated to the lowest functioning class and given IBI as a treatment of intervention. Of the schools that do say they accept autistic children, they usually are the cherry-picking kind, preferring the ones who fit neatly into the class structure; in other words, less costly to manage.

It is ironic that MLA, once a school where kids were farmed if they couldn't do school, has become the closest to an all-inclusive one (although I wish to be diligent here that we need to produce more schools with the principles of diversity and social justice/egalitarianism. These would educate all children with an enriched disability studies curriculum where teachers learn to teach courses on deaf sign language, autism sensory experience, and so on. At the moment, our imagining of autism or special needs and education seems to be located in the margins of real education which must be changed).

The Applied Behavioural Therapy that has now anchored itself as the treatment of choice has become government-sanctioned segregation. As I predicted in 2005 on my *Joy of Autism* blog, parents now have little choice where children are to be managed rather than educated. As there is no inclusion because the government only funds ABA treatment here in Ontario – this is based on the principle that people must be remediated before the right to inclusion – parents feel compelled to go where their kids receive funding with the promise to normalize for the purposes of inclusion. To move outside of that framework requires substantial parental time and other resources. What I have learned in the past 13 years is that parents who have learned that autism schools will never provide all the answers, and no one person will solve all your perceived problems, that MLA will stick with you to make it work for your child. As I wish to follow what our Canadian legislation mandates, which is access and inclusion no matter what the disability, I follow this social justice principle rather than paying lip-service to it. For us, our entry into MLA was the chance that I was waiting for, and that has clearly benefited Adam.

I'm doing my bit here to possibly save the school that gives kids the opportunity to learn about the world they want to learn about, while allowing for the other accommodations that children need. I know that all of us want our children to feel great about themselves, to be happy and most of all, to feel accepted as they are. I know there are kids who wanted to graduate high school at MLA next year after having invested so much time. Please consider helping these kids and this school. I feel MLA has given us the chance to know that this set-up works. What many parents want for children is choice and opportunity. My choice for Adam, and Adam's own choice, has never been segregation. It has been education, inclusion, and acceptance for being autistic... all the way!

If you want to give it a chance or offer your support please contact: **Telephone: 416-661-4141 Email: merle@merlelevineacademy.com**

Merle Levine Academy



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[Advocating Otherwise: Problematizing Autism “Advocacy”](#)

Filed Under ([Advocacy](#), [autism](#)) by Estee on 27-02-2015

Read the work of Anne McGuire, now a Professor at U of T:

disCover: the war on autism with Anne McGuire



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[Technology & Autism: We Still Need Acceptance](#)

Filed Under ([Acceptance](#), [Capital](#), [Communication](#), [Computing/iPad](#), [Parenting](#), [Technology](#)) by Estee on 05-02-2015

Adam is learning to become an independent typist so quickly now. While it makes me proud and happy for him because he wants to be independent (he has written so many times), it is really important to know that independence, for all of us, is an illusion.

First, Adam has been typing since he has been around 4-5 years old. Most teachers and therapists aren't all familiar with how support can enable a non-speaking person to type (and possibly become independent). While we began early, we didn't obtain the commitment from teachers who would not learn how to support him, in my view, because they didn't understand the meaning of support.

When a person has many motor planning issues associated with their movement and speech, it can be very difficult to feel grounded enough to type. The purpose of support is to enable the body and the mind to ground (if you will allow me a metaphor). A support person also offers the emotional security in a task that is so challenging when the body and mind coordinate many different stimuli and tasks. We take for granted how we multitask, and how our bodies coordinate speech and bodily movements effortlessly. For Adam, he has expressed numerous times how he has required help.

The important addition in Adam's life has been the support we had been looking for all these years; this means daily use of typing in all settings, almost all of the time. Adam now has access and support every day. As such, he has moved so swiftly in his ability and language expression that we are all confident that he is moving to more consistent independence.

However, I want to caution everyone here, for the emotional support of others may be needed, as well as patient and gracious listeners. Just because Adam can often type without physical support does not mean that he might now need another person nearby giving him the confidence he needs. Also, while the level of support may fade, some people may always require some level of support throughout their lifetime. In my own research, I've found that a generous and encouraging *co-presence* – of love and a presumption that Adam is intelligent and curious, has encouraged him. He has been very frustrated for how he has been treated over the years as a boy who hasn't understood what is being said, and is eager to learn even though his day-to-day life may be challenging.

While the iPad has markedly changed the reception of Adam by others – providing Adam's voice and enabling friendships and school work through text-to-speech technology (we use Proloquo2go) – technology is not a panacea. Too often, we make the grave mistake of thinking that if we push our children hard enough, they will learn how to speak or type, etc. "Just as long as he can communicate" thinking will not erase the experience of being autistic. Our modern notions of independence are skewed by a market-economy that demands that we, as parents, produce the most efficient workers. This is also proving to be a big issue as our autistic children turn 21.

The ABA movement, when it was nascent here in Canada in the 1990's-present, presented itself as an early-intervention treatment to recover the autistic child. The idea that earlier (and quicker) is better, fuels parental desperation and fosters an inauspicious environment for learning. These therapies also promised parents that remediation was a passage to full inclusion in our society; that the only way to participate and contribute was to be cured of autism. Many a rights-based/legal argument constellates around the notion that to be remediated is a

right; to be cured is a right in order to assure this passage to normality. All of these notions are based on a modern concept of an abstract citizen as it was formed by way of the Social Contract. In this, *none* of us are citizens precisely because *none* of us can pull our own way; we are all dependent upon one another for every cycle of the market, and for the function of our daily lives. Every rich man or woman has an army of support that enables him/her to earn that living – or production; as such one can deduce that all participants of production should be “owners.” It’s about *who* has the power over that capital, of course, that is called into question and is part of the discourse regarding social support.

What would it mean to think of autistic contribution *and* the desire to be autistic? Adding to this, can we think outside the box of productivity as we currently conceive it in modern economic terms? We have seen autistic contribution *proved* many times, in speaking and non-speaking ways, and perhaps it is this aspect, as having to prove oneself as normal (as possible), that troubles me. I want to call into question about how we all market and market autistic contribution.

My interests are on how society expects autistic people to speak in “normal” ways as a passage to citizenship. As displayed in the film, *Wretches & Jabberers*, for instance, even when autistic people achieve communication, they are not considered full citizens; they are not included into schools or considered for employment. Here too we must acknowledge that in our society, there will be some bodies who have more material needs than others (Erevelles, 2011). How does the notion of achieving one’s “fair” or “equal” share leave out many people with significant disabilities? And what are we doing (positively and negatively) in terms of elimination of those bodies in the name of “equal” distribution?

Our questioning about autism and technology should be not just how it can make autistic people independent, but how we can change our views towards autistic people; and the right to support and education past the age of 21. Education is another system that supports economic output, of course, and needs to be reconsidered. Certainly we also know that for *all* of us, time-plus-experience enables knowledge. We need to provide education past that hurried (and hallowed) age of 21 and to grapple with the very troubling issues that confront us within our current system. All of these considerations may help us rethink our systems of support.

Just because we have new enabling technology doesn’t necessarily mean we accept autism. There are many contributions we all make to one another that are not counted as capital; that exist (and are valuable) outside the ledger. The ledger, after all, is a mere frame. We know there is always something left outside of it, and in this case, I am referring to a class of marginalized autistic individuals who are not considered equal because of economic potential. We need to think first about accepting autism while we consider how to educate and support autistic people with technology.

Reference:

Nirmala Erevelles, 2011. *Disability and Difference in Global Contexts: Enabling a Transformative Body Politic*. Palgrave MacMillan.

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[My Review of Wretches & Jabberers now in The Canadian Journal of Disability Studies](#)

Filed Under ([Communication](#), [Critical Disability Studies](#), [Discrimination](#), [Film](#)) by Estee on 23-01-2015



My review of the film [Wretches & Jabberers](#) can now be read in the Canadian Journal of Disability Studies: [CLICK HERE](#)

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[Do You Think Your Thoughts Can Effect A Rat's Behaviour?](#)

Filed Under ([Behaviours](#), [The Autism Genome Project](#)) by Estee on 23-01-2015

Listen to this study on [This American Life](#) and consider the implication for how our thoughts and expectations can effect the lives of our children. Interesting implications and I expect many discussions among your friends about autism, expectations, education and access. I wonder if our thoughts were positive about the genome could have the same affect. It's all about thoughts.

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[Autistic Mother Pride](#)

Filed Under ([Poetry](#)) by Estee on 22-01-2015

This might be worked on some more... I'm writing today and flipping through my binder of writing. I found this unedited poem as part of a poetic essay I was attempting last year. Please note I am not well-versed in the art of poetry, but enjoy the process of trying. I think it's fine to share it as is. I might consider it for that horrid month of April and again for our Pride Parade in Toronto this year:

Pride has this mother
protecting
Pride!
threaded by a label
and stitched with love

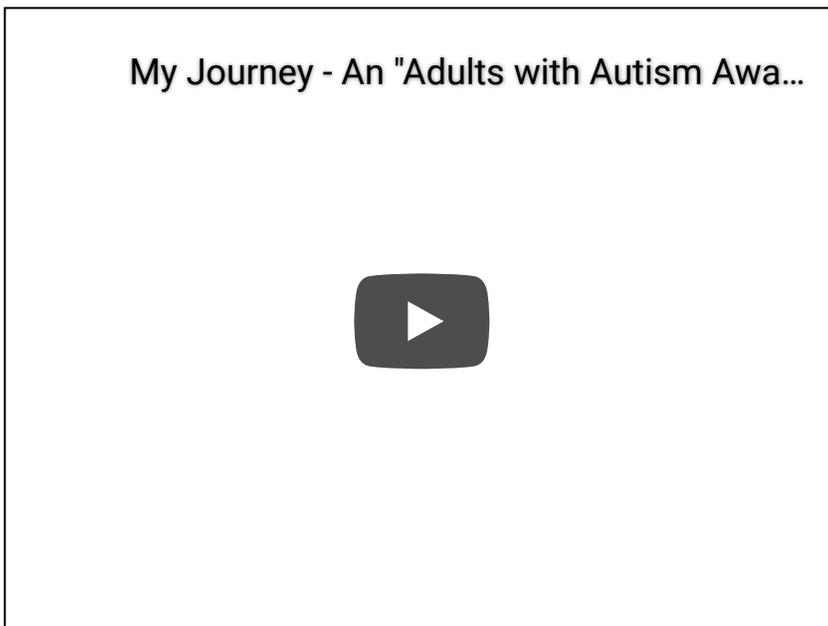
Claimed
As Kanner did
on the great
scientific mother-ship;
He said they didn't live before
as the "feeble-minded"
behind 19th century doors
of confinement
Pride!
coalescing
fragile identities
p-u-s-h-i-n-g
for new definitions
to be borne.

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[The Art of Autism](#)

Filed Under ([Acceptance](#), [Art](#), [Inspiration](#)) by Estee on 20-01-2015



This video by Alison Ludkin, among other pieces of artwork and writings, can be found on [Art of Autism](#) – a site bringing the work of artists labeled with autism online. I suppose I chose it for my blog as Adam takes the train everyday to school and I try to take in all the sounds and stimuli with him. I try to imagine. As for this site, I recommend supporting the artists.

[The Autism Acceptance Project](#) brought art by autistic artists in an online gallery back in 2005-2007, with exhibitions in Toronto and online participatory space. As our mandate always has been to ask autistic people first

what kinds of supports they want and need, the organization has (and continues) to seek autistic-person guidance and governance. When the site was maliciously hacked about two years ago, we lost much data and records, some of which is now stored at [Brock University Library Archives](#). I must admit that I really enjoyed those days of curating artwork and today, Adam's poetry and other endeavours, and nourishing them as best I can, is keeping me busy.

I am so grateful for the work by autistic people. My background as a curator of art (my first profession prior to my disability studies work) started my journey in looking at disability differently and began the whole blogging process back in 2005. I suppose when looking at shiny new sites – much better constructed than our budget or ability could muster back in the old-internet-age of 2005 – I am thrilled to have the opportunity to view work by autistic people. This site has such a wide array. This is work we saw much too little of prior to the Internet so it would be an interesting topic for many of us to explore (and a paper about online spaces I am writing at the moment).

May we also spread encouragement and support directly to the artists when we think about creating websites. I believe that the artists, if they are not directly reimbursed because of budget constraints, should at least be directly credited for their work with a link back to their galleries or websites may enable a generation of income and accolades. Also, it would be wonderful to promote not an “awareness” of autism – we certainly have that awareness out there. However, [it's the kind of awareness that can be problematic](#). As Kassiane S. states: “Awareness is easy. Acceptance requires actual work.” Perhaps a site dedicated to autism acceptance is critical now.

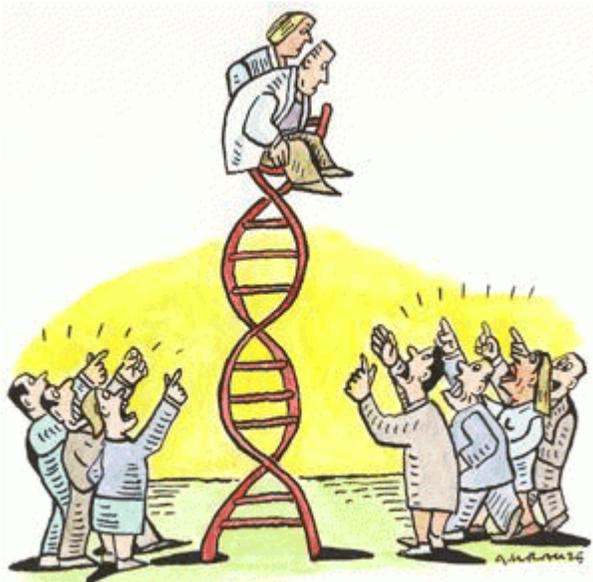
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[**Mental ability and the Discourse of Disease – another comment on a Globe & Mail article on “Treating the Brain and the Immune System in Tandem”**](#)

Filed Under ([Accessibility](#), [Critical Disability Theory](#), [Disability History](#), [Discrimination](#), [Ethics](#), [Eugenics](#), [Identity](#), [Inclusion](#), [Institutionalization](#), [Intelligence](#), [Media](#), [NEugenics](#), [Newgenics](#), [Research](#), [Science](#), [The Autism Genome Project](#), [What is Disability?](#)) by Estee on 19-01-2015



Again, the suggestion that mental illness – an umbrella term under which autism has also been thrust – is discussed in terms of biological disease. Says the *Globe & Mail* this morning: “It probably brings us closer to hammering in the idea that mental illness is a disease... It’s a disease we don’t fully understand.” [You can link to the full article here by clicking this sentence.](#) Let us put aside for the moment that our medical journalism lacks any critical thinking or understanding of a now broad oeuvre of disability theory and literature. A critique of the media is indeed part of this blog post. Journalism has become as cheap as reality-TV – let’s make something out of nothing. Sure, I’m a cynic, and I tire of news reports on autism and the discourse of mental illness as disease. They are indeed a big obstacle to much of Adam’s progress in terms of how people accept and view him.

The “great” modernist project has been built around not only biology, but *revolutionary* biology. This includes environmental – internal and external biological causes for “mental illness.” There are two components to that sentence to unpack; the first being that the modernist age has been defined by production and individualism. The notion of autonomy is conflated with the working citizen who fulfills the Social Contract by virtue of pulling oneself up by one’s own boot-straps. Simply put, it stands to reason in this view that our biological goals have largely been built on supporting what is a statistically “normal” “good”-working body. This was indeed a part of the Eugenics Project. Any *body* that falls beyond the bell curve, continues to be deemed a financial burden and a cost to society. Therefore, the creation of a dependent body is morally judged and biologically defined. This is typically what is constituted as a social construction under which we have created institutions, special education, early intervention and the like.

Modernity & Globalisation

The Enlightenment Project

- Modernist theories e.g. Marxism are part of the project- the idea that through reason and science, we can discover true knowledge and progress to a better society

I am tending to envision (as do others) our present age not simply a post-modern age – although I prefer post-modern theory to redefine the human and extend to other ways of knowing outside of the medical model – but a bizarre hyper-modern period (Umberto Eco used this term in hyper-reality, aesthetic, theory). Briefly, this means

that we have extended the Enlightenment project – the one that created modernity in search of normality – into overdrive, seeking to land the first man not on the moon, but to create his or her “theory of everything” to define disease – or the right or wrong kind of human. The first discoverer wins the big financial and reputational prize. Disability theorists do not *en masse* agree or disagree with the implications of biological alterations, and the use of technology has indeed proven to change the lives of many. I do not have the space herein to discuss all of these aspects.

Hypermodernity.... Or Supermodernity...?

- If all reality has been constructed then some theorists believe that what is actually left is hypermodernity and that this is the new ‘virtual’ world we live in in our technology and media saturated world.

Instead, let me point to a belief that every research project must create a cure as good as it was for polio. I mention this as an example of the drive to cure diseases of all man-made kinds as well (meaning the socially constructed ones). This raises all kinds of important questions about illness and pain itself including the right to live, die, moral judgements about illness, and so on. I am not mentioning polio for these reasons here, but as an example of how a drive for any cure or human improvement has taken on hyper-funded business investment in research and competition. As such, I am citing the profit incentive for medical research. The two tied are not necessarily wrong until or unless we examine our motives.

I challenge and disagree with many theorists (or bioethicists) who may purport that it is better to separate any linkage of today’s genome and biological research with early twentieth century eugenics. I believe (as Rembis, 2009; Hubbard and Wald, 1999) that we continue to link behavior with biology and have hybridized these into “mental illness/health.” This umbrella term seeks to broaden medical diagnostics from which many industries may profit, namely pharmaceutical and therapeutic occupations. The *DSM V* is nearly big enough to take a bullet, and it *will* continue to expand so long as we rely upon a medical model as our only source of knowledge. As such, autism numbers will continue to increase within this model, not because of something environmental or biological, but because of how we imagine and create discourses.

It’s not looking good for autism from where I sit under this rubric, I realize this. We all know that autism, like many other cognitive disabilities, are diagnosed by observation for which we have created an extensive lexicon of disease and abnormality. Bio-markers become a shared lexicon infused with moral implication. Yet, we also know that there are many other ways of knowing and a plethora of disability theory is ignored in most discussions driven by journalists or medical communities. Also, let us not ignore the criminalization of behaviour (an example of moral judgement stirred and shaken with biology) as a reason to create new research business. In this, please test my theory – there will not be one news report of a criminal act that is not linked to mental illness today. I’m not trying to create a conspiracy theory, but there is a definitive financial drive for ameliorating many bodies, and we all take a part in creating the discourse. (Reinforcing discourses is another blog post).

I will agree with Rembis when he states,

“Any informed discussion of the limits of behavioral genetics research must take into account the historically contingent socially situated nature of impairment itself. Such an argument would not deny the existence of impairment. Instead, it would begin with a critical analysis of the social, medical, scientific and juridical discourse at the root of taken for granted classifications of

impairment. This type of critical analysis is already taking place in some of the arguments concerning mental “illness” and mental health services ...as well as those concerning the social applicability and general reliability of the results of intelligence tests “(Rembis, 2009, 592).

He also bluntly states, “The recent emphasis on genes stems in large part from experts’ drive to tap into the hundreds of millions of dollars made available primarily through NIH Human Genome Project, as well as through huge multinational pharmaceutical companies. There remains, however, a much deeper desire among scientists of the world to bring the vagaries of human reproduction and development under scientific control that continues to drive much of genetic research. Only when we begin to think critically about taken for granted categories of impairment and examine the history of eugenics in a new light will we be able to assess the implications inherent in current and future efforts to control human reproduction and behavior.” (594).

Genetic discrimination (Hubbard and Wald 1999) is already in our midst as the “agents of truth” – a term used to describe how we take the words of medical researchers and how we view them (Rose and Rainbow, 2006) – have already defined autism as a genetic abnormality. Note, that I don’t agree with Rose and Rainbow, however, when they state that biopolitics is not about eugenics as much as capitalism and liberalism (211). Contrary to their position that we need to develop new conceptual tools for critically analysing how biopolitics plays out, I believe that it is impossible to untangle modernity, capitalism and our propinquity to find biological causes for aberrant behaviour and mental illness – morally judged designations with supposed (bad) economic implications. This blog post does not do all of these concepts and arguments justice; however, parents and professionals must all challenge the reasons for the propensity for researching biological causes for autism and/or mental illness. Without doing so, we risk losing opportunities for creating a vibrant future where autism is accepted and where our children may live in peace with education, friendship and family. It is a point of fact that charities such as Autism Speaks spends less than 4% of its budget on services for autistic people (*services* is another blog post too). Far from being utopian, this thought represents a need for examining social mores in order to overcome the obstacles that prevent social inclusion...for every *body*. Also, I will agree that the body is under great transformation in terms of identity politics in the way we imagine it, and the other ways of knowing and imagining it can and does exist outside of medicine.

Recently, I am interested, as a woman, theorist and mother, in the lovely intimacy I share with my son as caregiving can be a very physical act. Touted as a burden by many charities and the like – including fellow parents who yearn to have an independent child – I have been grateful to be put into a situation where my expectations have been radically altered; where caring has become an important part of my treasured (ever-changing) identity. This has been created by the reality of caring and the mutually negotiated relationship I share with my son. Therefore, reading accounts of genetically ameliorating autism, or relentless and repeated suggestions that disability (often shoved under the “mental illness” umbrella) is biologically caused or wrong, is troubling for my son and I on many fronts, some of which I have outlined here. Perhaps the *Globe & Mail* writer Wendy Leung may take some of these points into consideration. We need to imagine otherwise.

References:

Hubbard, Ruth. Wald, Elijah. 1999. *The Gene Myth: How Genetic Information Is Produced and Manipulated by Scientists, Physicians, Employers, Insurance Companies, Educators and Law Enforcers*. Boston: Beacon Press.

Rembis, Michael. 2009. (Re) Defining disability in the ‘genetic age’: behavioral genetics, ‘new’ eugenics and the future of impairment. *Disability and Society*, 24:5, 585-597.

Rainbow, Paul. Rose, Nikolas. 2006. Biopower Today. *Biosocieties*. 1, 195-217.

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[Adam's Disability Poem](#)

Filed Under ([Poetry](#)) by Estee on 15-01-2015



A Disability Poem

By: Adam Wolfond

big stairs laugh at him..
 Because hard to go up when you got just a wheelchair to get around in..
 I think the long road will be hard for him to travel..
 He feels like people dont understand him..
 I understand him like gains to be made in our lives just want to be interesting and loved totally..
 I could strive and make lives better

This poem was written by my 12 year-old non-speaking autistic son. He communicates on an iPad.

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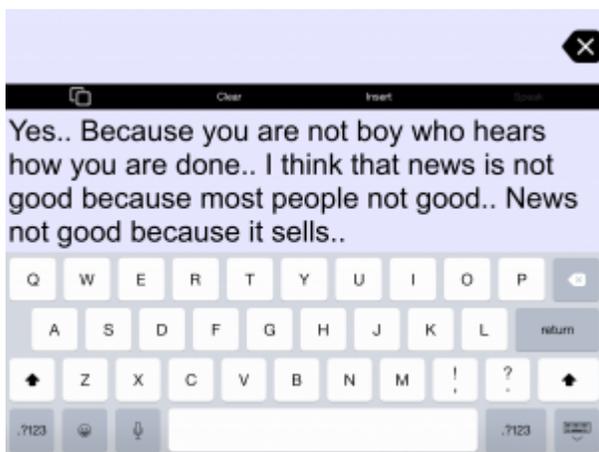
[My Son's Good News Journalism](#)

Filed Under ([autism](#), [Communication](#), [Inspiration](#), [Parenting](#)) by Estee on 13-01-2015

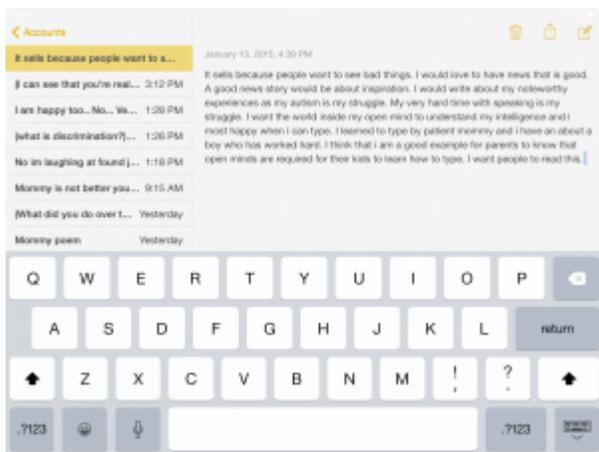
Today I received a call from the school (a good call) that Adam was upset. After given the chance to type about why he was upset, he was talking about the news and of justice. He is beginning to learn about Martin Luther King. He wrote at school:

“People keep talking shit about justice...laugh out loud in life there is no happy and free people.”
 He was asked if he saw this on the news: “Yes at home and on subway...Hang the reporters ...on the news my feeling is that it only shows really one sided opinions...great people are ignored and also sad to hear about death...”

My first instinct as Adam's mom was to help him understand bad news by thinking of how we all cope everyday. We hear of terrorism, killings in our own city, many injustices. It is hard to watch your own child be pained by it all. I told him about how I think we don't understand joy unless we experience struggle and also that we cope everyday by thinking about the people we love and the things we love to do. It's all I could come up with as he listened intently while noshing on rice snacks after school today. Then I commented on all that bad news we hear and rhetorically asked why that is. I would ask any other grade seven student the same question, so why not Adam? I commented that some people only watch the news when it's bad news. Then I grabbed my copy of the Sunday *New York Times* and we looked for some good news stories. Dismayed that I could not find anything in the front section, I leaped to the arts section and we found a story about inspiration. I thought we could go with that. Adam leaned in and I started talking about how we need good news journalists. This is what he wrote and with his permission, he does want this published on my blog:



Then *Proloquo* (the program he uses to type) jammed so we moved to a notes section and he continued:



It's hard to read from the screen shot so here it is again:

“It sells because people want to see bad things. I would love to have news that is good. A good news story would be about inspiration. I would write about my noteworthy experiences as my autism is my struggle. My very hard time with speaking is my struggle. I want the world inside my open mind to understand my intelligence and I most happy when I can type. I learned to type by patient mommy and I have an about a boy who has worked hard. I think that I am a good example for parents to know that open minds are required for their kids to learn how to type. I want people to read this.”

Adam, the good news journalist, wants you to read... and to hear.

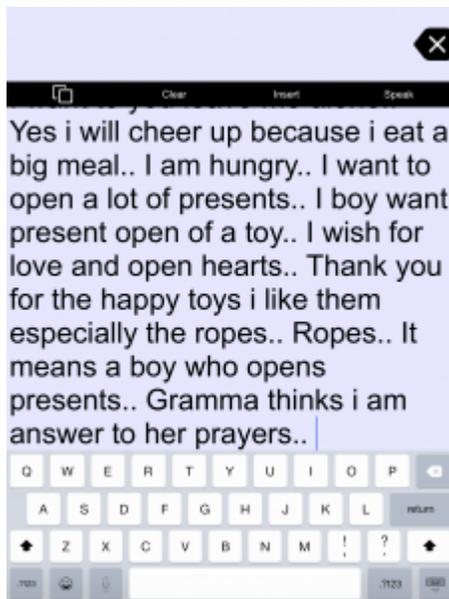
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[With Tidings of Struggles and Joy](#)

Filed Under ([ABA](#), [Acceptance](#), [Activism](#), [Communication](#), [Community](#), [Critical Disability Studies](#), [Discrimination](#), [Human Rights](#), [Inclusion](#), [Joy](#)) by Estee on 29-12-2014



This is a short post to wish all of you a happy holiday and New Year. Adam and I have had such a wonderful year – his wish now to write a book and all that progress with his typing. Finally out of the clutches of autism schools that haven't realized Adam's abilities, Adam is now doing his grade seven curriculum. Thanks to everyone who has supported us this year! It has been a joy for all of Adam's family and closest support staff to witness Adam's happiness and self-esteem that is noticeably changed since he talks more with friends and family by typing.

That said, despite proof, I am dismayed with “autism programs” here in Canada and the lack of activism we engage in as families. Compliance and normality still propel autism programs here, and rape a family's emotional and financial well-being with the empty promise of recovery, cure and a semblance of “normality.” I ache for families and more so for autistic children – many forced behind closed doors for hours a day in “therapy.” This is no quality of life, no joy. This is child-abuse and unless we begin to identify the violence of these programs, little will change. When I think of a New Year, I spend most of my time thinking about the work that needs to get done. I think about what my obligation is as Adam's parent and it's not about therapy.

It is our obligation as parents to understand the autistic community that is comprised of other autistic people. We are much more obliged to read and try to understand the experiences of autistic people for the positive development and growth of our children. The autism agenda (that is research and policy) is set by non-autistic people who are telling parents that is their obligation to do everything and anything to cure their autistic child – this spans from starving them from certain foods so they appear less autistic to forcing normalizing therapies. Even if in a situation (because true inclusion and acceptance is far from achieved in our country) where there *seems* to be little choice at but to put a child in an autism school (typically with ABA therapy), a parent must do everything to find a learning and social situation that supports difference (and I realize that using that term risks totalizing) without the propensity and impulse to normalize. Sure, these are loaded sentences that I've spent

since 2004 working through (you can read them in the blog), but they need to be because the situation is not as black and white as most media outlets (I need to write that letter to the CBC!) and research outfits will have you believe.

As a parent, I also have to pick my battles because there are so many to be had every single day. It is the reason why we can't write about every injustice everyday here on this blog (although I think about it). Instead, I am working with Adam and his team on delightful things – his words, his thoughts, and yes, his pain that he cites within a society that doesn't accept him. Even though that incites me, Adam is so full of love and acceptance for that very world in which he wants to belong. I'd like to think that maybe I've had a bit to do with that. Exposing Adam to autism conferences where most autistic people go (as opposed to the ones where researchers and parents go), has changed Adam in profound ways. I consider these to be in part, my parental obligation to him.

But speaking of battles, at the moment, I'm challenging a ski program here in Ontario that seems to be practicing a qualified inclusion. *Qualified inclusion* means that an autistic person needs to be independent before the right to participate. I'm trying to explain to these folks the meaning of what I call for now, "enabled participation." This suggests that many folks require their own chosen support staff (chosen and employed by the autistic person) in order to participate in ways also chosen by them. This process takes time. Consent and choice is a multi-faceted process – not necessarily a *yes or no* answer. When someone is challenged with verbal communication, they require many opportunities to respond to how they want to live their lives. They require people who believe in them and who know how to support their movements and communication.

When I mentioned to this ski program that excluding autistic people from autism programs is discrimination because it is qualified on the concept of normality, I received an email that Adam would be accepted on the ski hill. Since then, however, I've received an email that Adam will "be assessed." At the moment, those criteria for assessment remain invisible to me; they have not disclosed their terms and I may only assume that independence is top of their list, even though they have accepted him with his assistant on the hill. **Such assessments need to be fully transparent.** When they are, we have the right to critique them (because we know that all assessments are based on discrimination and bias – that only verbal, normalized ways of participation and response are acceptable). I am not only a parent, but a scholar in this field being talked down to and to some extent, manipulated. One would think that many-a-program, to avoid human rights complaints in the future, would tap my knowledge of policy and law and how to better "the autism program." Autistic folks and some folks working in Critical Disability Studies are able to provide this input for policy-making and this needs to be harnessed. But...

This is the struggle that we all face as parents and we have to understand that the rules are set by non-autistic people that want to make systems that befit them, not the autistic person. Remediation, cure, recovery, normality, independence – these are NOT criteria for inclusion. This is not substantive equality in the legal sense. Substantive equality enables the disabled person in their disability to participate as they are. So, I've targeted a battle, a struggle. It is a frustrating process to trouble such organizational policies, but this is a real job as parents. Don't buy into the rubbish that autistic people are trouble and the "problem" of autism must be eradicated. That's a backwards way to look at the issue. Instead, as parents who have long-supported damaging policies and educational/therapeutic models that autistic people have long been critiquing (as they have been hurt by them), it is time we turn our minds and our hearts to supporting our children, no matter what age, to change the rules that have long excluded them.

To that, I want to end by reiterating Adam's Christmas wish that he typed on Christmas eve: "I wish for love and open hearts."

One must also believe that open hearts may open doors too. Wishing EVERYONE some joy amidst these continued struggles.

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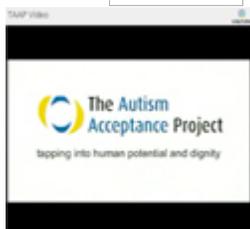
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About Me



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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The Joy of Autism:

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.

The Joy of Autism

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