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Talking About Autism & Building Community

Filed Under ([Autism Theories](#), [Autistic Self Advocacy](#), [Community](#), [Language](#), [Media](#), [Research](#), [Uncategorized](#)) by Estee on 11-11-2012

How can *The Toronto Star* and by many autism charities address the diverse needs and views of the autism community? My concern is that there is little (if not any) of critical disability perspectives. Typically, journalists run to autism “experts” with medical backgrounds and this becomes the only lens through which we have come to understand and view autism. Autism, a classification imagined and made by humans, has become reified. This essentialist view is the most troubling for our community.

My questions of late are: How can we facilitate a respectful discourse among autistic people with different experiences? How can we include non-autistic family members into the dialogue who are also stakeholders, but whose very involvement in autism charity (which directs research) can be considered based in positivism and reflective of an imbalance of power? In other words, concerning the latter, as non-autistic parents and medical “experts,” we impose a concept of normalcy that we are discovering through autistic communication of experience that, in fact, is different from how many of us non-autistic people view things. We (typicals) consider our viewpoint over and above the experiences of autistic people. We produce knowledge that is language-based and that is taken as more true and accurate. I’m also very curious how we all appropriate such impositions upon our own identities? For instance, if you are given a narrative about yourself (autistic or not) and how you must be, do you then turn it inward (this has also been referred to as [internalized ableism or oppression](#))? How does this effect the questions posed here?

Autism charities, researchers and news media need to consider these questions to reflect the broader autism discourse, even when many views run counter to their marketing campaigns and economic research interests (or should I say, *especially when*). By doing so, we may discover ways to better address the real needs of autistic people specifically. I’d like to see autism charities take up this dialectic discourse. It doesn’t have deadlines or meet fundraising goals, but this is what our community needs the most. I get concerned when autistic individuals are folded into big charities largely populated by non-autistic interests.

Feminist research has pointed to a constructive confrontation. “bell hooks (1990) declares the need for ‘meaningful contestation and constructive confrontation between different perspectives and urges the creation of safe spaces where critical dialogues can take place between individuals who have not traditionally been compelled...to speak with one another.’”(Hess Biber, Leavy, 2007)... constructing a space that is open to dialogue across... voices are granted equal air time, we actually build community...” This comes from feminist research methods which has changed the way we have been able to do research. Both feminist empiricism and emancipatory methodology can provide useful examples to the way we approach autism research and community.

Reference:

Sharlene Nagy Hesse-Biber & Patricia Lina Leavy, *Feminist Research Practice*, London, Sage Publications, 2007.

[If you are interested in a Media Analysis of Disability, See the Research done by Disability Rights Promotion International.](#)

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[Exporting The Autism Genome Project To China](#)

Filed Under ([Newgenics](#), [Research](#), [The Autism Genome Project](#)) by Estee on 10-11-2012

Tagged Under : [The Autism Genome Project](#)

The Toronto Star has dedicated a series of stories about autism. It's cheaper to hire a scientist in China — about \$16,700 a year reports the Star's Tanya Talaga. Autism...the "creeping, silent epidemic," (yes that language is still being used which should tell us that the reporters aren't reporting from a critical perspective), and it "needs to be cured like cancer." Bring on more puzzle-washing – Autism Speaks still runs its campaigns like the very controversial cancer charities (aka: Pink Washing).

There's no mention of how the autism category keeps changing with the years and changes with society's fears and imaginings. There's no interviews with autistic individuals (yet), and none from the disability rights movement to support autistic people. I'm hoping they will come out to support us.

Like our economy, we focus mapping autism genes now to China — the company BGI has apparently very big machines running twenty-four hours a day, seven days a week to break down DNA. BGI has "mapped the genetic code of the giant panda, a grain of rice, a silkworm, soy, tomatoes, chickens..." Dog gone it, let's find the hundreds of genes to cure autism and then the economy will be well again.

I mean, isn't this what it's about? It's certainly on our minds with the "fiscal cliff" just ahead. "Most children with autism are rejected by kindergartens and schools...staying home becomes the only option for a large majority of these children...by leaving them on their own, these children lose all chances of developing their potential talents that they originally might have," reports Tanya from the Star.

Let's break that down. Yes, access to schools is a big problem. The Supreme Court of Canada just ruled that public schools now have an obligation to accommodate to which [The Globe and Mail editors reported would "bleed" from other programs](#). The Globe editors stated that the Supreme Court "overstepped their authority," but I wonder if they would have said the same had the ruling be in favour of segregating children with special needs. After all, the Toronto District School Board just cut its special education programs and Educational Assistants as a cost-saving measure. Children with special needs are expendable. It seems children with special needs are a huge economic burden, or so think the Globe editors and a whole bunch of other people.

Next, I'm wondering about those talents, after all. The Star says that autistic children have "potential talents" that they might "originally" have. Is the writer suggesting that autistic people have talents if they were to become normalized or that autistic talents in and of themselves are not being nurtured and educated? Is the journalist accepting that autistic people have any talents or potential? If so, it would go against Globe Editor

notions of talent and shall we say, productivity — so central to our epistemological understandings of shall I put it, the industrious person serving the economic well-being of the state.

Finally, and I will be writing more posts in response to The Star's one-sided, unbalanced reporting so far, is this then the reason to cure autistic people; because it's hard to get into schools? This for me is the most frightening absurdity of the article. It is the notion that the blame (and we've tried to blame mothers, and now it's the old fathers), on the individual body. The onus is on our bodies to change, not on society to change it's attitudes and systems to support autistic individuality and yes, potential — body-politics indeed. Further, the fact that we've exported this work to China where people are worked to the bone in huge factories, does nothing to soothe me or make me happy about finding the autism genes. It points so strongly to the fact that we have exported to China the creation of the great Newgenics machine, and we do it gaily. Think of China and sex selection and then to the issues that if say, autism is found to be more common in boys than in girls, that would make sex selection likely, okay.

I think that the autistic self-advocacy movement and allies have to do something much greater now . We are doing the hard work for sure, but these large spread gigantic projects without equal critical reflection makes me worried and I hope you are too. I think we have to gather to run a critical reflection campaign devoid of propoganda. We want society to not just see us and help us for who we are, but consider our rights to be who we are and to have assistance. First, we may wish to begin by using The Autism Project as a platform as the *creators* of the autism “problem,” not autistic people. Autistic people and families require a set of complex supports and understandings also because not every autistic person or family is alike. I would like to ask reporters to do a finer job of doing real, even emancipatory journalism and not spectacular reporting from a neurotypical birds-eye view in the name of selling more papers.

Upcoming in The Toronto Star's Autism focus will be topics on “diagnostic odyssey, navigating school, transition to adulthood, mothers on the spectrum, ageing with autism.” We'll soon see how the stories are covered, and I'm sure there will be stories that we can all relate to. I want you to watch, however, for *who* and *what* will be blamed in order to solve the autism “problem.”

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[A Short Blurb on Language and Citizenship](#)

Filed Under ([Language](#), [Research](#)) by Estee on 09-11-2012

Reading, reading. Writing, writing. I can't believe I've almost finished a third of my M.A. and applying for Ph.D. We'll see how all that goes. In the meantime, Adam and I feel co-joined. What do I mean? Well, as always I adore him. I need to put more of my own words to how I may move around him and how I see him move around me, how we can make each other happy (or sad). I never stopped joining him, nor him, me. Is this simply a mother's love talking? The nuances of our communication — this is what I try to put words to. My language doesn't do this justice. In lay terms, we interact with our surroundings, we “dance” around each other in a type of language. What is language anyway? “The forest thinks in trees,” I'm reminded. I'm not a philosopher, yet find myself needing to enter. I'm trying to resist names-of-things, for things; to reify. Adam doesn't do this. Why must I?

I stand and wait in a grocery line. I hear people talking about the autism spread in [The Toronto Star](#) today. I haven't read it yet. I will. Like a car accident I am compelled to look. We are teaming up with China on autism

science? What will genetics do to one's right to live and be? How will this shape us? "That's great," I hear someone say. I'm not so certain it's great. Viscerally, there's something wrong. I feel it, and it's not with Adam, not with autism. There is something amiss with how we value, who we value, who gets to value... people.

I am intrigued with Barnbaum's analysis of theory of mind theory. I am still thinking about it in creative terms — the way I feel and interact with Adam, typical English language failing me, of course. Is it possible to create a new language with my translations and his?

While the following premise rests on the theory, I feel it can be also applied in general terms. In other words, I feel that people have a right to be disabled. Everyone has a right to equal citizenship and we need to unpack how we arrive at capacity/competency citizenship-notions because at the moment, autistic people are not considered (or treated as) equal members of society:

...persons with autism are individuals, with personalities and preferences just as varied as those of the non-autistic population. It is a similar moral wrong... that persons with autism should be valued because they make non-autistic people better... to foist a "cure" on a person with autism fails to recognize him as a person in his own right, because that cure assumes that the person would be better off cured. There is no reason to assume that once theory of mind is restored that an adults with a mature set of preferences would undergo a personality shift such that he would suddenly come to enjoy the world of mentalizing. If a member of the non-autistic population were confronted with a comparable option — 'Let us change you fundamentally, and trust us, you will come to love your new life' — we would find this a horrific violation of that person's autonomy. The person's integrity as an autonomous individual would be compromised... curing cancer or restoring sight to the person who was blind would not fundamentally change that individual qua person. But restoring theory of mind would... An ethic that requires the non-autistic population to respect the differences of the autistic population places the burden on the non-autistic population." (Barnbaum, 2008).

Reference:

Deborah R. Barnbaum, (2008), *The Ethics of Autism*, Bloomington: Indiana University Press, p.206.

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[New Autistic Self-Advocacy Projects Worth Watching](#)

Filed Under ([Activism](#)) by Estee on 28-10-2012

There are those that say we don't exist. There are a few who says neurodiversity is simply an ideology and not about "real" people. Those in the videos, they claim, aren't autistic at all. They are fakers. They don't have it as bad.

There are people who continue to parse hierarchies of suffering in order to make a case that they are more right and the rest are wrong. Those who claim privilege of declaring a "truth" or "reality" should be approached with caution.

To that end, I invite you to consider what makes a social movement? What makes a culture? If shared experience, arts, space, embodiment, to name a few attributes we might use to describe them, then I think the

continued affirmation of autistic existence that has created a neurodiverse culture or movement (that is the label as it stands today anyway, so let's go with it) can expand our understanding of human difference and the challenges that many of us, or our loved ones, face. We are all on the ability-disability continuum by virtue of life, ageing. While I do not claim to share the exact embodiment and experience of my son, I share the effects of his disablement in society every day. Considering the personal and shared experience of disability might be a way that we can forge empathy, sensitivity and new understandings. We have so much to share and discuss and there are many serious issues facing us.

I introduce (to those who haven't discovered them yet) two new autistic self-advocacy organizations (this first one is a project OF The Autistic Self Advocacy Network), [The Loud Hands Project](#),



[and Autistic Intelligence Org, a mix of autistic self advocates and allies.](#)

Also check out the [Autistic Passing Project](#)

I'm enthusiastic also about the age group of some of the new autistic self advocacy orgs, projects and blogs that are sprouting into public view. It's not going to be easy. Autism organizations have racked up a questionable history, and there are many issues that we need to trouble and talk a lot about. Claiming identity and being proud of it is something personal as well as communal. Self identity and embodiment is also shaped by challenges, pain and even suffering — within the body and outside of it by the barriers we claim to belong to social construction. Organizing can be a way to welcome more people into the discourse. Embracing all of the aspects of being disabled or impaired is a way to be inclusive of everyone who has a stake in this.

I think all of us should encourage and support the efforts by autistic people. Projects help us to work out the way we think and feel about our situation as well as working for needed supports and asserting rights. If we are to critique them, let's do so with respect. I think the purpose of self-advocacy movements has been largely misconstrued (or not even understood in a culture that both raises money for curing just about everything and proclaims that other bodies outside of their familiar own are “tragic”). We need to work on improving our efforts at enabling respect for all human life without demeaning or belittling an assertion of an autistic identity (if one chooses to self-identify as such) or reinforcing the power structures that have oppressed disabled people for hundreds of years.

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[Goodnight Moon](#)

Filed Under ([Institutions](#), [Love](#), [Poetry](#)) by Estee on 26-10-2012



Goodnight Moon
in the rocking chair,
your body cradled in the
safe bed of my arms.
Now your cherub cheeks
fall.
Soon a deepening voice
will sweep like a brushstroke
and we'll forget

pointing tiny fingers finding little mice
tracing the arc of the cow
to our song;
a coterie

How can time move forward
in your face,
vibrate in your body
yet remain still in your room?

A page turns slowly,
please slowly.
Your head now fits
In the crook of my arm
before you sleep.

In the schoolyard
we play in chilly air.
Blustering wind tears leaves
like perforated certainty.

The helium voices chatter
on the opposite side of the park.
You silently climb the slide.

They found the same mice,
traced the same cow,
recited the same rhymes and
dreamt of red balloons.

Still now...
In a special school.
For safety?
Whose safety?
Maybe we are safe
I can't say for certain.
I need more time.

Bulldozers nearby
tear down and
build up concrete progress.

What are we making?

Remember
the other little children behind locked doors
who never came out,
who never saw parents,
who were never cradled to goodnight,
who slept under the same moon.
Was it really so long ago?
This echoes.

Huddled are we –
rocking,
enveloped by quiet night
in our own peace.
Slowly, please slowly.
I will love you forever.
Goodnight.

Goodnight Moon - Hila Plitmann



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[Disability Studies in ABA practice](#)

Filed Under ([ABA](#), [Critical Disability Studies](#)) by Estee on 07-10-2012

“The voice of disabled people should be present in both disability studies and applied approaches to disabled people, but the voice should take different form in each. The influence and direction of disabled people should permeate the applied fields. If rehabilitation professionals really believe in self-determination for disabled people, they should practice what they teach by adhering to an active affirmative action program in their own departments; by adopting the books and essays of disabled people into their curricula; and by demanding that disabled people have an active voice in conference planning and on the platform at conferences. In the liberal-arts active voice, the creative voice, the narrative, can be articulated in the humanities, and in qualitative and interpretative research in the social sciences.” — Simi Linton, *Disability Studies/Not Disability Studies*, (p. 141-142).

I would like to *very* briefly discuss the current qualifications of becoming a Board Certified Behavioural Analysis – the practitioners of the most popular therapy for autistic children in Canada which is Applied Behavioural Analysis. It is an excellent topic for further discussions and research into clinical and educational rehabilitation in the field of autism in Canada which support a medico-pedgogical approach that has become problematic for autistic agency.

This from [The Insitute for Applied Behavioural Analysis](#):

DEGREE VERIFICATION: ALL applicants for eligibility to sit for the examination for Board Certified Behavior Analyst MUST attach documentation that they have a graduate level degree (master’s or doctorate level) in behaviour analysis or a related field, as recommended by [ONTABA](#).

[An example reading list which is telling of the area of focus is here.](#)

Here is a description of ABA from [ABA International Org](#):

As in other experimental sciences, research is usually classified as basic or applied. In behavior analysis, basic research attempts to identify principles underlying behavior change. For example, basic research may attempt to improve our understanding of reinforcement or shaping.

Applied research attempts to identify effective ways of dealing with behavior problems in schools, clinics, workplaces, and other settings.

Recently, I had a private discussion with someone who is to become a Board Certified Behavioural Analysis who has a personal interest in critical theory and interpretations of disability. This person was having some major difficulty with the attitudes and procedures surrounding the approach and decided to take the interests further. There are a few people in ABA who have endeavoured to study critical interpretations of disability studies for similar reasons. While this individual remains a practitioner, it was conveyed to me that allegedly, a Master's degree in *Critical Disability Studies* (or I gather any Liberal Arts studies) will no longer be accepted. (Note that CDS falls under the Faculty of Health at York University, but is a multidisciplinary area of study). Rather degrees in support of the psych-sciences are necessary for becoming a BCBA (as they are for other rehabilitative professions). I think it would be an important research direction for someone to examine this further, and to invite those within the field to engage in discussions why a critical study of disability is important to the field of autism education and inclusion and social equity in the same way Simi Linton discusses in the quote I began with in this post.

The criteria for acquiring a BCBA certification is a Masters degree. However, the BCBA programs now direct it's applicants seemingly away from Critical Disability Studies towards "Applied Disability Studies" in some academic institutions like [Brock University](#).

Linton's article is titled *Critical Disability Studies/Not Disability Studies* to highlight areas of difference between the clinical practice/approaches between one where the voices of the disabled are included, not objectified. In thinking about inclusion in making clinical practice better, she says, "feminist scholarship has also turned the entire academic curriculum inside out to reveal the epistemological consequences of the androcentric biases in the knowledge base" (p. 142).

She also highlights the objectification of disabled people through the sciences and that it "can be redressed by developing scholarship from the position of the disabled subject; by developing alternative methodologies to the empiricist approaches that have dominated the study of disability; by developing an active voice in the humanities; and by breaking down stereotypes through the analysis of metaphors, images, and all representations of disability in the academic and popular cultures." (ibid).

Do ABA practices continue to perpetuate bio-determinist views; to "explain human behaviour and achievement in terms of biology?" (ibid). While I would argue that yes it does, I would also like to suggest ways and open up the discussion with clinical practitioners to not simply objectify the literature, performances, art, and other contributions for *analysis*, but to consider ways of including both critical interpretations and the inclusion of autistic people as part of our learning and practice, and in shaping the practices that have been so often used *on* people with autism. I agree with Linton that there are many people in clinical fields working for political change for the disabled, but as she importantly notes, it's not because of the knowledge acquired from the applied sciences, but from a "personal and moral commitment to improve the lives of disabled people." (p.148). Further consideration into multidisciplinary curricula in the area of clinical practice should be discussed. Including autistic people and work is a way towards creating supports that could lead to more effective and supportive methods that also acknowledge autistic challenges, strengths, and inherent civil rights.

Reference:

Linton, Simi. "Disability Studies/Not Disability Studies" in *Claiming Disability: Knowledge and Identity*, pp. 132-156, 1998, New York University Press.

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[Reflections on the Acceptance of Disability in Society](#)

Filed Under ([Acceptance](#), [Autism History](#), [Autistic Self Advocacy](#), [Critical Disability Studies](#), [Disability History](#), [DSM V](#), [Ethics](#), [Inclusion](#), [Research](#)) by Estee on 06-10-2012

Is there a place for the disabled in society?

The purpose of the title is from historical readings that the disabled in history were displaced and living on the margins of society. Who were considered/are considered valued members of society? Societies have been obsessed with placing the disabled into a variety of contexts that justifies human existence, or fears (demons, monsters, mad, deviants) making the normal the privileged members. Without a comparative measure, as it were, what would we humans deem ourselves to be?

I have a series of questions that I'll be considering (probably for a lifetime). Feel free to try and contribute thoughts in the comment box.

Pro/claiming Autistic Identity:

Is claiming biological identify leading to another possible eugenics movement? Is there a danger to biological self-identification? How important are self-identification and self-advocacy and pride-movements?

Are pride movements perpetuating the dis/abled dichotomies that already oppress? Do you think they have a positive purpose? Should there be a point at which we stop advancing pride movements, in other words, move beyond them? When is a good time to do so?

How important is the label autism to accommodation if autism is a social construct? (It is). Where "special" and enforcing "inclusion" have already proved challenging, maybe even impossible thus far, is it so because we continue to place the disabled out of the confines of the norm. In other words, are we continuing to perpetuate a false dichotomy that does little to value and serve, but more to segregate and isolate? By wanting inclusion, we are saying we are excluded? Does this stance further the goal itself, or not any longer?

Who Gets To Produce Knowledge About Autism?

The DSMV, behavioural analysis and observation, and the categorization of people.

Who gets to diagnose whom? Who gets to produce knowledge and categories about autism? In the past, and to a large extent today, it is non-autistic or "normal" people and we now witness a gradual inclusion of disabled "voices" to this mix. Do disabled individuals appropriate notions of impairment and abnormality enforced by long-held categories made originally by people who have not had disabilities? After all, autistic people are still largely tokenized minorities among autism charities, autism committees, and as participants in autism research studies.

Accommodation and Acceptance:

To what extent is the citing of needs/impairments an important part (or not) of acknowledging that we are all part of the abled-disabled continuum, which herein, I have already parsed?

Do you think the term autism and/or disability will exist one hundred years from now? Or are we a society that simply wears the same dress, just in different colours?

Have we learned anything from autistic self-advocates that assist us to simply accept autistic individuals and value the right of all people to exist, be educated, and be valued, no matter what level of disability, in society?

Utopias and ideals have perpetuated individual and societal notions about what we should be – what we are versus what we aspire to be. To what extent may this continue to be a driving force (as in survival of the fittest) under an capitalist/economic lens, and where are we now with this “force” in viewing the disabled as part of this? As disability has always been a part of human existence, despite eugenics movement’s attempts at normalizing society and eradicating “deviant” people from the norms, how far have we come to accepting, embracing and valuing human difference? After all, while the eugenicists caused great harm to many people, and have continued to do so as a legacy, they didn’t succeed in eradicating human difference.*

Reference:

*In reference to the eugenics movement from Davis, “Constructing Normalcy” in *Enforcing Normalcy: Disability Deafness and the Body*, pp. 23-49, 1995:

“The conflation of disability with depravity itself expressed itself in the formulation ‘defective class.’ As the president of the University of Wisconsin declared after World War One, ‘we know enough about eugenics so that if the knowledge were applied, the defective classes would disappear within a generation.’ At it must be reiterated that the eugenics movement was not stocked with eccentrics...Rockefeller, Churchill, Roosevelt, H.G. Wells, John Maynard Keynes”...among a longer list. Some food for thought when thinking about such questions.

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[Creation by Everyone: A Mandate for Building Inclusive Community?](#)

Filed Under ([Inclusion](#), [Uncategorized](#)) by Estee on 29-09-2012

I love my City of Toronto where I was born and have lived for most of my life. I’ve lived on the outskirts and downtown and midtown and I never loose interest or discover new pockets of Toronto. I never liked “bedroom communities” and I don’t thrive well in them. As an art curator, I used to cite the many aesthetic issues as well as social consequences of bedroom communities when I had my own newspaper column, even though most of us don’t have any choice to live in them, as was the situation with my family. Others claim they prefer not to live in “the big city,” and that’s fine too. For me, however, I enjoy being able to walk out the door and take a few steps to the corner to get what I need, to walk or bike to, and be among people. When I talk about my city, I’m really talking about community and there are many notions of community that are important in discussing inclusion and people with disabilities.

After a divorce, I had to move back uptown. My partner and parents live downtown and I am backing-and-forthing. I’ve envisioned Adam’s future downtown, where transportation is accessible, where the chances of

having employment could be easier because of accessibility to them; where support in the way of people may be more readily available, and for him to also feel a part of the daily pulse of life among his fellow citizens. I take it for granted, perhaps as a matter of necessity or as a premise unto itself, that he is a valued member of this community, even though we encounter many barriers and prejudices — sometimes subtle and other times overt. It's an ideal, of course. At some point in the near or distant future, when our lives don't demand the need to be uptown, I will move us mid or downtown again. Accessibility and being with people is key for me, my vision for Adam, and for our growth as a family that fit with my values.

Along Christie (it's a street in Toronto), a quote from Jane Jacobs remained unfinished graffiti on a cement partition along the sidewalk. For nearly a year, only half the sentence was written, waiting for someone to bring a can of spray paint and fill it in. "Cities have the capability of providing something ..." I felt compelled to drive up and down Christie for the past several years not only because it seems to be one of my favorite areas in Toronto, and one of the first points of arrival when my dad immigrated to Canada, but also because I wanted to see if the sentence would ever read complete.

About this time last year, someone filled it in, but it was incorrect. A few weeks later, it was erased. I waited again and kept driving. In the true Jane Jacob spirit, the practice of finishing the sentence, albeit a quote from her, had to be accessible and inclusive. (Thank goodness Mayor Rob Ford's attempts at erasing all graffiti from the city didn't strike this wall). Finally, a few months ago, the sentence was completed:

"Cities have the capability of providing something for everybody only because, and only when, they are created by everybody."



The notion of creating and including everybody is appealing to me, and I gather for this reason, an idea was germinating. How can we cooperate and create our communities that support and include autistic people? Is there a way to use Jane Jacob's model and discuss the pitfalls and possibilities of creating what we need for ourselves, outside of the systems that can sometimes oppress us? Is there a value to doing both? These are some of the questions I have in disability policy. I'd like to use this blog as a little laboratory for discussing these ideas, and for practicing them.

Jane Jacobs: Neighborhoods in Action



In Michael Prince's paper, [Inclusive City Life: Person's of Disabilities and the Politics of Difference](#) (Disability Studies Quarterly), he highlights some of the issues raised by a citizen in an open letter to Canadian politicians:

I used to adore Toronto. As an able-bodied person, it was relatively simple to get around and I appreciated having access to all Toronto had to offer. I didn't pay attention to the lack of elevators, escalators and ramps. I am 30 years old and have multiple sclerosis now. I am no longer able-bodied but disabled. These days I use a cane or walker to aid my gait, making uncomplicated things more demanding. I now despise Toronto due to its lack of accessibility. I miss the things I once loved and want to enjoy them again but I cannot because establishments are inaccessible. Why am I being penalized for a disease that caused me to become disabled? Why is this kind of discrimination allowed?

His article highlights the ideas of various civic leaders and thinkers and some of the issues that confront people with disabilities in cities. One of them he cites is Iris Marion Young, the author of [Justice and the Politics of Difference](#) to present a series of interesting premises' in the creation of accessible cities/communities:

"In the city," writes Young, "persons and groups interact within spaces and institutions they all experience themselves as belonging to, but without those interactions dissolving into unity of commonness" (1990: 237). Several premises are contained in this statement. One is that people, as individuals and in groups, have the capacity and opportunity to participate and interact with other people. A second is that sufficient and accessible public spaces and institutions exist throughout cities to enable the being together. A democratic politics, Young stresses "crucially depends on the existence of spaces and forums to which everyone has access" to participate — to speak, listen and bear witness (1990: 240). A third premise is that such interactions generate common experiences of belonging, a basic component of citizenship according to most commentators on the topic. Certainly, for people with disabilities, these public spaces require supports, services and likely adaptations to enable all to speak, to listen and bear witness, regardless of their abilities and capacities. The fourth premise is that individuals and groups participating in such public places and institutions are able, at the same time, to maintain a sense of their own distinctiveness, special status or group identity. Perspective 4 therefore contains, as do the other perspectives, a number of empirical perquisites, behavioural expectations and normative claims.

While the ideals of Jane Jacobs may not as of yet have reached our cities and communities, I think her notion of "creation by everyone" is a vital link to thinking about how we build them.

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[The Culture of Abuse?](#)

Filed Under ([Abuse](#), [Discrimination](#)) by Estee on 28-09-2012

This video from CNN, sadly, is just part of the abundance of abuse that autistic people face every day. While we watch the acts disclosed to us here, it is important to note this perverse normalcy of our culture of abuse and ask ourselves the question, to what extent are attitudes about autism contributing to systemic “sickness.” In other words, to what extent has neo-liberal society, the one that values independence under a capitalist system, promoted maltreatment and abuse? To that end, in what ways has “normal” society become sick? A few more reflections after you watch this:



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In my critical disability studies, I discuss these issues alongside disabled people who have also experienced abuse. I also sit in classrooms where people who work within the systems, including Applied Behavioural Therapy (ABA) have listened to the accounts of inside operations. I’m so glad members of the ABA community, btw, are looking at autism education from a critical disability studies perspective.

By way of these first-person accounts, and by case studies such as Paul Cambridge’s *The First Hit: a case study of the psychological abuse of people with learning disabilities and challenging behaviours* (1999), it is clearly evident that caregiver service providers do not have a proper system for the protection of whistle-blowers; that the caregiving industry is vastly undertrained and underpaid. The service delivery system requires a major audit. Here a quote from a service provider:

“I was told to do the first hit and then it would be OK...X never expressed any feelings of liking for the people and had complete control over them. [this meaning the intimidation practice of the more

senior staff to the newer staff]. You weren't allowed to show openly that you cared." (Cambridge, 1999)....

"Newly-appointed staff were placed in difficult situations, where the risk of failure was high. They also often lacked the necessary competence or experience to perform essential care tasks well. Their abilities were then challenged and they were emotionally undermined by the principal alleged abuser, a practice that was sustained by other staff in the core group who had moved from the old institution." (Cambridge, 1999).

In Toronto, we've heard of lots of abuse situations in residential living facilities. The scope of one blog post/reflection cannot encompass all the issues that are endemic/sick in our society that has laid the foundations for the way in which we employ, provide service and regard employment for clients with disabilities. If we do not value people with disabilities, we will not value the people who work within the service system which is an essential accommodation for the participation of many severely disabled people in our society. It is important to say here that I'm not at all excusing the individual acts of the abusers by stating it's just a systemic problem!

We still sequester the severely disabled. We don't want to see them. They provoke anxiety within us, and we rather turn away. Or, we'll throw charitable money at "the problem" to temporarily make ourselves feel better. This is one side of the coin. What we need is a service system we can trust, and that values the disabled (among many other points I could make here).

The way we value (or don't value) all members of our society is the linchpin of the future (bright or dismal) for pretty much all of us, not just the severely disabled. Consider that ability-disability is a continuum and that most of us will become disabled in our lifetime in one way or another (even ageing is in many ways a disabling condition), how are we supporting or even not supporting ourselves? Do we only think in terms of the individual — each one for himself? Or are bodies not only part of this continuum but also permeable bodies, that is bodies that effect each other; responsible for and to each other?

Today, I broke down in tears, which happens often when I meet prejudice face-to-face. Adam's regular doctor was not around to see him today. Adam was complaining that his ear hurt. Yet, he is terrified (and sensory defensive) of his ears being checked. Some doctors have more empathy and are better at getting Adam to agree to have his ears checked. Adam doesn't love this doctor — his memory is vivid and we've seen this one before, and he seems a little more nervous around him than I've seen him around others. It's important to note that he's not a "bad man," or anything of the sort that is so simplistic. This is to highlight the subtle nature of the prejudice and attitudes that paint "all" people with autism as one in the same. When I was there, I also wanted to discuss puberty and adolescence as I would if I had any other son. I received this response:

"Do you have any autistic doctors?"

"I've seen everybody. I sort of know of everyone here in the field," I responded a little disturbed, wondering where he was heading with the term "autistic doctors," as if they proliferate the field as answers to everything autistic.

"Well, what we know about autistics when they go into adolescence is that they become violent and aggressive. Like today. We had to hold Adam down today [to get his ears checked]. I can't do that again. He could hurt me."

I walked out, Adam in hand. When I got to the car, tears streamed. First, the doctor doesn't even *know* Adam save for the petite bundle of nerves when Adam sees him. All he saw was Adam's fear and resistance. Adam has never hurt anyone. Adam is kind-hearted, loving and happy, save for his anxiety and all that he must deal with in a world where normal is the top of the hierarchy. Adam will go through puberty like everyone else. I can't predict what will happen, except that I know who he is. I know how I was and that I was as moody as shit. Somehow, I even seem to know in my heart that everything, up and down as it will go, will be okay.

I cried for the parents who don't have the time to enter a disability studies program, or have the time to study philosophy or read about things or get in touch with other disabled people and their complex stories, although

there are more access people and resources than there ever were, so I'm grateful for that. Autistic people are available, their books are also on the shelves, their blogs accessible to all of us. Some of them will empower, many of them caution. I thought, if I didn't have my armour, what would I have made of that comment from a "medical expert" who actually knows less about autism than I do? I say that with confidence even though I stop at the point when I am fully aware I am not autistic and cannot appropriate the experience of being autistic in a highly prejudiced world.

To what end do bias and ignorance (lack of understanding and knowledge about people with autism that is dangerously over-generalized and misunderstood) espoused by some members of the medical community (and it is also important to note that not all of the medical community would say something so stupid), *create* a culture of abuse? After all, Mr. Doc gave me fair warning and can't check Adam's ears again...don't get me started on how the disabled don't get proper health care...

Reference (and I encourage you to find this one):

Cambridge, Paul (1999) The First Hit: a case study of the physical abuse of people with learning disabilities and challenging behaviours in a residential service, *Disability & Society*, 14:3 285-308.

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[The Importance Of Collecting And Preserving Autism History](#)

Filed Under ([Activism](#), [Autism History](#)) by Estee on 17-09-2012

Introduction:

You can't find a history of autism, or the term, prior to 1911 when Eugen Bleuler defined autism as a detachment from reality in terms of understanding schizophrenia. Try reaching for an autism history into the 19th century and beyond, and you won't find it, necessarily. Historians of autism, and there are few, draw upon historical figures that possess our modern understanding of autistic traits as presented in the DSM IV. Some of these historians include Uta Frith, Mitzi Waltz, Harlan Lane and Michael Fitzgerald. Waltz's book *Autism: A Social and Medical History*, is about to be released. It has been said that the practice of identifying autistic people in history is a bit like diagnosing the dead. Skepticism around the practice, perhaps assisted by current autism hype and politics, I would argue, might deter some historians from venturing into it.

In this post, I will cite the work of disability historian Geoffrey Reaume and his call for more research into the history of disability, and the proper saving of it amidst the tenuous nature of information located on the Internet. I will point out how autism history is relatively modern, how it can be in jeopardy by virtue of the "movement" for rights and recognition occurring online. To this latter point, I will mention The Autism Acceptance Project (TAAP) and its event *The Joy of Autism: Redefining Ability and Quality of Life* (2007) to illustrate how I, as its organizer and curator working with autistic board members and an autistic advisory committee, attempted to capture a recent autism history/movement by illustrating a few of the steps of assembly and dissemination as an historical exercise in itself. I attempt to illustrate potential issues and pitfalls in archiving a modern autism history. From reading Reaume, documenting thoughts, method and people is an important part of documenting history. This is already a long blog post and the topic deserves more attention than this format can provide. Finally, I will suggest that autism is still largely absent in the wider disability discourse, which might be more widely accepted if more research is done into the history of autism.

Collecting Autism History — Choices and Cautions:

The history of autism does not need to be limited to autistic people. As Geoffrey Reaume points out in his paper, *Disability History in Canada: Present Work In the Field and Future Prospects*, we need more research into the history of all disabilities including sensory disabilities, intellectual disabilities, physical disabilities, disability and eugenics, disability history as it intersects with race and immigration (and gender I would add), mad-people's history, and activist histories. He does not, however, cite autism history, specifically. As I mentioned, because autism is a very recent diagnosis (1993), oral histories and autistic memoir have coincided with a recent disability rights movement of the 1960's. These have contributed to a rapidly burgeoning Autism Rights Movement. We understand autism, therefore, in very modern terms and autism is still largely missing among a more vast body of disability history.

“In order to have a fuller sense of history, including where disabled people lead lives that are as mundane and full of contradictions as that of most people who are not disabled, a wide variety of sources need to be preserved and a wide variety of histories need to be told.” Reaume cautions us that the bulk of modern history, as it were, is locked up in our computers. One day, he argues, those computers will break down. The internet will dump our information; our emails are not printed on paper to be saved. Such correspondences have contributed to our understanding of how the disabled were treated and regarded by the medical profession. They also have illuminated the private lives and struggles of the disabled, as two examples.

This brings me to the thought of how much of our autism history, and the history of the Autism Rights Movement exploded online. Due to the very nature of computing and ease of use to communicate in this format for many autistic people, we also run the risk of losing it. It was one of the reasons I curated the exhibition during the event *The Joy of Autism: Redefining Ability and Quality of Life* in 2007. This comprised a series of events, lectures and visual exhibits.

Organizing TAAP and The Events:

As curator, (note, a non-autistic person) I attempted to capture the YouTube videos, the blogs by autistic people and autistic allies, the political debates and the resistance of autistic people to others ascribing an identity to them that was based in fascination and fear. Accounts had been recorded online as personal stories about behavioural treatment, schools, and institutionalization, parent abuse, infanticide, as well as statements about autistic perspective and personal strengths went unrecognized by the medical research community and the media. These usually took an online blog-form, although autistic people began socializing in online chat rooms and social games before then. Much of this was aimed at refuting popular mythologies that were proliferating about autism and people with autism as unaware and “not even in the room,” to describe a vacuous, unintelligent nature of autistic people.

We (interested volunteers and autistic people) exhibited important new websites and their content in a more traditional gallery-exhibition format. The exhibit was mixed with video, artwork, published work executed by autistic people on large signage, some printed on fibre glass as floating; thoughts, by autistic people, about how they had been treated and regarded. Different aspects were located in different gallery rooms at The Lonsdale Gallery in Toronto. Videos produced by autistic people and activists played on a loop so that the audience could watch as well as hear the voices of autistic people, some of them who used text-to-speech devices. YouTube was new at the time where people uploaded their videos. The generous size of the gallery befitted the echo of the videos — an autistic echo as the videos kept playing while the audience read signage and looked at artwork; a continual reminder of autistic presence. A room full of conference materials (conferences organized by and that included autistic people, such as Autism Network International's AUTREAT) was made available so that visitors could conduct their own research. A glossy magazine full of writings and artwork by autistic people as well as interviews of two major artists in the exhibition, Larry Bissonnette and Jonathan Lerman, was distributed.

To accompany the exhibition, the lecture series was held at the Al Green Theatre in downtown Toronto. We produced a glossy brochure with the artwork and the presentations of our autistic and non-autistic presenters along with the purpose of the event. We intentionally located the event in the middle of the medicalization of

autism and the “tragedy” model of disability and positioned autistic lives as a “joy.” This was done by writing title ideas down and distributing among the autistic advisory committee for comment and approval. The final decision for the event/exhibition title was reached by consensus of fifteen autistic people. The predominant othering of the autistic person was countered in the “redefining autism” part of the title in order to reaffirm agency and made the event activist in nature. It meant to *stare back* as a result of being *stared at*. Just recently, The Autism Acceptance Project which staged the events, has been recognized by The Autistic Self Advocacy Network (ASAN) as “one of the most important events in the history of autism acceptance.” This is a step to autistic people claiming their own history.

The Importance of Record Keeping:

With respect to record-keeping, we keep originals and make, then bind copies of newspaper ads and articles that gleaned a great deal of media and public attention at the time. All the lectures were taped and we will get permissions to get them posted online in an upcoming new iteration of the TAAP website. As for the exhibition, the content was photographed, so we have a few records in this format, although there are not enough to reflect the depth and scope of the exhibition itself. It is here I would recommend better photo and video recording and more thought into saving, archiving and disseminating the results and content of events. I had posted the limited exhibition photos online at The Autism Acceptance Project website (www.taaproject.com), along with the submitted artwork and writings by autistic people. Recently, as Reaume predicted in his essay, we lost that information when the website was hacked earlier this year. Not all of our content is recoverable.

Also important is the abundance of resources and contributions at **Neurodiversity.com**, the work of **ASAN** (The Autistic Self-Advocacy Network) as well as other major agencies and projects run by autistic people prior to and after TAAP. Specifically, nerodiversity.com remains one of the websites containing and assembling significant autism history that is at risk of being jeopardized if not kept in hard-copy. Specific and notable to Canadian autism history is Michelle Dawson, a Canadian autistic researcher. Her work, under the umbrella-title, *The Misbehaviour of Behaviourists*, is a significant piece of the history of how autistic people are mistreated in Canada (The Auton Case, The Human Rights Tribunal, and her exclusion at Autism Society of Canada). She has recorded her work at the website *No Autistics Allowed* (www.sentex.net/~nexus23/naa_03.html). These are only three examples of many more autistic-run online organizations and individuals — all which must be preserved, recorded and interpreted. This is something that more researchers may wish to consider.

Can An Autism History Really Exist?

“...we have to value all aspects of our past and to instil this value in others who keep these records so that future disability histories can be preserved, written and debated for generations to come,” says Reaume. “In doing so, the historical memory of our collective past can, one would hope, make for a better future where disabled people are not marginalized and oppressed as has so often happened in Canadian history. The history can influence a collective sense of identity and political engagement. It can also influence public policies that have a direct impact on people with disabilities as policy-makers learn from the past while being influenced to improve practices in the present.”

I would wager that most people don’t acknowledge that a history of autism either exists, or could exist. When autistic people take note that they “don’t exist” in the consciousness of society, it would be difficult to own a history. In an activist vein, neither the term autism nor the recognition of autistics as valuable or capable, even within the context of severe impairments, exists as a widely accepted definition or understanding of autism. Within Critical Disability Studies, there is a lack of use of the term autism as we otherwise hear of the deaf and blind communities, one might argue, precisely because there is little written about autism in history. This connotes that there is still not enough citation of autistic identity and history, even within Critical Disability Studies programs, although there is acceptance that this is an area in need of development.

As someone invested in autism, rights, inclusion and autistic citizenship and identity, I feel this absence when reading Reaume’s citations of particular disabilities written in historical contexts, likely in light of a recent diagnostic label. In Critical Disability Studies, autism is lumped under the broader label of intellectual disabilities. Yet this lumping often ignores the particular needs and struggles within this community. While

labeling can be dangerous and problematic, it can also lend itself to assisting and accommodating the unique needs of this population. Autism is unique in many respects, and requires a unique set of teaching methods, not analogous to, but parallel in terms of customization of education as we do for the blind, deaf or dyslexic communities. Autism also shares its history with the wider disability movement. It also intersects with race, gender, cultural, and socio-economic factors. It is important to note that while we share history within the context of our times, and with groups that may share discrimination issues, needs and histories are still unique. Further, not every autistic person shares the same experience, personal history, or opinion. In keeping with Reaume's call, these are some more reasons to pursue historical autism research.

So we need to keep telling our stories. Reaume cautions us, however, not to exclude or revise history. Problematic approaches to history can include hagiography (making disabled heroes), presenting disabled activists as “devoid of flaws,” or histories which reduce medical interventions as “automatically oppressive.” To this he reminds us to value “all aspects “of our history. I would add, an “inclusive history.”

Research in autism is dense with analyses of cause and behaviour. I often wonder how far we've come from The Age of Enlightenment which uses its scientific subjects to deduce not only the nature of man, but its abnormalities thereby reinforcing the concept of normalcy and perpetuating our binary understanding of disability — the normal versus the abnormal. Neuroscience inspires us with a promise of understanding our intrinsic nature and raises bioethical concerns. Typical to how we've acquired knowledge to-date in research, we use comparative scientific methods. Counter to research that merely objectifies autistic people as subjects, and normal-abnormal viewpoints, we have vibrant autistic community who argue that we are not just the sum of our genomes. Researchers often overlook autistic voices – in the various forms that autistic voice rises up — and perhaps unwittingly threaten autistic agency. It will be curious to look back at our history, if only we interpret it ethically and save it for future generations. We have to begin with the research of autism history in many contexts and keep records, preserving them from the threat of losing information on the Internet, and assert the existence and the complex lives of autistic people.

Reference:

Reaume, Geoffrey. “Disability History in Canada: Present Work in the Field and Future Prospects,” *Canadian Journal of Disability Studies* 1:1 (2012): 35-81.

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[Issues Arising From “Outside-In”Autism Research and Organizations](#)

Filed Under ([Inclusion](#), [Research](#)) by Estee on 13-09-2012

Attending IMFAR for me this year raised many more questions, if not affirmed some of my assumptions about the extent (or not) to which autistic individuals are involved in research as well as autism organizations. While more autistic people may be in attendance at conferences, or may sit as board members, issues about “tokenism” arise; to what extent do we enable autistic individuals to create a meaningful autism agenda? That is, who is establishing the questions about autism to be researched? Who is directing the goals of an autism organization?

Temple Grandin spoke at IMFAR at Toronto this year by webcam/Skype. She urged autism researchers to look at issues effecting autistic quality of life, rather than more studies on “face recognition.” Yet she did not acknowledge that many of these researchers are, a) not autistic or, b) do not practice emancipatory or

participatory research. Was this done for political reasons, or was it a gentle nudge to send more accepted research paradigms in directions that may be of use to autistic people, or perhaps an oversight? By definition,

“Emancipatory research (that is research which seeks to alleviate oppression) is critical in exposing the mechanisms for producing, maintaining and legitimising social inequities and domination.” (Ayesha Vernon, “Reflexivity: The dilemmas of researching from the inside” in *The Disability Press*.)

My assumption is that while Grandin is urging the researchers to reflect on what is important to autistic people, the model is more challenging at IMFAR which is largely based on a non autistic view of how autistic people think, perceive, function. The research was largely targeted to the “high-functioning” autistic population, likely, because this was the most effective, cost-efficient and timely way to complete the research projects. They did not employ emancipatory methods which may not use more common research designs. It is non autistic people largely determining what’s best for autistic people and the balance of power is clearly skewed — it is the researcher directing the goal of the research and the relationship of researcher-subject is established. Some quantitative research by autistic researchers has been presented at IMFAR, and we do need more in support of the issues and needs that are produced and articulated by people with autism. As non autistic people, charity organizers and researchers we have to acknowledge when we are looking from the outside-in, and consider changing our approaches in order to provide services that are directed by the autistic community.

Issues arise when thinking of involving autistic participants in establishing the research question, or the agenda of an organization. Sitting on boards with non verbal participants with significant challenges, non autistic members have to exercise patience and understanding with the length of time and the various outputs that enable an autistic person to participate, as an example. Some individuals communicate by typing very slowly, or using other text-to-speech devices. For others who do not have an organized communication system, the issue of involvement and later, dissemination of the research that is useful to autistic people becomes complex. Some have worked around the issue by stating that the autistic with the more proficient communication system is at least accomplishing part of the task of inclusion. We have to work on offering solutions to participation and autistic direction.

As the founder of The Autism Acceptance Project, I experienced these tensions of working as a non autistic person in an autistic space and tried to resist controlling the agenda, and admittedly while I sought a lot of direction from autistic people, this was very difficult to do. As an organized and fairly driven person, setting my own assumptions aside still requires me to slow down and think about my design of the TAAProject website: from to how to include autistic individuals in a way that they can direct the project while using my skills, and theirs, to developing the tools to perhaps target some of the issues that are barriers for all organizations that do not fully integrate and employ the needs and issues of our autistic community.

In addition to the intensive labour and time required to set up emancipatory research projects and the change the structure of autism organizations — both which seek to ameliorate the social oppression of autistic people — there is little capital out there for this. The larger autism charities focus more on causation research and are better capitalized as opposed to volunteer autism organizations more often led by autistic people (Arnold). So, if you are a researcher endeavouring to do this kind of research in autism, The Autism Acceptance Project would like to hear from you.

“Disability research should not be seen as a set of technical objective procedures carried out by ‘experts’ but part of the struggle by disabled people to challenge the oppression they currently experience in their lives.” (Oliver, 1992).

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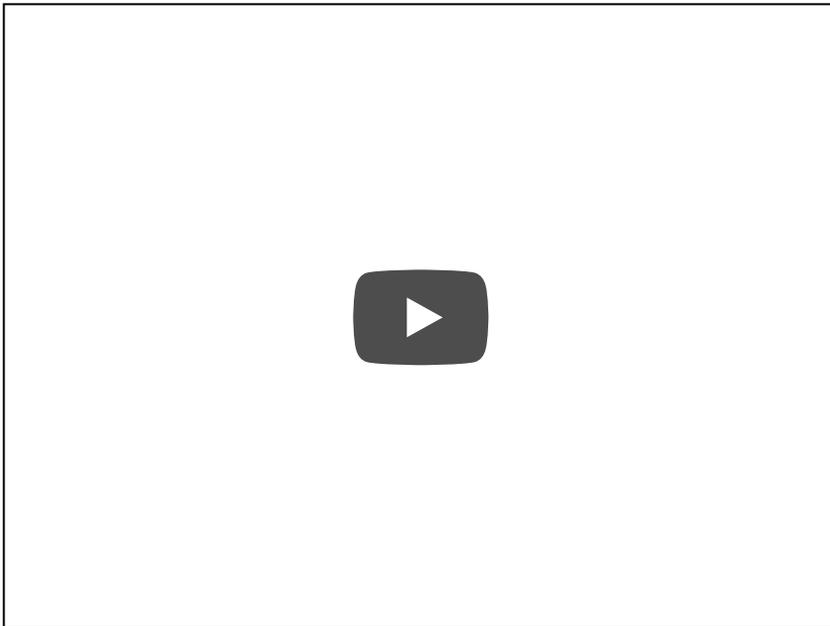
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[The Adam Family](#)

Filed Under ([Ableism](#), [Autism and Employment](#), [Autism and Learning](#), [Communication](#), [Critical Disability Studies](#), [Family](#), [Inclusion](#), [Inspiration](#), [Joy](#)) by Estee on 10-09-2012



We are The Adam Family. As we grow into our lives with autism, it becomes increasingly difficult to see the “normal” world as the actual opposite of what it purports to be by that label. The more on the margins of society we seem sit, the more absurd “the rules” seem to be. In thinking more about Inclusion and The Canadian Charter of Rights and Freedoms, I realized that the idea of Adam having his own family, therefore, is not a sight-out-of-reach. It is a possibility, his choice, and right which must be enabled and protected. How, on earth, if you are a new parent to an autistic child, particularly one like mine who has limited verbal ability, could this be possible? Well, it may seem a bit quirky, and some would be up-in-arms against us citing us as a future social welfare burden, but first let share this take on The Addam’s Family series:

Much of the humor derives from their culture clash with the rest of the world. They invariably treat normal visitors with great warmth and courtesy, even though their guests often have evil intentions. They are puzzled by the horrified reactions to their (to them) good-natured and normal behavior since they are under the impression that their tastes are shared by most of society. Accordingly they view “conventional” tastes with generally tolerant suspicion. For example, Fester once cites a neighboring family’s meticulously maintained petunia patches as evidence that they are “nothing but riff-raff.” A recurring theme in the epilogue of many episodes was the Addamses getting an update on the most recent visitor to their home, either via something in the newspaper or a phone call. Invariably, as a result of their visit to the Addamses, the visitor would be institutionalized,

change professions, move out of the country, or have some other negative life-changing event. The Addamses would always misinterpret the update and see it as good news for that most recent visitor.

(Wikipedia)

I wish we could all live with the same conviction. When parents get frightened about autism, it's usually because of fear for the future – will my child get married, go to school, have friends? The pressure to conform the unconformable is immense. For many years I quietly shared the same worries, although I feel my worries were more rooted in society's acceptance of Adam. My viewpoint is shared with the more widespread social model of disability — that our modern definition of disabled is a term to describe the social barriers that make a life living with an impairment exclusive/segregated. There are naturally going to be times in the beginning of having an autism diagnosis, most-likely if we've never experienced disability before, that we will be thinking in terms of our own lives, how we grew up, went to school, made friends, had our first boy/girlfriends and later, maybe even got married and had families of our own. When we don't see our children doing the same things in typical ways, we worry for them and maybe even for ourselves. The life trajectory is one that our society uses to plan every stage of our lives from how we go to school, to what we are supposed to become, to building our retirement nest-egg.

We expect to be on a path that is economically driven. We are raised to comply, to be a part of society. About a century ago, the formation of "school" was intended to prepare children for later entrance to the military. Today, we plan for our babies at the get-go with pre-school and envision them at Harvard – the ultimate preparation for a new kind of regime. We prepare our little ones for the economic march into consumerist culture. Our frame of reference for understanding is capitalist. [Erich Fromm](#) believed that we tend to categorize individuals "according to various types of status, to glorify superiors, and to look down on those who are regarded as of lower rank (e.g. persons belonging to other 'races') – must be understood in light of an authoritarian upbringing, which in turn is associated with other general authoritarian tendencies in the workplace and society in general." (Alvesson and Sköldberg). That "authority" well, to coin James Carville, is "the economy, stupid." (I'm using Carville's words and am not implying anyone is stupid. I want to acknowledge the sensitivity I actually have when people use words that can be used violently). While resources are an issue for supporting autistic individuals, others site Liberalism as a issue as it put great stake in "liberty, autonomy and choice... Given the reality that some persons with disabilities will necessarily be in situations of intense dependency and reliance, can liberty and autonomy — with their emphasis on freedom from — really be the lodestars liberalism has assumed?" (Devlin and Pothier).

When we bring an autistic child into the world, we don't fit the model pretty much from day one and especially after our children receive their first official diagnosis. We try to squeeze into charitable models for definitions of our existence, but they feel uncomfortable, placing us in (again) subordinate positions yielding to the "power" of the do-gooder/philanthropist and the "experts" in receipt of their research funds – an unequal relationship. Our families collide with ideologies that we are forced to question. Not "fitting in" is another way of describing how we are placed on the margins of society, or discriminated against. Relatively recent disability laws are made to protect us from exclusion, giving our children full citizenship rights.

Still, we struggle find such justice for them within their daily lives. We first look to school systems and are met with the red-tape of the process of getting IEP's and special accommodations and quickly realize it's a legal issue and process. I often wonder which "side" that law protects. We parents (I am writing as a mother so I have to assume that if you are disabled/autistic reading this, you will understand that I recognize this also as your issue) don't count on having to fill in reams of paper applications, spending hours in meetings, navigating government support systems and administration when we are swaddling our new bundles-of-joy. The navigation to be special – not that it's our choice – indicates from the start that we're not supposed to be this way. Our children aren't supposed to be autistic and public schools protect themselves from us with the red-tape, and we have to fight for our children to be included, not marginally integrated or tokenized. Most of us don't "fight," we become diplomatic contortionists and try to get our kids "in" to the extent we can. While it's a worthy fight, it's still one that we'd rather not spend our time on. We look forward to the day when autism – about twenty to thirty years behind our recognition of other disabilities, including intellectual disabilities – is widely accepted and

welcomed in society. With that welcoming is also a recognition of the intersections between race, culture, gender among other interlocking connections, that make up experience.

As I let Adam go into the world, with the support he needs in order to be an equal citizen, I am always working on my visions for him as a parent. The other day, I thought long and hard about a photo I collected from Toronto's [Abilities Arts Festival](#) a few years ago. It is a photo where two intellectually disabled parents sit on the couch with their three typical children — a “normal” family photo called “Lucky Strike.” The subjects also wrote a paragraph about how they got married and had a family with the help of their support workers. It dawned on me about Adam and his family: there is no reason why Adam may not have a family of his own, by accident or by choice as is the cycle of life for many a typical person. There is no reason why he cannot attend higher-education as an adult. There is no reason why he cannot participate in whatever he wants. It is, after all, the law, granted, subject to enforcement as well as interpretation and dominant social attitudes that are still weighted against the disabled person. We also know that not all our rights are enacted and there is a hesitancy by many families and individuals to go through the legal process. Not all universities understand the need and function of the aide worker. Although York University accommodates people with disabilities, [it found itself in a legal dispute with Ashif Jaffer, a student with Down syndrome, because he claimed the university did not accommodate his needs](#). For these reasons, we have to keep on working hard, and likely take a few risks, for the rights of our beloved family members to be included with the accommodations that they require. This means also the help of aide workers and various technologies, among many other individualized needs.

People can have families and also be supported by others. Our children, even our non-verbal ones, can have a say in their plans and lives with guided decision-making practices. Non-verbal people may be able to type or write visual essays and participate in research about autism, and all autistic people have a right to both participate in research and have results disseminated to them in ways they can use and understand. Check out [websites on emancipatory research](#) and visual essay formats. No it's not easy to do, but we're starting to do it and we are inevitably going to learn by doing.

An “emancipatory” life requires support and that support requires a vision of possibility, enablement, democracy and a plan. As a paraplegic requires a wheelchair, many an autistic person requires people in their lives to support them getting to and from destinations, to having families, to making decisions, to managing the many details of life. Some of this right now is a privilege for the families that can afford them. It is, however, everyone's right and I for one want to hear more stories about how families and autistic people are helping to let autistic people live their lives as autistic people. For the families who are able to provide the supports we seek from society and governments, we need to hear your stories in order to provide more building blocks of enablement.

What is independence? I can't work on the technology of my computer on my own. I need tons of help with it. I need extra hands to help me around the house and in managing a schedule as a single mother. I need teachers, handy-men and someone to help me when I'm ill. I build my human network as a result of necessity. Others also need me and I am able to lend my hand or my special skill set. For reasons revolving around Adam, I am sensitive to our capitalist notions of independence and how that seems to relate to the family and school. Are we creating communities of people who are interdependent on each other, or human silos? How “happy” does that latter future look like sitting there all alone in them?

Here's a future that I can see unraveling before my eyes, despite the struggles, tensions and issues we presently encounter and grapple with: I see more people employed in these areas to assist and guide, but further than this, to balance the power that can be offset by the “abled versus the disabled.” Ergo the terms “assistants and aide-workers,” not therapists. I see more effort towards emancipatory lives for the autistic, of all “functioning” levels. I see our growing ability to understand and respect one another, to honour the visual way and other modes of learning and communicating, presenting and even reading the materials by individuals with autism. It is a reciprocal human economy with autistic people in it.

For the first time since I've had Adam, I imagine that it might be possible, as Adam is my only-child, that I could one day be a grandmother after-all. It was actually one thing that made me a little sad when Adam was diagnosed — the world seemed to be locking its doors to us so soon. Of course, all of this is Adam's choice,

hopefully. It's the choice that matters. The principles upon which I now imagine and locate our lives, in practice as well as principle, is one of possibility and of how our lives can be enriched, even made better, by including autistic people in them.

Adam's life should be one of his own making, and I am here to support him down his many paths. The questions I now ask more often, are not only about how much work does Adam must do (as the onus has, to-date, largely be on the autistic person to become more normal *before s/he* can participate in society), but how can I help him obtain for himself not just a "quality of life," but a *vibrancy*, of life — the excitement of possibility and choice — that many of us took for granted while we were growing up? This also belongs to him.

This can be our future — for our children and even for us as parents of autistic children. This *is our* Adam Family.

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[Autism History and Identity and Why We Need It](#)

Filed Under ([Autism History](#), [Book Reviews](#)) by Estee on 06-09-2012

I'm back at York U and have taken it upon myself to pursue my M.A. in Critical Disability Studies and focusing on autism in every context I have time for. Outside of general readings, I noticed two books I've pre-ordered and eagerly await to devour:

[Far From The Tree: Parents, Children & The Search for Identity](#) by Andrew Solomon and *Autism: A Social and Medical History* by Mitzi Waltz.

"Disability" is a relatively new word in our language set to describe the social barriers that render some people unable to participate. It isn't a word that we will find in historical records about disability. Rather, we find words like "lunatic, idiot, leper, cripple," to name a few historical references to disability. While the history of disability is a burgeoning subject now, my generation never studied it in school. Some of us may not have even studied civil rights history. While we can locate histories in texts, records, art, and now through oral histories, we are just beginning to recognize that uncovering history is a very important aspect to identity. All of our histories are important and so many of them go unrecognized and untold. I remember learning British History in elementary school, and feeling valueless because my history was ignored, not validated, and considered not worthy of digging into. So many immigrants or different ethnicities feel the same way, although we have growing bodies of history that are now being taught in schools.

While autism memoirs are a way of telling our history now, we can do more to reach back and find autism in history. [Uta Frith](#) and [Harlan Lane](#) are two authors that come to mind who have written about specific autistic individuals in history.

Autism in history is a subject that requires much more attention. I'm hoping that the simple binary of "medical versus social model" of autism history will be avoided in the books about to be released. "Rethinking this polarity is what historical research and methodologies has to offer disability studies." (Anderson and Arden Coyne).

In terms of identity, autistic identity or the identity of families with an autistic member, it is important to avoid the stereotypes of this binary that we encounter, especially in autism "advocacy," although it would be an important a study unto itself of how we view autism today.

Our identities are complex, located within race, gender, income, nationality, culture, and so much more. We need to challenge ourselves to move away from the idea that all experiences of people with disabilities, or their family members, are "conflated." (Anderson & Coyne). History must also be viewed through the prevalent views of the time period, and we cannot impose of modern views upon it, for our interpretations would be skewed. It's more enlightening to look at history and compare it to our views today and in how we might improve as a society.

I hope for more literature on autism and history. I'm not of the belief that we all need to be autistic to write histories about autism but the practice of locating ourselves in any research must be something we undertake more rigorously, upfront, by stating our own views, considering our bias, and offering our biographies. I'd like to see this not only in social research, but also in medical research. We need to promote further studies to help define autistic identity. If we do it carefully and ethically, we could assist with the rights of the autistic person in our society.

Reference:

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[The Curiosity of School](#)

Filed Under ([autism](#), [Books](#), [Contributions to Society](#), [Inclusion](#), [school](#)) by Estee on 04-09-2012

It is the first day of school for just about everyone. Most discussions about autism has to do with learning and inclusion — keeping our children integrated, or keeping them home-schooled when appropriate, or even better for their needs, developing social skills, academics, life and communication skills. No matter what methodology — or school — we may consider, this question lingers—what we are trying to accomplish and how is equality reflected (or not) in our school systems?

I still struggle to fit it all in — a list of goals for Adam measured against the hours of the day and his own abilities, pace and interests. "Following Adam's lead" seems like an easier solution, and the ideas of "pushing" him, or any child for that matter to reach their "potential" and "following his interests," are ideas in constant tension in the autism community. Add to that the idea of "normalizing" or becoming a "productive member of society" against our ideas of what productivity means for a variety of different people, and we come up with more important questions about how we should help autistic people. Some might contend that our current notion of productivity has more to do with amassing material goods than about contributing to society.

Autistic education is located within our ideas, and conflicts about the idea of what we feel a school should be in this economics-as-material-consumption sense. Zander Sherman explores this and looks at the development of schools in Prussia which prepared students to become part of a strong army. He looks at testing, private schools, the military.

His new book is called *The Curiosity of School: Education and the Dark Side of Enlightenment*. The Globe and Mail reviewer, Ben Levin says that Sherman's thesis seems to be a quote from Einstein that he uses at the beginning of his book, "It is a miracle that curiosity survives formal education." Sherman was home-schooled himself until the age of 13 and thinks "that mass education is excessively focussed on the wrong things — compliance, a narrow curriculum, preparation to fit into a society and economy — and thereby does not give sufficient attention to real education, the pursuit of curiosity and personal challenge." (Saturday's Globe, page R15). It would be interested to review the book against others like *Elusive Justice* by Abu El-Haj and others that deal with education, equality and social justice. I have to ask, how do we nurture and promote Adam's own curiosity? Do we recognize and value it if it appears different to us? Isn't this value we attribute part of his right to be equal and different?

Adam is back at school as am I. We have always used the modes of learning that we have at our disposal, that seem to suit him best, but we have to admit our limitations in understanding our children. We try, they try, and as his mom in thinking about his whole life and the "quality" of it, and even how we define that, I feel it's my duty to him to ask myself the harder questions.

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[Awesome Anthony and Autistic Contribution](#)

Filed Under ([Acceptance](#), [Contributions to Society](#)) by Estee on 24-08-2012

I think Anthony is awesome.

I think that as autistic people age, it is wonderful that they can have assistants to enable them to participate in employment, college, university and like Anthony, starting a business.

I think that as parents, Anthony can help us understand that being in society is about supporting one another — that it's more than okay to be autistic and have support if it's required.

I think Anthony redefines what it means to be "productive."

I hope you do too. As we begin a new school year, let's think not only about inclusion, but how we can support autistic people as autistic people. Meet Anthony:

Meet Anthony, a guy with autism and his ...



Best of luck in your new business, Anthony!

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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.



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