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“We Are A Critical Mass of Wretches” – Larry Bissonette

Filed Under ([Acceptance](#), [Adam](#), [Communication](#), [Computing/iPad](#), [Development](#), [Inspiration](#), [Joy](#), [Uncategorized](#), [Writing](#)) by Estee on 16-07-2013

I am blissfully tired after our second day at the Communication Institute in Syracuse. This is Adam’s first autism conference and all that stuff that was happening beforehand has abated. He is happy here and spending time in a workshop in the mornings learning more skills, and sitting in talks for the rest of the day, and taking small excursions for his breaks. He has watched other typists here intensively and this always inspires him to do it. I’ve learned that he needs less support than I had been giving him, given the right tools, keyguards, anti-glare screens... I’m learning about iPad apps that will change his life and change the way we “do” school...not that most schools (most using ABA/IBI for autistic kids) in Canada understand or provide as of yet. Adam can’t be normalized but he is a very bright, very autistic, very wonderful and intelligent person.

One thing that really gets my goat, however, is the notion that there is no real purpose in teaching autistic people how to type, use AAC, or engage in an academic curriculum. It blows my mind that these things are under threat for autistic people – that communication tools risk being taken away in favor of verbal behavior, which, of course, harkens back to Oralism – when the deaf culture were denied sign language and were forced to speak and act in normative ways. We can look at Victor of Aveyron (1788-1828) for this under the tutelage of early behaviorist Dr. Itard who later abandoned Victor (although Victor could read and use text). Alexander Graham Bell also favored Oralism and it existed well into the 20th century. Today autistics face a kind-of Oralism in Verbal Behavior programs. It’s not that we don’t want our kids to speak if they can, but most autistic folks can’t speak for a full day or not at all and need other reliable sources of communication. These tools for autistic people are a right as sign language is for the deaf, and considering we are asking autistic people to communicate normatively, and autistic people say that they need this means to articulate their thoughts, it’s a complete mistake to even think of taking this away from people.

Society, in the general sense, doesn’t find that many autistic folks are economically productive enough to invest in them, so instead they are called the *burdens on society*. I’d like to invert that notion of what a burden it is for all of us to be underestimated and only be taught for the purposes of being the cog in a corporate wheel. May I suggest that we all be creative in thinking about the various kinds of purpose and contribution that humans can make, and rethink “productivity.” Then, I’d like to suggest that parents of autistic children who want their children to be accommodated, educated and literate as autistic people to adopt the mantra of those who doubt our children, “so what?” In other words, I think we need to develop a sense of entitlement when it comes to supporting autistic rights to communication tools, access and accommodations. We have to say “so what?” to being autistic, or our children being autistic. It’s a material reality that normative culture is a majority culture to which autistic people work so hard to adapt, and I think of the terrible injustice it is that autistic people have to prove their value and competence every single day of their lives (and often get held back because of it). I think the mantra “So what?” helps me to keep going against ignorance when people ask me why bother educating Adam as opposed to remediating him (before the right to participate or inclusion) or just teaching him functional

skills. We are here, literally, among the “wretches,” and there are quite a few here, folks. The critical mass is growing and we ain’t no epidemic. I don’t care what you think of Adam and his going to school or later, university. Just don’t take away his right to it. As for the wretches, they are doing a magnificent job in advocating for this right, and we have an obligation to support them.

Now I will turn my post back to Adam. He was proud of this little story he wrote today which was read aloud to the class – I can’t remember when a teacher presented Adam’s work to the class for such a long time now:

“One day two leaves fell early in the morning. They weren’t happy because they wanted to stay up on the beautiful branch. A nice boy called Adam found them and stuck them up for the rest of the day.”

A few minutes later he typed to me: “Real useful ideas.” Then, “The joy love you mom.”

Thank you my little one. I am your devoted wretch-in-arms.

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[What Adam Said This Morning](#)

Filed Under ([ABA](#), [Acceptance](#), [Adam](#), [Communication](#), [Movement Disturbance](#), [Sensory Differences](#)) by Estee on 11-07-2013

Adam and I sat on the stoop as usual this morning for his bus to camp. Yesterday, Adam was content and happy and then his assistants reported another sudden biting incident, to which Adam didn’t seem to remember. It lasted but a few moments, then he happily moved along. Of course, I’m in a newer territory now with his, new concerns and am back to re-reading.

When I asked Adam about remembering it, he said “no” in several formats, including pointing to his chart, typing it out, and also saying it (which came first). He was happy and contented last night, jumping on his mini trampoline in the basement, which is now partially repaired after the flood. After I gave him his ten minute warning that it was nearing time for bed, Adam came upstairs.

This morning, though, my heart broke a bit, but I am also determined to do my best that Adam has a positive self-esteem. Let me preface this by stating that when a person like my son doesn’t speak very much, people don’t tend to listen as they refer to speech as “psychotic” and nonsensical. I never take Adam’s words as such.

“I don’t know anything,” he mumbled.

“You know lots of things and you will learn lots of things. You are really smart,” I replied.

“Teeeee-cher,” he sang melodically. Then again, “Teacher, teacher.” He climbed into my lap to be cradled.

I’ve asked his ABA school of late to teach him to his age-level and invoke the Ontario Curriculum, to which Adam is entitled, and they have agreed. I am devoted to making sure that education is Adam’s right. I am working this out with Adam’s team which may include part integration, part home-school, getting out more into the art gallery, the museum (he enjoys such places) and the programs he has loved so much and integrating this into his own writing. In Canada, there’s little option but to make our own path at the moment, and families have

a right to choose what suits their children best. In Adam's case, he requires support, and this is also his right in order to participate in his community in the manner that he wants, needs and is able. It is great when teachers understand these complexities, and I encourage everyone to continue to learn outside of the behaviour paradigm, and to listen to autistic people. (I think you can sense how concerned I am about what is reflected back at Adam in terms of his person-hood and self-esteem as an autistic person – a complete and whole person).

Post-Blog Comment:

Thanks to an email that pointed out something important to me which I must write here – in it, the person mentioned that the Ontario Curriculum is “useless.” I want to extend how I appreciated the comment as important and hope more comments will come. My comment to extend on that one would be that I feel that education is a right, but the manner in which that education is delivered to Adam must be customized. He still has a right to it, and the reality is that's what he needs to fulfill to move on to higher ed if he desires it. There are many tensions at play here – my own personal experiences as a normate which must always be questioned; the changing needs and nature of education overall; the normative linear developmental model that represents the mutually supportive notions of social and neo-liberalism; and this quest for a specifically autistic education that fits Adam's learning style and abilities while also providing him with opportunities to contribute to society as an autistic person – and this is the ultimate challenge when society doesn't value people with severe disabilities.

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[Loving Lamposts, Autism, and Remembering What's Important](#)

Filed Under ([Acceptance](#), [autism](#), [Inspiration](#)) by Estee on 09-07-2013



In 2007, I went to Edmonton to speak at [Autcom](#). I happen to be presenting again at Autcom in Colorado this year about **how to support autistic rights** as parents, teachers, therapists and caregivers.

At that conference, I was interviewed for the movie [Loving Lamposts \(2008\)](#) which I saw briefly when it was released in 2011. I've spent much of the day today re-watching it as I write my thesis. I recommend you watch it for Roy Richard Grinker, Ralph James Savarese, D.J. and Emily, Kristina Chew, Charlie and James Fisher, Dora Raymaker, Sharisa Joy Kochmeister and her father Jay, Stephen Shore, Simon Baron Cohen, Paul Collins, Christina Nicholaidis, Kassiane Sibley, Nadine Antonelli, Lila and Lyndon Howard (boy you touched my heart), and more... and of course the maker of the film, Todd Drezner, his wife and the person *they* think about all the time, Sam.

It is an important movie for parents (and educators and doctors and...) of autistic children to watch. I don't think there is any parent, no matter how accepting of our children, who don't struggle with the temptation to succumb to the prevalent notion that we should be doing more therapy, advocacy, volunteer work and the like. The temptation to believe something is wrong when your child is the minority remains strong, and I remind myself how equally strong parents have to resist this negative vortex that takes away valuable relationship time. And, as stated in the movie, much of my thesis also has to do with how negative views, notions of abnormality and the language we use to describe autism can be assimilated by autistic people as part of their identity. This is really important to me as Adam's mother. He is now half-way through the age of eleven, and after a really tough

couple of months this year, as Adam was communicating something important to me, I consider that pondering my role, my beliefs, how I interact with Adam is, for me, a daily activity. In other words, the work I have to do as his parent on myself is not yet complete; what he wants for his own life and what he can and cannot do just is and I have to help him with that. In this, accepting autism is the hardest work I've ever done, and more often than not, the most gratifying. So, I just want to say thanks again for *Loving Lamposts* to remind me of this, for I believe we could all use reminding. Along with [Wretches & Jabberers](#), it's one of my favorite autism flicks.

It's time to think about screenings and have more serious discussions here in Canada regarding how we support and regard autistic people. I sometimes get despondent when I see that ABA is the only option for our autistic children, and how that movement has gained such a hold in the field. It is of utmost importance that we discuss various habilitative services, the right to choice, the right to communication and devices and workers to support communication, to be autistic, the right to be accepted, to love, to be educated, to be supported in life and in finding purpose. My job as Adam's mother is to make sure he has everything he needs to be an autistic person and everything he needs to fulfill what he wants to do in his life. And what I want for both of us is to enjoy our time together. It's really important not to forget that.

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[Scary Rain](#)

Filed Under ([Adam](#), [Estee](#)) by Estee on 09-07-2013



Adam started camp and he has become content again, as I'd hoped. I'm tired around here after another flood in Toronto. Loud thunder and lightening struck just at the moment Adam's bus came to the house. More than a month of rain dumped on Toronto in an hour.

"Scary, scary!" Adam said, reluctant to leave the bus.

"It's okay Adam, just come now," I urged, trying to sound calm as I saw the water billowing over the drain in my driveway, about to flow into the garage. So many things to attend to, but keeping Adam safe and calm is my top priority...but also keeping his basement dry keeps him calm...oh, what to do?!

Although we repaired the basement and Adam was so happy about that, a bit of water came in yesterday, but not nearly as much as the big flood several weeks ago. Then, our power went out and I was so grateful when my handyman saved us with a car battery (I hadn't even thought it was hooked into the power and didn't have a

battery backup). We hooked that to the new sump pump. As night fell, I was waiting for more rain while Adam was asleep, sitting beside a candle and my transistor radio. I waited to turn the battery on, but alas, no more *scary rain* came. Finally, I fell asleep with the window open, attentive to the sirens and then, sudden quiet. At 3 a.m. the power came back on and I was only slightly disappointed – I loved the quiet but was glad to be able to re-plug in my sump pump to the power. More rain is coming for Toronto today and tomorrow. Considering that people were stuck on the Go Train until 1 a.m., rescued by boats, and that I saw basement flood trucks running up and down my street last night, I thought that we did all right. Now just some more tweaking, a generator, another sump pump, a deeper well... My water house still needs work.

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[The never-ending labyrinth](#)

Filed Under ([Anxiety](#), [Behaviours](#), [Medications](#), [Movement Disturbance](#), [seizures](#), [Sensory Differences](#)) by Estee on 28-06-2013

Adam's jerking has increased as it was a few years ago... when we did the EEG and they said he had no seizure activity. My own anxiety feels seismic, and I wonder when all of this can explode, get worse, or if all my calming strategies for Adam are working. I've spoken with his doctor almost every-day this week, his school, his OT – doing what I feel I must to get all the information. It may be information I've learned along the way, sometimes we see things differently or new things at different points in our lives. We've generally avoided many medications but over time, things can change. Although we will visit the neurologist, it's not time to act...

I hope that camp again abates Adam's jerking and the stress he must feel he's under. His basement flood, the end of school, a new baby on his dad's side of the family. Sometimes I think that Adam is the strongest, most "controlled" person I know! When I think of his body and how hard he works to get through his day, I just can't believe his strength!

Every day I ask Adam how he's feeling. He usually says "I'm fine" with the same tone. Sometimes I get a "good." Since his allergies, turned viral croup turned jerking and biting (conflated with the other changes in his life) this has changed – "I'm feeling sick," he says. At least he's loving his chewy tubes! He knows I love him too...that's a good place to start. I know he needs my counts to five, my voice to help him move more days than others. A weighted vest seems to help and holding things in his hands. And although everyone is working as fast as they can for him, his space in our basement is not yet complete. It's the space where he can engage in a lot of sensory activity.

I'm feeling sick – I don't take Adam's words as gibberish. His words may be few, but they are powerful to me. So I am trying to help him knowing the labyrinth we must travel through yet again, knowing that for every medication that is recommended, we would be treating a symptom, and where my real anxiety begins. It is here where the term autism, and perhaps its reified status, falls short in helping medical conditions for autistic people. I guess I don't believe in rushing in. There's just too much complexity about Adam and how he feels about things that this needs lots of time. Autism is too broad a term and Adam can appear as if he has Tourettes or seizures or movement disturbance like Parkinsons or at times, catatonia... Gah! He would fit just about every profile, my little guy. Anxiety and heightened arousal (either positive or negative) may trigger Adam's twitching or biting. Some days, just working on calming and ordering his body is work enough for him.

As I try to help Adam, and want to abate his pain as opposed to sedating my worry, I also try to finish a major research paper and am thinking of Larry's quote from *Wretches and Jabberers*: "autism is not abnormality of brain but abnormality of experience." Here, I question autism as a co-production of that experience, the way must describe it with language that is always half-formed, where normative views and experience may alter Larry's meaning in the way we perceive it, and where real pain of such a different experience may be missed or ignored because of the label, and perhaps where Adam may not feel supported, accommodated or maybe, even respected. All of these things I have to write down and run through my head over and over again; and this needs good communication from everyone involved. In any event, it can feel like an isolating experience because I must deal with all of this mostly on my own – I take the responsibility and the worry on, perhaps as the stereotype goes, like mother's do. But I realize that I have the the loving support of my parents and my partner, Adam's aide worker, and the other team members in our lives that he really needs in order to live a good life. Parents and autistic people require lots of love, support, inclusion. This includes general acceptance of the way things are, as well as acceptance that some people, like my son, sometimes cannot participate in normate ways. Instead, he can always participate given our patience, accommodation, consideration and respect. As I think about how I felt about rabbit-holes today – of medicines and men, and to use Adam's word, "catacombs" of our journey – I have talked myself out of feeling anxious and will continue plot along... just like Alice.

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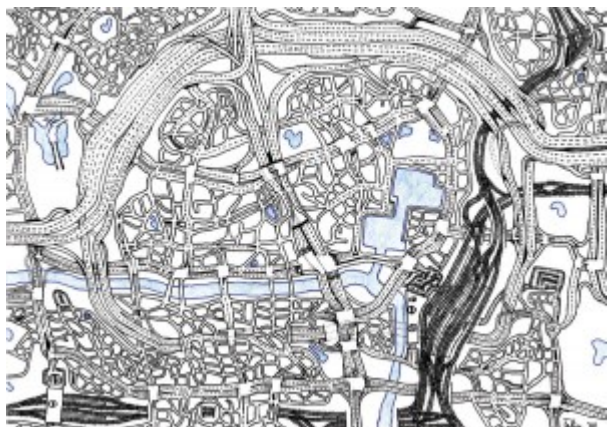
[Filed Under \(ABA, Ableism, Acceptance, Activism, Advocacy, Anxiety, Art, Autism and Intelligence, Autism and Learning, Behaviours, Communication, Computing/iPad, Contributions to Society, Development, Language, Law, Movement Disturbance, Obsessions, Parenting, Politics, Safety, school, Sensory Differences, Transitions, Wandering\) by Estee on 26-06-2013](#)

I've been thinking and planning with Adam's team the next stages of his learning and doing our map project. Every once in a while, I got down the dark whole of blog comments and blogs that consistently regard autism, even its many complications and struggles, as inherently "bad." The issue we have with thinking in these terms, although safety is an ongoing concern for many parents including myself, is that we think we can shape behaviour without truly understanding it, and that what we are talking about is bad behaviour. Behaviour is something that we can control, impulse and many disabilities are not constituted by the will of a person. So when we talk about shaping behaviour and "positive" behavioural support, we always have to question our subjectivity and how we've come to make sense of autism.

Given many of our children are not provided access to alternative communication support, and cannot tell us otherwise, and that it takes time and care for many autistic people to learn how to communicate (if they can), the Antecedent, Behaviour, Consequence (ABC) mode of tracking behaviour will remain problematic, and the very recognition of that can be helpful. There are often too many conflating factors that precede a behaviour so, while we do our best to interpret it, it is always difficult to claim one cause. Here I find that I'm needing to ask many different players in Adam's life for information so that I can cobble together the best interpretation I can, bearing in mind that this is merely an interpretation.

So with recent events and noticing Adam's propensity for visual memory, needing to know his environments, I continue to study maps and autistic art and will experiment how this might be useful for Adam. This is another

example of the visual map I found by an autistic artist found at [Drawing Autism: 50 WAtts](#). It's part of my interest in helping Adam draw his own maps as a way of understanding his own environment. This means, I have to be careful how I enable and support him, and be in a continuous reflexive state of mind in terms of enabling versus prompting him which would therefore NOT be his own communication.



Felix: Imaginary City Map, Age 11

Here's how the artist responded about the work:

What was the inspiration for this piece?

Generally I start drawing one street on different spots on the edge of my paper. I make the streets grow toward one another.

Who are some artists that you like?

None. I study road maps and atlases in detail and generally I scroll the full track of our trips on Google Earth.

I turn now to education in hopes to keep honing in and improving it when I think of Adam's needs. Under the rubric of the Medicaid system in the US – a system that is already in existence – advocates seek more, or varied, habilitative services for autistic individuals. This is an important beginning within an existing system and we have to keep discussing the medical model and its effects on the way autistics are included and regarded as full citizens, or not, in society. In Canada, we also require more choices that fit with parental values and wishes for their autistic children, and this was addressed by Doug Reynolds in his paper for [Autism Ontario: Looking Forward: Has Intensive Early Intervention Hijacked the ASD Agenda?](#) The work of autistic people in this is valuable in how I think about Adam and his education and the extra supports and help he needs. Bear in mind, I write here a blog post, not an essay. Here are some of the ideas that I think about that I have not yet formatted into a paper.

To go on, if a parent wants an education for their autistic child, they should be able to work with a school to attain it using some key principles:

- 1) Respect for autistic identity and personhood;
- 2) Understanding **learning at one's own pace** and an acceptance of it (as opposed to a linear model for learning and development);
- 3) Understanding and completion of complicated sensory profiles and the time it takes for accommodations to be put in place and,
- 4) recognition that accommodations frequently change and must remain flexible;
- 5) Recognition and acceptance of family-hired (which could fall under a direct-funding model from government support) support workers as reasonable accommodation in classroom – for transitions, programs, to help with accommodations and if needed, supported communication and whatever accommodation an individual and family might need to enable success;
- 6) Transparency by schools – to allow parents in for observation, to review class binders, etc. Considering many

of our children are non-verbal, it would be good to not only communicate in binders, but to allow drop-in visits (even if a bit of arrangement is needed to respect others). This enables open-hearted communication and better accommodations.

7) Communication aides and technology and access to supported communication and devices as legal right to communicate as autistic people. As an example, an ABA therapist will often say “use your words,” thereby implying that an autistic child is stubbornly with-holding them. Considering the levels of frustration an autistic person has when they cannot communicate, do we not think they would *use their words* if they could?);

8) Recognition that most autistic people we name as “inconsistent” and “discontinuous” or “having regressed” is often a result of sensory issues and transitions, and that learning happens at unexpected rates. Sometimes, the teaching agenda must be put aside when an autistic person may seem “disregulated” and build back tolerance. An autistic person can often jump several grade levels in reading, for instance, and then appear to have regressed. This is not necessarily indicative of a regression so much as a need for a body to regroup. Therefore,

9) testing autistic people academically so they can advance grades must happen with re-presented formats, over many sessions, and then, the **best result** should be taken as an achievement of grade or pass so that the autistic person is not held back until they “recover” from autism to normalcy and thus never allowed to advance, or potentially restrict their pace and ability. To understand the seriousness of withholding education as a right, see *Moore vs. British Columbia* and the note that remediation may result in adverse effect discrimination because it assumes a person has to reach a certain level of normal performance before granted the right to be educated. Of course we want children to generalize skills and be as independent as possible or to achieve an 80% mastery, but often this concept of discontinuity is missed or misunderstood and education is held-back.

These have been my considerations of late and, and I support a variety of methods that befit a child and the combination of many may suit for different people and different situations, so long as they do not harm or torture an autistic person.

ABA is pretty much the only method which is used in Canada to remediate autistic people before granted access to education (particularly people labeled with Low Functioning Autism, who are non-verbal, or who have complex sensory systems). It can be a useful strategy also within a curriculum but it needs to keep examining itself from within and by studying autistic autobiography and potential effects of behaviourism on self-identity. I am suggesting that autism schools also need trained teachers in regular and special education and need to:

- 1) Be inspected by the [Ministry of Education for meeting curriculum requirements \(the adaptation and accommodation piece is an extended discussion\)](#);
- 2) Adopt other methods that we know help an autistic person learn through re-presentation of materials ([see Judy Endow](#));
- 3) Be reflexive about the psychological effects of shaping behaviour and compliance may have on autistic individuals self-esteem and identity;
- 4) Learn creative methods and enable an autistic person to go on outings to educate not only life-skills, but other interests by using other methods and creative strategies. I remember one professor of an autistic child stating that when her son was interested (or people tend to label “obsessed” with asphalt), she took him to an asphalt factory.

Do schools undergo this kind of creative exercise for autistic children who, for instance, may bolt and may be so enamoured with routes and maps so as to learn something as opposed to controlling behaviour? Sure, we have to attend to immediate safety concerns, sensory regulation and building tolerance – these are important steps to an autistic person’s success. Yet my question persists – what can we do that teaches an autistic child to creatively channel their passions and proclivities? What are we telling an autistic child day-in and day-out about them when we ask them to “comply” to our agenda without enabling some of theirs? What is freedom if not mobility? Is an autistic person a slave to the performance of normalcy if they are not allowed to freely move their bodies in order to feel safe and secure? (See Judy Endow and [Tito Mukhopadyhay](#)). For instance, there is so much autistic autobiography about how autistic people need to protect themselves from over-stimulation – reverting to their iPad in order to be part of a group, squinting their eyes, or if they do not feel their bodies, they feel frightened and must flap their hands or lie on the ground in order to feel safe! If we are talking about “safety” how are we helping? To what extent to researchers and teachers use and take autistic autobiography seriously?

The other issue I need to bring up today is one of freedom of choice. What I find concerning about models of teaching for autistic people specifically is the judgement of some parents against other parents for choosing what they feel is right for their families and their children. It is not right to state that an autistic person has to undergo a certain drug or therapy or blame a parent or an autistic person. The freedom of families as well as autistic people is at stake, and while I wish to trouble this, I realize this has many angles and complexities within such a discussion. Some autistic people feel a parent agenda, if it is one of just becoming normal without critical regard, can result in problems when autism is seen as a disease that requires potentially harmful remedies. So by no means is this discussion an easy one, but there is no freedom if Canada only presents and makes available one kind of service. In short, Canada, with an autism agenda led mostly by parents, needs to consider what it's building and its long-term effects. There needs to be choice for families, a respect for values and an invocation of substantive equality in our systems.

Here I wish to close with an opening – with the words of Melanie Yergeau, autistic, from her essay, *Socializing Through Silence*:

“My silence is in fact a compliment. It means that I am being my natural self. It means that I am comfortable around you, that I trust you enough to engage *my* way of knowing, *my* way of speaking and interacting.

When I dilute my silences with words – your words, the out-of-the-mouth and off-the-cuff kind – I often do so out of fear. Fear that my rhetorical commonplaces – the commonplaces that lie on my hands, sprint in my eyes, or sit nestled in empty sounds – will bring you shame. Fear that my ways of communicating will be branded as pathology, as aberrant, as not being communication at all... This isn't to say that my use of your language is always a product of fear. There are times when I genuinely want to use it, understand it, and learn about and from it. I understand that speaking is how you prefer communication. I understand that speaking is how you best learn and interact...

But the burden can't always rest on me. I have a language too, one that I take joy in, one that I want to share. And when you deny me that – when you identify my silence as a personality flaw, a detriment, a symptom, a form of selfishness, a matter in need of behavioral therapy or 'scripting' lessons – when you do these things, you hurt me. You hurt me deeply. You deny me that which I need in order to find my way through this confusing, oppressive, neurotypical world.”

— From: *Loud Hands: autistic people speaking*, pp. 303-4, The Autistic Press.

Now, how can we respond?

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[Mothers](#)

Filed Under ([Parenting](#)) by Estee on 21-06-2013

Adam's twitching has not fully abated and he was up all night...not something we've seen to this level for over three years now. He seems to be happier and I am working on keeping him calm – and there's people who also help me to do that. I think I'm doing the best I can as a single parent and how it forces me to never give up, call out for support, and stay persistent in asking for help because I realize not everyone knows what kinds of help

we all need, or even how to help. I know this is not exclusive to women or single mothers, but to single fathers and married couples too. Yet I speak from where I stand today.

I never realized the extent to which this would be a challenge, not Adam per se, but being a mother alone in the middle of the night without anyone to talk to takes a toll on me; having to ask for help, or the right questions, in so many different ways. You have to stop caring what people think of you and go on for the sake of your child because we need as much information as possible. This takes a lot of time. As I care for Adam, it is often difficult to remember to take care of myself. I am thankful for my parents who help both Adam's father and I out; they are exceptional grandparents and I can't emphasize enough how important grandparents are! Adam's extended family is helpful too and although it is hard to let my child go, I know that people's intentions are for him and to support him, and I'm thankful for everyone involved. I am so tired today but I don't want to forget to thank people who extend themselves to support us.

Adam's basement is being repaired – a major renovation. On top of everything I live with a reno which takes its own toll of drilling while I'm trying to get things done...I also have a sensitive sensory system where noise is concerned...so it feels like a dentist drill to me. Yet I am also grateful for it getting done so quickly. Everyone is concerned for Adam to get everything back in place as quickly as possible.

Being on our own – no matter who we are – makes the generosity of others so apparent. My mother sent over a thermos of special tea just for me. That seemed to me like such a loving gesture that I almost cried. It's exactly what I needed – a mother needing some mothering. I drink now to get my strength back, to give back to Adam the mother he needs.

Speaking of which...Adam will soon today be Uncle Adam. His half-sister will also soon be a mother, perhaps a sleepless one for a while. Mazel tov, dear mothers (and fathers and grandparents too)!

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[Mapping Things Out](#)

Filed Under ([Acceptance](#), [Adam](#), [Anxiety](#), [Behaviours](#), [Contributions to Society](#), [Movement Disturbance](#), [Obsessions](#), [Safety](#), [Sensory Differences](#), [Transitions](#), [Wandering](#))
by Estee on 19-06-2013



Image by: *Stephen Wiltshire.*

I must admit time heals anxiety. After the darkness comes the light, or is it the other way around? Well, the globe rotates. As Adam seeks knowledge by going through doors, I have always needed to calm my own anxiety through books. As I think more again about Adam's need for doors, his curiosity for bushes, dark places, paths, and in particular, the doors within buildings, I've been thinking about maps and a book I bought for this purpose in considering Adam's interests – Denis Wood's, [The Power of Maps](#). As many autistic individuals proclaim a need to map, to visualize, and with an exceptional ability at visual memory (routes, maps), I feel that this is the next frontier for us: to learn how to make maps of our environments, to build a 3-D version of our house, and go from there.

“We are always mapping the invisible or the unattainable or the erasable, the future or the past, the whatever-is-not-here-present-to-our-senses-now and, though the gift that the map gives us, transmuting it into everything it is not, *into the real*. This month's *Life* leaps at me from the checkout counter: ‘Behold the Earth,’ it says. ‘Startling new pictures show our planet as we’ve never seen it before.’ Inside, below the heading ‘This Precious Planet,’ the copy promises ‘Striking new views from near space show us more than we could have guessed about our fragile home... I am overwhelmed by the solidity and apparent indestructibility of everything I see around me. Only the pictures – let us think about them as maps for the moment – convince me of the reality the captions evoke...’ ‘New picture’; ‘never seen it before’; ‘new views’; ‘show us more’; each phrase insists on the fact that indeed I *never have seen* the planet in quite this way” (p. 5).

It reminds me of Dawn Prince when she wrote in [Songs of a Gorilla Nation](#) of how she ran to greet every room of the house over and over again. Many other autistic people have superb visual memory (Stephen Wiltshire, Temple Grandin...). Adam once drew pictures that were so “correct” in their perspective despite the fact that he otherwise has weak motor control. This leads to the conditions in which a person with various sensory disabilities can and cannot perform the same task or function. Soma Mukhopadhyay speaks of this in her books on [Rapid Method Prompting](#), and I find them true to Adam – the way a keyboard is positioned, his orientation, the differences he experiences with his vision other body movements. Things have to be set up the right way for him, and I need to always pay greater attention because it is easy to fall back on my laurels and adopt my *take-it-for-granted* view of the world.

Sometimes it seems that I've always known that mapping could be Adam's hobby which might lead to map-making or building. He needs to know what's behind everything for what we call “obsession” or “stuckness,” automatisms and the like. [Lennard Davis discusses how we come to value obsessions, particularly the actions of artists as “obsessive acts,”](#) like Vincent Van Gogh. Instead of invoking a moral value (a trait or characteristic as inherently good or bad, positive or negative), we can come to accept these proclivities as inherent (even if it scared the living day lights out of me). Adam needs to explore and to know as I do by finding information in books. How might I make this something that works for Adam? This is my next frontier.

“The sphericity of the globe is not something that comes to us as seeing-hearing-sniffing-tasting-feeling animals, is not something that comes to us... *naturally*. It is a residue of cultural activities, of watching ships come to us up out of the sea *for eons*, of thinking about what that might mean, of observing shadows at different locations, of sailing great distances, of contemplating all this and more at one time. It is hard won knowledge. It is map knowledge. As such it is something that little kids have to learn, not something they can figure out for themselves. ‘Educators are living in a dream world if they assume young children understand that the earth is round’” (p.6).

So why do we prohibit Adam from being free to explore, to know what and how he needs to know? How can we keep him safe while doing so? How can we fuel his interests in ways that are productive for him, and perhaps for many others?

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[High Anxiety](#)

Filed Under ([Anxiety](#), [Safety](#), [Transitions](#)) by Estee on 18-06-2013

Two years ago today, to the day, Adam bolted. He has lots of need to run through doors, especially at my parent’s condo. I remember it well... my dad coming back from an enjoyable walk, his hand sweaty then off Adam went; *so fast* my dad said. When Adam saw the concierge he was familiar with when he got lost nearby their condo, he ran into his arms. My mom called me ...I was not far by this time after I jumped into a cab. By the time I was five minutes away she announced that Adam was found. Adam saw the police and seemed timid in their mighty kevlar presence. Then, strategies in place, Adam felt better. I called it “operation calm down.”

Today...I got a call from Adam’s dad that Adam had bolted in his condo. Police were called. I jumped in my car and started to fly down to them. I received another call. Adam was found in the stairwell. He was okay. I stopped the car.

What are the similarities between then and now, I asked myself? I’ve been trying to keep Adam calm, successfully doing so with his team this time, his school – using weighted knapsacks, keeping his hands busy, and a multitude of other little things that I know work for Adam because I am so close to him; to write them all down would constitute an Adam how-to manual (I think I’ve written it in emails to his school, his dad, and everyone in his life, actually). Well, two and a bit years ago, the house his dad and I shared, and the one Adam stayed in after I moved out, suffered a serious fire. Adam never went back...so he was suddenly extracted from his home. His dad moved in with his parents for a while where Adam became familiar. Then, his dad moved into a condo. This was all happening around the same time his aide worker of seven years moved on, and his school announced they were closing down his class. Ah, the merry month of June.

Two years forward: Adam suffered a very bad viral croup and was in bed for one solid week. Before that Adam suffered bad hay fever with nose bleeds... an all-in-all crappy month-and-a-half. That same week of the croup, his beloved basement flooded from a bad rain storm we had here in Toronto. It’s the room where he is KING – he controls his own videos (he likes the old VHS ones and I save the TV that can play them), his OT swing, toys, mini trampoline. He is a free spirit down there. After his week of sickness and flood repair (we’re still repairing after thousands of dollars worth of serious damage) he went back to school and was having a hard time adjusting. He clenched his body and started biting. This has now abated and he cleverly taught himself to bite into a chewy toy...good on him (it’s better than people or himself). “Operation calm down” requires lots of

pressure, a weighted knapsack on outings, structure, visual lists, emotional support, and more effort, planning and attention than is typically required...well I've said it above. I've learned that there are just some things that Adam needs and some things he just cannot do when certain things are happening in his life, and he communicates this loud and clear. I guess I can't understand why others don't understand that some people can't do everything that expected of them. I've been tuned into Adam's anxiety from the wee hours of the morning when he was born – no exaggeration. Seriously...way to sensitive myself here.

So as I've finished my self-help post, my hands have stopped shaking. He is safe. I've talked to his dad again and asked if he (dad) is okay...it's certainly a scary moment. Maybe I'll remember to take a deep breath after nearly a month now of holding it in. Tomorrow, back to teaching Adam. Back to strategic operations.

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[The Autism “Campus” and the Ableist Potential of “Potential”](#)

Filed Under ([Ableism](#), [Activism](#), [Institutions](#)) by Estee on 17-06-2013

Part of writing a blog and writing at all is the responsibility I tend to feel for supporting myself and others. Yet I have to tell you, since Adam was diagnosed with this ambiguous “autism” nearly 11 years ago now, anger and frustration and my love for him fuels writing and work – as it does for so many. Let me start here: we have a deeply engrained prejudice towards non-verbal people in our society, and towards those whose bodies don't conform.

The reality is, this is not a black and white issue so if one says one thing, it gets reified (e.g. autism is x or he does this *because* of autism). The complexity of human BEING is ignored, especially for autistic people. As I watch Adam's body tense and react to even the slightest pain (yesterday he hurt himself in a rose bush), these days with a bite, I am caught between feeling grateful for support but also upset that I have to be careful in how I question this support (for fear of losing it entirely... a crappy position many of us are forced into). Alas, we *have* to question it and everything that happens in an autistic person's life to fill out the picture and to support and autistic person well. We need to do this all together – to look at the whole person and not the label and not all behaviours as the result of autism or as, well, just a behaviour. Adam's body is intensely aroused and as this is happening at the beginning of puberty, I'm very worried about how long kids are asked to sit and comply. We must reconsider physical and behavioural compliance in the name of boys needing to be boys. This is recently [called the “feminization of boys”](#) and although gender-blame is problematic, it does point to an issue in how we approach education overall. Autistic boys should be considered in this respect as well. You can't remediate before you respect. You've got to respect and include autistic kids from the beginning. Differential treatment also can lead to equality and respect. Differential treatment need not be remediation; it is the form of accommodation, acceptance and respecting sensory and other differences and needs.

This leads to another concern I have – so-called “autism campuses” being created. How does that serve the rights of autistic people to be included in society? Back in the day, an asylum was considered a wonderful refuge where disabled people could learn life skills, do work in “sheltered workshops,” be “educated” to their potential. It was a hopeful place where people would be treated “with respect.” Does this sound familiar? I don't know about how you feel about it, but it reminds me of just how close we are again to re-institutionalization and the issue we have with notions of “potential” and “remediation.” There comes a point when educating to potential can turn into another form of ableism because it asks that a person become a normate. Potential doesn't necessarily mean “as close to normalcy as possible.” Now that Adam is experiencing this intense arousal (and he

has been already redirecting himself to an object to bite, without my telling him to do it), how will “the system” view him as a (non) person? Will our only choice be an autism campus? A thorny issue.

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[An Autistic Boy's Life is Not A Paragraph](#)

Filed Under ([Anxiety](#), [Books](#), [Development](#), [Parenting](#), [Transitions](#)) by Estee on 12-06-2013

Adam has progressively better days since the basement flood and croup. When he seems anxious or derailed by life events I quickly engage everyone on Adam's team – what has worked well for him is more predictability, gentle voices, activity including sports and sensory support that befits him. All I have to do is write things down and Adam reads lists and stories for me. Countdowns work, clocks and the like. It's important to set the time aside and concentrate on him until he feels better (and this makes me obviously feel better too). And while I've been bemoaning the loss of his cherub cheeks for quite some time now, puberty has officially begun. I can see it emerging as cherub cheeks turn in to pimply ones. It just really hit me this evening how much he suddenly changed. It seems as if the last two weeks have presented us with a lot and although I knew this day would come, I'm feeling a little strange about it, like, poof...the childhood is now officially gone. Of course, the transition is longer, but sometimes the way we view things seems so hyper-real. I've heard that boys stay close to their mothers, and while I'm really cognizant of him needing to spread his wings and be a boy, a teenager, a man, I still hope he will indulge my affections.

I picked a book up about boy's development the other day. I scoured a few to read what boys his age go through. Of course, these are supposed to be boys with typical skills, but I still found it so relevant in terms of body development and feelings. I want to support Adam into his teenage will (and whatever else comes with it). When I looked for “autism” in the index, I was surprised, actually, to see a reference. I flipped to the page, situated in the first third of the book, and read the “warning;” that is, the “negative” things that a boy may *not* develop which might indicate autism. I was disappointed if not bored (while I considered new parents paralyzed with fear). I mean, when will autism be included in the long life development model that I *need* to read, and not as a blurb or a warning in a paragraph?

Adam's life is not a paragraph. It doesn't necessarily belong to the “special” boys category of books, either. It is a long, developmental line (and hopefully life) and he feels and just like other boys feel, and sure, then some. It would be great to acknowledge all boys, not matter what their label, integrated within the context of a full and whole boyhood – to include the ways that all kinds of boys may experience their bodies and feelings. Yet, autistic boys get books on different shelves (if we get any at all outside of [Jessica Kingsley](#)). Maybe we should simply ask that our boys getting written in.

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[How I Deal](#)

Filed Under ([Ableism](#), [Acceptance](#), [Anxiety](#), [autism](#), [Estee](#), [Joy](#), [NEugenics](#), [Parenting](#), [The Joy Of Autism](#)) by Estee on 10-06-2013

So I've just put Adam to bed. We've had another challenging month – a major basement flood ruined his space where he jumps on a trampoline and has his OT equipment. It's his space where he is king. It's our second flood, but this one was much worse...expensive damage and more importantly, it had to be totally ripped apart. The same week, Adam suffered the viral croup that's been going around up here. Unable to move for a week, he hardly ate and broke out into frequent sweats. Unable to explain the way he feels in detail, or to have the energy to "type it out" as I say, I panicked and took him to the doctor three times to make sure he was going to be okay. In the middle of it all, my walls were being ripped out and fans and humidifiers hummed so loudly that it was difficult to feel at home let alone relax.

Then, Adam returned to school on Monday and started biting his wrists and arms. It hasn't abated yet – he's frustrated when his preferred activities are ending, he's starting puberty and my great little guy is on the anxious side to begin with. He has all the difficulties with transition and arousal as expressed by other autistic adults. It's very difficult to write about Adam in this way, but these challenges are inevitable in life. My mother confided in me that she used to bite her friends (she won't mind me writing about it now) because she was frustrated and angry. I expect Adam is a bit frustrated and angry too – his ripped up space, his sickness that has kept him immobile and now having to return to demands not to mention the need to express the free will of becoming an older boy. The way I deal (despite my own stress) is to bring back routine, use visual supports, gestures, counting, less words, gentle affect. In the midst of chaos, this is one thing I know to do. I also have a routine, it seems, when I'm overloaded. I get stressed out and then realize its time to shut everything down, off and focus on calm and Adam. Then, as I do, continue to support Adam's development and learning to cope with new experiences and on patience with the things that don't work out as planned.

I had two other thoughts this evening when I considered writing about challenges, which I am wary of doing for all the twists and turns I see stories take for some people's own self-interest. First, I recommend everyone to read Val William's book, [Disability and Discourse: Analysing Inclusive Conversation with People with Intellectual Disabilities](#). Using a conversational analysis between disabled and non-disabled support workers, she analyses the subtleties of our conversations, intonations and expectations against our desire to support autonomy and how we may in fact silence and disable it, as well as examples of how it can be enabled in people with severe communication disabilities, which is my area of special interest. I was considering how I might disempower Adam's free will and autonomy by analysing my own behaviour as his parent in how I talk to him, what my expectations are, how I may garner an answer from him. I asked myself if I praise him because he has answered in a way I expected, or made a choice I preferred. Then I asked myself (and am more aware of this now he is entering puberty) how often do I praise the choices he makes that I might dislike or are inconvenient for me? How can I encourage and support his autonomy if I only praise what I think is acceptable? These are the reflexive questions and sometimes, fine lines.

Then, I came across two recent books that mention my name and work. The first is by Michael Prince and Bruce Doern, [Three Bio Realms: Biotechnology and the Governance of Food, Health and Life in Canada](#). I have quoted Prince especially from his book *Absent Citizens: Disability Politics and Policy in Canada*. In *Three Bio Realms* he states:

“Bio-life technologies are especially susceptible to both the ‘wow’ and the ‘woah’ reactions and instincts. In this case, the ‘wow’ factor came in the announcement itself and press coverage of it. An immediate letter to the editor of The Globe and Mail newspaper expressed the ‘woah’ reaction in intensely human ways. The letter came from Estee Klar, who signed her letter as the founder of the Autism Acceptance Project (Klar, 2010). Her letter expressed the views of the mother of an autistic child reacting to the announcement about genetics and autism. She wrote ‘the lack of public awareness about autistic pride and the many autistic adults who have helped our understanding of

what it means to be ‘different.’ She expressed deep concern about language that might cast persons with autism as having fouled-up genes. Klar concluded by stating that autistic people ‘are more than their genes’ and that like non-autistic people, are shaped by [their] environment, supportive families, good education and so forth. (Klar, 2010 in Doern and Prince, 2013, 198).”

I was surprised to see this disability scholar refer to autism as a “disease” because the reality is, there is no known etiology of autism. While there are other issues that confront many different individuals with the label, the term itself is too broad and deterministic regarding autistic being and identity. I also think it prudent to cite the *woah* factor in a society that searches for a panacea – from pills to technology to gene-causation – in the pursuit of a (perfect) ability that I think will still experience or may create new disabilities. The way we parse humans as (dis)abled repeats self-evident ableism.

And then I came across this book *Bad Animals* by Joel Yanofsky who says,

“I’m recounting the highlights of a telephone interview I just had with Estee Klar. She’s a Toronto writer and curator I learned about when I read her heartfelt essay ‘The Perfect Child.’ It’s about her son Adam whose on the spectrum. Not long after Adam was diagnosed, she started TAAP or The Autism Acceptance Project. TAAP’s mission is ‘to bring about a different and positive view about autism to the public in order to raise tolerance and acceptance in the community.’ She also started blogging about her life and about autism, which she says on her website, is not about illness but a way of being. Even so, Klar is hardly starry-eyed. She knows first hand how tough dealing with autism is. She also knows that if she were to accept all the doom and gloom heaped on her over the years she’d be incapable of doing anything, including what she believes is best for her son. Currently, Klar’s blog reaches some two hundred and fifty thousand readers.”

I do think that many of us need to write-it-out, visit meet-up groups, talk it out, type-it-out despite some days I think I should just delete everything and walk away. For myself, I’m not a great writer but I just keep doing it. I have a compulsion and I guess it is a way I can deal, and if it helps you too to read it, then I’m glad for that. I am grateful that Yanofsky in that at least he highlighted that I am hardly “starry-eyed.” I guess despite the fact I can get very down just like anyone else, I am also determined to see that sun rise and know there are always many delightful days, and I don’t believe in simple answers and a final cure. I don’t believe in easy paths and the “pursuit of happiness” – when we think it is something to obtain and possess, it simply makes us more miserable. It’s like expectation – when we hold on to it, we will be disappointed. We can’t hang on to anything (obviously not a soothing statement for people who need regularity and routine). So why am I thinking about these two quotes about the way I think about autism and my life tonight? Well, if anything is final, my concern is the finality of the existence of people we deem not worthy to live because they do not fit an economic paradigm and who are considered burdens on society. The thrust of my work today deals with this and how we can support autistic people, and to reconsider how we view autonomy and independence as yet another path to normality (and oppression). Normal doesn’t exist and it never will for many of us, and for most, it is a mere delusion. Hmm...delusion. A way to survive the ultimate reality? Think about it.

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[**New Members of The Autism Acceptance Project \(TAAPProject\)**](#)

Filed Under ([The Autism Acceptance Project](#)) by Estee on 03-06-2013



TAAP New Members Meeting From Left to Right: Bev Leroux, Nelson Lui, Estee Klar, Todd Simkover, Michael Moon and Corina Becker.

Today we had our first offline TAAP meeting since the re-launch of the website and we look forward to more work ahead. I'd like to introduce you to some outstanding new members of TAAP, all who have already worked so hard to help autistic people and society's understanding of what autistic people need and experience. Soon, we will provide a background of each member's work as autistic self-advocates. I was only sorry that our honorary member, Adam, couldn't be with us today, but he will be in attendance at future meetings. TAAP has an email list if you wish to join for future news, articles and announcements. Please visit **The Autism Acceptance Project** official site as www.taaproject.com.

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[The DSM V and Services](#)

Filed Under ([DSM V](#), [What is Disability?](#)) by Estee on 03-06-2013

Tagged Under : ([Dis](#)) [abilities](#)

My copy of the DSM V is here. [Ari Ne'eman made this address regarding the how the DSM V may effect autism services.](#)

I wrote this response this morning on the Facebook link:

I agree with his point that suggests the hierarchy of disability and how we must work to build support and acceptance for all persons regardless of (dis) ability. Now not living in the US, and completely understanding that funding is presently coming from Medicaid, how can we call attention to inclusion issues and specifically education – that this is not a medicaid issue. Education is a right for all people. My concern here in Canada, and this was cited in *Moore Vs. British*

Columbia (2012), that the notion of remediation before the right to be mainstreamed risks adverse effect discrimination. I would be interested in discussing with you strategies that discuss this issue and how the public might only view autism as in need of services under Medicaid (which presumably means remediation before the right to be educated). Can you offer your input and can we work together?

Considering the empiricist history of creating normate culture, and an education system that supports that culture, Medicaid does not is the only issue we have facing us. Services need to be multifarious to answer a variety of needs for a diverse and complex autistic population. Looking at inclusion in a variety of ways, attitudes, changing the way we do autism research, participation by autistic people who will help reduce stigma and discrimination and policy and legal levels for all autistic people, and mostly inclusion in programs, education and a deep look into the types of accommodations that autistic people need are among some of the very urgent topics that require dialogue. We need to work together to look at every aspect of the way autistic people are currently treated in society to move forward, and acknowledge that a medical approach to autism will never be panacea. While Medicaid is a system in place to help in some areas, such as habilitative services, and autistic people have the right to access these services as much as anyone else, we do have a lingering and problematic issue of medicalizing every aspect of human existence and now, framing everything under the persistent mental health (or illness) umbrella. When does acceptance of human difference begin and when does pathologization stop? What is an illness and what is not an illness? The way we measure physical properties and the way we observe autistic people for “maladaptive behaviour” are different disciplines, the latter being subjective. And so, we have ever-changing humanly-made, observed definitions of what autism is supposed to be.

I have been thinking of cognitive prosthetics a lot lately and our penchant for (perfect) ability, and how utterly disabling our quest for perfection has become (think performance enhancement drugs, cosmetic surgery, technology and so forth). And now I speculate – once we all want to put a chip in our own brains because we admire autistic strengths, or to be more specific, implant ourselves to obtain these “magnified abilities,” as neuroscientists sometimes call them, then what aspects of our brain today (that we consider “natural” and morally *more* correct) might be disabled in order to make room for these “enhanced abilities?” After all, as theory presently dictates in binary terms, autistic people have strengths because of their disabilities. So, as we admire the abilities and are connected with technologies to achieve them, it’s only a matter of time that other aspects of our brains will become “dis”functioned. Now let us ask again, what is a disability? Let us continue to work to include everyone and to end the exclusion of human difference.

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[Personal Interest and Academic Reserach](#)

Filed Under ([Activism](#), [Adam](#), [Advocacy](#), [Autism and Intelligence](#), [Communication](#), [Community](#), [Computing/iPad](#), [Critical Disability Studies](#), [Living](#), [Politics](#), [Writing](#)) by Estee on 28-05-2013

The end of the day of Adam healing from the croup and us both watching repeats of *Wretches & Jabberers* for my thesis. Adam can’t help laughing at the scenes of Naoki jumping up and down to Rimsky-Korsakov’s *Flight of the Bumblebee* – flapping his hands, moving the window blind from side-to-side, opening and closing doors, and running up and down the stairs to then, finally settling at his computer utterly focused and well,

communicative. I can tell Adam's feeling better as he giggles and then afterwards decided to do some puckered-lip kissing practice on my cheek.

Watching these clips from YouTube are also very important for anyone wanting to discuss it. I would imagine we're all concerned about Tracy's living situation and want that to change. As I write an academic paper about a subject that I am personally invested in, I also feel a responsibility to my son's community. I am also selfish and grateful at the same time – selfish in not wanting Adam or anyone like him to have to be in Tracy's position as well as inordinately grateful to both Tracy and Larry and their supporters for going out into the world to do this work. We are all motivated by personal circumstances which enables our empathy. I am hoping to articulate my personal interests and vulnerabilities in my own academic writing, where one is otherwise *supposed* to be, in a traditional empiricist sense, emotionally removed and (supposedly) objective. Others have discussed this as well – Behar in *The Vulnerable Observer*, and Douglas Biklen in *Autism and the Myth of the Person Alone* and recently this new paper by Andrew Bennet in [this issue of Disability Studies Quarterly](#) discusses the possibilities of our mutual vulnerabilities – as researcher and research participants.

I really appreciate this clip that comes in addition to the film, as I wanted to know more about Mr. Thresher's situation. I don't live in Vermont, but I do think that the issue should be a politically active one here in Ontario as our autism societies take up adult autism issues. How can we enable autistic people to advocate on their own behalf for their own needs? How can we support them? This film should be shown at every chance in discussing positive living situations outside of institutions and segregated shelters.

Tracy's Living Situation



For Those With Autism, New Film Offers New Hope



I also work hard to get Adam to type and use AAC and seek people to support Adam. It is frighteningly slow for people to believe that Adam can understand, read, and have the ability to type and both of us need more support that is difficult to find here in Ontario. I've been writing this blog since 2005 and been telling people he could read words, numbers and book spines since he was 11 months old. I find it really frustrating if some verbal behaviourists teach him the word "cat" over and over again so he can *say* it correctly when he's been reading it since before he could walk. The autism curriculum must change to include education and academics in its programs to be truly supportive of the autistic person's right to education.

In terms of typing, his school will support him visually, and I think because of the time I've spent typing with Adam with support, that he is able to type to some extent at school without it. Yet I think with better support he could do better there and I'm trying to teach people myself. If you are a parent, you know this is a labour. However, I can't understand any longer, as Adam and I have also been informally tested (yes, that's the doubt people have about autistic people) that Adam's communication is his own, and that with the right kinds of supports and teaching, he could communicate better by typing. This is seen in the same way deaf sign language was once denied to deaf people in favour of lip reading and speaking. Yet, communication is also a right. To deny a person with a communication disability such support and access will become an issue for law and policy, but our important work for now as activists and educators is to keep showing the work of autistic self-advocates, such as Larry and Tracy, as well as autistic people who are prolific bloggers and writers, and to keep breaking down barriers within our own homes, communities and schools, one person at a time.

My last thoughts for the evening: Isn't it better to support an autistic person in their autonomy rather than to fret about what level of dependence they are going to have on their families or in group homes? In other words, isn't the support of autonomy and our mutual interdependence a much more empowering prospect for us all? (I have to add, I am not intentionally favouring those who are able or have the desire to type or use AAC. There are those who are not able to use it and we have to consider the people missing from this dialogue).

Part of my work wonders why such doubt exists regarding Adam and why we've had to struggle with so much resistance with educators and clinicians. I do think that Adam, like other autistic people, will dispel the doubts. But I also wonder if we have to ask ourselves what or why we doubt, exactly? What do we fear if people with communication disabilities can communicate via other means? Is this the right question?

Stories From The Road | Chapter Eleven | "Teaching The Te..."



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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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