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## Barriers to Information and Communication Technology

Filed Under ([Ableism](#), [Activism](#), [Autism and Learning](#), [Communication](#), [Discrimination](#), [Inclusion](#)) by Estee on 21-08-2012

Tagged Under : [Communication](#), [Inclusion](#), [Law](#), [Policy](#), [school](#)

### ICT = Information and Communication Technology

School is fast approaching and some autistic children get access to inclusive schools and others do not. One of the barriers to inclusion is access to technology and other supports that can enable and autistic person to participate and become successful. Many camps and schools have boycotted the use of iPads for fear it detracts from a student's attention. Some schools prefer "traditional" methods, and argue that technology takes away from that experience.

In the case for inclusion and access, these are some of the antiquated attitudinal barriers we must work to deconstruct. Many non verbal autistic individuals, and other autistic individuals who learn better with computers for visual reasons as well as reasons to do with less distractive stimuli that can impede learning, need technology (and other accommodations) not just for school, but for vital communication and everyday functioning.

In an effort to break down barriers to access, "The Council of Canadians with Disabilities (CCD), a national organization working for an accessible and inclusive Canada, recently consulted people with disabilities about ICT use and recommendations on barrier removal and prevention." Although there is a duty to accommodate, most schools and camps will not do so, especially for the autistic person. Here's some more examples:

### Stumbling Blocks

Although accessible ICT is available in the marketplace, it can take an incredible amount of self-advocacy and persistence for an individual to obtain it. Doreen Demas, who has vision impairment, discovered this when seeking an accessible cellphone from the Manitoba Telephone System (MTS). For customers without a disability, acquiring a cellphone that meets their needs is a relatively straightforward consumer activity. MTS's original offer to Doreen was an inaccessible BlackBerry. Over a period of several years, it took numerous frustrating sessions with MTS representatives and a complaint to the Canadian Radio-television and Telecommunications Commission (CRTC) for her to obtain a contract, with reasonable terms and conditions, for an accessible iPhone. The CRTC has a policy requiring that Canadian cellphone service providers include an accessible product in their catalogue of devices on offer to the public.

Some post-secondary students with disabilities encounter barriers related to ICT. While a student intern, who requires large print, may be most comfortable using a particular program to enlarge text,

the intern's field placement agency may think it is reasonable to expect that person to use whatever programs are available on the in-house system. Although educational institutions and employers have a duty to accommodate disability-related needs, individuals continue to struggle to have such accommodations provided.

The other barrier is poverty. Most of our disabled population, due to so many barriers to employment and educational institutions, end up living beneath the poverty line. This also make access to essential communication and technologies expensive:

Like everything in the marketplace, ICT comes with a price tag. People with disabilities experience a disproportionate level of poverty. People with disabilities of working age are about twice as likely to live on a low income as their counterparts without disabilities. "There is the assumption that everybody can afford a computer. That's an assumption. It is not a fact," says Marie White, Chairperson of CCD's Social Policy Committee. "Our most challenging issue is poverty." Some people with disabilities face additional costs because they have to buy ICT, and they also must purchase adaptive technology to make inaccessible technology usable. In some provinces, provincial programs provide people with disabilities access to technology.

While some autism organizations endeavour to provide some grants to autistic people for access to iPads and the government subsidizes other communication devices, there are wait lists and rental fees can still be expensive ([you can seek some assistance through the Ontario Ministry of Health and Long Term Care](#)).

For Adam's sake and like many other parent advocates, I've had to learn a lot about AAC (Assistive Augmentative Communication) and how to use it by myself through courses and "old-fashioned" book-learning. In turn, I train many of Adam's teachers and support workers in his use of the iPad and with typing. Finding SLP's trained well in the field is difficult but necessary, and there are a precious few who do it exceptionally well. While SLP's are typically trained in "speech" functioning, there is tremendous value in their teaching to the ways and means of autistic communication, literacy and the use of devices for advancing skills. The device is often referred to as the individual's own "voice" or "talk box," and should be treated with the same care and respect.

It's tough to still get people on board at the school level, to see devices as a necessity for many autistic people, and to include them with the same value and respect as we would the voice of any other child.

I hope you have some success in using this information when you approach the school boards and other support workers.

### **References:**

Integrated Access: The Right to Universally Designed Information and Communication Technology Evolution of Access—Building in Access to Information and Communication Technology, [Abilities Magazine](#).

Source: ["Personally Speaking: Poverty and Disability in Canada," Council of Canadians With Disabilities.](#)

[Video on The National Action Plan from the CDC:](#)

## CCD National Action Plan



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## [How Can Our Autistic Children Participate?](#)

**Filed Under ([Acceptance](#), [Autism and Learning](#), [Books](#), [Inclusion](#), [school](#), [Travel](#), [Uncategorized](#)) by Estee on 20-08-2012**

“Our job isn’t to figure out if a student should be participating. Our job is to figure out how a student should be participating.”

[This is a line from Paula Kluth’s DVD, author of \*You’re Going to Love This Kid\* on inclusion in the schools.](#)

We are on the brink of another school year. Many parents struggle with finding not only a placement for their autistic child, but the right placement. In Canada, as is for many places in the world where children are more likely than ever to be included, children and parents with autism are still some of the most excluded in our society. I often find it shocking the lack of support in my country where we seem to have otherwise great social supports. Despite there being many great and willing teachers, the school system is still one of the most unjust institutions for autistic students.

While many of us work to change attitudes and policy in Canada and the US, I want to reiterate what an important step integration and inclusion is for all of us. Watching Adam at camp and even younger people with disabilities, the younger generation already has much more exposure to kids with disabilities than my generation ever did. Many a parent I’ve met will register their child into an integrated school in order for their children to respect and value everyone. After kindergarten, however, the segregation typically begins. While we may have seen more effort towards inclusion, we are still teetering between the two extremes.

Watching Adam with other children and their patience and acceptance shouldn’t just happen once in a while or at summer camp. Adam has developed so much this summer, as he does every year, and his peers do too. They are much more tolerant and accepting than I can remember of my generation. It is an indication of how

important it is to start inclusion young and from the get go. I believe it is the older generations like mine who simply let old habits get in the way. Watching how easy it is for children to accept human difference is proof to me that inclusion is good for everyone.

This post is dedicated a couple of submissions I received this summer for review: Paula Kluth's website, DVD and book I've mentioned before, *You're Going to Love This Kid*; Eileen Riley Hall's *Parenting Girls on the Autism Spectrum*.

### Special Features: Ten Questions Asked and Answered - Par...



The key for teachers is to learn how to include. This involved adaptations in the presentation of lessons, to how a child can respond to lessons. Adam, for example, responds to multiple modalities, but the main way of teaching him and transferring his learning is through the visual — computers, iPads, manipulatives and actual experience in the field. Accommodations also include sensory breaks, exercise, and other adaptations to a classroom. For instance, Adam can focus better on a ball chair. Otherwise, he needs to move his entire body so this provides the feedback he needs right now in order to attend to his lessons.

While the pressure to “be normal” in its elusive forms and definitions was more difficult when Adam was younger, we have grown into another comfort level with our lives and ourselves. Adaptation is simply a wonderful way to make learning accessible to Adam and it's a joy to watch him grow and learn. Paula has many tips on adapting lessons and changing attitudes so that teachers and schools can adopt full inclusion. She makes it sensible and inspiring. I suggest you check out Paula's YouTube channel for more information.

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Eileen Riley-Hall is the mother of two autistic teenage girls and the author of [\*Parenting Girls on the Autistic Spectrum: Overcoming Challenges and Celebrating Gifts\*](#) (Jessica Kingsley Publishers). As the mother of a boy, I was wondering what I'd learn from Eileen, but knowing so many parents with young autistic girls, I had to recommend her book. Sometimes we just want to refer to another book by another parent for that down-to-earth advice. I would also recommend along with a how-to book such as this, all the books by autistic women including Donna Williams, Lucy Blackman, Dawn Prince, Temple Grandin, Jasmin O'Neill (among others) — some of the first autistic women to write from their own unique perspectives. I like to pair my parent-memoirs with those also written by other autistic people.

What I found most refreshing in Riley-Hall's book was Chapter 8 on “The World Wide Web.” Most books written by moms of autistic children usually contain lists of therapies and websites that can seem overly-diplomatic, noting down every therapy out there for the parent to sift through without any critical analysis of the therapy, the way it came to be in the vast array of (and history) autism “treatments,” and the controversies and

potential dangers surrounding them. In contrast, Riley-Hall offers some warnings and states the pros and cons of the many websites that parents must navigate when entering the autism community. “There are very distinct divisions within the autism community. So you have to know that whatever you read is fueled by an underlying position or philosophy about autism: what it is, what causes it, and how best to treat it..unfortunately there is very little middle ground in between.” (p.131). When I first started reading books about autism by parents ten years ago, I wish someone had provided me with that caveat.

In reviewing her list, it is apparent that Riley-Hall is recommending sites that support and accommodate the autistic as “complete,” an encourages society to value the autistic person. This book is part “how to” book and part memoir that makes Riley-Hall’s book accessible for the parent of an autistic girl. Best of all, it’s all about acceptance.

Best of luck everyone in prepping for another school year!

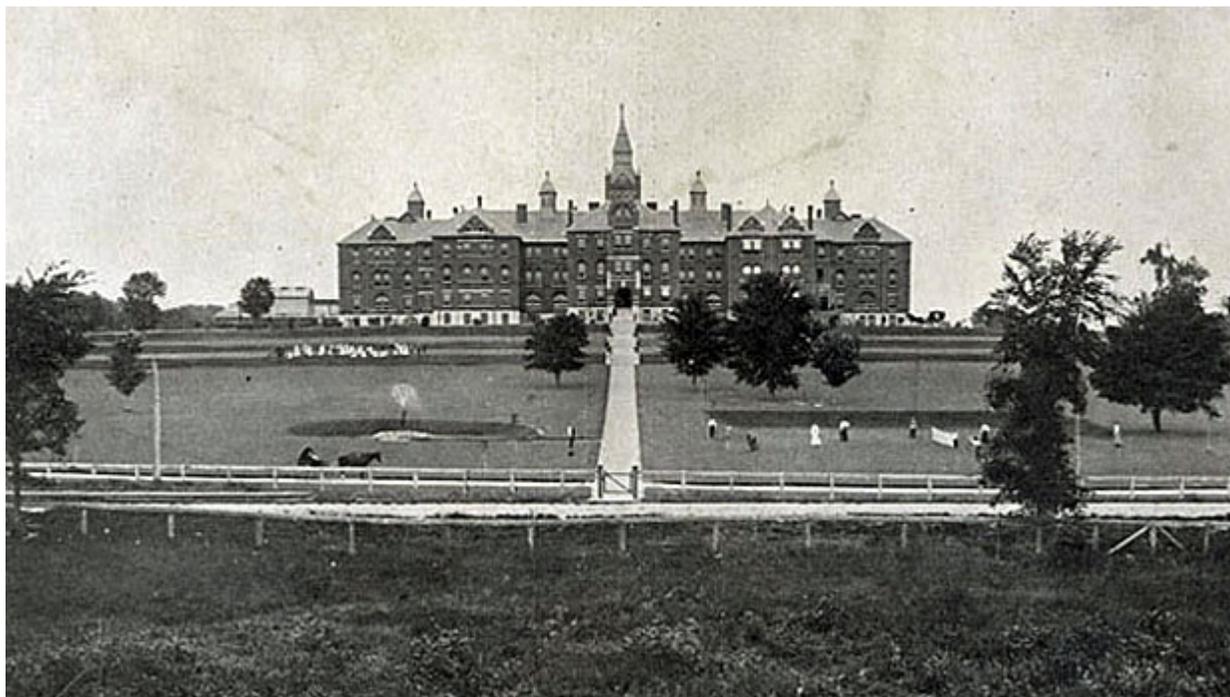
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## [A Mother’s Notes From The Ghetto](#)

**Filed Under ([Ableism](#), [Abuse](#), [Acceptance](#), [Activism](#), [Advocacy](#), [Book Reviews](#), [Critical Disability Studies](#), [Disability History](#), [Discrimination](#), [Inclusion](#), [Media](#), [Parenting](#), [Politics](#)) by Estee on 13-08-2012**



Like many of you, I watched the closing of the Olympic ceremonies. Today’s notes from the ghetto weave some thoughts about the Olympics, a book, a documentary, and the Canadian Charter of Rights and Freedoms.

In a waiting room this past week, *Sports Illustrated* lay limp and wrinkled on the table in front of me. An title about how the games were more inclusive this year caught my eye and I read it with disappointment. There was no mention of people with mental disabilities. I didn't take the copy of the article because it wasn't mine, and now I can't find it to cite. You'll just have to take my word for it unless you can find it for me.

I wanted to write a post remarking again how people with cognitive disabilities weren't visible or participating in the games. As much as I watch the Olympics, I can't help but see it as a symbol of our admiration of the able-bodied. Including some disabled people in the opening ceremonies and a Para-Olympian is supposed to change that view. The "main" Olympics gets the bulk of the media attention. In talking about the Olympics, then, the media coverage is a reflection of what the consumer wants to see. I'm not blaming the athletes for being able-bodied and I congratulate everyone for their remarkable achievements. I am, however, spotlighting the acceptance of exclusion.

Today I also finished Melanie Panitch's [\*Disability, Mothers and Organization : Accidental Activists\*](#) and read about the three mothers who worked tediously to get their children out of institutions in Canada and close them all down: Jo Dicky, Audrey Cole and Paulette Berthiaume. I read how these women lived in a time of not only gender inequality — "busy men" on boards versus women knocking door-to-door as volunteers — but also in a trail of institutions born from the eugenics movement. The first institution in Canada was the Huronia Regional Centre in Orillia, pictured above, which opened in 1876.

Ironically, as I finished reading the final chapter this morning, I tuned into the CBC documentary [The Gristle in The Stew](#) and listened to the stories of horrific abuse of the people who were labeled mentally "retarded" by professionals. These professionals told parents to just "forget about [their] children and move on." The government film ["One On Every Street"](#) told parents that 1 in 33 children had mental retardation and described institutions as happy places where children would be educated and rehabilitated in the name of getting them back into their communities. Not so for Paulette's son and others like him. Her son Louis lived in an institution for thirty years before she could get him out.

Audrey, Paulette and Jo were made to feel guilty for not only having disabled children, but were also pressured to put their children into institutions and be "good mothers" for doing so. Many families lived in fear of not placing their children in institutions because they did not have access to other services so they turned a blind eye to the abuse. There was no "unity" in their struggle, for these fearful parents criticized activists against the campaign to close institutions in Canada.

While these three mothers fought (and won) to get all people out of institutions in the name of their children, they were excluded and marginalized as "emotional" and "trouble-makers" along the way, often excluded from participating on major boards and committees. But they did not desist. These three women managed to close all institutions down in Canada, and worked arduously for over twenty years to do so. They worked in 1981 to include the disabled who were then omitted from Section 15, which dealt with equality, and secured human rights for the disabled in The Canadian Charter of Rights and Freedoms. They won an unprecedented \$1,400,000 in personal damages for 88 former residents of Saint-Theophile in Quebec in 1990 (pardon the omission of accents that I can't access on this blog), among many of their accomplishments. They did so as volunteers. One reviewer, Susan DeLaurier says of the book, "Disability is often viewed as a narrow field of social policy, programs and services that leads to a set of parallel social arrangements that have isolated disabled people in segregated systems. By looking at the mothers of children with disabilities and their insights and researching their activism, it is hoped that disability will be viewed as a broad-based inquiry commanding social and political analysis."

A class action law suit of \$3 billion for the plaintiffs incarcerated and abused in Institutions in Canada, simply for having a mental disability, will happen in September 2013. Listening [to Patricia Seth and Maria Slark, two of the plaintiffs in the documentary,](#) made me shudder. As a mother, I already know of gender discrimination — domestic and public as a mother of an autistic child and an activist — and there are challenges with this in helping Adam. To imagine how the "accidental activists" had to wait for so long to see their children free again, reminds me why I feel anxious so often. I feel I am always looking over my shoulder and can never rest where Adam is concerned. We have to respond when advocates for any "treatment" or "therapy" which uses the same

language and logic that incarcerated innocent people just a short time ago. In the ABA movement which started in Canada in the early 1990's many of the campaign phrases and threads of logic echo like the halls of institutions. The ABA movement was founded on the premise that autistic children would recover by age six with the treatment (and now the argument extends to older ages) and would therefore no longer require "state" funding. At the time, the estimated costs of funding an individual in an institution was \$85,000 a year. In 2012, I relate to the same feelings as these mothers and share their experiences even after feminism has evolved. The challenges and the way to help Adam become increasingly complex, there is resistance and fear of progress, old arguments persist and the "busy men" still exist.

Our situation remains fragile. Despite statutes, we have not achieved Inclusion for people with autism. Society does not see autistic or other mentally handicapped persons as truly valuable to our communities where definitions of "capacity" and "productivity" seem exclusive and informed by implacable economic theory. We see it at the most basic level as in extraordinary red tape in our education system and, after all, I'm "just a mother." Despite detailed notes and expertise about our children, the public system will hardly pay attention to it. They prefer a report from a professional using standardized tests which is an exclusive and unjust method of testing an autistic person. [I talked about some of this in another post about the many ways we experience exclusion.](#) "The briefing notes by the Community Association for Community Living in 1993 noted the same: "despite the protection afforded to people with disabilities in the Charter of Rights and Freedoms, many barriers to participation still exist in employment, immigration, education and the criminal justice system." (Panitch, p. 145).

There is another group who tell us to "never forget," and this same standard must be advocated for the disabled who have experienced formidable abuse in their lifetimes. When Pierre Berton reported about the abuses at the Huronia Regional Centre in Orillia (pictured above) in The Toronto Star, Berton noted that after Hitler fell, "many Germans excused themselves because they said they did not know what went on behind those walls. No one had told them. Well, you have been told about Orillia." Now I, along with others, am telling you about echoes; of the history that could repeat itself.

The Olympics is just one more timely, everyday example of using people as footnotes and keeping them in the ghetto. It is time to include all the Olympic events — special, para and everything else, under one umbrella. I work for the day when I can witness Adam attaining his full citizenship rights. Audrey Cole wrote a Manifesto with her two lawyers called A Manifesto of the Canadian Association for the Mentally Retarded in 1982:

"The Manifesto equated how the renewed constitution established the full autonomy of Canada within the community of nations with how the provisions of the Charter of Rights and Freedoms introduced a new history for people with disabilities as valued, participating members of the community. It concluded cautiously: 'The Charter of Rights and Freedoms obviously has very important implications for Canadians who live with a mental handicap. It is not possible to determine fully what those implications might be until the provisions of the Charter are considered by the courts in the contest [sic] of real life situations.'" (Panitch, p. 133).

Audrey Cole said in her interviews with author Melanie Panitch:

"Our struggle is long-standing. It will not only continue but will gain strength with every denial of a fundamental right to any person of any age with or without disabilities in this country... Outrage, as you know, can be a unifying force for the achievement of social justice." (ibid, p. 69).

We're living the relay race and our work is not yet done.

Reference:

Melanie Panitch, *Disability, Mothers and Organization: Accidental Activists*. New York, Routledge, 2008.

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## [iPads, notepads and a note about teaching methods](#)

**Filed Under ([Autism and Learning](#), [Communication](#), [Computing/iPad](#)) by Estee on 07-08-2012**

Adam's iPad wasn't working for a few hours over the weekend. It has been also phasing in and out — photos disappear then reappear. He uses his camera for his Pictello stories.

Meet a non verbal person — autistic or otherwise, and you'll see an array of devices at their disposal. Some are more convenient to talk with, often one conks out or something happens. It's technology. We need more than a reliance on the iPad.

I love the iPad. I've been teaching Adam to read a clock on and off for a while now. A sole reliance on "verbal behaviour" or output is not reliable. I had asked Adam to tell me the time. Now that I have the iPad, there is a "show me 4:30," etc, and he can pick from an array of five possibilities. He gets 100%. I do, however, have to tell him to "pick only one." That instruction works like a charm as he then understands that I'm not asking him to fool around and listen to kurplunks of wrong answers just for the fun of it.

I work between the iPad and the "hard copy." The iPad and computer programs are very helpful to teach and now to refine Adam's ability to listen to the instruction. As his part-time teacher, I model the correct response for him, and this makes it easier.

I've often noted that multiple choices are the way to go to determine his knowledge, as well as presentation. I believe Adam has taught himself many "subjects" and I get this confirmation every day. Here's another example:

I used to ask Adam to do word searches with me on paper. You have to read the word and find it in a jumble of letters across, down or diagonally. Adam would seem never to be able to do it. Now on the iPad, he scans and finds the words faster than I can. I didn't know he knew how to do it and I used to think he didn't understand when it was just those paper-kind of word-searches. I also consider that having to draw a circle around a word was very challenging for him. He is still working on his fine motor control. I think about all the effort it must take to circle a word, that then that becomes enough. That action in itself distracts from the actual word search game. It's like asking a non verbal autistic child to "tell time." It's just so hard to get out, then when the answer comes out, it may be incorrect.

Another anecdote from the movie [The Brain: A Secret History \(the title of the episode here reads "The Broken Brain" so I'm going to ignore the ignorance of that title for that is a social judgment of that which we still do not fully understand\)](#) A brain injured patient is asked to show, on his fingers, what number is being shown. On his fingers, the individual answers correctly by showing four fingers. Then, he is asked to say the number he says six. It's to me, exactly the same thing that happens to an autistic individual with verbal communication challenges, well, of Adam anyway. Often he knows the right answer but he just can't say it, or it comes out as the wrong answer.

I know that teaching has to be fun and interactive. I'm now at a stage where I'm going to have Adam tell me all about a story he has read with me. After that, I'll be working on some narration of his own. It's a process of picking up what I've read, using what I have at our disposal, some common sense and love at watching him grow and develop. Over the course of this summer, I've also noted that when we educate autistic children, we forego the academics for controlling the behaviour. I'm starting to believe again that attention can be

accomplished through active engagement, following the interests of the child, no matter how “odd” they may seem, and building the necessary skills this way through visual support, parental and teacher support, love and yes, devices. Feel free to add to this list.

The iPad reminded me that to rely on it alone is risky. We need the support, back-ups and a variety of presentations that help with learning and communicating.

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## [Some Thoughts About The Various Ways of Being Excluded](#)

**Filed Under ([Advocacy](#), [Autism and The Media](#), [Celebrity Advocacy](#), [Communication](#), [Contributions to Society](#), [Critical Disability Studies](#), [Discrimination](#), [Inclusion](#), [Parenting](#), [Politics](#), [Research](#)) by Estee on 10-07-2012**

I have a comment on comments, either in comment boxes or full blog posts about other writers and bloggers. Usually I won't write about it, but I decided to write in my own defence. In so doing, I've had other thoughts about the various ways of being excluded, as either autistic people, or as autistic allies.

Recently, I did a self-search on Google. I am sad to say that I get used to disrespectful commenters who seem to create a narrative about me that is unfamiliar to me. I am also delighted, however, by comments that build upon a constructive dialogue about autism and disability and how we can remove the barriers for autistic individuals. I happen-stanced upon a post from 2008 about my blog — that mostly I “get it right,” but advocate for doing “nothing” for the autistic person.

If you've been reading my blog since 2005 I've done nothing but critically evaluate everything that Adam and I have come across in terms of therapy, education, autistic/social value, and opportunities, and the lack thereof. While the nature of blogs has changed since 2005, many of which have become syndicated journalism, I've kept mine in journal-mode, writing about my own growth and development as an autism parent to my beloved Adam.

Adam has been in “therapy” since he's been 20 months of age and I have reams of notes and binders I have taken to create his programs, track his progress, develop his plans. I have created his programs along with other professionals that use ABA, RDI, Floortime and other methods. I have a decade of experience of autism education and various therapies, many of them dubious. I've witnessed improvements in the field where I continue to have a watchful eye. I predicted that we would be forced into an ABA program, and here we are, in an segregated school for autistic children. Not that it's a “bad” thing. I am actually grateful not to be in a system that completely disregards him, but is set up more *for* him. Adam, for now, is happy there and he is learning, but it's a fact that it's still exclusion which we mitigate with other inclusive programs.

ABA is something that we've had to contribute to improve upon because it's really hard to change the system. To me it is in part a method and in part a label for a type of education that in some schools, uses other methods in addition to it. Adam and I have to “fit” into a mold and make it the best for him — those are our barriers and limitations for now. We work to fill in the gaps ourselves. I learned and taught Adam how to type...by myself — by reading, studying and consulting others who have other expertise to add. Now his school builds upon what I started. Recently, I was asked to write a book about it, and may do so after this year of finishing my M.A. in Critical Disability Studies. I have now five years of typed dialogues between Adam and myself, methods and

back story of how it all began. He would never had had this opportunity had I not taken his education and communication upon myself, and I'm not shy to admit it because I hope it will become more mainstream. I am not alone in this among many autism parents. We make our own roads and other parents will share the work they've done.

We still work towards Inclusion, but when I made a recent query within the public system, as predicted, it ended up that Adam would be put in the "lowest functioning class" (their term, not mine). His cognition and "capacity" was determined by his limited verbal ability and results on standardized tests (which we know do not befit the autistic person as much as a dyslexic person cannot read typical text). How many students in these classes, no matter what their label, are not getting the education they deserve? Whose to decide on someone's functioning level and "capacity" when we give unsuitable tests? Who has the right to decide who is normal and abnormal and how do semantics and labels effect people's lives? Finally, if we decide to write off a "class" of people from the get-go, where do we end up? We are all effected, autistic or not. How we treat our collective members of society is a reflection of how we think about ourselves.

It seems there is a group of people who don't understand (or want to set others astray) on the meaning of neurodiversity, which basically acknowledges that different people have different neurologies that make them learn and interact in the world in various ways. Myths are spun because it is assumed that if we "embrace" autistic people (some of us have been labeled "Neurodiversity Advocates" in a negative context) it will not serve their politics. I suppose, in the system we currently have which are so exclusive and politically limiting to us, we can understand the method, but I think it's ultimately detrimental. An exclusive, "tragic" and medical approach to disability limits community membership and opportunity. Until recently, as autism parents, we have had to feed into the "autism tragedy" model in the belief that this is the only way to garner financial support and services. Despite inroads against the medical and disability-is-tragic models, there are many new parenting studies which seem intent on proving that autism causes families to break apart, which to-date, cannot be proven. This is another way of excluding autistic people and their families — by seeking something to blame, researching etiology and causation instead of spending money on understanding autistic individuals and bettering their quality of life.

If we accept and believe in our children and don't get tragically depressed, we are written off (as I have been on numerous occasions) as being in denial. I have been labled a neglectful parent, and a "mental case," (a revelation of the prejudiced inclination of the autism "advocate" who stated that about me). "Those who stray from the this prescribed script [the tragic or depression 5-staged model from grief to acceptance] — for example, by not being as depressed as predicted — run the risk of being regarded as in a state of denial and in need of further psychological guidance and counselling (Oliver, 1995; Reeve, 2000; S. Wilson, 2003)." I think life is all about struggle and we have to work with it. Nevertheless, when we write publically, we leave ourselves open to criticism of all kinds. I embrace that too, but I will also take it on.

It has been challenging to write this blog for the past few years. I'm not allowed, according to some autism parents, to take joy in my son for who he is as an autistic person. My own ups and downs are disregarded if I do not publically lament in the same fashion as everyone else. I opted not to do this because I always kept my son and his community in mind. If I were an autistic person, I thought, how might I wish to be regarded? I don't criticize others for their depression because each one of us has to take our own unique journey. I simply believe that I, personally, have to exercise a discipline in my thoughts and feelings, which is not to say I don't have the same kind as everyone else. I have imposed this upon myself. I have always kept Adam in mind when writing publically because I believe one day he may read this. I also wish to embrace and listen to the autistic community (that is, autistic people). It's unfortunate when others feel they have to "spin" for political reasons or their own benefit.

The other political debates and controversies lie in semantics and definitions. Words are important as they reflect our thoughts about the way in which we see ourselves. We work against traditional systems that have to-date, been oppressive and exclusive agianst the disabled. Paul Hunt first challenged what we call today 'abelism' (a society that favours the able-bodied), in his 1966 book, *Stigma: The Experience Of Disability*. He said, "We are challenging society to take account of us, to listen to what we have to say, to acknowledge us as an integral part

of society itself. We do not want ourselves, or anyone else, treated as second-class citizens, and put away out of sight and mind.” (p. 158).

The Union of the Physically Impaired Against Segregation (UPIAS) was formed in 1974. They re-defined the distinction between “impairment” and “disability” as part of their mandate to “criticize organizations controlled by non-disabled ‘experts’ for their failure to address the social barriers central to disabled people’s exclusion from mainstream economic and social activity and their lack of accountability to the disabled community.” (p.29)

– *impairment*: lacking part of all of a limb, or having a defective limb, organism or mechanism of the body;

– *disability*: the disadvantage or restriction of activity caused by a contemporary social organization which takes no or little account of people who have physical impairments and thus excludes them from participation in the mainstream of social activities. (UPIAS 1976z, p. 14).

This social model approach breaks the traditional causal link between impairment and disability. The ‘reality’ of impairment is not denied, but it is not necessarily a sufficient condition of disability. (p. 30).

Writing about autism as a joy, my absolute love of my son for who he is, my personal struggles without pandering to the pressure to lament in typical ways while embracing other’s need to make their own unique autism journey, is about inclusion of everyone. It begins with the fundamental acceptance and belief, however, that all autistic individuals are worthy and valuable members of our collective. It’s a necessary premise.

The social model is not about showing that every dysfunction in our bodies can be compensated for by a gadget, or good design, so that everybody can work an 8-hour day and play badminton in the evenings. It’s a way of demonstrating that everyone — even someone who has no movement, no sensory function and who is going to die tomorrow — has the right to a certain standard of living and be treated with respect. (Vasey, 1992a, p.44)

Reference:

Barnes, Colin, Mercer, Geof and Shakespeare, Tom. “Analysing Disability” in *Exploring Disability: A Sociological Introduction*, pp. 1-42. 1999 Polity Press.

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## [Towards a New Autism Research](#)

**Filed Under ([Ableism](#), [Acceptance](#), [Activism](#), [Advocacy](#), [Autism and Employment](#), [Autism and Intelligence](#), [Autism and Learning](#), [Autism and The Media](#), [Autistic Self Advocacy](#), [Book Reviews](#), [Communication](#), [Computing/iPad](#), [Critical Disability Studies](#), [Development](#), [Discrimination](#), [Family](#), [Movement Disturbance](#), [Research](#), [school](#), [Sensory Differences](#), [Transitions](#)) by Estee on 06-07-2012**

***“It doesn’t matter who you are, or how high you rise. One day you will get the call. The question is, how will you respond?” — African American U, Senior Administrator***

Adam left for camp this morning. Last week, he did well at his piano recital. His lessons have been adapted for him — colour coding left and right hands, bass and treble clef lines, to give a sense of the many adaptations we’ve learned. Not only have we adapted lessons for him so that he may learn in “typical” ways, but I also asked the teacher to let him explore the piano on his own, as well as have her play for him. I became a musician when I was very young, and a neighbour let me bang away at the keys doing whatever I wanted.

I was proud that Adam was able to attend and play well at his recital. I asked that he make his little bow, and sure, everyone thought that was sweet. Afterwards, as there was another special needs person as part of the concert, I was noticing faces as he sang — his articulation was challenged. I didn’t see gleaming “ain’t that sweet” smiles. I saw strained faces. Not until the children who were fluent with well-pitched voices were singing did the “ain’t that adorable” look beam as high as the church rafters. That effected me a lot, and I pay attention to these subtleties every day. I don’t think people realize the subversive effects of a mere countenance. I, at least, read faces well. Adam seems to pick up on vibes, but that’s my assumption after knowing him for so long.

Last week, Adam was more verbal — asking me “what are you doing?” when I was at work at my desk and he wanted to play. In addition to a successful recital and these questions, we had a “good” week. Having Adam ask me a rare question is exciting. I am happy when he gets more verbal, types on his iPad, and now, starts to ask me questions. When the camp bus came for a visit last week and Adam got upset afterwards, he typed (independently), “why is bus going?” It shows that his world is expanding by his growing ability to communicate. I find myself relieved because I think it will make his life more fulfilling, if not easier in a world that favours the able-bodied and the fluently verbal.

Two days after his verbal “spike,” however, something that comes and goes but improves steadily all the time (akin to a graph with a steady climb overall, but with monthly plateaus and slight dips), and also possibly correlating to the end of school, the transition to camp, a possible cold or allergies (get the picture?), Adam began to twitch more and he lost his ability to talk for a couple of days. He is better at being able to type a few words when he is under stress. He couldn’t do that at all before.

While I still worry, mostly if I see him uncomfortable when it happens, I’m getting better at waiting him out. Whatever is effecting him needs to be processed by him in his own way. Within a couple of days, although the twitching slowly abated. He started to smile and become more verbal after a couple of days of the most intense part of it. I really do not understand what is happening to him neurologically and neither does anyone else. Only some autistic people can give me a sense of it. There is no guru or expert or scientist who has truly “discovered” what causes Adam to tic and twitch the way he does. We know of similarities in other disabilities. Adam was tested for seizures and at least on the day he was tested, it showed negative. These are but some of the things we don’t fully understand about Adam and what we refer to as his autism.

As his mother, I’m well aware of my bias, in spite of my enduring “acceptance” of him. Bias and ideas are so deep-rooted in us that acceptance is something we have to work on every day. (Boy, would I love to read that caveat in someone’s research paper on autism). As Adam’s mother, I realize that although I love him dearly and accept him as he is, it is still difficult to resist the temptation to praise Adam’s “normal” feats and accomplishments only, and not recognize his autistic ones. Like all of us, we are under such a strong ableist or “normalist” influence that we don’t praise, cite, recognize autistic-ness as often as we need to.

We need so much more of a new kind of autism research — one that captures autistic accomplishment without sensationalizing autism. Too often any achievement by an autistic individual gets referred to as “genius.” While in some cases it may be extraordinary, we do this because we are still not looking at autism as a whole in the way we should look at all of humanity. We fracture autism into little bits and pieces as much as we end up doing people.

When I attended [Autreat](#) too long ago now (I am due for a revisit), I purchased fifteen years of workshop notes and presentations. I remember when I attended being giddy that there were workshops for autistic kids on how to

make their own stim toys. Autreat, founded by Jim Sinclair, who is also autistic, is run by and for autistic people.

For months now since he started in an autism school especially, despite my praise of Adam for his feats, I still wonder how I can nurture his autistic-self. So I went downstairs and dug the old material up. Here's a clue of what I wish to study more about:

**How to Play With Dolls: For Kids and Adults Jim Sinclair, disability educator and consultant, coordinator of Autism Network International**

For purposes of this workshop, a “doll” may be any inanimate object that we play with by imagining it to have aspects of personhood. This includes the traditional toy-human type of doll, as well as toy animals, and any other toys or objects that our imaginations transform into living entities. In this intergenerational workshop, we will share and explore different ways that autistic people can use doll play for fun and for learning, and ways that parents, educators, and therapists can use doll play to help autistic people in developing skills and understanding...”

**Music: What Is It, What Does It Mean To Us, and How Can We Use It?  
Katja Gottschewski, musician and music therapist, Bodo, Norway**

In this workshop, we will explore different aspects of music. We will look at differences and similarities in how we as individuals or as AC's and NT's [autistics and neurotypicals] define and experience music. It will be discussed how we can communicate through music. How is music different than language? Can music be a bridge between AC's and NT's?

**Understanding How Plants Can Facilitate Connection in Autistic Children and Adults  
George Salamunec, HTR, COTA/L, Certified Master Gardener, Susan Golubock, M.Ed., OTR/L  
Autreat 2004**

Working with, and understanding about, plants can be an effective tool for developing the senses, reducing stress, and learning to make new connections in autistic children and adults. Matching plants to one's personality and needs is an important first step. Plants provide opportunities for autistic children to explore life, nurturing, modulation, non aggressive options and choices for dealing with natural adversities, and why learning about other life (and people) outside of ourselves is so important...

**Making Employment Fit: Accommodations and Other Dirty Words  
Joel Smith, Autreat 2004**

Employment is difficult for many autistic people. We are square pegs who dont fit nicely into round holes. Rather than forcing the autistic into a job, would it be possible to change the job to better fit the autistic? In this presentation, ideas and real-life examples are presented of how jobs can be modified to best accommodate autistic sensitivities. We will also discuss how to modify your job without alientating your boss and co-workers.

That was from Autreat 2000 and 2004. Twelve years later, I am concerned (especially after attending [IMFAR](#)), how we hardly research autistic ways of being. We usually do it framed in a bias — comparative research against the “normal,” population.

We really don't value what makes up the true and different, “not less,” accomplishments of the autistic person. I've read blogs where “experts” bluntly claim that there is “no value” in lining objects up. I'm not going to target the scientist specifically here, but I wonder how many readers of this may have at one time or another thought the same thing? Other than people like Temple Grandin, how can we all study the value of object-organization and how that is transferable into learning at school and later, in the workplace? I don't think this is a trivial skill that needs to be solely relegated to the OCD side of the human column.

Just because we don't see the value doesn't mean it ain't there. We don't understand. We are viewing under a comparative, normal versus abnormal one, and that's so limiting. While I try to make the "least dangerous assumption," a term first coined by Dr. Anne Donnellan, I realize that I must *work* to continue to see Adam for who he is in all contexts. It's a absolute daily task and obligation of mine as his parent. I wake up every morning thinking about this, more than I pander to alarmism. In fact, next time an autism commercial brings you to tears, please ask what buttons are being pressed and why, and if there's a better way to achieve a quality of life for us all?

I'm also reading Anne Donnellan and Martha Leary's newly released book [Autism: Sensory-Movement Difference and Diversity](#) and I would highly recommend it. I liked especially this example:

According to Oliver Sack's book, *Seeing Voices*, in learning sign in infancy he will develop brain patterns remarkably different from his 'normal' peers. And he will continue to develop in different ways, but we can in no way call those differences 'deficiencies.' He will develop different social and cultural skills. If given the most standardized IQ tests, even with a signing interpreter, he will perform differently, and possibly less well, than his speaking/hearing peers. On tests that tap the developmental experiences of deaf people he would probably score far higher than his hearing friends. Yet it is no surprise but nonetheless sad to learn that for decades deaf children were routinely diagnosed as mentally retarded. Still today, they are often considered to have diminished capacity relative to their hearing peers, even when we clearly know that they can flourish if given the appropriate education and experiences. (p. 33).

Consider that, for the deaf which we think we've come, arguably, to understand and accept, of how far behind we are in autism to apply this level of consideration. Think how far behind! Thankfully, a small pool (and I hope a growing one) of researchers are taking up this call. In Steven Kapp's (et al) paper [Deficit, Difference of Both? Autism and Neurodiversity](#), there is also a call to discover the state of autism acceptance and "potential areas of common ground in research and practice regarding [how] autism [is] discussed."

Scientists, working with the community, can help stakeholders with competing agendas make informed choices between rights, responsibilities, and needs at personal, social, and political levels by affirming that diverse societies respect multiple perspectives.

I'd like to see us all work towards the question of how to nurture autistic strengths and learning and balancing the real need to cope in this world as a minority, as well as continuing to value autistic contribution and being in society.

### **A Whole Better World**

Autreat, May 2000,  
Clay Adams

I can imagine a whole better world,  
Where people don't laugh at each other's pain  
A world where the sun shines on every one  
And one's well-being is everyone's gain

Must we, in fact, feed off each other?  
Fool the unwary, to sell our wares?

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## [Needless to Say?](#)

Filed Under ([Acceptance](#), [Autism and Learning](#), [Communication](#), [Development](#)) by Estee on 27-06-2012

There's not much more to add to this. As Adam talks a bit more every year, he has become an independent typist and needs lots of help in order to tap into his potential here. It began with prompting and facilitating at a time when no one truly understood what that meant, and others, as a result of controversial court cases, didn't want to "touch" it with a ten foot pole. I like to ask myself some days where would he be if I had not pushed this forward, even with the doubters. I started because I knew Adam was already reading so it just made sense. Thankfully, we have continued with it against all odds, and we learn more about [Supported Communication all the time](#).

Anne, however, learned to type in a day before iPads and acceptance. You can read more of [her story here](#).



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## [Adam's Piano Recital 2012](#)

Filed Under ([Adam](#)) by Estee on 25-06-2012



Adam did really well at his piano recital yesterday and I'm so proud of him. I don't take video because I want to be there in the moment with him, not 'virtually there' by making sure I got great photos. Grandfather is better at that anyway. When his teacher called him up to play (she's standing behind him in the photo) *The Muffin Man* he walked up to the Grand Piano and played. Save for a few glances towards swirling fans high above in the church's ceiling, he got through it just fine. Two years ago he was completely distracted by a piano painted with butterflies, a "hey this is cool... nope wait... hey look at that one" distraction that derailed his performance. I never took him to the site ahead of time to get used to it. Live and learn.

Adam can read his notes now and play with both hands. We started by colour coding his hands and the keyboard and notes with numbers and moved on from there. Now he's learning his half notes and on we go, thanks also to his patient teacher and her assistant, Adam's grandmother, who does exceptional preparation for Adam's lessons.

Just before the concert, I kept Adam quiet and well fed. I wrote a quick schedule by hand listing the things we were going to do to prepare for the afternoon and we re-read it together. Then we practiced ahead of time — the walk, the playing, the bow. We arrived thirty minutes before the concert to walk inside and outside the building. He pulled at me when we arrived, wanting to explore. I purposefully stopped many times in hallways with lots of doors, which has caused Adam him lots of anxiety in the past — a compulsion to run off and open them. I then asked him to wait and talked him through it all quietly. I checked my phone, dug around his bag and I didn't hold on to Adam's hand. He waited with me even though I could feel he wanted to move on. When Adam calmly explored, and knew that he was going to get the chance with me, he was cool. He also accepted change of direction and areas that were off limits.

By the time it was time to sit down in his row for the performance, Adam was just fine. The sanctuary was hushed. He sat for the entire performance, bored sometimes and clapped others. When one of the boys got a little talkative, Adam laughed and wanted to talk back by repeating the last word he heard, "again." He's a giddy rule-breaker at heart.

We will definitely go back *again* next year.

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## Happy OM

**Filed Under ([Ableism](#), [Acceptance](#), [Adam](#), [Autism and Learning](#), [Development](#), [Joy](#), [school](#)) by Estee on 21-06-2012**

Should I be looking over my shoulder? As autism mom and son are confronted with many obstacles, feeling settled seems like something that will be stolen from us at any moment. Nevertheless, I'm going to write about how happy I feel today because I recollect the difficult June we had last year when Adam's former school shut down his class. They tried to place him elsewhere after we were given notice, but it didn't work out. We scrambled to find Adam a new school, and that school is an ABA school. I fretted, of course. While we've always done some ABA alongside play-based and other programs that were very effective in Adam's early years, we had good and not-so-good experiences. I learned that no matter what form of "therapy," you decide to use for your child, it can all go south if people believe autism can be cured, or that autism is something that is an unfortunate act of nature (or whatever). Adam is a person-first and there is a fine line between nurturing the person — their strengths and challenges — versus viewing autism as just a "problem" that should be fixed at any cost.

I realized during a camp meeting today that it is a year later since the difficulties of the last one. After working with the head of Adam's school, I feel we've got a pretty good thing going. We've worked together and with Adam's excellent team which has been quilted together over the past decade. I am able to provide a lot of input, and Adam's team go into the school to contribute to his typed communication, and other needs. Along with the structure that his type of school can provide, this is what makes it work for us because we can bring in the academic programs that Adam also needs and they are customized. We cobble our program together.

Adam seems more relaxed, cooperative, happier, and it feels like he's getting ready to spread his wings a bit farther. Every day, Adam takes his own iPad pictures and sends me an independently written recount of his day. I get this by email. I sometimes send pictures to the school of things they don't know anything about, and Adam recounts his weekend activities, for instance, on his own. They are still short sentences, and some days they are more detailed than others, but they are his. He has moved beyond sight-reading to phonetic reading and spelling, and this is pretty huge. He approaches his peers and wants to play with them in the way he never has before. He doesn't know how yet to ask "play with me," but it's the first time he consistently wants to be with other kids, and not just the adults. We have our mini-conversations on our way home from school in the car, and on some days, he sustains his eye contact and talks to me with such engagement and intention that he commands mine. He still struggles with spoken language, but he speaks a lot more now and it always improves, although he is inconsistent. I know this sounds confusing, but Adam is complex. He says some pretty neat and funny stuff too, attesting to his sense of humour. It's amazing what the man of few words is able to communicate and make us understand.

Today at the camp meeting — an inclusive camp — it was pure pleasure seeing everyone so excited to see Adam again. This is a camp that really cares about accommodating him and communicates well with us. I thanked my lucky stars to have such a wonderful group of people helping us out every single day as I sat around the table. For all the mountains I feel we climb, I just want to savour this. I want to thank all the fabulous people who make this happen for Adam which seems like a stark contrast to what the public system will offer us. In such good moments, I feel I must remind myself of how important it is to change the way we approach public education for autistic children. It is so disappointing how [the system wants to cut back Educational Assistants here in Toronto, and Special Ed](#), and inclusion seems a privilege for the verbal and "well-behaved." The system is sick, not autistic children. I keep wondering why the cut-backs here, and have to assume (lest I use a less polite word) it's because of the "cost," and the doubt that autistic people can contribute or be of any value to society— a ratio that tips the economic scales against us. It seems to boil down to that.

To close, I end with a more optimistic tone — how the camp head revealed that many counsellors asked to work with Adam this year. Apparently, so many people at camp always want to come over and say hello to Adam that they have to ask them to hold off in order that Adam can get on with what he's doing. He's like a "camp

celebrity” (their words, not mine). Here’s a kid who can’t speak fluently and who has many challenges; a child for whom standardized tests do not serve, and the public system underestimates.

This morning, Adam was chanting “Happy OM,” before he left for school, and I for the camp meeting. I didn’t know it was prophetic about the day so far. I hope for other positive signs.

Happy OM...happy OM....happy OMMMM.

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## [The Insidious Implications of The Judge Rotenberg Center](#)

Filed Under ([Abuse](#), [autism](#), [school](#)) by Estee on 13-06-2012



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When I watch parents defend the Judge Rotenberg Center, I think of children who can go on “loving” their abusive parents. Parents should be the base of not just survival, but of love. When we entrust schools to care for our children, it is disturbing to see how long Matthew Israel and others have defended the use of painful shock treatment because it’s “effective.” Sure it is. Abusers can get children to submit to anything with the infliction of pain. It’s just wrong.

Yet my version of black and white becomes perplexingly gray in the name of what’s effective for “these kids” — these “autistic/emotional challenged kids.” It leads me to wonder where the line is drawn. While The Judge Rotenberg Center is the extreme of how to “normalize” behaviour or allegedly stop self-injury, the implications of how we view autism, the meaning and communication of behaviours, and how we value autistic people become more insidious with what we see there.

As a more common example or possibility, what of the autistic child who may come out of any school who can't speak, but may have mysterious marks on their body? There are no cameras in other autism schools that I'm aware of. Shouldn't we, as parents and community, have the right to see what's going on when our children can't tell us for themselves?

I think all of us parents and teachers who love to teach, need to advocate for full transparency. We need cameras in classrooms, perhaps even webcams. Schools can protect themselves from teachers who may not be able to handle a situation well. If we believe in the value of autistic people, even with the challenges, transparency should not be an issue at all. We grow and become better with it.

For any therapist or teacher who may wonder why we autism parents fret every single day, it is because of not only stories like these at the Judge Rotenberg Center, but because our children cannot tell us how they are being treated. If we think of a typical child, they come home and tell their parents who is nice, who they don't like, and who may be bullying them. It is their intrinsic right to express themselves. For children who have more difficulty doing so, it is their right to be protected.

I, for one, will advocate for cameras in the classroom and the stop of abuse of autistic children. I will continue to write about stopping the abuse at the Judge Rotenberg Center.

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## [After The Wedding](#)

**Filed Under ([Ableism](#), [Adam](#), [Advocacy](#), [autism](#), [Autism and Intelligence](#), [Development](#), [Research](#), [school](#), [Sensory Differences](#), [Transitions](#)) by Estee on 12-06-2012**

Adam happily skipped down the aisle at his sister's wedding. He didn't sleep the night before, mind you, so I had to go with the flow. The question I asked myself was what was really important in this affair? First Adam, of course. If he were to have fallen apart that day, I would have aborted the mission. That didn't happen so my goal for him was to be calm and walk down that aisle. I was going to forget the photographs but he seemed happy enough to leave for the wedding on schedule. I made sure we arrived at the tail-end of the photographs to avoid long waits. I prepared his bag of tricks — food, fidget toys —and a schedule on his iPad using the [First Then app](#). I used the photographs from our visit to the facility earlier in the week, and wrote sentences from the time we entered to the end of his wedding duty. I recorded my voice with the pictures, and he loved that. He reviewed it many times before we left the house.

Arriving to the photography session, there was excitement and fuss — tightening his bow tie, buttoning his jacket, and he didn't like that much. He wasn't given any processing time. Then, Adam was lugged by the hand from this photo to that. He wasn't happy with that either, but maybe there'll be a couple of decent photos. Dad walked him down the aisle for practice and I asked if he could be excused from the formal rehearsal thereafter so he could have a quiet room and a break. This was successful. He ate some food, sat on the couch and seemed very happy. I think this was his chance to process where he was and that he was finally at Serena's wedding, for he indeed said "Serena, Serena..." followed by a giggle.

Then we were asked to vacate the groomsmen's room. We walked about the facility slowly, saying hello to people coming in. We were to wait around near the room where the wedding party would gather prior to walking down the aisle. Dad came when it was time to collect Adam and I took my seat.

Finally, what felt like a mile-long aisle, Adam walked down in the hands of his two older brothers and I fought back my tears. He started to skip a bit...Adam likes skipping more than walking. His brothers brought him to me and he sat down for the rest of the ceremony until the end, noshing on lollipops and a bag of grapes. He was picked up and driven home after the ceremony as I knew he would be exhausted from a sleepless night. Otherwise, he might have stayed at the party a little longer.

Later that evening, I looked at my phone and read “ambulance.” I quickly rose from my seat and called home. My parents, who took Adam after the ceremony, were with him at my home. They heard a sudden crash and went to check on Adam. He seemed okay so my father looked out the window. Their car was totaled in my driveway from an elderly man who lost control of his car (and tried to get away). I was so relieved to hear that no one was hurt, but I felt sick to my stomach that they had helped Adam out to make it possible for all the intricate wedding scheduling to happen, only to have their car wrecked. I know, it could have happened anywhere, but still.

~

The wedding is now over and after decompressing, Adam is back in school. I’m going through reports as I prepare for this summer and his next school year, as I will be returning to grad school in September in Critical Disability Studies, hopefully to help Adam, and to answer the many questions and issues I raise on this blog. There are so many that I would like to make a contribution to the body of work on what kinds of help autistic people need in order to contribute to society as autistic people. I thank many autistic people for helping me with that question when I first created [The Autism Acceptance Project](#). These conversations happened years ago when I was seeking input from autistic adults in creating an autism organization. Many parents want to get involved and for good reason. Yet, I thought that the charity models weren’t supporting autistic individuals well, and wanted to discuss this. I feel it’s now time for me to go back to the drawing board and contribute to the science.

~

Adam recently had a series of standardized academic tests. The testers acknowledged in the report that these standardized tests do not accurately reflect Adam’s “true potential,” and they have ordered the [Ravens](#) for him. Still, the report puts him in well-below average ranges. I don’t think there is any typical parent, who came home with a report card without at least a B, who hasn’t inherited the same feelings of what it means to be “successful.” My little guy who stims a lot, who can’t sit still, was placed in a little room for three days and expected to work for two hours at a table — while some painful teeth were coming in. While the testers acknowledge the many limitations for testing autistic folk like Adam, changes have not yet been made in terms of how we evaluate the autistic population. The testers stated that there should be computerized tests and I would add, there should be a sensory room and tools such as seating pads, and even a trampoline if necessary.

It was suggested that Adam have lots of breaks in school, use the iPad and computers for learning, yet the tests to determine autistic ability, intelligence, as well as areas that need to be further supported, don’t yet accommodate this learning style. They noted that in some areas Adam functions at a 13-year-old level and in others (like Math) at a grade one level. When I was in the testing room with him, I also realized that the many items they were asking Adam about, have NEVER BEEN TAUGHT to him. How, I thought, could he answer so many questions accurately when no one has even taught him these very specific things? I realize that no matter how much I talk about this, my comments seem to fall on deaf ears. Yet, this is an important link and a reflection of how Adam can teach himself. In this alone, we have to acknowledge an autistic learning pattern and ability to learn overall. In particular, Adam had excellent pattern recognition, and he knew sophisticated words that I know he has never been taught in school. Since he’s been very little one can always catch him reading a book, although I think most people don’t believe he was actually reading.

When I hear on the news of an autistic person having disappeared with a description of their functioning level, it frightens and disturbs me. I cringe when I hear that the person “functions at a five-year-old level” when they are 16. True, there is real disability here. But if I know Adam well, and I do, watch him type what he wants for a YouTube video, or something on the Internet. Listen to the teachers who also see Adam “perform” with 100 per

cent accuracy one moment, only to unravel to “a four-year-old level” the next. That to me is the nature of Adam’s autism. Having people understand the variances is so difficult and it’s tempting to want to give up. Making sure Adam is not placed in a class where he puts the same puzzle together seems to take enormous fortitude. We have to continue to serve, to address disability not as something to be ashamed of, but respected and accommodated, while ensuring autistic people receive the education that they rightfully deserve. This has to start at understanding not only the impairments but in the pathways and methods that are successful to learning. In addition, our charities and scientists have to work harder in promoting the value of the autistic population. Without this premise, we won’t be able to accomplish our important goals. Going from theory to practice takes a long time. We also have to also start in the testing room with the tools we have now.

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## [Adam the Groomsman](#)

Filed Under ([Family](#), [Inclusion](#)) by Estee on 08-06-2012



It has been a busy week of winding down the school year, preparing for camp and... Adam’s eldest sister is getting married on Sunday. My boy will be walking down the aisle in front of hundreds of people in a tuxedo. How do we prepare our kids for a large wedding like this, never mind one in which he will be looked at by many people? That’s nerve-wracking for most of us.

I don’t have a formula, but can only tell you what I’ve been doing. Adam and I visited the site and took pictures of it on his iPad together — from outside the building into the foyer, up the elevators — the whole part. It is a very big facility so I know he will be tempted to run to every dark nook and cranny. Using the pictures we took, which won’t look at all like the facility when it’s decorated, I wrote a story about the entire schedule of the event and what Adam will be doing... Adam’s own little visual wedding book. I say to Adam that there will be doors and he will be okay if he doesn’t go through them. For him it’s a huge curiosity and an area of anxiety if he doesn’t know what’s behind a door. Adam has been practicing walking down the aisle, and I’ve tried to glean aspects of the ceremony from his dad and sister so I can prepare Adam as much as I can. Lots of visuals, including a schedule on his iPad, discussions and practice are key to making Adam not only a part of the wedding, but hopefully, in making it work for him as well.

There will be a lot of waiting too. I’ve had to back Adam out of some of the family photographs and arrange to accommodate him so he doesn’t have to wait around for hours. It’s not important to be at every scheduled photo — he could be photoshopped in, and there will be other photo opportunities. It’s not important that he stay at the party, either, which will be hundreds of adults. He typically loves a good party — the flashing lights on the

dance floor and he can really cut the rug. In this case, being on a Sunday night, we'll play it by ear after the ceremony. He might hang for a bit, and if he can't that's okay. We've got someone on standby to whisk him home. A bag of food, his iPad and the things he likes will help for a while. I try not to get anxious about making it for every single part of the event.

One has to also ask what's really important with events such as these. It's important to make his sister happy and for him to participate in the way that he can. He's been asked to do it in a typical fashion, and with the help of his two brothers, I think it will work for Adam. For me, the goal is keeping Adam happy and calm for his walk down the aisle.

We can't prepare for everything, but we can prepare to a certain extent. I am excited to see Adam in his tuxedo and report back here. I am also excited that he will be a part and he will have a memory of participating in his big sister's, big wedding.

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## [The Purpose of Parenting Studies?](#)

**Filed Under ([Family](#), [Inclusion](#), [Joy](#), [Parenting](#), [Research](#)) by Estee on 29-05-2012**

At IMFAR and with other researchers I meet, I am confronted with many requests to participate in "parent studies." The purpose is to study what levels of stress, and how different it is to parent and autistic child. I am reticent to participate. What about parenting are the researchers trying to find? Are we attempting to affirm that life is harder with an autistic child? Of course, we have to ask what the researchers are hoping to find. Is the purpose to support parents, the autistic child, or both? Or is there a more insidious angle to this kind of research, that is to say, that autism itself is the problem? I know, that may sound blunt and provocative, but think about it. To what end are we really getting on with the business of helping autistic people contribute to society as autistic people? How are we really helping autistic people and their families with their quality of life?

Honestly, I don't see the purpose in trying to affirm that life might be tougher with an autistic child in it, and [I've written about that with the unconfirmed \(by research\) assumption that autism is the cause of increasing divorce rates here](#). All I know is that when Adam is happy and accommodated, I am very happy. If he is excluded, I too feel isolated. What is it that makes the perception of life harder, then? What about society could assist in supporting us all? These are some of the questions I wish the research would tackle.

A few parents and some commenters on other blog posts have stated that some parents, myself included, are in a state of denial by insisting that we find joy in our children. Asserting that your child is a joy is not a denial of the challenges that we all face. The act of assertion is the affirmation that our children's lives are important and valuable. On all counts, Adam has been my greatest joy. Yes, I get stressed in trying to understand his discomfort. No parent wants to see their child in distress, and we can focus on that in some of our research.

Most of the stress we faced lived in incompatible circumstances. Once I could see that our environment had to be calm, and that there was no time for compromise with people who had no interest in supporting us, life became a little smoother. I've had four years to wrap ourselves in the warmth of the people who really care about us. Let's face it, our plates are full and we don't have time for everyone. Energy must be spent wisely.

I don't like to give advice, but I've had a few thoughts over the past few years about parenting an autistic child. If there is parenting stress, perhaps evaluate the other underlying factors that could be relating to the stress instead of just focussing on the autistic person in the family. This would include all of your relationships, including the one with yourself. Think about how you communicate about autism, and consider changing your thought patterns, attitude and language surrounding it. I know that as a mom of Adam, I've had to work, and continue to work, daily at my expectations and putting them in check. I look at my own anxiety levels and what I do to add or detract from the stress. Even when I'm at my limit, I accept bad thoughts and let them go through me. I express them in private and then my head is clear again to see Adam for the beautiful boy he is. My attitude is very important. Loving and accepting Adam has also helped me to love and accept myself, which wasn't (and sometimes still isn't easy). Yet what's the point in having a double standard?

When others have accused me of being in denial of other people's stress or autism itself, I came to learn that my approach was my way, the way I was raised *and* my survival mechanism. There is absolutely no one who can tell you how you should raise your autistic child, and the assistance out there is on the journey as much as we are as parents. And, by the way, we all have a right to enjoy our children for who and what they are! It is up to us completely to advocate for our children — our right to have and enjoy them, to be included in society, for a good and suitable education, for accommodation, for respect, equality, and excellent opportunities and living environments into our children's adulthood. There's no getting around it and no excuses. It sucks some days, but we can't complain. We have to stick together and stop the urge of research and the typical population to pity us. Pity won't get us the services we deserve. If we continue on the path, we'll just get the dusty old van and the group home. Not to knock some of the individuals there who sacrifice and provide for our children on a daily basis. It's just that I think people with disabilities don't deserve dusty vans and the poverty line.

I just think we all deserve better. Parents feel stress because of the lack of support, accommodation and acceptance. We feel it because we are stared out in the check-out line, or at the park, or while waiting to get into school. We feel it when someone marks "retard" on the picnic table outside our kid's school. Can you add to the list? Yes, our children indeed have challenges. Stigma makes these challenges a whole lot more difficult. Now think of how the autistic person must feel.

On the up side, there are many couples and single parents who have found their niche and who have pulled together with stronger families because of the challenges that an Ableist society brings to us every day. There are friends who really pull for us and who believe in us as a whole, not a fractured, family. There are people rooting for us in every way. Here's where to put our focus.

I have only one child. Sometimes I think the time I spend on Adam may be like raising a group of children, but he's worth it. He's worth doing the IEP, organizing programs, doing advocacy work, managing teams, people because there are so few autism services and programs suited for the autistic person. It's like inventing the wheel over here. I don't have to manage the jealousies of same-aged siblings who don't understand why so much more time is spent with the special-needs child in the house, and even the sudden "adult" responsibilities they may feel. I know of many parents who do. We all have our own package of issues, though.

I hope that researchers doing parent-studies have these points in mind. Society's view of disability has a great deal to do with how we parent, how we view our lives, how we convey autism and disability to our communities and future generations, and how we are supported. It's not the fault of autism or the autistic child. We must be so cautious in slanting any research in this direction.

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## [Normally Autistic](#)

**Filed Under ([Autism and Learning](#), [Computing/iPad](#), [Development](#), [Parenting](#), [Play](#)) by Estee on 24-05-2012**

Adam had dental surgery this week and I've caught a cold. As we've both been recuperating on opposite ends of the couch — me with my copy of Betty, *The Fountain of Age*, and Adam with his iPad — I've been thinking what I saw at IMFAR and what I read on Facebook, and all the articles I read about autism. All that fretting and advice on what to do and what not to do, parents can drown in this stuff.

I offer a small insight to keep us afloat.

One of the sessions at IMFAR was about how the use of computers is bad for autistic children because it takes away from socialization. We seem to really fret about keeping our children engaged all of the time, and we particularly target the autistic ones. This post is about just letting things be some of the time. As I tell everyone these days, we are “normally autistic” around here.

During our last two days on the couch, Adam keeps checking in on me. He smiles, he tells me his ears and mouth hurt (his words). In between watching meaningless movies to eat up the hours, and when I have the energy to re-read Betty's take on the media's representation of the ageing population as a “burden” (ugh), I'm watching Adam and how he uses all this free time.

He's cuddly, he has watched a few meaningless videos, tutorials on YouTube on the game Minecraft, and he has been making up his own words on his iPad — “hotgod,” and “iceswim,” among others. He's checked out his math programs, and tries hard, without my prodding, to draw shapes on it (he is particularly challenged with fine motor here unless he uses a weighted pencil). My child who required supported communication and who was once “a sight reader,” now spells phonetically and types independently. My child who has limited verbal ability can navigate Minecraft and the Web. My child who “needs to be engaged all the time,” has used his time, well, pretty much the way I have.

I wish I could remember my own words and thoughts when the world beats in and makes me fret that I'm never doing enough for him, just because he's autistic.

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## [My First Impressions of IMFAR 2012](#)

**Filed Under ([Research](#)) by Estee on 18-05-2012**

This is my first IMFAR 2012 in my hometown, Toronto.

Let me just say, I think that everyone who attends IMFAR should attend AUTCOM and AUTREAT and be exposed to autism conferences run by autistic people. Temple Grandin, in receipt of her Advocate Award yesterday stated “Researchers, you must do more work in sensory processing and visual thinking in order to improve our quality of life.” She noted that there are already hundreds of papers on Face Recognition.

I want to extend that thought. While we are trying to understand autism, we are not much advancing the understanding of how autistic people think and learn and how we can assist autistic people live and thrive in our society as autistic people. As I sit watching sliced brains all it up in orange, blue and yellow, I twitch. Autistic people are referred to as THE OTHER.

“Research provides the foundation for reports about and representations of ‘The Other.’ In the colonial context, research becomes an objective way of representing the dark-skinned Other to the white world. Colonizing nations relied on the human disciplines, especially sociology and anthropology, to produce knowledge about strange and foreign worlds. This close involvement with the colonial project contributed, in significant ways, to qualitative research’s long and anguished history and to its becoming a dirty word.”

(From: *The Landscape of Qualitative Research*, Norman Denzin & Yvonne Lincoln).

There are quantitative and qualitative studies here, and I’m very interested in the how autistic people are *being studied*. The research uses the typical population for comparative analysis. Autistic people are being measured against the typical population therefore cannot be seen as they are. All I’m learning is what I’ve already been told over and over again: autistic people cannot measure up in the same way and manner as typical people, and that we view typicality and normalcy as our goal.

The studies here that I’ve seen use groups with High Functioning Autism, a term which is highly interpretive. Let’s assume, however, that this HFA group must be verbal and must be able to function fairly close to the typical population. This immediately rules out my son who has limited verbal ability, has pronunciation differences, and some idiosyncratic language. Also, the study groups would exclude him because he has many neurological “tics” and “stereotypy,” and has very limited “typical social skills.” As such, it would eliminate the contributions of most of the autistic population who contribute through writing, music, art and more. What of autistic narration? How is that important and valuable instead of merely fascinating? What kinds of insights do autistic people have that some of the typical population may not? It is hard for me to find such presentations here at IMFAR.

Today I did attend sessions on Brain Imaging and fMRI Cognition, Motion Perception and Function and Reward Processing. The most valuable presentations, to me, were two:

*Using Visual Strategies to Remember Verbal Information: An fMRI Study of Working Memory in Children with and Without Autism*, E.J. Carter, D.L. Williams, J.F. Lehman and N.J. Minshew. and,

*Increased Attentional Activation During Reading in ASCAn fMRI Study of Visual Language*, J.R. Cooperrider, J.A. Neilsen, J.S. Anderson, A. Froehlich, M.B. Dubray, A. Cariello, A. Alexander, E.D. Bigler, N. Lange, and J.E. Lainhart.

While I’m uncertain of the reliability of fMRI studies, I am very interested in the results. In summary, autistic people have compensatory reading and decoding strategies. I asked the researchers if they’ve ever compared the autistic population to the dyslexic one (one that I tend to do). I am often tired of the comparison of autistic individuals to the typical population as the only measure.

Rather, because we know that the Dyslexic community faced many social challenges including marginalization, stigma, exclusion, and because it took the school systems a while to understand Dyslexia in order to teach dyslexics, how can we study and understand autistic visual perception and conceptual understanding and the way they utilize the visual in order to decode language and the verbal?

I’m off to the “Stakeholder’s Luncheon” now where Stephen Shore will be one of a few speakers. There are a few autistic individuals here, but nearly not enough.

How do we get these scientists at IMFAR to collaborate with autistic people more? How do we move from using autistic people as “subjects” to including autistic people as collaborators?

We have a lot of work to do. Apologies in advance for any typos as I sit in a crowded foyer.

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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](http://www.taaproject.com)), and an enamoured mother of my only son who lives with the autism label. I like to write about our journey, critical issues regarding autism in the area of human rights, law, and social justice, as well as reflexive practices in (auto)ethnographic writing about autism.



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



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