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In Praise of Support Workers

Filed Under ([Transitions](#)) by Estee on 15-02-2011

I am very sad this evening. It is the sadness of knowing that someone who was part of your daily life has meant so much to you — who has been the centre of our lives.

This person is Adam's aide. She has never wanted to be named but is in the background of all my posts since 2005, obscured. She is called Adam's "support worker" in an upcoming issue in [Today's Parent called *The Joy of Autism. The March issue hits the stands February 21st.*](#) Today, Adam's aide has given us notice that she will be ending her support of Adam in order to move on to something else — time to grow, move on, as does everything in life. Who knows if she'll continue her work in this field — she thinks about doing other things now, and it's all natural, all good.

Yet I sit here alone this Tuesday night. Adam is skiing this evening and knows not that his life is about to change... again. "He's a duck in water," says my mom on the telephone as I'm in the middle of writing this. "Wow... wait... wow... look at him go!" I hear others in the background. It's only his second ski lesson.

He probably can't remember being without his aide worker. She entered when Adam was 20 months old — just over a month after he was first diagnosed with autism. She has been with us on all the ups and downs of our journey. We have made decisions together, and she has implemented them on a daily basis. She helped me when I was going through cancer and divorce in order to provide extra support to keep Adam strong, while I was not.

It has been a hectic day, but not just for this reason. Another urgent matter helped me shove the news I received early this morning into the background of my day. Yet, when I returned home and all was quiet, and I read that article, the black and white print jumped out at me. She is all over those four pages; the "joy of autism," the ride — me, Adam and his "support worker." I am still crying, mascara channels down my cheeks.

Does it take this kind moment to realize how much you can love someone? It's been eight years — I'd say that's a good chunk of relationship. I've always appreciated her, but parting is such sweet sorrow.

To all you aides, shadows, support workers and therapists out there (there are so many names to call you) please know how much you are, and have been so utterly appreciated. How lucky we are to have such relationships.

(Rare!) Helen Keller & Anne Sullivan (1930 Newsr...



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[Creative Behaviour](#)

Filed Under ([Art](#), [autism](#), [Autism and Learning](#), [Inspiration](#)) by Estee on 09-02-2011

I'm thinking a lot about behaviour today. I don't often re-post the articles of others, but in my search, I came across this blog: [Forward: FWD \(feminists with disabilities\) For A Way Forward.](#)

A study recently released in Delaware found that disabled students are more likely to be suspended for 'behaviour problems.' More specifically, while 20% of the students suspended were disabled, disabled students only make up 14% of the student body. The study questions this disparity, asking why it is that disabled students are at more risk of suspension although there is an established body of law that is designed to specifically provide protections for disabled students, and to limit the circumstances in which they can be suspended.

The article asks, not 'why are students with disabilities more likely to be suspended,' but 'what makes disabled students behave badly?' I personally think that's the wrong question. What is 'bad behaviour'? How is this being defined, and who is defining it? It's good to see some mandatory accountability in the form of tracking discipline numbers and reporting them, but accountability is only one part of the equation. If districts are not taking action to address the disparities, reporting them doesn't make that much of a difference.

And are schools adequately identifying disabled students? While there has been more of a push in recent years to identify and intervene when disabilities are observed in the classroom, there tend to be racial and class inequalities when it comes to diagnosis and treatment. Likewise, there are disparities in identification; a teacher may attribute differences in learning and communication styles to disability in a white child, and ‘bad attitude’ in a nonwhite child, for example.

The approach to this particular educational disparity seems to be focused on what ‘makes’ students ‘behave badly’ instead of asking whether teachers are being adequately trained to work with disabled students and asking what ‘bad behaviour’ is and who is defining it. It assumes that everyone should (and can) engage in specific patterns of behaviour and it suggests that ‘abnormal’ behaviour patterns should be punished.

Are students suspended for not using modes of communication familiar to teachers? For needing to stand or pace while learning? For needing a quiet environment for learning, and for becoming upset when one is not provided? For needing orderly and precise schedules? For not completing assignments they don’t understand or find impossible to finish? For attempting to create and maintain personal space? For expressing any number of needs and needing a space where they are accommodated? For ties in the classroom?

When nondisabled people are the ones defining ‘normal’ behaviour and deciding what is bad and worthy of suspension, inevitably you are going to end up with disparities in student discipline. When teachers are not provided with adequate training, when they are dealing with classrooms that have too many students in them, when they are being burdened with a lot of additional work outside the classroom, a tinderbox of circumstances is created and disabled students tend to lose.

Suspension is a serious punishment. Students missing a month or more of school is a serious problem. Until we reframe the way that we talk about classroom behaviour, we’re going to continue missing the heart of the problem.

— article by s.e. Smith

I quote this because I’ve been writing about behaviour recently, citing the issues with have with how we teach autistic people because their “behaviour” is, purportedly, the “issue” of learning, or at the heart of, we are told, “learning how to learn.”

Instead, I’ve coined recently the term “creative behaviour,” and am watching Adam learn and gravitate on his own. How do we continue to foster the creative process? How can we move away from thinking about autism as a set of behaviours, implicitly “bad.” How, is the ultimate question, do we help children like Adam, express themselves?

Let’s think about this for a bit — what we know about creativity and the work we can produce. Let’s step out of the autism box and all of the implications we press upon autistic people (for the label alone) and think about what it is we are really trying to achieve.

Creative thought is the ability to think about the world in unique and fresh ways and convey this to the world. By bringing our unique thoughts to others, we help to shape the way we do things, and the way we think about other people. Creative thought also helps solve problems. We hire people to do a lot of problem solving for us, yes?

I now turn to Twyla Tharp, author of *The Creative Habit: Learn It And Use It For Life*.

There’s paradox in the notion that creativity should be a habit. We think of creativity as a way of keeping everything fresh and new, while habit implies routine and repetition. That paradox intrigues me because it occupies the place where creativity and skill rub up against each other.

It takes skill to bring something you've imagined into the world: to use words to create believable lives, to select the colors and textures of paint to represent a haystack at sunset, to combine ingredients to make a flavourful dish. No one is born with that skill. It is developed through exercise, through repetition, through a blend of learning and reflecting that's both painstaking and rewarding. And it takes time. Even Mozart, with all his innate gifts, his passion for music, and his father's devoted tutelage, needed to get twenty-four youthful symphonies under his belt before he composed something enduring with number twenty-five. If art is the bridge between what you see in your mind and what the world sees, then skill is how you build that bridge." (p. 9)

Yes, skill is really important. A way in which to convey meaning to others is vitally important. The rituals and habits we establish are the practice we need in order to produce something. Creativity sparks when we stare into space, have that second snack from the fridge, putter, and when we appear to be doing nothing at all.

Adam takes piano lessons once a week. We've adapted the lessons, and his fingering is getting pretty good. I started teaching Adam to learn piano in a more traditional way a couple of years ago, even though we've learned to accommodate the lessons. He learns from a teacher who expects him to practice everyday and who can be stern about him sitting at the piano. In this case, Adam needs a bribe. I'll ask the teacher to make him work for the candy, and he'll oblige and finish practicing. Okay, it's hard to learn piano in the traditional way. Yet, like Twyla says, creativity is a habit. It requires tons of preparation. So we stick with the program.

I'm teaching myself how to play the guitar. I struggle with the chords, my fingers just beginning to become numb at the tips; hurray, I'm building my first callous on my left index finger — a good sign. I pick it up every morning while Adam waits for his ride to school. He comes over and strums a good rhythm. He smiles and then gets really into it and forgets I'm there. A couple of days later, as I'm making a second cup of coffee, Adam goes to get the guitar leaning against my bookcase. He takes it to the couch and begins strumming on his own. He's focused. This time, he doesn't want me to help him.

Two great examples, I think, between the art of repetition and practice, and the space to explore. Rather than seeing Adam as behavioural, because he may avoid that which is difficult in formal practice (I was the same, by the way, when I was a kid), I explore the value of both methods of teaching and learning.

Art and music have been part of my entire life. I've taken music lessons with the strictest of teachers. When I thought I could fart away in art class, Sister Collette (don't you just love that name that belonged to a Franciscan nun?), scolded me every week if I submitted a project late, and then loaded me with more work and deadlines because of it. While I was artistic, I didn't think an art teacher would be so strict. "Art," she said, "will teach you the greatest discipline more than anything else in your life." I probably worked the hardest when I was in her class, where I stayed for my entire five years of high school. Art was an elective course, an option. Art wasn't a "prerequisite" like math and science. We think of art in trite ways — all we have to do is be gifted, talented, and the muse will bless us.

Na uh. Art, like life and very much like in teaching autistic children, is the ultimate example. There is something intrinsic in all of us that we can express, and need to express. We find the tools to help us express it, and usually the ones that we most gravitate towards, but that doesn't mean learning how to use them is easy! We work daily because the manifestation of our inspired thought is more difficult to express to others.

What I'm trying to say is that teaching autism is an art and has to be viewed in similar ways. We find the tools (aka "accommodation") and we teach the child how to use them everyday. We repeat, but we do not de-value the unique process of taking in the world (aka: like when they are appearing to "not be in the room" or "in their own world"). And as the living art forms that all humans are, we must also as teachers and parents, forget looking at autistic kids as a Diagnostic Manual of symptoms and behaviours. For the human body and mind, in its infinite wisdom, finds the tools with which to also express itself. Let's learn how to use them.

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[Parenting An Autistic Child](#)

Filed Under ([Acceptance](#), [Autism and Learning](#), [Inspiration](#), [Parenting](#)) by Estee on 08-02-2011

We've been peaceful around here. This morning Adam picked up my guitar that I'm learning (really slowly), and he played it himself, strumming and enjoying the reverberating sound. I guess watching me and other people has inspired him. He already takes piano lessons and that's quite a formal learning process that he doesn't always like — we adapt the lessons but this type of teaching still requires those old reinforcements (I call them bribes... let's face it they work and that's exactly what they are. Must watch out though, he knows that he'll get that candy if he acts silly too). So, with the guitar, I want to let him explore. I took Royal Conservatory lessons for many years growing up. Piano teachers never liked when I sang in plays, or learned music by ear — which I was really good at doing. No, they were set in their formalized teaching method and there was no way I was allowed to waver. "It's either the play," said one of my piano teachers, "or piano." I didn't understand why one had to come at the expense of the other — it was all about music. I listened and won a few first place prizes at the Peel Music Festivals every year, but I played a lot more when I did my own thing. Perhaps we need more room for marrying creative exploration and formalized teaching. There's a lot of treasure that's discovered from staring out of a window, and learning things in our own unique way. It's part of the creative process. It's creative behaviour.

Despite my occasional worries (I'm a human being, a parent, that should say enough), I'm steady where Adam is concerned. When worry overwhelms me, I start reading more, reaching out and then I realize that I'm on the best track we can be on. The issue with parenting autistic kids is that there are too many opinions about how to teach and how to parent — hey isn't that the case for parenting all kids? So many opinions.

What kind of parent am I? I ask myself. What am I capable of doing? After listening to how other people do things (or how they think they *have* to do things, particularly in the field of autism education), this can make a parent's stomach churn with anxiety, and I think it's okay to say *enough*. After doing the due diligence work, there comes a point in all of our lives, whether we are parents or not, to follow what we think is right for us. Reading any latest edition of **The Autism News** or any other study will make your head spin. I've made the PECS, the visual schedules, I'm teaching Adam how to type independently (it's coming along well), he goes to a good school where I see he is learning new things, I seek input, advice, and lots lots more. It's what a parent does. I'm not a teacher, yet I've learned to work with them. I'm not a therapist, but I've learned to communicate opening and share ideas. When I heard [Rita Jordan](#) once say on CBC Radio One that parents have to follow their own values in parenting an autistic child, I knew exactly what she meant. How many of us are listening to those voices inside?

Adam needs me to be his parent. With open arms and the love, he snuggles up to me for comfort, and I happen to be really good at this thing called love. He doesn't need to know what I do for him behind the scenes. When he comes home, he just wants me to love him... as he is.

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[“I Had A Feeling That I Belonged”](#)

Filed Under ([Family](#), [Inspiration](#), [Joy](#), [Single Parenthood](#)) by Estee on 07-02-2011

Everyone who goes through a divorce will attest, after a significant chunk of time, you can feel cast out, a little lost.

It will be a year since Adam and I moved into our new home on February 14, ironically, Valentine's Day. As I prepared the house for him to move in, I purchased a sign that I placed on my mantel: "Friends and Family Gather Here." I knew what was important to me. I knew I wanted to finally build my own place where Adam and I would always belong. This coming Valentine's Day, although I hate the Hallmark cheese, I've got something really special to commemorate: creating love and a warm place to belong. This *is* a celebration.

People say that you have to live with intention. Well, I guess I did that. I make lists, I put my intentions out there a lot. I wanted to build tranquility, beauty and a happy home for Adam. After some difficult transitioning in the first few months (you can read those posts from a year ago), Adam adjusted. A bitter winter unfurled into spring and summer. Our friends came. Then, my big family on my mother's side. It has meant so much to me, and I know, for Adam who beams when he sees people here.

Before I got married, I used to play in bands, work in art, write (I've always written) and paint. I'm back at it. Adam loves it. Our home is filled with simplicity and lots of music. As I learn to play the guitar again, he strums while I learn the chords. I've also taken up my piano playing and Adam played improvised with me for over a half hour last week, proud that he could create something with me. It was just the two of us in the basement, communicating in our way.

I've just learned how to play **Fast Car** by Tracy Chapman on the guitar. I love this song about clawing one's way to a better life. Belonging is a big theme in my life. Ironically, it's also a big issue for disabled people.

“Me myself I got nothing to prove.”

Fast car -Tracy Chapman



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[Snow in Toronto](#)

Filed Under ([Acceptance](#), [Adam](#), [Inspiration](#), [Writing](#)) by Estee on 06-02-2011

Last week, **The Weather Network** announced that we were about to get a huge storm. The city prepared, remembering several years ago, when the army was called in. Last week, everyone prepared. Schools were shut down. I received an email from Adam's school that there would be no school the following day, anticipating the oncoming emergency. This was going to be serious.

The next day, Adam and I went for a walk. The streets were quiet and I scoffed at what Torontonians think of as a weather emergency. "Weathertainment," I've heard it called. To get an idea, check this out:

Special Report: Snow in Toronto



It snowed last night too. Today, Adam and I plan on taking the hills, facing the “danger” head on. Yes, we are going tobogganning. Remember those days? When we’d go out and play all day in the freezing cold and our parents didn’t give a crap if we got frostbite or not; when we went to friend’s houses who were sick anyway? Ah...those were the days.

Adam goes to Holland Bloorview for art classes. There, he gets to be surrounded in what I call a little piece of heaven, that place. The art studio is one of the most magnificent ones I’ve ever visited. The art projects are innovative.

I sit around the lobby while he takes his class, and I get to watch other people, talk to others. In wheelchairs, braces... people of all kinds, I feel more relaxed and human than any place else on earth. I study my books, think about my writing. I’m taking a memoir class with the wonderful person/writer, [Beth Kaplan](#). Yet, I keep trying to focus on the scene...the scene...zoom in the on the *SCENE*, I think. I’m trying to tell too much story to soon...I rush. Story of my life. My mom said since I was a little girl, I always wanted to know what was going to happen to me. The wisdom of slowing down is just beginning to absorb. But then again, we can’t change our essential nature. Maybe all we can do is train it a bit.

Then, for one of those moments that sink me, I think I can’t do it. *Just who do I think I am? A writer?* Yes, she assures in one class. It’s part of a writer’s list of fears.

It’s time to pick up Adam. I gather all my clothes...all of them...the UGG boots I took off because they make my feet too hot, and my heavy shearling coat (for the Toronto weather), and big bag of books I’ve brought along. I’m weighed down as I shuffle towards the glass studio. Adam is wearing an old shirt as a smock and it’s covered in paint. He’s in the corner near the bright twenty-foot window, a malleate in his hand, pounding a large piece of clay. He then takes a little piece and puts it where he wants it to be, and then pounds again. I stand back and watch, and then approach when I think he has taken a break. He sees me and walks towards, smiling. I lead him back to the lump of clay. “What is it?” I ask.

“It’s art,” he says without hesitation.

It is. I wish I could silence my inner critic.

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[New Behaviour](#)

Filed Under ([Adam](#), [Autism and Learning](#), [Behaviours](#), [Inclusion](#), [Sensory Differences](#), [Sleep](#), [Transitions](#)) by Estee on 04-02-2011

We talk often in autism about a dissonance of skills and “uneven learning.” It’s an easy thing to notice or say, but it doesn’t seem that easy to accommodate. Not easy, because we still have the expectation that an autistic person must respond typically.

Adam has had quite the transitional year. He has gone through parental separation, moved to a new home with me and started a new school where the expectation is that he sits at a desk. His sleep has worsened, and his avoidant behaviour in doing certain “tasks” has begun. And yet, my Adam is talking in full sentences more often, is telling me how he feels, and can play a mean “reciprocal” game of *I Spy* with me. He can draw well (if given the chance) with perspective that is more sophisticated than his same aged-peers, even if his motor planning, that is line, is not as sure and resolute.

I have to say that when someone talks to me about Adam’s “behaviour” I do think in the old-fashioned sense that he is not behaving “well,” as opposed to looking at what’s causing the behaviour. It still pops up from time to time, and I am concerned that implicating behaviour is a way to not only blame Adam, but put an expectation and onus on him that is not fair. That is but one legacy that ABA left behind, although I’m not commenting on some of the methods used by the practice as part of an overall pedagogy. I bribe him a lot to get things done.

Adam needs physicality, lots of movement, interesting content, and a chance to respond more by typing. He needs more preparation, I believe, to start his day, and a different kind of structure in it. What I mean is, by 2 p.m., the boy is tired. I am still trying to figure out what that structure should look like as I orchestrate new programs and activity in his life. Because, Adam is no longer a baby. He will be turning nine this April.

It seems to me that we are learning about how autistic children learn, or at least I’m learning everyday. My process of learning about Adam and trying to work with his team of teachers and supporters never ends. Sometimes, I sit and stare at the wall, I admit, and wonder why we still haven’t figured this out. Maybe I was secretly hoping we would have by now.

I’ve hit the books again. I’m watching Adam closely as he has trouble falling asleep at night. I watch my own responses to him when I feel tired and frustrated. And one thing that surprises me is that I still am not giving up. I don’t want to blame Adam for being autistic. I want so badly to support him and to have support. I am still trying to articulate what accommodation really means for him. I am constantly evolving my attitude, and behaviour, towards him.

Soon Adam will have an aide who will take him into the community, to help him be a part of it, make friends, take theatre classes and go skiing (he starts next week!). I hope to get him into Special Olympics and keep working with those who have helped us along the way. It is clear we don’t have all the answers yet. But if you have some success stories to share, we’d sure appreciate them.

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[A Skeptic's Snowday](#)

Filed Under ([Estee](#)) by Estee on 02-02-2011

Just as I thought. The news made a big hoopla about a big storm. As I predicted, we never got the snow they predicted. In fact, Adam and I are about to go out for a walk.

Seems the news is full of hype on all counts, whether it be about autism or the weather. Weather is big business. Except for the Tsunami in Indonesia. We needed the news reports then. But they never came. I hate being skeptical. Yet everytime **The Weather Network** predicts weather, and this comes from undocumented personal research, it's always less severe than they say.

In the meantime, I'm happy to report that after writing my post yesterday, after a while on waiting lists (we've been a year on some and still no word), Adam will try his first ski program next week.

Just another day in the life of a positive skeptic.

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[The State of Education for Autistic Children \(as I see it\)](#)

Filed Under ([Acceptance](#), [Activism](#), [Autism and Learning](#)) by Estee on 01-02-2011

Big snowstorm's coming. It starts tonight in Toronto and is supposed to continue into tomorrow.

Adam will be at home. He'll work on his computer, I on mine. We'll play piano and a few games. I still haven't had time to complete his art studio. My work will have to go on hold.

Life's changing here. Being a single mother has new challenges. I look for time to get things done, as it's just Adam and I and there's no one to help me in the early mornings if he's up too early, or sick. That's a big difference I'm sure many a single-parent will relate to. Time has become more limited when one has to rebuild, and even learn, from scratch.

So, I don't like problems thrown at me all the time. I'm impatient. I expect those who say they are experts to help us, not throw the problems back in my lap. When it comes to Adam and talking with those who help him out, I'm not certain they realize that's what I hear. Sure, we've got challenges. But it becomes overwhelming

when things are constantly presented as a “problem.” Hearing this for seven years now since Adam’s diagnosis, and maybe this will make sense.

If you are a therapist or a teacher or aide, consider this: that’s all we hear from the time our children are very young. From a parent’s perspective, it’s not only very scary in the beginning, but later, it’s just plain exhausting. In the beginning we scurry like there’s no tomorrow because we are trying to find the best program or school placement, and that’s not easy. Perhaps if you are going to present a challenge, offer a solution. I’m fortunate in that I do have people with whom I can strategize. Yet, there are few options out there for autistic people, and even therapists are hard-pressed to be able to find places for us to go. Schools are scarce. Inclusive schools are scarcer.

There are few adaptive services. I spend hours each week not only filling out forms and getting on wait-lists, but also phoning to find suitable sports and other programs for Adam. This begs the question: why are there so few of them? Why can’t Adam learn how to play baseball? I remember how easy it was for my step-kids and all the programs they had to choose from. I’m trying to reach Special Olympics, Boy Scouts, ski programs...it takes a while to hear back. For Adam, his options seem so much smaller than they were for his half-siblings. It’s not equal and it’s not fair.

Why should he have to go to an autism school if the autism school doesn’t fully integrate a variety of tools to support Adam’s strengths? Perhaps I’d go to the autism school if I felt it treated him like the magnificent person he is, addressing the challenges he has, and training him as an autistic person to prepare for college, university, or some other vibrant future. Believe me, if I could find an autism school that was as robust as those belonging to the deaf community, I’d consider it. At least there, using the deaf community as a model, autistic people would be allowed to act autistic, and build their own strong community. Instead, I see schools addressing “autistic deficits” in an ABA format, which I don’t believe works that well for Adam, as it escalates his anxiety. (Side note: and can we hire autistic adult teachers, please). Repeating skills in that format is good (belonging to ABA and other methods), sometimes positive reinforcement is good, but it’s not very creative because it teaches not so much content as much as it is a way to teach someone how to answer and respond. It’s not necessarily a “bad” thing, it’s just not the only way to teach, and I fear it lacks the engaging content my son needs. It doesn’t foster creative behaviour.

You see, I think discipline is really important. It’s an art to teach a very young, challenged child to be focused without also inspiring him and building his confidence. With Adam, this is especially difficult. Despite his communication challenges, he has pride, will avoid tasks that he thinks he likely will fail, and is very aware of his inability to communicate like other people. Force him to “put the puzzle” piece in for the 1000th time, and I don’t think that’ll do it. Offer him a candy to do a task, and he knows that if he avoids the task, he’ll get a candy. It works sometimes, but he’s outsmarted us. Still, breaking down tasks into smaller pieces, and repetition is a key to fluency and competence. Marry that with exploration activity and keeping the topics and materials moving along (he’s not a baby anymore), and that’ll keep his interest. I wonder if we just expect too little from him. An inspiring person/teacher, and tapping into Adam’s innate need to be proud of himself, and I wonder...

I don’t think that typical families understand the extent to which we have to hunt for places for our kids to belong, and I believe Adam has the right to be fully integrated and included into our community. I feel I am met with resistance, and I knew this would take a long time. I hope it doesn’t drag on well into Adam’s adulthood. This is a systemic problem. We simply don’t know how to teach autistic people, despite ABA being the purported solution. All we know is how to use a few PECS, schedules, and accommodate sensory differences. Sure, this is a big change from even a few years ago, but I’m becoming impatient. I have not seen any creative programming for autistic people. Is it because we don’t believe enough in autistic people to invest in fully inclusive programs that train facilitators in a variety of methods that must then be uniquely applied to each individual? Instead, it might be easier to say that an autistic person has this deficit and apply a one-size-fits all solution. As I used to work in public art galleries, and also used to teach young children art through music, I’m thinking a lot lately of helping schools use an art program to teach other topics such as math and science. And if you want to see another extremely creative parent, [check out Kyra and Fluffy at thismom.com. Kyra completely blows me away with her boundless energy and ideas. I’m not as creative as she is.](#) I just hope people take a look

at some the projects she works on with Fluffy (she homeschools him). I hope, using them as one positive example, that we never give up on autistic folk.

I meet wonderful teachers. I wonder why I don't see the programs to place them because autism seems of great interest to many. When I consider Adam, I think of just last night as we practiced piano and how he became enamoured with the low G. As he continued to play it, I improvised. He smiled and we made music for over 30 minutes, coordinating together. I think of how he can get so focussed in art-making and all the things we can learn from making it. Art can be therapeutic, sure, but what of all those lost learning opportunities because our teachers are not trained in using these tools so easily accessible for Adam? If Adam is any example, he does well when we find a patient person who listens, who wants to learn how he learns, and who can accompany him in the community that he's so interested in. I have a boy yearning to try new things. Thank goodness for his camps. There is has learned to climb walls, archery, and many other wonderful skills. He seems happiest at camp, learning from physical activity to quiet art and loves drama and creative movement — hmm.. we hear autistic people can't do the latter, right? Not so for my guy.

I just thought I'd write this because we have huge scarcity in Ontario and I keep looking to autism websites here and don't find much. Social skills groups are always full and I wonder what they teach anyway? How to say hello? Play with the plastic doll? Okay, that's a skeptical comment, but what creative programming exists within the skills that autistic children need to also learn? We *can* inspire our children. People think we need autism schools, but that's not necessarily the solution. It seems easy because at least that's a place to *put* autistic kids. I like it that Adam sees everyone and that he be seen, and where he can feel competent as he is (this is a problem if we stick our kids in typical schools where they then remain on the sidelines). I still see people wanting to change him and fill in his "gaps." Certainly, they exist; Adam has challenges. Yes, I hear about them all the time. I see them everyday. I am supposed to be teaching him at home more too — the onus is always on us. How much more time do we have?

Okay, just so this post doesn't come off as a rant (I hope), [here's a link to Hopeful Parent](#). Maybe it's the snowstorm coming, the large piles of paper I have to get through, and a team meeting coming up tonight.

I am hopeful. Maybe I can help out through teaching again. Just one of my many thoughts as I figure out the future these days.

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[About Control](#)

Filed Under ([Activism](#), [Behaviours](#), [Contributions to Society](#)) by Estee on 26-01-2011



Yesterday, The Globe and Mail published, [For A Child, It's All About Control](#). The premise of the study, conducted by researchers in New Zealand followed 1,000 children for more than thirty years. The findings, published in the **Proceedings of The National Academy of Sciences** stated that “those children who demonstrated strong self control skills as early as age three were less likely to abuse drugs, and develop health problems, experience financial difficulties or be convicted of a crime.” The ability to control one’s own behaviour is an indication, therefore, of future success. I guess that makes most of us the doomed portion of the population.

I’m not just writing this because I felt like I was reading a paper in 1900, not 2011. I’m writing because I have an autistic child, where the controversy in his way of being is primarily described as behavioural — difficulties with attention, focus and impulse control. Children diagnosed with ADHD, ADD share similar impulse control “issues.”

It’s an odd time we live in. We diagnose every possible human way of being under the sun, while also being able to appreciate, paradoxically, the creative contributions and potential of people with, as we say, “different kinds of minds.” Despite all our best efforts to use medications to control behavioural issues, the individuals we medicate are often incredibly able, talented, and have been, in fact, insanely successful. An official [ADHD website proudly lists successful people with the disorder](#), the list including Albert Einstein. [And this list](#). In keeping with funny little lists, [here’s one that cites some successful autistic people](#). [And another one](#).

Most of us have heard and read about [Donald Treffert’s work](#) in giftedness and autism, although not every autistic person possesses exceptional gifts (even though everyone is exceptional). The real issue seems not to be that the ability to exercise self-control makes us more successful, but in how we learn to work within the frameworks we’ve got. The most heralded people of our culture are the ones who are able to think out of the box; in other words, differently.

Another issue is one of pedagogy. The study insinuates, for me anyway, that all children should be alike: focussed, sitting at their desks and compliant with their teacher. A child like Adam is a sure candidate then, to be banned from schools that use these criteria as a series of prerequisites. Sure, we all have to learn the rules, but the rules also have to bend for the accommodation of individuals so that they *can* learn. One example is having children move throughout their day in order to think. As physical programming gets slashed and Canadians, in a recent CBC report, are getting fatter, it might be no wonder how children have difficulty concentrating. There are many different ways to learn. Most autistic children need sensory stimulation throughout their day, similarly, to be able to focus.

“Self-control is a vital skill for scanning the horizon to be prepared for what might happen to you, for envisaging your own future possibilities, for planning ahead to get where you want to go, for controlling your temper when life frustrates you,” says Terrie Moffitt from Duke University, quoted in the article. Really? Can we truly plan ahead? I mean, a few years under my belt and I’ve been stimied over and over at the universal joke: that life never ends up the way we plan. Nevertheless, we’re all supposed to have a good one. While it’s not the entire point of my post here, some of the reasons cited as necessary for being in control of oneself in the study seem a little silly.

How many of us have had behavioural issues in our lifetime, or a real diagnosis effecting our ability to control our impulses? Have the researchers considered the contributions made to our society by individuals who have severe difficulties with it? How many of us might have to use many accommodations throughout our day in order to be “successful” — the very word raising many other questions on what success really means?

“You’re training people to think about long-term consequences of their behaviour,” Professor Piquero was quoted.

Indeed.



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[A \(Short\) Paradox of Love and Letting Go](#)

Filed Under ([Adam](#), [Parenting](#)) by Estee on 17-01-2011

Adam tried to pull me out the door with him in the morning. Since I returned home from vacation or after weekends apart, he tugs at my hand. He is bundled in his heavy red winter coat for the minus twenty-something temperature we’ve been having in Toronto the past couple of days. I know he has been effected by my absence. With separation and divorce, all kids and parents must traverse this similar path of custody arrangements.

So, these absences are not entirely within my control, although even married, parents do have to leave their children for work, for travel, for one circumstance or another. Adam’s Christmas vacation is split between mom and dad. While I’m not with Adam, I want to build my life. I am trying to figure out if there is a way to refine the fine art of living life and parenting. I’ve concluded that the best way I can be Adam’s parent is to remain my simple self, and including him in all of it. Sure, I have to accommodate the way in which he can be included in it, but that’s a different post.

Once in a while I get a report from his aide or teacher that he has asked for mommy while I am away. I can't tell you the wave of love and tremendous guilt that overcomes me when I get those reports, or lately, even a short email now from my son. Then, I tell myself that this is the test of our love: that we can miss each other and always return, the universe willing. Still, for a young boy, typical or autistic, a parent's absence must feel like the end of the world. Adam can't tell me the depth of feeling he must have, but I can imagine it. I can remember what it felt like when I was a child and I use those memories to help me in the way I treat Adam.

"Come with me," he says as he grabs my hand. Then the words don't come — he simply tugs. His cherub cheeks peek from behind his ample hood with a tuft of faux fur. His eyes begin to look distressed.

"I can't come to school with you honey," I implore. "I will see you in a few hours." He tugs harder, my body leaning into the warm hallway, his boot already on the icy front step; I'm afraid he will literally tumble out the door. He tugs for as long as he can before I kneel down and face him.

"I love you. I'm proud of you and I will be here when you get home," I reassure, rubbing the sides of his down-filled arms, caressing his cheek, and then kissing his small, pouted lips.

He lets go reluctantly, dragging his knapsack behind him on the driveway and climbs into the car. I stand at the window with pangs in my stomach — to let him know I am watching. I am also jubilant at the same time, remembering how my mother did the same thing (the apple doesn't fall far from the tree). I wait in the window, like my mother did with my father and I, to let Adam know the depths of my love. I'm pretty sure he knows this innately, but still.

The car pulls away and he looks at me longingly through the backseat window. I wave thinking that this is, paradoxically, one of the best moments of our lives.

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[Our Monthly Flight](#)

Filed Under ([Adam](#), [Communication](#)) by Estee on 14-01-2011

About once a month Adam cannot sleep. It's so regular, in fact, that I've come to call it our "monthly trip to Europe." The time zone change would feel about the same.

So it was we had another one of those nights last night. It's been a bit of a crazy week — I just returned from Costa Rica and am trying to pull myself back together. Adam also had some vacation time with me down south and then spent the rest of the time with his father. He returned to me on Monday and I was expecting him not to sleep on the first night of his return home — not the fourth.

Last night, we also played a game of I Spy. We used one of Adam's books for this. For those of you who are not yet aware, Adam is not a fluent talker. I was quite surprised that we could play this game back and forth for about thirty minutes.

"I spy with my whittle eye something that dances," he said in his tiny staccato voice, so soft like a whisper. While Adam has typed a few sophisticated sentences before, we've rarely had such interchanges, let alone ones where he's asking me to guess the object by naming its attribute.

“Is it the ballerina?” I asked him, pointing to it.

“Ballerina, yes,” he replied.

Maybe his head was dancing for the rest of the night. Dreary eyed today, I’m still so very thrilled about the interchange.

A belated Happy New Year to everyone, by the way. I tried so hard not to blog while I was away.

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[Clumsy Respect](#)

Filed Under ([Acceptance](#), [autism](#), [Inclusion](#)) by Estee on 19-12-2010

I know that gait in a split second. The one where I can tell that someone is autistic. It’s a little stiffer. The arms, they hang differently. The eyes blink and look intent on, say, a door. The door he is waiting to go through.

His brother comes. They look like identical twins. His brother’s body looks a little more relaxed and he guides his stiffer brother through the door to the line up at Adam’s favourite burger joint.

“What do you want on your burger, buddy?” He pats his brother on the back.

The stiffer brother wants the “asian” onions, which are really only plain fried onions. I stand behind with Adam while the same young man briskly puts his two fingers in front of his eyes. Then his hand goes down.

I tap his brother on the shoulder. I don’t usually do this. It’s Adam’s PD Day and just before the holidays.

“My son is similar,” I say, smiling.

“Oh, he’s autistic?” replies the fluid brother, the one who opened the door.

“Yes,” I reply, Adam looking at the hot peppers he has taken to recently. His eyes move towards the hands in latex gloves behind the glass, slathering burgers with mustard and relish. “He’s a wonderful boy. I am lucky,” I say that because I feel I have to. I *do* feel lucky but I’m hoping the conversation won’t take a negative turn, whatever that might be. After a tap on the shoulder, I could be entering territory I am not really prepared for today. Yet, I am curious. “Are you twins?” I continue.

“Nah, he’s my older brother,” his face is friendly, and he seems to relish in the fact that his brother is older. He’s relaxed talking to me. “We’re out today shoveling snow for money,” he says in that *hey buddy* kind of voice.

“That’s great,” I say. I get a little more story about the two brothers as Adam looks as if he’s staring down the mustard behind the glass. The other brother, right ahead of Adam is looking at the asian onions, but I have a feeling he is paying attention. I know that Adam does. He will now respond to many things that I say, precisely when it appears he isn’t listening. Adam often surprises me with his comments that often come a few long seconds, sometimes minutes, after I have finished talking.

“It’s really nice for me to see everyone out and about. I think for parents it’s good for us to see that we all belong in our communities. I hope that older autistic people will help Adam. It gives me hope.”

We share a few niceties. The burgers are served and we eat in separate booths. Adam first eats the hot peppers, then pickles, tomatoes and finally, the onions, picking small pieces with a delicate pincer grip. The actual hamburger is left to last, and he only takes a few bites. Suddenly, I feel a tap on my shoulder.

“Merry Christmas to you, eh?” says the brother. His autistic brother is standing further back, facing our direction.

“Hey, thanks so much. Merry Christmas to you too.” I turn to face his brother and smile. Although I wonder why I didn’t address his brother directly while standing in the line, I’m still hoping that my way of saying hello was okay. I’ve addressed and worked with other autistic adults before, but uncertainty lingers. I cringed inside, thinking of myself as that kind of person who addresses the aide, and not the handicapped individual. You know, like one typical person talking to another typical person as if the handicapped person is incapable. Maybe I was trying to find a way to segue into a possible inclusive conversation? Perhaps I was just trying to find that communion, there, standing in line?

Approaching any new person isn’t easy. I know I’m appreciative of people who try to approach me. Respect isn’t always smooth. I just wanted to talk and then I had thought of it afterwards like this. Still, I think I’ll commit to tripping, fumbling and making mistakes. As long as it keeps leading me to new people and we can keep learning.

As Adam reached for his last piece of hamburger covered in mustard, I stared out the window, other customers surrounding us in their booths.

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[Terminal Fates](#)

Filed Under ([Activism](#), [Advocacy](#), [Discrimination](#), [Politics](#)) by Estee on 29-11-2010



“You can’t say your child is great,” I was told when looking into services for Adam. As part of our growing process, we have to know what is available to us. I was discussing how Adam has many challenges and is also:

- affable
- affectionate
- likes to be social but has difficulty at times...

“He sounds great,” interrupted the woman I was speaking to on the telephone who had asked me what Adam was like. “Just so you know, I have a child with Down’s syndrome. It’s a drag to have to paint the worst scenario, but in order to get services, you just have to.”

Why subjugate our wonderful children, young and old, to terminal fates? You remember — the ones “worse than cancer.” Why must we have to paint a dismal picture, or view people with disabilities as something horrible and devastating to us and society? This is the very reason why we’ve had such misrepresentation that hurts autistic people, and why parents are literally forced to represent ourselves as desperate, our children as hopeless without certain types of services. People with challenges have a right to support. At the same time, we have a right to love and cherish our children and believe in them. We have a right to think our children our terrific, great, a joy, even. It’s not sugar coating anything (back in the day, I was accused of this). My child needs lots of support. I do not wish to embellish anything. I simply want to tell people what he needs as his inherent right. As it is, the services and supports for autistic people here in Ontario are neither diverse nor robust.

If there is a thing called fate, I think it’s terminal for all of us, isn’t it? I sure wouldn’t call autism a fate worse than cancer and to be honest, I find it really hard to speak about my son in a way that I find demeaning to him. There are facts, and there are exaggerations. We all want to make the best of the lives we have, and so we should — with the support we need, and the love in our hearts that we just need to express.

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[Push](#)

Filed Under ([Poetry](#)) by Estee on 22-11-2010

A little something I'm working on:

Push

By: Estée Klar

I pushed you into the world.
I wanted you.
I'm sorry.

The white hospital room and metal equipment
fluorescent lights and beeps
no air
until your lungs were suctioned
over one minute.

I waited
anxiously,
afraid I would never meet you.
But you cried
as nature intended,
as medicine assisted.
I'm sorry.
I'm glad.

You are eight now.
Goodbye my toddler –
the one I weep over.
Time barged in.
My toddler
proclaimed autistic
at 18 months.
The number of life.
Chai.

When the life as you now know it began
behind closed doors with strangers –
enthused young therapists –
to heal the world
in tight jeans
and you, their mission.

Your life started for me when you kicked.
I watched your foot underneath my skin,
when you held your head up for the first time,
from the crook of my arm,
as you sucked the nutrients you needed
from my full body
releasing love.

Your eight-year-old head
still soft
I put my face in your hair,

and hold you for fun,
in the crook of my arm
(sometimes you smile).
But I think
that you can't remember.
Your writhing body pushes
to climb
the growth chart,
we marked last year –
and away.

Since I pushed
the way I always do
through life
to life
to you,
I say daily goodbyes.
Ah, your little hand in mine.

“Bye-bye, yes,” you say anxiously.
Difficult words for you to speak
You try so hard.

When the people came —
as they do in our autistic life —
the ones who needed to close the doors
like heavy iron gates
I heard you wailing.
My bosoms leaked
my arms yearned
my heart
ached.
I should have done something to protect you.
I tried so hard.

Preschool.
Leaving you in the schoolyard
you circled perimeters
maybe watching,
for comfort,
I waited.
“It's time for you to say goodbye,”
the teacher said.
I wasn't sure
if you were happy,
if I should have yanked you home.

You tried so hard —
with loud children
a crowded room
you found quiet corners
books
and alphabet letters
that you wiggled in front of your eyes

a dance from A to Z —
your solace.

*You are my boy —
the one who read book spines
from the shelf you laid beside
before you could walk.*

You were pulled away,
told to sit down,
taught to use picture symbols,
to kiss the baby doll.
That would satisfy them —
plastic affection,
obedience
and oh,
to communicate.

Kindergarten —
a quieter place
little shoes lined up in the hall.
You learned your routine,
to cleanup,
put in your chair,
sit with kids.
Those kids —
fast talking, moving, sharing tea cups, Lego, dolls
like the blur of the ceiling fan.
They didn't come over.
I ached for you,
for me
they didn't see.
The fan above
kept you company
and you waved hello.

You made things
you showed me your love of animals and dinosaurs
you made drawings with details
that your peers couldn't draw.
Their voices were louder,
their hands stronger,
thicker lines on paper —
typical lines.
So people praised them
while you circled the room
trying not to be seen.

You see things
you know things
you can't say things
very often.
Wordless
yet full of hums, clicks and whoops,
you uttered many

like jazz
I seemed to understand.

Your words come sometimes
you push out,
the assumptions
about a humming boy.
I have to pay attention
or the soft words uttered,
cannot be retrieved
from vanishing speech bubbles
above superheroes
poof.

The sounds you made when dad and I split —
your body spasming relentlessly —
I feared.
Probes placed on your body, your head,
that precious cranium
from inside my flesh to the crook of my arm
they prepped and monitored
for seizures.

Your body
protesting change
in the brittle cold of February
thrashing and falling
with pain,
confusion –
I'm *so* sorry.

We calmed into
the sun of summer
warming us into fall.
We grew
from under
dead leaves
to fertile soil.
Ripe green shoots
of Hostas unfolded.

You have started a new school.
You leave every morning,
your soft lips kissing mine
my face brushing cherub cheeks
thinning
your body stretching
in a monogrammed sweater.
The toddler a shadow of you,
the boy taking over.

I see a future in your face,
a history already written.
I say goodbye —
the smooth soft skin

sweeping across mine.
The door angled
you exit
gentle air wafts
as I close.

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[Compassion](#)

Filed Under ([Advocacy](#), [Critical Disability Studies](#), [Discrimination](#)) by Estee on 17-11-2010

Below is a reading from my favourite author Milan Kundera excerpted from *The Unbearable Lightness of Being*. It would have made (and now makes) an appropriate accompaniment to my essays of several years ago titled [The Economy of Pity](#) and [The Mismeasure of Autism](#) — the latter which was included in Wendy Lawson's book [Concepts of Normality: The Autistic and Typical Spectrum](#):

poignant reading from "The Unbearable Lightnes...



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About Me



ESTÉE KLAR

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

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The Joy of Autism:

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

The Joy of Autism

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