

Estée Klar

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Assistive Devices for Autism

Filed Under ([Advocacy](#), [Communication](#)) by Estee on 17-03-2010

While Slade is using the Dynavox in this video, I have to attest as we prepare for Adam's new device (which will not be the Dynavox but a similar device) that this can really change your child's life. I am so excited that we are entering this new phase of his life soon, and we have done it with the help of others who are experienced in this field.

It takes time to teach the child HOW to use the device and I have to admit that having Adam use the Qwerty board in preparation for receiving this device, it does help with the navigation. One can begin with low-tech options to prepare a child for such communication including PECS (Picture Exchange System) as well as using computers. Adam does most of his school work on a MAC computer to-date, and he has used the Alphasmart Neo to type because it is easy and lightweight. As Adam improves his reading/comprehension skills (expressive output I'm referring to as we never know the extent to what Adam knows), he answers his multiple choice questions one-hundred percent correctly. However, if Adam would be asked a comprehension question in an open-ended manner, he may not always answer correctly.

I encourage people to look at AAC and our institutions to take it VERY seriously in providing this opportunity for our non-verbal autistic children. It is one step closer to enabling their "voice."

Slade Helwig - DynaVox: Autism AAC Success St...



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Break Time?

Filed Under ([Acceptance](#), [Adam](#), [autism](#), [Transitions](#)) by Estee on 12-03-2010



I was taking a forced break this week. I contracted that nasty stomach flu last Friday and today is the first day I'm feeling better. It'll knock you down off your feet if you get it.

I realized too that it was a forced break and how I push myself too hard. I had been moving and fixing this new house for a year, I'm still doing it, I tried (with success) to transition Adam through a difficult time moving homes and then I suppose I should not be surprised that I got that nasty flu bug.

I got to thinking about how we push through things and quality of life. I'm a real doer by nature and compulsive at that. I often put way too much on my plate until I realize I simply cannot complete all the things I set out for myself. I don't like to call it 'setting myself up for failure,' but rather just that I still need to learn that compulsive *doing* is perhaps a way to avoid other things (which granted, I've been dealing with), and it's just time to slow down and catch my breath.

We do it with our children too. We can throw so many things at them and change the course too soon. We doubt their schooling, their programs and we throw, oftentimes, too much at them to see “what will work” (to make them “better” or “progress”). Despite my intellectual knowing that this can create stress on children as well as adults and stress hinders any kind of progress, I’ll admit that I have the same feelings as many other parents out there. Thankfully, for the most part with Adam, I’ve stayed the course, that is, once we found the course that seemed right for him.

Adam and I are due for a break soon — to enjoy our new house, take leisurely walks in our new neighbourhood — to learn the routes that Adam enjoys creating to soothe himself and feel at home. We need to play a board game and some more *Go Fish*. We were doing nicely with that game. I helped Adam turn-take by using visual cues and the joy of this is, we are enjoying each other’s company in playing it.

I am feeling better now and Adam has been smiling a lot in his new home. One of my strategies was to bring Adam home early from school with his aide and surround him with familiar people, and this helped a great deal. It took three weeks before I really saw him begin to settle in. As you may remember from previous posts, he was having severe spasms that made us very worried about him, not to mention extreme sleep difficulties. Anxiety will create sleep difficulties in anyone, not just autistic people. In order to ease his anxiety, I’ve followed Adam’s lead and have tried to stay on top of when he is about to become over-aroused so I can redirect him to something less upsetting. Adam is pretty good at trying to do all of this for himself, but there are simply times, as he is still a child remember, that he needs some guidance and support. It strikes me as odd that we expect our autistic children to “behave better,” and do not consider the stressors in their lives with more deliberation and compassion. It was when I wrote down many notes about Adam’s behaviour during this transition, for there came a point that I didn’t know what else to do, that I not only came to see the patterns clearly, but I, as his parent, could settle down myself. My worries and expectations about Adam may have been so high, that I forgot to slow down for him too. I thought I had charted a pretty good course, but it wasn’t exactly what he had needed. It was at this point I decided to bring him home early from school for two weeks and enable him to have fun in his new home. It was also at this point that we began to see positive results.

Transitions are one thing — they are very difficult for all children, autistic people and especially for Adam. During these times, we have to take more time out of our “regular” routines to accommodate our autistic children. Sometimes we think we are doing everything we can and we can become frustrated with our efforts as parents. When we take the time to look carefully, it becomes easier to alter the accommodation to meet the person’s needs.

So we’ve come this far, and indeed I’ve learned another valuable lesson. Now...BREAK TIME! (Or maybe some *Go Fish*).

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[Love Goes Deeper](#)

Filed Under ([Acceptance](#), [Adam](#), [Communication](#)) by Estee on 08-03-2010

Eustacia Cutler is the mother of Temple Grandin. With the recent HBO program lately on her, I returned to Eustacia’s book, [A Thorn In My Pocket: Temple Grandin’s Mother Tells The Family Story](#).

It's not all that easy to read in this day and age of watching our words regarding "struggle" and "fight," so overused and sensationalized in the media to the detriment of autistic individuals. She uses these words more often although the tone of acceptance runs throughout, and this is a point I like to make often about autism acceptance: it doesn't come without facing our inner doubts. If it were, it would lack real meaning and substance. Acceptance is something we must earn by facing them.

Adam spends some weekends with his father. This particular weekend, I caught the the stomach flu. Alone and sick (thus feeling particularly so...it always happens when we're not feeling well), I yearned to speak Adam more often and to ask how his day went. I was yearning for connection and I was also feeling guilty of not being able to take Adam back on Sunday night, when I would typically after a full weekend with his dad. I wished to explain this to him, but Adam does not love sticking the telephone to his ear. In fact, he is exceptionally averse to it. My mother says Adam lives in the right era with all the technology that can help him. I'm not certain it is as good as we yet want it to be, but one thing's for sure — thank goodness for Skype.

Skype is a recent life-saver. Adam's dad and I have begun using it often and Adam holds his attention longer than using a telephone, as the visual is easier for him to understand. I can see him and he can see me and I feel a sense of huge relief. Then I wondered if Adam did too as he had to stay two extra nights with his dad because I did not want him to catch this outrageous flu. He loves his dad, but I wondered if he had natural questions about what was happening to his routine, and his mommy.

It was in Eustacia's introduction that I tried to seek solace from this weekend. She said, "I've learned how the parents of autistic children suffer from a loss of their own sense of self. We all know that a baby needs a mother to know she's a baby, but, equally true, a mother needs a baby to know she's a mother."

My friends and family, even my ex, all assure me that Adam knows I'm his mother during my more vulnerable moments, like this past weekend. I asked his aide today to help him understand that Adam would have to wait one more day to see mommy — as I was hoping he could come home, but I am still too ill (do you understand how worried I was about this yet?). Adam texted me the following, I'm fairly sure, with a few reminders from his aide:

hi mommy

i like mommy

i like dinosaurs

mommy feeling sick. Feel happy. Feel better

i had chocolate after lunch

bye mommy

love you

Adam

I'll take it. Yet I wondered today if Adam really missed me. It's a natural wonder, I think. Even parents of neurotypical children might wonder the same when their children are with another parent, or with friends. We too need to receive love. We need these expressions of love that we have become so used to.

Later on Skype this afternoon and evening, I had a virtual "dinner" with Adam, thanks to his dad who put the camera straight on him. After he became upset later in the evening, his dad put him in front of the camera. When he saw me, he calmed right down and smiled again. I spoke to him softly in my mother-voice, reminding him that I will see him again tomorrow. Again another smile; crying abated. That is the mother's reward — her ability to calm her child. I completely understand the angst mothers feel when they do not feel they can appease their child's pain or distress because I too have been through that.

So I am elated for it's what I get — not yet the long drawn out conversations about what is happening, what may be confusing him, what he is excited about. Yet I think I can decipher it enough. We are communicating. Indeed, I need to remind myself of this in such times when I think of Adam as a person and his future, and my future as Adam's mother.

“Think of me as your future,” says Eustacia. “I am where you will be many years from now, when you know how it all played out, when ‘what will be’ has turned into ‘what was,’ and you will have to come to terms with it.

Perhaps not in the way you thought you would, but you'll no longer feel trapped in a morass of angst and guilt. You will have resolved your child's future and your own. You'll know you've given full measure, and the measure you're given has never been pointless.

I offer you my story as a promise of that: an overall insight to carry with you as a talisman. And I promise that, in the future, to your surprise, your dreams will have changed and changed you.

I know that's not what you want.

What you want is a real talisman, a magic something you think I conjured up to coax Temple into joining life, as you hope your child will. There was no magic; there was just doing the best I could. That's the point; that's the talisman.”

I've understood my son. Maybe he understands me better than I can know in the obvious, typical way. For certain, love goes deeper.

And it is louder than words.

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[The Process: More Important Than The Prize](#)

Filed Under ([Acceptance](#), [Writing](#)) by Estee on 08-03-2010

In part, this blog was to discuss the process of writing a book and of writing itself. Many people like to think that the end result is easy. Most writers know this is not so. While I'm not a new writer, I've not yet written a book.

Much like how we view people and autism — that there is a goal that must be reached — that only one end result is desirable or feasible — we forget the journey and the process as the greatest creation of all. When all is said and done and the product is finished perhaps a few people will read our work, perhaps fewer will remember it (or as Elizabeth Gilbert and J.K. Rowling will attest — sometimes there is “freakish” success). But that does not make the doing, the making, any less significant. An act of creation is no waste of time. It pains me sometimes when I watch a culture so invested in the end result that we continue to churn out less creators and more factory-line producers in business administrators and lawyers (but let us not forget that there are wonderful creators in these professions as well). I have a real issue with “professionals” being churned out of universities, as I find that those without such degrees can be equally, if not more competent, in business. I believe university is an opportunity to receive the Universal Education – not a place to learn a trade. It's not that I do not appreciate trades and craftsmanship, for I have *great* respect for it and also believe we undervalue true craftsmanship. I

believe learning a craft is equally as important as learning philosophy, literature, art, and the sciences. My real point is, life is more than the products we produce. It is the intricacies, decisions, confusions and the work in between that is often more meaningful and interesting to us in the end. The “wax on, wax off” of the *Karate Kid* was more important than the rush to learn Karate. If the process of our lives wasn’t important, we wouldn’t be writing and producing biographies of people and their private lives — we just wouldn’t be that interested in them. We always need and want to know the story behind the creator.

I like to think of writing a book or a blog as a process as important as writing the Book of Life. As I went to a funeral last week, the Rabbi concluded that the “book of [the person’s] life had now ended.” Our lives are complex narratives. We are reluctant to put the book down. When reading, we have been so invested in the journey. If this is not testament to how important a process is, I don’t know what is.

It was listening to a number of authors last week talking about process that I realized we are not a culture that appreciates it very much while it’s underway. We have our eyes on the prize. One author even stated that there is no such thing as a failure in writing. We must have many of them. In this sense, there is no such thing as a failure.

I’m still writing and doing a lot of research now that the bones of what I want to write seems to be constructed. The research is so much a part of my journey that I can see how some writers may not want to stop. Yet certain chapters have to be written. Some have to end. There is always something new to write about. There will be an ending to mine soon. But until someone reads the last sentence in my own Book of Life, I’m going to try and continue to relish the process.

I hope it need not be mentioned that this post is a metaphor for all of life, and for our autistic children with whom we place so much stake on performance and end results. It seems a bit of a let-down to have to spell it out.

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[It’s Just That Simple](#)

Filed Under ([Acceptance](#), [Advocacy](#), [Autism and Intelligence](#), [Autism and Learning](#), [Contributions to Society](#)) by Estee on 02-03-2010

I love this video. It’s just that simple. “You get rid of the autism gene and you get rid of Mozart, Einstein, Silicon Valley...” I love how Temple advocates and it’s this kind of advocacy that assists us in putting ourselves, as neurotypical parents and teachers and therapists, with outrageous expectations, under a much needed spotlight. Beyond listening to her story about “gifts” is an opportunity to consider the disconnect we create when we try to “fix the problem.”



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[It's Always Darkest Before The Dawn](#)

Filed Under ([Acceptance](#), [Activism](#), [Advocacy](#), [Autism and The Media](#), [Discrimination](#), [Inclusion](#), [Single Parenthood](#)) by Estee on 01-03-2010

Now I know first hand what it's like to feel dark inside — when my child is disorganized and appears to be in pain and cannot tell me. These are the toughest moments when a parent feels helpless. Also frustrating are schools that claim they are there to support autistic children but will not take “non verbal” autistic children. Believe me, the conditions out there in order to participate in society are just plain ridiculous and prohibitive, so I'm going to make a strong plea to everyone — INCLUSION IS NECESSARY. Stop pretending to be inclusive to autistic children if they have to “talk and walk” at the same time. It's *not* autism-friendly! Argh.

Yet when I am feeling depleted, I fight it and I will urge every single one of you to do it too. For each one of us has that power, if we can be aware and monitor what's happening to us inside. It's important to remain honest with ourselves and then be able to step back from those feelings that can suck us down.

I reach out for help. I call people. I call Adam's aides and therapists for help when I'm feeling overwhelmed. This is a good place to start. Always call for help and bring in only those who support you and your child in the manner that you need. Do not bring people in who will put you down, make you feel lower or try to fix your child. The most important thing you and your child need are love and respect.

One thing I know FOR SURE, is that there comes a time in life when we really do have to muster every bit of strength we have and resist the calls of the demons. The echoes of [The Autism Everyday video and “wanting to](#)

[drive over the George Washington bridge](#) is like a siren call and this is why this kind of marketing — the kind that exploits and capitalizes on people’s pain — should be illegal in my opinion. It’s not that I disrespect Allison Tepper Singer for her genuine feelings that might be expressed cautiously in a book or another venue. It’s about how those feelings were exploited for capital gain: *make autism desperate enough and we can raise money to cure it*. Well, I’ve said it before and I’ll say it again: I believe this kind of marketing (consider type of presentation, method of delivery etc.,) is more harmful to parents than ever.

People shouldn’t have to stifle their feelings — that doesn’t help and can have an adverse effect. I’ve read Sylvia Plath’s **The Bell Jar** and it’s all about wanting to die. Beautiful work exists because of honesty and by sharing honest feelings we do not feel alone. There are expressions of hopelessness everywhere — and some quite well-written in fact. Yet these can be used to empower and can also be used as cautionary tales. It’s the latter cautionary tale I wish to dwell upon. People must reach out in a world where literature on loneliness prevails. In this past weekend alone, I’ve found one book on [Lonely](#) by Emily White (it destigmatizes loneliness and *it is* an interesting read) and two articles on loneliness and depression (*The New Yorker* and a review of White’s book in Saturday’s *Globe & Mail*). It feels as if we live in a technologically hooked-up world that seems, in fact, to be coming socially undone.

This morning I find the following story on the murder of an autistic child (see below) which is why [Autism Acceptance](#) is so vitally, URGENTLY important — not just for parents but for society at large. Society must begin to realize the incredible challenges that families with autistic kids have when they are NOT included and accepted. If we are a community, then EVERYONE IS RESPONSIBLE. I take the story of Gigi (excerpted below...almost there) very seriously. It shows that no amount of money can fix anything. Better spent, is money accommodating autistic children and making sure every child gets a fair shot at being included and educated. If I have one dream, it would be for [The Autism Acceptance Project](#) to raise more money to advocate more strongly that acceptance is a social responsibility, and to make a place where autistic kids can be fully accepted and receive an amazing education.

My former neighbour [Mike Lipkin is motivational speaker extraordinaire and author of several books](#), one called **Strong Mind, Strong Heart**, co-written with Dr. Bernard Levinson. I’m very good friends with his exceptional wife and herself an inspiration, Hilary. Re-reading some of his chapters after a very challenging couple of weeks with Adam reminded me how certain thoughts are defeating. Mike reminds us:

“Are you worried about your children’s future? Are you unsure whether you’re on the high road or the low road? Have you noticed that everyone you talk to has a different idea of where you should be going? Are you slightly confused? Are you a little exhausted by having to make so many decisions all of the time? Are you being bombarded by massive change? Is your brain frying?” (p.88)

I think that many parents can say *yes* to all of these questions. We worry what will become of our children and where they’ll end up.

We want our kids to go to school, to have places to be social and be accepted there too. With so much negative information getting into our brains from the media or from individuals who believe that an autistic person is only better once they are cured, there are real dangers that lie ahead. By reading Gigi’s story (still coming, I promise) it was clear that she was overwhelmed with trying “fix the problem.” When one discovers that autism cannot be fixed or changed, but perhaps begins to appreciate that while there are challenges, there are many advantages, life begins to look a little less desperate. I urge everyone to consider the list of what an autistic child contributes to the family instead of what s/he takes away. While the rhythm of life certainly changes, it is only those who can adapt and learn to walk to the beat of the new drum who will find joy in life. An autistic child demands that we learn to go with the flow.

Mike Lipkin talks about this a bit, albeit not about autism specifically. He talks about how life “will hit you hard like hail from the sky.” (p. 79) He says that people need to learn how to be resilient. *“Resilience is the ability to heal after a hurt. It’s the knowledge that bad things happen in this world, but just because bad things happen, it doesn’t mean you’re bad. People who lack resilience are people who invest too much negative meaning in what*

has happened to them. They obsess on the dark side of their psyche. They focus on why the knocks happened to them. They ask the fatal question:

Why does this have to happen to me?" (p 80)

We all have dark days. Autistic people also have dark days and learning to be resilient is hardest for them. The world is tough and it hits you hard. And you have to fight it with everything you've got. Gigi Jordan could not:

A few weeks ago a terrible story unfolded in a posh midtown Manhattan hotel where a 49-year-old mother, Gigi Jordan, was found "babbling and incoherent" beside the body of her eight-year-old son Jude, dead from an apparent overdose of ground up prescription pills, including Ambien and Xanax. Later it was revealed Jude was autistic.

In his press conference, the stunned and shattered father, estranged from his ex-wife and son for the last two years, said he had no idea what provoked his ex-wife to kill their child. "To be honest, she was the most wonderful mother I've ever seen. She left her business, left everything, just to take care of Jude." Her oldest friend, Dr. Marcus Conant said, "She went to clinics all over the country looking for new treatments, grasping at straws, trying to fix the problem."

The kind of hopelessness that Gigi faced might have been averted. Also new as a single mother, I know those nights when I feel I have no one to call upon. In those moments, I know I have to pull myself together again and remember that it's always darkest before the dawn. It doesn't have to be Adam that can make me feel this way. It could be a separation, a loss of a loved one.

Mike Lipkin would agree:

"One of the greatest sources of stress afflicting the people who come to us is the discontinuity that prevails everywhere. Just when our clients thought they had finally figured out a pattern, the pattern splintered into pieces again." (p. 88) That pattern in the autism world is expectation. If we expect our children to change, to be fixed, to adapt easily, we cannot be resilient parents.

Mike suggests that we "sketch out many different paths" in our minds to "create an array of different possibilities." He reminds us that not only is life unstable but that "as human beings, we have deep-rooted desire for certainty and stability," and quotes Francis Bacon who nearly 400 years ago said, "If a man begins with certainties, he shall end in doubts. But if he will be content to begin with doubts, he shall end in certainties."

In autism too, there are no certainties. The article that talks about Gigi, talks about how the autistic brain "hardens" at the age of eight, and it would make any parent want to cry if you'll believe it. Again, the article is somewhat misleading. It's only through misleading expectations that a child must be fixed before the age of eight or all is lost that sends many parents into a tailspin like Gigi. Not only is this inaccurate about autistic people, but it's this type of limited thinking that can stifle us and make us feel hopeless.

I for one know that autistic people continue to learn and the possibilities are endless as they are for any human being. Instead, as Adam also turns eight this April, I will ask myself how Adam and I can make a difference in the lives of others who are also on this path. For helping others and having this self-ascribed mission helps us. We have opportunities to learn. Every hard-knock and experience is another opportunity to learn. We get our hard-knocks every single day every time a school or a program doesn't appreciate the special contributions Adam can make to the world. It's enough to make me want to start my own school — and I know many other parents feel the same way (can we harness this energy??).

Do not listen to the media, but trust that your child is a human being filled with potential. The media will always be there, and sometimes it's just a good idea to turn it off or give it a hearty *guffaw* because you will be tempted to feel sorry for yourself and this will deplete your capabilities as a parent. Become the kind of warrior that fends off the demons of the mind and the media. Remember that every child has difficult times and when our autistic children have them, we have to take deeper breaths, ask for help and figure out where this journey is supposed to

take us alongside our children. While times seem a little easier for those with special needs, there's a whole lot of discrimination still going on in our communities. WE have to change this together and support each other in our efforts.

“So once again, here's one unchanging Life Principle over and over again,” says Mike. “You need a Still Mind to think through the confusion and noise. The only way you can master the cacophony on the outside is to have harmony on the inside. Without inner harmony and quiet, you cannot have a Strong Heart. And without a Strong Heart, where are you going to find the resources to not only brave the darkness, but lead others as well?” (p. 90).

It looks like all of us have to lead. It is also important to stop listening to others and begin believing in ourselves and our children. We are forging ahead with a new demand in this world and that demand is that our children be integrated into our communities. For this, we need to be brave.

Adam and I had a tough weekend adapting, still, to his new home. So much so that I've asked his aide to bring him home early so we can begin implementing fun activities here and teach him some structure. It is my hope that he will swagger on his turf soon and we can both get back on the path of working on our mission which is to help others along in the [Inclusion Process](#).

Yesterday morning, after a very dark night, I stopped my inner fight. I leaned in to Adam (who has difficulty speaking but not always understanding), and modeled language (this means that I say a sentence that he might wish to say himself in order to show him that I understand) while he was trying to soothe himself by playing on the computer. “I'm not feeling well, Mommy,” I said in a soft sweet voice. Immediately, Adam stopped what he was doing, came over and leaned his head of feather-hair into my arms for a hug, and we remained like that for a while. As the day wore on, Adam became calmer and things got a little better.

This morning, the sun came out and his happy grin made me shine inside. If we can hold on, the sun will come out again and the possibilities are endless. But you have to believe it. I hope by sharing a bit of our story and adding some inspirational words from my friend Mike, I have helped anyone who is reading this a little too.

[For more reading on how to cope with dark days and how to take care of yourself in order to care for your child:](#)

Still Mind, Strong Heart by Dr. Bernard Levinson and Mike Lipkin (not specifically on autism but created for inspiration)

More Than A Mom by Amy Baskin and Heather Fawcett

Autism Acceptance and Survival Guide by Susan Senator

[Other Back to Basics Autism Books:](#)

The Autism Answer Book by William Stillman

Ten Things Every Child With Autism Wishes You Knew by Ellen Notbohm

Autism Handbook for Parents: Facts and Strategies for Parenting Success by Janice E. Janzen

Parenting Your Complex Child, by Peggy Lou Morgon

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[Is there a “best place” to write?](#)

Filed Under ([Writing](#)) by Estee on 28-02-2010



I'm taking a break and writing at my desk while Adam plays. We've had a difficult weekend with anxiety so I'm taking a moment to permit myself to daydream a bit. Writing the book is a challenge with Adam's needs. I haven't showered since Thursday.

I have to admit I'm dreaming of a little white cottage on the beach by the sea. For some reason, I think I'll just be pumping out the writing there. Isn't that how we all dream it will "happen," without the reality that it just takes daily effort and practice? But ah, the dream... For now I settle for handwriting when traveling. I wrote a novella during my last trip Paris in the coffee shops where no real Parisian would dare to be seen writing. It's what labels me a true foreigner there, apparently, alongside how I order my coffee and what kind of coffee I order at any particular point in the day. Yet I didn't care. I loved every minute of it.

[I'm interested for all you bloggers out there, when it's the best time and place for you to write.](#) I've got my little white office and I stare out at the street through two thinning pine trees.

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[A Mother's First Reponse to the "Maternal Sensitivity" Study](#)

Filed Under ([Acceptance](#), [autism](#), [Communication](#), [Discrimination](#)) by Estee on 28-02-2010

This study sent a little shiver through my body. Remember the story of the big bad "[Refrigerater Mother?](#)" She was the mother who was blamed for causing autism in her child in the 1960's. Many mothers during that period were tormented for being pushed to believe they were the cause of their child's autism. I wonder if the legend survives. From a peripheral read of the following study, this mom had a maternal "first response:"

[A new study by researchers from the University of Miami shows that maternal sensitivity may influence language development among children who go on to develop autism. Although parenting styles are not considered as a cause for autism, this report examines how early parenting can promote resiliency in this population. The study entitled, "A Pilot Study of Maternal Sensitivity in the Context of Emergent Autism," is published online this month and will appear in an upcoming issue of the Journal of Autism and Developmental Disorders.](#)

I am not commenting on how the study was conducted nor the value of "resiliency." I am commenting on the inference. I am a sensitive mother. Some say I'm pretty good at mothering. I'm extremely sensitive to my son, and he is *non verbal*. He can manage a word or phrase now and again, but at nearly eight years of age, it's pretty difficult. I engaged Adam. I did everything (and still do everything) I can think of. He is a wonderful child who is anxious and has some sleep issues. I'm not sure I could have been even more sensitive than I was to make him more resilient. While he's pretty good at moving around the community, going to school (with an aide),

traveling, he does have extremely difficult days too and we are going through some of them RIGHT NOW during a major transition in our lives. Because of Adam I continue to grow and learn how to work *with* him, and there is always something new for me to learn.

With this study, I fail to see an acknowledgment (in the links I could find tonight, I have to qualify this) that for many autistic individuals the inability to speak fluently, or at all, is neurological, not just dependent on the sensitive mother. The term “re-wiring” is used a lot for individuals with brain injury and just as often by gurus selling therapies for curing autism. I will never argue that, as parents, we all want to try and help our children in a world that is often confusing and frustrating for them. Yet, I also wonder if teaching autistic children how to communicate is something very different than re-wiring, for that implies that we are fixing something to make it better. Adam communicates all the time. Like the two-year-old who may have warbled speech indecipherable to many but the parent, some of us close to Adam know what he is communicating — and quite boldly. Perhaps we might consider that working with autistic children is like figuring out the intricate wiring that already exists. Like the ill-suited American plug to the European outlet, maybe we aren’t meant to re-wire the autistic brain into a neurotypical one.

“In this study, maternal sensitivity (and primarily, sensitive structuring) was more predictive of language growth among toddlers developing autism than among children who did not go on to an autism diagnosis. One possible explanation is that children with autism may be more dependent on their environment to learn certain skills that seem to come more naturally to other children.”

I would agree that our children need our support, and this does take extra effort on our part.

“Parenting may matter even more for children with developmental problems such as autism because certain things that tend to develop easily in children with typical neurological development, like social communication, don’t come as naturally for kids with autism, so these skills need to be taught,” says Jason K. Baker, a postdoctoral fellow at the Waisman Center, University of Wisconsin-Madison, who conducted the study with Messinger while at UM.”

I don’t disagree with the idea that autistic children require more support and accommodation in a confusing environment, and that “being sensitive” is especially important. Many of this know this. I tend to see this as part of the autism and NT (neurotypical) equation, for the key is that we as parents learn how our children learn and how they see the world. I don’t see it as a tugging into “our world,” but a sharing. It’s the manner in which we, as parents, figure out *how* to be with the child who is already with us, with challenges in a world that has such difficulty understanding autism, but also with many strengths and attributes. Acceptance is a daily exercise and the idea will challenge us day in and day out — some days (and nights) more than others. Every day Adam works so hard to accept me, to accept this world and the people around him, and I wonder if that’s all we seem to ask him to do. The least we can do is to accommodate him and what he needs and wants from this world.

This article ends with a shallow disclaimer: “We know that parenting doesn’t cause autism. The message here is that parents can make a difference in helping their children fight against autism.” Okay, it doesn’t *cause* autism, but the implication is that the sensitive mother can improve language acquisition and resiliency skills. The results may have been one hundred percent true according to the study design, but the key piece of accepting autism is missing.

While it is certainly advantageous to have a sensitive parent to ANY child, I would hate to think that one might judge me as being an insensitive one if my son is not able to speak. Further, the focus on mothers specifically has reminded me of times I thought had long gone by. Maybe the **Refrigerator Mother** still lurks in the dark recesses of some minds. To conclude from my peripheral read and no reading of scientific critique on how the study was conducted, I sniff not only an omission or two, but a little bias.

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[Autism And The Whale](#)

Filed Under ([Acceptance](#), [Advocacy](#), [Discrimination](#)) by Estee on 25-02-2010



Tilikum is the “killer” whale confined at Seaworld with an apparently demanding entertainment schedule. Listening to Naomi Rose, head of the American Humane Society and a mammal scientist on CBC News at Noon today, she noted that Tilikum is not meant to “be a clown,” and that this puts a great deal of stress on the animal, explaining reasons for its aggressive behaviour. She spoke about Orca Whales as “individuals,” and discussed them and their families, as well as their social networks, and that when in their natural environment, do not attack humans.

In the media, the debate rages as to whether the whale should be put down, kept at Seaworld to remain an entertainer, or be sent to a Sea Tank in Iceland — a choice which Rose recommends. Transcribing her statements on CBC today, she noted that Tilikum has a history of this behaviour and should not be kept under the same conditions. In other words, *get the message!*

“He could be trained to adjust to going out into the open ocean to exercise and get more choices and then maybe his stress would be reduced,” she said, suggesting Tilikum may have simply been trying to play with his trainer.

“If they keep him in isolation the way they do, they keep him in that small tank that he’s in, this is going to happen again.”

There sure is a lot of attention for this beautiful creature. All the talk about how the animal is under stress and how that animal communicates that stress naturally got me thinking about Adam, autism and methods of communication and how many of us do the same things over and over again to no avail. Working against nature doesn’t *work* for very long. It has real consequences.

We are calmer on the home-front again and Adam seems to have found his place here in the house that has been understandably strange. I expect that while he is calm now, we will have a few more bouts of stress. Like Tilikum, we cannot demand that he perform like nothing has happened to him, or not react to this kind of change. Adam will communicate his true nature and it is up to me to listen.

Now if autism advocates would advocate for autism they way Naomi Rose does for Tilikum...

In keeping with the theme of this story is a post by Clay I would urge readers to visit: [“Violated for Having Autism.”](#)

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[Back to the ABC's](#)

Filed Under ([Acceptance](#), [Adam](#), [autism](#), [Communication](#), [Sensory Differences](#)) by Estee on 23-02-2010

We are confronted with new challenges in our new home. Adam seemed to transition well at first, but now it is difficult again. As mentioned in the previous post, we do not know if Adam's spasms are seizures or are spurred by tumultuous transition. On my end, all I want to do is get back on track with Adam. I for certain want my sleep as I function horribly without it. I want him to get over the hump as smoothly as possible until he can have his tests and/or become comfortable in his new home and situation.

But there's another problem.

It could be me.

I need to re-learn my ABC's. Remember those: Antecedent, Behaviour, Consequence? We put an autistic child under our neurotypical microscope (as if *that* doesn't cause distress), and evaluate the antecedent (or cause) of a behaviour so that we can seek to change (or eliminate) it. The Consequence in behavioural-speak is what happens after the behaviour. I'm not saying that these tools are not useful to us. They can be if we learn how to assist autistic children cope. I'm not a fan of eliminating behaviour. But there's another side to this story.

When I worry I am studying Adam. I watch for every little sign. Then I realize that I'm not watching myself. How am I feeling? How has my anxiety triggered a course of events? Adam just wants to explore, and yes, he cannot sleep like most autistic people who, as they become adults, learn to cope on very little. In his new home, Adam is very "disorganized" in his body (for those unfamiliar with this language, it means that Adam is moving his body in unfamiliar ways or hyperactive ways and it can appear distressing), and I still do not know for sure if it's medical.

Yet, I also am thinking he is learning about every nook and cranny of the house as he used to memorize routes on road trips from school to home or from his old house to the park. While he didn't get upset if we changed the route, he certainly memorized it. I'm thinking of Dawn Prince Hughes, author (and new friend of mine since I met her in Toronto a couple of years ago — little did she know that I was a HUGE fan of her book beforehand) of [Songs of A Gorilla Nation: My Journey Through Autism](#) and the excerpt on herself as a child running around in the same circle in her house. Experiencing this first hand, it's exhausting for a parent who wants their child to "behave" or settle. Then I have to think again.

"The way I said 'siiiiilvrrr doooollllaaarr' was only the start of a profound pattern I had throughout childhood saying words and phrases in peculiar, experimental ways and having a complete fascination for words. When I was young, my parents and I often stayed at my mother's new house, and my favorite uncle lived there also. A hallway ran around the perimeter of the house, past the dining room, the bedrooms, the bathroom, the front door, and through the living room back to the dining room, in a big circle. My favorite game (to the exclusion of all others) was to wait in the dining room for the adults to come up with a word — the more difficult the better — and then I would speed off down the hallway, in the same direction every time, either on my tricycle or on foot, repeating the word over and over." (pp. 17-18).

Hughes describes then running to each of the rooms saying the word "where the word would absorb the comfort of my grandparent's bed, their clothing, the beauty of the vanity table, and the smell of cedar drawers..." (p. 18)

Not only have I found Adam enclosed in drawers, but under the bed, and in the deep dark crawl space in our new basement. It takes a lot of effort for me to stay awake and keep an eye on him, as his safety always comes first. His body jerks, he lays on his back and holds his legs. He opens every cupboard, closet and drawer and is still absorbing them — and maybe he can do this better when he can enter them. Save for the things that he

knows — books, his computer that still has the same “Alligator King” from Sesame Street on it, and a cupboard full of crackers and goodies he now knows is his own, he is still disorganized here but is working so hard himself on trying to get organized and calm. Indeed, my boy is making gargantuan efforts.

To this Hughes writes, “I also wanted to keep as many of my own accoutrements as possible the same. This meant that I did not want a new toothbrush, new clothes, new shoes... When I went shopping for clothes with my mother [Hughes describes being afraid of mannequins]... My strategy for survival was to hide inside the clothing racks... the lack of light would calm me down. Hiding was yet another thing that later connected me to my gorilla family — when they went behind the hills to sit or seek out the little caves in the underbrush or rock to be by themselves, I would understand.” (p.21). Similarly, Adam has gone to the books that were the same from his old house. He is not interested yet in new things.

Adam’s grandparents have been around a lot to support him. I believe his grandparents are two of his favorite people (and most consistent). Again this relates so closely to Hughes: “When I was young I stayed with my grandparents on the weekends, and those were among my favorite times. I did feel safe there.” (pp. 21-22). Ask my parents and they’ll likely say that their condo is his “turf.” They have been helpful to Adam and I during this time.

Adam craves lemons during this year of transition. To this, Hughes writes, “I craved salt and would eat it straight from the shaker. I craved burnt matchheads and would suck on them whenever I could find them. I craved Alka Seltzer for its taste and feel.... A sound like the thrum of a tumbler full of milkshake when it was tapped [Adam does this all the time] by a spoon or the Westminster chime of the clock would fill me with rapture.”

So I give Adam his lemons. Right now, I’ll buy him a bucketfull, although other people will tell him to “stop eating lemons,” or, “stop doing that.” Sure, I worry about his teeth, or of Adam’s safety in potentially dangerous situations. I’m not saying that we have to allow our kids to do everything, but I have to let him do more than usual and I have to change my behaviour to accommodate it right now, for this is an exceptional situation. I’m always trying to stay one step ahead of Adam to figure out how he can explore safely.

“Most autistic people need order and ritual and will find ways to make order where they feel chaos. So much stimulation streams in, rushing into one’s body without ever being processed: the filters that other people have simply aren’t there. Swimming through the din of the fractured and the unexpected, one feels as if one were drowning in an ocean without predictability, without markers, without a shore. It is like being blinded in the brightness of a keener sight. Autistic people will instinctively reach for order and symmetry; they arrange the spoons on the table, they line up matchsticks, or they rock back and forth, cutting a deluge of stimulation into smaller bits with repetition of their bodies’ movements.” (p. 25).

This is quite an overwhelming statement for me on how Adam may be experiencing his new life situation. It is quite a disability and a sensory overload.

My point is, Adam is adapting as naturally as he can in a home that is entirely new to him. He will thrust his body upside down, will spin, will seek those dark tight spaces and not be able to sleep in his new bed precisely because he has not yet created his order. But he is doing what he needs to do. I, on the other hand, despite knowing this, am having difficulties of my own in managing it. Watching my son in distress distresses *me*. While this may be natural for Adam, it was re-reading some of Dawn’s excerpts this morning that helped me realize what I’ve learned in the past, but am now experiencing first-hand in a larger way.

I realize that I too am adjusting to my new surroundings as I listen to the house and figure out how I’m supposed to live in it. Things break down and I get frustrated because I am not yet calm and oriented, and this is difficult on both Adam and I. While I feel guilty much of the time that my own anxiety is not helping Adam, I know too that we are not in control of everything that happens to us. Life happens. We are dealing with it. Like Adam, I am human.

So I was thinking about going back to the ABC's and I thought of using it as a pun on behavioural-speak because what most of us want to try and do is "fix" the situation or behaviour. Today, I am reminding myself that this needs exploration and time — we've only been in our new house for a week! Not only does the alphabet, which Adam loves, stay constant in a world that is always changing, but re-reading Dawn's book has helped me realize what tumultuous change feels like to an autistic child. It may require more effort on my part now to help him adapt by creating safe ways for him to do so. Adam will reach for his ABC books that always stay the same and he's doing his part, and I am having this feeling he will eventually make lemonade out of lemons.

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[Is autism really a "problem?"](#)

Filed Under ([Acceptance](#), [Adam](#), [autism](#), [Autism and Intelligence](#), [Autism and Learning](#), [Communication](#)) by Estee on 20-02-2010



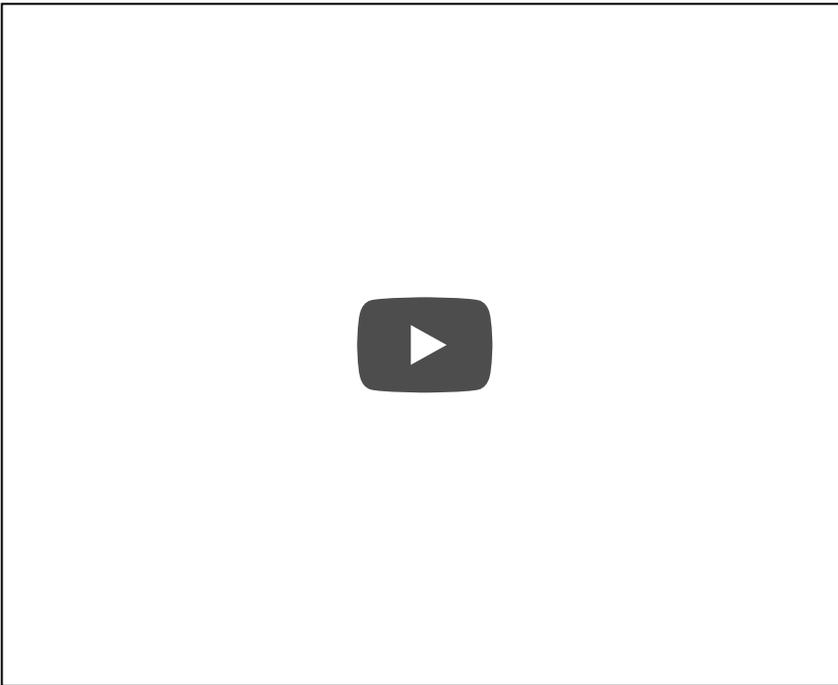
We've had some encouraging messages lately, haven't we? The [HBO production of Temple Grandin](#) played by Claire Danes shows that while (and many of us have read Temple's books already) the world caused her anxiety, she could "see details other people are blind to," she says. "I have a gift."

Certainly the idea of giftedness, which happens in non autistic and autistic persons, can be yet another stereotype in assessing autistic people. Perception, on the other hand, is something to think about deeply.

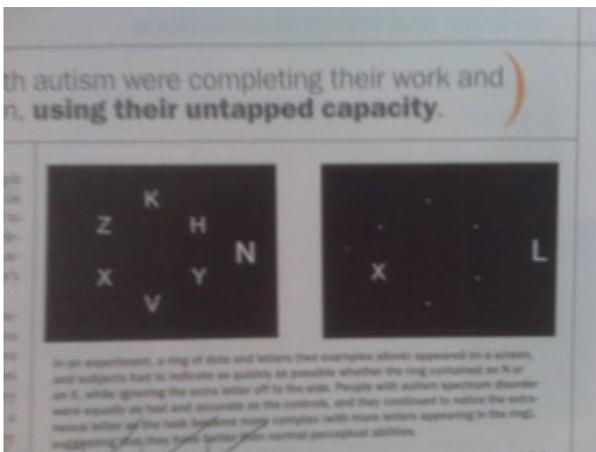
When Adam was very young, we had these water blocks that were dyed different colours. Adam was mesmerized by these blocks watching the water swish and swoosh. Then all of a sudden, my wobbly toddler took them up to the window and peered through them. *Ah, I thought. If only we could all stare at the world through coloured water blocks. How beautiful it would be.* I know was also in part a cooing mother of a young autistic boy, so anything he did like this made me hyper-aware. But still.

When he got his "legs" and we began walking around the neighbourhood, Adam memorized his routes. To this day, if we take him to his old house and walk from there or the park nearby, he will remember how to get to that park or get back through the old "secret pathway" to the old house — which has even since been torn down and rebuilt! Remember, that was his two-three year old brain. In April, he will be eight-years-old.

Coming out soon will be a new version of Lewis Carroll's **Alice in Wonderland**, directed by Tim Burton. Many people suspect that Carroll was himself autistic with his different perceptual abilities. He is often cited as a person who "suffered" from micropsia and macropsia, which is a neurological condition that changes the way the brain perceives the size of objects. When Alice falls down that rabbit hole, we get a look into Carroll's mind.



[Scientific American Mind](#) published [Extraordinary Perception by Wray Herbert](#) this month. It discusses how [psychologists at University College London](#) "think that it might be a mistake to consider [autistic] distractability as simply a deficit. To the contrary, Anna Remington and John Swettenham and their colleagues speculate that people with ASD might have *greater* than normal capacity for perception, so that what appears as irrelevant distraction is really a cognitive bonus." I added **autistic** to **distractability** as many therapies for autism as well as medications are geared at lessening it.



The test, the article shows, was for subjects to "rapidly determine if the letters N or X were present in the ring" on a computer screen. Participants had to then "hit the corresponding key on the keyboard. Some of the circles — those with more letters — were more difficult to process than others. There were also other letters floating outside the circle, but the subjects were specifically instructed to ignore those letters. Those floating letters were the laboratory equivalent of an irrelevant distraction in the real world." In measuring perceptual capacity, researchers saw that "everyone was slower at the task when the ring contained more letters. The researchers were also measuring distractibility. When a letter outside the ring was one of the target letters (N or X), the subjects often took a longer time finding the N or X in the ring — indicating they were distracted by the presence of a target letter in the location that they were supposed to ignore."

The researchers reasoned “that as long as the subjects’ total perceptual capacity was not exhausted, they would also process the irrelevant, distracting letters within their visual field. **Once they had surpassed their perceptual capacity — once the ring of letters was sufficiently complex — irrelevant processing would stop** [bold mine]. So if ASD subjects in fact have greater processing capacity, then they should process more distracting information even as the main task becomes increasingly complex.”

In conclusion, “although there was no difference among subjects in either reaction time or accuracy on the main task, those with ASD processed the irrelevant letters while solving much more complex problems...**Put another way, they weren’t ignoring the main task, nor were they distracted away from it. Instead they were completing their work and moving on, using their untapped capacity**” [bold mine].

This article also concludes that while this is a benefit, it also does have “real-life consequences.” They begin and end the article citing [Tim Page, an author with Aspergers from his book, Parallel Play: Growing Up With Undiagnosed Asperger’s](#). Page recounts his time in school who failed an essay about his field trip which was quite detailed in terms of his way of perceiving it, and how he was scolded for writing in that particular way. “I had noticed the wrong things,” he writes.

As a parent of an autistic child who has difficulties with verbal communication, I have to ask the question: “whose *problem* is this anyway?” Certainly I have been dealing with issues, at least issues for me as Adam cannot comment here yet, so I am fully aware that I need to be fair. He has very real sensory and perceptual differences, so I set up a basement full of equipment for him to self-soothe. He has even learned to “self-regulate” by going to read his own books, and I never had to teach him that. His body will completely quiet as he flips through pages of encyclopedias, dictionaries, cookbooks, among many other subjects. He may even appear to layperson as not really paying attention and just flipping pages, but I know it’s more than that. His body-jerking almost always stops, which is how I conclude that he is soothed by his books. I am imagining him looking at those books over and over again, and what he may be gleaning from them. Still, when it comes to getting the responses WE need, he using a “special” reading program at school. Indeed it is really helping with his expressive reading ability, and maybe even with his vocabulary. So I need to let him do both. He needs to learn to respond in a world that doesn’t yet understand the way he learns. He also needs to flip through pages and pages on his own. I can sit beside him sometimes also and talk about the books he is reading. We can type about what he is reading, we can draw stories and make more conclusions or assumptions about what he is reading. When we do things together calmly, we are having lots of fun.

When we teach him a new communication device, it may appear to the person who is teaching that Adam is not focused enough — indeed he appears to be “highly distracted.” On an AAC device (we are still awaiting one from a service-provider here in Toronto) his finger will go to the right picture, letter, or answer, and then he will quickly go to another one to check out what it will do. A keyguard helps him direct his finger more quickly to the correct response. He may have trouble finishing sentences (when he types) and then be reminded to “stay on task.” This is in large part what Facilitated Communication attempts to assist with if done correctly — to remind and assist with the focus. To a person who cannot detect that Adam was about to give the “right” answer (or rather the answer that was requested of him), he would receive a failing grade. Adam is very young and I believe he is not given the benefit of the doubt enough, although his team members are good with this.

It is only fair to say that we do not KNOW everything he knows. We do not fully understand how he takes all this knowledge in and we are the ones that deem his versions of knowledge as irrelevant. We have not developed sufficient ways to measure his responses or his way of learning and seeing, except for the ways we measure responses and knowledge from people who are not autistic. This brings me back to the old ABA adage, “if we can measure it, we can deal with it.” Unfortunately, the way we have historically dealt with autism is by eliminating the behaviours and learning patterns that are essential to an autistic person’s existence. Perhaps continuing to fund this research more heavily is important because as we understand how autistic people learn, we can not only develop better learning tools, but come to better appreciate our children.

Trying to understand this is a first step. As Adam’s parent, I see many of the so-called “issues” being mine, and yes, I become just as frustrated as many other parents out there. It’s really hard to see Adam in distress and it’s even harder to always be guessing what may be causing anxiety or body-jerking (Lack of calcium? Trouble at

school? New self-awareness of difference? Trouble with transitioning from task to task? Lack of sleep? Seizures? A very long winter? Lack of exercise? Another neurological issue?... The guess work list is too long). Since Adam appears to be in discomfort since late last fall, I am really working hard at figuring this out (wait-lists are long here in Toronto). Sleep issues, anxiety issues — I know when I have a level head, there is more that I can do for him to ease the situation. We need science now to figure out many of our questions.

Sometimes it feels that makeshift solutions only lead to more issues. Sure, we all want things to be a little easier, but Adam requires more consideration in order to achieve that balance between helping him through discomfort as well as accommodating his needs. As I have been through a difficult year, like many of you out there, I completely understand the reasoning, but I have to keep a level head and look at what Adam has also gone through with a “broken” family. I have needed my sleep, but if Adam cannot, I have to find safe ways of letting him stay up until his body will sleep naturally. I know what I’m saying isn’t easy and there are still days I will resort to the Melatonin, even though, because of the guesswork involved, it pains me to do so. Yet I also know it’s important to stop and slow down and think about how Adam feels and perceives. When I do, everything seems a little easier. As a parent, I can even become proud of myself (it’s important) that I’ve not only managed well, but have helped Adam out too. We are still on that path to finding out if we can help Adam, but I am always wondering excessively about how I perceive the “problem.”

I’m interested in what people in science think about this Perception study. I think we have to spend a lot more time imagining what it feels like to be in Wonderland.

Excerpts from:

“Extraordinary Perception” by Wray Herbert in March/April 2010 issue of Scientific American Mind, pp. 68-69.

Further Reading:

Selective Attention and Perceptual Load in Autism Spectrum Disorder, Anna Remington, John Swettenham, Ruth Campbell and Mike Coleman in Psychological Science (in press). Published online October 14, 2009. www3.interscience.wiley.com

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[So Happy Together](#)

Filed Under ([Adam](#), [Joy](#)) by Estee on 19-02-2010

I’m clicking my heels this morning. Adam is so happy in his new home that it seems he likes it better than his old one! So all that worry has turned into joy, joy, joy.

This isn’t much of a post except that I had this song in my head this morning and I dedicate it to my Adam:



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[Third Time's A Charm](#)

Filed Under ([Acceptance](#), [Adam](#), [Communication](#), [Single Parenthood](#), [To Get To The Other Side](#)) by Estee on 18-02-2010



I'm not talking about relationships. I'm talking about Adam's third night at his new home. After letting him explore, be tense, be happy and then settle, he spent his third night in his own bed.

The past two days when I've picked Adam up from school he has been running into my arms with a huge grin on his face. I have to admit that his hugs and grins are like Valium — the moment he does that my entire body relaxes. As his mother, I am happy when Adam is happy. Adam is happy when I am happy.

One thing is for sure as I watched his face searching mine this morning and on his way out the door to school is that for Adam, *I* am home. This is home because I am here. For all the worrying I've been doing, it dawns that I am the most important person in Adam's life. I am the most constant, the most present, although, of course he has many people who also love and support him.

Below is a little snapshot of Adam when he came home from school as I let him relax. It doesn't show the exuberance that came afterward — and the searching for mommy in order that he could snuggle in the crook of my arm for me to read him his favorite books (**Little Ms. Shy** and **Mr. Quiet**, no less). As I watch what Adam does and how he does it; as I pay attention to the books he brings me, he is telling me a whole lot. I say this as I am also skeptically [reading about a cuddle drug for autism](#) (Adam is the *best* cuddler and most affectionate child). It can be frustrating when I am worried about Adam and he cannot communicate everything that's on his mind. Considering all the issues with autism and communication, it is those moments when I step back and pay attention that I can really appreciate Adam and the many things he has to say. **Thank goodness for autistic behaviours** for they are telling me so much! Adam is telling me how much he needs me and my support. He is telling me how much he loves me!

We are home.

Here's the little after-school video:

[VID 00039](#)

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[My Life In Files](#)

Filed Under ([To Get To The Other Side](#)) by Estee on 17-02-2010



I'm filing. Yes, it sounds tedious but I'm trying to approach this with a new zeal. Moving into a new home is one thing. Moving into a new life after a separation where all of a sudden I have to learn things like personal finance among many other nitty gritty things once shared with a spouse can be a little overwhelming at first. There are no secretaries to do the filing for me. No one to make that call or file that paper. I am taking care, for the first time in my life (believe it or not) of everything. I mean, I am a capable human being, but what is it about suddenly being on one's own to encourage this level of emotional stress? Ah, right. It was loving someone. It was remembering when someone used to make me a cup of tea and when I helped that someone with other tasks. It was sharing.

Now, it feels like all I have are to-do lists for Adam, the house, for me... for EVERYTHING that it resembles Santa's Wish List from all children around the globe.

I have to admit I am getting cranky. I felt guilty about that until I read (in a Toronto service for divorced people) a check-list for stress. One of them is being irritable and easy to set-off. The stress is pretty heavy. I'm trying to transition Adam and forgot that I am also still transitioning myself. I've gained weight (I am the kind who puts on weight when stressed out). I haven't been looking after *me* — something that most moms of special needs kids talk about a lot, never mind adding divorce stress on top of it. Maybe it's a little feminist of me to suggest that maybe I let other people take care of me a little too much. I resemble the capable, intelligent woman who

deferred many of these tasks to a man. Yet I also don't believe that sharing the tasks is a bad thing at all. It's not learning and not knowing *how* that can be dangerous. When confronted now with sorting new things out in life, it feels foreign and I need to map it out.

To my surprise, Adam was very happy last night exploring the new house and making quite a mess of it — opening doors, taking things out of cupboards and I figured that as long as he was safe this was important for him to do. Like discovering routes (yes, intended pun), my little Autie is making himself feel at home. Who am I to tell him to put everything away when I'm trying to make him as comfortable as possible? He needs to know what's behind all those doors. He needs to sort out his new environment. Many an autistic person will attest, like Adam, that routes and familiarity are very important.

So the house was in shambles this morning. I tidied up after Adam left. Putting things away leaves me with a sense of order and peace that I'm looking for in my transition right now. I'm trying hard to slow down instead of rushing forward. I have decided today to take breaks which is something new for me — the kind of person who always always ate lunch at her desk. And yes, I'm filing. It is helping me think. Everything has a place and there's a place for everything, as the saying goes.

My life is out of the boxes, but it's going in files. It is helping me understand my new life as much as Adam needs to empty out all the closets.

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[So far... Success](#)

Filed Under ([Adam](#), [To Get To The Other Side](#)) by Estee on 15-02-2010

I just want to report that little Adam came to his new home. He was quiet. Grandma, grandpa and mommy all gathered around him and ate dinner and he just looked and looked. He hadn't been to the house in the evening before. The lights cast a gentle glow. Evening is a time when everything feels strange. The day is ending and dusk is uncertain.

“Raindrop,” he said of my lamp that hangs like that in the corner of our living room. “Bubble lamp -” we named our chandelier over the table. His eyes were focused on the light.

We all snuggled around him after dinner on the couch and watched a quiet video of photos of Adam's family and this past year that grandpa had made with classical music. Adam enjoyed it and was also content to read the books and look at the toys I had placed in the room. We went gently upstairs and he climbed into the “snuggle chair” I bought so that the two of us can read together. With very little struggle, he then fell asleep.

He knows everything has changed. Yet I've done my absolute best to make all the time leading up to this transition as smooth and as positive as possible. As you readers know, I was quite worried about all this, and even though I'm somewhat relieved, we still have some days ahead of us that I cannot predict.

But now the first night is done. And it seems we're off to a good start.

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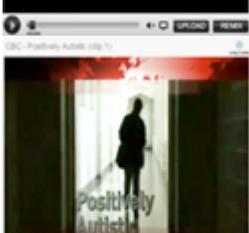
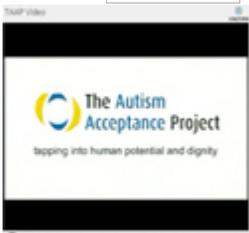
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About Me



ESTÉE KLAR

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

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The Joy of Autism:

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



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