

I also have a list of prominent unconfirmed participants, who should be confirmed shortly.

I am looking for Canadian autistic persons to consider joining the board. Please send letters of interest to:

estee@wolfond.com

[PERMALINK](#) POSTED BY ESTEE KLAR-WOLFOND AT 3/16/2006 11:19:00 AM
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TUESDAY, MARCH 14, 2006

The Difficulty of Knowing

There is an old adage: Ignorance is Bliss. In the case of liberal eugenics, human genome research and ethics, some people might think this as they read on. As we come closer to discovering what makes us physically human, we come closer to becoming god-like. In the name of progress we fly higher and seek control. Apollo had a son called Phaethon, who was human. Phaethon nagged at Apollo to let him borrow the sun chariot and fly across the sky. Finally Apollo agreed. Phaethon proudly drove the sun chariot up into the sky, but then he lost control of the horses. The sun chariot dived towards the earth, burning everything. Finally Jupiter had to stop him with a thunder bolt.

In the name of progress, human genetics, biotechnology and the economic engine that will profit dearly from it all, this movement will go on. To what end is yet to be determined. In the meantime, let's keep talking about what this all means as my son hugs me from behind with his cherub smile this morning.

I've been pondering my first pregnancy with Adam. The expectation of him. Needless to say, after thirty-six years of waiting, I was ecstatic. I was in Barcelona when I found out, unknowing of the apparent irony of Gaudi's warped buildings, Dali's surrealism – beauty born from "juxtaposing unrelated systems and altered established visual order."

When I came home to Canada was when my apparent joy was met with foreboding – my first ultrasound and nuchal screen and then shuffled in to a genetic counselor's office to talk about the 1 in 244

chance of giving birth to a child with some kind of genetic defect. I think they told me what kinds of defects, but the discrepancy between them obviously meant nothing to me because I can't remember. That was like throwing a bucket of water on my flame. Not having children before, I had no idea I would be subjugated to a tiny office with a stranger giving me statistical factoids – whose supposed *disengagement* angered me. In fact, I remember feeling pressed, asking questions of what it all meant...I just remember that severe countenance giving me probabilities devoid of empathy.

I called my obstetrician and asked him what it all meant. Did he or did he not feel that from my test results I was going to give birth to a defective child? He tried to root himself in statistics, reserving himself to the facts instead of any judgment. I searched for a tone of voice that might allude to an opinion. I found myself in an unexpected ethical debate with myself – strewn into a situation of making prenatal decisions about my child that I was wholly unprepared for, and in fact, given a choice that I never asked to have.

I felt jilted out of my joy. The news of risk not sobering, just agitating. It was overwhelming information. I did not know what to do with it. If I wasn't so excited with having my first child, would I have listened to that counselor and aborted? I did not have the amniocentesis. Sheer excitement and determination was the force behind the birth of Adam.

Doctors, geneticists and genetic counselors are trying to remain in the neutral ethics zone. Remembering the false neutrality of that counselor, how I was shuffled into a genetics counseling office without given the choice, the warning of what that was going to be all about, I consider that the scales are tipped against this whole movement towards the rights of the disabled, and for that matter, the fetus. It is said that The Human Genome Project will identify over 100,000 genes and diseases without cures over the next ten years. I think it is obvious to state that ethically, we are not ready for this. What do we do with all that information, all that choice? There is difficulty in knowing.

I take these thoughts to daily life with friends. I know a dermatologist, working with people's desire to transcend time, people's vanity. I remember once how she considered to pin back

her son's ears for fear that he might be ridiculed in school. Of course, readers who know me will understand how absurd I feel this procedure is in the context of human difference. Let him have his ears, I say! Let him exult in his uniqueness! Yet, I know she is trying to protect him, as all parents are inclined to do. What cost is her seemingly innocent motive to "protect" her son, to the rest of us who fight furtive discrimination every day? Discrimination is so deeply rooted within us, perhaps within human nature itself, that we must tear down concrete walls with bare hands.

There are many people who put their children on Ritalin because kids simply cannot not perform in school or complete their homework. The Ritalin "is amazing," they all say. "Joe's [made-up name] teachers have said he is doing so well." The teachers are satisfied that little Joe doesn't act out in class anymore, now uniform and compliant, I suspect. "Joe" can now focus on what he has to do, I'm not saying that in itself is a bad thing. Parents are often left with no other recourse. What I am saying is that it's a shame that the "system" won't accept him for who he is. A friend asked me once "what if there was a pill Adam could take..." Ah, that thought was for a moment, tempting. I could escape all my worries if Adam's autism could be cured by a little pill, right? This is an excellent question. What if? Would I stop this rampage about discrimination and eugenics if Adam were, all of a sudden, normal? After all, what would I have left to fight for?

Little pills, escape from any kind of struggle or pain, is all too tempting, I might speculate, for all of us. What kind of absurd world might we have if we were all operating on even-keels, on pills? (I always tend to use Ritalin as an important part of this debate). I think of a Stepford Wives world here. Within the "normal," rigid classroom, a child who acts, or thinks, outside of the box is rejected. I must admit that to undertake the alternative, to stand up against the school system is a difficult and time-consuming undertaking. My friends do not willingly choose the path of such resistance, nor are they in a position where they need to. They are extremely intelligent and hopefully will recognize the importance of this posited argument.

I have a big reason to be concerned. My father was a victim of the [Lebensborn](#) movement in Germany, and if not specifically bred for Nazi parents, he was stolen from a Polish or Scandinavian family and put into a German one in Breslau "for his Arian features." As a

result, he had a difficult relationship with his parents and after coming to Canada in 1952, left his parents at fifteen, the pain of being any part of Nazi Eugenicism a complete repulsion to him at that young age. He tried to convert to Judaism. His daughter brought that realization full circle as he now has a Jewish grandson.

I am considering today how the Eugenics Movement has too much steam in its disguised innocuous research, and ideals that can be traced back to the universal worker of Karl Marx, who sought uniform and idealistic physical traits of workers, for the sake of the nation.

Just how much do we conduct science for the sake of mankind? Or is it the quest to be like the gods? What drives us in these quests? The greater good, or control? If we want a greater good, we always have to take the other, more unpleasant side or progress. We also have to understand that all words may sound the same, but have entirely different meanings.

I am certainly not saying that most people are evil or have evil intent by actively participating in cleaning up the human race. I am not accusing parents who give their children Ritalin or consider pinning back their ears for aesthetic reasons. I am suggesting, however, that the pressure to belong, to fit in this "normal box" is immense. I am also suggesting that wrapping up language and intention in palatable words, ones that seem to be harmless, or disguised for the greater good of humanity, may in fact be just the opposite. Hitler's propaganda promised a better Germany – more jobs, economic stability. You can wrap up intention in all kinds of good words, but it doesn't mean the same thing.

In looking deeper into my social responsibilities, in putting some intention and action behind my beliefs, I have to reconsider the rights of animals, the rights of minorities, the poor. I can't sit back and scratch myself debating this intellectually as I sit comfortably in my chair. I am considering how I can best participate. I am incorporating a Canadian organization which will deal with acceptance. Yet, I consider that as the years progress, this will evolve into an organization to undertake political action. It is unknown territory for me (any words of advice are welcome at this stage). Let me begin with incorporating and organizing the exhibitions and lectures this fall. (help me with the name please – I

like Action for Autism and Project Ability – both out of the UK). I'm not exactly sure where I'm headed. There is difficulty and responsibility in knowing.

[PERMALINK](#) POSTED BY ESTEE KLAR-WOLFOND AT 3/14/2006 09:16:00 AM
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MONDAY, MARCH 13, 2006

To Live is So Startling...

To live is so startling it leaves little time for anything else --Emily Dickinson



We didn't make it to Vail. Life intervened. This time, with a flu bug and a nasty fever. Henry and Max have gone ahead, leaving Adam and I alone this week to get better and perhaps discover the unexpected.

There are a few things going through my mind -- a luxury of unscheduled, impromptu time. I am going to be 41 next week. I have two frames of mind right now about growing older:

1. I'm not really ready (or am I?);
2. Let the wind blow where it may (this thought takes a little effort).

Children punctuate [time](#). Before Adam, I was husband-less and free, for a time. I met Henry with four children and that stopped this nomadic existence -- moving senselessly from here to there. I could forget about obligations when the kids were not with us -- we had them only part-time. I got married and had my first child

at 37. The mind-clock began here. Time is always felt most dramatically in connection with birth and death. On Saturday, I chatted with Henry's 92 year-old grandmother. "Where does the time go?" she asks. Adam will be four in April. Where *does* the time go? It's been two years since he diagnosis. Where did that go? Perhaps it is good to remember that the grim reaper looms not too far off in the distance, that time is a huge train station clock hovering over our heads.



My favorite clock at Musee D'Orsay -- Henry, Joe and Max in the background. 

We can measure it, forget it for a while, melt away within it, distort it, but time will keep on ticking. Time, it's the only thing we really have -- it cocoons my mother who has struggled with two bouts of cancer, carrying her fragile body, for now, with grace. It wisps around my father whose spirit remains timeless, but peppers his blond hair with grey, freckles his Nordic skin a little more each year. It has made its first sinister introduction to Henry in his aching hands, and me, while I don't remain unscathed, untouched by time, I hear it brushing against my door, scurrying busily about the neighbourhood. I watch as it nears my bell -- all too aware that it is coming close. If time is the only thing we really have, let it be full of events, people, places, moments, and joy (we can feel joy only in the presence of its counterpart: pain). I cannot fathom a life without time framing it, without beginning, middle and end. Henry does not like to think of the end and would take the immortality pill if it were ever available. I suppose I need clearer boundaries.

I've been re-reading comments on my blog. I enjoy re-reading well-thought out comments. In my post [The Lonliness, The Struggle and the Profound Joy of Autism](#), *Lisa Fischler* said...

*I highly recommend the book "**The Spirit Catches You and You Fall Down**" which is the story of a young girl with*

epilepsy. The book deals with issues of how we define illness, quality of life, adequate treatment, etc. according to our cultural beliefs and practices. Many cultures don't tolerate disability of any kind, but some consider it to be part of human nature and are able to see what is special and, more to the point, human about those in their midst who are a bit "different".

Maybe it's because we are so obsessed with success that we have a hard time appreciating what is joyful and worthy in any life, even one that is painful. Westerners have an aversion to difficulty and pain, to the point where we can't understand why someone would "want" to suffer - which is odd, considering that suffering was once taken to be noble and spiritually uplifting in Western religious traditions. I personally found a lot of value in a spiritual path that teaches that we don't have to "do" or "be" anything special in order to fulfill our life's work - that just sitting and breathing, or whatever you're doing, is "enough". Being 100% engaged with life, whatever life might look like, is doing life's work. This perspective says that life is worthy when you're imprisoned or oppressed, when you're ill or dying, when you're shunned or beloved or misunderstood.

And it has always struck me as foolish to write someone off as "damaged" when I've personally worked with kids who have defied the odds. I look at Helen Keller, Stephen Hawking, Temple Grandin, and other notable examples of folks with one difference or another who've been able to rise up, and the common thread I see is that these are people who fully engage with life and somewhere along the way had people believe in them at a critical time in their development. As long as our kids have that, who knows what could happen. Not that our kids need to be physicists or PhDs - they already are who they are. Just like the rest of us.

Considering my thoughts about another looming birthday, about the journey so far with Adam, and how I see he is growing before my eyes more quickly than I could have ever imagined, I have to let Lisa's comment envelop me. I have to remember that my life, my time, is not defined by how hard I work and what I seek to achieve, but by simply being. Success and achievement serve one final function -- to remain immortal. Gilgamesh (see [Epic of Gilgamesh](#)) worked so hard to achieve immortality and it fashions the way we live today. It drives business people, authors and

artists to make art, write books, build buildings with their names on them. It is a difficult construction, this immortality business, this quest for Holy Grails, for Utopias, for Ideals. It provides steam under Eugenicist movements, while at the same time, inspiration that we all have something to offer in this world. Inspiration, Aspiration, Hope and Being also have their counterparts. It is up to us what we decide to build with our blocks of time.

I wonder if I can die content with the fact that I'll just be dust in the wind -- immortal only as long as Adam lives and remembers me. He is, however, my life's work. Time will certainly get me, but my legacy will live on, if only in him.

[PERMALINK](#) POSTED BY ESTEE KLAR-WOLFOND AT 3/13/2006 09:28:00 AM 4
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FRIDAY, MARCH 10, 2006

Bikini in my Baggage

I am frantic, so why the hell am I sitting here and blogging today? In a few minutes I will return upstairs in the midst of sweaters and toys that will fly around the room as I pack for Vail. I will confirm the many reservations I have made to accommodate Adam and our family.

Blogging is a nice escape from the inevitable hectic journey ahead. I have closed my door and am drinking a nice LARGE cup of coffee. I really hate packing. I hate unpacking even more. I hate planning how many pairs of socks and underwear I will need. I labour over which outfit I need for the evening – what if I don't feel like wearing the one I chose come Tuesday night? How I yearn for those days when I could just pack a little bikini and head onto the plane – without making any plans. Okay, fine. I've never walked on a plane with just a bikini in my bag, but oh how I long to. Imagine if I can just walk into the middle of some strange place and let experience become me -- to let it unravel me, shape me, and become part of my memory forever. I came close many times. Living in Europe, when I had little money, it seemed I could breath in everything more fully, walk for hours, meet new people, taste the food sold on the street – flavours, locations, the people who with whom I ate -- still a colourful memory today.

I took reprieve in cathedrals on cold walking days, reading the story of stained glass windows, meditating and keeping warm amidst the low rumble and shuffle of visitors. I ate bratwurst with sauerkraut in the *Markt* between classes, watching German folk buy their fruits and vegetables at a price that choked me back then. I've walked the cobblestones of Strasbourg, close to where I studied and the fanciful boulevards of Paris from the outside looking in. I loitered along the solitary paths of the Black Forest Mountains after a snowfall, nary a cow or person in sight the higher up I went. I've traversed to carpet vendors in Turkey, and sipped Turkish coffee in stalls on hot summer days, stopping to listen to Muslim chanting over speakerphones, golden turrets above my head. I've visited *David* in Florence, and walked in the footpaths of great men. I've waltzed to grand Vienna and visited the singing hills of Salzburg, feeling Mozart not too far behind. I've entered the universities, the music schools to hear other student's aspirations climbing *do re me* in cavernous halls, history listening. I remember the full taste of Schaumwein (Strawberry Wine), a three *Deutsche Mark* luxury to the pops and cracks of New Year's Eve in Freiburg and recall the vision of gypsy huts behind treeless and grassless apartment buildings in the Slovak Republic, the decorative embroidery of table clothes and doilies trying to brighten the history of their Marxist oppressors. I've hitched rides to see jungles and monkeys on remote parts of islands – visited only by die-hard surfers searching for bigger waves. I've soaked in sunshine with the smell of warm beer and roasting chickens on the west side of the Atlantic, where African winds blew gentle kisses across my cheek.

I long to see the colourful markets of India punctuating the duller shades of a spent land. I hear the voices of Ethiopia call me to see with my own eyes, the suffering. I wait to visit Israel this May, to take a dip into Middle Eastern sand. Without walks, without journeys, without time, without freedom, we cannot discover. I've been on the outside looking in, and now with age and a little more money, been on the inside looking out. It is these poorer times that remain the most endearing and memorable, as well as the times when spontaneity had little use for money. The rich man's vacation is sometimes very poor by comparison.

The family vacation: Hmm...structured, another home-away-from-home. Yes, Adam will indeed benefit from a new experience, and yes, he will likely enjoy all this novelty, and yes, it will be a lot

easier to have everything around me, easily accessible. Daycares, swimming pools, shops, movie theatres. The first-world has become a series of Disney locations – one-size-fits-all, with the conveniences of home.

There is something to be said, and welcomed in convenience, in being prepared. I will think about transitioning Adam onto the plane, making books for him to visualize the experience. I have yet to pack the DVD's the books, the food, the toys, the crayons, the hats, mitts, ski pants...and of course there are my books and computer because I don't ski anymore (knee injury). I'll work out, go cross-country skiing and snowshoeing. One does need a lot of STUFF for a March Break ski trip.

Adam will wear skis for the first time on Monday. I've enrolled him in the Adaptive Ski Program. In the afternoon, we will mush with the dogs on our first dogsledding escapade. Of course, I do not know, nor can really predict how Adam will take to all of this. I suspect he will cry when ski boots are placed upon his feet – he won't understand why they will move, or barely, like lead. He will hate wearing the helmet and will scream (he hates putting anything on his head or near his ears). I will hold it on and say "you have to wear this," sweetly, lovingly, as I break out in a sweat, hoping for him to calm himself. I will watch him crying, becoming scarred going down the hill, the lovely people helping him – they will be dear, I suspect. Adam will get the hang of it, he will enjoy the movement, the feeling of gravity moving down the hill. The movements will be repeated and he will become a little more at ease every time.

To further prepare, I will take him to the ski shop tomorrow. We'll try on boots, look at skis and then talk about it some more at home with pictures. While this may make the equipment look a little familiar, it will be the experience that will make the lasting impressions.

I remember my first trip away from home with my parents. I was as old as Adam is now. It was to Ottawa. The trip was made by car, and to me it felt like a very significant journey, with stops and a night over in Kingston. When we reached our destination, we visited the Parliament Buildings. I still have a picture of myself, standing against my father at the Eternal Flame, in my little green dress with a newly bought pair of sunglasses to match and fancy

white shoes. I marveled at those sunglasses, those rose-coloured lenses, and consider the memories that Adam will cherish forever from this trip, suitcases, DVD, Pringles and all. I will be looking through Adam's lense and savour the unexpected joys of being his mom. I may still bring the bikini (there is a swimming pool), even if it comes with the rest of the baggage.

[PERMALINK](#) POSTED BY ESTEE KLAR-WOLFOND AT 3/10/2006 12:32:00 PM 0
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THURSDAY, MARCH 09, 2006

There Are No Prodigies in Art

There are no prodigies in art -- Pablo Picasso

There is no art without the artist. For Jonathan Lerman [**see gallery statement and video footage in my sidebar**], as Lyle Rexer alludes, the self and the compulsion, not the subject or the talent, makes the art. Taking this view, as Picasso did -- "art came through the accumulation of experience, which kneads the unconscious and constantly reshapes it, thus making the prodigy self-less, the victim of whatever subject seizes him, victim of his own aptitude" -- gives Jonathan's savant label a different meaning. If we take the view that art is part of him and his universe, the method by which he has come to express himself, then Jonathan is really, different *and at the same time*, like the rest of us.

I took a trip to Vestal, New York this morning to meet with Jonathan's parents and to look at more work by him. I brought back with me some of the colour charcoal drawings this time, some completed when he was as young as twelve years of age (he is now eighteen). For Jonathan, charcoal is a native tongue. It is more acute for me after I viewed his oil paintings -- a lot more contrived (apparently he has an art teacher now, so this may be part of the reason). His sculptures are interesting and look like folk art. Yet his drawings sing. For a young man who has great difficulty communicating verbally, his line is lucid, sparse at times, but speak volumes. It is a sophisticated language, this, as verbal language is hard pressed to describe multiple states in a single word.

In some of his later pieces, I am struck by the numerous faces [not pictured here] that surround some of Jonathan's favourite rock

musicians, or renderings of rock personae unknown. Caren, his mother, states that she suspects Jonathan is suffering from temporal lobe seizures which may be resulting in some aggressive behaviour, and visual hallucinations. Caren notes that he sees different faces, sticking out tongues, heads floating in air. Jonathan "wants them [the hallucinations] to go away," she says, and looks forward to the day when someone can help him.

It is apparent to me, that these drawings are Jonathan's world -- a definition of himself within it, and affirmation of "I" in the universe, as well as a continuing investigation of it -- as he sees it and as it comes to him. Alan, Jonathan's dad, said to me today that he is interested in doing "something real," meaning, Alan thinks, that he wants to continue to do portraiture.

Jonathan is also interested in religion, and often asks other people "if they are Jewish," says Alan. He is also aware of ethnic origin and draws people of different races and makes up endearing names for his made-up characters.



The Jewish Shaw



Untitled, Jonathan Lerman



Untitled, Jonathan Lerman 

I will continue this investigation of art and autism, talent and savantism as I continue to head towards the "really big show" in October. Indeed, the tendency to classify all persons within and without of autism, seems to be the tether we can't do without.

[PERMALINK](#) POSTED BY ESTEE KLAR-WOLFOND AT 3/09/2006 03:37:00 PM 3
[COMMENTS](#) [LINKS TO THIS POST](#)

TUESDAY, MARCH 07, 2006

The Hotbed of Discrimination, Acceptance and Advocacy

Recently, I've seen two wonderful bloggers go "off the air." [This Mom](#) and [29 Marbles](#) have decided to take a reprieve from the consuming blogging universe. I am saddened by their departures, and consider the hotbed of issues being discussed can leave us all feeling dizzy.

Parents are trying to understand and raise their autistic children. When children are initially diagnosed, our first entry point is to a world of medical professionals trained in describing abnormalities, illness, deviations from the "norm." Other immediate entry points are the Internet and high-profile organizations raising money for autism research. I would imagine that it takes an extremely strong individual, or an experienced one, one who has been in a family with disability, to shove the apocalyptic voices aside. For most of us, it is a journey of understanding autism and coming to understand *our children with autism*.

For me, I quickly felt uncomfortable with professionals viewing my

only child as a pathology. I guess love did this, and that's a good thing. Acceptance is the next word that comes to mind, but the journey to acceptance, for me, is still an arduous one – the pull of therapies, professionals versus listening to myself, then, the strong voices of the autistic community often condemning parents as abusers. These are really harsh voices, and I'll be frank here – I do agree that there are therapies and parents that are harming their children – chelation, viewing autistic children as a set of bad behaviours, pathologies – it does take away the humanity of the autistic person. It is prejudice. Yet, there are parents still searching, trying to help their children function in the world without frustration, and those parents need supporting.

After acceptance comes a search into the history of disability, racism and human rights, the construction of normalcy, and the social construct of autism. These are weighty issues and my background is in fine art and literature, not philosophy, although I have an interest in it. As a parent, and a lover of knowledge, I am trying to go back to some of these roots in order to figure out where my belief systems come from.

I use myself as an example in [yesterdays post](#) regarding racism – a quick, seemingly innocuous, tapping of the keyboard that put two words together that are interpreted in a certain way, and I am reminded that semantics and words are indeed important. May we all learn from our mistakes, may those that cast the first stone not make the same mistake, harbour any furtive thoughts, or be self-righteous (“The greatest of all sins is [self-righteousness](#)”). I use myself as an example not to state that I am a racist – hardly – but rather, how stereotypes are firmly entrenched in our minds. This is a story about how our minds interpret the world.

On [Philosophy.com](#), Jonathan Miller author of *Beyond the Fringe* states, “The job of philosophy is not to find out the meaning of life, or our relationship to the larger metaphysical principles of the universe; it is finding our relationship of the mind to the world. How the world is represented in the mind; how do we come to have knowledge; what do we mean by certainty. These are the only things about which you can ask questions. I am interested in problems for which you can foresee a solution; questions to which there is possibly an answer.”

As I consider this, I still have yet to find that light at the end of the

tunnel. By slipping up, I have to look back at history to understand where I am coming from, all the walls I have to still tear down as I figure out how to best parent my son, how to dialogue in this hotbed of emotions from parents and autistic people.

In [Intellectual Conservative Politics and Philosophy](#), Wendy McElroy titles her article, “*Disability Must Be Defined Before Debated.*” It’s a good article about attitudes towards the spectrum of disabilities and I am reminded of the contention between various levels of functioning between autistic people. The story in essence, starts with Janeal Lee, Ms. Wheelchair Wisconsin who outraged others with muscular dystrophy because she could actually stand for ten or fifteen minutes on a good day. Judy Hoit, the treasurer of the organization stated, “you’ve got women who are in their wheelchairs all the time and they get offended if they see someone standing up.” This article is an example of people seeing themselves “as an oppressed minority, turning disability into a cultural and political identity...Thus, the now-deceased Christopher Reeve was severely criticized by some disabled advocates because he actively sought to ‘cure’ his paralysis rather than accept his disability.”

The article questions “what is disability?” and how we should react to it:

“Because my grandmother had German measles during her pregnancy, my mother was born with a malformed arm that ended in a claw-like appendage where most people have an elbow. At first, I didn’t know my mother was handicapped. She was just my mother: an attractive, smart woman who ultimately supported two young children after being widowed. It was the **attitudes of other people** [emphasis mine] that made me aware of her disability. Not that people expressed hostility or disgust; they were usually awkward, too helpful or furtive in their glances.”

McElroy summarizes: “By my definition, disability is a sliding scale. How people react to ‘the disabled’ hinges on where that person falls on the scale. An extreme disability often makes people uncomfortable because it connects to their own fears of infirmity.”

[Ayn Rand](#) states that the solution to racism is Individualism:
“`Rationality is man’s basic virtue, and his three fundamental values are: reason, purpose, self-esteem. Man – every man – is an

end to himself, not a means to the ends of others; he must live for his own sake, neither sacrificing himself to others nor sacrificing others to himself; he must work for his rational self-interest, with the achievement of his own happiness as the highest moral purpose of his life.' In this view, Objectivism rejects any form of altruism – the claim that morality consists in living for others or for society."

It is here I have a difficulty in seeing myself as an "autism awareness advocate," and understand the wisdom of *29 Marbles* and *This Mom* for taking reprieve, in Brett's case "trying to figure out what raising awareness means." We all want to help -- philanthropy a kind-of business. By helping, do we assist our own conscience, or others need? The whole concept of religion is now at stake here, and I am thinking of [Nietzsche](#)'s anti-religious view – seeing altruism as a kind of farce, rooted in monotheistic religion. "As an esoteric moralist, Nietzsche aims at freeing higher human beings from their false consciousness about morality (their false belief that this morality is good for them), not at a transformation of society at large."

You see, it's an interesting exercise to determine where belief systems lie, to consider that none of us have any unique thoughts, and how altruism can be interpreted by those we are seeking to help and support.

I still like President Clinton's summation which, for me today, is an easy way out of this labrynth: we are just "people helping people." I know I am trying to raise my son in a positive environment and accept him for who he is. I understand that I am a product of morals and ethics and build my actions on them, while studying the architecture of ideas. It is all I understand, for now, and the point from which this journey inititated.

LINK:

[History of Racism](#)

[PERMALINK](#) POSTED BY ESTEE KLAR-WOLFOND AT 3/07/2006 08:36:00 PM
[13 COMMENTS](#) [LINKS TO THIS POST](#)

[The Crusty Label](#)

I seem to have offended someone using the “[crusty Asian woman](#)” phrase in my post about Adam’s haircut. I appreciate the person, although remaining anonymous, for speaking out. My intent was not meant to be racist at all, although the person raises an interesting point about labels.

Here I am talking about being careful about semantics, and whack, I used the word “[Asian](#).” Now, I see that word as descriptive, for writing purposes – a set of physical attributes summed up in one word. If that person was German or Swedish (except that “they” are not visible minorities, I acknowledge) or whatever, I would have found a word to sum up a look in order to give this picture. I often describe people in terms of Black (a really general term considering the scope of the world where people are from), German, Jewish, British, Russian, Phillipino, Canadian, American, European. I try not to overgeneralize. Perhaps this is what makes any phrase slanted with racism. A label certainly doesn’t describe a person. It only describes a set of features and physical traits. Instead of a sweeping brush stroke to provide a picture, I instead put a black line through an entire race of people?

Of course my intent was not meant to be racist, except that in fact, I did offend someone, so I suppose for that reason alone, it can be considered racist. For that, I am sorry. It’s a good question, actually (feel free to answer it) -- what is racist in the scope of writing, in being descriptive? (I think I’ve in part answered it). If someone who is not Jewish speaks about the Jewish people, it often comes across all wrong, perhaps even if the person didn’t intend it as such. Just prefacing a sentence “I met this Jewish guy,” is like a loaded gun -- I find my hair standing on end, waiting for the next phrase, racist or not. Having converted into a Jewish family, my radar is a little more sensitive than it used to be, so I actually should have been more aware of this type of referencing. Yet, looking at the argument from the side of receiving supports for autism, what have we all come to that we can’t describe and state difference, and if we do, it appears to be discriminatory? How defensive are we that we must equate equality with homogeneity - - to whitewash description and difference entirely?

In my case, I do not intentionally use race to describe the *human being*. Except in my description, I placed together race and a description of the person “crusty” or abrasive, together. Any person of any race can indeed be unpleasant. Character traits

transcend race indeed. It also takes many encounters with a person, many paragraphs and descriptions to figure out if someone is a racist. Adolf Hitler's *Mein Kampf* is clearly a collection of rabid racism.

When I describe a person in my writing, I try to paint a picture of the character, hopefully in all their richness. If that character has unpleasant flaws does it make the writer a racist -- the collection and context of words is important here. Perhaps the description in my last post was simply too brisk of a sweep. If I describe a person autistic as a "bitch," (Autistic Bitch from Hell dubs herself, not me... and I think she is brilliant) does that make me bias against people with autism? Many parents can't take Michelle Dawson (I like her for what she is doing and the voice she has risen, I will state for the record, even if she might very likely find many flaws in me) – does that make them prejudice? It strikes me that if we are going to talk on an even playing field here, then we all have to *presume ourselves equal*, with difference -- an oxymoron indeed. To debate with Michelle Dawson *presumes her competence* to fight for her beliefs. In my case, when I call a person "crusty," it is because they damn well are, white or black or Jewish or Asian.

To me, this is what we are fighting for – perchance to transcend labels or to use them without prejudice, to acknowledge the beauty and the challenge of difference, and the freedom to say that someone stinks when they just, well, er... are. This is the heterogeneity of humanity. Let us be careful, however, how our words are interpreted and how we sweep our brush.

It's a difficult issue -- to equate a person with a crusty old label, still as thick as rye, yet to crumble.

[PERMALINK](#) POSTED BY ESTEE KLAR-WOLFOND AT 3/07/2006 03:17:00 PM
[21 COMMENTS](#) [LINKS TO THIS POST](#)

MONDAY, MARCH 06, 2006

Inspiration from President Clinton

***There is no happiness where there is no wisdom;
No wisdom but in submission to the gods.
Big words are always punished,
And proud men in old age learn to be wise.***

--Sophocles (*Antigone*, closing lines)

I went to see former President Bill Clinton speak at the *Friends of Simon Wiesenthal Center for Holocaust Studies* event last night. Clinton's long fingers typically rolled into that gestural fist with the thumb pointing out instead of his index finger to make a point. He is softer now, perhaps weakened by his surgery, a Dalai Lama of politics, if there can ever be one -- I think of Ghandi when I write this. He is soft and gracious when he speaks, his head often down thinking of every word. He is the epitome of a life-well-lived in my view -- of mistakes, of experience, of knowledge and smarts, boiling down to his essence...gracious and wise. I think he is a brilliant man.

You can see I had front row seats (ha!). In fact, the event was sold out and we got these seats at the last moment:



Here is my not so great photo of Clinton.

I couldn't have cared less. Just being in the same room with him was a thrilling honour. President Clinton spoke about how interconnected our world is becoming, but in that interconnectedness, we have more discord than ever before. Perhaps we get too close to one another, in all our differences, and then we have to deal with it instead of building the walls that formerly kept us apart. This is the price of interconnectedness: from Palestine's new government Hamas to Israel's front door, from people with varied religions living together, to neurodiverse and disabled people living with abled ones, we've got difference smack dab in our face. We live in an incredibly privileged economy and we have to deal with and be responsible to those living on less than two dollars a day. We have to be cognizant of what we are doing to our environment and become more responsible about that. In a privileged society, we ought to think less of ourselves and what we can do for others.



This one is for Camille who wanted to see my suit. 

There is no difference in my mind between these issues and those of human rights for the disabled. Across the board, there is predjudice and fanaticism that endangers all of us. He noted that those areas that support America today are Ache Province where the Tsunami hit, and Gujarat, India where the earthquake struck because Canadians, Americans helped people -- "people helping people," as he put it. Once we cross bridges and meet each other, it is always incredible how we are alike. Respecting differences -- from race, religion, culture, and ability can only enrich us all. Building walls can only lead to fear and hate.

If we truly live in a democratic society, then we have to continue to speak out against organizations that are seeking to do that which is against the wishes of the autistic community. We have to keep talking and talking, and wait for the gap when someone might just be listening -- or else we will never be heard. This is the inspiration I glean from a great President.

[PERMALINK](#) POSTED BY ESTEE KLAR-WOLFOND AT 3/06/2006 09:52:00 AM
[10 COMMENTS](#) [LINKS TO THIS POST](#)

SATURDAY, MARCH 04, 2006

To Say or Not To Say..."Autism"

Henry has been away since Thursday and I gave the nanny the weekend off. It's just been Adam and I. I like these times although they keep me busy – morning to evening uninterrupted by "intervention." This morning I took Adam to get his haircut at *Melonheads*.

We arrive early in the morning, vanilla soy latte and breakfast

cookie with blueberries in-hand. Typically, I would just grab the latest book that caught Adam's eye and let him flip through it as I placed him in a Thomas-The-Train seat. Usually, he would just flip happily through the book, letting Sherry, his regular hair-cutter, talk to him sweetly, cutting his hair gently and quickly. We discover that Sherry has unfortunately left *Melonheads* to pursue greener pastures. After I place Adam in the train seat, he wants nothing to do with *Curious George – a book of Opposites*. He is much more interested in the streams of other children coming in, the bins of toy cars ready for his plucking. It is a busy morning and instead of the usual attention, Adam waits a fairly long time until a crusty Asian woman with long scissors just starts going at Adam's hair from behind. No introduction – no sweetness that one would expect of a children's hair-cutting salon. Needless to say Adam leaps into my arms screaming bloody murder. Other parents stare and in a flash AUTISM is about to roll off my tongue ...but I manage to hold my breath.

"It's okay," I whisper calmly in Adam's ear while he holds on to me tightly, trying to get out of the train, scissors still swiping off uneven clumps of hair. "You're just getting your hair cut. You will be okay."

What would AUTISM have meant to this gruff woman who didn't seem to care except to get her next customer and tip? Besides, wouldn't any child have reacted to a stranger putting them in a headlock with a razor next to their ear? Even if I'd said that he gets "scared easily," or is "sensitive," would she have cared?

Adam manages to seat himself back in the chair, even though he continues to cry. In about five minutes, the ordeal is over and we grab a lemon lollipop from a clear bin by the cash.

I think all morning of when, how, and if to use the word autism at all – when it might stigmatize, marginalize, and remain meaningless except to possibly suggest that Adam is "not normal" -- something I do not wish to convey. I even struggle to use it now with persons in the know, who may be able to help him -- not because I am ashamed of the word or that Adam is autistic, but because it doesn't mean the same thing to every person, and every person with autism is not the same.

As this thought agitates me, Adam carefully works on the same

lollipop I gave him at the salon for about thirty minutes as we drive to pick up shoes to match the new Strenesse suit I will wear when I shake President Clinton's hand tomorrow night (my birthday is on the horizon so a new suit seemed in order). I shuffle him to music class, the French boutique an irresistible reprieve.

Music class is a challenge today. We arrive a little early from the efficacious shopping spree and Adam has a chance to move around while eating pizza Goldfish and drinking water. At the beginning of the class, Adam is visibly distraught. He is resisting control these days and doesn't like being pulled into circle by the music teacher. I decide this week to give him more choices over personal things like food, since he is also being toilet trained and has a couple of new therapists in his life. I figure he needs to also feel in control of his Personhood as I reflect on the week's "No, No, No, NO's!" that have bellowed out of him. Ah, I am grateful for those. I waited a long time for them. Nonetheless, I am a little beat from power struggles and decide that he needs my empathy and support. I step in, acting as Adam's shadow. He has missed a few classes – a trip to Florida, sick with the croup the weekend before that. We missed instrument and boat-making, so in fact, we have missed a lot -- without my support today, and he is like a boat without a mast.

Today we sail on a pretend ship, looking at pretend things on the pretend ocean. Adam enjoys the pretend waves as we rock to and fro. This "pretending" is tough, needless to say, but by the end of the class, between some successes – of moving and imitating and listening attentively to various sounds – Adam ends the session with a smile.

Pretend. Ugh. How does one explain to another who doesn't understand autism that it's hard for *him* to understand what he cannot *see*? What's the point? It's just a weekend music class – we'll practice at home. There are parts of the class that he truly enjoys and I don't want him to miss out on that.

When Adam was first diagnosed, I was urged by another mother of an autistic adolescent to get a Disabled Parking Permit. She said she used hers all the time. I couldn't do it. Adam is not physically disabled. He did not have meltdowns at the mall. Although I am entitled to get one, and was tempted by the ability to park anywhere I wanted, I didn't want that on my conscience – there

are people who physically need to use that spot.

Autism still means so many different things to different people. I sometimes have trouble using the word now because it doesn't have any ONE true meaning for most people. Just like Adam's pretend ocean –it is difficult to understand what you cannot see. Adam doesn't really look any different, although he may sometimes act a little differently, and even that is difficult to discriminate. [PreRainman Autism](#) talks about things like this all the time, before the "age of autism," before the time when everything has to be symptomatic of something.

I have been considering this week that the autistic community just might change the face of the disability rights altogether – for the better. There is a unique opportunity here for the vocal, articulate people with autism to communicate autistic experience in a society that barely tolerates difference. Then again, I wonder if we just might come full circle.

[PERMALINK](#) POSTED BY ESTEE KLAR-WOLFOND AT 3/04/2006 11:09:00 PM
[17 COMMENTS](#) [LINKS TO THIS POST](#)

FRIDAY, MARCH 03, 2006

Collection of Moments

I sat on the edge of my hospital bed, a small box of Kellogg's Corn Flakes and a tiny carton of milk for my effort – giving birth in eight hours, passing a kidney stone for four days before that. Adam was asleep in his clear plastic crib, swaddled tightly in blue hospital flannel. This is a moment I will never forget – how the air shifted, time punctuated.

Life is a collection of moments, memory the lingering perfume.

I am a collector of moments:

Adam rubbing his bare tummy against mine
Adam nursing and staring into my eyes
Adam weaned at 3 1/2 years and how I could have continued
Adam's gleaming smile
Adam's starry eyes
Adam running to me while I work, giving me gentle kisses on my

cheek

Adam running to me and saying "here I come!"

Adam crawling under the covers, utterly relaxed

The way Adam looks straight into my eyes like he's saying *I get you, I love you.*

Watching Adam interact with others

Watching Adam from afar, becoming more adept at everything

Watching Adam is like watching TIME with a pierced heart.

If this is autism, then it most certainly is God's correction of "normal."

[PERMALINK](#) POSTED BY ESTEE KLAR-WOLFOND AT 3/03/2006 03:25:00 PM 2
[COMMENTS](#) [LINKS TO THIS POST](#)

THURSDAY, MARCH 02, 2006

A Sledgehammer or a Song?

I've never hidden my views. I've also proclaimed that I do not know everything there is to know about autism and constantly turn to those people with it on how to teach, on perspective and so forth. I am not here to pontificate. I am here to learn and discover. Through the process I hope I can also become an "ally," as [Amanda](#) commented on [Kevin's](#) blog. I hope I can challenge other people as well, but often the best way to reach the inflexible mind is slowly, with history, with familiarity, with true stories by those who are autistic -- perhaps my preference is through literature, art and the like. In my view, we need sledgehammer's and we need songs -- I think I'm the latter. Whatever our style, we have to "speak" in a language that suits us best. While it is utterly IMPORTANT to speak up and show the inhumanities against autistic people, there are some people who can't be reached. This is the tragedy. This is why the dialogue can never cease no matter how much it sometimes beats us down.

I've been hinting of the history of [eugenics](#) in America. I'm actually quite surprised how few people picked up on that or didn't know what to say about it, or are fearful of "going there." I try and take a stand that shows rather than pontificates. If I say I believe something, another parent will accuse me of "speaking for" the autistic. I repeat: I am learning. The purpose of blogging for me is

to share my own little journey in this.

I am speaking to Amanda's comment as I mentioned, in Kevin's blog. She is strong in her response and for that reason, it speaks to me. She states:

"Basically, the autistic people most likely to be harmed by various "therapies" and "philosophies of autism," are not likely to be helped by the "let's respect the opinions of those who are doing this to me" thing. By all means respect people as people, but opinions are something different, and some opinions, some actions (and actions start with opinions), are just not excusable...Frankly when I see people talking about how all parents of autistic kids should have this kind of solidarity, it frightens me. It frightens me because I have seen the results of both parental hatred and parental well-meaning bad things directed towards autistic people, and this is so rarely acknowledged, that good intentions aren't good enough and that some parents do not love their children and that some parents who do love their children still horribly mistreat them....Isn't it possible to both be an example of acceptance and celebration, and at the same time say "No, some things just are not okay?" Isn't it possible to be both loving and take a stand? When people believe that peace is the absence of apparent conflict (while meanwhile the conflict all continues under the surface and harms and kills people and so forth) bad things happen. And most autistic people can't escape those bad things without allies, and where are the allies if they're all going into "sweep it under the carpet mode," if nobody's willing to confront anyone because it wouldn't be polite or validating or parent-solidarity or whatever?"

Amanda, I am so glad you wrote that. I can't say it like you say it. It wouldn't be the same, in fact, coming from me. I don't speak for you, but I can listen, advocate, ally. I can present the work of autistic people in special events, art exhibitions and I feel I need to. I must admit that it is unnerving as a parent who wants the best for her son, to undergo such "confrontation" as you put it -- when one would think that all parents would want the same. Yet, even those sentiments, as you said, do not address the injustices against the autistic population. I can say I want "the best" for my son, and in fact, do what's best for me. This is the semantic issue. It is consistent with Ebohlman's comment, also on Kevin's post:

"`Sincere,' does not mean `correct.' The most passionately and deeply held beliefs are those of bigots, zealots, and fanatics, the people who have the *least* hold on the truth. Believing that you're right is not the same as *being* right."

As parents, I think many of us grapple with this all the time. What is the difference between what I want, what I think Adam needs, and what he needs or wants. At this young age, as a custodian of my son, these are difficult decisions for any parent, autistic or not. However, with a child with autism, the issue is more serious. There are too many pulls for insidious therapies, too many organizations that appear to befriend the "struggle" and appeal to parents on this basis that totally ignore the discrimination issues and the voices of those with autism.

So people like you need to keep speaking up for yourselves and people like me need to make way. The truth of the matter is you've just got to keep sending your message to the parents. They are the nucleus of everything for the autistic child -- they are the point at which all views about you in society can possibly be changed.

Kevin, Ebohlman and Amanda -- thank you for your posts, your strong words. They came at a time when I needed them most. I'm going to keep singing.

[PERMALINK](#) POSTED BY ESTEE KLAR-WOLFOND AT 3/02/2006 12:11:00 PM 9
[COMMENTS](#) [LINKS TO THIS POST](#)

WEDNESDAY, MARCH 01, 2006

The Lonliness, The Struggle, and The Profound Joy of Autism

For the past couple of days I've been very sad. Sadness for me often turns into agitation. Agitation a sign that there is change going on from within. Talking about autism is like talking about religion and trying to say one is more "right" than the other. The tone of the dialogue is depressing me these days as I look upon my son's sweet cherub face (it really is, he carries all his weight in his cheeks while his pants keep falling off), as I wake every morning to

watch him open his eyes and smile at me, each day more shiny and new for him as it should be for all of us, and at night when he cradles himself in his bed in the crook of my arm and falls asleep -- a sweetness so joyous and a dialogue so painful, it is making me bawl.

Then, I turn on CBC Radio One and Ellen Schwartz of [Jacob's Ladder](#) is speaking. Ellen happens to be the sister-in-law to one of Adam's therapists, Bianca. Ellen's eight-year-old son Jacob has Canavan's disease and was never expected to live -- he is not expected to live past his tenth birthday. Their lives are challenging at best -- taking 45 minutes to leave the house for any family outing as Jacob requires medications, air tanks, and more. Ellen makes me bawl some more in the car as I am about to view my son's art show at school. I feel ridiculous -- eyes red and puffy, I have to wear my Jackie Kennedy sunglasses and take a time-out to grab a vanilla soy latte to warm myself in Toronto's recent frigid air.

I get back in the car quickly to catch more of her interview. She and her husband have developed a screening program so that carriers of this disease can be informed before they make a choice to have a child. She says, "why would I want to bring a child into the world who I know will suffer and then die?" She acknowledges that the ethical issue is different for all people, but she wants them to have a choice. By the same token, through all of her family's suffering, she acknowledges how Jacob is a gift for her. She talks about how her heart will unexpectedly turn sad as she watches his cousins playing while he is confined to a cot. I erupt again thinking of Adam's ten cousins running around on socializing on Shabbat, his same-aged cousin Annie so swift and talkative -- he just can't keep up with her. While Ellen accepts and loves Jacob with all her heart, she acknowledges the struggle with the disease, the hard life of Jacob, of acceptance and sadness mixed with her profound love.

We all have opinions about what is best for our children. We all have different "religions" so to speak. I am not very tolerant of evangelism -- I must be honest with my bias' -- but I believe that everyone has a right to express themselves, to discover their views, to evolve. This, for me, is what blogging was in part about. It was intended, for me, to be an exploration of views, "lenses to try on" as I stated in my profile, to hopefully develop and grow.

Some people take these debates, points of view, so personally (a hazard of religion as it involves so much emotion), that I have discovered a very dark side of autism. I discovered that parents with autistic children are so divided that the support I was seeking is hard to find. Instead of a journey to discovery, it is starting to look more like a war out there. I want to agree with [Susan's](#) post today that we have to have a gentler approach. I am thinking about "celebrating difference" as I have through the art shows I've done so far, the lectures I've organized, the floating wall of quotes from people with autism that spoke more loudly than the words themselves.

So for me I suppose this is my best "reprieve," other than my own thoughts and words -- there is still no friend who truly understands, no fellow parent of an autistic child who doesn't have an alternate "politik." I struggle to find that middle ground -- that ground where parents can feel safe to state their struggle, to express their opinions, to be allowed to take care of themselves (I've gained about ten extra pounds of "armour" since Adam's diagnosis but am now allowing myself some time to work it off), to even be accepted by the autistic community for this evolutionary process. To be accepted as equals, sometimes we have to express empathy for others. I am left wondering if this is an ideal, if this type of repartee can be achieved.

In looking to history, we can learn about ourselves by understanding what is at the root of our beliefs. It deconstructs them, and I think that is a very healthy undertaking. When we think we believe something, we quickly learn that the belief does not really belong to us. We are not the authors of our own destinies, really. We are not free-thinkers, truthfully. We inherit so many ways of thinking -- we can not claim our thoughts as our own. When we take a look at our own beliefs in this way, I think we can grow more tolerance for each other.

Adam's OT reads my blog. She was mentioning how sensitive even "celebrating" autism is for some families -- she knows of an autistic girl who poked her eyes so many times that she has now blinded herself. For some families, she reminds me in my quest for acceptance and *celebration of difference*, this "enlightenment," this belief, is pretty difficult to muster. I am not sure how to address this, and by no means do I want to undermine the struggle of some families out there. It is not my right to shove "celebrate"

in front of their faces when they just do not feel like celebrating.

Ellen's dialogue today reminded me of something I've said to myself before: **joy does not come without struggle, it doesn't come for free.** I've found joy only through my journey with Adam. I too thank God for him every day. He has brought so much purpose to my life, and I am grateful for all that I am learning because of him. My joy and my sadness are always intertwined which is why Ellen's interview struck a chord with me today. In the struggle to find the black and the white, I find nothing. In the acknowledgement of the rainbow, there lives everything. As I cry a little more, the sun comes out. It is frigid out there, but at least the light brightens my outlook.

[PERMALINK](#) POSTED BY ESTEE KLAR-WOLFOND AT 3/01/2006 11:32:00 AM
[12 COMMENTS](#) [LINKS TO THIS POST](#)

TUESDAY, FEBRUARY 28, 2006

Master of Our Own Destinies?

For those of you interested in the History of the American Eugenics Movement, go see this interesting website: [Image Archive of the American Eugenics Movement](#), further to my earlier post: [A Better Breed of American](#)



Captain of my own destiny, keeper of my dreams. 

Hard to believe that such a movement would state that my son be sterilized, marginalized, and worse, would not deserve to exist. The movement is all to recent to forget, and perhaps lurks around the corner again.

[Autism Diva](#) wrote a post on mercury today and I wrote a comment on her blog quoting from the site mentioned above: "By mid-19c most scientists believed bad environments caused

degenerate heredity. Benedict Morel's work extended the causes of degeneracy to some legitimate agents -- including poisoning by mercury. Richard Dugdale believed that good environments could transform degenerates into worthy citizens within three generations." The talk of mercury now, and the words from history, send shivers up my spine.

Must there be a "cause" for autism? Is it another attempt to "degenerate" the autistic?

All I can say today is, let us never forget.

[PERMALINK](#) POSTED BY ESTEE KLAR-WOLFOND AT 2/28/2006 12:30:00 PM 3
[COMMENTS](#) [LINKS TO THIS POST](#)

MONDAY, FEBRUARY 27, 2006

This Is What It's All About

I am compelled to share a paper that landed on my computer this morning written by my 16-year old step-son, Max:

Adam's World to Mine

By: Max Wolfond

I was thirteen years old and preparing for my Bar Mitzvah (Jewish ceremony into manhood) at my desk when I heard yelling from the room down the hall. My heart began to pound, as it often does when I hear panic. Moments later I heard my step-mom Estee scream "My water broke!" At an instant my dumbfound face turned immediately to a smile. She was rushed to the hospital by dad and a mere eight hours later, Adam was born. Unlike my clever response at age three when my sister was born, "I knew it was going to be a boy or a girl," when I first saw Adam I was speechless. I had never been so happy to see a baby cry in my entire life. I don't know if I realized it consciously or subconsciously, but at that moment, I knew my life would change forever.

About a year and a half later people began to notice things. Adam was not making eye-contact like most 18-month old babies, nor was he socialable as the other kids in his nursery. It became somewhat of a concern to the family and to Estee

especially. I cam home from school one cold December afternoon to find Estee struggling to hold back tears. She told me that Adam had been diagnosed with autism. At the time I was not exactly sure just what autism was, although I had known somebody at camp who was autistic. I did my best to show sympathy for my dad and Estee by saying I was 'sorry.' So life went on and Estee began to hire therapists to work with Adam. She hired two therapists who worked closely with him, on basic skills such as interaction as well as trying to strengthen his verbal and non-verbal communication skills. At about one, my brother Adam took a keen interest in letters. Soon, he could recite the whole alphabet and identify letters at random. He could also count to twenty.

Adam is now three and two-thirds old and is working with a therapist daily as well as attending Nursery School for half the day. He has a very busy life and no doubt keeps Estee and my dad's lives busy as well. Adam is now able at less than four years of age to read a number of words and write the letters of the alphabet. He is very compassionate and gives a hug to just about every friendly face he sees. Like any kid his age his favourite foods are pizza and chocolate. Something as simple as juggling can make him smile and laugh, and often cause him to burst into song. When he hurts himself (bumps his head or falls), it takes all of thirty seconds to put a smile back on his little face. He is the most loving and happy three-year-old I have met to-date.

I find "Adam's world" to be the most intriguing of anyone in our family or any of my friends. This is not to say I love him any more than the rest of my siblings or my parents, but his interaction with others is more fascinating than most people I have met without autism. The goals of the work Adam is doing with Estee and the therapists have changed since he started. Where as the initial goal of the therapists and our family was to "cure" Adam of autism, it is now quite the opposite. We believe that it is not Adam who needs to be cured, rather, our society who needs to be cured of its phobia of difference. Society needs to learn to accept people for who they are, not who they want them to be. Our new goal is to try to get a better understanding of Adam's way of thinking and how he sees the world, to better the way we can interact with him. I feel people around can learn from Adam and learn other things from other's with autism. A common misconception and assumption people make is that all

people with autism have the same problems and same strengths as one another. In truth just like all human beings, people with autism spectrum disorder are all extremely unique. Techniques we use to help Adam may be different than the ones to help "Sue," but the primary goal remains the same: Acceptance.

On April 11, 2002, the stork dropped off a helluva gift. My baby brother has given me so much love and happiness, and so much to learn. I am certain he will gain abilities that will take him on an endless path of success in his life and I pray people will be able to see past the word often put in front his name: Autism. The uniqueness he possesses will show the world that "they" are not all the same, and are wonderful people too. The initial tears on my step-mother's face the day she got the news have quickly turned to tears of joy. Adam is growing into a sensitive yet strong human being. He is to me a brother, a friend, and a teacher, and I am certain my life could never have been so great without my younger brother Adam.

Could a brother and an old step-mom be any luckier? Can a sixteen-year-old change the world?

[PERMALINK](#) POSTED BY ESTEE KLAR-WOLFOND AT 2/27/2006 01:48:00 PM
[13 COMMENTS](#) [LINKS TO THIS POST](#)

SUNDAY, FEBRUARY 26, 2006

A Better Breed of American

The Sunday New York Times reviews a book that some of you might also be interested in: **Better for All the World: The Secret History of Forced Sterilization and America's Quest for Racial Purity** by Harry Bruinius.

The book reveals how in 1904 biologist Charles Davenport established the Cold Spring Harbour Laboratory on Long Island as a national center for eugenics research and policy planning. Several years later Davenport created a Eugenics Record Office with Harry Laughlin at its head, "sending field workers across the country to identify the 'germ-plasm' of unfit family strains so it could be eradicated... Bruinius deftly plays up the contrast between the eugenicist's obsession with cold measurements of human value and their own messy lives, which were marked by

disease and behaviour that could have qualified them as unfit."

"Cold human measurements of human value," can be attributed all the way back to Gottfried Achenwall in 1749 who created the word *statistik* -- used as a political arithmetic, but that concept was later applied to the body in medical science. Bisset Hawkins defined medical statistics in 1829 as "the application of numbers to illustrate the natural history of health and disease." (Disability Studies Reader). It was the French, Adolphe Quetelet (1796-1847) who applied the most generalized sense of the normal. "He used the "law of error" by astronomers to locate a star by plotting all the sightings and then averaging the errors, [and noticed] it could be equally applied to the distribution of human features." (Disability Studies Reader, Edited by Lennard J. Davis, p.11) "He then took a further step of formulating the concept of *l'homme moyen*, the average man. As we can see, an ideology about a middle class was born from these early concepts.

"In America and elsewhere," *The New York Times Review* states, "enthusiasm for eugenics was broadly supported by elites. In Britain, people as varied as Winston Churchill and George Bernard Shaw embraced its goals, and there was lively debate about how much the state itself should control reproduction on individuals. Eugenic science especially appealed to Fabian socialists, who saw it as further justification for abolishing class -- after all, once the playing field was level the effect of heredity could finally express itself clearly and be studied....

Bruinius sees America's leading role in the eugenics movement as a reflection of its utopianism. 'Seeing their country as a land of innocence, many Americans had long clung to the idea of self-purification, attempting to excise that which posed a danger to the social good...Bruinius describes how Hitler modeled Germany's sterilization policies on California's 1909 sterilization law. While reports of Nazi racial policies provoked a growing outcry among the American public, eugenicists themselves remained enthusiastic, with some traveling to Germany to study its program.'

Some of us may already know that the so-called "mentally ill" and "developmentally disabled" in 33 states underwent the procedure of sterilization.

Perhaps this book and understanding the history of eugenics and the quest for perfection only hovers beneath the frightening surface of the Holocaust and awaits its day to seep out of the cracks of biotechnology and genetic engineering. It lives in marketing pulls for things as seemingly trite as botox, plastic surgery and the quest to stay "perfect" for as long as possible.

It is the American Dream gone way way awry.

[PERMALINK](#) POSTED BY ESTEE KLAR-WOLFOND AT 2/26/2006 09:07:00 AM 3
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SATURDAY, FEBRUARY 25, 2006

The Wind and the War

The migraine has passed and I spend some time reading on the beach print-outs from autistics on rights, Jim Sinclair's good piece "Don't Mourn for Us," the ongoing online debate between Michelle Dawson and Wade Rankin, and my Disability Studies Reader.

Adam runs up and down the beach, watches sea gulls and parasails on this windy day in Miami, happy, but...oblivious to the hundreds of man o war (sp?) that in the last few minutes, have swept up onto the beach. It is the first time I've seen so many man o war but I've heard of what they look like -- these blue balloon-looking creatures. I jump out of my chair and pull him away from the water quickly.

The wind and the war -- may the wind blow away the injustices and wash the war away.

[PERMALINK](#) POSTED BY ESTEE KLAR-WOLFOND AT 2/25/2006 04:03:00 PM 0
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FRIDAY, FEBRUARY 24, 2006

What I've Learned So Far

In my recent quest to ask some lingering questions about autism, I've learned that all parents love their children and the journey with autism is a complex and emotional one.

I think there is a point here for all activists, even to those who are autistic, in fighting for equality. The emotional journey this is for parents is significant and shouldn't be underestimated for the sake of philosophy. Sometimes, the fight becomes more important than the person, and when this happens, we have to reconsider the position from which we argue. I think parents deserve all the kudos in the world for doing everything they can for their kids with autism. As long as we all have an open mind and an open heart, our kids will thrive. Children thrive on love. (disclaimer: sometimes parents do things out of "love" for their kids that are medically dangerous -- I will never agree with parents on that).

In respecting parents, emotions, feelings, (I have my moments), when we have the energy, the arguments for equal rights for the disabled, I believe, are still vital ones in order to obtain the respect and concessions our kids will need. We may debate a great many issues, but let us never judge one another through a blog -- we can never know how people live, in what circumstances, and just as much as we have to respect the rights of people with autism, we have to respect the work of the people who parent them.

I've been debating what to write this past day or so -- what it means to write a blog (a self-gratuitous act, notes for my book, sharing with a community), and have come to the conclusion it is all of that. I may be wrong, I may be right, I may provoke to the point of annoyance, but in sharing all of our words, the point of this, for me, is to learn. And I must say, many of you are helping (read Zilari's response to my request to write on "How and What to Teach" -- thank you so much, Zilari!! (see PartProcessing in sidebar). As a parent, I am no expert on what it feels like to be autistic -- from a social discriminatory sense, from a sensory perspective, but I can be an advocate for my son and continue to try and work for his best interests. I AM, however, an expert in what this feels like for me, and how incredibly insensed I become at anything that smells of discrimination, or alludes that my son is less than human, normal, because he is autistic.

I will continue to have many questions -- I will debate and provoke standards, systems and popular thinking because it is important for ME on MY journey -- I'm very interested in the rights of the disabled, a movement which has only surfaced recently despite an enormous international disabled population.

The next questions I will have when I get home from Florida is the construction of "normalcy," a construct that is as recent as the mid-1800's. Also, I am interested in PreRainManAutism's (see sidebar for link) posts on anthropology and autism, which puts a lot of today's hype into focus.

So for what it's worth, as I suffer from a migraine and consider the burdens I often feel in the face of what may lie ahead for us, despite debates, my heart is with every fellow parent out there.

[PERMALINK](#) POSTED BY ESTEE KLAR-WOLFOND AT 2/24/2006 04:49:00 PM 6
[COMMENTS](#) [LINKS TO THIS POST](#)

THURSDAY, FEBRUARY 23, 2006

Deconstructing A View Continued: Autism as a Gift

Kev of Left Brain/Right Brain made a comment about Sigourney Weaver's "autism is a gift" statement in reference to her newly released movie "Snow Cake" where she plays an autistic woman. Weaver talks about how she came to talk to autistic adults and observed a greater appreciation, in them, for the details of life -- a child-like view and a sense of wonderment as Einstein once stated. While I initially thought of Weaver's comment that "autistic people are gifted" a little naive because it is a generalization, I have to rethink this in terms of the pool of humanity -- each of us having inherent gifts within us.

In our society, which values homogenization -- a mediocratization of humanity and its manifestations, the idea of giftedness is translated into genius. The two are connected, but not the same. I prefer Michael Fitzgerald's definition of genius which states that a person with it must alter the way we view the world. Giftedness can be viewed as having a special ability or talent. In this wider definition, we can view everyone as gifted in one area or another. In short, it is a similar concept to "different intelligences."

Jasmine O'Neill, author of **Through the Eyes of Aliens: A Book About Autistic People**, and herself autistic, seems to also view autism as a gift:

"I believe there are intelligences that cannot be measured. I believe Autism is one of these. Autistic people must be discovered [Donna Williams' version of the "cat" mentioned earlier]. They must be coached to reach their full potential. They are worth much more than being subjected to idiotic therapies, which push them to repeat endless tiny tasks. Use tiny tasks as stepping-stones to mysteries beyond. Autistic people must be allowed to live their lives the way they please. They need to feel happy about themselves and be proud of who they are." (pp 56-57)

In this morning's post of mine *Asking the Questions - Deconstructing a View* that I wrote while packing my bags this morning, I ask the question of what we are teaching to autistic people is right. Is acceptance about transforming autistic people to our way of responding to and acting in the world?

"Their [autistics] gifts are formidable assets. Even autistics who aren't savants have special gifts, which aren't present in non-autistics. Autistic people naturally are better at simply being themselves. They are not magicians. They should never be criticized or called stupid because of the way they live. People who are adept at focusing attention like a laser beam are people who can retain details. The tiniest details they notice escape other people's attention. Minute details are important too. They exist. Plus, they can build up one another to create big details.

Savant gifts are present from birth. They are honed, as the person grows older. A misconception is that only mentally slow autistics can be savants. I am a savant in music, writing poetry, drawing and some electronics. Savants are amazing, fascinating people. They may never be able to live independently. Some of them never grasp the complexities of regular human life enough to be able to drive a car, or look after a bank account by themselves. Yet, they have one or more very superior gifts which they can perform better than other people can. Also, there are those savants who do very well at many things; they have their specific savant abilities, combined with a knack for picking things up rapidly (one sign of the type of intelligence measurable in IQ tests), and they are whizzes at various things. They thirst for knowledge. They are insatiable.

Contrary to what a few teachers still believe, most autistics enjoy learning. There are many examples of this. If an autistic is

interested in learning, but is unable to get others to teach her, she will find a way to teach herself. Sometimes, communication skills aren't developed enough to tell others what she wants to learn about. Other times, too many surrounding people don't have faith in this 'autistic cripple.' If other people are condescending, and have no faith in the special child or adult, he will begin picking that up and have no faith in himself." p.57

In my post called *Sensing the World Into Existence*, I entertained this notion of intuition and exceptional sensing by Adam. The way he hones into my emotions in a split second, the way he inherits them as his own and is so sensitive to people in general -- there are many times I believe that his sense about people is much more acute than mine (and I like to think I'm pretty intuitive). There is just as much, if not more value in this way of living, and like Weaver suggests, and the way Albert Einstein stated, our society no longer values the child-like perspective, the sense of wonder that gets lost in the face of the quest for the material, the quest to be like others, and hence, nothing.

I hope this extensive quote from Jasmine's book further suggests that autism is a gift, and further, how we may be misguided in our approach to teaching our autistic children. If we take this view, perhaps we can create learning environments that nurture inherent strengths and talents instead of focussing on the negative, on remediation (sorry, there's that word again), and on changing autistics to be like us.

(I'm in Florida now and can't yet figure out how to make links for you on this computer...bear with me!)

[PERMALINK](#) POSTED BY ESTEE KLAR-WOLFOND AT 2/23/2006 05:02:00 PM 7
[COMMENTS](#) [LINKS TO THIS POST](#)

Asking The Questions -- Deconstructing A View

In a world that I cannot fully understand how do I know how and what to teach? I've asked the question to [Zilari](#) who wrote a great post "Listening or Not Listening" about what is important to teach autistic children.

My main concern is that we are trying to teach "connections," and

“appropriate responses” to people who see the world upside down, so to speak. I am doing just this – trying to interpret Adam’s perspective and finding the modes of teaching that will nurture his inherent strengths. Because we live in the environment we do, see the way we see, we do not know what else to teach. We set up classrooms in a particular way, we talk to respond to questions, write tests -- it seems that autistic intelligence and perspective is completely different from our own and that perhaps we should not be the ones imposing teaching styles and methods upon our children. So, hopefully our friend Zilari (and the rest of you with autism, I hope), will continue to shed light on this as much as Larry Bissonnette, Sue Rubin, Lucy Blackthorn did in Biklen’s book

Autism and the Myth of the Person Alone.

I also find words of wisdom from [Squaregirl](#), who is autistic and teaches children with autism. Donna Williams who consults online has agreed to attend my festival this October. I have also discovered a great deal about Adam through correspondence with her. In trying to support people with autism, I really seek out their advice. It largely comes out in their writing, as it can be the easiest means in which to communicate.

Donna wrote me that typical teaching styles do not always befit the child. In the case of Adam, he is like a “cat,” she said, and when cats are ready, they will join in. I don’t think that RDI or ABA will be patient enough for cats. RDI claims that the autistic child is “confused” about the environment and we, as parents, have to be their guides. That sure makes sense to me. In this methodology, we are teaching children how to have a relationship with us, assuming that this could never develop on its own, in an autistic way, and perhaps that way is not acceptable to us as parents who long to hear the voice of their child, who crave a hug and affection. But does this show of affection and relationship mean the same thing to an autistic person who doesn’t see anything inherently wrong with the way they see things, but rather, struggle within a world that forces them to be like us, or may show affection in an utterly different fashion? Did Tito’s insistent mother convince him what was “good” for him? Did Stephen Shore, whose mother didn’t have any interventions, fare any worse? Acceptance and what that fully means is a fundamental question as I continue my struggle to understand.

As a parent, it feels wrong to sit and do nothing. There is an autism

culture out there pressing us to give our kids tons of remedies and therapy. Our culture is wrought with pressure to hire an expert, buy a drug, go on a diet...DO SOMETHING to fix things, because the way things are can never be right. There is always some marketer out there who says we can have more, do better. Then, in our kids we see improvements, so it must be right, right? Do we ever consider if "improvement," whatever that means, could happen on its own, with an individual's development of consciousness or SELF? Afterall, where would these kids be without remediation? Out of love for our kids, I too justify my actions – trying to help Adam "connect with the world" (do I presume he doesn't in his own way?), respond, get by in school, keep him safe in an unsafe world. All seem to be worthy goals, and they are done out of sheer love, and fear, for our kids.

Mainstreaming seems to be a goal too – anything that helps our kids "blend in," garner a group of peers so they won't feel alone – this is one aspect of autism that shakes us parents to the bone, and one that kept me in shock the minute my husband uttered the word "autism" on November 28, 2004 at 3:30 in the afternoon. Picturing my son without friends, or with peers that look at him oddly, judgmentally, simply broke my heart.

Today, when I read people with autism, I feel more at ease about autism but now worry that what I am doing still does not honour Adam's way of being fully. The intellectual debate is important because we are at a stage when we do not accept difference and disability entirely.

In a discussion with my husband about words, he stated that the word "remediation" is like "splitting hairs." His eldest son, who went to an all boys academic school, did a math remediation course, he said. So, on the surface it seems harmless. And yes, it may be splitting hairs. But what of "remediation" classes for special needs kids in public schools? Is that the right word? It offends me because it assumes that all special needs kids are cognitively delayed ---that they need to be fixed.

"Too often, individuals with autism are asked to make accommodations, to use 'typical behaviour,' and to learn 'appropriate social skills.' Instead of asking students with autism to make all of the adjustments, teachers and students without identified disabilities can rethink their ideas about concepts such

as ‘typical,’ and ‘appropriate’ and question whether conforming is always the best way to support students with autism. For instance, instead of asking the student with autism to study all of the social norms of attending a basketball game (e.g.; sitting on bleachers, cheering when the home team scores), all students and teachers in the school might expand their notions of what appropriate participation looks like.” (From Paula Kluth **Your'e Gonna Love This Kid: Teaching Kids with Autism in the Inclusive Classroom** p.107).

Taken a step further, if we can accept differences in development, that development does not always occur on the same timeline for everyone, then we might be able to rephrase education as “individual.” Individual Education. It is a term that is used today but not to its fullest potential. Think of all the skills and talent we could develop if we really understood different ways of learning, seeing, understanding? I think there is a lot of possibility in that. For this reason, I turned to a lot of books on different intelligences and gifted learning to discover that most gifted people have a learning disorder. In the face of autism, that makes complete sense. It acknowledges that giftedness is inherent in so many of us, despite other areas of weakness. If we can view all of us as gifted in some way, in a more general sense, then we might be able to honour the person’s individuality, and difference.

To me this is the most important thing we can do as parents to help our children and ourselves in appreciating them. It is reframing our views, thinking about our actions, our words and what [Being, Belonging and Becoming](#) means in this question of what it means to be human.

We are off to Florida to visit Adam’s grandparents now. It is a time when I can stop and watch Adam run sand between his fingers and stand at the foot of the ocean, wondering how this world looks to him without always having to “re-direct” him. There is a kind of freedom in acceptance.

[PERMALINK](#) POSTED BY ESTEE KLAR-WOLFOND AT 2/23/2006 09:09:00 AM 3
[COMMENTS](#) [LINKS TO THIS POST](#)

Stumbling Over Words

I anguish over how to put things. I find that expressing myself often comes out wrong in this heated dialogue about autism. I stumble over my own words, trying to say the politically correct thing, something that sums up a thought just so, a word to describe the formidable nature of autism and acceptance -- and turn to autistics for answers. I seem to never never get it "right," as being who I am is intrinsically wrought with problems from a set of experiences that inhabits the way I see things.

But the words must continue to flow, the effort must never cease.

I am confused as to why, when I say that we need to accept our children the way they are translates to some of you as a parent who idles – does nothing for one's child. In some personal emails directed my way, I am under the impression that my use of that term “acceptance” means I sit back, marvel at Adam flicking his hands in the air and say everything is okay -- that somehow there is simple poetry in that and it should just be. (There is some poetry in it, by the way, but it can get in the way of learning). That baffles me. Accepting the autism does not mean giving up, it does not mean that children of all kinds do not need to learn. It does not mean that everything about autism is wonderful. It simply means I accept the autism in my son as his way of being, for better or worse. As he grows older, he will have a way of showing me the way he sees the world. I accept that he will not be like me. He will have obstacles and he needs my support and society’s acceptance the way he is in order to feel like a validated and contributing member of society, and to feel a part of it.

I am constantly anguishing over teaching styles and do not abandon a style of teaching simply because I hold these principles of accepting the autism. I just do not want anything to harm my child, or to squelch any of his sense of SELF. -- it is a myth that autistics are not intrinsically motivated by many things and must be constantly reinforced artificially. As I said in my previous entry, I simply try to cull from different teaching approaches to find what works for Adam. I have an “antibehaviour behaviourist” (her words, not mine) consultant on my team, who has learned to welcome many styles of teaching. We debate and follow Adam’s lead in what he wants to learn because I see that he has many interests. At this stage, Adam’s perfectionism sometimes prevents

him from trying again, so lots of praise is important for him now. I want to encourage every attempt he makes. He is so intelligent, my little guy. I pains me to think that just because he doesn't want to say hello to someone on cue that his entire mental faculty is judged in an instant.

I am incited by people who want to cure autism. This is clearly against the wishes of those with autism. Strict behavioural approaches also hurt people with autism. It's not that I don't think all behavioural tactics are horrible – we use them everyday with all kinds of children to motivate them from potty training "stickers," to stars on a spelling test.

Whatever language you are using, "remediate," "teach," "help," "help connect" -- many of us are simply trying to help our kids learn within the environment we live, and with the obstacles that are present. At the same time, other people who use those same words "accept" are doing just the opposite in the way they do things. Some people talk the talk, but they definitely don't walk the walk. Meaning is subjective and words can be manipulative.

Accepting autism does not mean that we as parents do not want to help our children function and hopefully enjoy the world in which they live. We simply want to respect the viewpoint, the perspective so that the world will make a place for them, give them a voice, let them make choices for themselves. As I said in my post "[What Is Quality of Life?](#)" empowerment is about choice and it belongs to everyone with any kind of disability. If we do not continue to raise awareness and BELIEVE in autistic intelligence and competency, then society will not provide autistic people with any rights of self empowerment. This is why I think language is important – we always have to think about how the rest of society will decipher it when it comes to creating tolerance and opportunity for our children as they grow into adults.

I know I've started a debate about semantics and how I believe it reflects the way we think and feel and then how we act in society. It seems I too am making a lot of mistakes in my own semantics, and look to the community of autistics for help. Even that word "autistics" I discovered, is the more accepted word, where I thought referring as "people with autism," was more respectful. I am wrong, however. [In Why I Dislike First Person language, Jim Sinclair wrote in 1992:](#)

But when I – and other autistic people – choose to refer to ourselves as autistic and express our preference for being referred to that way, and we are told that our opinions don't count because non-autistic people have decided it's better for us to be called something else, this shows absolute contempt for us as self-aware, communicatively competent people. The idea of putting the “person first” in language makes about as little semantic sense as saying “White Christmas” is racist...To put it bluntly, your prejudices are not our problem, and you should find ways to deal with your prejudices without trying to cut our nature off from our personhood. It is tremendously invalidating to say that people's basic perceptual and mental processes are so inferior that they're not compatible with personhood.

I apologize if I've offended anyone with autism. I am always stumbling over my words. Everyday, I seek to find the politically right way to state things. I encourage autistics to help me along the way, for I will never know what it means to be you and how you feel about the way I represent you in my writing.

The language debate takes its toll. Kit Weintraub likes to really twist language around to state that autistics who dispute her are “not really autistic at all,” and that the plight with her son is different, more serious. This is an example of a parent of an autistic child who is doing nothing to advance her child's rights and opportunities and in fact is herself, discriminatory against autistics. This is just one example how parental community is ripe with prejudice:

[*In Support of Michelle Dawson and Her Work from autistics.org,*](#) Kit Weintraub “claims that she doesn't want her children to be cookie-cutter people, but on the other hand says that if she could erase her son's quirkiness, she would, because people don't accept him for it. She describes medicating her daughter for her behaviour and hospitalizing her to use a ‘tough’ behavioural approach to get her to eat when she started having sensory aversions to food textures, and makes it sound as if this the only possible solution to these situations. Above all, Weintraub does the usual things that are done to dismiss the opinions of autistic people:

- She questions whether we are really autistic at all, showing the

- skills we do have, particularly intellectual and writing skills;*
- She simultaneously makes accusations about lack of empathy, insight, or compassion that are often leveled against autistic adults who disagree with the presumed parental status quo;*
 - She mistakenly equates the statements “We don’t want a cure,” “Autism is an integral part of who we are,” and “We don’t want ‘help’ that harms us” (which we do say) with the very different statements of “We don’t want help with anything,” “We have great lives,” and “We think all parts of autism are absolutely wonderful” (which we emphatically do not say).*
 - She brings out descriptions of her children that are intended to show how different her children are from us, without ever meeting us to know how we were at their age or even how we are now. As Dawson herself says, “How you can tell me when exactly it became good science to diagnose over the Internet.”*
 - She makes it sound as if problems (when they are actually problems) have an all-or-nothing solution – either her methods or nothing, and that means Dawson is advocating neglect.*
 - She blames her children’s difference for the cruelty that other people show to people who are different, thereby shifting the responsibility for their actions off intolerant people and onto autism.”*

From Weintraub's words to our ears, this example shows how semantics reflect the way she views her child and people with autism. It is very important that we all try to watch our words because others are listening and interpreting them. I don't think dismissing it as "perilous territory," is an excuse to give up on trying. The work on our part, will always be to clarify our meaning.

On a personal note, Adam found the right words today. A child was bullying him and Adam retaliated by pushing them away and saying "NO!" I say this because in the past he has always been passive to a bothersome tug. I have been hoping and praying for him to find the words and initiation to retaliate when people bother him. He is truly a little cherub, snuggling sweetly to me, hugging the dear people in his world. At times I'm afraid that he doesn't discriminate enough -- not everyone will be his friend in life. Yesterday, he developed some canker sores in his mouth and he looked to me for help, putting his hand to his mouth saying "mouth, ouch!" I was so happy to hear his little voice. It is afterall, what I need to understand his needs. I'm happy he is finding his voice so he can speak up for himself. It certainly doesn't matter

how he communicates, it just matters to me that he can so that I, the alien in his world, can help him.

None of us know it all and it is vitally important that we open our ears to autistics. What drives us emotionally may not always be in the best interests in our children. The head and an open heart must work harmoniously. Autistics.org, is a great site that demystifies autism and speaks for the rights of autistics. I find the site is extremely helpful to me in raising Adam and helping me see him. Here is another quote from *In Support of Michelle Dawson and Her Work* article:

“Some of us assist parents in finding solutions of how to raise their children in a way that respects their uniqueness, including autism, and does not hurt them, but also helps them grow. We do not think of parents as the enemy, nor as refrigerator parents, but we have little patience for the particular parents who insist we are bad for discouraging harm to autistic children. We are not oblivious to the difficulties involved in raising autistic children, particularly in current societies, and we are not ignorant about possible solutions that don’t involve mistreating people. We simply don’t believe that being the parent of an autistic child, or even loving one, means that a person suddenly becomes incapable of harming that child.”

I like to think about how my son would feel if I told him he had to be “remediated,” which implies, rectified or fixed. Once I think of it that way, I can steer clear of those words and find other ones that reflect better my absolute love for him, and my efforts to learn about autism and accept him for who he is with it. It is important to think of these words because someday, science may just one day find a way to “fix” our kids and then there will be no more like them. Is that what we want?

Insidious harm can most definitely dwell in words.

[PERMALINK](#) POSTED BY ESTEE KLAR-WOLFOND AT 2/22/2006 06:32:00 AM
[13 COMMENTS](#) [LINKS TO THIS POST](#)

MONDAY, FEBRUARY 20, 2006

No Pessimist Ever Discovered the Stars

It is wonderful how much time good people spend fighting the devil. If they would only expend the same amount of energy loving their fellow men, the devil would die in his own tracks of ennui. Helen Keller

There is such dissention among parents about autism. Parents “fight the battle against autism,” “remediate autism,” and use behavioural methods to make their kids more like them. Let’s stop beating around the bush and call a spade a spade.

I understand and empathize with the process of learning about autism and how difficult it is to just accept it -- the way we view the world is difficult to transcend. The important point is to transcend it.

I will reveal how I’ve come to this point on my journey, a journey like every other parent I’ve read, more or less. First, I noticed parents were in some kind of reticent competition to see whose child was “doing better.” I noticed this when my son was first diagnosed – some sort of strange comparison between parents as to whose child was going to “beat” autism first. It was thought that if one child was verbal, that child had an advantage over the other. We all wanted our children to be PDD-NOS or Aspergers, if we had to have a diagnosis at all – anything that eluded to normality, better functioning, and to being more acceptable to society.

Catherine Maurice said she “cured” her kids of autism. We all believed her. So, we all wanted to try as many strategies as possible to “remediate” the autism, and most of us went to every conference and workshop imaginable (RDI, Floortime, ABA conferences...I traveled all over the US in search for a way to “cure” Adam as “quickly” as possible).

If I had to describe my journey in all of this, I can tell you right off that not one person could “cure” the autism out of Adam. I hired and brought to Canada every person I could. If I couldn’t, I went to the US to visit them personally. The unexpected happened during the process -- another kind of transformation, and a more fundamental and important one at that.

When viewing how little “experts” understood my son, and viewed him as pathology, a set of “behaviours,” or as diseased, I knew that we had taken a wrong turn. When we practiced more social strategies (RDI was a turning point, I must say), Adam lighted up.

It was like he was happy to be acknowledged, to play. But the Connection Centre took our full fee and stopped servicing us because I needed to integrate their strategy with ours. Doing an obstacle course three times a day for fifteen minutes hardly seemed like enough. (We never got our money back, by the way). Just before I was to enter Adam in nursery school, Dr. Gutstein told me directly not to: "It doesn't matter when he enters school," he said to me firmly. While I agree, it hardly matters in the sense of time, it did in that Adam derives a great deal of satisfaction from being with peers and is a wonderful observational learner. I wouldn't have discovered that if I hadn't put Adam into school.

We still use many modals of teaching today, but in our own way that is successful for Adam. Everyday, we do the hard work of figuring out how best to teach Adam – and believe me we really have to find answers ourselves. I always appreciate a new strategy practised or researched by another to see how we can cull from it. Adam, if I must provide a progress report (seems to be wanted) is happy, he is in nursery school and he will be attending a "regular" primary school -- I am working with that school to obtain the accommodations he needs. I found a school that is flexible, private, and willing to work with us to teach Adam in a way he needs. None of this will be easy, but I find a positive attitude goes a long way with teachers.

Over time, in researching autism and running my son's team as my full-time job, I stopped listening to the "experts" and turned to people with autism. It is through them that I am at a wonderful place on this journey – learning to absorb, live with, and continue to try and understand autism perspectives. I have come to view it as another marvelous way of being and I believe this benefits Adam and my entire family. Adam continues to learn as we respect his many needs. I believe he could have become aggressive, banged his head – and he might if he meets the wrong teacher. I know that it is because we acknowledge his frustrations and help him through them that he is a "well-adjusted" kid – he seems to be developing good sense of self and a healthy attachment to me. There were signs early on that this could have been quite a different scenario. Had I listened to the experts, we would not be at this point today.

Stephen Shore is autistic and obtained his doctoral degree in Special Education at Boston University. He noted that during his

day, there were no interventions for autism, with the exception of his mother who did "what she felt was right." (from **Reflections of a Different Journey: What Adults with Disabilities Wish All Parents Knew**, p.57). "It is important to do what seems right for your child."

All in all, a parent really has to learn, study, and trust themselves and respect the point of the journey that they are on -- the journey never ends. I know this is hard to take in an era of gurus and genome research – and a view of science as a new God with supposed cures and answers for everything. At the heart of the matter, this all has to do with embedded stereotypes about disability.

Here are some points that I have come to learn and believe on my journey as a parent of a child with autism:

1. All autistic people deserve to be accepted for who they are with autism. They cannot change, and becoming “indistinguishable from one’s peers” should not be the ultimate goal in teaching them. In fact, it’s a horrible and sinister goal.
2. People with autism deserve a right to be treated and taught intelligently and be offered the supports that help them learn in the style that befits them. Not all autistic people learn in the same way; not all autistic people are created equally.
3. Autism cannot be [remediated](#). Period.(Semantics reflects thought so watch your words!)
4. No parent should support any organization that seeks to cure autism. Any one person or organization that uses these terms is fundamentally against the lives of our children. To them, my child is an aberration, and the “enemy.”
5. My child deserves to have patient teachers -- ones that do everything in their power to find what drives him to learn.
6. My child has a right to learn the following: want, wonder, discovery and desire – not simply learn “how to respond.” He has the right to choose and make decisions about his own life and to be presumed competent.

7. My child deserves and will likely go to university. A child most often (albeit not always) lives up to the expectations of their parents. It's all about what we believe. Further, various supports and accommodations at university can be made.

8. Achievement carries no timetable.

9. As a parent, I am my child's one and only advocate. I do not expect an expert, a teacher, and an organization to do this for us.

10. No Jim Partington, Catherine Maurice, Steve Gutstein, Ron Leaf, Stanley Greenspan and the like is our saviour or will save my child from autism. Some people have talents in operationalizing teaching methods. These people have done just that. There are good things in many methodologies, but not one is "autism religion."

I highly recommend autism cynics to start reading books written by autistic people. Also, read **Reflections from a Different Journey**. (See sidebar).

No pessimist ever discovered the secret of the stars, or sailed to an uncharted land, or opened a new doorway for the human spirit.

Helen Keller

[PERMALINK](#) POSTED BY ESTEE KLAR-WOLFOND AT 2/20/2006 02:58:00 PM
[18 COMMENTS](#) [LINKS TO THIS POST](#)

A Happy Day for Autism

The [Globe and Mail](#) today put on its front page, an article with Michelle Dawson and Dr. Laurent Mottron from Montreal. They are colleagues "The Postie and the Prof" who have pooled together to dispel all myths about autism. There is a scientific community who believe in the intelligence of the autistic population! "The

problem is that autistic intelligence is not measured accurately," Dr Mottron said..."In much of the autistic community -- support groups dominated by parents of autistic children ... is public enemy number one. They want autism to be a sickness that needs to be cured," she said. "They say horrible disgusting things so they can get more money for their lobby groups. They make me sick," Dawson said.

Bravo. Read the [Globe and Mail](#) link for full story above.

[PERMALINK](#) POSTED BY ESTEE KLAR-WOLFOND AT 2/20/2006 09:41:00 AM 4
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SATURDAY, FEBRUARY 18, 2006

Autism R and D

Three points converge to a head.

Point One--Awakening: I turn on my blackberry to receive an email newsletter from NAAR stating that their merger with Autism Speaks is completed, and they will together "fight the battle against autism." Like the war on drugs and the war on Iraq, they got the President Bush's wife to join in. It's all sympathetic to the triumphant war hero, and many like to be just that, even at doing so at the expense of others. Even Alan Greenspan has decided to get "bullish on autism."

Point Two -- Early A.M.: Had breakfast and went to get an overdue pedicure before a short jaunt to see grandparents next week in Florida. Hubby bought me Jasmine Lee O'Neill's book, **Through the Eyes of Aliens: A Book About Autistic People.** I read while my feet are immersed in soothing warm water. I consider buying it in bulk for the [October show](#), for my family and friends as the Autism Reader 101. I am nearly in tears at her ode "For An Autistic Child:"

*To you in your world,
Locked inside yourself,
An island,
Isolated winds in your mind,
To you, locked inside beauty,
Inside anguish, inside joy,*

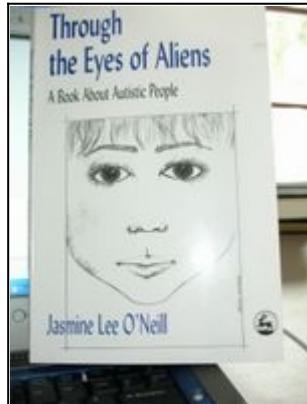
*You live
Breathe
Die
Emotions*

*too profound to understand,
Little one curled up rocking,
Your floor your world,
Safe,
Just you,
Your little expressive hands,
Like tiny little birds,
talking in flutters,
your little angry snarls
repel a monstrous outside realm,
your beloved treasures:*

Buttons

*Diminutive faery animals
Smooth wooden beads
Dots of sunlight on your wall
Humming your songs
to calm your anxious hands,
Safe,
Just you,
At one with rhythm,
Your world
only bits of those others
who come and go like currents of air,
barely ruffling your forelock,
Your face a delicate empty mask
to those who see only with eyes,
Those who don't understand,
your world,
To me,
watching you,
I see myself,
I sing songs for you,
little one, to tell you,
You don't have to forsake your world to be free.*

I hold back the tears behind my new reading glasses, hiding my face behind the book face:



Through the Eyes of Aliens by Jasmine Lee O'Neill...should be Autism 101 Reading. 

“The autistic world isn’t a dark and horrid chamber. It perhaps sometimes appears that way to outsiders. Knowledge and understanding will lessen the fear. For, as an autistic fears new or unknown people, events, places, even foods, a non-autistic may also fear a world inside another that seems incomprehensible...” (p.18)

Fear is the ogre. It is the war-monger. It lives in Presidencies, in massive organizations, and in research that seeks to ameliorate people with autism.

Point Three -- Lunchtime: Picked up Adam and we go to music class -- we haven't been in two weeks because of how ill he has been. On the positive side, he was watching his peers and especially the teacher – he seemed to be having a good time. On the other side, he preferred to lie down and watch the ceiling in circle, and he didn't want to be “redirected.” I felt that he was being directed so much at one point, that he wasn't allowed the time and space to be competent. He preferred to circle and watch like a cat, and when he was ready, he pounced in. The other children were watching him. It is all too noticeable, being a parent, trying so hard to appreciate him for himself, for his autism, to appear on the surface accepting and unaffected, and watching other eyes full of judgment and wonder -- in children as young as three.

“You should not seek to change what you are, or try to do it to another. I also don’t agree with the therapists who try to prevent an autistic child from seeking refuge in her inner world. There are extroverts and introverts. If an autistic person doesn’t

It all comes to a head -- P.M.: Begin writing and am feeling discombobulated --- Why or why do we have so much fear of people who are different in the world who can persuade the Laura Bush's with words like "fight," "battle," and "war" and a multi-million dollar budget. I call for peace. Stop the fight against my son. Love him and accept him for all his wonderful traits. Let's start a new Autism R&D project – Autism Respect and Dignity.

[PERMALINK](#) POSTED BY ESTEE KLAR-WOLFOND AT 2/18/2006 03:40:00 PM 6
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FRIDAY, FEBRUARY 17, 2006

Drops in the Desert

One day a family drives to Haifa -- a son with cerebral palsy and a hearing aid. Thirty-six years ago, hearing aids were obvious – wires coming down from the ears and a box against the chest. Mother, father and son had to make a stop. Father got out and two young children, around the age of six, came out of a store and stared at the boy in the car with the hearing aid and mumbled something to themselves. Mother notices and says,

"Do you want to know what this is about?"

The children hesitated, unsure of what to expect.

"Come, let me show you," she beckoned.

The children approached slowly while Mother took one of the earphones out of her son's ear. The son couldn't move, so Mother explained to the children why he couldn't move and why he had the funny earphones with wires.

"Why did you do that?" asked an observer. "Do you think they will care?"

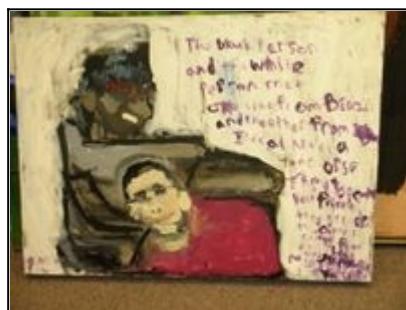
"It's like a drop of water in the desert," said the Mother. "Over time, there will be more drops and then something will grow."

When it comes to creating tolerance and awareness in our society

about disability, we are pouring drops in the desert. It seems like we'll never get far, that our voices will never be heard, but over time the drops will become more frequent and we may have ourselves one fine oasis.

Dr. Nehama Baum has people with complex disabilities enter her centre. Some are suicidal, homicidal, and incredibly aggressive when they arrive. Most have come from complicated backgrounds, some even abusive – from families who have tried so hard to change them, and like putting a square peg into a round hole, we all know this is impossible. When they enter MukiBaum and are acknowledged for who they are, however, with schizophrenia, autism, and a number of other complex issues, they are able to calm down, learn and attain the [quality of life](#) I talked about in yesterday's post. When one is talking about autism in this context, I must also refer to other disabilities. I cannot interchange one for another when it comes to conversations about acceptance.

"If one can acknowledge the other's voices in their heads and enter their inner world," (referring to schizophrenia) says Nehama, "they feel respected and become easier to reach." No matter what, Nehama wants to enable Identity in some of the most severe cases of disability you will ever hear about. Some continue to paint and have become quite prolific while others have used art as a therapeutic tool.



Jordan, from MukiBaum Centre for Complex Disabilities has 5 diagnosis'. One of them is schizophrenia. 

So why am I going on about this? I do so to continue to raise awareness and will be setting up an organization to do this. I am organizing another big arts event this October -- so far featuring Donna Williams, Michael Moon, Mukibaum patients, and Jonathan Lerman. I will be seeking more -- email me if you're interested. We are all bricklayers – we need to build the bridge between the world of disability and the rest of us. As [Autistic Bitch from Hell](#)

states (I love her writing, but hey, can you change your name...you are hardly a bitch), the true meaning of Neurotypical is that there is, in fact, no such thing as normal:

"The neurodiversity movement is based on the belief that there is no such thing as normal when it comes to the human mental landscape. The neurotypical person simply does not exist. Together we display a wide variety of neurological behaviors and abilities..."

Consider that for a moment so we can stop creating that lingual and conceptual divide between “us and them.”

And the drops in the desert story? It belongs to Dr. Nehama Baum.

[PERMALINK](#) POSTED BY ESTEE KLAR-WOLFOND AT 2/17/2006 05:02:00 PM 4
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THURSDAY, FEBRUARY 16, 2006

What Is Quality of Life?

Front and centre of this dialogue about autism is inclusion. At the heart of the matter, understanding and acceptance that people with autism and other disabilities is needed, and as parents and people diagnosed with ASD, we need to keep up aggressive dialogue and awareness-raising so that equality can be achieved.

Too often, “mainstreaming” and “integration” are touted as goals for children with autism without recognizing the missing components that make this successful. As mentioned in recent posts by [Autism Diva](#), and [Elmindreada](#), “mainstreaming” currently leads to bullying because children are not taught to accept difference, and integration is mere lip-service as schools try to integrate by have little idea of how to successfully include and educate children with learning differences. As Adam and I prepare for entry into JK, I think long and hard about what we are in for in terms of prejudice, snubbing by his peers, and his need for a different mode of learning in order to achieve the quality of life I believe we are all referring to.

When we talk about quality of life for people with autism we

usually talk define it in subjective terms as “being happy,” “being fulfilled,” “having a job,” “getting married.” While these should still remain goals, we cannot reach them if we do not acknowledge the missing links in the system that result in endless obstacles.

In essence, we are talking about a paradigm shift in thinking – an evolution of how we view disability. While it has changed significantly over the years, we still run into a general concept that “quality of life” for people with disabilities is the physical care of them, while ignoring other spiritual needs -- as caregivers do not believe these needs are at all present or desired in people with disabilities.

So what is quality of life for persons with disabilities? Society, for the most part, still largely shoves its differently-abled members in places where it will not disturb and perturb them, where it will not agitate their homogeneous state. As I noted in my post [Smack Dab in the Middle](#), a recount of my first visit to the [MukiBaum Centre for Complex Disabilities](#) in Toronto, my personal prejudices, despite my having a child with autism, were all too notable. In this recognition of my state, and how I arrived to it, I realized how hard we must work to include the heterogeneous members, the disabled members, into our communities more rigorously.

[Nehama Baum](#), PhD and founder of MukiBaum, talks extensively about quality of life for people with disabilities, and the power of art education in embedding a sense of self and identity. In her paper, “Enhancing the Quality of Life of People with Dual Diagnosis: The Power of Art Education” ([The Journal on Developmental Disabilities](#), December 1997), she notes through her research that “[people with disabilities] are seen [by their caregivers] as not being able to make decisions because of a lack of intellectual ability, and more simply, because they do not know how. The perception is that they cannot interact because they are acting out and they do not possess talents because people with developmental disabilities are not capable of creativity. As a result of these long-held beliefs, caregivers have felt that their role was predominantly to care for the physical needs of the people in their charge and to ensure that they comply with what the caregivers perceived to be the ‘best for them.’”

As I continue to evolve the way I myself view disability, autism, and my son, I consider in this last statement, all the therapies and

modes of autistic education that teach compliance because “it is best for them.” Is it? In doing this, are we truly accepting and understanding the difference? While I cannot entirely change my viewpoint (I have my limitations), I will still want Adam to pay attention when he is learning, or when I am speaking, but perhaps I will also be able to adapt and empathize that he comes about things differently.

Baum goes on to define quality of life encompassing these basic human needs:

Being = refers to one who is an individual

Belonging= refers to a person’s fit with his/her environment

Becoming=refers to the intentional activities a person becomes involved in when striving to achieve goals and actualize wishes

We must ask ourselves if the scientific communities and organizations like NAAR are enhancing these opportunities for personal power of those with autism in their use of phrases like “epidemic” and other negative semantics that paint a picture of people with autism as slightly less capable, a little less than human. In preparing marketing campaigns and slogans for the purposes of fundraising, what damage are they doing to the ongoing struggle to obtain “[equal rights](#)” and acceptance of people who are different?

“Reiss, Levitan and Syszko (1982) observed that, in many cases, when an individual has a developmental disability, other aspects of his/her life are not acknowledged. Reiss et al. called this phenomenon ‘overshadowing.’...Such perceptions influenced the development of services that were provided to these individuals over the years (Menolascino, 1994). Programs for people with dual diagnosis tended to emphasize teaching based on the perceived deficits of the individual, without taking into consideration areas other than practical skills for living and adaptive behavior. Such programs gave little attention to exploring and developing the potential of these individuals...Furthermore, this approach has also emphasized behavioral interventions with externally imposed standards of appropriate conduct. No acknowledgement was given to other possibilities. Therefore, programs that accentuated such areas of life as creativity, artistic talent, inner growth, cultural identity, economic self-sufficiency and community inclusion, were not developed.” (p.103)

Organizations like NAAR, Autism Speaks, Cure Autism Now, many behavior analysts (not the evolving ones), many peddlers of autism products, diets, cures, some scientists, even some parents ascribe to a reductionist view of the person with autism – a judgmental view regarding a person’s Being. (see yesterday’s post on [Do Animals Have Feelings, Do Autists?](#)). “For example,” states Nehama “if it is assumed by others in his or her environment, that an individual is manipulative, suspicion about the motives of all the person’s interactions may develop. Similarly, when an individual is evaluated as an ‘aggressive behavioral problem,’ the social environment might become more rigid in its expectations and more restrictive in its allowance of freedom and choice. In turn, this increased restrictiveness could affect the individual’s ability to intentionally choose goals, initiate activities, adapt to life changes, and develop as a person (i.e.; the Becoming area of life).”

When [Dr. Joseph Buxbaum](#) indicated the plight of parents, and I hear parents who want a cure for autism because their kids are banging their head against the wall, I consider that these components of enabling a sense of empowerment and self have been ignored in exchange for the ongoing struggle to make our children “like us.”

Nehama goes on to say that while quality of life is a complex concept, with subjective and objective evaluation of physical, material, social and emotional well-being, the holistic approach touches upon many aspects of a person’s life and incorporates both empowerment and choice. (p.99) As much as the objective realm is important (housing, employment, income), “the subjective realm (social support) is comprised of a general feeling of well-being, feelings of positive social involvement, and opportunities to fulfill one’s potential.” (p.102) I do believe that fulfilling potential is the utmost goal for Adam because I see so much potential. As a curator of art, this was also apparent in the work of Jonathan Lerman – how the spiritual side of him is still growing, exploring and is utterly intact (**see my side-bar for video footage of the exhibition.**)

“In order to enhance quality of life of individuals with developmental disabilities...an added effort has to be put into developing opportunities in both the objective and subjective dimensions. In doing this, there needs to be an emphasis on creating a balance between them. This should be a process that is

person-centered and person-referenced, but that also takes into consideration environmental realities.” In her studies, art (painting, drama, movement and music) “are psychodynamic therapeutic modalities for the promotion of consciousness, emotional growth, and well-being of children, youth and adults with dual diagnosis.”(p.103)

In my posts [Sensing the World Into Existence](#), and [On Becoming a Self](#), I also explore the a need to enable self-fulfillment, actualization and awareness through sensing, art, and acceptance. As we learn to appreciate and accept people with autism, as we begin to think about and define what we mean by quality of life for people with differences, we will be able, as parents of children with autism and as adults with autism, advocate for the supports that will enable a sense of SELF. Even more important, we will offer people with autism empowerment and choice over their own destiny.

[PERMALINK](#) POSTED BY ESTEE KLAR-WOLFOND AT 2/16/2006 12:29:00 PM 5 COMMENTS [LINKS TO THIS POST](#)

TUESDAY, FEBRUARY 14, 2006

Do Animals Have Feelings....Do Autists?

A recent article in *MIND* (Scientific American February/March 2006 issue), discusses scientists who debate the issue about whether animals not only have emotions, but are aware of their emotions. It is this self-awareness and reflection that connotes an emotional sophistication akin to humans.

Charles Darwin was the first to devote an entire book on the topic, *The Expression of the Emotions of Man and Animals* and concluded “striking similarities between human and animal behavior.” Later, reductionists stated that “all animals are merely organisms that follow hardwired, instinctual behavior patterns. They are devoid of feelings.” (p.26)

This statement resonates with similarities to our scientific community studying autism today. From Hans Asperger to Simon Baron Cohen’s mind-blindness theory (see [Zilari's](#) post on the topic) to recently [Joseph Buxbaum's](#) rather sinister personal response to my blog, the person with autism is reduced to a subset

of component parts. By looking in too closely, some scientists cease to see the forest for the trees.

Antonio Damasio who wrote [Looking for Spinoza](#), cites the difference between social and instinctive emotions. He notes that feelings stem from self-reflection. “Primary emotions include fear, anger, disgust, surprise, sadness and joy, and Damasio ascribes them to many animals....To Damasio and many others, emotions are physical signals of the body responding to stimuli, and feelings are sensations that arise as the brain interprets those emotions...For social emotions, he lists sympathy, embarrassment, shame, guilt, pride, envy, jealousy, gratitude, admiration, contempt and indignation.” (p.27) Some scientists believe that these emotions are largely automatic and inborn – “routinized mechanisms to help them survive.”

Sound familiar?

Feelings, the article states, are born of awareness of the body’s response to emotions and an ability to self-reflect on those emotions. “Damasio theorizes that pygmy chimpanzees, for example, may be able to show the social emotion of pity for other animals but that they do not realize they are exhibiting pity.” (p.28) This sounds like current autism theory “children are unable to attribute the beliefs of others.” Or taken further, people who claim that people with autism are unable of feeling empathy.

In response to that theory, I think about Dawn Prince Hughes who has Aspergers, and her learning of herself through her Gorillas in [Songs of a Gorilla Nation](#). Here she speaks of one Gorilla she names Nina:

“...She stood up and with a flourish snapped the burlap from her neck, then let it billow out before her while she held two of its corners between her thumbs and fingers....She spread it out on the grass and smoothed out the wrinkles. When the material was perfectly flat, Nina eased herself down in the middle of her picnic blanket and looked up to the keeper after letting out a long sigh. She seemed suddenly self-conscious as she noticed the look on my face. It had been an incredibly involved set of steps, and we were awestruck.” (p.126)

Hughes not only observed the Gorillas and decoded many of their

complex social and emotional nuances, but she came to learn about herself through them:

“Very cautiously, I tried to apply the things I’d learned from the gorillas in social situations. I tried to put people at ease by acknowledging them with quick sideways glances and smiles – which evolved from submissive primate grimaces and are intended to convey that no harm is meant.” (p.134)

Here is another example:

“...Eventually I showed him the contents of my lunch...He pointed to the bottle. Still feeling stupid, I shoved the bottle against the window and shrugged my shoulders – it wouldn’t fit through, I tried to say. He pointed to the wall where the keeper threw his treats. He knew the trail led to a secret area close to where I sat. He raised his eyebrows. ‘Walk up there and throw it down to me...what kind of stupid gorilla are you, anyway?’ he seemed to say.

I shook my head and pointed to my seat and notes, a feeble attempt to demonstrate my duties. He turned his body away from me and reached back to bank the window with his fist, pursed his lips, let out a raspberry, and then pointedly ignored me. Occasionally, he would turn to look over his shoulder and purse his lips in my direction. He didn’t need to say it in English; I knew what was going through his mind.

This was one of the first times I remember knowing for certain what another person was thinking and feeling, and that my actions were a direct cause of their subjective experience. Something about the directness of his communication, combined with the honesty of his body language and his emotions, painted a kind of consistent and forthright picture that allowed for a moment of communication that was, paradoxically, more intense and more subtle than that of a human person. It demanded that I stay engaged until the moment had resolved with both of us as participants. It is clear to me that not only do apes have a language that is complex and holistic, but by communicating with us, they illustrate that it may be we who are less skilled at the art of sharing true subjective experience.” (p.136)

This is obviously the problem of humankind – our arrogance and

delusion of superiority over other species and even, other humans.

The article in *MIND*, notes that feelings such as joy arise from the mind's awareness in bodily emotions. Sumatran "orangutans swing from branches and splash their hands into pools of water for no apparent purpose than just for the fun of it." (p. 29). Studies show that brain metabolism for animals is not very different from those in humans. In the end, it is still "not possible to prove whether an animal possesses conscious feelings [any more] than we can be sure about what another person is truly experiencing." (p. 29)

Again, science has no slam-dunk answer. I posit that there are elusive things in life that simply aren't measurable through fMRI's, namely the complex process of imagination, perception, emotion and self-awareness. While we may see areas of the brain fired up in response to certain stimuli, the complex ingredients of being human can never entirely be distilled. For to distill them is to reduce humanity to component parts.

It could be said that we have Damasio approach to understanding autism – how people with autism think and feel to an extent that some scientists reduce the person to a mere organism, and an aberration of nature at that. The approach is disturbing when it splices characteristics of our children into little bits, and those little bits are INTERPRETED by the scientist, hence subjective and often wrong.

I will argue that there is no such thing as [empirical science](#) -- it has been argued before. Go on line and take a look at some of the research projects going on out there. Every abstract, every project is subject to the scientist's bias, presentation of stimuli, environment...it is so difficult to obtain an unbiased view. At least an artist, a scientist of sorts, and in my view a better expert of what makes up the sea of mankind, admits to viewing the world through a set of inherited lenses.

Science is still filled with fallibility, subjectivity, and judgment. One theory in science and in art will always supercede another. We will forever be changing our view of the universe. May the arguments continue so that we can stay [true](#).

MONDAY, FEBRUARY 13, 2006

Happy Valentine's Day



Happy Valentines Day Bubby, Zaida, Serena, Joseph, Max, Maddie, Grandma, Grandpa, and Daddy....I am feeling better as you might see from my jumping 

[PERMALINK](#) POSTED BY ESTEE KLAR-WOLFOND AT 2/13/2006 02:54:00 PM 3
[COMMENTS](#) [LINKS TO THIS POST](#)

Autism Kisses

Remember that nanny I was telling you about in my previous [LOVE](#) post? Well, she took off. Adam was sick yesterday with the croup and stopped breathing and she just LEFT. I couldn't believe it. Good riddance, I guess. The good news is Adam is better today, taking Prednisone and breathing a lot easier. It was a scary day yesterday.

My heart breaks. It is because of Adam that she left. For him, my heart gets all ripped up. I don't care about her. I care about him, and all the people who come in his life and those who don't stay because they can't handle "having to play" with him. I know, I know...what did I do keeping a girl like that? A favour to my other part-time, 15-year loyal nanny? Partly. Hope in a human being, always. I always think that people will "come around."

I should have listened to my instinct. It's always too damn right. Never fails. Every time I turn my back on instinct, I screw up. I was right. Should have listened to [Blink](#).

Blink, written by Malcolm Gladwell, a University of Toronto history grad, quotes [Simon Baron-Cohen's](#) Mind-Blindness theory in his arguments about intuition. He notes that people with autism

cannot “read” minds in the important first-impression stage and are at a disadvantage where intuition is concerned, thereby losing an edge the rest of us have to make split second, profitable decisions (yes, it’s all about BUZINESS -- at least business people seem to be the book’s primary audience). People with autism claim that “real-time” mind and body reading are difficult, but are hardly incapable of understanding others. I am always interested in how people with autism claim that they can think of their responses long after a conversation – how the processing takes longer. I suppose there are millisecond clues that are processed unknowingly by me...those clues we can’t break down into little bits, and call intuition. All I can do to perhaps come close to understanding that difficulty are those times when I am stumped by a person’s words – all those witty responses and come-backs I could have said long after the moment is over. Yet I hardly think that experience does the ACTUAL autistic experience justice.

Anyway, my heart will mend. No matter how hard I try to find the right people to encircle Adam, to be part of his world, I am guarded. I only want positive people around him, but I cannot always thwart off the negative, hurtful ones. I cannot always be around.

On the upside, I have written little about the people who do love him, from within and out of the family. Laura, his wonderful therapist who has gone on this journey with me and who is the most wonderful part of Adam’s expanding life; Morgan, Adam’s loving shadow at school who has unshattering belief in Adam’s abilities; Bianca, who is leaving us to have a baby, but who has stood by Adam and felt the hurt along with me; Ellen, Adam’s OT who has been more ‘right’ about Adam than any psychologist or doctor or “expert”; Stacy, who works with Adam once a week at OT with an unending white smile and more recently, Leslie, who has brought her lovely, calm and positive attitude into Adam’s life and is helping to shape his programs; to Flor, who stays by Adam and who plainly loves him; to Jaclyn who has taught Adam how to “bend his knees”; to Paula and Nancy, his teachers at Nursery School who always go the extra mile for Adam; to my friends who pass no intrinsic judgment and ask Adam to come over and play; to his music teachers who accept him for who he is; to the Snoezelen people who let him relax and just be; to grandparents who take this journey with Adam and I daily; and of course to my immediate family who deal with it all so lovingly. To all of you, a hearty thank

you.

I talk too little of these people who make our lives wonderful and hopeful every single day. Without all of you, my optimism and strength would not be possible.

Tomorrow is Valentine's Day. Hubby is skiing with daughter in Whistler. I am planning a sweet dinner (Pickle Barrel with candles?) with my other true love and reason for being. I didn't budge all day from Adam's side yesterday and in between his wheezes for air, I realized again how large love is and how my little heart can hardly contain it. Like today, Adam will surely lean into me tomorrow and give me his little kiss – for his "senses" or for love, I'll take his "autism kisses" any day.

[PERMALINK](#) POSTED BY ESTEE KLAR-WOLFOND AT 2/13/2006 01:22:00 PM
[10 COMMENTS](#) [LINKS TO THIS POST](#)

SUNDAY, FEBRUARY 12, 2006

The Poetry of Autism

It is perhaps difficult to consider the poetry of autism as my son struggles for air, looking up at me searchingly – "what is happening to me?" He is sick and we are on pneumonia watch. He doesn't have it yet, but he is very ill this weekend. I write in the darkness of his room as he sleeps, not letting my eyes off him.

I imagine the poetry of autism is similarly difficult to comprehend and a parent watches one's child bang their head against a wall, or bite oneself in the frustration of not being understood. The following premise "the poetry of autism," is not in any way to belittle or forget these moments. Rather, I consider that autism, its way of seeing and sensing the world, poetic. As I read Donna Williams, Susan Golubock, or Larry Bissonnette, their style of communication and use of written language is plump with metaphor and meaning. In fact, it takes me a few repetitious readings of a sentence or a paragraph at times, to fully appreciate the entire meaning. As in poetry, the language of autism sometimes requires unraveling. The language reads sometimes like stream-of-consciousness writing.

Here is what Donna Williams wrote me in response to Adam's schedule;

*"yes, grandparents are really important
Having other attachments
Being flexible about new discovery environments
That's building WANT and wonder."*

I want him to have hands on 'doing' based, tactile, kinesthetic experiences with sound, form, line, light, movement, space so he WANTS to talk about, draw, build, compose as expression brewing from these things...if he chases the world, then the potential is great...so activities should inspire, be about DISCOVERY and wonder and one discovers and wonders when the answers aren't already jumping out at you, then the understanding isn't 'theirs' its 'yours' and that builds self and a relationship with the external world as 'one's own world.' Without this, it is 'their world.'

Donna's grammar is more intact than some. Her writing leads us from one image to another which leaves my head swimming – one has to dive in to her language to understand the rhythm of her world. It is in joining this rhythm that we perhaps catch a glimpse of the way she sees it.

Even more akin to "poetics" is the prose of artist with autism, Larry Bissonnette:

*"Casting teepee posts of happiness in the ground of slaves to big accounts will never make your life better." (Biklen, **Autism and the Myth of the Person Alone**, p.169)*

Larry's political views are apparent, as most artists struggle between the call of money versus the call for Truth, which is within our grasp, through art.

"Tapping well of silence with painting permitted songs of hurt to be meted with creativity." (Biklen, p.170)

The phrases 'well of silence,' 'songs of hurt,' and 'casting teepee posts of happiness, 'in the ground of slaves,' are all distinctly visual and metaphorical images. Silence is a well. Hurt is a song. Teepee posts of happiness can rise and fall. Slaves are often confined to the

ground, work the earth, and are as good as dead.

“Leaping into stream of creativity prepares artist for partnering technique with passion and dramatic vision of malleable for beauty real world. Same beam of enlightened belief in artist’s ability as is shown on president of nation is required.” (p.175)

If the president could tout the artist’s ability here, acknowledge the fluidity of thought and process, might we be able to change the notions of autism? If we shared the same ‘beam of belief,’ like the light of TRUTH, then it is possible.

“My pent-up time in tested for learning patterns of best behavior institution wasn’t entirely greys; it offered personal periods of great relationships with friends with disabilities.” (p.174)

Bissonnette was thought of as mentally retarded so he was institutionalized during his youth. “Tested for learning patterns of best behavior,” tells us that his life was full of tests, and he deciphered through patterns, what was expected of him. When Adam did ABA therapy, he was tested all the time. (I only did so-called ABA therapy for 2 months when we started this journey...thank God.). I could see as well, that Adam could learn the expectation at 20 months, very quickly. But it didn’t teach him anything about his world. James Partington told me once in a conversation over the phone: “all we’re trying to do is teach your child how to respond.” It was that statement that made me close the door to “pure” (whatever that really means) VB and ABA forever. I didn’t just want to teach Adam how to respond, I wanted to teach him how to learn for himself, enjoy the world, garner what he wanted from it, and I still believe and see through him that this is possible for all people with autism, and is happening for Adam.

“Past life of institutionalized person lets in novel ideas. Outsiders to this life can’t go out and obtain it. It’s significant that my artistic style lets me express personal perspectives of autistic but intelligent old Vermonter.” (p.177)

Indeed, Bissonnette is an intelligent “old-Vermonter.”

“Producing art is like making puppets on strings because massive edges of inspiration in creating graspable figures get constricted by people’s patterned control of sticks put on strings. Not

allowing people with disabilities their patterns of inspiring art through total freedom of expression is like limiting creativity with censorship.

Artists like Larry urgently make situations of doing art into large statements; occupying worlds of public awareness; calling for justice for people without speech; praying for true freedom of splashing language over pricey spreads in people beautiful but superficial magazines; moving down stereotypes of disability and leaving people speechless over power of brushed on with wild, outside the mainstream ideas, steeped in the tradition of autistic compulsivity.” (p.179)

And,

“Look up early lessons in learning about my struggles to communicate and determination of others to make me learn to eat neatly and talk clearly was really most important factor in my rostering of skills. I am seriously past learning swimming in the shallow end of the pool of language but I am ever told ‘can do’ words by others like Aunt Theresa and that is the sled that pushes me to accept excellence over languishing in mediocrity.” (p.181)

Needless to say, we as parents should accept this kind of equality for all our children, no matter what type of disability obstructs. There is not one person with autism who hasn't told me that there was someone believing and pushing them to succeed (and that success is different for everyone). It is the parent's will to accept this equality of excellence, meaning that we all have a right to work towards and attain it, to accept and believe that everything is possible, even with children who have been diagnosed at the “severe” end of the spectrum.

*“...I'm not asking that life's expectations
be changed for me.*

*I seek only acceptance for the ways I choose to meet them.
Remember what gives joy to you
is often very uncomfortable for me.
The way you would do something
is often not the way that would
enable me to best succeed.*

*Or more importantly
find pleasure of self-satisfaction
in what I might accomplish.
I don't experience loneliness
or have the same needs and wants that you do,
so don't pity me for not having what I don't miss or want.
I recognize that your life,
with all its complexities
has its own set of difficulties.
Your definition of accomplishments
and what you find encouraging
go beyond the simplicity
which defines me.
I'm only asking for the same rights
and freedoms you seek for yourself:
To be accepted for who you are,
To be the best you that you can be.
Don't assume that I want or think or experience
the way that you do.
As nice as you think it is to be you,
I only want to be me."*

----Susan Golubock from "Our Lives in the Universe of Autism,"
Women from Another Planet, pp. 70-71

That, my friends, is the sum of all these parts.

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FRIDAY, FEBRUARY 10, 2006

Sensing The World Into Existence

What if Adam can sense the world? What if this sense, his intuitive sense even, is more robust than his other senses? In my conversations with Donna Williams, this seems plausible. I have been so focused on visual-spatial skills, but not of Adam's other sensing mechanisms. As I was disorganized and literally sick to my stomach at temporarily losing some of my vision at the eye-doctor (see yesterday's post "Unfathomable Mind"), I realized how I have come to over-rely on my vision and hearing, and under-rely on my other kinesthetic and other sensing mechanisms. In essence, those of us that share the same faculties have come to view the world

through a very narrow tunnel of vision – where other worlds can be experienced through different avenues of perception.

This led me to think about Bruce Chatwin's *The Songlines*, which I read years ago. The main character, Arkady, spends time with the Walbiri Aborigines of Alice Springs. The Walbiri sing the "world into existence." Without having traversed the country, the world doesn't exist.

"He liked Aboriginals. He liked their grit and tenacity and their artful ways of dealing with the white man. He had learnt, or half-learnt, a couple of their languages and had come away astonished by their intellectual vigour, their feats of memory and their capacity and will to survive. Arkady learned of the labyrinth of invisible pathways which meander all over Australia and are known by the Europeans as 'Dreaming Tracks,' or Songlines to the Aboriginals as 'The Footprints of Ancestors' or 'The Way of the Law.' Aboriginal Creation Myths tell of the legendary totemic beings who had wandered over the continent in the Dreamtime, singing out the name of everything that crossed their path – birds, animals, plants, rocks, waterholes – and so singing the world into existence." (Bruce Chatwin, *The Songlines*, p.2).

Does what we perceive really exist? If it exists does it exist in the same way for others? As I consider that a blind person perceives the world entirely different from the way I do, I can easily suggest that we each perceive the world differently. If we believe this, then we must believe that the way people with Autism perceive is differently from us, and even among themselves as a group labeled Autistic. If perception is different, then we must completely rethink the way we evaluate and teach people with Autism. ABA leaves little room for creativity, discovery, and kinesthetic exploration. We are dealing with a group of people who are simply human with a set of different sensing and perceptual mechanisms – entirely valuable, completely fascinating. As I consider this along with my own biases, perceptions and the layers of belief systems that I have inherited through an inflexible world, I am coming to appreciate Adam and his wonderful complexities.

Like the Walbiri tribe, I suggest that Adam is sensing his way into existence. His visual and touch senses, his intuition, his ability to feel rhythm and pattern may be his strategies for making sense of

this world and finding himself within it. While we both make the journey to cross each other's paths, as his parent, I am obliged to SEE him, his world, as much as I hope that he will continue to join me in mine.

[PERMALINK](#) POSTED BY ESTEE KLAR-WOLFOND AT 2/10/2006 12:22:00 PM 7
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THURSDAY, FEBRUARY 09, 2006

Unfathomable Mind

I got my first pair of reading glasses. I call it the perils of turning 40. I went to the ophthalmologist and got two doses of eye drops – the yellow one that burns and then the ones that dilate the pupils.

I have always thought of myself extremely eye-sensitive. I remember as a toddler, my eyes were at the same height of the hooks that held various tools at the hardware store and I used to squirm and squint – the thought of me falling into them and poking out my eyes all too consuming.

Then came friends with contact lenses. I would watch their first trials of putting them in and being unable to take them out of their eyes, or worse, getting them stuck in their lids. Ugh. Just the thought makes my skin crawl. Needless to say, I will never be a candidate for contact lenses. I've had wonderful vision all of my life until about a month ago, I picked up a medicine bottle and couldn't read the fine print like I used to. In desperation, I picked up those drug-store glasses, the magnifying ones, and I could read the fine print much better. One morning, I woke and couldn't see the TV screen. Thankfully, this was short-lived. Soon after, I noticed that when I read, the words were jiggling on the page.

So I went to the eye doctor.

When she put those drops in, I couldn't read a thing – not my watch, not my phone. My eyesight was so profoundly affected I couldn't even dial the phone by myself. This alone, sent me into chaos – an unmanageable oblivion. I couldn't see the contents of my handbag to pay, I couldn't find my keys, I was dropping all my receipts from the day all over the floor and I couldn't find my prescription for the glasses the doc just handed to me. Losing some

of my sight for a short time put me into a tailspin. I had a headache from straining to see. I felt sick. I couldn't work or even watch TV. I had to lie down for the remainder of the afternoon.

My dependence on my sense of sight is all too profound. By losing part of my sight for this short period of three hours, I became disoriented, unable to coordinate the rest of my body, even. I realized how underutilized my other senses are, and this lead me to think about how we under-appreciate the use of other sensing mechanisms that people with ASD may use to compensate for the sensing on which I have come to over-rely. Dr. Oliver Sacks talks a lot about compensatory abilities in the deaf and the blind. So too, I feel that Adam intuits, senses people and his environment in order to manage. I am sight-centric as well as audio-centric. I process primarily through these avenues while avoiding or ignoring and underutilizing my other capacities. In a conversation I've been having with Donna Williams about my son, I have come to realize that he may be about 50% meaning deaf and he intuits the rest of meaning through pattern, theme and feel. Donna says regarding Adam: "BUT he'll likely become such a master at this compensation he'll do it better than most non-auties ever could...that's enough to 'get by' receptively, but it'll be a challenge when people expect their dialogue to be responded to more specifically, more precisely, their instructions followed more accurately."

**The mind of man is the world's true dimension
And knowledge is the measure of the mind;
As the mind in her vast comprehension
Contains more worlds than all the world can find,
So knowledge doth itself far more extend
Than all the minds of men can comprehend. ---- *from A
Treaty of Human Learning by Fulke Grenville (1554-
1628)***

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TUESDAY, FEBRUARY 07, 2006

The Changing Face of Autism

“Thinking in Pictures,” is a phrase used long before Temple Grandin did for the title of her own book to describe the way she perceives the world. It is a phrase that is used by many people with various diagnosed learning disabilities, dyslexia, and autism spectrum disorder to describe the way they understand the world and how they think. In order to comfort parents, many artists, writers and scientists were able to achieve a great deal with some form of substantial learning disability: Hans Christian Anderson, Albert Einstein, Thomas Edison, Gustave Flaubert, Thomas Jefferson, Harvey Cusing, Auguste Rodin, Leonardo Da Vinci, George Patton, Ludwig Wittgenstein, William James, Woodrow Wilson, Nelson Rockefeler, William Butler Yeats, Lewis Carroll and someone we hear little about, Michael Faraday, who Thomas West introduces in his Overview of ***In the Mind’s Eye***.

In 1841, Michael Faraday was recognized as one of the leading scientific minds of Queen Victoria’s Britain (West). Faraday’s visual imagination, more akin to a poet than a scientist’s, his mind’s eye, is responsible “for many fundamental discoveries in chemistry and physics although he hated these specialist terms. He preferred to call himself a ‘philosopher.’” (West, p.29). His most known achievement was the concept of subtle electromagnetic “lines of force” as well as the concept of the nonvisible electromagnetic “field.” “So sensitive was Faraday to these ‘lines of force’ that for him they were ‘as real as matter.’ His powerful visual conception of these ideas provided the basis for James Clerk Maxwell’s famous mathematical equations which, in turn, provided the foundation for modern physics by defining the relationship between light, electricity and magnetism” (West, p.29). They were also the foundation for Einstein’s later theory of relativity. Faraday was horrible at mathematics and could not transcribe his intuitive, visual theories which are the basis for the way we live today – “Faraday perhaps the greatest electrical inventor of all, was completely innocent of mathematics, and he developed his notion of lines of force in a remarkably unsophisticated way, picturing almost like rubber bands (West). There was ambivalence towards Faraday in the scientific community – “showing their difficulty in taking seriously a scientist who was not a mathematician, no matter how original, productive or prescient the scientist may have been” (West, p.30).

By the 1860’s Maxwell, an admirer of Faraday, put his theories into mathematical analysis, which proved to be solid. “Maxwell

explicitly stated that the development of his own equations was merely a translation of Faraday's ideas into conventional mathematical form." (p.31).

In terms of thinking in pictures, Thomas West states, "One might wonder whether the time for this mode of thought has entirely passed, or whether there is much value to be gained by returning to it to deal with some difficult contemporary problems....A partial answer to this question might be obtained by reminding ourselves that 'sensitivity' to 'lines of force,' also seems partly to characterize the thought of Albert Einstein. Einstein's 'productive' thought was intensely visual in nature..." (West, p.33)

It is interesting now to note that Faraday expressed a learning disability, Einstein, possibly dyslexia or ASD (I'm still not sure whose poster child Einstein really is) and a notable bunch of leading thinkers had tremendous difficulty in typical learning environments. In reading about dyslexia and learning disabilities in Thomas West's *In The Mind's Eye*, I am reminded how many a disability is really a trend, perhaps a fabrication of our day in the sense that we identify absent or weak skills in people while ignoring strengths on the basis of what we value.

In the late 1800's, in a literary society, and until more recently, people with dyslexia were considered "stupid," or cognitively delayed. While many dyslexics will attest that they expend an enormous amount of energy compensating for their deficit, in other words, disguising it, it is also well recognized that people with dyslexia have a number of significant or special abilities, primarily visual-spatial ones. In the 1980's more prominent people began to reveal their dyslexia. "As dyslexia and learning disabilities have become more clearly identified with persons of high intelligence and ability, these conditions seem less frightening and people are less reluctant to admit the problem and seek appropriate help." (p.46) Today, we would hardly consider dyslexia a major "disorder" requiring a "cure." We have learned to appreciate the abilities and have come to learn to teach people with dyslexia so that we hardly think twice about it.

It is on this last point I will posit that Autism is the new Dyslexia. It is the New Trend in the disability realm -- being touted as an elusive disorder, a "behaviour," and prescribed limiting modals of teaching, while a multi-modal approach would respect the unique

learning styles and perceptions of the Autistic. I also propose that Autism, like Dyslexia-Past, is a construction of our society -- our expectations of what is considered “typical” behaviour and performance, as defined by our economy and educational system. In our economy we value language – our world is filled with marketing symbols and verbal messages. Language is also the *sine qua non* of development if we take a look at modern development “scales” as one example. Classrooms are taught primarily with text books. For children who do not think literally, the education system is quite a challenge. Further, as West notes, “our educational system, in focusing on remediation of certain disabilities, may be dealing with only half a condition, and the least interesting half. Somehow, a way needs to be found to deal with a very broad range of skill levels to address both unusual abilities and special difficulties in the same individuals” (p.41). We often note the people in history who have succeeded despite their disability, when we should be noting that they succeeded *because* of it. The value of particular abilities is time specific. Today, we value a literal and literary society. We value a homogenized society at the expense of possibly losing a huge pool of gifted, but unusual people. It is because of the fact that the brain is “wired” differently, for the reason that some people with ASD sense the world or see in pictures, that many major achievements have been realized.

I have argued earlier in this blog, and West seems to agree, that computerization of current systemized professions like law and medicine, will change the face of our economy yet again. If we have a society that appreciates visual-spatial intelligence, and an economy that rewards it, this may change the face of autism all together.

Autism and its prevalence of diagnosis because of changes in the DSM IV in 1993, has become a new economy unto itself – full of interventions, tests that are akin to snake-oil salesmen preying on unknowing and terrified parents. As a parent, I would like to see less hype in the Autism communities, and more *work* being done in appreciating our kids for who they are while obtaining the support and strategies they require. I prefer that my child not be treated as an elusive specimen requiring reams of data.

“Einstein first played with images in the visual right hemisphere, the apparent source of new ideas or perceptions of order, possibly relatively independently of conventional thought, current scientific

understanding and education....Such observations as Einstein's occur frequently in the literature of creativity. The concept of two modes of consciousness has been cropping up in the medial literature for at least a hundred years, particularly with reference to artists, musicians, and composers. What is new is that research on the two hemispheres of the brain has yielded such substantial evidence that serious investigators have been forced to reverse a major trend of scientific thought (behaviorism) and not only recognize once again, the concept of consciousness, but also entertain the concept that there are not one but two major modes of consciousness, each fundamentally different from the other – one that we know a little about, the other that we know almost nothing about." (p.26). In observing and appreciating my son's perceptual abilities and trying to understand them, I believe I am coming closer to understanding autism than many a scientist.

I feel we have lost sight of the big picture. I believe that noting intelligence – those who have made remarkable achievements because of the special wiring of their brain, need to be mentioned for the sake of understanding autism and learning disabilities in general. By remembering these marvellous stories of success, people with autism may be able to gain access to education they require and deserve. It took society to realize that prominent people of their time had dyslexia for it to receive different teaching approaches and strategies. I believe the same has to happen with autism.

I also believe that we may be focusing in too closely on autism – putting it under a microscope – to the detriment of those who have been diagnosed with it. "Sometimes if you focus in too closely, too early, you run the risk of losing sight of a larger pattern, one that is only visible by stepping back a distance, to get a view of several variations on a theme, a view of the pattern of the larger whole." (West, p.80). I think all parents can relate to viewing every little motion as something to do with an "autistic behaviour," rather than a typical course of development. It is also ironic that in doing so, we may be losing sight of the wonderful processing that is occurring but which we cannot see or understand.

I can hear the gasps as I write this. Yet, I think we all have a lot to learn from history. We all seem to acknowledge that Autism's landscape -- it's shape, our perspectives on it and more specifically, our children -- is changing from day to day. Let us all

keep an open mind for the benefit of our children.

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SATURDAY, FEBRUARY 04, 2006

The Colour Autism

Will the real Autism please stand up? I'm not sure what colour Autism we're talking about. Often, I hear that the goal for people with Autism, goals prepared by people without Autism is to render the person *with* Autism "indistinguishable from their peers" -- in other words, to make people with Autism appear more "normal."

I suppose it's an easy trap because we live (as parents, educators and the like) in the colour typical (well, this too is debateable). At cocktail parties, social dinners, if I get an audience interested in Autism, I usually get hit with the same array of questions:

1. How's Adam doing? (Like he's got a cold -- just when will he get *better*?)
2. Will Adam go to a normal school?
3. Will he go to university?
4. Will he get married?

These are honest questions coming from people who want a picture of Autism. They are the questions that we parents think about every day, maybe even aspire to -- we want our kids to be fulfilled and that may include these milestones. I know that I hold pretty much the same expectation for my son as I did before he was diagnosed with Autism except the frame has changed. I hold this expectation because I can also see that, with support, he can achieve these goals. The framing of expectations means that I don't change them, I just change how I view the journey.

If we are not paying attention, however, we can fall into the trap of making Autism appear more acceptable by making it look the same as the rest of us. In other words, these are the benchmarks of success in the colour typical. If people with Autism talk, that is more acceptable. If they can go to a "regular" school, that is even more acceptable. If they go to university or we call all Autistics "geniuses" we do so at the peril of those with Autism who cannot

or who are not so. We have to be careful what colour we are painting Autism and not be afraid to use a different hue.

I experienced this directly by visiting the MukiBaum Centre this week (see post titled "**Smack Dab in the Middle**") and by going to the Snoezelen Pool today. Watching other kids with Autism, teenagers, some kids with Cerebral Palsy, yelping with their teenage and toddler voices layered in glee, and my little Adam bouncing on Grandpa's lap, I saw the colour Autism...and it was beautiful.

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FRIDAY, FEBRUARY 03, 2006

Love

My husband comments, "wow, your last post is reeeealy long."

I know. Pardon me, dear readers, I've had a stressful week -- Adam's emergency trip to the dentist, a scheduled dental surgery in March with general anaesthesia, and the flu, an emotional visit to MukiBaum (see last post)...I've come to know love.

Two of my four stepchildren lived with me for two weeks while their mother was in Israel. Every night, I reveled in making dinner, planning dishes, chit chatting about our day. Adam relished in their company -- he particularly likes to call out his brother's name "Max," with an emphasis on the X as he holds it until it sounds like an S. Max and Maddie, his half-siblings would play with him in his room and snuggle with him on the couch, juggle for him every time he said "juggle!" and Max even tried to put him on the potty. Even though my husband was out most of those evenings, I had the kids wrapping around our circular kitchen table keeping us warm.

Donna, a part-time nanny who has been with me since Adam was six months old, has left. Her last day was January 30th. She, like Flor my other nanny (hey, there are five kids in this household) who has been with the family for fifteen years, has seen Adam before and after his diagnosis. You go through times like these, you really get to know someone.

On Wednesday, they all left. The kids' mom came back and Donna left. Adam was searching the hallways to no avail. He searched Wednesday and Thursday and by Thursday evening, the dinner table quiet with just the two of us again watching *Treehouse*, the desolate quiet sent me into tears.

We called the kids at their mom's. We got the voice mail. "Adam, say Max I miss you," I said.

"Max, I mi you," he slurred.

"Say Maddie I miss you."

"Maddie I mi you," his voice as melodious as mine.

There are times when the running up and down of stairs, the slamming of doors and coming in at one in the morning can get on my nerves. There were times when Donna was oversensitive or over-protective of Adam when I needed her to challenge him a little more.

I wonder what Adam thinks now that Donna is gone, Max and Maddie's rooms, dark. They say you never know what you are going to miss until it's gone.

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Smack Dab in the Middle

I remember seeing Nehama Baum introducing Dr. Oliver Sacks at The University of Toronto last fall. Her voice deep and soft with a Hebrew accent, red hair cascading her shoulders, I could barely see her eyes over the microphone as she strained to reach it. Yet despite her small frame, Ms. Baum in the world of disability is no bush leaguer. In fact, I am tempted to call her a goddess with those red locks -- a defender of sorts. A clinical psychologist and a lifelong advocate of the disabled, she is the mother of a now forty-two-year-old multi-handicapped son. Nehama founded The MukiBaum Centre for Complex Disabilities in Toronto twenty-five years ago. The Centre services children and adults with a dual

diagnosis (an intellectual disability and an emotional, behavioural or psychiatric disorder). Her programs provide treatment, education, sensory-motor therapy, music and art therapy, vocational training, adult day programs and a residential program. Some kids come to the day program from abusive backgrounds; some have Schizophrenia, others Down syndrome, Landau-Kleffner syndrome and some other rare disorders that we never hear about.

On this grey day in January, unusually warm at nearly nine degrees Celsius, I am invited to MukiBaum to visit the children's day program, and to consider curating a show of student and adult work. I meet MukiBaum fundraiser and events coordinator, Ashley Grant at the head office. Ashley introduces me to the art show idea while I can't help but notice the impressionable art on the walls – art executed by the so-called "disabled." Ashley speaks compellingly about Nehama and the tireless projects she has initiated, her voice swiftly switching from one related topic to another. Right down to business, we take her Volkswagen Golf to visit the day program which treats and educates people from five to twenty-one years of age.

We drive across Dufferin Avenue to the boxy schoolhouse, stuck in the middle of a Toronto-Italian neighbourhood, replete with arches and embellished fences that surround post-war bungalows. As we walk towards the main door, I noticed a garden obviously made by the students smack dab in the middle of this otherwise monotonous area.

As we sign in, busy yet cheerful staff greet us -- some students are coming in for their medications. I have to admit, seeing these BIG kids (BIG is anything over 10 to me) is a dose of reality, and I always like to take a nice clean swig of that. Here I am, right in the middle of more serious cases of Autism and other disabilities, witnessing a world not solely through my cute little pischer Adam waiting for me at home – a well-adjusted autistic four-year-old. As I brace myself, we walk by a heavy set pre-teen as we look for Michelle, head of the school. He scrutinizes us the entire time.

"Why did you come to visit us?" he asks curiously, his face ticking and mouth stuttering trying to form his next sentence, or perhaps recover from his last one. This is an obvious effort.

"We came for a tour today," replies Ashley cheerfully. "This is Estée."

"So you came to visit us?" he acknowledges happily, his neck snapping to the right.

"Yes! Nice to see you again," Ashely shakes his hand.

"Nice to meet you," I say, extending my hand next. He happily accepts it. I am ashamed to admit that for a few moments before this, I was uncertain of this child who was watching our every move upon entry. I had no idea if he would approach me aggressively. As he limply shook my hand, I recovered, but I was plainly reminded of what fear of the disabled felt like, and my own bias that I have carried all these years into this doorway, into this young man's hand. Despite having a child with Autism myself, the struggle is notable.

Out of breath enters Michelle Manning - a slim young woman with her brown hair drawn back hastily into a ponytail, t-shirt ruffled from a day's work. Her face is clear, her eyes are bright.

"Nice to meet you," she beams at me, hands clapping her lap like she's ready to go. I can already tell she is determined in situations that might beat down the best of us.

As we enter the hallway, pictures of faces on the wall strike me. One half of the face is cut from a magazine, the other half is drawn in by the students in order to match and then recognize the emotion. I will take that idea home, I think.

"You can see how much this student has progressed," says Michelle noticing my intrigue. She points to a picture of a happy face on the wall – the eyebrow, eye and mouth positioned a little too high, the face drawn too narrow. "Compare it with this one," she moves to another picture by the same student. "See how much better he matches here and the face is rounder." It is true. It is now a perfect match, but truth be told, I like the more abstract one purely for aesthetic reasons.

We move a few steps to the first classroom. The door is slightly ajar and I can peer inside.

"This class has some Aspergers, some Schizophrenia, some abused kids and Autism," she tells me. Without naming them, I can tell that she knows her students like the back of her hand perhaps by what she doesn't say about them.

"The class was initially a little aggressive. I would be on the phone across the hall and some not-so-appropriate words would be spilling out of there... I would be like 'no everything's okay' to the other person on the line." She chuckles at this like it's all in day's work. "Today the class is doing so much better." It sure looks like a good day to me. All the kids are facing the teacher and working studiously.

Michelle takes us down the hall from door to door. I take in the tired seventies Bauhaus hallway peppered with artwork. I notice a musty smell. The building is too old, I think. They need trees and lots more windows. I went to a school just like it -- spotted tile, plywood doors and brown grass. Yet, the school's inner spirit counters the structure.

I gawk curiously at the music class. Three teenage boys "play percussion." One stands twirling a bowl repetitively while looking out into the room, the other is playing "the spoons" on his lap as a teacher models silently, and yet another wanders our way towards the door. He comes close and then turns to an adjacent room until he is guided back to the group.

"He just got here two days ago," says Michelle. These same kids will be playing in some part of a MukiBaum theatre or band project in the future. One small step at a time.

Michelle works her way to the adjacent room where a teenage girl "Sally" (not her real name) swings. "Sally needs the swing several times a day." MukiBaum incorporated Sensory Integration Therapy several years ago into its programming. Michelle notes in the school's video that "sensory programming is built in every ten to fifteen minutes and within a year the kids can sit at their desks...at the beginning of the year, some kids are barely verbal and by the time they leave, they are completely verbal using words as a source of communication."

Sally who is Autistic, clutches a stuffed animal and looks relaxed. Her hair is matted, her face spotted with a few freckles. She wears

grey sweatpants and a dark green sweatshirt. She smiles while hunching over the teddy bear. There are two squishy spiked balls and Michelle decides to throw them to her. She catches and returns them with fair ease, becoming excited, squealing each time she catches.

"Do you this one or this one?" Michelle asks her, holding each ball up at a time.

"This one or this one," Sally echoes, reaching clearly for the ball she wants.

It falls my way and I toss it back to Sally and then we have to say goodbye. She says goodbye, the smile still there. I don't want to leave her just yet.

Michelle leads us to the gym where I peer through the tiny window -- the young men playing some sort of game with the teacher. They all look adept, running back and forth, the coach trying to tag them.

"I'm going to create a water room in here," Michelle says opposite me. But I want to watch the young men in the gym enjoying themselves. "A child can sit under a waterfall and feel that input while the water collects around them. There will also be a sprinkler."

"That will be great," I reply, now attentive. "The kids will really get off on that sprinkler," I joke, knowing how Adam loves to watch water or flick it with his hands to watch the droplets.

"Oh yeah," she acknowledges with a knowing snort.

We continue down the halls, as I listen to what goes on in each classroom, broken up by Michelle into an interesting array of progress, kinds of kids, and "issues" in each room. Some kids are verbal, others are not, some kids, just emerging with their words. Without naming any of the kids, I can tell Michelle knows them intimately and tracks every one of them from the time they enter the school until the day they leave. She is like a walking database and basin of endless devotion. It is akin to a mother's knowing – every fall, every triumph, the history of ever scar. I wonder if she does anything outside of her life at MukiBaum.

"We don't see the diagnosis or the behaviour," says Nehama in her video, "we see the person behind that." Even though Michelle notes the labels for my sake, without names or by pointing individuals out, I can see the ease with which she handles the kids. There is an obvious equality here, not unlike any other school. These are just "the kids."

Next, we visit various sensory rooms -- Snoezellen, the O.T. room, and the black-light room. The MukiBaum program is renowned for its individualized, multi-modal, and sensory-based programming. Through Sensory Integration Therapy, and the development of sensory "diets," children learn to develop coping strategies, emotional regulation and self-expression.

As we enter the black-light room, two students are resting -- a young woman with earphones who can hear us coming from down the hall, and the other, a young Asian man rests on a vibration mat.

"Do you want it on?" asks Michelle as we enter. I feel intrusive, seeping light in to their restful space.

"No," he says, his hands covering his eyes from the open door. I don't think she hears him.

"Here, I'll put it on."

"No!" he says again, sits up and moves away from her.

"Okay, the button is here if you want it."

Michelle continues to show me her dollar-store finds that help with body awareness and visual tracking. She tosses a spider ball to me that glows in the dark. Another great idea, I think. I can get a black light and some glow in the dark toys and help with Adam's body awareness by tossing this stuff to him, or putting it on his body. The black light helps delete other visual distraction, thereby helping one to visually track a tossed ball, for instance.

"Sweetie, you have to get up soon, your bus will be here," says Michelle to the girl with the earphones who is also Autistic.

"Want to feel better... Want to feel better," she presses her fingers between her eyes.

"You would feel tired all the time too if you didn't sleep all night," Michelle says of the girl who never sleeps. I decide not to tell my feeble story of waking up with Adam every hour and a half for two years.

"Are you tired?" I ask. She sits up and looks right at me.

"Yes."

"You have to go home now sweetie," a rotund bus driver walks in. He sits down beside the girl so she can adjust to leaving. "You can go to sleep at home, star." I want to burst into tears at his terms of endearment.

"Some drivers leave after three minutes of waiting," Michelle notes

"But this guy is great."

"The others leave and the kids have to wait until seven till their parents come and get them."

The lights of the black-light room come full on.

"Go!" says the young Asian man. And he is gone.

I am uneasy at my voyeurism, my curiosity of the Autistic because I have a son with Autism. I am gingerly walking the halls, trying to engage with some of these kids. Michelle, in her daily rigor, does it with absolute ease.

"Here the kids created a garden box and bench on AutoCAD. They have been cutting and preparing the wood. The project will take a year before it's finished," Michelle beams with pride, knowing the accomplishment despite the timeline.

"The weather doesn't always permit them to complete it. So, it will be a year." She shrugs happily. I am looking at the AutoCAD design posted on a bulletin board in awe. It might take me two years before I could finish the garden-box-bench-thing that the

students have designed. I notice a backroom and Michelle focuses her attention on it. There is a washbasin to the side.

"Our kids collected money this year from cans. They wrote letters in Italian and English (this is an Italian neighbourhood), and handed them out to all the homes. The neighbours were so great, they left out all their cans," her eyes become moist for an instant. "The kids took wagons and collected the cans, washed them and recycled them for money. The first time, they used the money to go to Canada's Wonderland. But the second time, they decided to donate the money to the Food Bank. You know, it's amazing -- some of these parent's already have to use the Food Bank, and here the kids are giving back to it."

I am listening and my heart is sinking. Food Banks? Cans for money? My version of the purposeful life changes like a lightening bolt. My definitions of success, obliterated in an instant. I have forgotten the purpose, the context, perhaps even with my own life, with Adam. These kids are being taught to be self-sufficient in the face of challenges I can barely imagine. They also know innately, the spirit of giving. This is humanity distilled to its purest, simplest essence – an ounce inspiration in the face of hopelessness. For these students, success may not include a university education and a corner office, or even a job as a letter carrier. But it will include a developing sense of self and pride.

"We teach the young people how to write resumes, how to interview, how to dress for the interview," Michelle continues as I peer into a vocational training class. The young men look adept and are talkative. One was writing purposefully at his desk. I learn that even a few of MukiBaum's students have entered college. "We also help with vocational training after they leave the day program."

The kids get on their buses and we say goodbye to Michelle so that I can meet Nehama back at head office. I think of Nehama saying "Inspiration comes day to day working with the students moment by moment." If any person is an inspiration, it is Michelle and her team who work tirelessly here at the day program.

Nehama greets me warmly after speaking to her husband on the phone in Hebrew. Her voice is calm her eyes, experienced. She is retiring next year, I learn. She wants to open a research facility to

study quality of life for families with disabilities. The sound of that is like an open meadow to my ears – something as a parent I would welcome. MukiBaum's mission is to "discover the human treasures within disability," Nehama tells me as she points to the marketing materials that reiterate it. "I am not interested, dare I say it, Mickey Mouse art," she says. "I want to show the treasure and talent inside these people.

She doesn't have to say a word more.

"I'll do it," I say. "and I want to see more."

Watch for us in October 2006. Lonsdale Gallery, Toronto.

[PERMALINK](#) POSTED BY ESTEE KLAR-WOLFOND AT 2/03/2006 05:10:00 PM 2
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WEDNESDAY, FEBRUARY 01, 2006

Response from Dr. Joseph Buxbaum

Dr. Joseph Buxbaum, who I cited in this blog (see my post "Autism and Paradox") does genetic research funded by NAAR. He kindly wrote a response to me personally, and I would like to give this opportunity for him to be heard:

The first thing to remember is that unlike some other disorders, there is evidence that behavioral interventions work in autism, at least in some cases. In addition, although it has certainly not been proven, the general thought is that early and more intensive intervention will be more effective than later and less intensive intervention. So, in complete contrast to what you suggest, I am of the thought that prenatal, perinatal and postnatal testing will allow for appropriate behavioral interventions for children at risk.

Note that the question of testing and of recurrence risk is the question that I most often receive from parents. I think this reflects the deep concern of parents with one seriously affected child that desire to have another child. I think we can be sure that none of the parents who ask me about these issues are the parents of a Bill Gates or an Albert Einstein.

*With best regards,
Joseph Buxbaum*

First, I would like to thank Dr. Buxbaum for his reply. As I've said in this and to NAAR directly, I believe it is important for open debate and dialogue. I still believe that the ethical question lingers with this research, even with Dr. Buxbaum's *intent* of earlier intervention. With the choice of whether or not to have another child with autism, there exists the likelihood that many a parent will choose not to. It is not that I don't believe in the right to choose. I do, however, believe in the GREAT need for autism awareness. Positive awareness. This is not about Bill Gates or Albert Einstein. This is about a human being -- many people with autism who appear "severe" have articulated in writing that they just don't understand why the world has so much trouble accepting them for their difference. I admit that before I had Adam, I may have chosen not to if I had been given the opportunity prenatally. However, after the fact, after I have learned so much *because* of Adam, I believe there is a greater need for putting the voices and people with disabilities at the forefront of this dialogue. Had I understood and been given the opportunity to KNOW people with disabilities when I was young, perhaps if they were integrated with me during my school years, I would not have grown up with preconceived prejudices about these members of our society. Too often, we hear the voices of parents and researchers. These are often bias voices. We need to hear from those with Autism and organizations like NAAR need to make way on their "stages."

This, Dr. Buxbaum, is where I think you've got it wrong. I believe these are complex issues that require years more of deliberation. Without having an opportunity to raise positive awareness about the "normal Joe" with autism, and making way for their point of view, the entire research goal is sorely incomplete, perhaps even misguided. In fact, I've asked NAAR why you as scientists are not asking those with autism what research they would like to see. Why are you deciding and why are the parents? This is my raison d'etre for raising awareness -- your semantics and that of NAAR's have political affect -- using words that express despair and a loss of hope(cures are for terminal illnesses, not for autism) are indeed closing many a school door for us RIGHT NOW. By suggesting that parents have "deep concerns" and arguing from this angle is not helping my child who is living, breathing and has a right to the same opportunities, education, and indeed additional supports as

needed within these environments. I am not saying that the job of the parent with a child with autism is easy. I *am* such a parent. Yet I deliberate every day at why obtaining a school placement with concurrent supports and intellectual rigour for my son is so difficult. Why is it that he cannot be integrated with his peers -- something from which he benefits? Why do schools that claim to service the "Learning Different" hum and ha when I mention the word AUTISM? Why is it that when schools claim that they are integrated, leave the child with autism largely alone? Why are IEP's so difficult to obtain and implement? Research and fundraising vernacular, in my view, is serving to marginalize my son, not advance his opportunities or understanding, and acceptance in the world. This is where you and organizations like NAAR can really help!! Help build understanding about autism that leads to tolerance. It is fine to state that the means to an end is "early intervention" and no one will argue with you. But I think you have to consider the people who are living with autism, how arguments are presented, who is truly guiding the research, and how your semantics effect societal attitudes toward disability as a whole.

Once again, I appreciate your response.

[Link](#) [PERMALINK](#) POSTED BY ESTEE KLAR-WOLFOND AT 2/01/2006 09:18:00 AM [7 COMMENTS](#) [LINKS TO THIS POST](#)

MONDAY, JANUARY 30, 2006

On Becoming a SELF

"Wa wa..woo. Wa Wa...woo." Adam's hands open and close to his own utterance of "quack quack..ribbet. Quack quack...ribbet," like he's using his hand as a puppet. In fact, on a Baby Einstein video, there is a little performance by a duck and a frog. You too might be intimate with this little act if you've watched Baby Einstein as much as we have in this house. I digress. The duck and the frog do their little bit until ALL OF A SUDDEN, the duck ribbets, and the frog quacks! Adam seems quite amused by this little interchange. So much so, he has enacted the scene with his very own hands.

I have a little theory. (I have many about autism, but I'm not autistic just a very close observer). Adam seems to be talking to

his hands at times. Sometimes his fingers do a little dance that wiggle in sync with *Mary Had A Little Lamb*, and other times, his hands open and close like those puppets to various dialogue. The obvious insight is that Adam has taken the scene and adopted it himself..the first stages of pretend play. But the real *a ha* for me is the realization that his hand is an extension of himself, let me press, could at times EVEN BE HIMSELF as he sees himself.

"Body awareness" is difficult, it is said, for people with autism. Tito Mukhopadhyay says it took him years before he realized he had a body. He discusses that he wondered if he lived just in his thoughts rather than in the physical world. Adam can see his hands. It is easier for him to imitate with an object, for instance, than it is with his body alone. I see Adam's hands and simultaneous dialogue a little deeper than sheer stereotypy. I see it as his practising dialogue and speaking through his hands. If he can't SEE himself talk, perhaps it is easier for him to WATCH himself through his hands. I consider that like an actor, who projects a character that is not himself, does in fact REFLECT his own true character. The PROJECTED OTHER and the SELF are entwined.

Projection/reflection through puppets is a technique often used with abused and traumatized children. It is easier for such a child, perhaps, to enact a scene without having to identify one's true nature, or character. Children often draw scenes to communicate because it is often too difficult to do so verbally, especially painful experiences.

Adam is projecting, practising, through his "characters," the duck and the frog. He is practising language. I am wondering that to talk to his hands, if he feels more grounded, more aware that HE IS HERE.

This is abstract stuff. I have a wonderful new supervisor who is BCBA but also has a Ph.D in sensory issues. I find her very sensitive to Adam and useful in the sense that Adam really wants to learn new skills now and she is doing a marvellous job with him - just one of those really good, intuitive teachers who has a little extra knowledge. Originally, the *type* of ABA, and later, VB we received was distasteful to me. All these so-called "experts" treated Adam as a pathology. No one seemed to understand that at 20 months of age, he needed to be happy, to play and understand the value of relationship. After I fired a bunch of "supervisors" Adam still learned skills all along the way because I believe that through his joy and learned ability to relate, he

began to express that he wanted to learn -- express his intrinsic motivation. Now, for things that are tougher and more demanding, I searched for a very skilled and sensitive person to join Laura (one of Adam's therapists) and the team to provide additional advice and training. Ms. Doc (I don't mean this is a derogatory way -- she is a lovely person but I don't want to disclose her name for her sake), has said to me many times "stereotypy is Adam's enemy." I don't necessarily like to coin it this way myself. In a way, I can definitely see how Adam stops learning if he engages in too much self-stimulation (I'm talking during learning time here, not when a person needs to wind down). However, I still feel strongly, that "STIMS" can serve important functions, which is why I watch him carefully and question. Is this something that Adam needs to explore or this an obsession? The lines are never clear, nay, always shifting.

Last night, five of us were sitting at the dinner table. Adam was tired and we were all chatting away to each other until he said loudly and clearly "Quiet please!" in a firm but polite tone. Indeed we all quieted down and ate our dinner. (!!!!!!!!)

[PERMALINK](#) POSTED BY ESTEE KLAR-WOLFOND AT 1/30/2006 04:35:00 PM 6
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SUNDAY, JANUARY 29, 2006

Neurotypical Syndrome

I'm not meaning to frighten you, but I think I have something going on and it might raise doubts...I don't know...I hope I don't raise something that you find wrong in yourself too...I haven't wanted to speak of it, well, not until all of this diagnostic stuff came out. Well here goes:

I seem to be putting on facades. I mean, everyone expects that I act and be a certain way. They expect me to say nice things even when I'm not thinking nice things. I guess this is called social etiquette, and it really exhausts me. Nevertheless, I lie. Yes, that's right. I tell someone I like their hair when I really hate it. Or I say "no you're not fat!" when it's darn sure that the person I said that to has put on a few. Or "nice to see you" when I really couldn't care if I saw you a hundred years from now. Lying to people is a number one symptom of Neurotypical Syndrome (NT). I read all

about it today.

"Those with Neurtotypical Syndrome express a qualitative impairment in being alone as manifested by at least two of the following:

- (a) lack of ability in spending time in the company of oneself for a long duration;
- (b) preoccupation with being with others, and social events."

Here's another one: I think I am superior. Yes, that's right. To anyone who cannot do as I do. In fact, there's no one as good as me. I believe this is called arrogance in the diagnostic criteria for NTS:

- (c) preoccupation with oneself, one's career, one's material and physical image;
- (d) preoccupation with one's social status, fame and income."

I do too many things and don't really focus on one. Instead of just focussing on one thing at a time, like I would like to do, I try to do too many things and it seems like I've got it all figured out, but I really don't. "Inability to focus intensively on one interest," is a definite symptom.

Judgement. I judge everyone. I judge based on whether you are like me or not like me. I expect everyone to blend together, to homogenize. If there is any difference, I become afraid and have to send that different person away. "Persistent intolerance of others," is another symptom.

I am highly impatient. I guess that's why I don't really think that hard about anything. It takes up too much time when I have to get my hair done. I thought about becoming a musician once, but eh, I just wanted to go to the clubs with my friends, instead. Not to mention impatient with others. I don't have time to listen to your bla bla!

I take things for granted. Um hum. Big time. I don't take time to "smell the flowers" or watch the rain fall... Who has time? I need to stand in line at Starbucks while I'm rushing to get to work!

It says in this manual I read today, that "the onset of Neurotypical

Disorder is prior to three years of age....there is also a strong fascination for social belonging to the point of chronic lying...In most cases, there is an associated diagnosis of depression, substance-related disorders, sedative dependence, and other behavioural symptoms including inability to listen carefully to others, difficulty with empathy, and a deep fear of heterogeneity."

There were more symptoms in this manual I read ...I'm too upset to write them all down. You will have to look them up in the DSM. If you have more than three symptoms, I think that means you are lower functioning. If you have just one or two, there's more hope. I am in BIG trouble. I am not normal!!!

[PERMALINK](#) POSTED BY ESTEE KLAR-WOLFOND AT 1/29/2006 10:38:00 PM 8
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FRIDAY, JANUARY 27, 2006

Dancing

"One two three four five six seven...basic, that's good. Now side to side, open....crossover. Turn in, comb, check, two turns, arm up...snap hand..." The music is rapid as reams of instructions fly at me like words dissipating into thin air...bla bla blee bla bla...

I can't THINK and dance. I have to FEEL the dance. Taking my first salsa lesson yesterday, my instructor said I accomplished two levels in one session. Somehow, I have the music in me and I can intuitively feel dance steps. But when broken down piece by piece, I think TOO much and my feet stumble. Give me the essence and give me the music, but translate dancing into words and I get all mixed up.

Adam enjoys "dancing." I hold him in my arms and make him extend his arm and hold my hand like a gentleman. "Da, de da, de da, de da..." Our version of the dance is mommy bobbing up and down the hallway with Adam in my arms. He enjoys the bobbing, and enjoys echoing the "da, de da, de da..." We do this a few times before I get winded --he's almost four and getting a little heavy.

I am still Adam's needed dance partner. We, as his teachers (he has a few), teach him how to feel things. In order to learn HOW to play, dance, put something together he still needs us to prompt

him from behind (This is the best way to teach independent skills. If the child sees you prompting from in front, it is an extra step because you are now associated with the action. If prompted from behind, I can fade myself and my physical prompts faster. Adam gets the feel, faster). I do this from putting on socks...1st we put in the thumbs, 2nd we open the sock, 3rd we put the sock over our toes, and 4th we pull the sock on. I do a hand-over-hand prompt until the pull part. (He still has trouble opening a tight sock and putting it independently over his toes). I am "backward chaining" my teaching so that he gets each part of it on his own. His fine motor and bilateral skills are still a little weak, but coming along. Soon, I am sure he will show me just what he can do! But, if I just sat in front of Adam and recited instructions he would be peering out the window! In autism, the steps are broken down, but the tactile sense, the learning by doing, is the easiest way for him to "get it"...with lots of practise!

"Can't do it for myself. Can't do is as myself. Can't do it by myself." The words of Donna William's from her book [Exposure Anxiety](#) reverberate in my head pretty much all the time now. Everytime Adam walks away and observes from the periphery of an activity and needs to be nudged in, I think about how he needs the little push on his back to walk again. I think about the movie *AWAKENINGS* from Oliver Sack's novel, and remember the catatonic woman who rose from her chair because of the pattern on the floor. The pattern was the impetus, the fluidity, the guide to get her to the window. When the pattern stopped, so did she. When Adam stops in his tracks and watches like he is on his way to something, and then just stops for no apparent reason, I think of those similar examples. If prompting, a little nudge, gets him back into things, so be it. Hopefully, he will find his own way to nudge himself back into the world.

Today, Adam started a music class. There was no aide, no shadow, but a nice small group of five little children. There were some imaginative movements, and musical instruments. I was so proud of him and always want to keep him in some activities without an aide because I can see how he was watching the teacher, watching the children, joined in the circle independently, expressed some delayed imitation! (We can practise banging on the drum at the same time as everyone else at home -- coordinated activities also have to be practised). Most of all, he was gleaming again. When Adam gleams, everyone smiles. Adam is practising his skills on his

own, and I think that he has to feel that he can do it without anyone else's help. Right now, he is beginning to and I don't always want to get in the way of that.

[PERMALINK](#) POSTED BY ESTEE KLAR-WOLFOND AT 1/27/2006 05:30:00 PM 1
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Between a Rock and a Hard Place

I run, with therapists, a facilitated playgroup at my home. It has been going very well -- a mix of kids with and without autism. But I have to admit, keeping the mix is getting harder.

Yesterday, a mom pulled her kid (autistic) without warning because there were other programs she enrolled him in -- she said. That really irked me -- not because people naturally move on, but because she did this without warning, so that the dynamic of the group is now affected.

I am also looking for a new therapist too...one of my leads is pregnant, and I'm finding it really hard finding a therapist with experience who is willing to work fifteen hours a week.

Running a home-based program, without agency support is rewarding, frustrating and terrifying some days, like all of Adam's progress and development is at stake because of what I do, or don't do for him. If I hire an agency here in Ontario, I don't receive adequate communication, (my team talks weekly, meets bi-weekly), and the therapists (the one's I've met), have been doing something that looks and talks like ABA, but it's not ABA.

I think most parents who use agencies, go to schools, or try to find play groups might also feel caught between a rock and a hard place. Speaking for myself, I feel we have to seep through the system, find a way to glide through the cracks, in order to get the services and education that Adam requires. Work with the system the best you can, I say to myself, and after that, do it yourself.

Today, tears well in my eyes about Adam's social world...he is just beginning to really observe and WANT to do what his peers are doing. This wouldn't have happened without our playgroup. And now, it seems to be falling apart. So I consider charging the

\$250.00 that the other Facilitated Play Groups here in Ontario charge. But how on earth will that attract the parents of kids without Autism? The whole thing seems screwed up and no matter how hard we try, this will stigmatize Adam.

Adam got his passport photo taken the other day. He obeyed the photographer, taking a step on to the stool, standing still, facing him. He gleamed a smile. One of the store clerks insisted strongly that Adam close his mouth (it was hardly open).

"Close your mouth!" Adam wiggled, still smiling.

"Close your mouth! They won't accept the photo like that. Close your mouth!" The stout little man with no hair pursed his lips. His angular features punctuating his words, and effeminate voice beginning to feel like steel wool on my skin.

Finally, I blurted, "it's hard for him...he has Autism." My gut sank. For all of my wishes to not label Adam, I labeled him anyway. I suppose I could have just said, "it's difficult for him," without any further explanation. Yet, it was his utter lack of empathy, or obeservation, or assumption, that I found repulsive. This is the dilemma -- to not identify Adam in times of need (I'm not saying this was a time of need, but there will be other times), will not allow him any special acommodation or support he may need. To identify him (his label), will lock him out of other opportunities that may benefit him.

"Close your mouth!" shouted a number of times at Adam felt totally foreign, and I realized how difficult it will be for him for a while. Or maybe me.

[PERMALINK](#) POSTED BY ESTEE KLAR-WOLFOND AT 1/27/2006 07:40:00 AM 5
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WEDNESDAY, JANUARY 25, 2006

Starry Night

Adam loves [Vincent Van Gogh's Starry Night](#). Since he was three. Morgan, his of his art "instructor" (we do art -- I'm a curator, what can I say), brings cards with various paintings and they talk about them. Adam loves to label even the more abstract ones, telling me

that he has a sense of representation (symbol recognition is another way to say that). Morgan thought it would be good to begin with the impressionists. But when she pulled out *Starry Night* on the floor, he twisted his body and peered at it from various angles -- something he did when he reamed off his letters and numbers that were on the floor at 11 months of age. I believe the sweeping, rough, and swirling short lines (thus adding to the feeling of movement) must *actually* move for Adam -- the undulating night sky quivers.

Then, I saw a preview for Little Einstein. Eureka! There it was...the Rocketship swooshes into Van Gogh's sky -- the swirling starry night. Needless to say, Adam stops dead in his tracks when that preview comes on. There is this aspect of Van Gogh's art that leads me to think that theories he was autistic might be true. He created areas of flat unbroken colour -- a revolutionary approach to art-making that was viewed as crude at the time. His stark figures are outlined with dark cloisonne line against flat backgrounds or busy patterned walls that nearly distract the eye from the subject. Or consider *The Night Cafe*, or *The Yellow Room*, with seemingly distorted (but logically true) perspective, and harsh disharmonies of colour. Van Gogh "could not be taught" and therefore, was a self-taught artist. Today, he would be classified in the "Outsider Art" genre. He was later plagued with seizures, unsettled relationships, and except for a short, tumultuous stint with Gauguin, lived alone.

So I have to wonder: does Van Gogh's *Starry Night* appeal to my little Adam for the reason that they might share a similar perception? Adam has expanded (on his own) his repertoire of painting techniques -- studying the brush and using various sides of it, and lately, splaying the paint on the paper like Jackson Pollock. So I eagerly wait and see if he can represent his experiences on paper.

When my eyes get tired these days, the outer edges of objects begin to quiver (I've made an optometrist appointment). Instead of finding it annoying (which it can be), I stop and revel in another way of seeing things.

Decoding Perception

In my previous post, **Body and Mind**, I try to decode Adam's perceptions and experiences through the eyes of Tito Mukhopadhyay, autistic author of several books including **The Mind Tree**.

This is all about understanding autism and decoding perception -- someone else's. In Adam's early years I watch him curiously, learning from others how he might be experiencing his environment. But even these clues from Tito are not necessarily *Adam's* experiences.

Autism as "mystery" is at the heart of our fascination. Science thinks it can solve the "mysteries" of the brain. In 1977, [Noam Chomsky](#) was not optimistic about the future of brain research. He said: "It may very well be that, among the theories we are unable to attain by our biological endowment, there is included the theory of mind...it will appear that human beings have mystical, unintelligible properties because we, as biological organisms, will not have within our range the theory that would, in fact, explain it."

Each scientific community -- neurology, psychology and so on have so many of their own theories about the brain, and yet even today, all of it still remains pretty much a *mystery*. Autism can be viewed as the embodiment of this metaphor. We are fascinated by autism for what it shows us we can be (ability) for as much as what is different. The idiosyncratic language, the sensory issues (which seem to be an oversensitivity and heightened awareness of the environment), to non-verbal intelligence...our society is curious to know *how* we tick -- and autism is a part of this search. We are similarly interested in a stroke victim's ability to adapt -- using different parts of the brain to relearn speech is a good example. A real mystery is also that -- human adaptability. Perception is elusive. Yet, it is all we have -- seeing how an artist views the world can shed light on how we view it -- it can make our world, our perceptions more three-dimensional.

What is perception? Is it a visual world? Is it something that happens to us? Is it tactile? Certainly, perception is different for all of us... the blind perceive and experience the world differently

from those who are not. The way they describe their perceptions is not at all the way I might describe the same experience.

Perception is the biological as well as the psychological, and as much as biology takes a part in autistic perception, the psychological and environmental factors also take a role. In addition, there seems to be some universal perceptual consensus -- for example, we all agree what "red" looks like so we, for the most part, have a universal perceptual language. Do we *feel* red the same way? The experience, and language is different for a blind person who has never seen red, but who may interpret red. That said, a colour-blind person also has no concept of that visual language. A full understanding of the mind is intangible. We may be able to plot physical and chemical events that an object triggers in the retina and in the perceptual centre of the brain, but will detailed knowledge of which nerves fire and the patterns of nerve activity ever adequately describe the *experience* of seeing the object?"

I consider Autism and human evolution -- a language distilled, that is, a different language, non-verbal, visual, musical, mathematical -- a language without words. I've heard of speculations that human language will evolve from verbal language to a sort-of computer movement language -- highly visual. How have computers even altered the way we think and the way we communicate today? Perhaps that language is easier to comprehend for those with autism?

Adam went to the dentist a couple of days ago. It was not pretty. He's been pretty good so far, but for whatever reason, the dentist, before showing his face to Adam, went right into his mouth from behind, holding his head down with his arm while his purple-gloved hands pried Adam's mouth open. Adam was terrified, I think, because of this. It is like when Henry approaches him from the rear to put on a shirt with a narrow hole and Adam can't see for a couple of moments...not only could he not see Henry coming from behind, but all of a sudden, he is blinded and confined by the hole -- and again, he is terrified. Trying to put the pieces together, I am presuming that Adam is highly visual and anything that impairs this skill that he has come to over-rely on, is exceptionally scary. If all of a sudden I lost my sight, I would be afraid. If I lost the feeling of my legs, I would be terrified. We come to *rely* on our strengths. Adam's strength is his sight -- but what of his perception? This is what I'm always wondering about -- what does

Adam see that I cannot understand? Is this sense like looking through a thick lense -- blurred and images melded together? Or his his sense so sharp and lucid -- that the sharpness of colour and line can be painful? I would like to look through this lense one day. The closest I've come is through art. For me, it is the unviersal non-verbal language. Or music. Right now, Adam does not verbally offer many clues, so what I do is decode his behaviour. Like the curator of art that I once was, I decode perception.

[PERMALINK](#) POSTED BY ESTEE KLAR-WOLFOND AT 1/25/2006 10:37:00 AM 5
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SUNDAY, JANUARY 22, 2006

Body and Mind

I think about the times when I live just in my head -- I can sit for days and read, and write -- making unconscious trips to the kitchen for yet another coffee with too much sugar. A month or two of this can pass until I decide it might be a good idea to reconnect with my body in a yoga class or two. While goading my limbs to "enter a pose" just a little further between grunts I realize my body is trying to connect with my mind -- trying to *just let go* in blissful symbiosis. I am shocked at the huge disconnect between my body and mind and wonder where *I've* been.

I try to give this feeble analogy in an attempt to understand what it might feel like for those with autism -- where body awareness is not altogether intact. I struggle to understand a lack of body awareness that otherwise comes so naturally to me.

Tito Mukhopadhyay states that no one autistic person can follow a command if they are not aware that they have a body. In autism, this disconnect seems to be magnified -- of "not knowing where my knee is, if I even have a knee, when my instructor demands 'touch your knee.'" I considered his responses to Biklen's questions and reflected upon Adam's life:

"Am I made of thoughts or am I made of my body? I usually experience either, one at a time. I had to shut my eyes on the road because the whole road seemed to become so alive, although my logic told me that it could not be so. Only when my mother took me to some other lane, could I open my eyes...I had

"to learn about my body, because I could not feel the pain, or realize it, till I was taught. So without knowing anything about the body, how could I apply parts to do different activities, which people do? So when someone asks you to do something manually, I get clumsy. You have to map yourself, map the part of the body you are going to use and time it up, because someone is waiting for you to complete the task. You know that your intelligence or stupidity would get measured by that performance of yours." (p.122 Biklen)

I think of all the times Adam squints his eyes. I have always called him a "visual" child, he can read, decode, and his primary stims (self-stimulatory behaviour) are visual ones. But now I consider that he is also shutting his eyes to feel the world, for to see it is just *too much information*, thereby making the world too overwhelming to feel and comprehend. I also consider all those standarized testing situations that have evaluated Adam's performance without considering the difficulty of body awareness.

"Games can get awfully puzzling. Exercising can work better because you are sure what you are supposed to do. Limited boundaries of movement can save a lot of strain."

I think of all the activities that should be close-ended and structured so that Adam can learn to become competent, and later, more fluid in other settings. The speed of play in a children's playground is still too much for Adam. He observes, I feel he is trying to join, but he doesn't know HOW to join or what to do. If the game was close-ended and more structured, we could teach Adam how to join in play and he could feel more competent and happy with himself, thus enjoying the experience.

On the association of Mental Retardation and Autism:

*"It is the most disgraceful label which the term Autism is associated with. Yes, some areas remain less developed because of a lack of associating the mind with the body and environment. I had been labeled as mentally retarded when I had my first encounter with the psychologist. I was three years old then. I was not able to apply my knowledge although I could understand perfectly what was being asked....I do not blame the psychologist. **Seeing is believing** [bold mine]. They should begin with the attitude that the client is understanding him and*

not wonder where to start or what to start. Start with anything. And grow around that anything. Talk with an easy tone because the client is not hearing impaired. Trust that the client is capable of understanding. And then 'Carry on.'"

I think of all the myths about autism as a parent I try to diffuse -- the myth that 2/3 of the autistic population is mentally retarded, the myth of low functioning autism and high functioning autism -- the view that LFA renders that person "less" human or intelligent or for that matter, capable. It really just is about the amount of obstacles we have to learning -- some have more, some have less.

"It took me many years to realize that I have a body. I think that is not because of my preoccupation with other thoughts. I was totally aware of sounds and colours, which my senses picked up for me...Even this day sometimes I feel that I am walking without legs...Many Autistic people need to be helped because of this reason. How can they perform a task using hands if they just cannot feel them? And without any feeling how should they have control over them?...as I grew up and started my mirror gazing, I became more aware of my looks and size. I had a favourite bed sheet which I loved to wrap around my body so that I could enjoy it....When I learnt that a swing was not anything which could kill you, I started using it a great deal. Half my school hours are spent on the swing. I enjoy climbing up a staircase also because the gravity acts on my body as I apply myself against it. Escalators are wonderful as I can be sure of getting the feeling of my body gradually. At home a little rocking and spinning also helps. Thank god mother doesn't stop me." (p.138)

This tells me the importance of Occupational Therapy in Adam's life -- his need to experience and feel his body as an essential component to completing the simplest tasks to problem solving. It tells us that spinning isn't a "behaviour" that needs to be "extinguished," but an essential need for the person autistic to KNOW themselves, to feel alive. Providing for this makes the world easier to understand and easier to join. The goal for Adam is...SELF AWARENESS.

"To think about it, I recall that I learnt every skill through touch method. I have a problem imitating any movement by looking at people performing or mapping my body accordingly to the instructions given to me...I am stressing on how to do and not

what to do because no one should have the impression that I did not know what to do. Different skills need different time to practise depending on the feeling of awareness of that part of the body. Sometimes I feel my legs better than the hands. But I needed my mother's help to learn the tricycle. She had to manually push my legs because I could not do the movement. It needed some practise before I could ride it independently."

(p.138)

I am always doing this with Adam. I am pushing and squeezing his legs so he can FEEL them -- in hopes that he will eventually correlate the feeling to the action in his own mind. He has pedaled independently a few times now...but I expect it to be a few more months because it's not something we practise intensively. I also believe that we should teach in the easiest possible manner for the learner -- we want learning to be as fluid as possible. Adam is a kinesthetic learner -- learning by doing. If he needs me to nudge him from behind, some hand over hand -- whatever it takes to get him started and eventually independent, is the right way to teach.

"Life can become very boring for an Autistic person if he does not learn how to play -- touch is always a big help when an activity is new for me. Only through practise and gradual fading of the touch the activity can be done independently."

It's what I always tell people...**Autism is not NOT KNOWING, it is not knowing HOW.** We teach Adam HOW to do everything. A lot of times, he can generalize himself afterwards. He is lucky in this regard.

"I could not point at objects for many reasons. The most important reason is that I had very little sensation of my body. So the technique of moving my right handed needed control over the ball and socket joint of the shoulder and then hinge joint of my elbow and finally fold the other fingers and keep the point finger out...It is an essential skill because I can go to a shop [now] and point out exactly what I want. I can point to my forehead and show the doctor exactly where I had got the knock because he should not end up treating my nose." (p.133)

Although Adam is verbal, this is still an important skills for intention. "Show me" skills are important -- even if he can't find

the word. He is okay at pointing to concrete objects close up. We have to work on those things that are further away. I like how Tito describes all the steps that one simple point requires. It illuminates the laborious steps to be learned for an Autistic person.

"Exposure to variations be it clothes or food, place or timetable, help us to, if not love, but to tolerate and understand our role in situations better." (p. 141)

I've mentioned it before in this blog. If this is one thing we learned early if even by default, is to expose Adam to EVERYTHING. His life, aside from his special training at home, is no different than any other child's. He goes to regular school, he has a playgroup, he goes to the Ice Capades, children's performances, the art gallery, and travels on planes. He is flexible and enjoys the novelty.

"Many Autistic people try to cut away the various inputs of sounds by producing their own convenient sounds so that the other sounds get to the background and the sound which he is making gets all the attention and concentration. He should not get away with that because it would lead him to nowhere other than get entangled in its own intoxicating effect leading him to get deeper trapped in the obsessive nature of that sound....That can make his life miserable."

Adam babbles a lot. I use Tito's suggestion intuitively -- of turning on the radio, or changing the environment to bring Adam back to the world. I have to be careful, though. His articulation is sometimes off, and I try to recognize when he's actually trying to say a full sentence. If it's repetitive, I can usually tell that it's self-preservation.

"Mother asked me what I would like to do next, or what I shall like to have for dinner...Later in life I had faced similar questions about my likes and preferences. I kept myself prepared by finding a more honest answer before telling somebody that I liked something. I have seen people asking other Autistic people, showing two objects and inquiring whether they would have this or that. And the Autistic person randomly replies this or that. Nobody answers "both," although some may not mind having both. When the prospect of an answer is so narrow and the tendency to escape is more, how could the person grow and organize his reasons? So although it is difficult to face an open

question, it should be introduced. Escapism is the doom for any development."

Here I think of the perils of Verbal Behaviour methods. We have stumbled into the same roadblocks with Adam, trying to introduce "choice" questions. Instructors (thankfully not mine -- Adam has a great therapist named Laura) can get so lost and wrapped up in their goal for the lesson (child to make a clear choice from two objects), that they can forget that the child may want neither or both and the lesson hasn't been set up for that possibility. It might be better to enable Adam by using textual and pictoral choice boards, so that he understands that he is free to express himself, rather than just meet an "expectation." We also have to be open to his own responses, the ones we don't expect.

"There are many approaches to a question. 'What is this?' is a very rudimentary approach to communication. When my speech therapist asked me 'What is this?' and tried to get an answer out of me by telling me more than half the answer that 'this is a _____' he forgot that I had already authored more than a hundred poems by then and two of them were already published. Naturally, I did not like this two-year-old treatment just because he had the advantage of speech. I could have started my answer when he was showing me a picture of the cat like this ---

*Call me a cat
Or call me a feline
Call me any name
I shall haunt
Your doors at night
Now, then and again.*

That would be an open-ended response to any question rather than restricting the wonderful prospect of answering with a sentence like 'this is a _____. My ego is always important matter to me." (p.136)

Self-awareness, ego, self-mastery, competence. These are the ultimate goals for helping our children. This is the GRAIL. And it is attainable.

CONNECTION ALERT!

An eight year old boy wanders in the room with toys and then beelines towards *Cranium*.

"Would you like me to play that with you?" asks the therapist.

"I most certainly would," replies the boy unpacking the box on an opposite table to her. His hair is cut in a kind-of mohawk, sticking up at the crown like ostrich plume. His face is changing, even I can tell...he is slowly losing his cherub cheeks and soon he will look like a teenager. Our eyes meet for an instant. I sit furtively, pretending to read my book.

"First, we're going to talk about our engines."

"Okay...I'm with you," he replies sprightly.

"Can you please come over here and sit in the chair?" He sits on a tricycle next to the chair.

"I need you to sit here in the chair." After some shuffling, he sits.

"How are you feeling about Cranium?"

"Excited."

"Right, excited. And how fast is your engine running, too fast or too slow?"

"Too fast."

"But that's okay because you are excited."

"Right."

"Tell me something that makes you feel sad."

"CONNECTION ALERT!" he blurts.

"Can you show me something that makes you sad?" The therapist has the boy enact a number of scenarios that arouse different emotional states in him. When he doesn't quite know an answer (I am guessing here), when something doesn't make sense to him, or if something makes all too much sense -- perhaps too arousing to mention -- he blurts "CONNECTION ALERT!"

What a strategy! I am thinking of all the times that I get stumped, confused, over-emotional and I try to cover it up and be cool. How many of us do things we don't really want to do, particularly in the social realm, or act one way when we feel another? If I could yell "CONNECTION ALERT!" every time I stumbled inside, maybe people would understand me and leave well enough alone.

The therapist, for the purposes of teaching emotional/self regulation and emotion recognition in tandem with pretend scenarios (brilliantly taught, I might add), didn't acknowledge his *connection alerts*, but rather, kept probing him on how he was feeling in that moment to get him to recognize himself. By recognizing our emotional states, we can self-regulate. Further, we can become self-aware.

Emotional/self regulation is one of the challenges in autism. Michael Moon, a musician/composer/presenter/astrologist with autism, presented at The Muki Baum Centre last Thursday night in Toronto. Michael is 38 years old and notes that it wasn't until he learned he had autism that he could begin to become self-aware and in control of his future. For the purposes of not wanting to label him, his mother, who was present, eschewed the system (i.e.; believing that he could do anything) and didn't tell Michael of his autism. But he states that his learning about it enabled him to understand himself and overcome the obstacles that confronted him in life.

It seems to me that the people I've read and met with autism get really good at understanding what makes us all tick. If you had a challenge in an area and were compelled to learn everything about it, then you would likely become so proficient at it. This is how I'm feeling about everyone I've mentioned in my blog thus far. People with autism can, in fact, understand what it means to be human perhaps better than "the rest" of us.

FRIDAY, JANUARY 20, 2006

I Know What I Want and Want What I Know

To know what we want, or think we know what we want is largely based on what we know. It isn't any different for someone with autism.

Adam asked for eggs for breakfast. "Eggs!" he blurted, checking out the kitchen counter. All by himself. He didn't see an egg, he asked for one. I made him one (he is into them sunny side up). He devoured it. He saw it a few times before and asked for it.

I am lucky that at the first sign of Adam's fussiness over food, I offered different types of food. He got used to various textures early on because I didn't give him any choice but to try different things. I admit it wasn't always easy. Today, Adam sometimes grows curious at what I am eating. A couple of months ago, he saw me eating an egg sunny-side up and he wanted a try....he ended up eating the whole egg! Pretty awesome for a guy who cringed at jiggly, slimy things.

Jonathan Lerman began to draw suddenly at the age of ten -- completely non-verbal at that time, no one understood or even realized that Jonathan had a rich "inner life." At an afterschool program, he had a serendipitous date with a piece of charcoal and paper and he began to draw -- not crude backgrounds and stick figures, but sophisticated renditions of faces. One major message his parents give to others is "expose your [autistic] child to everything because you never know what's going to happen."

There is a fundamental message here -- do not coop Adam up in special schools, do not isolate him because it might be hard [on me], and expose him to every opportunity because I **MUST ASSUME THAT HE IS COMPETENT**. Further, it is known that "learning by doing" as opposed to ONLY sitting at a table is really the most efficient and successful way to learn for many people labeled autistic (their account, not mine -- read Sue Rubin on kinesthetic learning). As a mom, I can see that Adam definitely benefits by generalizing skills as a first option to teaching, not after spending hours at a table. I know that every person must learn

differently, but if we stand by the belief that our children are competent, then we must approach teaching this way. Constantly practising skills makes Adam's learning more successful in a setting and yes, sometimes they have to be taught "in isolation" if a particular skill requires extra attention.

I don't think I know very much -- like most of us, I haven't experienced, yet, everything I've wanted to. In fact, I cringe at how little I know -- how there is so much more to read and so much more to learn from others. I am a product of my upbringing, my standard of living, and what I expose myself to daily. I went to a salsa lesson yesterday and saw a whole new world of people taking the night to enjoy a couple of hours of merengue with each other -- wow -- what am I missing?! There is a whole other subculture here. Anyway, my simple point is this: we are the sum of our experiences and it is imperative to provide our children with as many as we can offer.

Paul Collins in his book **Not Even Wrong: Adventures in Autism** (another great one I highly recommend), is where I first learned of "The Wild Boy," later named Peter. He begins his book with this story and as an historian mirrors his studies against the development of his own son with autism. He notes that Peter was first found as a creature in the Black Forest lurking on the riverbank in 1725. Among the forest "was the rarest of wild animals: a human." It is a story of this young boy, with autistic traits who had run away -- left to his own devices in the wilderness. When he was found, he was summoned to London, dressed to meet aristocracy. He was brought to civilization although he spent years learning to adapt like other animals, was taught new skills which he learned to a certain extent: "*The wild boy who had been living in the trees just months before was to receive the finest education in the land... Many years later, Peter had run away and was picked up in Norwich:*

"Who are you?"

"Wild man."

"Where are you found?"

"Hanover."

"Who is your father?"

"King George."

"What is your name?"

"Pe-ter."

*A dog was pointed at.
"What is that?"
"Bow wow."
He was then asked to name the family horse.
"Cuckow."*

He understand everything he hears, the mistress assured...And he could sing too: he loved songs and would rattle his collar tag in joy when music was played...when the song was over and the cathechism of simple questions exhausted, the [now] old man would fall silent and would not say anything more. (Paul Collins pp. 44-45).

The wild boy couldn't be entirely taken out of Peter, but it is obvious that he was "tamed," or civilized to a certain extent that as an old man, he could answer these questions.

P.S. Tabula Rasa: A phrase (meaning blank writing tablet) from the Latin translation of Aristotle's **De anima**. It does **not** occur in Locke's **Essay** (1690), though it is present in Pierre Coste's French translation (1700). The **Essay**, in its statement of the empiricist these that there is nothing in the mind that was not previously in the senses, speaks rather of the mind at birth as 'white paper' awaiting ideas from experience. (from Oxford Companion to Philosophy edited by Ted Honderich)

P.S.S. Thanks to everyone's intelligent and inquisitive comments and posts. It gets us all thinking!!

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THURSDAY, JANUARY 19, 2006

The Importance of Presuming Competence

Biklen, from who I borrowed the title for this post, sums it up in that sentence -- how important it is for us to assume that ALL autistic people are competent and intelligent. I've written it before and I will keep writing it.

I believe that to coin autism in any negative sense is not our

perogative -- it is the right of those with autism to tell us like it is, not for us to interpret their behaviour ("behavioural deficits") or presume that typical responses are the only or *right* responses. I believe that the decisions to be made on what should be done in the research and therapeutic fields should be determined by those with autism. Reading the stories of Richard Attfield, Sue Rubin, Donna Williams, Temple Grandin, Stephen Shore, Lucy Blackthorn and many others for the exhibit I put together of Jonathan Lerman (I prepared an exhibit upstairs titled "The Voices of Autism" with floating quotes from those labelled with autism), has only made my opinions more resolute.

As organizations, teachers, fundraisers and parents, we MUST make way for these accounts. We must provide supports (determined by those with autism who decide what supports they need) to enable people with autism live successful lives. As I presented in previous posts, the success of the person classified autistic lies in our supports, our school systems. If our organizations for autism only present in terms that make autism sound TERMINAL (cures should be sought for cancer, not necessarily for autism), this will effect the way people think about the people labeled with it -- without hope. I believe that the act of advocating the rights of our children is a priority in this "journey."

"In its simplest articulation, presuming competence means that the outsider regards the person labeled autistic as a thinking, feeling person. This is precisely the stance that every educator must take -- failing to adopt this posture, the teacher would forever doubt whether to try to educate at all, and would likely be quick to give up the effort. Aside from the optimism it implies, another benefit of presuming competence framework over a deficit orientation -- where particular levels of incompetence (e.g., belief that the person is incapable of learning to read or lacks the ability to appreciate other people's perspectives) are presumed -- is that when a student does not reveal the competence a teacher expects, the teacher is required to turn inward and ask, "What other approach can I try?" (Biklen, p. 73)

Of all the stories I've read, it is interesting to note that so-called "behavioural deficits" have been often identified as the result of anger and frustration on the part of the person labeled autistic -- sometimes also being misunderstood by others who have preconceived notions of what it means to be normal, thereby

silently, or perhaps not so silently, passing judgement on them. Richard Attfield notes that he cannot perform for such people. I know that Adam will not perform for such people.

The people with autism who feel "successful" labeled "low-functioning" in their childhoods, were the ones whose parents believed in them and worked with them. Biklen was asked "What percentage of people with autism can be expected to achieve the communication abilities of Albert Frugone or Richard Attfield or Lucy Blackman has achieved?" He suggests "*that the percentage is likely to be a reflection of context. How many have parents -- in the main this has been mothers -- who can contribute huge amounts of time and energy to their education? How many have access to academic school curricula? How many enjoy access to communication training and hundreds of hours of practise? It is likely not insignificant that [the aforementioned -- Frugone and so on], all had mothers who devoted themselves to providing intense instruction and who interceded with schools to see that they received academic content even when social policy and prevailing professional and social doctrine and attitudes discouraged it.*" (p.67)

This is not a profitable stance nor does it relieve parental guilt of never feeling like we're doing enough for our children. But it seems to be true. I know many mothers who sacrifice their time and their work in order to study and teach for the sake of helping our kids. I'm not taking a Bettelheim stance here, but intensive practise and advocacy and working with curriculae is an everyday job of the parent with a child labeled autistic.

P.S. Will the scientific community ever buy the "nurture" argument?

[PERMALINK](#) POSTED BY ESTEE KLAR-WOLFOND AT 1/19/2006 01:58:00 PM 6
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WEDNESDAY, JANUARY 18, 2006

Dr. Phil's "Extreme Disorders"

Please go to side and click on **Autism Edges** blog for a review of Dr. Phil's good ol' Hollywood style. Unfortunately, I didn't get to see the show, but am concerned about this sensationalist

approaches to autism...who says disability doesn't pay? Dr. Phil is making loads!

Fortunately, a CTV program here in Canada called Vicki Gabereau interviewed Temple Grandin and the mother/author of **Artism**. It was inquisitive and intelligent.

[PERMALINK](#) POSTED BY ESTEE KLAR-WOLFOND AT 1/18/2006 05:34:00 PM 2
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Small Talk

Language, spoken that is, seems to be the *sine qua non* of early childhood development, THE benchmark of whether a child is developing "normally" or not. Perhaps we depend on it more than we realize, and without being able to express oneself verbally is clearly a disadvantage in a verbose society.

Today, I think about how urgently we are trying to get Adam to SPEAK. How we seem to only measure his comprehension and his acquisition through his verbal responses. It is clearly difficult for Adam to talk. He is encouraged moreso by cues -- if I start the sentence and he can fill in the word (intraverbal), if (when I must) sound out the first letter of the expected response. At other times and unexpected conditions, he talks completely on his own for things he sees or wants..."I see a bus!" or "I'm hungry!," among others. If I was a pessimistic parent, I might grieve over the lack of reciprocal conversation at this early stage, when other children might be speaking in more complex sentences, and comprehending more of my spoken language.

Here's an example of how I talk to Adam right now, when I'm asking (expecting) a response:

Me: Where are we going Adam? We're going toschool?

Adam: School

Me: Where are we going?

Adam: School

Me: That's right.

Me: Adam when you make a poo poo we go to thebathroom?

Adam: Bathroom

Me: Where?

Adam: Bathroom

Me: Good job, when we make poo poo, we go to the bathroom.

Then, there are easier concepts:

Me: What do you want Adam?

Adam: Chips

Me: Okay...here's your chip.

Other fluent Adam-mands are:

Hungry! Snack!

Squish

Turn it on!

Open Door!

Happy!

Tired!

Sleepy!

Water!

On the Potty!

Come!

Lately, I've been teaching Adam to read full sentences out loud with great success. He picks the right cards that go with the right match, then he reads the full sentence while pointing to the words using his index finger.

"The bird is blue," and so on. I'm not sure if he's going to chunk colours with the *is*, but it's worth a try.

I guess one could say this is the ultimate small talk. Right now, Adam is not conversing with me about all kinds of things fluently. But here's something that happened last night:

I was on the bed reading for a while. Adam came over and pulled me to his magnadoodle. He said to me "draw!" so I wrote the word draw, as this is what he usually loves -- me writing the words he says. Then he told me to write down the following words on his own (i.e.; absolutely no prompting!)

Jump

Tickle

Eat

As the proverbial interpreter, I was thinking he was telling me of the things he liked. Then, he grabbed the pen and began to draw. He starts his drawing the same way an airplane draws and airplane in the sky with its fumes (from one of his Baby Einstein videos). It's an exact replica until his hand doesn't know when to stop. When he was finished his drawing, he took my hand and said "Airplane!" So I assumed he drew an airplane, was telling me it was an airplane, so I wrote AIRPLANE down. When that was finished, he drew another picture. When it was finished, he took my hand again and said "Sailboat!" so I wrote it down. He did it again -- another new drawing -- "Motorboat!"...It stopped after that. Adam is learning about airplanes and boats in school right now. I found it interesting that he could draw a representation (his own) and tell me what it was supposed to represent *and*, that he was taking in what he was learning in school. Symbolic thought? I THINK SO! See -- so much is flawed with this mind-blindness theory.

Adam knows so much that he can't tell us. It is unfair to judge a person with autism as cognitively delayed. What is deficient is the typical way of responding. We do not know what Adam knows and comprehends unless he can show or tell us in some way. Here is a quote from Richard Attfield (autistic) taken from Biklen's book (I know - I'm still reading him...):

All my life I have been considered stupid. I understand that autistic people are intelligent and if you people admitted that you cannot understand us then perhaps we could try in a way to understand each other as fellow human beings. I get so frustrated in this useless body. If you just expressed some understanding and treated me as an intelligent person I could try to talk to you instead of feeling frightened to express and opinion. I know that I am intelligent...will you ever take what I say seriously? (p.58)

Lucy Blackman, author of ***Lucy's Story*** (also recounts her own story about being autistic), indicates like in the other stories, that there is profound awareness in the world "Most people need proof [of the student's competence]. How can the disabled meet such a gauntlet?" Isn't this what I, we, are after? Proof that Adam

knows? And if we impose standard ways of measuring that, aren't we setting him up for failure? Lucy notes that she is able to attend school because she is allowed to pace up and down the hall when she needs to assimilate information. As an aside, she also notes that walking away from a conversation may reflect excitement or a desire to manage excitement, not an indifference to conversation. (Biklen). We forget to realize that also, certain conditions affect whether an autistic person can respond or "perform." We have to figure out for our children the most fluid path to be able to respond to what we are trying to teach. This is SUPPORT. With support, we feel empowered, we can perform, we can feel worthy and HUMAN> What the autistic person needs is our TIME. They need time to process in order to respond...one of the major issues I am learning is that once they are able to respond, we have already long left.

I believe writing will be an avenue Adam will be able to take. Since he reads already...(still need to teach him what words mean) -- it is a strength he will likely use for the rest of his life. I have purchased a toddler keyboard and mouse, and will teach him how to use it. My only present concern is making activities structured and close-ended so that he will stick with it before he gets frustrated.

I think of watching one of Brigit Taylor's presentations at New Haven conference held here in Toronto about a year and a half ago. She was dealing with social scripting. I remember feeling appauled at watching kids look at a list of questions,then being taught how to use their fingers to remind themselves of question one, two and so forth without the paper. Today, I see how I teach Adam scripts all the time. We practise hello, bye-bye, play, and all kinds of things every day. I see the value of scripts today now that I understand that I am not teaching Adam to ACT human. He IS HUMAN, with the same feelings as you and I. He is only challenged in this area, at this point in time (I don't know what the future holds). I think it is this fact,however, that teachers and parents either may forget or ignore the capabilities of children with autism.

I do not particularly enjoy walking into a cocktail party making small talk -- the weather, the presentation, the drive, the holidays -- but I'm definitely learning the value that we, as social animals, place on it. For the person with autism, cocktail parties and crowds seem to be the number-one stressor. While it is unnerving for

many of us, it seems to be a hundred times moreso for people like my son. Small talk is the entry point -- do I want to get to know this person or not? There is a lot at stake with small talk.

[PERMALINK](#) POSTED BY ESTEE KLAR-WOLFOND AT 1/18/2006 10:19:00 AM 5
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TUESDAY, JANUARY 17, 2006

Einstein Dreamed About Riding on a Beam of Light

This picture was taken when Adam was fourteen months old:

His little legs barely steady, he walks over to a toy truck, turns it over resolutely, and begins to spin the wheels with his index finger.

“He’s checking out the properties of things,” I imagine. “What a smart little guy.”

He plunks his diapered bottom to the ground and continues spinning one wheel religiously. “Vroom,” I say, scuttling to him on my knees. “The car goes vroom, like this.” Just when I take it to show him how to drive the car on the floor, he leans his hands to the floor before standing. He moves away from me to the corner of the L-shaped couch.

“Come play, Adam. Come play with the car,” I plead, holding it out and returning to my demonstration. Adam stares beyond me and resumes running back and forth, crashing into the couch.

“What about these Adam, look!” He continues to ignore me, running back and forth. “Oooo, look at this, so cool!” I try emphatically holding up blocks to invite him to build a tower. “Look how high it is.” It seems to grab his attention now so he comes over and bangs it down.

“Come build a T-O-W-E-R!” I model and begin again, stacking one block over the other slowly.

End of picture show.

Will Adam will be able to do something special with his life? I believe this is a secret wish of all parents. As he peers out the window with his transparent-coloured blocks, observing intensely at the age of 3 how the outside can be red, yellow or blue, or as he flips through the pages of his book of planets and reads Mars, Jupiter and Pluto, I begin to wonder what autism is, how Adam sees the world wrapped in autism-speculated legends of Mozart, Einstein, Wittgenstein, Mozart, Jefferson or even contemporary artists like Jonathan Lerman, who, with autism, began drawing suddenly at the age of ten. Just what do these stories have to lend to the average Joe with autism? What light might this shed on the autistic mind, and are the gifted just different from the rest of us, with autism or not?

I know that many are skeptical about diagnosing the dead. Michael Fitzgerald, Ph.D., Deidre Loveky, Ph.D., and others insist there is enough (reams, in fact) of biographical data to make reasonable assessments about historic figure and AS and HFA (Autism and High Functioning Autism – terms used commonly in this context so I will keep using them here for the sake of this argument). I have to speculate that diagnosing the dead is as perilous as diagnosing children today – we have the guidelines – but as the landscape of autism is constantly evolving for our kids as the years pass, as people grow and change, as standardized tests and assessments serve to label and perhaps create more conditions, well, I think, speaking from an art-historian's point of view, we can make fair judgments based on historical data, albeit never conclusive. We can fairly determine the nature of a person and frame their image as good as any portraitist in a particular point in time, as well as any DSM (Diagnostic Statistical Manual of Mental Disorders)-- whatever edition. We know about Van Gogh's life from his letters to Theo and Paul Gauguin and others. We can appreciate his art as much as for his way of making it as for his 'psychosis' – now thought of to also be autism.

Fitzgerald argues that giftedness is anyone who changes the way we previously view things, who offers a change from the way we've studied, perceived something in the past. He believes that giftedness can only exist for AS or HFA people, and not LFA (low-functioning autism), and excludes precocious skills from giftedness – such as musical ability, for example. Simply put, an exceptional piano player wouldn't fit the bill for giftedness in Fitzgerald's definition. To fit it, this person would have to be an

exceptional composer. To him, there is a difference between ability and changing the world, or at least the way we view the world. He has set the standards high, and perhaps that's a good thing.

Einstein developed the theory of relativity at the tender age of sixteen but how long was he thinking about it before then? Did he spend his days watching the air move and dust particles dancing in the air at the tender ages of two and three? We know that his speech was profoundly delayed. We learn in his later childhood years of his lack of affect and socialability, intense focus, awkwardness, his poor performance on tests. But we can never see his earliest years, the years of toddlerhood, when we, at this point in time, place our children under the autism microscope.

[PERMALINK](#) POSTED BY ESTEE KLAR-WOLFOND AT 1/17/2006 03:38:00 PM 1
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Little Drummer Boy

If a man does not keep pace with his companions, perhaps it is because he hears a different drummer. Let him stop the music which he hears, however, measured far away. --- Henry David Thoreau, Walden, Conclusion.

So my little drummer boy is still trying the potty -- he is a willful little one. I am thinking about all this motivation stuff -- extrinsic and intrinsic motivations of the autistic person. I do believe we all need our trophies and ribbons, but in the case of Adam, his competency *seems* to be the Holy Grail (or is it mine?). External motivators, or reinforcers have to be used oh so carefully and faded as quickly as possible. I know Adam needs to be pushed now, at this stage. We can try. We can see.

I think of motivation and the person with autism. Maybe being with us, or what we do, or what we think is "normal," just isn't that interesting. So, just what is rewarding?

First Category, *Survival:*

1. Food

2. Water
3. Shelter and Warmth
4. Love (people)

Second Category, *things that lead us to first category:*

1. That which comes easily;
2. That which feels good (pleasure which is sensory);
3. That which we get lauded for (fame);
4. That which buys us what we need or want (fortune);

In Adam's case, in an environment where much of the above is already provided for, what he finds motivating is:

1. Sensory Play
2. Food
3. Running Outside
4. Balloons and Bubbles
5. Swinging
6. Praise
7. Independence (competence -- ability to play and do things without having to ask for help)

It is the last point that I'm really noticing and for what I believe he will be willing to learn *our way* - no matter what else tries to pull him away. We can help him with those things by providing temporary ways to get his attention. On other days, the things he does on his own and that we try to interpret (his "behaviours") give him so much pleasure. We can look at that as negative by stating that these activities suck him away. Donna Williams seems to describe it as such. Yet, I will never forget the lines she wrote in *Somebody Somewhere*, when she rented a house and she was lying in the grass describing the environment -- the breeze, the trees, probably the way the air moved...she was lost in the world around her...THIS world, our world, perhaps her world, in a state of rapture.

I sit here in icy-cold Toronto. There is freezing rain beginning to come down, trapping me in the house this grey upon grey day...layered so thick now I hardly want to open my eyes. I rather dream about Donna's world under the trees. I believe most of us dream about such moments of losing ourselves and becoming

larger.

Carry on, my little drummer boy. I consider this journey between you and me as somewhere between two worlds, both yours and mine.

[PERMALINK](#) POSTED BY ESTEE KLAR-WOLFOND AT 1/17/2006 01:11:00 PM [1](#)
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MONDAY, JANUARY 16, 2006

Intuition Precedes Science

Reading about autism can both help and hinder me. Two years ago, when Adam was initially diagnosed with autism, I began reading the typical stuff -- Catherine Maurice and then moved on to so-called "experts" -- scientists, academics. I have a Masters Degree in Fine Art History -- I am a wannabe to a certain extent. Yet, when it comes to Adam, and I'm sure many parents will relate to this, I just KNOW. It's not that I know what to know, but I feel and have always felt at odds with the many elusive theories out there about autism. And so, two years have gone by and I realize that it is not my son that wears me down on the days "the cup is half empty," but rather, all those "experts" out there whose egos come before our children, who must push their theories without ever having given birth to, or raised a so-called "autistic" child. Worse, autism as metaphor (Biklen) has permeated clinical and educational consciousness to such an extent, that our kids do not even have a fair start out the gates. They are doomed before they begin. Parents who are not inclined to trust themselves, to read, to question, who believe in clinicians and their assessments that set our kids up for failure at the get go, feel overwhelmed and depressed.

I've never had a great love of science. I believe science must be rigorous and I wish academic egos could go in the garbage where they belong. (Read The **Behaviour Analyst** journal for some of the most hilarious studies I've ever read like "How to introduce new foods to autistic children" -- gosh golly, ever asked a mother? And all of this gets funded, people!!). Foregoing the obvious fact that nothing is perfect and we still need science, then comes along a researcher or two that actually furthers our understanding about autism in a positive way. Please read Douglas Biklen's book

(Autism and the Myth of the Person Alone). It is a wonderful read.

The problem with autism now, NAAR, Autism Society, many clinicians, teachers, some behaviour analysts and other therapists (even RDI and Floortime ones), is the absolute belief in autism as "inside the person" as Biklen puts it. In fact, in my earlier days at NAAR, I also held the same belief that autism somehow "masked" my true son before I realized that autism is simply a way of being. There was good reason I held that previous belief and they were the theories of Mind-Blindness, Central Coherence theory and the theory of impaired Executive Function.

As time went on and I tried to hold up these theories against my son, it felt like trying to squish him into other identities. I didn't see that he had any problems with memory, affection, wanting to be social, linking concepts, shifting attention, eye contact, joint attention...he's got all of that. What I did recognize that he needed to be shown how to do a lot of things -- how to play with a toy, how to join a group. His biggest challenges to date is "stereotypy" or "stims" and attention which is affected because of them. On the whole, Adam is a child who wants to learn and be independent and takes pride with his competence. Adam's language is delayed --he speaks but it may take him time to process, or it is still prompt-dependent. When he's not sure what the answer to a question is, he is echolalic. Yet, when I write the answers down for him, he reads them fluently. Written language seems to flow while processing verbal language is more difficult. But it is coming with lots of practise. Motivation is often identified as a challenge for him, and for many children with autism. But even "motivation" is too general a term when we learn from Biklen's synopsis of other science that what we thought as lack of motivation (again another small box that doesn't seem to fit my son), could be related to other factors:

"Bara, Bucciarelli and Colle hypothesize that a single rather narrow impairment such as attention difficulties could affect a range of other cognitive functions, thus causing a person to appear incompetent in higher-order thinking, when the problem is really more on performance (2001, p.219) under particular conditions." (p.42-3). In regards to theories on so-called impairment of Executive Function, Biklen states that the genetic view to autism is pessimistic and does not consider the person who is classified autistic as *elastic* like the rest of us:

"The nature side of the argument holds that people are born smart or not, thus exonerating socially created inequities such as poverty and poor educational opportunity from culpability for stunting a person's development. Similarly, when a theory treats autism primarily or exclusively as an internal state or trait, it may, albeit possibly unintentionally, imply biological determinism. Save for the unlikely prospect that science could cure a person of the presumed internal flaw, such a theory is fundamentally a pessimistic stance. The theory defines the person as more or less bound in and made static by trait, with any chance of "improvement" (i.e., becoming more "normal") being modest or unlikely." (Biklen, p.45)

To say that a person classified as autistic is not at all influenced and nurtured by the environment is absurd. To hold the view that one's child will never develop and grow is not only bleak, but unfair and it is the fault of those scientists who push the deterministic views upon parents.

About a year ago, Adam, Henry and I took part in the baby sibs research project here in Toronto. Adam underwent a series of cognitive assessments by a former behaviourist student who was hired by this particular researcher. It was your typical assessment -- and she spoke what I call "dumbspeak" to Adam the whole time, you know, that deliberate higher pitched tone of voice. I swear to this day, here is a person who has no empathy and a set of presumptions about autism. She would look at me like I was in denial about Adam's abilities (no, disabilities in her view). She would peer at me from behind her black rimmed glasses. I am certain to this day that Adam could sense her lack of faith in him. I am certain that any child who has been given the diagnosis of autism knows who believes in them and who doesn't. To this day, I want to smack that girl. To this day, it baffles me when I hear parents say with such certainty that "my child will end up in an institution," or "my child will never do x,y or z." And it may just be so. Not because the child, or adult, cannot grow, but because they perhaps may not be growing in an environment that is nurturing. For all we do as parents, the one thing we must have is optimism and faith in ourselves and our children.

It is difficult to interpret the way Adam sees or experience the world. Interpretations of his behaviour are inherently dangerous,

so thanks to all those people who have expressed themselves who are autistic. I think my family and I try to interpret Adam every day. It in fact bothers me when someone says he wants something as presumption without any intentional or verbal communication from Adam. We are all learning to wait him out. If he needs time, it's okay to give it to him. Autism needs time, and yes, more research. But listening to instinct is an underrated skill in science and yet, science has nothing to argue without it.

[PERMALINK](#) POSTED BY ESTEE KLAR-WOLFOND AT 1/16/2006 08:53:00 AM 4
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SUNDAY, JANUARY 15, 2006

Through the Looking Glass

I watch Adam observing the dust particles spotlighted by the beam of sunlight through the window. Daddy tried to make him pee on the potty until I heard "mom, mom, mom...come!" He was happy to see me, obviously not wanting to sit to pee, but more interested in the dust particles happily dancing in front of his eyes. Yesterday, it was the reflection of water against the wall, again aided by the sun's reflection. He was swimming with grandpa in the pool of their condominium, and the water performed a dance like it was just for him.

I've heard other people with autism express how they can SEE the air moving. My Adam is intrigued when rain or snow is falling from the sky -- no small miracle in his eyes, I presume.

He is interested in putting on my sunglasses -- whoa -- the world must look interesting through those, or putting the coloured water blocks to his eyes and then to the window, to see how the outside looks all blue, yellow or red. These are quiet moments, totally entralling for Adam. His babbling stops and I want so badly to see what he sees like I am missing out on one great miracle, or secret, exclusive to his eyes, his world.

Other days I want to give him rose-coloured glasses - the kind that might make the world look like a jollier place. A mother's interest to protect her son.

Adam is busy today -- Sunday. He has O.T., P.T. meeting with his

new consultant with our lead therapist and I'm meeting a possible new therapist. If I have time to write more today, it will be by the graciousness of my husband....

Adam is in a session now with his new consultant and our lead therapist, Laura. He is tired after O.T. and P.T. and barely eating because of a stomach virus that's been plaguing us on and off all week. But he always has such a happy disposition. This part of me leaves me amazed and wanting to be like that -- although his happiness must be, in part, genetic.

I feel like describing my days as cup half full or half empty ones -- perhaps I'll begin a daily barometer so you, the reader, can tell from which side of the fence I will be talking about our lives and autism. Today has been a waffling kind of day. The weekends are tougher because I have less supports around. I began thinking about freedom as standing in the Starbucks line with a bunch of other adults. Ahh...and coffee -- definitely associated with Nescafe moments.

Does Adam feel free? Is he affected by "the big black nothingness"(Donna Williams), the sense of imprisonment? Will he as he gets older? "Exposure Anxiety is a invisible cage and to those who live with it, that invisible cage is either their prison warder-monster-saboteur or their saviour, helping them to cut off, shutdown and keep the world of overload at bay." (Williams, p.83) Overall, freedom is based on perception -- entirely resting upon our daily barometers. Freedom can exist in the mind even behind bars, I've heard. How much is autism a prison within? And then there is the prison outside of autism, those that the rest of society constructs.

How much of looking at dust particles is Adam's prison, or personal world, or escape? "It's like trying to remove a parasite which has become finely intertwined with the person's own functioning; they may respond to this 'help' as though it were an assault on selfhood...the self of mind which may be free, and the self of will which opposes the desires and needs of the mind..." (Williams, p.83) When I read that I can't help but think about the box, the way of looking at the world, depression, and all of that which suck like parasites on all of us.

I have to move on, paradox keeps tripping me up!

Now to MacLeans Magazine: **The Next 100 Years. One Child's Journey to 2105 - How She'll Live, Love and Never Really Die.** By 2055, scientists state that there "will be a cure for everything." Yikes. Consider this want ad for a mate:

Tall Blonde. Attractive SWF 29 who is educated looking for SWM 25-35 who is of good moral fibre, monogamous, yet extremely loving and playful. DNA screened for all neurogenerative and metabolic diseases including diabetes, Alzheimers, [Autism] and Parkinsons. Carrier of longevity gene.

Not only will we live forever, but the species that we are attempting to create is perfect. What does that say about my son and his future? What does that say about society's true goals for supporting and enabling the "disabled," and of acceptance of difference? I certainly never wanted to live that long, not until I had Adam. Still, I do not want to live forever as I believe it will effect the quality of my life in the sense that if we have an endless supply of something, we cease to appreciate it.

Yesterday, I laid down on my couch and watched the air move. I watched the clouds drift by on that windy day, undulating swiftly. Sadly, I was missing the transparent coloured blocks.

[PERMALINK](#) POSTED BY ESTEE KLAR-WOLFOND AT 1/15/2006 09:34:00 AM 2 COMMENTS [LINKS TO THIS POST](#)

SATURDAY, JANUARY 14, 2006

My husband just told me that I sound like a pro-lifer in my last post. I'm certainly not the type to stand in front of an abortion clinic and make protest.

I am a mother in love with her son who happens to be autistic. In him, I see miracles everyday. I admit that prior to having a son with autism, I would have been fearful of autism, downs syndrome...it is not a condition people would prefer to deal with because people have no idea what it involves without having had the experience. This is why we as parents have so much awareness-raising to do. Before I had my son, I feared anything that was "different." After the experience, I would have opted to

have a child with any "special" need. Yes, it is challenging in a society that does not yet provide enough supports, but having known what I know today, this is just life and all of this genetic pruning for perfection leaves me to think of how base and banal a society we might become.

[PERMALINK](#) POSTED BY ESTEE KLAR-WOLFOND AT 1/14/2006 09:26:00 AM 3
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FRIDAY, JANUARY 13, 2006

Autism and Paradox

Everytime I have a resolute opinion about autism, a moment later, I feel I must offer an antithesis. The feelings conflict because autism is itself a paradox. Of knowing and unknowing, of ability and inability, of what is present and what is missing. Perhaps only as an outsider do I view it this way.

First, there is Donna William's description in her book Exposure Anxiety: "Can't do it for myself; Can't do it by myself; Can't do it as myself." And yet, a person with the diagnosis of autism, let's use my son as an example, does many things by himself, albeit not always under scrutiny or on demand. What appears like a missing piece or to a layperson, a cognitive delay or inability, is in fact **ability obscured**. Autism is indeed not what it appears, and the way we treat it is ultimately paradoxical -- trying to teach someone who knows inherently, like teaching emotion to an autistic person highly tuned in to it -- perhaps it's knowing and perceiving without knowing how to translate it into another language -- the langauge the rest of us understand? But then this is not so with writers and artists who are autistic, who have found a common ground with which to communicate. Going back to face recognition seems almost ridiculous when we begin to understand the complexity of perception and thought beneath the surface of autism's appearance. But in order to translate it to operating in our world, the common language, simply put, must be used?

The way I deal with autism in the way we teach Adam is in constant flux as a result of him -- it is trying to find a way to teach that challenges him while at the same time bringing him to respond at any time. I am trying some behavioural approaches without wanting to subscribe to behaviourism, solely because

learning is in large part based on pride, and marathons are won with ribbons. I like what Donna Williams says about work on behaviour: "for with Exposure Anxiety, more than any other condition I can imagine, compliance is not a long-term sustainable answer if our goal is independence in capable people who cannot handle awareness of the self." Or consider this quote about social-emotional development:

"The only things that could actually lend support rather than add to incapacity were things like objects, nature, reflection or the sense of myself in the third person as a form of company. Essentially, these "autistic" self-reassurances made it more possible to dare communication, expression, or involvement or a true self-expressive kind (as opposed to avoidant, diversion, and retaliation responses). It's important to realize here that what I was probably trying to get around was not an emotional development issue, but the interference of my own chemistry mechanisms which were triggered too easily. Many people think that getting through to people is the answer. When you are looking at underlying physiological problems and their impact, there may be very little the outside world can do to reassure. It maybe more a matter of doing what one can do to help people chemically and understand how the behavioural approach may interact with that chemistry to the benefit or detriment of the person's cognitive, communication and socio-emotional development." ***Exposure Anxiety, p.41***

Ok, I'll have to work out these raw thoughts. What I'm trying to allude to is the utter confusion between our way of looking at things, at how we should view the world, interact and communicate and all the nitty gritty in between that makes autism difficult for the rest of us to perceive and understand. We do everything in our power to change the autistic person. We do it under the premise of helping them "cope" and "adapt" (my own goals -- I still grapple with them), without actually knowing what it is a person with autism wants. It is so difficult when they cannot tell us themselves, or when children are so young, we try as parents interpret and make choices in their best interests.

I believe that this ethical grappling as a parent must be crucial -- always trying to understand and figure out the best we can do while honouring our children and who they are with autism.

I received a disturbing link today on Dr. Joseph Buxbaum's research on MSNBC -- NAAR supported:

"Dr. Joseph Buxbaum heads up the Autism Genome Project at the Mount Sinai School of Medicine. Buxbaum says he expects major progress in identifying the genes associated with autism in the next decade.

"I think within ten years we'll have found the genes of major affect and most of the genes of minor affect," said Buxbaum. "That will then lead to reasonable targets for drug interventions. It will lead to much better diagnosis and certainly earlier diagnosis."

Buxbaum says there could be a prenatal test within 10 years.

"If we get to the point where we have 10 genes that predict risk to some significant degree, then there is a prenatal test," he said.

Once genes are identified, there will be targets for drug intervention.

What does this imply? Why do we have prenatal testing - to what end? I think the likelihood that abortion will be offered if an autistic fetus is identified. Does anyone think of the repercussions of all this research? Abortion of so-called "disabled" fetus' is akin to ethnic cleansing in my opinion. We are not ready to make these decisions, we have not had enough time to debate these important bioethical issues, these researchers and the organizations that support them are like bulldozers trying to pushing this along before we really talk about what's at stake. Whether you believe the following people are Aspergers or not(I acknowledge that there is uncertainty, but let's use as examples for the sake of this argument), "would the world consider aborting the next Bill Gates or Albert Einstein?" asks Arthur Kaplan at the Centre for Bioethics at the University of Pennsylvania. He states that the future of society depends on how we answer these questions, and I believe he is right.

I have HUGE problems with prenatal testing for autism and I urge all of you reading this to join me in this dialogue and raise your objections everywhere. If any of you are lobbyists, come aboard. This is a very disturbing trend that needs a whole lot of dialogue.

PERMALINK POSTED BY ESTEE KLAR-WOLFOND AT 1/13/2006 03:17:00 PM 2
COMMENTS LINKS TO THIS POST

THURSDAY, JANUARY 12, 2006

Autism as a Social Construct

Last summer, I read the story of Hugh Blair -- a son of landowners who was married off and inherited the estate. The only reason we know of him today is because of court records -- his brother sought to take the estate away from Hugh, who today we understand to have been autistic. In it, there are accounts of how he curiously lived his life -- and was described as mentally incapacitated, unable to live on his own. When reading these accounts of nearly two hundred years ago, Hugh, through the eyes of his contemporaries, appears like a caricature. Due to his "mental incapacitation," he was deemed by the courts as unable to look after himself, live freely and keep the estate his mother endowed to him.

So what role does our society play in viewing and thinking about those with autism? We have progressed so far in terms of our knowledge about autism from the days of Leo Kanner and Hans Asperger. Yet the words of history resonate to this day. When autism was first described by these men in 1943, the frame autism was placed in, although yellowing at the edges over 50 years later, remains in the same frame. It appears that the views of society wallow in the safety of history. But if we take apart the vernacular used back then, we can see clearly how history, society and personal bias takes a huge part in how we view autism today.

Let us start with Leo Kanner and pay attention to judgmental language. He described characteristics of autism as "a marked **limitation** of spontaneous activity, "**stereotyped** movements," "a child's **inability** to relate to themselves" and called autism "inborn autistic **disturbance** of affective contact." Hans Asperger describes autism thus: "The autist is only himself and is **not an active member of a greater organism** which he is influenced by and which he influences constantly....The essential **abnormality** in autism is a **disturbance** of the **lively**

relationship with the whole environment." Abeit these are brief examples and perhaps not the best ones in their repertoire, but these descriptions do not describe the abilities of autism or even assume that the life of the autistic person is rich with perception, intelligence, thought or even prefers to be alone and quite content with that -- it assumes that what is not like the rest of us, is abnormal and "tragic." (*Read Douglas Biklen, Autism and the Myth of the Person Alone* for further reference to this).

This is the main thrust of behaviourist and many other operationalized principles: it is taking a view about autism that does not belong to one who has been diagnosed with the condition of autism, but rather, the rest of us who are not autistic have more authority in terms of labelling, diagnosing, assessing and interpreting autism and autistic behaviour. It assumes that:

1. Autism is a socially inappropriate way of behaving that must be corrected;
2. People with autism do not want to be social so we must teach them social skills or assumes that they want to be social and we must help them be so (do we ever really know the desires of others if not articulated to us?);
3. It accepts the behaviourist's or any other therapist's *intepretation* of the behaviour as the true meaning of that behaviour.

Simon Baron-Cohen, whose theories I believe are fundamentally wrong (assuming people with autism are mind-blind as he also states "knowing seems beyond most children with autism") is his *judgement* alone. I've met many a "low-functioning" (hate that term -- it means nothing), person who possess great intellectual ability, emotion and perception of others, despite their outward appearance or way of being. Further, does outward appearance and action reflect thought? Would we classify Stephen Hawking as "low-functioning?" (*Biklen refers to Hawking in this context as did I in a paper last year*).

It is important that we all understand that judgement and bias is innate in the "scientific" theories about autism -- we must account for the scientist's own personal bias, social influences, judgements and opinions and the history of disability, and how that has influenced our thoughts and opinions. However, we seem to be taking all of these accounts now as today's TRUTH about autism.

Parents and educators assume that these resonating words, unworthy as they are, are absolute truths. Parent's invest dollars in therapies that claim to be "scientifically proven," when they are not. I call these vapours -- and we stake children's lives upon them?

How do we evaluate success? What frame do we put that in as another absolute? How do we even evaluate progress in therapy for that matter? All this therapy, 40, 50 hours a week, and yet I've not yet met one person who is no longer "autistic." There is no proof. Is the goal of becoming "indistinguishable from one's peers," an honourable goal? Is it in the best interest of the child? Making one "indistinguishable" can be translated into "acceptable." And what does that say about us and how we view genetic diversity?

I will be writing more...I have to go pick up Adam from nursery school now...

[PERMALINK](#) POSTED BY ESTEE KLAR-WOLFOND AT 1/12/2006 10:06:00 AM 3 COMMENTS [LINKS TO THIS POST](#)

WEDNESDAY, JANUARY 11, 2006

Paying Attention to Autism Vernacular

In autism and dealing and describing our children, I believe that how we describe them reflects how we as parents VIEW them. The use of language in how we refer to autism directly relates to how we feel and relate to our children.

I admit that some days I feel confused. I use terms like "an autistic child" as opposed to "a child who happens to have autism." It is true that we are all more than our labels. Autism is a difference, not a disability. I find myself constantly correcting my language, or making mistakes. Yet, I think as parents especially, we ought to be cognizant and careful of how we use it.

Wrong Ways of Stating Things:

My child is autistic

My child is disabled

Autism is a disease

Autism is a disorder

My child is special needs

My child will be in an institution

ABA is the only LIFESAVING therapy for autism

Autism is an epidemic

Right Ways of Expressing Things

My child learns differently

My child is unique

My child has special requirements

My child has ability

My child will learn on his/her own timetable

My child can learn

There is more...anything that chips away at the unique identity of the child, the child as a whole person instead of "half" of one (normal versus abnormal), is wrong.

It is easy to pull out my hair with autism therapies too. ABA, RDI, Floortime, SI, whatever. At the end of the day, I still ascribe, with my whole heart, to a program that meets THE UNIQUE NEEDS OF EACH CHILD. The problem with programs, per se, is a dangerous lull to blanket approaches, thereby assuming that every autistic child has the same learning needs. In fact, there is nothing more difficult than to help our children and program for them because of adherences of certain teaching communities to one program or another. A parent really has to have some balls. A parent has to have faith amidst all the influences and seeds of doubt that many communities wish to impose upon us. It takes a lot of research and a lot of guts. I call every parent to acknowledge the doubt and exercise the time and patience it takes to learn everything you can get your hands on. *Then*, go back to watching your child and your intuition. Then and only then do I think we can do the best things for our children.

Here's an answer that I repeat to myself when this or that comes pounding in -- *what is making Adam attentive and willing to learn? What makes him happy? What makes him able to adapt to the world around him? What are his abilities I can use as bridges to learning?* If we can answer those questions, we are well on our way to building a program that works for him.

I used to be co-chair of NAAR here in Toronto (my title changed a couple of times from sponsorship chair to co-chair, so I'm not sure

what I was, actually...I raised some money...). NAAR uses vernacular I highly disapprove of, albeit I do appreciate all the research that they do support. It uses CURE to market itself and since there is no, and likely never will be, a cure for autism, I find this highly objectionable. I prefer to address the research in order to understand autism, teach better and create more awareness and understanding. I find the CURE for autism, highly controversial and takes the negative and disabling view towards our children. Instead of fostering a community of genetic diversity, and accepting that as parents and fundraisers, there is a community of people who hate people with autism and insist on CURING them. Think of it that way for a change. Maybe we will all view our children a little differently now.

[PERMALINK](#) POSTED BY ESTEE KLAR-WOLFOND AT 1/11/2006 10:43:00 AM [4 COMMENTS](#) [LINKS TO THIS POST](#)

TUESDAY, JANUARY 10, 2006

Wisdom Comes Through Suffering

As I said earlier, optimism doesn't come for free. I look at all kinds of positive stories about those who are autistic, who "presented" similarly, or even worse than Adam in the early years. The purpose of looking at positive stories is the same as an athlete's visualization -- the goal has to be clear. I believe the same approach holds for my son Adam. For me, it is a marathon that never seems to end right now. For Adam, it is the marathon he doesn't quite yet understand. Some parents who write to me seem so low -- their child will "never" do this or that, instead of realizing that their marathon, no matter how old the autistic person is, is just not over yet. Development can occur at any age. I've heard of 42 year old autistic people just becoming independent, just acquiring a new stage with such joy and sense of accomplishment. So I read and talk to parents of autistic people, now in their twenties and thirties, who struggled just like us, but now study jazz guitar, or teach mathematics. Things that just didn't seem possible happen only with plain faith and constant chipping away. This is the journey of autism.

I would be lying to you if I didn't tell you the moments of worry and doubt. These moments keep wanting to press in and strangle me. It is a battle not to let them. Here was one last night: I dreamt

that I died while taking care of Adam. I am most often alone here with him in the house -- my husband works long hours and I don't have any live-in help. I dreamt that Adam's nanny was also sick and didn't show up the next morning, my husband was out of town and I died. Adam was alone in the house, his diaper getting fuller so he took it off and the feces bothering him that he smeared it all over the upstairs in an attempt to clean himself. He kept coming to me and pulling my arm, crawled all over me for a "squish," oblivious to the fact that I died. He soon gave up and chattered to himself in his room, preserverating with toys, walking back and forth, playing with his hands. This goes on for a while. He pees, he gets hungry. The phone rings -- my parents think we just must be out. Adam gets hungrier. He cries. He tries to climb over the dangerous gate to go down the stairs to get some food. He tries to wriggle under it (there is a space). He gets stuck and screams. No one can help him....

Isn't that awful? Consuming thoughts like this happen once and a while. I have to fight them off. I take a deep breath as I write this down, my eyes tearing. Deep breath again. I must shake this.

Isn't this the worry of all parents with autistic children? Just how long can we live so we can take care of our children? Eighty years? Ninety? What if I get sick? I am already forty years old. He is just turning four this April. When he is twenty, I'll be fifty-seven. When he is forty, seventy-seven (my aunt just died at seventy-eight). I don't think there is one parent I've met who doesn't have the same thoughts run across their minds.

Adam's stims have gone way up these days. I see so much potential in him, but these are the biggest obstructors. I am installing a swing in the basement for vestibular feedback (he becomes so much more organized when we incorporate movement into his day). We need to teach him more functional play skills so that he can redirect himself. We will provide him with a visual box that he can have at prescribed times during the day to give him the feedback he needs, but teaching him that he has to do others things at other times of the day.

I have been teaching him reading. This is going well. He does have some issues at discriminating words -- words that I know he knows will get confused with same-letter words if he is distracted. But if I teach him this skill, I am convinced it will help him

communicate. I also notice that he is terrific with intraverbals, but I think he has learned to speak this way, so I am getting him to read complete simple sentences now in the hopes that he will understand them and use them. I am also fading back (backward chaining) my intraverbals in order to get him to say the last two words of a sentence instead of just the last word. I've just started doing that and it seems to be working. If I had to evaluate his progress against last year's, he really is speaking a lot more. He is transitioning well, he has been weaned effortlessly, and he is taking to potty training very well. He loves art-making, has begun to spell words (albeit with inconsistent interest in doing so), and is learning to read. He adores music and is singing more songs and is slowing learning to imitate actions, even if they are still delayed responses, he never did actions before. He has improved his motor skills -- can hold a pencil better, can draw, can climb, and is beginning to jump off higher surfaces. There is more, but I think that's enough to convey how much progress he has actually made. It is all these steps we have to remember every day.

[PERMALINK](#) POSTED BY ESTEE KLAR-WOLFOND AT 1/10/2006 09:41:00 AM 1
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MONDAY, JANUARY 09, 2006

Parents and Therapists - A Vulnerable Partnership

As some of you know from reading my blog, I run my own in-house therapy team. Here in Ontario, I have not yet found an agency flexible or sensitive enough to meet my son's needs or work with me to approach Adam as an individual as opposed to just another boy with autism -- with a generalized, blanket approach to his therapy.

I've hired my own therapists, psychologists, SLP's, OT's.... all have been exceptional. There is, however, perils to these relationships. Typically, the therapists we hire to work with our children on various ABA and Floortime or RDI therapies are young, in their twenties, having come to this via a university posting, an ad, to make a little bit of extra money. Some go on and continue to work in the field as they discover a love of working with autistic children. Others are simply good at it, but so young that visions of having

their own families supercede their loyalty.

This is just a harsh reality for families like ours. Right now, I am looking for another therapist as one of my excellent ones is pregnant and dreamily drifting through her days in happy anticipation. I don't hold it against her -- I understand it perfectly. But as a family with autism trying to work in these early years in preparation for full-time school, it leaves us feeling hostage. If you have a good therapist and she wants more money...guess what? You're going to pay it because your son's progress is dependent on her and there are so few good therapists out there. When you find someone you really like, you want to hang on to her. But I have to say that I feel abandoned and a little peeved at being left without their help in finding me a replacement. I've wanted to help them on in their career, paid them the money, and in the end, this is the harsh reality. People will come and go no matter how hard you try to keep them. Very few therapists that I've encountered are seeking their M.A.'s or Ph.D's in the field. They do not know yet if they want to stay committed to it.

This is my venting of the day. In the end, as parents, we are alone with this. There are days when I want to get peeved, but I can't. People will come and go -- in and out of Adam's life.

[PERMALINK](#) POSTED BY ESTEE KLAR-WOLFOND AT 1/09/2006 09:19:00 AM 0
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SUNDAY, JANUARY 08, 2006

Raindrops from God

Just when I am at my lower points, I receive raindrops from God. (Not even sure I believe in God, or fate, per se, but then moments like this make me wonder...).

Adam's stims have been way up these days. When I say that I mean that he flicks his hands in front of his eyes in a frenzy, he constantly babbles and talks to himself, as if leaving a silence would be torture, or he licks a window, a wall, a toy. It is then so hard to get his attention. My otherwise intelligent young boy who I've seen do so many things, here and there and all too inconsistently. He gives me flashes of his brilliance some days (like reading headlines of books -- like the headings in encyclopedias or

reads the names of planets), just plain normal interactions on other days. Yet on other days I need to constantly repeat myself, use chips to have him sit down so I can teach him a skill, or he seems to forget how to read the simplest words I've seen him spell with his magnadoodle. Skills come and go and the fear is always if he still has the skill he once so brilliantly displayed. I believe that everything in his brain is stored and as more linkages are made and concepts fuse, his skills will become more consistent.

Stims give me the most fear because he is then at his most unreachable. They are like hurricanes -- much stronger than I am. There is little use fighting them and I want to respect the need and the reason behind them. Donna Williams writes a lot about the senses in **Exposure Anxiety: An Exploration of Self Protection Responses in the Autism Spectrum and Beyond**. The doctor I will be working with, who has her BCBA as well as a Ph.D. in Sensory Integration, suggests I delegate a visual box 6 times a day for 10 minutes at a stretch. It is a behavioural approach and I deeply wonder if this will help Adam -- I still want to honour his way of seeing the world while building bridges so he can interact with me and others. But when Adam isn't listening, I find myself at odds with my own principles. I am afraid if an approach will harm him and dishonour him in an effort to "normalize" his behaviour. This is the paradox of autism. It is a skill that is there one day, gone the next. It is a parent's optimism and days of utter gloom. It is a battle within one's self to do what is right for one's child -- honour them and their difference -- while balancing a need to have them join us. Schools hardly help us with this paradox -- they only seem to make the conflict worse.

So, when I am at this low point today (my husband is gone for almost the entire week and then gone again this weekend with his other children skiing while I stay home with Adam who is getting sick -- his stims always get worse as he gets sick), Adam's lead therapist brings the book **Autism and the Myth of the Person Alone** by Douglas Biklen. He is the co-producer of the CNN documentary **Autism is a World**. Everything he says supports my philosophies of acceptance and integration. It is again an affirmation that in my hours filled with doubt, there is someone out there who does think the same way. Here are a few paragraphs from a chapter "Framing Autism:"

...building understandings from autobiographical narratives may

prove challenging precisely because it requires a shift in perspective from the so-called normal body to other bodies, and from enforcing narrowly defined, dominant ideas of normal to embracing difference as normative. In general, the distinction of disability is fundamentally connected to the notion that there is a normal body. The person with the nondisabled body runs in a particular way, eats with utensils in a particular way, crosses the street, builds objects, dances, and speaks in sentences. The person classified as autistic, who might not do some of these things or who might do them in clearly different ways from the so-called norm, is in the position of being seen as awkward or inadequate, or even as an 'individual failure.' Thompson (an autistic person), puts it this way:

'So powerful is the cultural imperative to structure experience with absolute categories that figures who seemingly defy classification-- such as mulattos, freaks, transvestites, bisexuals, and other hybrids -- elicit anxiety, hostility or pity and are always rigorously policed. The rigidity of social order testifies to the destabilizing threat of ambiguity.'

The policing of people classified as autistic may include, for example, desires to 'cure' autism, forced segregation of people labeled autistic in special schooling and housing and insistence that the person perform within completely normate standards, rather than in ways that reflect how autism is experienced. The idea of being policed runs through the autobiographical accounts. Fortunately, the contributing authors also explain how they often resist regulation." pp. 71-2.

I even have disagreements about respecting autism with my very own husband, who loves Adam with all his heart. His doubts work overtime as well -- the lull of chelation therapy, diets, gurus and ABA all too strong. Family members who do not spend as much time as I do with Adam, find it difficult to embrace his differences and struggle to make him more "normal." I worry about my tendencies to do this as well, as I get different inputs from various doctors and therapists. They can leave you feeling dizzy at the end of the day. To find one with the level of empathy and respect that I wish to achieve with my son without the endless worry that seems to parallel it, is still slightly beyond arms-reach. I still have years of living with autism and I want to understand how Adam thinks so badly. But I can't reach this level of understanding without

acknowledging the things out there that try to pull us away from our goal -- of accepting, understanding, loving and helping our son. At the end of the day, Henry and I are both there for Adam and we love him to the end of the earth.

I've had parents who have read my blog, sending me information on diets I've tried with no success, or promoting ABA programs which I do to some degree, but with other therapies as well. Their suggestion is always that Adam would "do better with ABA." This is an example of all the things that pull on a parent in this arena every single day. When Adam begins to stim more, it is easy to think that something else would work better. It is harder to trust ourselves.

I believe a parent has to have eyes and ears open, acknowledge self-doubt and listen to oneself with as much knowledge in hand as possible. The expert on the child *is* the parent. Each autistic child can benefit from different teaching strategies and those strategies may change over time depending on the child's need.

I would also never advocate a therapy that is in direct contradiction to autism -- against the best interest of autism and the child who is autistic. Any strategy for autism must honour the autism as part of the child, not attempt to conquer, heal or cure it. To do so is to consider autism, and then your own child, the enemy. And I believe a child can feel that.

[PERMALINK](#) POSTED BY ESTEE KLAR-WOLFOND AT 1/08/2006 01:33:00 PM 1
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WEDNESDAY, JANUARY 04, 2006

Canada AM aired the piece on Jonathan Lerman today...I'll try and download it soon for access.

Potty training is going very well. Adam has made 5 pees on the potty during training time.

[PERMALINK](#) POSTED BY ESTEE KLAR-WOLFOND AT 1/04/2006 03:12:00 PM 1
[COMMENTS](#) [LINKS TO THIS POST](#)

TUESDAY, JANUARY 03, 2006

We have begun potty training -- seriously this time. Before the holidays, I was designating a half hour -- 5 minutes off, 2 minutes on. I have written "I need to go potty" on a few index cards and have deposited them around the house. As part of the training, I take Adam to the card first, in hopes that this will one day help him articulate it. He is finally anticipating his pee now, holding his crotch, holding it in. He never did this before and I think it is in part because of the training. We can't necessarily wait for our kids to be "ready," because there are gaps. We have to train and teach things systematically first and then the concepts come together. Now that this has happened, holding his pee that is, we can begin more rigorous training. He is holding it in now though -- either insecurity or a control issue -- I'll let you know. Just like weaning, all of this requires a parent's energy and readiness as well. I am ready -- for kicking or screaming if need be. He is whining a bit, none of that aggressive stuff. Either it is sheer luck or my perserverence -- I won't take no guff, so to speak. He's going to transition, he's going to eat all kinds of foods, he's going to use his fork, and he's going to use the toilet dag nam it! And guess what? He does. Without much fuss too. Day in and day out, no matter how long it takes, practise, practise and more practise. It doesn't mean that I'm neither flexible nor empathetic. I certainly am!! But my dad taught me this perserverence and I reiterate the same thing to Adam that my father said to me all the time: "If at first you don't succeed, try and try again." Yes, it's tiring, yes, sometimes it breaks my heart. But I think what has carried me through all this is the view to the future. If I don't do this now, then when? And the older Adam gets, the harder it will be.

It effects me -- I have to lose 10 or 15 pounds that all of this work has brought upon me. I struggle to find the time to do the work I need to run his program, to do what I love (writing and lately, awareness-raising about autism), and then to take care of myself. There are always projects I want to do. So as we all do every New Year, I am taking time to re-evaluate my goals and time commitments. Soon, I will have to submit a part of my manuscript weekly to an author/editor -- a self-inflicted task, really -- an attempt to keep my book on course.

I received an email from a reader today -- indicating that it seems that Adam is high-functioning. I've been thinking a lot about high-functioning versus low-functioning and how it's all rather

arbitrary. We seem to take the view that lower-functioning people with autism have more cognitive challenges and are, in large part, non verbal. Yet, I've seen many "low-functioning" people who have incredible insights. Jonathan Lerman is an example. And if one person who is like this indicates otherwise, then I MUST assume that all people can think this way. To think otherwise would be discriminatory. One person with autism may have the talents to express themselves and so we must assume that just because the other does not have the same talent, there is no sententiousness. Like you and I, an artist may have the ability to express in a way I can not but it doesn't mean that I don't feel, see, and interpret. Ergo, even these labels are problematic, another attempt to make one kind of autism a little more acceptable than the other kind. It's unfair to those with so-called "low-functioning autism" because if you think doors are closed for kids like my son, imagine all the more doors closing for these other kids.

[PERMALINK](#) POSTED BY ESTEE KLAR-WOLFOND AT 1/03/2006 03:09:00 PM 0
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MONDAY, JANUARY 02, 2006

Adam's Hyperlexia

Well, what I've been writing about the past few days is working like a charm: Adam's reading skills are so strong that I can write something down that is verbally more challenging, and Adam can follow the command. I've begun putting labels (textual only) all around the house. I've tried PECs but he just doesn't get as turned on by those -- it's not that I won't use them, but if I can accelerate Adam's language this way, I'm going to do it! I've been reading **When Babies Read** by Audra Jensen over the holidays and it inspired me. Although knows hundreds of site words and I have to move him a little further into the program, it is also showing me to move back a little so I am sure Adam can pair the object with the word. I know he *knows*, but sitting at the table, I wonder if he will respond appropriately. I also began carrying the small magna-doodle all around with us today -- I used it to explain the following:

My Questions: "Where are we going?"

Text Prompt and Adam's response: "Store"

Me: "What do we buy at the store?"

Text Prompt and Adam's response: "Food"

I made sure to do it again in the store. So I do this a few times before we go somewhere and again when we are there.

Soon, I will write the question down, then the answer. The perhaps Adam will be able to fill in blanks, categorize and more. His site reading is very strong and he does sound out some words phonetically on his own (no one has ever taught him to read).I am going to make him books too. The first one I make is about his family and the second one will be about school. It all has to be about Adam's life...FUNCTIONAL stuff.

We came home from *Blue Balloon*'s facilitated playgroup (a group being conducted until school starts next week). Another autistic boy was there today and does a lot of high-pitched whooping. Adam does this occasionally too, but this child does it a little more often at the moment and has his own way of doing it. But, when Adam came home, he started whooping just like his friend. This tells me he is watching and listening to his friend! I don't know what causes our children to whoop. Has anyone ever come across research that discusses it?? I wonder if it has anything to do with a sensory need. Is it something like the babble?? Sometimes I know it is the sounds from Adam's Baby Einstein videos -- child-like sound effects. Some other times he does it when he's anxious.

Oh yeah... the babble that sounds like a real sentence, but has no meaning. I'll try and write an example...it sounds like poems sometimes (and have been repeated often), full diatribes at others. He was standing at my parents window today looking out at something and spoke a couple of beautiful sentences like he was speaking another language. We always stop and try to discern if there is any sense to them -- something, anything we can understand. Or this little diddy he likes to sing:

"Happy days
a way oh a
wha say you" -- with a distinct and consistent melody. He particularly enjoys singing it while jumping up and down when his older brother Max jingles balls.If Max drops the ball, Adam will

stop dead in his tracks, like he's rewinding the song. When Max begins juggling, Adam resumes the song like pressing the *PLAY* button.

Speaking of songs -- ever notice how many of our kids never sing along -- but maybe after, or quite a while later? I look forward when Adam sings a song along with me...I know it will happen some day soon.

Adam began using his fork independently -- that took about a year. I don't say it to denigrate the achievement, in fact, I believe it is a significant one and Adam makes so many of them!!

So, I look forward to the year ahead as we get Adam ready for school. I saw the movie **Munich** over the holidays (my husband said that he loves to watch the previews to see how many movies we don't get to see), and came out wondering what the world is coming to. The movie poses the problem that Isreal and the rest of us face -- the utter hatred towards us. The answer to the question is that there is no answer. Facing all of this, we must work for peace, for hope in all things. This is life. It does not run smoothly.

[PERMALINK](#) POSTED BY ESTEE KLAR-WOLFOND AT 1/02/2006 07:17:00 PM 0
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SUNDAY, JANUARY 01, 2006

It's New Year's Day and we're headed back home today from Miami to Toronto. Not really looking forward to the dank and cold. I write this while Adam awaits to make his final visit to the beach with Bubby while I pack...he enjoys playing with the TV buttons, no matter how many times I say NO. I figure at least a million times, and maybe, just maybe, he'll comply. The compulsion to turn buttons on and off seems stronger than I am. Nonetheless, he does listen to me most times.

I've been looking at the Dan Marino Centre for Autism here in Miami. Next time I come down, I want to check it out. One thing I liked (just from viewing it online), was that the centre's therapists all collaborate, much like what I do with my own team. OT's, SLP's, and other therapists meet weekly to discuss what each child is learning. If a child is doing Mr. Potato Head (I saw this in their

promo video online), the OT will also develop motor skills by having that same child draw Mr. Potato Head. I've been doing this for two years. It's been so important to build comprehension about Adam's world. I still strive, with my team that is, to build more synchrony (I always think that having someone who can really manage and who knows about how important curriculum development is, would be the ultimate for Adam -- he needs a program that keeps him interested and challenged while also working on areas where he is challenged). We struggle with curriculum building (none of us are educators per se). I have very high expectations and I think for the most part, Adam has an excellent team of people and I've been able to build likely a great team of people. The key is for the parent (especially in the absence of centres like the Dan Marino Centre) to be really involved. A parent has to be involved in that case too. Teaching occurs every day, every moment, in every setting. Yes, I feel bad when Adam cries. I want him to be happy. But he must respond when I ask him something. I must wait him out for him to tell me what he wants. Otherwise, he will be a frustrated man.

We are going home and all I think is what I have to do for Adam when we get back. The sense of urgency never leaves me. He is turning four in April. He was diagnosed at 19 months. The first book I ever read, like most parent's, was Catherine Maurice's *Let Me Hear Your Voice*. According to her, Adam should have been cured by now. So either she is very successful at making most parents feel utterly inadequate, or we all quickly learn that her version of the story isn't all that accurate. On the one hand, I feel I have implemented the best resources for Adam and on the other, I feel there is never enough time in the day to implement the things I want to try for him. I think right now of a mom I talked to in the beginning who implemented a 50-hour a week ABA program for her son, and how she said to me he was in a regular school but never wanted to talk about autism again. All of this puzzles me. Is her child really ok? Did he suddenly turn non-autistic? I don't believe that he turned typical, but instead he learned to function and become less confused about his environment. This is what it is all about, isn't it? Getting our children to function in the world. But is denying his autism respecting him? I really do have such a hard time with denial. Some children will learn to function in a "typical" environment, others won't. We really have to listen to the autistic -- I am trying so hard to understand autism in order to help, and respect my son.

He has gone to the park first with Bubby. I luxuriate in a dark cup of coffee before I get busy again...something I wouldn't have considered a luxury before Adam. Here, in a different environment, I chase him down the hall, ask him to come back four, maybe five times, insist on mands, ask him questions, keep him from stimming on sand by using it in different ways so that he can still enjoy it, but build on it and understand what he can do with it, teach him how to pick up seashells and put them in the pail, bring them back, count them and stick them in the sand...

It is time to pack our bags and go home. It's a New Year and the goal for Adam this year will be to get him ready for JK and ultimately a regular school, in essence, attending. When Adam is attending, he is so *ON*. I also want to help him with his reading skills. With all of this, I believe he is capable. I hold high hopes for him. I expect him to have his Barmitzvah and I will be overjoyed. I expect that he will graduate high school and go to university -- all the typical benchmarks of success. I speculate at the other unexpected successes he will bring, and all the possible jobs he may be able to do in life. I will be with him every step of the way. I will find the people to support us who believe that this goal is achievable. And when these goals are achieved, whenever they are (timeframes are quite irrelevant, actually), I will know every memory, every step it took to attain them.

[PERMALINK](#) POSTED BY ESTEE KLAR-WOLFOND AT 1/01/2006 08:28:00 AM 0
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THURSDAY, DECEMBER 29, 2005

I am in Florida and have had no time to write down anything...until now. Adam has been keeping me busy here...he loves the waves of the ocean, running up and down the beach (with a huge grin I have to add), and enjoys throwing sand in the water when not letting it spill from his hands so he can enjoy the visual part of this. He still jumps up and down and flicks his hands in the air -- his visual self-stim. It really is the most interfering behaviour he has. Everything else is manageable -- he doesn't stim to self regulate, he is easy to transition, enjoys novelty. We are lucky -- but I wonder how much of the work that has been done with him has helped too. I remember when he was so stuck on his routes and if we took one

wrong turn away from the park, there was a major meltdown. So, we just kept breaking our routines to keep him flexible. One thing is for sure, as a parent, we have to endure the crying to move beyond the stickiness of autism -- the areas where our children find it either difficult to transition or can't disengage from something.

I have started reading *When Babies Read: A Practical Guide to Helping Young Children With Hyperlexia, Asperger Syndrome and High-Functioning Autism*, by Audra Jensen. She writes down everything as prompts for her child. Now that I'm getting into potty training with Adam, I'm going to try what she suggests -- putting index cards around the house "I need to go potty," and at scheduled times, go to the card, make him say it, then take him to the potty. It worked for her child to articulate that he needed to go -- the most challenging part of potty training for Adam and I right now. In an attempt to get Adam to speak, my therapists want to pull back to one-word mands because Adam is chunking his sentences (ie; confusing "come here Flor" for everyone instead of just "come here"). This says that Adam doesn't truly understand what he's saying (the difference between the command and Flor's name in this instance). Yet, everytime I write something down, Adam understands what to do. I know it is still a prompt, but who cares? I want my therapists to really understand his reading capability to prompt and teach him. I also want Adam to learn to read before it's too late (the window begins to close at 4, apparently). Adam can read and decode words, but he can't do it with all words. He needs to be taught phonetics. Once he has this tool, then it is easier to teach him so many things.

Of course, I feel I need to jump all of this today, as the sun rises in front of me above the ocean. Ahhh. But I think I'll hold back a bit and just use a card here and there this week. Adam is on his vacation and I only want to help him enjoy it.

Check this out:

<http://29marbles.blogspot.com/2005/12/art-as-insight-into-autistic-mind.html>

It's Christmas Day and Adam has gone for a long walk with grandma. We are off to Florida tomorrow to see Bubby and Zaida. I know Adam will love it. Now that I've taken him off milk, I notice a difference in his language again. He is speaking more and is much more attentive and intentional in his communicative gestures. Either it's just a coincidence or it's the milk that aggravated him. I'm letting him relax this week -- enjoy the sounds and smells of the ocean, the feel of the sun. It is so grey and damp here in Toronto -- it also dampens the spirit.

I was up until 4 a.m. last night. My head keeps spinning. This time I was thinking about how much all of this therapy costs us a year, and all the other families who struggle to afford it. My girlfriend, whose child is recently diagnosed ADD, is going to put her son on Ritalin. After all her research, she determined that it was the best thing for him. She said to me, "imagine if Adam could take a pill in the morning..." I did imagine it. It did seem easier. I admit it. If it would make him less confused about his envrionment, then I imagine he would want it. I don't know. These issues, and the bioethical ones I've been thinking about, are not easy.

Our kids need the therapy. Our kids need the research. Autism is the most underfunded area of research, yet it effects so many children. While debating many of the issues, I never want to undermine the research -- it helps us understand the functions of the brain, autism, and if we are wise, we must always struggle with issues surrounding tolerance and disabilty, ability...

Adam is doing great again. He has figured out how to jump from high surfaces into the pool or into beanbags -- something he could not do before. He is speaking more and I am determined to help him to read more -- as he does it naturally and I believe this is a gateway to more learning for him.

[PERMALINK](#) POSTED BY ESTEE KLAR-WOLFOND AT 12/25/2005 12:11:00 PM
[1 COMMENTS](#) [LINKS TO THIS POST](#)

In the dark hours of 2 a.m., my son asleep at his grandparent's place, I twirl my hair obsessively whirling thoughts on my pillow instead of closing my eyes. It is yet another sleepless night when tomorrow morning I have to meet with a new school for Adam. Instead of just thinking, I kept the promise I made to myself many a sleepless night ago to just grab this computer and write the damn stuff down.

I entertain thoughts of the salsa lessons I always wanted to take, maybe a hip hop lesson or two -- to get connected to my body again -- this one that is sagging just a little more than it used to -- a far cry from my fitness instructor/modelling days of my twenties -- those jobs I juggled while going to school. Now, when I get work, my mind disconnects from the body and while it reels, I feel more tired and sluggish. It's all about time and paying attention to these things of health and vanity. Like Emmanuel Kant, I consider the rituals of daily walking, at the very least, to stay connected to myself and other possibilities that surround me. Walking, for Kant, prepared him for his daily writing. I truly love being immersed in work, but I also long for a kind of freedom I once had -- smoking cigarettes on my window sill in Freiburg (I've long since quit and can't stand the stuff), luxuriously writing down poems, stories and diaries of worries that now seem sensual and sometimes, just plain trivial in the grand scheme of life as it is for me today. That is what youth is for -- all of those wonderful experiences that prepare us for the life ahead -- the life of giving another young person the same opportunities. Marriage for a woman should definitely be put on hold until at least 30. There is so much wonderful living to do before we have children. Then, at least when we have them, there is no real unknown or imagined life. Only the reminisced one.

I believe I also can't sleep because Adam isn't home. For all the work our children bring, we miss them so when they go out. Everyone I talk to seems to have the same experience. Love is truly built out of all the tough steps of life -- and sometimes, just sticking together. It amazes me, because remember I only have one child of my own, the infinite love I feel for Adam. I wish, sometimes, I could have more children, but Henry has 5 and he's done. I respect that and now that I'm getting older, I feel I am done too. Adam can get the benefit of all of me instead of a sibling. I was an only child too. It just is what it is. Is there any point living the imagined life?

THURSDAY, DECEMBER 22, 2005

As I've been calling schools -- and the ones who might take Adam (there are only 2 that integrate) -- I've come to the conclusion that I, and my therapists, must do more to prepare Adam for the basics: ability to sit and attend. Schools consider it a disruption to the class if children are wandering around. We really have to push him harder and I have to give him a little more "tough love." I suppose I am terrified at any other option and I feel that he has so much to offer it would be ashame if he couldn't get into one of the integrated schools.

Adam is downstairs now in his facilitated play group. Two other boys in the group are also autistic -- but they talk and attend more. It terrifies me. I wonder why Adam doesn't talk and interact as much as they do. I hear him crying. He does not want to be down there with those kids today. But he has to be. There is no other way through this barrier than to push him. When he begins to interact more with other kids, and talks to them, I will be so happy.

[PERMALINK](#) POSTED BY ESTEE KLAR-WOLFOND AT 12/22/2005 01:42:00 PM
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WEDNESDAY, DECEMBER 21, 2005

Helping or Hindering: ABA cases and it's role in discrimination of autistic children. That's the topic I will write on soon. Keep checking in for it.

I've called OISE at U of T. They too do not take kids with autism. Everywhere I ask, we get turned down. I keep asking myself why? With all the legislation to provide equal rights to education, WHY? I know we can't legislate prejudice away, but maybe it's a step in the right direction. Without legislation and advocacy, where will our children go?

I am disappointed with the ABA schools -- I called Montessori School for Autism -- and although its director is so very nice, and

she wants to integrate, she is new and her program only services half-days for kids with autism. So too, it is too specialized. The goal of integrating is not yet achieved here.

We need a small school to start the model for integrating autistic kids -- providing enriched programs and IEPs (Independent Education Plans) to service everyone from the gifted to the delayed, while keeping them together. In such a school, the neurotypical kids can build their self-esteem by learning to help and teach those that require extra assistance, thereby building a future model for tolerance in our society. In autism, where expression is largely different or difficult, I truly believe that exposure is also important. We must never underestimate the cognitive abilities of autistic people. Just because the manifestation or output is atypical, it doesn't mean that autistic people aren't absorbing everything that is presented. We need a school that honours this while providing supports so that people with autism feel empowered and can build their self-esteem. I am shocked how we are being turned away at every school. The alternative is that I do this myself -- and I already have people ready to jump aboard. It will have to start small, and as I said, the model will be built so that it can be supplanted to other schools. What I envision is a plan that will finally make Ontario legislation for inclusive schools possible, successful and efficient.

As for the piece I am preparing on ABA cases, I believe the plight of parents is the same as mine-- the struggle to educate our autistic kids. I don't believe in the slow-paced approach and isolation that ABA programs cultivate (most therapists won't expose kids to new things until the task is "mastered" -- thereby totally viewing the typical response as the means to the end). The main and big difference is the legal argument used -- constructed with semantics like disability, inability and dependence -- the view that in the end, strips away the dignity of autistic people as people who want to be independent, are abled, require special assistance, but also have equal rights. When I get frustrated with autism, it is my problem, not my son's. This frustration is built from years of my growing up NOT exposed to different people. Now that I've learned otherwise, I believe we must grow and nurture a youth that will support and include our kids in society.

TUESDAY, DECEMBER 20, 2005

Yesterday, I was frustrated. So Adam demonstrated what he could do. Here's a little note I wrote to all of Adam's therapists this morning:

It is interesting to note that Adam does not stim at all during art activities. He is focussed and engaged. This tells me that he enjoys the visual stimulation of art and that he is desperate to learn. Morgan always plays classical music while he's making art. Adam loves music too -- all of this is a great gateway to learning, language and socialization.

Here's a little story of what happened last night: As you know, Adam's stims have been up this past week or so. His attention has been challenged (seemingly). I've been teaching him how to dress himself intensively this week. Last night, before bed, I took off his socks and threw them over the bed adn onto the floor. When Adam was playing on the bed a little later, he spotted one of his socks. He focussed on it, got off the bed, grabbed it, came back on the bed and laid on the pillow and began putting on his sock. He said, "sock on.....watch!" Every time I worry, he gives it to me. He lets me know he's paying attention, even though it doesn't look like it and he can frustrate me. There is no doubt that he has to learn what's appropriate by learning to pay attention -- especially in the classroom or with other teachers. But then, Adam teaches me that even though he doesn't look attentive, he is paying attention. Sooo, I wonder if this is a fine balance of moving along with programs and EXPOSING him to lots of things even when you think he hasn't mastered it, even if done incidentally before formally. Because of lack of attentiveness, I believe that kids with autism could be held back needlessly because the rest of us think they aren't learning. I sure hope that Jonathan and Adam have demonstrated that this is not necessarily so.

Adam always gives me these surprises, just so I know that he's with me.

Now, I have another good story after all the disappointing school calls I've been making: Eric from Crestwood Valley Day Camp. I

had a long conversation with him and have enrolled Adam in his camp for 3/4 days. He wants Adam and asked all the right questions and wants to keep him challenged while recognizing his needs. It was a relief to finally talk with someone who cares and gets autistic children. We talked about the challenges of finding schools and he suggested Willow-wood. I will have to check them out. Apparently they have done a nice job with integration, even though they started out as a more special needs school. So too, I will be meeting with Gail Baker of The Toronto Heschel School to see if she would be amenable to my starting a program there that would work for autistic kids. The goal really is to keep them integrated. I know Adam would do well there, and it is not fair for us to discriminate against him, and children like him, just because we think they are not paying attention. Not when he will actually get something from the experience, even if it looks different the way the rest of us acquire knowledge and learn. I think this just about sums it up. If we truly appreciate the way the kids learn differently, the way they need to be with other kids of all types, perhaps we and teachers will learn to appreciate their unique style of learning and being, and never underestimate them again.

So I am sorry I said I hated autism yesterday. Like us all, I have moments of frustration and self-doubt. It lasts about an hour, at worse, a day. I'm just trying to be honest here. Otherwise you might think I'm not real. And boy, this is REAL.

[PERMALINK](#) POSTED BY ESTEE KLAR-WOLFOND AT 12/20/2005 09:47:00 AM
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SATURDAY, DECEMBER 17, 2005

Consider these thoughts from Paula Kluth on Inclusive Education:

Some parents and teachers assume that some students with disabilities cannot be provided an inclusive education because their skills are not similar enough to those of students without disabilities. This is perhaps the most common misconception about the law that exists among families and teachers. Students with disabilities do not need to keep up with students without disabilities to be educated in inclusive classrooms; they do not need to engage in the curriculum in the same way as students without disabilities; and they do not need to practice the same

skills as students without disabilities. In sum, no prerequisites are needed for a learner to be able to participate in inclusive education....students with disabilities can participate in general education without engaging in the same ways and without having the same skills and abilities others in the class may have. In addition, this example highlights ways in which students with disabilities can work on individual skills and goals within the context of general education lessons. It is also important to note that the supports and adaptations provided ...were designed by teachers and put in place to facilitate a [particular students'] success. [A special student] is not expected to have all of the skills and abilities possessed by other students in order to participate in the classroom. Instead teachers [can create] a context in which [a student] could "show up" as competent."

Although understanding inclusive education, the laws related to it, and practical strategies are important, nothing is more helpful in learning about inclusive schooling than doing it. Teachers in today's schools must make a commitment to value the participation of all and to work toward good inclusive practices every day. It is my hope that readers will understand this chapter as a call to action, begin to see inclusive schooling as a verb, and help students with autism gain access to inclusive classrooms and educational experiences.

Perhaps the most important reason to pursue inclusive education, however, is to provide all students with an education that respects the diversities they bring to our schools. As one teacher commented, inclusive schooling is not for about students with disabilities, it is for and about all learners. 'I don't call it inclusive because of [my students with autism]. I call it inclusive because ...I am a teacher of all kids.' (Kasa-Hedirkson, 2002, p.145)"

By moving towards inclusive education I guess it is political. There is no way avoiding it, I have moved into action. Everyone I talk to doesn't understand inclusive education or understand that special kids can integrate into the classroom. Money, resources, training, all come into dialogue. What it requires is a change of heart and mind - thinking out of a very narrow box.

FRIDAY, DECEMBER 16, 2005

To open a school or to create a type of Outreach Program to integrate one or two autistic kids in a regular classroom -- with well trained teachers and with a flexible and open school staff -- that is the question today. If I could do this in one school, then perhaps it could be used in others -- and the legislation that exists for inclusive education would be much more effective.

I am so concerned about schools. I am talking with my friends today who are experiencing the same plight as I am, but they are two years ahead of me -- schools who turn their autistic kids away, schools that turn us away without being blunt about it. There is no place for them, and now there are so many children with autism. How many more years is this going to take?? Even schools who teach the learning disabled don't want the autistic kids, because the social component is difficult to teach and deal with. Then there are the ABA schools, and there are lots of parents like me who do not want our kids there. I do not want exclusive ABA all day long for my child.

Where integration would help my son, with extra assistance, it remains elusive. Will continue this later...a ladder has to be put into my office library now...

[PERMALINK](#) POSTED BY ESTEE KLAR-WOLFOND AT 12/16/2005 02:40:00 PM
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THURSDAY, DECEMBER 15, 2005

For those of you who were looking for the segment on Canada A.M. yesterday, it has been postponed to air between Xmas and New Years.

In the meantime, I have refocused on Adam again. He is so cheerful these days. But I need to do more to make him talk and become more independent. Nannies and loving grandparents just put food in front of him and don't give him choices. In a rush to get to school, we don't give Adam enough time to dress himself. We are not giving him opportunities to discover, try and make mistakes. When he's pushed, he does so well, but it does take a

great deal of patience and budgeting of time. There is a price to doing exhibitions and writing books -- the price is less time for my Adam.

I went to The Alan Waldorf School yesterday, which is not the school for autistic kids. They claim to be co-educational, but after interviewing a couple of schools now, I can see how talking the talk and walking the walk are two completely different things. The principal said they would take him but I couldn't talk to a "remedial" teacher (hate that word), until I paid the \$100 deposit for registration! She went on and on about how the school "taps into the energy of the universe." Medieval penmanship is a requirement as well as drawing for every single subject -- the student notebooks look like artifacts but I wonder how much they are actually learning. I asked that principal if a child with motor difficulty could use computers. There was no flexibility -- the penmanship seemed more important than the content. We all know that it doesn't matter how we write, it matters that we UNDERSTAND. In this school, every teacher looked like a hippie -- one teacher may teach Sanskrit while yet another teachers about the Saints and yet another into gnomes (yes, it's true). So when it came right down to it, she said, while using her fingers as quotation marks, that "so called high-functioning autistic children" may not be able to move too far in the school, to which I wanted to reply - why would they?

Discrimination abounds. It is disguised which is the most disgusting kind. It is disguised by principals saying they are "open" to having children who are different, but really, they are not and push you away with rigid programming and lack of flexibility. It is disguised by friendly voices, and the hiring of "remedial staff" and "educational assistants," most of whom know nothing about autism. As parents, we are invited in for tours just so those schools can't be blamed for being prejudiced. As parents and autistic people, we are pushed to the margins so that others do not have to deal with us and our children.

What kind of society are we? THIS IS NOT GOOD ENOUGH. I want to expose all this ugliness and each and every school I encounter that does this to us. I want to tell you of all the good I find in the world as well, so that gets more exposure in the end than those ignorant people that run schools like The Alan Waldorf School, The Willow School, and The Mabin School -- all who have

turned us away with disguised discrimination. (The Mabin said to us that there is not enough room in the classrooms for shadows). At least the Willow School -- who told us they have one autistic child as a favour to someone they know -- said straight up that they don't take autistic kids. In the end, ignorance about autism is no excuse and furtive discrimination for those with any special needs is akin to any other kind of racial or ethnic discrimination.

We have schools that are fractionalized, even an autistic community within itself, divided in what we believe is good for our children. There are more schools popping up for kids with Learning Differences. The Public School system tries to integrate and I still have to look at the ones that have been recommended. Discrimination abounds but it always takes me by surprise. I mean, my son is beautiful in every way. I am always shocked that he, and other innocent children like him, are subjected to such naivete.

I believe that we parents are given assignments. Every child requires *something*. There is a great irony when I hear another parent complain that their otherwise unscathed child is not developing the way s/he likes -- I marvel at the luxury of that complaint.

And yet everything about Adam is a gift. He has taught me to slow down, to appreciate every single step. He doesn't lie, he is not greedy like some other children. Buying him toys where other children would become spoiled does not effect Adam in the same way. Toys are his tools for learning -- much more so than non-autistic children. I see him playing with toys and exploring him in a way that a one year old does easily. Where other parents get caught up in which Ivy League School they would prefer their kids to go to, what cars to buy them (my husband does this with our other kids, so I see it in my own household!) I will receive simpler and what I think are richer gifts -- the gift to learn what it means to be human -- of patience, kindness, of frustration and triumph, the pain of isolation and the utter joy of when he will gain a friend, or even a girlfriend one day. When Adam celebrates his Barmitzvah, it will be a momentus occassion -- instead of getting caught up in the carnal hype of the party -- the party will be woven from the painstaking steps to get there -- and those are the best parties of all. Happiness really does come from the simple things that the rest of us take for granted. From talking and

reading other parent accounts, I am preparing myself for the future while also taking in the moments as they occur. Moments of bliss are constructed of painstaking work. I can't write naively about the joys of my son without discussing the pain and frustration which is part of the package.

So I do worry that Adam isn't speaking like his fellow autistic peers. I consider it my fault because he *is* capable and I'm still doing too much for him. So I do get tired sometimes, impatient too. I make mistakes. All one can do in life is keep trying.

[PERMALINK](#) POSTED BY ESTEE KLAR-WOLFOND AT 12/15/2005 12:53:00 PM
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FRIDAY, DECEMBER 09, 2005

The best has happened - the show now has a life of its own. The Toronto Star covered it to a point beyond my expectations. I was on CBC Metro Morning and Global TV and tomorrow we're on Canada A.M. And this is all to raise positive awareness about autism. There is a steady stream of visitors to the gallery making comments in the guestbook like "this is a very important exhibition." I think so. I believe that awareness does change the world one tiny step at a time.

I believe strongly in inclusive education and changing the way we view people with so-called "disabilities." I am currently researching models around the world of inclusive schools -- they don't take the resources and the money that we think they do. And they are so successful in other countries. For reference, take a look at Inclusive Education sites online and the UN Convention on The Rights of the Child, the UN Standard Rules on the Equalization of Opportunities for Persons with Disabilities and the UNESCO Slamanca Statement. These documents recognize the human right of all children to inclusive education. Also there is The Ontario Coalition For Inclusive Education.

I am pressed to get back to Adam's programs now. I am concerned that he is displaying some inconsistencies, which may tell me that we have to cut back on some of his programs in order to refocus on some missing component skills. I always feel that if I take my attention away for too long, this happens. It must be a parent's

inclination to feel like they are never doing enough. In particular, Adam is having difficulty with making choices. Instead of consistently saying what he wants from two items, he echos both items, or says the thing he doesn't really want (he gets the broccoli and he gags!). We try writing out the sentences (which he likes and can read), but it's not helping with the concept of making the choice. So his SLP at school will give him a blank item (piece of paper) and the item of choice, and repeat it until he grasps the concept. Laura is giving him just the two objects, and that still seems to be the best option yet.

Also, the Neoprene Vest seems to be helping at school. When Adam is motivated, he is so focussed and attentive, but when he's not, or if he's tired, he just keeps moving around. He is seeking out a lot of deep pressure these days -- crawling under pillows and asking for "squish." So the vest gives him some pressure and he seems to enjoy it.

His OT wants to try having a visual box -- a box consisting of visually stimulating toys that he can play with 5 times a day for a limited period. She wants to do this to fulfill his visual stimulation needs. She finds that the visual distracts him the most in the classroom. Although he is easy to redirect and focussed and attentive while doing something, if left to his own devices, most (not all) of the time, he would be looking around the room. I am wondering if the visual stimulation will over-arouse him or fulfill the need. Everything is a test.

He was so tired this afternoon, my Adam. This morning he was so affectionate and snuggled into my arm making the sweetest sounds of contentment. This afternoon, he nested his little head into the crook of my arm and fell asleep. Such a far cry from the days of nursing himself to sleep -- a far cry from the child weaned only two months ago. I tried weaning him for months (years, actually). I tried giving him a bottle from the time he was an infant. He would have nothing to do with it! Then, one day, I decided to try again -- this time with a glass of warm chocolate milk (just a pinch of cocoa for the taste). It worked because he was ready. It didn't work a year ago, or the year before that. One just has to keep trying. One worries so much about all of these steps. Then when they are accomplished, the struggle to get there is easily forgotten. That part amazes me. How we quickly forget the effort. This is the kind of effort an autistic child must make every

single day.

[Link](#) [PERMALINK](#) POSTED BY ESTEE KLAR-WOLFOND AT 12/09/2005
10:21:00 AM 0 COMMENTS [LINKS TO THIS POST](#)

FRIDAY, DECEMBER 02, 2005

I am marvellously tired. The opening and autism awareness event went as good as I hoped -- everyone seemed touched by Jonathan and floored by his work. We had over 200, maybe 300 people attend the opening! It was on Global TV. Friends who believe in me, admitted they were not expecting work of this calibre. I can understand -- what one might expect when you talk about raising awareness for autism is a nice little exhibit of student calibre work -- wonderful expressions of the human spirit, but still, not necessarily excellent works of art. That's the other reason why I picked Jonathan for this exhibit. Just like you and I, autistic work can be good or average. Why I picked this work is not only for its intense emotional conveyance, but for its artistic excellence - simple strokes of line that, like a well-written sentence, becomes loaded with feeling and innuendo. By picking good art, writing, music, the message is clear. The message about what is possible for autistic people is clearer. Like the rest of us, we trascend the burdens of life in the works of Mozart, Van Gogh, Picasso, Hemingway...you get the idea. Most people intuitively know the difference between great and average, and we seek the former in order to see ourselves and all that we can be. We rather fly freely in the simple sweeping air, than become snarled in confusion. Jonathan's work is simply that: lucid.

The evening was crowded, filled with the music of Rosemary Galloway and the Norm Amadio trio. Wine poured while everyone marveled or quietly took in the panels I installed, "The Voices of Autism: In Their Own Words," and contemplated. People commented how overwhelmed they felt. I was overwhelmed that they were overwhelmed, and I said it. I was excited that the audience related so well to this show, and yet grounded in my passion to express my belief in the abilities of autistic people, of my son. These expressions, the work, is easy when it comes to one's child.

Dr. Roberts spoke eloquently and it was wonderful how she shared

the humour and the poetry of her autistic clients. Alan Lerman was incredible -- his dedication to his son was so apparent. Jonathan wore his headphones to muffle the sounds and greeted everyone with a hand-shake and asked lots of questions about the people he met -- names, where they were from. He asked my husband Henry, "why don't you have any eyebrows?" and Alan commented there would soon be a painting or drawing of him!

Jonathan insisted on staying until the end. He basked in the limelight and I was so excited for him. We stopped at Shopper's Drug Mart on the way back to their hotel (Jonathan's lense popped out of his glasses), and Alan ran in. I asked Jonathan, "Do you want some music?"

Pause. "Yes"

"Do you like classical music," I asked, twisting around to watch him.

Pause. "Noo!" An emphatic negative from a typical teenager in the backseat, in the dark.

"How about rock?"

Pause. "Yes." All was good now. I put on Q107 and on came The Doors.

"Do you like this?"

Pause. "Yes." He seemed calm. The flurry of the night ending as we rested on Cloud Nine. I thought I'd stop talking and let him relax, until he asked, "Are you sleeping?"

He was great. I could relate to some of this conversation with my son, as I teach him how to answer questions. He pauses as he needs more time to think about how he's going to answer, or what might be the right answer. I worried about speaking what I call "dumbspeak" to Jonathan -- that slower, more articulate way of speaking as if he can't understand if I go too fast. I worry I might be patronizing him, patronizing Adam. I can talk normally to Adam and now much of the time, he'll just do what I say, if it's a direction or I say we're going to do something. It's a hard call. Sometimes I

have to repeat myself to Adam, to give him more time to process, and other times, it's just as fluid as can be.

In the car with his dad and I, Jonathan would make comments, but mostly ask questions, or answer them. Conversation is more difficult, disjointed. His hand and his art are his dialogue instead. When Jonathan was younger, he didn't communicate. Now that he's older, he's communicating more. When he's older still, who knows? More still? Probably. People with autism often develop these skills later.

Caren, his mother, said to me today, that no parent should give up hope for their child. Autistic children need to be exposed to everything just like other kids, for you never know what they have inside them. She speculates that they would have never known that Jonathan had any artistic ability unless he had that serendipitous date with a piece of charcoal and paper at an after-school program.

I am glad that many people from the autism community came -- even the ones I may not agree with. I am terrible at politics and find it difficult to take extreme political stances in these court cases. I just can't agree with ABA and how they -- and this is a new one -- call it "the only *life-saving* therapy for children with autism." You gotta like that life-saving bit. Really makes a point, doesn't it? And yet there are so many parents I've met now who feel just like me. We see that therapies that focus social interaction skills help our kids significantly. Extracting from different approaches helps too -- I do a bit of behavioural conditioning in that we may use bubbles to get a response out of Adam that is more difficult to get -- but it's natural -- like giving a kid a lollipop to learn how to toilet train. In cases where motivation may not be as apparent to learn something, this approach can be helpful. But as soon as a connection is made, we don't rely on reinforcement, other than praise, for the sake of reinforcement. And we really don't use this that often because we taught Adam the joy of relating early on -- and that in itself garners his attention - something you need in order to learn. At the end of the day, children with autism benefit significantly from good teachers. Patient, knowledgeable, willing to adapt to the child and his/her needs. It is not the teacher's agenda, but child's we're interested in. One can't learn, or learn the joy of learning and then become independent, if one doesn't feel the motivation from within. And to think that autistic

children do not intrinsically have that motivation, some, *any* motivation within them, is to say that they are not human. Finding that motivation is the key to unlocking the learning process and the joy of living in the world -- something all autistic people are entitled to.

Even if at odds philosophically, we parents love our children. I hope the autism community can de-politicize autism so that we can get on with the business of helping our children -- seeing them as whole beings, accepting them for who they are, and helping them in areas of need as well as finding their niche in life.

[PERMALINK](#) POSTED BY ESTEE KLAR-WOLFOND AT 12/02/2005 09:58:00 PM
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Beyond Words: The Drawings of Jonathan Lerman

- Insight into an autistic Mind -

By: Estée Klar-Wolfond, M.A., Curator

There are many myths about autism. Perhaps because there are so many pieces of the puzzle, so many areas of the brain that are affected and are still being studied, that it leaves room for too much speculation. As a result, we take the view that people with autism, and their behaviors, are a mystery to us. Like aliens or foreigners, we watch their behavior with bewilderment, and sometimes fear.

This view is a danger to people with autism because so many people are affected. Currently 1:166 children are diagnosed with autism in Canada and it is most diagnosed after mental retardation and cerebral palsy. The condition affects communication, socialization, perception and movement. Its symptoms can be mild or severe. Children with autism are treated all to often for their behaviors and not the core of autism, which then reduces their self-esteem. Too often, we hear that we are seeking to CURE autism, when many autistic people say they do not want to be cured. While one opinion may not reflect another, it does alert parents that we must be careful of whose interests we're purporting.

Michelle Dawson, who was profiled in Canadian House and Home (2003) is a letter carrier in Montreal who has autism. "She laughs

easily, reads voraciously and takes pride in her perfect work record. She has language problems – she's not sure if she really understands the words she uses or if she just memorized how to use them. She says, 'I really like books, but mostly I like looking at the words. But having read the same stories over and over again, I have them in my head and use whole sentences from them.' She says that because of her quirks, people may judge her to be weird – unfairly, she states, 'because it's much like judging a blind or a deaf person while not acknowledging that the person is blind or deaf.' Michelle is adamant that people like her be judged for who they are and what they can do, and not some behavioral standards developed by so-called "normal" people. 'What's wrong with being autistic?' she asks. 'Why are we considered to be so disastrous? Why are we such a mystery? I think we should be allowed to be who we are. We work hard, we're honest, and we contribute a lot without getting much back.' Michelle wants people to understand that it's not easy having autism in a non-autistic world. 'I think people should recognize that the entire burden should not be on us to be like them, but rather, to acknowledge how hard it is for us.'"

Autism is not really a mystery. At the core, people with autism are like all of us – they need to be accepted for who they are, to be happy, to have fulfilling work and to be loved. As a mother of a 3 year old son with autism, I feel strongly that he, and others like him, be integrated in a regular classroom – as integration in the school sets up the foundation for a democratic society where no one person with special needs be marginalized. Consider this from a severely autistic adult:

All my life I was enrolled in classes for the profoundly retarded. The pain of that isolation, I can't describe. Some classes consisted of putting flashlights together and then they would be taken apart for the next day's project. I never spoke or made eye contact. I hummed and self-stimulated. No wonder they thought I was hopeless. I was always treated well but my intellectual needs were never addressed because nobody knew I had any intellect at all. Sad to say, many like me remain in that same hellish situation. (Treacy, 1996, as taken from Paula Kluth, You're Gonna Love this Kid: Integrating Autistic Kids in the Classroom)

When Jonathan Lerman was 2 years old, his parents state, "he slowly began to slip away." A formerly alert and cheerful infant, he

now wouldn't respond when his parents called out his name. "The few words he once knew were gone," they write. "He would tear his hair out in clumps when he was upset. And although we longed to comfort him, he resisted our attempts. It has long been widely believed that children with autism do not comprehend emotional states of others and, indeed, may be extremely limited in their ability to understand or experience their own emotional states. For many years, we assumed it was so for Jonathan." Then, one day, when Jonathan was ten years old, his parents received a phone call from he school. Jonathan began drawing – "not stick figures and crude backgrounds," as art historian Lyle Rexer states, "but parts of eyes, mouths, stylishly rendered. In a short time, he was drawing entire portraits, some from life but most from personal sources such as television and magazines. He worked rapidly and with uncanny expressiveness, capturing the essence of his subjects in sharp, sweeping lines and smudged shadows. He was a prodigy, a savant of the charcoal crayon" (Lyle Rexer, How to Look at Outsider Art, pp.64-5). That was written when Jonathan was twelve years old. Today, at eighteen, Jonathan has demonstrated that he, as reflected in his art, is growing through varying representations of people, their interactions and positioning. He also paints and sculpts. The Lermans write: "What does Jonathan's talent mean in the larger scheme of things? We believe that Jonathan, through his work, teaches us that we must open our eyes to the world of people with autism. He is helping us expand our knowledge and transcend our beliefs about their perceived limitations....Jonathan may only be one person with autism, but we have no way of knowing that other people with autism do not experience a similar degree of emotional connection and simply lack the talents to express it."

Jonathan's work has been categorized into the Outsider Art genre – which refers to self-taught art. The critical art world has begun to take it seriously, people collect it, and its market is far-reaching – he is quickly becoming and "insider." Perhaps Outsider Art has gained status in the art world because as in modern art, let's use Jackson Pollock or even Vincent Van Gogh as examples, artists are regarded just as much for their psychoses as for their art. The human mind and its manifestations are intrinsically entwined. As I researched and studied creativity and autism, learning about Henry Darger, Joseph Connelly, as autistic artists, or other gifted minds such as writer Lewis Caroll, or philosopher Ludwig Wittgenstein, scientist Albert Einstein, or entrepreneur Bill Gates,

those whom I call autism celebrities, I was staggered when I came across Jonathan's faces. To-date, I have found no other artist with autism like him, who perceives humanity with such profundity. It now becomes impossible for you to leave here today, carrying the myths in your mind that autistic people are rendering machines – only capable of quick calculations and are robotic in the way they live upon the earth. This is why I eagerly wanted to share Jonathan's work with the Toronto community. Finally, we begin to see visually what is possible. We can see for ourselves that he registers and feels intense emotion, that he has an incredible intellect despite the way he functions. But perhaps, if we were to only consider the surface of him, we would be unaware of it. This is Jonathan's way to let us into his world. It is his way to self-actualize. By looking at his work, we must then consider how every "disabled" person in the world may have a vibrant inner life. It can be a painful thought, as we who are abled find it difficult to consider a body without movement to be anything other than a quiescent being. The rest of us have not experienced the awesome malleability of the human brain and spirit -- the human ability to adapt to the environment no matter what area of functioning may be impaired.

We know from research by Dr. Patricia Czapinski that anatomical issues may be a factor in facial expression in some autistic people. We know that registration of intense emotions may make eye contact difficult for people with autism. Sad to say, that when we don't see affect from some autistic people, the inference is that autistic people don't have emotions. I hope you are now convinced that this is nonsense. What friends and family can do is to speak to an autistic person with respect, directly to them as if he or she is listening, with emotion towards them because they are human and need you. As a mother, I want you to understand that my son, and people with autism have physiological and neurological difficulties with things that the rest of us take for granted.

I don't really want to bore the reader with the construct of our day. There are many parents of autistic children who live it the same way, more or less. But for those of you unfamiliar with this world, I might be remiss to leave out at least, its essence. Our day is filled with teaching, of learning HOW to use a toy, to put on a sock, to play with a friend, to answer a question, to feed a doll, trying to peddle a trike while steering, or clap hands to a song on cue. Once the how is learned, Adam begins to take off. But the

learning is deliberate – step-by-step - and a great deal of patience and understanding is required. Days are filled with therapists coming and going from our home, Occupational Therapists, Speech-Language Therapists, therapists who teach cognitive, social and self-help skills. Weeks are spent organizing of team meetings, programming, more research, advocacy, meeting with nursery teachers, and for us soon, meeting with elementary schools and trying to find the most flexible ones. Adam, and children like him, works hard to learn about their world and function within it, unlike other kids who learn naturally from their environment. Days are filled trying to understand and assist Adam's sensory requirements as he flaps his hands above his head because he needs to, or wants to be squished underneath a pillow in order to relax. For other parents it may involve dealing with seizures and medications, or episodes of frustrated aggression. My days are spent with endless worry about the future (no matter how optimistic I try to be) – of whether my child will be accepted or bullied, and wanting to protect him from the pain and isolation that discrimination may bring.

No one child or insensitive person will be able to beat the autism out of Adam. Autism is a way of being and experiencing the world. I hope to teach him that no one person can beat his spirit. Autism is so pervasive that it affects the way one moves, feels, and sees. It affects all the senses. My husband once asked the question of “why do therapy if the goal is not to cure autism or make Adam appear less autistic?” to which I responded that the goal for Adam is to understand his world, to learn how to communicate his thoughts and desires, to self-advocate and self-actualize and in essence, to feel fulfilled. Adam is a partner in his own therapy as we learn to respect the way he sees the world while helping him to communicate his own thoughts. It is an unfortunate fact that we feel less valued if we can't communicate and then get left behind. I uphold the belief that if we build supports to set children up for success, even the most affected can be fulfilled. Autism is as much a social construct in that we do not yet provide enough opportunities to enable self-esteem or identity.

Research, as done by Dr. Wendy Roberts and others around the world, helps us identify early markers so we employ interventions as early as six months of age. We can begin working on socialization and pragmatics earlier which has proven to be beneficial. Thanks to research, some of which becomes refuted or

improved by more research, helps us understand the inner workings of the autistic mind. It helps me as a parent understand and empathize with my son so that I can be a better parent. I call upon everyone to support research that enables us to provide better therapeutic interventions.

Upstairs, I have created a wall called the Voices of Autism. These are the people who can talk or write about what it feels like to be autistic. Like all of us in this room, we have different talents and capabilities. Some autistic people are artists, musicians, writers, computer programmers, scientists, bus drivers, professors, doctors, and others have a more difficult time, being in need of extra care.

I am only one parent of a young autistic child who wants to raise awareness so that my son can reach his potential with less discrimination in the world. I am adamant that he not be forced to live in the margins of society because people do not understand autism. But it is those with autism who must also step up to the plate and speak, or draw, communicate in some way on their own behalf, and our responsibility as parents, fundraisers, teachers and scientists to make way. Autism may sometimes be beyond words, but the voices, both reverberant and real, continue to fill my head. May the collective voices of the autistic community become loud enough for us to hear what it means to be human so we can build a more tolerant society.

Estée Klar-Wolfond, M.A.

<http://joyofautism.blogspot.com>

Curator of Beyond Words: The Drawings of Jonathan Lerman

December 1-22, 2005.

Lonsdale Gallery, Toronto.

[PERMALINK](#) POSTED BY ESTEE KLAR-WOLFOND AT 12/02/2005 09:55:00 PM
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MONDAY, NOVEMBER 21, 2005

A day in the life of Speech Language Therapy:

Estee,

I pressed Adam today as I increased my expectations (moving towards joint attention), and introduced some new activities into our repertoire (e.g. Elefun, pretend play with the picnic/food). Adam was not interested in the picture schedule I showed him. If I had to venture a guess as to why he moved the blue card away it would be because I chose all of the activities without asking for his input.

The first game was the Elefun game. Adam and I shared in the excitement of the ‘butterflies’ flying around and he watched me as I caught them with the net. With encouragement and direction, Adam helped me re-load the butterflies into the machine. He was determined to figure out the on/off button by himself. At one point he got up, walked around the toy house and then came back to try again, this time with success.

Next, we worked on a puzzle, a new puzzle. Adam was not interested in this at all! He inserted one of the four pieces I left for him and then refused to do any more. He walked away from the puzzle and headed for the spare bedroom. He stood there he said, “open door”, “I want open door”. I followed him to the door but hesitated before opening it for him. When he looked at me I opened it and told him, “It’s good to talk and look”. Once inside the spare room, we played our favorite Pillow Plop game for a bit of a break.

After that, I began to set the table for the stuffed bear and the toy person. I used a lot of self talk as I put the items on the table. Adam wandered about the room, occasionally looking towards me and what I was doing. Eventually he came close enough to the table to signal interest in the activity. I invited him to join in and he helped set the table and distribute food to the toys (e.g. “Bear needs a spoon. Give Bear a spoon” or “What does bear want to eat? Corn or spaghetti?”). Adam fed the Bear ‘pizza with peppers’ with a hand over hand prompt.

Finally, we played with bubbles. I used this activity to target joint attention and cued Adam to look at me after looking at the bubbles (I pointed back and forth between the bubbles and my eyes and

told him to “say and look”). This worked well while I was holding the bubble container. Adam complied and went for a walk around his toy house before returning to me for more of the same. I moved the house away from its corner location and Adam stayed with me for two consecutive turns, whining before each one. Eventually I placed the bubble container in front of me. He picked it up and placed it in my hand!

Some things I noticed:

- 1) Adam had a fascination with round objects today. He picked up the net, the stepping stones, and the pizza pan to wave or to turn them around, like a steering wheel, watching the objects closely. He was deep in thought during these moments and did not connect with me at all, even if I imitated the action.
- 2) Adam’s walk around the toy house may have provided him with additional time to process changes, re-group, and self-regulate his emotions. He used this walk twice throughout our session, both after the puzzle and during the bubbles. When I moved the house he did not modify his path, and thus did not have the opportunity to reduce his anxiety. Sorry Adam.

Alisa

[PERMALINK](#) POSTED BY ESTEE KLAR-WOLFOND AT 11/21/2005 04:20:00 PM
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I'm hoping that many people will come to Jonathan's opening on December 1st at Lonsdale Gallery. He and his father are driving up from New York to be at the opening. TV will be there. I want everyone to come, afterall, this is a show to promote awareness about autism that is becoming so prevalent. I do not want my son to live on the margins of society, and no autistic person should have to.

I'm including an excerpt on Jonathan's work in the context of art-history:

Art And Autism

When Jonathan Lerman (b.1987) was barely three years old, his

parents noticed that instead of continuing to develop normal intellectual abilities, he began to withdraw from the world around him. His capacity to speak, play, experience emotion, and relate to others began to erode. Intensive therapy and special schools could not bring him back, and he slipped into a sort of arrested life. He was diagnosed with autism, a neurological disorder. Then, suddenly, at the age of ten, he began to draw. He did not compose stick figures and crude backgrounds, as children usually do, but parts of faces, eyes, mouths and noses stylishly rendered. In a short time, he was drawing entire portraits, some from life but most from impersonal sources such as television and magazines. He worked rapidly and with uncanny expressiveness, capturing the essence of his subjects in sharp, sweeping lines and smudged shadows. He was a prodigy, a savant of the charcoal crayon.

In clinical parlance, Lerman suffers from a severe form of autism known as Kanner's autism. As less serious but more prevalent form is known as Asperger's Syndrome. Kanner's autism is often associated with prodigious achievements in a single narrow area – rendering, calculating, memorizing, or playing music, for instance. Autistic artists like Lerman live in a largely visual world, which they can render but not interpret symbolically, a world very different from the schizophrenic, whose constant task is interpretation. According to neurologist Oliver Sacks, these so-called savants lack the very basis of artistic expression, the capacity to transform what they see – imagination. They are rendering machines, and their work cannot be regarded as purposeful, symbolic communication. At a deeper level, according to Sacks, people with autism lack what imagination itself depends on, the ability to experience their own inner states or intuit them in others. In the words of the author Temple Grandin, who is herself autistic, such people confront other human beings like “an anthropologist on Mars.”

According to this description, the “art” of the people with autism springs full blown and can never develop, since they accumulate no intrinsic creative awareness of past work against which to measure current creations. Their productions are, in Sack’s telling phrase, “raw, pure expressions of the biological,” their lives, “a collection of moments,” vivid, isolated, devoid of any deeper continuity. As Picasso famously remarked, there are not prodigies in art. That is, art is the product of experience and reflection as much as it is the expression of raw rendering talent. Beneath the dizzying variety of

styles and abilities of artists with autism – styles as different as the precise multicoloured architectures of Jessica Park (b.1958), the rough-framed, google-eyed self-portraits of Larry Bissonnette (b.1957), the graphic industrial fascinations of Laan Irodjojo (b.1969), and the bold gestures of Lerman – lies an unreflective, unchanging void, a negative nirvana.

If Oliver Sacks is right that artists with autism never develop as acculturated, “real” artists do, then, like gods and monsters, they do not bear the burden of time and cannot tell us something essential about being human. They cannot inspire us with forms of celebration in the face of our progress toward oblivion. But this is misleading. Only modern art has explicitly assumed the tragic burden of isolated self-consciousness and a temporality that hurtles us forward into the unknown. Earlier art and most sacred art sees the world as more static, and human consciousness as only one of its elements. The fact that the “vision” and technique of artists with autism do not seem to change or expand in range or depth means that their relationship to the world is not changing. Is that relationship incomplete? Certainly. Is the self behind it incomplete, limited? Perhaps, but the self as expressed in art is not some discrete thing but only the gestures that embody it, the traces it leaves behind. The repertoire of gestures can be rich and varied or narrow and repetitive, but the validity of any gesture cannot be dismissed without a loss to our sense of what it means to be human and the ways that created forms can testify to the diversity of that experience.

From Lyle Rexer's, How to Look at Outsider Art

[PERMALINK](#) POSTED BY ESTEE KLAR-WOLFOND AT 11/21/2005 04:01:00 PM
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SUNDAY, NOVEMBER 20, 2005

My mother's birthday yesterday and her eldest sister died. I couldn't sleep again all night thinking about life, death, what's important and what's not. How unremarkable a life seems at the point when it is all over...how most of us will be forgotten. I

thought about deathdays as opposed to birthdays -- and how significant they are. I remember the days my grandparent's died. When I walk around Mount Pleasant Cemetery, I study not only the life span but wonder about those deathdays...how I wish I knew mine, knew Adam's...how long do we have and what will the rest of our lives look like? I just can't help myself think like this. The mind reels over and over in the darkest hours of 3 a.m.

I think about Jonathan coming to Toronto and how excited he is about having his show here in Toronto and how he should be excited. Everything he's about is being validated. And it's not just for the sake of his autism that I'm doing this. He is also a strong artist. His mother, Caryn, told me how he's having a hard time these days -- some aggressive bouts, how he hates having them. Is it the hormones of adolescence? Seizures? The medication he has to take? Frustration with not being able to communicate so that others understand him? One or all of the above? That's the mystery of autism. For many, it has some tough sides. Yet, his mom says that 90% of the time, he's happy and social, enjoys the recognition of his art ... a "joy," she says. I sighed. I can relate to that word.

Going to a regular nursery school was the best choice I could have made for Adam at this time. For all the fretting I did at the beginning, he is talking and relating more and more all the time. All of us have noted the changes. He is more curious about his environment and he plays more functionally on his own than I've ever seen. He still can do repetitious things, but sometimes I let it go for a while, and once he's finished, he stops and moves on, on his own.

It is Sunday. We're going to O.T. soon. We do it 2x a week now. It's been the best thing for him. Learning how to use his body, how to sequence his actions to do a task, has done wonders for him exploring the environment on his own -- like typically developing children do without any help.

My O.T. said that the DSM is going to change to include Sensory Disorders -- it certainly makes me wonder how many diagnoses' will change yet again. Everyone is getting diagnosed with autism now, but as we continue to refine the specifics of each child, we'll be better able to tell if a child who has sensory issues is as autistic as the psychologists tell us. Certainly, these are all brands of

neurological differences in our children. But the more we know, the more we can do in the way of therapies. I truly hope I will never have to put Adam on any medication. I am so anti-meds -- I see them as temporary solutions, not cures. I prefer to take the therapeutic routes. Work and play and relate day in and day out. People don't realize my schedule or the schedules of other parents with children with special needs... Wake up, teach how to dress, teach how to eat with a fork (all of this takes a little longer), go to school, meet with teachers, work on programs, find a smidgeon of time to write, pick up Adam, have lunch -- teach to use that fork, get ready for therapy, meet with therapists, take part in part of therapy, put Adam for nap, relax with Adam (mommy time), get ready for dinner, all the while teaching how to request for things, to answer my questions, to discriminate between objects, make a choice... it goes on all day long... then at night, we have a new sleep ritual so that Adam can learn to self-regulate since his brain goes non-stop and he could otherwise stay up all night.

He plays around me now and waits for me to do something with him, circling my chair -- sweetie.

Max, Adam's 16 year old half-brother plays with Adam everytime he's here. It just comes naturally to Max...and last night at my mom's birthday dinner, we talked of Wills and who would take care of Adam should something happen and Max just said, "I'll take care of him." Just like that. No big deal. And I know he can and he would. And I know that out of anyone in the family other than my parents, he knows about Adam intuitively and he's seen what goes on day to day in this house. I know that he get's it. So Adam is truly lucky to have him. I am touched and even relieved to know that there is a person like this in Adam's life. I don't have any brothers and sisters, so this touches me to the core.

[PERMALINK](#) POSTED BY ESTEE KLAR-WOLFOND AT 11/20/2005 09:56:00 AM
[0 COMMENTS](#) [LINKS TO THIS POST](#)

WEDNESDAY, NOVEMBER 09, 2005

For many months Adam never took to teddy bears. He does not cling to a blankie or a bear the way we see many other children do. Other comfort objects have included books, and comfort tactics, stroking his belly or my arm.

Yesterday, I pulled out the many stuffed animals we acquired from friends and family over the first few years. Adam hugged them and really took to Elmo and Cookie Monster. He loves Elmo and I realized that when he becomes distressed sometimes he says "baby Elmo!" almost as if he's asking Elmo to rescue him -- it has that same intonation.

He couldn't get enough of Elmo when I pulled him out last night. We sang "Elmo's Song" together (this Elmo is a puppet, so I used him as such). We sang over and over and over again -- he kept passing Elmo to me and asking "Elmo! Elmo's song!" He sings the last words of a sentence -- I've been using that intraverbal tactic for some time. We did the same for "C is for Cookie" song. I thought I was going to lose my voice, but hearing Adam's voice singing and all that eye contact and joy between us, I would have sung 'til I dropped.

So I put Elmo and Cookie Monster to bed with Adam last night. He gave Elmo "five", kissed him. I'm trying to use them for pretend play and the development of symbolic thought. He didn't seem to have any problem with any of it accept that it was repetitive. He did Elmo first, then Cookie Monster and we kept going like this. I then tried to vary it each time.

Every week, it seems the lights keep getting brighter in Adam. He still needs his time to do his letters (I let him line them up after a session or in the evening). He needs to do what he likes and what relaxes him like us all. But I find when we balance between having to keep working on his engagement and his skills, and letting him be obsessive for a little while, he is a happy, balanced kid. I'm not trying to extinguish Adam's "behaviours"...I'm trying to expand it without taking it away, for to do so might result in a behavior that is more difficult to cope with. I have seen little aggression in him. He gets a little angry with me if I don't do what he wants or one day, if I don't take him to bed and he's super-tired. I find that if I acknowledge that he's frustrated, he is grateful and calms right down. It all comes down to respecting your child and reading them correctly. If we feel acknowledged and loved, we all do better in life.

I'm trying to always figure out his sensory requirements. He is squinting a lot these days and I wonder if all the visual stimulation

(he is a visual learner), hurts his eyes, or if he's just checking out the world -- what it looks like when he squints. He does love to hold up his arms and flick his hands (he has found that it makes shadows) and I am trying to just replace that with something else. I find if I start saying "hands down," it just makes the action more obvious to me, to him and to everyone else. It's like Tourettes and I see how neurologically there is a connection -- the body does things involuntarily. If you tell a Tourettes person to stop, they have to "do" their tics even more. So I try to replace it subtly by distracting Adam. Better to look at a book or play with something else. And at home, give him times to just do it. I find that all his "stims" just end up going away. Another one pops up -- they all come and go.

I've been optimistic these days. I said to another couple two days ago that I wouldn't change Adam. He is the boy I have and who I love. I still lay awake many nights thinking about all this, worried about other kids who have autism who do not have the resources to pay for therapies, schools -- people who can help them along in life so that they are less frustrated. I have a dream -- that awareness about autism can be raised to such a level where we can set up systems to enable them.

[PERMALINK](#) POSTED BY ESTEE KLAR-WOLFOND AT 11/09/2005 09:59:00 AM
0 COMMENTS [LINKS TO THIS POST](#)

SUNDAY, NOVEMBER 06, 2005

Beyond Words: the drawings of Jonathan Lerman
-- Insight into an autistic mind --

Londale Gallery
410 Spadina Road
December 1-20, 2005.
Exhibition Opening: December 1st 6-10 p.m.

Jonathan Lerman is an artist with autism. He is unable to speak so we cannot ask what inspires him or what triggered him to suddenly begin drawing at the age of ten. Today, at seventeen, Jonathan is prolific and shows no signs of slowing down. He has been featured in the New York Times, on The Today Show. He is in high demand because, as an artist with autism, he draws faces

with uncanny insight. Publicity is not something he's keen about, says gallery owner Kerry Schuss, his representative in New York City who bravely took Jonathan on at the age of twelve – something his colleagues in the industry felt he was crazy for doing. "He has trouble with crowds and cannot stop moving around. When you see him, you might think he isn't capable of anything."

Lyle Rexer, who wrote a book about Jonathan and also *How to Look at Outsider Art* writes: "Looking at Jonathan's work is an affirmation that he sees everything. Working with the assurance of Matisse and the speed of Picasso, and the humour born of a cartoonist, Lerman has created an unforgettable body of work. His drawings include portraits of actual figures as well as figures from his own imagination, and rendered with great acuity. These drawings overturn the stereotype of the so-called savant artists as an unchanging talent sprung to life fully-formed. Instead, Lerman shows the detail, the restless experimentation and rapid growth of an artistic sensibility."

Lerman is first an artist, and second, a person with autism. His drawings refute theories that people with autism are "mind-blind", in other words, cannot perceive emotions or understand that others have their own thoughts. It is unusual, in fact, to find an artist with autism who draws faces with the depth of perception that Jonathan does. It therefore shows that an autistic person can have enormous capacity for perception.

As art, Lerman's drawings stand alone. They draw the viewer in like a good novel and make us ask for more. We witness a beginning, where Lerman's body parts are dismembered and then watch them come together like a recognition of others and of himself. Associations are made ("The God is Wrong") so that we wonder what meaning they have for Jonathan. Like the autistic artist Joseph Connelly who brings together multiple objects in his shadow-boxes, associations between objects holds great significance, again blowing the theory that autistic people have difficulty with symbolic thought.

Jonathan Lerman, like some other people with autism, is a person with a gift. Michael Fitzgerald, who writes about Autism, Aspergers entwined with creativity and genius writes: "Ever since the term autism entered the public mind, its perception has not

been linked with genius and creativity. Rather, in the minds of many people, autism is associated with a very significant learning disability. A genius is a person with high ability, with or without autism, who produces a work that changes our view of a subject.” Is Jonathan a genius or a person with a gift? At seventeen and still going, we have time to wait and see.

As a mother with a young son with autism, curator of the show, Estée Klar-Wolfond wanted to use art to raise awareness about autism. She wanted everyone to know that lack of speech and different types of behaviour do not indicate a lack of intelligence, but quite the opposite.

Through Jonathan Lerman’s work, we can begin to see that even the most affected people are capable of thought and a unique perception. We are viewing here a “different sort of person” and Estée hopes that by taking a view into Lerman’s world, we can begin de-pathologizing the phenomenon of autism and respect this community’s insights and abilities.

Proceeds from sales go to autism causes.

[PERMALINK](#) POSTED BY ESTEE KLAR-WOLFOND AT 11/06/2005 10:05:00 AM
0 COMMENTS [LINKS TO THIS POST](#)

WEDNESDAY, NOVEMBER 02, 2005

I have to write a press release for Jonathan Lerman's exhibit. Like most nights, I lay awake grappling with myself -- wondering how to communicate about him, and about autism, in a way that doesn't belittle his work. He is first an artist, and second, a person with autism. The interest in the show is autism, for sure, but how do I resist the sensationalization of autism? I think just by stating that it is indeed a struggle to avoid talking about autism -- I mean, those of us without it, are innately fascinated by the brain's functioning, and any other perspectives, like autistic ones, that help us to understand the enormity of human capacity.

Can someone with autism please write to me?

[PERMALINK](#) POSTED BY ESTEE KLAR-WOLFOND AT 11/02/2005 09:29:00 AM

MONDAY, OCTOBER 31, 2005

There was an article in *The New York Times* a couple of weekends ago where a mother discusses the emergent sexuality of her teenage autistic son. She talks about how he is finding girls "hot" and asking even the "hottest" girls out on dates, unaware of the cliques and social niches that may influence other boys. She is concerned he'll have his heart broken, but then she notes that he doesn't seem to mind.

A response to this article that I read yesterday was by an enraged mother with another son with autism -- a child with lower functioning. She was upset how this mother was upset, or representing her son -- noting that not all autistic people are verbal and that all parents of autistic children work hard.

I am, quite frankly, upset by the politics of autism. The politics of which therapy is better, the court cases, whose doing a better job, which child is doing better -- the comparisons of one autistic child to another -- which is probably done by the best of us, but which is unfair to the child.

Has there ever been so much competition in the Deaf, Blind, Downs, Cerebral Palsy and other communities? What does all this dissention serve?

One mother may want to avoid me because Adam is "doing better" than her son. I may then turn around and sigh as I see another autistic child who is doing something that Adam cannot yet do. I know that comparisons that we make, even silently, are inevitable, but they are torture and in the end, are useless.

I see autism as a spectrum. Each child is on a different point on the spectrum. In other words, each child learns differently and has to jump different, and in some cases, more hurdles. But I believe the learning can happen. Does it really matter when it happens. Whose time line are we on anyway? So what if it takes someone until the age of 40 to become independent. I think we should be so glad for it and glad for that person.

Autism, the way I understand it, is a different brain construct. Instead of superhighways (those connections in the brain that make certain things for us a given), are as Dr. Gutstein puts it, "country roads in persons with autism." The processing takes a little longer, but with more and more use and practise, we can mold that maleable brain into making the connections more efficient.

Dr. Sacks talks frequently about the incredible pliability of the brain -- we certainly do know the abilities of stroke victims who are able to reconstruct speech and other areas of functioning using completely different areas of the brain -- different than the areas that those functions were originally based.

Every person with autism can and will learn. I wish parents would stop the painful comparisons that torture them and begin looking at autism, even at its most challenging, with more hope.

[PERMALINK](#) POSTED BY ESTEE KLAR-WOLFOND AT 10/31/2005 02:04:00 PM
0 COMMENTS [LINKS TO THIS POST](#)

SATURDAY, OCTOBER 29, 2005

My eyes are blurred. I've been up every night this week -- either from 3 a.m. on (Adam's sleep patterns are changing again and he wakes talking about the things he's seen the previous day), or, I've been out until 3 a.m. at fundraisers. Met some genome researchers last night from Toronto Western Hospital.

Then today, I took Adam to the Snoezellen Pool at Bloorview Macmillan Centre. The word snoezellen is actually taken from two Dutch words: "snuffelen" meaning to seek out and explore and "doezelen" which means to relax in a wonderful place. The idea is to expose children with various issues to relax and in Adam's case, the visual stimulation and relaxation enables him to talk more and focus.

So I take Adam to the change room -- there is another mother needing the large flat changing table to change her child with cerebral palsy who must be around 7 years old. The girl is listless and her eyes are nearly closed, leaving the impression that she could be sleeping. The mother talks sweetly to her child, getting

her ready to enjoy the pool -- a shallow pool where the lights are dimmed so we can see changing-coloured fibre optics, lights and shapes on the walls, with soft music piping in.

Another child -- a young teenager cannot move around much. She is taken from her wheelchair and placed in the shallow water path that leads like the yellow brick road into the actual pool. I'm afraid she is going to drown as she sucks in some water and cannot move her head well.

A young boy -- not much older than Adam is also autistic. He is afraid of the water and screams as he's being placed in it while the bright lights are on. Soon, the lights are dimmed, and he calms down. His mother can gradually take him into the water as they watch the shapes move on the walls and he is relaxed and learning to enjoy the water. He cannot talk.

Adam is delighted (we taught him how to swim with a suit that keeps him afloat -- he was no longer as fearful and he learned how to doggy-paddle with a look of glee). He wants to jump in. He is yelling "water, water!...1,2,3 Rocketship!" as he pleads with me to throw him up in the air on the count of three. He is singing "twinkle, twinkle little star" when he sees the stars projected onto the walls. He swims to the lights, to the bubble tank. He lets me swish him around. He jumps up and down and sings with me in the shallow end. He says "splash, splash" as he kicks the water around.

I felt at odds, really. Adam was having a ball. He could move his body at will. The visual stimulation fulfills his sensory needs so he can talk more (although he is talking more in general at home too).

Here I am talking about CURES for diseases without considering the thoughts and desires of those who cannot move their bodies at will. While Dr. Sacks talks even of paraplegics who learn to adapt, I take a deep breath about my recent arguments and what they imply. I can talk only of the community I am directly in -- the community of autism, and from a parental perspective, not an autistic one. I honour the words written and spoken by autistic people and I encourage them to keep talking about themselves and their perspectives. I can only hope to facilitate some of this.

I cannot speak for the parents whose children are physically disabled, for instance, but I do know one mother of a child with CP

who talks with pride about the major achievements of her child -- milestones that are part of everyday life for the rest of us. These are the miracles that the "abled" world cannot partake in. They make us appreciate life, in all its forms.

[PERMALINK](#) POSTED BY ESTEE KLAR-WOLFOND AT 10/29/2005 03:18:00 PM
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THURSDAY, OCTOBER 27, 2005

Back to my musings about CURES. I suppose I should clarify why it is I have the perspective I do. After working as an art curator, I became a very adept fundraiser, so much so, I was hired to lead various arts festivals and later, became director of corporate development for some health charities here in Toronto. I am the developer and the mind behind one charities' click to give program, which was called "Click for the Cure." Alongside one other major charity, I was the first in Canada to get it online and generate corporate support for it.

So I know the leverage and power of that word from a marketing perspective. In order to have the needs of the charity met, the drive had to be goal driven. Being goal-driven gives a reason to support a cause. If not a cure, then why? Why give? To give for any other reason than a cure seems too evasive and uncertain.

Of course, within autism, I do hold a different perspective. I believe that research has enabled us to understand the complex framework of autism so that we can understand people with autism and offer them a better quality of life through such understanding, and providing better and more appropriate education.

It is not as if I am saying stop the research. I am not daring or confident enough halting hundreds of years of PROGRESS. I do ask questions, though. I believe we are all asking the questions about what progress actually means, at what costs do we achieve it, and, are we really progressing?

Through science, technology, economics, we have nearly deified ourselves. We have come to a point where we believe we can FIX anything. The environment has gone to pot? -- it's okay, we can fix

it when we need to. Getting old? -- don't worry, we can extend your age and cover it up with botox. Progress seems to be intrinsically entwined with having control, and with immortality. Remember Gilgamesh? We have become victims of our own hubris. Jane Jacobs states: "History has repeatedly demonstrated that empires seldom seem to retain sufficient cultural self-awareness to prevent them from overreaching and overgrasping. They have neglected to recognize that the true power of a successful culture resides in its example. To take it successfully, a society must be self-aware." (p. 176 **Dark Age Ahead**). In terms of a cure of autism, which will sometime be on the horizon, I ask that we continue to ask the questions that I mentioned in my previous entry.

Adam is talking more than ever these days. I've been insisting that he answers questions, I model the answer or I have prompted it -- he had a difficult time understanding what yes meant until I put it over and over into context. Now, he's telling me he's hungry, he answers me when I ask him if he wants something (Yes or No), he calls for me, or Flor, he answers all kinds of questions and he understands receptively. He can print his own letters, and do so many things that he couldn't do a year ago.

As in progress, it is better to measure it in years and months than in days or weeks. It is easier to see the huge and deliberate strides Adam has made within a year.

[PERMALINK](#) POSTED BY ESTEE KLAR-WOLFOND AT 10/27/2005 09:34:00 AM
[0 COMMENTS](#) [LINKS TO THIS POST](#)

TUESDAY, OCTOBER 25, 2005

I talked earlier about the quest for the cure -- that Holy Grail if each and every disease and disorder (and I think we are creating more of them than ever).

Dr. Sacks spoke about the Deaf and the Blind. When he asked people who adapted -- adapted their brains, their senses after a period of having hearing or sight and then losing it, most of them claimed that they would not want to be cured. They stated that

they would not know how to cope going back after this period.

On the radio program that I keep referring to, **The Infinite Mind**, AS panelists said they did not want to be cured -- that they didn't feel "broken." They felt that they were better off "than the neurotypicals."

I had this discussion with NAAR - **The National Alliance for Autism Research** -- as I was the sponsorship chair this past year. The word cure is part of their marketing and their raison d'etre. The money gets dispersed to prominent researchers around the world to study autism. In my view, it is a greater understanding of autism that is enabling us to provide better therapies and making us better parents in dealing with autistic children. I believe in the research, but I'm not sure about the cure. Yet, I know there are some families who desperately want to find a cure. I asked NAAR, in honour of autistic people who are offended by the semantics of *cure, disability, abnormal, erradicate autism*, to be careful of those words and to exchange them for *difference*.

In my strong opinions about not abiding by one type of therapy, draconian approaches in some ABA programs, poor teachers and agencies who claim to be the experts in autism, and basically, those aiming to financially benefit from the plight of others, I am aware I run the risk of certain people being wary of me.

Like an autistic person, I feel misunderstood. Shouldn't we be asking the question about what it may mean if we find a cure for autism?? Should we not leave the decision to cure autism to those who are autistic? And if we do have cures, which part of autism will it address -- there are so many areas of co-morbid disorders in some people autism -- anxiety, self-injurious behaviours, and many more. Which parts can be addressed with "a cure?" If we find a cure, what aspects of autism -- the gifted parts -- can we maintain? Autistic people claim that autism is part of their personalities. Are we stripping away their being by taking away their autism? Are we saying that they, as autistic people, are not vital and important? Are we suggesting that they are....broken? By making people the same, are we therefore not running the risk of homogenizing society?

These are questions that we must ask ourselves now. We may be 50 years from some sort of "cure" and in the meantime, we should

be debating this bioethical issue.

I hope I can make a dent in furthering awareness about autism. It will be autistic people who will ultimately have to keep advocating for themselves as they will have the strongest voice, and I'm so glad for their website, aspie.com, and the many books that are written by them including Donna Williams, Dawn Prince-Hughes, Stephen Shore, among the many others.

I attended a school meeting today. One father mentioned that he never understood the *culture of difference* until he had a son with an issue. I am learning that we "normal" people are closed to a wonderous world. There are cultures of different kinds of people out there that are truly fascinating and have every right to the same education and places we do. Deaf people have their own graceful dynamic language, autistic people curiously migrate to one another. There is a world out there that is bigger than we are.

When I was born, my mother used to tell me the story how she counted all my fingers and toes was grateful that I came out "normal." I think about that today, and consider how absurd a thought that was, now that I have a son with autism. We must ask ourselves what *is* normal? Normal seems to be one of those mytholgical vapours that have been passed down -- normal seems to be anything that does not act differently in any way than a neurotypical person. But considering how vast the population is of people who are not NT, perhaps we must reframe our way of thinking.

And so I come to autism as a social construct. We create difference and inequality in society by how we provide, or do not provide supports. Paula Kluth in her book about inclusive education for autistic children **You're Gonna Love this Kid** states:

"Many people with autism have experienced difficulties due to societal and cultural ideas of how people should look, interact, move and behave. Although most people with autism will tell you that "it" is real, that they do experience things in different ways, that their bodies are uncooperative, or that they have sensory or communication problems, it might also be suggested that autism is in some ways exacerbated by an inflexible society. That is, autism is a social construction; it is a phenomenon that is created and recreated through culture, interaction and social

circumstances. For instance, people may feel more or less disabled on any given day based on whether appropriate supports are provided for them or whether they are expected to communicate in a conventional way."

Jonathan McNabb, she writes, suggested that neurotypical individuals (people without autism), stop assuming that **difference** means **deviance** and start understanding the autistic experience from those who live with it. Consider a passage written by people with autism where they imagine a world where autism is the norm and being typical is a problem:

"Neurotypical syndrome is a neurobiological disorder characterized by preoccupation with social concerns, delusions of superiority, and obsession with conformity. Neurotypical individuals often assume that their experience of the world is either the only one, or the only correct one. NTs find it difficult to be alone. NTs are often intolerant of seemingly minor differences in others. When in groups NTs are socially and behaviourally rigid and frequently insist on the performance of dysfunctional, destructive and even impossible rituals as a way of maintaining group identity. NTs find it difficult to communicate directly, and have a much higher incidence of lying as compared with persons on the autistic spectrum. NT is believed to be genetic in origin. Autopsies have shown the brain of the NT is typically smaller than that of an autistic individual and may have overdeveloped areas related to social behaviour."

Bravo.

Researcher Uta Frith also notes how mental disorders "are largely defined by the social context of their time." More children now than ever are being diagnosed with autism. Is the result of nature, the environment or new diagnostic criteria (The DSM IV) that came out in 1993? Schools lack the resources to truly understand and service the autistic child. Emergent curriculum is extremely helpful, but most schools use the canned curriculum. Integrated schools with Emergent Curriculum could help foster in a broad sense, an equitable and democratic society, while addressing the specific learning needs of each child (the Indpendent Educational Plan). I am dreading the challenge of finding the ideal school for Adam and wonder if I should open my own. Did you know that most gifted children are learning disabled? Food for thought, dear

reader.

I am waiting for Adam to write words, now that he is writing letters. He has already spelled words with his magnetic letters. As a mother with a child with autism, I hold the same hopes and dreams as I would for any other child. I hope he will be able to recount these days for me (most autistic people have incredible memories because the same neural pruning that occurs in other children at 18 months of age doesn't happen -- many autistic people recount their own births, which I find fascinated [*see Dawn Prince Hughes for reference on that*]). One mother wrote a book of her interpretations of her son's behaviour and later, the autistic child was able to write why he behaved the way he did and recount his perspective.

Most of all, as a parents with children with autism, we can never lose faith and optimism. Yes, in reality there are worrisome days (what parent doesn't have them?), but something tells me to go out dancing and be happy. I have a beautiful son.

[PERMALINK](#) POSTED BY ESTEE KLAR-WOLFOND AT 10/25/2005 11:35:00 AM
[0 COMMENTS](#) [LINKS TO THIS POST](#)

MONDAY, OCTOBER 24, 2005

I am organizing an exhibition of Jonathan Lerman's work at The Lonsdale Gallery in Toronto. Jonathan is a 17 year old autistic young man. It will run from December 1st-20th. What struck me about Jonathan's work are his faces. So far, in my study of art executed by autistics, the execution of faces isn't typical. Maybe doll-like faces like Henry Darger, but not the kind of faces that show such depth of perception of his subject's character. They may be primitive and Picasso-like, but the type of observation that is beneath the surface is evident. Simon Baron-Cohen, in his speculations about the absence of Theory of Mind in autistic people can now be debated. (Theory of Mind suggests that autistic people are not capable of empathy or recognizing expression because they are mind-blind, in other words, not aware that other people have their own point of view separate from the autistic person).

On some occasions, and even today, when a child cries in Adam's class, Adam will go to that child and hug them. He will get jealous

when other kids pay attention to his shadows at school. If Adam is "incapable" of understanding others, then how is he capable of these actions? Obviously, the theory is somewhat flawed.

Other HFA/AS (High-Functioning Autistics/Aspergers) who have verbal skills, eloquently express that they can understand body language and have emotion, understand emotion, etc., but what makes social interaction difficult is understanding all of this in real time. Because body language is so fast and fluid and coincides with speech -- the processing of all of this at the same time can be difficult for some autistic people.

Just when others don't think an autistic person isn't paying attention, beware. I have a theory that their way of observing may not be entirely typical, but in fact, over sensitive in many cases. Either through peripheral vision, sensitive hearing, everything is getting in -- if even in an overwhelming way. I never doubt that Adam is exceptional in many ways. I never doubt that he is listening and understanding. I have learned that sometimes he just needs a little extra time to process things.

[PERMALINK](#) POSTED BY ESTEE KLAR-WOLFOND AT 10/24/2005 05:23:00 PM
[0 COMMENTS](#) [LINKS TO THIS POST](#)

SUNDAY, OCTOBER 23, 2005

On the radio program called The Infinite Mind, well-known panelists such as Simon Baron-Cohen, Stephen Shore and others talk about an autistic expression of love -- that parents must reframe their experiences. Instead of a hug, an autistic person might pull hair as an expression of love -- the context must be observed.

Last night at University of Toronto, Dr. Oliver Sacks appeared warm and meticulous, possessing eyes that smiled with a humble defiance that comes with age. In fact, as the evening wore on, I realized that this was THE trait that the actor Robin Williams captured of him brilliantly in the movie **Awakenings**. Dr. Sacks was articulate yet hesitant in his speech and spoke about "different modes of being." Like the AS people who spoke on **The Infinite Mind** as well as those that write on **aspie.com**, he feels that society needs to rid the notions of normal and abnormal. Instead,

we must replace this notion with another semantic, and the word different kept popping up.

I write in my book that Adam's ABA therapists pathologized him. This for me, a mother and an ardent observer of my son, was not only distasteful, but unbearable. How can a good therapist come into a home of a different sort of person, and begin to follow a list of skills and behaviours and suggest that we would want to make that child as they *should* be? Surely, when Adam was diagnosed, I thought that this indeed was the goal. But as our lives progressed, and progressed with these new people, therapists, consultants, supervisors and government representatives coming and going daily from our house, I began to feel uneasy. The ABA people came in with the promise of making him "functional," and spent little time observing him as a person but more as an aberration.

Luckily I fired all my ABA supervisors and agencies that I tried for Adam within the first four months of his therapy which began at age 20 months. I also pressed my husband to abandon TPAS (government) funding as they mandated us to do a minimum of 30 hours of ABA therapy a week -- an impossible demand of such a young child. It's difficult for me to hear the glee of parents in school hallways these days "we're so relieved we got TPAS funding yesterday..." (The government recently increased the age to receive this funding past the age of 6 and all of a sudden people seem to be getting funding everywhere). I know of parents who have fought court cases for this funding and have lost their homes and have had to move out of the city. The stress that this puts on a family is too high a cost for the return. Certainly, ABA is NOT the only scientifically proven therapy that works in autism. The myth that it is keeps getting regurgitated by so many -- parents use this in the papers, in our first phone calls when Adam was diagnosed. Parents are putting all their stakes on the vapours of this myth, and that's scary indeed. There are many therapies that work and ABA is the fashionable therapy of the day. Indeed Oliver Sacks also said that about every four years, the hip therapy of the day predominates. Funny how the government wouldn't look at ABA 10 years ago. Anyway, in my view, it has become all too political at a great cost to people with autism.

Once Henry asked the question, "if you believe Adam will always be autistic, why do therapy? Isn't your goal to make him more normal?" I struggled with this question for a while until I realized

that the purpose of therapy was to make Adam a happier person -- to help him understand himself and his world, to increase self-esteem, to learn new skills that would enable all of this, and most importantly, relate to people. I turned to therapies that felt more suitable for Adam -- to work on sharing and relating, to help with skills that would give him a sense of pride so he could continue with them at will. We moved to approaches like RDI and Floortime and just plain old "incidental teaching" if we want to use technical words here (I ascribe to no one therapeutic approach -- but bits and pieces of those techniques that reach a child). When we did, it was like Adam had his own awakening -- he became so happy and related to us in a way he never had before. He enjoyed playing peek-a-boo, sleeping bunny, and other games and giggled all the time. He became extraordinarily affectionate. My mother said it well : "it was like we were alone in the room when we were with him and now it's completely different."

So, after trial and error, some research and plain old instinct, I can say a year and a half later that listening to Oliver Sacks last night was a confirmation of what I came to believe on my own: that we must honour Adam's autism as part of the person he is and we must nurture his obsessions (or strengths) as well as challenge him in areas that will make him feel competent and give him more self-esteem. I believe in challenging at the right time. There was a day when he wouldn't be able to play with a certain toy because of motor problems, but when he is ready, it is time -- and then he can play on his own without assistance. This independence is critical in life and to make us feel whole. I don't believe that even people with the most severe of disabilities can't have some semblance of this feeling, no matter what their limitation. Dr. Sacks mentioned we must encourage activities that enable IDENTITY. Certainly we all feel expanded when we engage in creative pursuits, sports, cooking... It is what makes us human and frees us from the heaviness of life and the limitations of SELF.

Dr. Sacks said "autism must be recognized as a different mode of being and must be proud of itself." As a mother, I do still struggle. The outside always wants to pound in, in such negative ways. School is on the horizon with its rigid curriculae, notions of normalcy, standardized testing. The world is not so empathetic, although we are making strides. Adam is an only child with four older half-siblings, two who are now in university. So I view him as an only child in the sense that he doesn't have a sibling in his face -

- relating and demanding on a daily basis. I feel the onus is on me to keep the relating going -- from school, to facilitated play groups here in the house -- I feel a need to keep him exposed to other children in the absence of this sibling. When Henry is not home in the evenings, the onus is on me to play with him, to keep relating. It makes me tired some nights and when I am, I often feel guilty or angry that I'm tired. Logically, I know it is the way it is and I cannot be so hard on myself. I don't have complete control and we all do adapt, and Adam will too. And for that matter, my control could also have a negative impact. It's all a fine balance, I know. Then again, down time and just hanging with mom or dad, is just as important. Being with Grandma and Grandpa for a few hours on the weekends is a gift and a memory he will have forever when they are gone.

Life is pain and happiness and they are intrinsically connected. Without one, we couldnt' feel the other.

[Link](#) [PERMALINK](#) POSTED BY ESTEE KLAR-WOLFOND AT 10/23/2005
07:23:00 AM [0 COMMENTS](#) [LINKS TO THIS POST](#)

SATURDAY, OCTOBER 22, 2005

Regression in autistic child development is common, I hear. Adam will progress in many areas and at times, he appears so "normal" and I feel we are "scott free." And then it happens. For a week or two, he regresses into repetitive behaviours, in particular, visually scanning letters and numbers, lining them up, or getting a letter, in sequence, go jump on trampoline, get next letter and so forth. I thought I got used to these little regressions with the relief of knowing that he would still learn and that curve would keep going up, up, up...

I just experienced his longest regression and I became quite upset about it. He started a new integrated nursery school. It is a busier setting and more demands are being placed on him. There are two carpets in the room, one with letters, the other with numbers. Of course, his safe place, when he's uncertain, are letters and numbers, so everytime I peeked in, I would see him contort his body on the floor to look at each letter or number in sequence. At the beginning of week four, I'd had enough. "Push him," I urged the teachers and his shadows. "If he's not transitioned out of there

and taught how to play with others and other things, he will never feel competent."

I was so freaked out (it seems I am always pushing people where Adam is concerned), I cried in front of Adam. I think he understood, because that same afternoon, he "snapped" out of it. He began to use his words, he was so "on." I will have to find the psychiatrist's name of the phenomenon that I've heard about -- where parents and children mirror each other's emotions, but when the child feels understood, they feel they can move on. I'll get that reference later.

As far as letters go, I let him do them when he finishes other things. In fact, at age three, Adam is writing his own letters on his magnadoodle. I am so amazed at his determination. I've heard of other kids using keyboards, but not write, and not this young. Has anyone else encountered this? It's also amazing because Adam had fine motor problems, yet with focus and determination, I guess anything can happen. This is autism's gift. It enables focus of such high degree, that so much can be achieved in the niches that interest our children.

For fun, I've been teaching Adam the piano. He has begun to use two hands now, just having fun. It's great. That's how I became interested in the piano -- just hacking around. The only thing I do is play for him. I've also taught him do, re, me. He has begun to imitate me.

So, I've been thinking this week of how the scale tips so dramatically when Adam learns. He exceeds in one area and the other seems like it has gone away forever. But I believe that can't be. It seems to be stored somewhere until another connection is made. Then another concept is understood, a new skill emerges. Tiny building blocks are constructed each day, and his learning is so intricate and deliberate that I am fascinated some days and awe-inspired on others.

I'm going to listen to Oliver Sacks tonight at University of Toronto. He's speaking on sensory integration. Keep you posted.

MONDAY, OCTOBER 03, 2005

Adam is at the park with Donna, his nanny. I'm trying to get him tired for a nap before going to his bubbly's for Rosh Hoshana.

He was so happy today and at school. We are attempting to set up a facilitated play group here at the house with some of the kids at school - many of whom are non-verbal or have trouble with verbal expression. They have all gravitated to one another, this group, like they appreciate each other and they are still clear in their communication. They likely understand each other and appreciate the fact that someone isn't babbling their heads off so fast that they can't understand or keep up.

Henry and I spent some time together this weekend and we are both newly determined in eating better and losing some weight. This is refreshing, so I worked out for an hour and a half today, in my new attempt to lose 10 or more pounds.

Adam is back from the park, so it is time for me to put him for a nap. He is saying my name, mum, mum...It is time.

[PERMALINK](#) POSTED BY ESTEE KLAR-WOLFOND AT 10/03/2005 02:11:00 PM
[3 COMMENTS](#) [LINKS TO THIS POST](#)

SUNDAY, OCTOBER 02, 2005

You can tell I'm better 'cause I haven't written here in a while. It's amazing how much one must catch up with after an illness. I'm watching Elmo with Adam while writing this...unless I won't have time...he went to Downey's Farm with Henry and my father while my mother and I went to a smokey baby shower that my cousin was throwing for her daughter...I lasted 15 minutes there with my chest...I can't believe how incredibly negligent it was of my cousin to organize a shower in a smokey environment with her daughter who is pregnant, her mother, who is on an oxygen tank and my other aunt who is severely asthmatic.

Anyway, I left after 15 minutes and my mother stayed. My poor mother. I wanted to support her but I really have a hard time with the smoke.

I gotta go already. Too many people need me. :)

[PERMALINK](#) POSTED BY ESTEE KLAR-WOLFOND AT 10/02/2005 03:06:00 PM
[0 COMMENTS](#) [LINKS TO THIS POST](#)

SUNDAY, SEPTEMBER 25, 2005

I am moving around now and hoping to take Adam to school this morning. So much happens when you're not looking. I need to really know how Adam is doing at school this week. I didn't even know that the language group he partakes in has begun...no one told me when I called the school this week, and the shadows didn't tell me either.

I will try my damndest to find a school that fits him. I don't want him in the public schools where they will funnel him into the special needs classes. I will be looking for integrated schools. As difficult as those curriculuae can be to organize, I believe in integration, philosophically.

My team of therapists is great, but I still have to stay on top of paperwork, Adam's programs. No one cares as much as I do, and I'm always trying to up the ante, to find a new way of doing things, or use the most effective way. It's a constant quest on what and how to teach. Sometimes, I wish I had someone who could expedite the management of the team. I am always trying to stay on top of everything at home and school, and I take a large part in what is important to teach. Everyone has a different style of teaching, and he is doing well by them. So this is the most important thing. Yet, with my pneumonia, I do notice that letting go a little makes me feel uneasy. Just being part of taking him to and from school let's me know how he's doing because I get to see and hear for myself. When I'm lying in bed, I don't get to see a thing and I don't have a real handle on how his week went. It all sounds good, and he seems well, so I'm sure he is fine.

This is the obsessive part of being a mom with an autistic child. Maybe some moms don't do as much or trust more people... so called "experts," but I don't. His life is in my hands. I don't believe anyone will care about him more than I will. Adam is engaged for almost the entire day. His down time is spent with me. As he's engaged with therapists, I come and go. Adam is such an active

guy that if he wasn't engaged, he would have ended up in repetitive activities. This way, he learns and he is happier for it. He plays a lot and always wants to play with others.

I do notice his peers in the neighbourhood have surpassed him in play and verbal skills. They play together, group together...Adam tries to join in but can't keep up with all of them. It always appears as if he's a step behind. At school, there are enough varied kids, that he seems to do better there. There are other non verbal children as well as autistic ones. Some kids in Adam's neighbourhood group are quieter than others. I just hope he finds the crowd that he can interact with. Everyone has to find where they belong.

I can't say that I don't worry. Some days I do, but it depends on HOW I think. If I think of those other kids in the neighbourhood and the cafe klatches I'm missing because he can't keep up, I may feel down. If I think about how far he has come, that he actually does make some buddies at school, I feel fine. I can't expect him to be like everyone else overnight and there's a part of me that doesn't want him to be like everyone else. I do want him to feel socially competent, though. Enough to have a few friends.

He's three and a half. I don't have him toilet trained yet. It's another thing I have to work on when I'm better. I'm going to cancel all therapy and people in the house so that it's just Adam and I for a couple of days doing this. He's so good with me. And it's really something that should be done with mommy.

[PERMALINK](#) POSTED BY ESTEE KLAR-WOLFOND AT 9/25/2005 10:56:00 AM 1
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SATURDAY, SEPTEMBER 24, 2005

I am able to move around more this morning and sit with Adam during breakfast while my mother and Henry help out around me. I'm so grateful for my mother being here.

So, Henry said our friend of ours suggested that we should look at the Montcrest School for him. I heard it's a good school. It is a school for children with learning disabilities but is integrated. I'm not sure how they teach or how they integrate yet, so that is a

number one factor. It's not what the glossy marketing words suggest-- it all sounds good -- it's what they actually do and what their philosophy is.

Last week, I took Adam to a neighbourhood drama/music class hosted in a friend's house. This friend built a separate building attached to her home with a glass tunnel. The building is like a school house - amazing for kids -- so she hosts this class and invited Adam to attend. I said that he should have his shadow there (therapist), so she just told us to show up. I thought it would be lovely for him to be with his neighbourhood peers. Treasa, this crazy woman with skraggy, curly hair that was thicker at the crown than at the ends, striped Lululemon pants and bulging eyes. She spoke cacophonously while rapidly moving from one activity to another. I didn't expect that Adam could take her shrill voice let alone pace. But he was so happy to be with his peers. He followed them and pretended to be an elephant -- I've never seen him try this before. So he was clearly gaining something from the experience. Yet at the end, she didn't want us to come back. Despite the fact that he was a doll, was not disruptive in any way and was the only kid who could name the Dreidel song, she didn't want him back because he had a shadow, and I expect, because he is special. She said she would try with him later, but as I considered it at the pressing of my friends to return, I decided that it is better for Adam to be around teachers who really believe in him.

I expressed my disappointment to the host. I told her that I found Treasa horrible for doing this. And now I may have made ourselves the target in their eyes -- a sensitive mom and a her disabled child. It's a terrible stigma, but I have to get over it. First, I feel I have to pick the best teachers for Adam. Second, I feel I have to speak up for him, but I wonder at what cost? If I speak up do I run the risk of stigmatize him more? Do I make him the centre of a negative kind of attention? Or does he get treated differently than the others. And is that bad? Here is the area that is new to me and I try to navigate. Now our friends are suggesting special schools for him. Do they do so out of kindness? Do they do so because they think Adam is not capable? I think he is capable of anything. In fact, I know he is smarter than the other children in some areas, and maybe even overall, but he can't express it all in the same manner yet. I refer to a quote from another autistic child from Paula Kluth's book, **You're Gonna Love This Kid:**

"All my life I was enrolled in classes for the profoundly retarded. The pain of that isolation, I can't describe. Some classes consisted of putting flashlights together and then they would be taken apart for the next day's project. I never spoke or made eye-contact. I hummed and self-stimulated. No wonder they thought I was hopeless. I was always treated well but my intellectual needs were never addressed because nobody knew I had any intellect at all. Sad to say, many like me remain in that same, hellish situation."

His area that needs work is the social area and that may come more and more once he feels confident about all the other areas of his life -- knowing how to play and being able to handle the materials. Also, learning how to pretend play -- symbolic thinking, is something we are working on now too. All this will lend itself to an easier time in the social arena. Eventually, it will happen for him.

So it is not a surprise that I isolate myself a little. People who try to help, really don't get it at all, even though I appreciate their kindness. And in their helping, they innocently and unknowingly, isolate me even more. How can people know autism if they are not living it? He is not mentally retarded, so he can't be treated like that. He is not socially functioning like his peers either, so he is at risk for being treated like he is not intelligent. As Paul Collins wrote in his novel, ***Not Even Wrong***, "autism is as much an ability as a disability, it is as much of what is present as what is missing." I've memorized that quote. It's perfect.

Or my other loving friends often ask how Adam is like he's got a virus. It's like he's supposed to be better soon, like his autism will go away. In the heyday of the "cure" -- when all charities and diseases are raising money for that grail -- I understand why this is an everyday question. But he will always be autistic. He will always be different. But he will be different too, thank God. He will be unique, intelligent, and if nurtured, may be able to exhibit his intellectual gifts as his vocation.

By the way, the reason why I called this blog joyofautism is because I thought that no one else would put those words together (all the other titles I wanted were taken and I later found out that there are plenty of references to autism and the joy of having a child with it). Autism, which is part of who my son is, is a joy to me. He may not be a label inasmuch as those may treat him in a standardized and therefore, destructive way, but autism is part of who he is. He is as much an individual as any of us, but the autism also makes up part of how he moves within the world. He is wonderful to watch. His moves are not random or behaviourally quirky if you look closely. They are strategic and orchestrated -- curious and innocent. Watching him helps me learn to see things in a different way. Watching him reminds me of how important focus and concentration are to become really good at something. His smiles, affection and abilities bring endless days of joy and I thank God for him every day.

[PERMALINK](#) POSTED BY ESTEE KLAR-WOLFOND AT 9/23/2005 12:17:00 PM 1
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It's been a week now that I've had pneumonia, so I have time to write this. It amazes me how much the building of our new house and taking care of Adam has really taken its toll. More the house than Adam. Adam is a passion. The house is lovely and at times, fun, but this and that needs to be finished, workers always need to be prodded. I am thinking that my life should become simpler, that going back to the friends who actually care about me is what matters. I've had so little time for making connections, having coffee with people who mean something to me. Instead it's always about the to-do lists -- a disease that inflicts most of us and I believe effect our children, especially our children with autism. I am investigating now how autism is largely a social construct. Will talk more about this later on.

I saw a round table hosted by the Dalai Lama on the CBC with representatives from all religions, including Bishop Desmond Tutu. I didn't catch the whole program, but what struck me was their humanity, their humility. That's what I respect. I also respect those from all factions who can get together and talk only to find, that we are all pretty much the same.

I have converted to three religions in my life, and I've had enough religion to know that I'll never be religious. But I'll be inherently interested in the universal messages. For this reason, I am interested in philosophy.

I am sick and I haven't seen Henry much all week...Last night he went to the hockey game with his buddy in from Montreal who is helping shoot a film here -- I prodded Henry to get the footage of his 93 year-old grandmother -- the story of her life. I wanted to book the film crew for his birthday and I'm glad he is finally taking the time out of his schedule to document her stories and memories -- it will be so important in the years to come. One life is so rich and active and before we know it, as Joan Didion says, "you sit down to dinner and life as you know it ends." Every life deserves to be documented and remembered. So, my parents are helping Adam and I out while Henry is doing this.

In the meantime, I must simplify my life for me and for the sake of Adam. He is such a happy, delightful little boy and when I feel remotley down, I just think of his face. He is everything I live for. Life doesn't seem that full when it's all about acquiring things for the house, and organizing all day long. Life is more full when one is invested in things one is passionate about. Reading a good book, seeing a great play or movie, having a great hour with my son...all of those moments are infused with more meaning. Life is about experience. I've had so little of that.

Blog and Blaa sound much the same. This is what this sounds like, but hey, this ain't literature I'm writing here. If you want to read it, so be it. If it's crap, move on.

[Link](#) [PERMALINK](#) POSTED BY ESTEE KLAR-WOLFOND AT 9/23/2005 11:40:00 AM [1 COMMENTS](#) [LINKS TO THIS POST](#)

WEDNESDAY, SEPTEMBER 21, 2005

Still feeling terrible. Henry off early again and luckily my mother will help get Adam ready for school.

In his first week, Adam wasn't as social as he was at Yes I CAN!. But he was there for only two mornings a week and now he is at

Play and Lean for five. He became very "social" at the other school, which was mainly comprised of girls, but interestingly, he began to lead another little autistic boy named M. M was non verbal and very disconnected, but when I watched him, had exceptional skills, like drawing. When I saw M I commented on how much I loved his drawing and I know he heard me. When I said it, his therapist, who shadowed him at the school jumped in and said, "yeah look at this....M, draw a triangle." Her tone was patronizing. Sure enough, M complied and drew the triangle and then went right back to his own drawing.

Was this an ABA therapist's version of success -- the imitation of the triangle? The fact that he could comply with her lame command? In my view, his success was his love of drawing and the fact that when I commented on it, he did it more. Isn't self-motivation and will the point? This is only one of my examples, and there will be more, of the failure of behavioural teaching with autism. M is smart enough to know he has to listen to his teacher. But his true abilities are being ignored by his behavioural therapists.

When M couldn't talk for himself, he began to take Adam's lead. Adam was quite adept at winning the affections of his teachers with his own affection. M would take Adam's hand and Adam would lead him. They sat beside each other. Willingly. Did they have some innate understanding of one another?

Researcher Simon Baron-Cohen lead the research on mind-blindness in autism. What this means is that it is difficult for autistic people to understand that other people possess different thoughts. Some autistic people take many years before they come to this realization. Often, his theories get over-simplified and people say that autistics don't recognize emotion. But they do. They can recognize it in pictures, but they may not be able to read complex social cues in real time. In fact, Adam can seem to empathize and where researchers such as Baron-Cohen say autists cannot. If Adam sees another child crying, he will go to that child and play alongside him or give him something to play with. It's all non-verbal but communication can be without words. If Adam sees me crying, he doesn't come up to soothe me, but he seems to pick up on my emotions. If I am distressed, he may become distressed. I wonder if he feels I am distressed at him, or if he takes on my emotions as if I am an extension of him. But the

empathy he has shared with his peers is distinctive from the mirroring of my emotions.

Perhaps some people might say that Adam isn't autistic. Adam was diagnosed with autism, by three doctors, at nineteen months of age. He wasn't engaged, he involved himself in repetitive behaviours, he couldn't engage in typical or pretend play and he was obsessed with letters, numbers and was hyperlexic by the age of eleven months. At three, he can read. Some diagnosed him with moderate autism and others higher functioning autism. At the end of the day, the nuances of diagnosis don't mean a thing. Autism gave me a frame of reference from which to learn about Adam, and now I find myself having to view him as a unique being, with a learning style that is all his own, that may share some universal qualities with other categorized neurological phenomenon like ADHD, giftedness, Aspergers and even Parkinson's disease.

I watched Oliver Sack's movie version of his book, Awakenings, last night again. The movie is marvelous-- suggesting the human behind the being, behind the catatonic bodies that otherwise appear unresponsive and lifeless. I see so many autistic children. I've attended a year of conferences and visited many schools. When Adam was diagnosed, I wanted to learn everything I could. I started with ABA, with agencies here in Toronto, behavioural analysts from the US (I would fly them in), and fired them all. I attended all of Gutstein's RDI seminars and even took Adam to his office in Houston. I tried and dumped all the diets that didn't work. Vitamins too. Adam's success began when I began to have faith in him and my decisions for him. The turning point for me was when I was about to fly in Dr. Jim Partington. The behavioural analyst I was using, J. P., kept insisting I bring him to see Adam. She used to come into my home with lists from the Hawaiian Development Profile to see what Adam should be doing and based his teaching on that. She viewed Adam as a pathology. Every behaviour went under a microscope and had to be "extinguished." But there was never ever empathy, any view that he was exceptional in some way and he was spoken to in such a contrived tone and presented with external reinforcements like he was an animal. So, when Dr. Partington said to me "we are only teaching your child how to respond," I held by breath and wondered, is it? I am not just teaching Adam how to respond. I am teaching him how to understand, how to do things, develop a sense of self, be able to understand his needs, desires, limitations and much more. Adam

didn't need their approach. The turning point was RDI for us, but it still wasn't the end. Gutstein would have had me delay entering Adam into school and thank God I didn't listen because Adam craved social interaction, even if he didn't know how to interact. Gutstein would have had me keep him at home until he mastered Stage Three of his protocol. Yet, Adam learned with help, with RDI at home, and with exposure to school, with teaching him how to share, to play. If we followed RDI to a T, Adam wouldn't be where he is today, either. This was my mapped journey to understanding autism. I still wonder if any of these therapies are really necessary at all. I sometimes think that just good teaching and an understanding of the child and of autism, is essential to a person's success.

It was the combination of our intuition, the therapies that made sense, like RDI, Floortime, teaching skills to increase Adam's sense of competency and self-worth so that he felt confident in knowing HOW to play so that he could do so with his peers.

And so, Adam just went to school again today while I am stuck in bed. The process I have just described isn't easy. What I didn't understand and am also just learning is how long it takes for him. We parents want instant results. We want a CURE, a PILL, anything to bring our children back. I find the emotions complex. My husband said to me once, when I was arguing about semantics, "Isn't that what you're trying to do, Estee... aren't you trying to make Adam more like his peers?" I couldn't say yes or no. I couldn't imagine Adam any other way than what he is. I help him because he has to be taught like any child with a learning difference. I want him to understand, to communicate, to be able to play with his peers because he wants to. I want to give him the tools he needs so that he can do the things he wants to do. I can see he wants to. We are giving him the tools to put the steam behind his motives. The heartbreak part for me is if he had the motivation but couldn't follow through, if he wanted friends, but didn't have them because he looked different or didn't know how to interact. If I fear anything, it is that.

I hope I am not a parent who is trying to change her child into someone I believe he should be. I am just trying to understand who he is, what he wants and hopefully, provide the teaching he needs so that he can do what he wants to do in life. It is not so simple to sit back and think this -- I struggle to understand the

complexities of autism and the mind -- or to at least appreciate them. I am not a scientist, but I try to read a lot of their work.

I found a wonderful book, by the way. I don't recommend a lot of books unless I find one that really sums up a lot of works in a useful way. Henry actually found it: "**You're Going to Love This Kid: Teaching Students with Autism in the Classroom**" by Paula Kluth. Good for parents and for teachers.

[PERMALINK](#) POSTED BY ESTEE KLAR-WOLFOND AT 9/21/2005 06:15:00 AM 0
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TUESDAY, SEPTEMBER 20, 2005

Funny. I'm struck down with pneumonia and I finally open the blog I've been thinking of for a while. I am a mother of a three year old boy with autism. His name is Adam. Since nineteen months, he has worked with therapists to help him play, communicate, socialize, understand how to do things that the rest of us found easier at his age. What I've come to realize over the past year and a bit is that Adam is not the aberration that the behavioural analysts used to try and make me believe (and boy they tried hard), but a wonderous addition to the world around him.

Okay, you might think only a starry-eyed mother could say that. I figure, from the many down-and-out moms I meet who also have children with autism, I need to speak like that because simply, I believe it. In fact, I find it really depressing looking at the other blogs out there on autism -- parents who believe their children are broken in some way. Words are permeating our consciousness and shaping our behaviour -- words like disabled, disorder, cure and epidemic -- words that as a parent, I have found at first scarry and later, scandalous and unjust to the thousands of people who are autistic.

I surely have had confrontations with teachers who know nothing about autism, mother's in school hallways who ask "is your kid normal, or is he special needs?" We have always had a need in society to discriminate, at the peril of hurting others. As Adam's mother, it's my job to be his advocate. First, I must talk about that word N-O-R-M-A-L. A strange word. I hear people use it in so many contexts, and it seems to haunt us --a lingering apparation

in our minds that keeps us from doing many things for fear we may not appear normal. The word is strange and ineffable because there is no "normal." There is only difference. Yet we spend most of our lives anguishing to be like others.

Luckily, there are more teachers that are realizing the unique learning styles of many children, including those with autism. Not everyone is as unaware as those mothers in the hallway who believe they are harmless.

I'm stuck in my bed and I hear my little boy call my name "mum, mum, mum," the m's melding into one another. He wants to see me. He comes now with a big smile on his face, climbing up the bed. I pause. He wants to be on my body but I feel like I'm about to vomit. It pains me to ask my mother to pull him off. I ask him to be gentle, this little happy cherub, the simple happiness of being around mommy.

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