

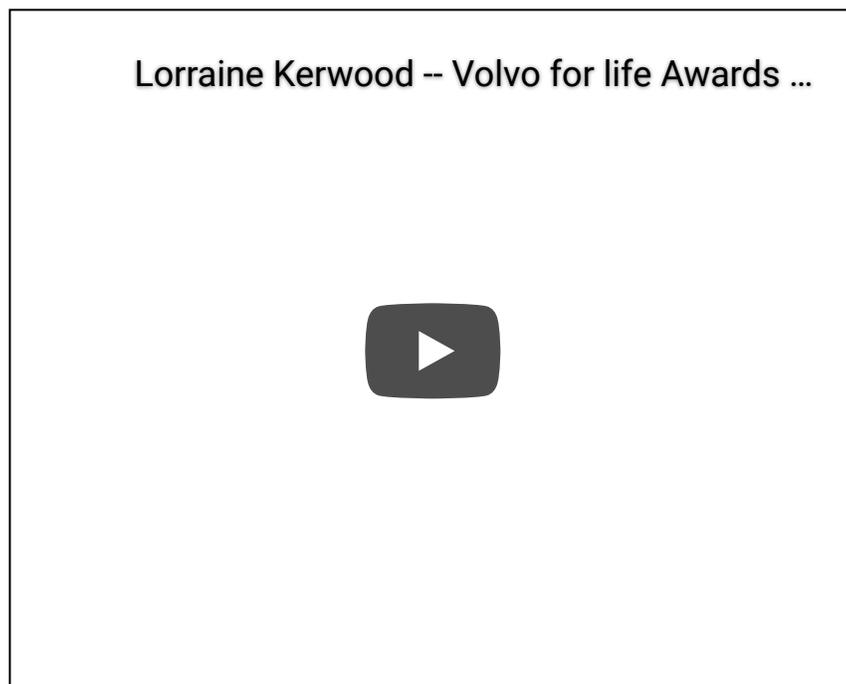
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Lorraine Kerwood: “I didn’t perceive myself intelligent in any way”

Filed Under ([Autism and Intelligence](#), [Contributions to Society](#), [Obsessions](#)) by Estee on 24-11-2009

Lorraine came to me by way of my own website, which attests to the power of the Internet in making connections these days. Reviewing her own work with recycling computers, and how she came to regard herself by way of other people’s view of her, I of course cannot help but think about autistic people and what a “contribution to society” can look like:



For people who view obsessions as negative, this video is another story of how our “obsessions” are pathways to creativity and invention. [Visit the Next Step Recycling website.](#)

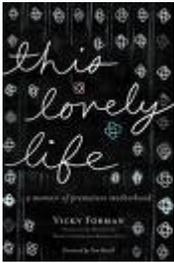
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[This Lovely Life](#)

Filed Under ([Critical Disability Studies](#), [Writing](#)) by Estee on 24-11-2009



There are some things that silence me for a few moments. The death of a child, the poignant line. Vicki Forman's **This Lovely Life: A Memoir of Premature Motherhood** does both. About the premature birth of her twins, the death of one child and the survival of her son with multiple disabilities, Vicki must navigate life's toughest challenges. Just the first paragraph alone will be enough to make you gasp, sit silent and want to read the rest of her book:

“I learned about grief during this time. I learned that no matter the true temperature, grief made the air crisp and cold; that it caused me to drive slowly, carefully; there was very little I could eat. I learned that I didn't notice things until they flew out at me and that most stories and books and news articles were unreadable, being accounts not of the events themselves, but of me. Of what I had lost and would never have again, of what I had once allowed myself to want, the things I used to love. Of small consolations no longer available. I learned that my heart could stop and start a dozen times a day and that my throat felt so sore and tight I often had to swallow air simply in order to breathe. The world receded; everything took place in slow motion and was viewed as if down the wrong end of a very long telescope. So much was unfamiliar that if I was asked my name, I had to think for long moments. ‘Grief is a visceral process of disengagement,’ a friend said. In my grief, old versions of disembodiment became a cruel joke. You thought that was bad, not being able to walk into a roomful of strangers without disassociating or turning remote and distant? That was nothing. Try this. Try heart-stopping, immobilizing grief.” — Vicki Forman, **This Lovely Life**, Houghton Mifflin Harcourt publishers, 2009.

Tom Bissell, who writes the forward describes Vicki's journey well: “*She does not claim she is always correct; she sometimes expresses anger at certain doctors, and she occasionally behaves in ways that some readers may find appalling. But just as this is not a depressing book, it is also not an angry book. It is a book filled with love and wonder — enriched by the kind of grief that those of us who are not parents cannot imagine and those of us who are will not want to.*”

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[How did we manage that?](#)

Filed Under ([Single Parenthood](#), [To Get To The Other Side](#)) by Estee on 23-11-2009

How did I manage it, I think as I sit in an assessment for Adam today for a new AAC device. I want him to be eligible for government funding for it. I arrive at his school tired and disheveled in my leggings and baggy sweater that I rushed to put on, and my hair is whisked into something I can't quite call a pony tail or a bun. Adam has not been sleeping the past couple of nights and I wonder how he can seem so much more energized than me. When I arrive he is reading and answering comprehension questions and he is doing so well sitting studiously, pointing to correct answers, his cherub voice affirming his choice. I sit low on a child's chair watching from the right.

How did I manage to go through a separation and do all that and heal and still be on top of everything for Adam, I am thinking without coffee, watching my child work so well with the same sleep deprivation.

You see, I'm quite dumbfounded thinking how the year sort of just whooshed by and I was in a daze. I think when people go through separation and divorce, it is typical to heal for a year or two, and indeed I've felt sort of paralyzed. I remember thanking everyone around me *profusely* for their incredible support for the first eight months. I learned the importance of reaching out, and I sit now watching, less nervous and anxious than a few years ago when we would go through the same assessments.

When I look back on the past year, I can't help marveling at Adam during his assessment today and think about every evening when he comes home from school when he reads to me about what he's accomplished at school. He has learned to read out loud. He has learned to become an independent typist, and now he is drawing like never before. Yes, we have our challenges too — he is more rebellious these days, knowing what he wants, not unlike many other seven-year-olds.

Sometimes I wonder if children also rise to the occasion, and I believe Adam has done just that. I'm reading my blog **The Joy of Autism** — the older version before it was mistakenly taken down to reminisce. As I watch Adam now and process the year that has passed, I sense a great transformation that is happening in both of us. I see how I've evolved and softened, wanting to change direction a bit from the way I wrote and blogged in previous years. I see how Adam wants to be mommy's big boy and how he makes an extra effort. Hindsight is not just 20/20 — it makes me appreciate just how much we've actually accomplished, and how much of a team we've become.

It's hard for me to write this. I've got butterflies like a person who is trying to get back out there, trying to re-launch and I know I'm quivering and teetering. Yet today I sit even more diligently than ever, writing my fifteen pages a week. Adam and I launch into projects like we never have before.

I guess *we* managed.

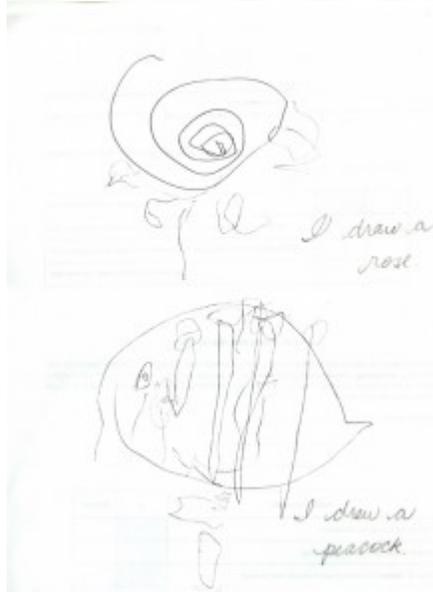
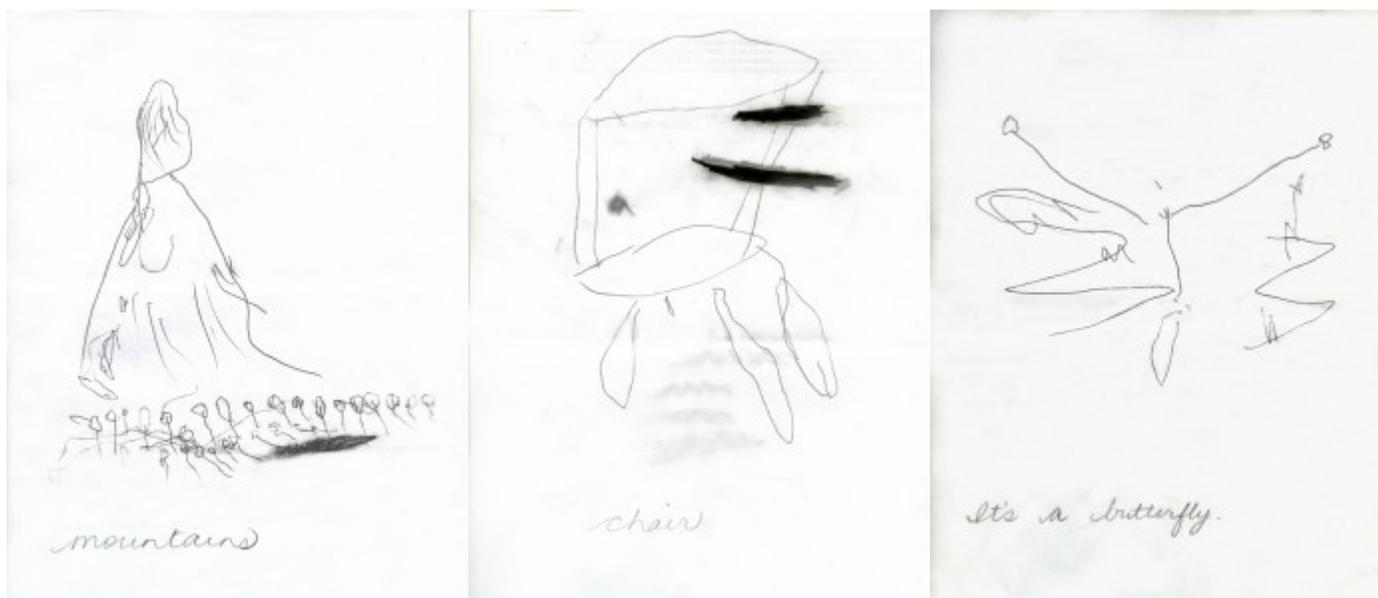
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[Adam's Delicate Line](#)

Filed Under ([Adam](#), [Art](#), [Autism and Intelligence](#), [Autism and Learning](#), [Communication](#))
by Estee on 19-11-2009



As a curator of art I have a special interest in “self-taught” art, otherwise known as “Outsider Art” or “Naive Art.” I find these latter terms unfortunate if not unnecessary and, noting my bias, degrading as terms to describe the work, typically, of challenged individuals. In the Art World, the term was used to create a category of art because it did not seek a point of reference from within the “higher” art world.

This post for me is thrilling. [Today's Parent](#) magazine in an article called “*Is It A Learning Disability?*”, [suggested that children with learning disabilities \(LD's\) ..” don't draw,” the caption said, “they scribble.”](#) They is used as yet another “outsider” term, using the “they” as a foreign connotation. I retorted at how important any human marking is, a scribble or a sun. Adam's motor planning issues makes holding a pen or pencil very difficult. He could draw letters lightly when he was very young and his first “picture” was a happy face with long hair when he was six years old. When I asked him who it was he said “mommy.” Of course that stays in my treasure chest forever.

I like to draw and I'm quite average at it. This past summer, I spent a few hours with Adam drawing what was around us at the cottage we rented, and I tried to teach him how to paint by numbers with a watercolour set — to “stay within the lines.” So counterintuitive is the paint-by-numbers set to me, but I noticed Adam's willingness and effort to gently use a small watercolour brush, and his keen interest in painting. It also doesn't hurt that one of his grandmother's is a painter, his grandfather is a photographer, and his half-brother, a master at etch-a-sketch, not to mention his other artistic pursuits. Adam is interested in all of their work and I'm certain they have all imparted their own abilities to him.

I was not expecting these drawings passed to me from school the other day because I guess we can never know if or when we can expect things to happen, and it wouldn't be anything I'd force upon him. Adam draws, as of this week, by his own motivation. He suddenly copied pictures from books and I'm utterly breathless at his line and his attention to detail. He told his aide what the pictures depicted and you can see her handwriting — a verbatim record of what he said. From a developmental perspective, I suppose you could say he is seeing the “whole picture.” His attention to detail, bearing in mind his motor challenges, seem remarkable particularly when one's child has not been able to express themselves easily.

Art can tell us a lot about what a person sees, how they see it, and how they can express it with certain challenges. As I was always certain that Adam could “see the whole picture,” I post here, I suppose, what society needs and what it likes to chew on, which is the sad part of being a part of such an achievement-oriented society. But let's for a few wonderful moments just savour how beautiful his lines are — how delicate and careful.

Maybe we all need to be as delicate and careful when discussing the abilities and challenges of all people. We may not all become artists, we may not all talk, but it certainly does not mean that we do not understand or have anything to say.

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[The Wild Boy](#)

Filed Under ([Children's Literature](#)) by Estee on 18-11-2009



We all love to read to our children. I have my own favorites and Adam has his. He will sit calmly in my arms reading [The Giving Tree](#) by Shel Silverstein. His favorite are [The Mr. Small and Mr. Giggles books](#). Adam can begin to tell me his favorite parts and why they are his favorite parts — something that he could not articulate when he was two or three-years-old. He loves reading cookbooks, all kinds of books now, when in his toddler years he would seem to only be drawn to books with letters and numbers. While he still occasionally looks at those, they are not all he looks at anymore. Did I teach him to like other books? Not particularly. There was no forcing I could do to get him interested, no “program” with a reward system of getting him to like reading other books. Instead all I think I did was use the books he was already reading, describing pictures within them, talking about other words that began with the letter of the day. Come to think of it, I should have been hired by Sesame Street for coming up with everything that goes with the letter A.

As Adam grows older, I'm interested in books that have meaning for us without hard-boiled moral endings. Books about the dentist are good. Books about doctors — good too. The books I come about autism and friendships are okay but the majority are made with the intention of raising money to cure the child which minimizes the purpose of not only the message, but the complexity of it.

Remembering the [Wild Boy of Aveyron](#), I decided to purchase the children's version by Mordicai Gerstein. When found in the wild living among the animals, the "Wild Boy" was brought to Paris. He was found living successfully in the wild. Yet trying to "civilize" him in Paris was a challenge. The boy, never having been socialized with humans, could not talk. His sensory system was different (he could survive in the cold winters without clothes). He was observed and stared at as a strange creature, and written about in the media to the fascination of all who read about him. Because he didn't listen they determined him to be deaf and mute. Of course, the boy tried to run away back to his woods, but he was captured so that scientists and scholars could study him.

He ignored the sound of guns shooting next to his ears, but not the sound of a cracked walnut in the next room. "He loved walnuts." He would not eat the food civilized society gave him, but only nuts, potatoes baked in the coals. He didn't seem to feel pain as they pinched him. They could not get his attention with toys and after weeks of examination.

"The boy's behavior,' they said, 'places him below all animals, wild or domestic. He is hopeless.' Then they lost interest in him."

Until John-Marc Itar, a young doctor cared for him and decided to teach the boy he named Victor. He began to learn the things Dr. Itar taught him, but he could never learn to talk. Then,

"One sweet spring morning, Victor woke and, without thinking, ran off to find the woods. He became lost in the suburbs of Paris and spent the night hiding in a park till the police found him." They brought him "home."

His hair was combed, he could set the table, he was proud of himself when he could solve difficult problems. "He wasn't wild anymore."

"But he did remain silent, and could never tell of his wild life. And something of the wild was always in him... The sound of a rising wind, or the sight of whirling snowflakes or the sun bursting from behind a cloud made him tremble with excitement and wild joy." Victor would gaze every night at the moon and the doctor would wonder what he saw there.

Mordicai Gerstein, [The Wild Boy](#), Sunburst Edition, 2002.

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[A Mother's Writer's Block](#)

Filed Under ([To Get To The Other Side](#), [Writing](#)) by Estee on 16-11-2009

There are days I'm not sure how to write. This ache of inertia stops me short — what do I tell, what do I leave out? It's a problem, actually, of writing about oneself; a problem that many writers experience when writing about life.

The mother always has to think twice. More like a thousand times a day. A mother has to wear a shield around her so she does not upset the children she loves so much. A mother has to be solid, grounded — a monolith

MOTHER as described on the tombstones in Mount Pleasant Cemetery in Toronto where many of us Torontonians walk and run through every day like Central Park. I know, it's a more melancholy park, you're thinking. But it's truly spectacular for it's scale and landscape in the centre of our city. I walk by stone angels here almost every day. "Beloved wife of," "Mother of." That seems to be our legacy — and while it is an important one, it is peripheral and lonely. I am reminded of Margaret Laurence and her Hagar.

MOTHER — it describes everything and nothing out here in the cool fall air. If I were not a mother, I'd be pining to be one, envious of the epithet. If you don't know me, now you do in part. I wanted a child so badly and had I not had one, I'd be crying now. I walk among the stones reading them, picking up brown oak leaves that smell fragrant as they decompose, wondering what my stone will read. I gather the oak leaves in my hand because that's what I do when I go out on my walks. I collected my first three four-leaf clovers this year after looking for the previous forty-two of them. I would look for hours as a child. I'd search within the thick bush of clover knowing that one day I'd find my luck, but all I found were the common three-leaved variety. The rich green mass became too overwhelming to continue the search, and mother called me in for dinner. I found three this year when I wasn't looking, and in the nick of time. Going through a separation while recovering from cancer surgery was the worst event of my life, so someone wanted to tell me something, I figure. Now, I pick up four oak leaves because the oak tree symbolizes strength and courage and you must know me — I've got a lot of that.

We are born into this life, a blank slate of possibilities and stories to be written. The stone that remains is a summary. The men in this cemetery typically get some interesting descriptions — heroes and veterans particularly so. I look for the mothers and wives, thinking that, like the sullen ambrosia of the leaves and earth, our time here is short but never lost; the earth and leaves beneath my feet are the smell of life that goes on forever. Dust to dust indeed — our fragrance is sweet.

Among phallic monuments erected to the family name or patriarch of the family, I'm particularly drawn to a modest stone laid just before it on the slant of a gentle hill. Sitting low to the ground, an older worn stone with the block letters spelling MOTHER. She is modest there in front of the huge piece of marble pricking the empty sky.

Underneath the "monolith," the woman's world is rich and wrought with things some children will never know. Why is it that men do not hide their desires as well? Why do they live out loud? *Why do they get to?*

It's a problem, really, as a writer. I could dress her up in fictitious clothes — a universal mother, woman with desires and unmet dreams, who has been hurt, who has stories that can never be told, or if they are, told carefully.

I write around and around her like a rubber tube spinning so much harder and faster than the centre of the rim. The core that stands so open, awaiting the spear of the archer's arrow, or my pen. Yet it compels, so to want to get to know her. I wish I could grab a cup of tea and look through her photo albums, have a woman-to-woman chat. I bet she shared her life with many of her friends. I bet she has a great story that should have been told. I bet it would have helped my own.

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[Slipping Through My Fingers All The Time](#)

Filed Under ([Development](#), [Joy](#), [Single Parenthood](#)) by Estee on 15-11-2009

“Barely awake at the breakfast table, I let precious time go by...”

Hovering over the small stainless frying pan I cook his eggs, sunny side up. He always likes them sunny side up. I think it started when I started making them into “Baby Einstein Eggs,” I would call them where I would place his favorite vegetables and transform two eggs into eyes, then glasses then thinly sliced peppers into cow-licked hair.

“Baby Einstein Eggs,” he said back deliberately, his voice still sweet and squeaky with staccato rhythm as the words were hard to say. I watched him look at the eggs with such delight, moving his head closer and then back again like the humming bird I always call him, his hands flapping just as fast. I remember now because the eggs have lost their appeal. *When did it happen?*

He goes to the door now on his own in the morning. He gets his shoes and puts them on before I ask him to. He has even taken to putting on his coat, ready to start his day. Ready to go outside before I am ready. Ready to leave. His assistant arrives to take him to school. He grabs his lunch bag on his own, no need to remind this day. He trots out the door.

“Good-bye, Adam,” I say, hoping the desperation is hidden behind my eyes. “Have a nice day. I love you!” He turns and smiles at me.

“Bye-bye, yes.” The yes is the punctuation mark. It’s the *you want me to say good-bye to you so here it is*, kind of yes that has become his signature. It’s the way I know he acknowledges that he must say the same thing back, or that he’s heard me. He doesn’t use the *yes* when it’s a sentence all of his own making. Those sentences are few, but so precious.

When I pick him up or when he arrives home by another, he is so happy to see me and it makes me want to sing. I am relieved to see him. He grabs me and hugs me hard. When he leaves — now to school, to his dad — or later to his life or maybe even his wife, it will be exactly the same. He grows differently but also like any other. They change, they become independent or maybe even quasi-so, but things do change. Every morning seems the same. I wake. I’m tired. Barely awake every morning, I try to remember never to forget. For the moments, as they should, are slipping through my fingers all the time.

Meryl Streep (w/Amanda Seyfried)—Slippi...



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[Writing About Illness](#)

Filed Under ([Writing](#)) by Estee on 13-11-2009

‘Tis the season of H1N1 and I am reminded of how many writers write about illness. I began The Joy of Autism blog in 2005 whilst suffering from pneumonia. I devoured the prose and poetry of Audre Lourde when I was diagnosed with cancer. Here’s an excerpt from Virginia Woolf on illness I found interesting, and which reminds me why many of us are compelled to write:

Considering how common illness is, how tremendous the spiritual change that it brings, how astonishing, when the lights of health go down, the undiscovered countries that are then disclosed, what wastes and deserts of the soul a slight attack of influenza brings to view, what precipices and lawns sprinkled with bright flowers a little rise of temperature reveals, what ancient and obdurate oaks are uprooted in us by the act of sickness, how we go down into the pit of death and feel the waters of annihilation close above our heads and wake thinking to find ourselves in the presence of the angels and the harpers when we have a tooth out and come to the surface in the dentist’s arm-chair and confuse his “Rinse the mouth – rinse the mouth” with the greeting of the Deity stooping from the floor of Heaven to welcome us – when we think of this, as we are so frequently forced to think of it, it becomes strange indeed that illness has not taken its place with love and battle and jealousy among the prime themes of literature.

From “On Being Ill,” by Virginia Woolf. First published by the Hogarth Press, 1930.

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[The Fishbone](#)

Filed Under ([Creative Non Fiction](#)) by Estee on 13-11-2009

“We all take for granted the little miracles,” she said afterwards there, in the dark.

She said it after I pulled out the fishbone from my throat – about an inch and a bit long. I did it outside, after they said the meal was on the house, choking next to the kitchen asking for help quietly.

“You should have seen your face,” her eyebrows furrowed with worry, “it was going red.”

It was my usual fish – the filet of sole that I always ask to be de-boned. We were enjoying an evening out, two single women — admiring, being admired and that’s enough for the soul to ride on after a long swim in the dark. Just opening up can be enough. Opening my mind, my world, my eyes and the whole world smiles with me.

Until...I choked.

On a fishbone.

Almost choked to death as we headed to emerg.

Emerge.

And then I pulled the little bugger out, giving the term “dig deep” a whole new meaning, there, outside on the sidewalk away from the people, wondering if this little fishbone “was it.” This little soft bone the thread between air and breathlessness.

“We can never take for granted the little miracles that happen every day,” she said again, shaking her life-affirming head and pursing her lips. “You better frame that thing.”

Perhaps I should as the little reminder of being one step away from floating with the fishes.

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[An Artist's Life](#)

Filed Under ([Poetry](#)) by Estee on 11-11-2009

Hovering like barometric weight,
each morning before I wake
an effort looms.

It was your idea,
your invitation
upon the podium I stood.
You wanted words of hope, I thought –
Of the little engine that could.

Lauded once and quoted some
for better and for worse.
There I learned but also burned
A scorch within the wood.

Shaded once by gilded trees
like cold metal – forlorn.
The artifact, the word, the thought
A dropped seedling in the dirt.

*Cut it down, say no more,
words of love be gone!
Do not remind us, this plight we lead,
or of dreams – you cling on.*

*Be gone you feckless writer!
Just who do you think you are?
If we smite you and apprise you,
You can go — afar.*

Of books, of words of thoughts and form,
some mold and shape and bend.
With exaltations and deflations,
An artist's life is spent.

— by (me)

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[Expression](#)

Filed Under ([Autism and Learning](#), [Development](#)) by Estee on 10-11-2009

I'm hard pressed to ever state that Adam really can't express himself. I mean, I find myself saying it some days in terms of verbal communication. But really, he is an expressive guy. If I were to take an accounting of his "expressiveness" and his "ability to communicate," I might end up with something like this:

- 1) He is so affectionate, but not to everyone. He is discerning in who he expresses affection to;
- 2) He only really wants mom and dad and gives us extra special hugs and tends to shun others away as he wants us all to himself;
- 3) He knows who his family is because he has variants of affection for different people;
- 4) He cries when he knows he has broken or made a mess of something;
- 5) He cries when he thinks he's upset someone, or that he knows someone is upset;
- 6) He dances when he's happy (not the happy dance, but real dancing);
- 7) He sings what he can't say — when mom and dad were together with him the other day, he sang Beyonce's "I'm a Single Lady" — a song that came out at the time of the separation. Here I will add a little bit of my memory of other children I knew when they were little who dreamed of their parents back together again. I imagine this is Adam's way of telling us the same and that he recognizes the current situation;
- 8) He laughs at funny things — he laughs at my jokes and he laughs when he's trying to make me laugh;
- 9) He talks more and more each day;
- 10) He types more and more (independently) each day;
- 11) He reads out loud and understands what he is reading;
- 12) He knows how to manipulate certain people who all respond to different things. He knows how to "work it";
- 13) He uses a word to describe what he is looking at (i.e.; he may type sock and then I can help him build a sentence to correlate with the work **GAP** he is peering at on his sock so he can **type, see and say**).

I could go on but it's late and I'm tired and I'm just basically trying to say how Adam is such a Mensch to me in every way. He works really hard, he wants to do things, he loves people, and his will is strong. I see and experience how hard it is sometimes for him to stay focused and I'm still very proud of him. When his fabulous assistant (she has been with us for five years now and counting), told me that he went wild for *Carmina Burana*



at school, I smiled. I went wild for Carmina Burana when I was young and consider it to be my foray into classical music because it's so dramatic. Adam danced and moved his body to the music. When I see his notebook wherein Adam is struggling to draw, he is specific about what he is drawing (his assistant writes what he has named his characters that he struggles motorically to draw). And all I can do is keep trying hard with him, to learn, to keep an open mind, to provide him various modalities with which he can work and express himself.

Expression, thank goodness, comes in so many colourful forms.

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[When The Wall Came Tumbling Down](#)

Filed Under ([Uncategorized](#)) by Estee on 09-11-2009

It's quite a night for me to watch this twenty years since the Berlin Wall came down. I remember exactly where I was watching a younger CNN minute-by-minute, glued, because the year before I had just been there. I visited East Berlin where the group I was with were searched, when we were escorted to the places we were only meant to see. Bullet holes still embedded in old buildings were not just the remnants of the the war, but of a regime too tired to rebuild its environment or nurture its people. For me, Berlin is also the place of Bertolt Brecht, who I studied in university:

*Brecht's Marxist political convictions led him to propose an alternative direction for the theatre that would fuse the two functions of instruction and entertainment. In this way the theatre could project a picture of the world by artistic means and offer models of life that could help the spectators to understand their social environment and to master it both rationally and emotionally. The main concept of Brecht's program was that of *Verfremdungseffekt* ("alienation"). In order to induce a critical frame of mind in the spectator, Brecht considered it necessary to dispense with the empathetic involvement with the stage that the illusionary theatre*

sought to induce. Generally, this has been understood as a deadening coldness in the productions, but such an interpretation proceeds from a general ignorance of Brecht's own writings on the subject. Rather, he insisted, as Appia, Craig, and the Symbolists did before him, that the audience must be reminded that it is watching a play. (Stanford University website).

And it was rather like that, my visit to East Berlin — a carefully staged tour, a kind of theatre of pretense. Yet what remained hidden remained so visible in its absence.

I've not yet been back since the wall has come a-tumbling down, but I'm in awe of the art installation of dominoes to commemorate this important point in our history. May all walls that separate our ideals come tumbling down with this both historic and symbolic event.

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[Diagnosis, Determinism and the DSM V](#)

Filed Under ([Autism and Learning](#), [Autism Spectrum and Diagnosis](#)) by Estee on 09-11-2009

I was sitting in a waiting room recently when I picked up this from the April 2009 issue of [Today's Parent magazine's article, *Is It A Learning Disability*](#) by Marcia Kaye. I turned the pages reading about “conceptual and motor problems,” and in the middle of the page was a photo of a drawing.

“They don't draw, they scribble,” said the caption.

Who are they? I thought. Does she really know who she is referring to?

The *they*, is the Adam who when he made his first intentional scribble on the page, I jumped happily. Whose “motor problems,” and indeed they are challenges, in holding a pencil or a crayon seemed to be surpassed. At least the first step had been made. You see, I've kept every one of Adam's “scribbles,” his effort rewarding by his marking that later turned to a happy face, a letter, a sun and a tree and one day, a happy face with long hair which he named “mommy,” at the age of six. The *they* are people. *They* are Adam. *They* are individuals who are challenged but not unintelligent, who continue to progress at their own rate on the exterior, while on the inside, have many ideas and things to share.

And then there is the category of **Non-Verbal Learning Disabilities**, which I read with great interest. For the **Today's Parent** article stated that “*this category encompasses non-verbal learning disabilities (NLD's), which is a controversial area, with possible overlap into Asperger's syndrome and mental health issues. But the LDAC [Learning Disabilities Association of Canada] considers NLD to be a bona fide learning disability. A child with an NLD may have a great vocabulary, a good memory and an excellent grasp of detail, but miss the bigger picture. He may be a good reader, but a poor comprehender...if you say 'Oh great, I have to get a root canal!' they may take you seriously.*” It goes on to describe the social awkwardness and anxiety issues that we so often talk about with regards to autism.”

And to muddy the waters even a little bit more, we have the discussions over DSM V [Diagnostic Statistical Manual] and removing Aspergers or what differentiates individuals along the autism spectrum:

The Neurodevelopmental Disorders (ND) work group's discussions have focused on three areas:

1) Possible modification of ADHD criteria to allow for co-morbidity of autism and ADHD (currently excluded). The ADHD & Disruptive Behavior Disorders Work Group has agreed to consider this possibility.

2) Discussion of the validity of Rett's disorder as a separate disorder and inclusion of a new modifier within the Autism Spectrum Disorders (ASD), which might include genetic and medical disorders and other biologically-definable conditions.

3) How to address Pervasive Developmental Disorders – Not Otherwise Specified (PDD-NOS). The individuals currently diagnosed with PDD-NOS may still be described in DSM-V, but the work group will discuss whether they can redefine ASD in such a way that the PDD-NOS diagnosis isn't necessary, as this diagnosis currently captures a very heterogeneous group of individuals.

The ND Work Group will be seeking additional feedback from advisors and other experts prior to "finalizing" any recommendations.

Questions still under active discussion for ASD include:

1) How to describe the "spectrum" of disorders now known as ASD (e.g., how many domains will define the disorder);

2) What is the specificity of repetitive behaviors in ASD and how might they be better defined;

3) Whether Childhood Disintegrative Disorder (CDD) is a unique and separate disorder, and if so, what are its defining characteristics;

4) Whether autism is a life-long diagnosis or whether it is possible to recover/remit to the point where the diagnosis is no longer applicable;

5) Whether Asperger's disorder is the same as "high-functioning autism";

6) How the DSM-V can alert clinicians to common medical comorbidities (including genetic disorders, epilepsy/EEG abnormalities and sleep, or GI problems) and potential biomarkers;

7) How to include consideration of severity and impairment in diagnosis (currently defined as "qualitative impairments") and how to integrate these with the overall structure of DSM-V; and

8) How/where to discuss cultural influences on diagnosis (e.g., Korean use of reactive attachment disorder rather than ASD to avoid family stigmatization).

What is most poignant to me is the purpose of both the differentiation and the suggestion that the atypicalities are abnormal rather than a way of being in the world. If Adam's way of obtaining and processing information about his environment and the people around him are respected (as they are in his household and school), then he continues to grow, mature and learn. And while there continues to be little research that truly helps us understand how "severity" has often to do more with outward "functioning" rather than intelligence, I struggle with articles that fail to discuss how society tends to want to categorize and differentiate individuals based on the severity of their learning disability rather than discussing how people with different or atypical learning needs learn and how we can better support them.

When I read the suggestions for broadening autism to encompass Aspergers and other characteristics in the DSM V, the issue as I see it is [not the damaging effects that calling Asperger's or PDD-NOS](#) or NLD to autism is to the person or family. For I view it as the families' discomfort in perhaps being associated with autism. I see the issue is a continued determinism about autism and herein lies the problem. Until autism and many issues are no longer viewed as problems to be solved, but rather atypicalities that require our understanding and providing for, we will forever find ourselves spinning on the hamster's wheel.

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[H1N1 Vaccine Day](#)

Filed Under ([Autism and Vaccines](#)) by Estee on 08-11-2009

Nope. No qualms about it here. When it comes to life or death, or the risk thereof, it's a no-brainer. Today we line up at our local clinic. Pack the backpack with food, toys, books, lollipops (wasn't my last post about the dentist...oh boy....)....here we go....

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[Blind, Autistic Woman Rakes Leaves To Pay For Dental Work.](#)

Filed Under ([Uncategorized](#)) by Estee on 06-11-2009



[Heather Stone collects leaves earlier this week at a home where she and some volunteers raked leaves to help Stone raise money to have dental work done. Stone has raised \\$41 so far toward a \\$12,000 visit.](#)

When I read this story I thought of Adam. How a month ago we spent another day in the hospital pulling and repairing his teeth, for indeed he, like many autistic folk, need to be sedated during this stressful experience. I am there helping hospital staff deal with Adam and in turn Adam is managing better and better every year as he matures brilliantly. I am becoming an old hat with hospital staff and they in turn seem to appreciate the calmness and information about Adam I can share. *That* came with time and experience.

Living in Canada, we do not pay for such visits if we have dental insurance. We do not pay for the hospital visits at all, as we are covered in Ontario under OHIP. We parents have to advocate and teach others how to help our

autistic children through stressful periods like this. I hope that Heather will be able to raise the amount she needs.

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About Me

ESTÉE KLAR

I'm a PhD candidate at York University, Critical Disability Studies, with a multi-disciplinary background in the arts as a curator and writer. I am the Founder of The Autism Acceptance Project (www.taaproject.com), and an enamoured mother of my only son who lives with the autism label. I like to write about our journey, critical



issues regarding autism in the area of human rights, law, and social justice, as well as reflexive practices in (auto)ethnographic writing about autism.

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The Joy of Autism:

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



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