

## Estée Klar

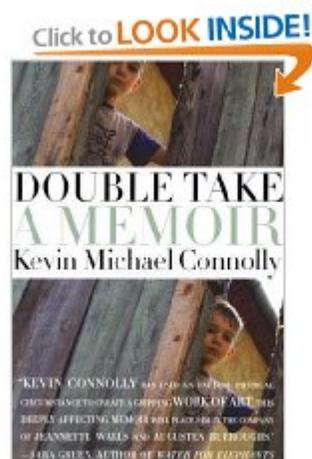
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## Do You See?

Filed Under ([Book Reviews](#), [Critical Disability Studies](#), [Writing](#)) by Estee on 29-12-2009

“You didn’t see me.” That must be the most popular line of relationship distress we’ve all ever heard and the reason for much heartache. With those who are closest to us, we yearn to be seen meaning, we want to be seen for who we really are — all that vulnerable, squishy stuff inside of us that we want others to take in their arms and hold gently.

What does it mean to “be seen?” I mean, out here in Miami there is no lack of men and woman stripping nude, or nearly nude, wanting to be seen. Hair coiffed just so, a pair of trendy sun glasses and a spray-on tan, and off they go into the public to show off with their heads held just so — pretending as if they are not aware that others are staring. These people may want to be seen all right, but they want us to pay attention to what they want us to see. It is a far cry from being seen.



If you think this post is about relationships it certainly could be. This is the meaty stuff of what makes or breaks many of them and why life is so hard sometimes. In his book **Double Take: A Memoir**, Kevin Michael Connolly travels to more than seventeen countries and captured 33,000 photographs along the way about the way people see him. Born without legs, “being seen” takes on a whole new meaning.

The photos in his book titled **The Rolling Exhibition** (named after his rolling around on a skateboard: “This Is A Legless Guy’s Skateboard. Please Please, Don’t Steal” he writes upon it), have been featured at museums and galleries around the world. They are taken from his perspective, low to the ground, (he is lying on his back when he takes some of them) with people staring down at him, which of course has a pent-up meaning in itself when talking about disability and the way people stare. They are passer’s by, whisking past him and he has caught their fleeting yet loaded glances. How could one describe them? Curiosity? Fear? What does it mean to be a subject of a stare when you have not intentionally invited it, unlike those plastic Miami boobs?

(Interesting to go off on a tangent here to recognize that those fake boobies are in the same sense **a prosthesis** that we admire rather than fear. Of course, we have the same curiosity and sometimes repugnance at the fake boobie because we understand that some person has intentionally gone under the knife and altered herself to make her more attractive for sex and they don't look quite real. So we stare to make up our minds, or stare because we are just so darn curious. [Aimiee Mullins](#), who has designed for herself a series of gorgeous looking prosthetic legs that can make her various heights has also noted the lack of difference between her legs and the many prosthetics men and women now use by choice in order to alter their appearance).

Like the performance artist [Petra Kupperts](#), who with her disability stages performances that also investigate the stare, in fact invite it, Connolly has invited it by his being born with bilateral amelia (meaning born without limbs). It's an unintended invitation, like being born into royalty with paparazzi following your every move. You don't ask for it; it's just sort of a birthright and a burden, whichever way you look at it — they seem to go hand-in-hand.

What I love about the camera is that it's like staring back. Being a photographer means you are like a voyeur, capturing other's most private moments. One simple glance or expression, as they saying goes, captures a thousand words. Connolly has taken the stranger's stare and turned it back on them. It's rather empowering to turn the investigated into the investigator. If I were Petra Kupperts, I'd be performing. If I were Estee Klar, I'd be writing. It's what people who need to express a point, do. The camera captures private moments the way people stare at many disabled people who cannot fend off the stare. Often, we are intrepid lenses unwelcome in private moments. Yet Connolly, like all people who put their expressions out into the world has a conscience as he reflects in Sarajevo:

“What's wrong,” [Beth] asked softly, her hand on my back.

“I don't think I can shoot this anymore.”

“Why not?”

“I think I'm hurting people.”

“How?”

“People think I'm a beggar of someone who was hurt here.”

“Well, yeah. Maybe some people. But that doesn't make you any more of a beggar than you were a month ago. You and I know who you are, so don't let it get to you.”

“Yeah, but I'm using them for the photos.”

“So? It's not as if their entire day is ruined or anything. You're getting too wrapped up in everything. If you stop shooting and just quit, you're going to hate yourself forever.” (p. 198)

It's a question of art to a certain extent — this idea of truth-telling and who and what moments we use as subjects. When we take our personal experiences and use others to reflect a truth, are we doing unto others as they do unto us? The discussion about staring at people who look different or disabled is a sensitive one, and the more others can see themselves, the more we all can understand the effects of what we do everyday — those things we think are harmless like taking about an autistic person like they are not present, or criticizing the family, the parent, or autistic individual who needs to fight for things that come automatically to other families like access to education, services, and just acceptance into our communities without having to talk about autism, acceptance and the like. From a personal point of view, although I have to end up talking about it, I don't want to talk about it everyday. We want (and deserve) to live our lives with autism as does any other person who wants to live their lives in peace, without having to justify the reason why they deserve to be here — why they “have” autism, where it “comes” from, or *why* they should have access to that school or that aide.

As a writer who likes to write about certain instances in our day-to-day lives — from the person who stares at Adam's wildly flapping hands, to the friend whose account I once used about, when I was new to autism writing and the idea of “normal,” *her* desire to change the appearance of her child's ears (I used the story about our quest to make our children appear indistinguishable and in Adam's case, it's simply impossible) — it's really difficult to write about these real-life events. Yet there is a need for many of us to write, or make photographs and art, about them. It seems that everyone is sensitive, but the context in which these accounts are written are important. The consciousness of not wanting to hurt other people, seems to me, is a must in the making of art, not that the hurt won't be there. In the world of black-and-white autism politiking, there is a need for education through

thoughtful literature, memoir, art projects like Connolly's. These projects help us understand life from a different perspective, and because it has been "done to him," Connolly has a need to state his sensitivity. The outcome of his work is worth it. Like art and writing, the poignant point is made when it is evident that the artist has weighed the cost and the benefit of telling true stories.

In his *Epilogue*, Connolly reflects how the looks, no matter how experienced or hardened we become, still effect him:

"As these pages show, my lack of legs has generated a lot of strange looks. Those stares still get to me sometimes. Sometimes I wonder if I should explain myself to the people who shoot a sad direction in my direction. Maybe, if it would relieve that moment of guilt or pity from their lives, it would be worth it. But most of the time, I let those stares slide off my back. A lot of times, I don't want to talk about my lacking legs.

Maybe it's because dialogue has a tough time blooming when it's about negative space. There's only so much you can discuss about something that isn't there, and isn't forthcoming. And rather than try to make a bad riff on a Beckett play, I'd prefer to end this page with what I do have...

So maybe the reason I've been so frustrated at times by the question What the hell happened to you? [**what caused your son's autism? — my interjection here**] is because it's simply the wrong one to pose. It focuses too much on a physical circumstance based on a singular point in time, rather than on all of the influences and characters that followed.

Perhaps *Where the hell did you come from?* is what we all should be asking." (pp.226-27)

I would agree. It would be nice to be asked that question rather than "what happened" to us, even though autism is certainly a part of our lives. The question is, *Do you see me?* For Adam and I, and Kevin Michael Connolly, it seems, it means the whole package.

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Kevin Michael Connolly, **Double Take: A Memoir**, New York: Harper Collins, 2009.

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## [Merry Christmas](#)

Filed Under ([Uncategorized](#)) by Estee on 23-12-2009



I'm wishing all of you a very Merry Christmas, and if you get caught in the snow, may a fire let you gather with those you love and warm your hearts.



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## [Tis The Season To Love](#)

Filed Under ([Acceptance](#), [Joy](#)) by Estee on 22-12-2009



A couple of weeks ago [I wrote about Barb and Tim Farlow and Justice for Annie](#). She has been interviewed in **Bloom**, Bloorview Kid's Rehab's magazine in [For The Love of Annie](#). I've known Barb for a few years now and the work she has done attests to her love of Annie, her daughter, born with Trisomy 13. Reading her story reminds me why I do what I do for Adam and even the prices I may have paid for it — *any* parent with disabled child may attest to those prices paid, and most parents would say that they would pay them again. Me too. There is not I price I wouldn't pay for getting Adam the acceptance, access and rights that belong to him.

In two days I will be reunited with my son Adam for Christmas. As I have been without him for a week, I am starkly reminded of how closely connected we are and how I understand Barb and her decisions because of it.

Tis the season. May we all find our joy, our happiness and remember the importance of this most valuable thing of all. This little thing called love.

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## [Rethinking Autism...dot com](#)

**Filed Under** ([Acceptance](#), [Activism](#), [autism](#), [Autistic Self Advocacy](#), [Celebrity Advocacy](#), [Websites](#)) by Estee on 21-12-2009

[Rethinkingautism.com](#) is a site that has taken [The Autism Acceptance Project](#) goals to a new level. "One video at a time," they seek to use the same tools that media use in shifting and reframing the dialogue about autism:

## Rethinking Autism: Autistics Speak



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### [Just because he's laughing....](#)

**Filed Under ([Adam](#), [Discrimination](#), [Family](#)) by Estee on 16-12-2009**

All of us have encountered ongoing misunderstandings about our autistic children. Adam, going through something at the moment, could also very well be going through stress. Perhaps delayed, perhaps not, what really worries me is the assumption that just because he appears happy, that he must be happy and as such, because of his autism he is neither affected by nor registers the new people in his life and the separation itself. To borrow a recent post by [A Life Less Ordinary](#), Emily writes of this regarding the autistic child and school and it resonated with me in these days of Adam's apparent stress levels:

–An autistic child can often be "low arousal" in certain ways. That means that even a brutal and ill-intended pummeling may not elicit a visible or detectable response. Never assume that such behavior is being taken in good part just because the autistic child isn't crying or complaining about it.

–An autistic child may not tell an adult about physical and emotional bullying unless they are very close to and comfortable with that adult.

–An autistic child may not respond to repeated insults until some unclear breaking point is reached. The autistic child may then respond. Just because the autistic child made no previous mention of the bullying doesn't somehow make the bullying OK or negate the fact that the child's response was provoked.

–An autistic child may not express the emotion you expect. An autistic child in great pain—emotional or physical—may smile or even laugh right through it. I can assure you that the laughter does not mean the autistic child is actually having a good time.

–An autistic child does not express himself or herself the way a neurotypical child or adult might. Try not to judge an autistic child’s facial or emotional expressions through a neurotypical filter or from a neurotypical viewpoint. You’ll never have the correct understanding of the autistic child if you do.

–An autistic child may look like s/he is having a great time. If that child is, however, in the midst of a scrum of running, pushing, verbally sparring children, that child likely has no idea what is really going on. And that child is also likely a target of under-the-radar bullying that you’ll never hear about.

–An autistic child in an unstructured, chaotic social situation is a child who is likely completely at sea and who is likely the target of bullying, both subtle and overt, both physical and emotional. Don’t ever lapse into thinking otherwise.

–An autistic child in the midst of more than a couple of neurotypical peers in an unstructured situation is never fully armed, never as completely socially able, never truly interacting on a level playing field as the neurotypical peers. Never.

To assume otherwise is not to understand the autistic child.

Like everyone, Adam responds well to a good vacation and in addition to some upcoming necessary tests, I’m glad he will have one soon and hope for a resolution so that I really know what I’m dealing with. He appears to be doing well in school, and accompanied by an aide, I am assured he is not being bullied. Yet I also wonder how he views himself now that he is maturing, next to his “typical” peers and indeed, we are in a completely new phase of our lives.

So a vacation is needed and mom needs to think. Unlike previous years, he will first go with his dad and then be rejoined with his mom in Florida. I am definitely concerned as his mom with all the transitions he has had to endure (as an autistic person they are far more stressful than for an average child) and the assumption that this separation has not effected him deeply, even though as parents, we are doing the best we can.

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## [Home, home, home](#)

**Filed Under ([Adam](#), [Joy](#), [Single Parenthood](#)) by Estee on 15-12-2009**

I always knew Adam was a tough little egg. As I had written earlier today, he defied the sleep aid in the hospital that would knock, likely, a typical kid on their back. Not my Adam; he was fighting this sleep. Maybe he was

determined to defy any hospital hand after the weekend. No electrode would be placed on his adorable little autie head this morning.

I have to admit, this single mom is pooped. A couple of canceled events — of course I was going to cancel them and do everything and anything for the little man — all the worry, sleepless nights and all that social deprivation! We met with unknowledgable Emergency Room staff (Did I say that? I really wanted to use the word *graceless*), I slept beside him in the pediatric ward for the first time since he was born, I orchestrated (felt more like moving mountains) to get this EEG *this week*, instead of in February. And NADA. Anyone have a Grey Goose on ice?

Yet, just as it always goes when life seems to feel a little dark (it is December after all), I decide tonight that Adam, who has of late not been sitting very still or sleeping very much, will watch *E.T.* with me this evening. Movie watching can be a little precarious with Adam. He has been known to leave dark, hushed theatres mid-performance. I think the movies he has sat through from start-to-finish, so far, have been **Happy Feet**, **WALL-E**, surprisingly, **Charlotte's Web** and that silly one with the hamsters playing 007 in 3-D, whatever *that* was. At home where he is allowed to roam freely to the kitchen, get his toys, his books, movie-watching can be next to impossible. So sleep deprived? Too bad. There is usually no rest in this house even when we are weary.



I am happy to report that tonight, I managed to keep him with me on the couch — many a wriggle and a wrestle, a salty cracker or two. Okay, maybe three. When he saw *E.T.* and that typing device, I told him to look. He was, even though he would also wriggle, look at a book, eat a cracker, a banana, a glass of water, and peek often in between. “Look at Elliot,” I would urge, pointing my finger hoping for that good old joint attention. “Look, look at E.T.! Isn’t he *cute*,” Adam looked at me with a smile, which, if you really had seen Adam’s pain the past few days was lovely, relieving and made me appreciate every moment like this we’ve EVER had. His cheeks seemed fuller, maybe because his colour came back. As he rubbed his soft head into my face, I could still detect the whiff of medicinal smell from the gel they had placed on his scalp. He rubbed his cheeks back and forth against mine for the feel of it, like Eskimo kisses and I laughed. It felt like a bucket of soft feathers pouring over me, but really, it was love. He seemed to enjoy my antics more than the movie, or maybe he just liked it when mom sat there with him on the couch, eating crackers, drinking water, and fun-wrestling in my arms.

“Home, home, home,” he said at that point in the movie when the music billows, the volume rises, and the story ends. Home indeed. There’s no place like it.

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## [One tough little egg at the EEG](#)

Filed Under ([Adam](#)) by Estee on 15-12-2009

Well, we attempted the EEG with zero success. Adam is an antsy kind of guy and even chlorohydrate does not put him to sleep as hospital staff had hoped. From past dental surgeries, I knew it would not, but I was hoping it

would make him drowsy enough to stay still. It has, as I have seen in previous dental surgeries, lessened Adam's fight, but as I've learned from doing an EEG, one cannot move... AT ALL. Every movement records and Adam, even with sedation, is up and down on the gurney like a yo-yo, sort of drunk but not inebriated enough by medication to have a happy drunkard's sleep. It's sort of like watching a person who wants to rest, but his body won't allow it. And I'm wondering if he needs to move more, now that we live in a city where children don't really go out to play much, but are over-scheduled instead with instruction and programs. It makes me want to say, *fly little bird fly*, and in about an hour, that's just what I'm going to let him do at the park. He needs exercise, some sun, yes, that might do some good too. I've done about everything I can do now. Now we have to wait to see the neurologist and for other subsequent appointments I've lined up to, hopefully, cross all more serious suspicions off the list.

We did had a good day yesterday and so far so good today (Adam did not get upset by going back to the hospital and was back to his funny, affable self). And I'm hoping that after we do what we must to rule out or find some facts, Adam might just have his issues resolved when he heads down to Florida to his favorite spot — the beach.

In the meantime, this mom is still clutching to her anxiety, which is sort of the aftershock of being in hospital and orchestrating many people to have made this EEG happen today. It should be understandable why I'm disappointed and still concerned. I certainly do relate to many of you out there these past few days when times have been tougher for you too. When all is said and done, I will have amassed a checklist that I must hopefully remember to share.

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## [We're in the "struggle" part](#)

**Filed Under ([Adam](#), [autism](#), [Discrimination](#)) by Estee on 13-12-2009**

When I wrote **The Joy of Autism** blog, I wrote a mantra with one line that said "because joy doesn't come without struggle." I don't know if it's part of the way I think about things, something about me, but my friends certainly share the struggle part. I am lucky to be able support some friends in some difficult times right now as my friends are supporting me. I have to think long and hard these days about joy and struggle and still, I am so convinced that if people understood autism a little more, we would not have necessarily had insult added to injury in the emergency ward.

Adam and I returned from the hospital yesterday after observation Friday night. We did not go to our usual hospital, and the benefits of not going to it may have been some extra attention in the end. But attending emergency was a bit of a nightmare as everyone who registered after us, got admitted before us, even though they didn't look that ill at all (and consequently they all got discharged while we were still sitting in emerg). After having asked the triage nurse "how much longer, can't you see he's in pain writhing over there," in a relative calm voice, she told me not to yell at her (are they trained in saying that even though someone is not yelling?). I had to do my part in managing her the way she was, I suppose, trained in managing me. It took some, let's just say, urging after that to get Adam in (she had been lying about the crowds in the hallways inside because once we got in, it was relatively empty) or else we would have likely spent another three hours just sitting there without any help or attention. There was absolutely no visibly known/obvious reason for this after we were admitted.

Many families can imagine a child screaming so much til they are red in the face. In addition to whatever is happening with Adam, going to the hospital and waiting is one of his number one stressors. "Can he at least have a sedative?" I asked after waiting six hours like this, Adam's face apple red, his lips quivering, his whole body shaking and contorting into a letter C. Nothing.

Thankfully, from my trip to Paris, my bag was full of goodies. I found melatonin strips buried deep at the bottom and after six hours of waiting for any kind of help, gave him a strip. By the time Adam's dad and grandfather arrived, the edge was gone and Adam was lying on top of me on a gurney.

The doctor was prudent enough to want to observe Adam overnight and I got to sleep with him in the pediatric ward. Later arrived his bag from home with DVD's, some food, his P.J's so I could try an emulate the comforts of home. Bloodwork was then taken with little trouble due to the melatonin and the hours of previous crying which had completely exhausted Adam.

My mother went to the nurses station. "You are the talk of the station," she said. "They didn't know melatonin worked for autistic kids."

*YIKES*, I thought. Melatonin may not work for all autistic kids. In fact, some families have told me melatonin stops working. While I am grateful for the female doctor (not from Canada), for her soft bedside manner and her prudence with regards to his body jerks and spasms, I am still very concerned that hospitals do not understand the needs of autistic people and the stress levels that going to hospitals can create. I mean, as Adam was screaming, one staff in emerg said "Oh you mean he isn't always like this?"

And readers of this blog and my Facebook will know that uh, no, he is not "always like this." Adam does not always spasm, contort, and melt-down. He has some anxiety but he is a very happy little guy. In addition, what would have happened if I did not have that melatonin on me? I mean, his heart was beating so fast I was concerned he'd go into cardiac arrest. When they witnessed the calming effect they said, "Can you give him another 3 mg before we give him his bloodwork?" Folks, as "autism parents" we have to advocate for our children, and carry our "bag of goodies," every day. Some days it seems that there is no one out there to help us when the times get tough. When there is one good person, they shine like the rays of light in an otherwise dark day. It is a universal truth, I believe, that every single one of us finds the "advocacy" part exhausting as our children our lumped into the autism stereotype. And it's not helping, that stereotype, and this is what I hope to stress here in this post. It just seems to mean that Adam gets ignored because of it. Well, at least in the emergency ward (which needs a complete systemic overhaul in my opinion).

While we await an EEG this week to hopefully rule out epilepsy, I am rudely awakened, despite all exhaustion today, that we still have lots of work to do. There is joy, there is struggle. There is paradox. As my grandfather always told me, "that's life."

My friend Leda sent me this piece of music today (see below). It calms me after the "storm." I think Adam will love it because it is calm. It's sad and beautiful and just a piece of music for the moment because I am worried and a little "spent." Yet, even in this struggle, Adam is my joy and my life. He is the joy in our autism and for and because of him, we keep on going despite all with which we must deal.

In the words of Goethe: "*Der Zweck des Lebens ist das Leben selbst*," I believe life is not just how "good" we live it (that has been filtered down in our society to mean something quite trite) but in accepting and living with its struggles. Afterall, we just don't seem to have a choice.



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## [Waiting to hear....](#)

**Filed Under ([Adam](#)) by Estee on 11-12-2009**

I've decided to use this post for community feedback. We are at a new point in our autism journey that we have not yet figured out. Adam is in a state of pain that seems uncontrollable.

It began over a month ago, longer perhaps, when Adam began jaw clenching which moved into whole body spasms. Usually, when Adam is ill, or is getting a cold, he can't stop moving his body and manifests his physical discomfort in body jerks and movement so much so, I feel his pain. If his ears hurt, or his mouth hurts, he has come to tell me so. But not this time.

So I've reached out to a few of my autistic friends to ask about myclonic seizures or other types of seizures that appear like body spasms and occur while a person is still conscious. It's the kind of thing that I can't tell is a bladder infection, growing pains, stress, or something more serious. Yesterday we began a whole new exploration and as I write this, Adam is uncomfortable upstairs and I can understand the moments when parents are beside themselves with worry.

Thanks for input but please make it kind and productive.

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## [Oops they did it again... on CNN](#)

**Filed Under ([Autism and The Media](#)) by Estee on 09-12-2009**

Every time I watch a new episode on autism from CNN, I'm ready to turn off all phones. For certain, I'll get a call about ABA, and that maybe Adam "should have had more of it," and then there is all that dark talk about autism and "sieges" and gosh, it's no wonder I want to write about other things. All we want to do is live our lives in peace! Why can't autistic people be permitted to do so without constant references that they are not good enough with pithy reports by CNN? Heck, why isn't inclusion, autism and disability (all in the same sentence) headline news?

[Giving the benefit of the doubt to Karen Siff-Ekorn and her family, I wonder how CNN edited this piece as it so neatly angled to support the recent Geraldine Dawson study on Early Intervention.](#) The CNN piece, with Siff-Ekkorn, described how ABA recovered her son Jake. The implication here is that ABA is the Early Intervention in question by association. Yet, no parent can claim that one particular kind of therapy can "recover" all autistic people. No one parent or clinician can speak for all individuals and all families. In all fairness it might be more accurate to say that every autistic person responds to different teaching methods, well, differently. "Evidence" abounds, but the discussion of study-design is conveniently left out. In every statement or claim, *context is everything*

When Adam had a rigorous ABA program for the first two years after his diagnosis, his anxiety got in the way of his learning. All of those M&M's and "look at me's" sent him through the roof. One therapist even tried to physically wrestle him into submission (there is one thing that is certain — like his mother, Adam will not be wrestled with). It is definitely not a successful way to teach Adam. It seems like so long ago now, but remembering actually gives me a lot of pain.

I definitely see that Adam has benefited by early play therapies, occupational therapy, visual supports, keyboards, computers, and recently we restarted speech language therapy because it didn't make much sense to do SLP on a child who couldn't talk well enough and got extremely anxious when he tried. Once ready to "articulate," he is now responding very well to SLP. In other words, you can't fight mother nature, but you can support her. We've all got to try and figure out the best approach for our unique children and understand when certain autistic children are ready for certain approaches.

In our case, ABA would have created anxiety in Adam that would likely have been irreparable. And let's face it, every year, there are better therapists emerging, integrating a variety of methodologies and eager to understand how an autistic person learns well. Adam today is a happy little boy (still with some sensory and anxiety issues that are being managed) who has begun to draw, who speaks more this year than last year, who types now independently, who is learning his life skills well, and who can do more with his body than he could a few years ago. These achievements can never be taken for granted. It saddens me if people do not acknowledge his marvelous successes (because he remains autistic) for he really does work very hard. But that is not, thankfully, our experience here on the blog. I hate to think that there is an autism archetype he must measure up to — that paradigm of recovery. What if he doesn't talk fluently or require an assistant in his future to live? I mean, the boy must continue to learn and feel successful and gratified in his life! Does being fully independent matter? I know we all want it, if not covet it, but is it that important under the circumstances? If an assistant or a visual aide or a keyboard is what he needs to be in the world, then isn't that enough? Being a parent of an autistic child in this day and age requires constant internal dialogue and discipline.

I would also like to refer readers to [Kristina's Chew's blog](#) and others who do not on any account suggest that their children have "fully recovered because of ABA," but who discuss ABA and autism thoughtfully. Few parents of autistic children will dispute that engaging an autistic child is important, and all of us do this in one way or another and for lack of proof (mainly in our very own living rooms) have tried a variety of approaches.

Also very important living with autism is idiosyncratic rest and play, (I say this because autistic play is deemed abnormal by our society and many, not all, ABA proponents, while autistic adults have discussed how vital and important that play can be to their development and understanding of their environment), and being with family and friends, even if “being with” looks a little different. So is living within one’s community as a respected human being. So is acceptance and support of children past those ABA years into adulthood. If autistic people have to recover, then what of those adult years?

I cannot crystal ball gaze, but I am grateful for what Adam has been given in life so far, and as all parents, I fret about middle school and high school lest someone tries to attempt to beat him once again into submission, or turn him away. I guess mom is still wrestling with the issues that CNN creates when it presents one-sided recovery reports — lack of acceptance, lack of supports, lack of employment opportunities and the like.

The “full recovery” tales are dangerous without balance and without discussing what can happen by suggesting that normalcy, the way we have come to understand it in our society, is the Holy Grail of being, or in this case “becoming” human. CNN once again only tells half a story. They also stigmatize families like my own where we are accused, by insinuation, of not doing enough for our children when we are doing absolutely everything humanly possible to create the best future for our kids. Actually, in autism politics, we are living in a Catch-22 nightmare where we can hardly speak a word about a success or a word about a challenge. No matter which way we all turn as autistic families, we are criticized, which is why I want to give Karen the benefit of the doubt and congratulate Jake on his wonderful achievements — not because he “lost his autism diagnosis.” I congratulate all the autistic families and all of their achievements too, not that I matter so much in all of this except for in Adam’s life, but isn’t this what we should all be doing?

CNN does not like seem to cover stories often enough about autistic people living in adulthood who require supports, assistants, and who, living as autistic people, or “people with autism,” live “successfully,” (or perhaps they may feel they do not, which also warrants fair discussion). It is once again the hero-story or story of some triumph and autism *must* be the enemy. Naturally, I disagree with that kind of manipulation. CNN especially doesn’t like to pick autistic people who would take issue with the angle of that recovery report in order that the complex issues really get covered. CNN does not report stories like ours often enough, where families work so hard to provide the love and supports our children require to communicate, learn and, **if physically possible**, talk more, while leaving out “the siege” angle and uncovering more complex notes that joy does exist with intense struggle as simple as is the metaphor of life. I would like Adam to talk more, and he is every year. But if he does not talk consistently in his future, I will not judge him nor myself. I made that deal with myself a couple of years ago every time I gasp for air in some fleeting moment of panic. I will not say our trials at “recovery “were unsuccessful for that word is not in my vocabulary in the way that we typically refer to it. Let’s face it, our definitions of “success” need some serious rethinking.

So like the Brittany Spears song goes, CNN, “oops [you] did it again.” You told the world (again) that recovery is possible and thereby suggested that this is what all autistic people and their families *must* do at all costs, and yet our families remain unsupported in all stages of life. You run the risk of sending millions of parents and families into despair if their children do not “recover” in the manner you show and suggest. You endanger about eighty million disabled people in North America with the suggestion that disability is not an acceptable state of being human (not that all disabled people understand autism, this is true, or that all disabled people are in agreement about disability issues). You tell half a story, and it is *not* the story of so many families. There are many stories of great happiness in families out there living with autism as there are stories of “sieges,” and much of life’s success comes from how we regard and deal with things. Stories like this one do not help with the need to be positive when there are many pressures beating upon us.

And believe me, even with all of this, the joy does exist with autism too.

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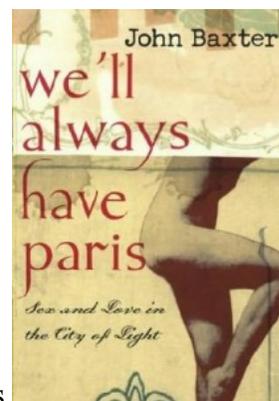
## [Ready, Set, Go!](#)

**Filed Under ([To Get To The Other Side, Writing](#)) by Estee on 07-12-2009**

I hear Adam's cherub voice, *Ready. Set. Go!* in my head as I've returned from Paris with fifty-two pages of something I think is finally good. It's a little more than the weight and size of the limited edition of [Jeanette Winterson's Dog Days](#) when I hold it. I can hear "ready, set go," — that phrase we taught Adam to plunge him into a game or an activity, and I don't forget the sound. Time, people, events happen so quickly and memory is fragile.

Over the past ten years, I've written two books, both incomplete and yearning to come together. At the Humber College for Writers and The University of Toronto, where I've attended writer's conferences in the past, I was told that one's first book takes about seven years to accomplish. Other writers have told me ten to fifteen years, which had me scratching my head at the John Grishams of the world and how on earth could they churn books out so fast. With my extraordinary impatience and harsh self-judgment, a difficult year has introduced me to some gentilité with myself and with others. So please "God," this just *has* to be my year.

Thanks, [John Baxter](#), and his punctual rendezvous *avec moi* in front of *Les Deux Magots*, and *avec Flannerie* along Rue de Bonaparte and Rue Jacob, taught me a little bit more of the Paris that once belonged to Hemingway, Fitzgerald, Joyce, Miller and Gertrude Stein, among some other great literary figures. Thank you for also letting me hold a letter from [Anais Nin to Jean Fanchette](#). I have come to realize why I became a curator but to understand the importance of preservation and memory.



I would recommend anyone out there to read John's memoirs from Paris. He has written a series of that help describe the underbelly of and life in Paris.

It was not difficult to be alone in Paris and John's paragraph caught my eye when I ran across it: "For a woman, Paris is a good city to be alone... Most of the expatriate writers who, since the turn of the century, created our image of the city — Edith Wharton, Jean Rhys, Janet Flanner, Nancy Mitford, Mavis Gallant, Dianne Johnson — were laureates of loneliness, who, even though sometimes married, preferred to live and work by themselves." (page 137, Harper-Perennial edition, 2005.) So here I was, a "ready, set go" decision to go to Paris, meet John, Leda and write. Another "laureate of loneliness," but with no complaints.

Which leads me to also thank profusely, my long-time friend and *pianiste extraordinaire*, Leda Perac, who is another laureate living in Paris. I studied and became great friends with Leda in Germany fifteen years ago in colder, hungrier circumstances, nevertheless playing and singing our way through it all with Tori Amos. This time, having dinner in *Le Châteaubriand* with my face, she noted, visibly drawn from flight-fatigue, and undoubtedly the weight of a difficult year, she presented all of the letters I had sent to her in German when I returned to Canada in 1995 and 1996. Reading them between courses of *poisson* and some flirtatious chitter-chatter between myself and our exceptionally handsome waiter with the beautiful smile, I required her to

translate the some of the very words I had written fifteen years later, to my chagrin. Leda, you helped bring back memories that remind me of who I was, who I am, and maybe more importantly, why I am.

And thank you, Paris. You gave me Adam, love, and fifty-two good pages. I'm ready to really begin.

Vive la présentation et le préservation.

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## **“Relating is an act of life”**

**Filed Under ([To Get To The Other Side, Writing](#)) by Estee on 01-12-2009**

Anais Nin is a woman who is true to herself and true to her writing from a woman's perspective. I hope to visit her house in Louveciennes this week. Perhaps this short portion of the talk is a way for us to think about how true we are to ourselves when we write from where we are, which is hard to do when we hear so many ideas and inherit artistic styles. As I listen to her and write my way through this life as autism mom, single mom, and woman on a her own unique adventure, I am also learning that I have to go “the woman's way:”

### Anais Nin Tribute



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## [Barb, Tim and Annie Farlow and the quest for justice](#)

Filed Under ([Critical Disability Studies](#), [Discrimination](#), [Ethics](#)) by Estee on 30-11-2009

What does the story of a three-month-old baby with Trisomy 13 and her death have to do with the rights of all disabled individuals? It's a question that Barb Farlow and her husband Tim have raised for the past several years, and today, the loss of their court case was featured in [The National Post](#).

I've known Barb for several years and supported her after we shared numerous emails a couple of years ago about her daughter, Annie. Only because of a difficult year in my own life was I unable to support Barb more actively in her quest in 2008. Barb with her husband Tim, have pursued justice for their three-month-old relentlessly. Not only has their struggle symbolized a deep respect for the life of their daughter, but for the rights and dignity of all disabled individuals. They have argued that because Annie had Trisomy 13, hospital staff executed a DNR from a subsequent illness without her parent's permission. The Farlow's, having taken great pains and effort to ask questions and pursue the case, have raised the question about how we value the life of disabled individuals, no matter how severe their disability.

[Noreen Kelly wrote in her piece Crusade for Change:](#)

“Most infants born with Annie’s genetic condition die shortly after birth; few live past the age of 10. Despite these odds, Barbara and her husband Tim decided, after much research and deliberation, that the right thing to do, for them and their family, was to give Annie a chance and to make medical decisions for her in the same way as a child without disabilities. The Farlows were assured that Annie would be treated like any child, and that if surgical considerations arose, they would be discussed and a decision would be arrived at mutually with the physicians.

Annie was born full term and received excellent supportive care at a Canadian hospital for the first several weeks. In August 2005, when she was not yet three months old, she suffered episodic respiratory distress. Annie died within 24 hours of arriving at the hospital. At that time, her parents believed that she would not have survived surgery and that her death was natural.

After obtaining the medical records and discovering the shocking facts of Annie’s last hours, Barbara and Tim Farlow made an exhaustive effort to seek answers and a resolution with the hospital. When this effort failed to yield much beyond an insincere apology and token, ineffective plans, they believed they had no choice but to sue the hospital and two doctors involved. The allegations included practicing a policy of non-treatment for children with certain genetic conditions and secretive euthanasia. Annie’s story is a multi-faceted case including allegations of violation of civil laws of consent and violation of international human rights laws, including the Convention on the Rights of the Child.”

Barb and Tim loved Annie deeply — that is evident from the emails I’ve shared with Barb. As a mother with a special needs child, though, I also feel deeply indebted to her, her family and to Annie as they have helped to raise awareness in hopes that more disabled people everywhere will be granted the same “net worth” as those living without disabilities.

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## [Sweet Dreams](#)

**Filed Under ([Single Parenthood](#)) by Estee on 27-11-2009**

One of the most difficult things about being a single parent is letting go. Not only is it difficult for me to be without Adam some nights, but I do worry so often how he feels about missing mom or dad when he is not with us as we were. I know, many families get divorced and the children do okay. But I am not from a family of divorce and I spend most days wondering how children cope (I had four step-children as well so I was always thinking about how they were coping) and it all leaves me feeling a little melancholy. I hear that families are co-parenting successfully, whatever that really means — some “business” relationship where the couple only speaks about the children. But it’s never the same. That daily interaction where the details we took for granted are often the details that never get discussed. Maybe sometimes for some families it’s better. And for some it’s worse. And for others still, life just goes on and we make it the best we can because families, these days, seem to come in all shapes and sizes.

This song says absolutely everything about how I feel when Adam is not with me, and I do not believe that even as time smooths the hard edges of life that I will ever be used to a house with an empty bed. Thankfully, Adam has a loving family with grandparents and a mom and dad who love him so very much. So at least both mom and dad can hope that Adam will have sweet dreams because he will always know how much we love him:

An evening with The Dixie Chicks - Godsp...



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## [Finding Me in Paris](#)

**Filed Under ([To Get To The Other Side, Writing](#)) by Estee on 25-11-2009**



After listening to *La Vie En Rose*, I booked a last-minute ticket to Paris. I leave next week to meet my girlfriend, Leda, who I became friends with while studying in Europe fifteen years ago. Leda is a pianist and her father is a well-known composer from Zagreb. I mention this because I need my artist friends. I need to be around them like I need food or else the daily ups and downs of markets confines the spirit to downward spirals only waiting for outside influences to send them up again. Art puts everything into perspective and reminds me that it's wonderful to be a part of the human drama. Perhaps because of our foreignness in a foreign country — we were both struggling to be part of German life in a town called Friburg — and because we shared Croatian roots, and maybe just because we both loved music, Tori Amos and lots of laughter, we became good friends.

I met Leda again in Paris while I was married a few years ago. Our visit was too short. My ex was not that interested in listening to our memories, which made me feel pressured to cut my visit short with her as most of us do when we know someone is waiting. Thanks to email and Facebook, I've reconnected with many of my friends and I decided at the last minute to meet her next week.

I don't know if it's part of the divorce process — that bucket list of things we're going to do only because we are not married anymore. Or perhaps it's due to the sheer desperation to find and become something new, someone different, and the best way to begin is with a list. Like a compass, it can point you in any direction. All you have to do is choose.

It's difficult, though, to travel with a child waiting for me at home. A child who knows poignantly when I am not with him, with his few but precious words, I am told, says "mama...mama..." and who is visibly missing me. If Adam only knew the sickness in my stomach that I feel every time I leave him for just a few days. I hate that he misses me or thinks I am gone forever and I worry about it until I'm nauseous. It stopped me from taking many long trips my ex otherwise wanted me to take with him. When your child cannot talk easily with you about his feelings or over the telephone, the worry plummets deeper. So I only booked myself away for five days.

In the earlier days when I knew Leda, when we were younger but not less hopeful, I would have booked several months away under similar circumstances and I would challenge myself even more. It's like teetering on the edge of an old and new life like standing on the Prime Meridian in Greenwich, which I actually did once at The Royal Observatory. Real and imagined, even with five days, I am crossing a line. While I always hate leaving Adam, I still feel a rush of excitement about going to the airport, which despite the relative ease and economy of travel these days, and with delayed flights, packed airports and flaring tempers, still elates me and I might as well be back in the 1950's traveling as far and foreign as Asia. I feel excited watching all the people getting ready to go to their destinations — people who speak different languages. I will fiddle with my bag, dig out my book and sit beside strangers knowing that just one conversation can change a person's life. I love the smell of engine fuel and the sound of them revving before lift-off, the movie selection and bad airplane food and the struggle to sleep because tomorrow will be well underway when I arrive.

As I prepare by launching into a temporary state of transformation, I listen to Parisian music. I have booked a full schedule of concerts, literary walks and dinners with Leda when I arrive. I will bring my journal, put on red lipstick and pearls, and smear my coffee cups and wine goblets with red stains, and find a good pen to buy. I can almost smell the Marlboroughs in the air, and hear the echoes in skinny lane-ways on the Left Bank of lovers

talking and giggling and the sound of my feet behind them like Anais Nin's as the night clears the air. In **Tender is the Night**, F. Scott Fitzgerald describes the phenomenon of people changing and becoming like the environment they visit. While witnessing a group of Americans in Paris he describes them as “undergoing a sea-change, a shifting about of atoms to form the essential molecules of a new people.” Travel, he implies, changes us and I yearn to be changed, if only for a week in time.

I am ready walk out into my life again in my little black dress — of rediscovering myself and perhaps who I will become. And I am discovering myself also as a single parent to my son who, even while schlepping to parent-teacher meetings, Adam's team meetings, O.T., SLP and other like meetings in her Honda, enjoys her red lipstick and Coco Chanel. Discovery is a wonderful thing, and we can be many things to ourselves and to others. But most importantly, the best kind of travel and adventure is the kind where I know I still have Adam to come home to.

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# About Me



## ESTÉE KLAR

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

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### 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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