

## Estée Klar

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## The Autism Acceptance Project Site Has Been Hacked

Filed Under ([Uncategorized](#)) by Estee on 06-03-2012

I'm writing to inform you that [www.taaproject.com](http://www.taaproject.com) (The Autism Acceptance Project website) has been maliciously hacked. We have to take the site down and likely rebuild it.

Please do NOT go to that link. If you do, your computer may be compromised. Share this information. We will also be sending out a newsletter to all of our members as soon as possible.

We apologize for any inconvenience this may cause.

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## Call For Autistic Pride Day Articles

Filed Under ([Advocacy](#), [Inspiration](#), [Writing](#)) by Estee on 01-03-2012

What does [Autistic Pride Day](#) mean to you?

[The Autism Acceptance Project](#) will promote stories from autistic people, family members and others who have an autistic person in their life. If you are interested in writing, please enter your submissions to [esteeklar@rogers.com](mailto:esteeklar@rogers.com).

All submissions will be reviewed by a small panel and will be posted on The Autism Acceptance Project website for **Autistic Pride Day** on **June 18th, 2012**. TAAPProject will also be promoting your stories to the media.

Deadline for submissions: May 15, 2012.

Maximum Words: 1500.

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## [Star Dust](#)

**Filed Under ([Inspiration](#)) by Estee on 27-02-2012**

I have a soft spot for Christopher Plummer. When Adam was a year old, he was mesmerized by the *Sound of Music*. He loved when Captain Von Trapp used the whistle to call for his children and keep them “in line.” I enjoyed Adam’s baby belly laughs every time he heard that whistle scene. For years Adam loved that movie. I think he fell in love with Maria. Most importantly, the songs and lines in that movie were some of Adam’s first words.

So when we spotted Mr. Plummer at the Four Seasons Cafe in Toronto when Adam was nearly three, I couldn’t resist. I’m not the kind of person who goes up to celebrities and asks for the autographs. I don’t like to disturb private lives. As Adam and I were leaving, we walked past Mr. Plummer and his wife who were sitting near the front of the cafe. The thought of missing an opportunity to thank him (for he did not know that Adam was autistic and could not speak) prompted me to turn around with Adam, who would not have recognized the older Plummer as his dear Captain.

“Excuse me, Mr. Plummer?” I approached timidly with Adam by my side.

“Yes!” he said delightedly, his eyes darting up at me who had interrupted a quiet conversation he seemed to be having with his wife. Already I was taken.

“I just want to let you know that my son is a big fan. He watches *The Sound of Music* over and over again.” Mr. Plummer’s face was so gracious. At that point, I could have gone into a little diatribe of how Adam was autistic and how much that movie meant to us, but I didn’t want to take up Mr. Plummer’s precious time.

“Well,” he responded in that well-known dignified voice. “It’s so nice to see that my audience is growing younger and younger.” We both chuckled and I said thank you and goodbye.

Maybe Adam will enjoy that story one day. I sure enjoyed watching Mr. Plummer receiving his well-deserved award with the same graciousness we experienced that afternoon. Little did Mr. Plummer know what a difference he made in Adam’s young life — how the movie taught him some language, music, made him laugh and calmed him nearly every night before bed. I suppose none of us truly realize the sprinkles of star dust we can leave upon each other.

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## [Digging Up](#)

**Filed Under ([Estee](#)) by Estee on 24-02-2012**

William Morris admonished, “Have nothing in your houses that you do not know to be useful, or believe to be beautiful.” Was he ever in a house with kids and a to-do list for an autistic one that seems to run miles ahead of me?

Ugh. I’m obsessed with clutter and yet I’m a secret stasher. My house looks organized, but watch out for those closets and filing cabinets! I like to hang on to everything! As many of you understand, my life is too busy to often think about things, so they get stored. Over the years though, the things in my life grow and gather and I find the closets too full, the toys too plentiful and I’m getting too tense with it all. Even with my autistic child and all the things I have to look ahead and plan for, I want a simpler life!

I look in the basement at all the toys. As is the case for many of our autistic children, baby toys are still comforting. It’s especially hard to toss out the old when, in Adam’s case, it becomes new again. Or for the toys that we were told to purchase when he was in early therapy, I keep thinking that someday, we’ll still get to them. Someone will want to teach him how to use the board games for reciprocal play.

I met [Gretchen Rubin of The Happiness Project](#) at the [Blogger Conference in New York City](#) several years ago. Her idea of living a happy life is de-cluttering our lives. I had to say that the idea of organizing didn’t make me happy, but the idea of having less to worry and think about does. Today, as I confront my office files and piles of Adam’s artwork before I get to his toy area, I’m so tense that I had to take a break and write this post just to avoid it! Why is clearing the clutter so anxiety-provoking? Why am I breathing heavier? Is it the time I know I going to have to invest? Will it take days? Weeks? What of the many lists and projects might I find that I have left undone? If they are to do with Adam, I’ll feel really guilty — the PECS I made, the schedules, the social stories, the other stories I write and leave in unpublished piles. What if I find out that I could have done more for Adam in all those to do lists that were left unchecked?

Ack. It seems I’ll be digging up more than just clutter.

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## [Torontonians: The New Snow Wusses](#)

Filed Under ([Media](#), [Parenting](#), [school](#)) by Estee on 24-02-2012

This will date me. When I went to school, I used to trudge through deep snow. No, I didn't walk three miles like my grandmother did, but there was lots of snow and we weren't afraid of it. During recess, we'd slide down any hill we could find and even forget our snow pants. The teachers didn't make a fuss if we came back into class soaking wet. After school, I walked back home; back through the deep snow, even blowing snow, beating like needles against my face. There were no nannies to wait for me and walk me back like there are in the city now. Parents didn't worry about us being out there in the blowing snow. In their minds, it was good for us to outside almost all day long.

Adam has been home from school all week because of the flu. Finally this morning he woke up jumping. "I'm fine!" he declared as I entered his room. I'm so glad. One problem though: Last night, before any snow fell, I received an email from his school that it might close in case of snow. I was worried this would happen; that he'd be raring to go and get back to school and his friends, and not be able to.

When I was growing up, we never got notices like that. There would have to be five feet of snow outside our door and some severe wind for us to turn on the radio to try and hear if the school was closed. Like all children, I'd wait in anticipation to find out, and if it was, I couldn't wait to get outside and play in it. Now we get an email suggesting the school may be closed if there is snow. The news gets more ratings with impending weather. They scare people like there's a hurricane coming and we all better prepare. "Snowmageddon," it's now called — just a tad alarmist, I think, as I see a single snow flake float by my window.

The street is clear and the snow looks like it is just beginning to fall fairly gently. I'm emailing and calling, trying to get in touch with anyone who might be checking at Adam's school. "Is the school open today? There is no snow," I write.

I know, there's more traffic. When the roads become icy, the roads aren't fun to drive on. Perhaps calling in the army nearly a decade ago in Toronto after a big snow storm made everyone a little more cautious. But still. It's just snow, and we seem afraid to let our children out in it.

Children don't walk to school anymore. They are nannied, day-cared, and car-pooled to school. Let's face it, we don't let our children grow up until they're thirty-five. Granted, I know when we are talking about autistic children, we all know they require more attention for their safety. Autistic adults may also need assistants when they are older. It still doesn't mean we have to baby them, nor do they want to be babied. I think our over-protective parenting and super-cautiousness have negative effects on all of society. Now back to the snow...

The school is even located near the subway, you know those things that Mayor Rob Ford wants more of. That means we can even travel *under* the snow! So doesn't that mean that there is a way to get around after all? They are calling for five, yes five (wow) centimeters of snow in Toronto today. That's a far cry from the five *feet* outside our doorway when I was Adam's age.

I just don't know what has happened to us. Could it be that this is the first real snow of our Toronto winter that we've wimped out? Are we so excited that we have to declare it a city holiday? What happened to us fearless Canadians and the Canadian winter? More importantly, what is all of this doing to our children?

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## [Are You My Mother?](#)

Filed Under ([Autism and Intelligence](#), [Family](#), [Single Parenthood](#)) by Estee on 23-02-2012



“Mommy!” Adam looks into my eyes and says my name as if he’s reassuring himself. It’s as if he’s saying you’re my mommy, *and that is that*.

“Yes, Adam, I’m Mommy.” I say. He’s eyes are glued to mine until I answer him. After I do, he looks relieved and goes back to his business. The look reminds me of that [P.D. Eastman story I used to read Adam over and over again when he was a baby, “Are You My Mother?”](#)

I hear “Mommy” after he’s visited his dad’s house. What could he be thinking, I wonder? Is he confused, as many children are, of the other women in their father’s life? If Adam were a more verbal child, what would be the many questions he’d have of the divorce, and his dad returning to his first ex-wife with whom Adam shares half-siblings? I have experienced such younger “typical” children with many questions. I’ve often wondered if people just carry on as if it’s not confusing for Adam at all because they don’t believe that he understands, or at least has many questions that he can’t articulate? No matter how nice people are to Adam over the years, he will always have questions, and he has the right to have them answered. It’s always better to answer children with the facts rather than emotion or pretense, in ways appropriate to their age. I’m taking the inquisitive “are you my mother?” look he frequently gives me now as something much deeper. I’ve read him children’s books about divorce but I think Adam is beginning to have more questions.

The past few days, Adam has also had the flu. It’s all my fault. I caught a bad one and he got it from me. We’ve been down and out for a week now. I know Adam is really ill when he doesn’t move around much and when he’s not eating, of course. Yesterday, he spent the whole day with me sitting on the couch, and today will be the second day. We watched tv, he played with his iPad and rested. He’s body was close to mine — his way of comfort and reassurance. If I got up to do something, he would grab my arm to stay with him.

As a single mom, I don’t have anyone else to delegate all my responsibilities. Yet the feel of Adam’s overly warm body needing mine for comfort and security is more important to me than any bill or piece of paper sitting on my desk. Those things will have to wait. I could complain, but then I realize that I am the most important person in the world to him right now. I have been his rock, his “constant person.”

That’s right, Adam. I am! *I am* your mother!

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## [The New Technology and Autism Awareness](#)

**Filed Under ([Autism and Intelligence](#), [Autism and Learning](#), [Communication](#), [Development](#), [Uncategorized](#)) by Estee on 15-02-2012**

[This article on technology and autism appeared in The Globe and Mail today.](#)

I'm worried that some people will view it as another autism miracle. Don't get me wrong, I'm ecstatic about the iPad and other technologies and the awareness this brings about autistic intelligence. I have cited the research about the EEG's and FMRI's in previous blog posts where it shows the brains of non verbal individuals with various severe disabilities lighting up like typical brains. In other words, we have evidence that many non verbal individuals can understand what is said to them and have complex thoughts. What was presumed as "functioning at a level of an infant" can no longer be assumed.

I feel compelled to remind readers and hopefuls of a couple of things. The first being that non verbal individuals with various "severe" disabilities (I use quotes because of the way that's been so misunderstood in terms of intelligence), have been using devices for years. Typewriters, computers, Vantage Lites, Lightwriters and more. With Adam, I chose to use the Alphasmart Neo because it was cheap and portable and I could download our conversations onto the computer. Yet all it offered was the chance to practice typing. It did not have the windows and picture symbols of other programs found in expensive devices. Now the iPad provides this.

Many of these devices are so expensive that it is not feasible for many families to obtain them, costing upwards of sixteen thousand Canadian dollars. Repairs can also cost thousands. The advent of devices like the iPad makes communication so much more accessible, although many adults and families can still not afford them. They may, however, be easier to get into their hands through schools and subsidies.

My point is that we've known for a long time that technology is important, and that autistic individuals can communicate with them. It's not a sudden miracle or epiphany, I hope, to realize that autistic people are intelligent, and the community is as diverse as any other, meaning, that levels of ability and intelligence are variable in every group that we are trying to define.

Now to my next point. We can't expect to plunk an iPad into the laps of our children and expect them to know how to communicate with it.

Just over five years ago, I began typing with Adam. I found I had to facilitate him by supporting his lower forearm. If I had not, he would have typed the letters over and over or typed a word he loved. It continues to be a challenge to get him to focus because open-ended communication is very difficult for him. Supporting him did not mean I directed him. I learned by people at the University of Syracuse, and through my own studies, how to support him and apply, in his case, a backward resistance pressure. By actually holding his hand back from the keyboard, he had to type with more force and intention and this seemed to help him complete a sentence. I neutralized his hand in the centre of the keyboard and he went from there.

I received a whole lot of criticism because of the FC controversies back then. I still did not give up. I knew, because Adam could read since eleven months of age, that he was a candidate to become an independent typist and communicator.

Fast forward five years later and we're still at it. I've been observed by many Centres and professionals and I've not known a lot of what Adam types in order to prove that his communication is reliable. I do this by asking him questions or talking about things he did that I would not know. I have to keep my skills in check.

Today, he types somewhat independently. He sends me a short email everyday from school, primarily because they have not been trained in supporting him. If I need to support open-ended communication, my hand is further back on his arm. He will usually say the word or letter now before he types it and he types fast that if I don't slow him down, he may lose sight of what he is trying to write. For communicating wants and needs, Adam can verbalize or type on his own. Give him YouTube, and he'll type whatever he wants — from “water slides,” “Walt Disney,” and “Psychedelic Cartoons.” We recently visited an AAC expert (Augmentative Assistive Communication) and her response to my support was that my method was not very “facilitated,” just some marginal support. Not only that, all the nuanced support I give him all the way down to my patience and energy is difficult to document, but so important in teaching how to use a device for “functional” or “social” communication.

Adam also uses picture symbols on devices. For this, he can communicate mostly on his own, unless he gets distracted or is very anxious. When an autistic person is anxious, communication tends to fall apart. Text to speech functions have enabled him to speak in full sentences.

We are still learning. My point is that I am always learning to be an effective and patient communication partner. Reciprocal, social, open-ended, unpredictable communication is not so easy for him, and many other autistic people like him. While technology is a doorway, we can't just open it without excellent guides, or without the commitment to keep at it for many years, even perhaps when it seems as if we are making little progress. When someone says to me that “Adam doesn't type with me,” I immediately know that there is a lack of training or understanding what being a communication partner really means. It is an affirmation that the expectation and onus falls upon the autistic child — not the parent, therapist or teacher.

My hope is that, in addition to providing much needed resources like communication apps and iPads, we have better understanding and training to engage with autistic people as they are. Adam mostly communicates in metaphor. His language acquisition is unique and different than that of his typical peers. He could read and count by eleven months of age, but he couldn't “talk” to people. Certainly he didn't stop acquiring language or learning after that! As I've watched him over the years, I try to see the way he scaffolds his language and knowledge. His language and way of seeing the world seems mostly associative, symbolic and visual.

The iPad and other accessible technologies are encouraging in so many ways. I hope that the EEGs, FMRI's and the other “proofs” we seem to require from autistic people in order to validate them, also lead to an enthusiastic desire to understand autistic people — their value, humanity, and of course, how they learn.

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## [Google's Valentine](#)

Filed Under ([Inspiration](#), [Joy](#), [Play](#)) by Estee on 14-02-2012

I'm sure you've all seen the Google Valentine co-animated by [Michael Lipman](#). The boy keeps trying to win the girl's heart with things. In the end he does simply by sharing in the same activity with her.

It reminded me of how to engage with our autistic children this day and every day. Sometimes when our children engage in “self-stimulatory behaviour,” we don’t view it as functional so we don’t engage in it ourselves. Without making a big deal of it, try to do it quietly. The less words I use and the more I am with Adam, the more he can be with me. I am always taken aback at out loudly people talk to autistic children in particular, and how often we ask kids to mimic our “normal” behaviour. We need to take time to engage in the activities that make them happy. We also need to do it in order to see the value of our children as autistic people.

It’s cute. Enjoy it, and have a great Valentines Day, every day, with those you love.

### Valentine's Day Google Doodle



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## [The Colour of Love](#)

Filed Under ([Family](#), [Inspiration](#)) by Estee on 13-02-2012



I love colour. After my separation and divorce, the colours I picked for our home were all grey. As first couple of years separation passed, and then meeting someone very special and having lots of friends and laughter in our home, I've been picking more colour. Every piece of new fabric is like another step towards feeling comfortable here, another step towards creating our unique family. I write a lot about home because to me it is symbolic (or I should go into interior design). When Adam and I moved here, I found three four leaf clovers on the property. While I was a little superstitious before, I now really believe in omens.

Recently we've been fixing our kitchen and doing a bit of re-decorating, managing to fix things, making the house more ours than the previous owners. It was my decision to put our whole selves here because it's the only way to grow. I decided we can't live life half-way, waiting for it to happen to us. As I add fabric — purples, yellows, vibrant ochres and the yellows I saw in Sri Lanka, I feel more relaxed. Adam burrows himself under the lavender blanket by the window on the new couch, or sits and reads his books and he looks so, well, at home. Someone said to me that choosing colour because I'm happier, and they are right. Adam, of course, picks up on this. We are growing our roots again.

Two years ago, Valentines Day, Adam and I had to leave the home that sadly caught fire last year, ironically also in February. It was a home we had built ourselves. I felt awful because it was still the home Adam later visited his father after I moved out. Adam did a lot of crying and spasming when he had to make the move. In the past several months, I drove Adam past the other house, which is still standing, and Adam wanted to go in. When I explained that he no longer lived there any more, he didn't fuss. He knows his home is here now. I felt, though, that I owed him some gentle explanations and drive-bys — everytime we went near after the fire, he would crank his neck out the back seat window of my car to try and see his "old" home across the park or down the street. I felt awful not letting him back initially, but I had to make sure he would be able to handle it.

I think about that move and how hard it was on Adam, and on me. Our home now is a place where love thrives and I thank those who are close to us for bringing it back into our lives.

Happy Valentines Day.

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## [Back Seat Driver](#)

Filed Under ([Adam](#), [Autistic Self Advocacy](#)) by Estee on 11-02-2012



“This way!” Adam says firmly from the backseat of our car. He points to the direction he wants me to turn as he declares it. It’s not always safe for me to see where he’s pointing while I’m driving. I am asking him to tell me whether to go left, right or straight.

He’s usually directing me to the local grocery store he prefers. He likes to go almost every day after school. I’ve turned my grocery shopping into a daily routine, and generally buy only what we need for dinner that evening. It is not only turning into an exercise in frugality — buying only what we need — but one where Adam now shops for himself.

Adam was getting a little fixed on the one grocery store, so I mixed it up — Loblaws, Brunos, the “big store,” the “little store,” and the “dollar store.” I decided to shake it up a bit when Adam got fixed on Ginger Bread cookies at Brunos. Adam would need to buy a ginger-bread cookie, preferring to look at it rather than eat it. Once our cupboard was getting full of Gingerbread Snowmen, Christmas Trees and Stars of David, I had to ask myself what I was going to do with them all — make a house out of them or just say no. I ended up doing both. He soon tired of the cookies, thank goodness, and moved to the deli section, picking tender pieces of steak, big lean hamburgers and veal schnitzels. From there, he’s moved to different stores.

We don’t always need something from the grocery store, of course, so I’m finding other things to do. I realize that Adam, while he seems to be a little foodie, also just likes doing something after school before he goes home. We can go out to dinner, he goes skiing once a week — he loves that. He needs the outside world. He’s so anxious to take a bite, and his explorations seem to begin with a routine.

“That way,” he points. He’s leading me toward the little store. No matter where I am on the road, he knows the direction. Sometimes he even just wants to drive around. Sometimes I don’t feel like it.

“We’re going home now,” I say. He whines in protest.

“That way!” he insists.

“It’s time to go home,” I say with a melodic voice laced with an *I’m-not-flinching* tone. I hear his red, goose-down-filled arm shuffle, pointing. He looks like the 1960’s kid who can’t move in the snowsuit.

“This way,” he says pointing to the left. I turn my head and our eyes mirror defiance.

“Home time,” I say, keeping it clear. I’m holding my breath hoping that my simplicity will help avoid crying or whining. Sometimes Adam gets upset, although his protests are generally abating as he I notice he’s beginning to learn how to negotiate with me. If I say it’s dinner time, he may tell me what he wants to eat instead of being fixed on going to a store. “We’re going home now.”

“Pizza!” he demands.

“Okay, Adam, tonight you can have pizza.” Well, he can if it’s only once a week.

He’ll accept more, but I do often give Adam a lot of choice, especially if he has decided to “dance” with me and negotiates for what he wants (in fact, I’m thrilled about it). I do want Adam to take a bite out of the world and savour it. I do want him to learn how to negotiate, and he seems to be learning it all on his own.

I suppose I don’t mind having him as my bossy little back seat driver right now. In fact, I remember the days when I longed for him to boss me around — to talk to me. I’m even at the stage when I’m demanding a *please* and *thank-you* from him. Metaphorically he’s no longer in the back seat. He’s pushing his way, as he should, right up to the front.

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## [Judith Snow at the ROM \(closes March 4th\)](#)

Filed Under ([Advocacy](#), [Art](#), [Inclusion](#)) by Estee on 09-02-2012



### **Who’s Drawing the Lines: The Journey of Judith Snow**

#### **A celebration of an artist’s triumph over perceptions of disability**

Opening August 20, 2011, the Royal Ontario Museum (ROM) presents *Who’s Drawing the Lines: The Journey of Judith Snow*. This intimate exhibition explores paintings by Snow, a quadriplegic artist and world leader on inclusion issues for people labeled as disabled. *Who’s Drawing the Lines* reveals how, through her unique way of creating art, Snow overcame a lifetime of perceived limitations to express “all that is in [her] heart”. Featuring over 20 works by Snow and several by another artist in her Toronto guild, the exhibition confronts common perceptions of disability and illustrates the artist’s emancipation from these stereotypes to honour her physical, intellectual and emotional diversity. *Who’s Drawing the Lines: The Journey of Judith Snow* is on display in the Hilary and Galen Weston Wing, Level 2 until January 20, 2012.

“Who’s Drawing the Lines is the most recent in a series of ROM displays illuminating contemporary issues that affect the community at large,” said Janet Carding, ROM Director and CEO. “Exhibitions such as *Out from Under* in 2008, and last year’s *House Calls with my Camera* shine a spotlight on diverse aspects of society and expand our understanding of the human condition. I know visitors will be moved by Judith Snow’s personal journey and motivated to help her create a world where we all celebrate our differences instead of being defined by them.”

### **About the Exhibition:**

*Who’s Drawing the Lines*, showcases 27 paintings—23 by Snow and four by Felicia Galati, a fellow artist in the Laser Eagles Art Guild, an initiative founded by Snow to offer individuals with limited physical mobility the opportunity for self expression through art. Many of the paintings reflect Snow’s innovative approach to art-making: she has used a head-controlled laser to indicate selections, and currently works with a “tracker”, a person who follows her spoken or gestural directions in order to express her emotions and create these artworks. Captioned videos and photos in the exhibition also depict the various artistic techniques used by members of the Laser Eagles and contextualize Snow’s personal journey to become an artist and social innovator.

The ROM has created several accessibility initiatives complementing the exhibition. All label text is amplified to a larger font and is placed lower on the walls to be easily viewed by visitors using mobility aids. For visitors who are blind or who have vision loss, a tactile book accompanying the exhibition is available incorporating Braille, large print text and graphic raised-line drawings. Also available is a descriptive audio recording interpreting seven of the key art pieces presented in the exhibition, creating a visual image for those who would not otherwise be able to experience the art. An interpretive pamphlet summarizing the exhibition’s themes and content is available in person and online for all visitors. For more information on accessibility at the ROM, visit [www.rom.on.ca/visit/access/index.php](http://www.rom.on.ca/visit/access/index.php).

### **About the Artist:**

“Inclusion is about the willingness to take a unique difference and develop it as a gift to others. It is not about disability.” ~ Judith Snow

Judith A. Snow, MA (York University, Toronto, 1976) is a social inventor and a builder of inclusive communities that welcome the participation of a wide diversity of people. She is also a visual artist and the Founding Director of Laser Eagles Art Guild. Snow is known for championing inclusive education, support circles, individualized personal assistance, person-directed planning and facilitated art. Born in Oshawa, Ontario in 1949, Snow was diagnosed as being quadriplegic at seven months of age. At age 12 she made her first sketch while at a rehabilitation centre. However, her artistic talents were not nurtured until, at age 55, Judith found a way to paint. This led to the liberation of her passionate expression—in art and in life. Since then she has experienced the dichotomy of being seen by many as severely disabled and by others as being a fully contributing citizen and inspiring leader. For more information about the Laser Eagles Art Guild, visit [www.lasereagles.net/pages/default.asp](http://www.lasereagles.net/pages/default.asp).

### **Other Links Regarding Judith Snow and Her Work:**

[The Judith Snow Foundation](#)

[The Toronto Star](#)

[“Creating What I Know About Community.” Article for Inclusion Network by Judith Snow](#)

[“The Quiet Voice” by Judith Snow](#)

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## [Belly Laughing](#)

**Filed Under ([Joy](#)) by Estee on 08-02-2012**

I had electricians in my house today as I finish fixing my kitchen. While they were doing their work I was fooling around on Facebook. There's a new map application that let's us mark where we are visiting. Seeing as how I made my first visit to the east recently, I wanted to gain some satisfaction by looking at my jaunts like red pins on paper. The blank white spaces in Africa and Russia reminded me how much more there is to see and learn. The white spaces felt like hope and possibility. As the last outlet was installed, I sighed at the continents.

If I get those calendars that list the countries and their codes, I have to put a check mark where I've been. With this new Facebook app, I was writing down all the places I've visited and lived until I received a message. "Wow you travel fast," it said. "Are you Santa Claus?" I clicked back to my "wall." I realized that the app posted every place I've visited as someplace I was *currently* in. "Estee Klar is in South Carolina. Estee Klar is in Freiburg." The list was long and I realized that all my friends were receiving these endless messages on the "home" page. It appeared that I had traveled from Alaska to Sri Lanka in one day. How embarrassing, but it's such a *me* thing to do.

I've made a vow to myself not take these minor stories for granted. So tonight, I was telling it to my boyfriend. Adam was sitting in between us before his bed time. I was laughing so hard at my own "joke" that I couldn't even tell the story to him clearly. Adam thought this was hilarious.

"Laugh!" he exclaimed as I managed to get out the first two words. "Laugh. Laugh!" he said giggling at me, leaning his whole body in my lap. He looked into my eyes and laughed harder and we fueled each other until I was breathless. This was a good moment for him. He's at that age when he makes himself laugh endlessly just so he can keep on feeling good. I remember when I did the same thing.

After the fact, I have to wonder how many times Adam gets to see his mother come undone in such a happy way. It's nice to be okay with my "mistakes" and laughing at myself for it, even if I need some Facebook lessons. It's even better when Adam laughs with me.

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## [Everyday Is A Work of Art](#)

**Filed Under ([Art](#), [Inspiration](#), [Joy](#)) by Estee on 07-02-2012**

**Tagged Under :** [Joy](#)



I have a favorite non-autism blog right now. It's by friend/artist Carla Lipkin called [A Water Colour A Day](#). I love Carla's work (and she's a lovely person too). The blog is a work of art — you must check it out.

It got me thinking of how another friend of mine, years ago when Poloroids were the rage, took pictures of herself every day the year before she turned fifty. On her fiftieth birthday, she put them all up and they made an exceptional piece. Blogging and journaling can be art too. The watercolour above is something I did a couple of months ago really quickly. I used to paint all the time while I was taking art studio and art history. Now it seems my duties as mother have taken precedence over the projects I really love doing. I have to ask myself why this has happened?

Looking at Carla's blog made me think about the importance of the everyday. For some of us, we like to document it. We really do take the small stuff for granted. Adam also has artistic ability. Wouldn't it be fun to make a little time every day to document something of our lives, no matter how seemingly trivial or small. At the end of the year these little things add up. Besides, isn't every life a work of art?

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## [Autistic Pride Day](#)

Filed Under ([Uncategorized](#)) by Estee on 06-02-2012

Tagged Under : [Autistic Self Advocacy](#)



A year ago during Gay Pride Day, I had posted that we should organize something for Autistic Pride Day. Well, I'm beginning to hear from a group of Ontarians interested in doing it here in Toronto. If you are interested, please contact me at [esteeklar@rogers.com](mailto:esteeklar@rogers.com).

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## [Guilty Or Not Guilty? Is That The Question?](#)

**Filed Under ([Travel](#)) by Estee on 02-02-2012**

As I begin to come out of my jet-lagged delirium from my thirty hour flight from Sri Lanka, I can talk more about my trip. I realized that yesterday when I was answering a friend's questions about it. As I talk, the thoughts crystallize. It is only now that I'm beginning to realize that I was on the other half of the world; only now that I realize how much I miss it and want to see more.

“You can do it again,” said my friend, shifting her briefcase from one hand to the other at the doorway. I am sitting waiting for Adam to finish his O.T. session. She is also an occupational therapist who worked with Adam for several years, but I regard her as a friend since I've known her for so long. I suddenly felt a quiver inside my belly, a sick feeling. I realized, as I heard Adam laughing in the next room, that I longed to go back as much as I long to hear that laughter. When I travel, I long to be back with Adam. Later at home, I found myself googling “mother's guilt over taking vacations.”

I'm pretty good at dealing with mother-guilt, that is, I can put things in perspective. Adam's father and I discussed Adam going to Disney with him to break up the time I was going to be away. On the one hand, I was a bit sad that I wasn't able to see Adam's reactions to his first visit, yet on the other, I did not want to deprive Adam of the opportunity. I have to be honest — it, in part, appeased my guilt and anxiety over leaving him. While I was away, I was so happy to see beaming pictures of Adam there. Apparently Adam had some difficulty adjusting to the hotel room, but he loved the rides. It is but one of the issues arising from moving houses especially since the divorce — Adam's issues with his environments really started at this time.

While at a place called Ulpotha in Sri Lanka, there were two European children running around. They had arrived after a visit to Israel, where their mother was from. Ulpotha is a yoga retreat in the jungle run by the villagers. The parents were hired to manage the guests for six weeks (Ulpotha is only open to the public for a small part of the year). I watched the children play freely, despite the poisonous snakes and other creatures. They were having a ball and socialized with the guests. I had wished and wondered about whether Adam could make the trip. What would living with monkeys and villagers who take care of this self-sustaining village be able to provide for him, I thought?

I can't say that I wasn't having some “the rice patty is greener on the other side” moments. What would getting away from the pressures and superficialities of Western life teach Adam? What would cultivating food and housing and belonging to a community provide for us? I kept thinking of the isolated box we live in back home, and how neighbours rarely talk to each other, and felt dismayed. What kind of community do we really have, I ask myself as an adult who in part continues to perpetuate the kind of city I live in. While we have our conveniences, I believe all of us feel this lack. I kept wondering about my own ability to live in such circumstances and felt in awe of Rupert Isaacson, the author of [Horseboy](#), who traveled all the way to Mongolia with his autistic son, Rowan.

I did have moments of longing for Adam more when I saw the children, as much as I knew that I deserved and needed my time away. When one of the parent’s asked why I didn’t bring Adam, I didn’t want to get into a lengthy explanation about parent schedules or how such a short trip would make it difficult to travel with him as an autistic person. Traveling across the globe with him would require more practice on longer flights, breaking up the journey and longer stays in each location. The diet is different too, so it would take a lot of preparation.

So I guess there are a couple of issues here: imagining some future travel with Adam in order to expand our experience, and feeling guilty or even guilty for not feeling guilty. Perhaps there are so many lessons for me to learn for myself and the way I live, and in my efforts to create a meaningful life with Adam.

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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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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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