

North American Inclusion Month

NAIM

BUILDING AN INCLUSIVE JEWISH COMMUNITY

WELCOME TO HOLLAND

"I am often asked to describe the experience of raising a child with a disability- to try to help people who have not shared that unique experience to understand it, to imagine how it would feel. It's like this..."

"When you're going to have a baby, it's like planning a fabulous vacation trip- to Italy. You buy a bunch of guidebooks and make your wonderful plans. The Coliseum, Michelangelo's David, the gondolas in Venice. You may learn some handy phrases in Italian. It's all very exciting.

"After months of eager anticipation, the day finally arrives. You pack your bags, and off you go. Several hours later, the plane lands. The stewardess comes in and says, 'Welcome to Holland.'"

'Holland?!? You say. 'What do you mean, Holland? I signed up for Italy! I'm supposed to be in Italy. All my life I've dreamed of going to Italy.'

"But there's been a change in the flight plan. They've landed in Holland and there you must stay.

"The important thing is that they haven't taken you to a horrible, disgusting, filthy place, full of pestilence, famine and disease. It's just a different place.

"So you must go out and buy new guidebooks. And you must learn a whole new language. And you will meet a whole new group of people you would have never met.

"It's just a different place. It's slower-paced than Italy, less flashy than Italy. But after you've been there for a while and you catch your breath, you look around, and you begin to notice that Holland has windmills, Holland has tulips, Holland even has Rembrandts.

"But everyone you know is busy coming and going from Italy, and they're all bragging about what a wonderful time they had there. And for the rest of your life, you will say, 'Yes, that's where I was supposed to go. That's what I had planned.'

"The pain of that loss will never, ever, ever go away because the loss of that dream is a very significant loss.

"But if you spend your life mourning the fact that you didn't get to Italy, you may never be free to enjoy the very special, the very lovely things about Holland."



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Holland Schmolland

By Laura Krueger Crawford

If you have a child with autism, which I do, and if you troll the internet for information, which I have done, you will come across a certain inspirational analogy. It goes like this: Imagine that you are planning a trip to Italy. You read all the latest travel books, you consult with friends about what to pack, and you develop an elaborate itinerary for your glorious trip. The day arrives. You board the plane and settle in with your in-flight magazine, dreaming of trattorias, gondola rides and gelato.

However, when the plane lands, you discover, much to your surprise, you are not in Italy—you are in Holland. You are greatly dismayed at this abrupt and unexpected change in plans. You rant and rave to the travel agency, but it does no good. You are stuck. After a while, you are tired of fighting and begin to look at what Holland has to offer. You notice the beautiful tulips, the kindly people in the wooden shoes, the French fries and mayonnaise, and you think, “This isn’t exactly what I planned, but it’s not so bad. It’s just different.” Having a child with autism is supposed to be like this – not any worse than having a typical child—just different.

When I read that, my son was almost three, completely non-verbal and was hitting me over a hundred times a day. While I appreciated the intention of the story, I couldn’t help but think, are they kidding? We are not in some peaceful countryside dotted with windmills. We are in a country under siege—dodging bombs, trying to board overloaded helicopters, bring officials—all while thinking, what happened to our beautiful life?

That was 5 years ago. My son is now 8 and though we have come to accept that he will always have autism, we no longer feel like citizens of a battle torn nation. WITH the help of countless dedicated therapists and teachers, biological interventions, an enormously supportive family, my son has become a fun-loving, affectionate boy with many endearing qualities and skills. In the process we’ve created our own country, with its own unique traditions and customs.

It’s not a war zone, but it’s still not Holland. Let’s call it Schmolland.



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In Schmolland, it is perfectly customary to lick walls, rub cold pieces of metal across your mouth and line up all your toys end to end. You can show affection by giving a “pointy chin.” A “pointy chin” is when you act like you are going to hug someone and just when you are really close, you jam your chin into the other persons shoulder. For the person giving the “pointy chin” this feels really good, for the receiver no so much, but you get used to it. For citizens of Schmolland, it is quite normal to repeat lines from videos to express emotion. If you are sad, you can look downcast and say “Oh Pongo.” When mad or anxious, you might shout, “Snow can’t me!” or “Duchess, kittens, come on!” sometimes, “And now your feature presentation” says it all. In Schmolland, there’s not a lot to do, so our citizens find amusement wherever they can. Bouncing on the couch for hours, methodically pulling feathers out of down pillows, and laughing hysterically in bed at 4:00 am, are all traditional Scmutch pastimes.

The hard part about living in our country is dealing with people from other countries. We try to assimilate ourselves and mimic their customs, but we aren’t always successful. It’s perfectly understandable that an 8 year old boy from Schmolland would steal a train from a toddler at the Thomas the Tank Engine Train Table at Barnes and Noble. But this is clearly not understandable or acceptable in other countries, and so we must drag our 8 year old out of the store kicking and screaming while all the customers look on with stark, pitying stares. But we ignore these looks and focus on the exit sign because we are a proud people. Where we live, it is not surprising when an 8 year old boy reaches for the fleshy part of a woman’s upper torso and says, “Don’t we touch boodoo?” We simply say “No, we don’t touch boodoo” and go on about our business. It’s a bit more startling in other countries, however, and can cause all sorts of cross-cultural misunderstandings. And, though most foreigners can get a drop of water on their pants and still carry on, this is intolerable to certain citizens in Schmolland who insist that the pants must come off no matter where they are, and regardless of whether another pair of pants are present.



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Other families who are affected by autism, are familiar and comforting to us, yet are still separate entities. Together we make up a federation of countries, kind of like Scandinavia. Like a person from Denmark talking with a person from Norway (or in our case someone from Schmenmark talking with someone from Schmorway), we share enough similarities in our language and customs to understand each other, but conversation inevitably highlight the diversity of our traditions. Oh your child is a runner? Mine won't go to the bathroom without asking permissions. "My child can't stand to hear the word no. We can't use any negatives at all in our house." We finally had to lock up the VCR because my son was obsessed with the rewind button."

There is one thing we all agree on: we are a growing population. 10 years ago, 1 in 10,000 children had autism. Today the rate is approximately 1 in 250.

Something is dreadfully wrong. Though the causes of the increase are still being hotly debated, a number of parents and professionals believe genetic pre-disposition has collided with too many environment insults—toxins, chemicals, antibiotics, vaccines—to create immunological chaos in the nervous systems of developing children. One medical journalist speculated that these children are like the proverbial canary in the coal mine here to alert us to the growing dangers in our environment. While this is certainly not a view shared by all in the autism community, it feels true to me.

I hope that researchers discover the magic bullet we all so desperately crave. And I will never stop investigating new treatments and therapies that might help my son. But more and more my priorities are shifting from what could be to what is. I look around at this country my family has created, with all its unique customs, and it feels like home. For us, any time spent "nation-building" is time well spent.



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Questions for Welcome to Holland

- 1) What is the message of this article?
- 2) What do you think the authors feelings on having a child with a disability are?
- 3) Do you think the author's child with a disability is "high" functioning or "low" functioning?
- 4) Do you feel like the author is painting an accurate picture of raising a child with a disability?
- 5) Have you ever been surprised and disappointed in your life, and discovered that it turned out the best? Share and discuss with the group
- 6) Do you think this is a good metaphor for raising a child with a disability? Why or why not?
- 7) This article talks about the power of a positive attitude, do you think this is fair to expect?

Questions for Holland Schmolland

- 1) Why do you think the author chose to write this 'in response' to Welcome to Holland?
- 2) What do you think the authors feelings on having a child with a disability are?
- 3) What is the author's message to the rest of the world is?
- 4) What does the author want us to take away from reading this story?
- 5) How do these pieces relate to the message of NAIM: North American Inclusion Month?



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