Interview with Thomas McKean

By Diane Kalning

How have things changed with regard to how autism is viewed from when you were a child?

Things have definitely changed. Autism is better understood. Or at the very least it is more accepted. The public is far more aware of autism, there are a lot more therapies (not all of them valid, unfortunately), and we have an autism awareness month in April, which I personally had a part in creating.

Children are being diagnosed much earlier than when I was young. This is good because early intervention is the best therapy for autism. I wasn't diagnosed until I was 14 (this was in the 70's and that was common back then), and by then a lot of opportunity had already come and gone.

But the changes aren't all good. Autism is far more prevalent nowadays. Back when I was with the ASA in the early and mid nineties, it was 1 in 20 some thousand. The latest stats I have heard are 1 in 150.

There are many more debates now as well. Is autism genetic? Environmental? Is it caused by vaccines? The vaccine debate is particularly difficult because it has been proven and disproven so many times that there is no way to really know what to believe. So people form an opinion and stick with it, right or wrong. This has led to fights and hard feelings and the end of relationships.

What was your childhood like? Did your family understand autism?

My family was unaware of the autism until I was into my 20's. No one ever told them about it. Why the doctors never told my parents, I don't know. They just said I was "developmentally delayed."

What is the one thing that you wish more people knew about autism?

That a lot of what you see on the internet with people who claim to have autism is a very distorted and unrealistic view of what autism really is.

You can spot these people by the absolute pride they have in their condition. They say autism is the best thing ever and some of them even say it places above the general population and makes them better or superior in some way.

I have no problem with having a bit of pride in who you are. Self-esteem is a very good and necessary thing. But at the same time, you can't go attacking parents because they are doing a particular therapy for their children. You can't tell someone you don't know and have never met that they are a bad parent for doing ABA or some other therapy. That's just wrong.

What are three myths about people who have autism which are absolutely untrue?

1. Statistics say 70% of people with autism are mentally retarded, usually within the mild to moderate range. My experience is this is not true. I have met many people with autism, even the non-verbal ones, who obviously have a great intelligence.

2. People with autism do not have emotions or do not form attachments. Any parent can tell you this is just not true.

3. There is also a misconception that all people with autism have savant abilities. My understanding is about 20% of people with autism are savant, which is about the same amount of people with autism who have a seizure disorder. (The seizure disorder of autism will usually appear during adolescence.)

What is your personal definition of autism?

I don't know that I have one. There seem to be two schools of thought on this. Some believe it is more cognitive whereas others believe it is more sensory. My own definition would have to lean more towards the sensory.

What are some of the early signs of autism that parents and caregivers should watch out for?

There are many signs to look for.

The child does not respond to his/her name.
The child cannot explain what he/she wants.
Language skills or speech are delayed.
The child doesn't follow directions.
At times, the child seems to be deaf.
The child seems to hear sometimes, but not others.
The child doesn't point or wave bye-bye.
The child used to say a few words or babble, but now he/she doesn't.
The child throws intense or violent tantrums.
The child has odd movement patterns.
The child is hyperactive, uncooperative, or oppositional.
The child doesn't know how to play with toys.
The child doesn't smile when smiled at.
The child has poor eye contact.
The child gets "stuck" on things over and over and can't move on to other things.
The child seems to prefer to play alone.
The child gets things for him/herself only.
The child is very independent for his/her age.
The child does things "early" compared to other children.

The child seems to be in his/her “own world.”
The child seems to tune people out.
The child is not interested in other children.
The child walks on his/her toes.
The child shows unusual attachments to toys, objects, or schedules.
Child spends a lot of time lining things up or putting things in a certain order.

Keep in mind that having a few of these symptoms does not necessarily mean there is autism. Only a qualified doctor can make that diagnosis.

Is there a difference between Autism and Asperger's Syndrome?

Yes. But the difference is purely political.

What would you say is the most difficult challenge of having autism?

For me personally, the most difficult challenge would be the sensory problems. There is more about this on my site, mentioned below.

What is the best thing about having autism?

I don't know that there is one? *Blink*

What would you like to tell parents and families who have just found out their child has autism?

I would say there are four first steps to take.

1) Go to the library and start reading. But be very careful about what you choose to read. Check the copyright dates and don't get anything too old or you could do more harm to your child than good. Autobiographies may be an exception to this as a life story is never outdated. (This means for me that one of my books is outdated and one of them isn’t!)

2) Find a local autism support group. Whatever issues you are dealing with, chances are someone else has already been there and can give you advice on how to deal with them. You are not alone.

3) Attend conferences and seminars. This is the best way to get new information and to network with others.

4) Have you child evaluated and treated by an occupational therapist trained and certified in sensory integration. My own opinion is this is one of the very best things you can do for your child when you first receive a diagnosis.

Any last thoughts or ideas you would like to add?

Yes. Over the past few years, autism has become a very political disorder. I have found this distracts from the therapies and support needed to treat those who have it and this troubles me. The politics of autism have also created a very hostile environment on the internet. There are many autism support sites on the internet that are more about fighting and arguing than they are about support. Wrong Planet, Aspies for Freedom, and even the Autism Speaks (or should I say *especially* the Autism Speaks) forums are examples of this.

This has bothered me enough that I have created my own autism support site for parents, professionals, and individuals with autism. There is no fighting, only support. This site is what an autism site should be. We have active forums, an active live chat (secure and safe, unlike many other chats), an arcade with over 400 games, and other features. I do not allow the kind of bullying that goes on at other autism sites on the internet. Anyone who is frustrated by the bullying on the net when they are trying to find support is welcome to join us. I am very active on this site. The address is:

http://www.neurointegrity.com/

Or you can visit my personal web site here:

http://www.thomasamckean.com/

Thank you, Thomas!