

## Interview with Sam (Part 2)

Contributed by Gayle Nobel  
Tuesday, 26 May 2009  
Last Updated Thursday, 28 May 2009

Here's where we left off in Part 1 of my interview with Sam, a young man who has Aspergers. You can read Part 1 in the archives by scrolling down to the bottom of this blog section.

Me: What's the best part of having Aspergers?

Sam: You get to be different, I wouldn't consider myself boring.

Erin: There are very few times when the three of us are together that we don't laugh ourselves silly.

Sam: There have been a lot of very intelligent people that are on the spectrum. Albert Einstein, Thomas Edison and Benjamin Franklin all qualify now. We could throw around names all day. We could throw Bill Gates in there. It's really just a different way of looking at things, I guess you could say. Tony Atwood said it's the Aspies who keep humanity interesting. We're the ones that add flavor to humanity. Being sensitive to noise isn't necessarily a bad thing.

Me: We all are to some degree.

Sam: I don't know if you've ever read anything by Tony Atwood. In his book called "The Complete Guide to Aspergers Syndrome," he tells this story about a little boy who had to get on a train on a regular basis and he managed to tell his family twenty minutes before the train got there. When he was asked how he knew, he said could hear the sound and could feel the vibrations in his tummy. So it's not necessarily a bad sense.

Me: Do you think Tony Atwood is pretty on target about what he says about Aspergers?

Sam: I haven't read a lot by him but what I have has been very eye opening. I have one of his books at home. It was very helpful to me as far as understanding who I am and why I am the way I am.

Me: What are your quirks?

Sam: I do stim a little bit in case you haven't noticed. My legs shake, I do various things with my hands and I love the smell of paper and the feel of rubbing it between my fingers. Somebody was saying it's not a matter of whether or not the activity itself is so strange; it's a matter of degree. As far as strange interests, I like collecting old radio programs and shows. I enjoy listening to them and collecting them. I like to read and classic movies.

Me: So do you like to talk about the movies.

Sam: Yes , I love to.

Me (to Erin): Do you find it interesting?

Erin: Yes, I like the fact that they're not anything I have experience with.

Me: You sound like you're in a really good place about yourself? Is there anything you are working on that you would want to change about you?

Sam: The only thing I would want to change is the living situation. That's really it, to be honest. I'm not the type who would cry about being on the autism spectrum. If people can't accept somebody for who they are, it's their own fault. Especially in this day and age where there's a lot of information out there about Aspergers. I've run into my share of people who saw how I was and wouldn't really accept that. The reason I don't go out is that one night the group I was with didn't know how to read my face or thought I was lying. People with Aspergers, even when they're honest, all have a liar's face. We're known to be brutally honest to the point of being a fault.

Me: What do you think when you hear about the movement to cure autism or "fix" people with autism?

Sam: People that really try will actually pass themselves off as non-autistic and that's actually to their own emotional detriment. That's why I think the suicide rate is so high. These people are being inundated with cure autism, cure autism, cure autism. Nobody is really approaching them with the idea that we accept these children as they are.

Erin: Do you think these kids know that they have autism or is it just they know that they're different, they know something's difficult and they know that they can't connect, and that is why they want to kill themselves?

Sam: Yes, that's very true. I wanted to kill myself when I was 10, and it popped up again at 12 and 14. It's just that there was really nothing out there for me. There were no friends and nothing to help me get plugged in without having to pass off as normal. When we talk about cure we can end up producing an atmosphere where people on the spectrum are pressured to be something they're not. I think it's to everybody's best interest to learn how to embrace each other and not try to cure each other and make room for everybody.

Me: Do you think a lot of people with Aspergers feel the same way?

Sam: Yes. Alex Plank started a website for people on the autism spectrum called wrongplanet.net. He got tired of not having anything out there for people on the spectrum so he created his own internet community, and now it's got 3000 members. There's also the autistic self advocacy network and it's definitely not pro-cure. Its attitude is "nothing about us, without us." The videos the president puts out say "anti-cure, doesn't have to mean, anti-progress." I don't want it to sound like anybody's rejecting the idea of treatment.

Me: For my son, my goal is to help him be the best he can be, and we keep going toward that.

Sam: Have you ever watched the movie "Autism, The Musical." It's a documentary of five people putting on a musical about autism. The father comes out and talks about the different stages he had to go through with his child, and they are actually similar to the stages of losing a loved one. First you want to fix it; it's a natural first stage, but you have to move on. As the years went on, it wasn't happening, and he became depressed. As he moved through his depression, he learned to accept his child. Once he learned how to accept his child and how to love the child. I sometimes suspect when I see parents of autistic children on TV, they might be fixated on the first stage.

Me: What would you advise parents?

Sam: Encourage them to love their child for who they are and allow themselves to actually grieve the loss of their dreams.

Me: Where do you see yourself in the future?

Sam: I would like to be living on my own. I don't want to get married. I want to keep my job, work my way up and get better schooling. I might go back to school, but only if it's a good school for accommodating special needs. I may get help from SARRC for assisted housing.

A final thought : Sam wishes his parents would learn more about autism.

