

My Diagnosis with Autism (Asperger's Syndrome)

The first time I ever heard of Autism was at a Saturday recreation program for retarded children. "Retarded" was the word we used then. I think I was about 12 or so and I volunteered at the program partly because my sister went there. Terry was about a year older than me and had Down Syndrome. She would probably be considered low to moderate functioning-- semi-verbal, needs support for basic self care. "Trainable" was one of the old-fashioned words that was often used to describe her level of functioning back then.

I liked to go there to play with the "retarded" kids. One of the kids there never seemed to play with the others. He mostly sat by himself wearing a football helmet. I asked and was told that he was autistic and that he had to wear the helmet because he sometimes bashed his head on the floor. To me, he looked like he wanted to play so I went over about 7 feet away from him and sat on the floor. I rolled a basketball toward him. He rolled it back. We kept playing this way until the end of the day when his parents came to pick him up. They spoke to the adult counselors for some time and I noticed that they were crying. After they left, I asked the counselors what they were crying about. I was concerned that I had done something wrong. The counselors told me not to worry about it. They said the parents were crying because they were happy to see their son playing with somebody. They hadn't ever seen that before.

At the time, it made me feel kind of special. This kid interacted with me when he wouldn't interact with anyone else. But the experience also gave me a sort of terror of autism. He seemed so lonely and he was denied some of the most basic of freedoms for fear that he would hurt himself.

That was in the mid-seventies. Asperger's was not in the DSM yet. My parents knew there was something different (wrong?) with me but nobody imagined that it was related to autism. After all, I was smart. I could read and talk and I didn't bash my head on the floor. They provided me with an excellent counselor whose diagnosis was that I was a "genius". She did some excellent therapy with me (mainly CBT) to try to help some of my social difficulties and she recommended that I be placed in a special school for smart kids. The teachers there may not have known about Asperger's Syndrome but they had lots of experience with "genius" kids and most of them understood that many of us were pretty weird and needed more social support than academic support. The program was great for me but it only lasted for the 7th and 8th grade. The school figured that by the time we were in high school we could just take more advanced classes and we no longer needed the special school. This was a mistake.

I ended up dropping out of high school part way into my junior year. My parents desperately wanted me to go to college but I hated high school so much I just

couldn't do it. They finally told me that they didn't care if I graduated from high school as long as I went to college. I didn't particularly want to go to college but I was willing to do anything to get out of high school. So off I went to college.

When I got to college it was wonderful. They gave me lots of tests and when they found out that I already knew something (English, Biology) they gave me credit for it and didn't make me take the class. Instead they gave me classes that really challenged me. I loved it. I also got good social support in college. At my father's insistence, I pledged a fraternity. It was not a group that was known for academics. In fact, their charter was in some danger on the basis of their low cumulative GPA. They needed my straight A's and I needed their social support. I remember taking my books with me to parties. When I got overwhelmed with the party I would retreat to a corner and study for a while. Nobody dared to tease me about it or bother me when I retreated because my fraternity brothers would have beaten them up if they had.

I never considered the possibility of autism until my son was diagnosed with Asperger's Syndrome. We tried to find an appropriate diagnosis for my son for many years and nothing seemed to fit. The idea of High Functioning Autism was new to me and I was very resistant to it because, in my own mind, autistics were still people who didn't talk, never looked at faces, and bashed their heads on the floor. I had to learn a lot more about autism before I was willing to accept that my son was autistic.

Once I accepted his diagnosis, I had to face my own. I knew about the highly genetic nature of Asperger's Syndrome (80-90% depending on the study.) I knew his genes had to come from somewhere and it certainly wasn't from my wife. Still, I told myself for quite a while that my symptoms were mild enough that they did not rise to the level of being "diagnosable". After all, I was a functional adult. I had a wife, a job, a family. I was a respected member of the community. How could I be autistic?

And yet, my autistic symptoms regularly had a profound impact on my "major life functions." I have almost lost my job a number of times over my clothing and my sandals. I can't wear shoes and the clothing that most people associate with "professionalism" is intolerable to me. While I like academia I really don't have much other choice because colleges are one of the few places that have a high tolerance for eccentricity. My family and I pay dearly for that tolerance in the form of far lower pay than my education and abilities would be worth in the private market. I make irrationally long car trips for conferences because I can't face the crowds, noise, and disrespectful treatment that are part of air travel. This list could go on and on.

Having a diagnosis has helped my marriage therapist to more effectively work

with me and my wife. Learning about autism has made it easier for both of us to understand each other. It has also helped my family to accept certain things about me and their support has taken forms that are much more likely to actually be of help.

It has also made it easier to advocate for my needs at work. I can better explain why I need things to be a certain way and I now have the provisions of the ADA to protect me from being fired on the basis of my disability. A request from me is no longer "Ramon being a pain in the ass again. Can't he ever just follow the same rules as everybody else?" These requests are now "reasonable accommodations, in accordance with the provisions of Americans with Disabilities Act."

My diagnosis has also made it possible for me to get a certified service dog. I had an emotional support dog (otherwise known as a pet) for many years and I relied on him to help me calm down and get control of my emotions and my anxieties. But, as a pet, I could only make use of this at home. Now that I have a service dog, I can take her with me anywhere I go. She makes it possible for me to function in public at a much lower cost, both emotionally and in terms of anxiety.

I have described my diagnosis as I personally experienced it. I should point out that my son's diagnoses did not really precede mine. According to my wife and our therapist, it was the realization that I was autistic that led to considering whether that might be the issue with my son. They did not tell me about it at the time. They correctly surmised that I was not ready to hear it yet. I really needed to come to it slowly on my own as I gradually replaced my prejudice with knowledge in my effort to understand my son.

I now think that I had more in common with that autistic kid in the Saturday recreation program than any of us realized at the time. I think I was able to empathize with his needs better than many other people because his needs were not so different from my own. I didn't need for him to look at me or acknowledge me in some way before I initiated our ball game. Other people always tried to get his attention first before they did anything else. Failing that, they never did anything else. I just assumed I had his attention and went on from there.

Autistic minds and Neurotypical minds really do work in different ways. And, while I can simulate Neurotypical behavior somewhat, when I really have to, it is achieved more through intellectual effort than through instinct. And, it rapidly exhausts me to do so. People often say that we autistics lack Theory of Mind. What I truly have difficulty with is Theory of Neurotypical Mind. I'm pretty good with Theory of Autistic Mind. Most Neurotypicals that I know (with the exception of some truly amazing parents of autistic children) suffer from a profound lack of

Theory of Autistic Mind.

I think it was my instinctive Theory of Autistic Mind that allowed me to connect with that autistic kid at the recreation program. And, even though he was more severely autistic than me, I also believe that he had sufficient Theory of Autistic Mind that he truly connected with me.

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