

“Growing up in a Family with Autism”

It has taken me two years to write this article. Two years ago, my family and I went through a huge transformation. Two years ago my brother--at the age of 50--received a diagnosis of High Functioning Autism (HFA). Up until his diagnosis, he had grown up with the label “learning disability.” When Sam was diagnosed with HFA, I went through what I call a mini-mourning period. I had mixed feelings of shock, disbelief and sadness. My brother was no longer someone with a learning disability, but someone with Autism! I now realize that my mother was also on the Spectrum (but that is another story for another time).

As a result, I have spent the last two years revisiting my entire childhood, because the childhood I thought I had, disappeared and was replaced by a mom and a brother who were on the Spectrum. I now recognize that there are three cousins on my mom’s side who are also very quirky and different, and if not actually on the Spectrum, have some of the characteristics of someone on the Spectrum. Resolving this disconnect has helped me so much in my relationship with my brother. I have always admired my brother for his quiet dignity and perseverance through the enormous challenges he has faced in his lifetime. He is intellectually my superior, and one of the most generous and thoughtful people I know. His diagnosis of HFA has allowed me to become much more accepting of his unique perspective on life. And yet, I can still become uncomfortable sometimes when he says or does something that might be construed by others as sarcastic or lacking in empathy.

Growing up, my brother had severe speech, language and communication delays. He was nonverbal for the first few years of his life, and would wander off in stores. Whenever we went shopping, my mother would put a “child leash” on my brother as he was very inconsistent in attending to his name.” In fact we called him “Sammy boy,” because my mom told me that this tended to help my brother “hear” his name. When Sam did begin speaking, my parents and I were the only ones who understood him. I was his

translator until he was nine. Even after that, unfamiliar adults had trouble understanding Sam much of the time. It’s hard for me to know what Sam “sounded” like when he talked, because I understood everything he said, even as others couldn’t. When I look back, I realize that we didn’t engage in true back-and-forth conversation. We played games together that I initiated, or I would tell him stories and he passively sat and listened.

Academic learning was an absolute nightmare for my brother. His frustration and anger grew as he watched everyone else around him learn to read and socially interact so easily and effortlessly. After he was given his label of learning disability, he was placed in the one-size-fits-all special education room that existed back then. There he stayed until high school when he transferred to a vocational-technical high school and trained to become a machinist.

In retrospect, I believe not having the label of Autism as a child may actually have benefited Sam, in that, my dad had the same expectations for him as he did for me. We were both expected to clean our rooms, get up for school and do homework. The routine of homework for me was that I would go in my bedroom and close the door. Sam’s homework routine was very different. Every evening my dad would say, “Sam it’s time to read.” Sam would begin to yell, “No, I don’t want to.” My dad would then have to drag my screaming and kicking brother to their reading spot, and Sam would have to read a Dr. Seuss-type book over and over again. I agree with Temple Grandin that expectations should be placed on all children. We need to assume that all children can learn and THEN see what they can do by themselves and what they need help with. My brother is a living example of this philosophy. Sam was a non-reader until middle school. My dad saw his son as a child who was capable of learning, but needed support to achieve academic success. My brother is now an avid reader who loves to read science fiction books.

I have really had to work out my emotions regarding my childhood as an adult. I remember feeling embarrassed about my brother’s

not fitting in, and also very sad at watching him struggle to learn academically and to fit in socially. I was an early talker and language came very easily to me. I often felt guilty that speaking, reading and socially fitting in were so easy for me, and so hard for Sam. I used to pray for God to take away some of my reading ability and to give it to my brother. To this day, I feel very guilty about being embarrassed of my brother as a teenager, especially when I was with friends. But I also remember the moments that my parents and I were so proud and excited for Sam, e.g., when he passed his written and road driving test and got his license! This was a huge victory and celebration for Sam. Sam had wanted to take the oral test, but my dad insisted that Sam first take the written test and only if he didn’t pass, would he then take the oral test. Sam was SO PROUD when he passed the written test the first time!

Sam and I had a very intense and competitive relationship with each other from about 3rd grade on. He was very volatile as a child, and could become very violent when enraged. I wasn’t always safe around him. My friends never really interacted with Sam, as he was so quiet and socially awkward; conversations were usually very short and not repeated. I had to watch others, including my friends, give Sam the “what’s wrong with you” look and it was so painful every time it happened. It still is.

I am fortunate in that as Sam got older, his ability to communicate with language improved. Now as an adult, he is employed full time, drives and has a social network through ABOARD. Receiving the diagnosis of HFA has boosted his self-esteem immensely. He loves meeting other adults on the Spectrum, and knows that he is indeed a very bright, intelligent person who happens to perceive life differently, and THAT’S OKAY. My brother and I are now extremely close and are both involved in the ABOARD-sponsored adult social group for adults 18 years + with HFA/Asperger’s.

It’s interesting how our life experiences impact our career choices. I now know

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that growing up watching my brother struggle to succeed academically and socially, shaped my decision to become a Speech-Language Pathologist. I never thought about it at the time: when I looked over the curriculum for Communication Sciences and Disorders, I felt like I had come home! In graduate school, I had no idea that I would end up specializing in providing language intervention for children with ASD. It just sort of happened late in my career after I moved to Pittsburgh from Arizona in 2001. I took a job at The Children’s Institute, and for the first time, was seeing a significant number of children on the Spectrum. That’s when everything “clicked” and I realized that this is what I was meant to be doing!

As an adult and a speech-language pathologist, I am very empathetic with the families who have children or siblings on the spectrum. I am passionate and dedicated to helping children like my brother have easier days than he did, and empower them to believe in themselves. I don’t believe that I would understand children with ASD the

way that I do if I had not grown up with my brother and my mom. Although I am definitely a sister to Sam, I have also taken on a semi-parental role with him since my mom passed away. I am very fortunate that my husband is unbelievably supportive and understanding. Together we helped find a training program for Sam and got him hooked up with the Office of Vocational Rehabilitation (OVR) where he found a job through *Life’s Work*. I also helped get him involved with social groups until we found the current group for adults on the Spectrum who are High Functioning or have Asperger’s.

Another positive that came out of Sam being recognized as having Autism was my dad and I set up an estate trust fund for Sam. We have been able to ensure that housing, income and a caregiver will still be there for Sam, in the event we’re not around. We are very lucky in that we have extended family members who are willing to take on the role of caregivers in a worst case scenario.

My brother will continue to live with my dad. For a few months after his diagnosis I

grieved over the fact that Sam probably wasn’t going to move out and live on his own, get married and have a family (this is the disconnect that I spoke about earlier—because none of these things would have happened anyway, but somehow the denial allowed my dad and I not to have to deal with it). I now completely accept that my husband and I will be the caregivers for my brother when my dad is no longer around; I am now very comfortable with the reality.

I’ve always believed that things happen for a reason. My brother (and my mom) have given me the unbelievable gifts of compassion, tolerance, and having the luxury of being able to step out of the “box” that all of us neurotypicals live in, and to appreciate and enjoy the different world that “out of the box” thinkers like my brother live in every day of their lives.

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