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I Am Asperger Syndrome

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October 7th, 2009

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Will you think of me differently after you read the next sentence?

I have Asperger Syndrome.

While I just got the diagnosis, this means I've had the condition all my life. It's not a huge surprise. My son was diagnosed with Asperger Syndrome in 1997 and my wife, Julie, and I have often spoken about my having "Asperger-like" behaviors. In 2003, I left a long corporate career to work with Julie in a family business making videos about Asperger Syndrome and autism.

At Julie's urging, I finally went through an evaluation process and recently received the Asperger Syndrome diagnosis. For me, it's a positive step. It helps me understand tendencies that have been a mystery my whole life, and gives me (and Julie) insights we can use going forward. The evaluation wasn't just about how I am now. It was also a review of how I'd felt and acted and reacted throughout my life.

My diagnosis helps explain countless memories such as, "the theater incident." When I was little, my father took my sister and me to a Disney movie at our local theater. I got up and went to the bathroom. When I tried to return to my seat, an usher stopped me and told me the show was sold out and there were no more seats. All I had to do was tell him I had a seat and had just gone to the bathroom. Instead, I walked home by myself. What kept me from speaking up? I never understood until now.

Asperger Syndrome has offered me inconsistencies and paradoxes. Growing up, why was I comfortable speaking in front of a group of people, but often tongue-tied when I tried to make small talk with someone I'd just met? Why could I remember lines and scenes from books and movies in encyclopedic detail, but have difficulty remembering people's names? Why did I need to take detailed notes when a teacher or boss gave me an assignment?

Then there's the empathy thing. I often hear people say that people with autism and Asperger Syndrome lack empathy. I didn't lack empathy. I often felt deeply for other people, but didn't know the right way to express those feelings. After getting burned for

expressing things inappropriately, I learned to pull back and study other people to learn how to act. I learned to listen.

Shortly after I got my diagnosis, I happened to be looking at my high school yearbook. I was struck by the number of people who wrote in that book what a good friend and good listener I was. And I remembered how often in junior high I felt embarrassed that I'd acted inappropriately, and how hard I studied other people and tried to do the right thing in high school. I was not naturally intuitive about other people's feelings, but I learned to read people. And my improving social skills helped me succeed in other areas. Starting as a goofy high school freshman, I progressed to being editor of the school paper and the master of ceremonies for all school assemblies my senior year.

My awkward experiences made me more empathetic. When I worked in corporations, I often attended business social events where people would stand in groups talking. My radar was always up for people who would walk into the room and stand by themselves. I felt compelled to approach these people and bring them into a conversation. I remembered how painful it was to stand apart waiting to be included.

I think wanting to be included has something to do with my work ethic. When I was a television writer/producer/director for AT&T, one of the cameramen I frequently hired said to me, "You work harder than anyone I know."

I hadn't thought about it that way. He was talking about the fact that I spent long hours planning every detail of a video shoot to ensure it would go right. I think now that when I was young, I saw working hard and excelling as a solution to some of the awkwardness caused by Asperger Syndrome. If you excel, you can make yourself into someone other people want to greet and talk to when you walk into a room. You don't have to include yourself if you can make other people want to include you.

As a kid, I was also affected by reading about runner Glenn Cunningham. When Cunningham was eight years old, his legs were horribly burned in a fire that killed his brother. All the flesh was seared from his knees and shins and he lost all the toes on his left foot. His doctors doubted he would ever walk normally again and recommended his legs be amputated. He begged his parents so hard for his legs that they refused to allow the amputation. It took Cunningham two years to learn to walk again. Then he started running. During the 1930's, he set new world records seven times in one mile and 1500 meter length races.

This made a lasting impression on me. Have a limitation? Work hard to compensate. Sometimes you can surpass people who didn't have the limitation in the first place.

Of course, hard work is not always enough. I was fortunate enough to be able to continuously improve my social awareness. Many people with Asperger Syndrome have a harder time with this than I did. That's where educating others can help them meet people with Asperger Syndrome half-way.

It's partly about fighting the label thing. Asperger Syndrome is considered a form of autism.

When many people hear the word “autism,” they mentally label you and put you in a category that falls outside the bounds of “normal.” It often involves feelings of sympathy or shame and can cause fear or avoidance.

I think we can trace these reactions back to a time when people believed acting odd or different meant you were being punished by God. That caused families to deny the differences and sometimes hide their relatives away. Who’d want to associate with or do business with or marry into a family that was on the wrong side of God?

Years after the age of enlightenment, many families still feel shame and some won’t admit to themselves they have a child or relative on the autism spectrum. Other people use what little they understand (or misunderstand) about autism to exclude autistic people from those they’d hire or want to date or have anything in common with.

I’ll admit that when my wife suggested I get evaluated, the effect that getting a diagnosis of Asperger Syndrome could have if I ever decided to apply for a job with a corporation again crossed my mind. Didn’t stop me, but it did cross my mind.

When I think of the misconceptions about people on the autism spectrum, and the discrimination that many of us face, I think of an episode of the sitcom, “Designing Women.” Julia Sugarbaker, played by Dixie Carter, was defending her eccentric aunt, Bernice, played by Alice Ghostley. As I recall, Julia delivered this comeback to someone who’d made a disparaging remark about Bernice’s odd behavior, “No one in the South asks if you have crazy people in your family, we just ask what side they’re on!”

What Julia was really saying was that she loved and accepted Bernice for who she was. There was no reason to be ashamed of her aunt or make fun of her or hide her from the world.

She was also throwing back into the person’s face that everyone has some connection to people who are different, but not everyone feels the need to hide it.

As I write this, I’m looking at an Associated Press story in which the U.S. Centers for Disease Control cite new studies that reveal one child in 110 has an autism spectrum disorder. This includes children diagnosed with Asperger Syndrome.

I think of this as “six degrees of Asperger Syndrome.” It’s the notion that none of us has to look far to find a connection to Asperger Syndrome. When I mention that my business is making videos supporting people with Asperger Syndrome, I frequently hear reactions that begin, “my nephew” or “my grandson” or “my neighbor’s brother” or “my boss’s daughter.”

I like to think that as much as hearing about my Asperger Syndrome diagnosis may define me in some people’s eyes, I can also help define Asperger Syndrome.

People with Asperger Syndrome can be as different from each other in their abilities, limitations and challenges as people who don’t have Asperger Syndrome. But in the range of what’s possible, from my experience, Asperger Syndrome is something you can have and be a disc jockey, television weatherman, national media spokesperson, corporate vice president and business owner. You can have a great wife and great kids. You can be happy.

I’m still the person I always was, and now we know that person has Asperger Syndrome.

I hope I can help people see that there's no real dividing line between "normal" people and "different" people. We can all be on the same side. Aunt Bernice and I are already here.

Join us.

ABOUT THE AUTHOR -- Dan Coulter is the producer of the DVD "Asperger Syndrome at Work," which is scheduled for release in late October, 2009. You can find more articles on his website:www.coultervideo.com [7].

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