

What I Have Learned About Autism from Autistic People

By Brenda Smith Myles, PhD



Although I may have initially learned through journals and discussions with family members, almost everything that I know that is meaningful about autism has come directly from autistic people. I've observed. I've listened. I've asked questions, when appropriate. It is that straightforward.

What have autistic people taught me?

1. Autistic people are not broken.

Autistics have a neurology that responds in specific ways to the environment. Unique sensory experiences, learning style, and challenges in self-regulation are related to the autism neurology.

2. Theory of mind goes both ways.

We neuromajority² people have always thought - erroneously, I might add - that we had the corner on the theory of mind market. That is, we were convinced that the way we think and the way we interpret events, actions, and thoughts of others was absolutely correct. We thought that autistic people had it wrong. However, theory of mind goes both ways. We all have a theory of mind, and each theory can be as valid

as another. It is important that we understand each others' theory!

3. Autistic people have empathy. If cursing in an article were allowed, I might insert a colorful word or two here. Autistic people have empathy. I would further posit that many of the autistic people I know are very empathetic. In fact, I would describe some of my autistic friends as being overly empathetic. A "lack" of empathy often comes from a lack of understanding and having different life experiences. And we all want to understand each other. I have a friend with autism who broke her arm and did not experience much pain; when I broke her arm, she was surprised to hear that I was in severely hurt. Similarly, another autistic friend had "minor" surgery that left her in so much pain that she needed very strong medication. I had the same surgery several months before and experienced no pain. So, it can be difficult for neuromajority people to understand the autistic experience and vice versa. It has nothing to do with empathy. Autistic people can be tremendously empathetic.

4. Nothing is really obvious. I've spent some time talking about the importance of ensuring that autistic people understand the hidden curriculum - the unwritten rules and expectations that are often unclear to autistic people. I have (finally) realized that the items that fall under the hidden curriculum are often poorly worded, misleading, and sometimes a bit funny. An example can be found on an actual sign found in a community bathroom: "Toilet out of order, please use floor below." The sign really means to use the restroom located on the next floor/story down - but is that what the sign *really* says? Thank you, Judy Endow, for calling this to my attention.

5. Autistic people accommodate more than the neuromajority. We neuromajority folk talk about all of the accommodations that we make for autistic people, and we are proud of this fact. We talk about it a lot: we've reduced the number of problems; we've posted a visual schedule; we've lowered the television volume. Aren't we great neuromajority people for

doing this? We never stop to think about how much autistic people accommodate us. The world is not built for the autistic neurology. From the moment autistics get out of bed in the morning to the time they go back to bed at night, they are continuously adjusting to us. They accommodate for (a) how we present information (verbally vs visually); (b) how much loudness and light is in the classroom; (c) how we use nonliteral words to explain ideas and situations; and (d) so many, numerous unanticipated changes. Think about it. People with a different neurology (that can make life challenging) accommodate for the neuromajority all of the time - and they seek no accolades. Autistic people simply do it!



What have autistic people taught me? To be a better human being.

6. Autistic people have limitless potential (thank you to Lee Stickle who first used this term with me). Most innovations have occurred as a result of people who think differently or because of people who have inspired others to think differently. Unfortunately, most autistic people have not been provided the support to reach this potential. Whose fault is this? We in the neuromajority must shoulder the burden for this. That is, if we teach and support autistic people the way they need and deserve ... if we structure the environment in a way that is consistent with the autistic neurology -- think of the accomplishments that the world would experience.

What have autistic people taught me? To be a better human being. ■

REFERENCE

¹ The term "neuromajority" is used throughout this article instead of the often-used term "neurotypical" as, I believe, there is nothing typical about people known as neurotypicals. There just seems to be more of them - hence the term "neuromajority". Thanks to Judy Endow for sharing this wisdom with me.



The Autism Digest is pleased to introduce in this issue Brenda Smith Myles, Ph.D., who has contributed two incredible pieces. Dr. Myles is one of two of the most prolific productive applied researchers in ASD in the world. Her expanded biography is printed at the end of her second piece "Prediction and the Autistic Brain."