What IHave Learned From Individuals on the Spectrum

Brenda Smith Myles, Ph.D

I have known thousands of individuals on the spectrum over the last 30 years. I have made more than 3,000 presentations worldwide and have authored more than 300 articles and books on autism spectrum disorder (ASD). However, anything meaningful and insightful that I have learned about autism has come from an individual living with autism spectrum disorder. Initially I may have learned from journals, direct observations and discussion with family members, but it was ultimately the validation of my learning by individuals with ASD that has shaped all that I do.

To learn about autism, I listened and asked questions when I could. It is that simple.

What have individuals with ASD taught me?



Individuals with autism are not hroken.

People with autism have a neurology that responds in specific ways to the environment, or in other words, their nervous system functions differently. They have unique sensory experiences, a variety of learning styles, and challenges in self-regulation. These are all related to the autism neurology. In many outdated therapies and mindsets, the goal was to "fix" autism. In reality, there is nothing to be repaired. Individuals with autism simply see the world from a different, often inspiring, point of view. We can help children by giving them the best tools to help them with their challenges and trying to see the world from their point of view.

Many neurotypical individuals thought – erroneously, I might add – that we had cornered the market on the theory of mind. In other words, we were convinced that the way a neurotypical individual thinks and interprets events, actions and thoughts was absolutely correct. Expressing affection is one area where this can be seen. A parent might want to express affection by giving hugs and cuddling, but a child with autism might express affection by being helpful, or being in a parent's vicinity. Why can't society view these as expressions of affection? Theory of mind goes both ways, and is valid for all.

The theory of mind goes both ways.





Individuals with autism are empathetic.

Autistic people have empathy. In fact, many of the autistic people I know are very empathetic. I would describe some of my autistic friends as being overly empathetic. A lack of empathy often comes from a lack of understanding. We all want to understand each other. I have a friend with autism who broke her arm but did not experience much pain from the injury. She was surprised to hear that when I had previously suffered a broken arm, I was in severe pain. It was important for each of us to understand that although we had broken arms in common, our experiences were different. This is where empathy is derived — from understanding another person's experience. As it related to autism, it can be difficult for neurotypical individuals to understand the autistic experience and vice versa. I have learned that individuals with autism do have empathy. In fact, they often understand the experiences of others far better than a neurotypical individual understands the autistic experience.

In many of my lectures, presentations and books, I have spent some time talking about the importance of ensuring that individuals on the spectrum understand the hidden curriculum. These are the unwritten rules and expectations that are often unclear to people with autism. I have finally realized that the items covered by the hidden curriculum are often poorly worded, misleading, and sometimes amusing. For example, the following is wording on an actual sign found in a bathroom: "Toilet out of order, please use floor below." The sign *really* means to use the restroom located on the next floor or story down. But is that what the sign really says? I appreciate my friend, Judy Endow, for bringing this to my attention. Is it up to people with autism to understand hidden meanings, or is it up to those without autism to be more obvious?

Nothing is really obvious.





We constantly talk about the accommodations that we make for people on the spectrum, and we are proud of this fact. For example, we posted a visual schedule and we lowered the television volume. Have you ever stopped, however, to think about how accommodating individuals with autism are? From the time we get out of bed in the morning to the time we go back to bed at night, individuals with autism are adjusting to a neurotypical world. Among other things, they have to deal with the following: how we present information (verbally vs visually); how much loudness and light are needed in the classroom; how we use nonliteral words to explain things; and numerous unanticipated changes. People with autism make life-challenging accommodations all the time without complaint. I am in awe of the kindness shown.

Most innovation has occurred because of the efforts of people who think differently, or of people who have inspired others to think differently. It is up to all of us to provide our children with the support needed to reach their full potential. Think of all that autistic people could accomplish to make this world a better place.

Individuals with autism have limitless potential.



So what have individuals with autism taught me? They have taught me to be a better human being.



Brenda Smith Myles, Ph.D, formerly, a professor in the Department of Special Education at the University of Kansas, is the recipient of the Autism Society of America's Outstanding Professional Award, the Princeton Fellowship Award, The Global and Regional Asperger Syndrome (GRASP) Divine Neurotypical Award, American Academy of Pediatrics Autism Champion, and two-time recipient of the Council for Exceptional Children Burton Blatt Humanitarian Award.

She served as the editor of Intervention in School and Clinic, the third largest journal in special education and has been a member of the editorial board of several journals, including Focus on Autism and Other Developmental Disabilities, Remedial and Special Education, and Autism: The International Journal of Research. Brenda is a prolific writer on the topic of ASD. In addition, she collaborated with the National Professional Center on Autism Spectrum Disorders, National Autism Center, and the Centers for Medicare and Medicaid Services — organizations that identified evidence-based practices for individuals with autism. Further, in the latest survey conducted by the University of Texas, she was acknowledged as the second most productive applied researcher in ASD in the world.

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