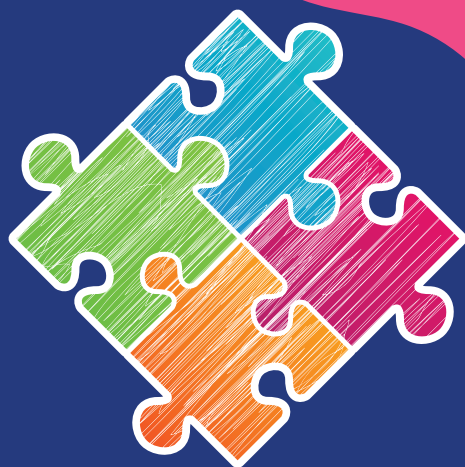


What I Have Learned About Autism from Autistic People

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."



PREDICTION AND THE AUTISTIC BRAIN

By Brenda Smith Myles, PhD

Imagine not being able to predict what is going to happen next. What would you do? Most likely you would:

- Cling to the activities and events that are familiar to you;
- Decide not to willingly try new ventures;
- Experience anxiety and/or behavior challenges when you are *merely introduced to the possibility* to participate in new events or activities;
- Protest, refuse, or meltdown when forced to engage in a new activity or event;
- Feel overwhelmed by the possibility to actually have to change.

The Neuromajority¹ and the Autistic Neurology

How important is prediction in daily life? Research suggests that even **before** activities and events occur, people know or can largely estimate what is likely to happen. This is known as “external prediction.” People also estimate their chance of success even before they attempt an activity or event, which is called “internal prediction.” The ability to predict guides us toward tasks and problems we are likely to solve, and it steers us away from those that might be too difficult.

Peter Vermeulen writes in his book, *Autism and the Predictive Brain: Absolute Thinking in a Relative World* (2023) contending that “prediction is neurologically based.” He explains that the way people experience the world comes from within. Brains sense in advance what they will see, hear, touch, smell, taste and feel. In fact, the brain actually can create a model of what is expected.

The autistic neurology, however, does not know how to predict (Vermeulen, 2023).

Autistic people experience challenges in knowing what will happen next. Often, they cannot anticipate how they are to react; and many do not have a sense

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that they will be successful. Indeed, they generally anticipate the opposite: confusion and failure.

Sinha et al. (2014) shares this quote about prediction, equating it to magic:

An essential component of a magical phenomenon is the lack of a discernible cause: An event that we are unable to predict happens “as if by magic.” Given how well-honed our predictive abilities are, magicians have to resort to clever contrivances to achieve their mystifying effects. However, if our predictive abilities were somehow to be compromised, then even mundane occurrences in the environment might appear magical. Although a brief magical performance is enjoyable, unrelenting immersion in it can be overwhelming. A magical world suggests lack of control and impairs one’s ability to take preparatory actions. (p. 15220)

Indeed, an inability to predict means that the autistic individual cannot prepare for upcoming events and activities, so he might feel as if he has no control over their environment. In the above, substitute the word “terror” for “magical” and we might begin to understand why autistic people cling to sameness, do not like change, and consider surprises as negative. It explains why many autistics experience meltdowns.

Samples of Interventions that Support Predictability

How do we make the world more predictable? We start by understanding the importance of prediction in the autistic neurology. Then, we provide supports that create predictability. The following briefly describes some of

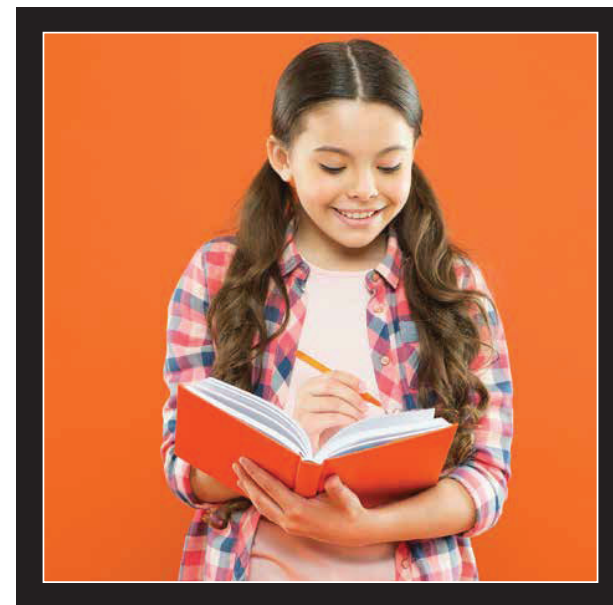
the supports that can make the world more predictable and how to teach predictability.

Visual Supports: The autistic brain learns and processes information best when it is visual. Hence, visual supports help create predictability in a manner that is consistent with the autistic neurology. Visual schedules, posted rules, routine cards, voice volume scale, problem solving charts, and visual boundaries’ markers each create predictability.

Priming: Priming is an intervention that introduces information or activities prior to their use. Almost every adult

primes themselves on a daily basis. Each time an individual looks at their planner, agenda or calendar the evening or morning before an activity, they are engaging in priming! Priming for autistic students includes reviewing the visual schedule as well as the actual materials that will be used in a lesson the day before or the morning before the activity. In some cases, priming may occur right before the activity, such as when a peer mentor overviews what will occur during the science experiment just prior to science class. It is most effective when it is built in as a part of the student’s routine.

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Priming should occur in an environment that is relaxing. The mood of the primer (the person doing the priming) should be patient and encouraging. The priming sessions should be short. Materials should merely be introduced; priming is *not* teaching, correcting, or testing. Priming is a relatively easy and time-efficient strategy that helps to create predictability while reducing stress and anxiety.

Social narratives: Social narratives are briefly written paragraphs that provide support and instruction for autistics by describing environments, social cues, the individual's perspective, and the actions of others; also, discussing potential responses to behavior, events and activities; while providing rationale and encouragement.

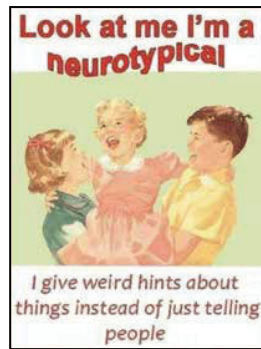
Written by educators or parents at the individual's instructional level, and often using pictures or photographs to confirm the content, social narratives can promote self-awareness, self-calming, and self-management as well

as predictability (Myles, Trautman, & Schelvan, 2013). Samples of social narratives include: (a) *Social Stories™* (Gray, 2016), (b) descriptive stories, (c) scripts, (d) the Power Card Strategy (Gagnon & Myles (2016), and (e) conversation starters.

Hidden curriculum: Every environment has a hidden curriculum – the unwritten rules, expectations, assumptions, the do's or don'ts that are not spelled out but that everyone somehow knows (LaVoie 1994; Myles, Endow, & Mayfield, 2013). The hidden curriculum includes idioms, metaphors, slang, multiple meaning words, nonliteral phrases, pleasing behaviors, whom to interact with and whom to stay away from, behaviors that attract negative or positive attention and more. Understanding the hidden curriculum can make a huge difference in the lives of autistic people: it can help create predictability, facilitate success, reduce anxiety, and help develop friendships.

Many words, phrases, rules, and

guidelines used by the neuromajority are tricky and sometimes seem nonsensical to autistics. The neuromajority are definitely not literal. For many autistic people, hidden curriculum items are problematic – their meaning is not clear, and the curriculum is not taught, because they are assumed or expected knowledge. The following figures provide a brief insight into the hidden curriculum and why it is difficult for autistic people to understand.



Direct instruction is required. Teaching one hidden curriculum item per day can be life-changing for many autistics. Teaching the hidden curriculum is strongest when context (Vermeulen, 2012) and prediction (Vermeulen, 2023) are included in instruction.

For example, when teaching the hidden curriculum item, state that "Acceptable slang that may be used with your peers (e.g., dawg, phat) may not be acceptable when interacting with adults." Ask learners (a) where and when this item may be true or false (context) and (b) what would happen if slang were used with a principal, police officer, college admissions officer, or human resources officer conducting an interview (prediction).

Summary

The autistic neurology thrives on predictability; yet the autistic doesn't know how to create or identify predictability. In short, the world was not constructed to be compatible with the autistic brain. Thus, it is incumbent on the neuromajority¹ to facilitate the introduction of predictability into the lives of autistic people. This can be done in myriad ways, including (a) visual supports, (b) priming, (c) social narratives, and (d) the hidden curriculum. Using these methods and others can help autistics reach their limitless potential (Lee Stickle, *Personal Communication*, 2015). ■



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 the journal *Intervention in School and Clinic* and has been a member of the editorial board of several journals. Brenda has made over 3000 presentations all over the world and written more than 300 articles and books on ASD. She also collaborated with the three organizations who identified evidenced based practices in autism. 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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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.

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