Nonverbal Behavior and Communication in Autistic Individuals

Imagine you are at a coffee shop. It’s a relaxing Sunday, and you're ready for a Venti Latte to complement your newspaper. After you order your drink, you find one of the comfy over-stuffed couches in the corner and settle down nicely. You're looking for serenity, and there is only one table even close to your spot. Not too long after you start reading, a family of four (mom, dad, and two daughters) walk in and sit at the table you prayed would remain vacant. You notice the barista asking what everyone would like to drink, except for the younger looking daughter. You hear her mother say, “Latte for me, and she will take a hot cocoa,” and point at the seemingly silent younger girl. A few minutes later, when you're thoroughly engulfed in your newspaper, you’re interrupted by a loud bang. You turn in response to the noise, and see a balled fist slam down on the table for a second time.

There is the quiet girl from before, looking quite distraught. Her face is bright red, that balled fist belongs to her, and is going for round three with the table. You watch as she rises her other hand in a cup formation and puts it over her ear. She then adds to the ruckus by humming the loudest you have ever heard anyone hum, and rocking her body slightly from front to back. At this point you are unable to avert your eyes, and are appalled her parents have let this go on for so long. This display of “inappropriate” nonverbal behavior is just one example of millions that I believe most of us are completely unaware of.

After working with children and adults with autism for almost four years, my experience leads me to decode this behavior completely differently. The red face would tell me she is probably extremely upset, which is further confirmed by the fist slamming down on the table.
The cupping of her ear would lead me to think she is experiencing some sort of auditory stimulation. Her loud humming, would indicate she probably was going through some sort of auditory overstimulation and was self-stimulating with her own noise to drown out the one that was causing the overstimulation. To me, I still could be wrong, but there is much more to this than a “tantrum”. Her mom said “cocoa”, her choice was made for her. “But I want a mocha!” she might be screaming inside. She may be included as part of the conversation, but they keep moving despite her involvement. As soon as she develops a response in her head, they are already laughing about something else, and she missed the punch line. Their laughter is rudely overtaken by the rumble of the coffee grinder. But to her this isn't just an annoyance. It’s painful, it’s too much, it’s like someone is running their nails across a chalkboard right in her ear. Any sensory experience for someone with autism may be something much different then what we imagine everyone experiences. When someone's experience of any given situation is altered, we cannot expect them to respond the same.

Temple Grandin is one of the most well-known names in the autism community. She was diagnosed with Asperger's Syndrome (an autism spectrum disorder) and age two and half. Over the last sixty years she has significantly changed the understanding of autism. "I had all the classic signs of autism: no speech, no eye contact, tantrums, and constant repetitive behavior. In 1949, the doctors knew nothing about autism, but my mother would not accept that nothing could be done to help me" (Grandin, 3-4). Grandin's mother worked against the negative and limited future the doctors were convinced her daughter would have. Today Temple has her PhD in Animal Science and is a professor at Colorado State University. Temple continues to advocate for herself and the autism community by sharing her experiences with social, communication, and sensory processing complications.
Temple Grandin said "Loud noises hurt my ears like a dentist’s drill hitting a nerve" (81). This is just one example of an auditory processing issue, sensitivity to noise. But this can also affect the individual’s ability to discriminate different sounds from each other, like hearing your name being called over the sound of shuffling papers. These are just a few examples of a single sensory processing struggle; the variations are seemingly infinite. Sensory processing comes in many other shapes and forms (smell, taste, and touch) and can cause the individual with autism to actually feel physical pain if there is too much stimulation of a specific sense. Another major process that is affected is the visual processing, which can be identified by "lack of eye contact, staring at objects, or using side vision" (Grandin, 89). I tried to imagine what it would feel like to visually process things differently. The best analogy I thought of was those thick lensed “beer” goggles they let you try on in middle school health class. Blurry vision, altered depth perception, enhanced sensitivity to light, etc. This could be the world of an individual with autism.

With these just being a few of the struggles an individual with autism must live with, I am baffled at how we expect them to respond traditionally to life. In many of the case study’s I read, they all seemed to require visual identification, or verbal/written response. Frequently used testing methods were those such as ADI-R (The Autism Diagnostic Interview Revised) and DAS (Differential Ability Scale). For example, the study “Associations Between Restricted and Repetitive Behaviors and Nonverbal IQ in Children with Autism Spectrum Disorders,” used both of those assessments. But I think these initial assessments are too restrictive, which would have a huge impact on the accuracy of the results of the study. ADI-R is said to be "comprehensive" but is just a "caregiver interview covering most development and behavioral aspects of autism" (Bishop 251). The parents or providers were asked to rate the behaviors on a scale of 0-3. "A score of 0 indicates that the specific behavior is not present, a score of 1 indicates that the
specific behavior is present to some degree, a score of 2 indicates that the behavior is sufficiently frequent and/or severe as to interfere with the individual's ability to carry out certain activities, and a score of 3 indicates that the behavior is so intrusive that it causes severe social impairment, completely prevents the individual from participating in certain activities, and/or substantially interferes with family functioning" (Bishop 252). The behavior in correlation with nonverbal IQ being a major part of this study’s objective, I have some trouble with this assessment. There is no actual observation done on these children's behavior. Therefore sensory processing or stimuli are not factors at all. Second hand recollection these behaviors is what the data is based off. The current emotions or unawareness of the parents and providers also could have a huge effect on their responses in these surveys.

Paired with ADI-R, was the DAS (The Differential Ability Scales) test. DAS consists of 5 subtest categories: 1) Verbal subtests, which are composed of 4 different cognitive tests that all require the participant to verbally respond to spoken instructions or still images. 2) Nonverbal/Spatial subtests, which has 5 different assessments, but 3 out of 5 of these require the participant to write or draw their responses. 3) The Nonverbal (Fluid Reasoning) subtests consisted of two tests in which the participant has to visually identify patterns in still images. 4) Early Numbers Concepts is a single assessment where the participants are presented a still image and oral instruction of a math problem. 5) Achievement subtests are 3 different tests that all require the participant to write or read aloud (Dumont). While the subtests and their according assessments seem to cover a broad range of abilities, I still think something huge is being overlooked. Again we have no consideration of these sensory processing struggles that might limit a traditional response. While I wasn't surprised the Verbal subtests all require some sort of verbal interaction, the Nonverbal subtests really surprised me. Visual identification and pointing
or written response were the only option for a participant to express themselves. If the individual with autism is suffering from some sort of fine motor or visual processing impairment, how could they physically express their response? If verbal communication is not possible, the correct answer could be trapped inside the brain of that individual.

"For the most part the data available on the nonverbal skills of people with autism have been obtained during experiment tasks that require arbitrary judgment of still or static images" (McGee and Morrier, 311). How on earth can someone who has a visual processing problem successfully complete this with full accuracy? Despite the intelligence, the ability to process the stimuli might not be present. Therefore the person may compensate and rely on other stronger senses to learn and respond. This would significantly limit the accuracy of the research and in turn the people it would benefit. Someone with extremely high intelligence may not be able to respond or select the right answer if the information is only presented in one way. These types of assessments affect children and adults from both ends of the spectrum. The ability to speak, in reference to autism, is not necessarily the same as the ability to express your thoughts and emotions. I do think the effect is more obvious in the nonverbal individuals with autism, where the behavior is the only means of communication they have at all.

As stated before, I have been working with adults and children (both nonverbal and verbal) for almost four years now. I'd like to share a story that really helped me start to think about the big picture of the nonverbal behavior of individuals with autism spectrum disorders. The spark that set my world on fire was in 2010. I met a 23 year old woman who would change my life forever, and open my eyes to a community I didn't know existed. She is a beautiful brown-eyed girl, who is also nonverbal and autistic. Over the next 3.5 years she would teach me lessons I couldn't have learned anywhere else. She accomplished all of this without ever saying
one word. We spent six hours a day together, five days a week and developed a typical relationship for women our age (shopping, coffee dates, perfume, make-up sampling, baking, fashion magazines, etc.). During my first few hours with her, I was already fascinated with trying to decode and find deeper meaning in each and every action, movement, or facial expression.

Every once in a while when we used to go shopping, she would become very obsessive about opening the doors inside the store (ex: storage rooms, break rooms, emergency exits). I would try and redirect her by explaining to her the different reasons why we couldn't go through each door, and turn her away so we could continue around the store. Though we would move on, I waited and watched for more doors to try redirecting her again. One time, when we were at Shopko, she had been particularly forceful and persistent on opening the doors. She tried to push past me and was getting really upset when I wouldn't let her open the doors. I decided she was getting so upset and obsessive that we better just leave the store and take a break. We approached the front door and she started to speed walk/slow run, which initially caught me off guard, but I was curious where she was going so I quickly hurried after. A few seconds of light jogging later, I was at a loss of words. We were standing in front of the women's restroom. She quickly opened the door, continuing her slow jog to a stall, slammed the door without locking it, and released what sounded like an intense amount of urine. She had been looking for the bathroom the whole time. Every time she opened the doors, she was just searching for the room with the toilet. This is a perfect example of how this nonverbal behavior can get decoded incorrectly by us bystanders. I consider myself to be an “out of the box” thinker and I still misread her behavior.

"Dr. Margaret Bauman, Neurologist at Massachusetts General Hospital emphasizes that we strongly assume that 75% of nonverbal individuals are mentally retarded" (Grandin 127). This is an alarming estimate. These "strange" behaviors, meltdowns, and lack of spoken words
have created a false assumption. Imagine the world around you constantly underestimating and doubting your intelligence, wants, or needs. Or never considering that you also might be seeing the world a little differently than everyone else. I think any of us would be frustrated in that situation. But we could collect our thoughts, and express how we really felt or what we really wanted. Autism can steal this away from an individual. Their outward behavior, mannerisms, and body language are their means of communication. The behaviors we observe and sometimes seemingly rule "inappropriate" to me, are now justified.

These sensory processing differences are another huge contributor to the nonverbal behavior in both verbal and nonverbal autistic individuals in my opinion. While thinking about the different types of processing and how they can be personally altered depending on the individual with autism, I had a realization. We all know the different learning styles (kinetic, visual, auditory) and probably have had to take some sort of assessment to identify which is best/predominant in ourselves. Last year I realized I am a kinetic learner. So making note cards, and actually writing my notes out instead of printing lecture notes helps me retain information much more efficiently than if I was just listening to the lecture. I believe the sensory processing differences of an individual with autism can be compared to the different learning styles of neurotypical individuals. In neurotypical individuals this learning style is a strength, the one that works best for us. But unfortunately, an individual with autism may only be physically able to process 2 out of 5 senses. Also they may be only able to engage in one type of processing at a time (eg: can't focus on walking down stairs while someone is talking, auditory sense is currently predominant). This means learning and communicating is quite literally impossible if these processing struggles aren't identified. This should be part of the screening or placement assessment a child with autism has to routinely undergo. Without identifying the predominant
processing function, the true abilities of the individual with autism may be deeply underestimated.

The most fascinating finding I have had in reference to autism and these processes was the Rapid Prompting Method (RPM) developed by Soma Mukhopadhyay. She explains what she calls "open learning channels" (Mukhopadhyay 91) as the different learning style of each individual, neurotypical or autistic. She then says when implementing RPM with a person with autism, you must acknowledge the strongest open learning channel. "RPM is therefore individualized. It identifies and then creates the ideal learning condition of the students open sensory channel, so that optimal learning may take place," (Mukhopadhyay, 92). Soma elaborated on the epiphany I had been contemplating, with much greater detail. She has developed this method based on the same idea, though. Learning is a different experience for everyone, autistic or not. Out of all the research done on autism, nonverbal behavior and communication, and teaching methods, this was the newest and most widely discussed.

*A Mother's Courage: Talking Back To Autism* was an inspiring movie of one family's journey from Iceland to America to meet with Soma Mukhopadhyay. The Icelandic family has an 11 year old son with severe autism, Keli. He is nonverbal and shows many signs of sensory processing struggles. Keli's mother, Margret Ericsdottir, meets with several people before Soma including the mothers of other nonverbal autistic teens or preteens who had benefited from RPM. By benefited, I mean had gone from no form of communication for years to being able to communicate thoughts, wants, and humor. Margret finally takes Keli to HALO (Helping Autism thorough Learning and Outreach), Soma's facility in Austin, Texas. Within the first few visits, there are signs that over time, Keli would potentially be able to break out of his body and begin to communicate with his family for the first time ever. He responds when Soma
begins taping on the answers with her pencil to the basic questions she is asking Keli. Once she
develops an interaction with Keli she brings out a letterboard and helps Keli spell out his first
word “piano”. This eye opening documentary is video footage of several successful trials of the
Rapid Prompting Method helping these individuals. These are intelligent human beings who
have been denied the chance to learn through traditional methods. The consistency in the success
of the RPM method just furthers my belief that every individual with autism has something to
say, an intelligence to share. We just have to be conscious of learning/processing differences.

Through my research I found that there is a need for more clinical studies and
alternative intervention methods for autistic individuals. We are missing a huge part of this
autism puzzle by not acknowledging all the challenges of sensory processing. These children and
adults have things to say, a brain that wants knowledge, and unique interests of their own. In my
job, I believe it is my responsibility to help discover these “open learning channels". As a general
community member, I still believe there is a job to be done. All I ask you to do is be aware. Just
imagine what life would be like with those “beer” goggles on, and the heavy metal music stuck
on maximum volume, at any given time or place. Imagine being able to think what you wanted
to eat for lunch everyday, but never once being able to ask for it. In reference to me feeling
responsible for helping these individuals discover their “opening learning channels,” I believe
it’s time for more of the medical field to get on board with this mindset. An initial sensory
processing assessment should be paired with the diagnosis of autism. Then we can start to shift
the focus from what the autistic individual can't do, to what the autistic individual can do.
Works Cited


