



## What Those Not on the Autism Spectrum Should Know

### *Students on the Spectrum Club Participants Share Personal Perspectives on Autism Awareness and Acceptance*

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When learning about autism, it is always important to gather information from the perspectives of individuals on the autism spectrum. This article provides the perspective of some adults on the autism spectrum who have been members of a student club at Indiana University.

The Students on the Spectrum Club (S.O.S) became an official student group at Indiana University in the fall of 2009. The Indiana Resource Center for Autism (IRCA) saw the interest and need for a space for students on the autism spectrum to come together. IRCA invited interested IU students with autism to discuss how to support a student group for students on the autism spectrum. The following semester the group became an IU registered student organization and began recruiting members and meeting regularly. IRCA staff have supported the S.O.S. Club in various ways from the start, including serving as an advisor for the Club.

The S.O.S. Club has evolved according to the needs and interests of its members. A mix of socially engaging activities along with discussions around topics of interest have been the focus of Club meetings. Some members have been interested in sharing and spreading awareness about autism. This article is the result of several discussions over the years when the topic of autism awareness and acceptance on campus, and in the community were discussed.

This article summarizes the collective voices of over a dozen adults on the autism spectrum. It is focused on information this group feels is important for others who are not on the autism spectrum to understand. The individuals who participated in these S.O.S. Club discussions hope everyone reading this article will strive to understand and embrace the perspectives of people on the autism spectrum. The nine sections of the article were chosen as key focus points to help highlight and emphasize their collective experiences and perspectives.

Note: Person first language is interspersed with identity first language. This is the choice of the S.O.S. Club members. Those involved in the discussions respect both options for autistic people/people on the autism spectrum to choose and use freely without judgement.

### **Communication Differences (varies from person to person)**

People on the autism spectrum want others to know that they desire to be contributing members of conversations, just like everyone else. Unfortunately, some things can get in the way of participation including slower processing time, a tendency to take things literally and trouble initiating and asking for clarification.

In addition, individuals might communicate in unexpected and/or unintended

ways. Facial expressions may not reflect true feelings. Eye contact, tone of voice and how loudly or softly someone speaks may be perceived as different and possibly uncomfortable to others. Listed below are some other common issues experienced by individuals with autism which may hamper communication. A person with autism:

- Might not realize a certain topic will trigger certain emotions in others; turn people off.
- May experience significant discomfort making eye contact.
- Might ramble and have trouble getting to the point.
- May have difficulty with the give and take of a conversation; instead may dominate and focus on a topic of interest. (We may need support to help us change.)
- Might say what comes to mind with no filter.
- Related to pragmatic communication which is difficult for us: we may be too blunt, not stay on topic, may be lacking “social cues” such as smiling, and indicating interest in others.
- May display facial expressions that may not reflect our true feelings.
- May understand and use sarcasm; which can cause confusion.
- Often finds phone conversations can be more difficult; more distractions and feel a time crunch.

Though real-time conversation is difficult, autistic people might succeed when using

a device that provides a written means of communication. This is because there is more time to process what we want to say. For some autistic people, written communication including texting is their preferred or primary way to communicate.

### **Mind Work, Mind Games and Thinking Outside the Box**

Autistic people are very independent thinking, creative individuals. People on the autism spectrum, tend to approach problems in their own way and often use novel thinking and creativity to come to a solution instead of asking others for the answer. While this has many potential benefits, it can also create a lot of frustration between parties when trying to complete a task. At times, autistic people are rigid in their thinking, and do not realize they need to ask questions. Important information to know about how the minds of people on the autism spectrum work include:

- Perfectionism can be a powerful urge; VERY hard to control, though intellectually “know better”. Can be triggered by stress.
- May apply critical thinking and intuitive thinking from a different viewpoint.
- Sometimes, certain steps can be confusing or harder to execute, and as a result, an individual will find alternative routes to achieve the same task.
- Cognitive processing tends to be a bit slower, or faster if a topic is of intense interest.
- Black and white thinking can be a problem.

- Perseverative thinking can be a plus when concentrating on finding solutions, however, this is not always seen as helpful or appreciated when working with others.
- Sensory overload sometimes makes it difficult to concentrate.
- Executive function skills such as prioritizing, planning, organizing, focusing and shifting attention, for example, can make problem solving and reaching a goal take more time.

Please keep in mind that the task will get done, but it may take us longer and the task may be done in a different way than others may have initially thought.

### **Motor Skills**

Motor skills vary greatly from person to person on the spectrum. This can affect both gross motor and fine motor skills. For some, autistic individuals certain motor skills may not develop at all. These differences may be due to the neurological and developmental basis of autism. Some individuals with autism choose not to drive a car, in part, because their motor reflexes are slower. Motor skills are not necessarily a reflection of individuals' mental capabilities. Other important information about the motor skills of a person with autism include:

- Fine motor skills such as writing may be difficult, but in comparison, the same person on the autism spectrum may have exceptional drawing ability.
- Walking or moving “normally” may cause discomfort so a person with autism’s gait may look unusual.

- Motor skills displayed may not be consistent.
- Coordination may seem exceptionally good or poor.
- People with autism are often not good at sport skills such as throwing, bouncing and catching a ball.
- Balance, body awareness and motor control may also affect participation in sports, especially team sports.
- Some on the autism spectrum are, in fact, good at sports, including team sports.

Do not assume your help is needed because an individual moves or talks differently. If you are concerned, ask the person if s/he needs help. It could be they just need more time and patience to accomplish the task on their own.

### **Social Differences**

Socializing often takes a lot more energy for autistic people than it does for non-autistic people. In some ways, it can be explained as a kind of introversion. Individuals on the autism spectrum tend to be sensitive to social and sensory stimuli. Behaviors others see as different and unexpected may be an adaptive strategy used by the person with autism to help them handle a situation. There are a smaller number of people with autism who are described as socially active but odd. At times, they may be described by others as having no social filter or being socially inappropriate and rude. Unfortunately, this pattern can also get in the way of socializing and developing lasting friendships.

Many on the autism spectrum have a strong sense of social justice and high ideals. It can be a challenge for autistics to advocate for their ideals, especially when some restraint is needed. Sometimes the logical and social rules of the world do not make much sense to individuals on the autism spectrum and sometimes we don't understand why we must conform to them when given the reason that "it's just what people do".

Our ability to empathize is misunderstood. Many of us, in fact, empathize "too much" but may show it differently. Some autistic people will openly express their feelings of empathy both because they feel the very intense feelings and additionally because they want to help others feel they are understood and not alone.

Some people on the autism spectrum will try to avoid or block out intense feelings because it's more emotionally intense than they can handle. We often need more time to process the emotions and come back later. This can cause confusion. Sometimes the emotional response of a person on the autism spectrum seems to be unrelated to the situation. For example, the emotion is so overwhelming and intense, instead of crying at something that is sad, we might display laughter.

Please be cautious about judging our social behavior. We may be processing and displaying emotions differently. The behavior we display may mean we need a break from people. Again, it needs to be emphasized that social interactions take a lot of energy for people on the autism spectrum. It is easier for us to recharge mentally when we are alone. However, when taking this time alone, we feel that we risk making others think we are anti-social, or that we don't need friends and that is not true. In fact,

people on the spectrum may experience intense loneliness. Other important information about social differences we want you to know:

- It can be hard to get a group of autistic people together; reclusive and solitary personalities are abundant.
- Boundaries can be an issue; understanding who is a friend and how far to take something is difficult. Often boundaries need to be taught and each situation may be different.
- Big groups (for work or recreation) can be overwhelming at times. It requires juggling too much information at once.
- Sometimes we feel guilty about our unintended behavior.
- We may react in unexpected ways (expression, tone of voice, etc.) which can cause problems.
- Sometimes an autistic person feels lonely and afraid to seek others out; it helps when others initiate.
- Some prefer less interaction: will want relationships where interaction is more limited.
- Not being sure how to connect with others, can prevent seeking out others.
- We tend to take things literally, which can cause confusion.

### **Sensory Differences**

Many of us experience sensory overload. These sensory issues can interfere with our participation in various activities and

environments. Important to know is that many of us have found various supports and adaptations to enable us to participate and contribute even though affected by sensory issues. Noise canceling headphones, hats, dark tinted glasses and carrying sensory calming items can help us to work with these sensory differences. Sometimes taking a break and/or having a plan to “escape” is important. Sensory issues we find problematic include:

- Many of us are sensitive to lights including fluorescent lighting and amount of lighting.
- Public places can overwhelm; can feel like we are “attacked” by smells, lights, sounds, and people, resulting in a panic attack.
- Physical contact can be overwhelming; being bumped or hugged, shaking hands, etc...
- Taste, smell, textures and consistency of food can be problematic; strong food preferences may not be understood.
- Hearing and processing verbal messages in “noisy” rooms is very difficult.
- Smells of people or environments can be overwhelming; perfume, hair spray, deodorant, cleaning supplies, flowers, etc.
- Patterns of flooring can cause problems; can be disorienting.
- Voices on a phone may be too loud or jumbled; also, TV and movie theaters, can be problematic due to sound sensitivities; texting/closed captioning helps a lot.

- We may be unable to filter sounds, as a result, everything is heard at the same level.

## **Stress Issues**

There are things we worry about a lot and/or fears we have as a result of having autism.

A question we often ask ourselves is, “should I disclose my autism diagnosis to others?” Many of us fear that if others know we are autistic, they may see us as less and not capable.

Many on the autism spectrum wish that people would see our differences as just that, differences. Not problematic behavior or things to be fixed. At times, we feel people don’t take our opinions seriously because we are autistic. If we point something out that we think is a problem, please take it seriously.

It is common for autistic kids to feel mistreated by peers as well as by adults, due to a lack of patience, understanding, resources, or other reasons. Sometimes, even people who mean well and want the best may be mistaken with their approach. It is valuable to consider the autistic persons perspective and reassess your own actions. Here are some of the things that cause stress for many of us:

- Fear of what others think or how others will react to our differences.
- Disclosure concerns: when and with whom to disclose.
- Fear that others may not accept our limitations, and/or acknowledge or believe that true limitations exist.

- Difficulty finding common ground (topics of conversation) with peers.
- Fear of not meeting expectations.
- Not recognizing an emotion and being “disconnected”.
- Being judged; such as when feeling safe in a private space, others often feel we are anti-social.
- Issues with being social; causes stress when it “doesn’t work”.
- Understanding what is socially acceptable in the autistic world vs. the non-spectrum world.
- Distractions and interruptions which cause us to lose our train of thought/focus.
- Others losing patience with us or someone else.
- Not being given the benefit of the doubt.
- Unrealistic and/or unspoken expectations.
- Adjusting to the non-spectrum world.
- Ability to do things of interest/comfort when stressed.
- Being forced to do things or watching others being forced to participate.
- Fear of being misinterpreted.
- Expectations of remembering faces and names (for many).

## **Coping Skills and Strategies**

To navigate the world successfully and manage anxieties, uncertainties and struggles, we may use many adaptive coping strategies in our daily lives. Some strategies have been taught while others we figure out or “find” on our own. When we are stressed, we may:

- Stim; engage in repetitive gestures such as twisting body hair, hand flapping, wringing or “waving” hands or body rocking.
- Find a place to be alone.
- Move to another location or do something else.
- Very carefully monitor our behaviors in public.
- Use sarcasm or passive civil disobedience.
- Use yoga and/or meditation.
- Listen to music.
- Use a laptop, or other device, for games or social media.
- “Suck it up” and “get over it”.
- Use breathing techniques.
- Tell ourselves it is a choice.
- Participate in physical activity.
- Use ear plugs, tinted glasses and hats to block out stimulation.



- Seek time with sensory friendly objects such as a soft item or a weighted blanket.
- Interact/communicate in writing, rather than verbally.
- Ask the same question over and over to get the same response.
- Seek time with pets/animals that give unconditional love and do not judge.
- Ask for supports, when possible.

## **Strengths**

We want family, friends, teachers, co-workers and other allies to please support us to focus on our strengths and help us to build our self-confidence in this world where we often function differently from others. We need opportunities to focus on strengths. What follows are some common strengths for people on the autism spectrum.

- Memory skills: facts and details, though tend to remember selectively.
- Persistence to pursue information and activities of interest.
- Out-of-the-box/independent thinkers; though conversely, may need help with knowing boundaries.
- Good critical thinkers.
- Multi-dimensional brain/thinkers.
- Creativity.
- Unique sense of humor.
- May see something others do not see.

- May see patterns very clearly.
- May be good at creating systems for daily life and employment (if given the time and support).
- May be good at mechanical tasks.
- May be good at computer programming.
- Genuine and honest character.
- Desire to help others.
- Great interest and ability to befriend neuro-diverse people despite life experiences.

## **Self-Confidence**

Persons with autism live with a lot of worry, fear, and often failure which we are unsure how to turn around. These circumstances often lead to less self-confidence in ourselves. Self-confidence can help people build resilience and success in many aspects of life. When friends, family, and other allies understand us better and take action to show acceptance of autistics it can go a long way in supporting our self-esteem and self-confidence.

Some important information about what can often build (and crush) self-confidence for autistic individuals is one more thing we want others to understand.

Things that build confidence (which allies/others can support):

- Give everyone a break: those on autism spectrum take longer to mature.

- Focus on ways to succeed and grow; personality and other characteristics are important.
- Focus on interests and strengths.
- Looking to positive role models (pick positive attributes from several people).
- Including people with autism in the diagnosis (assessments, evaluations and treatment information, etc.).
- Including people with autism in developing goals.
- Providing unconditional positive regard and tolerance.
- Providing mentors.
- Giving respect for individuality.
- Opportunities available for structured group activities (orchestra, choir, dance, chess club).
- Opportunities to connect with other people with autism.

Things that crush confidence (which allies/others can strive to avoid):

- Being given expectations without guidance.
- Being treated differently or negatively.
- Feeling or being left out.
- Being given unrealistic expectations (too high or too low).
- Pity from others.
- Impatience of others.

- People treating a person (with autism) differently after learning about diagnosis.
- Being treated inhumanly or like a burden.

People on the autism spectrum have strengths and limitations. Identifying ourselves as autistic and neurodivergent means we believe both our strengths and limitations are part of who we are. We are not better or worse than anyone else. We are wanting to be better understood and accepted; autism is a part of us and that is okay. Please accept us without judgement; this goes a long way in helping to support us and to help us build self-confidence and self-esteem.

In conclusion, we want to emphasize autism is a multidimensional spectrum. To classify people as “high-functioning” or “low-functioning” is not an accurate picture of an individual’s abilities. Strengths and limitations vary for each individual. All the information discussed here, both strengths and limitations, are just a list of possibilities. It’s impossible to create a one-size-fits-all description of autistic people. Like all people, we need understanding and a positive environment to do our best. Thank you for your support of autism awareness and acceptance for all.

*Note: A version of this handout has been used successfully for focused discussions in a variety of situations with a varied audience. Examples of people or groups that have or might find this handout to be useful include friends, family, class instructors, classmates, colleagues, employers, newly diagnosed adults and anyone that wants to support individuals on the autism spectrum.*