



Understanding and Assessing Autism Across the Spectrum

Autism Across Individuals

Autism spectrum disorder is a developmental disability that impacts social-communication skills and involves the presence of repetitive movements, actions, or language patterns. Autism is a spectrum, which means that the differences and intensity of these variations are different with each person that receives this diagnosis.

Clinical indicators of autism consist of two categories:

Social communication differences, which fall into three principal areas:

- Social-emotional reciprocity
- Using and understanding nonverbal communication
- Difficulty developing and maintaining relationships

Repetitive and restricted behaviors and interests, which need to be present in at least two of the categories below:

- Repetitive motor movements, speech, or use of objects
- Interest in specific topics
- Difficulties with transitions or changes in routines
- Sensory differences

It is important to recognize that these behaviors and interests do not always get in the way of an autistic person's functioning and can often serve as an area of strength.



This pamphlet is intended for school-based providers and other professionals who want to learn more about the subtle traits and presentations of autism. This could include school psychologists, speech and language pathologists, psychologists in a clinical setting, and anyone else who provides autism diagnoses.

Development of Masking

Masking is when certain characteristics unique to autism are hidden and replaced with behaviors that appear more neurotypical.

Autistic individuals may mask their traits and work hard to appear more neurotypical in order to:

- Navigate professional and social situations, especially when societal expectations are not made explicit; and/or
- Avoid punishment for acting in a way that differs from the neurotypical norm.

Some autistic individuals describe masking as a survival tool that helps them navigate social and professional environments. Since often the expectations in these environments are implicit rather than stated directly, autistic individuals may be placed at a disadvantage.

For many autistic individuals, ongoing masking can lead to consequences that can negatively impact their sense of self, social connections, academic engagement, and mental health.

Autistic students frequently mask in the school setting where there is a mismatch between the environment and the needs of the students. In environments that celebrate and support diversity, autistic students may have the opportunity to be their true authentic selves. Where students do not feel safe and supported, they may experience the need to consciously or unconsciously mask their characteristics for fear of looking different.

“It is easier for some autistic people to mask themselves into an early grave, than it is to step off the cliff and fall into who they truly are.”

– Kieran Rose, autistic advocate

While masking can function as a protective response, it can also lead to negative consequences. The following are common negative consequences of masking that have been shared by many autistic self-advocates:

- Chronic stress, often resulting from the constant cognitive load of self-monitoring social behavior that is not intuitive for the autistic individual.
- Emotional exhaustion and burnout, often resulting in anxious and depressive symptoms, suicidal ideation, and a sharp decline in one’s capacity to function.
- Social isolation despite “blending in,” resulting in difficulties establishing authentic relationships and feeling misunderstood.
- Diagnostic overshadowing, resulting in an increased risk of a missed autism diagnosis or misdiagnosis due to the more intense expression of mental health difficulties.

Burnout can be a common experience for autistic individuals due to continually masking and hiding certain characteristics. It has been described as living in a state of relentless vigilance, an endless need to monitor or adjust oneself just to keep pace with expectations in a neurotypical world.

Emotion Regulation and Autism

Autistic individuals interact with the world in countless ways across different contexts and settings. When unexpected changes occur or demands increase, the neurotypical world may expect them to adapt and understand how to move forward. However, for autistic individuals, this can be difficult as there is often a mismatch between how they process both sensory and social information in the world around them. Furthermore, they may struggle to understand their own needs during times of change, when high social demands are placed upon them, or when sensory aspects in the environment are overwhelming. These difficulties with navigating the social world can lead to both physical and emotional regulation challenges.

With the mismatch between brain processes and environment, autistic individuals can struggle to regulate themselves. When autistic individuals become dysregulated, they may experience an autistic meltdown and/or burnout.

Autistic Meltdown

While autistic meltdowns may look like a tantrum (e.g., crying, becoming aggressive, engaging in self-harm), it is important to distinguish between the two. Autistic meltdowns are not a form of manipulation to achieve a goal but instead are an automatic response to an overwhelming situation. In situations where autistic individuals may experience change, sensory overload in their environments, or high social demands, they may temporarily lose control of their behavior.

Regulation Burnout

Autistic individuals may experience burnout in different ways. In addition to masking one's autistic characteristics, burnout can also be caused by difficulties with dysregulation in one's environment. When an environment does not match the needs of the autistic individual and they are unable to regulate themselves, they may have difficulties tolerating different experiences, leading to burnout. Autistic self-advocates often describe burnout as "the shutting down of the mind and body" as well as "crashing out."

Alexithymia and Interoception

Dysregulation often stems from a mismatch between how the brain processes what is happening in the world and the information that is provided. Often, information about emotions and others' experiences is not explicit, contributing to autistic individuals' difficulties understanding their own and others' emotions and bodily cues.

What is alexithymia?

Alexithymia is broadly defined as difficulty identifying and describing the emotions that individuals experience. Alexithymia can make it difficult to understand and respond to the emotional state that one is in.

Alexithymia affects individuals differently. Some individuals can easily identify certain emotions while they may be unaware of other emotions. Others may be able to recognize whether an emotion is positive or negative but struggle to pinpoint what the exact emotion is. Some may misinterpret one emotion as another entirely.

Individuals with autism tend to experience alexithymia more often. A study by Kinnaird and colleagues in 2019 found that 49.93% of their autistic participants presented with alexithymia, whereas 4.89% of their non-autistic participants experienced the phenomena.

What is interoception?

Interoception allows one to feel body signals and internal sensations which indicate certain needs and feelings.

When individuals have difficulty noticing internal body signals or connecting those signals to an emotion, their emotional experiences can feel vague or confusing. Some may experience body signals that are so intense they become overwhelming, while others may have body signals that are too small, which can go completely unnoticed. Autistic youth are 2-4 times more likely to have clinically significant emotion regulation impairments compared to neurotypical peers (Mazefsky & White, 2013).

Considerations and Strategies for Assessing Autism and Emotional Regulation Differences

Interoception, masking, and dysregulation can greatly influence how providers perceive and understand autism. We will now consider how these differences may impact the assessment process and our conceptualization when conducting autism evaluations.

The Potential Impact of Masking

When assessing autism in an individual who masks, it can be difficult to understand their behavior across settings. At school, they may behave in a way that is similar to their peers, while in other settings they may present many more autistic characteristics. Many individuals can expertly mask their characteristics, making it difficult to understand how they may align with autism.

The Potential Impact of Interoception

Individuals with interoception differences may have difficulties identifying how their own body feels, making it hard to know when something is off or when they don't feel well. This may limit the ability of a psychologist to recognize the individual's internal experiences.

The Potential Impact of Alexithymia

Similarly, individuals who experience alexithymia may have difficulties understanding their emotional state, making it a tough task for psychologists to decode how the individual is feeling. Alexithymia can impact how an individual's needs are conceptualized, as they may not be able to describe their emotional experiences.

The Potential Impact of Autistic Meltdown and Burnout

Autistic meltdowns can look similar to characteristics of other diagnoses (e.g., oppositional defiant disorder, adjustment disorders), making it difficult to differentiate during the assessment process. Individuals may experience meltdowns due to burnout and exhaustion from their environments.

Gather a Richer, More Authentic and Comprehensive Understanding of Autism

The purpose of the assessment process is to gather information about the individual's experiences in full detail. Connecting the best assessment practices with the consideration of masking, interoception, autistic burnout, and meltdown, as well as the influence of alexithymia, can provide a deeper picture of how an individual may present. Gathering information directly from the individual as well as from caregivers and teachers and conducting observations is important to develop a holistic perspective about the learner's internal experiences and behaviors across settings.

Observation Techniques

Observations can give us so much information about what makes autism unique for each person. It is important to focus on various factors of behavior, especially when considering the full spectrum of the autistic presentation. These can include:

- Frequency/rate of the behavior;
- Time during which these behaviors occur;
- Duration of the behavior; and
- Time between behaviors.

Observation Setting

To capture these different elements and idiosyncrasies, it is key to observe individuals in different settings/ environments. In school settings, psychologists may observe students in adult- and student-directed environments or in structured and unstructured settings to gather a richer understanding of how the student behaves with different demands or individuals. Further, observing students across highly preferred and non-preferred tasks can provide good insight into elements like masking and other complexities. Observing across tasks may allow one to see a contrast in how the individual presents during interactions and activities that are aligned with their strengths versus interactions and activities that may be more difficult for them.

Masking

Masking can be difficult to observe, as individuals may covertly hide their true selves throughout their daily lives. However, observing across different settings and interactions may provide to a richer understanding of how the individual may mask.

Research in this field has focused on understanding masking in individuals both through report measures and observation tools. This includes the Playground Observation of Peer Engagement (POPE) (Kasari et al., 2005), which is a measurement tool that is used to understand camouflaging in school-aged children by observing them in different scenarios (e.g., interacting with peers, playing independently).

Interoception

Observing interoceptive awareness in individuals may require some forethought of things to watch for. It is important to consider differences in an individual's pain perception, temperature recognition, and other differences sensing bodily cues that one may observe. Just as with masking, it is important to use these observations to create further questions to gain more information.

Those who may have interoception differences may present as students who go outside during recess without a coat despite cold temperatures, don't get upset when injured due to differences in pain tolerance, or experience toileting accidents during the day due to difficulty recognizing when their body needs a restroom break.

Interview Techniques

Our observations can help to guide and formulate questions about the individual's behavior, giving us a richer understanding of how they may align with autism. Based on what data is gathered, psychologists may want to ask individuals, their caregivers, and teachers questions about interoception, masking, and other differences.

Below are lists of questions from Donna Henderson and colleagues (2023) and autistic self-advocates that are grouped by informant and topic. Consider including some of these questions when conducting interviews during autism evaluations.

“Relying solely on observation can be problematic, as autism is not behavior; it is a way of experiencing and responding to the world.”

(Henderson and colleagues, 2024, p. 88)

Interoception Question Guide

Questions to ask educators:

- How do they manage personal space? Is it ever too much or too little?
- What is their pain tolerance like? Do they have a strong response to pain or a low pain threshold?
- Do they fail to notice when they are injured or ill? Or when they are hungry, thirsty, or tired?

Questions to ask caregivers:

- How do they manage personal space? Is it ever too much or too little?
- What is their pain tolerance like? Do they have a strong response to pain or present with a low pain threshold?
- Do they fail to notice when they are injured or ill? Or when they are hungry, thirsty, or tired?
- Do they know when they need to go to the bathroom? Or did they require reminders long after the age when other children are able to do this on their own?
- Do they crave certain experiences because of the way they make them feel (e.g., enjoying extreme sports, liking the feeling they get from engaging in self-harm behaviors)?

Questions to ask the individual:

- How is your pain tolerance? Do you have any examples of it being particularly high or low?
- Do you get hungry or thirsty very much? How does your body feel when you are hungry or thirsty?
- Do you tend to crave certain experiences because of the way they make you feel? For example, you may enjoy engaging in extreme sports or spinning really fast.
- Do you recognize when you've injured yourself, or do others tell you that you have hurt yourself?
- Can you recognize when you need to use the bathroom, or do you tend to use the bathroom because it has just been a long time since your last restroom break?
- Do others often have to tell you to give them space because you are too close to them?

Masking Question Guide

Questions to ask educators:

Do you ever notice that they act in different ways depending on the activity or the person they are interacting with? How so?

Questions to ask caregivers:

- What does your child typically do at home after school?
- Did they have to work hard to overcome early challenges in interacting/communicating?
- When or with whom do you think they can be completely themselves?

Questions to ask the individual:

- Can you tell me about a time when your outer behavior did not match your inner experience? How frequently does this happen? In what circumstances?
- Do you ever use a script or a plan when navigating a social situation? Do you find it helpful or even necessary to rehearse what will happen ahead of time?
- When do you use a script to navigate a social interaction? What would it look like and feel like if you didn't use that script?
- When or with whom can you be completely yourself with?
- Do you feel like you have to change or hide aspects of yourself to fit into certain groups?
- How much energy do you put into thinking about and doing things that make interacting and communicating easier for you?

Alexithymia Question Guide

Questions to ask educators:

- How well do they express positive feelings towards their friends and towards those they interact with at school (e.g., teachers, staff, other professionals)?
- Do they seem to show a typical range of emotions?

Questions to ask caregivers:

- Do they show a typical range of emotions?
- Is it easy or hard for others to “read” how they are feeling by their body language and facial expression? For instance, do they look sad or grumpy when they are in a neutral or happy mood?
- Have there been times when their affect didn't make sense given the situation?

Questions to ask the individual:

- Do people find you “hard to read,” or have they commented that you don't show your emotions?
- How does your body feel when you're happy/anxious/angry/etc.?

Burnout/Meltdown Question Guide

Questions to ask educators and parents:

- Do they seem exhausted if they have to be in a social situation for too long?
- How do they react to big or small changes? (It is important to look for resistance, defiance, avoidance, overreactions, or anxiety.)
- Do you have to prepare them for change or help them recover from it?
- How do they respond if things are not in a particular way or order? Has this ever been a problem?

Questions to ask the individual:

- Are you prone to shutting down? What causes you to shut down?
- Are there times when your feelings get really big and you respond in a way that others may not expect (e.g., running away, sleeping, hitting, etc.)?
- How does it feel when you experience these moments of intense big feeling?
- What do you do to cope with these big feelings?

Summary

Along with traditional assessments for autism, the concepts of masking, interoception, alexithymia, and autistic burnout and meltdowns are important considerations throughout the evaluation process. Asking questions and explicitly observing these behaviors can help to gain a broader understanding of autism and how it may look in those with whom you work. Traditional assessments like the ADOS-2, the Social Responsiveness Scale, Second Edition (SRS-2), and the Childhood Autism Rating Scale Second Edition (CARS-2) are valuable in making a diagnosis, but they do not always capture presentations that vary from what is typically thought of as autism. When working with individuals who may mask, present with alexithymia or interoception, or who experience burnout, these measures may miss critical information to make a diagnosis. It is important to make sure that you gather information from multiple informants, using multiple different measures to capture the qualities and characteristics of the individual.

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A more detailed review of this toolkit and additional resources can be found in the [interactive online course](https://triad.vkclearning.org/en-us/Toolkits) (triad.vkclearning.org/en-us/Toolkits).

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