## AUTISM SPECTRUM DISORDER

A Reference Guide

Rachel K. Earl, Jessica L. Peterson, Arianne S. Wallace, Emily Fox, Ruqian Ma, Micah Pepper, & Ghina Haidar

> Bernier Lab University of Washington Center for Human Development and Disability Bernierlab.uw.edu



### **Autism Spectrum Disorder: Overview**

### What is Autism Spectrum Disorder?

Autism Spectrum Disorder (ASD) is a complex disorder of brain development characterized by social communication impairments and restricted, repetitive patterns of behavior<sup>1</sup>. Social communication deficits include difficulties with social-emotional reciprocity (e.g., reduced sharing of interests or emotions, difficulty maintaining back-and-forth conversation, failure to initiate or respond to social interactions), limited nonverbal modes of communication (e.g., eye contact, gestures, facial expressions), and difficulty initiating and sustaining relationships with peers. Restricted or repetitive behaviors include unusually intense interests or preoccupations, repetitive or ritualistic behaviors, unusual sensory interests or aversions, significant difficulties with changes in routine or environment, and stereotyped verbal or motor mannerisms (e.g., hand flapping, arms waving while rocking). Symptoms of ASD emerge early on in development, and can vary widely depending on the individual's cognitive and language capabilities, as well as comorbid psychopathology. There is currently no cure for ASD. Research shows certain therapy approaches work well for some, but not all individuals with the disorder.

### **Prevalence and Diagnosis**

- Current prevalence estimates: 1 in 68 children and 1 in 42 boys diagnosed with ASD in the United States.<sup>2</sup>
- ASD can be reliably diagnosed as early as two years of age by an experienced professional; however, the average age of diagnosis in the United States remains approximately 4 years of age and even later for medically underserved ethnic and racial minority populations, highlighting the need for earlier detection and more equitable access to services.<sup>3-4</sup>
- ASD is diagnosed with a comprehensive evaluation, including a clinical examination and a developmental history, conducted by a professional with expertise in autism. Gold standard assessment tools used for the evaluation of ASD include the Autism Diagnostic Interview Revised (ADI-R)<sup>5</sup> and the Autism Diagnostic Observation Schedule-Second Edition (ADOS-2)<sup>6</sup>. This evaluation may also include a hearing and vision screening, neurological testing, genetic testing, speech and language evaluation, and other medical testing.



### **Current Information Regarding ASD Etiology**

- There are still many questions regarding the biological and environmental underpinnings of ASD. Below, we briefly review several important empirical findings.
- Genetics play key role: ASD is more common in people with certain genetic or chromosomal conditions. About 10-20% of individuals with ASD are identified as having Down Syndrome, Fragile X, tuberous sclerosis, and other genetic and chromosomal conditions including rare de novo (non-inherited) genetic mutations. Individuals who have a sibling with ASD are at a higher risk of also having ASD.<sup>7-9</sup>
- Environmental risk factors: Certain prescription medications taken during pregnancy are associated with a higher risk of ASD, including valproic acid and thalidomide.<sup>10</sup> Older parental age (both paternal and maternal) is also associated with increased risk of ASD.<sup>11</sup>

### **Cognition and Learning**

- Approximately 44% of individuals with ASD have average to above average intelligence. Intellectual disability in ASD ranges from mild to profound.<sup>2-3</sup>
- Individuals with ASD often show significant strengths in nonverbal reasoning, which means that utilizing visual stimuli and materials will likely aid in learning and development with this group. Conversely, some individuals with ASD demonstrate significant strengths in language and verbal reasoning and have less developed non-verbal and spatial skills. Learning strategies should be tailored to an individual's profile of unique strengths and challenges.
- Individuals with ASD often present with learning challenges, including difficulties generalizing information and skills across contexts.
- Difficulties with processing speed and capacity are common in individuals with ASD, and information may need to be presented at slower rates and/or in smaller amounts.
- Literal and concrete thinking is common in ASD. Therefore, it can be helpful to teach abstract concepts in a concrete way, which may be accomplished through the use of visual representations, repetition, and adjusting language accordingly.
- Some individuals with ASD may have exceptional skills in memory, math, music, visual, or other specific skills.

### Language and Communication

Earl, R.K., Peterson, J., Wallace, A.S., Fox, E., Ma, R., Pepper, M., & Haidar, G. Bernier Lab, Center for Human Development and Disability, University of Washington bernierlab.uw.edu P a g e | 2



- Speech and language skills of individuals with ASD may range from nonverbal (no expressive language) to fluent use of complex speech to communicate. Approximately 25% percent of individuals with ASD are nonverbal.<sup>12</sup>
- History of speech delays is common in individuals with ASD, although not all individuals have delays in language.
- Augmentative Alternative Communication (AAC) devices (e.g., Proloquo program, Picture Exchange Communication System (PECS)) are strategies used to improve communication for those who are non-verbal or when natural speech does not meet an individual's needs for functional communication.
- Individuals with ASD may also show an atypical pattern of language development (e.g., expressive skills superior to receptive language).

### **Co-Occurring Conditions**

- 1. There is a high rate of psychiatric comorbidity with ASD, particularly ADHD and internalizing conditions such as anxiety, depression, and Obsessive-Compulsive Disorder.<sup>13</sup>
- 2. Behavioral problems and/or aggression are also common and tend to be more prevalent in individuals with ASD versus individuals with intellectual disability and no ASD diagnosis.
- 3. Fine and gross motor delays or skill deficits are also frequently seen in this population and may persist into adolescence and/or adulthood.
- 4. Common medical comorbidities include: epilepsy, gastrointestinal problems (e.g., chronic constipation and/or diarrhea, GERD, inflammatory bowel conditions), sleep disturbances, and feeding difficulties.<sup>14</sup>



# General strategies for working with individuals with ASD

When working with an individual who shows symptoms of ASD, the key word is *FLEXIBILITY*. Given the variable presentation of ASD, some strategies may work very well for some but not all. The following strategies are often helpful with clients with ASD, although, as with all therapies, it's especially important to adapt strategies based on the individual and presenting concerns.

### **Communication Strategies**

- Each individual with ASD has unique strengths and challenges in communication. It is important to explore alternative modes of communication (e.g., speech, writing, communication devices) and find the best method for each individual. If your client is using AAC devices at home or at school, make sure to offer to incorporate those communication modes in session.
- Give clear, simple instructions:
  - Use fewer words
  - Provide longer wait time/processing time during communication
  - "First, then..." instructions (e.g., "First we finish this worksheet, then you can play with the iPad").
- Include visual schedules to help your client orient to what you will be doing in session and what to expect, as well as when teaching a new skill.
- Regardless of the communication level of your client with ASD, visual supports may be helpful and can be adapted to include words and verbal instructions with a more verbal client.
- When teaching a new skill, "show, tell, do." Breaking lessons down into smaller steps and scaffolding your client's skill-building will likely be helpful.
- Individuals with ASD often require increased repetition and practice for better generalization of learned information and skills, including the opportunity for increased use of information and skill practice across contexts.
- Due to variable language and attention capabilities, individuals with ASD may benefit from the use of technology in both therapy lessons and practice.
- While some individuals with ASD may be limited in their verbal communication, others may speak in full sentences but have trouble reading social cues and carrying on reciprocal conversation. During session, if you find that your client is struggling to stay on topic or is talking for long periods of time about a restricted interest, provide clear redirection to the topic you are working on in session (e.g., "I can tell you





really love Minecraft. We're not going to talk about Minecraft right now because we have some work to do. When we have a break in 10 minutes, we can talk about Minecraft some more.").

### Social Strategies

- It may take more time to build rapport with a client with ASD. Spend ample time building rapport, potentially capitalizing on their special interests. It will also be important to learn the client's individual communication and interactions styles, as well as to identify additional unique needs beyond the presenting concern.
- Incorporate an individual's restricted interest in therapy as a way to increase buy-in during sessions (e.g., if your client is particularly interested in Batman, design lessons around Batman, such as "How does Batman deal with tough feelings?").
- Social skills, particularly regarding appropriate and inappropriate social behaviors, may need to be explicitly taught in session.
- Generalizing social skills to other settings may be more challenging for individuals with ASD. Your client may benefit from opportunities to practice skills in multiple contexts with the help of their caregivers and providers (e.g., parents, teachers, therapists, peers).
- Individuals with ASD can have trouble with social boundaries and can engage in socially disinhibited behaviors or topics of conversation. Clear expectations around physical contact or appropriate topics may be necessary (e.g., requesting high fives instead of hugs, redirecting when your client asks too personal a question).

### **Behavior Strategies**

- Individuals with ASD often need additional time to transition from one activity to another, especially from preferred to less preferred activities
  - Give advanced warning before a transition (e.g., "In 2 minutes, iPad time will be over and it will be time to work.")
  - Follow through with what you promise be accurate and follow through on time limits.
- Build in frequent breaks during sessions as your client may have more trouble sustaining attention and motivation compared to typically developing peers. Visual timers can be used to delineate time spent working vs. playing.
- Use of tangible incentives or time engaging in preferred activities may be helpful rewards to increase participation and compliance. Praise for positive behaviors is also important.
- If an individual with ASD becomes dysregulated during session, it is important to consider whether task demands are appropriate and whether your client "cannot" or "will not" participate. If the demand is



incongruent with the individual's skills, the structure of sessions and therapist expectations may need to be adjusted. Increasing external rewards is often helpful to increase participation of a client whose task demand is appropriate to his/her developmental level.

### Safety Strategies

- If your client begins exhibiting aggressive or self-injurious behaviors, pay attention to ways to make the environment safe for your client and those around them (e.g., removing dangerous objects, creating space between you and the client).
- Use concrete, firm language depending on the client's developmental level (e.g., "no hitting," "keep your body safe", "I don't feel safe").
- If your client becomes dysregulated, reduce task demands and decrease the amount of sensory input in the room (e.g., quiet the room, dim bright lights).
- It may take more time for an individual with ASD to get back to baseline, so allow space and look out for the first appropriate behavior you can praise after your client has calmed.
- As mentioned previously, individuals with ASD can struggle with understanding and respecting social boundaries, both physically and in conversation. Setting clear and concrete expectations about appropriate topics or gestures of affection may be helpful.

#### Sensory Strategies

- Individuals with ASD may seek out certain sensory sensations (e.g., seeking external pressure, smells, tastes, touch), while others may have aversions to different sensory experiences (e.g., sensitive to noises, smells, textures). Sometimes, an individual can present with both. It is important to find out about these preferences in order to better understand your client's behaviors, as well as to provide potential strategies for calming your client. It may take some trial and error in finding sensory activities that are calming to your client. For example, play-doh may be a highly preferred sensory activity for one client, but it may be aversive to another. Asking caregivers and teachers what works at home and at school is a good place to start.
- Introduce relaxation activities that are mindful of your client's sensory sensitivities or needs (e.g., listening to calming music, dimming the lights, providing a weighted blanket or vest).

### References



- 1. American Psychological Association (APA). (2013). Diagnostic and statistical manual of mental disorders (5 ed.). Washington, D.C.: Author.
- 2. Christensen, D. L. (2016). Prevalence and characteristics of autism spectrum disorder among children aged 8 years—autism and developmental disabilities monitoring network, 11 sites, United States, 2012. MMWR. Surveillance Summaries, 65(3), 1-23.
- 3. Baio, J. (2014). Developmental Disabilities Monitoring Network Surveillance Year 2010 Principal Investigators; Centers for Disease Control and Prevention (CDC). Prevalence of autism spectrum disorder among children aged 8 years—Autism and developmental disabilities monitoring network, 11 sites, United States, 2010. MMWR Surveillance Summaries, 63(2), 1–21.
- Mandell, D. S., Wiggins, L. D., Carpenter, L. A., Daniels, J., DiGuiseppi, C., Durkin, M. S., ... Kirby, R. S. (2009). Racial/Ethnic Disparities in the Identification of Children with Autism Spectrum Disorders. American Journal of Public Health, 99(3), 493–498.
- 5. Lord, C., Rutter, M., & Le Couteur, A. (1994). Autism Diagnostic Interview-Revised: a revised version of a diagnostic interview for caregivers of individuals with possible pervasive developmental disorders. *Journal of Autism and Developmental Disorders*, 24(5), 659-685.
- 6. Lord, C., Rutter, M., DiLavore, P.C., Risi, S., Gotham, K., & Bishop, S.L. (2013). Autism Diagnostic Observation Schedule (2 ed.). Los Angeles, CA: Western Psychological Services.
- Iossifov, I., O'Roak, B. J., Sanders, S. J., Ronemus, M., Krumm, N., Levy, D., ... & Smith, J. D. (2014). The contribution of de novo coding mutations to autism spectrum disorder. *Nature*, 515(7526), 216-221.
- Krumm, N., Turner, T.N., Baker, C., Vives, L., Mohajeri, K., Witherspoon, K., Raja, A., Coe, B.P., Stessman, H.A., He, Z., Leal, S.M., Bernier, R., Eichler, E.E. (2015). Excess of rare, inherited truncating mutations in autism. *Nature Genetics*. 47(6):582-8
- Gaugler, T., Klei, L., Sanders, S. J., Bodea, C. A., Goldberg, A. P., Lee, A. B., ... & Ripke, S. (2014). Most genetic risk for autism resides with common variation. *Nature genetics*, 46(8), 881-885.
- Christensen, J., Grønborg, T. K., Sørensen, M. J., Schendel, D., Parner, E. T., Pedersen, L. H., & Vestergaard, M. (2013). Prenatal Valproate Exposure and Risk of Autism Spectrum Disorders and Childhood Autism. JAMA, 309(16), 1696–1703.
- 11. Frans, E. M., Sandin, S., Reichenberg, A., Långström, N., Lichtenstein, P., McGrath, J. J., & Hultman, C. M. (2013). Autism risk across generations: a population-based study of advancing grandpaternal and paternal age. JAMA psychiatry, 70(5), 516-521.
- 12. Tager-Flusberg, H., Paul, R., Lord, C., Volkmar, F., Paul, R., & Klin, A. (2005). Language and communication in autism. Handbook of autism and pervasive developmental disorders, 1, 335-364.
- 13. Simonoff, E., Pickles, A., Charman, T., Chandler, S., Loucas, T., & Baird, G. (2008). Psychiatric disorders in children with autism spectrum disorders: prevalence, comorbidity, and associated factors in a population-derived sample. *Journal of the American Academy of Child & Adolescent Psychiatry*, 47(8), 921-929.
- 14. Kielinen, M., Rantala, H., Timonen, E., Linna, S. L., & Moilanen, I. (2004). Associated medical disorders and disabilities in children with autistic disorder a population-based study. *Autism*, 8(1), 49-60.



