AASPIRE Healthcare Toolkit

Autism Information, Diagnosis, and Referrals

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Autism Information, Diagnosis, and Referrals: Autism Information, Diagnosis, and Referrals

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1 ASD criteria and manifestations in adults

The DSM-5 specifies diagnostic critera for ASD.[24] The following table summarizes the DSM-5 criteria, with examples of how these criteria may manifest in adults.[22]

Examples of how critera may manifest in adults

A. Persistent deficits in social communication and social in-teraction across multiple contexts. (Diagnosis requires person meets all three criteria.)
1. Deficits in social-emotional reciprocity. Difficulty initiating or sustaining back and forth conversation; tendency to monologue without attending to listener cues; unusual response to greetings or other so-cial conventions. 2. Deficits in nonverbal communicative behaviors used for social interaction. Lack of eye contact; difficulty understanding non-verbal communication; unusual tone of voice or body lan-guage. 3. Deficits in developing, maintaining, and understanding relationships. Challenges adapting behavior to match different social settings such as when interacting with family, friends, authority figures, or strangers; difficulty developing or sustaining friendships; greater

than usual need for time alone.

B. Restricted, repetitive patterns of behavior, interests, or activities. (Diagnosis requires person meets at least two of four criteria.)1. Stereotyped or repeti-tive motor movements, use of objects, or speech. Repetitive move-ments or ”stimming” (e.g., rocking, flapping, pacing, or spinning for enjoy-ment or as a coping mechanism); arranging objects in a very precise man-ner; echolalia; continuously repeating sounds, words, or phrases. 2. Insistence on sameness, inflexible adherence to routines, or ritualized patterns of verbal or nonverbal behavior. Greater than expected degree of distress with changes in routines or expectations; difficulty transi-tioning between activities; need to do the same thing in the same way each time; greater than usual reliance on rituals for accomplishing daily tasks. 3. Highly restricted, fixated interests that are abnormal in in-tensity or focus. Intense special interests (e.g., looking at spinning objects for hours, learning the detailed schedules of an entire public trans-portation system, or becoming an expert in seventeenth century art) while having significant difficulty attending to topics outside of one’s areas of spe-cial interest. 4. Hyper- or hyporeactivity to sensory input or unusual interest in sensory aspects of the environment. Being hyper-or hypo-sensitive to sounds, lights, smells, or textures; having an abnormally high or low pain threshold; difficulty processing more than one sense at a time (e.g., not being able to understand spoken language while looking at someone’s face); tendency to become confused or overwhelmed by sensory stimuli; challenges with body awareness or separating different types of sen-sations.

C. Symptoms must be present in the early developmental period (but may not become fully manifest until social de-mands exceed limited capacities, or may be masked by learned strategies in later life) Though characteristics should have been present through-out one’s lifetime, a change in circumstances can disrupt coping strategies and make characteristics more pronounced; alternatively, environmental fa-cilitators, supports, and coping strategies may make characteristics less noticeable.

D. Symptoms cause clinically significant impairment in social, occupational, or other important areas of current functioning. Characteristics lead to difficulty obtaining or sustaining employment, doing basic or instrumental activities of daily living, maintaining social life, or integrating with community. For example, there may be signifi-cant mismatch between educational attainment and occupational history.

E. These disturbances are not better explained by intellectual disability or global developmental delay. Intellectual disability and autism spectrum disorder frequently co-occur; to make comorbid diag-noses of autism spectrum disorder and intellectual disability, social commu-nication should be below that expected for general developmental level.

Though the DSM-5 conceptualizes ASD primarily as a social-communication disorder, there is a growing literature supporting the hypothesis that ASD is primarily characterized by differences in informa-tion processing.[23] See, for example, the intense world theory of ASD.

Adults on the autism spectrum may display autistic traits differently from children. Most people, regardless of whether or not they are on the autism spectrum, mature and behave differently as they get older. As such, adults on the spectrum may not fit society's images of autistic children. In addition, adults often find coping strategies that help them function in the world, but that may make autistic traits harder to recognize.

There is great heterogeneity in the clinical presentation of ASD. Although anyone on the spectrum would be expected to have challenges with social communication, these challenges can show up in many different ways. For example, a person may not be able to speak, may misunderstand facial expressions and body language, or may take language too literally. A person may have difficulty starting a conversation, may need more time alone than most people, or may feel uncomfortable socializing with others without a planned activity.

Likewise, anyone on the spectrum would be expected to have restricted or repetitive patterns of behaviors, interests, or activities, but that can be different for each person. For example, a person may look at spinning objects for

hours, learn the detailed schedules of an entire public transportation system, or be an expert in seventeenth century art. Many people on the spectrum appreciate structure and can find routines very helpful in understanding or coping with the world. For example, they may always need to take the same route to get somewhere or may use a very complex organizational system to function at work or remember to eat. Unplanned events or changes in routines may cause anxiety for people on the autism spectrum.

People on the autism spectrum may experience sensory input differently from other people. For example, a person might have very sensitive hearing, whereas another might have an extremely high pain threshold. Often people may have a very hard time coping with certain sensations, such as fluorescent lights, loud sounds, light touch, or particular textures or smells. They may not be able to process more than one sense at a time. For example, they may not be able to understand spoken language while looking at someone's face. They may also get overwhelmed when there are a lot of sensory stimuli happening at once.

Some people on the spectrum may have difficulty with motor skills. Examples may include difficulty with handwriting, catching a ball, or planning complex, multi-step actions like learning a dance sequence.

Traits of autism can be strengths or challenges, or sometimes both. For example, some autistic individuals develop great expertise in their areas of special interests, or capitalize on their need for routine and consistency to effectively self-manage chronic conditions. Not all people on the autism spectrum have stereotypical positive traits such as being good at memorizing things or using computers. Similarly, people on the autism spectrum do not always shy away from social interactions, and many can maintain strong friendships or relationships.

2 Changes in autism-related criteria between DSM-IV TR and DSM-5

The DSM-5 significantly revised the criteria for diagnoses on the autism spectrum. Formerly, the DSM-IV TR had a category called Pervasive Developmental Disorders (PDD), which included separate diagnoses of autistic disorder, Asperger's disorder, Rett's disorder, childhood disintegrative disorder, and pervasive developmental disorder - not otherwise specified (PDD-NOS). (See DSM-IV diagnostic criteria).

Asperger's disorder had similar criteria to autistic disorder in regards to impairments in social interaction and restricted interests, but it stipulated that individuals must not have clinically significant delays in general language development, cognitive development, or development of adaptive skills, other than in social interaction. PDD-NOS was to be used when there was a severe and pervasive impairment in the development of reciprocal social interaction associated with impairment in either verbal or nonverbal communication skills or with the presence of stereotyped behavior, interests, and activities, but the criteria were not met for a specific Pervasive Developmental Disorder.

Distinctions between autistic disorder, Aperger's disorder, and PDD-NOS were inconsistent in clinical practice, with great variation depending on clinical setting and diagnostician. The DSM-V unified the diagnoses of autistic disorder, Asperger's disorder, childhood disintegrative disorder, and PDD-NOS into one diagnosis called autism spectrum disorder (ASD).

Rett's syndrome has since been found to be caused by mutations in the MeCP2 gene. Individuals with Rett's syndrome who meet the clinical criteria of ASD will now be classified as having ASD, with the label 'associated with Rett syndrome' or 'associated with MeCP2 mutation'. This approach is similar to what is used for individuals with fragile X syndrome or tuberous sclerosis who also meet clinical criteria for ASD.

3 Risks and benefits of adult diagnosis

Many adults who meet diagnostic criteria for ASD do not carry formal medical diagnoses of ASD, either because they have never come to medical attention or because they have been misdiagnosed with a differential condition (e.g., social anxiety, intellectual disability, obsessive-compulsive disorder). When deciding whether to refer an adult patient for a diagnostic evaluation for ASD, one should consider potential risks and benefits of a diagnosis, and should discuss these possibilities with the patient and, if applicable, his or her supporters.

Potential benefits of a formal diagnosis are as follows.

- Would confer legal rights to accommodations in school, at work, in healthcare, or in other settings.
- May assist the individual in developing a better understanding of self.
- May provide peace of mind through the professional confirmation of life experiences.
- May provide means to experience better coping or quality of life by more directly helping in recognizing strengths and accommodating challenges.
- May provide others means to understand and support the individual.
- May qualify the individual for benefits and services for people who have an ASD diagnosis.
- May qualify the individual for programs for people with disabilities, such as scholarships or incentives that are meant to increase workplace diversity.

Potential risks associated with seeking an ASD diagnosis are as follows.

- The process of seeking and being evaluated for the diagnosis may be stressful.

- The person may perceive the interaction with the diagnostician or provider as negative, disrespectful, or otherwise uncomfortable.
- The interpretation of ASD criteria and subsequent diagnosis varies by provider, particularly in the adult presentation.
- Information about an individual's ASD could potentially negatively impact child custody cases.
- Others in individual's life may still not be supportive, even with the diagnosis.

4 Diagnostic referrals

Finding a provider who is qualified to diagnose ASD in adults may be challenging. Professionals who commonly diagnose individuals on the autism spectrum include psychiatrists and psychologists. Providers who predominantly work with children, however, may or may not accept adult patients or have a full understanding of how autism manifests in adults. Similarly, many psychiatrists and psychologists who primarily work with adults may not have expertise in autism. It is best to contact potential providers to assess their willingness and expertise in working with adult patients on the autism spectrum. In general, diagnoses should be made using input from a variety of sources including standardized diagnostic instruments such as the ADOS or ADI-R.

Health insurance coverage for ASD diagnoses can vary. Clinical history and observation within the context of a billable clinical visit may be sufficient to make the diagnosis. Coverage for mental-health visits varies by plan. Complete testing may or may not be covered by certain payers, and may require prior authorization. Vocational rehabilitative services may provide assessments that are indicated to help an individual in his or her desire to achieve employment.

5 Referrals for therapies and assistive technologies

Though there is greater attention to, and controversy about, therapies intended to treat ASD in children, providers often under-utilize referrals for therapies, services, and assistive technologies for adults on the autism spectrum. Such therapies, services, or technologies are not meant to treat or cure autism, but can potentially help adults on the autism spectrum improve function or quality of life. The aim is to help patients address challenges, increase coping strategies, treat co-occurring conditions, or obtain needed accommodations or supports. Participation in therapy should be the patient's choice.

The following are a few examples where providers may consider referring adult patients on the autism spectrum for additional therapies, services, or assistive technologies.

Many individuals who have limited speech can benefit from the use of assistive and augmentative communication (AAC) technology, such as picture boards or text-to-speech devices. There are countless examples of individuals who could not communicate effectively until they learned to use assistive technology as adults. Typically, such patients' intellectual capabilities are under-estimated. Patients also may continue to develop and mature well into adult life. Failed attempts to use assistive communication in the past should not preclude reconsideration of a referral for adult patients with limited communication skills.

The benefit of AAC is not limited to individuals with minimal speech. Many people on the autism spectrum report that their ability to communicate using speech varies significantly from one time to the next, or in different situations. Similarly, even people who sound as if they have fluent speech may find that they communicate much more effectively using AAC devices such as text-to-speech programs. Conversely, patients who have difficulty writing may benefit from speech-to-text or word completion programs. AAC and assistive writing technologies can be used with free-standing devices, computers,

or smartphones and other mobile devices. When caring for patients on the autism spectrum who report challenges with spoken or written language, consider offering referrals to Speech and Language Pathologists or Occupational Therapists who have experience with these technologies. Other assistive technologies that may be useful to adults on the autism spectrum include electronic organization or reminder systems.

Many patients on the autism spectrum experience mental health problems such as depression, anxiety, and post-traumatic stress disorder. One should not assume that mental health problems are inherent to autism. Identifying and addressing co-occurring mental health issues is important. In some cases, patients may respond well to typical therapies such as antidepressants. In other cases, it may be critical to find a therapist who understands how to work with adults on the autism spectrum, because typical assumptions about how to communicate effectively with patients or foster strong therapeutic relationships may or may not apply to individual patients.

Mental health therapists may also be able to offer strategies or ideas for accommodations to help with communication, organization, or sensory sensitivities. Some mental health therapists can help patients learn ways to understand and manage social situations. Patients may find therapy helpful in finding ways to understand and respond to negative emotions or to help prevent melt-downs.

Speech language pathologists and occupational therapists can potentially help adult patients find effective strategies for improving social communication and increasing independence in activities of daily living. Vocational rehabilitation services are often available to help patients on the autism spectrum obtain or sustain employment.

Local autism centers, autism organizations, developmental disability programs or offices, or professional organizations may have names of therapists who have expertise working with adults on the autism spectrum. Autism NOW lists many national and local resources for individuals on the autism spectrum.

6 Associated conditions

There is scare data on the health status of autistic adults. However, some studies show that autistic adults have high rates of chronic medical conditions including epilepsy, gastrointestinal disorders, metabolic syndrome, anxiety, depression, sleep disturbance and exposure to violence and abuse.[1],[2],[3],[4] Autism is associated with reduced life expectancy, especially for those with epilepsy, moderate to severe intellectual disability and female sex. Preventable causes such as accidents, trauma and barriers to accessing medical care may also contribute.[5],[6],[7]

Roughly 20-30

Autistic people are also at risk for physical and sexual violence from partners, supporters and peers. Other forms of abuse include neglecting to provide needed care, economic abuse or withholding an assistive device.

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