

FREQUENTLY ASKED QUESTIONS ABOUT AUTISM SPECTRUM DIAGNOSES

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What is a diagnosis?

A diagnosis is a categorical term that describes a group of behaviors or characteristics that, in most cases, are linked with a particular disease or disorder through cause, trajectory and effective treatments.

How is a diagnosis of an Autism Spectrum Disorder (ASD) different from other diagnoses?

Because we do not know the causes, ASD diagnoses are based purely on observations or reports of behaviors. Unlike many medical syndromes, ASDs are not diseases. They are not contagious and are not yet treatable through medication (though medicine can help some symptoms). They are developmental disorders that reflect differences in the way that children develop from very early on (from infancy and toddlerhood) and that usually continue to affect development into adulthood. The primary treatments are educational (e.g., teaching individuals with ASDs ways to do things that may not come as easily for them) and compensatory (e.g., helping individuals learn to use their strengths to make up for areas that are more difficult), as well as behavioral (e.g., helping individuals and families to minimize behaviors that interfere with daily living, such as tantrums or self-injury).

How are Autism Spectrum Disorders defined?

ASDs are defined by difficulty in three areas of behaviors: 1) reciprocal social interaction, 2) communication and 3) repetition and insistence on sameness. Exactly how an individual is impacted across these three areas varies greatly. There is no one behavior that is present in all individuals with ASDs or that would rule out ASDs in every person. Many, but not all, individuals with ASD have language delays. Some individuals with ASD, but not all, have lifelong language disorders. Some, but not all, individuals with ASD also have mental retardation that affects development of nonverbal problem-solving, everyday self-care (e.g., dressing; academics) and language.

Are there different types of ASDs? Are some cases of ASD more severe than others?

Within the category of Autism Spectrum Disorder (sometimes known as Pervasive Developmental Disorders or PDD), there are a number of subtypes that are associated with different levels of severity in different areas.

Autism is the disorder that has received the most study and has been recognized for the longest time. It is defined by the presence of difficulties in each of the three areas listed above (social deficits, communication problems and repetitive or restricted behaviors), with onset in at least one area by age 3 years. It may or may not be associated with language delays or mental retardation.

Asperger Syndrome is a form of ASD that is often identified later (e.g., after age 3, usually after age 5) and is associated with the social

symptoms of autism and some repetitive interests or behaviors, but not with language delay or mental retardation. Many parents and professionals use this term with older and/or more verbally fluent individuals with autism because they feel it is less stigmatizing.

Rett Syndrome and *Child Disintegrative Disorder* are both very rare, severe forms of ASD that have particular patterns of onset, and, in the case of Rett Syndrome, a specific genetic basis.

Pervasive Developmental Disorder - Not Otherwise Specified (PDD-NOS) is a form of ASD used to describe individuals who meet criteria for autism in terms of social difficulties but not in both communication and restricted, repetitive behaviors. It can also be used for children who do not have clearly defined difficulties under age 3 or later. This term is often used by professionals when they are not quite sure of a diagnosis or when the symptoms are mild. Several epidemiological studies have reported that as many or more children have PDD-NOS or less clear symptoms as have classic autism. The difficulties of children and adults with Asperger Syndrome or PDD-NOS are similar, and milder than those of individuals with autism, suggesting that these distinctions are fairly arbitrary and should not be used to limit services or benefits.

What benefit is a diagnosis of ASD?

A diagnosis should go beyond a description of defining features of a disorder to provide important information about other aspects of behavior or development. For example, where ASDs are concerned, it is essential to know that families with one child with ASD are at greater risk for having another child with ASD, though this risk is probably less than 1 in 5. Also important is the fact that adolescents with ASD are more likely to have a seizure or develop epilepsy than other children their age. Most important of all, a diagnosis often provides children access to services through school systems and early intervention networks. It can also provide adults access to services through vocational programs. A diagnosis can give parents and family members a way to start acquiring information about other children with similar difficulties and ways to find support through local, national and international organizations.

A diagnosis should provide information about effective and ineffective treatments. Though there is no one-size fits all treatment for ASDs, it is clear that low intensity interventions that are not built on engaging a child in social interaction and communication, and that do not involve parents, are not appropriate programs for young children with ASDs. In ASD, many children's behavior problems (e.g., tantrums) are linked to not being able to communicate. Providing the child with a way to let others know what he or she wants (e.g., through words or signs or pictures) and helping the child understand what others are saying (also through pictures or objects or gestures) can decrease problem behaviors greatly. Medications may help treat additional symptoms in ASD, such as hyperactivity, but are often less effective in children with ASD than other children.

A diagnosis is necessary for doing research to find the causes and to improve treatments for ASDs, so that scientists can know who they are studying and can compare findings across different research projects. Because there are probably many subtypes of ASD, researchers need to work with large numbers of children and families in order to have adequate numbers of similar children. This means that researchers need to merge samples, which requires that they agree on common diagnostic procedures (or else they will not know what differences across samples mean if they occur).

What are the differences among screening, diagnosis and a full assessment of ASD?

A screening involves determining if a child or adult is at risk for having an ASD and should have a more detailed assessment. This screening may be specific to autism or may be part of a more general screening for developmental disorders such as language delay. Screenings are intended to be brief, easy to use (by parents and professionals), and inexpensive. A positive screening should be followed up by a diagnostic assessment. The biggest difficulty in autism screenings to date is that, at least with young children, children later determined to have autism are often found to have been missed by earlier screenings. Thus, if parents are concerned, they should be wary of quick screenings and reassurances that everything will be all right without careful attention to their concerns.

What makes a good diagnostic assessment?

Because children and adults with ASDs have such varying profiles, most good diagnostic assessments provide a description of strengths and weaknesses, including attention to children's language, cognitive and other skills. These factors are often as important as the actual diagnosis of an ASD in setting appropriate goals and intervention plans. In the end, the most important factors in a diagnosis are the experience and care of the diagnostician. Many different healthcare professionals can diagnose autism including a child psychiatrist, clinical psychologist, developmental pediatrician, or a speech-language pathologist. In most cases, more than one discipline should be involved, if not at the same visit, at least in communicating their perspectives with each other.

A diagnostic assessment for ASD should involve both a history and a description of current behavior by a caregiver, as well as direct observation of the behavior of the child or adult suspected of having ASD by an experienced clinician. These observations require sufficient knowledge that having a less experienced person (e.g., a clinical assistant, a resident) do the assessment and then consult with the more experienced supervisor is generally not appropriate.

The most well-known diagnostic instruments for ASD are the Autism Diagnostic Interview – Revised (ADI-R) and the Autism Diagnostic Observation Schedule (ADOS). The ADI-R is a caregiver interview that takes about 2 hours; the ADOS is a series of play-based tasks administered to the child, usually with the parent(s) present. These instruments require training to administer and require more specialist hours than most health insurance is willing to reimburse. Many centers may use different combinations of these instruments and other, quicker measures (e.g., parent questionnaires) in a diagnostic assessment. What is important is not so much the specific instruments, as the combination of information from the caregivers and from an expert working with and observing the child. Also vital is the assessing clinician's experience with ASD.

In almost all cases, interpreting diagnostic information also requires knowledge about the child's receptive and expressive language and nonverbal functioning. A child who is very far behind in all areas (e.g., a 3 year-old who has the abilities of a 9 month-old) may score in the range of autism, not because he or she has ASD, but because there are so many things he or she cannot do, that scores will be high on any instrument. A very bright verbal 3 year-old with ASD will not have the same behaviors as a child with ASD with a severe language delay in comprehension and expressive language. Other pieces of information (e.g., ensuring the child can hear and that there are no contributing medical conditions, talking to the child's current teachers, if he or she is in preschool) are also important to a diagnosis of ASD. With increasing media awareness, many professionals who are not experts in ASD can recognize some symptoms of ASD and suggest possible diagnoses. Because of the variation in ASDs, however, experts in these disorders often can provide information beyond a diagnostic term that can help parents in making decisions about treatments.

How young can a child be to receive a diagnosis of ASD?

Some children have such clear symptoms that they can be reliably diagnosed with ASD at 12 - 15 months, but most clinicians will want to wait until a child is 18 - 24 months before giving a diagnosis. Diagnoses made under age 3 are less reliable (e.g., less predictive of stable diagnoses over time) than diagnoses made in older children, so it is important for children who receive diagnoses when they are very young to be re-evaluated each year, including measurement of changes in cognitive and language skills. In later years, re-evaluations usually focus more on how behaviors and skills have changed more than on diagnosis.

What is the relationship between getting a diagnosis and getting services?

Legally, in the United States, a child is supposed to receive educational and early childhood services according to his or her needs, not according to a diagnosis, but many states and school systems do differentially allocate services to children with autism diagnoses. Some states do not provide the same services to children with a diagnosis of PDD-NOS or Asperger Syndrome as they do to children with a diagnosis of autism. This is not scientifically or educationally justifiable, but it means that families may feel pressed to get a clear diagnosis of

autism in order for their child to receive the services he or she needs, even though they, and professionals, may prefer the more ambiguous classifications (e.g., PDD-NOS, Asperger) because they imply milder symptoms. While sometimes service providers may treat autism (and scores on autism diagnostic instruments) as all or none, this is not correct. This is one reason to be sure that a child's evaluation is done by someone experienced and knowledgeable about ASD.

Are there ways to get the most out of a diagnostic assessment for ASD?

The more prepared parents are for a diagnostic assessment, the more they will usually get out of it. If at all possible, both parents should attend the assessment so that both can see what was done and be able to ask questions. If this is not possible, having a relative or friend come along can be very helpful, too. Preparing a list of questions to ask the clinician both before the assessment and after can be very helpful. Making copies of these lists to give to the clinicians may help the clinician remember to address what is most important to the caregiver. Taking a list of people who already work with the child, their phone numbers, and good times to reach them can also save tracking information down later. In addition, taking copies of any previous assessments and reports is a very good idea. Even if the parents want an independent assessment, being able to tell the examiner what tests their child has already had can save time and money.

Whether it is the child's pediatrician or a local autism society or a friend, asking the person making the referral for the assessment to describe what to expect and how to prepare can be useful. Taking snacks and small toys that a child likes is often helpful. (Sometimes, rather than giving them to the child right away, it is best to ask the clinician if he or she would like to use them.) If the child can understand, rehearsing with him or her where they are going, who they will see, and what they may do (e.g., play with toys), is usually a good idea as well. With a young child, a parent or parents should almost always be present during the evaluation, unless the child is so distracted by the parent's presence that the examiner cannot get a fair assessment. Reviewing the child's baby book and talking to other people who knew the child when he or she was younger can also be helpful in refreshing a parent's memory in order to provide a more accurate history.

If parents feel that they have not had enough time to process the information they are getting, they should ask to come back in a week or two and review the results after they have had time to think about it. Or, if this is only an assessment clinic, they might ask the clinician to refer them to someone who does follow-up. The value of an assessment is not in the assessment process, but in what the family learns and is able to take back to the community in terms of being better able to understand and advocate for the child.