What is Autism?

According to the Diagnostic and Statistical Manual (DSM-5)\(^1\) autism spectrum disorder (ASD) is classified as a developmental disorder, with or without intellectual disability (ID), which is characterized by impairment(s) in reciprocal social communication and social interaction (i.e. turn taking activities, such as a two person conversation) and restricted, repetitive patterns of behavior, interests or activities (i.e. an individual who talks exclusively about trains). These characteristics are typically present from early childhood and may limit or impair everyday functioning. The term “spectrum” is used because there are many diagnoses that fall “on the autism spectrum” which used to be treated as separate diagnoses including autistic disorder, pervasive developmental disorder not otherwise specified (PDD-NOS), and Asperger’s syndrome. All of these conditions are now considered to be within the autism spectrum and are called ASDs.

People who have autism can have other developmental disabilities in addition to an ASD. For example, some individuals who have a diagnosis of ASD may have above average IQs, while others may have a diagnosed intellectual disability. Likewise, some individuals may have other conditions in addition to an ASD (such as cerebral palsy or Down syndrome) while others do not.

How Many People Have ASDs?

The number of people who are receiving a diagnosis on the autism spectrum is increasing. It is not clear whether this is due to the creation of a broader definition of ASDs or better diagnostics. Regardless, a true increase of autism diagnoses is apparent. The CDC estimates that roughly 1 in 68 children in the United States have ASDs.\(^2\) Autism is more common than multiple sclerosis, cystic fibrosis, childhood cancer, cerebral palsy, Down syndrome, AIDS, and diabetes.\(^3\)
Who Is Most Often Affected?
While ASDs occur in all racial, ethnic, and socioeconomic groups, boys are five times more likely to have ASDs as compared to girls. However, boys, siblings of individuals who have autism, and people who have certain other developmental disorders, such as Fragile X syndrome, are more likely to receive a diagnosis of autism.4

When is it Time for an Evaluation for ASD?
The Eunice Kennedy Shriver National Institute of Child Health and Human Development (NICHD) provides three categories of behaviors that indicate a need for further evaluation: communication, social behavior, stereotyped behavior, and those that are categorized as “other.” Behaviors that may indicate a need for further evaluation may include:

- Absence of response to the child’s name by 12 months of age;
- Not pointing or waving “bye-bye”;
- Disinterest in other children;
- Poor eye contact;
- Repetition of words or phrases;
- Flapping of their hands, rocking their body, or spinning in circles;
- Sensitivity to noise; or
- Engagement in violent tantrums.

The presence of these signs does not prove that a child has autism, just as the presence of developmental milestones does not mean that the child does not have an ASD. But, it does mean that the child should be evaluated further by an interdisciplinary team (a health care team typically consisting of a neurologist, psychologist, developmental pediatrician, speech/language therapist, learning consultant, or other professionals knowledgeable about autism).

How Are ASDs Diagnosed?
Diagnosing ASDs can be challenging since there is no medical test (like a blood test) to verify their existence. Health professionals consider the child’s behavior and development to make a diagnosis. An ASD diagnosis is considered reliable by age two, although most children do not receive a final diagnosis until they are much older.

Typically, two steps are taken to diagnose ASDs:

1. **Developmental Screening:** This is a short test to determine if the child is meeting developmental milestones (learning basic skills at the age they should be learning them). A delay in any area could be cause for concern. Children should be screened specifically for ASDs during regular well-child doctor visits at 18 and 24 months, with additional screening if a child is at high risk for ASDs or if behaviors associated with ASDs are present; and

2. **Comprehensive Diagnostic Evaluation:** The second step is obtaining a comprehensive evaluation that may include looking at the child’s behavior and development and interviewing the parents. Hearing and vision screening, genetic testing, neurological testing, and other medical tests are often conducted as well. The primary care doctor may choose to refer the child to a specialist for further testing; such specialists include developmental pediatricians, child neurologists and child psychologists or psychiatrists.

To get one of these screenings, parents should ask their pediatrician for a recommendation to a developmental pediatrician for a developmental screening. For a more comprehensive diagnostic evaluation, parents should explore programs at hospitals, research institutes, universities, and places where individuals with developmental or intellectual disabilities are served. They could also look for clinics that specialize in working with people who have disabilities, as well as ask for referrals from other parents of children with disabilities as well as pediatricians and other doctors that their child might already see.

How Does The Arc Help People with ASDs and Their Families?
People with ASDs and the family
members who care about them need support in many ways. Parents often turn to The Arc for support and services that aren’t available from other sources. Families need help navigating these various systems in getting the support they need.

The Arc has over 650 state and local chapters that serve people with various intellectual and developmental disabilities, including autism. A 2011 survey of The Arc’s chapters showed that 93% of chapters across the country serve individuals who have a diagnosis on the autism spectrum. The Arc’s Autism Now: The National Autism Resource and Information Center is a lifeline for families in need. It is a dynamic and interactive, highly visible and effective central point of quality resources and information for individuals with ASDs and other developmental disabilities.

For more information, visit The Arc at thearc.org and The Arc’s Autism Now Center at autismnow.org.

References:
1 Diagnostic and Statistical Manual of Mental Disorders 5th Edition, 2013