



Autism Spectrum Disorders (ASD) Frequently Asked Questions By Providers

What are Autism Spectrum Disorders (ASD)?

Autism and Pervasive Developmental Disorders (PDD) are perplexing developmental disorders that affect 5 to 15 in 10,000 children and are two of the disorders included in Autism Spectrum Disorders (ASD). Children affected by these neurologically-based disorders come from all countries, cultures, and economic backgrounds. There is strong evidence that autism is present at birth. Characteristics become noticeable between the ages of one and three years, in most cases, and affect the development of speech and social interactions, especially interactions with other children. These disorders are also often, but not always, associated with difficulties in attention and range of interests. These terms are not used to describe a delay in development, but rather a difference or deviation in development in the areas of communication, social interaction, and attention to objects. Children between the ages of one and three are often more likely to receive a diagnosis of PDD because of the high degree of developmental variation across children in this age range, and because some of the behaviors associated with autism would not be expected to be well-developed in children under the age of three.

ASD encompasses PDD and also includes autism, Rett's Disorder, Childhood Disintegrative Disorder, Asperger's Syndrome, and Pervasive Developmental Disorders-Not Otherwise Specified (PDD-NOS). These disorders describe qualitative and quantitative differences in the child's ability to communicate, interact socially, and interact with objects and routines. The number of behaviors and the range of severity of involvement in each area is used to determine the specific diagnostic category. For very young children, use of the term Autism Spectrum Disorders may be more accurate because certain communication and play skills would not be expected to have developed at the time of initial evaluation. While children may change diagnostic labels within the spectrum over time, they are likely to continue to be included within ASD. For parents and providers, the important thing to focus on is not the specific label a child receives, but what can be done to help the child develop skills in the areas of concern. Programs should be developed and implemented based on the unique behaviors of the child and family (concerns/priorities/informed decision making).

What characteristics should alert early intervention service providers that a child may have autism/PDD?

The time between a parent's first concern about the development of a child and an accurate diagnosis of autism/ASD can be as long as two years. Many parents report frustrating experiences with pediatricians and other professionals who first meet with them regarding their child's development. Because toddlers develop at different rates,

many pediatricians advise parents to “wait and see.” However, this often results in loss of valuable intervention time, and eventual anger on the part of the parents. Therefore, it is very important to listen to parents describe their child’s strengths and weaknesses and, if appropriate, to make an early referral for evaluation and appropriate services. A screening for autism, such as the Checklist for Autism in Toddlers (CHAT), can be completed, information about the disorder can be share with families, and/or families can be given contact information for parent groups or organizations focusing on children with autism. For children with these disabilities, research is clear that intensive early intervention results in improved long-term outcomes.

Many professionals think of behavioral excesses, such as spinning, flapping, rocking, head banging, etc., when they hear the word autism. Actually, these symptoms are secondary. The major difficulty for children with autism is in the area of understanding and using reciprocal interactions. This does not mean that children with autism are not affectionate, cannot make contact with other people, or are simply delayed in the development of social skills. Children with autism/PDD have a qualitative difficulty with the give-and-take nature of language interactions, interactive play, and relating to others.

Parents frequently report that their concerns were dismissed because their child demonstrated one behavior that a provider felt ruled out autism/PDD. This diagnosis is not made or ruled-out based on any one behavior. It is diagnosed by a cluster of behaviors in the areas of communication, socialization, and interest/attention. Often the differential diagnosis of autism from PDD requires a diagnostician who has extensive experience with ASD.

Providers should be alerted to several themes in developmental histories of children with autism/PDD. The following characteristics are frequently reported by may parents of young children with these diagnoses.

The child has:

- Normal language development for a period of time, with a loss of language or plateau between 24 and 36 months.
- Fleeting attention span for most activities, yet can spend long period of time focused on one activity of his/her own interest.
- Motor skills, memory, and nonverbal problem solving are developing at a normal or relatively advanced rate when compared to language and social skills.
- A tendency to play alone or to engage in active play with other children but not in sit-down parallel or interactive play.
- A way of pulling the parent to items of interest rather than pointing, vocalizing, or using coordinated eye gaze.

- Difficulty imitating actions.
- Episodes of giggling or crying for no apparent reason.
- Echo-like speech (answers questions by parroting them back).
- The ability to sometimes appear deaf yet hear sounds from a distance when they are particular favorites (ice cream truck, TV theme song, commercial).
- A preference for repetition (lining up toys, sorting, watching Preview Guide or Weather Channel).

What is the treatment for autism/PDD?

Research over the last thirty years suggests that the most successful treatment for children with autism/PDD is intensive and systematic educational programming, including a heavy emphasis on language and social development. Other therapies have been proposed, however, the bulk of research suggests that the educational focus is most effective. Within the educational realm, there are several recognized approaches that are effective. There is no one approach for all children with ASD. Each child needs a comprehensive, coordinated, consistent approach that involves care providers and typically developing peers.

What should I do if I suspect autism?

The seriousness of this diagnosis may scare providers from mentioning it to parents as a possibility. It is vital to provide parents with your honest opinions, and to urge them to consider evaluation if you feel it is appropriate. You may be wrong, but if you are correct, no valuable time will be lost. The first step is a comprehensive evaluation by professionals knowledgeable about autism. There are several potential referral resources. Evaluations, telephone assistance, and referral to local resources (family support groups, evaluators, etc.), as well as family services for children are available across the state. Contact your local Babies Can't Wait Early Intervention Coordinator for resources in your area.

What should I say to the parents of a child whom I suspect has autism/PDD?

Generally, information that is not technically correct can do more harm than good. Therefore, we suggest that you simply mention these diagnoses as something that the family may want to investigate as a possible explanation of the child's developmental pattern. Provide the family with the Babies Can't Wait Autism Fact Sheet and the ASD Frequently Asked Questions By Families. Parents can also contact the Autism Society of America (ASA) at 800-328-8476 or visit their website at www.autism-society.org/. ASA has available via fax many documents/brochures for parents at no cost.