



Discussing the Diagnosis of Autism Spectrum Disorder With Your Child

Should I tell my child about her autism spectrum disorder (ASD) diagnosis?

As your child gets older, she may read reports or hear the word *autism* in reference to her. Some children are aware of their diagnosis, but some are not aware, and the parents may worry that their children will become upset when they find out they have autism.

This is a valid concern, and it is better if your child is told about his diagnosis by you in a safe and supportive environment rather than on paper or through conversations with others.

A conversation with you about your child's diagnosis will provide an opportunity for your child to ask questions and share her feelings and concerns. It will also give you an opportunity to provide support or decide what types of supports are needed to help your child process the diagnosis.

Many individuals with ASD have said that it was helpful to learn they were on the autism spectrum. The diagnosis explained why some things had been difficult or why they may have been treated differently by others. It also gave them a way to explain their behavior to other people in a way that they would understand. For some, the diagnosis helped them not feel as if their past problems resulted from some personal failings. Instead, some of their difficulties could be explained by a medical condition.

When should I tell my child about his ASD diagnosis?

While it is important to tell someone with ASD about their diagnosis, there is no "correct" age or time to tell him. A child's personality, abilities, and social awareness are all things to think about when deciding when he is ready for information about his diagnosis. For example, a parent may decide to talk about ASD when a verbal child begins asking questions like "Why won't some children play with me?" or "Why do I leave class to work with a teacher and my friends don't have a special teacher?" or a nonverbal child shows signs of recognizing differences among his peers.

How can I best explain to my child that she has ASD?

1. Before you begin, assess what your child already knows and how well she will be able to understand a discussion about ASD. Even if a child does not ask questions with verbal speech, she may still benefit from explanations. For children who are verbal, you might say, "Tell me what you have heard about autism," or, "Do you know anyone with autism?"
2. Deliver the news at the right level. Prepare to explain ASD in words your child or teenager can understand. Too vague an explanation may not satisfy a curious teenager. Too technical an explanation may confuse or frighten a child of any age. In a very early first discussion about your child's differences, you may choose not to use the actual ASD label. Instead, you might discuss how some children learn differently or need help with certain things at school. The actual words can be given after waiting until your child's understanding grows. For older children or teens, using the term *autism spectrum disorder* or the abbreviation *ASD* can be important. As they get older, they may read school papers or reports listing the diagnosis, or others may use the term or abbreviation thinking they already know.

It is better if they are told their diagnosis by someone they trust and have the opportunity to have their questions answered.

3. Be positive. When sharing news of a diagnosis with your child, you will want to keep things very positive. It's also a good idea to choose a time when you and your child are feeling good and when you won't be interrupted or distracted.
4. Make your explanation of ASD right for your child's own needs and understanding. Start with discussing your child's positive qualities, then address areas that are challenging for your child. It is important to tell your child that you love all the "good stuff" about her and you wouldn't ever want her to change. But also your child has been struggling in some areas because of ASD. It's OK to say that ASD makes some things hard and also say that it is not your child's fault.
5. Describe ASD by saying everyone is unique or different. It may be helpful to illustrate how all children learn differently by giving examples of children your child knows who excel in certain areas but might need help in others. Another example of differences might be twins who look just alike, but you can tell them apart because they have unique features, like one has a narrow face and the other has a rounder face.



How can I best explain to my child that she has ASD? (continued)

6. Let your child know there are a lot of other people with ASD, including famous people such as actors and scientists. Your child is definitely not alone, and it is important to let her know this. Your child may be interested in meeting others with ASD. Your child's pediatrician or school may be able to help you find support or social groups so that your child can meet others with ASD. However, some children with ASD do not want to be different from peers and may not want to go to a group.
7. Raise your child's awareness. Even before you discuss your child's diagnosis with her, it may be helpful to read books or watch shows and movies together in which characters have ASD or other disabilities. In this way, the idea of being different is presented gradually and as part of everyday life.
8. Say that you love your child just the way she is. Talking about ASD in a positive, matter-of-fact, and child-friendly way helps set the stage for a child's ability to get used to the reality of an ASD diagnosis. Keep in mind that the whole idea of "having ASD" is a lot to take in. It is going to take some time, with new questions asked and more understanding gained as your child grows.

Resources

American Academy of Pediatrics HealthyChildren.org:
www.HealthyChildren.org

Applied Behavior Analysis Programs Guide "30 Best Children's Books About the Autism Spectrum":
www.appliedbehavioranalysisprograms.com/30-best-childrens-books-about-the-autism-spectrum

Carbone PS, Rosenblatt AI. *Autism Spectrum Disorder: What Every Parent Needs to Know*. 2nd ed. Itasca, IL: American Academy of Pediatrics; 2019

Interactive Autism Network "ASD Diagnosis: What Do We Tell the Kids?": www.iancommunity.org/cs/articles/telling_a_child_about_his_asd

National Autistic Society "After Your Child's Diagnosis":
www.autism.org.uk/about/diagnosis/children/recently-diagnosed.aspx

Handout derived in part from Foden T, Anderson C. ASD diagnosis: what do we tell the kids? Interactive Autism Network website. https://www.iancommunity.org/cs/articles/telling_a_child_about_his_asd. Accessed May 20, 2019. Handout reproduced in part with permission of Kennedy Krieger Institute, Baltimore, MD.

