

THE DEVELOPING MIND

The Boone Fetter Clinic: Diagnostic, Clinical and Research Center for Autism and Other Neurodevelopmental and Behavioral Disorders



Talking to Your
Child About Their
Diagnosis, Page 2

Welcome

It is sometimes difficult to find a trustworthy source for answers to complex questions about your child's health and development, so we provide this newsletter to bring you up-to-date information from specialists and researchers at Children's Hospital Los Angeles, a proud member of the Autism Speaks Autism Treatment Network. For more information about the Boone Fetter Clinic or if you have a question about your child's development, please call the Autism Warm Line at 323-361-6102.

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To make an appointment, call the Autism Warm Line at 323.361.6102, email BooneFetterClinic@chla.usc.edu or visit CHLA.org/AUTISM.

1300 N. Vermont Ave., Ste. 905, Los Angeles, CA 90027

Talking to Your Child About an Autism Diagnosis



Parents sometimes struggle with the question of whether or not to talk to their child about his or her diagnosis of autism. While every situation is different, the following guidelines can help you decide how to approach the conversation.

Talking about autism can help your child understand existing differences with siblings and peers, and why some things are more challenging or stressful. Greater self-awareness can help build a sense of pride for special skills, strengths and knowledge, and may also help improve behaviors and social interactions.

On the other hand, you may be concerned that knowing about the diagnosis could hurt your child's self-esteem or cause frustration or depression, or that others' knowledge of it could lead to social isolation or even bullying. Whether or not to disclose the diagnosis depends on the individual child and your family's situation. Consider these questions:

- What is your child's ability to understand this type of information?
- Has your child already asked questions about autism, or about his or her condition?

- Is your child hearing others refer to his or her condition at school, in therapy or at home?
- Is your child able to control what he or she tells others, with some awareness of socially appropriate behavior?

If you do decide to talk about the autism diagnosis with your child, here are some suggestions:

- Find a quiet, low-stress time and place to discuss the information.
- Consider talking to your child's pediatrician, therapist or other professional to help with the discussion.
- If other adults are involved, make sure you all agree on the information to be shared.
- Rehearse the discussion ahead of time, and decide which parent is most comfortable initiating the conversation.
- Have a separate conversation with siblings, so that all can react in their own way.
- Ensure that the conversation is not a reaction to a negative event, but takes place when everyone is comfortable and ready to hear the information.
- Give simple, honest and clear explanations.

- If your child asks questions, provide answers that specifically address the question.
- Follow your child's lead. When your child seems to have had enough conversation, stop and look for another time to continue talking.
- Reassure your child that autism is part of who he or she is, but does not define a person.
- Be sure to emphasize that everyone is different, and each person has different strengths and weaknesses. We all have things we can work on, and we all have things we are good at.

Above all, the conversation should be relaxed, honest and caring. As your child gets older, you will have the opportunity to give more in-depth explanations and have deeper discussions. For now, focus on where your child is developmentally, and on your whole family's needs and values.

How to Start the Conversation

Find natural opportunities for a conversation in a relaxed setting when everyone is calm, with the knowledge that this will not be your only conversation. Little bits at a time are better than one big, long serious talk. Follow your child's lead and keep in mind the child's developmental stage and communication abilities. The examples below may need to be simplified for young children, or for those whose communication or cognitive abilities require a simpler explanation.

Look for opportunities that your child is giving you to have a conversation; for example, when he or she is telling you about a problem making friends, or about feeling different, or that something is hard. This is a good time to let your child know that, while these issues can be worked on and things can get better, he or she was born with some special gifts, and also some

special challenges. Help your child understand that autism may contribute to those challenges, but it is something a person has, not something a person is. Asking questions and learning your child's perceptions of things can help you know how to proceed better than a "sit down and let me tell you something" conversation. It is best to meet your child where he or she is.



Opportunity Example #1

Child: "No one likes me at school. I try to make friends but I just can't."

Parent: "That's tough. Have you noticed what gets in the way?"

Child: "They say I'm weird. I'm just not like everyone else."

Parent: "You are not weird. We are all different. It is true that you have a lot of great things about you that other kids don't have, like [give examples of your child's special gifts]. Some things are pretty tough for you, like making friends. Sometimes kids are born with challenges making friends, talking to other people, understanding the games on the playground or accepting

when unexpected things happen. Those specific challenges are called autism [or you can say ASD or whatever you'd like]. There are lots of kids and adults who have autism, like some of the kids in your class [or social skills group/dance class/Boy or Girl Scouts, etc.]. Have you ever heard that word before? What do you think it means?"

Then go on to explain. Stop if your child becomes disinterested or seems upset. These should be gradual and natural conversations that are revisited casually.

Opportunity Example #2

Child: "Why do I have to go to so many therapies and my sister doesn't? It's not fair and I'm sick of all these people. I just want to play with my iPad and be left alone."

Parent (answer similar to Example #1):

"We are all different, and some of us are born with challenges that make us need extra help. We all have great skills and some not-so-great skills. Can you tell me some of your great skills? Have you noticed any ways you need a little extra help? Some kids need certain kinds of help with [list some ASD characteristics that are particular to your child]. You are doing a great job working so hard to get better at [...], and you may notice that other kids need the same kind of help with [...]. That's because they have something called autism."

Child: "What is autism?"

Parent: "It's something that some people are born with that gives them special gifts and talents, and also gives them some special things that are really hard, like [...]. It's not anyone's fault, and the things that are hard for you are not your fault. Scientists are trying to figure out what makes kids have autism, but right now no one knows why. Luckily, there's a lot we can do to make things better. Is there anything you can think of that you want to tell me about?"

Opportunity Example #3

Parent: "Have you ever thought about why we go to Bowling Buddies after school, or to see Dr. Smith?"

Child: "Because it helps me? Because I like it?"

Parent: "Yes! Those are both reasons. Do you know why you need a little boost with [...]? Well, sometimes kids grow up with extra challenges [follow example above], because they have something called autism."

A real-life example from Leslie Richard, MD, and her discussion with her adult brother, Rodney

Leslie: "Rodney, do you know why you are a member of the Lanterman Regional Center?"

Rodney: "Yes. Well (pause), it's because I have 'refined autism.'" (Spoken with great affect and pride, along with the spontaneous production of an English accent, while eating six tacos.)

Leslie: "Oh? What is refined autism?"

Rodney: "Well (pause), it means there are some things I can see and understand that no one else can see, and there's a whole lotta stuff you other people can see and do that I just don't understand at all! Yeah, that's it."

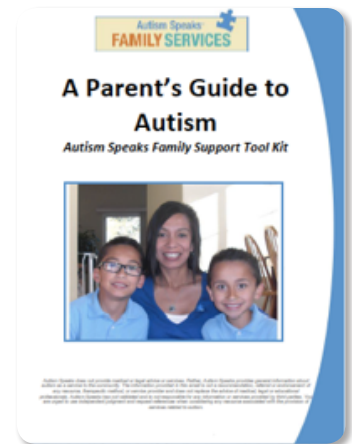
Well said, Rodney!



Autism Speaks Family Support Toolkits

It is quite true that it takes a village to raise a child. It is important for parents who have received a diagnosis of autism spectrum disorder (ASD) to surround themselves with a community of people who will be there for the many joys and challenges that come with having a child with ASD. Family and friends, who many times make up this "village," will often have little or no knowledge of what autism spectrum disorders are, or how to be supportive of parents and their child as they go through this journey. The Autism

Speaks Family Support Toolkits for parents, siblings, grandparents and friends of children and young adults on the spectrum can offer help. The purpose of each toolkit is to teach family members and friends about autism and its effects on families. The toolkits also provide resources and tips to help families lead joyful and fulfilled lives with their loved ones with ASD. You can access the Family Support Toolkits and other great resources by visiting: www.autismspeaks.org/family-services/tool-kits/family-support-tool-kits.



Parent Tips: Back to School

Back to school time can be both exciting and stressful, especially for children with autism spectrum disorders. Children may get nervous about starting a new school or going back to school. A big part of a successful first week of school is preparation and establishing a routine. Being involved with your child's education is important, but it's also hard work. Nobody knows your child better than you, so follow your instincts. Here are some ideas to help smooth your child's transition.

- Contact the school to ask for a tour before the year begins. With permission, take pictures of the school, playground, classroom and teacher to create a picture book for your child.
- Arrange to meet with the school principal to talk about your child's needs, and ask about the school's experience with autism and how the staff works with children on the spectrum.

- Talk about school often with your child. Look at pictures of friends and school activities from the previous year to encourage conversation.
- Try to keep at least one thing consistent when starting the next school year, especially if your child is changing classrooms, teachers or schools. For example, if you are happy with your child's aide, try to keep the same aide for the coming year.
- If your child has a friend who is moving to the same school, arrange play dates during the summer or before school starts and let your child know the friend will also be at the new school.
- Don't be afraid to meet the teachers for the new school year. If possible, visit the classroom the week before school starts, as the teacher will likely be there preparing. It will give you a chance to discuss seating, potential distractions, and your child's strengths and needs.

- Play school at home to help your child get used to school activities and offer ideas on dealing with any questions or fears.
- Mention frequently throughout the summer, several times a week if necessary, what grade your child will go into when school begins, how proud you are, and how big he or she will be entering a new grade level. You can use a countdown calendar if that would be helpful.

