HOW TO TALK TO YOUR CHILD ABOUT AUTISM

WHEN SHOULD I TELL MY CHILD ABOUT HIS DIAGNOSIS?

Children under age of 5, and those who are nonverbal, are typically not able to understand or greatly benefit from knowing about their diagnosis. When children begin to notice they have differences, and begin asking or making comments about their differences, they may benefit from learning about their diagnosis. This awareness typically begins to develop around 7-10 years of age. Waiting until the child is a teenager may be more challenging, as many teenagers become very sensitive about their differences. Also, waiting too long carries the risk that the child will find out about the diagnosis from someone else or by accidentally seeing a reference to their condition on school forms or medical documents.

Another consideration is how comfortable with and educated about autism you feel as a parent. Sometimes parents need some time after an initial diagnosis to "get their head around it" and to feel a sense of acceptance about the disability. Spending several weeks reading, talking to your spouse or with friends, and exploring treatment options that were recommended is perfectly reasonable. Your son or daughter may also benefit from your greater sense of calm when you finally do choose to have the discussion. Most clinicians will also be willing to have a second feedback session after some time has passed, if you think that having the discussion with a professional would be useful.

WHY SHOULD I TELL MY CHILD ABOUT HIS DIAGNOSIS?

Many parents worry about sharing information about the diagnosis because they are concerned their child may think negatively about themselves, develop anger or depression, or use the diagnosis as an excuse. While these outcomes are possible, it is important to talk to your child about autism so that they to begin to learn about how autism impacts them, ways to maximize their potential, and how to accept and use what they know about autism to advocate for themselves. Not telling a person about autism can sometimes lead to more problems or negative feelings as children may blame themselves for their difficulties. Many newly diagnosed adults express a sense of loss and regret that they did not know about the diagnosis sooner, as having a framework for understanding their struggles would have been informative, validating, and in some ways liberating. They often reflect that many things would have been easier had they known sooner.

If you are worried about how your child may react, remember that many children with autism respond positively and embrace their diagnosis, especially when they see their parents doing the same.

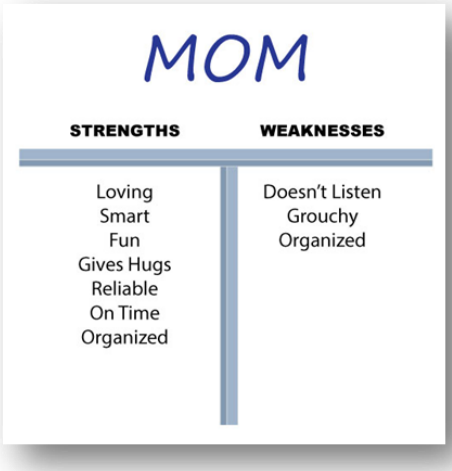
WHO SHOULD TELL MY CHILD ABOUT HIS DIAGNOSIS?

In some cases, parents tell their children about their diagnosis. Some parents feel very comfortable and equipped to share this information. Their children may be very open and interested in learning about autism, and may ask questions.

Some parents want the help of an experienced professional to begin the conversation about the diagnosis. It is sometimes helpful to have a professional share information about the diagnosis with their child so that the parents can primarily take a supportive role. Some children may find it hard to seek comfort from their parents if they are the source of difficult news. A professional can also provide parents with strategies on handling the child's reaction to learning about the diagnosis.

HOW DO I TELL MY CHILD ABOUT HIS DIAGNOSIS?

Autism is a complex disorder that can be challenging to understand. The information you present should be age appropriate and it is often helpful to include visual supports.



A good place to start, even well before you plan on talking to your child, is to make a point to talk regularly within the family about how all people have strengths and difficulties and pointing out each family member's particular strengths and challenges. One activity that can be used for older children is to use a white board or large sheet of paper, split it into two columns, and start by asking family members to make a list of mom or dad's strengths and difficulties, gaining input from everybody involved. Then, move on to other family members and eventually to your child with autism. Think of strengths and difficulties that relate to autism. Make sure to list more strengths than difficulties to keep the perception of having autism positive. Then, in your own words, you might say:

"When scientists discovered the pattern of strengths and difficulties listed on the whiteboard across many different people, they gave it a name. The name of that pattern is autism and autism is the reason

you have many of these strengths! So congratulations! Sure, there are some difficulties that come with it, but we all have difficulties, that is part of being a human being."

When creating the list, make sure to include some instances in which the same feature is placed as both a strength and a weakness (such as detail-oriented thinking style, rule adherence, honest/frank conversation). Depending on context, a feature can be a strength or a weakness. For example, honesty can be a strength when it comes to a person's overall character, however it can be problematic in certain social situations where it is best to *not* be forthcoming with one's honest opinion about something (e.g. disliking a friend's new haircut). The point to make with your child is that "we don't want to take these things away, we just want to help you learn how to get the most out the good side of them and not struggle as often with the bad side." This sort of "both good and bad" discussion can apply to other, non-autistic characteristics in other family members, too.

You may need to dispel some negative perceptions about autism your child has, and you will likely need to address any worries that arise during the discussion. For example, if you are concerned your child might think negatively about himself based on what he knows about autism, or if he might have heard negative perceptions about autism elsewhere, you might directly say, *"You are not crazy/weird/bad and you are not defective in any way, you just have a different form of intelligence that comes with really great things, and some things that will be harder for you."* Also, if your child knows other children with autism, you may want to explore some of those similarities and differences. For example, if your child is high functioning and knows someone with autism who is very delayed/impaired, it is not inappropriate to talk about that person and how autism impacts their life. You can then talk with your child about how autism might affect his life differently. This can be especially useful if your child seems concerned that they may be more severely impaired than another child or fearful about what the future holds.

Writing a narrative or short book about your child with illustration or pictures is also a good way to introduce the topic. Start with positive characteristics, list several difficulties your child experiences, and end on another positive note. For some children, having an individualized book made can be clearer than using a published book that may discuss autism in more general terms. For other children, reading published books may be appropriate. It can also be helpful to tell your child about the famous people who have or are thought to have had autism and have made excellent contributions to the world.

Somewhere towards the end of your conversation, you can help your child understand that the label of autism is useful to help organize how you, he, and others think about these strengths and differences, but that nothing has really changed from before he got the label. You can say something reassuring like

“You're still my kid and I'm still your parent and I will still make you brush your teeth before bed and walk the dog, and you can still count on me to make your favorite pasta dinner on Wednesday nights.”

Remember, you don’t have to say everything to your child in the first conversation. Try to focus on a few main points and address any specific questions he/she may have. Then let him know that you will probably talk more about this again in the future, and that he can always come to you with questions. In addition to avoiding information overload, this approach also allows you to measure how much information your child is ready to hear. At the end, a simple *"that's probably enough for now, let's get back to XYZ”* can give the child some time to process the conversation.