

## *Ten Tips for Talking to Your Child About Their Autism Diagnosis* By Sara Woods, PhD, Clinical Psychologist, UW Autism Center

Children and adolescents learn about their autism diagnosis in a variety of ways. Older children sometimes read up on autism by themselves and already have a sense of what it means before they are even diagnosed. Younger children might overhear adults talking about the fact they have autism. Some children find out with a gradual, supportive discussion with their parents and other supportive people. Others may see a parent come out of a doctor's office visibly upset and be left to wait and wonder what was said and what it all means. When autistic people are not told about their diagnosis at all, they are more likely to become depressed, anxious, or have other negative mental health outcomes\*

In general, experts and autistic adults tend to agree that parents should talk directly to their children about autism. These are some steps parents can take to make it an easier discussion with more positive outcomes.

- 1. Make it an *ongoing conversation* with a gradual introduction of information. As the child's understanding develops and they are introduced to new ideas, new issues will come up. Keep the doors open for talking about autism over time. Help your child feel comfortable introducing questions and concerns about the diagnosis. Be prepared to seek out new materials and resources as needed. For example, for younger children, the book *Ada Twist, Scientist* by Andrea Beaty might provide a useful story to open a discussion on different ways of thinking. Older children might respond well to talking about brain differences more directly (e.g., the Autistic Self-Advocacy Network offers this book resource:
- <u>https://autisticadvocacy.org/book/welcome-to-the-autistic-community/</u>
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- 2. Discuss the fided that there are many *uggerent types of brans* and styles and that the would be boring if everyone was the same. Remind them that there are certain skills and activities that seem easy for them, but that are harder for other people. Give examples of their strengths (e.g., maybe they are great at building with Lego, playing a certain instrument, taking objects apart and putting them back together). This emphasis on valuing different types of brains can be modeled even before discussing your child's diagnosis directly.
- 3. *Validate the difficulties* that they have. Explain that they have probably noticed that certain tasks are harder for them than for other people or that they like to do tasks in a different way than others do and that's okay. Explain that other people who have struggled with some of the same issues have learned many different ways to make life easier and more enjoyable. We can learn from books, websites, autistic people who have written about their experiences, and scientists who have done research on autism. Also, explain that their opinion counts; they know what works for them and what doesn't and you are always ready to hear their feedback.
- 4. In general, it is best to tell a child that they are autistic as early as possible. Your choice of timing and modality will vary somewhat depending on your child's age, developmental level, and your own readiness to discuss it in a straightforward and positive way. You can explain that the combination of strengths and difficulties that



they have is called autism. It may also be called autism spectrum disorder (or Asperger's in Europe). Explain that every autistic person is different from every other autistic person, but they usually have certain things in common, such as having a different way of interacting and making friends with other people, and having different types of habits and interests than other people. Autistic people may also see, hear, and feel things around them in different ways than other people. Certain sounds and clothes that do not bother other people may bother autistic people, but certain sights, feelings, and sensations may feel wonderful to autistic people and may not be as appreciated by others. Sometimes autistic people notice details that others miss and have unique creative skills that are partly linked to their sensory differences.

- 5. Provide autistic role models. Discuss some of the ways in which autistic people have been able to use their autistic traits for their own benefit and to benefit others. Include famous people. For example, Satoshi Tajiri (inventor of Pokemon) was very focused on insects and on videogames as well. He was so interested in these topics that other people thought it was unusual. Later, he was able to combine these two interests to create pocket monsters - or Pokemon. Now people all over the world enjoy his creative ideas and games. (Also see: https://the-art-of-autism.com/howsatoshi-tajiris-autism-helped-create-pokemon/). Dan Aykroyd was highly focused on ghosts and police and he used these interests to develop Ghostbusters. Hannah Gadsby is a famous comedian who credits her autism with giving her a unique perspective on social interaction and life in general. She has won awards for changing comedy and has entertained and inspired people worldwide. Greta Thunberg credits her autism to helping her resist peer pressure and that has helped her develop into a famous environmental activist. Daniel Tammet is a famous author whose sensory differences help him remember numbers incredibly well (e.g., he memorized pi to 22514 digits). In addition, many famous inventors, artists, and musicians are believed to meet criteria for autism (e.g., see Different Like Me: My Book of Autism Heros by Jennifer Elder). The UW Autism Center has a series of short biographies that you and your child can read and discuss ( https://depts.washington.edu/uwautism/resources/neurodiversity/biographies-ofautistic-people/). In addition to talking about famous autistic role models, try to connect your children with people in the community who are autistic who can talk to them about their experiences and strengths. There are Facebook groups designed for parents to connect with autistic adults and local community organizations are making this a priority.
- 6. *Explain bias*. Explain to children that the world, in general, has been designed for people who are not autistic so certain aspects of life may be harder for them. Explain that other people may not always understand autism, but the world is changing, and people are slowly starting to understand it more. Tell them that employers, teachers, and people in general are starting to learn more about autism and are getting more interested and open to learning about their experiences. Also, tell them that they can speak up to ask for what they need or ask for a parent or teacher to help them.
- 7. *Encourage them to learn more*. Provide books, videos, and developmentally appropriate resources that they can use to understand their diagnosis. An example of

a helpful video to watch together and discuss would be this episode of *Arthur* (When Carl Met George: <u>https://pbskids.org/video/arthur/1447843659</u>)

- 8. *Give them control*. Children may or may not identify with the autism label initially. Let them know that even though autism is nothing to be ashamed of, they can decide how to describe themselves. They do not have to tell anyone that they are autistic/have autism. They can decide who to tell and when and their preferences may change over time. You can help them with these decisions.
- 9. *Ask them what they know*. Ask children what they have already learned about autism. Clear up any misconceptions supportively. Let them know that they may know more than you do about certain experiences. Let them know that learning about their particular experience of autism is an ongoing journey that you can navigate together. Tell them you are committed to being there along the way.
- 10. *Encourage them to ask questions*. Be open to answering questions. Let them know that they are encouraged to bring up new questions as new situations arise. If you do not know an answer, simply say "I don't know, but I will help you find out" and then do some research together. Enjoy the journey and be ready to learn something new!

\*Stagg and Belcher (2019). Living with autism without knowing: receiving a diagnosis in later life. *Health Psychology and Behavioral Medicine*, 7, 348-361. DOI: <u>10.1080/21642850.2019.1684920</u>