CARING FOR CHILDREN WITH AUTISM SPECTRUM DISORDERS: A RESOURCE TOOLKIT FOR CLINICIANS, 2ND EDITION

Discussing the Diagnosis of Autism Spectrum Disorders With Your Child

Parents may wonder about when and whether to tell their child about his autism spectrum disorder (ASD) diagnosis. Following are some commonly asked questions about discussing diagnosis of an ASD with a child:

Should we tell our child about her ASD diagnosis?

Parents may worry that finding out about an ASD diagnosis will be hard on their son or daughter. Some children can initially find the news upsetting, especially if they are very sensitive to any suggestion that they are different from their peers. Many individuals with ASDs, however, have shared that learning they were on the autism spectrum suddenly made clear why so many things had been difficult or why they had been treated differently. With increased awareness of ASDs, diagnosis also may provide a reason for their behavior that they think other people might understand. For some, diagnosis can take away the notion that past problems had all been the result of some personal failing; replacing this with the notion of a legitimate condition helps explain their challenges.

When should we tell our child about his ASD diagnosis?

While it is important to tell an individual with an ASD about his diagnosis, there is no exact, "correct" age or time to tell a child. A child's personality, abilities, and social awareness are all factors to consider in determining when he is ready for information about his diagnosis. For example, a parent may decide to talk about ASDs when a child begins asking questions such as, "Why am I different?"

Considering the potential effect of the information, how can we best explain to our child that she has an ASD?

- 1. Before you begin, assess what your child already knows and how well she will be able to take in or process a discussion about ASDs.
- 2. Deliver the news at the right level. Prepare to explain ASDs in terms your child can grasp. Too vague an explanation may not satisfy an inquisitive teenager, while too technical an explanation may confuse or frighten a child of any age. If circumstances lead to a very early first discussion about your child's differences, you may choose not to use the actual ASD label but discuss how some children learn differently or need help with certain things at school; the actual label can be given after waiting until your child's understanding grows. For older children or teens, using the term ASD can be important. As they get older, they may read school documents or reports listing the diagnosis, or others may use the term assuming 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. Tailor your explanation of ASDs to your child's own situation. Start with discussing your child's positive attributes, 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. Undoubtedly, however, your child has been struggling in some areas because of the ASD. It's OK to acknowledge these difficulties while emphasizing that it is not her fault that some things are tough.

- 5. Describe ASDs in terms of everyone being unique or different. It may be helpful to illustrate how all children learn differently by giving examples of children she knows who excel in certain areas but might need help in others. One example might be an excellent athlete who cannot sing a tune.
- 6. Let your child know there are a lot of other people with ASDs. Your child is definitely not alone, and it is important to let her know this. Your child may be interested and benefit from meeting others with ASDs. Your child's pediatrician or school may be able to help you find support or social groups where your child can meet others with ASDs.
- 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 together in which characters have ASDs or other disabilities. In this way, awareness of individual differences is presented gradually and as part of everyday life.
- 8. Stress that you love her just the way she is.
 Sharing information about ASDs in a positive, matterof-fact, and age-appropriate way helps set the stage for a
 child's ability to understand, accept, and adapt to the reality
 of an ASD diagnosis. Keep in mind that the whole concept
 of "having an ASD" is a lot to take in. It is going to be a
 process that takes some time, with new questions asked and
 deeper understanding gained as your child matures.

Resources

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

Foden T, Anderson C. ASD diagnosis: what do we tell the kids? http://www.iancommunity.org/cs/articles/telling_a_child_ about_his_asd. Accessed April 5, 2012

National Autistic Society. Diagnosis: telling a child about their diagnosis. http://www.autism.org.uk/about-autism/all-about-diagnosis/diagnosis-the-process-for-children/after-diagnosis/diagnosis-telling-a-child-about-their-diagnosis.aspx. Accessed April 5, 2012

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