

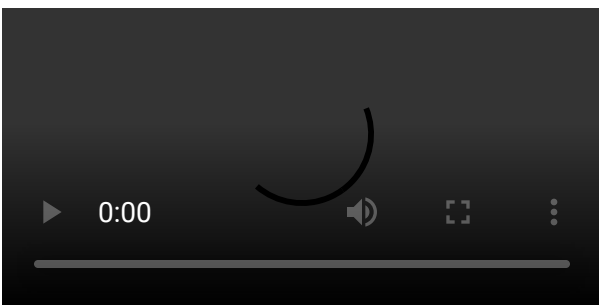
# When (and How) Should You Tell Kids They Have Asperger's?

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Tips for parents on timing and how to explain the diagnosis

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## *Adiagnosis*

of Asperger's can be an overwhelming experience for parents and children. Some parents may feel a sense of relief at finally getting an explanation of their child's difficulties; at the same time, it also can foreshadow a road ahead full of therapies, academic difficulties, and [social skill building](#). As clinicians who often evaluate and treat children with Asperger's, we are frequently asked whether parents should share the diagnosis with their child. This is a decision that deserves careful consideration.

## **Sense of belonging**

Children who have been given an understanding of the label of Asperger's may feel a sense of belonging after realizing that there are lots of children out there like them. Rather than feeling stigmatized, they may experience a sense of empowerment in having a community of like-minded children they may find at school, camp, or in various social skills groups or other treatment settings. It can offer opportunities for forging connections with others who share similar challenges.

Children may use their Asperger's label as a potential cornerstone for building self-advocacy skills, and it can help facilitate a sense of control in their lives. For some, Asperger's may be seen less as a disorder and more as a positive and fundamental part of their self-concept.

On the other hand, to some children, the word Asperger's can feel like a disease or a term describing what is "wrong with them." We have seen children who were exposed to the word Asperger's when they were diagnosed but avoid saying it, because of the sense of impairment it represents. In this regard, it can feel like an albatross. They may see Asperger's as a challenge that holds them back from reaching their potential.

Disclosing the diagnosis can present other issues. For example, because children with Asperger's often have difficulties with the subtle nuances of communication, it may be hard for them to learn when it is appropriate or inappropriate to share the information with others. Furthermore, there is misunderstanding about the diagnosis at a societal level and all too often it is framed in terms of its deficiencies rather than its differences.

We think this is an issue that needs to be dealt with carefully and sensitively to maximize the child's adjustment to what lies ahead. This article presents some guidelines to help parents make the best decision for their child.

## **Stigma persists**

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For better or for worse, our society feels differently about psychiatric diagnoses and medical diagnoses. Many parents feel less conflicted about the prospect of telling their child that they have a pervasive medical condition such as diabetes or asthma than a psychiatric one. So, why the difference? One of the big answers is stigma. Despite how far we've come in the field, disorders of the mind are viewed and treated differently than those of the body. And even parents of special needs children, while likely more sensitive to the effects of the stigma, are not necessarily immune to them.

On the other hand, there are some in the field who don't view Asperger's or autism spectrum disorders as disorders at all but rather as unique ways of perceiving the world that should be embraced rather than cured. This makes it harder for parents to gauge the meaning of the diagnosis and cautious about attributing a label that can be lifelong.

## **Parents have feelings, too**

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Another important consideration is the parents' reactions to the diagnosis. When a child is struggling, more often than not, one or both parents identify with what their child is going through because they experienced similar struggles themselves.

Acknowledging their child's diagnosis may trigger painful memories and powerful defenses for parents. Therefore, if you are considering having this discussion with your child, we recommend first taking the time into explore your beliefs and biases about the diagnosis. Even if you hold these views close to your chest, your children may pick up on them. We are big advocates of parents meeting with a psychologist to process their own feelings about their child's diagnosis and help formulate the best way to present it to their child.

## **Consider both age and maturity**

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Children can be diagnosed as young as two or three or well into *adolescence*,

so the discussion about when and how to talk to a child about the diagnosis will be impacted by the age of the child and his level of emotional maturity. Some children may be able to grasp the nature of the diagnosis at seven and eight, while for other children, it may seem too abstract, even at 16 years old.

## **How to talk with your child**

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Whether the decision to share the diagnosis is being prompted by a recent evaluation, or parents have chosen to delay the conversation until the child seems ready, most children know something is different about them. In general we have found that children construct all sorts of fantasies and ideas about what is wrong with them and having a candid discussion may actually dispel some of their fears. Below are a few suggestions to foster an open discussion with your child.

## **Highlight strengths and weaknesses**

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We all have them, and it's pretty easy to come up with a list for each of us. It might be helpful for each of the family members, including parents, to speak about three things they are good at and three things that they struggle with. What is unique about children with Asperger's is the level of discrepancy that can exist between different areas. A 10-year-old with Asperger's may have a reading level equivalent to high school student, but math abilities of a five year old. What can be difficult for the child is the feeling of having such a large split inside of them. It can also be valuable to highlight the feeling of this dramatic chasm between the areas.

## **Use simple metaphors**

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Even though each child's challenges are unique, there are characteristics that are common in children diagnosed with Asperger's. It might be helpful, again depending on the age and maturity of your child, to use metaphors to talk about some of these symptoms. For example, to explain executive functioning difficulties, you may talk

about a huge pile of papers, with no folders to organize them. To explain cognitive inflexibility, you may talk about a child's brain getting "stuck" and unable to move past something. For emotional dysregulation, you may talk about a child whose feelings feel way too big for his little body, and for social deficits, you may talk about going to visit a foreign country and feeling like you have a hard time understanding the language or culture.

We have found the use of metaphors particularly valuable in highlighting what it can feel like for a child with Asperger's dealing with these difficulties. These metaphors can also be used to explain to siblings, family members, friends or teachers when they don't understand why your child is having a difficult time in some of these areas.

## **Find role models**

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Many role models exist who speak openly and share their challenges. It can be helpful to have your child learn about different role models in pop culture or sports who have specific areas of difficulty who embrace their challenges and model optimism, perseverance and hard work. For example, finding a baseball player with an area of difficulty for a child interested in baseball, or learning about an engineer with difficulties for a child who loves transportation, or an actor on a child's beloved television show who has shared some challenges.

## **Respect their processing style**

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Children's reactions to these talks reflect a full range of responses. Some will have many questions and want to understand more. They may want to look up what different words mean and feel like they can't stop talking or thinking about it. Other children will be resistant to talking more about it, and will want some space to process this information in their own quiet way.

The biggest gift you can give to your child is to respect her uniqueness and provide her the space and an opportunity to think and reflect about this information. You may want to enlist the help of mental health professionals to facilitate the healthy processing of some very complicated information. We believe that the understanding and synthesizing of this information is integral to your child's forming of his identity. While it may take time, supporting this process will help empower him for success and self-actualization through hard work, insight, and understanding.

*Autism Spectrum News is a quarterly print and online publication dedicated to providing parents, professionals, and individuals on the spectrum with a trusted source of science-based education, vital information and a roadmap to quality resources in the autism community. To view the current issue or the archives, please visit [www.mhnews-autism.org](http://www.mhnews-autism.org).*

## Frequently Asked Questions

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How do I help a child with Asperger's?

Asperger's is an outdated term used to describe some people who have *autism spectrum disorder*.

You can help a child with Asperger's by emphasizing that everyone has unique strengths and weaknesses and using simple metaphors to help them understand why some things are challenging for them. You can also help them learn about how their role models have overcome challenges.

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