



# Getting Started: Introducing Your Child to His or Her Diagnosis of Autism or Asperger Syndrome

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Who, what, when, where, how, and why are all important questions parents ask themselves when problem solving and making decisions about issues in the lives of their children. Discussing an autism or Asperger Syndrome diagnosis with your child is a very important issue and one for which many parents seek advice. This brief article will focus on aspects of explaining your child's diagnosis to him or her, and about resources that can assist and guide you.

## Why Tell?

"Why tell my child about their diagnosis of an autism spectrum disorder?" will probably be the first question parents ask themselves. Parents go through a range of emotions when given their child's diagnosis and hopefully find support as they begin their journey with this new information about their child. Sometimes siblings, grandparents, and other family members go through a variety of emotions and stages of dealing with the autism spectrum diagnosis of a family member. Isn't it reasonable to consider that the child themselves should also be given information about their diagnosis and support for understanding and coping with this new information? All children need to be understood and respected. At some point, people who are successful have learned who they are, and accept and use that information to help themselves become the best they can be in life. Shouldn't children with an autism spectrum diagnosis have the chance to understand and accept themselves by being given information about their disability?

Parents may fear a number of things if they tell their children (and sometimes others) about their child's disability. For example, they may fear that their child will not understand, that their child may lose some of his/her options in life, that their child will become angry or depressed because they have a disability, that the child (or others) will use the disability as an excuse for why they can not do something, or even that the child will think of themselves (or others will think of the child) as a complete failure with no hope for a positive future. These problems may or may not happen, but can be dealt with if needed. Most of these problems and others may also surface whether or not the child and others are told of the diagnosis. Shouldn't all involved, the child included, have important information about autism or Asperger Syndrome since the diagnosis will affect various aspects of the child's life?

Certainly, the possibility of problems occurring is more likely when someone is not told about their disability and given the support they need. Consider the stories told by many individuals with an autism spectrum diagnosis who were not told, and/or not diagnosed until they were adults. Not understanding others or social situations for many leads to poor interactions with others and results in ridicule and isolation. Being told, "You should know better" or "stop being so stupid" and not having a clue what they did or how to "fix" or change the situation lead to frustration and confusion. Many adults share how they felt, they were seen as a major disappointment and failure to their families and others, but had no clue why they failed or how to do better. Over time, the end result can be low self esteem and/or self acceptance problems among other issues. Many of these individuals feel that with the correct information about their diagnosis and what their differences are they now have a better chance of being successful.

Your child may know that s/he is different, but like all children at certain developmental stages they come to the wrong conclusion about their perceived differences. They may even wonder if they have a terminal illness and are going to die. They see doctors and therapists and go for treatments, but are not told why. Even the child or adult who does not ask and/or verbally express concern about being different may still be thinking those thoughts. Even children with autism spectrum disorders, like all children, can sense the frustration and confusion of others and make wrong assumptions about the cause of the turmoil around them.

If the child is under 18 years old, it is the parent's decision whether they share information about the diagnosis with their child. It can seem like an overwhelming task, especially when day-to-day issues consume all the time and energy of a family. It may be helpful to discuss your concerns and possible options for disclosure with others that know your child well, other parents of children on the autism spectrum, and even individuals with an autism spectrum disorder who have been told about their diagnosis.

## When to Tell?

There is no exact age or time that is correct to tell a child about their diagnosis. A child's personality, abilities and social awareness are all factors to consider in determining when a child is ready for information about their diagnosis. Starting too early can cause confusion. If older when told, they may be extremely sensitive to any suggestion that they are different. You can look for the presence of certain signs that the child is ready for information. Some children will actually ask, "What is wrong with me?," "Why can't I be like everybody else?," "Why can't I \_\_\_\_\_?," or even "What is wrong with everyone?" These types of questions are certainly a clear indication that they need some information about their diagnosis. Some children, however, may have similar thoughts and not be able to express them well.

Some children do not get a diagnosis until they are in their teens or older. Frequently those who are diagnosed later have had some bad experiences that can influence the decision of when to share information with them about their diagnosis. They may not be emotionally ready to cope with the new information because of the toll the bad experiences have taken on their self-esteem and confidence. They may be very sensitive to any information that suggests that they are different. Thus they are not ready for any diagnostic information. On the other hand, an older child may already know about a previous diagnosis such as Attention Deficit Disorder, Conduct Disorder, and/or an emotional disorder of some kind. Because of this history with another label or diagnosis, it may be an appropriate time to share the diagnosis and some concrete information about the disability.

Many families have found that setting a positive tone about each family member's uniqueness is a wonderful starting place. A positive attitude about differences can be established if you start as early as possible, and before the diagnosis is mentioned. Everyone is in fact unique with their own likes and dislikes, strengths and weaknesses, and physical characteristics. Differences are discussed in a matter of fact manner as soon as the child or others their age understand simple concrete examples of differences. With this approach, it is more likely that differences, whatever they are, can be a neutral or even fun concept. Matter of fact statements such as "Mommy has glasses and Daddy does not have glasses" or "Bobby likes to play ball and you like to read books" are examples. The ongoing use of positive concrete examples of contrasts among familiar people can make it easier to talk about other differences related to your child's diagnosis with him or her.

Many adults with an autism spectrum disorder express the view that children should be given some information before they hear it from someone else and/or overhear or see information that they sense is about them. A child may have the view that people do not like them and/or that they are always in trouble, but do not know why. If given a choice, waiting until a negative experience occurs to share the information is probably not the best option.

## What/How to Tell?

Autism spectrum disorders are complex. Everyone with a diagnosis is unique. It is important that the process of explaining an autism spectrum diagnosis to a child is individualized and meaningful to them. A child should not be given too much information. It can be hard to decide what and how much information to begin with. If the child has asked questions, it will give you a place to start. Make sure that you understand what they are asking. Recall that it is easy to misinterpret the meaning of their words.

Remember your child's ability to process information and try to decide on what and how to tell. For those children who have a keen interest in their diagnosis and those whose reading ability is good, there are currently a few books written by children with an autism spectrum diagnosis that may be of interest to them (Hall, 2001; Jackson, 2003).

There are also many more books being written by adults with an autism spectrum diagnosis. Some of these books are meant to be read by any interested persons, but a few are meant to be read by others with a diagnosis of an autism spectrum disorder. The author with an autism spectrum diagnosis is reaching out to others with a diagnosis by sharing experiences, sharing tips on life's lessons, and helping the reader feel that they are not alone in the journey of life (Gerland, 2000; Newport, 2001; Willey, 1999; Lawson, 2003).

Most children may need minimal information to start. More information can be added over time. Be as positive as possible. Your positive attitude and the manner in which you convey the information is important. To make what you discuss with your child meaningful, you can begin by talking about any questions that s/he has asked. You may want to write down key points and tell him or her that others with this diagnosis/disability also have some of the same questions and experiences. Then you could ask if they would like to find more information by reading books, watching videos, and/or by talking with other people. If asking your child if they want information is likely to get a "no" response you may choose to not ask, but tell them that you will be looking for information and would like to share it with them. Let them know they can ask any question they want at any time they want.

Frequently when individuals with an autism spectrum diagnosis have an opportunity to meet others with a diagnosis, they find it is an eye opening and very rewarding experience. Individuals with an autism spectrum diagnosis can sometimes better understand themselves and the world by interacting with others who have an autism spectrum diagnosis. Interacting with others on the autism spectrum can help individuals realize there are other people that experience the world the way they do, and that they are not the only one.

There are various possibilities for "meeting" others on the spectrum. There are a few camps around the country that offer various programs specifically for those on the autism spectrum. There is the MAAP Services for the Autism Spectrum yearly conference and the MAAP newsletter which frequently publishes letters poems and other contributions from individuals of all ages with an autism spectrum diagnosis. There are also various listserv groups on the internet, some hosted by individuals with an autism spectrum diagnosis. Carol Gray's Pen Pal Registry is a project that helps school-aged students with an autism spectrum diagnosis get connected with others. This interest in connecting with people is something most of us can relate to, especially if you've been in a foreign country for very long! Think about it.

Currently, there are a few workbooks that provide a structured guide for the process of telling a child with an autism spectrum diagnosis about their disability (Gray, 1996; Faherty, 2000; Vermeulen, 2000). The workbook format is designed to provide activities that help organize information about an autism spectrum diagnosis as well as making the information more child specific and concrete. The different lessons suggest how the information is shared with the child. The worksheets can be completed together by the child and a trusted adult. In many cases

they can also be modified for the different ages and functioning levels of the child who would be using the materials.

## Who Tells/Where to Tell?

Certainly circumstances vary from family to family. If your child is asking questions don't put off answering them. You should be forthcoming and not suggest talking about it later. Not providing an answer could increase the child's anxiety and make the topic and information more mysterious.

For many families, using a knowledgeable professional to begin the disclosure process instead of a family member or a friend of the family might be the best option. Having a professional involved, at least in the beginning stages of disclosure, leaves the role of support and comfort to the family and those closest to the child. For someone with an autism spectrum disorder, it can be especially hard to seek comfort from someone who gives you news that can be troubling and confusing. Having a professional whose role is clearly to discuss information about the child's diagnosis and how the disability is affecting his/her life can make it easier for family members to be seen by the child as supportive. The professional discussing information with the child about his/her disability can also help the parents understand the child's reaction and provide suggestions for supporting their child. Having a professional involved also allows the use of a location outside of the family home for beginning this process.

Explaining an autism spectrum diagnosis to an individual can not be done in one or two encounters. The individual needs time to assimilate the new information about him/herself at their own pace. It may take weeks or months before the child initiates comments or asks questions about the new information. The process of explaining an autism spectrum diagnosis is ongoing. Making the information meaningful from the child's point of view will greatly enhance the learning process. A positive focus helps maintain self esteem and an effective atmosphere for learning. There are materials available to help this learning process and hopefully you have others that know your child who can help support you and your child in this process. Now, is it time for you to get started?

## Resources

Faherty, C. (2000). *What does it mean to be me? A workbook explaining self-awareness and life lessons to the child or youth with high-functioning autism or Aspergers*. Arlington, TX: Future Horizons, Inc.

Gerland, G. (2000). *Finding out about Asperger Syndrome, high functioning autism and PDD*. Philadelphia, PA: Jessica Kingsley Publishers, Ltd.

Gray, C. (1996). *Pictures of me*. Jenison, MI: Jenison Public Schools. ([www.thegraycenter.org](http://www.thegraycenter.org))

Hall, K. (2001). *Asperger Syndrome, the universe and everything*. Philadelphia, PA: Jessica Kingsley Publishers Ltd.

Jackson, L. (2003). *Freaks, geeks and Asperger Syndrome: A user guide to adolescence*. Philadelphia, PA: Jessica Kingsley Publishers Ltd.

Lawson, W. (2003). *Build your own life: A self-help guide for individuals with Asperger syndrome*. Philadelphia, PA: Jessica Kingsley Publishers Ltd.

Newport, J. (2001). *Your life is not a label*. Arlington, TX: Future Horizons, Inc.

Vermeulen, P. (2000). *I am special: Introducing children and young people to their autistic spectrum disorder*. Philadelphia, PA: Jessica Kingsley Publishers Ltd.

Vicker, B. (2003). *Disability information for someone who has an Autism Spectrum Disorder*. Bloomington, IN: Indiana Resource Center for Autism

Willey, L.H. (1999). *Pretending to be normal: Living with Asperger Syndrome*. Philadelphia, PA: Jessica Kingsley Publishers, Ltd.

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