

How Will I Deal with the Diagnosis? How Will this Affect My Family?

Even though it is your child who has the Asperger Syndrome/HFA diagnosis, it is important to acknowledge that autism spectrum disorders “happen” to the whole family. They affect every member of the household. Asperger Syndrome can be difficult to deal with, both for the person diagnosed, and the family. It can lead to many changes in the family, both inside and outside the home. Luckily, with heightened awareness, there are many places to go for support and help. As you move forward with your child and your family as a whole, the staff at the Mayo Clinic has come up with the following advice to help you on your journey:

- *Learn about the disorder. Just 15 years ago, many pediatricians hadn't heard of Asperger Syndrome/HFA. Now, there are numerous books and Web sites dedicated to the disorder. Do some research so that you better understand your child's challenges and the range of services in your school district and state that may help.*
- *Learn about your child. The signs and symptoms of Asperger Syndrome/HFA vary for each child, and young children have a hard time explaining their behaviors and challenges. But, with time and patience, you'll learn which situations and environments may cause problems for your child and which coping strategies work. Keeping a diary and looking for patterns may help.*
- *Find a team of trusted professionals. You'll need to make important decisions about your child's education and treatment. Find a team of teachers and therapists who can help evaluate the options in your area and explain the federal regulations regarding children with disabilities.*
- *Help others help your child. Most children with Asperger Syndrome/HFA have no visible sign of disability, so you may need to alert coaches, relatives and other adults to your child's special needs. Otherwise, a well-meaning coach may spend time lecturing your child on "looking at him while he's talking" — something that can be very difficult for a child with Asperger Syndrome/HFA.*
- *Help your child turn his or her obsession into a passion. The tendency to fixate on a particular narrow topic is one of the hallmarks of Asperger Syndrome/HFA, and it can be annoying to those who must listen to incessant talk about the topic every day. But a consuming interest can also connect a child with Asperger Syndrome/HFA to schoolwork and social activities. In some cases, kids with Asperger syndrome can even turn their childhood fascination into a career or profession.*



Explaining the Diagnosis to Your Child

■ According to experts, it is essential for parents to explain the diagnosis to their children. Oftentimes, this can help put children on a path to self-acceptance, and can allow them the time to understand and ask questions. With no knowledge of their diagnosis, children with Asperger Syndrome can often compare themselves to others and come to unfounded conclusions about themselves and their own well-being.

Children younger than eight years of age often do not think they are different from their peers, so the bigger picture of a developmental disorder may be too complex for them to understand. When talking to your child, remember to use age appropriate words and to think about it from his or her perspective, in order to improve the communication between the two of you. It can help to talk to your child about being an individual and explain that differences exist between all people. Using play, and sometimes books, can also aid in helping children with AS to better understand themselves and their diagnosis. Be sure to emphasize your child's strengths as well as his or her areas of challenge. It is helpful to point out that everyone has areas of strength and weakness.

Telling Family Members

■ The following article, adapted from *Does My Child Have Autism?*, by Wendy L. Stone, Ph.D., provides some helpful information for talking to your parents and close family members about the autism or AS diagnosis.

Reactions vary widely. But whatever reaction you get, it will be very important to educate your parents about the nature of autism after you have told them about the diagnosis. To begin your discussion, you might talk about specific behaviors. For example:

“You know those behaviors we’ve been confused about for so long? Well, now we have a name for them and an explanation for why they occur. Howie doesn’t act the way he does because he’s spoiled or because he’s shy or because he doesn’t like us – he acts that way because he has autism. Autism explains why he doesn’t speak or use gestures and why he doesn’t seem to understand what we say. It explains why he’s not as interested in interacting with us as the other children in the family have been and why he plays with spoons and bottles instead of toys. I know this is upsetting news for all of us. But the good news is that the disorder has been diagnosed early, and there are a lot of things we can do to help him. He’ll be starting some therapies soon, and I’ll be learning about things I can do to help him at home. I know that you will need some time to think about all of this. But if you have any questions as we begin his therapy, I’ll be glad to try my best to answer them. I know we’re all hoping for the best outcome possible.” After the initial conversation about this diagnosis, continue to keep your other children and your extended family in the information loop.



Telling Others

The following article from the book *Overcoming Autism*, by Lynn Kern Koegel, Ph.D. and Claire LaZebnik, offers a suggestion for how to tell people, and explains why for some people, it can make life easier for you and your friends.

You should, you know. Tell people. You don't have to walk up to strangers on the street or anything, but confide in the people who love you. That was one thing we did right: we told our families and our friends right away. First we called them, and then we copied a good comprehensive article someone wrote about autism and annotated it with specifics about Andrew, and we mailed it out to everyone we knew. (You could do the same things with sections from this book, by the way.) None of our good friends pulled away from us because our kid had autism. Just the opposite – our friends and families rallied around us in amazing ways and have continued to cheer Andrew's progress on year after year. In all honesty, telling people what we were going through only made our lives easier. Before then, we worried that Andrew's occasionally aberrant behavior was off-putting. But once he had a formal diagnosis, everyone cut us a lot of slack, and instead of wondering what the hell was wrong with us as parents, most people we knew admitted to a newfound respect for us for dealing with so much. Real friends don't love you more for being successful or less for having problems. If anything, it works the opposite way – we're all so busy that sometimes we forget to stay in touch with friends when everything's fine for them, but we rush forward when they need us. Now is the time to take advantage of that. Talk your friends' ears off, complain, bitch and moan to them. You're dealing with a huge challenge, take advantage of every minor plus it has to offer.

Telling Peers

Talking with peers and other students is crucial to helping a child with AS become more comfortable in school or social settings. If peers are aware of their classmate with AS and understand the reasons behind their sometimes odd behavior, this will increase acceptance and limit bullying or taunting. It is important to explain Asperger Syndrome to children in a way that they will best understand their friend or classmate. For example, talk about the fact that many of us have challenges. While one classmate might be unable to see and might need glasses as a result, this other child has trouble in social situations and needs support as a result. It may help to identify one or two peers who can serve as "buddies" to help your child feel more comfortable in school.

Stephen Shore developed a four-step process for disclosing AS, which he has found effective in a number of settings. In essence, it's a tool for placing a child's AS in context, and helping others to understand that AS is not a "handicap," but rather a collection of strengths and challenges. Through accommodations and support, people with AS can not only succeed but can even thrive.



Start by delineating your child's strengths and challenges. Use the word "challenges" instead of "weaknesses" because you can address challenges. If Joe's been in class for a little while, a parent might say "Joey is very good at following the rules. When there's a change in the schedule, though, you'll see Joey get a little anxious."

Try to find a strength that your child uses to accommodate for a challenge. For example, during lecture parts of class, your child might use a computer to take notes. A parent might say "Joey finds that writing by hand is very tough, so this is how he takes notes."

Talk about other people's characteristics to place your child in a broader context. A parent might say, "Joey has these strengths; other people have other strengths. We all try to build on our strengths to lead to productive lives."

Lastly, bring out the label. Explain that AS is a set of traits, strengths and challenges, and that doctors and scientists have identified these characteristics as Asperger syndrome.

Join a Support Group

■ Consider joining a support group. It may be helpful to listen or talk to people who have been or are going through a similar experience. Support groups can be great sources of information about what services are available in your area and who provides them. You may have to try more than one to find a group that feels right to you. You may find you aren't a "support group kind of person." For many parents in your situation, support groups provide valuable hope, comfort and encouragement.

