



## Parenting a Child with Autism Spectrum Disorder: What is the Latest Research?

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### What is Autism?

Autism is the common name used to describe autism spectrum disorder (ASD). The word “spectrum” describes a wide range of symptoms, skills, and impairments that individuals with ASD may experience as a result of the disorder. The *Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition [DSM-V]* uses five criteria to characterize and diagnose ASD:

- Persistent deficits in social communication and social interaction across multiple contexts
- Restrictive, repetitive patterns of behavior, interests, or activities (current or in the past)
- Presentation of symptoms in the early developmental period, which is approximately between 2-6 years of age (Berk, 2008)
- Clinically significant impairment in social, occupational, or other important areas of current functioning resulting from symptoms
- Disturbances that are not explained by intellectual disability or global developmental delay

The diagnosis organization for ASD was recently changed. In the *Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition*, ASD was separated into five different disorders. One commonly known disorder that fell under ASD was Asperger syndrome. However, an individual with what was previously called Asperger syndrome is

now diagnosed as having autism spectrum disorder. Asperger syndrome was eliminated because it is not clinically separate from ASD.

ASD is a complex neurological and developmental disorder that involves the structure and function of the brain and nervous system. The disorder affects an individual’s social skills and communication abilities. Behaviors of a child with ASD differ noticeably from those of typically developing children of the same age. A distinctive characteristic of someone with ASD is the display of repetitive behaviors and restricted interests (American Psychiatric Association, 2013). For example, some children obsessively line up all of their toys, flap their hands or repeat sounds. Restricted interests can manifest themselves in many ways, such as eating the same food everyday or rigid ways of thinking and approaching problems.

Individuals with ASD vary in intelligence level and communication skills. Approximately 40% of those on the spectrum are of average or above average intelligence (Autism Speaks, 2013b). However about 25% of those with ASD are nonverbal. Sometimes these individuals find other ways to communicate, for example, through use of gestures and eye contact (Autism Speaks, 2013a). ASD also possesses a gender component, with a disproportionate percentage of males affected by the disorder. About 1 in 54 boys are diagnosed with ASD whereas only 1 in

252 girls receive the same diagnosis (Baio, 2012).

### **Signs and Symptoms**

The signs and symptoms of autism spectrum disorders are not the same in all cases. Some children may present symptoms as early as the first few months of life while others do not show signs of the disorder until 2-3 years of age. The Centers for Disease Control (2013) lists many signs and symptoms of autism spectrum disorders; however, not all symptoms appear in every case. The signs and symptoms are:

- No response to being called by name by 12 months of age
- No pointing at objects to show interest (e.g., pointing at an airplane flying overhead) by 14 months
- No playing of “pretend” games (pretending to “feed” a doll) by 18 months
- Avoiding eye contact and wanting to be alone
- Having trouble understanding other people’s feelings or talking about their own feelings
- Delayed speech and language skills
- Repeating words or phrases over and over
- Giving unrelated answers to questions
- Getting upset by minor changes in routine
- Displaying obsessive interests
- Rocking their body or spinning in circles
- Having unusual reactions to the way things sound, smell, taste, look, or feel

### **What “Causes” Autism?**

There is not a singular cause of ASD. Instead, it is generally understood to be a mixture of genetic and environmental components. It is important to dispel the myth that there is any link between a diagnosis of ASD and “bad” parenting. It is also important to dispel the myth that a chemical found in vaccines called thiomersal causes ASD. Based on initial findings by Verstraeten et al. (2003), researchers do not believe chemicals found in childhood vaccines cause ASD. There are no known ways to prevent ASD, but there are ways to minimize the potential negative effects of the disorder on development.

Researchers have found the risk of ASD is higher in children with a sibling that was previously diagnosed with the condition (Constantino, Zhang, Frazier, Abbacchi, & Law, 2010). Within a family, the chance that a child will develop autism increases 2-8% when another child in the family is diagnosed with autism (Hall & Graff, 2011). This suggests a genetic component for the disorder. Also, researchers have found an association between increased maternal age and ASD (Sandin, Hultman, Kolevzon, Gross, MacCabe, & Reichenberg, 2012). Children of mothers older than 35 years have 30% increased risk for developing the disorder. A father’s age also has been shown to increase the chance that a child will be born with autism, with older fathers at a higher risk of having a child born with the disorder (Hultman, Sandin, Levine, Lichtenstein, & Reichenberg, 2011). Fathers over 50 years of age are nearly 3 times more likely to have a child with autism and fathers over 55 years of age are over 4 times more likely to have a child with the disorder.

## **Autism and Its Effects on Parents**

Parenting is challenging for any parent, and children with special needs often require extra parental attention. However, research supports a number of strategies that parents raising a child with ASD can adopt:

- In two-parent families, it is important that both parents communicate with each other and be unified in the ways that they parent their child. One very important topic parents should agree upon is a treatment plan for their child. It may involve changes to home and work life, therefore parents should establish clear expectations of each other, such as who is responsible for certain household chores.
- In families where parents are not living together, parents raising a child with ASD reported being highly stressed and also reported difficulties working together in parenting (Hill-Chapman, Herzog, & Maduro, 2003). Helpguide.org, an online resource, emphasizes the importance of providing structure and safety for a child with ASD. A helpful strategy for parents in separate households may be to design a schedule and follow it so the child knows what to expect. This resource also recommends using rewards to positively reinforce the child's good behaviors. Both parents should agree upon a rewards system and be consistent carrying it out.
- Another strategy for reducing parental stress, and supported by research, is for parents of children with ASD to seek support from their spouses or their own parents (Hall & Graff, 2011). Though forms of helpful support will vary for every family,

some couples may find it valuable to take time together away from their children. This can give them an opportunity to strengthen their relationship and therefore be a strong unit for their child. It may benefit some single parents to move closer to family members for support.

- An often-discussed and suggested form of support is a family support group. However, researchers have found that parents have mixed feelings about the usefulness of such groups, as many parents do not like to talk about their family issues with strangers (Hall & Graft, 2011). Nevertheless, it may be useful for parents to experiment with support groups to determine if they are a supportive strategy for their individual family situation. Parents should also consider individual, marital, or family counseling if feeling stressed, depressed or relational tension. Counseling is a way to reduce anxiety by talking about feelings and working out problems.

## **Autism and the Classroom**

One area of specialized care received by children with ASD is assistance with school related matters. Public schools are required by law to develop Individualized Education Programs (IEP) for children diagnosed with ASD and other developmental disorders. Parents can contact the Special Education Administrator of their child's school and request information about developing an IEP. The school will perform an evaluation, which tests the child's general intelligence, reading comprehension, psychological states, social development, physical abilities, and interfering behaviors (Autism Speaks, 2011). The school will work with specialists and the parents to develop a plan that meets the needs of the child. In

addition to the development of the IEP, there is an annual IEP meeting to update the plan as well as ongoing communication between parents and teachers throughout the year. Developing these plans are especially important to make sure the child gets the attention that he or she needs in school.

Having an IEP will not only help the school meet the needs of the child, but will be helpful to parents in promoting an awareness of their child's abilities. Although ASD is characterized by differences in social, communication and behavioral development as well as motor development, children with ASD benefit from the same activities and interactions that typically developing children benefit from. For example, researchers have found that children with ASD are able to practice age-appropriate play and socialization skills when they play with typically developing children (Provost, Lopez, & Heimerl, 2008). Children with ASD will develop by playing with children in the classroom, but interactions can also be facilitated outside of the classroom. For example public playgrounds are great places for children to interact with each other. However, it is important that children with ASD be supervised by parents in these settings and for parents to be ready to assist their child if any issues should arise.

### **Diagnosis and Treatment**

It is important for parents to have their child evaluated if they suspect that he or she shows signs or symptoms of ASD. There are no medical tests for ASD, such as a blood test, so doctors must evaluate a child's behaviors and development in order to make a diagnosis. A primary care physician or pediatrician can administer a developmental screening to initially check

for signs and symptoms of ASD. Although developmental screenings are routinely done for all children, parents should not hesitate to let their doctor know if they detect that their child may be exhibiting signs of ASD.

If a doctor finds reason for concern, the doctor will likely recommend that the child undergo an in-depth evaluation. This evaluation is called Applied Behavioral Analysis and includes a psychologist, neurologist, psychiatrist, speech therapist and other professionals, such as an audiologist (a hearing professional). If a child has delayed speech development, for example, it is important for the child's hearing to be tested as well since hearing problems may cause signs and symptoms similar to ASD (National Institute of Health, 2013). Since autism is a spectrum disorder, the abilities of children with ASD vary and therefore it is important for a child to receive a thorough diagnosis so that the child can receive the specialized care he or she needs.

### **Conclusion**

Parenting a child with ASD poses challenges that are unique to the child's skills and symptoms. The abilities of children with ASD vary, and all children have the opportunity for a high quality of life. Research supports a number of strategies and tools that parents of children with ASD can utilize. There are also a variety of resources and sources of support for parents. As ASD becomes increasingly prevalent, researchers, physicians, specialists, and schools are becoming better informed and better equipped to meet the needs of children with this disorder and to assist parents in parenting a child with ASD.

## References

- American Psychiatric Association. (2013). *Diagnostic and statistical manual of mental disorders* (5<sup>th</sup> ed.). Arlington, VA: American Psychiatric Publishing.
- Autism Speaks. (2013a). *Seven ways to help your nonverbal child speak*. Retrieved from <http://www.autismspeaks.org/blog/2013/03/19/seven-ways-help-your-nonverbal-child-speak>
- Autism Speaks. (2013b). *What is autism?* Retrieved from <http://www.autismspeaks.org/what-autism>
- Autism Speaks: Goodwin & Proctor. (2011). *Individualized education program (IEP): Summary, process and practical tips*. Autism Speaks Inc.
- Baio, J. (2012). Prevalence of autism spectrum disorders – autism and developmental disabilities monitoring network, 14 sites, United States, 2008. *Morbidity and Mortality Weekly Report (MMWR)*. Retrieved from [http://www.cdc.gov/mmwr/preview/mmwrhtml/ss6103a1.htm?s\\_cid=ss6103a1\\_w](http://www.cdc.gov/mmwr/preview/mmwrhtml/ss6103a1.htm?s_cid=ss6103a1_w)
- Berk, L. E. (2008). *Infants, children, and adolescents*. Upper Saddle River, New Jersey: Pearson Education, Inc.
- Center for Disease Control [CDC]. (2013). *Autism spectrum disorder (ASDs): Facts about ASDs*. Retrieved from <http://www.cdc.gov/ncbddd/autism/facts.html>
- Constantino, J., Zhang, Y., Frazier, T., Abbacchi, A., & Law, P. (2010). Sibling recurrence and the genetic epidemiology of autism. *The American Journal of Psychiatry*, 167, 1349-1356.
- Eunice Kennedy Shriver National Institute of Child Health and Human Development. (2013). *Autism spectrum disorder (ASD): Condition information*. Retrieved from [www.nichd.nih.gov/health/topics/autism/conditioninfo/Pages/default.aspx](http://www.nichd.nih.gov/health/topics/autism/conditioninfo/Pages/default.aspx)
- Hall, H. & Graff, J. (2011). The relationship among adaptive behaviors of children with autism, family support, parenting stress, and coping. *Comprehensive Pediatric Nursing*, 34, 4-25.
- HelpGuide. (2014). *Helping children with autism*. Retrieved from [http://www.helpguide.org/mental/autism\\_help.htm](http://www.helpguide.org/mental/autism_help.htm)
- Hill-Chapman, C., Herzog, T., & Maduro, R. (2013). Aligning over the child: Parenting alliance mediates the association of autism spectrum disorder

atypicality with parenting stress. *Research in Developmental Disabilities*, 34, 1498-1504.

Hultman, C., Sandin, S., Levine, S., Lichtenstein, P., & Reichenberg, A. (2011). Advancing paternal age and risk of autism: New evidence from a population-based study and a meta-analysis of epidemiological studies. *Molecular Psychiatry*, 16, 1203-1212.

National Institute of Health [NIH]: National Institute of Neurological Disorders and Stroke. (2013). *Autism fact sheet*. Retrieved from [http://www.ninds.nih.gov/disorders/autism/detail\\_autism.htm](http://www.ninds.nih.gov/disorders/autism/detail_autism.htm)

Provost, B., Lopez, B., & Heimerl, S. (2007). A comparison of motor delays in young children: Autism Spectrum Disorder, developmental delay, and developmental concerns. *Journal of Autism Developmental Disorders*, 37, 321-328.

Sandin, S., Hultman, C., Klevzon, A., Gross, R., MacCabe, J., & Reichenberg, A. (2012). Autism: A review and meta analysis. *Journal of the American Academy of Child & Adolescent Psychiatry*, 51, 477-486.

Verstraeten, T., Davis, R., DeStefano, F., Lieu, T., Rhodes, P., Black, S.,... Chen, R. (2003). Safety of thimerosal-containing vaccines: A two-phased study of computerized health maintenance organization database. *Pediatrics*, 122, 1039-1048.

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