

# Table of Contents

<b>What is Autism?</b> .....	3
<b>Prevalence</b> .....	3
<b>Characteristics of Autism</b> .....	4
<b>What Causes Autism?</b> .....	5
<b>Diagnosis</b> .....	5
<b>Consulting with Professionals</b> .....	6
<b>Working with Professionals</b> .....	7
Choosing Appropriate Interventions for Children with Autism .....	7
<b>Understanding and Evaluating Interventions</b> .....	8
<b>Interventions Strategies</b> .....	9
<b>Moving Forward After the Diagnosis</b> .....	10

# Characteristics of Autism



## What is Autism?

Autism is a developmental disability that is the result of a neurological disorder that affects the normal functioning of the brain, impacting development in the areas of social interaction and communication skills.



Symptoms of Autism generally manifest before age 3 and can adversely affect a child's educational performance. Some autistic children are not diagnosed until school age; and some may have spurts and plateaus in development. The rates of physical, cognitive, social, and emotional growth may be very inconsistent.

Autism is a multi-spectrum disorder that may range from mild to severe. It interferes with the ability to navigate the environment. Both children and adults with Autism typically show difficulties in verbal and non-verbal communication, social interactions, and leisure or play activities.

Other characteristics often associated with Autism are engagement in repetitive activities and movements, resistance to environmental changes or change in daily routines, and atypical responses to sensory experiences. Autism cannot be cured, and there is NO medication or drug treatment.

## Prevalence

Some autistic children are not diagnosed until school age. Given that behaviors related to Autism are usually present before the age of 3 years, it is important to make sure individuals are being identified as soon as possible and are receiving appropriate early intervention services.

- ANY child can have Autism regardless of their race, ethnicity, culture, family income level, or educational level.
- For reasons unknown, there has been a noticeable increase in the number of children diagnosed with autistic-like features (source: DSM IV).
- Autism is one of the most common of the Developmental Disabilities, it is estimated that up to 560,000 individuals between the ages of birth to 21 have Autism.
- Roughly translated this means an estimated 1 in 500 births are affected.
- Boys are four times more likely than girls to have Autism.
- Approximately 66% have mental retardation or mental illness as adults.

**Source:** Centers for Disease Control Prevention, <http://www.cdc.gov/>

## Characteristics of Autism

Autism is a spectrum disorder which means it covers a wide range of behaviors and ability levels. All people are different, this includes individuals with Autism. NO two individuals with Autism behave and/or have the same ability and capability levels. For example, two individuals with the same diagnosis can behave entirely different from one another. Some of the general characteristics of Autism are as follows:

### **Absence or delay of speech or other communication skills:**

- Repetition of words instead of normal verbal communication.
- Pointing or gestures to communicate in place of verbal requests, cues or words.
- Little to no use of verbal communication.

### **Difficulty relating to others:**

- Little to no eye contact.
- Lack of responsiveness to other people.
- Nonresponsive to verbal requests and cues.
- Nonresponsive to name being called.
- Prefers to be alone; avoids physical contact.

### **Out of the ordinary behaviors:**

- Self-stimulation (e.g. spinning, rocking, hand flapping, etc).
- Unapparent laughter, crying or tantrums.
- Inappropriate and/or obsessive attachment to objects.
- Ritualistic or repetitive behaviors.
- A need for sameness and a resistance to change.
- Self injurious behavior.
- Acting-out behaviors.

### **Sensory Challenges:**

- Over-sensitivity or Under-sensitivity to the senses.
- Not wanting to hug or be hugged.
- Over-sensitivity or under-sensitivity to pain.
- Mental retardation frequently present.
- Seizures are not uncommon, especially during adolescence.

**Source:** *AutismInfo.com*, <http://www.Autisminfo.com/WhatIs.htm>

*Adapted from the original by Professor Rendle-Short, Brisbane Children's Hospital, University of Queensland, Australia.*

## What Causes Autism?

At this time there is NO known single cause for Autism. The cause of Autism is still undergoing research. Researchers are investigating a number of theories. A commonly accepted theory on the cause of Autism is the development of abnormalities in the brain's structure and/or function. This is generally determined by brain scans administered by a medical professional, who can evaluate the shape and structure of the brain in children with and without Autism.

However, there is some evidence that suggests the existence of genetic link, although the topic is still under debate. A number of experts and parents alike believe that some children are born with a predisposition for an Autistic Disorder. Research studies have shown that there may be a pattern of Autism or related disabilities in many families. This supports a genetic origin to the disability. While NO one gene has been identified as the cause for Autism, researchers are looking for irregular fragments of genetic code that are hereditary in children with Autism.

Other researchers are investigating problems during pregnancy or delivery as well as environmental factors, such as viral infections, metabolic imbalances, and exposure to environmental chemicals. Some experts feel the disorder may or may not be triggered very early in life by some neurobiological trauma, such as food allergies inoculation or bodily infection like meningitis.

**Sources:** Autistic Services Incorporated, <http://www.autisticservices.org/>  
Autism Society of America, <http://www.Autism-society.org>

## Diagnosis

There are NO medical tests for diagnosing Autism. A diagnosis must be made by a medical doctor after a comprehensive evaluation. An evaluation can consist of observing the individual's communication, behavior, and developmental levels and may also include physical, neurological, and genetic testing.

Various assessment tools have been developed to evaluate Autism. NO single assessment should be used as the sole basis for diagnosing. Additionally, observing an individual in one single setting cannot present an accurate representation of an individual's abilities and behaviors. Other sources of information that are important components of making an accurate diagnosis are parental/caregivers' and/or teachers' input and health care professional's direct observation of behaviors.

Many of the characteristics and behaviors associated with Autism are also common in other disorders, therefore a variety of medical evaluations may be necessary to rule out or identify other possible causes of behaviors being exhibited.

Many times persons with Autism may appear to have Mental Retardation, Behavior Disorders, and/or Hearing Impairments. Because the Office of Mental

Retardation/Developmental Disabilities does not provide services to children birth to 3 years, it is imperative that children suspected of having Autism be diagnosed as soon as possible.

It is important to note that an individual with Autism can also have Mental Retardation, a Behavior Disorder, and/or a Hearing Impairment at the same time as being Autistic which can further compound the evaluation process.

**Source:** Autism Society of America, <http://www.Autism-society.org>

## Consulting with Professionals

Once your child has been suspected to have Autism by you or a health care professional you will need to be referred to a health care professional specializing in diagnosing Autism. These professionals may include a developmental pediatrician, a psychiatrist or psychologist. Other professionals may be included to have a thorough and accurate evaluation for your child.

A multidisciplinary assessment team may include some or all of the following professionals. Some of these professionals may also be involved in intervention programs.

**Developmental pediatrician:** Treats health problems of children with developmental delays or handicaps.

**Child Psychiatrist:** A medical doctor who may be involved in the initial diagnosis; can prescribe medication and provide help in behavior, emotional adjustment and social relationships.

**Clinical Psychologist:** Specializes in understanding the nature and impact of developmental disabilities including Autism. May perform psychological and assessment tests and may help with behavior modification and social skills training.

**Occupational Therapist:** Focuses on practical, self-help skills that will aid in daily living such as dressing, eating; may work on sensory integration, coordination of movement, and fine motor skills.

**Physical Therapist:** Helps to improve the use of bones, muscles, joints, and nerves to develop muscle strength, coordination and motor skills.

**Speech/language Therapist:** Involved in the improvement of communication skills including speech and language.

**Social Worker:** May provide counseling services or act as case manager helping to arrange services.

## Working with Professionals

Children will benefit from parents and professionals working together. As a parent/caregiver you have insightful information about your child's abilities and capabilities and professionals have the experience and training to make recommendations about interventions. That is why it is so important that parents/caregivers and professionals work together to find the best intervention specific to your child needs.

Once an intervention has been selected and implemented that meets your child's specific needs open communication between parents/caregivers and professionals is critical in monitoring your child's progress. Here are some guidelines for working and communicating effectively with professionals:

- **Be informed.** Learn as much as you can about your child's disability so you can be an active participant in determining care. If you don't understand terms used by professionals, ask for clarification.
- **Be prepared.** Be prepared for meetings with doctors, therapists, and school personnel. Write down your questions and concerns, and then note the answers.
- **Be organized.** Many parents find it useful to keep a notebook detailing their child's diagnosis and treatment, as well as meetings with professionals.
- **Communicate.** It's important to ensure open communication - both good and bad. If you don't agree with a professional's recommendation, speak up and say specifically why you don't.

**Source:** Autistic Services Incorporated, <http://www.autisticservices.org/>

## Choosing Appropriate Interventions for Children with Autism

Choosing an appropriate intervention for your child with Autism can help them develop their needed skills. It is important to note that there is NO one method that addresses all the behaviors and characteristics of Autism. Some intervention methods may include:

- **Educational interventions:** special small classes or 1 to 1 play sessions.
- **Therapy interventions:** speech pathology or occupational therapy.

It is important to match children's specific needs with interventions or methods that are likely to be effective in moving them closer to determined goals that will help them meet their maximum potential. When choosing an intervention look for the following common criteria (Prior and Roberts, 2006):

- **Autism-specific content:** The intervention should focus on skill development in areas including communication, social skills, play and managing behavior
- **Regular intervention activities:** It is important that services are provided by professionals and activities include family members as part of everyday interactions with their child

- **Family involvement:** Family members should be included in accessing education about Autism and participate in intervention activities
- **Involvement with other children:** Children with Autism should interact with other children who are typically developing as much as possible
- **Focus on predictability and establishing routines:** Methods used to generate skills should transcend from home to school
- **Communication skill development:** The use of other forms of communication such as pictures or sign language and visual supports help language development

**Source:** Putting Children First, the magazine the National Childcare Accreditation Council (NCAC) Issue 26 June 2008 (Pages 12-15)

## Understanding and Evaluating Interventions

Intervention methods are continually progressing as more is learned about Autism. There are many programs that focus on replacing dysfunctional behaviors and developing specific skills.

Take your time when selecting an intervention because sudden changes or differences in expectations could be stressful and confusing for your child. Make sure to investigate the intervention's appropriateness to your child's specific needs before proceeding.

Other parents with children with Autism may have tried interventions that were successful, but this does not mean you will have the same results with your child. Professionals will also have different theories and/or approaches that they feel are the most successful interventions for Autism. It is important as a parent/caregiver to learn to sort through all the information you will receive. You must examine ALL interventions critically and make rational, educated decisions on what is the most appropriate for YOUR child's specific needs.

As a parent/caregiver you are the expert on your child's day to day life. You know best their needs and the unique ways Autism impacts their daily living. You must learn to trust your instincts as you research, reflect on and apply the different interventions available.

When researching different interventions always contact a qualified professional and seek out parents of or individuals with Autism who have personal experiences with that specific method.

**Source:** National Association of School Psychologists, <http://www.nasponline.org/>  
Autism Society of America, <http://www.Autism-society.org>

## Intervention Strategies

- **Involve your child in turn-taking activities that require shared space and materials.** Provide structure and support to help your child remain engaged and wait their turn. Use familiar short songs or counting activities in a predictable way.
- **Encourage your child to join a peer who is using a favored toy.** Model and parallel talk appropriate ways for your child to join their peer.
- **Use pictures and visual charts so that your child does not have to rely on language, especially during transition.** In school or home, it is helpful to use picture systems to represent daily activities such as snack, music, gym, etc.
- **Pictures can also be used to help communicate wants and needs.** Pictures of favorite activities can be used to help your child learn to make more choices and to help give them a sense of control.
- **Break down directions into short, simple statements.** The use of predictable and consistent language is also a key to helping your child process and respond to the direction or tasks at hand.
- **Reduce the level of distraction and stimulation so that your child can attend to language.** The child's ability to process language may vary depending on the level of environmental stimulation, activity level, how new the situation or emotional factors such as anxiety, frustration or fear. Increased structure and visual cues may be necessary to help your child focus attention.
- **When possible, look at the communicative intent of your child's behavior.** Provide them words that describe what they are attempting to communicate.
- **Teach social skills and social interactions specifically in a structured way.** This enables your child to prepare for situations and interactions which are most likely fear-and anxiety producing.
- **Be aware of sensory stimulation in the environment, and help your child plan ahead and anticipate sensory input.** In addition, use sensory input to help your child de-escalate behavior or focus attention.
- **Students with Autism often have a difficult time transferring a skill they have learned in one setting and applying it to another setting.** It is important to teach skills in as many environments with as many people as possible.

**Source:** National Association of School Psychologists, Dr. Elizabeth Rudrud, Minneapolis Public Schools.

## Moving Forward After the Diagnosis

Families are often confused, angry and filled with hopelessness, after receiving the medical diagnosis of Autism. Do not beat yourself up! These are normal feelings that families go through. It is important to know that there is not only life after a diagnosis, but a child with Autism can have a very fulfilled and rewarding life.

As a parent/caregiver you can help your child discover the wonders of the world around them. There are 10 basic steps that should be taken after a diagnosis. These steps are as follows:

**Step 1: Learn and read as much as possible.** The amount of available information may seem overwhelming, the more you read and discover, the easier it will be to understand new information. However, always consider the source of any information you find. And do not focus exclusively on one intervention or therapy; no one treatment works for everyone.

**Step 2: Network with other families.** Families in similar situations are often important sources of support. You can become active in the Autism community by attending support group meetings and conferences to meet other parents who are going through the same struggles and are happy to share their experiences.

**Step 3: Test, Test, Test.** Test your child early to get a baseline picture of where he or she is. A clear picture of your child's biological condition provides a roadmap for treatment and therapies to follow. If you can't afford all of the tests you need up front, prioritize them with your medical providers' help.

**Step 4: Investigate sources of financial aid.** Autism can quickly exhaust your resources, but, fortunately, funding and assistance do exist. Financial aid is generally available at the county level for children under the age of 3 (you'll need to apply for the Medicaid waiver). Also, keep good financial records, and avoid using the words "Autism" or "PDD-NOS" with insurance companies, especially HMOs, as many exclude Autism in their policies. If there is a biological abnormality that's being treated, have the doctor code it as such.

**Step 5: Consider major lifestyle changes.** As Autism treatment can seriously affect your financial resources, you may have to make major changes (such as changing your job or downsizing your home) or short-term sacrifices to allow for the funds you need to treat your child. Also, if you have a spouse or significant other, you need to establish a division of labor and responsibilities regarding the care of your child. Autism treatment takes sacrifice, but the hard work pays off. Many parents will tell you that the emotional rewards are much more lasting than any hobby or house can bring.

**Step 6: Set up an educational/behavioral program in your home.** If you can afford it, a structured one-on-one program focusing on education and behavior works for many children with Autism. Make sure the program is reputable and that it shares your expectations and goals. You and your tutor/consultant should both sign a contract stating who is responsible for what.

**Step 7: Begin therapies.** You may be referred to other specialists for therapy, including speech, occupational and physical therapy. These therapies will help your child gain

communication, social and physical skills. Insurance providers, including Medicaid, often cover the cost.

**Step 8: Address diet and nutrition.** Since dietary sensitivities affect many people with Autism, consider trying special diets (such as wheat-free/dairy-free) for your child. Based on medical testing and your doctor's recommendations, you should also start your child on vitamin/mineral supplements geared to his/her needs. Be sure to consult with a nutritionist and pediatrician with expertise in Autism.

**Step 9: Don't give up. Attitude is everything!** Try to be a morale booster for your family and your team of professionals. Educate doctors who are unfamiliar with Autism and provide up-to-date information for those who can help. Be patient as many treatments and interventions take time to produce results. Most importantly, remember to laugh and have fun together as a family.

**Step 10: Get out and relax.** Make time for yourself. You must take care of yourself to be of any good to your child. Encourage your spouse/significant other to take time to recharge as well.

**Source:** Shore, S.M., & Rastelli, G.L. (2006). *Understanding Autism for Dummies*. Wiley, John & Sons, Inc.