Autism Spectrum Disorders (ASDs)

What is Autism?
Autism is a complex developmental disability that causes problems with social interaction and communication. Symptoms usually start before age three and can cause delays or problems in many different skills that develop from infancy to adulthood.

What is an Autism Spectrum Disorder (ASD)?
Different people with autism can have very different symptoms. Health care providers think of autism as a “spectrum” disorder, a group of disorders with similar features. One person may have mild symptoms, while another may have serious symptoms.

Currently, the autism spectrum disorder category includes:
- Autistic disorder (also called “classic” autism)
- Asperger syndrome
- Pervasive developmental disorder not otherwise specified (or atypical autism)

In some cases, health care providers use a broader term, pervasive developmental disorder, to describe autism. This category includes the autism spectrum disorders above, plus childhood disintegrative disorder and Rett Syndrome.

The autism spectrum disorders can often be reliably detected by the age of 3 years, and in some cases as early as 18 months. Studies suggest that many children eventually may be accurately identified by the age of 1 year or even younger. The appearance of any of the warning signs of ASD is reason to have a child evaluated by a professional specializing in these disorders.

Parents are usually the first to notice unusual behaviors in their child. In some cases, the baby seemed “different” from birth, unresponsive to people or focusing intently on one item for long periods of time. The first signs of an ASD can also appear in children who seem to have been developing normally. When an engaging, babbling toddler suddenly becomes silent, withdrawn, self-abusive, or indifferent to social overtures, something may be wrong. Research has shown that parents are usually correct about noticing developmental problems, although they may not realize the specific nature or degree of the problem.
A recent study of a U.S. metropolitan area estimated that 3.4 of every 1,000 children 3-10 years old had or has autism. The earlier the disorder is diagnosed, the sooner the child can be helped through treatment interventions. Pediatricians, family physicians, daycare providers, teachers, and parents may initially dismiss signs of ASD, optimistically thinking the child is just a little slow and will “catch up.” Although early intervention has a dramatic impact on reducing symptoms and increasing a child’s ability to grow and learn new skills, it is estimated that only 50 percent of children are diagnosed before kindergarten.

Is Autism More Common in Certain Groups of People?
Three groups are at higher-than-normal risk for autism spectrum disorders, including:
- Boys
- Siblings of those with autism
- People with certain other developmental disorders, such as Fragile X syndrome

What are the Symptoms of Autism?
The main signs and symptoms of autism involve problems in the following areas:
- **Communication** – both verbal (spoken) and non-verbal (unspoken, such as pointing, eye contact, and smiling)
- **Social** – such as sharing emotions, understanding how others think and feel, and holding a conversation
- **Routines or repetitive behaviors** (also called stereotyped behaviors) – such as repeating words or actions, obsessively following routines or schedules, and playing in repetitive ways

Communication Difficulties
By age 3, most children have passed predictable milestones on the path to learning language; one of the earliest is babbling. By the first birthday, a typical toddler says words, turns when he hears his name, points when he wants a toy, and when offered something distasteful, makes it clear that the answer is “no.” Children the ASD present differently:
- Some children diagnosed with ASD remain mute throughout their lives.
- Some infants who later show signs of ASD coo and babble during the first few months of life, but they soon stop.
- Others may be delayed, developing language as late as age 5 to 9.
- Some children may learn to use communication systems such as pictures or sign language.
Those who do speak often use language in unusual ways such as:
- Unable to combine words into meaningful sentences.
- Speak only single words.
- Repeat the same phrase over and over.
- Parrot what they hear, a condition called *echolalia*. Although many children with no ASD go through a stage where they repeat what they hear, it normally passes by the time they are 3.
- Inability to understand body language, tone of voice, or “phrases of speech.” They might interpret a sarcastic expression such as “Oh, that's just great” as meaning it really IS great.
- Mildly affected children may exhibit slight delays in language, or even seem to have precocious language and unusually large vocabularies, but have great difficulty in sustaining a conversation. The “give and take” of normal conversation is hard for them, although they often carry on a monologue on a favorite subject, giving no one else an opportunity to comment.

The body language of a child with ASD is also difficult to understand:
- Facial expressions, movements, and gestures rarely match what they are saying.
- Their tone of voice fails to reflect their feelings.
- A high-pitched, sing-song, or flat, robot-like voice is common.

Without meaningful gestures or the language to ask for things, people with ASD are at a loss to let others know what they need. As a result, they may simply scream or grab what they want. Until they are taught better ways to express their needs, ASD children do whatever they can to get through to others. As people with ASD grow up, they can become increasingly aware of their difficulties in understanding others and in being understood. As a result, they may become anxious or depressed.

**Social Symptoms**
From the start, typically developing infants are social beings. Early in life, they gaze at people, turn toward voices, grasp a finger, and even smile.

In contrast, most children with ASD seem to have tremendous difficulty learning to engage in the give-and-take of everyday human interaction. Such as:
- Even in the first few months of life, many do not interact and they avoid eye contact.
- They seem indifferent to other people, and often seem to prefer being alone.
• They may resist attention or passively accept hugs and cuddling.
• Later, they seldom seek comfort or respond to parents’ displays of anger or affection in a typical way.

Research has suggested that although children with ASD are attached to their parents, their expression of this attachment is unusual and difficult to “read.” To parents, it may seem as if their child is not attached at all. Parents who looked forward to the joys of cuddling, teaching, and playing with their child may feel crushed by this lack of the expected and typical attachment behavior.

Children with ASD also are slower in learning to interpret what others are thinking and feeling.

**Subtle social cues – whether a smile, a wink, or a grimace – may have little meaning.** To a child who misses these cues, “Come here” always means the same thing, whether the speaker is smiling and extending her arms for a hug or frowning and planting her fists on her hips. Without the ability to interpret gestures and facial expressions, the social world may seem bewildering. To compound the problem, people with ASD have difficulty seeing things from another person's perspective. Most 5-year-olds understand that other people have different information, feelings, and goals than they have. A person with ASD may lack such understanding. This inability leaves them unable to predict or understand other people's actions.

Although not universal, it is **common for people with ASD also to have difficulty regulating their emotions.** This can take the form of “immature” behavior such as crying in class or verbal outbursts that seem inappropriate to those around them. The individual with ASD might also be disruptive and physically aggressive at times, making social relationships still more difficult. They have a tendency to “lose control,” particularly when they're in a strange or overwhelming environment, or when angry and frustrated. They may at times break things, attack others, or hurt themselves. In their frustration, some bang their heads, pull their hair, or bite their arms.

**Repetitive Behaviors**
Although children with ASD usually appear physically normal and have good muscle control, odd repetitive motions may set them off from other children. These behaviors might be extreme and highly apparent or more subtle.
• Some children and older individuals spend a lot of time repeatedly flapping their arms or walking on their toes.
• Some suddenly freeze in position.
• They might spend hours lining up their cars and trains in a certain way, rather than using them for pretend play.
• If someone accidentally moves one of the toys, the child may be tremendously upset.
• ASD children need, and demand, absolute consistency in their environment. A slight change in any routine – in mealtimes, dressing, taking a bath, going to school at a certain time and by the same route – can be extremely disturbing. Perhaps order and sameness lend some stability in a world of confusion.

Repetitive behavior sometimes takes the form of a persistent, intense preoccupation. For example, the child might be obsessed with learning all about vacuum cleaners, train schedules, or lighthouses. Often there is great interest in numbers, symbols, or science topics.

**Possible Indicators of Autism Spectrum Disorders**

• Does not babble, point, or make meaningful gestures by 1 year of age
• Does not speak one word by 16 months
• Does not combine two words by 2 years
• Does not respond to name
• Loses language or social skills

**Some Other Indicators**

• Poor eye contact
• Does not seem to know how to play with toys
• Excessively lines up toys or other objects
• Is attached to one particular toy or object
• Does not smile
• At times seems to be hearing impaired
# Problems That May Accompany ASD

| Sensory problems | Many ASD children are highly attuned or even painfully sensitive to certain sounds, textures, tastes, and smells.  
| - | Some children find the feel of clothes touching their skin almost unbearable.  
| - | Some sounds – a vacuum cleaner, a ringing telephone, a sudden storm, even the sound of waves lapping the shoreline – will cause these children to cover their ears and scream.  
| - | The brain seems unable to balance the senses appropriately. Some ASD children are oblivious to extreme cold or pain. A child may fall and break an arm, yet never cry. Another may bash his head against a wall and not wince, but a light touch may make the child scream with alarm. |

| Mental retardation | Many children with ASD have some degree of mental impairment.  
| - | When tested, some areas of ability may be normal, while others may be especially weak. For example, a child with ASD may do well on the parts of the test that measure visual skills, but earn low scores on the language subtests. |

| Seizures | One in four children with ASD develops seizures, often starting either in early childhood or adolescence. |

| Fragile X syndrome | This disorder is the most common inherited form of mental retardation.  
| Named because one part of the X chromosome has a defective piece that appears pinched and fragile when under a microscope | Affects about two to five percent of people with ASD.  
| - | It is important to have a child with ASD checked for Fragile X, especially if the parents are considering having another child. For an unknown reason, if a child with ASD also has Fragile X, there is a one-in-two chance that boys born to the same parents will have the syndrome. |
Tuberous Sclerosis
Tuberous sclerosis is a rare genetic disorder that causes benign tumors to grow in the brain as well as in other vital organs

- It has a consistently strong association with ASD.
- One to four percent of people with ASD also have tuberous sclerosis.

What are the Treatments for Autism?
There is no single best treatment package for all children with ASD. One point that most professionals agree on is that early intervention is important. Another is that most individuals with ASD respond well to highly structured, specialized programs.

There are ways to help minimize the symptoms of autism and to maximize learning.

Treatment Options for ASD

Applied behavior analysis (ABA). Among the many methods available for treatment and education of people with autism, ABA has become widely accepted as an effective treatment. Thirty years of research has shown the effectiveness of applied behavioral methods in reducing inappropriate behavior and in increasing communication, learning, and appropriate social behavior. This therapy includes intensive, one-on-one child-teacher interaction for 40 hours a week. **The goal of behavioral management is to reinforce desirable behaviors and reduce undesirable ones.**

An effective treatment program will:
- Build on the child’s interests,
- Offer a predictable schedule,
- Teach tasks as a series of simple steps,
- Actively engage the child's attention in highly structured activities, and
- Provide regular reinforcement of behavior.

Parental involvement has emerged as a major factor in treatment success. Parents work with teachers and therapists to identify the behaviors to be changed and the skills to be taught. Recognizing that parents are the child's earliest teachers, more programs are beginning to train parents to continue the therapy at home.
As soon as a child's disability has been identified, instruction should begin. Effective programs will teach early communication and social interaction skills. In children younger than 3 years, appropriate interventions usually take place in the home or a child care center. These interventions target specific deficits in learning, language, imitation, attention, motivation, compliance, and initiative of interaction. Included are behavioral methods, communication, occupational and physical therapy, along with social play interventions. Often the day will begin with a physical activity to help develop coordination and body awareness; children string beads, piece puzzles together, paint, and participate in other motor skills activities. At snack time the teacher encourages social interaction and models how to use language to ask for more juice. The children learn by doing. Working with the children are students, behavioral therapists, and parents who have received extensive training. In teaching the children, positive reinforcement is used.

Children older than 3 years usually have school-based, individualized, special education. The child may be in a segregated class with other autistic children or in an integrated class with children without disabilities for at least part of the day. Different programs may use differing methods but all should provide a structure that will help the children learn social skills and functional communication. In these programs, teachers often involve the parents, giving useful advice in how to help their child use the skills or behaviors learned at school when they are at home.

- In elementary school, the child should receive help in any skill area that is delayed and, at the same time, be encouraged to grow in his or her areas of strength. Many schools today have an inclusion program in which the child is in a regular classroom for most of the day, with special instruction for a part of the day. This instruction should include such skills as learning how to act in social situations and in making friends. Although higher-functioning children may be able to handle academic work, they too need help to organize tasks and avoid distractions.

- During middle and high school years, instruction will begin to address such practical matters as work, community living, and recreational activities. This should include work experience, using public transportation, and learning skills that will be important in community living.
The Adolescent Years
Adolescence is a time of stress and confusion; and it is no less so for teenagers with autism. Like all children, they need help in dealing with their budding sexuality. While some behaviors improve during the teenage years, some get worse. Increased autistic or aggressive behavior may be one way some teens express their newfound tension and confusion.

The teenage years are also a time when children become more socially sensitive. At the age that most teenagers are concerned with acne, popularity, grades, and dates, teens with autism may become painfully aware that they are different from their peers. They may notice that they lack friends and unlike their schoolmates, they aren't dating or planning for a career. For some, the sadness that comes with such realization motivates them to learn new behaviors and acquire better social skills.

Dietary and Other Interventions
In an effort to do everything possible to help their children, many parents continually seek new treatments. Some treatments are developed by reputable therapists or by parents of a child with ASD. Although an unproven treatment may help one child, it may not prove beneficial to another. The following are some of the interventions that have been reported to have been helpful to some children but whose efficacy or safety has not been proven.

**Dietary interventions** are based on the idea that 1) food allergies cause symptoms of autism, and 2) an insufficiency of a specific vitamin or mineral may cause some autistic symptoms. If parents decide to try for a given period of time a special diet, they should be sure that the child's nutritional status is measured carefully.

- **Gluten-free, casein-free diet:** Some parents have found this diet was helpful to their autistic child. Gluten is a casein-like substance that is found in the seeds of various cereal plants – wheat, oat, rye, and barley. Casein is the principal protein in milk. Since gluten and milk are found in many of the foods we eat, following a gluten-free, casein-free diet is difficult.
- **Vitamin B6, taken with magnesium:** Magnesium makes the vitamin B6 more effective. The result of research studies is mixed; some children respond positively, some negatively, some not at all or very little.
- **Secretin:** In the search for treatment for autism, there has been discussion in the last few years about the use of secretin, a substance approved by the Food and Drug Administration (FDA) for a single dose normally given to aid in diagnosis of a gastrointestinal problem.
Anecdotal reports have shown improvement in autism symptoms, including sleep patterns, eye contact, language skills, and alertness. *Several clinical trials conducted in the last few years have found no significant improvements in symptoms between patients who received secretin and those who received a placebo.*

**Medications Used in Treatment**
Medications are often used to treat behavioral problems, such as aggression, self-injurious behavior, and severe tantrums, that keep the person with ASD from functioning more effectively at home or school. The medications used are those that have been developed to treat similar symptoms in other disorders. Many of these medications are prescribed “off-label.” This means they have not been officially approved by the FDA for use in children, but the doctor prescribes the medications if he/she feels they are appropriate for the child.

A child with ASD may not respond in the same way to medications as typically developing children.
- It is important that parents work with a doctor who has experience with children with autism.
- A child should be monitored closely while taking a medication.
- The doctor will prescribe the lowest dose possible to be effective.
- Parents should ask the doctor about any side effects the medication may have and keep a record of how the child responds to the medication.

**Anxiety and Depression**

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<tr>
<th>Selective serotonin reuptake inhibitors (SSRIs) are the medications most often prescribed for symptoms of anxiety, depression, and/or obsessive-compulsive disorder (OCD).</th>
<th>Fluoxetine (Prozac®) has been approved by the FDA for both OCD and depression in children age 7 and older</th>
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<td>Treatment with these medications can be associated with decreased frequency of repetitive, ritualistic behavior and improvements in eye contact and social contacts.</td>
<td>Fluvoxamine (Luvox®), for OCD age 8 and older</td>
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<td>Sertraline (Zoloft®), for OCD age 6 and older</td>
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<td>Comipramine (Anafranil®), for OCD age 10 and older</td>
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The FDA is studying and analyzing data to better understand how to use the SSRI's safely, effectively, and at the lowest dose possible.

### Behavioral Problems

**Antipsychotic medications** have been used to treat severe behavioral problems.

These medications work by reducing the activity in the brain of the neurotransmitter dopamine.

- Risperidone (Risperdal®)
- Olanzapine (Zyprexa®)
- Ziprasidone (Geodon®)

All of these are still under study, but results look good.

### Seizures

**Anticonvulsants.** The level of the medication in the blood should be monitored carefully and adjusted so that the least amount possible is used to be effective.

Although medication usually reduces the number of seizures, it cannot always eliminate them.

- Carbamazepine (Tegretol®)
- Lamotrigine (Lamictal®)
- Topiramate (Topamax®)
- Valproic acid (Depakote®)

### Inattention and Hyperactivity

**Stimulant medications.** These medications may decrease impulsivity and hyperactivity in some children, especially those higher functioning children.

- Methylphenidate (Ritalin®)

**Antidepressants**

The safety and efficacy of these medications in children with autism has not been proven. Children taking these medications should be monitored closely by the Physician.

- Naltrexone
- Lithium
- Diazepam (Valium®)
- Lorazepam (Ativan®)
Is There a Link Between Autism and Vaccines?
There is no conclusive scientific evidence that any part of a vaccine or combination of vaccines causes autism. There is also no proof that any material used to make or preserve the vaccine plays a role in causing autism.

Although there have been reports of studies that relate vaccines to autism, these findings have not held up under further investigation.