

Understanding Autism Spectrum Disorder (ASD)



American Academy of Pediatrics

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Understanding Autism Spectrum Disorder (ASD)

What is autism spectrum disorder (ASD)?

Autism spectrum disorder (ASD) is a neurologically based disability that affects a child's social skills, communication, and behavior.

Because most children with ASD will master early motor skills such as sitting, crawling, and walking on time, parents may not initially notice delays in social and communication skills. Looking back, many parents can recall early differences in interaction and communication. However, ASD symptoms may change as children get older and with intervention. While infrequent, some children improve so much that they might no longer be considered to have a diagnosis of ASD. Many of them, however, as they develop, will likely have other developmental, learning, language, or behavioral issues or diagnoses.

The sooner ASD is identified, the sooner an intervention program directed at the child's symptoms can begin. Each child with ASD has different needs. The intervention that helps one child may not be as helpful for another. Research shows that starting an intervention program as soon as possible can improve outcomes for many children with ASD, so children can and should be referred for diagnosis and early intervention (EI) services as soon as ASD symptoms are noted. The Early Intervention Program for Infants and Toddlers with Disabilities (also called "Part C") helps each state offer EI services for infants and toddlers with disabilities, birth to 3 years of age, and their families. For more information and to find an EI program in your area, see the Resources section.

Aren't there different types of ASD?

The symptoms that define ASD are described in a book called the *Diagnostic and Statistical Manual of Mental Disorders (DSM)*. This manual lists definitions for behavioral, developmental, and psychiatric disorders. Several conditions used to be diagnosed separately under the term "pervasive developmental disorders" or "autism spectrum disorders." Those conditions were autistic disorder, pervasive developmental disorder—not otherwise specified (PDD-NOS), and Asperger syndrome. With publication of the fifth edition of the *DSM* in May 2013, these terms are no longer used and these conditions are now grouped in the category of autism spectrum disorder or ASD.

How common is ASD?

ASD affects an estimated 1 out of every 68 children. The number of children reported to have ASD has increased since the early 1990s, and the increase could be caused by many factors. Many families are more aware of ASD. Pediatricians are doing more screening for ASD and children are identified earlier. Also, there have been changes in how ASD has been defined and diagnosed. In the past, only children with the most severe ASD symptoms were diagnosed. Now children with milder symptoms are being identified and referred to intervention and educational programs. Boys are diagnosed with ASD about 5 times more often than girls.

What are the early signs of ASD?

Many children with ASD may show developmental differences throughout their infancy, especially in social and language skills. Because they usually sit, crawl, and walk on time, more subtle differences in the development of gesture, pretend play, and social language often go unnoticed by families and doctors. In addition to delays in spoken language, families may notice differences in interaction with peers.

Delay or lack of joint attention

One of the most important developmental differences between children with ASD and children without ASD is a delay or lack of joint attention. Joint attention is looking back and forth between an object or event and another person and connecting with that person. It is a building block for later social and communication skills. Engaging in many back-and-forth social interactions, such as exchanging a lot of emotional expressions, sounds, and other gestures, is called reciprocal social interaction. Delays in joint attention skills are found in most children with ASD and rarely seen in children with other types of developmental problems. Thus, joint attention deficits are thought to be among the most characteristic deficits of ASD. There are several stages of joint attention. Children with ASD usually show delays or absent skills at every stage.

Subtle milestones in use and understanding of gestures occur at the following times:

At about 10 to 12 months of age, most typically developing children will immediately look in the direction of an object to which a parent is pointing. They will then look back at the parent and mimic the parent's expression, usually a smile. Children with ASD will often ignore the parent. This often causes parents to worry about their child's hearing.

Most children are able to point to out-of-reach objects that they want by 12 to 14 months. The child with ASD may instead take a parent's hand and lead the parent to the object without making eye contact. Sometimes the child may even place the parent's hand on the object itself.

By 14 to 16 months of age, most children point at objects they find interesting. Children will look back and forth between an object and a parent to make sure that the parent is tuned in to what they are looking at. The child with ASD only will point to an object because he wants the parent to get it for him, not because he wants the parent to enjoy looking at an object together.

Language delays

Almost all children with ASD show delays in nonverbal communication and spoken language. They may have words that they use to label things but never request things. They may have unusual words for their overall language level, such as saying letters or numbers when they do not yet have names they use for family members. Most young children go through a phase where they repeat what they hear. Children with ASD may repeat for a longer period and repeat movies or conversations with the tone of voice in which they heard them. Children later diagnosed with higher functioning ASD will seem to have met language milestones during the toddler years, but use of language may be abnormal or overly sophisticated or mature (little professors).

Regression in developmental milestones

About 25% of children who are diagnosed with ASD will seem to have typical or near-typical development until about 18 months of age, after which they may gradually or suddenly stop using words they once had or become more socially withdrawn, which is considered a regression of skills. Some families will recall subtle differences that might have been present prior to the regression, such as the child not turning when his name is called.

How might a child with ASD act?

One child with ASD will not have exactly the same symptoms as another child with ASD—the number and severity of symptoms can vary greatly. Here are examples of how a child with ASD may act.

Social differences

- Doesn't keep eye contact or makes very little eye contact
- Doesn't respond to a parent's smile or other facial expressions
- Doesn't look at objects or events a parent is looking at or pointing to
- Doesn't point to objects or events to get a parent to look at them
- Doesn't bring objects of personal interest to show to a parent
- Doesn't often have appropriate facial expressions
- Unable to perceive what others might be thinking or feeling by looking at their facial expressions

- Doesn't show concern (empathy) for others
- Unable to make friends or uninterested in making friends

Communication differences

- Doesn't point at things to indicate needs or share things with others
- Doesn't say single words by 16 months
- Repeats exactly what others say without understanding the meaning (often called *parroting* or *echoing*)
- Doesn't respond to name being called but does respond to other sounds (like a car horn or a cat's meow)
- Refers to self as "you" and others as "I" and may mix up pronouns
- Often doesn't seem to want to communicate
- Doesn't start or can't continue a conversation
- Doesn't use toys or other objects to represent people or real life in pretend play
- May have a good rote memory, especially for numbers, letters, songs, TV jingles, or a specific topic
- May lose language or other social milestones, usually between the ages of 15 and 24 months (often called *regression*)

Behavioral differences (repetitive and obsessive behaviors)

- Rocks, spins, sways, twirls fingers, walks on toes for a long time, or flaps hands (stereotypic behavior)
- Likes routines, order, and rituals; has difficulty with change
- Obsessed with a few or unusual activities, doing them repeatedly during the day
- Plays with parts of toys instead of the whole toy (for example, spinning the wheels of a toy truck)
- Doesn't seem to feel pain
- May be very sensitive or not sensitive at all to smells, sounds, lights, textures, and touch
- Unusual use of vision or gaze—looks at objects from unusual angles

What causes ASD?

Many factors may lead to symptoms of ASD. If a family already has a child diagnosed with ASD, the chance that a sibling might also have ASD is 10 to 20 times higher than in the general population. Environmental factors likely play a secondary role in some children with ASD, but what these factors are and how or when they affect development is not yet known. This is, however, an important area of research.

Studies have shown that relatives of children with ASD are more likely to have some similar social and behavioral characteristics to those seen in children with

Is there a link between vaccines and ASD?

In the past, some individuals thought that vaccines were a cause of ASD. However, many studies have been done, and there is no scientifically proven link between childhood vaccinations—including the measles-mumps-rubella (MMR) vaccine—and ASD. In fact, the research article that first suggested a link between the MMR vaccine and ASD has been retracted (that is, removed permanently) because the research was done incorrectly. There also is no scientific proof to support a link between thimerosal (a mercury-containing preservative) and ASD. Even so, almost all vaccines given to children in the United States no longer contain mercury.

The American Academy of Pediatrics urges parents to have their children fully immunized. Vaccines are a safe and effective way to protect children from diseases. Autism Speaks states that, “Vaccines do not cause autism. We urge that all children be fully vaccinated.”

Families who remain concerned about vaccines and ASD should talk with their pediatrician.

ASD but not be severe enough to merit a diagnosis. These difficulties may include social awkwardness, inflexibility and repetitive behaviors, and others. ASD may occur more often in children with certain medical conditions or high risk factors. Medical conditions include fragile X syndrome, tuberous sclerosis complex, Down syndrome, or other genetic disorders. However, most children with ASD do not have these or any other specific genetic conditions. Babies born prematurely are another high-risk group. Considering whether a child with ASD has a genetic condition is an important part of the initial evaluation.

What is known about brain development in ASD?

The specific abnormalities in brain function that cause ASD are not known. However, research has shown that

- There is a difference in brain growth in children with ASD, with a tendency for brains to grow faster and be larger than usual in early childhood (often with a large head circumference).
- There are various microscopic abnormalities in brain areas of people with ASD, such as the cerebellum, limbic system, and cerebral cortex. This was revealed thorough autopsy studies of the brains of people with ASD.
- There are differences or abnormalities in some brain chemicals in children with ASD. These brain chemicals are important regulators of brain development, nerve communication, and function. However, no abnormality has been found in all people with ASD.

- There are some differences in function of certain parts of the brain in ASD, including how the brain recognizes faces, processes language, and allows for imitation.

Measurement of chemical neurotransmitters and imaging techniques of brain function are not currently indicated in routine clinical practice. These and other studies may be important in research. Although our understanding of differences in brain structure and function is increasing, there is still much to be learned.

How is the diagnosis made?

Diagnosis of ASD can be complicated for a number of reasons. There are no specific medical tests (for example, a blood test) to diagnose ASD, so primary care doctors must rely on information from families about the child's development and behavior and on what can be observed during well-child checkups. The condition is complex, and symptoms are different for each child. This is why the American Academy of Pediatrics (AAP) recommends that there be screening for ASD at specific well-child checkups (18- and 24-month visits) as well as ongoing surveillance in the course of well-child care. Talk with your doctor if you feel your child needs to be screened and share your concerns—you know your child the best.

Evaluation

When ASD is suspected as a cause of language and social delays, the child should be referred for EI services and a comprehensive evaluation to determine if ASD is the proper diagnosis. The evaluation may be done by a doctor or psychologist who has expertise in the diagnosis of ASD or, preferably, by a team of specialists that might include developmental pediatricians, child neurologists, child psychiatrists, psychologists, speech/language pathologists, occupational or physical therapists, educators, and social workers. Testing of developmental abilities may occur through EI programs or the school system (depending on the child's age).

Typically, an evaluation will include

- Careful observation of play and child-caregiver interactions.
- Detailed history and physical examination.
- Review of records of previous EI, school, or other evaluations.
- Developmental assessment of all skills (motor, language, social, self-help, cognitive). ASD is suspected when the child's social and language functioning are significantly more impaired than the overall level of motor, adaptive, and cognitive skills.



- Hearing test. All children with any speech delays or those suspected of having ASD should have their hearing formally tested.
- Language evaluation that provides standardized scores of expressive language (including speech) and receptive language, as well as an evaluation of pragmatic language (social use of language) and articulation (pronunciation).

Diagnosis of ASD is made by using all the information collected by history, observation, and testing.

Medical tests

ASD may be associated with a known syndrome or medical condition. Newer, more sensitive tests have determined an underlying cause of ASD in many more children than was previously thought. Laboratory tests may be indicated to rule out other possible medical conditions that could cause ASD symptoms based on the child's history and physical examination. If indicated, the child may be referred to other specialists, such as a geneticist or a pediatric neurologist, to help diagnose medical conditions that might cause or be associated with symptoms of ASD.

- **Genetic tests.** It is recommended that families be offered genetic testing, such as cytogenetic microarray testing. At present, up to 10% to 20% of children with ASD have abnormalities of their chromosomes identified using cytogenetic microarray testing. Fragile X syndrome may be present in up to 2% of boys with ASD, so fragile X testing should also be considered. Testing girls with ASD symptoms for Rett syndrome may be discussed depending on the child's history and physical examination. Genetic testing should be strongly considered if a child has unusual physical features or developmental delays or if there is a family history of fragile X syndrome, intellectual disability of unknown cause, or other genetic disorders. Other genetic tests may be needed in certain cases. Recommendations for genetic testing may change as new tests are developed.
- **Lead test.** Lead screening is an important component of primary care. A lead level should be performed when a child lives in a high-risk environment, such as older buildings, or continues to put things in his mouth.
- **Other tests.** Based on the child's medical history and physical examination, an electroencephalogram (EEG), a magnetic resonance imaging (MRI) scan, or tests for metabolic disorders may be ordered. Children with ASD may be picky eaters, so your child's pediatrician may recommend looking for evidence of iron or vitamin deficiencies (especially vitamin D).

Note: There is not enough clinical evidence to recommend any of the following tests specifically for ASD: hair analysis, routine measurement of multiple vitamin or nutrient levels, intestinal permeability studies, stool analysis, urinary peptides, or measurement of mercury or other heavy metals.

Screening in siblings

Because younger siblings of children already diagnosed with ASD have a much higher risk for also having ASD, parents and pediatricians are encouraged to carefully watch for developmental concerns, especially delays in social and language skills. Screening tests should be used at the 18- and 24-month well-child checkups to target skills that are typically deficient in children with ASD.

More importantly, parents, caregivers, and pediatricians are encouraged to watch for early signs of ASD during the first 2 years of life. Parents should report any concerns to their child's pediatrician. In addition to delays in joint attention, gestures, and speech, parents should tell the pediatrician if the younger child has

- No babbling by 12 months
- No pointing or other gesturing by 12 months
- No single words by 16 months
- No 2-word phrases by 24 months
- Loss of any language or social skills at any age

There could be many reasons besides ASD for why a child may fail to perform these skills, but a child with any of these signs should be fully evaluated for ASD and other developmental disorders.

What are some other medical disorders associated with ASD?

Here are some conditions that may be associated with an increased risk of a child also having ASD.

Fragile X syndrome

Fragile X syndrome is a genetic disorder affecting the X chromosome. It is the most commonly inherited genetic cause of intellectual disability passed down from the mother's side of the family. Males have only one X chromosome, so they are usually affected more severely than females. Certain physical features, such as large ears, a long face, loose joints, and large testicles (after puberty), may be associated with this condition, but they're not always present, especially in a very young child. Testing for fragile X syndrome is routinely recommended for children with ASD.

Tuberous sclerosis complex

Tuberous sclerosis complex is a genetic disorder that causes lesions to grow in the brain, skin, and other organs. It is commonly associated with epilepsy. Specialized genetic testing should be considered in children with ASD and seizures who also have light patches of skin that look like birthmarks or other characteristic skin

lesions. DNA testing can identify the underlying genetic basis in about 70% of individuals with this disorder.

Rett syndrome

Rett syndrome is a genetic disorder occurring almost solely in girls, with onset during the first 2 years of life usually following a period of typical development. It is characterized by loss of hand control; characteristic hand-wringing, patting, or mouthing movements; unsteady motor skills; significant intellectual disability; slowing of head growth (after a period of normal growth); seizures; and impaired social skills. DNA tests can be performed to identify the genetic mutations on the X chromosome underlying the disorder in nearly all cases.

Angelman syndrome

Angelman syndrome is a genetic disorder affecting the 15th chromosome. It is characterized by significant intellectual disability, a happy facial expression, atypical laughter, unsteady walking, a small head, and seizure disorder. Many children have repetitive hand clapping or similar hand movements. Specialized DNA testing is required to make this diagnosis.

Down syndrome

Down syndrome is a common cause of intellectual disability. It is caused by an extra copy of the 21st chromosome. While the majority of children with Down syndrome do not have ASD, a minority do meet diagnostic criteria for ASD. Many others have repetitive behaviors but do not have the differences in social reciprocity that are characteristic of ASD. Because developmental regression may occur later in children with Down syndrome than in other children with ASD, doctors need to continue developmental screening later in childhood.

Other genetic disorders

There are a number of other genetic disorders that, although uncommon, should still be considered by doctors when evaluating a child for ASD. *Smith-Lemli-Opitz syndrome* is caused by a problem in cholesterol production and can be diagnosed with a special blood test. It is important to think about whether a child might have this because it might occur in 25% of future pregnancies. Another genetic disorder associated with ASD and large head size is a mutation in a gene called *PTEN*. Parents and children with this mutation have an increased risk of cancer. *Smith-Magenis syndrome* is another genetic disorder associated with ASD that is caused by an abnormality on chromosome 17. Children with Smith-Magenis syndrome may have significant sleep problems and characteristic repetitive behaviors in addition to ASD.

Modern medical care and practices have almost eliminated some causes of ASD. These include *phenylketonuria*, a metabolic disease that was a cause of severe intellectual disability and ASD in the past but, due to universal newborn screening in all 50 states, is now a detectable and treatable disease. *Congenital rubella*, which results from a mild viral infection with the rubella virus during pregnancy, is completely preventable by immunizing against rubella during childhood.

What are some of the medical conditions associated with ASD?

Seizures

Over the life span, about one-fourth of children with ASD may have a seizure. Seizures are more common in children younger than 3 years and in the teen years. A seizure is a sudden, unexpected change in behavior caused by abnormal brain electrical activity. It may include sudden changes in behavior such as jerky movements of the arms or legs, loss of consciousness, or brief staring spells. Parents should contact their pediatrician if their child experiences these symptoms and ask if an evaluation is necessary. Evaluation for seizures may include a physical and neurologic examination and possibly special tests, such as an EEG and MRI, or referral for further evaluation by a neurologist. There are medicines that can be used to treat seizure disorders.

Nutrition or gastrointestinal disorders

While the prevalence is still unknown, gastrointestinal (GI) symptoms such as abdominal pain, constipation, diarrhea, nausea, and bloating may be more common among children with ASD. If GI symptoms are serious, they may interfere with sleep, behavior, and mealtimes and make children very uncomfortable.

Food selectivity is reported in most children with ASD and may be an early indication of developmental difference. Many children will eat only a select number of foods. Some children don't like certain textures and colors of food. Other children are very particular about how food is given to them; they will only use certain plates or will not eat food that touches other foods. Most children with ASD grow well, and while they eat limited diets, they are not underweight. However, some children are so selective that they may not be getting the nutrients they need.

If there is concern about a child's growth (height or weight) or if the child has frequent GI symptoms, the family should talk with the child's pediatrician. Children with significant GI symptoms or food selectivity may need additional testing.

Because some families are concerned about GI symptoms, the question of food allergies or sensitivities to foods such as gluten (wheat) or casein (milk) often comes up. Many families try special diets that eliminate these foods. Research studies have

not confirmed that special diets treat the symptoms of ASD. Children with ASD can have lactose (milk sugar) intolerance or celiac disease like any other children. GI symptoms in children with ASD need to be individually evaluated. Parents should consult with their pediatrician before starting any special diets.

Tics

Tics may occur more frequently in children with ASD than in the general population. Tics are involuntary brief motor movements or sounds. They may occur in up to 6% of children with ASD. Medicine may be part of an approach to tic management.

What are some of the behavioral conditions associated with ASD?

Attention and hyperactivity difficulties

Attention and hyperactivity difficulties are very common in children with ASD and may include problems paying attention or staying on task, increased impulsivity, and hyperactivity.

Obsessive or repetitive patterns of behaviors

Some children with ASD may have more of a tendency to be “stuck” on certain behaviors (repeating them over and over) and have problems with changes (routines are important). There are many types of obsessive behaviors; some children become upset if a different route to school is taken, while others become anxious if a familiar routine is changed.

Aggression and agitation

Because of their communication problems, sometimes children with ASD ask for what they need or want or ask to be left alone by acting out with aggression or agitation. Sometimes agitation may occur with discomfort from stomach pain, a headache, a toothache, or other discomfort.

Self-injury

Sometimes children with ASD seem to be hurting themselves for behavioral reasons similar to those noted earlier for aggression and agitation. Some children may strike their heads or otherwise hurt themselves if they have an earache or a toothache. Any children with new self-injury, especially children who cannot express pain with words, should be examined by their pediatrician for a medical condition that may be causing pain.

Self-stimulation (repetitive behaviors)

Some children engage in repetitive sensory or motor behaviors such as flapping their hands, ripping papers, toe walking, or other behaviors that may not seem to have a purpose. These behaviors may calm children who feel distressed or provide stimulation to children who do not have play skills or language they can use when bored.

Sleep disorders

Sleep problems, such as trouble falling asleep or frequent night awakening, are more common in children with ASD than children with typical development. Some children with ASD seem to need less sleep than other children. Children with or without ASD who have sleep difficulties may have a medically diagnosed condition such as obstructive sleep apnea, gastroesophageal reflux, or restless legs syndrome. Most children with ASD respond to behavioral intervention strategies and good sleep hygiene for their sleep problems. There is increasing evidence that the over-the-counter hormone melatonin may be helpful for regulating sleep in some children with ASD, but families should discuss use of any over-the-counter medicine with their pediatrician.

What are some of the emotional conditions associated with ASD?

Anxiety disorders

Symptoms can range from general feelings of nervousness to intense fears and panic attacks. Physical symptoms of panic attacks may include rapid heart rate and hyperventilation. Children with ASD can get even more anxious if they are unable to respond or cope appropriately. A combination of medical and behavioral interventions may be helpful.

Mood disorders (depression and bipolar disorder)

Like anxiety disorders, mood disorders can have many different symptoms. Children with depression can lose interest in favorite activities, be less active, and sleep more. They can also become hyperactive and irritable and sleep less. Older children may become depressed because they don't know how to handle the stress of being different, teased, or bullied. Some children may show cycling behaviors between withdrawal and depressed states and manic or hyper states. A combination of medical and behavioral interventions is often recommended.

What are some of the developmental conditions associated with ASD?

Intellectual disability or cognitive deficits

Cognitive deficits may occur in up to half of children with ASD. Intellectual disability is suspected when children show global delays (especially in self-help and problem-solving skills) as well as delays in language and social skills in addition to symptoms of ASD.

Verbal apraxia (dyspraxia)

Verbal apraxia is a neurologically based disorder that affects speech. Children with verbal apraxia are unable to initiate certain speech sounds or speak easily.

Living with ASD

There are many different strategies and techniques to help children with ASD learn to interact with others and acquire new skills that may help them talk, play, participate in school, and care for their needs.

Effective educational programs

According to an expert panel writing for the National Academy of Sciences, effective educational programs designed for children with ASD from birth to 8 years of age should

- **Offer choices.** The program should offer a variety of behavioral, language, social, play, and cognitive strategies that are individualized to the child. If possible, the child should also receive direct speech, occupational, and physical therapies according to individual need.
- **Have clear goals.** An individualized plan should include specific, observable, and measurable goals and objectives in each developmental and behavioral area of intervention.
- **Be intense.** The program should be intense, with a goal of 20 to 25 hours of planned intervention or instruction per week. It should be given year-round. Most children benefit from a staffing ratio of 1:1 or 1:2 with an adult in initial interventions.
- **Encourage parents to be fully involved.** Siblings and peers should also be included in the program. Children often learn best by modeling typically developing children in inclusive settings. The family should have support from the therapy team so it can promote social skills, functional communication, and appropriate behavior at home.



- **Take place in everyday settings.** To promote generalization of newly acquired skills, interventions should take place in everyday settings. Playing and learning with children without ASD may help children with ASD learn social and language skills.
- **Address behavior problems.** A functional analysis of behavior should be done when there are behavior problems. Information gained should be used to design a behavior management plan. The family should be involved so it can work on the child's behavioral needs too.
- **Monitor progress often.** If goals and objectives are not being met in a reasonable amount of time, the program should be evaluated and revised as needed.

The types and quality of services may vary depending on where a family lives. Efforts are being made nationally to increase funding and training so professionals can meet the needs of children with ASD in medical and educational settings. While resources vary among communities, a combination of parent and professional interventions can improve the development of children with ASD.

Children should be referred to an appropriate community-based program as soon as a delay is suspected. Parents should not wait for a definitive diagnosis of ASD because this may take quite some time. For example, speech therapy evaluation and treatment should be started as soon as a communication delay is identified. Once ASD or another developmental disability is definitively diagnosed, the specific program or goals of the program can be changed to best meet the needs of the child and family. Keep in mind that diagnosis can be an ongoing process as additional signs and symptoms become noticeable or others improve.

Although all children with ASD will need some type of educational services and support and most may need therapy and behavioral intervention, only certain children will need medicine. Medicine may be used to help decrease behaviors that could interfere with making progress, such as learning or interaction with others, aggression, obsessions, or hyperactivity.

Parents are encouraged to learn as much as they can about all the different treatments available. Treatment should focus on supporting the child to succeed in the real world.

Public programs

Services are available for children once problems become evident. Pediatricians can help identify where the family should take the child suspected of having ASD for diagnostic assessment and intervention.

Early intervention program

For children younger than 3 years, the referral may be to a local EI program (see Resources section). Families may also contact the EI program directly. This is

a federally and state-funded program that helps infants and toddlers with delays or behavioral challenges. If a child is eligible for services, a team of specialists will, with family input, develop an Individual Family Service Plan (IFSP). This program becomes a guide for the services that will be provided until the child turns 3 years of age. It may include parent training and support, direct therapy, and special equipment. Other services may be offered if they benefit the child or family. If continued help is needed after 3 years of age, the child's program is transferred to the local school district for administration.

Individualized Education Program

If a child is 3 years or older at the time of concern, the referral may be to the local public school district. Families may also contact the local public school directly. If the child is eligible for services based on the diagnosis of ASD and supporting educational, IQ, and language testing, the school district staff will, with parent input, develop an Individualized Education Program (IEP). This plan provides many of the same services as the IFSP, but the focus is different, as school services are mainly for the child. The level of services also may be different. If the child continues to need special education and services, the IEP will be reviewed and revised periodically. The IEP should be revised to meet the child's changing needs as he grows older and develops new skills.

Additional programs

While federal law mandates a free and appropriate education for all children, some communities have private schools and other supplemental services specifically designed to help children with ASD. Families may seek out additional services to supplement the public school program. Families should review their child's program with their pediatrician to make certain they are accessing all the services that may benefit their child.

Treatment strategies used in children with ASD

Developmental and behavioral interventions

Developmental and behavioral interventions are the mainstay for educating and supporting individuals with ASD. They are interrelated. Developmentally based interventions tend to focus on the basic building blocks in motor, visual, and hearing processing; sequencing; attention; problem solving; communication; and social skills. This may be most effective in some children if done in a play setting where an adult helps a child build skills through engagement. In children with ASD, strengthening communication and social skills often helps to decrease behavioral problems. Alternative and augmentative communication aids (such as picture cards) may be useful in the development of communication skills.

Behavioral interventions focus on changing specific behaviors and symptoms. As these behaviors change, social relationships and mastery of basic developmental capacities improve. Behaviorally based programs that are tailored to teach children the skills needed for play and communication can take place in the classroom or individualized settings. When language and social skills are lacking, challenging behaviors are often children's only means of communicating their needs or fears to others. While behavioral interventions may be used to decrease challenging behaviors, they are also used to teach children the things we want them to do. There are several different types of behavioral interventions.

Behavioral intervention strategies may be directed by a therapist or teacher by prompting the child toward an intended goal or intervention. The therapy can also be incidental, such as when the child is caught attempting a desired task and the adult helps the child accomplish it. The goal of behavioral interventions is to change the problematic behavior by rewarding acceptable behaviors with positive reinforcers such as food items, praise, or a hug. On the other hand, unacceptable behaviors are ignored, corrected, or redirected in an effort to stop them. Other general strategies include providing an overall structured learning environment for children with routines that support them in their daily activities. Behavior problems may be reduced when children are told ahead of time that a routine may change and taught how to prepare for the change.

Regardless of the intervention strategy chosen, if a behavior is preventing developmental or educational progress, it is often helpful to begin with functional behavioral analysis (FBA). FBA consists of identifying the events leading up to the behavior and the consequences that maintain it. Sometimes this information is readily obtained by carefully observing children in their natural settings with their usual caregivers. Other times, a trained behavior specialist must be consulted. The behavior may be an effort to communicate the urge to escape, the need for attention or some tangible object (for example, food or a toy), or discomfort from too much or too little sensory stimulation. Once the cause(s) of the problematic behavior is identified, the specialist will determine which caregiver reactions are promoting the behavior. Based on FBA information, the behavior specialist will develop an intervention strategy to avoid or modify these conditions to help change the behavior. Finally, positive reinforcers that will aid in maintaining more appropriate and desired behaviors will be identified. This behavior intervention plan will need to be evaluated and modified on an ongoing basis as children mature.

Here are several approaches that are often used for children with ASD.

- The **Treatment and Education of Autistic and Related Communication-Handicapped Children (TEACCH)** program is one of the oldest and most widely used programs in schools. The program focuses on individualized assessment and treatment and encourages parents and professionals to work closely together. Parents and teachers are taught how to develop structured teaching programs with an emphasis on building on the child's learning strengths and

functional communication. Visual organization cues are used to maintain a consistent and structured daily routine that helps build new skills and independence. The program spans from preschool to adulthood. Planning for transition from school to supported employment includes an emphasis on developing appropriate social, adaptive, and communication skills. Parents are regarded as critical agents of change, not only for their own child but also in service development and the community as well. Read more about TEACCH at www.teacch.com.

- **Applied behavior analysis (ABA)** is the process of systematically intervening to increase the likelihood of desired behaviors or skills and decrease the likelihood of undesired behaviors. ABA strategies are not unique to ASD, but ABA-based programs have been used extensively and have been successful in children with ASD. Specific goals are set and the therapist works intensively with the child, one-on-one and one goal at a time. ABA has been found to improve functional skills and reduce challenging behaviors. Various programs have been created around the theme of ABA, such as discrete trial training (DTT), Pivotal Response Treatment (PRT), functional communication training (FCT), and Verbal Behavior Therapy (also known as Applied Verbal Behavior or AVB). Although O. Ivar Lovaas, PhD, one of the most well-known proponents of DTT, recommended 40 hours per week of one-on-one intervention by a professional trained in the principles of ABA, many experts feel that less-intensive intervention (programs that are not exclusively 1:1 ABA treatment) for fewer hours (for example, 20–25 hours) may also be appropriate, depending on the needs of the individual child and family.
 - DTT is an important feature of ABA. A therapist working one-on-one with a child presents an instruction or request (called a discriminative stimulus) to the child and delivers reinforcement for the correct response. This sequence is repeated until the child learns to make the expected response.
 - In PRT, the goal is to effect change in pivotal areas such as responding to cues, motivation, self-management, and self-initiation, in the hope that improvements in these areas will lead to changes in other functional areas.
 - FCT and AVB attempt to improve the functional communication skills of children with ASD using principles of ABA.

Skills learned in the educational environment need to be generalized to unstructured settings to be functional. Recently, there have been several modifications to this type of program to use natural environments and incidental learning (natural opportunities) in addition to the more traditional strategies.

- **The Developmental, Individual Difference, Relationship-based (DIR) Model (also known as the Greenspan/Floortime Approach)** attempts to provide a comprehensive framework for helping children with ASD work on the core deficits of ASD. The DIR approach tailors the assessment and intervention to the child's unique developmental pattern. It focuses on the developmental level

of the child's social, emotional, and intellectual capacities; the child's individual ways of experiencing and understanding sensations such as touch, sound, words, and movement; and learning relationships geared to these patterns. Although it has elements in common with other methods described here, it differs in that it does not follow a solely adult-directed curriculum.

Like ABA, the DIR Model involves a comprehensive approach with an intensive home program of appropriate therapies and an educational program. It differs in that caregivers, educators, and therapists (for example, speech and occupational therapists) work to follow the child's lead in playful interactions. A series of floortime strategies are used to help the child learn to engage in several back-and-forth interactions, use ideas in pretend play, and communicate. Variations on this model have been developed, each with its own approach to parent-child interaction. To date, there have been few peer-reviewed, published studies of the effectiveness of the DIR approach for children with ASD. Read more about DIR at www.icdl.com.

- **Combined treatment programs.** Researchers are examining how to best combine treatments to meet the needs of families and young children with ASD. The Early Start Denver Model provides a combination of developmental and behavioral approaches to address the basic core symptoms of ASD in young children, first at home and then in a structured preschool. Core features of the Denver model include involvement of an interdisciplinary team to implement a developmental curriculum, focus on interpersonal engagement, develop spontaneous and reciprocal imitation and object use, focus on cognitive aspects of play, and partner with parents. While the exact approach used in the research may not be available, some preschool programs may incorporate many of the elements that were studied.
- **The Social Communication, Emotional Regulation, and Transactional Support (SCERTS) Model** is intended for use by parents and school personnel to understand the motivation and communication of students with ASD and flexibly adapt programs to support communication and social development. Read more about SCERTS at www.scerts.com.
- **The Relationship Development Intervention (RDI) therapeutic program** is family based, with trained consultants supporting parents in their interactions with their children with ASD. Objectives are developmentally staged to optimize communication and social and emotional functioning in the child's natural environment. Parents use natural events to model appropriate responses and provide opportunities to teach their child developmental skills. Read more about RDI at www.rdicconnect.com.

[Communication interventions](#)

Children with ASD may not understand the purpose of verbal and nonverbal communication. Thus most, if not all, children will benefit from formal speech and

language interventions. There is a wide range of severity of communication disorders in children with ASD. Some children can't express themselves at all. They may need intensive treatment that may include teaching a nonverbal means of communication such as using the Picture Exchange Communication System (PECS) or other picture-based systems or using electronic communication devices (such as speech-generating devices). The range of communication skills is quite variable, depending on the severity of ASD, including children who have normal vocabulary and use of grammar but deficits in the social use of language for conversation.

Many children with ASD who do develop speech may communicate in unusual ways (see Language delays on page 3). Speech therapy must address these difficulties at different levels. Treatment is provided or directed by a trained speech/language pathologist. Family and other members of the team are also involved in the treatment plan. Therapy is aimed at using any effective means of providing communication, while at the same time working to increase all levels of communication, including verbal output or speech. For children who do not use words, therapists will promote the use of natural gestures, teach sign language, or use pictures or a device to communicate. Some parents worry that these methods will prevent their child from learning words. Research supports the opposite conclusion: children who have developed some means of communication, even if it is nonverbal, may develop speech skills more quickly.

PECS is a nonverbal visual language system that uses photographs, line drawings, and pictures to teach children to request items that they want or need. Visual language systems like pictures and signs are paired with spoken language and can be used to teach basic aspects of communication.

The communication program is usually a part of a larger developmentally or behaviorally based program. The speech/language pathologist should help the other team members make sure communication goals are included in the service plan and addressed in the educational setting.

For children with ASD and fluent language, goals of treatment should include a focus on the social use of language, back-and-forth conversation, and building social skills and relationships. Any treatment program must include frequent reassessment of progress, and goals should be adjusted as needed.

Social skill interventions

Many children with ASD learn to interact through communication. Joint attention is a building block for later social and communication skills. In fact, research studies have shown that functional language often begins to appear about 1 year after a child has mastered joint attention. Joint attention and communication are most efficiently learned in daily interactions in the family. Learning experiences should be incorporated into a child's regular daily activities. These activities should begin as early as possible, as soon as language delays are identified.

Outside the family, the most important strategy in improving social skills is providing children with as many opportunities as possible to play and interact with typically developing peers. As children get older, they will need explicit teaching to learn to interact appropriately with peers at school and in the community. This teaching should include direct social skills therapy sessions as well as coaching and support in class and less structured times like lunch and recess.

Ways to help children with ASD learn joint attention skills

Children with ASD learn joint attention skills in 4 stages.

Stage 1: Joining in with the child. Children with ASD are often very content to play alone. This does not help them build important social skills.

What the parent can try: Observe what the child is playing with, then join in by pointing at the object. Make comments about the object or what the child is doing with it. If the child looks up at the parent, the parent should reinforce the action with a smile and encouraging words and attempt to foster engagement and back-and-forth interaction by building on this interest. Next, the parent can gradually attempt to challenge the child to solve problems. For example, if the child is moving a toy car back and forth, the parent can pretend her hand is a hill the car needs to drive over and can engage the child by saying, “Oh no, there’s a hill. Can you drive your car up the hill? Great job! Can you drive the car down the hill? You’re a very good driver.” The parent should try to keep the back-and-forth interaction going.

Stage 2: Following a point. At around 10 months of age, typically developing children spontaneously begin looking in the direction of their parent’s gaze or point as the parent points to a distant object or event. Children with ASD lacking this skill can often be taught.

What the parent can try: Throughout the day, the parent might point at objects or events in an effort to get the child to look at them. At first, the parent can point to objects that interest the child to promote early successes.

If the child simply won’t follow what the parent is pointing to, the parent may have to prompt him by tapping on his shoulder or even manually turning his head in the direction of pointing. When the child is successful, the parent can start pointing to new objects or events that the child has not noticed in the past. The parent should praise the child’s efforts, especially if after looking at the target, the child makes good eye contact with the parent and shows appropriate facial expression. Examples include joy at the sight of a new toy, eagerness at the sight of the ice cream truck, and fear at the sight of something scary. Training opportunities can occur during normal activities such as eating, dressing, and toileting. For example, the parent can say, “Look! The toast is done cooking!” as it pops out of the toaster. Car rides, when the child is a captive audience, may be especially fruitful. Say, “Look! See the...,” and point to pictures on billboards, objects or animals along the roadside, or other vehicles of various colors and shapes.

Stage 3: Pointing to request. At about 12 months, children begin to point to let others know what they want or need. Children with ASD will often just cry or lead an adult by hand to the desired object.

What the parent can try: If the child leads the parent to the refrigerator, the parent can encourage the child to point to the object first before giving the child anything. The parent might do this by pushing the desired object way back so the child can't quite reach it and then acting confused so the child needs to gesture with her hand or finger. If the child will not point, the parent can take the child's hand and form it into a point and point to items that the parent is quite sure the child does not want. This will provide the child opportunities to make decisions by frowning, shaking her head, or saying "no." Then the parent can help the child point to the item that the parent thinks the child does want. Before giving it to her, the parent can say, "Oh, so this is what you want! Thank you for showing me." As practice continues, the parent can try to fade out the hand-over-hand prompts so that the child will point spontaneously to desired objects.

If the child is standing by the door to go outside, the parent might pretend to be confused so the child has to point to the doorknob that she wants turned. If she does, the parent might try to turn it but fail. Then the parent can say, "We need Daddy to help us." If the child doesn't understand, the parent might gesture for the child to get Daddy. The child might then walk over and pull Daddy to the door. Try once again to get her to point.

Stage 4: Pointing to show or comment. Most children point to get their parents to look at something interesting at about 14 to 16 months of age. Children with ASD usually do not try to engage their parents at this age.

What the parent can try: Once pointing skills are mastered, the parent should try to teach the child to point to objects or events that interest him to get adult attention so that the experience can be shared. Teaching this skill is a bit more challenging. At first, this might involve catching him doing quasi-showing acts. For example, if the child brings the parent a box of cookies to open, the parent should not open it right away. Instead, the parent might comment about the box, point out some of the pictures on it, talk about its contents, or anything to keep the back-and-forth social interaction going. Then the parent can say something like, "Thanks for sharing this with me. That was very nice of you."

When the child persists, the parent can then say, "Oh, so you want me to open this for you. OK, I will, but thanks again for showing me the box." At other times, the parent may observe the child looking at something of interest, like a helicopter in the sky, but he does not point to get the parent to look at it. The parent could take his hand, form it into a point, and point at the object, and then say something like, "Oh, now I understand, you want me to look at the helicopter! Yes, that is a big helicopter. I wonder where it is going. Do you think it is flying home?" The parent may need to prompt the child by turning his head back and forth between the object

and the parent's face. Always reward even small attempts to get the parent's attention, especially when the child makes good eye contact.

In summary, the parent needs to try to connect with the child throughout the day with gestures, pointing, and words (using most, if not all, of these at the same time). Use naturally occurring objects or events as targets for joint attention and ongoing social interaction. Even though the child may be happy playing alone, the parent should join in with him at regular times. The parent should not be concerned about using gentle physical prompts such as forming his hand into a point, tapping his shoulder, or physically turning his face from the object to the parent's face and back again. Also, the parent should not be concerned about playing dumb to encourage the child to explain to the parent what he wants. The parent needs to literally get in the face of a child with ASD when trying to teach him joint attention and social interactions.

Theory of mind: seeing things as others see them

Theory of mind is the ability to see things from another person's point of view. This skill naturally appears in typically developing children at about 4 years of age.

The ability to see things from the perspective of another person builds on earlier developmental capacities. To understand the intentions and feelings of others, children must first master joint attention and feel pleasure or joy in connecting with others. They then need to experience the wishes or feelings of others through back-and-forth exchanges of gestures and sounds. It is through experiencing other people's gestures and sounds and responding to them that children begin to understand how other people feel. When children begin to be able to use words, true signs, or picture symbols, they can give a voice to this gradually emerging understanding of the intentions and feelings of others. They begin to show the capacity for taking the perspective of someone else, including empathy, or a theory of mind.

Children with ASD may have a difficult time taking the perspective of another person. Strategies have been developed to teach children how to understand the thoughts and feelings of others (see Resources section). One method that is helpful in children who have reached the developmental age of at least 5 years uses cartoonlike drawings showing children in various situations. The child is asked to describe how she thinks the child in the cartoon might feel about the situation pictured. If the child with ASD has limited speech, she can respond by learning to point to one in a series of face drawings on the page that represent feelings of happiness, sadness, anger, and fear.

Social stories

Once a child has more language, instruction may progress to social stories. In this approach to help a child with ASD learn how to behave in various situations, a script or cartoon is created showing how the child might feel and appropriate ways

to respond. Sample social stories published in books (see Resources section) provide information about various social situations through the use of pictures and text to prepare a child before he actually encounters a similar setting. The stories provide a springboard for back-and-forth discussion about what conversations and behaviors might be expected to occur in that setting to offer suggestions to the child and prevent difficulties and embarrassment. The use of social stories is supplemented with modeling and role-playing of appropriate behavior as well as corrective feedback. This technique may still be very helpful even in teen and adult years. Parents or caregivers are encouraged to create novel stories with multiple variations and twists on the published stories that are better suited for their own child's activities, situation, and level of understanding.

Other approaches to social skill development include having children with ASD interact with other children without ASD in group settings. This may include structured play or conversational activities with a trained adult at home or school.

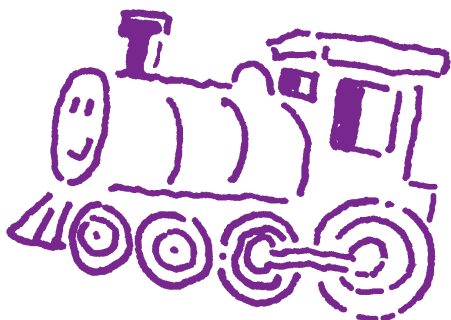
Sensory-motor interventions

Many children with ASD seem to have unusual sensory aversions or cravings. They may dislike touch, hugging, certain sounds such as motors or machinery, textures, and consistency of certain foods. It is difficult to understand the meaning of such aversions for these children. There may be other behaviors that children use to actively seek certain sensations, such as smell or deep pressure. Some children engage in repetitive self-stimulating behaviors such as rocking back and forth, spinning, self-injurious behavior (such as self-biting, head banging, and skin picking), and repetitive oral exploration (mouthing) of nonedible objects.

It has been suggested that children with ASD may have a disorder of *sensory integration*. Basic brain research is finding that people with ASD may have difficulty processing information that comes in through visual, hearing, and other sensory pathways at the same time.

Sensory overload has been cited as a potential cause of tantrums or disruptive behaviors. Children with ASD may seem to ignore or crave sensory input. Sensory processing difficulties are symptoms of central nervous system problems that are common in individuals with a variety of developmental disabilities and are not unique to ASD.

Sensory integration therapy as currently provided by occupational therapists uses procedures such as deep pressure, brushing, wearing a weighted vest, and swinging to regulate sensory input. These therapies appear to have a calming effect in some children and are often cited as proof that they are effective.



Although widely practiced and currently being studied, little data support the claims of benefits of such interventions at this time. Other interventions, such as auditory integration training (AIT) or behavioral optometry, are also used to regulate or change the response to sensory input. They also currently lack data to support their claims. These latter interventions are not endorsed by the AAP.

Medicines

Medicines have not been shown to change or improve the core features of ASD; however, they may be helpful in addressing symptoms that affect daily functioning and a child's ability to make developmental progress.

Medicines may be helpful when behaviors interfere with progress in a child's intervention program. Such behaviors may include hyperactivity, inattention, irritability, aggression, self-injury, repetitive behaviors, mood disturbances, anxiety, and behaviors related to GI issues or sleep problems. The use of medicine is sometimes considered when these behavioral symptoms are judged to be interfering with learning, socialization, health and safety, or quality of life and the symptoms are not responding enough to behavioral treatments. Occasionally, medicine may be needed as a first-line intervention when the safety of others or the child's safety is at risk. Sometimes a child may have an additional diagnosis, such as depression or a seizure disorder, that may be treated with medicine.

Commonly used classes of medicines include atypical or second-generation antipsychotics (like risperidone and aripiprazole), stimulants (like methylphenidate and dextroamphetamine), selective serotonin reuptake inhibitors (like fluoxetine), alpha-2-agonists (like clonidine and guanfacine), sleep-inducing medicines (like melatonin and trazodone), and certain antiseizure medicines.

The 2 medicines that are now approved by the US Food and Drug Administration (FDA) for treatment of the related behavioral problems seen in children with ASD are risperidone and aripiprazole. Risperidone has been approved for use in children with ASD aged 5 to 16 years, and aripiprazole has been approved for use in children with ASD aged 6 to 17 years. Both of these medicines are atypical antipsychotics and can treat irritability as well as other behavioral features often reported in children with ASD. Children treated with these medicines should be monitored closely for potential side effects such as sedation, excessive weight gain, hyperglycemia (high blood sugar), and abnormal twisting movements of their face or upper body.

Before starting a medicine, it is important to look for medical factors that might cause or contribute to the behavior. For example, the child may have a hidden medical source of discomfort, such as constipation or an ear infection, that is causing agitation. There may also be environmental factors, such as changes in school routines, that are upsetting to the child and causing disruptive outbursts. An FBA may help to determine the cause of new disruptive behaviors and with making decisions about medicines.

In recent years, larger, better-designed studies have been done to determine which medicines are helpful for children with ASD and associated behavior problems. For example, several studies have shown risperidone to be very effective for the treatment of tantrums, aggression, or self-injurious behavior in children with ASD. Melatonin may be helpful in regulating sleep. Doctors are guided in the use of medicine by research studies not only in children and adults with ASD but also in related disorders such as attention-deficit/hyperactivity disorder (ADHD), obsessive-compulsive disorder, depression, and anxiety. If symptoms of these disorders are also present in a child with ASD, stimulants, antidepressants, antianxiety agents, and other medicines might be considered if behavioral strategies are not successful alone.

It is always important to consider the potential benefits and side effects when making a decision about treatment. Such decisions are best made in partnership with doctors, therapists, teachers, and, most importantly, parents. It is best to rely on more than one source for information concerning the effectiveness of various medicines commonly used in children with ASD because no medicine has been universally helpful in all patients.

Target behaviors must be measured or assessed to determine what effect the medicine is having, and monitoring for side effects is very important. Only one medicine or treatment change should be made at a time. The medicine dose often has to be adjusted depending on how well it is working and whether there are any side effects. A medicine is continued only if benefits outweigh any negative effects. Although few medicines will directly enhance language and social skills, the goals of most medicines are to allow the child to benefit more fully from educational and behavioral interventions, be included in settings with typically developing children, improve functional independence, and experience a higher quality of life.

Complementary and alternative medicine (CAM) treatments

The most effective treatments include a comprehensive, intensive program of educational, developmental, and behavioral therapies. However, progress may be slow and because researchers have not been able to explain what causes ASD, many families may try treatments that may not have been scientifically studied. These types of treatments are called complementary and alternative medicine (CAM) treatments.

Many families learn about these treatments on the Internet, in books and magazines, and from other parents of children with ASD. It may be difficult to tell which treatments have scientific support and which don't. Parents interested in using any of these treatments should discuss them with their child's pediatrician. It is important to understand all of the potential benefits and risks of any chosen treatment. Some "natural" treatments can have serious side effects. Researchers have found that 50% or more of families of children with ASD are using traditional (behavioral, educational, speech therapy, medicine) and CAM treatments, sometimes even before the diagnosis of ASD is confirmed. The AAP advises pediatricians to be supportive of families in their search for interventions, encourage parents to be careful in their

interpretation of claims from scientific and nonscientific sources, and monitor the child for target symptoms to be treated and possible side effects when families elect to use CAM.

There are 2 types of CAM, biological and nonbiological. Popularity of CAM interventions varies over time depending on the availability of practitioners in a given region and the occasional coverage by insurance or provision by schools. Here are some treatments that are currently popular.

Biological CAM treatments

Nutritional (dietary) supplements. Supplements are used for many disorders in addition to ASD because families assume that they have fewer side effects than prescription medicine and are a “natural” treatment. Nutritional supplements are not monitored by the FDA, so the concentration of the active ingredient may differ from brand to brand or batch to batch. Also, labels on supplements do not always include information on the proper doses for children. An adult dosage may cause side effects in a child.

Commonly used supplements include essential fatty acids (sometimes in cod liver oil form), vitamin B₁₂, dimethylglycine, vitamin B₆ with magnesium, vitamin C, and vitamin A (found in cod liver oil). There could be potential side effects from doses in the toxic range. Such side effects may be seen with vitamin B₆ (hand tingling), magnesium (GI symptoms, heart irregularities), and vitamin A (rash, increased pressure around the brain). No scientific studies have been done to look for toxic effects from long-term vitamin supplement use in young children. The pediatrician should be informed if a child is taking nutritional supplements.

Diet changes. Changes to diet are another “natural” approach to treating many chronic conditions. Some families believe a gluten (wheat)-free and casein (milk)-free diet can help with symptoms of ASD. This is based on the theory that some children with ASD may have a “leaky” gut that allows some partially digested proteins to worsen symptoms of ASD. There is no evidence to support the leaky gut theory or that this diet improves the symptoms of ASD. However, if GI symptoms are improved by removal of certain foods, behavior in general might also improve. Children with ASD and GI symptoms might have celiac disease (gluten intolerance) or lactose intolerance (inability to digest milk sugars). Children who have diarrhea or other significant GI symptoms should be evaluated by their pediatrician. Before trying this diet, the family should talk with their pediatrician and perhaps a dietitian. Adequate calcium, vitamin D, and protein need to be provided in other foods if dairy products are eliminated. Vegetable substitutes for milk may not be nutritionally equal to milk.

Prescription or over-the-counter medicines. Sometimes novel treatments include medicines (prescription or over the counter) ordinarily used for other purposes. For prescription medicines, this is called off-label use or a use not approved by the FDA.

One example is secretin, an intestinal hormone, which came to attention in 1998 as a possible treatment for ASD behaviors.

Many scientific studies have been done and have failed to prove that secretin is effective as a treatment for ASD. Other medicines that are sometimes used in children with ASD for behavior that have not been studied include bethanechol and famotidine, which control the function of the GI tract.

The immune system is another focus of medical treatment, with off-label use of medicines to decrease inflammation or overgrowth of bacteria, viruses, or yeast. Each of these treatments has its own risk of side effects that must be considered in view of the limited proof to support their use. While probiotics may be beneficial for some GI problems, the use of probiotics or other treatments to increase the microflora of the intestine has not been studied specifically for treatment of behavioral symptoms. Parents should tell their pediatrician if their child is taking any of these medicines or supplements. Although there may be immunologic factors involved in the cause of some cases of ASD, there is not enough scientific proof at this time to support these modalities to treat ASD.

It has been suggested that mercury from the preservative thimerosal in some vaccines may cause ASD. Other forms of mercury found in the environment are known to cause symptoms of brain damage that are different from those of ASD. Thimerosal was taken out of standard childhood vaccines in the United States in 2000. In 2004, the Institute of Medicine concluded that there is no proof that thimerosal causes ASD, as there were no differences in the rate of ASD in children who were and were not given vaccines with thimerosal. Studies since that time have not identified an association between vaccines and ASD.

Despite the lack of proof, some practitioners have still supported the use of certain medicines to chelate (extract) metals such as mercury. Medicines used for chelation are not approved by the FDA for treatment of ASD and are not recommended for general use at this time. They also can remove metals needed for body function.

Another controversial treatment for ASD is hyperbaric oxygen therapy. The scientific support for this intervention remains weak, and there is risk for side effects.

Nonbiological CAM treatments

Auditory integration training. Children with ASD who receive AIT are conditioned to tolerate certain sounds by listening to filtered music in a sound booth twice a day over a period of time (usually 2-4 weeks). There is no evidence that AIT benefits children with ASD.

Facilitated communication enlists a second person (facilitator) to help a child with ASD point to letters or words on a communication board or type by holding the child's hand or supporting the arm. Scientific studies have shown that facilitated

communication is largely a function of the thoughts and activities of the facilitator and do not actually represent the thoughts or feelings of the child with ASD.

Facilitated communication is different from alternative and augmentative communication, in which picture books or lap boards containing words, numbers, and letters or electronic devices (some speech generating) are introduced with a goal of independent use for communication by an individual with ASD. Augmentative communication may be helpful in learning to communicate.

Other interventions include the use of an interactive metronome, in which rhythm is used to enhance attention, and craniosacral manipulation, in which the chiropractor or motor therapist supposedly manipulates the pressure of the fluid around the brain by touch. Scientific data are not available to confirm or refute how well these techniques and others work.

Treatment, whether conventional or CAM, should be adequately monitored. Parents should inform their child's pediatrician about all treatments the child is using. Families should work closely with their pediatrician and intervention team to

- Determine the specific symptoms or behaviors that they hope will change or improve with any treatment.
- Determine a method to monitor these symptoms or behaviors (for example, daily ratings).
- Collect baseline data before treatment is started.
- Continue data collection when treatment is started.
- Continue data collection for long enough to account for outside changes (for example, sick child, change in family schedule).
- Have a "blind" observer who also collects data (such as a therapist who does not know about the treatment change) if possible.
- Make only one treatment change at a time.

Family support

Families of children with ASD may experience stress before, during, and after diagnosis. Parents often consider family support to be a vital part of an overall intervention plan. Many families feel that they do not get enough help from the professionals involved with their children to learn about the practical aspects of how to obtain services for their children and family members.

Family-centered planning is essential to address the unique needs of each family member and is part of the pediatric medical home. Studies show that parents with more support from other parents and community organizations have less stress. Families of children with ASD can assist each other with finding help in their communities.

As soon as a diagnosis of ASD is made, families should be referred to parent support groups in their communities. Family group meetings provide parents with a

chance to meet other families with children with ASD and may be a major source of information and comfort. At first, many families may prefer not to share their feelings with others. Support groups give information about resources and provide excellent opportunities for networking.

There are many different types of support groups, including

- National organizations with local chapters. Some families help other children with ASD and their families by getting involved with organizations such as the Autism Society of America.
- National parent-run organizations like Autism Speaks and the Autism Science Foundation. Families can help advance efforts for research about ASD through these organizations and obtain information about local resources.
- Local organizations such as local and state parent groups.
- Special interest support groups such as families who have specific treatment interests (for example, ABA or dietary treatments), siblings of children with disabilities, and teens and adults with ASD. Members of these support groups informally help parents and individuals with ASD as they were once helped by others.
- Online support groups. To successfully address the stressors related to the behaviors of ASD and advocate for services and related issues, parents of children with ASD need to support each other. All adult caregivers should work together to address behavioral concerns and support one another.

Similarly, extended family members, such as grandparents, may play an important role in supporting the decisions and behavioral limit setting of parents, as well as being able to help out with the care of children with ASD.

Respite services

When extended family or friends are not available to care for a child with ASD, respite services (child care provided by trained individuals) can help parents by allowing them to attend to other family needs. Although agencies that specialize in respite services for children with disabilities are usually available in most large cities, they may not be in smaller communities or rural areas.

If parents need help paying for respite care, money may be available through state agencies, serving persons with intellectual disability or ASD or other mental health disorders. These funds are often referred to as Medicaid waiver funds because parent income often, though not always, is waived and only the degree of disability determines a child's eligibility for funding.

Parents are encouraged to apply for funds as soon as a diagnosis of ASD is made because there are often long waiting lists. Once a child with ASD becomes eligible for funding, the child may be eligible for respite and recreational activities such as

summer camps. The child may also become eligible for Medicaid health insurance. Depending on family income, the child might already be eligible for Medicaid.

What support do children with ASD have in school?

The Individuals with Disabilities Education Act (IDEA) states that children with disabilities (including ASD) in the public school system should be educated in inclusive environments with typically developing children to as great an extent as possible (in other words, the federal law principle of *least restrictive environment*). However, such placement should not negatively affect the child's progress or minimize the services that should be provided as outlined by an IEP. Stated simply, the child should be provided with all needed support to be successful in the regular classroom and not simply "put" there, expecting normal peers to take on the entire load of teaching social skills. There can be an important role for education, at least part of the time, within a self-contained special education classroom such as an ASD support classroom.

Special concerns in the teen and adult years

Teens and adults with ASD may have special concerns.

Teen years

The dominant theme of the teen years is to plan an appropriate transition to adult life in the community. Areas of concern may include

Transition planning

By law, children with disabilities are entitled to an appropriate, free, and individualized education until the age of 22 years. The Individuals with Disabilities Education Act (IDEA) specifies that transition planning should begin at 14 years of age. During the transition period, social skills, leisure skills, daily-living tasks, self-care, and hygiene issues, in addition to certain academic subjects, should be addressed in preparation of moving into the adult world. In addition, older teens with ASD need to transition to adult medical and behavioral health professionals. They will need to understand their diagnosis and participate in health care visits depending on their language abilities and judgment.

Self-determination

Quality of life can be improved significantly by teaching teens and their families the values of self-determination. Teens need to learn to make responsible decisions, including those that will determine how and where they will live as an adult. They must also learn how to seek the support needed to reach their goals.

Behavioral challenges

The teenage years may be a time of changing behavior patterns for those with ASD, just as they are in those who do not have ASD. New behavioral challenges arise from frustration when teens are having problems communicating in a positive way or are challenged by the changing social rules of adolescence. It is also important to understand that teens with ASD have typical physical sexual development and may need to learn what sexual behaviors are appropriate in public versus private settings.

Adult years

Adults with ASD and average-range intelligence may be able to live with various degrees of independence. Some may attend college and marry and have families. More children are being diagnosed and receiving appropriate interventions earlier and therefore may be better prepared for adult responsibilities. It is also important to emphasize that adults with ASD can continue to improve in language, social interactions, and problem solving. This means that the principles described earlier for children should continue throughout adulthood. Areas of concern may include

Employment

Current data indicate that relatively few adults with ASD are employed in competitive jobs. Many will need job coaching and a supportive work environment, and some may need continuous close supervision for successful employment. It is possible that there are many adults with Asperger syndrome and high-functioning ASD who are working successfully in the community. Better understanding of the symptoms of ASD in adults will help identify where adults with ASD are living and working and how to better meet the needs of teens and young adults as they transition to adult services.

Independent living

Success in independent living is more likely for individuals who have learned tools for effective communication during their school years. If an adult cannot live independently because of the social problems associated with ASD or the associated intellectual disability, caregivers (usually parents) should make a plan for other long-term care and living arrangements. One possibility is a group home. Group homes should look and function as close to a typical home as possible. They should be staffed by individuals who are experienced and sensitive to the unique needs of adults with ASD. It is very important that the environment is highly structured, safe, supervised, and predictable. At the same time, the adult's right for self-determination must be upheld as much as possible. It may be challenging to balance safety and independence.

Financial and legal planning

Parents of children with ASD or any disability should develop a long-term financial plan that includes

Supplemental Security Income

Children who are Medicaid eligible (based on parental income) may also be eligible for monthly Supplemental Security Income (SSI) benefits if a significant disability is diagnosed.

Many teens with ASD, especially those with intellectual disability, become eligible for SSI benefits on their 18th birthday. At that point, the SSI eligibility requirement no longer depends on the joint income of the parents but rather solely on the income of the adult child with ASD. The young adult may then begin to receive monthly subsidies if she is not gainfully employed.

There are no entitlements or grants-in-aid that offset the personal cost to the family specifically for out-of-home living arrangements. However, some communities have nonprofit agencies, partially supported by state funding, that provide supervised living arrangements.

Special needs will and trust

Parents should contact a lawyer to help write a special needs will to make sure the child's rights are protected. For a child with a disability, it is important that the will makes it clear that the child's inheritance can only be spent on items and services that are not already covered by federal subsidies to which the child may be entitled (such as Medicaid, Medicare, or SSI). Otherwise, the child will lose these subsidies until the inheritance is spent down and he once again meets the financial criteria for benefits.

Guardianship

Unless prior legal arrangements are made, all teens, including teens with ASD and intellectual disabilities, become adults and their own legal guardians on their 18th birthday. If an individual is not capable of making responsible decisions, a formal evaluation should be done to determine the need for guardianship. This should be pursued with great care because guardianship contradicts the values of self-determination and may not be a straightforward decision, especially when the adult has borderline cognitive skills. If it is determined that the young adult with ASD is indeed not capable of making responsible judgments, the family will need a lawyer to help assign a legal guardian. Parents may remain legal guardians, or an adult sibling, a relative, a family friend, or a professional may be designated as the legal guardian.

The future

Children with ASD are affected by many factors that will shape their future. Overall, the long-term outcomes of children with ASD have been improving. In general, the sooner ASD is identified, the sooner appropriate intervention programs can begin. While some children make significant developmental gains with early and intense intervention, some children may make slow progress depending on their intelligence, the severity of their ASD symptoms, and whether they have associated medical problems such as seizures or significant behavioral disorders. The goal of all parents is to help their child reach his full potential with the help of all available resources.

“Learning your child has an ASD can certainly change your perception of what you thought your life might be. You may have to restructure your priorities and develop new coping skills. And you may have to change some of your plans for the future. But in their place will be new dreams, new goals, and new priorities. The key is finding ways to adapt and adjust that suit your family, your needs, and your circumstances. It likely won’t be easy. But people often find strength from within and from those around them to succeed. By loving your child dearly, you will be inspired to do what you can to learn as much as possible about ASDs so that you too will be rewarded as you discover what works for your family.”

—American Academy of Pediatrics, *Autism Spectrum Disorders: What Every Parent Needs to Know*;
Alan I. Rosenblatt, MD, FAAP, and Paul S. Carbone,
MD, FAAP, editors

Resources

Books

American Academy of Pediatrics. *Autism Spectrum Disorders: What Every Parent Needs to Know*. Rosenblatt AI, Carbone PS, eds. Elk Grove Village, IL: American Academy of Pediatrics; 2013

Attwood T. *The Complete Guide to Asperger’s Syndrome*. London, England: Jessica Kingsley Publishers; 2007

Baker J. *Preparing for Life: The Complete Guide for Transitioning to Adulthood for those with Autism and Asperger’s Syndrome*. Arlington, TX: Future Horizons; 2005

Bashe PR, Kirby BL. *The OASIS Guide to Asperger Syndrome: Advice, Support, Insight, and Inspiration*. Rev ed. New York, NY: Crown Publishers; 2005

Coplan J. *Making Sense of Autistic Spectrum Disorders: Create the Brightest Future for Your Child With the Best Treatment Options*. New York, NY: Bantam Books; 2010

Glasberg BA, LaRue RH. *Functional Behavior Assessment for People with Autism: Making Sense of Seemingly Senseless Behavior*. 2nd ed. Bethesda, MD: Woodbine House; 2015

Gray C. *The New Social Story Book*. Rev ed. Arlington, TX: Future Horizons; 2010

Harris SL, Weiss MJ. *Right from the Start: Behavioral Intervention for Young Children with Autism*. 2nd ed. Bethesda, MD: Woodbine House; 2007

- Hodgdon LA. *Visual Strategies for Improving Communication: Practical Supports for Autism Spectrum Disorders*. Rev ed. Troy, MI: QuirkRoberts Publishing; 2011
- Cluth P, Shouse J. *The Autism Checklist: A Practical Reference for Parents and Teachers*. San Francisco, CA: Jossey-Bass; 2009
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- Notbohm E, Zysik V. *1001 Great Ideas for Teaching & Raising Children with Autism or Asperger's*. 2nd ed. Rev ed. Arlington, TX: Future Horizons; 2010
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- Volkmar FR, Wiesner LA. *A Practical Guide to Autism: What Every Parent, Family Member, and Teacher Needs to Know*. Hoboken, NJ: John Wiley & Sons; 2009
- Wiseman ND. *Could It Be Autism? A Parent's Guide to the First Signs and Next Steps*. New York, NY: Random House; 2006

Web sites

American Academy of Pediatrics

www.aap.org

www.aap.org/autism (AAP Council on Children With Disabilities Autism Subcommittee)

www.HealthyChildren.org (official AAP Web site for parents)

Autism Science Foundation

www.autismsciencefoundation.org

Autism Speaks

www.autismspeaks.org

Centers for Disease Control and Prevention

www.cdc.gov/autism

www.cdc.gov/ncbddd/actearly

Early Childhood Technical Assistance Center (Early Intervention and Special Education)

www.ectacenter.org/families.asp

Easter Seals

www.easterseals.com/autism

National Institute of Mental Health

www.nimh.nih.gov

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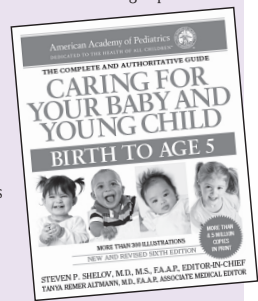
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Caring for Your Baby and Young Child: Birth to Age 5

New edition! More than 4.5 million copies sold! This is the "instruction manual" for children. Every aspect of basic child care is covered—infant care, nutrition, discipline, safety, caregiving, emergencies, common illnesses, immunizations, and environmental hazards, to name a few. New content includes a chapter on the effects of media and technology exposure in children, many content updates, and special messages for parents and stepfamilies. **CB0088**

To order this and other parenting resources, visit the HealthyChildren bookstore at shop.aap.org/for-parents.



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