

AUTISM

Information Packet

American Academy of Pediatrics

- Understanding Autism Spectrum Disorders (ASDs)

Autism Today

- What is the DSM IV, to Determine the Diagnosis?

Autism Society of America

- What is Autism
- What Causes Autism
- Diagnosing Autism
- Consulting with Professionals
- Treatment and Education
- Treatment Options

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Creating Opportunities, Building Relationships, Improving Lives For Children And Adults With Developmental Disabilities Since 1952

About Autism

Source: Autism Society of America

Autism is a complex developmental disability that typically appears during the first three years of life and affects a person's ability to communicate and interact with others. Autism is defined by a certain set of behaviors and is a "spectrum disorder" that affects individuals differently and to varying degrees. There is no known single cause for autism, but increased awareness and funding can help families today.

In December 2009, the Centers for Disease Control and Prevention issued their ADDM autism prevalence report. The report concluded that the prevalence of autism had risen to 1 in every 110 births in the United States and almost 1 in 70 boys. The issuance of this report caused a media uproar, but the news was not a surprise to the Autism Society or to the 1.5 million Americans living with the effects of autism spectrum disorder. Nonetheless, the spotlight shown on autism as a result of the prevalence increase opens opportunities for the nation to consider how to serve these families facing a lifetime of supports for their children.

Currently, the Autism Society estimates that the lifetime cost of caring for a child with autism ranges from \$3.5 million to \$5 million, and that the United States is facing almost \$90 billion annually in costs for autism (this figure includes research, insurance costs and non-covered expenses, Medicaid waivers for autism, educational spending, housing, transportation, employment, in addition to related therapeutic services and caregiver costs).

Know the Signs: Early Identification Can Change Lives

Autism is treatable. Children do not "outgrow" autism, but studies show that early diagnosis and intervention lead to significantly improved outcomes.

Here are some signs to look for in the children in your life:

- Lack of or delay in spoken language
- Repetitive use of language and/or motor mannerisms (e.g., hand-flapping, twirling objects)
- Little or no eye contact
- Lack of interest in peer relationships
- Lack of spontaneous or make-believe play
- Persistent fixation on parts of objects

There are no medical tests for diagnosing autism. An accurate diagnosis must be based on observation of the individual's communication, behavior and developmental levels. However, because many of the behaviors associated with autism are shared by other disorders, various medical tests may be ordered to rule out or identify other possible causes of the symptoms being exhibited. At first glance, some persons with autism may appear to have mental retardation, a behavior disorder, problems with hearing, or even odd and eccentric behavior. To

complicate matters further, these conditions can co-occur with autism. However, it is important to distinguish autism from other conditions, since an accurate diagnosis and early identification can provide the basis for building an appropriate and effective educational and treatment program.

A brief observation in a single setting cannot present a true picture of an individual's abilities and behaviors. Parental (and other caregivers' and/or teachers') input and developmental history are important components of making an accurate diagnosis.

Why Early Identification is Critical

Research indicates that early identification is associated with dramatically better outcomes for individuals on the autism spectrum. The earlier a child is diagnosed, the earlier the child can begin benefiting from one of the many specialized intervention approaches to treatment and education.

The American Academy of Pediatrics (AAP) recommends that all children be screened for autism by their family pediatrician twice by the age of 2, at 18 months and again at 24 months. The AAP also recommends that treatment be started when an autism diagnosis is suspected rather than waiting for a formal diagnosis. Go to <http://www.aap.org/> to see the complete list of recommendations. The advantages of early intervention cannot be overemphasized. Children who receive intensive therapy can make tremendous strides in their overall functioning and go on to lead productive lives.

Screening and Screening Instruments

The Centers for Disease Control and Prevention and the National Center on Birth Defects and Developmental Disabilities also provide a wealth of information on the early signs of autism through their ["Learn the Signs. Act Early." initiative](#).

While there is no one behavioral or communications test that can detect autism, several screening instruments have been developed that are now being used in diagnosing autism:

1. CARS rating system (Childhood Autism Rating Scale), developed by Eric Schopler in the early 1970s, is based on observed behavior. Using a 15-point scale, professionals evaluate a child's relationship to people, body use, adaptation to change, listening response, and verbal communication.
2. The Checklist for Autism in Toddlers (CHAT) is used to screen for autism at 18 months of age. It was developed by Simon Baron-Cohen in the early 1990s to see if autism could be detected in children as young as 18 months. The screening tool uses a short questionnaire with two sections: one prepared by the parents; the other by the child's family doctor or pediatrician.

3. The Autism Screening Questionnaire is a 40-item screening scale that has been used with children age four and older to help evaluate communication skills and social functioning.
4. The Screening Test for Autism in Two-Year Olds is being developed by Wendy Stone at Vanderbilt and uses direct observations to study behavioral features in children under two. She has identified three skill areas that seem to indicate autism: play, motor imitation, and joint attention.

Who Makes a Diagnosis?/Diagnostic Tools

Whether you or your child's pediatrician is the first to suspect autism, your child will need to be referred to someone who specializes in diagnosing autism spectrum disorders. This may be a developmental pediatrician, a psychiatrist or psychologist, and other professionals that are better able to observe and test your child in specific areas.

This multidisciplinary assessment team may include some or all of the following professionals (they may also be involved in treatment programs):

- Developmental pediatrician - Treats health problems of children with developmental delays or handicaps.
- Child psychiatrist - A medical doctor who may be involved in the initial diagnosis. He/she can also prescribe medication and provide help in behavior, emotional adjustment and social relationships.
- Clinical psychologist - Specializes in understanding the nature and impact of developmental disabilities, including autism spectrum disorders. May perform psychological and assessment tests, as well as help with behavior modification and social skills training.
- Occupational therapist - Focuses on practical, self-help skills that will aid in daily living, such as dressing and eating. May also work on sensory integration, coordination of movement, and fine motor skills.
- Physical therapist - Helps to improve the use of bones, muscles, joints, and nerves to develop muscle strength, coordination and motor skills.
- Speech/language therapist - Involved in the improvement of communication skills, including speech and language.
- Social worker - May provide counseling services or act as case manager helping to arrange services and treatments.

Working with Professionals

It is important that parents and professionals work together for the child's benefit. While professionals will use their experience and training to make recommendations about your child's treatment options, you have unique knowledge about his/her

needs and abilities that should be taken into account for a more individualized course of action.

Once a treatment program is in place, communication between parents and professionals is essential in monitoring the child's progress. Here are some guidelines for working with professionals:

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

Getting Past the Diagnosis

Often, the time immediately after the diagnosis is a difficult one for families, filled with confusion, anger and despair. These are normal feelings. But there is life after a diagnosis of autism. Life can be rewarding for an individual with an autism spectrum disorder and all the people who have the privilege of knowing that individual. While it isn't always easy, you can learn to help your child find the world an interesting and loving place.

Understanding Autism for Dummies (Wiley Publishing, Inc., 2006) by Dr. Stephen M. Shore and Linda G. Rastelli, MA, outlines the following 10 steps families should take after a diagnosis.

1. *Learn and read as much as possible.* Although the glut of available information may seem overwhelming, the more you read and discover, the easier it will be to understand new information. However, always consider the source of any information you find. And do not focus exclusively on one intervention or therapy; no one treatment works for everyone. You need to find the right combination for your child.
2. *Network with other families.* Families in similar situations often provide the most important support system of all. Get active in the autism community by contacting Autism Society chapters and attending these or other support group meetings and conferences to meet parents who are going through the same struggles and are happy to share their experiences. Visit the Autism Society's online database, [Autism Source](#), for nationwide listings of parent support groups and other organizations.

3. *Test, Test, Test.* Test your child early to get a baseline picture of where he or she is. A clear picture of your child's biological condition provides a roadmap for treatment and therapies to follow. If you can't afford all of the tests you need up front, prioritize them with your medical providers' help.
4. *Investigate sources of financial aid.* Autism can quickly exhaust your resources, but, fortunately, funding and assistance do exist. Financial aid is generally available at the county level for children under the age of 3 (you'll need to apply for the Medicaid waiver). Also, keep good financial records, and avoid using the words "autism" or "PDD-NOS" with insurance companies, especially HMOs, as many exclude autism in their policies. If there is a biological abnormality that's being treated, have the doctor code it as such.
5. *Consider major lifestyle changes.* As autism treatment can seriously affect your financial resources, you may have to make major changes (such as changing your job or downsizing your home) or short-term sacrifices to allow for the funds you need to treat your child. Also, if you have a spouse or significant other, you need to establish a division of labor and responsibilities regarding the care of your child. Autism treatment takes sacrifice, but the hard work pays off. Many parents will tell you that the emotional rewards are much more lasting than any hobby or house can bring.
6. *Set up an educational/behavioral program in your home.* If you can afford it, a structured one-on-one program focusing on education and behavior works for many children with autism. Make sure the program is reputable and that it shares your expectations and goals. You and your tutor/consultant should both sign a contract stating who is responsible for what.
7. *Begin therapies.* You may be referred to other specialists for therapy, including speech, occupational and physical therapy. These therapies will help your child gain communication, social and physical skills. Insurance providers, including Medicaid, often cover the cost.
8. *Address diet and nutrition.* Since dietary sensitivities affect many people with autism, consider trying special diets (such as wheat-free/dairy-free) for your child. Based on medical testing and your doctor's recommendations, you should also start your child on vitamin/mineral supplements geared to his/her needs. Be sure to consult with a nutritionist and pediatrician with expertise in autism.
9. *Don't give up. Attitude is everything!* Try to be a morale booster for your family and your team of professionals. Educate doctors who are unfamiliar with autism and provide up-to-date information for those who can help. Be patient as many treatments and interventions take time to produce results. Most importantly, remember to laugh and have fun together as a family.
10. *Get out and relax.* Make time for yourself. You must take care of yourself to be of any good to your child. Encourage your spouse/significant other to take time to recharge as well.

What causes Autism?

There is no known single cause for autism, but it is generally accepted that it is caused by abnormalities in brain structure or function. Brain scans show differences in the shape and structure of the brain in children with autism versus neuro-typical

children. Researchers are investigating a number of theories, including the link between heredity, genetics and medical problems. In many families, there appears to be a pattern of autism or related disabilities, further supporting a genetic basis to the disorder. While no one gene has been identified as causing autism, researchers are searching for irregular segments of genetic code that children with autism may have inherited. It also appears that some children are born with a susceptibility to autism, but researchers have not yet identified a single "trigger" that causes autism to develop.

Other researchers are investigating the possibility that under certain conditions, a cluster of unstable genes may interfere with brain development, resulting in autism. Still other researchers are investigating problems during pregnancy or delivery as well as environmental factors, such as viral infections, metabolic imbalances, and exposure to environmental chemicals.

Genetic Vulnerability

Autism tends to occur more frequently than expected among individuals who have certain medical conditions, including Fragile X syndrome, tuberous sclerosis, congenital rubella syndrome, and untreated phenylketonuria (PKU). Some harmful substances ingested during pregnancy also have been associated with an increased risk of autism. Read more about [related conditions](#).

Environmental Factors

Research indicates that other factors besides the genetic component are contributing to the rise in increasing occurrences of ASD, such as environmental toxins (e.g., heavy metals such as mercury), which are more prevalent in our current environment than in the past. Those with ASD (or those who are at risk) may be especially vulnerable, as their ability to metabolize and detoxify these exposures can be compromised. Read more about [environmental health and autism](#).

Frequently Asked Questions and Answers

What is autism?

Autism is a complex developmental disability that typically appears during the first three years of life and is the result of a neurological disorder that affects the normal functioning of the brain, impacting development in the areas of social interaction and communication skills. Both children and adults with autism typically show difficulties in verbal and non-verbal communication, social interactions, and leisure or play activities. Autism is a spectrum disorder and it affects each individual differently and at varying degrees.

What are the most common characteristics of autism?

Every person with autism is an individual, and like all individuals, has a unique personality and combination of characteristics. Some individuals mildly affected may exhibit only slight delays in language and greater challenges with social interactions. They may have difficulty initiating and/or maintaining a conversation. Their communication is often described as talking at others instead of to them. (For example, a monologue on a favorite subject that continues despite attempts by others to interject comments).

People with autism also process and respond to information in unique ways. In some cases, aggressive and/or self-injurious behavior may be present. Persons with autism may also exhibit some of the following traits:

- Insistence on sameness; resistance to change
- Difficulty in expressing needs, using gestures or pointing instead of words
- Repeating words or phrases in place of normal, responsive language
- Laughing (and/or crying) for no apparent reason; showing distress for reasons not apparent to others
- Preference to being alone; aloof manner
- Tantrums
- Difficulty in mixing with others
- Not wanting to cuddle or be cuddled
- Little or no eye contact
- Unresponsive to normal teaching methods
- Sustained odd play
- Spinning objects
- Obsessive attachment to objects
- Apparent over-sensitivity or under-sensitivity to pain
- No real fears of danger
- Noticeable physical over-activity or extreme under-activity
- Uneven gross/fine motor skills
- Non-responsive to verbal cues; acts as if deaf, although hearing tests in normal range

What is the difference between autism and PDD?

The term "PDD" is widely used by professionals to refer to children with autism and related disorders; however, there is a great deal of disagreement and confusion among professionals concerning the PDD label. Diagnosis of PDD, including autism or any other developmental disability, is based upon the *Diagnostic and Statistical Manual of Mental Disorders - Fourth Edition (DSM-IV)* (American Psychiatric Association, Washington DC, 1994), and is the main diagnostic reference of mental health professionals in the United States.

According to the *DSM-IV*, the term "PDD" is not a specific diagnosis, but an umbrella term under which the specific diagnoses are defined.

What is Asperger's Syndrome?

What distinguishes Asperger's Syndrome from autism is the severity of the symptoms and the absence of language delays. Children with Asperger's may be only mildly affected and frequently have good language and cognitive skills. To the untrained observer, a child with Asperger's may seem just like a normal child behaving differently. They may be socially awkward, not understanding of conventional social rules, or show a lack of empathy. They may make limited eye contact, seem to be unengaged in a conversation, and not understand the use of gestures.

One of the major differences between Asperger's Syndrome and autism is that, by definition, there is no speech delay in Asperger's. In fact, children with Asperger's frequently have good language skills; they simply use language in different ways. Speech patterns may be unusual, lack inflection, or have a rhythmic nature or it may be formal, but too loud or high pitched. Children with Asperger's may not understand the subtleties of language, such as irony and humor, or they may not recognize the give-and-take nature of a conversation.

Another distinction between Asperger's Syndrome and autism concerns cognitive ability. While some individuals with autism experience mental retardation, by definition a person with Asperger's cannot possess a "clinically significant" cognitive delay, and most possess average to above-average intelligence.

Why is early intervention so important?

Early intervention is defined as services delivered to children from birth to age 3, and research shows that it has a dramatic impact on reducing the symptoms of autism spectrum disorders. Studies in early childhood development have shown that the youngest brains are the most flexible. In autism, we see that intensive early intervention yields a tremendous amount of progress in children by the time they enter kindergarten, often reducing the need for intensive supports.

Understanding Autism Spectrum Disorders (ASDs)



American Academy of Pediatrics
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Understanding Autism Spectrum Disorders (ASDs)

Autism spectrum disorders (ASDs) are a group of related brain-based disorders that affect a child's behavior, social, and communication skills. They include 3 of 5 disorders known as pervasive developmental disorders (PDDs). These are autistic disorder, Asperger syndrome, and PDD-not otherwise specified (PDD-NOS).

Because most children with ASD will master the early motor skills such as sitting, crawling, and walking on time, delays in social and communication skills may not be as obvious to parents. Looking back, many parents of children with ASD can think of specific examples that suggest something was different, but nothing indicating a serious problem.

Autism spectrum disorders are lifelong conditions with no known cure. However, children with ASD can progress developmentally and learn new skills. Some children may improve so much that they no longer meet the criteria for ASD, although milder symptoms may often persist.

It is important to start an intervention program as soon as possible. The sooner autism is identified, the sooner an intervention program can start. Each child with autism has different needs. What works for one child may not work for another.

The amount of information available about ASD can be overwhelming. This booklet was written by the American Academy of Pediatrics (AAP) to answer some common questions about ASD.

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How common are autism spectrum disorders?

Autism spectrum disorders affect an estimated 4 to 6 out of every 1,000 children. The reported number of children with ASD has increased since the early 1990s. The reason for the increase is unclear. It may be because of many factors, including an increased awareness of what ASDs are, more screening tools and services, and/or changes in how ASD has been defined and diagnosed. In the past, only children with the most severe autism were diagnosed (the tip of the iceberg). Now children with milder symptoms are being identified and referred to intervention and educational programs.

What are the symptoms of autism spectrum disorders?

No 2 children with ASD have the exact same symptoms, but the criteria are somewhat standardized. The number of symptoms and how severe they are can vary greatly. The following are examples of how a child with ASD may act:

Social differences

- Doesn't snuggle when picked up, but arches back instead
- Doesn't keep eye contact or makes very little eye contact
- Doesn't respond to parent's smile or other facial expressions
- Doesn't look at objects or events parents are looking at or pointing to
- Doesn't point to objects or events to get parents to look at them
- Doesn't bring objects to show to parents just to share his interest
- 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

Communication differences

- Doesn't say single words by 15 months or 2-word phrases by 24 months
- Repeats exactly what others say without understanding its meaning (parroting or echolalia)
- 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" (pronominal reversal)
- 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, songs, TV jingles, or a specific topic
- Loses language milestones, usually between the ages of 15 to 24 months in a few children (regression)

Behavioral differences (stereotypic, repetitive, and restrictive patterns)

- Rocks, spins, sways, twirls fingers, or flaps hands (stereotypic behavior)
- Likes routines, order, and rituals
- Obsessed with a few 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)
- May have splinter skills, such as the ability to read at an early age, but often without understanding what it means
- Doesn't cry if in pain or seem to have any fear
- 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
- May have unusual or intense but narrow interests

What are the different types of autism spectrum disorders?

As mentioned earlier, ASD includes 3 of 5 disorders known as PDDs. Pervasive developmental disorders are defined in the fourth edition of the *Diagnostic and Statistical Manual of Mental Disorders (DSM-IV)* and the revised *Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition, Text Revision (DSM-IV-TR)*. These manuals are published by the American Psychiatric Association and describe behavioral and mental health conditions. Pediatricians may use the *Diagnostic and Statistical Manual of Mental Disorders, Primary Care (DSM-PC)* version published by the AAP. Although many doctors use the term PDD as published in the *DSM*, most experts in the field now use the term ASD.

The following are descriptions of autistic disorder, Asperger syndrome, and PDD-NOS:

Autistic disorder

Autistic disorder is the term used when a child meets all the necessary criteria listed in the *DSM-IV*. Children with autistic disorder have problems with language skills that are absent, delayed, or abnormal; problems relating to others socially; and unusual or repetitive behaviors. While social symptoms are usually present in the first year of life, language problems show up in the second year and stereotypic behaviors show up later. Many of these children will have intellectual deficits; others might appear to have deficits when, in fact, scores on intelligence tests are low because of lack of cooperation. Others may have normal scores on intelligence tests, yet they may have trouble with abstract and real-life reasoning. Children with autism are often labeled as *high functioning* when intelligence is in the normal range.

Asperger syndrome

Asperger syndrome is usually not diagnosed until preschool age or later. This is because early speech development, especially language and sentence structure, is relatively normal. Sometimes children with Asperger syndrome speak in an odd way. Some children may speak in the same tone of voice without raising or decreasing the pitch of their voice. Other children may speak in language above what you would expect for their age like "little professors." They may make little eye contact while talking and may have trouble maintaining a back-and-forth conversation. They usually obsess over 1 or 2 topics and will talk about these topics whether the listener is interested. Children with Asperger syndrome often interpret language literally and may have particular trouble with humor, teasing, and figures of speech. Many may also have problems with motor coordination. Intelligence is normal. Some experts do not consider this a separate disorder from high-functioning autism.

Pervasive developmental disorder-not otherwise specified

Children with PDD-NOS or atypical autism show some signs of autism or other PDD, but don't meet the criteria to be diagnosed with one specific disorder.

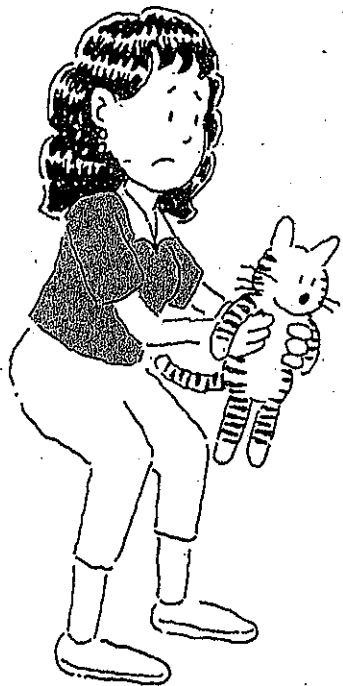
What causes autism spectrum disorders?

No one knows exactly what causes ASD. Years ago "poor, non-nurturing" parenting was thought to be a possible cause of ASD, but this is not the case. Today scientists know from twin and other family studies that genetics play a major role. Although many chromosomal and gene abnormalities have been identified, none of these are present in all children with ASD. If a family already has a child diagnosed with ASD, the chances that siblings might also have some form of ASD are 10 times higher than in the general population. Environmental factors may also play a secondary role, but this has not been proven yet.

Studies have shown that in families with autism, there are often other developmental problems. These problems may include language delays, learning disabilities, anxiety, or mood disorders among family members.

Autism spectrum disorders, particularly autistic disorder, also tend to occur more often in people with certain medical conditions, such as fragile X syndrome, tuberous sclerosis, congenital rubella syndrome, and untreated phenylketonuria (PKU).

Two prescription medicines that have potentially been linked to ASD are thalidomide and valproate.



Current scientific proof does not support a link between the measles-mumps-rubella (MMR) vaccine or any combination of vaccines and ASD. There also is no scientific proof to support a link between thimerosal (a mercury-containing preservative) and ASD. In any event, vaccines no longer contain mercury.

What is known about brain development in autism spectrum disorders

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

- There is a difference in brain growth in ASD, with a tendency for brains to grow faster than usual in early childhood and then to grow more slowly.
- Thorough autopsy studies of the brains of people with autism have revealed various microscopic abnormalities in brain areas such as the cerebellum, limbic system, and cerebral cortex.
- There are differences or abnormalities in some brain chemicals in ASD. These brain chemicals are important regulators of brain development and function. However, no abnormality has been a consistent feature in ASD.
- There are some differences in function of certain parts of the brain in autism.

The tests that reveal differences in brain chemicals and function are helpful in research studies, but are not yet useful in evaluating children clinically. Although our understanding of differences in brain structure and function is increasing, there is still much to be learned.

What are the early signs of autism spectrum disorders?

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, these more subtle differences often go unnoticed.

Social skills

In looking back on their child's development, parents will often say that something seemed different from the beginning. For example, a child with ASD may have

- Not smiled back to you or smiled less often or less enthusiastically than you expected.
- Not cuddled like other children.
- Not made as much eye contact with others.
- Not responded to her name being called.
- Seemed to tune others out. At other times, she may have seemed to hear environmental sounds, even very faint ones, perfectly well. This was probably confusing and may have caused you to worry about a hearing problem.

One of the most important developmental differences between children with ASD and other children is a delay or lack of *joint attention*. Looking back and forth between the same object or event and another person and connecting with that person is called joint attention. It is a building block for later social and communication skills. Engaging in many back-and-forth social interactions, such as exchanging lots 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.

Children with ASD often don't

- Follow a point when parents point at an object and say, "Look!" At about 10 to 12 months of age, most typically developing children will immediately look in the direction of the object to which the parent is pointing. They will then look back at the parent and mimic the parent's expression, usually a smile. Children with autism will often ignore the parent. For example, a parent might point at the household pet that has just entered the room and say, "Johnny, look! Kitty has come inside to play with you!" Johnny will likely continue what he was doing and not even look up even though the parent may call out several times. This often causes parents to worry about their child's hearing.
- Point to out-of-reach objects that they want. The child may instead take a parent's hand and lead the parent to the object (for example, a cookie jar on the countertop). Sometimes she may even place the parent's hand on the object itself. (Most children are able to point to out-of-reach objects that they want by 12 to 14 months.)
- Bring objects to simply show parents. Most typically developing children take pleasure in bringing an object to a parent for a comment like, "Wow, that is pretty." Children with ASD rarely do this, except to get parents to open a container or wind up a toy.
- Point to interesting objects, people, or events to get parents to look at them. Most children can do this by 14 to 16 months. Children point at objects (for example, a helicopter in the sky) not to enlist the parent to get the objects for them, but simply for the enjoyment of sharing the sight together. Children will look back and forth between the object or event and the parent to make sure that the parent is tuned in to what they are looking at.

Other differences in children with autism spectrum disorders

- May use fewer gestures or none at all. For example, they may not wave goodbye, reach up to parents to be held, or play patty-cake.
- May be attached to hard objects. Many typically developing children become attached to a comfort item that helps to soothe and console them in times of stress. Usually this is a soft object such as a favorite blanket, stuffed animal, or pillow. However, children with ASD often insist on carrying a hard object with them at all times. The object could be a pen, a piece of string, an action figure from a favorite TV show or video, or sometimes an unusual object like a toilet plunger or soft soap dispenser. The children may have severe temper tantrums if the object is taken away. These unusual attachments often change from one object to another over time.
- May demonstrate repetitive actions such as hand flapping, rocking, head banging, twirling, or pacing back and forth across the room.
- May not engage in pretend or make-believe play with dolls or stuffed animals as if they were having a tea or birthday party.

On the other hand, some children with ASD may be especially talented in putting complex puzzles together or playing computer games.

Language delays

All children with autism show significant language delays. Those children later diagnosed with Asperger syndrome will seem to have met language milestones during the toddler years, but use of language may be abnormal.

- Talk very little. Many children with autism talk very little, if at all. It may sound like they're talking to themselves in a foreign language without any effort to get their parents' attention or to communicate a need or request. Unlike most children who speak gibberish for only a short period during the early stage of normal language development, children with ASD may seem stuck in this stage.
- Don't take turns. They don't take turns in these early talking efforts with their parents.

- Use pop-up words. Sometimes children may say a very clear word or short phrase such as "fire truck" or "stop that" that seems to be advanced compared with their usual speaking skills. These are called *pop-up* words or phrases because they just pop up every once in a while. They seem out of context and don't appear to reflect any recognizable effort to communicate a real message to parents. Although they may pop up several times in one day, they may never be spoken again.
- Repeat words. Some children will repeat what they hear on TV or videos or from the conversation of others. This is sometimes called parroting or echolalia. They might actually be very good at this and even seem gifted with an unusual memory for TV jingles, ABCs, nursery rhymes, or songs.
- Unable to communicate basic needs. Some children may be able to name colors and shapes or read flash card words or books at a very young age, but can't tell you their basic needs. This uneven pattern of speech development is characteristic of ASD and can be quite confusing to parents and doctors. It sometimes leads to an overestimation of the children's true functional language skills, causing a delay in diagnosis.

Regression in developmental milestones

About 25% of children will seem to have normal development until about 18 months, after which they will gradually or suddenly

- Stop talking (if they had begun to say a few words).
- Stop waving goodbye.
- Stop turning their heads when their names are called.
- Withdraw into a shell and seem more distant and less interested in their surroundings.

However, a careful review of home videos of these children taken at their 1-year-old birthday parties (*before* they actually regress) often shows subtle signs of ASD that were missed at the time. One of the most common signs in these videos is children not consistently turning their heads when their names were called.

How is the diagnosis made?

Diagnosis of ASD involves many factors. There are no specific lab tests for ASD, so pediatricians must rely on information from parents and what can be observed during well-child checkups. The condition is complex and symptoms are different for each child.

Screening in siblings

Because younger siblings of children already diagnosed with ASD have a higher risk for also having ASD, parents and pediatricians are encouraged to carefully watch for developmental problems, especially delays in social and language skills. Specific ASD screening tools, such as the Checklist for Autism in Toddlers (CHAT) or the Modified-CHAT (M-CHAT), may be used at the 18- and 24-month well-baby checkup to target skills that are typically deficient in ASD. More importantly, parents are encouraged to watch for the early signs of ASD throughout the child's first 2 years of life and report any concerns to the pediatrician. Many times a parent, another family member, or a child care provider will notice developmental delays. In addition to delays in joint attention, gestures, and speech (described on pages 8-10), tell your 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 your child may fail to perform these skills, but if you answered "yes" to any of these signs, your child should be fully evaluated for ASD and other developmental disorders.

When an ASD is suspected as a cause of language and social delays, a full evaluation should follow. This may be done by a doctor or psychologist who has expertise in the diagnosis of ASD or, preferably, by a team of specialists that may include developmental pediatricians, child neurologists, child psychiatrists, psychologists, speech or language pathologists, occupational or physical therapists, educators, and social workers. Typically, an evaluation will include the following:

- Careful observation of play and child-caregiver interactions.
- Detailed history and physical exam.
- Developmental assessment of all skills (motor, language, social, self-help, cognitive). Autism spectrum disorders are suspected when the child's social and language functioning is significantly more impaired than the overall level of motor, adaptive, and cognitive skills.
- Standardized autism-specific tool. Special training is usually needed to administer a standardized behavioral or developmental tool that has been specifically developed to help diagnose ASD. There may be few clinicians in a given community with these qualifications. However, every school district should have at least one professional (usually a child psychologist) that can administer an autism-specific tool. Tools may include the Childhood Autism Rating Scale, Gilliam Autism Rating Scale, Autism Diagnostic Interview-Revised, and Autism Diagnostic Observation Schedule.
- Hearing test. All children with any speech delays or those suspected of having ASD should have their hearing evaluated by a pediatric audiologist.
- 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).

Medical tests

In fewer than 10% of children diagnosed, ASD may be associated with a known syndrome or medical condition. Lab tests may be needed to rule out other possible medical causes with similar symptoms. Your pediatrician will recommend what's best based on your child's history and physical exam. Tests should be ordered only if the results will provide useful information. Your child may be referred to other specialists, such as a geneticist or a pediatric neurologist, to help with this search for an underlying cause.

Genetic tests

A high-resolution chromosomal analysis (500 bands or higher) and fragile X DNA test are recommended, especially if a child has atypical physical features and/or global developmental delays or if there is a family history of fragile X syndrome or mental retardation of unknown cause. Other genetic tests may be needed in certain cases.

Lead test

A lead level should be performed when a child lives in a high-risk environment and often puts objects in his mouth.

Other tests

Under special circumstances, an electroencephalogram (EEG), a magnetic resonance imaging (MRI) scan, a computed tomography (CT) scan, or tests for inborn errors of metabolism may be ordered.

There is not enough proof to recommend any of the following tests: hair analysis, micronutrient levels (such as vitamin levels), intestinal permeability studies, stool analysis, urinary peptides, or mercury level.

What more common syndromes are associated with autism spectrum disorders?

Although syndromes are rarely associated with ASD, some are more likely to be associated than others. It should also be noted that not all children with these syndromes have ASD. The syndromes include the following:

Fragile X syndrome

Fragile X syndrome is a genetic disorder affecting the X chromosome. It's the most commonly inherited genetic cause of mental retardation. It is passed down from the mother's side of the family. Males have only 1 X chromosome, so they are affected more severely than females. Certain physical features, such as large ears, a long face, loose joints, and postpubertal large testes, may be associated with this condition, but they're not always present, especially in the very young child. If a child with ASD has mental retardation or global developmental delays or if there is a history of mental retardation on the mother's side of the family, DNA tests for fragile X syndrome should be done.

Tuberous sclerosis

Tuberous sclerosis is a genetic disorder that causes lesions to grow in the brain, skin, and other organs. It's commonly associated with epilepsy. DNA testing can identify the underlying genetic basis in about 70% of individuals with this syndrome. If a child with ASD has documented seizures, tuberous sclerosis should be considered as a possible cause. All children with global developmental delays should have a thorough skin exam.

Rett syndrome

Rett syndrome is a genetic disorder occurring almost solely in girls with onset during the first 2 years of life after a period of typical development. It is characterized by loss of control of hand skills, characteristic hand-wringing movements, unsteady motor skills, mental retardation, decelerated head growth (after a period of normal growth), seizures, and impaired social skills. DNA tests can now 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's characterized by severe to profound mental retardation, a happy facial expression, atypical laughter, unsteady walking, and seizure disorder. DNA/methylation tests can identify more than 80% of cases.

Landau-Kleffner syndrome

Landau-Kleffner syndrome is a neurologic disorder that causes seizures in children, usually between the ages of 3 and 7 years. Children with this disorder may be treated with medicine to stop the convulsions. Because social skills remain normal and language regression occurs much later, it is usually easily distinguished from ASD. The diagnosis is made by EEG testing throughout all 4 stages of sleep. This disorder should be considered when there is a history of significant regression in language skills.

Phenylketonuria

Phenylketonuria is a metabolic disorder. It affects the body's ability to process a specific chemical found in many foods, which results in the buildup of this substance to levels that are toxic to the developing brain. Fortunately, PKU is identified in most (but not all) newborns in the United States in the first few weeks of life by routine blood testing. Treatment may include removing certain foods from the diet. This will prevent further brain damage and later symptoms of mental retardation or autism in young infants that make PKU a rare cause of ASD.

Congenital rubella

Rubella is even more rare a cause of ASD. Infants born with congenital rubella usually have many birth defects in addition to severe developmental delays and autistic symptoms. It results from a mild viral infection in the pregnant mother. Fortunately, most women (and their unborn children) are now protected from rubella because they have received the MMR vaccine.

What are some of the associated disorders or symptoms?

Some children with ASD may also be affected by other health problems such as associated medical disorders, behavioral challenges, or emotional and developmental disorders. A child may have one or many problems.

Health problems

Seizures

Over the life span, about one fourth of children with ASD will 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 and/or legs, loss of consciousness, or brief staring spells. If your child experiences any of these or you have any concerns about severe changes, talk with your pediatrician about having your child evaluated.

Evaluation for seizures may include a physical and neurologic exam 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 the seizures.

Nutrition or gastrointestinal disorders

Children with ASD may have gastrointestinal (GI) symptoms such as constipation, diarrhea, gastroesophageal reflux, or food selectivity. If the symptoms are serious, they may interfere with sleep and mealtimes and make children very uncomfortable. Studies are currently being done to see if these symptoms truly occur more often in children with ASD compared with other children.

Food selectivity may be very severe in otherwise healthy children with ASD. Many children won't eat certain foods, such as vegetables or fruits, and will only eat carbohydrates. Some children are fussy eaters because they don't like certain textures and colors of food. Other children are fussy about how the food is given to them. For example, a child may only drink from a special cup or won't eat foods that touch each other on the plate.

If you are concerned about your child's growth (height or weight) or if your child has frequent GI symptoms, talk with your pediatrician. Your child may need to be tested to see if her nutrition is at risk or if there is an underlying intestinal disorder.

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 yet confirmed this as a treatment for symptoms of ASD. Talk with your pediatrician before starting any special diets.

Tics

Some studies report as many as 6% of children with ASD have chronic tics. Tics are involuntary brief motor movements or sounds. Some medicines can control tics, while others may increase tics.



Behavioral challenges

Attention and/or hyperactivity difficulties

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

Aggression and agitation

Sometimes the only way children with ASD may know how to ask for what they need or want is by acting out with aggression or agitation. In addition, these behaviors may be a response to medical problems that the child cannot communicate. For example, belly pain caused by constipation may make your child cranky.

Obsessiveness or repetition of behaviors, problems with transitions

Some children with ASD may have more of a tendency to be "stuck" on certain behaviors and have problems with changes (routines are important). For example, they may need to have what's in their lunch boxes arranged the exact same way and follow the exact same route to school each day.

Self-injury

Sometimes children with ASD may seem to be hurting themselves for reasons similar to those noted earlier for aggression and agitation. For example, some children may strike their heads if they have an earache or a toothache. Any child with a new self-injury, especially one who is not talking, should be examined by your pediatrician for a medical condition that may be causing the pain.

Self-stimulation

Some children engage in repetitive sensory or motor behaviors such as flapping their hands, rubbing body parts on furniture, ripping papers, or other behaviors that may interfere with daily life. These behaviors may provide stimulation in under-stimulating conditions or tune out stimulation in overstimulating conditions.

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.

Emotional disorders

Anxiety disorders

Anxiety disorders may be caused by chemical imbalances in the brain. There may be a history of anxiety in family members without ASD. 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 is often helpful.

Mood disorders (depression)

Depression may be caused by chemical imbalances in the brain. There may be a history of mood disorders in family members without ASD. Like anxiety disorders, mood disorders can have many different symptoms. Children with depression can lose interest in favorite activities, are 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. A combination of medical and behavioral interventions is often recommended.

Developmental disorders

Mental retardation or cognitive deficits

Cognitive deficits may occur in up to two thirds of children with ASD. However, this statistic may decrease as better methods for testing children with ASD have been developed and because children with Asperger syndrome are now being included in ASD research. By definition, a child with Asperger syndrome has average to above-average intelligence. Although PDD-NOS is generally considered a milder form of autism, a child with PDD-NOS may occasionally have more significant cognitive deficits. Mental retardation is suspected when the child shows global delays (especially in self-help and problem-solving skills) as well as delays in language and social skills.

Verbal apraxia

Verbal apraxia is a disorder that affects the muscles used in speech. Sometimes a child will have trouble making even simple sounds. Other children might just lack the oral-motor skills to speak easily. This milder condition is often called *verbal dyspraxia*.

Living with autism spectrum disorders

There are many different strategies and techniques to help children with ASD interact with others and learn new skills that will help them talk, interact, play, learn, and care for their needs. So far, no one technique has been proven significantly better than others. However, effective programs should be intense, address behavior management as well as communication and social skills development, and encourage parents to get involved. The ultimate goal of all programs should be the successful integration of the child with ASD into inclusive environments with typically developing peers as early as possible.

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.
- 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 20 to 25 hours of planned intervention or instruction per week. It should be given year-round. The majority of children benefit from a staffing ratio of 1:1 or 1:2 with an adult. For each child there should be 1 teacher, and there should be no more than 2 children per teacher.
- Encourage parents to be fully involved. Siblings and peers should also be part of the program. Children often learn best by modeling typically developing children in inclusive settings.
- Take place in everyday settings. To promote generalization of newly acquired skills, interventions should take place in everyday settings. Natural reinforcers should also be used.
- 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.
- 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 you live. Unfortunately, few communities have programs with all, or even most, of these recommendations. Usually this is because there isn't enough public funding and/or experienced staff. Efforts are being made nationally to increase funding and training, but such changes will take time. However, many children will still benefit from a limited program versus no program at all. Often this is possible because of a team effort from staff and parents.

In general, whichever techniques are used, the more and sooner, the better. Children should be referred to an appropriate program as soon as a delay is suspected. Parents should not wait for a definitive diagnosis of autism because this may take quite some time. When ASD or another developmental disability is diagnosed, the program can be changed to best meet the needs of the child and family. Keep in mind that this can be an ongoing process as additional signs and symptoms become noticeable or others improve.

Although all children with ASD will need developmental and educational services and most will need therapy and behavioral interventions, only certain children may need medicine. Medicine may be needed to control behaviors that could interfere with ASD interventions. Aggressive or disruptive behaviors can become a problem when they cause physical harm to others (or to the child himself) or when they prevent him from cooperating with therapists or teachers.

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.

What is a medical home?

Parents, pediatricians, and other health care professions are encouraged to work together in cooperation with other systems affecting children, such as developmental and educational systems. The AAP calls this the *medical home*. The medical home is a place of care that is continuous, comprehensive, compassionate, and culturally responsive to the needs of families. Parents know their child the best and over time, they usually become experts concerning their child's disability. Parental knowledge and opinions should be recognized and respected. They should be encouraged to seek information, ask questions, and trust in their intuition.

Public programs

Your pediatrician may refer you to a local developmental or school program that provides intervention services. Services are available for children once problems become evident.

Early Intervention Program

If your child is younger than 3 years, the referral may be to an Early Intervention Program (EIP) in your area. This is a federally and state-funded program that helps children with delays or behavioral challenges. You may also contact the EIP directly.

If your child is eligible for services, a team of specialists will, with your input, develop an Individual Family Service Plan (IFSP). This plan becomes a guide for the services that will be provided until your child turns 3 years of age. It may include parent training and support, direct therapy, respite, and special equipment. Other services may be offered if they benefit your child or family. If your child needs help after 3 years of age, the EIP staff will refer your child to the local school district.

Individual Education Program

If your child is 3 years or older at the time of a concern, the referral may be to your local public school. You may also contact the local public school directly. If your child is eligible, the school district staff will, with your input, develop an Individual 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 your child continues to need special education and services, the IEP will be reviewed and revised from time to time. The IEP should be revised to meet your child's changing needs as he grows older and develops new skills.

Private programs

Some communities have private schools or foundation-funded nonprofit programs specifically designed to help children with ASD. Depending on the family's resources, parents may choose to enroll their child in these programs or supplement public programs with private therapy services.

Treatment strategies used in children with autism spectrum disorders

Developmental and behavioral interventions

Developmental and behavioral interventions are the mainstay of supporting individuals with autism. 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. In children with ASD, strengthening communication and social skills often helps to decrease behavioral problems that may exist.

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 the child's only means of communicating her needs or fears to others. There are several different types of behavioral interventions.

Behavioral intervention strategies may be directed by the therapist or teacher by prompting the child toward an intended goal or intervention, or direction can be incidental, such as when the child is caught attempting a desired task and the adult helps the child accomplish it. The latter is considered by many to be more effective. 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 the child with routines that support her in her daily activities. Behavior problems can 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 a functional analysis of behavior (FAB). A FAB 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 the child in her natural settings with her usual caregivers. Otherwise, a trained behavior specialist must experimentally control the environment to arrive at the cause or causes of the behavior. 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 causes of the problematic behavior are identified, the specialist will determine which caregiver reactions are promoting the behavior. Based on FAB information, the behavior specialist will develop an intervention strategy to avoid or modify these conditions to help stop 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 the child matures, especially at the time of puberty and hormonal changes.

The following are descriptions of 3 specific programs that are often used in children with ASD:

Treatment and Education of Autistic and Related Communication-handicapped Children program

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. Eric Schopler, PhD, and colleagues at the University of North Carolina School of Medicine in Chapel Hill developed it in 1966.

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 special interests. Visual organization cues are used to maintain a consistent and structured daily routine that helps build new skills and independence. The program covers the age span from preschool to adulthood. Planning for transition from school to supported employment includes an emphasis on developing appropriate social 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.

Applied behavior analysis

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. Applied behavior analysis strategies are not unique to ASD, but ABA-based programs have been used extensively and have been successful in some children with ASD. Specific goals are set and the therapist works intensively with the child, one-on-one and one goal at a time. Applied behavioral analysis 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 Training (PRT), Functional Communication Training, and Applied Verbal Behavior. Although Ivar Lovaas, PhD, one of the most well-known proponents of a type of ABA (DTT), recommends 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 for fewer hours may work just as well.

- Discrete Trial Training is an important feature of ABA. An instructor working one-on-one with the child presents an instruction or request (called a discriminative stimulus) to the child and delivers a consequence based on the expected response from the child. 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-initiations, in the hope that improvements in these areas will lead to changes in other functional areas.
- Functional Communication Training and Applied Verbal Behavior attempt to improve the functional communication skills of children with autism 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 of this type of program to use natural environments and incidental learning in addition to the more traditional strategies.

Developmental, individual-difference, relationship-based approach
The developmental, individual-difference, relationship-based (DIR) approach (also known as the Greenspan/Wieder floor-time model) is another developmental model that 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 somewhat similar to other methods described here, it differs in that it does not follow a solely adult-directed curriculum.

Like ABA, the DIR approach involves a comprehensive program 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 floor-time 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 no peer-reviewed, published studies of the DIR approach's effectiveness for children with autism.

Scientific studies are needed to confirm the effectiveness of all of these programs for children with ASD.

Communication interventions

Autism spectrum disorders by definition affect 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 have problems understanding at any age level and can't express themselves at all. Other children may need intensive treatment that may include nonverbal means of communication such as picture exchange communication system or electronic communication devices. Finally, children with Asperger syndrome may appear to have normal vocabulary, but have deficits in the social use of language. In many cases, these children may not receive services or if they do, not until they are in school.

Many children with ASD who do develop speech may communicate in unusual ways (see Language Delays on pages 9-10). Speech therapy must address these difficulties at different levels. The treatment is provided or directed by a trained speech or language pathologist. Family and other members of the team are also involved in the treatment plan. The 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. The therapists and team members work to increase eye contact of the child with others because this is an important means of getting information from others. For children who do not use words, the therapists will promote the use of natural gestures, teach sign language, or use pictures

to communicate. Some parents worry that these methods will make a child "lazy" and prevent him from learning words. Research supports the opposite conclusion—children who have developed some means of communication, even if it is nonverbal, will more quickly increase speech skills.

Picture exchange communication system is a nonverbal visual language system that uses 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. As the child learns the meaning of and how to use visual and gestural communication, the therapy team works on spoken language.

The communication program is usually a part of a larger developmentally and/or behaviorally based program. The speech or language pathologist should serve as a consultant and member of the interdisciplinary team to make sure communication goals are included in the service plan and addressed in the educational setting. Other treatments such as sensory integration techniques may help to improve ability to focus on language treatment goals.

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.

Your child's rights

The Individuals with Disabilities Education Act 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 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 the IEP. Stated simply, the child should be provided with all needed support to be successful in the regular classroom and not simply dumped 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 autism support classroom.

Social skill interventions

The capacity to engage with others, such as pointing out objects or events of interest to share experiences (joint attention), can be learned by many children with ASD. As mentioned earlier, 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 the child has mastered joint attention.

The role of the family in daily interaction is critical in teaching the process of joint attention and social communication. Learning experiences should be incorporated into your child's regular daily activities. These activities should begin as early as possible, even before or during the formal diagnostic process.

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.

Ways to help children with autism spectrum disorder learn joint attention skills

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

What you can try: Observe your child to see what she is playing with, then join in by pointing at the object. Make comments about the object or what she is doing with it. If your child looks up at you, reinforce the action with a smile and encouraging words. Attempt to build on this interest to foster engagement and back-and-forth interaction. Gradually attempt to challenge her to solve problems. For example, if she is moving a toy car back and forth, you can pretend your hand is a hill the car needs to drive over. You can engage your 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." 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 you can try: Throughout the day, you might point at objects or events in an effort to get your child to look at them with you. At first, point to objects that you know interest your child to promote early successes. If he simply won't follow your point, you may have to prompt him by tapping on his shoulder or even manually turning his head in the direction of your pointing. When he becomes successful, start pointing to new objects or events that he has not noticed in the past. Reward his efforts, especially if after looking at the target, he then makes good eye contact with you 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, you 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 you know what they want or need. Children with ASD will often just cry or take your hand and lead you to the desired object.

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

If your child is standing by the door to go outside, you might pretend to be confused so the child has to point to the doorknob that she wants turned. If she does, then you might try to turn it, but fail. Then you can say, "We need Daddy to help us." If the child doesn't understand, you 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 you can try: Once pointing skills are mastered, you should try to teach your child to point to objects or events that interest him to get your attention so that you can share the experience together. Teaching this skill is a bit more challenging. At first, this might involve catching him doing quasi-showing acts. For example, if he brings you a box of cookies to open, don't open it right away. Instead, act as if you thought he was simply showing it to you and 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 say something like, "Thanks for sharing this with me. That was very nice of you." When he persists, then say, "Oh, so you want me to open this for you. Okay, I will, but thanks again for showing me the box." At other times, you may observe your child looking at something of interest like a helicopter in the sky, but he does not point to get you to look at it. You should then take his hand and form it into a point and point at the object. 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's flying home?" You may need to prompt him by turning his head back and forth between the object and your face. Always reward even small attempts to get your attention, especially when he makes good eye contact with you.

In summary, try to connect with your child throughout the day with gestures, pointing, and words. Use naturally occurring objects or events as targets for joint attention and ongoing social interaction. Let no event go unnoticed. Even though your child may be happy playing alone, join in with him at regular times. Don't be afraid to use physical prompts such as forming his hand into a point, tapping his shoulder, or physically turning his face from the object to you and back again. Also don't be afraid of playing dumb to force him to have to explain to you what he wants. You need to literally get in the face of children with ASD when trying to teach them joint attention and social interactions.

Mind reading (or theory of mind)

Mind reading 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 mind read builds on earlier developmental capacities. To understand the intentions and feelings of others, the child must first master joint attention and feel pleasure and joy in connecting with others. She then needs to experience the wishes or feelings of the other person through back-and-forth exchanges of gestures and sounds. It's through experiencing the other person's gestures and sounds and responding to them that the child begins to understand their feelings. When the child begins to be able to use words, true signs, or picture symbols, she can give a voice to this gradually emerging understanding of the intentions and feelings of others. She then begins to show the capacity for taking the perspective of someone else, including empathy, or a *theory of mind*.

Children with ASD seem to have *mind blindness*. Sometimes they can learn to mind read with intensive and specific training. Curricula have been developed and published to teach children how to understand the thoughts and feelings of others (see Resources on pages 42-43). One method that is helpful in children who have reached the developmental age of at least 5 years uses cartoon-like 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 pointing 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 some degree of verbal language, instruction may progress to social stories. Sample social stories published in books (see Resources on pages 42-43) 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.

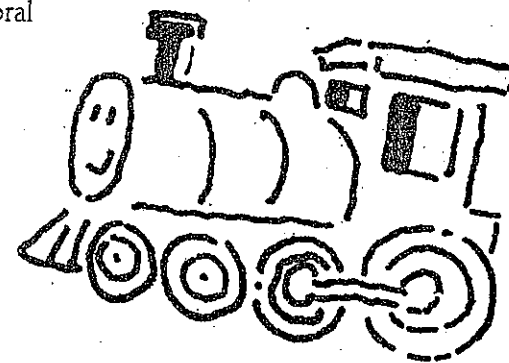
Sensory-motor interventions

Many children with autism seem to have unusual sensory aversions. Examples include an aversion to touch, hugging, certain sounds such as motors or machinery, textures, and consistency of certain foods. These aversions are sometimes neurologically or behaviorally based. Loud noises, for example, may seem even louder, to the point of pain, to the child with ASD. It is difficult to understand the meaning of such aversions for the child. 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*. They are unable to integrate sensory information from the environment with information from their own muscles and body position. Some professionals feel that this is caused by sensory overload and that unimportant stimuli are not filtered out and pushed into the background. This sensory overload has been cited as a cause of tantrums or disruptive behaviors. Sensory integration 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 uses procedures such as deep pressure, brushing, wearing a weighted vest, and swinging. These therapies appear to have a calming effect and are often cited as proof that they're effective. Some of the effect may be attributable to behavioral desensitization. Although widely practiced and currently being studied, there is little data to support the claims of the benefits of such interventions at this time.

Other interventions such as auditory integration training 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 interventions are not endorsed by the AAP.



Medicines

Medicines have not been shown to consistently improve the core deficits of ASD, and there are no medicines that have been approved by the Food and Drug Administration (FDA) specifically for treatment of ASD in children.

However, medicines may be helpful when behaviors interfere with progress in the child's intervention program. Such behaviors may include hyperactivity, inattention, irritability, aggression, self-injury, repetitive behaviors, mood disturbances, anxiety, and 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 herself is at risk. Sometimes a child may have an additional diagnosis, such as depression or seizure disorder, that is treated with medicine.

Commonly used classes of medicines include atypical or second-generation antipsychotics (like risperidone), stimulants (like methylphenidate), selective serotonin reuptake inhibitors (like fluoxetine), alpha-2-agonists (like clonidine), and certain anticonvulsants.

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 source of discomfort, such as constipation or an ear infection, that is causing him to hurt himself. There may also be environmental factors, such as a change in the routine at school, that is upsetting to the child and is causing disruptive outbursts. A FAB may help to determine the cause of new disruptive behaviors and help 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 (an atypical antipsychotic) to be very effective for the treatment of tantrums, aggression, or self-injurious behavior in children with ASD. Physicians are guided in the use of medicine by research studies not only in children and adults with ASD, but also by studies of these medicines in related disorders such as attention-deficit/hyperactivity disorder, obsessive-compulsive disorder, depression, and anxiety disorders. If symptoms of these disorders are also present in a child with ASD, stimulants, antidepressants, antianxiety agents, and other medicines might be considered.

It's 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's 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.

The target behaviors must be measured or assessed to determine what effect the medicine is having, and monitoring for side effects is very important. 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 the 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 the 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 medical 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 new treatments that may not have been scientifically studied. These types of treatments are called complementary and alternative medical (CAM) treatments.

Many families learn about these treatments on the Internet, in books and magazines, and from other parents of children with ASD. It's hard to tell which treatments have scientific support and which don't from these sources. If you are interested in using any of these treatments, you should discuss them with your pediatrician. It's 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 both 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 treatment, encourage parents to be careful in their interpretation of claims from non-peer-reviewed (scientific) 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 vary over time depending on the availability of practitioners in a given region and the occasional coverage by insurance and/or provision by schools. Following are descriptions of treatments that are currently popular:

Biological complementary and alternative medical treatments

Nutritional 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, there may be no warning of what amount may be toxic.

Commonly used supplements include dimethylglycine, vitamin B6 with magnesium, vitamin C, and vitamin A (as cod liver oil). There could be potentially serious side effects from doses in the toxic range. Such side effects may be seen with vitamin B6 (nerve damage), magnesium (heart irregularities), and vitamin A (severe rash or 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.

Diet changes

Changes to diet are another "natural" approach to treating many chronic conditions. Some families believe a gluten (wheat)-free and/or 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 food products to escape into the bloodstream and travel to the brain, where they have a neurologic effect, resulting in symptoms of ASD. Although this treatment is controversial, scientific studies are being done to evaluate the nutritional and behavioral effects of this diet. Before you try this diet, you should talk with your pediatrician and perhaps a dietician. 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. So far there are many scientific studies that have failed to

prove it is effective as a treatment for ASD. Other medicines that are sometimes used in children with ASD 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 fungi-like 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. 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 types of treatment.

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 typical of ASD. Thimerosal was taken out of most childhood vaccines in the United States in 2000. In 2004, the Institute of Medicine concluded that there is no proof at this time that thimerosal caused autism, as there were no differences in the rate of ASD in children who were and were not given vaccines with thimerosal.

Despite the lack of proof, some practitioners have still supported the use of certain medicines to *chelate* (extract) metals such as mercury. However, medicines used in chelation may have significant side effects, are not approved by the FDA for treatment of ASD, and are not recommended for general use at this time.

Nonbiological complementary and alternative medical treatments

Auditory integration training

Children with ASD who receive auditory integration training (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 to 4 weeks). There is no scientific proof that AIT is effective for general improvement in the behaviors of autism.

Facilitated communication

Facilitated communication enlists a second person (a *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. Standard scientific studies show that true facilitated communication is largely a function of the activities of the facilitator and do not actually represent the thoughts or feelings of the child with ASD. Facilitated communication is different from *augmentative*

communication, in which lap boards containing words, numbers, and letters or mechanical devices are introduced with a goal of *independent* use for communication by an individual with ASD. Augmentative communication may be helpful in learning to communicate. It is unlikely that facilitated communication would be helpful.

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.

Before any treatment, conventional or CAM, is tried, families should know what specific symptom or skill the treatment should be affecting, possible side effects (temporary or permanent), what research has shown of its effectiveness in the past (and how good the study was), who would be monitoring the progress or side effects, and what alternatives are available. The best results will occur if all parties communicate and work together in the context of the medical home.

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 child to learn about the practical aspects of what to do to obtain services for their child and family members. Family-centered planning is essential to address the unique needs of each family member. 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 the diagnosis of ASD is made, families should contact 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.

- Parent-run organizations like the National Alliance for Autism Research or Cure Autism Now. Families can help advance efforts for research about ASD through these organizations.
- Local organizations such as schools.
- 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 autism or Asperger syndrome. Members of these support groups informally help parents as they were once helped by others.
- Online support groups.

To successfully address the stressors related to the behaviors of ASD and to 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 the parents, as well as being able to help out with the care of the child.

Respite services

When extended family or friends are not available to care for a child with ASD, child care provided by trained individuals (called *respite services*) 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 you need help paying for respite care, money may be available through your state agencies, serving persons with mental retardation and/or autism or 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 the child's eligibility for funding) or *Katie Beckett funds*.

Parents are encouraged to apply for funds as soon as the diagnosis is made because there are often long waiting lists. Once the child becomes eligible for funding for respite and recreational activities such as summer camps, the child also becomes eligible for Medicaid health insurance. Depending on family income, the child might already be eligible for Medicaid.

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 the following:

School 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 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.

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

Parents of teens should try to respond to behavioral challenges, especially when they are destructive or aggressive, with compassion and patience. Often such behaviors arise from frustration when teens are having problems communicating in a positive way or being steered away from activity that they enjoy or is important to them. Try to avoid negative phrases like "Don't do that," "That is not allowed," or "No" because these disapproval signals may not be understood by people with ASD. Instead, use positive signals and gently attempt to shift attention to another activity. There must be access to specialists who can be called on to assist with FAB and advice about appropriate behavioral interventions and supports. It's 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.

Adults years

Some adults at the higher-functioning end of the autism spectrum are able to live with various degrees of independence. A few 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 the following:

Employment

Of those adults with ASD who are able to work, current data indicate that relatively few will be employed in competitive jobs. Many will need job coaching and a supportive work environment, and some may need continuous close supervision.

Independent living

Success in independent living is more likely in individuals who have learned tools for effective communication during their school years. If an adult with ASD cannot live independently, sometimes because of mental retardation, caregivers (usually parents) should make a plan for other long-term care and living arrangements, such as a group home. Group homes should be 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's 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. In some cases, this can be a delicate balance between safety and independence.

Law enforcement

Law enforcement personnel should understand the special behavioral characteristics of ASD because they may be called during a public incident of disruptive or apparent aggressive behavior. Individuals with ASD subjected to excessive physical restraint may panic and seem even more out of control. Autism spectrum disorder support groups have educational materials suitable for law enforcement personnel.

Financial and legal planning

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

Supplemental Security Income

Children who are Medicaid eligible (based on parental income) may also be eligible for monthly Supplemental Security Income (SSI) benefits (up to \$600 a month) if a significant disability is diagnosed.

Many teens with ASD, especially those with mental retardation, become eligible for SSI benefits on their 18th birthdays. 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 adult child may then begin to receive monthly subsidies if he 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

If you have a child with a disability, it's important for your will to make 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 your child may be entitled (such as Medicaid or Medicare and SSI). Otherwise, your child will lose these subsidies until the inheritance is spent down and he once again meets the financial criteria for benefits. You should contact a lawyer to help you write a special needs will so you can make sure your child's rights are protected.

Guardianship

Unless prior legal arrangements are made, all teens, including teens with ASD and mental retardation, become adults and their own legal guardians on their 18th birthdays. 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 is not a black-and-white issue, especially when the adult has borderline cognitive skills. If it is determined that your adult child is indeed not capable of making responsible judgments, you will then need a lawyer to help you designate a legal guardian for your child. 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 and the better the outcomes. However, children may be limited in what they can do depending on their intelligence, the severity of autistic symptoms, and whether they have associated medical problems such as seizures.

Children with intelligence in the normal range and milder autistic symptoms generally have better outcomes. Those with Asperger syndrome are thought to have somewhat better outcomes than children with other types of ASD if they don't have additional medical or emotional problems.

The goal of all parents, whether their child has a disability, is to try their very best to help their child reach his full potential with the help of all available resources.

Resources

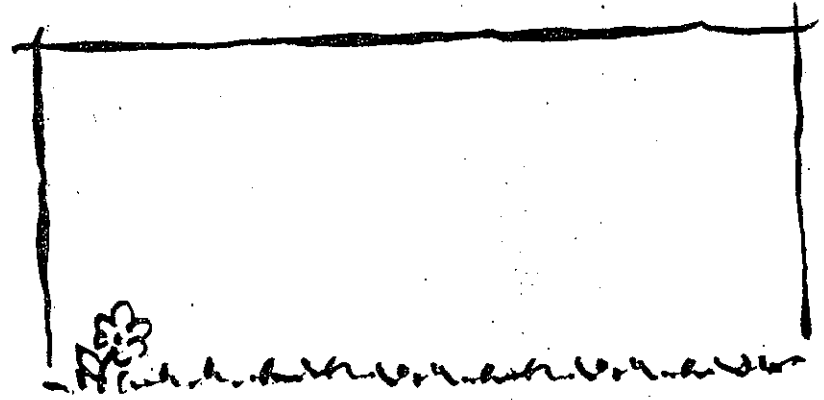
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Web sites

- American Academy of Pediatrics National Center of Medical Home Initiatives for Children With Special Needs
www.medicalhomeinfo.org/health/autism.html
- Autism Society of America
www.autism-society.org
- Centers for Disease Control and Prevention Autism Information Center
www.cdc.gov/ncbddd/dd/ddautism.htm
- Cure Autism Now
www.cureautismnow.org
- National Alliance for Autism Research
www.naar.org

Please note: Listing of resources does not imply an endorsement by the American Academy of Pediatrics (AAP). The AAP is not responsible for the content of the resources mentioned in this brochure. Web site addresses are as current as possible, but may change at any time.



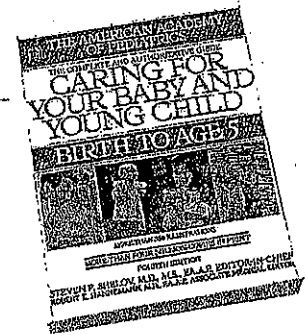
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What is the DSM IV, To Determine the Diagnosis?

Source: Autism Today (www.autismtoday.com/autism_dsmiv.htm)

This description of PDD and autism is from the DSM (Diagnostic and Statistical Manual of Mental Disorders). It may seem somewhat pessimistic, but we need to remember that in order to diagnose the disorder, the psychiatrist must focus on the "problem behaviors". Remember that children are not defined only by their "label"; children will have strengths that will help them cope with the problems that their disorder gives them. We must be aware of, but never governed by the described limitations of this disorder.

DSM IV Descriptions:

Autistic Disorder (299.00) and Asperger's Disorder (299.80):

Diagnostic criteria for 299.00 Autistic Disorder

A. A total of six (or more) items from (1), (2), and (3), with at least two from (1), and one each from (2) and (3):

1. Qualitative impairment in social interaction, as manifested by at least two of the following:

- (a) Marked impairment in the use of multiple nonverbal behaviors such as eye-to-eye gaze, facial expression, body postures and gestures to regulate social interaction.
- (b) Failure to develop peer relationships appropriate to developmental level
- (c) A lack of spontaneous seeking to share enjoyment, interests or achievements with other people (e.g. by a lack of showing, bringing, or pointing out objects of interest)
- (d) Lack of social or emotional

2. Qualitative impairments in communication as manifested by at least one of the following:

- (a) Delay in, or total lack of the development of spoken language (not accompanied by an attempt to compensate through alternative modes of communication such as gesture or mime)
- (b) In individuals with adequate speech, marked impairment in the ability to initiate or sustain a conversation with others
- (c) Stereotyped and repetitive use of language or idiosyncratic language
- (d) Lack of varied, spontaneous make believe play or social imitative play appropriate to developmental level

3. Restricted repetitive and stereotyped patterns of behavior, interests and activities, as manifested by at least one of the following:

- (a) Encompassing preoccupation with one or more stereotyped and restricted patterns of interest that is abnormal either in intensity or focus.
- (b) Apparently inflexible adherence to specific nonfunctional routines or rituals
- (c) Stereotyped and repetitive motor mannerisms (e.g. hand or finger flapping or twisting, or complex whole-body movements.)
- (d) Persistent preoccupation with parts of objects.

B. Delays or abnormal functioning in at least one of the following areas, with onset prior to age 3 years: (1) social interaction. (2) Language as used in social communication, or (3) symbolic or imaginative play.

C. The disturbance is not better accounted for by Rett's Disorder or Childhood Disintegrative Disorder.

Diagnostic criteria for 299.80 Asperger's Disorder

A. Qualitative impairment in social interaction, as manifested by at least two of the following:

- (1) Marked impairment in the use of multiple nonverbal behaviors such as eye-to-eye gaze, facial expression, body postures and gestures to regulate social interaction.
- (2) Failure to develop peer relationships appropriate to developmental level
- (3) A lack of spontaneous seeking to share enjoyment, interests or achievements with other people (e.g. by a lack of showing, bringing, or pointing out objects of interest to other people)
- (4) Lack of social or emotional reciprocity

B. Restricted repetitive and stereotyped patterns of behavior, interests, and activities, as manifested by at least one of the following:

- (1) Encompassing preoccupation with one or more stereotyped and restricted patterns of interest that is

abnormal either in intensity or focus

(2) Apparently inflexible adherence to specific, nonfunctional routines or rituals

(3) Stereotyped and repetitive motor mannerisms (e.g., hand or finger flapping or twisting, or complex whole-body movements)

(4) Persistent preoccupation with parts of objects

C. The disturbance causes clinically significant impairment in social, occupational, or other important areas of functioning.

D. There is no clinically significant general delay in language (e.g., single words used by age 2 years, communicative phrases used by age 3 years).

E. There is no clinically significant delay in cognitive development or in the development of age-appropriate self-help skills, adaptive behavior (other than in social interaction), and curiosity about the environment in childhood.

F. Criteria are not met for another specific Pervasive Developmental Disorder or Schizophrenia.

Overall, a gross and sustained impairment in social interaction and restricted, repetitive and stereotyped patterns of behavior, interests and Recreation, occurring in the context of preserved cognitive and language development.

Pervasive Developmental Disorder Not Otherwise Specified (including Atypical Autism)

This category should be used when there is a severe and pervasive impairment in the development of reciprocal social interaction, verbal and nonverbal communication skills, or the development of stereotyped behavior, interests and Recreation, but the criteria are not met for a specific Pervasive Developmental Disorder, Schizophrenia, Schizotypal Personality Disorder, or Avoidant Personality Disorder.

Examples include:

Atypical autism: cases that do not meet the criteria for Autistic Disorder because of the late age onset, atypical symptomatology, or sub-threshold symptomatology, or all of these.

[About Autism](#) >> What is the DSM IV



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5 THINGS YOU SHOULD NEVER SAY TO A PARENT WHOSE CHILD HAS AUTISM

If your child has autism then you're a walking target for friends, relatives and even strangers to offer unsolicited advice. You realize they have good intentions but it's still a very hurtful experience. We've compiled a list of common mistakes that people make. When talking to parents whose children have autism, here are five things you should never say.

1. Autism does NOT mean deaf

You're chatting to your friend and you notice her child engaging in some strange behavior. You're curious and you ask "What is he doing? Does he always do that?" Questions like these place a parent in a very difficult situation. They are also very damaging to the autistic child's self esteem. The child might not look up at you but he heard what you said.

A common misconception is that people with autism don't comprehend the world around them. Nothing could be further from the truth. People with autism might not respond or react in typical ways. They might not have much speech but they do understand what's being said. Keep in mind that many of them have acute hearing and can hear what you're saying clear across a room.

2. Actions speak louder than words

You're standing in line a busy store. The woman in front of you is struggling to keep her sanity intact. Her child is running off and pushing items off the sales racks to the ground. "What an insolent child" you think to yourself. "His mother should discipline him better!"

Don't jump to conclusions just yet. It's very possible the child has autism. Even if you're tempted, do not roll your eyes and shake your head in disdain with other customers. This mom faces judgment at every turn. You will make her day if you smile broadly at her. Then offer to keep her place in line so that she can redirect her child.

3. Discipline advice

You're visiting a friend whose child has autism. Her child is painstakingly building a tower and he accidentally knocks it over. Devastated at his mistake, he flies into a rage and hurls the blocks through the air. Your friend quiets the situation but you don't approve of the way she handles it. Shocked at her son's inappropriate outburst, you offer some well meaning advice and share your discipline tactics.

Children with autism often don't respond to conventional methods of discipline. This mom deals with more than you can possibly imagine and has probably tried every discipline tactic in the book. She's afraid you'll be judging her actions. A warm smile and a swift change of subject will do wonders for her.



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4. You can leave him behind

You're planning a trip to the amusement park. You'd love to go with your friend but you're in a dilemma. Her typical kids love the amusement park but her child with autism seems to have a difficult time. So you come up with a solution. "Come with us to the amusement park" you tell her. "Your kids will love it. Well except for Tommy, but you can find something else for him to do that day."

Inviting a family to join you, except for their child with autism is a very crushing experience to a parent. Your intentions might be good but that doesn't make the experience less devastating. Parents that have children with autism desperately want their kids to be accepted in the community. Rise above the judgments of others and invite the whole family. If you feel that isn't a viable option, leave your invite for another day when the whole family can be included.

5. Therapy recommendations

Your grandchild has autism. You're distraught that your children have such a rough road ahead of them. You're devastated that your gorgeous grandchild is autistic and you want to help. Having already raised your own children you've learned a thing or two. You cringe as your daughter tells you about the therapy option she's picked and the behavior management she has for her child. You give the gift of wisdom and let her know how she should do it differently.

Parenting a child with autism is totally different from raising a normal child. You have to live it to really understand. If you want to do something wonderful, be supportive to the parents. Give your love, follow through on their decisions and stand by their side. You will become a hero to parents who desperately need your acceptance and support.

To all the parents whose children have special needs, we commend and praise you! Your road is rocky, filled with joy and challenges. To everyone else, we stand in gratitude. Your love and support is immeasurable for parents and their special needs kids. Thank you for standing by their side.

- By Jene Aviram

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