

# Are we making progress against autism?

Scientists are learning more about this baffling disorder, but a cure is a long way off.

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**AUTISM IS ONE** of the most challenging disabilities you'll encounter among pediatric patients. A major developmental disorder of unknown cause, it requires intensive multidisciplinary intervention—and lasts a lifetime. No cure exists, but health-care professionals and families of autistic persons are working hard to forge effective interventions.

## Historical overview

Although many people first became aware of autism only from the 1988 hit movie *Rain Man*, clinicians have known about the disorder for nearly 100 years. The term autism derives from *autismus*, coined by Swiss psychiatrist Eugen Bleuler in 1910 to describe a subgroup of schizophrenic symptoms. (“Autos” is Greek for “self.”) Bleuler used *autismus* to describe the condition in which a person is an isolated self, removed from social interaction. In 1943, psychiatrist Leo Kanner published the first major paper on childhood autism, portraying it as a severe disorder of communication and social interaction, commonly coupled with bizarre and repetitive behaviors and interests.

Until well into the 1970s, psychiatrists led by the influential Bruno Bettelheim blamed autism on poor parenting—specifically, emotionally distant and cold “refrigerator mothers” (in Bettelheim’s memorable phrase). Eventually this theory was proven false but it caused much harm for decades. Subsequent research decisively shifted the search for a cause to neurology and brain functions. For the last quarter of a

century, that’s where researchers have been looking.

Today many professionals use the broader term *autism spectrum disorders* (ASDs) to refer not just to autism but to a broader group of related developmental disabilities, such as Asperger syndrome and the rarer Rett syndrome.

## Prevalence and epidemiology

ASDs occur in all cultures and socioeconomic groups. In the United States today, approximately a half-million to 1 million individuals have ASDs. The Centers for Disease Control and Prevention estimates that 1 of every 150 children has an ASD. The diagnosis is five times more common than Down syndrome and three times more common than type 1 diabetes mellitus. For unknown reasons, four of five children diagnosed with ASDs are boys.

Some people believe the incidence is increasing. Undeniably, identification of ASD has skyrocketed, and the condition is now 25 times greater than it was 30 years

ago. But does this mean we’re seeing a pandemic? On this important point, controversy rages. Many professionals believe the seeming increase stems mainly from better and earlier diagnosis. Parent groups argue that environmental causes—especially certain childhood vaccinations—may be the culprit in many cases, even though research has disproved any link between autism and childhood vaccinations. With research suggesting that siblings of persons with ASD have a 3% to 8% chance of being diagnosed, most experts believe genetics must play at least some role. Recent MRI research suggests that the amygdala, the brain region linked to mental processing of faces and emotions, is abnormally large in young children with autism. Typically, such children show impairment in these two functions.

## Assessment and diagnosis

No genetic or medical tests exist for autism. Specific signs and symptoms that lead experts to diagnose childhood ASD haven’t changed much since Kanner’s seminal paper 66 years ago. (See *When experts suspect autism*.)

Clinicians diagnose the disorder from behavioral observation, generally quantified through the use of standardized diagnostic scales. Usually, diagnosis is a two-step process involving screening and a comprehensive evaluation.

## Screening

Most well-child checkups include a developmental screening. Parental

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## LEARNING OBJECTIVES

1. Describe how autism is diagnosed.
2. Identify medical interventions for autism.
3. Discuss nursing interventions for autism.

observations, impressions, and concerns are crucial. When parents express concerns—typically that their toddler seems to be delayed in acquiring communication and social skills, including eye contact and affection—they may be asked to complete a standardized screening test, such as the Checklist for Autism in Toddlers (CHAT) or the Screening Tool for Autism in Two-Year-Olds (STAT). Suggestive results warrant a full diagnostic evaluation.

### Comprehensive evaluation

To confirm a diagnosis of ASD, the child must undergo a comprehensive evaluation involving a multidisciplinary team—psychologist, neurologist, psychiatrist, speech pathologist, and sometimes a special educational evaluator and occupational therapist. If clinically indicated, the child also undergoes metabolic or other targeted tests, brain imaging, and electroencephalography. In many cases, hearing tests and screening for lead exposure are done.

Major standardized measures for ASD are the Autism Diagnostic Observation Schedule (ADOS) and the Autism Diagnostic Interview-Revised (ADI-R). When given together, these tests are the gold standard for diagnosing ASD. However, their validity is doubtful when performed by untrained persons or on children younger than age 2.

### Intervention

Today, experts recommend immediate and intensive intervention as soon as a child is diagnosed with ASD. Although scientific proof is lacking, professionals increasingly believe that the earlier intervention begins, the better the child's prognosis for life functioning, including communication, self-care, socialization, and academic learning. In the past 20 years, several major forms of treatment have been shown to help remediate ASD and reduce family stress—pharmacologic therapy,

## When experts suspect autism

The Autism Diagnostic Interview-Revised (one of the two major standardized tests for autism) comprises three main categories—abnormalities in reciprocal social interaction; abnormalities in communication; and restrictive, repetitive, and stereotyped behavior patterns. A diagnosis of autism is appropriate only if individual features in two or three of these categories are present.

Typical features of autism include:

- severe difficulty learning language
- peculiar speech patterns, such as echolalia, using words nonsensically, or speaking in a monotone
- poor eye contact
- indifference to or avoidance of social contact, such as disinterest in interacting with family members
- inability to understand others' feelings
- need for a rigid, highly structured routine
- severe distress in reaction to changes in routine
- repetitive body movements, including pacing, hand flapping, finger flicking, spinning, rocking, and hitting oneself
- frequent crying and tantrums for no apparent reason
- insensitivity to pain or temperature extremes
- abnormal responses to sensations, such as to light, sound, and touch; at times, the child may appear deaf while at other times may show hypersensitivity to sensory stimuli
- impulsive behavior
- decreased fear of danger
- unusual attachment to inanimate objects, such as toys, strings, or spinning objects.

The greater the number of reported signs and symptoms, the more likely the diagnosis of autism becomes.

py, special education, and speech-language therapy.

### Pharmacologic therapy

Medication is commonly prescribed for children with ASDs. Although drugs haven't been proven to significantly improve core symptoms, they sometimes reduce secondary or comorbid symptoms. Risperidone may decrease irritability, repetitive behaviors, and aggression. Other antipsychotics are used to treat similar behavior, although their effectiveness hasn't been demonstrated. Currently, no drugs are useful in improving the social and communication impairments seen in ASD.

Some children with ASD experience digestive problems, including diarrhea, constipation, gastroesophageal reflux, and extreme dietary selectivity. Therefore, secretin (a digestive hormone), bethanechol (a cholinergic), and famotidine (a histamine<sub>2</sub>-receptor antagonist) may be

prescribed. Such medications may be effective in treating digestive problems, but no evidence indicates they affect autism itself.

**Complementary and alternative medicine.** With no current cure or dramatic treatment available, many families choose unconventional therapies in conjunction with or instead of accepted approaches. Some parents make this choice after considerable research; others turn to it out of frustration or desperation.

Complementary and alternative approaches include unconventional diets (such as casein-free and gluten-free diets), vitamin supplementation, sensory integration, auditory integration, and craniosacral manipulation. While these approaches haven't been shown to cause harm, they haven't been thoroughly evaluated for efficacy and aren't endorsed by the American Academy of Pediatrics. Nonetheless, interest in alternative

therapies is steadily growing.

According to one theory, children with ASD may have celiac disease, and dietary restrictions may ease their ASD symptoms. In celiac disease, an excessively porous intestinal wall inhibits proper nutrient absorption; clinicians typically prescribe a diet free of gluten (wheat) and casein (milk). When used for children with ASD, this dietary intervention is based on the assumption that inability to metabolize gluten adequately may interfere with the body's opioid receptors, associated with mood and behavioral disturbances. However, such a diet may raise the risk of protein malnutrition and vitamin D deficiency.

Some healthcare practitioners believe ASD symptoms are caused by mercury toxicity and therefore recommend mercuric chelation or detoxification; these therapies may be given orally or I.V. But removal of heavy metal toxins hasn't been approved by the Food and Drug Administration for this purpose. What's more, these therapies may cause liver and kidney toxicity and electrolyte imbalance.

### Special education

In early intervention and special preschool programs for children with ASD, trained educators provide highly structured learning tasks. Initially, these programs focus on improving communication, basic self-care, and social interaction. Formal academic skills, such as reading, writing, and math, are taught in small groups with adapted learning methods. Vital to such programs is a psychological method called Applied Behavioral Analysis (ABA). (See *ABA: A special education technique*.)

Nonetheless, although some children with ASD eventually are able to graduate from college and gain commensurate employment, more than 80% have an intellectual disability and will require significant care in adulthood, despite any special education programs they've attended.

## ABA: A special education technique



Special education programs for autistic children may involve the psychological technique called Applied Behavioral Analysis (ABA). The central theory behind ABA is that when desired behaviors are rewarded (reinforced), they're more likely to be repeated than behaviors that are ignored. Providing descriptive praise, for instance, is vital when an autistic child is learning a new task, such as self-feeding or starting a classroom assignment. An example of such praise might be, "You're holding your spoon very nicely. Keep up the good work!" While ABA can't "cure" autism, the method has been proven effective in promoting positive behaviors and reducing negative behaviors.

### Speech-language therapy

Central to a diagnosis of ASD, communication deficits contribute to behavioral problems. Therefore, the role of speech-language therapy is vital. Many speech-language therapists who assist autistic persons are trained in ABA to improve eye contact and social speech (known collectively as social pragmatics). Sometimes teachers use a communication board to help teach language skills to those with severe impairments.

### Family support

Several decades of ASD treatment have shown the importance of family support. Caring for a child with autism is highly stressful and can lead to emotional and physical burnout among family members.

Today, experts favor an integrated model of family support in which services are based on family traits, dynamics, and lifestyle. Using this model, families can choose from various types of support to find the one that best meets their needs at a particular time. The three most common types of family support are the following:

- **Parent training** focuses on providing up-to-date information on autism, including related health issues, treatment strategies, and educational programs. It emphasizes providing clear, accurate information.

- **Parent support groups** stress emotional support, including empathy, catharsis, and mutual problem solving. Participants are encouraged to share their frustrations, joys, and advice with each other. In some areas, adjunct groups geared to the same purpose are available for siblings of autistic children. A counselor, a social worker, or an adult sibling may serve as facilitator for group sessions.
- **Respite services** provide a much-needed break for the family. No matter how well-informed and loving families are, eventually they need a break from their caregiving efforts to avoid burnout from mounting stress. Typically, respite care takes place in a special homelike setting with trained staff for an evening or weekend visit by the person with ASD.

### Nursing interventions

The Individuals with Disabilities Education Act mandates that all disabled children, including those with severe autism, receive an education through age 21. Thus, many children with ASD receive nursing care in school settings. Such care requires up-to-the-moment knowledge of the disorder, patience, and much creativity. Even seemingly simple tasks, such as assistance with feeding and dressing, toileting, and first aid, can pose a challenge, because new environ-

ments and changes in routine cause these children stress or even terror. A visit to a healthcare office may induce severe tantrums, self-abuse (such as attempted head-banging or self-biting), and physical aggression. In many cases, those who know a child well can predict a severe tantrum from subtle warning signs, but a relative stranger (such as a nurse) may have no warning of a behavioral eruption.

To prevent such situations, many experts recommend that children with autism undergo desensitization by visiting the healthcare office regularly and getting familiar with the environment and staff. No procedures should be attempted during this “get-acquainted” period. Instead, the child should be led step by step through a process such as the following: For several visits, the child enters the office, sits in a particular area, waits to be called, greets the nurse, and leaves without having an invasive procedure. At the next visit, the child may be shown a thermometer and asked to show the nurse his or her hand and open the mouth. With subsequent visits over time, the potential for a tantrum or other behavioral eruption decreases.

### **“Are we communicating?”**

Poor communication is a chief limitation for children with ASD, as many have a severe language impairment. Your efforts at communicating are most likely to succeed if you speak clearly, using short sentences and crystal-clear phrases. Be as concrete as possible. Ask specific questions, such as, “Does your tummy hurt?” or “Does your head hurt?” instead of the vague “What hurts you?”

Use repetition and keep your tone of voice pleasant and cheerful. If verbal intervention is ineffective, be aware that some autistic children may respond to visual cues.

### **Nothing is routine**

Nursing procedures considered typical in most school settings may be

challenging for children with ASD. For those who are hypersensitive to touch, health screenings may be difficult; what other students experience as an empathic hand on the shoulder might feel painful to one with autism. So before initiating any assessment or procedure, be sure to establish eye contact. Know that calling the child’s name may have no effect, so you may need to gently turn the child’s head toward you.

Research consistently shows that praise is an effective reinforcer. When the child complies with a request, offer a warm compliment that specifically identifies the behavior you wish to reinforce, such as, “What a good job you’re doing with turning toward me!” or “Thank you for looking at my face.”

Don’t be surprised if you need several sessions to complete a simple screening process with an autistic child. During interactions that require routine nursing care, such as taking a temperature or auscultating the lungs, you may find distraction an effective tool.

Alerting parents to upcoming health screenings is useful in the preparation process. Some children with autism are extremely sensitive to changes in routine; therefore, parents may prefer that screening be done at the child’s usual place of medical care.

### **Administering drugs**

If the child takes medications, try to administer them using exactly the same procedure and words each time. To teach the child to accept and swallow the medication, first write out all the steps involved: Sit down appropriately, open the mouth wide, and so on. Choose a motivator that’s personally relevant to the child (say, a piece of apple) and reward each cooperative step.

Whether performing a screening or a procedure such as medication administration, always maintain a safe environment. Before the appointment, remove from the exam area any object the child could use for self-injury

or aggression. Be aware that increased risk for such injury is related to the tendency of many children with ASD to exhibit impulsive and disorganized motor activity, self-stimulatory behaviors, pica, possible seizure activity, and altered sensitivity to pain. Keep in mind the risk of injury from self-abuse or a severe tantrum.

### **Value vigilance**

Children with ASD require significant nursing awareness on an ongoing basis. Some have chronic somatosensory disturbances that may involve extreme sensitivity to sounds, odors, touch, and textures. Others have sensory underreactivity, including imperviousness to pain. During drug administration or events such as nosebleed or physical injury, such over- or underreactivity can be challenging for caregivers.

For example, an autistic child may become extremely agitated if you attempt to apply an adhesive bandage; as an alternative, use spray-on or liquid bandaging to cover an open wound and prevent the spread of body fluids. Another child might fly into a hysterical tantrum if an ice pack is applied, precluding the usual first-aid treatments. Consult with the parent when choosing appropriate care measures.

Stay alert for self-injurious behaviors, such as head-banging, hair pulling, and biting or scratching oneself (which may present as scars or open wounds on the hands or wrists). Some children repeatedly pick at sores until they bleed. Typically, these behaviors occur when the child is frustrated, fatigued, or overstimulated, and may come to the school nurse’s attention if they require treatment. Maintain good communication with teachers and parents when caring for such injuries.

### **Help for adults with ASD**

After age 21, obtaining educational services for persons for ASDs become more problematic, especially in locales without ample funding.

Educational programs for adults with autism include day-treatment programs and sheltered workshops (See *Programming for adulthood*.)

## Autism and the future

Massive efforts are underway to unravel the causes of ASD and develop effective treatments. Recent trends focusing on increasingly early diagnosis (before age 2) and earlier interventions are likely to continue. Parents' expanding role in remediating autism's severe social deficits seems to be a promising trend, as does rapid improvement in infant brain imaging. While a cure for this baffling and frustrating developmental disorder is unlikely in the near future, autism is undoubtedly yielding steadily to public and professional awareness. ★

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## Programming for adulthood

Most programs for adults with autism spectrum disorders (ASDs) are run by private, nonprofit agencies. Known as sheltered workshops and day-treatment programs, these structured settings employ nurses, special educators, and trained aides along with consulting psychologists, speech-language pathologists, occupational therapists, and psychiatrists.

### Sheltered workshops

Sheltered workshops focus on vocational preparation. Emphasizing basic job-related skills such as travel training, they may enable participants to seek community employment. Contracting with local merchants, some sheltered workshops provide on-site, supervised, piecework employment. Generally, though, the goal is to help participants learn the skills they need to get competitive community jobs. In these workshops, nurses commonly teach medical self-management skills related to medication administration and hygiene.

### Day-treatment programs

Generally, day-treatment programs focus on improving self-care and socialization skills in a school-like milieu. Participants are placed with peers at a similar level of daily functioning; most classrooms have a special educator and one or more aides. Because persons with ASD tend to have more severe behavioral issues than those in sheltered workshops, these programs usually involve nurses in the multidisciplinary treatment process. The nurse helps formulate behavioral goals for each participant and monitors progress in such domains as reducing self-injury and increasing cooperative activity.

### Family life education classes

In both day-treatment programs and sheltered workshops, nurses may teach family life education classes. Based on the concept that all adults with disabilities (including those with ASD) have a full right to express their love and sexuality, such classes teach students about human anatomy, responsible sexual behavior, use of contraceptives (including medication), and related topics. Community residences for adults with ASD employ nurses on either a part-time or full-time basis. In such settings, nurses play the same kinds of roles as required in day-treatment programs and sheltered workshops.

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