

N I C H D

National Institute
of Child Health and
Human Development

National Institutes of Health



Autism Research at the NICHD



U.S. Department of Health
and Human Services
National Institutes of Health

Autism Overview: What We Know

The **National Institute of Child Health and Human Development (NICHD)**, part of the National Institutes of Health (NIH), within the U.S. Department of Health and Human Services, is one of many federal agencies working to understand autism. The NICHD supports and conducts research on what causes autism, how many people have autism, how best to treat the symptoms of autism, and other topics.

Even though autism was first described in the 1940s, little was really known about the disorder until the 1990s. Even today, there is a great deal that researchers, scientists, and health care providers don't know about autism.

But there are things that we do know about autism. This fact sheet offers broad information about autism and answers some of the more common questions that parents and families often have about the disorder. You can get more detailed information on these topics from the sources listed in the *References* section. Keep in mind that the articles listed are geared toward scientists and researchers, so the information is more technical than what is presented here.

Knowledge of autism is always growing as research examines more and different sides of the disorder. The NICHD joins other federal agencies, organizations, and support groups in helping those with autism achieve their full potential to live healthy, productive lives.

www.nichd.nih.gov

What is autism?

Autism is a complex neurobiological disorder of development that lasts throughout a person’s life. It is sometimes called a *developmental disability* because it usually starts before age three, in the developmental period, and because it causes delays or problems in many different skills that arise from infancy to adulthood.

Check the Glossary on Pages 14-15 to learn how to say the **bolded** words and what they mean.

The main signs and symptoms of autism involve¹ language, social behavior, and behaviors concerning objects and routines:

- Communication—both verbal (spoken) and non-verbal (unspoken, such as pointing, eye contact, or smiling)
- Social interactions—such as sharing emotions, understanding how others think and feel (sometimes called empathy), and holding a conversation, as well as the amount of time a person spends interacting with others
- Routines or repetitive behaviors—often called **stereotyped behaviors**, such as repeating words or actions, obsessively following routines or schedules, playing with toys or objects in repetitive and sometimes inappropriate ways, or having very specific and inflexible ways of arranging items

People with autism might have problems talking with you, or they might not look you in the eye when you talk to them. They may have to line up their pencils before they can pay attention, or they may say the same sentence again and again

to calm themselves down. They may flap their arms to tell you they are happy, or they might hurt themselves to tell you they are not. Some people with autism never learn how to talk. These behaviors not only make life challenging for people who have autism, but also take a toll on their families, their health care providers, their teachers, and anyone who comes in contact with them.

Because different people with autism can have very different features or symptoms, health care providers think of autism as a “*spectrum*” disorder—a group of disorders with a range of similar features. Based on their specific strengths and weaknesses, people with autism spectrum disorders (ASDs) may have mild symptoms or more serious symptoms, but they all have an ASD. This fact sheet uses the terms “*ASD*” and “*autism*” to mean the same thing.

What conditions are in the ASD category?

Currently, the ASD category includes:

- Autistic disorder (also called “classic” autism)
- Asperger syndrome
- Pervasive Developmental Disorder Not Otherwise Specified (or atypical autism)

In some cases, health care providers use a broader term—*pervasive developmental disorders (PDD)*—to describe autism. The PDD category includes the ASDs mentioned above and: Childhood disintegrative disorder, and **Rett syndrome**.

Depending on specific symptoms, a person with autism may fall into the ASD or the PDD category. Sometimes, the terms “*ASD*” and “*PDD*” are used to mean the same thing because autism is in both categories.

What causes autism?

Scientists don’t know exactly what causes autism at this time.

Much evidence supports the idea that genetic factors—that is, **genes**, their function, and their interactions—are one of the main underlying causes of ASDs. But, researchers aren’t looking for just one gene. Current evidence suggests that as many as 10 or more genes on different **chromosomes** may be involved in autism, to different degrees.

Some genes may place a person at greater risk for autism, called **susceptibility**. Other genes may cause specific symptoms or determine how severe those symptoms are. Or, genes with changes or **mutations** might add to the symptoms of autism because the genes or gene products aren’t working properly.

Research has also shown that environmental factors, such as viruses, may also play a role in causing autism.

While some researchers are examining genes and environmental factors, other researchers are looking at possible neurological, infectious, metabolic, and immunologic factors that may be involved in autism.

Because the disorder is so complex, and because no two people with autism are exactly alike, autism is probably the result of many causes.

Is there a link between autism and vaccines?

To date, there is no conclusive scientific evidence that any part of a vaccine or any combination of vaccines causes autism, even though researchers have carried out many studies to answer this important question. There is also no proof that any material used to make or preserve vaccines plays a role in causing autism.

Although there have been reports of studies that relate vaccines to autism, the findings have not held up under further investigation. Researchers have been unable to **replicate** the studies that reportedly found a link between autism and vaccines.

There is a great deal of research and discussion on the topic of vaccines and autism—too much to cover here. The *U.S. Centers for Disease Control and Prevention (CDC)* conducts and supports most of the federal **epidemiological studies** that seek to answer questions about vaccines and autism.

Currently, the CDC provides the most accurate and up-to-date information about research on autism and vaccine research, both supported by the federal government and funded independently. For more information, visit <http://www.cdc.gov/nip/vacsafe/concerns/autism/default.htm>.

How many people have autism?

Currently, researchers don't know the exact number of people with an ASD in the United States.

Researchers use different ways to determine **prevalence** that often give different results.

Some estimates of prevalence rely on previously published studies. Researchers review all the published data on a topic and take the averages of these calculations to determine prevalence. Independent researchers³ recently conducted two such reviews. Based on these studies, the best conservative estimate⁴ of the prevalence of ASDs in the United States is that one child in 1,000 children has an ASD.

Is autism more common now than it was in the past?

Researchers are not certain whether autism is more prevalent now than in the past for a number of reasons. Although more cases of autism are being identified, it is not clear why. Some of the increase may result from better education about the symptoms of autism or from more accurate diagnoses of autism.

The new definition of autism as a spectrum disorder means that even people with mild symptoms can be classified as having an ASD, which could also account for the increase in identified cases. As research moves forward using the current definition of ASDs, more definite numbers may be available to answer this question.

Is autism more common in certain groups of people?

Current figures show that autism occurs in all racial, ethnic, and social groups equally, with individuals in one group no more or less likely to have ASDs than those in other groups. Three groups are at higher-than-normal risk for ASDs, including:

- **Boys.** Statistics show that boys are three to four times more likely⁵ to be affected by autism than are girls.
- **Siblings of those with ASDs.** Among families that have one child with an ASD, recurrence of ASD in another sibling is between⁶ 2 percent and 8 percent, a figure much higher than in the general population.
- **People with certain other developmental disorders.** For certain disorders, including **Fragile X syndrome, mental retardation, and tuberous sclerosis**, autism is common in addition to the primary symptoms of the disorder.

When do people usually show signs of autism?

A number of the behavioral symptoms⁷ of autism are observable by 18 months of age, including: problems with eye contact, not responding to one's name, joint attention problems, underdeveloped skills in pretend play and imitation, and problems with non-verbal communication and language.

Some studies also note that, although more subtle, some signs of autism are detectable at eight months⁸ of age.

In general, the average age of autism diagnosis is currently three years old. In many cases, a delay in the child's starting to speak around age two brings problems to parents' attention, even though other, less noticeable signs may be present at an earlier age.⁹

Studies¹⁰ also show that a subgroup of children with ASDs experiences a "*regression*," meaning they stop using the language, play, or social skills they had already learned. This regression usually happens between the first and second birthdays.

Researchers are still learning about the features of regression in ASDs, and whether the features differ from those shown by individuals who show signs of autism in early life.

What are some of the possible signs of autism?

Parents, caregivers, family members, teachers, and others who spend a lot of time with children can look for "*red flags*." Some may mean a delay in one or more areas of development, while others are more typical of ASDs. A list of red flags appears to the right.

Possible Red Flags for Autism¹¹

- The child does not respond to his/her name.
- The child cannot explain what he/she wants.
- The child's language skills are slow to develop or speech is delayed.
- The child doesn't follow directions.
- At times, the child seems to be deaf.
- The child seems to hear sometimes, but not other times.
- The child doesn't point or wave "bye-bye."
- The child used to say a few words or babble, but now he/she doesn't.
- The child throws intense or violent tantrums.
- The child has odd movement patterns.
- The child is overly active, uncooperative, or resistant.
- The child doesn't know how to play with toys.
- The child doesn't smile when smiled at.
- The child has poor eye contact.
- The child gets "stuck" doing the same things over and over and can't move on to other things.
- The child seems to prefer to play alone.
- The child gets things for him/herself only.
- The child is very independent for his/her age.
- The child does things "early" compared to other children.
- The child seems to be in his/her "own world."
- The child seems to tune people out.
- The child is not interested in other children.
- The child walks on his/her toes.
- The child shows unusual attachments to toys, objects, or schedules (i.e., always holding a string or having to put socks on before pants).
- Child spends a lot of time lining things up or putting things in a certain order.

In addition, your child’s health care provider will send your child for an evaluation if you report any of the behaviors listed below; such an evaluation would consider ASDs, among other possible causes.¹²

If the child...

- Does not babble or coo by 12 months of age
- Does not gesture (point, wave, grasp, etc.) by 12 months of age
- Does not say single words by 16 months of age
- Does not say two-word phrases on his or her own (rather than just repeating what someone says to him or her) by 24 months of age
- Has *ANY* loss of *ANY* language or social skill at *ANY* age

What should I do if I think my child has a developmental problem or autism?

Tell your child’s health care provider *immediately* if you think something is wrong.

According to the *American Academy of Pediatrics (AAP)*¹³, “Pediatricians should listen carefully to parents discussing their child’s development. [Parents] are reliable sources of information and their concerns should be valued and addressed immediately.”

Your child’s health care provider will note your comments and concerns, will ask some other questions, and will determine the best plan of action. In some cases, the health care provider will ask you to complete a questionnaire about your child to get more specific information about symptoms. To rule out certain conditions, the health care provider will also test your child’s hearing and check your child’s lead level before deciding on a course of action.

If *red flags* are present, and if the lead and hearing tests show no problems, your child’s health care provider may refer you to a specialist in child development or another specialized health care provider. The specialist will conduct a number of tests to determine whether or not your child has autism or an ASD.

What if I don’t notice any symptoms?

If you don’t report any of these signs, your child’s health care provider will continue to check for problems at every well-baby and well-child visit.¹⁴ If your child’s health care provider does not routinely check your child with such tests, you should ask that he or she do so.

In this **developmental screening**, the provider asks questions related to normal development that can help measure your child’s specific progress. Typically, these questions are similar to the red flags listed earlier. Based on your answers, the health care provider may send your child for further evaluation.

The AAP recommends¹⁵ that health care providers ask questions about different aspects of development. These questions include (but are not limited to) those listed here.

Does your child...¹⁵

- Not speak as well as other children his/her age?
- Have poor eye contact?
- Act as if he/she is in his/her own world?
- Seem to “tune out” others?
- Not smile when smiled at?
- Seem unable to tell you what he/she wants, and so takes your hand and leads you to what he/she wants, or gets it him/herself?
- Have trouble following simple directions?
- Not play with toys in a usual way?
- Not bring things to you to “show” you something?
- Not point to interesting things or direct your attention to items of interest?
- Have unusually long or severe temper tantrums?
- Show an unusual attachment to objects, especially “hard” ones, such as a flashlight or key chain, instead of “soft” ones, such as a blanket or stuffed animal?
- Prefer to play alone?
- Not pretend or play “make believe” (if the child is older than age two)?

Is there a cure for autism?

To date, there is no cure for autism, but sometimes, children with ASDs make so much progress that they no longer show the full syndrome of autism when they are older.

Research¹⁶ shows that early diagnosis and interventions delivered early in life, such as in the preschool period, are more likely to result in major positive effects on later skills and symptoms. The sooner a child begins to get help, the more opportunity for learning. Because a young child’s brain is still forming, early intervention gives children the best start possible and the best chance of developing their full potential. Even so, no matter when a person is diagnosed with autism, it’s never too late to benefit from treatment. People of all ages with ASDs at all levels of ability generally respond positively to well designed interventions.

*Public Law 108-77: Individuals with Disabilities Education Improvement Act*¹⁷(2004) and *Public Law 105-17: Individuals with Disabilities Act, or IDEA*¹⁸ (1997) require your child’s primary care provider to refer you and your family to an early intervention service. Every state operates an early intervention program for children from birth to age three; children with autism should qualify for these services. Early intervention programs typically include behavioral methods, early developmental education, communication skills, occupational and physical therapy, and structured social play.

What are the treatments for autism?

Currently there is no definitive, single treatment for ASDs. However, there are a variety of ways to help minimize the symptoms and maximize learning. Persons with an ASD have the best chance of using all of their individual capabilities and skills if they receive appropriate behavioral and other therapies, education, and medication. In some cases, these treatments can help people with autism function at near-normal levels.

Some possible treatments for autism are explained below. If you have a question about treatment, you should talk to a health care provider who specializes in caring for people with autism.

Behavioral therapy and other therapeutic options

In general, **behavior management therapy** works to reinforce wanted behaviors and reduce unwanted behaviors. At the same time, these methods also suggest what caregivers should do before or between episodes of problem behaviors, and what to do during or after these episodes. Behavioral therapy is often based on **Applied Behavior Analysis (ABA)**. Different applications of ABA commonly used for people with autism include: Positive Behavioral Interventions and Support (PBS), Pivotal Response Training (PRT), Incidental Teaching, Milieu Therapy, Verbal Behavior, and Discrete Trial Teaching (DTT), among others.

Keep in mind that other therapies, beyond ABA, may also be effective for persons with autism. Talk to your health care provider about the best options for your child.

A variety of health care providers can also help individuals with ASDs and their families to work through different situations.

- *Speech-language therapists* can help people with autism improve their general ability to communicate and interact with others effectively, as well as develop their speech and language skills. These therapists may teach non-verbal ways of communicating and may improve social skills that involve communicating with others. They may also help people to better use words and sentences, and to improve rate and rhythm of speech and conversation.
- *Occupational therapists* can help people with autism find ways to adjust tasks and conditions that match their needs and abilities. Such help may include finding a specially designed computer mouse and keyboard to ease communication, or identifying skills that build on a person's interests and individual capabilities. Occupational therapists may also do many of the same types of activities as physical therapists do (see below).
- *Physical therapists* design activities and exercises to build motor control and to improve posture and balance. For example, they can help a child who avoids body contact to participate in activities and games with other children.

Special services are often available to preschool and school-aged children, as well as to teens, through the local public school system. In many cases, services provided by specialists in the school setting are free. More intense and individualized help is available through private clinics, but the family usually has to pay for private services, although some health insurance plans may help cover the cost.

Educational and/or school-based options

Children with ASDs are guaranteed free, appropriate public education under federal laws. *Public Law 108-77: Individuals with Disabilities Education Improvement Act*¹⁷ (2004) and *Public Law 105-17: The Individuals with Disabilities Education Act—IDEA*¹⁸ (1997) make it possible for children with disabilities to get free educational services and educational devices to help them learn as much as they can. Each child is entitled to these services from age three through high school, or until age 21, whichever comes first.

The laws state that children must be taught in the least restrictive environment, appropriate for that individual child. This statement does not mean that each child must be placed in a regular classroom. Instead, the laws mean that the teaching environment should be designed to meet a child's learning needs, while minimizing restrictions on the child's access to typical learning experiences and interactions. Educating persons with ASDs often includes a combination of one-to-one, small group, and regular classroom instruction.

To qualify for special education services, the child must meet specific criteria as outlined by federal and state guidelines. You can contact a local school principal or special education coordinator to learn how to have your child assessed to see if he or she qualifies for services under these laws.

If your child qualifies for special services, a team of people, including you and your family, caregivers, teachers, school psychologists, and other child development specialists, will work together to design an **Individualized Educational Plan (IEP)**¹⁹ for your child. An IEP includes specific academic, communication, motor, learning, functional, and socialization goals for a child based on his or her educational needs. The team also decides how best to carry out the IEP, such as determining any devices or special assistance the child needs, and identifying the developmental specialists who will work with the child.

The special services team should evaluate and re-evaluate your child on a regular basis to see how your child is doing and whether any changes are needed in his or her plan.

A number of parents' organizations, both national and local, provide information on therapeutic and educational services and how to get these services for a child. Visit <http://www.nlm.nih.gov/medlineplus/autism.html> for a listing of these organizations, or check the local phone book.

Medication options

Currently, there is no medication that can cure ASDs or all of the associated symptoms. Further, the *Food and Drug Administration (FDA)* has not approved any drugs specifically for the treatment of autism or its causes. But, in many cases, medication can treat some of the symptoms associated with ASDs.

Please note that the NICHD does not endorse or support the use of any of these medications for treating symptoms of ASDs, or for other conditions for which the medications are not FDA approved.

Medication can improve the behavior of a person with autism. Health care providers often use medications to deal with a specific behavior, such as reducing self-injurious behavior. With the symptom minimized, the person with autism can focus on other things, including learning and communication. Some of these medications have serious risks involved with their use; others may make symptoms worse at first or may take several weeks to become effective.

Not every medication helps every person with symptoms of autism. Health care providers usually prescribe medications on a trial basis, to see if it helps. Your child’s health care provider may have to try different dosages or different combinations of medications to find the most effective plan. Families, caregivers, and health care providers need to work together to make sure that medications are working and that the overall medication plan is safe.

Medications used to treat the symptoms of autism²⁰ may include (but are not limited to):

- *Selective serotonin re-uptake inhibitors (SSRIs)* are a group of antidepressants that treat problems, such as obsessive-compulsive behaviors and anxiety, resulting from an imbalance in one of the body’s chemical systems that are sometimes present in autism. These medications may: reduce the frequency and intensity of repetitive behaviors; decrease irritability, tantrums, and aggressive behavior; and improve eye contact.
- *Tricyclics* are another type of antidepressant used to treat depression and obsessive-compulsive behaviors. Although these drugs tend to cause more side effects than the SSRIs, sometimes they are more effective for certain people.
- *Psychoactive or anti-psychotic medications* affect the brain of the person taking them. Use of this group of drugs is the most widely studied treatment for autism. In some people with ASDs, these drugs may decrease hyperactivity, reduce stereotyped behaviors, and minimize withdrawal and aggression.
- *Stimulants* may be useful in increasing focus and decreasing hyperactivity in people with autism, particularly in higher-functioning individuals. Because of the risk of side effects, health care providers should monitor those using these drugs carefully and often.
- *Anti-anxiety drugs* can help relieve anxiousness and panic disorders associated with autism.

What is secretin and is it an effective treatment for autism?

Secretin is a hormone produced by the small intestine that helps in digestion. Currently, the FDA approves a single dose of secretin only for use in diagnosing digestive problems.

In the 1990s, news reports described a few persons with autism whose behavior improved after getting secretin during a diagnostic test.

However, a series²¹ of clinical trials funded by the NICHD and conducted through the *Network on the Neurobiology and Genetics of Autism: Collaborative Programs of Excellence in Autism (CPEAs)* found no difference in improvement between those taking secretin and those taking placebo. In fact, of the five case-controlled clinical trials published on secretin, not one showed secretin as any better than placebo, no matter what the dosage or frequency. For this reason, secretin is not recommended as a treatment for ASDs.

Are there other disorders associated with ASDs?

In about 5 percent²² of autism cases, another disorder is also present. Studying this kind of co-occurrence helps researchers who are trying to pinpoint the genes involved in autism. Similar disorders or disorders with similar symptoms may have similar genetic origins. In cases of one disorder commonly occurring with another, it could be that one is actually a risk factor for the other. This kind of information can provide clues to what actually happens in autism.

Some of these co-occurring disorders include:

- **Epilepsy or seizure disorder**—Nearly one-third²³ of those with autism also show signs of epilepsy by adulthood. In most cases, medication can control and treat epilepsy effectively.
- **Tuberous sclerosis**—About 6 percent²⁴ of those with autism also have tuberous sclerosis, a disorder that shares many symptoms with autism, including seizures that result from lesions (cuts) on the brain.
- **Fragile X syndrome**—Nearly 2.1 percent²⁵ of those with autism also have Fragile X, the most common inherited form of mental retardation.
- **Mental retardation**—About 25 percent²⁶ of persons with autism also have some degree of mental retardation.

Many people have treatable conditions in addition to their autism. Sleep disorders, allergies, and digestive problems are commonly seen in those with ASDs, and many of these can be treated with environmental interventions and/or medication. Treatment for these conditions may not cure autism, but it can improve the quality-of-life for people who have autism and their families.

References

1. Filipek, et al. (2000). Practice Parameter: Screening and Diagnosis of Autism—Report of the Quality Standards Subcommittee of the American Academy of Neurology and the Child Neurology Society. *Neurology*, 55:468-479.
2. *Diagnostic and Statistics Manual, fourth edition*. (1994). American Psychiatric Association: Washington, DC.
3. Fombonne, 2002; and Gilberg and Wing, 1999. As cited in: Immunization Safety Review Committee, Institute of Medicine, National Academy of Sciences. (2004). *Immunization Safety Review: Vaccines and Autism*. National Academy Press: Washington, DC.
4. Immunization Safety Review Committee, Institute of Medicine, National Academy of Sciences. (2004). *Immunization Safety Review: Vaccines and Autism*. National Academy Press: Washington, DC.
5. Volkmar, 1993; and McLennen, 1993. As cited in: Ashley-Koch, et al. (1999). Genetic Studies of Autistic Disorder and Chromosome 7. *Genomics*, 61:227-236.
6. Gillberg, 2000; Chakrabarti, 2001; and Chudley, 1998. As cited in: Muhle, et al. (2004). The genetics of autism. *Pediatrics*, 113(5):e472-e486.
7. Lord, 1995; Stone, 1999; and Charman, 1997. As cited in: Filipek et al. (2000). Practice Parameter: Screening and Diagnosis of Autism—Report of the Quality Standards Subcommittee of the American Academy of Neurology and the Child Neurology Society. *Neurology*, 55:468-479.
8. Cox, 1999; Mars, 1998; Werner, 2000; and Baranek, 1999. As cited in: Filipek, et al. (2000). Practice Parameter: Screening and Diagnosis of Autism—Report of the Quality Standards Subcommittee of the American Academy of Neurology and the Child Neurology Society. *Neurology*, 55:468-479.
9. Johnson, CP. (2004). New tool helps primary care physicians diagnose autism early. *AAP News*, 24(2):74.
10. Goldberg, 2003; and Rodier, 1998. As cited in: Lord, et al. (2004). Regression and word loss in autistic spectrum disorders. *Journal of Child Psychology and Psychiatry*, 45(5):936-955.
11. Filipek et al. (1999). Screening and diagnosis of autistic spectrum disorders. *Journal of Autism and Developmental Disorders*, 29(6): 439-484.
12. Filipek et al. (2000). Practice Parameter: Screening and Diagnosis of Autism—Report of the Quality Standards Subcommittee of the American Academy of Neurology and the Child Neurology Society. *Neurology*, 55: 468-479.
13. Media Resource Team, American Academy of Pediatrics (AAP). (2001). Guidelines on Diagnosis and Management of Autism. *E-News*, May 2001 [Electronic Version]. Retrieved November 5, 2004, from <http://www.aap.org/mrt/May01.htm>.
14. Committee on Children with Disabilities, AAP. (2001). The pediatrician's role in the diagnosis and management of autistic spectrum disorder in children. *Pediatrics*, 107:1221-1226.
15. Committee on Children with Disabilities, AAP. (2001). Technical report: The pediatrician's role in the diagnosis and management of autistic spectrum disorder in children. *Pediatrics*, 107:e85. Retrieved November 4, 2004, from <http://www.pediatrics.org/cgi/content/full/107/5/385>.
16. Dawson, 1997; Hurth, 1999; Rogers, 1989; Hoyson, 1984; Lovaas, 1987; Harris, 1991; McEachin, 1993; Greenspan, 1997; Smith, 1997; and Smith, 1998. As cited in Committee on Children with Disabilities, AAP. (2001). The pediatrician's role in the diagnosis and management of autistic spectrum disorder in children. *Pediatrics*, 107:1221-1226.
17. For complete information about the reauthorization of IDEA, visit <http://www.ed.gov/policy/speced/guid/idea/idea2004.html>.
18. For complete information about the 1997 authorization of IDEA, visit <http://www.ed.gov/offices/OSERS/Policy/IDEA/regs.html>.
19. Adapted from NICHD, NIH, DHHS. (2003). Are there treatments for Fragile X syndrome? *Families and Fragile X Syndrome* (NIH Pub. No. 03-3402). U.S. Government Printing Office: Washington, DC; pages 24-31.
20. Adapted from: Potenza and McDougle. (2001). *New Findings on the Causes and Treatment of Autism*. CNS Spectrums, Medical Broadcast Limited. Retrieved November 8, 2004, from http://www.patientcenters.com/autism/news/med_reference.html.
21. *Study confirms secretin no more effective than placebo in treating autistic symptoms*, NICHD, November 2001. Retrieved November 08, 2004, from http://www.nichd.nih.gov/new/releases/news_key.cfm?from=autism.
22. Gillberg. (1998). Chromosomal disorders and autism. *Journal of autism and developmental disorders*, 28:415-425.
23. Tuchman, et al. (2002). Epilepsy in autism. *Lancet Neurology*, 1:352-358.
24. Fombonne, et al. (1997). Autism and associated medical disorders in a French epidemiological survey. *Child and Adolescent Psychiatry*, 36:1561-1569.
25. Kielinen, et al. (2004). Associated medical disorders and disabilities in children with autistic disorder. *Autism*, 8(1):49-60.
26. Sigman M, Dissanayake C, Arbelle S, and Ruskin E. (1997). Cognition and emotion in children with autism. In Cohen and Volkmar (Eds.) *Handbook of Autism and Pervasive Developmental Disorders*, second edition (pp. 248-265). Wiley and Sons: NY.

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Glossary

The word...	Is pronounced...	And means...
Applied Behavior Analysis	ah-PLYED bee-HAY-vyur ah-NALL-uh-siss	An intervention that relies on the theory that rewarded behavior is more likely to be repeated than ignored behavior. This theory provides the foundation of several different methods of behavioral management often used with persons who have autism and other developmental disorders.
Behavior Management Therapy	bee-HAY-vyur MANN-ej-ment thee-ree	A method of therapy that focuses on managing behavior—that is, changing unwanted behaviors through rewards, reinforcements, and by confronting something that arouses anxiety, discomfort, or fear and overcoming the unwanted responses.
Chromosomes	kro-mu-SOM	One of the "packages" of genes and other DNA in the nucleus of a cell. Humans have 23 pairs of chromosomes, 46 in all. Each parent contributes one chromosome to each pair, so children get half of their chromosomes from their mothers and half from their fathers.
Developmental screening	dee-vel-up-menn-tul skree-ning	A check-up similar to the physical check-up a child gets from a health care provider, but that focuses on a child's social, emotional, and intellectual development. This screening monitors and charts development to make sure that the child is developing as expected for his or her age.
Epidemiological studies	epp-ih-DEEM-me-oh- loj-i-kul STUH-dees	Studies of the number of people with a disease(s), the locations of these people, the patterns of the disease(s), and what contributes to or causes the disease(s) or related events in certain groups.
Epilepsy	epp-ih-LEPP-see	A brain disorder in which clusters of nerve cells, or neurons, in the brain sometimes signal abnormally. In epilepsy, the normal pattern of neuronal activity becomes disturbed, causing strange sensations, emotions, and behavior or sometimes convulsions, muscle spasms, and loss of consciousness.
Fragile x syndrome	FRA-jell EKS sinn-DROM	Is the most common form of inherited mental retardation. A mutation in a single gene, the <i>FMR1</i> gene located on the X chromosome, causes Fragile X syndrome and can be passed from one generation to the next. Symptoms of Fragile X syndrome occur because the mutated gene cannot produce enough of a protein that is needed by the body's cells, especially cells in the brain, to develop and function normally.
Gene	jeen	Pieces of DNA. They contain the information for making a specific protein.

Glossary (Continued)

The word...	Is pronounced...	And means...
Individual Education Plan (IEP)	INN-div-ih-djewel ED-djew-kay-shun plan	A written set of instruction goals, or specific skills, for every child in a special education program that is required by law. The document is an agreement between the school and the family about a child's educational goals. The IEP is reviewed every year and, if needed, changed to meet a child's new or changing needs.
Mental retardation	MENN-tul ree-tarr-DAY-shen	A term used when a person has certain limitations in mental functioning and in skills such as communicating, taking care of him or herself, and social skills.
Prevalence	prev-uh-lens	The number of people in a given population who have a certain condition or disease.
Replicate	repp-li-KATE	Describes a situation in which many studies that use the same methods and steps have gotten the same outcome, suggesting that a finding is likely to be true.
Rett syndrome	RETT sinn-DROM	Mostly caused by mutations in the <i>MECP2</i> gene on the X chromosome. Rett syndrome is a disorder of brain development that occurs almost exclusively in girls. After a few months of apparently normal development, affected girls develop problems with language, learning, coordination, and other brain functions.
Seizures	SEE-jurs	A sudden attack, often one of convulsions, as in epilepsy. Seizures don't necessarily involve movement or thrashing; they can also make someone seem as though they are frozen, unmoving.
Stereotyped Behaviors	STARE-ee-oh-tipd bee-HAY-vyurs	Actions that are repeated without change.
Susceptibility	suss-ept-ih-BULL	The state of being predisposed to, sensitive to, or of lacking the ability to resist manifestations of something (such as a pathogen, familial disease, or a drug); a person who is susceptible is more likely to show symptoms of a disorder.
Tuberous sclerosis	TOOB-er-us sklar-OH-siss	A rare, multi-system genetic disease that causes non-cancerous tumors to grow in the brain and on other vital organs such as the kidneys, heart, eyes, lungs, and skin. It commonly affects the central nervous system and results in symptoms including seizures, developmental delay, behavioral problems, skin abnormalities, and kidney disease.

How can I get involved with studies of autism?

If you are interested in taking part in one of the CPEA studies, or if you want more information about one of the CPEA sites, visit <http://www.nichd.nih.gov/autism/cpea.cfm>. You and your family are welcome to take part in many different studies, but you can only take part in one genetics study at a time.

To find out what studies related to autism are currently looking for participants, go to <http://www.nichd.nih.gov/autism/research.cfm> and choose the “Autism clinical trials currently recruiting patients” link.

You can also visit <http://www.clinicaltrials.gov> or call 1-800-411-1222 for more information on federally funded studies that are seeking participants.

Where can I go for more information about autism?

For more information about the CPEA Network, genetic studies, or autism research, contact the NICHD. The NICHD supports and conducts research on topics related to the health of children, adults, families, and populations, including autism and developmental disabilities. The mission of the NICHD is to ensure that every person is born healthy and wanted, that women suffer no harmful effects from the reproductive process, and that all children have the chance to fulfill their potential for a healthy and productive life, free of disease or disability, and to ensure the health, productivity, independence, and well-being of all people through optimal rehabilitation. You can contact the NICHD through the **NICHD Information Resource Center** at:

Mail: P.O. Box 3006, Rockville, MD 20847

Phone: 1-800-370-2943 (TTY: 1-888-320-6942)

Fax: (301) 984-1473

E-mail: NICHDInformationResourceCenter@mail.nih.gov (Please use AUTISM in the subject line)

Internet: <http://www.nichd.nih.gov/autism>

The National Library of Medicine also provides information on ASDs at <http://www.nlm.nih.gov/medlineplus/autism.html>. The NIH Web site also has information about ASDs at <http://health.nih.gov/result.asp/62>.