



Autism Spectrum Disorders

Pervasive Developmental Disorders



DEPARTMENT OF HEALTH AND HUMAN SERVICES

NATIONAL INSTITUTES OF HEALTH

NIMH
National Institute
of Mental Health

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ot until the middle of
the twentieth century
was there a name for
a disorder that affects
thousands of children,
a disorder that causes

disruption in families and unfulfilled lives for many children. In 1943 Dr. Leo Kanner of the Johns Hopkins Hospital studied a group of 11 children and introduced the label *early infantile autism* into the English language. At the same time a German scientist, Dr. Hans Asperger, described a milder form of the disorder that became known as Asperger syndrome. Thus these two disorders were described and are today listed in the *Diagnostic and Statistical Manual of Mental Disorders* DSM-IV-TR (fourth edition, text revision)¹ as two of the five pervasive developmental disorders (PDD), more often referred to today as autism spectrum disorders (ASD). All these disorders are characterized by varying degrees of impairment in communication skills, social interactions, and restricted, repetitive and stereotyped patterns of behavior.

The autism spectrum disorders can often be reliably detected by the age of 3 years, and in some cases as early as 18 months.² Studies suggest that many children eventually may be accurately identified by the age of 1 year or even younger. The appearance of any of the warning signs of ASD is reason to have a child evaluated by a professional specializing in these disorders.

Parents are usually the first to notice unusual behaviors in their child. In some cases, the baby seemed “different” from birth, unresponsive to people or focusing intently on one item for long periods of time. The first signs of an ASD can also appear in children who seem to have been developing normally. When an engaging, babbling toddler suddenly becomes silent, withdrawn, self-abusive, or indifferent to social overtures, something is wrong. Research has shown that parents are usually correct about noticing developmental problems, although they may not realize the specific nature or degree of the problem.

The pervasive developmental disorders, or autism spectrum disorders, range from a severe form, called autistic disorder, to a milder form, Asperger syndrome. If a child has symptoms of either of these disorders, but does not meet the specific criteria for either, the diagnosis is called pervasive developmental disorder not otherwise specified (PDD-NOS). Other rare, very severe disorders that are included in the autism spectrum disorders are Rett syndrome and childhood disintegrative disorder. This brochure will focus on classic autism, PDD-NOS, and Asperger syndrome, with brief descriptions of Rett syndrome and childhood disintegrative disorder on page 4.

Prevalence

In 2007—the most recent government survey on the rate of autism—the Centers for Disease Control (CDC) found that the rate is higher than the rates found from studies conducted in the United States during the 1980s and early 1990s (survey based on data from 2000 and 2002). The CDC survey assigned a diagnosis of autism spectrum disorder based on health and school records of 8 year olds in 14 communities throughout the U.S. Debate continues about whether this represents a true increase in the prevalence of autism. Changes in the criteria used to diagnose autism, along with increased recognition of the disorder by professionals and the public may all be contributing factors. Nonetheless, the CDC report confirms other recent epidemiologic studies documenting that more children are being diagnosed with an ASD than ever before.

Data from an earlier report of the CDC's Atlanta-based program found the rate of autism spectrum disorder was 3.4 per 1,000 for children 3 to 10 years of age. Summarizing this and several other major studies on autism prevalence, CDC estimates that 2–6 per 1,000 (from 1 in 500 to 1 in 150) children have an ASD. The risk is 3–4 times higher in males than females. Compared to the prevalence of other childhood conditions, this rate is lower than the rate of mental retardation (9.7 per 1,000 children), but higher than the rates for cerebral palsy (2.8 per 1,000 children), hearing loss (1.1 per 1,000 children), and vision impairment (0.9 per 1,000 children).⁵ The CDC notes that these studies do not provide a national estimate.

For additional data, please visit the autism section of the CDC Web site.

Rare Autism Spectrum Disorders

Rett Syndrome: Rett syndrome is relatively rare, affecting almost exclusively females, one out of 10,000 to 15,000. After a period of normal development, sometime between 6 and 18 months, autism-like symptoms begin to appear. The little girl's mental and social development regresses—she no longer responds to her parents and pulls away from any social contact. If she has been talking, she stops; she cannot control her feet; she wrings her hands. Some of the problems associated with Rett syndrome can be treated. Physical, occupational, and speech therapy can help with problems of coordination, movement, and speech.

Scientists sponsored by the National Institute of Child Health and Human Development have discovered that a mutation in the sequence of a single gene can cause Rett syndrome. This discovery may help doctors slow or stop the progress of the syndrome. It may also lead to methods of screening for Rett syndrome, thus enabling doctors to start treating these children much sooner, and improving the quality of life these children experience.*

Childhood Disintegrative Disorder: Very few children who have an autism spectrum disorder (ASD) diagnosis meet the criteria for childhood disintegrative disorder (CDD). An estimate based on four surveys of ASD found fewer than 2 children per 100,000 with ASD could be classified as having CDD. This suggests that CDD is a very rare form of ASD. It has a strong male preponderance.** Symptoms may appear by age 2, but the average age of onset is between 3 and 4 years. Until this time, the child has age-appropriate skills in communication and social relationships. The long period of normal development before regression helps differentiate CDD from Rett syndrome.

The loss of such skills as vocabulary are more dramatic in CDD than they are in classical autism. The diagnosis requires extensive and pronounced losses involving motor, language, and social skills.*** CDD is also accompanied by loss of bowel and bladder control and oftentimes seizures and a very low IQ.

* *Rett syndrome*. NIH Publication No. 01-4960. Rockville, MD: National Institute of Child Health and Human Development, 2001. Available at <http://www.nichd.nih.gov/publications/pubskey.cfm?from=autism>

** Frombonne E. Prevalence of childhood disintegrative disorder. *Autism*, 2002; 6(2): 149-157.

*** Volkmar RM and Rutter M. Childhood disintegrative disorder: Results of the DSM-IV autism field trial. *Journal of the American Academy of Child and Adolescent Psychiatry*, 1995; 34: 1092-1095.

What Are the Autism Spectrum Disorders?

The autism spectrum disorders are more common in the pediatric population than are some better known disorders such as diabetes, spinal bifida, or Down syndrome.² The earlier the disorder is diagnosed, the sooner the child can be helped through treatment interventions. Pediatricians, family physicians, daycare providers, teachers, and parents may initially dismiss signs of ASD, optimistically thinking the child is just a little slow and will “catch up.”

All children with ASD demonstrate deficits in 1) social interaction, 2) verbal and nonverbal communication, and 3) repetitive behaviors or interests. In addition, they will often have unusual responses to sensory experiences, such as certain sounds or the way objects look. Each of these symptoms runs the gamut from mild to severe. They will present in each individual child differently. For instance, a child may have little trouble learning to read but exhibit extremely poor social interaction. Each child will display communication, social, and behavioral patterns that are individual but fit into the overall diagnosis of ASD.

Children with ASD do not follow the typical patterns of child development. In some children, hints of future problems may be apparent from birth. In most cases, the problems in communication and social skills become more noticeable as the child lags further behind other children the same age. Some other children start off well enough. Oftentimes between 12 and 36 months old, the differences in the way they react to people and other unusual behaviors become apparent. Some parents report the change as being sudden, and that their children start to reject people, act strangely, and lose language and social skills they had previously acquired. In other cases, there is a “plateau,” or

leveling, of progress so that the difference between the child with autism and other children the same age becomes more noticeable.

ASD is defined by a certain set of behaviors that can range from the very mild to the severe. The following possible indicators of ASD were identified on the Public Health Training Network Webcast, *Autism Among Us*.⁴

Possible Indicators of Autism Spectrum Disorders

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

Some Other Indicators

- Poor eye contact
- Doesn't seem to know how to play with toys
- Excessively lines up toys or other objects
- Is attached to one particular toy or object
- Doesn't smile
- At times seems to be hearing impaired

Social Symptoms

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

In contrast, most children with ASD seem to have tremendous difficulty learning to engage in the give-and-take of everyday human interaction. Even in the first few months of life, many do not interact and they avoid eye contact. They seem indifferent to other people, and often seem to prefer being alone. They may resist attention or passively accept hugs and cuddling. Later, they seldom seek comfort or respond to parents' displays of anger or affection in a typical way. Research has suggested that although children with ASD are attached to their parents, their expression of this attachment is unusual and difficult to "read." To parents, it may seem as if their child is not attached at all. Parents who looked forward to the joys of cuddling, teaching, and playing with their child may feel crushed by this lack of the expected and typical attachment behavior.

Children with ASD also are slower in learning to interpret what others are thinking and feeling. Subtle social cues—whether a smile, a wink, or a grimace—may have little meaning. To a child who misses these cues, "Come here" always means the same thing, whether the speaker is smiling and extending her arms for a hug or frowning and planting her fists on her hips. Without the ability to interpret gestures and facial expressions, the social world may seem bewildering.

To compound the problem, people with ASD have difficulty seeing things from another person's perspective. Most 5-year-olds understand that other people have different information, feelings, and goals than they have. A person with ASD may lack such understanding. This inability leaves them unable to predict or understand other people's actions.

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

Communication Difficulties

By age 3, most children have passed predictable milestones on the path to learning language; one of the earliest is babbling. By the first birthday, a typical toddler says words, turns when he hears his name, points when he wants a toy, and when offered something distasteful, makes it clear that the answer is “no.”

Some children diagnosed with ASD remain mute throughout their lives. Some infants who later show signs of ASD coo and babble during the first few months of life, but they soon stop. Others may be delayed, developing language as late as age 5 to 9. Some children may learn to use communication systems such as pictures or sign language.

Those who do speak often use language in unusual ways. They seem unable to combine words into meaningful sentences. Some speak only single words, while others repeat the same phrase over and over. Some ASD children parrot what they hear, a condition called *echolalia*. Although many children with no ASD go through a stage where they repeat what they hear, it normally passes by the time they are 3.

Some children only mildly affected may exhibit slight delays in language, or even seem to have precocious language and unusually large vocabularies, but have great difficulty in sustaining a conversation. The “give and take” of normal conversation is hard for them, although they often carry on a monologue on a favorite subject, giving no one else an opportunity to comment. Another difficulty is often the inability to understand body language, tone of voice, or “phrases of speech.” They might interpret a sarcastic expression such as “Oh, that’s just great” as meaning it really IS great.

While it can be hard to understand what ASD children are saying, their body language is also difficult to understand. Facial expressions, movements, and gestures rarely match what they are saying. Also, their tone of voice fails to reflect their feelings. A high-pitched, sing-song, or flat, robot-like voice is common. Some children with relatively good language skills speak like little adults, failing to pick up on the “kid-speak” that is common in their peers.

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

Repetitive Behaviors

Although children with ASD usually appear physically normal and have good muscle control, odd repetitive motions may set them off from other children. These behaviors might be extreme and highly apparent or more

subtle. Some children and older individuals spend a lot of time repeatedly flapping their arms or walking on their toes. Some suddenly freeze in position.

As children, they might spend hours lining up their cars and trains in a certain way, rather than using them for pretend play. If someone accidentally moves one of the toys, the child may be tremendously upset. ASD children need, and demand, absolute consistency in their environment. A slight change in any routine—in mealtimes, dressing, taking a bath, going to school at a certain time and by the same route—can be extremely disturbing. Perhaps order and sameness lend some stability in a world of confusion.

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

Problems that May Accompany ASD

Sensory problems. When children's perceptions are accurate, they can learn from what they see, feel, or hear. On the other hand, if sensory information is faulty, the child's experiences of the world can be confusing. Many ASD children are highly attuned or even painfully sensitive to certain sounds, textures, tastes, and smells. Some children find the feel of clothes touching their skin almost unbearable. Some sounds—a vacuum cleaner, a ringing telephone, a sudden storm, even the sound of waves lapping the shoreline—will cause these children to cover their ears and scream.

In ASD, the brain seems unable to balance the senses appropriately. Some ASD children are oblivious to extreme cold or pain. An ASD child may fall and break an arm, yet never cry. Another may bash his head

against a wall and not wince, but a light touch may make the child scream with alarm.

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

Seizures. One in four children with ASD develops seizures, often starting either in early childhood or adolescence.⁵ Seizures, caused by abnormal electrical activity in the brain, can produce a temporary loss of consciousness (a “blackout”), a body convulsion, unusual movements, or staring spells. Sometimes a contributing factor is a lack of sleep or a high fever. An EEG (electroencephalogram—recording of the electric currents developed in the brain by means of electrodes applied to the scalp) can help confirm the seizure’s presence.

In most cases, seizures can be controlled by a number of medicines called “anticonvulsants.” The dosage of the medication is adjusted carefully so that the least possible amount of medication will be used to be effective.

Fragile X syndrome. This disorder is the most common inherited form of mental retardation. It was so named because one part of the X chromosome has a defective piece that appears pinched and fragile when under a microscope. Fragile X syndrome affects about two to five percent of people with ASD. It is important to have a child with ASD checked for Fragile X, especially if the parents are considering having another child. For an unknown reason, if a child with ASD also has Fragile X, there is a one-in-two chance that boys born to the same parents will have the syndrome.⁶ Other members of the family who may be contemplating having a child may also wish to be checked for the syndrome.

A distinction can be made between a father's and mother's ability to pass along to a daughter or son the altered gene on the X chromosome that is linked to fragile X syndrome. Because both males (XY) and females (XX) have at least one X chromosome, both can pass on the mutated gene to their children.

A father with the altered gene for Fragile X on his X chromosome will only pass that gene on to his daughters. He passes a Y chromosome on to his sons, which doesn't transmit the condition. Therefore, if the father has the altered gene on his X chromosome, but the mother's X chromosomes are normal, all of the couple's daughters would have the altered gene for Fragile X, while none of their sons would have the mutated gene.

Because mothers pass on only X chromosomes to their children, if the mother has the altered gene for Fragile X, she can pass that gene to either her sons or her daughters. If the mother has the mutated gene on one X chromosome and has one normal X chromosome, and the father has no genetic mutations, all the children have a 50-50 chance of inheriting the mutated gene.

The odds noted here apply to each child the parents have.⁷ In terms of prevalence, the latest statistics are consistent in showing that 5% of people with autism are affected by fragile X and 10% to 15% of those with fragile X show autistic traits.

Tuberous Sclerosis. Tuberous sclerosis is a rare genetic disorder that causes benign tumors to grow in the brain as well as in other vital organs. It has a consistently strong association with ASD. One to 4 percent of people with ASD also have tuberous sclerosis.⁸

The Diagnosis of Autism Spectrum Disorders

Although there are many concerns about labeling a young child with an ASD, the earlier the diagnosis of ASD is made, the earlier needed interventions can begin. Evidence over the last 15 years indicates that intensive early intervention in *optimal educational settings for at least 2 years during the preschool years* results in improved outcomes in most young children with ASD.²

In evaluating a child, clinicians rely on behavioral characteristics to make a diagnosis. Some of the characteristic behaviors of ASD may be apparent in the first few months of a child's life, or they may appear at any time during the early years. For the diagnosis, problems in at least one of the areas of communication, socialization, or restricted behavior must be present before the age of 3. The diagnosis requires a two-stage process. The first stage involves developmental screening during "well child" check-ups; the second stage entails a comprehensive evaluation by a multidisciplinary team.⁹

Screening

A "well child" check-up should include a developmental screening test. If your child's pediatrician does not routinely check your child with such a test, ask that it be done. Your own observations and concerns about your child's development will be essential in helping to screen your child.⁹ Reviewing family videotapes, photos, and baby albums can help parents remember when each behavior was first noticed and when the child reached certain developmental milestones.

Several screening instruments have been developed to quickly gather information about a child's social and communicative development within medical settings. Among them are the Checklist of Autism in Toddlers (CHAT),¹⁰ the modified Checklist for Autism in Toddlers (M-CHAT),¹¹ the Screening Tool for Autism in Two-Year-Olds (STAT),¹² and the Social Communication Questionnaire (SCQ)¹³ (for children 4 years of age and older).

Some screening instruments rely solely on parent responses to a questionnaire, and some rely on a combination of parent report and observation. Key items on these instruments that appear to differentiate children with autism from other groups before the age of 2 include pointing and pretend play. Screening instruments do not provide individual diagnosis but serve to assess the need for referral for possible diagnosis of ASD. These screening methods may not identify children with mild ASD, such as those with high-functioning autism or Asperger syndrome.

During the last few years, screening instruments have been devised to screen for Asperger syndrome and higher functioning autism. The Autism Spectrum Screening Questionnaire (ASSQ),¹⁴ the Australian Scale for Asperger's Syndrome,¹⁵ and the most recent, the Childhood Asperger Syndrome Test (CAST),¹⁶ are some of the instruments that are reliable for identification of school-age children with Asperger syndrome or higher functioning autism. These tools concentrate on social and behavioral impairments in children without significant language delay.

If, following the screening process or during a routine "well child" check-up, your child's doctor sees any of the possible indicators of ASD, further evaluation is indicated.

Comprehensive Diagnostic Evaluation

The second stage of diagnosis must be comprehensive in order to accurately rule in or rule out an ASD or other developmental problem. This evaluation may be done by a multidisciplinary team that includes a psychologist, a neurologist, a psychiatrist, a speech therapist, or other professionals who diagnose children with ASD.

Because ASD's are complex disorders and may involve other neurological or genetic problems, a comprehensive evaluation should entail neurologic and genetic assessment, along with in-depth cognitive and language testing.⁹ In addition, measures developed specifically for diagnosing autism are often used. These include the Autism Diagnosis Interview-Revised (ADI-R)¹⁷ and the Autism Diagnostic Observation Schedule (ADOS-G).¹⁸ The ADI-R is a structured interview that contains over 100 items and is conducted with a caregiver. It consists of four main factors—the child's communication, social interaction, repetitive behaviors, and age-of-onset symptoms. The ADOS-G is an observational measure used to “press” for socio-communicative behaviors that are often delayed, abnormal, or absent in children with ASD.

Still another instrument often used by professionals is the Childhood Autism Rating Scale (CARS).¹⁹ It aids in evaluating the child's body movements, adaptation to change, listening response, verbal communication, and relationship to people. It is suitable for use with children over 2 years of age. The examiner observes the child and also obtains relevant information from the parents. The child's behavior is rated on a scale based on deviation from the typical behavior of children of the same age.

Two other tests that should be used to assess any child with a developmental delay are a formal audiologic hearing evaluation and a lead screening. Although some hearing loss can co-occur with ASD, some children with ASD may be incorrectly thought to have such a

loss. In addition, if the child has suffered from an ear infection, transient hearing loss can occur. Lead screening is essential for children who remain for a long period of time in the oral-motor stage in which they put any and everything into their mouths. Children with an autistic disorder usually have elevated blood lead levels.⁹

Customarily, an expert diagnostic team has the responsibility of thoroughly evaluating the child, assessing the child's unique strengths and weaknesses, and determining a formal diagnosis. The team will then meet with the parents to explain the results of the evaluation.

Although parents may have been aware that something was not "quite right" with their child, when the diagnosis is given, it is a devastating blow. At such a time, it is hard to stay focused on asking questions. But while members of the evaluation team are together is the best opportunity the parents will have to ask questions and get recommendations on what further steps they should take for their child. Learning as much as possible at this meeting is very important, but it is helpful to leave this meeting with the name or names of professionals who can be contacted if the parents have further questions.

Available Aids

When your child has been evaluated and diagnosed with an autism spectrum disorder, you may feel inadequate to help your child develop to the fullest extent of his or her ability. As you begin to look at treatment options and at the types of aid available for a child with a disability, you will find out that there is help for you. It is going to be difficult to learn and remember everything you need to know about the resources that will be most helpful. *Write down everything.* If you keep a notebook, you will have a foolproof method of recalling information. Keep a record of the doctors' reports and the evaluation your child has been given so that his or her eligibility for special programs will be documented. Learn

everything you can about special programs for your child; the more you know, the more effectively you can advocate.

For every child eligible for special programs, each state guarantees special education and related services. The Individuals with Disabilities Education Act (IDEA) is a Federally mandated program that assures a free and appropriate public education for children with diagnosed learning deficits. Usually children are placed in public schools and the school district pays for all necessary services. These will include, as needed, services by a speech therapist, occupational therapist, school psychologist, social worker, school nurse, or aide.

By law, the public schools must prepare and carry out a set of instruction goals, or specific skills, for every child in a special education program. The list of skills is known as the child's Individualized Education Program (IEP). The IEP is an agreement between the school and the family on the child's goals. When your child's IEP is developed, you will be asked to attend the meeting. There will be several people at this meeting, including a special education teacher, a representative of the public schools who is knowledgeable about the program, other individuals invited by the school or by you (you may want to bring a relative, a child care provider, or a supportive close friend who knows your child well). Parents play an important part in creating the program, as they know their child and his or her needs best. Once your child's IEP is developed, a meeting is scheduled once a year to review your child's progress and to make any alterations to reflect his or her changing needs.

If your child is under 3 years of age and has special needs, he or she should be eligible for an early intervention program; this program is available in every state. Each state decides which agency will be the lead agency in the early intervention program. The early intervention services are provided by workers qualified to care for toddlers with disabilities and are usually in the child's home or a place familiar to the

child. The services provided are written into an Individualized Family Service Plan (IFSP) that is reviewed at least once every 6 months. The plan will describe services that will be provided to the child, but will also describe services for parents to help them in daily activities with their child and for siblings to help them adjust to having a brother or sister with ASD.

There is a list of resources at the back of the brochure that will be helpful to you as you look for programs for your child.

Treatment Options

There is no single best treatment package for all children with ASD. One point that most professionals agree on is that early intervention is important; another is that most individuals with ASD respond well to highly structured, specialized programs.

Before you make decisions on your child's treatment, you will want to gather information about the various options available. Learn as much as you can, look at all the options, and make your decision on your child's treatment based on your child's needs. You may want to visit public schools in your area to see the type of program they offer to special needs children.

Guidelines used by the Autism Society of America include the following questions parents can ask about potential treatments:

- Will the treatment result in harm to my child?
- How will failure of the treatment affect my child and family?
- Has the treatment been validated scientifically?
- Are there assessment procedures specified?
- How will the treatment be integrated into my child's current program? Do not become so infatuated with a given treatment that functional curriculum, vocational life and social skills are ignored.

The National Institute of Mental Health suggests a list of questions parents can ask when planning for their child:

- How successful has the program been for other children?
- How many children have gone on to placement in a regular school and how have they performed?
- Do staff members have training and experience in working with children and adolescents with autism?
- How are activities planned and organized?
- Are there predictable daily schedules and routines?
- How much individual attention will my child receive?
- How is progress measured? Will my child's behavior be closely observed and recorded?
- Will my child be given tasks and rewards that are personally motivating?
- Is the environment designed to minimize distractions?
- Will the program prepare me to continue the therapy at home?
- What is the cost, time commitment, and location of the program?

Among the many methods available for treatment and education of people with autism, applied behavior analysis (ABA) has become widely accepted as an effective treatment. *Mental Health: A Report of the Surgeon General* states, "Thirty years of research demonstrated the efficacy of applied behavioral methods in reducing inappropriate behavior and in increasing communication, learning, and appropriate social behavior."²⁰ The basic research done by Ivar Lovaas and his colleagues at the University of California, Los Angeles, calling for an intensive, one-on-one child-teacher interaction for 40 hours a week, laid a foundation for other educators and researchers in the search for further effective early interventions to help those with ASD attain their potential. The goal of behavioral management is to reinforce desirable behaviors and reduce undesirable ones.^{21, 22}

An effective treatment program will build on the child's interests, offer a predictable schedule, teach tasks as a series of simple steps, actively engage the child's attention in highly structured activities, and provide regular reinforcement of behavior. Parental involvement has emerged as a major factor in treatment success. Parents work with teachers and therapists to identify the behaviors to be changed and the skills to be taught. Recognizing that parents are the child's earliest teachers, more programs are beginning to train parents to continue the therapy at home.

As soon as a child's disability has been identified, instruction should begin. Effective programs will teach early communication and social interaction skills. In children younger than 3 years, appropriate interventions usually take place in the home or a child care center. These interventions target specific deficits in learning, language, imitation, attention, motivation, compliance, and initiative of interaction. Included are behavioral methods, communication, occupational and physical therapy along with social play interventions. Often the day will begin with a physical activity to help develop coordination and body awareness; children string beads, piece puzzles together, paint, and participate in other motor skills activities. At snack time the teacher encourages social interaction and models how to use language to ask for more juice. The children learn by doing. Working with the children are students, behavioral therapists, and parents who have received extensive training. In teaching the children, positive reinforcement is used.²³

Children older than 3 years usually have school-based, individualized, special education. The child may be in a segregated class with other autistic children or in an integrated class with children

without disabilities for at least part of the day. Different localities may use differing methods but all should provide a structure that will help the children learn social skills and, functional communication. In these programs, teachers often involve the parents, giving useful advice in how to help their child use the skills or behaviors learned at school when they are at home.²⁴

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

During middle and high school years, instruction will begin to address such practical matters as work, community living, and recreational activities. This should include work experience, using public transportation, and learning skills that will be important in community living.²⁵

All through your child's school years, you will want to be an active participant in his or her education program. Collaboration between parents and educators is essential in evaluating your child's progress.

The Adolescent Years

Adolescence is a time of stress and confusion; and it is no less so for teenagers with autism. Like all children, they need help in dealing with their budding sexuality. While some behaviors improve during the teenage years, some get worse. Increased autistic or aggressive behavior may be one way some teens express their newfound tension and confusion.

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

Dietary and Other Interventions

In an effort to do everything possible to help their children, many parents continually seek new treatments. Some treatments are developed by reputable therapists or by parents of a child with ASD. Although an unproven treatment may help one child, it may not prove beneficial to another. To be accepted as a proven treatment, the treatment should undergo clinical trials, preferably randomized, double-blind trials, that would allow for a comparison between treatment and no treatment. Following are some of the interventions that have been reported to have been helpful to some children but whose efficacy or safety has not been proven.

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

A diet that some parents have found was helpful to their autistic child is a gluten-free, casein-free diet. Gluten is a casein-like substance

that is found in the seeds of various cereal plants—wheat, oat, rye, and barley. Casein is the principal protein in milk. Since gluten and milk are found in many of the foods we eat, following a gluten-free, casein-free diet is difficult.

A supplement that some parents feel is beneficial for an autistic child is Vitamin B6, taken with magnesium (which makes the vitamin effective). The result of research studies is mixed; some children respond positively, some negatively, some not at all or very little.⁵

In the search for treatment for autism, there has been discussion in the last few years about the use of secretin, a substance approved by the Food and Drug Administration (FDA) for a single dose normally given to aid in diagnosis of a gastrointestinal problem. Anecdotal reports have shown improvement in autism symptoms, including sleep patterns, eye contact, language skills, and alertness. Several clinical trials conducted in the last few years have found no significant improvements in symptoms between patients who received secretin and those who received a placebo.²⁶

Medications Used in Treatment

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

On October 6, 2006 the U.S. Food and Drug Administration (FDA) approved risperidone (generic name) or Risperdal (brand name) for the symptomatic treatment of irritability in autistic children and adolescents ages 5 to 16. The approval is the first for the use of a drug to treat behaviors associated with autism in children. These behaviors are included under the general heading of irritability, and include aggression, deliberate self-injury and temper tantrums.

Olanzapine (Zyprexa) and other antipsychotic medications are used “off-label” for the treatment of aggression and other serious behavioral disturbances in children, including children with autism. Off-label means a doctor will prescribe a medication to treat a disorder or in an age group that is not included among those approved by the FDA.

Other medications are used to address symptoms or other disorders in children with autism. Fluoxetine (Prozac) and sertraline (Zoloft) are approved by the FDA for children age 7 and older with obsessive-compulsive disorder. Fluoxetine is also approved for children age 8 and older for the treatment of depression.

Fluoxetine and sertraline are antidepressants known as selective serotonin reuptake inhibitors (SSRIs). Despite the relative safety and popularity of SSRIs and other antidepressants, some studies have suggested that they may have unintentional effects on some people, especially adolescents and young adults. In 2004, after a thorough review of data, the Food and Drug Administration (FDA) adopted a “black box” warning label on all antidepressant medications to alert the public about the potential increased risk of suicidal thinking or attempts in children and adolescents taking antidepressants. In 2007, the agency extended the warning to include young adults up to age 25. A “black box” warning is the most serious type of warning on prescription drug labeling. The warning emphasizes that children, adolescents and young adults taking antidepressants should be closely monitored, especially

during the initial weeks of treatment, for any worsening depression, suicidal thinking or behavior, or any unusual changes in behavior such as sleeplessness, agitation, or withdrawal from normal social situations.

A child with ASD may not respond in the same way to medications as typically developing children. It is important that parents work with a doctor who has experience with children with autism. A child should be monitored closely while taking a medication. The doctor will prescribe the lowest dose possible to be effective. Ask the doctor about any side effects the medication may have and keep a record of how your child responds to the medication. It will be helpful to read the “patient insert” that comes with your child’s medication. Some people keep the patient inserts in a small notebook to be used as a reference. This is most useful when several medications are prescribed.

Anxiety and depression. The selective serotonin reuptake inhibitors (SSRI’s) are the medications most often prescribed for symptoms of anxiety, depression, and/or obsessive-compulsive disorder (OCD). Only one of the SSRI’s, fluoxetine, (Prozac®) has been approved by the FDA for both OCD and depression in children age 7 and older. Three that have been approved for OCD are fluvoxamine (Luvox®), age 8 and older; sertraline (Zoloft®), age 6 and older; and clomipramine (Anafranil®), age 10 and older.⁵ Treatment with these medications can be associated with decreased frequency of repetitive, ritualistic behavior and improvements in eye contact and social contacts. The FDA is studying and analyzing data to better understand how to use the SSRI’s safely, effectively, and at the lowest dose possible.

Behavioral problems. Antipsychotic medications have been used to treat severe behavioral problems. These medications work by reducing the activity in the brain of the neurotransmitter dopamine. Among the older, typical antipsychotics, such as haloperidol (Haldol®), thioridazine, fluphenazine, and chlorpromazine, haloperidol was found

in more than one study to be more effective than a placebo in treating serious behavioral problems.²⁷ However, haloperidol, while helpful for reducing symptoms of aggression, can also have adverse side effects, such as sedation, muscle stiffness, and abnormal movements.

Placebo-controlled studies of the newer “atypical” antipsychotics are being conducted on children with autism. The first such study, conducted by the NIMH-supported Research Units on Pediatric Psychopharmacology (RUPP) Autism Network, was on risperidone (Risperdal®).²⁸ Results of the 8-week study were reported in 2002 and showed that risperidone was effective and well tolerated for the treatment of severe behavioral problems in children with autism. The most common side effects were increased appetite, weight gain and sedation. Further long-term studies are needed to determine any long-term side effects. Other atypical antipsychotics that have been studied recently with encouraging results are olanzapine (Zyprexa®) and ziprasidone (Geodon®). Ziprasidone has not been associated with significant weight gain.

Seizures. Seizures are found in one in four persons with ASD, most often in those who have low IQ or are mute. They are treated with one or more of the anticonvulsants. These include such medications as carbamazepine (Tegretol®), lamotrigine (Lamictal®), topiramate (Topamax®), and valproic acid (Depakote®). The level of the medication in the blood should be monitored carefully and adjusted so that the least amount possible is used to be effective. Although medication usually reduces the number of seizures, it cannot always eliminate them.

Inattention and hyperactivity. Stimulant medications such as methylphenidate (Ritalin®), used safely and effectively in persons with attention deficit hyperactivity disorder, have also been prescribed for children with autism. These medications may decrease impulsivity

and hyperactivity in some children, especially those higher functioning children.

Several other medications have been used to treat ASD symptoms; among them are other antidepressants, naltrexone, lithium, and some of the benzodiazepines such as diazepam (Valium®) and lorazepam (Ativan®). The safety and efficacy of these medications in children with autism has not been proven. Since people may respond differently to different medications, your child's unique history and behavior will help your doctor decide which medication might be most beneficial.

Adults with an Autism Spectrum Disorder

Some adults with ASD, especially those with high-functioning autism or with Asperger syndrome, are able to work successfully in mainstream jobs. Nevertheless, communication and social problems often cause difficulties in many areas of life. They will continue to need encouragement and moral support in their struggle for an independent life.

Many others with ASD are capable of employment in sheltered workshops under the supervision of managers trained in working with persons with disabilities. A nurturing environment at home, at school, and later in job training and at work, helps persons with ASD continue to learn and to develop throughout their lives.

The public schools' responsibility for providing services ends when the person with ASD reaches the age of 22. The family is then faced with the challenge of finding living arrangements and employment to match the particular needs of their adult child, as well as the programs and facilities that can provide support services to achieve these goals. Long before your child finishes school, you will want to search for the

best programs and facilities for your young adult. If you know other parents of ASD adults, ask them about the services available in your community. If your community has little to offer, serve as an advocate for your child and work toward the goal of improved employment services. Research the resources listed in the back of this brochure to learn as much as possible about the help your child is eligible to receive as an adult.

Living Arrangements for the Adult with an Autism Spectrum Disorder

Independent living. Some adults with ASD are able to live entirely on their own. Others can live semi-independently in their own home or apartment if they have assistance with solving major problems, such as personal finances or dealing with the government agencies that provide services to persons with disabilities. This assistance can be provided by family, a professional agency, or another type of provider.

Living at home. Government funds are available for families that choose to have their adult child with ASD live at home. These programs include Supplemental Security Income (SSI), Social Security Disability Insurance (SSDI), Medicaid waivers, and others. Information about these programs is available from the Social Security Administration (SSA). An appointment with a local SSA office is a good first step to take in understanding the programs for which the young adult is eligible.

Foster homes and skill-development homes. Some families open their homes to provide long-term care to unrelated adults with disabilities. If the home teaches self-care and housekeeping skills and arranges leisure activities, it is called a “skill-development” home.

Supervised group living. Persons with disabilities frequently live in group homes or apartments staffed by professionals who help the

individuals with basic needs. These often include meal preparation, housekeeping, and personal care needs. Higher functioning persons may be able to live in a home or apartment where staff only visit a few times a week. These persons generally prepare their own meals, go to work, and conduct other daily activities on their own.

Institutions. Although the trend in recent decades has been to avoid placing persons with disabilities into long-term-care institutions, this alternative is still available for persons with ASD who need intensive, constant supervision. Unlike many of the institutions years ago, today's facilities view residents as individuals with human needs and offer opportunities for recreation and simple but meaningful work.

Research into Causes and Treatment of Autism Spectrum Disorders

Research into the causes, the diagnosis, and the treatment of autism spectrum disorders has advanced in tandem. With new well-researched standardized diagnostic tools, ASD can be diagnosed at an early age. And with early diagnosis, the treatments found to be beneficial in recent years can be used to help the child with ASD develop to his or her greatest potential.

Disorders/Vaccinations

The Institute of Medicine (IOM) conducted a thorough review on the issue of a link between thimerosal (a mercury based preservative that is no longer used in vaccinations) and autism. The final report from IOM, *Immunization Safety Review: Vaccines and Autism*, released in May 2004, stated that the committee did not find a link.

Until 1999, vaccines given to infants to protect them against diphtheria, tetanus, pertussis, *Haemophilus influenzae* type b (Hib),

and Hepatitis B contained thimerosal as a preservative. Today, with the exception of some flu vaccines, none of the vaccines used in the U.S. to protect preschool aged children against 12 infectious diseases contain thimerosal as a preservative. The MMR vaccine does not and never did contain thimerosal. Varicella (chickenpox), inactivated polio (IPV), and pneumococcal conjugate vaccines have also never contained thimerosal.

A U.S. study looking at environmental factors including exposure to mercury, lead and other heavy metals is ongoing.

Research on the Biologic Basis of ASD

Because of its relative inaccessibility, scientists have only recently been able to study the brain systematically. But with the emergence of new brain imaging tools—computerized tomography (CT), positron emission tomography (PET), single photon emission computed tomography (SPECT), and magnetic resonance imaging (MRI), study of the structure and the functioning of the brain can be done. With the aid of modern technology and the new availability of both normal and autism tissue samples to do postmortem studies, researchers will be able to learn much through comparative studies.

Postmortem and MRI studies have shown that many major brain structures are implicated in autism. This includes the cerebellum, cerebral cortex, limbic system, corpus callosum, basal ganglia, and brain stem.²⁹ Other research is focusing on the role of neurotransmitters such as serotonin, dopamine, and epinephrine.

Research into the causes of autism spectrum disorders is being fueled by other recent developments. Evidence points to genetic factors playing a prominent role in the causes for ASD. Twin and family studies have suggested an underlying genetic vulnerability to ASD.³⁰ To further research in this field, the Autism Genetic Resource Exchange, a project initiated by the Cure Autism Now Foundation, and aided by an NIMH

Cerebral cortex – a thin layer of gray matter on the surface of the cerebral hemispheres. Two-thirds of its area is deep in the fissures or folds. Responsible for the higher mental functions, general movement, perception, and behavioral reactions.

Amygdala – responsible for emotional responses, including aggressive behavior.

Hippocampus – makes it possible to remember new information and recent events.

Basal ganglia – gray masses deep in the cerebral hemisphere that serves as a connection between the cerebrum and cerebellum. Helps to regulate automatic movement.

Major Brain Structures Implicated in Autism

Brain stem – located in front of the cerebellum, it serves as a relay station, passing messages between various parts of the body and the cerebral cortex. Primitive functions essential to survival (breathing and heart rate control) are located here.

Corpus callosum – consists primarily of closely packed bundles of fibers that connect the right and left hemisphere and allows for communication between the hemispheres.

Cerebellum – located at the back of the brain, it fine tunes our motor activity, regulates balance, body movements, coordination, and the muscles used in speaking.

grant, is recruiting genetic samples from several hundred families. Each family with more than one member diagnosed with ASD is given a 2-hour, in-home screening. With a large number of DNA samples, it is hoped that the most important genes will be found. This will enable scientists to learn what the culprit genes do and how they can go wrong.

Another exciting development is the Autism Tissue Program (<http://www.brainbank.org>), supported by the Autism Society of America Foundation, the Medical Investigation of Neurodevelopmental Disorders (M.I.N.D.) Institute at the University of California, Davis, and the National Alliance for Autism Research. The program is aided by a grant to the Harvard Brain and Tissue Resource Center (<http://www.brainbank.mclean.org>), funded by the National Institute of Mental Health (NIMH) and the National Institute of Neurological Disorders and Stroke (NINDS). Studies of the postmortem brain with imaging methods will help us learn why some brains are large, how the limbic system develops, and how the brain changes as it ages. Tissue samples can be stained and will show which neurotransmitters are being made in the cells and how they are transported and released to other cells. By focusing on specific brain regions and neurotransmitters, it will become easier to identify susceptibility genes.

Recent neuroimaging studies have shown that a contributing cause for autism may be abnormal brain development beginning in the infant's first months. This "growth dysregulation hypothesis" holds that the anatomical abnormalities seen in autism are caused by genetic defects in brain growth factors. It is possible that sudden, rapid head growth in an infant may be an early warning signal that will lead to early diagnosis and effective biological intervention or possible prevention of autism.³¹

The Children's Health Act of 2000—What It Means to Autism Research

The Children's Health Act of 2000 was responsible for the creation of the Interagency Autism Coordinating Committee (IACC), a committee that includes the directors of five NIH institutes—the National Institute of Mental Health, the National Institute of Neurological Disorders and Stroke, the National Institute on Deafness and Other Communication Disorders (NIDCD), the National Institute of Child Health and Human Development (NICHD), and the National Institute of Environmental Health Sciences (NIEHS)—as well as representatives from the Health Resource Services Administration, the National Center on Birth Defects and Developmental Disabilities (a part of the Centers for Disease Control), the Agency for Toxic Substances and Disease Registry, the Substance Abuse and Mental Health Services Administration, the Administration on Developmental Disabilities, the Centers for Medicare and Medicaid Services, the U.S. Food and Drug Administration, and the U.S. Department of Education. The Committee, instructed by the Congress to develop a 10-year agenda for autism research, introduced the plan, dubbed a “matrix” or a “roadmap,” at the first Autism Summit Conference in November 2003. The roadmap indicates priorities for research for years 1 to 3, years 4 to 6, and years 7 to 10.

The five NIH institutes of the IACC have established the Studies to Advance Autism Research and Treatment (STAART) Network, composed of eight network centers. They will conduct research in the fields of developmental neurobiology, genetics, and psychopharmacology. Each

center is pursuing its own particular mix of studies, but there also will be multi-site clinical trials within the STAART network.

The STAART centers are located at the following sites:

- University of North Carolina, Chapel Hill
- Yale University, Connecticut
- University of Washington, Seattle
- University of California, Los Angeles
- Mount Sinai Medical School, New York
- Kennedy Krieger Institute, Maryland
- Boston University, Massachusetts
- University of Rochester, New York

A data coordination center will analyze the data generated by both the STAART network and the Collaborative Programs of Excellence in Autism (CPEA). This latter program, funded by the NICHD and the NIDCD Network on the Neurobiology and Genetics of Autism, consists of 10 sites. The CPEA is at present studying the world's largest group of well-diagnosed individuals with autism characterized by genetic and developmental profiles.

The CPEA centers are located at:

- Boston University, Massachusetts
- University of California, Davis
- University of California, Irvine
- University of California, Los Angeles
- Yale University, Connecticut
- University of Washington, Seattle
- University of Rochester, New York
- University of Texas, Houston
- University of Pittsburgh, Pennsylvania
- University of Utah, Salt Lake City

The NIEHS has programs (<http://www.niehs.nih.gov/translate/children/ctr-desc.htm>) at:

- Center for Childhood Neurotoxicology and Assessment, University of Medicine & Dentistry, New Jersey
- The Center for the Study of Environmental Factors in the Etiology of Autism, University of California, Davis

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For more information on autism spectrum disorders

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NIMH supported clinical trials

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U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES
National Institutes of Health
National Institute of Mental Health

NIH Publication No. 08-5511
Printed 2004 Reprinted 2008