STEPHEN WILTSHIRE is an artist with autism. He was mute as a child, and at age 5 he began to communicate by drawing on scraps of paper. He now talks with reporters and others who want to interview him about his work. Wiltshire lives in England, but has made a number of trips to America. These trips gained him much publicity in America and stimulated his “American Dream” series of art. He uses his visual memory to remember scenes he wants to sketch later. Very seldom does he sketch or paint while he is actually seeing the image for the first time. Most of his early work was done with pen and ink, but he has recently completed art school, where he learned the techniques of using color and paint. The drawing here is of St. Peters, Kensington Park Road.
Belinda and her husband are well-educated people and loving parents dedicated to their three young children. Everything was going perfectly for them. The business Aneel began after graduate school was becoming highly successful, and they loved being together. They decided it was time to start a family. Their first-born, a beautiful boy, was diagnosed with autism after Belinda was already pregnant with the twins. Here she recounts how her family’s course changed when a child was diagnosed with autism and they entered the special education maze.

My husband and I have two boys with autism. Receiving a diagnosis of autism is difficult, in large part because there is no universally accepted treatment protocol at this time. The professional making the diagnosis does not say, “He has autism. This is what you should do...” Parents are left to research different interventions on their own, and most choose a course of treatment without much professional advice.

Imagine yourself in a maze—not the simple kind used with rats in the psychology lab, but something bigger and darker with dozens of choices at every turn. The well-being of your child—indeed his very future—rests upon your ability to navigate this maze successfully. You are being timed, and the penalties for standing still are stiff. At the entrance to each corridor is a gatekeeper who will charge you time and money to enter. Some of the most promising corridors are too expensive. Others have prohibitively long lines of people waiting to get in. Several corridors look inviting, but after investing your time and money, you find a dead end. Now here’s the kicker: for most, the maze never ends. You can only hope to get as close to the jackpot as possible.

Since our first child was diagnosed two years ago, we have investigated applied behavioral analysis (ABA), speech therapy, occupational therapy, music therapy, auditory integration therapy (AIT), art therapy, and water therapy. We have looked into therapeutic riding, dolphin therapy, the picture exchange communication system (PECS*), megavitamin therapy, chelation, antifungal treatments, serotonin inhibitors, secretin, antiyeast agents, and gluten-free/casein-free diets. We have had the boys tested for chromosomal abnormalities, allergies, lead poisoning, and mercury poisoning. Am I forgetting anything? Oh yes, we spoke with a doctor who prescribes blood thinners for children with autism despite the fact that he has no scientific data to back up his theories.

After two years of navigating the maze, my husband and I have decided that certain corridors are not worth investigating. We do not enter corridors that might be potentially harmful to our children. We steer clear of those choices that might benefit our sons at the expense of the family unit. Most important, we have learned to ignore the ticking of the ever-present clock. We have decided that success at any age is still success.

1. What needs to happen so that parents of children with autism do not have to face such a confusing maze of people and services?

2. What do you think the future holds for this family?

* For more about PECS, see the “Family” section of this chapter and the “Validated Practices” box.
Think for a minute about all the things you do throughout the day that involve communicating with other people. Whether going out to buy some new clothes, going to class, or just hanging out with our friends, we communicate with others. Given the proliferation of cell phones and e-mail, one might conclude that communicating is central to the human experience. Through communication with others, we mediate our experiences, articulate our thoughts, describe our needs, express our desires, learn new skills, understand each other’s perspectives, and relate to one another. In general, relating to and communicating with others is so effortless, so much a part of who we are and what we do, that we rarely realize how integral it is in our lives.

Now imagine that communication is difficult for you. That is, imagine that even though you hear people talking, you do not understand the words you hear. Imagine that you are unable to produce words and that you do not know how to use other sorts of nonverbal communication strategies, such as gesturing or using your eyes to express yourself. Imagine further that being near another person is difficult for you. That is, when people approach you, even if it’s just with their gaze, you are unable to respond. For most of us, this is a world we truly cannot imagine. For many children with autism, however, this may be what life is like. Given a supportive and structured environment, however, children with autism can learn important communication and interaction skills—skills that will help them lead more independent lives.

Overview

Autism is a specific diagnosis included under the broader term, autistic spectrum disorders (ASD). In addition to autism, Asperger’s disorder, Rett’s syndrome, childhood disintegrative disorder (CDD), and pervasive developmental disorder—not otherwise specified (PDD-NOS)—are part of ASD. All conditions included in ASD are characterized by problems in three areas of development: communication, social skills, and range of interests. But, as the word “spectrum” implies, ASD falls along a continuum in each area of development ranging from severe problems to above-average abilities. No facial characteristics or other physical features help to identify children with ASD, so ASD is sometimes thought of as an “invisible” disability. The effects of ASD on children’s access to full participation in mainstream society, however, are all too visible. Historically, it was thought that 1 out of 10,000 children would be diagnosed with autism. Recently, however, more children are diagnosed specifically with autism and generally with ASD, and the increase is dramatic. For example, experts now estimate that 1 out of 500–700 children has autism. Even with this increase, ASD—its syndromes and disorders—comprise a low incidence disability affecting about 0.002% of the population.

Self-Test Questions

Focus Questions

- What is the relationship of autistic disorder, or autism, to autistic spectrum disorders?
- What is meant by the term spectrum, and what does this term imply about people diagnosed with ASD?
- What is the cause of autistic disorder? Why is this sometimes a controversial issue?
- What are some ways in which the learning environment can be modified and adapted for students with autism?
- Why should instruction in nonacademic areas such as social skills be included in educational programs for students with autism?

Challenge Question

- What are some of the implications or effects of autism being an “invisible” disability for the child and for the child’s family? What are the implications for educators? for other professionals?
OPPORTUNITIES FOR A BETTER FUTURE

With the 1997 reauthorization of IDEA, autism became an independent special education category*. However, considerable confusion remained about definitions and qualifications of those who can diagnose or label children with autism and the other autistic spectrum disorders (ASD). The independent classification coincided with increased attention on this disability. The results have been more coverage in the popular press and increased funding for research. Current research is focusing on determining the cause, developing new treatments, determining effective treatments, and how best to prepare school personnel to work with children with ASD. Clearly, the future holds promise for these children and their families.

TURNING LEGACIES INTO LESSONS

The study of autism as a field has existed for at least sixty years. In that time, many insights have been gained and advances have improved the quality of life for children with autism and their families. However, missteps have been made along the way. Here’s an important example: During the 1960s, Bruno Bettelheim, a psychologist, suggested that autism was caused by the cold interaction styles of mothers with their children. This theory, “the refrigerator mother theory”, has since been proved false, but the tragic, residual effects of this theory, or belief, are still felt today. Sometimes, professionals consciously or inadvertently blame parents for their child’s behavior or parents feel guilty thinking that their behavior may in some way have caused their child to become autistic. As scientists become better able to describe the causes for autism, this hurtful, discredited, and inaccurate view of the disability will disappear.

THINKING ABOUT DILEMMAS TO SOLVE

People with autism have deficits in skill areas that make learning difficult. As you read this chapter, consider

- How the three deficit areas (communication, social skills, and range of interests) affect how and what children with autism learn
- How the wide range of abilities within autism affects educational programming
- How deficits in nonacademic skills influence academic learning
- Ways to educate people about the facts of autism while debunking the myths
- How autism affects families
- How to provide instruction for children with autism so that they can more fully participate in the general education curriculum

* For a review of IDEA and its reauthorizations, see Chapter 1.

AUTISTIC SPECTRUM DISORDERS (ASD) DEFINED

Autistic spectrum disorder (ASD) is a broad term that groups together five specific disorders:

1. Autistic disorder or autism
2. Childhood disintegrative disorder (CDD)
3. Asperger’s syndrome
4. Rett’s syndrome
5. Pervasive developmental disorder–not otherwise specified (PDD-NOS)

These disorders share similar behavioral traits, characterized by problems with communication, social skills, and patterns of behavior or range of interests. The key word in the term ASD is spectrum, which implies similar characteristics but great variance in the actual skills exhibited. The National Research Council describes ASD in this way:
ASD varies in severity of symptoms, age of onset, and the presence of various features, such as mental retardation and specific language delay. The manifestations of ASD can differ considerably across children and within an individual child over time. Even though there are strong and consistent commonalities, especially in social deficits, there is no single behavior that is always typical of autism or any of the autistic spectrum disorders and no behavior that would automatically exclude an individual child from a diagnosis of ASD. (National Research Council, 2001, p. 2)

What differentiates the five types of ASD?

Each disorder included in ASD has specific diagnostic criteria. So, one way to think of ASD is as an umbrella of disorders—one of which is autism—that share a range of behaviors or common traits. Figure 12.1 illustrates ASD in this way. Now, let’s examine each condition to gain a clearer understanding of the similarities and differences among them.

- **Autism or Autistic Disorder** Technically, the terms *autism* or *autistic disorder* refer to a specific diagnosis, much like the word *Coke* refers to a specific type of soft drink, rather than generically referring to many brands of cola or all soft drinks. The term *autism* is often used in place of the term ASD to refer to all of the disorders and syndromes included under the ASD umbrella. Through IDEA, the federal government defines autism in this way:

  A developmental disability significantly affecting verbal and nonverbal communication and social interaction, generally evident before age 3, that adversely affects a child’s performance. Other characteristics often associated with

![Figure 12.1 Autism Spectrum Disorders (ASD) Umbrella](image)
autism are engagement in repetitive activities and stereotyped movements, resistance to environmental change or change in the daily routines, and unusual responses to sensory experiences. The term does not apply if a child’s educational performance is adversely affected primarily because the child has a serious emotional disturbance. (U.S. Department of Education, 1999, p. 12421)

The IDEA definition of autism is a general description and lacks the specificity needed to fully understand the disorder. The American Psychiatric Association (1994) in the fourth edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM-IV) provides specific diagnostic criteria for autism (see Table 12.1).

Table 12.1 DSM-IV Diagnostic Criteria for Autistic Disorder

<table>
<thead>
<tr>
<th>A. A total of six (or more) items from (1), (2), and (3), with at least two from (1) and one each from (2) and (3):</th>
</tr>
</thead>
<tbody>
<tr>
<td>(1) Qualitative impairment in social interaction, as manifested by at least two of the following:</td>
</tr>
<tr>
<td>(a) Marked impairment in the use of multiple nonverbal behaviors such as eye-to-eye gaze, facial expression, body postures, and gestures to regulate social interaction</td>
</tr>
<tr>
<td>(b) Failure to develop peer relationships appropriate to developmental level</td>
</tr>
<tr>
<td>(c) A lack of spontaneous seeking to share enjoyment, interests, or achievements with other people (e.g., by a lack of showing, bringing, or pointing out objects of interest)</td>
</tr>
<tr>
<td>(d) Lack of social or emotional reciprocity</td>
</tr>
<tr>
<td>(2) Qualitative impairments in communication as manifested by at least one of the following:</td>
</tr>
<tr>
<td>(a) Delay in, or total lack of, the development of spoken language (not accompanied by an attempt to compensate through alternate modes of communication such as gesture or mime)</td>
</tr>
<tr>
<td>(b) In individuals with adequate speech, marked impairment in the ability to initiate or sustain a conversation with others</td>
</tr>
<tr>
<td>(c) Stereotyped and repetitive use of language or idiosyncratic language</td>
</tr>
<tr>
<td>(d) Lack of varied, spontaneous make-believe play or social imitative play appropriate to developmental level</td>
</tr>
<tr>
<td>(3) Restricted repetitive and stereotyped patterns of behavior, interests, and activities as manifested by at least one of the following:</td>
</tr>
<tr>
<td>(a) Encompassing preoccupation with one or more stereotyped and restricted patterns of interest that is abnormal either in intensity or focus.</td>
</tr>
<tr>
<td>(b) Apparently inflexible adherence to specific, nonfunctional routines or rituals</td>
</tr>
<tr>
<td>(c) Stereotyped and repetitive motor mannerisms (e.g., hand or finger flapping or twisting, or complex whole-body movements)</td>
</tr>
<tr>
<td>(d) Persistent preoccupation with parts of objects</td>
</tr>
</tbody>
</table>

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

| C. The disturbance is not better accounted for by Rett’s disorder or childhood disintegrative disorder. |

Source: Reprinted with permission from the Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition (pp.70-71). Copyright 1994 American Psychiatric Association.
Note that according to this description all children with autism have impairments in communication, impairments in social skills, and restricted and repetitive behavioral patterns or range of interests.

Children with autism do not communicate with other people in typical ways. Approximately 50 percent of children with autism do not talk to communicate; these individuals are nonverbal (Sturmey & Sevin, 1994). Of the other 50 percent, some children are verbal, but much of what they say is merely a repetition of what they have just heard, this is called echolalia (Wetherby, Yonclas, & Bryan, 1989). Some children with autism generate verbal language, but make errors when using personal pronouns or have a difficult time understanding or forming semantic categories (Ramberg et al., 1996). Here’s an example: People with autism have difficulty understanding that the word dog refers to a general category of “dogness” as well as to specific examples of dogs. Regardless of the actual verbal abilities of a particular child, all children with autism have trouble with the use or pragmatics of language. Typically, they do not understand that communication happens between people nor do they understand that nonverbal cues and personal perspectives are important to successful communication (Wetherby & Prizant, 1993).

Children with autism also have problems with social interactions. They often appear to live in their own world and may not seek out the company of peers or adults. Many children with autism seem to use people as tools (Powers, 2000). For example, a child may lead an adult by the hand to the refrigerator and push the adult’s hand towards the juice the child wants. In this way, the child with autism is using the adult as a means to an end. Also, children with autism do not generally initiate social situations and do not engage in social turn-taking just for the pleasure of being part of a social interaction.

Children with autism have repetitive or odd patterns of behavior, stereotypic behaviors, unusual interests, or strange responses to the environment (Lewis & Bodfish, 1998). They may be attracted to specific aspects of a toy. For example, a child with autism may be interested only in spinning the wheel of a toy car or may be interested only in wiggling the string of a pull toy. Some children may have rigid or set patterns of behavior. For example, one child might line up his or her toys in a specific way, and might have to follow the same routine every day. If these patterns of behavior are violated, a tantrum might result to protest the disruption. Other children may repeat the same movement over and over again. For example, a child may wave his hand in front of an eye frequently. Not a lot is understood about the function of this type of behavior. Interestingly, children diagnosed with autism at a young age (around the age of 2 years) do not exhibit much of this type of routinized behavior. It is not known, however, if whether children with autism learn this type of behavior in response to their experiences in the world, or whether this aspect of the disorder just does not develop until children are older.

Intelligence scores are not considered in the diagnosis of autism, yet most children (approximately 75 percent) diagnosed with autism also have mental retardation (Sturmey & Sevin, 1994). Thus 25 percent of the autistic population has at least a normal level of intelligence. This wide range of cognitive ability has resulted in people using terms such as low-functioning autism and high-functioning autism. Low functioning autism often refers to children with autism and mental retardation; whereas, high functioning autism often refers to children without mental retardation. The term high functioning autism should not be thought a synonym for another type of ASD.

Are there types of autism? As the discussion above has illustrated, the skills that children diagnosed with autism exhibit vary greatly. Some experts think that the different levels of intellectual functioning, variety in the age of onset, and number and severity of symptoms suggest subtypes of autism (Koegel & Koegel, 1993; Wing, 1989). But, other experts do not agree. Currently, no consensus among experts has been achieved about the existence of subtypes of autism or whether subtype distinctions would be useful.
Regardless, one potential subtype of autism or group of people, **autistic savants**, is of far more interest to the general public than to researchers. The number of autistic savants is very small, only about 5 percent of individuals diagnosed with autism, but the public seems fascinated by the almost bizarre inconsistencies in this group’s abilities (Begley & Springen, 1996). For example, some, like the character Raymond in the film *Rain Man*, can instantly count the number of wooden matches that have fallen on the floor, remember the dates of important events, or recall the numbers of all of the winning lottery tickets for the past year. Others have outstanding musical or artistic abilities. But, even in light of these talents, these individuals are unable to initiate or maintain conversations. For example, nine-year-old Alex Mont can solve complicated mathematics problems, even calculus, but has difficulties comprehending social cues. Alex also could not distinguish a horse from a cow until after he finished kindergarten. While these splinter skills are fascinating to the observer, they are rarely functional for the individual.

<table>
<thead>
<tr>
<th>Table 12.2 DSM-IV Diagnostic Criteria for Childhood Disintegrative Disorder</th>
</tr>
</thead>
<tbody>
<tr>
<td>A. Apparently normal development for at least the first 2 years after birth as manifested by the presence of age-appropriate verbal and nonverbal communication, social relationships, play, and adaptive behavior.</td>
</tr>
<tr>
<td>B. Clinically significant loss of previously acquired skills (before age 10 years) in at least two of the following areas:</td>
</tr>
<tr>
<td>(1) expressive or receptive language</td>
</tr>
<tr>
<td>(2) social skills or adaptive behavior</td>
</tr>
<tr>
<td>(3) bowel or bladder control</td>
</tr>
<tr>
<td>(4) play</td>
</tr>
<tr>
<td>(5) motor skills</td>
</tr>
<tr>
<td>C. Abnormalities of functioning in at least two of the following areas:</td>
</tr>
<tr>
<td>(1) qualitative impairment in social interaction (e.g., impairment in nonverbal behaviors, failure to develop peer relationships, lack of social or emotional reciprocity)</td>
</tr>
<tr>
<td>(2) qualitative impairments in communication (e.g., delay or lack of spoken language, inability to initiate or sustain a conversation, stereotyped and repetitive use of language, lack of varied make-believe play)</td>
</tr>
<tr>
<td>(3) restricted, repetitive, and stereotyped patterns of behavior, interests, and activities, including motor stereotypes and mannerisms</td>
</tr>
<tr>
<td>D. The disturbance is not better accounted for by another specific pervasive developmental disorder or by schizophrenia.</td>
</tr>
</tbody>
</table>

*Source: Reprinted with permission from the *Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition* (pp. 74–75). Copyright 1994 American Psychiatric Association.*
• **Childhood Disintegrative Disorder (CDD)**  Childhood Disintegrative Disorder (CDD) is very rare—far rarer than autism. The DSM-IV description of CDD is found in Table 12.2 on page 421. The most distinguishing aspect of CDD is that these children develop as their nondisabled peers do until they are 5 or 6 years old, at which time a developmental regression begins. In particular, these children lose already acquired language and social skills. Eventually, their behaviors are similar to the behavior patterns of children with autism, however, their long-term outcomes are far worse.

• **Asperger’s syndrome**  Dr. Hans Asperger was the first to describe and classify Asperger’s syndrome as a collection of behavioral characteristics. Asperger’s syndrome is characterized by problems with social skills and by restricted or unusual behaviors or interests. Table 12.3 provides the DSM-IV description of this type of ASD. Although the communication of children with Asperger’s syndrome may be peculiar, this characteristic is not due to a delay in the development of speech or language. In fact, children diagnosed with Asperger’s syndrome develop speech and language on a par with children without disabilities. Other aspects of communication, however, are problematic. Some children with Asperger’s syndrome understand language very literally, which can make it difficult for them to form conceptual categories, understand jokes, or interpret nonverbal language (such as gestures). For these individuals, the social use of language can be a particular

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**Table 12.3 DSM-IV Diagnostic Criteria for Asperger’s Syndrome**

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

B. Restricted repetitive and stereotyped patterns of behavior, interests, and activities, as manifested by at least one of the following:
   1. Encompassing preoccupation with one or more stereotyped and restricted patterns of interest that is abnormal either in intensity or focus
   2. Apparently inflexible adherence to specific, nonfunctional routines or rituals
   3. Stereotyped and repetitive motor mannerisms (e.g., hand or finger flapping or twisting, or complex whole-body movements)
   4. Persistent preoccupation with parts of objects

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

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

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

F. Criteria are not met for another specific pervasive developmental disorder or schizophrenia.

challenge, as can be the ability to comprehend other people’s feelings or mental states (Safran, 2001).

Unlike children with autism, the majority of children with Asperger’s syndrome have normal intelligence, and should not be confused with those individuals with high functioning autism. Because children with autism are diagnosed when a delay in speech or language becomes apparent and children with Asperger’s syndrome develop normally, a diagnosis should never change from autism to Asperger’s syndrome. The distinction between autism and Asperger’s syndrome, however, may turn out to be only a matter of semantics. Presently, there is controversy about whether any meaningful differences in the behaviors or performance of people with high functioning autism and Asperger’s syndrome exist. In the future, results from psychological testing, quality of life measures, and brain activity might solve this controversy.

- **Rett’s syndrome** Rett’s syndrome, sometimes called Rett’s disorder, is a genetic condition discovered more than 40 years ago by Andreas Rett, an Austrian physician. The DSM-IV description of this syndrome is shown in Table 12.4. Signs of Rett’s syndrome appear early in life when development appears normal and then stops. Unlike many inherited conditions, Rett’s syndrome is more common in girls.

### Table 12.4 DSM-IV Diagnostic Criteria for Rett’s Syndrome

<table>
<thead>
<tr>
<th>A. All of the following:</th>
</tr>
</thead>
<tbody>
<tr>
<td>(1) apparently normal prenatal and perinatal development</td>
</tr>
<tr>
<td>(2) apparently normal psychomotor development through the first 5 months after birth</td>
</tr>
<tr>
<td>(3) normal head circumference at birth</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>B. Onset of all of the following after the period of normal development:</th>
</tr>
</thead>
<tbody>
<tr>
<td>(1) deceleration of head growth between ages 5 and 48 months</td>
</tr>
<tr>
<td>(2) loss of previously acquired purposeful hand skills between ages 5 and 30 months with the subsequent development of stereotyped hand movements (e.g., hand-wringing or hand washing)</td>
</tr>
<tr>
<td>(3) loss of social engagement early in the course (although often social interaction develops later)</td>
</tr>
<tr>
<td>(4) appearance of poorly coordinated gait or trunk movements</td>
</tr>
<tr>
<td>(5) severely impaired expressive and receptive language development with severe psychomotor retardation</td>
</tr>
</tbody>
</table>

Source: Reprinted with permission from the *Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition* (pp. 72–73). Copyright 1994 American Psychiatric Association.
Behaviorally, it is characterized by repeated, stereotypic hand wringing; lack of muscle control; along with communication and social deficits. Sometimes misdiagnosed as autism, Rett’s syndrome has different characteristics. Autism is not usually characterized by hand wringing. Children with autism tend to have better motor skills than children with Rett’s syndrome. Children with Rett’s syndrome tend to have better social skills when compared to children with autism. And, while about half of the individuals with autism have mental retardation, most children with Rett’s syndrome have mental retardation and those cognitive disabilities are more severe than what is observed in people with autism.

- **Pervasive Developmental Disorder–Not Otherwise Specified (PDD-NOS)** Problems in the areas of communication, social skills, and unusual behaviors including restricted range of interests are the three common characteristics of ASD. Each ASD condition—autism, CDD, Asperger’s syndrome, and Rett’s syndrome—is different because of the profile of behaviors exhibited by the individual or by the pattern of development observed. (While the DSM-IV describes PDD-NOS, it does not provide a table of its common characteristics.) When children do not display problems in all three areas, or when problems in all three areas are mild, a different diagnosis is made. In these cases, the disorder is identified as pervasive developmental disorder–not otherwise specified (PDD-NOS). The PDD part of the diagnosis signifies deficits similar to those of autism, CDD, Asperger’s syndrome, and Rett’s syndrome. The NOS part refers to other specified disorders or syndromes. Although they share characteristics, PDD-NOS is distinct from high functioning autism and Asperger’s syndrome.

**Are there other ways to organize ASD?**

Professionals are just beginning to understand ASD, so different views of the conditions themselves, and of their symptoms and severity, are still developing. To some, these different disorders and syndromes represent different types of autism. Others, however, suggest that types of autism may be formed across diagnostic categories and may instead be based on level of intellectual functioning, age of onset, or number or severity of symptoms (Tanguay, Robertson, & Derrick, 1998). Still others suggest that the child’s level of activity (e.g., active or passive) is the correct dimension on which to formulate subgroups (Rogers, 1998). And, as understanding of the genetic basis of ASD continues to develop, some suggest that differences in genetics may exist and that these differences should underlie any groupings. As it stands now, no consensus exists among experts about what dimensions should be used to develop subtypes of ASD, or even about whether it is useful to establish such categories.

**How are children with autism identified?**

Until recently, children with autism were not diagnosed until the age of 5, but now it is possible to diagnose children before the age of 3 (Stone et al., 1999). In part because of the development of new assessment tools, some children are even being identified as early as age 2. For example, the Autism Diagnostic Observation Scale (ADOS) and the Screening Test for Autism in Two Year Olds (STAT), along with developmental assessments and parent reports, help to identify very young children with autism. Because many typically developing children are just beginning to develop spoken language at the age of 2, and because the diagnostic features of autism include language delay, both the ADOS and the STAT include measures that also examine other skills, such as children’s ability to imitate motor movements. In other words, children with autism seem to also have deficits in motor imitation skills that can be used for diagnosis before other problems (e.g., deficits in language) become apparent.
Although current assessment procedures cannot diagnose children younger than 2, researchers are working to develop valid and reliable assessments to identify even younger children with autism. It is likely that these efforts will be successful, because researchers can now diagnose children retrospectively when they are 1 year old. Specifically, Julie Osterling and Gerry Dawson examined videotapes parents had made of their children’s first birthday parties. They recognized that the children who were later diagnosed with autism behaved differently from typically developing children (Osterling & Dawson, 1994). They have identified four major differences that distinguish these children. The children later diagnosed with autism

- Did not use a finger to point at an object
- Did not show their presents to others
- Did not respond to their names
- Did not make direct eye contact with others

Interesting as this information is, it has not yet been incorporated into an assessment instrument that can be used prospectively to diagnosis 1-year-olds with autism.

Efforts are underway to develop methods to detect autism even before a child’s first birthday. Around nine months of age, children without disabilities begin to engage in what psychologists describe as joint attention. Joint attention involves two people such as a child and a parent. It occurs when first one person looks at an object, then looks at the other person, and finally when the two people simultaneously look at the object. That is, they together (or jointly) look at (or attend) to the same object. Researchers believe that joint attention is important in the development of both language and social skills (Mundy & Neal, 2001). While children with autism do participate in joint attention episodes, their pattern and type of participation is different from that of children without disabilities. (Shienkopf et al., 2000).

Why is this information important? Potentially, it can help us understand more about the development of social and language skills as well as the core characteristics of autism. Such information might also lead to earlier identification of children with autism. No diagnostic tools are currently available that address deficits in joint attention, but many psychologists look for a child’s joint attention skills when forming their clinical impressions about him or her.

Most assessment instruments used to diagnose children with autism are administered by trained psychologists with experience diagnosing children with autism. One screening tool, the Checklist for Autism in Toddlers (CHAT), was developed to help physicians spot early warning signs. Another measure, the Childhood Autism Rating Scale (CARS), is widely used to confirm a diagnosis and also to monitor the child’s growth over time. The CARS also describes the severity of problems that a child with ASD demonstrates.

What is the impact of this disability?

Autism is a significant, lifelong disability. Even for those with average intelligence, long-term outcomes in terms of independent living, employment, and life satisfaction are bleak (Sperry, 2001). In fact, most people with autism require comprehensive services and extensive supports for their entire lives. Effective services and supports require high levels of coordination and consistency. Unfortunately, these are difficult goals to achieve through the often fragmented services offered by social service agencies, health care providers, and the educational system.

From the start of life, the skill deficits of children diagnosed with autism affect their learning and development of social relationships. Children with autism do not participate in turn-taking exchanges. This lack of social interaction directly and adversely affects the acquisition and use of preverbal communications (e.g., gestures) as well as the eventual acquisition of speech and language skills (Stone & Yoder, 2001). Most cultural mores are passed from generation to generation via
Oliver Sacks, in the foreword to Temple Grandin’s (1996) biography, *Thinking in Pictures and Other Reports of My Life with Autism*, underscores the importance of her insights about her disability. Unprecedented because there had never before been an “inside narrative” of autism; unthinkable because it had been medical dogma for forty years or more that there was no “inside,” no inner life, in the autistic, or that if there was it would be forever denied access or expression; extraordinary because of its extreme (and strange) directness and clarity. Temple Grandin’s voice came from a place which had never had a voice, never been granted real existence, before—and she spoke not only for herself, but for thousands of other, often highly gifted, autistic adults in our midst. She provided a glimpse, and indeed a revelation, that there might be people, no less human than ourselves, who constructed their worlds, lived their lives, in almost unimaginably different ways.

Temple does not romanticize autism, nor does she downplay how much her autism has cut her off from the social whirl, the pleasures, the rewards, the companionships, that for the rest of us may define much of life. But she has a strong, positive sense of her own being and worth, and how autism, paradoxically, may have contributed to this. (pp. 11, 16)

Temple Grandin, an adult with autism, describes her thought processes as being very different from those of most other people:

I think in pictures. Words are like a second language to me. I translate both spoken and written words into full-color movies, complete with sound, which run like a VCR tape in my head. When somebody speaks to me, his words are instantly translated into pictures. Language-based thinkers often find this phenomenon difficult to understand, but in my job as an equipment designer for the livestock industry, visual thinking is a tremendous advantage. . . . [O]ne third of the cattle and hogs in the United States are handled in equipment I have designed. (p. 19)

She helps us understand autism better by explaining how her senses are too active:

Overly sensitive skin can be a big problem. Washing my hair and dressing to go to church were two things I hated as a child. . . . Scratchy petticoats were like sandpaper scraping away at raw nerve endings. . . . When I was little, loud noises were also a problem, often feeling like a dentist’s drill hitting a nerve. They actually caused pain. I was scared to death of balloons popping, because the sound was like an explosion in my ear. Minor noises that most people can tune out drove me to distraction. . . . My ears are like microphones picking up all sounds with equal intensity. (pp. 66–68)

Grandin talks about her emotional differences, which may help us understand different behavior patterns in children with autism:

Some people believe that people with autism do not have emotions. I definitely do have them, but they are more like the emotions of a child than of an adult. My childhood temper tantrums were not really expressions of emotion so much as circuit overloads. . . . When I get angry, it is like an afternoon thunderstorm; the anger is intense, but once I get over it, the emotion quickly dissipates. . . . I don’t know what it is like to feel rapturous joy. I know I am missing something when other people swoon over a beautiful sunset. Intellectually I know it is beautiful, but I don’t feel it. . . . Emotional nuances are still incomprehensible to me, and I value concrete evidence of accomplishment and appreciation. . . . I still have difficulty understanding and having a relationship with people whose primary motivation in life is governed by complex emotions, as my actions are guided by intellect. (pp. 87–90)

Grandin describes typical autistic behaviors not as an observer, but as the participant. In doing so, she gives us guidance about how educational programs should be developed:

I would tune out, shut off my ears, and daydream. My daydreams were like Technicolor movies in my head. I would also become completely absorbed in spinning a penny or studying the wood-grain pattern on my desktop. During these times, the rest of the world disappeared, but then my speech teacher would gently grab my chin to pull me back into the real world. . . . Autistic children will remain in their own little worlds if left to their own devices. (p. 96)

[Teachers must] be able to determine whether a tantrum or other bad behavior is caused by fear or pain or a learned avoidance response. Sometimes it’s because of pain from sounds that hurt their ears or fear of an unexpected change in routine. . . . Autistics are afraid of the unexpected. (pp. 149–150)

Source: From *Thinking in Pictures and Other Reports from My Life with Autism* by Temple Grandin, copyright ©1995 by Temple Grandin. Used by permission of Doubleday, a division of Random House, Inc.
implicit teaching that involves social interactions and observational learning. Both of these means of learning represent deficit areas for children with autism. Most instruction at school is socially mediated and language-based, again problem areas for children with autism. Thus the social and communication problems faced by children with autism create a cascade of obstacles to learning in general (Carpenter, Pennington, & Rogers, 2002). In this way, autism pervasively affects the child’s entire developmental trajectory.

Even high-functioning individuals with autism face considerable challenges. In a fascinating account of her own life, entitled *Thinking in Pictures and Other Reports from My Life with Autism*, Temple Grandin (1995) shares with the world what it is like to experience the pains of isolation and of being very different from her peers. Excerpts from her biography appear in the accompanying box. Dr. Grandin holds a doctorate in animal science from the University of Illinois and is currently a professor at Colorado State University. She is well known for her designs of livestock-holding equipment, and one-third of all such equipment in this country was designed by her. You may be thinking, “How could someone with such a significant disability be such a successful scientist?” Truly, she is unique. However, her insights may help others.

Dr. Grandin writes about her early frustrations with not being able to talk, even though she understood language. She also mentions her hypersensitivity to sound and touch, which caused her to withdraw from people and the world outside herself. She continues to experience motor problems, having difficulties with balance and with coordinating multiple motor responses simultaneously. Even today, she says, she cannot move two or three levers at the same time. She is a strong advocate of early intervention programs. She maintains that young children with autism must not be allowed to “tune out.” She believes that these children must remain engaged with others in activities at least 20 hours per week; they must not be allowed to withdraw into their own worlds and shut everyone and everything out. A lot can be learned from Dr. Grandin’s insights, for despite her successful career, she continues to experience many of the symptoms of autism. She certainly is proof that people with autism can function in the community with supports. Unfortunately, most adults with autism do not fare as well.

**HISTORY OF THE FIELD**

Although autism has probably always been part of the human condition, its discrete identification is relatively recent. In 1943 Leo Kanner, a child psychiatrist at Johns Hopkins University Medical School, first described children and the condition he called “early infantile autism.” (Independently, but almost simultaneously, Hans Asperger described a similar condition that would be named Asperger’s syndrome.) Kanner’s use of *early infantile* reflects his strongly held belief that the condition he was describing was present at or shortly after birth. Kanner borrowed the term *autism* from Eugen Bleuer, a Swiss psychiatrist who had coined the term in 1911. Bleuer used the term *autism* to describe patients with schizophrenia who actively withdraw into their own world. Unfortunately, the notion of voluntary withdrawal also became associated with children with autism, inviting the fallacious notion that these children were withdrawing because parents, particularly mothers, were cold or uncaring. The outcomes of these ideas were devastating to families and resulted in children being removed from their families and raised in institutions (Powers, 2000).

In the 1960s, the treatment of autism changed. First, enough scientific evidence
had been collected to rule out the idea that the “refrigerator mother” (or parent) caused autism. Instead, experts began to believe that autism probably resulted from neurological or biochemical problems. Second, parents organized themselves and advocated for themselves and their children. Bernard Rimland spearheaded this advocacy movement. He was a psychologist who dedicated his career to studying autism after his son was diagnosed with the condition. Rimland helped to collect and organize the information known about autism, but he also joined with other parents to form a parent advocacy group called the National Society for Autistic Children (now called the Autism Society of America). This major advocacy group, armed with data collected by the Autism Research Institute (which Rimland founded in 1967) successfully lobbied for the independent classification of autism in the 1990 reauthorization of IDEA (Rimland, 1994).

Currently, several major parent organizations advocate for the rights of children with autism and their families. These organizations raise money for research, hoping to find a cure for autism. The federal government has also increased funding for research to determine the causes of autism, as well as to develop medical and behavioral/educational treatments for this condition.

PREVALENCE

No precise census, or count of the number, of children with autism has been made, so it is not possible to say exactly how many people have autism. Since 1990, when autism became a separate special education category, the states have reported to the federal government the number of students served in special education programs. In the 1999–2000 school year, some 61,406 students between the ages of 6 and 17 received special education services (U.S. Department of Education, 2001). Although it is not possible to chart prevalence rates of autism across time, parents, professionals, and policymakers tend to agree that many more children are diagnosed with autism today than received this diagnosis in the past (Burton, 2002). Two sources of information are used when reporting prevalence: epidemiological studies and the data collected by states about enrollment in special education programs (National Research Council, 2001).

Epidemiological studies conducted in ten countries with approximately 4 million children reveal that the incidence rate of autism has increased from about 2 to 5 children out of every 10,000 diagnosed with autism in the 1970s to 7.5 children out of every 10,000 being diagnosed with autism since 1987 (Fombonne, 1999). When Asperger’s syndrome and other ASD diagnoses are included, the incidence rate increases even more.

Exact estimates vary, but data from school districts’ special education programs confirm this increase. Figure 12.2 illustrates the numbers of students in California who have received special education services under the state’s autism category since 1991. As you can see, there is a dramatic rise in the number of children with autism receiving special education services. Three possible explanations for this increase are

1. Improved diagnostic methods
2. Use of the broader term ASD instead of the narrower term autism
3. An actual increase in the condition

Although no strong evidence supports any one of these explanations over the others, most experts believe that the increased incidence of autism is due to better diagnostic procedures, along with the use of the broader ASD definition (National Research Council, 2001). This conclusion, however, is controversial. Some experts and many parents believe that an actual increase in the number of children with autism is occurring. However, until a good census is completed or until there is a
known cause for this disability, the reason for the increased number of children diagnosed with autism will continue to be debated. Remember that even with this increase in diagnosis, ASD remains a low incidence disability. Most pediatricians and general education teachers are likely to have no or little opportunity to meet or work with children who have the disorders or conditions included in this spectrum.

**CAUSES OF AUTISM**

Experts have been trying to identify the causes of autism, but to date no definitive answers are available. With no specific causes having been identified, it is impossible to develop prevention strategies. This situation is frustrating to people who work with children with autism, but perhaps it is most frustrating to families. Because they want to know the chances of having another child with autism, it is important for researchers to continue their work in determining whether there is a genetic basis for these disorders.

Although precise causes have not been identified, a number of suggestions and reasonable conclusions have been made. First, several suggested causes of autism have been ruled out. Here’s one such example: autism is not the result of inadequate parenting. There’s something that we know is not the reason for the disability. Most experts agree that autism is a lifelong neurological disorder. Some researchers believe that at least some forms of autism are caused by injury to the brain stem (Koegel et al., 1995). Others suggest that autism is basically a failure of the frontal lobe (Dawson et al., 1998). Regardless, it appears that autism probably has a genetic basis (Piven, 2002).

Until such time as more specific causes are identified, speculation about a range of possibilities will persist. The causes suggested in recent years, have included: environmental toxins; gastrointestinal anomalies; and ingredients in the measles, mumps, and rubella vaccines. Such speculation about possible causes of autism creates dangerous situations. For example, some parents believe that the measles/mumps/rubella vaccine causes autism. Although little evidence exists that the vaccine plays any role as a cause of autism, some parents are not protecting their children from these diseases, leaving them vulnerable to conditions that are known to cause disabilities (Cowley, Brownell, & Footes, 2000).

Just as there are few known causes, no consistently effective treatments are available (Seroussi, 2000). The Internet and popular press are littered with stories of children being “cured,” but these accounts often involve the use of vitamins, special diets, or medical drugs. The parents and professionals who support these alternative treatments may believe in them and may believe that the treatments help remediate

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**Figure 12.2** Prevalence Rates of ASD in California


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**Making Connections**

For a comparable situation, see the “History” section of Chapter 4 and think about the confusion surrounding the selection of treatments when causes for a disability are not known.
a child’s symptoms, but no scientific evidence validates these claims. Until autism is well understood and consistently effective treatments are developed, the causes and treatments for autism will remain the subject of considerable speculation and conjecture.

**CHARACTERISTICS**

Despite the heterogeneity of autism, some general statements can be made about characteristics that people with this disorder share (see Table 12.5). Autism is a lifelong disability, and no specific physical features are associated with the conditions. Although identified during early childhood, autism is present from birth or very early in the developmental period. Although autism results in unique profiles of symptoms across individuals and conditions, it typically affects three important areas that help to define the condition (Barnhill, 2001):

<table>
<thead>
<tr>
<th>Table 12.5 Characteristics of Autism</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Impairment in Reciprocal Social Interactions</strong></td>
</tr>
<tr>
<td>• Normal attachments to parents, family members, or caregivers do not develop.</td>
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<tr>
<td>• Friendships with peers fail to develop.</td>
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<tr>
<td>• Cooperative or peer play is rarely observed.</td>
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<tr>
<td>• Emotions, such as affection and empathy, are rarely displayed.</td>
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<tr>
<td>• Nonverbal signals of social intent (smiling, gestures, physical contact) tend not to be used.</td>
</tr>
<tr>
<td>• Eye contact is not initiated or maintained.</td>
</tr>
<tr>
<td>• Imaginative play is seldom observed.</td>
</tr>
<tr>
<td>• The lack of social-communicative gestures and utterances is apparent during the first few months of life.</td>
</tr>
<tr>
<td>• Preferred interaction style could be characterized as “extreme isolation.”</td>
</tr>
<tr>
<td>• Understanding of others’ beliefs, emotions, or motivations is greatly impaired.</td>
</tr>
<tr>
<td>• Joint attention deficits (not being able to cooperate or share interest with others in the same event or activity) impair normal social reciprocation.</td>
</tr>
<tr>
<td><strong>Poor Communication Abilities</strong></td>
</tr>
<tr>
<td>• Functional language is not acquired fully or mastered.</td>
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<tr>
<td>• Content of language is usually unrelated to immediate environmental events.</td>
</tr>
<tr>
<td>• Utterances are stereotypic and repetitive.</td>
</tr>
<tr>
<td>• Gestures, facial expressions, and nonverbal cues are poorly understood.</td>
</tr>
<tr>
<td>• Conversations are not maintained.</td>
</tr>
<tr>
<td>• Spontaneous conversations are rarely initiated.</td>
</tr>
<tr>
<td>• Speech can be meaningless, repetitive, and echolalic.</td>
</tr>
<tr>
<td>• Many fail to use the words I and yes and have problems with pronouns in general.</td>
</tr>
<tr>
<td>• Both expressive and receptive language are extremely literal.</td>
</tr>
<tr>
<td>• Verbal turn-taking, choosing a topic, and contributing properly to a conversation are rare.</td>
</tr>
<tr>
<td><strong>Insistence on Sameness</strong></td>
</tr>
<tr>
<td>• Marked distress is typically experienced over trivial or minor changes in the environment.</td>
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<tr>
<td>• Aspects of daily routine can become ritualized.</td>
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<tr>
<td>• Obsessive and compulsive behavior is frequently displayed.</td>
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<tr>
<td>• The need to complete self-imposed, required actions is intense.</td>
</tr>
<tr>
<td>• Stereotypic behaviors (rocking, hand-flapping) are repeated in cycles difficult to stop.</td>
</tr>
<tr>
<td><strong>Unusual Behavior Patterns</strong></td>
</tr>
<tr>
<td>• Hypersensitive and/or inconsistent behaviors are the response to visual, tactile, or auditory stimulation.</td>
</tr>
<tr>
<td>• Aggression to others is common, particularly when compliance is requested.</td>
</tr>
<tr>
<td>• Self-injurious or outwardly aggressive behavior (hitting, biting, kicking, head-banging) is common and frequent.</td>
</tr>
<tr>
<td>• Extreme social fears are manifested toward strangers, crowds, unusual situations, and new environments.</td>
</tr>
<tr>
<td>• Loud sounds (barking dogs, street noises) can result in startle or fearful reactions.</td>
</tr>
<tr>
<td>• Severe sleep problems occur with frequency.</td>
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<tr>
<td>• Noncompliant behavior to requests from others results in disruption to the individual and others (tantrums).</td>
</tr>
<tr>
<td>• Self-stimulation (twirling objects, rocking) consumes a considerable amount of time and energy.</td>
</tr>
<tr>
<td>• The ability to pretend is lacking.</td>
</tr>
</tbody>
</table>
1. Communication
2. Social interactions
3. Restricted range of interests or behavioral repertoires

Here are a few more specifics. Among children with autism,

- 75–80 percent have a concurrent diagnosis of mental retardation
- 50 percent never develop functional speech
- 40 percent engage in self-injurious behavior
- 4 out of 5 are male
- 33 percent develop seizures (Sturmey & Sevin, 1994)

In addition to these characteristics and the characteristics described by the diagnostic criteria, children with autism may be sensitive to sensory input, such as loud noises or soft touches (Talay-Ongan & Wood, 2000). They have trouble developing the abilities necessary to understanding other people’s perspectives or to predicting others’ behavior—both important skills for successful communication. (Baron-Cohen, 2001). Regardless, remember that children with autism are children first and thus are more like other children than they are different from their peers.

**EARLY CHILDHOOD EDUCATION**

While children can be diagnosed with autism before the age of 3, little empirical data suggests which practices and programs are best for these very young children. In other words, the ability to diagnose children with autism has outpaced the
validation of effective interventions. A few practices developed for older children with autism and other developmental disabilities have also proven to be effective with toddlers with autism. For example, the increased frequency of making choices causes increases in appropriate engagement and also decreases inappropriate behavior (Reinhartsen, Garfinkle, & Wolery, in press). Similarly, the Walden Program is effective with 3-to-5 year-old children with autism, and has been adapted to serve even younger children. Others, like the Inclusive Program for Very Young Children with Autism, are being developed from collective information about child development, the nature of autism, and existing interventions that have been validated with 2-year-olds with autism (Marcus, Garfinkle, & Wolery, 2001).

Educational programs for 3- to 5-year-old children are some of the most developed and best studied, but much is still to be learned (Handleman & Harris, 2000). For example, no one program is consistently effective, so universal recommendations about educational programming cannot be made. Also, no guidelines can suggest whether one type of program would be better than another for a particular child. Finally, few studies have measured the effectiveness of a treatment program using a randomized, experimental study, and no studies have compared the effectiveness of one program against that of another.

Although no programs have been totally validated, research has identified some key features of effective programs for preschoolers. These key features are apparent even across programs that differ in philosophy, theoretical background, intensity of services, and timing of instruction with peers (Dawson & Osterling, 1997; Harris & Handleman, 1994). Key elements of all successful programs include:

- Supportive teaching environments
- Plans for generalization
- Predictable and routine schedules
- Functional approaches to address problem behaviors
- Supports for program transitions
- Family involvement and support

These programs also include some common targets for instruction. Students with autism often do not profit from instruction that is not clear, specific, and concrete. The “Tips for Teachers” box identifies some important instructional content that teachers should include in their curriculum for these preschoolers.

Even though most effective programs for young children with autism share some features, significant differences exist across programs. (Some disagreements among the advocates of different programs have been so intense that they have had to be resolved in the courts!) Two particular programs are popular in the education of preschoolers with autism: the Treatment and Education of Autistic and Communication-Handicapped Children (TEACCH) and the Young Autism Program (YAP). Let’s look at some highlights of each program.

### What are some features of TEACCH?

TEACCH was developed at the University of North Carolina at Chapel Hill. The program emphasizes the use of structured teaching (Lord & Schopler, 1994). Structured teaching involves adapting materials and environments to help children make sense of the world. Once new skills are acquired, children are taught to
perform them more and more independently. The program relies on “start-to-finish boxes” as well as visual supports and schedules in teaching. The underlying philosophy of the program is that children with autism are missing skills that they cannot learn but that can be compensated for through visual supports and other forms of structure. TEACCH is an individualized program that supports families through collaboration and training. In this program, parents become co-therapists.

**What is the Young Autism Program (YAP)?**

The Young Autism Program (YAP) grew out of the work of I. Ovar Lovaas at UCLA (Lovaas, 1987). Sometimes it is simply referred to as the “Lovaas Program” or, incorrectly, as ABA (which stands for applied behavior analysis¹). YAP is an intensive (usually 40 hours a week) program that uses the principles of applied behavior analysis (e.g., positive reinforcement) as well as the instructional strategies that have been developed by behavior analysts (e.g., task analysis and discrete trial training). The goal of this program is to teach children, one skill at a time, all the skills the child needs to be able to participate independently in all facets of daily living.

**Why are blended programs being developed?**

Although the theoretical bases of two popular intervention programs—TEACCH and YAP—are very different from one another, they have many similar components because both include empirically validated strategies. Also, the strategies of both programs target the same skill areas: communication, social skills, toy play, attention, and motor imitation (Dawson & Osterling, 1997). Many researchers, teachers, and parents of children with autism are more interested in effective intervention strategies than in strictly following a particularly philosophy or theory. Thus, combining or blending some elements of established programs, such as structured teaching with discrete trial teaching, is becoming commonplace. One example of a blended program being developed by researchers who are including successful aspects of established early interventions programs is the Developmentally Appropriate Treatment for Autism Project (DATA Project) at the University of Washington in Seattle. In this program, strategies that are effective for a particular child are applied without regard to the theoretical background from which the strategy was initially developed. In other words, they use what works and assess effectiveness through program evaluation. Such types of programs use elements of a variety of procedures (e.g., structured teaching, behavioral principles, discrete trial training, or various combinations) (Schwartz et al., 2001).

**ELEMENTARY THROUGH HIGH SCHOOL**

Although most established and researched intervention programs for children with autism are designed for preschool children, many of the same principles and strategies are applicable for older children as well. In particular, consistent structure,

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¹People often refer to the UCLA program as ABA. This is technically incorrect. ABA stands for applied behavior analysis. Applied behavior analysis is the science of studying observable behavior in settings where people spend time (homes, schools, etc.). The basic principles are those of behaviorism as articulated by B. F. Skinner and others. YAP and other programs for children with autism use ABA principles in designing interventions, but ABA is not synonymous with any one treatment program.
support of functional communication, instruction on social skills, and a functional and positive approach to supporting behavior are important for school children with autism (Scott, Clark, & Brady, 2000). One technique that is commonly used in classrooms where these children participate is functional behavioral assessments (Horner, 1994; Sugai et al., 1999). An example of the application of this technique is found in the “Achieving Discipline” box.

When planning educational programs for children with autism, educators must work together to develop plans for the delivery of an appropriate education for each individual. Here are some questions that educators typically ask themselves during such planning sessions (Scott, Clark, & Brady, 2000):

- What skills will help this child in his or her current and future environments?
- What skills will help this child be successful in less restrictive environments?
- What age-appropriate and socially valid goals does this child need to learn?
- Are support and instruction being provided for skills the child is good at and enjoys executing?

In addition, most programs for this age group specifically include instruction on social skills. Difficulty with social interactions is a defining characteristic of ASD, and the basis for some of these problems lies in the fact that these individuals seem unable to comprehend other people’s emotions, feelings, or perspectives (Barnhill, 2001). Many of these individuals are unable to take turns or execute “polite” behaviors without direct and systematic instruction. Deficits in these areas can lead to lifelong problems in the community and in the workplace. Instruction on social skills can be incorporated into children’s entire school day, or such activities can take place during specified, social skills group times. Typically, goals and objectives include learning how to take another person’s perspective, how to make and maintain friendships, and what social behaviors are appropriate in different contexts. Children with autism often develop good job skills but cannot keep jobs because of their social performance. Thus, social skills instruction is imperative.

While there are many strategies for teaching social and communication skills to children with autism, many of these strategies involve the use of visual cues or supports. For example, in the technology section of this chapter, you will learn more about the picture exchange communication system (PECS), which is proving to be effective in helping children with autism develop language and communication skills (Bondy & Frost, 2002; Schwartz, Garfinkle, & Bauer, 1998). Here, students use pictures to express their desires and needs to others. Written text and pictures are also proving to be effective interventions to facilitate development of social skills (Thiemann & Goldstein, 2001). In one approach, students are shown cartoon-like drawings of appropriate social behaviors (e.g., how to gain someone’s attention properly, how to initiate conversations) as part of an instructional routine that includes role playing, modeling, and rewards.

Some children with autism find that a hobby such as photography can help them relax and focus their attention on different activities.
Collaboration for Inclusion

Children with autism must have access to least restrictive environments. Sometimes, this access is hard to achieve and maintain. Using techniques such as functional behavioral assessments (see again the “Achieving Discipline” box) can help teachers encourage behaviors that will allow students to remain engaged in instruction provided in the general education classroom. Such interventions, along with many adjustments and accommodations, become part of the package necessary to ensure LRE and FAPE to youngsters who are difficult to teach. Multidisciplinary teams of professionals—including general and special educators and behavior specialists—must work together to identify the specific accommodations needed by each child. Those modifications discussed in the “Accommodating for Inclusive Environments” box are some commonly selected adjustments.

It is imperative that students with autism experience normative, programmed, and supported interactions with typically developing peers. Such inclusion provides these youngsters with appropriate role models, where they can observe how others behave and interact with each other. Some programs, such as Learning Experiences: An Alternative Program for Preschoolers and Parents (LEAP), integrate children

Making Connections
For a review of FAPE and LRE, see Chapters 1 and 2.

Making Connections
Review the “Accommodating” boxes in Chapters 3–13 for more ideas about ways to modify the learning environment to maximize success.
with autism into inclusive settings at the outset of treatment (Hoyson, Jamieson, & Strain, 1984). Other programs, such as TEACCH and YAP, systematically include peer models in special programs as the child learns interaction and communication skills. Regardless of the approach, many children with autism do well in inclusive environments. But remember that the following elements must be present:

- Sufficient structure
- Supports for functional communication
- A functional approach to problem behaviors
- Supports for social interactions

Accomplishing these aims requires the combined and concentrated efforts and collaboration of teams of professionals.

**TRANSITION THROUGH ADULTHOOD**

Few supports are typically available to persons with autism as they transition into adulthood. Although many persons with autism have skills that would make them employable, their difficulty with social skills and their need for routine often keeps them from being hired or prevents them from being able to remain employed. In general, the difficulties faced by people with autism are similar to those faced by others with severe disabilities. Transition plans can be helpful, but issues such as living and working independently are major problem areas for people with autism and their families. Transition experts have reached consensus about the skills necessary for independent living. Those transition outcomes, which should become some of the goals for these students’ education and should be mastered by the time they complete their schooling, are described in Table 12.6.
For people with autism, life as an adult can be challenging for themselves and for their families. Many of these individuals, like Jessy Park, seem happy enough, particularly when they are able to retreat to the world they understand—often a world of their own making complete with structure and security in routine patterns and limited contact with others (Park, 2001). Jessy is an artist, whose work is now getting some national attention, but she is unable to live independently or interact with people comfortably enough to live and participate in the community without extensive supports. Anthony Crudale, another recognized artist with autism, is a college graduate and a marathon runner (Raia, 2001). Although he drives a car, at age 24 he still cannot live independently or sustain competitive employment. His mother reports that people do not understand autism and that Anthony’s inability to maintain eye contact with other people, his short verbal responses, and his inability to carry on conversations make others uncomfortable. She believes that he, and others with autism, would make excellent employees because of characteristics like focusing on specific tasks, attention to detail, and the need to complete jobs. Thus, although many people with autism are now living in the community (instead of in institutions), their participation in and full access to mainstream society remains distant goals.

**Families**

Having a child with autism is difficult even for the most confident parents (Powell, Hecimovic, & Christensen, 1992). These children often lack independent play and leisure skills, which means that parents must spend more time providing direct care...
to their children. One result is that these parents have less time to take care of other important activities of daily living, such as self-care and household chores.

Perhaps more frustrating for these families are ways their children seem different. Some parents report difficulties connecting with or relating to their child. This experience is common with children who do not like physical affection such as hugs or who are extremely socially avoidant. Parents who believe they are in part responsible for their children’s instruction often find it very frustrating when learning is not achieved or is achieved very slowly.

Autism is nevertheless an invisible disability: these children do not have any facial or physical features indicating the disability. Although this may seem fortunate, many families find it a source of stress. For example, one mother was worried that on shopping trips, strangers would say “hi” to her child. The mother worried that her child would ignore the stranger’s greeting and the stranger would assume that she was a bad mother because her child was rude. To prevent this from happening, the mother used signs with the child, even though the child did not understand them. The mother thought that her use of signs would cue others that her child had a disability. Another mother kept in her purse a letter from her son’s pediatrician, describing her son’s autistic diagnosis. Her son was nonverbal but screamed when overstimulated or when the environment was too unpredictable for him. This screaming had happened several times in public, resulting—more than once—in the police being called. This mother was afraid of being arrested for child abuse.

Validated Practices

The Picture Exchange Communication System

What Is the Picture Exchange Communication System?
The Picture Exchange Communication System (PECS) is a method of providing communication support to nonverbal individuals. PECS uses pictures to represent categories such as clothing, toys, activities, feelings, special events, foods, body parts, and more. The pictures are computer generated or cut out of old magazines. Students begin by using single pictures and eventually form requests using complete sentences.

Why the Picture Exchange Communication System Is Beneficial
It is easy to ask nonverbal individuals what they want, rather than allowing them to tell us. Students who are taught to use PECS are able to request items they need or want. This communication act is initiated by the student, not by you, and allows students to ask for and receive concrete objects within real-life, social situations. Students have also been taught to use PECS to engage in positive peer interactions.

Implementing the Picture Exchange Communication System
Bondy and Frost (2002) provide a detailed description of the PECS program. A brief description of the first four initial phases is given here. For more in-depth procedures and examples, please refer to the articles listed in the research foundation list.

Phase One: Initiating Communication
- Students are taught to request an object, rather than your asking, “What do you want?”
- Two adults are needed (a communicative partner and a physical prompter).
- Select a desired item and don’t allow the student to use it for a brief time. This is so the student will “miss” the item and be motivated to ask for it.
- The communicative partner sits directly across from the student with the desired object but provides no verbal prompts.
- The physical prompter guides the student to give the picture to the communicative partner, rather than picking up the item.
- When the student places the picture in the communicative partner’s hand, she or he immediately gives the object.

Phase Two: Expanding the Use of Pictures
- The communicative partner no longer sits across from the student. This means the student must find the adult when
The behaviors that define the spectrum of autistic disorders make being a parent challenging. Many programs recognize these difficulties and provide supports for families. Some programs offer support groups and information on how to access such community services as respite care. Other programs help parents develop skills they need to raise their child more effectively. For example, the TEACCH program in North Carolina offers an eight-week course for parents. These “teaching sessions” provide information about the nature of autism, as well as presenting techniques whereby parents can “co-treat” their child with autism. Regardless of the model, support from professionals, support from other parents of children with autism, access to information, and access to high-quality comprehensive services are paramount.

TECHNOLOGY

Children with autism usually do not need the high-tech supports that many children with other disabilities do. Rather, the technology that is useful to these children revolves around two areas:

1. Visual supports to help simplify and structure the environment
2. Augmentative and assistive communication (AAC) to increase language

The main goal is to ensure that students are able to discriminate between pictures, demonstrating that they understand what they are asking for.

Select one favorite picture (e.g., a toy) and one that the student dislikes (e.g., carrots).

Say, “What do you want?” and allow the student to select the picture.

Give the selected item to the student. You will know by the student’s reaction if he or she selected the correct picture.

Add more pictures once students can discriminate between objects they like and those they dislike.

Students exchange the picture for the desired item.

Phase Three: Choosing the Message Within PECS

Phase Four: Introducing Sentence Structure Within PECS

Place the “I want . . .” or “I see . . .” card on the sentence strip.

Students select the picture of what they want and place it on the strip. See Figure 1 for an example.

Students give the sentence strip to you.

You read the sentence, encouraging the student to touch each picture as you read.

Figure 1 Example of a Sentence Strip

This scientifically validated practice is a teaching method proven by systematic research efforts (Bondy & Frost, 2002; Garfinkle & Schwartz, 2001; Frost & Bondy, 1994; Schwartz, Garfinkle, & Bauer, 1998). Full citations are found in the “Technology” section of the references for this chapter.


MAKING CONNECTIONS

To review ACC, see the “Technology” section of Chapter 5.
Visual supports help simplify and structure the environment and can many forms and serve many purposes. For example, concrete objects, photographs, drawings, or words can create a schedule and cue the child about tasks to complete that day. Baskets, templates, and other visual adaptations can reduce nonessential cues in the environment and draw attention to cues that are useful.

AAC devices are helpful for children with autism because they provide children with an alternative system for communication. For example, children with autism have been taught to sign exact English, to point to pictures, and to press a machine’s button for a pre-recorded voice message of their intended communication. Only one AAC system, however, was specifically designed for children with autism, although it is also used with children who have other types of disabilities. The Picture Exchange Communication System (PECS) combines prompting and fading techniques to help children learn how to use the system, while at the same time teaching the basics of communication. For example, this program teaches that communication is between people, that to be a successful communicator one needs to be persistent, and that communication is about something specific (Frost & Bondy, 1994). PECS has been validated through research and has proved to be an effective and efficient system (Schwartz, Garfinkle, & Bauer, 1998). Nearly all children with autism learn how to use PECS, and more than half of those who master the program also develop some language. An example of the application of PECS is found in the accompanying “Validated Practices” box.
**Self-Test Questions**

**Focus Questions**

**What is the relationship of autistic disorder, or autism, to autistic spectrum disorders?**

Autistic disorder, or autism, is one of five disorders or syndromes now recognized as part of autistic spectrum disorders (ASD).

ASD is the broader term, but people sometimes use ASD and autism interchangeably, causing considerable confusion.

**What is meant by the term spectrum, and what does this term imply about people diagnosed with ASD?**

Autistic spectrum disorders (ASD) are defined by the word spectrum, which implies that within a particular child and across children with the same diagnosis, a wide range of skills, cognitive abilities, and severity is exhibited.

**What is the cause of autistic disorder? Why is this sometimes a controversial issue?**

The exact cause of autism is currently unknown.

The cause is probably neurobiological, with a genetic origin.

Lack of known causes leaves room for speculation about other causes.

**What are some ways in which the learning environment can be modified and adapted for students with autism?**

Learning environments should be predictable and should provide structure. Especially valuable is the use of pictures or symbols to help children organize time, learn new skills, and communicate more effectively.

**Why must instruction in nonacademic areas such as social skills be included in educational programs for students with autism?**

One of the areas in which children with autism have deficits is social skills. Social skills, however, are critical life skills. Children with autism need instruction in social skills so that they can form friendships and other relationships, so that they can participate in instruction in other content areas, and so that they will have a greater opportunity to qualify for and keep jobs.

**Challenge Question**

**What are some of the implications or effects of autism being an “invisible” disability for the child and for the child’s family? What are the implications for educators? for other professionals?**

Children with autism physically do not look as though they have a disability.

Parents often find this lack of identifiable characteristics stressful because no cues alert strangers to the disability.

Sometimes, others wrongly assume that the child’s inappropriate behaviors are the result of bad parenting, rather than a behavioral manifestation of a disability.
Core Standard 6: Language

- **Assistive communication**: Augmentative, alternative, and assistive communication strategies (Technology)
- **Support communication**: Use strategies to support and enhance communication skills of individual with exceptional learning needs. (Early Childhood Education and Elementary Through High School)

Core Standard 7: Instructional Planning

- **Functional assessments**: Use functional assessments to develop intervention plans. (Achieving Discipline)

INTASC Principle 2:
The teacher understands how children learn and develop and can provide learning opportunities that support their intellectual, social, and personal development

- **Developmental progressions (physical domain)**: The teacher is aware of expected developmental progressions and ranges of individual variation within each domain (physical, social, emotional, moral, and cognitive), can identify levels of readiness in learning and understands how development in any one domain may affect performance in others. (Characteristics)

INTASC Principle 3:
The teacher understands how students differ in their approaches to learning and creates instructional opportunities that are adapted to diverse learners.

- **Teacher expectations**: The teacher believes that all children can learn at high levels and persists in helping all children achieve success (Transition to Adulthood)
- **Valued as people**: The teacher makes students feel valued for their potential as people, and helps them learn to value each other (Defined)
- **Services or Resources**: The teacher can identify when and how to access appropriate services or resources to meet exceptional learning needs. (Collaboration for Inclusion)

INTASC Principle 10:
The teacher fosters relationships with school colleagues, parents and agencies in the larger community to support students’ learning and well-being.

- **Collaboration**: The teacher is willing to work with other professionals to improve the overall learning environment for students. (Collaboration for Inclusion)

Standards in Practice

The beginning general education teacher is not likely to encounter a student with autism spectrum disorder. These knowledge statements, dispositions and skills might be demonstrated by the beginning teacher as the ability to be able to search and find appropriate resources. The beginning teacher should also be able to function as a contributing member of an educational team.

Go to the companion website (ablongman.com/smith5e) for detailed text correlations to CEC and INTASC standards, PRAXIS II™ exams, and other state-sponsored licensure exams.

**Supplementary Resources**

**Professional Readings and Resources**


**Popular Books**


Videos and DVDs

House of Cards (1993). Miramax

After Ruth’s husband’s death, her young daughter develops symptoms of autism. Ruth takes her daughter to a specialist in childhood autism named Jake, who employs a strictly traditional approach to therapy at his special school. However, Ruth does not accept that Jake’s method is the only treatment, so she attempts to connect with her daughter to see the world through her eyes. Through further examination, Ruth and Jake realize that the little girl was not really autistic but is just coping with her father’s death in a very unconventional way.

The little girl presents an example of the detachment exhibited by people with autism. This film offers a good look at a proper specialized educational facility for young children with autism. Autism is a growing concern because very little is really known about autism, including how one contracts it, how to cure it, or how to treat it effectively.


Charlie Babbit receives word that his wealthy father has died and that the majority of the estate is bequeathed to an autistic brother, of whom he was unaware. Charlie kidnaps his brother from the institution where he had been living in for over 30 years, in an effort to get custody of Raymond so he can gain access to the inheritance. However, Charlie grows to care for Raymond and comes to realize that Raymond’s disability is too overwhelming, requiring professional care.

This film explores a rare form of autism, where in the person is extremely gifted (autistic savant) in mathematics but is extremely low functioning in adaptive skills. Although Raymond is more verbal than most people with autism, many scenes depict the “disconnectedness” they often exhibit. Furthermore, the film demonstrates Raymond’s dependence on familiarity and sameness and on an environment providing comfort, routine, and safety. This film won Oscars in the categories of Best Director, Best Original Screenplay, and Best Picture, and Dustin Hoffman’s performance as Raymond earned him the Best Actor award.

Parent, Professional, and Consumer Organizations and Agencies

National Autism Hotline/Autism Services Center
Prichard Building
Huntington, WV 25710-0507
Phone: (304) 525-8014

Autism Society of America
7910 Woodmont Avenue, Suite 300
Bethesda, MD 20814-3067
Phone: (800) 3AUTISM; (301) 657-0881
E-mail: info@autism-society.org
Web site: www.autism-society.org

VideoWorkshop Extra

If the VideoWorkshop package was included with your textbook, go to Chapter 12 of the Companion Website (www.ablongman.com/smith5e) and click on the VideoWorkshop button. Follow the instructions for viewing Video clip 13. Consider this information along with what you’ve read in Chapter 12 as you answer the following questions.

Video Clip 13: Working With Families (Time: 5:22)

1. In the video one parent explains that she spends hours each evening helping her daughter with homework. Family members must wear many hats, serving as parent, teacher, medical caregiver, therapist, friend, and comforter, when they have a relative with a disability. According to your text, what are ways in which teachers can help and support the caregiving family members?

2. Read Temple Grandin’s comments. Given her comments and those of the parents in the video, briefly outline the educational program and options you might plan for an elementary school student with autism. How might this program change as the student advanced to high school?

Academic Internet Publishers. $44.78

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