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Understanding Autism

Autism is a way of being. It is pervasive; it colors every experience, every sensation, perception, thought, emotion, and encounter, every aspect of existence. It is not possible to separate the autism from the person.

Jim Sinclair (1993)

Our first chapter will focus on understanding autism spectrum disorder (ASD) for one simple reason: Informed support leads to better outcomes. Although topics related to autism are frequently in the news, the disorder is not widely understood. Many people still perceive individuals with autism based on movie depictions like *Rain Man, Forrest Gump, Mozart and the Whale,* and *Adam.* Although there is some truth to these depictions, each is really just a portrayal of one individual. To complicate matters, a student with autism may show little evidence of a disability. The student is not using a brace or walking with a guide dog. He appears typical, with no physical evidence of a challenge. Despite outward appearances, the diagnosis leaves the student disconnected from others while distorting his perceptions of the world in which he lives.

There is less tolerance in schools and society in general for disabilities that are hidden. It's much harder for students and adults to understand differences they can't see. The student with ASD senses things differently than his typical peers and may respond in unusual ways.

As a result, the student is frequently misunderstood. Misunderstandings can lead to mistreatment, exclusion, and perhaps even abuse. Understanding

the range of potential characteristics of this disorder will empower you to be an effective advocate and teacher.

In addition to supporting students' academic needs in the classroom, you will also need to bridge the gap of understanding between students with autism and their peers without disabilities—not always an easy task when you consider the sometimes baffling behaviors of the student with autism that at times seem far from typical. Nevertheless, with knowledge and training you can reduce misunderstandings, while increasing acceptance and even friendship.

Relationship building is the key to reaching the potential of students with ASD. Strive to establish a connection with the person. Your time and effort will be rewarded.

INTRODUCTION TO AUTISM

Autism is a neurological developmental disorder, believed to have a genetic basis, affecting the brain's ability to process and interpret varying types of information. Deficits can occur in a constellation of behaviors, but generally fall into three broad areas:

1. Social interaction
2. Verbal and nonverbal communication
3. Restrictive patterns of interest and behavior

Autism is considered a developmental disability because symptoms of autism typically manifest before age 3 and continue throughout the life span. In fact, autism has a profound impact on a child's development. Students with autism have significant challenges with communication development. They lack appropriate expressive language starting in early childhood. They may not engage in eye gaze when a parent approaches their crib or smile and interact as typical babies do. Later, the varieties of typical play behaviors like spontaneous make-believe play and sharing of interests with others is noticeably reduced or absent. They struggle to understand and relate to the thoughts of others. Nuanced forms of nonverbal and spoken communication, like body language, gestures, tone of voice, sarcasm, and the use of idioms, are misinterpreted or go unnoticed. Some students display "stereotypical behavior," meaning they are drawn to narrow, atypical interests and behaviors that identify them with the disorder.

The term "autism" was first described in the 1940s by Leo Kanner, an American psychiatrist, when writing about a group of children who displayed similar patterns of behavior (Kanner, 1943). Today, more than 60 years later, autism is referred to as a pervasive developmental disorder or an autism spectrum disorder (ASD) because the range (spectrum) of potential differences varies widely from very moderate to significant and affects

each person differently and to varying degrees. In fact, The *Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition, Text Revision (DSM-IV-TR),* published by the American Psychiatric Association (2000) to assist in the diagnosis of mental disorders in both children and adults, has actually identified five subgroups under the umbrella of pervasive developmental disorders: autistic disorder, Asperger syndrome, pervasive developmental disorder not otherwise specified (PDD-NOS), childhood disintegrative disorder, and Rett's syndrome.

To gain a better understanding of autism/autistic disorder, look over the following *DSM-IV-TR* diagnostic criteria:

DSM-IV-TR DEFINITION OF AUTISM/AUTISTIC DISORDER[1]

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

  (1) qualitative impairment in social interaction, as manifested by at least two of the following:

    (a) marked impairments in the use of multiple nonverbal behaviors such as eye-to-eye gaze, facial expression, body posture, and gestures to regulate social interaction

    (b) failure to develop peer relationships appropriate to developmental level

    (c) a lack of spontaneous seeking to share enjoyment, interests, or achievements with other people (e.g., by a lack of showing, bringing, or pointing out objects of interest to other people)

    (d) lack of social or emotional reciprocity

  (2) qualitative impairments in communication as manifested by at least one of the following:

    (a) delay in, or total lack of, the development of spoken language (not accompanied by an attempt to compensate through alternative modes of communication such as gesture or mime)

    (b) in individuals with adequate speech, marked impairment in the ability to initiate or sustain a conversation with others

    (c) stereotyped and repetitive use of language or idiosyncratic language

    (d) lack of varied, spontaneous make-believe play or social imitative play appropriate to developmental level

[1]Reprinted with permission from the *Diagnostic and Statistical Manual of Mental Disorders* (Fourth Edition, Text Revision), Copyright 2000. American Psychiatric Association.

(3) restricted repetitive and stereotyped patterns of behavior, interests and activities, as manifested by at least one of the following:

(a) encompassing preoccupation with one or more stereotyped and restricted patterns of interest that is abnormal either in intensity or focus

(b) apparently inflexible adherence to specific, nonfunctional routines or rituals

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

(d) persistent preoccupation with parts of objects

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

(C) The disturbance is not better accounted for by Rett's disorder or childhood disintegrative disorder.

ASPERGER SYNDROME

Complicating the autism spectrum further is a group of individuals who do not fit the "classic" autism profile. Students diagnosed with Asperger syndrome (AS) share many of the same challenges as students with ASD; however, their cognitive and linguistic profile is closer to typically developing students.

In 1944, Hans Asperger, an Austrian physician, described children seen in his Vienna pediatric clinic who tended to have average to above-average intellectual functioning with less apparent communication and social interaction challenges than children with more classic autism. In four boys, Asperger identified a pattern of behavior and abilities that he called "autistic psychopathy," meaning autism (self) and psychopathy (personality disease). The pattern included "a lack of empathy, little ability to form friendships, one-sided conversation, intense absorption in a special interest, and clumsy movements" (Asperger, 1944). Asperger noticed that these children could talk about their favorite subject in great detail. While they talked in a more typical manner compared with children with classic autism, they appeared very eccentric and socially awkward.

Students with Asperger syndrome tend to appear more typical in early childhood (i.e., more typical parental attachment patterns and the seeking of adult and peer social interaction). Because they seem to interact like typically developing babies and toddlers and to have no evident cognitive delay, they may remain undiagnosed longer than children with autistic disorder. From the perspective of many diagnosticians, typical early language development and social and adaptive behavior coupled with the

age of onset disqualify these children from the diagnostic label of autism (Attwood, 2008; Volkmar & Lord, 2007).

Confounding their profile further, as these children with Asperger syndrome mature, they tend to speak with grammatical form and content in a more mature manner than children without disabilities. As they enter the highly social world of elementary school, their communication challenges become more apparent. Conversational topics center on their narrow, unusual interests without regard for or apparent awareness of the listener's level of interest or engagement. Although their speech *seems* mature, in actuality these students are simply displaying more nuanced forms of a social-communication challenge. Not surprisingly, children with Asperger syndrome may not be diagnosed until they start elementary school, with mean age of diagnosis being 11 years (Howlin & Asgharian, 1999).

There is some controversy over the diagnostic criteria for Asperger syndrome. The validity of Asperger syndrome as a diagnosis separate and distinct from autism is currently under review (Tryon, Mayes, Rhodes, & Waldo, 2006). It is anticipated that Asperger syndrome will be eliminated as a distinct disability subcategory of autism when the American Psychiatric Association (APA) publishes the *Diagnostic and Statistical Manual of Mental Disorders, 5th Edition (DSM-V)* in 2012 (Swedo, 2009). Despite the anticipated official elimination of this diagnostic label, you will most likely encounter students and parents who identify with Asperger syndrome. It therefore seems appropriate to include the diagnosis as a subcategory of autism until the change occurs and for you to familiarize yourself with the following *DSM-IV-TR* diagnostic criteria:

DSM-IV DEFINITION OF ASPERGER SYNDROME

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

B. Restricted repetitive and stereotyped patterns of behavior, interests and activities, as manifested by at least one of the following:
   1. encompassing preoccupation with one or more stereotyped and restricted patterns of interest that is abnormal either in intensity or focus
   2. apparently inflexible adherence to specific, nonfunctional routines or rituals

3. stereotyped and repetitive motor mannerisms (e.g., hand or finger flapping or twisting, or complex whole-body movements)
4. persistent preoccupation with parts of objects

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

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

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

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

As previously mentioned, along with autism and Asperger syndrome, there are three other diagnostic labels that fall under the umbrella of pervasive developmental disorders: pervasive developmental disorder not otherwise specified (PDD-NOS), childhood disintegrative disorder, and Rett's syndrome. Each will be described in brief. PDD-NOS is a condition in which there is marked impairment of social interaction and communication and/or stereotyped behavior patterns or interest, but when full features for autism or another explicitly defined autism spectrum disorder are not met (Volkmar & Lord, 2007). Rett's syndrome is an X chromosome–linked dominant disorder that primarily affects girls. It is characterized by normal early growth and development followed by a progressive slowing of development, loss of purposeful use of the hands, distinctive hand movements, slowed brain and head growth, problems with walking, seizures, and intellectual disability (Ellaway & Christodoulou, 1999; Volkmar & Lord, 2007). Childhood disintegrative disorder is considered a rare condition and occurs more frequently with boys than girls. A child with this disorder shows typical development of verbal and nonverbal communication; social relationships; and motor, play, and self-care skills until about 2 to 5 years of age. Then, over several months, the child will dramatically deteriorate or regress in the areas of intellectual, social, language, play, and self-care (e.g., bladder and bowel control) abilities and may resemble a child with a severe form of autistic disorder (Attwood, 2008; Volkmar & Lord, 2007).

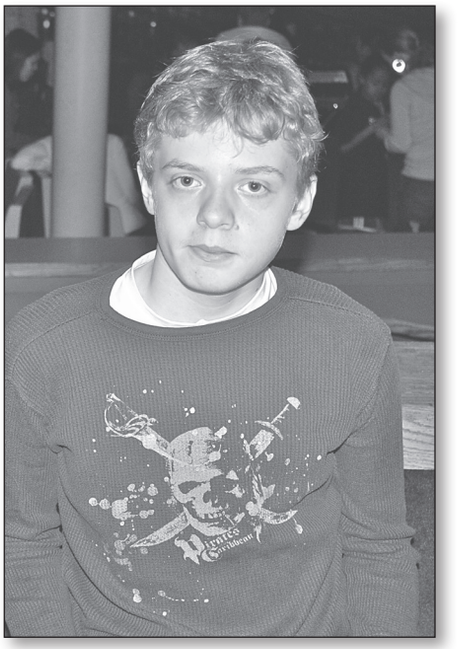
FUNCTIONING ALONG THE SPECTRUM

No two individuals on the autism spectrum share exactly the same characteristics, strengths, and challenges. Each individual experiences autism uniquely, in both form and degree of symptoms. Unfortunately, the diagnosis of autism is often divided along an arbitrary continuum based on how nearly the person "functions" to typically developing individuals. In

general, individuals who have the most severe forms of autism with intellectual challenges are referred to as "low functioning." Individuals who possess characteristics closer to typical development and intellectual functioning are referred to as "high functioning."

Be aware of preconceived notions. A one-dimensional, low- or high-functioning label is too imprecise and most often misleading. Understand that these labels are controversial and not that useful in fully understanding the student's learning and behavioral profile. There are students who appear low functioning with minimal verbal language, are very eccentric, and display atypical behavior, but who are quite intelligent. They don't show their intelligence in ways that we understand given the level of autistic-like behaviors and social challenges they present.

Figure 1.1 A Person—Not a Label



Some students with ASD have a mixed profile of traits showing both "high" and "low functioning" characteristics. Autism can exist with or without intellectual challenges. Some students with ASD have excellent written language skills but atypical verbal language. Others may be highly intelligent but need attendant care.

The point is this: Don't jump to conclusions about the student's level of functioning based on outward appearances or even a single formal test score. Tapping into the potential of a student with autism takes time, multiple observations in a variety of settings, and a thorough understanding of the student's expressive and receptive communication styles and abilities.

Assume competence. The student who is nonverbal can expand his expressive vocabulary through alternative and augmentative communication systems. The student who is intellectually challenged can perform modified academic tasks with support and encouragement. Students who struggle to interact with peers can make friends if a support system is in place that encourages acceptance and respect. Get to know the student and develop a relationship. You will most likely be pleasantly surprised at what you learn.

Also, remember that individual outcomes vary widely and are highly dependent on the quality of support the student receives. One of the most fascinating aspects of autism and Asperger syndrome is how highly individualistic students tend to be. Each person is a unique individual with his own set of characteristics, talents, strengths, and challenges. Take this into account when working with the student. Avoid the temptation of relating to the diagnosis at the expense of the person behind the label. View each student as a unique individual.

PREVALENCE OF AUTISM

Autism is one of the most common developmental disorders, affecting approximately 1 in 110 births (Centers for Disease Control and Prevention,

2010). Roughly translated, this means more than 1.5 million Americans today are believed to have some form of autism, and this number is on the rise. Considering statistics from the U.S. Department of Education and other governmental agencies, autism is growing at a startling rate of 10% to 17% per year. At this rate, the Autism Society of America (ASA) estimates, the prevalence of autism could reach 4 million Americans in the next decade. The diagnosis of autism occurs with equal frequency across diverse racial, ethnic, social, and economic lines. Family lifestyle and educational level do not influence the disorder's prevalence. Although the overall incidence of autism is consistent around the globe, the ratio of boys to girls with autism is approximately 2 to 1, while for Asperger syndrome it is 5 to 1 (Fombonne, 2005).

CAUSES AND RISK FACTORS

We do not know all of the causes of autism. However, we have learned that there are likely many causes for multiple types of autism. There may be several risk factors before and after birth that make a child more likely to have autism, including environmental, biologic, and genetic factors (Centers for Disease Control and Prevention, 2010). Furthermore, we do know that the once common belief that poor parenting practices could cause autism is not true.

To understand why genetics play a role, researchers have studied the rate of autism in identical twins. Identical twins share 100% of their genes because they are conceived from a single egg cell that splits in two. Fraternal twins are genetically different. They are conceived from two separate egg cells. In studies of identical twins, it has been found that in 60% to 96% of births where autism was diagnosed, both twins were found to have autism (Centers for Disease Control and Prevention, 2010). By comparison, in fraternal twins, the likelihood that both will have autism ranges from 0% to 3%. This rate matches the number found in non-twin siblings.

Researchers are now attempting to locate the exact genes that cause autism. It is currently suspected that as many as 15 different genes could be involved. The pattern of how these genes interact to cause autism is complex. Each may play a small role, or mutations among these genes may interact in some way to cause autism. Adding to the research challenge is the fact that how autism is diagnosed really involves a subjective description of behaviors and characteristics, which may actually hide the fact that several different causes could have an outwardly similar presentation. In other words, what looks like autism may be a different disorder or combination of factors.

There is no consensus in the research community about what specific environmental factors contribute to the likelihood a child will acquire autism. Scientific evidence does exist that exposure to toxins, chemicals, pesticides, flame-retardants, and pre- and postnatal viruses may be linked

Table 1.1 What Causes Autism?

Possible Cause	Likelihood	Comment
Vaccines	Low	CDC and the NIH say that there is no relationship between vaccines and autism.
Genetics	High	Parents from families with autism tend to have children with autism at a higher rate.
Immune Deficiency	Low	National Institutes of Health studies say evidence is weak.
Food Allergies	Low	Some connection has been found but the evidence is weak.
Atypical Brain Development	High	Researchers have found differences between the autistic and typical brain, particularly the frontal cortex region.
Bad Parenting	Unfounded	There is no causal relationship between autism and the parenting style of the child's parents.

Source: Centers for Disease Control and Prevention. Autism Information Center (2010).

to autism (Roberts et al., 2007), but conclusive proof is lacking. Exposure to excessive amounts of mercury, particularly in the preservative thimerosal, once found in childhood vaccines, was suspected to be a causal agent. However, scientists have not discovered a definite link (Sears, 2007) and the substance is no longer used.

Some parents worry that the increasing number of vaccines given to children may compromise their child's immune system—especially the measles, mumps, and rubella (MMR) vaccine—and lead to the child developing autism. Extensive investigation by researchers (Dales, Hammer, & Smith, 2001; Taylor et al., 1999) have failed to find evidence that the MMR vaccine causes autism (Sears, 2007).

More research will be needed before researchers conclusively identify the genetic and environmental causes for autism. We may not know the cause of autism with 100% certainty for many years.

As complex as studying autism is, solid research is taking place across the globe, and newly acquired knowledge influences the direction of future inquiry. Funding for autism research has increased dramatically in the past 10 years and continues to increase as nonprofit and government sources focus more resources on the disorder. Today, autism as a research area involves many different types of science, from medical and biological to behavioral, communication, and educational.

FROM DIAGNOSIS TO THE CLASSROOM

As previously mentioned, there continues to be misunderstanding about the diagnosis of autism in schools that adds to the challenges of educating students with ASD in general education settings. Dealing with the unknown leads to discomfort and even fear by teachers and students. Some teachers worry that the student's presence in the classroom will disrupt the learning process. Evidence is lacking to support this concern. Research suggests that the majority of high school students diagnosed with ASD function in general education settings with minimal to moderate academic support. The National Center for Special Education Research reports that overall 33% of students with ASD receive the same instruction in general education classes as their neurotypical peers, while approximately 47% need "some modifications" to the general education curriculum (Newman, 2007). These statistics call into question the notion that students with ASD need separate educational placements.

It can be argued that the presence of students with autism can actually enhance the learning experience for typical students and increase awareness (Chandler-Olcott & Kluth, 2009).

It is encouraging to know that instructional interventions designed to support learning for students with ASD actually help students without disabilities as well. We will explore these strategies in detail in later chapters.

The student's ability to participate and learn depends on informed support. Once teachers understand the diagnosis of autism, they are less apprehensive and more willing to accept the student as their own. Please keep in mind: It is not enough simply to be aware of the student's diagnosis. Teachers also need to understand how autism affects the individual student's experiences. Parents report that teachers who understand ASD are typically more tolerant of the student's personality profile (Jackson-Brewin, Renwick, & Schormans, 2008).

An understanding of ASD also allows teachers to perceive potential challenges and to help the student cope by creating a supportive classroom environment.

The following sections will assist you in understanding the range of potential social, communicative, sensory, motor, and behavioral characteristics unique to this disorder and to develop the knowledge and skills necessary to advocate for and support the student's full participation in the classroom.

SOCIAL SKILLS AND COMMUNICATION

> *For the adolescent and teenage person with AS, deciphering other kids' meanings is harder than deciphering hieroglyphics.*
>
> (Jackson, 2002, p. 100)

Communication as a means of sharing information and experience is an important social activity that forms the basis for relationship building.

It is essential for making sense of experiences and connecting with others. Students who know how to listen well and convey their message to others are almost always more confident than students who haven't learned these skills.

There is a common myth that individuals with ASD are antisocial or apathetic toward others. This is untrue. They are perfectly capable of forming connections with friends and family. The disconnect lies in fully expressing their emotions in a manner easily understood by friends and loved ones. They struggle to express internal thoughts and feelings and are frustrated and anxious when others misunderstand their communicative intent.

The unusual interests of children and adolescents with ASD complicate friendship making. Conversational topics are usually of their own choosing with little awareness of the listener's level of interest. They tend to miss nonverbal cues and have difficulty understanding that other people have their own thoughts, feelings, and perspectives. If the person doesn't share the same interest as the student, there's little compromise in finding common ground to form the basis for friendship. When they attempt to join in conversation, they miss the point while asking off-topic, irrelevant questions; digress to an unrelated topic; or switch the focus to their special interest with no transition to inform the listener of a change in conversational direction. This personality profile is referred to as "unskilled social activeness" (Myles, 2005).

Autism Myth

"Bad parenting causes autism."

Fact

Bad parenting does not cause autism. If bad parenting causes autism, why would one child in a family be affected but not an other?

Social skills training sessions do not always improve social awareness. The student may be very successful during social skills training at choosing the meaning of facial expressions on picture cards or practicing the appropriate response to a social encounter in isolation. Despite this clinical practice, students with ASD struggle to generalize these skills to real-life spontaneous meetings with people outside the clinic setting (Koning & McGill-Evans, 2001; Myles, 2005). The range of human expression is much too nuanced and complex to quantify into simple categories to then retrieve and use in meaningful ways to fit the hundreds of social situations that occur spontaneously each day. If role-playing sessions are conducted, it is essential that skills be generalized through repeated practice embedded across settings with neurotypical peers.

Many students with ASD appear to lack common sense and misapply social rules in real-life settings. Social rules are often applied too literally. It is not unusual for students with ASD to extend a greeting and ask a classmate his or her name. The problem is that the greeting looks rehearsed and unnatural. For example, when Sam approaches someone to speak, he extends his arm to measure his distance from the person and adjusts himself back and forth until he's sure the distance rule has been properly applied. His greeting comes off as robotic and rigid. Instead of gaining a connection with the person, an impression is conveyed: "This guy is strange!"

> *Annie, after being trained to greet people when entering a room, states "Good morning!" to all 28 students by name when she enters the classroom. Needless to say, her literal interpretation of "greet people when you enter a room" causes much annoyance among her peers. After hearing "Good Morning Susan, Good Morning Lawrence, Good Morning Jay, Good Morning Michelle, Good Morning Chris, Good Morning Kori, Good Morning Steve, Good Morning Ina," Annie's classmates call out, "Stop the greeting thing!" (Author)*

Although students with ASD lack social awareness, many are painfully aware that they are different from their peers. This awareness increases when students reach middle school and self-esteem is challenged. Without informed support, these students can spiral into depression leading to anxiety, emotional episodes, and withdrawal (Adreon & Stella, 2001).

Embedding social skills training in natural, age-appropriate settings and learning in context with the support of typical peer role models has gained favor in the research literature (Koegel & Koegel, 2006; Odom & Strain, 1984; Strain & Schwartz, 2001). The generalization of age-appropriate communication is naturally embedded into regularly occurring classroom experiences. We see impressive reductions in "autistic-like" behaviors when students are exposed to repeated and prolonged interactions with typically developing peers. We will discuss intervention strategies in depth in later chapters.

THE NAIVETÉ FACTOR

Compared with nondisabled students, children with autism are four times more likely to be bullied and twice as likely to be abused by adults, peers, and siblings (Little, 2002). Students with expressive communication challenges may lack the tools to communicate the abuse to an adult.

Some adolescents with autism wear clothes more appropriate for younger students. Instead of moving into adolescent interests like Facebook and Twitter, they remain preoccupied with their atypical interest, making it challenging to connect with peers.

Many students have poor motor coordination. This leaves them out of school sports, typically an important area of status and friendship. A 14-year-old adolescent with ASD may have a fully developed male or female body, but lack understanding of flirtation and nonverbal sexual cues, making him or her susceptible to harassment, inappropriate advances, and exploitation. Clearly, much education, guidance, and support are needed in this area.

> *We arranged a field trip for our students with ASD and their neurotypical peer partners to visit the train museum downtown. Instead of driving by car, we traveled by light rail train for the experience. Our group of 12 students, accompanied by four adults, is randomly seated in the passenger car while happily moving down the track looking forward to a fun day at the museum. At one of*

> *the stops, a disheveled man in his 50s enters our car. He is dirty, smells bad, and is clothed in rags. To my surprise, he sits on the same bench next to my female student, 14-year-old Melissa, a pretty girl diagnosed with autism. As luck would have it, I am sitting in the seat in front of her. The moment the man sits down, Melissa turns to him and says, "Hi, I'm Melissa! Would you like a kiss?" Before the man can respond, I calmly take Melissa to another seat where we have a chat about talking to strangers. (Author)*

BEHAVIOR AND EMOTIONS

The behavioral and emotional challenges students with ASD experience are largely connected to social and environmental factors that they perceive as beyond their understanding and control. They sense that "unpredictable things happen, and I don't understand them." Wanting to interact with a peer and not knowing how; trying to follow teacher directions, but not understanding what is being said; hearing peers laugh around you and not getting the joke—these are all stressful situations that students with ASD experience daily (Myles & Southwick, 2005).

Behavior challenges occur for many reasons. Although knowing the why behind the behavior is not always easy, one thing is certain. Challenging behavior signals that something very important is missing from the student's life. During class, Jim blurts out angry words similar in content to the argument he heard between his parents last night. He looks traumatized. When the teacher hands out a worksheet for Jim to complete, he gets agitated and pushes the paper aside. Jim's response to the arrival of a math worksheet on his desk is to get angry. Is it the math or is it something else?

Figure 1.2 Accentuate the Positives

Challenging behaviors may be a reaction to disliked tasks, the setting, people, sensory needs, confusing or mixed social signals, changes in routine, problems at home, and many other external and internal stimuli. The child may have an underlying mental health issue (e.g., depression, anxiety disorder, etc.). Students with ASD are more vulnerable to anxiety-producing situations. It takes a relationship with the student to begin to understand the reasons behind the behavior.

For adolescents with ASD, attending school can be enormously stressful. Compared with elementary school, the school size is larger. Expectations are higher. Social expectations increase and peer relationships are more complex (Mullins & Irvin, 2000). Students experience a larger and more diverse student population where conformity and social competence are stressed. Alongside these demands, students must handle difficult situations with the physiological changes associated with puberty. Students who lack the skills necessary to cope with these demands often experience significant problems in adjustment, achievement, and

feelings of self-worth (Shoffner & Williamson, 2000). As Temple Grandin reflects,

> At puberty, fear became my main emotion. When the hormones hit, my life revolved around trying to avoid a fear-inducing panic attack. Teasing from other kids was very painful, and I responded with anger. I eventually learned to control my temper, but the teasing persisted, and I would cry. Just the threat of teasing made me fearful; I was afraid to walk across the parking lot because I was afraid somebody would call me a name. (Grandin, 1995, p. 88)

There is enormous pressure to conform during adolescence. Students with ASD may be excluded, teased, and bullied, leading to conflicts and emotional outbursts. They are especially vulnerable in less structured settings where misunderstandings with peers lead to rejection and social isolation. Depression, anxiety, and aggression can follow (Barnhill, 2001; Bauer, 1999).

The anxiety experienced by Dr. Grandin in adolescence forced her to withdraw to avoid painful experiences. Many students with autism respond this way. Because their ability to understand the environment and the actions of others is limited, they overcompensate by withdrawing into a protective shell to relieve the extreme anxiety caused by their sense of helplessness (Bellini, 2006).

Other students may lash out in response to confusing social signals. Research suggests that students with ASD frequently misinterpret the actions of others as aggressive (Carothers & Taylor, 2004; Kaland et al., 2002).

> *Dean, a student with ASD, is standing in line for lunch. Suddenly, the line surges forward, causing the student behind Dean to press against Dean's back. In response, Dean spins around and swings his lunch pail, smacking the boy behind him in the side of the head. Dean misinterpreted the boy's actions as aggression. In reality, the boy was nudged forward in line, causing him to unwittingly move into Dean's space. Instead of stating, "Hey back, up!" or adjusting by moving slightly forward, Dean's agitation escalated. His inability to verbalize his discomfort coupled with his tactile sensitivity caused Dean to lash out and smack the boy. (Author)*

Emotions can rise when the student's routine is interrupted. School assemblies, fire drills, and unfamiliar people can cause emotional outbursts. Avoid upset. Prepare students with and without disabilities in advance. In addition, bullying and teasing by insensitive and uninformed peers can cause considerable upset, leading to emotional outbursts.

> *I am reminded of an incident where a child was in crisis. Fourteen-year-old Brittany, an 8th-grade girl diagnosed with ASD and bipolar disorder, was cycling into a depressive period that rendered her especially vulnerable to criticism. While seated in the cafeteria eating lunch, a boy called her fat. The insult*

was more than Brittany could take. She screamed out, "Leave me alone!" and then hurled a cup of yogurt across the floor. When we intervened, Brittany was in tears and unable to speak. Streaks of yogurt covered the floor from the cup she had slung across the room. We attempted to comfort her. Later in the day, we arranged a meeting between Brittany and the student who teased her. She expressed to the boy how his teasing upset her and he apologized. This intervention helped the boy see Brittany as a person with feelings. We later learned that the boy became a friend who helped her in times of crisis. (Author)

Would the above challenges be present across all environments and situations? Are they unique to particular settings, unforeseen changes of routine, people, and environmental challenges? Being teased, bullied, pressured to conform, and coping with loud noises and crowded rooms are situations that occur in context and under specific circumstances. They influence behavior and emotions. All of us act differently according to the time, place, and situation we're experiencing at the moment. Our behaviors are influenced by the presence or absence of certain people.

Considering the circumstances that lead to emotional incidents is the first step when a student with autism lashes out. When the student can't sort out a difficult or painful situation, we need to help. Think through all the potential reasons for the outburst. Every reason you consider is a possibility that might unlock the origins of challenging behaviors and emotions and lead to improved outcomes.

COGNITION AND LEARNING

The cognitive abilities of students with ASD are sometimes hard to measure and often misunderstood. It is widely believed, for example, that all persons diagnosed with autism possess extraordinary skills or talents in a specific area of knowledge or ability. The term "autistic savant" is the label used when referring to individuals matching these characteristics. Many people diagnosed with autism have special interests and talents. However, less than 10% are considered autistic savants. In reality, the learning capacity of students with ASD varies widely—from gifted to intellectually challenged.

Figure 1.3 Connecting Through Shared Experiences

Accurate measures of intelligence for students with ASD are difficult to obtain because the symptoms of autism affect the assessment process (Edelson, 2005). A valid measurement of cognitive abilities requires student motivation, social interaction, communication, and compliant/cooperative behavior. The adolescent is required to interact and cooperate with the examiner, often a stranger. As we have learned, this is extremely difficult for students with ASD. They are extremely sensitive to novelty and uncomfortable around strangers. They follow rigid routines; are less flexible to change; and have repetitive and stereotypic patterns of behavior, interests, and activities, which are often at odds with the examiner's test protocols. It takes

just a few stubborn refusals, off-topic irrelevant responses, or a test booklet thrown across the room to prompt the examiner to nervously write "untestable."

> *If you judge a fish by its ability to climb a tree, it will live its whole life believing that it is stupid.*
>
> (Albert Einstein)

If you run across low IQ scores or excessive, negative reporting when examining a student's school records, be mindful of the information learned here and de-emphasize their significance. Encourage others to look beyond negative input as well. School records that focus on deficits far more than capacities may not be objective or accurate. If you work with students long enough, sooner or later talents and capacities will emerge that challenge the validity of IQ testing and deficit-based perspectives. Look for and share the students' abilities and advocate for their talents and strengths.

Big idea to remember: Make sure IQ scores and other standardized measurements of intellect and ability do not limit opportunities for students. As mentioned, standardized assessment practices follow strict protocols that may not allow for the idiosyncrasies of some students with special needs, especially students with ASD. The true potential of the human intellect defies measurement. De-emphasize test results, while providing opportunities for the student to show competence in other ways. In so doing, perceptions are formed that more accurately reflect the person's potential.

Students diagnosed with autism spectrum disorders vary widely in their learning capabilities and needs, just like their nondisabled peers. A few of the common challenges to learning that students with ASD experience include, but are not limited to, (1) fine motor control—many find handwriting very difficult; (2) difficulty understanding abstract concepts; (3) challenges maintaining attention and concentration; and (4) difficulty following lengthy verbal directions. No single method for addressing these learning challenges and teaching students with ASD is successful for all students. Also, a student's needs change over time, making it necessary for teachers to be flexible in their approach.

Supporters of inclusive education reject the notion that placement decisions should be determined based on the "readiness model" where students *earn* the right to belong in general education classes based on academic skill. As you will learn in later chapters, subject content and time lines can be modified to meet the student's unique learning needs. Learning challenges can be overcome with the classroom teacher's support in cooperation with the student's family, the special education teacher, support staff, and the student's peers.

SENSORY CHARACTERISTICS

Sensory integration refers to our natural ability to absorb information through the senses of touch, movement, smell, taste, vision, and hearing,

and then combine, organize, and interpret the information in meaningful ways. For most people, this process is automatic. We can selectively listen to a single person in a crowded, noisy room while our minds automatically filter out the extraneous sounds around us. We gain pleasure from the sensory input of music, a massage, smelling the aroma of fresh-cut flowers, and viewing a beautiful landscape. Students with ASD frequently experience unusual responses to their sense perceptions. They may struggle to "modulate" (alter the intensity) of incoming sounds, smells, light, and touch. Some students struggle to filter out unwanted stimuli. They might not tolerate one or more sensory stimuli and become agitated from the interference the incoming stimuli bring.

Like other challenges for students with autism, sensory issues are highly individualistic. Some students struggle with filtering out the sounds of a leaf blower but have no issues with lighting. What bothers one student may have no effect on another.

Many students struggle with the same sounds typical people find annoying: car alarms, loud intercoms, and passing bells. Yet, certain students may react negatively to sounds we find pleasing. As Temple Grandin explains,

> My hearing is like having a sound amplifier set on maximum loudness. My ears are like a microphone that picks up and amplifies sound. (Grandin, 2000)

Some students with ASD have the opposite challenge. They are underresponsive to incoming sensory input and have an almost insatiable desire to seek more. They may seek out constant stimulation by pressing and squeezing sand between their fingers, rubbing a small object between their thumb and index finger, seeking pressure from tight squeezing, bouncing on a trampoline, or listening to music. These sensory seekers sometimes have a high tolerance for pain or objects that are too hot or cold. They may need high-intensity input to relax and concentrate.

REPETITIVE MOVEMENTS

Repetitive movements are commonly found in students with autism and often serve to help the student regulate incoming sensory stimuli. The behavior may include hand flapping, object spinning, and rocking. Temple Grandin (1995) describes how repetitive rocking and spinning helped shut out the world when noise became overwhelming:

> Rocking made me feel calm. It was like taking an addictive drug. The more I did it, the more I wanted to do it. My mother and my teachers would stop me so I would get back in touch with the rest of the world. I also loved to spin, and I seldom got dizzy. When I stopped spinning, I enjoyed the sensation of watching the room spin. (p. 45)

Repetitive movements help the student cope with stress, fatigue, and sensory overload. When the senses are bombarded by competing incoming stimuli impossible to filter, the student may use repetitive movements to center attention on one sense. Vigorously shaking the hands draws the mind away from the sensations that can't be sorted. The student is unconsciously thinking, "I can't deal with all this noise and light, so I'll just rock in my chair." Other examples of repetitive movement and sensory-seeking behaviors include the following:

- Visual: staring at lights, blinking, gazing at fingers, lining up objects
- Auditory: humming, mumbling under one's breath or making noises
- Smell: smelling objects, sniffing food
- Taste: licking objects, placing objects in mouth
- Tactile: scratching, clapping, feeling objects, hair twisting, toe-walking, rubbing parts of the body
- Vestibular: wiggling legs, tapping fingers, flapping, rocking, spinning, jumping
- Proprioception: repetitive pacing, bumping into people and things

Let's face it: Most people engage in repetitive behaviors when stressed or excited. During a typical day, we notice people tapping fingers, twiddling locks of hair, and rhythmically chewing gum. It becomes a problem when excessive movement stigmatizes the student and interferes with learning. Liane Holliday Willey, a woman diagnosed with Asperger syndrome, describes how her behaviors seemed unique to her peers:

> I came to notice that everyone had some odd little habit they used in times of distress and absent-mindedness. I noticed the nail biting, the lip biting, the hair chewing, and the tiny muscle twitches. I heard friends humming to themselves, sucking their teeth, and tapping their feet. I knew there were all kinds of rules that people followed in order to calm themselves or occupy their time, but I think my favored habit was unique, at least among my friends. (Willey, 1999)

What should the teacher do when a student engages in these behaviors? If possible, leave the student alone. Allow him or her to self-regulate incoming sensory stimuli through one of the above-mentioned behaviors. If the behavior becomes a distraction to the student or others, interferes with learning, or is self-injurious, like hair pulling or repeated rubbing of skin, then express your concerns to the parent, special education teacher, or therapeutic specialist.

Occupational therapists (OTs) specialize in helping students with autism manage sensory input challenges. The OT may involve the student in exercises and activities that improve performance and reduce repetitive movements. Sensory activities, when used on a regular basis, can help with focus, alertness, and organization. Sometimes the OT will develop a

sensory diet—a set of scheduled activities designed to meet the student's specific sensory needs.

For some students, deep pressure to parts of the body can promote relaxation. Things like elastic tight-fitting vests that wrap around the student's trunk and midsection may work for reducing stress. Weighted tube collars that rest on the shoulders and neck can also help. Headphones are extremely comforting to students who find auditory stimuli aversive. Simply turning off the lights and using incandescent lamps instead can comfort students who are ultra-sensitive to fluorescent light.

Although students diagnosed with Asperger syndrome have similar sensory issues to those of students diagnosed with autism, students with Asperger are more likely to have an emotional reaction when they experience sensory overload (Myles et al., 2004). The important point to remember is this: Be aware of the student's environmental stressors and work to avoid these stressors, or at least minimize their effect on the student.

MOTOR ABILITIES

Children with ASD often have gross and fine motor challenges. Motor development may be delayed in early childhood. More often, the delays involve the more complex motor skills that come later in a child's development, like riding a bike, catching a ball, and using small tools.

Students with autism sometimes display asymmetrical or uneven gait, poor manipulative skills, and deficits in visual-motor coordination. The areas of challenge we most frequently encounter include holding a pencil; fastening buttons, snaps, clasps, and zippers; and tying shoes. Competitive sports can be challenging for students with ASD but should not be avoided due to the student's physical coordination challenges. Encourage coaches and PE teachers to de-emphasize competition or at least brainstorm ways the student can participate successfully in the game.

Therapeutic interventions can help students with fine and gross motor challenges reasonably participate. Solutions may include targeted physical exercise and adaptive equipment to improve fine and gross motor functions.

Figure 1.4 De-emphasize Difference by Showcasing Talent

SUMMARY

The challenges and capacities of students diagnosed with ASD are many and varied. Autism is a complex neurological disorder that can occur in a large constellation of behaviors but generally falls into three broad areas: social interaction, verbal and nonverbal communication, and restrictive patterns of interest or behavior. Students with all forms of autism have difficulty understanding and relating to the thoughts of others. They struggle to understand subtle or nuanced forms of nonverbal and spoken

communication. As a result, they struggle to make friends. Without some form of intervention, misunderstandings and social isolation follow.

Autism is a developmental disability in which characteristics of the condition are present before age 3 and continue throughout adulthood. To date, there is no known cure. There is disagreement in the medical and research communities as to the causes of autism; however, there is substantial evidence that autism is genetically derived with an environmental agent acting as the triggering mechanism. The exact environmental agents that trigger autism have not been discovered to date. The rates of autism have increased substantially over the past 20 years, causing alarm in the medical community and general public. The current rate of autism is estimated at 1 in 110 births. Roughly translated, as many as 1.5 million Americans today are believed to have some form of autism, and this number is on the rise. This increase may be due to improved diagnostic practices. Increased awareness by the medical community is, in part, responsible for the increase in the number of identified cases.

Among the most critical factors contributing to school success are communication support, academic and environmental modifications, peer support, and positive behavior support. Inclusive education with informed support in cooperation with the student's family is key to improving outcomes.

RESOURCES

Autism Information Center
http://www.cdc.gov/ncbddd/autism/

Autism Research Institute
http://www.autism.com/index.asp

Autism Society
http://www.autism-society.org

Centers for Disease Control and Prevention
http://www.cdc.gov/ncbddd/autism/index.html

FURTHER READING

Grandin, T. (1995). *Thinking in pictures: And other reports from my life with autism.* New York, NY: Vintage Press.

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Simpson, R. L. (2005). *Autism spectrum disorders: Interventions and treatments for children and youth.* Thousand Oaks, CA: Corwin.

Myles, B. S. (2005). *Children and youth with Asperger's syndrome: Strategies for success in inclusive settings.* Thousand Oaks, CA: Corwin.