Introduction

Characteristics of Children and Youth With Asperger Syndrome

CASE STUDY: BENNETT

Bennett, a six-year-old child with Asperger Syndrome, appears to have highly developed verbal skills since he is able to read aloud the daily newspaper with fluency, but he has difficulty asking and answering basic questions about his wants and needs. Often Bennett will show his frustration by crying or throwing himself to the floor when he is unable to express himself in a way that his teacher or peers understand. Changing activities can be stressful for Bennett, especially when the change is unexpected. Bennett will drop to the floor and whine instead of changing activities. During free play, he will position himself away from the other students, always choosing to use Lego's to build the Mars Land Rover, Space Shuttle, or Hubble Space Station.

CASE STUDY: OLIVIA

Olivia, a middle school student with Asperger Syndrome, began speaking at the same age as her peers, but she did not use speech fluently until the age of five. Although she has never been to England, her speech resembles that of someone from that country who speaks very formally and precisely. Academically she is at

grade level or above, yet her social skills are limited. She lacks the skills to initiate, maintain, or terminate conversations. Her special interest of aerospace engineering borders on an obsession, which tends to discourage her peers from interacting with her because that is the subject she continually wants to talk about.

In the hallway between class periods, if someone asks Olivia, "Do you have the time?" (meaning "What time is it?") she interprets the question literally and responds by saying, "No, I am on my way to Mr. Desmond's class and I cannot be late!" or "Yes, I have the time. I have a new watch and it has a calculator, a stop watch, and an alarm." When Olivia becomes excited or nervous, she may rock forcefully in her chair or flick her fingers in front of her face. She will also refuse to participate in activities or experiences that involve close proximity to her peers, such as playing basketball in gym or working in groups on the floor. At other times, Olivia will "police" the hallway, pointing out rule infractions that students have committed and reminding students of the appropriate behaviors that should occur during passing times. Interactions such as these get Olivia labeled as being "really weird."

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Despite the fact that Asperger Syndrome (AS) is an increasingly prevalent disability, it is not widely recognized. In fact, children and youth with AS are misunderstood partially because of the lack of information available about them, but also because of their inconsistent academic, emotional, and social behaviors. They have expressive language skills and intelligence quotients (IQ) that fall within the normal range, and yet they have social, emotional, and learning characteristics that make them a significant challenge for educators, parents, and the children themselves.

Generally, children and youth with AS receive the majority of their instruction in general education classrooms where teachers are expected to design and carry out their educational programs, including social skills training, often without training and frequently with little support from special educators. In recognition of these challenges, this book was written to familiarize general education classroom teachers and other personnel with the characteristics and educational strategies that have proven effective for this population of learners.

The disability now known as Asperger Syndrome was first discussed in 1944. However, this exceptionality was generally unknown in the United States until recently (Klin, Volkmar, & Sparrow, 2000; Myles & Simpson, 2003). The Identification and condition known as Asperger Syndrome is attributed to Hans Asperger, a Viennese physician who also studied a group of children who demonstrated a significant disability. Although Asperger observed that these children had many characteristics that were

typical of children with autism, he stated that the children and youth he studied were different from those with autism.

For almost 40 years after Asperger's original work, virtually nothing related to AS was published. In 1981, however, a British psychiatrist, Lorna Wing, published a paper describing a group of individuals who presented with characteristics that seemed similar to those described by Hans Asperger. Awareness and recognition of Asperger Syndrome was further advanced in 1994 in the United States when the American Psychiatric Association added the syndrome to its list of pervasive developmental disorders, which it identified in its widely used *Diagnostic and Statistical Manual of Mental Disorders* (4th Edition) (American Psychiatric Association [APA], 1994).

Today the clinical term Asperger Syndrome is used by professionals, parents, and others throughout the world, including general education teachers who face the challenges associated with educating these children. There is still much we do not know about AS, including how many children have this disability (APA, 2000; Kadesjo, Gillberg, & Hagberg, 1999; Klin et al., 2000) and whether or not it is part of the autism spectrum or is an independent disability (Klin et al., 2000; Prior, 2003).

The attention on AS is, in part, related to its increased prevalence (Ehlers & Gillberg, 1993; Kadesjo et al., 1999) as well as the significant challenges that these students present for educators and families (Gill, 2003). Estimates on the number of students with AS are widely debated. For example, Volkmar and Klin (2000) reported "the present data are, at best, 'guesstimates' of its prevalence" (p. 62). Indeed, the most recent edition of the *Diagnostic and Statistical Manual of Mental Disorders* (DSM-IV, TR) (APA, 2000) omitted the prevalence estimate for AS because definitive data do not exist. Kadesjo et al. (1999), on the other hand, estimated that as many as 48 per 10,000 children may have AS. In the meantime, educators increasingly comment on the astonishing increase in the number of students diagnosed with AS, especially in general education programs.

Accompanying the increased recognition of AS is the awareness that much remains to be learned about this disorder. General education teachers and other educators who are responsible for planning for and teaching students with AS generally have not been provided the skills and knowledge to do so (Myles & Simpson, 2003). Crafting and implementing suitable supports and interventions for students with AS is especially difficult because of the lack of a clear understanding of the disorder, an absence of clearly defined educational methods and strategies, and scarce professional development programs. It is in this connection that this book was written. That is, strategies for educators are offered with special attention

to general education teachers who teach children and youth diagnosed with AS. Strategies that can be used by special educators are also described in this book, so that all educational professionals have an awareness of the myriad supports that are needed to help children and youth with AS succeed in school.

IDENTIFICATION AND DIAGNOSIS OF CHILDREN AND YOUTH WITH ASPERGER SYNDROME

Clinically trained professionals, such as psychiatrists and clinical psychologists and other nonschool professionals, typically diagnose students with AS based on criteria provided in the DSM-IV, TR (APA, 2000). These criteria appear in Table I.1.

Even though school personnel do not directly rely on DSM-IV, TR criteria to make diagnoses of AS, they should be familiar with this widely used system. However, educators should keep in mind that the DSM-IV, TR does not provide a description of the characteristics of AS that most directly relate to school performance. Thus school professionals, especially general educators, must understand school-related social, behavioral/emotional, intellectual/cognitive, academic, sensory, and motor characteristics of students with AS.

Currently AS is a medical diagnosis that is often difficult to diagnose in the traditional medical setting. The characteristics of children and youth with AS are best seen (a) in interactions with peers, (b) in stressful situations, (c) in environments where the schedule or routine is not predictable, (d) when a high degree of structure is and is not in place, (e) when sensory stressors are apparent, and (f) in situations that are new for the students. These characteristics are evidenced over time in multiple environments and typically do not occur in a physician's office.

Since observations by physicians across multiple environments and over extended time is usually not feasible, the medical community must rely on the observations and reports of those who know the individual best—his or her teachers and parents—who have been shown to be reliable observers of children (Myles, Bock, & Simpson, 2000). Thus teachers and parents must be an essential part of the assessment process, including reporting behaviors that may lead medical practitioners to reliably identify AS. These factors must be communicated in a clear, consistent, and concise manner to physicians to ensure reliability and validity in diagnosis. The Asperger Syndrome Diagnostic Scale (ASDS) (Myles, Bock, et al., 2000), for example, was developed for this purpose. The ASDS is a norm-referenced instrument that parents and educators can complete and share with physicians to facilitate a diagnosis of children and youth.

Table I.1 DSM-IV TR Diagnostic Criteria for 299.80 Asperger's Disorder

- ❑ Qualitative impairment in social interaction, as manifested by at least two of the following:
  - 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
  - failure to develop peer relationships appropriate to developmental level
  - 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)
  - lack of social or emotional reciprocity
- ❑ Restricted repetitive and stereotyped patterns of behavior, interests, and activities, as manifested by at least one of the following:
  - encompassing preoccupation with one or more stereotyped and restricted patterns of interest that is abnormal either in intensity or focus
  - apparently inflexible adherence to specific, nonfunctional routines or rituals
  - stereotyped and repetitive motor mannerisms (e.g., hand or finger flapping or twisting, or complex whole-body movements)
  - persistent preoccupation with parts of objects
- ❑ The disturbance causes clinically significant impairment in social, occupational, or other important areas of functioning.
- ❑ 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).
- ❑ 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.
- ❑ Criteria are not met for another specific Pervasive Development Disorder or Schizophrenia.

SOURCE: APA, 2000.

SOCIAL AND COMMUNICATION CHARACTERISTICS

As originally noted by Asperger (1944), and confirmed by others (Frith, 1991; Myles & Adreon, 2001; Wing, 1981), the social and communication disorders within AS are particularly prominent. Children with AS are often socially isolated and demonstrate problems in interacting with others that cannot be explained by shyness, short attention span, aggression, or a lack of experience (Barnhill, 2001). However, individuals with AS want to interact with others despite their lack of skills. For example, an adolescent with AS may appear different from his peers because of his continuous insistence on sharing facts about washers and dryers, even though it is generally known by other students that nobody else is interested in this particular topic.

The social difficulties of persons with AS may range from social withdrawal and detachment to unskilled social activeness (Church, Alisanski, & Amanullah, 2000). Particularly challenging for both educators and peers is the fact that the social and communication challenges of children with AS may be masked by advanced verbal skills. That is, their one-sided conversational style and monologues on narrowly focused interests often lead others to believe that the child is socially competent. Those who know individuals with AS, however, recognize that they have communication and social problems. They often cannot share conversational topics and appear unwilling to listen to others. They are often perceived as adult-like, talking down to peers and teachers. The term "little professor" has been used to describe the speaking style of some children with AS (Myles & Simpson, 2003). Mali talks incessantly about Catherine the Great, not because she is rude but because she finds the topic extremely interesting. She does not understand why others do not share her passion. When children in her class begin to talk about the famous singer Beyonce's latest concert, Mali finds the topic of little importance and quickly tries to change the topic back to Catherine the Great.

Students with AS frequently have difficulty comprehending abstract concepts; understanding and correctly using metaphors, idioms, parables, and allegories; and grasping the meaning and intent of rhetorical questions. Because these conventions are commonly used in school settings, deficits in these areas negatively impact students' academic success. When Martin, a 10-year-old child with AS, was told by his teacher to "shake a leg," he began to do so—literally. He did not understand that he was supposed to hurry and became very upset when some of the children in class began to laugh at him.

Children and youth with AS often do not understand nonverbal cues—including facial expressions, gestures, voice tone, and physical proximity—that occur when interacting with others. In addition, they have difficulty understanding the thoughts, feelings, and perspectives of others, particularly when they differ from those of the individual with AS. To further add to the difficulty in understanding individuals, children and youth with AS may be able to infer the meaning of facial expressions as well as match events with facial expression in isolation; however, they are frequently unable to interpret or identify these variables when they occur simultaneously (Koning & McGill-Evans, 2001). This accounts for the inconsistent behavior of children who can name emotions when shown pictures or identify what they were to do in a social interaction, yet cannot use these skills in everyday life.

It is not unusual for students with AS to be able to engage in basic and introductory social interactions (e.g., basic greetings, asking someone her name) without being able to engage in reciprocal conversations. That is,

many children and youth with AS are described by families and peers as (a) lacking awareness of social rules; (b) lacking common sense; (c) misinterpreting social prompts, cues, and unspoken messages; and (d) displaying a variety of socially unacceptable habits and behaviors (Gagnon & Myles, 1999). For example, Johanna told her parents that she played with her "best friends" at recess. It was not until her parents talked with Johanna's teacher that they understood what Johanna actually did at recess. Her teacher reported that Johanna would approach a small group of girls and say hello. She would then continue to stand near them and wait for a response, or she would immediately launch into a discussion of horse breeds. Even though her "best friends" would generally not respond, Johanna would just stand there. Not only were Johanna's parents at first unaware of their daughter's attempts at making friends at school, but Johanna's teacher had misinterpreted Johanna's behavior. She thought that Johanna just wanted to watch her peers and would interact appropriately with them when she was ready.

It is also common for students with AS to become easily stressed (Barnhill, 2001; Myles & Adreon, 2001). For example, students with AS may become upset if they think others are invading their space or when they are in unpredictable or novel social situations. However, in contrast to most of their peers, many children with AS do not reveal stress through voice tone, overt agitation, and so forth. As a result, they may escalate to a point of crisis because others are unaware of their excitement or discomfort, and because of their own inability to predict, control, and manage uncomfortable situations (Myles & Southwick, 1999). When John's teacher announced to the class that an assembly was scheduled in one hour, she noticed that John began to clear his throat rapidly. She knew that this seemingly minor behavior meant that John was stressed and might escalate to a tantrum. Therefore, she immediately went to him and talked with him about the assembly—who was featured, how long it would last, where John would sit, what John would do, and so on. She also wrote these things down as she spoke with John. Once John knew what was expected, he calmed himself and was able to attend the assembly with the rest of the class.

Although they lack social awareness, many students with AS are painfully aware that they are different from their peers. Thus self-esteem problems and self-concept difficulties are common. These problems are often particularly significant during adolescence and young adulthood (Myles & Adreon, 2001), when most individuals, including the most well-adjusted, are challenged in these areas.

The complexity of social situations and lack of rules that can be applied consistently make it difficult for students with AS to interact with

others without instruction and support. Social rules vary, and their lack of consistency is confusing for children with AS. These individuals often painfully discover that interactions that may be tolerated or even reinforced in one setting are rejected or punished in others (Myles & Simpson, 2001). For example, one first-grade student with AS found it difficult to understand why his calling his teacher "Pee-Pee-Head" and "Mrs. Pee" in unsupervised settings such as the restroom was the source of great delight to his peers, while the same response in the classroom, in the presence of the teacher, Ms. Peters, drew a much different response.

Children and youth with AS do not automatically acquire greater social awareness as they get older. This is problematic in that students are required to use more sophisticated social skills and to interpret even more subtle social nuances as they progress through school. As a result, individuals with AS are vulnerable to developing a variety of problems. Studies of adolescents with AS have found out that they often experience discomfort and anxiety in social situations along with an inability to effectively interact with peers (Ghaziuddin, Weidmer-Mikhail, & Ghaziuddin, 1998). In addition, depression and anxiety may also occur (Barnhill, 2001; Ghaziuddin et al., 1998; Wing, 1981).

BEHAVIORAL AND EMOTIONAL CHARACTERISTICS

The behavioral and emotional problems experienced by children and youth with AS are often connected to their social deficits. Moreover, these problems and challenges frequently involve feelings of stress or loss of control or inability to predict outcomes (Myles & Southwick, 1999). In brief, students with AS typically have behavior problems connected to their inability to function in a world they see as unpredictable and threatening.

In one of the few studies that attempted to identify the nature of behavior problems and adaptive behavior among students with AS, Barnhill, Hagiwara, Myles, Simpson, Brick and Griswold (2000) compared the perceptions of parents, teachers, and students. The authors found that parents had significantly greater concern about the behavior and social skills of their children than did the students' teachers. Responses also revealed that parents perceived their children to have challenges in a variety of social and behavioral areas. Teachers, on the other hand, perceived the children and youth in the study to have both fewer and less significant deficits than did parents, although they did view the students to be "at risk" in the social and behavior areas. Students, on the other hand, reported that they were free of any social or behavioral challenges.

INTELLECTUAL AND COGNITIVE CHARACTERISTICS

A defining feature of AS is generally an average to above-average IQ (APA, 2000). However, given the importance of this variable, surprisingly little is known about the cognitive abilities of students diagnosed with AS.

In one of the few studies of the cognitive abilities of children and youth with AS, Barnhill, Hagiwara, Myles, and Simpson (2000) assessed the cognitive profiles of 37 children and youth with AS, as measured by the Wechsler scales (Wechsler, 1989, 1991). The scores generally fell within the average range of abilities, although the IQs ranged from intellectually deficient to very superior. It is important to note, however, that this and other studies have not identified a specific cognitive profile among individuals diagnosed with AS.

ACADEMIC CHARACTERISTICS

Because most students with AS receive their education primarily in general education classrooms, general education teachers are usually responsible for their education with the support of special educators and related services personnel.

In many ways, students with AS benefit from general classroom experiences. They typically have average to above-average IQs, are motivated to be with their general education peers, and often have good rote memory skills that support educational success. However, they often experience significant academic problems and many are thought also to have learning disabilities (Klin & Volkmar, 2000). In addition, students' special interests, concrete and literal thinking styles, inflexibility, and problem-solving and organizational challenges often make it difficult for them to benefit from general education placement without support and accommodations (Church et al., 2000). However, with support, many students with AS are able to be successful in school, and a number are able to attend college and enjoy successful careers.

Many teachers fail to recognize the special academic needs of children and adolescents with AS because these students often give the impression that they understand more than they do (Myles & Simpson, 2001). Their professor-like tone of voice, seemingly advanced vocabulary, rote-like responses, and ability to word recall without having comprehension skills to understand what they read may mask the deficits of some students with AS (Griswold, Barnhill, Myles, Hagiwara, & Simpson, 2002).

SENSORY CHARACTERISTICS

In his original study of children with AS, Asperger (1944) observed that his subjects had peculiar responses to sensory stimuli. Today this pattern continues, and teachers and parents often observe atypical sensory responses in the majority of children with AS they teach or live with (APA, 2000; Dunn, Myles, & Orr, 2002; Myles, Cook, Miller, Rinner, & Robbins, 2000). For example, it is not unusual for students with AS to be hypersensitive to certain visual stimuli, such as fluorescent lights, and particular sounds, such as the echoing noises common in a gym filled with playing children. Such sensitivity may cause anxiety and behavior problems.

Some individuals with AS have been reported to have an inconsistent tolerance for physical pain. Tijon tearfully begged his mother to take him to the hospital emergency room for his very painful hangnail. Tijon's mother could not believe that this was the same child who, last week, did not notice that he had a one-inch sliver of glass lodged in his foot.

Students with AS often engage in stereotyped or repetitive seemingly nonfunctional behaviors (e.g., obsessive object spinning, hand flapping), particularly when they are under stress, or when they experience fatigue, sensory overload, and so forth. The sensory issues seen in children and youth with AS appear similar to those of individuals with autism; however, their reactions to sensory issues seem more negative than those seen in individuals with autism. That is, students with AS are more likely to have a tantrum or other disruptive behaviors than children with autism when they have a sensory overload (Myles, Hagiwara, et al., 2004).

MOTOR CHARACTERISTICS

Wing (1981) and others have observed that children with AS often have poor motor skills along with coordination and balance problems (Dunn et al., 2002; Myles et al., 2000). These deficits are significant. First, being awkward and clumsy makes it difficult for students with AS to successfully participate in games requiring motor skills. Because participation in games and related activities is a social activity for children, problems in this area often go well beyond issues of motor coordination. Second, fine-motor skill difficulties may interfere with a variety of school activities, such as handwriting, art, and so forth (Myles et al., 2000).

SUMMARY

Children and youth with AS have many characteristics that place them at risk for school problems. Often misunderstood because of their average to above-average IQs and expressive language skills, these individuals have great potential that may go unrealized because of the modifications they require to be successful. The following chapters highlight myriad strategies that can be used to support students with AS in general education classroom settings.