CHAPTER 1

INTRODUCTION AND OVERVIEW

More children and youth are being diagnosed with autism spectrum disorder (ASD) than ever before. Epidemiological research indicates a progressively rising prevalence trend for ASD over the past decade (Wing and Potter, 2009). Autism is much more prevalent than previously thought, especially when viewed as a spectrum condition with varying levels of symptom severity and need for support. Recent findings of the Centers for Disease Control and Prevention (CDC) Autism and Developmental Disabilities Monitoring Network ADDM (2014) indicate that one in every 68 school-age children (or 14.7 per 1,000 eight-year-olds) in multiple communities in the United States has been identified with ASD (Centers for Disease Control and Prevention [CDC], 2014). This estimate is roughly 30 percent higher than the estimate for 2008 (1 in 88), 60 percent higher than the estimate for 2006 (1 in 110), and 120 percent higher than the estimates for 2000 and 2002 (1 in 150). Approximately 80 percent of children identified with ASD either had eligibility for autism special education services at school or had an ASD diagnosis. The remaining 20 percent of children identified with ASD had documented symptoms of ASD in their records, but had not yet been classified as having ASD by a community provider. Autism is the fastest growing serious developmental disability in the United States and continues to be an important health concern (CDC, 2014).

A number of explanations for the dramatic increase in the incidence and prevalence of ASD have been advanced. It is widely accepted

that at least a significant part of the reported increase in autism over the past decade is due to a combination of factors which include: (a) broadening of diagnostic criteria and concepts; (b) recognition that ASD frequently co-occurs with other conditions and includes a wide range of cognitive abilities; (c) increased awareness on the part of professionals and the public leading to more (and earlier) referrals for assessment; (e) increased sensitivity of diagnostic tools and better access to services; (d) decreasing age at diagnosis; (e) differences in the definition of autism and case-finding methods; (f) differences in the size of the population being studied, and (g) diagnostic substitution and reclassification of children with other disabilities (Fombonne, 2005; Polyak, Kubina, and Girirajan, 2015; Wilkinson, 2014a; Wing and Potter, 2009). Although a large proportion of the increase in the rate of ASD can be explained by these factors, researchers cannot rule out the possibility that there has been a true rise in the prevalence of ASD. Whatever the reasons, the current prevalence figures carry clear-cut implications for school professionals who share the challenge of identifying and providing interventions for an increasing number of children and youth with ASD (Wilkinson, 2014a).

ASD IN SCHOOLS

The increase in the occurrence of autism is also evident in the number of students with ASD receiving special educational services under the Individuals with Disabilities Education Act (IDEA, 2004). According to the U.S. Department of Education, Office of Special Education Programs, Data Analysis System (DANS), more than 5 million children ages 6 to 21 years received services through 13 disability categories in public school special education programs in 2012 (U.S. Department of Education, 2014). Although the overall population of students receiving services peaked in the 2004-05 school year and has declined since that time, the data indicate a divergence in the

trajectories of the individual disability categories. For example, while the number of students identified with specific learning disability (SLD), emotional disturbance, and intellectual disability decreased relative to other disability categories, the number of students with autism increased dramatically between 2003 and 2012, increasing from 1.5 percent to 7.8 percent of all identified disabilities. Autism now ranks fourth among all IDEA disability categories for students age 6-21. Similarly, the percentages of the total student population ages 6 through 11, 12 through 17, and 18 through 21 served under the IDEA, Part B category of autism increased 165 percent, 285 percent, and 290 percent, respectively. Autism now accounts for nearly 1 percent of the overall student population in our schools. Despite the dramatic rise in the number of students receiving special education under the IDEA category of autism, it has been suggested that the increase may actually underestimate the numbers of students in need of support under this category (Brock, Jimerson, and Hansen, 2006; Fombonne, 2003; Newschaffer, Falb, and Gurney, 2005; Russell *et al.*, 2010; Safran, 2008). For example, more capable students with ASD may not be included in the IDEA count because they often demonstrate academic strengths and more subtle social liabilities, and thus may not be readily identified with ASD. Many may also be home-schooled, enrolled in private schools, be clinically diagnosed but not receiving services, have not come to the attention of a professional, or fail to meet the eligibility for the autism category in their respective school districts and states. Further, there is evidence to suggest that gender and cultural/ethnic differences in the presentation of ASD often go unrecognized in both the school and community, and that language-based and socioeconomic disparities in access to services may be barriers to identification (Travers *et al.*, 2014; Wilkinson, 2008a; Zuckerman *et al.*, 2013). As a result, it appears likely that there are a relatively large number of unidentified and underserved students with ASD in our schools.

THE CHALLENGE TO SCHOOL PROFESSIONALS

The unique needs and multifaceted nature of autism, including co-occurring (comorbid) disabilities, have significant implications for planning and intervention in the school context. Placement in general education settings continues to be a predominant service delivery option for students with disabilities, including ASD. Most students with ASD receive their education in general education classrooms with teachers who often have limited experience and training in working with children with special needs (Williams *et al.*, 2011). From the ages of 6 to 12, the child with ASD faces many challenges with transitions to new learning environments and contact with unfamiliar peers and adults. The core deficits of ASD (i.e., social reciprocity and interaction, communication, and repetitive behaviors) affect the educational process and may adversely impact a child's performance in the following areas: academics, social/emotional development, communication, adaptive skills, and the ability to use and maintain skills across home, school, and community settings. The social-communication domains of development become more divergent from typical expectations as the student progresses through school. Children with ASD frequently experience problems related to their social communication deficits such as poor regulation of attention, emotional distress, academic difficulties, and high rates of internalizing and externalizing problem behavior (Mazzone, Ruta, and Reale, 2012; Sikora *et al.*, 2012). As a result, they are at risk for academic underachievement, school drop-out, peer rejection, and co-occurring conditions such as anxiety and depression (Mazzone *et al.*, 2012; Ozsivadjian, Knott, and Magiati, 2012). Because autistic traits exist along a spectrum of severity with respect to the core symptomatology, even mild deficits in social and communicative competence can be associated with teacher-reported problems in socialization and a wide range of behavioral and academic difficulties (Skuse *et al.*, 2009). Thus, social skills deficits that fall

below the threshold for a clinical diagnosis or autism eligibility for ASD can still result in functional impairment (Russell *et al.*, 2010). Therefore, school professionals must be prepared to recognize the presence of risk factors and early warning signs of ASD, engage in case finding, and be familiar with assessment tools and interventions in order to ensure that students are being identified and provided with the appropriate programs and services. Providing effective behavioral supports and interventions to the ever-increasing numbers of children with ASD continues to present a major challenge to the educational communities that serve them.

OVERVIEW OF AUTISM SPECTRUM DISORDER (ASD)

HISTORY OF CLINICAL CONCEPTUALIZATION

The earliest and most comprehensive description of what we now refer to as autism or ASD was documented by Leo Kanner (1943) who first introduced the term as a clinical syndrome to the scientific literature by describing eleven children with "early infantile autism." These children were characterized as relating better to objects than people and showing severe social and communication abnormalities as well as narrow and restricted interests. One year later, Hans Asperger separately published a work characterizing children with "autistic psychopathology" (Wing, 1981). These children were described as being verbally fluent but with peculiar language use and abnormal prosody. They were also socially isolated and demonstrated repetitive behaviors, a desire for sameness, interest in unusual topics, motor clumsiness, and a propensity toward rote memorization of facts. Clinical descriptions of ASD have changed considerably since this time. For example, the reconceptualization of autism into a separate class of neurobehaviorally-based disorders occurred with the publication of the DSM-III (American Psychiatric Association, 1980). Autistic disorder

was introduced in the DSM-III-R (American Psychiatric Association, 1987) with new diagnostic criteria. ASD was recently considered as an umbrella term which included a group of five disorders described under the category of Pervasive Developmental Disorders (PDD) in the DSM-IV (American Psychiatric Association, 1994), which was updated with a text revision in 2000 (DSM-IV-TR; American Psychiatric Association, 2000). The five pervasive developmental disorders are: (1) autistic disorder (autism), (2) Asperger's disorder, (3) childhood disintegrative disorder, (4) Rett's disorder, and (5) pervasive developmental disorder not otherwise specified (PDD-NOS). According to the DSM-IV-TR, these associated neurobehavioral disorders are characterized by a varying degree of qualitative impairment in three key areas of development that result in a distinct abnormality in comparison to expected developmental or mental age. This includes impairments in (a) reciprocal social interactions; (b) verbal and nonverbal communication; and (c) restricted and repetitive behaviors or interests, which together are often referred to as the "autistic triad of impairments".

DSM-5

The most recent conceptualization of ASD is reflected in the Fifth Edition of the Diagnostic Statistical Manual of Mental Disorders (DSM-5; American Psychiatric Association, 2013). The DSM-5 includes a new diagnostic category of autism spectrum disorder (ASD), which collapses the previously mentioned distinct DSM-IV-TR subcategories, including autistic disorder, Asperger's disorder (syndrome), childhood disintegrative disorder, and pervasive developmental disorder not otherwise specified (PDD-NOS) into a single diagnosis. Further, the DSM-IV-TR three symptom domains (i.e., autistic triad) of social impairment, communication deficits and repetitive/restricted behaviors, interests, or activities have been replaced with two domains, (a) persistent deficits in social communication/interaction; and (b) restricted/repetitive patterns of behaviors, interests, or activities (RRB).

Under the DSM-IV-TR criteria, a person qualified for an ASD diagnosis by exhibiting at least six of twelve deficits in social interaction, communication or repetitive behaviors. In contrast, the DSM-5 requires a person to exhibit three deficits in social communication and at least two symptoms in the category of restricted range of activities/repetitive behaviors. Changes also include greater flexibility in the criteria for age of onset and addition of symptoms not previously included in the DSM-IV-TR such as sensory issues and aversions. For example, the criteria now state that although ASD must be present from infancy or early childhood, it may not be identified until later in the individual's development. Likewise, unusual sensory responses (e.g., hyper- or hypo-reactivity to sensory input) are now included in the DSM-5 symptom criteria for restricted, repetitive patterns of behavior, interests, or activities (RRB). Individuals meeting criteria for ASD also receive a functional severity rating across a three-level scale (Level 1—requiring support, Level 2—requiring substantial support, and Level 3—requiring very substantial support) for both the social communication and restricted, repetitive behavior domains. Similarly, there are specifiers for the presence of accompanying intellectual disability and/or language impairment and associations with other known medical or genetic conditions (e.g., fragile X syndrome, Rett syndrome), environmental factors, other neurodevelopmental, mental, or behavioral disorders. The specifiers are not mutually exclusive; thus more than one specifier can be given (e.g., ASD with or without accompanying intellectual impairment or language impairment). Appendix A highlights the important changes from DSM-IV-TR-to DSM-5 for a diagnosis of ASD.

Another significant change in the criteria involves the diagnosis of co-occurring (comorbid) disorders. Unlike the DSM-IV-TR, the DSM-5 no longer prohibits the comorbid diagnosis of attention-deficit/hyperactivity disorder (ADHD). When the criteria are met for both disorders, both diagnoses are given. It should be noted that individuals with a well established DSM-IV-TR diagnosis of

autistic disorder, Asperger's disorder, or pervasive developmental disorder not otherwise specified (PDD-NOS) will not lose his or her diagnosis and should be given the DSM-5 diagnosis of ASD. Lastly, the DSM-5 includes a new diagnostic category of Social (Pragmatic) Communication Disorder (SCD) that is designed to capture social communication impairments not accompanied by restrictive and repetitive behavior/interests (RRB). Because both components are required for diagnosis of ASD, social (pragmatic) communication disorder is diagnosed if no RRBs are present (American Psychiatric Association, 2013). Individuals who have marked deficits in social communication, but whose symptoms do not meet the criteria for ASD, may be evaluated for social (pragmatic) communication disorder.

CLINICAL VS. EDUCATIONAL DEFINITION

The definition of autism differs among the various diagnostic and classification schemes. Both IDEA and DSM-5 have had the greatest impact on the assessment and classification of children and youth with ASD. In 1990, the United States Congress amended the federal special education law (now called Individuals with Disabilities Education Improvement Act, or IDEA, 2004) to make autism a category of special education disability. Unlike the DSM-5, which is intended as a diagnostic and classification system for psychiatric disorders, IDEA is federal legislation enacted to ensure the appropriate education of children with special educational needs. The IDEA recognizes 13 different disability categories under which 3- through 21-year-olds may be eligible for services (see Appendix B). As defined by IDEA, the term "student with a disability" means a student: "with intellectual disability, hearing impairments (including deafness), speech or language impairments, visual impairments (including blindness), serious emotional disturbance, orthopedic impairments, autism,

traumatic brain injury, other health impairments, or specific learning disabilities; and who, by reason thereof, needs special education and related services" (IDEA, 2004). According to IDEA regulations, autism is defined as follows:

> (1)(i) Autism means a developmental disability significantly affecting verbal and nonverbal communication and social interaction, generally evident before age three,that adversely affects a child's educational performance. Other characteristics often associated with autism are engagement in repetitive activities and stereotyped movements, resistance to environmental change or change in daily routines, and unusual responses to sensory experiences. (ii) Autism does not apply if a child's educational performance is adversely affected primarily because the child has an emotional disturbance, as defined by IDEA. (iii) A child who manifests the characteristics of autism after age three could be identified as having autism if the above criteria are satisfied. (Individuals with Disabilities Act of 2004, 34 CFR §300.8 (1)(i)-(iii))

IDEA shares a number of features with the DSM-5. Both are categorical systems (i.e., the individual meets or does not meet criteria) that focus on the description rather than the function of behavior, and have been used in legal decision making regarding special education placement and clinical treatment. Both definitions include impairments in social communication and restricted, repetitive patterns of behavior/interests. The DSM-5 conceptualizes ASD as a clinically significant syndrome or pattern associated with disability or impairment in one or more important areas of functioning (American Psychiatric Association, 2013). The IDEA definition also requires that the core behaviors of autism impair or have a negative impact on the student's educational performance. Unlike the DSM-IV-TR which required onset of symptoms prior to age 3, the DSM-5 and IDEA do not preclude a diagnosis or classification at a later age. This is especially important because many individuals with ASD are not diagnosed

in early childhood and can be identified for treatment and special education services at later ages.

Despite the similarities between the two systems, there are important distinctions between a clinical/medical diagnosis of ASD and a determination of eligibility for special education. School and mental health professionals should be aware that while the DSM-5 is considered the primary authority in the fields of psychiatric and psychological diagnoses, the IDEA definition is the controlling authority with regard to eligibility decisions for special education (Fogt, Miller, and Zirkel, 2003; Mandlawitz, 2002; Zirkel, 2014). While the DSM-5 criteria for ASD are professionally helpful, they are neither legally required nor sufficient for determining educational placement. Children with a clinical diagnosis of ASD do not automatically receive special education, nor are students who are eligible for special education under the IDEA category of autism required to have a clinical diagnosis of ASD. An evaluation assessing eligibility for special education does not replace a clinical diagnosis of ASD, nor does a clinical diagnosis of ASD determine eligibility for special education. School professionals should be certain that students meet the criteria for autism as outlined by IDEA and use the DSM-5 to the extent that the diagnostic criteria include the same core behaviors (e.g., impairment in social communication and interaction, and restricted, repetitive patterns of behavior/interests). It is important to remember that when it comes to special education, it is state and federal education codes and regulations (not DSM criteria) that determine eligibility decisions (Fogt *et al.*, 2003; Zirkel, 2014). Best practice in special education eligibility and program planning is discussed in Chapter 6.

THE GENDER GAP

Prevalence estimates of ASD are significantly higher among boys than among girls. According to the CDC (2014), boys are nearly five times

more likely to be identified with ASD than girls. (1 in 42 boys were identified with ASD; 1 in 189 girls were identified with ASD.) In fact, research has found that even when symptoms are equally severe, boys are more likely to be identified with ASD than girls (Russell, Steer, and Golding, 2011). There is also evidence to indicate that among children up to age eight, girls are diagnosed later than boys (Shattuck *et al.*, 2009). This gender "gap" raises serious questions because many female students with ASD are being overlooked and will not receive the appropriate educational supports and services.

Although few studies have examined gender differences in the expression of autism, there are some tentative explanations for this disparity. Since females are socialized differently, ASD may not be manifested in the same way as typical male behavioral symptoms (Wilkinson, 2008a). For example, social communication and pragmatic deficits may not be readily apparent in girls because of a non-externalizing behavioral profile. Thus, girls who have difficulty making sustained eye contact and appear socially withdrawn may be perceived as "shy," "naive," or "sweet" rather than having the social impairment associated with an ASD (Wagner, 2006). Girls on the higher end of the spectrum also tend to have fewer special interests, better superficial social skills, language and communication skills, and less hyperactivity and aggression than boys. As a result, the behavior and educational needs of boys are much more difficult to ignore and are frequently seen by teachers and parents as being more urgent, further contributing to a referral bias and lessening the probability of a girl being identified as having the core symptoms of ASD. Likewise, over reliance on the male model with regard to diagnostic criteria might contribute to a gender "bias" and underdiagnosis of girls. Clinical instruments also tend to exclude symptoms and behaviors that may be more typical of females with ASD. In addition, the diagnosis of another disorder often diverts attention from autism-related symptomatology. In many cases, girls tend to receive unspecified diagnoses such as a learning disability, processing problem, or internalizing disorder

(i.e., anxiety and depression). Unfortunately, the consequences of a missed or late diagnosis can result in girls facing social isolation, peer rejection, lowered grades, and a greater risk for mental health and behavioral distress such as anxiety and depression during adolescence and adulthood. Although a comprehensive review of this subject is beyond the scope of this Guide, best practice recommends that when a girl presents with a combination of social immaturity, restricted interests, limited eye gaze, repetitive behaviors, social isolation, and is viewed as "unusual" or "different" by parents, teachers and peers, the possibility of an ASD should be given consideration (Wagner, 2006). Likewise, girls who are diagnosed with ASD should be screened for internalizing problems such as anxiety and depression, and closely monitored for symptom occurrence.

CONCLUSION

We have only begun to appreciate the complex challenge of how to ensure that children with ASD are appropriately identified and provided with the opportunities and resources to learn, socialize, and become independent, responsible, and productive members of society. Unfortunately, caring for a child with autism places a serious burden on the health, social and financial well-being of individuals, families, and society. For example, the national cost of supporting children with autism, including direct non-medical costs, such as special education and early intervention services, and indirect costs, such as parental productivity loss, is estimated to be $61 billion to $66 billion a year in the U.S (Buescher, Cidav, Knapp, and Mandell, 2014; Lavelle *et al.*, 2014). Moreover, parenting a child with autism can place considerable stress on work, finances, personal health and psychological well-being, and marital relationships and responsibilities. Siblings, too, may be affected. Both the psychological and financial costs can be significantly reduced with early diagnosis and intervention/treatment. Therefore, it is critically important to identify

those children in need of further assessment in order to reduce the time between symptom appearance and intervention.

The best practice guidelines outlined in this text address the issues related to screening, assessment, and intervention planning in a comprehensive and flexible manner that is consistent with evidence based-practice. In order to derive the most benefit from this Guide, it should be read in its entirety. Because of the overlap between chapters, there is some repetition in content. Also note that the terms autism spectrum disorder (ASD) and autism are used interchangeably throughout the text to reflect the scientific consensus that symptoms of the various autism subgroups represent a single continuum (or spectrum) of impairment that varies in level of severity and need for support (American Psychiatric Association, 2013). Readers are encouraged to consider the best practice screening and assessment paradigms described in Chapters 2 and 3 when selecting instruments. Similarly, the systematic reviews and information presented in Chapters 5 and 6 provide an overview of evidence-based interventions and effective special education practices. The reader is also advised to consult the index to locate best practice references in each chapter and to supplement the information available in this Guide with additional and newly published information, as appropriate. The next chapter focuses on best practice in the screening process and provides a review of validated instruments that can be used by school-based professionals to identify children in need of a comprehensive developmental assessment.