Essentials

of Autism Spectrum Disorders Evaluation and Assessment

- Complete coverage of the identification and assessment of autism spectrum disorders
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Celine A. Saulnier
Pamela E. Ventola

Alan S. Kaufman & Nadeen L. Kaufman, *Series Editors*

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Pamela E. Ventola


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To Tony, for your eternal love, support, and patience—You are my everything; and to Lucienne and Vivienne, for being the light of my life. ~ Celine

To Noah, you are an inspiration; your unfaltering strength, love, and endless encouragement make it all possible; to Madelyn, you are truly the center of my world. ~ Pam

This book has a very special dedication to our beloved mentor and colleague, Dr. Sara Sparrow, for shaping our knowledge of childhood assessments, particularly the critical role of adaptive behavior in autism spectrum disorders. Working with you was an honor, and we miss you terribly. ~ Celine and Pam

Series Preface

In the *Essentials of Psychological Assessment* series, we have attempted to provide the reader with books that will deliver key practical information in the most efficient and accessible style. The series features instruments in a variety of domains, such as cognition, personality, education, and neuropsychology. For the experienced clinician, books in the series will offer a concise yet thorough way to master utilization of the continuously evolving supply of new and revised instruments, as well as a convenient method for keeping up to date on the tried-and-true measures. The novice will find here a prioritized assembly of all the information and techniques that must be at one's fingertips to begin the complicated process of individual psychological diagnosis.

Wherever feasible, visual shortcuts to highlight key points are utilized alongside systematic, step-by-step guidelines. Chapters are focused and succinct. Topics are targeted for an easy understanding of the essentials of administration, scoring, interpretation, and clinical application. Theory and research are continually woven into the fabric of each book, but always to enhance clinical inference, never to sidetrack or overwhelm. We have long been advocates of "intelligent" testing—the notion that a profile of test scores is meaningless unless it is brought to life by the clinical observations and astute detective work of knowledgeable examiners. Test profiles must be used to make a difference in the child's or adult's life, or why bother to test? We want this series to help our readers become the best intelligent testers they can be.

In *Essentials of Autism Spectrum Disorders Evaluation and Assessment*, the authors illustrate a comprehensive developmental model for multidisciplinary diagnostic

evaluations. They derived this model from years of experience in conducting diagnostic evaluations for ASD following standards of best practice. Given the neurodevelopmental nature of ASD, symptoms unfold over the course of early development and subsequently affect multiple areas of functioning. For these reasons, the developmental skills that need to be assessed often require clinicians with different disciplinary expertise. Thus, in this Essentials text, the authors outline the components of a state-of-the-art diagnostic evaluation for ASD and also highlight the necessity of integrating findings from multiple sources. The end goal is to provide one comprehensive and cohesive diagnostic formulation for an individual's optimal care.

Alan S. Kaufman, Ph.D., and Nadeen L. Kaufman, Ed.D.,
Series Editors
Yale University School of Medicine

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Finally, our overwhelming gratitude to the children and families from whom we learn every day. Thank you for sharing your lives with us.

Chapter 1

Overview

Autism spectrum disorders (ASD) are among the most common childhood disorders, with prevalence rates reaching near 1% of the population (CDC, 2007a, 2007b). Defined as a lifelong neurodevelopmental disorder with a complex genetic etiology, ASD's symptoms tend to unfold over the course of early development. Research indicates that 80% to 90% of parents report their first concerns about their child's development by the second birthday and often earlier. However, the mean age of diagnosis continues to be well over the age of three despite these concerns (Chawarska et al., 2007). Moreover, when experienced clinicians make a diagnosis of ASD at 18 to 24 months, the stability of diagnosis is quite strong, also around 80% to 90% (Chawarska et al., 2009). This highlights an extremely concerning gap between when first concerns are raised and when something is actually done to help the child; often because of a limited awareness of the early markers of ASD by professionals on the front line. These facts underscore the necessity for clinicians of all disciplines to learn about and be vigilant for the early signs of ASD, so that children can be effectively evaluated and efficiently diagnosed. Only then can these children subsequently receive the critical early and intensive intervention that is associated with optimal outcome (National Research Council, 2001).

Caution

Most parents of children who develop ASD express concerns regarding their child's development prior to the second birthday, well over a year before diagnostic evaluations take place, on average. Professionals need to be extra vigilant in not only validating concerns, but also in taking immediate action to assess and identify potential risk for ASD.

Diagnostic Criteria

Although the causes of ASD are likely neurobiological in nature, the spectrum of disorders still requires diagnosis based on behavioral symptomatology. The current diagnostic criteria put forth in the *Diagnostic and Statistical Manual, Fourth Edition, Text Revision* (DSM-IV-TR; APA, 2000) fall under the category of Pervasive Developmental Disorders (PDD), which includes Autistic Disorder, or autism; Asperger's Disorder, or Asperger syndrome, Rett's Disorder, Childhood Disintegrative Disorder (CDD), and Pervasive Developmental Disorder, Not Otherwise Specified (PDD-NOS). The behavioral features of all five PDDs fall within the following subcategories: (1) impairments in social interaction; (2) impairments in communication; and (3) restricted, repetitive, and stereotyped patterns of behavior, interests, and activities. A diagnosis of Autistic Disorder, the most prototypical of the PDDs, requires onset of delays or deviance in development prior to the age of three and a total of at least six impairments in all subcategories, with at least two falling within the area of social interaction.

Rapid Reference 1.1

Pervasive Developmental Disorders in the DSM-IV-TR

Autistic Disorder

Asperger's Disorder

Rett's Disorder

Childhood Disintegrative Disorder

Pervasive Developmental Disorder, Not Otherwise Specified

Asperger Syndrome

The description of Asperger syndrome is more complicated. The *DSM-IV-TR* defines the disorder as having impairment in at least two areas of social interaction and one restricted, repetitive, and stereotyped pattern of behavior, but not meeting full criteria for Autistic Disorder. The criteria further stipulate that there can be no clinically significant delays in the development of language, cognition, and self-help adaptive skills *during the first three years of life* (APA, 2000). However, many clinicians overlook the text of the *DSM-IV-TR* and resort only to the charts. In this case, the text signifying "during the first three years of life" would be missed, resulting in misdiagnoses of older individuals with Asperger syndrome who most certainly do present with areas of deficit in cognitive, adaptive, and language abilities (e.g., Klin et al., 2007; Saulnier & Klin, 2007).

Furthermore, if one refers only to the charts and not the text, the description of circumscribed interests—the all-encompassing preoccupations with topics of interest that tend to be more specific to Asperger syndrome than the other PDDs—would be similarly overlooked. These criteria have generated a great deal of controversy, resulting in tremendous variation in the diagnosis of Asperger syndrome, both clinically and in research. This variability and lack of consistency in defining the disorder has ultimately resulted in removal of the subtype from the forthcoming *DSM-5* (APA, 2010), which is not without controversy (e.g., Wing, Gould, & Gillberg, 2011).

Caution

Clinicians are cautioned against merely relying on the *DSM-IV-TR* charts for determining diagnostic criteria for the PDDs, as the descriptions of the most differentiating features of Asperger syndrome are included within the text of the *DSM-IV-TR* but not within the charts.

Clinicians and researchers who have closely studied and worked with individuals with Asperger syndrome invariably view this subtype as qualitatively distinct from the other PDDs, given the verbosity, social motivation, and fixation on topics of interest in these individuals. Ironically, these same symptoms can cause the most confusion in differential diagnosis. Common misconceptions propose those with Asperger's to be individuals without cognitive impairment; individuals with higher verbal than nonverbal IQ scores; individuals who have social intent; individuals who have mild or subtle social impairments; or individuals with perseverative interests, such as *Thomas the Tank Engine*—confusing getting “stuck” on a character or video rather than wanting to obsessively collect details about the topic of, for instance, trains. These misconceptions can have negative implications on outcome for individuals with Asperger syndrome because they are assumed to be less impaired and more able to navigate the world without supports—which is certainly not the case for many individuals.

Caution

Common misconceptions of Asperger Syndrome include the following characteristics interpreted in isolation:

- Individuals with ASD without cognitive impairment
- Individuals with ASD who have higher verbal than nonverbal IQ scores

- Individuals with ASD who have social intent and motivation to interact with others
- Asperger Syndrome is “mild autism”

It is not one of these behaviors, in isolation, that defines Asperger syndrome, but the overall profile of behavior, including developmental history. In early childhood, the social vulnerabilities of toddlers with Asperger syndrome are often masked by their relative strengths in other areas—such as their often precocious language; fixation on numbers and letters to the point of self-reading; and bourgeoning circumscribed interests. It is typically not until these children are immersed in social settings, where the social demands far outweigh their capacity to engage, that red flags are raised.

During the school-age years, individuals with Asperger syndrome tend to have more social motivation to interact with their peers, often inserting themselves into interactions inappropriately and/or lacking the appropriate social awareness to effectively navigate an interaction. Yet, they can have just enough awareness to understand the failed nature of their attempts, placing them at great risk for anxiety, depression, and isolation. In autism, individuals tend to be more socially passive; they certainly may respond to direct interaction, often even appropriately, but they are less likely to initiate interactions with their peers. Furthermore, self-awareness in autism can be more impaired, acting as a buffer in that individuals might not be as cognizant of their failed social experiences. Nevertheless, as stressed previously, social motivation should not be interpreted in isolation when distinguishing Asperger syndrome from other PDDs.

Caution

Unlike autism, Asperger syndrome is often not detected in the first few years of life because in early childhood, the social

vulnerabilities of toddlers with Asperger syndrome are often masked by their precocious language, affinity for numbers and letters, and regurgitation of facts on topics of interest. It is not until these children are immersed in social settings, such as preschool, that their true social impairments are recognized. For this reason, clinicians need to be extra vigilant in screening for social impairments in young children who have strong language and cognitive skills.

Don't Forget

Individuals with ASD, particularly those with Asperger Syndrome who tend to have a modicum of social awareness, are at great risk for mood disorders such as anxiety and depression. These symptoms can emerge as early as school age, but are most prominent in adolescents and adults and, therefore, should be monitored and treated accordingly.

Rapid Reference 1.2

Distinctions Between Asperger Syndrome and Other PDDs

Asperger Syndrome	**Autism, PDD-NOS**
• Early history marked by intact or precocious speech development	• Early history marked by significant language delays/impairments
• Extreme verbosity and one-sided conversations	• Limited speech and/or stereotyped language (e.g., echolalia, scripting)
• Social motivation in the absence of ability to effectively navigate social interactions	• Social passivity—more apt to monitor peers rather than initiate interaction
• May have stronger rote verbal than nonverbal cognitive scores—*though not diagnostic!*	• Tend to have stronger rote nonverbal than verbal cognitive scores
• Circumscribed interests—all-absorbing interest on a topic, including collecting facts on the topic, and this interest pervades and dominates conversations	• Perseverative interests—fixations on objects/movies/activities that become overly repetitive, and the individual has difficulty disengaging from the interest

Pervasive Developmental Disorder, Not Otherwise Specified

A diagnosis of PDD-NOS requires impairment in reciprocal social interaction (i.e., symptoms in subcategory 1) with associated impairments in at least one of the remaining two subcategories. Therefore, under the current taxonomy, an individual does not necessarily have to present with stereotypical behaviors (i.e., symptoms falling under subcategory 3) to carry a diagnosis of PDD-NOS. The proposed diagnostic criteria for a *DSM-5* diagnosis of ASD, however, require *at least two* stereotyped behaviors (see Table 1.1). This will most certainly impact many individuals who currently hold the label of PDD-NOS, as it raises the question as to what label, if any, will be appropriate to merit the same degree of services for these individuals.

Table 1.1 Comparison Between *DSM-IV* and Proposed *DSM-5* Diagnostic Criteria for Autism Spectrum Disorders.

	DSM-IV	**DSM-5**
Category	*Pervasive Developmental Disorders*	*Autism Spectrum Disorder*
Category Subtypes	**1.** Autistic Disorder **2.** Asperger's Disorder **3.** Pervasive Developmental Disorder, Not Otherwise Specified (PDD-NOS) **4.** Rett's Disorder **5.** Childhood Disintegrative Disorder	None

	DSM-IV	DSM-5
Symptom Subcategories	**1.** Impairments in Social Interaction **2.** Impairments in Communication **3.** Restricted, Repetitive, and Stereotyped Patterns of Behavior, Interests, and Activities	**1.** Deficits in Social Communication and Social Interaction **2.** Restricted, Repetitive Patterns of Behavior, Interests, or Activities
Diagnostic Criteria	**1.** *Autistic Disorder* = at least six total symptoms across all three subcategories, at least two of which are in social interaction **2.** *Asperger's Disorder* = symptoms in social interaction and restricted behaviors, with no delays in the development of language, cognition, or adaptive self-help skills in first three years of life; but not to full criteria for Autistic Disorder **3.** *PDD-NOS* = social impairments *and* symptoms in either communication and/or restricted behaviors; but not to full criteria for Autistic Disorder	**1.** *ASD* = three required criteria in social communication and social interaction *and* at least two out of four restricted and repetitive patterns of behavior **2.** Symptoms must be present in early childhood (even if not fully manifested until social demands exceed the child's level of social functioning)

Rett's Disorder and Childhood Disintegrative Disorder