

HANDBOOK OF  
**AUTISM**  
AND **PERVASIVE**  
**DEVELOPMENTAL**  
**DISORDERS**

**FOURTH EDITION**

VOLUME TWO

ASSESSMENT, INTERVENTIONS  
AND POLICY

EDITORS

FRED R. VOLKMAR  
SALLY J. ROGERS  
RHEA PAUL  
KEVIN A. PELPHREY



**WILEY**



# **HANDBOOK OF AUTISM AND PERVASIVE DEVELOPMENTAL DISORDERS**



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VOLUME 2: ASSESSMENT, INTERVENTIONS, AND POLICY

Fourth Edition

*Edited by*

FRED R. VOLKMAR, SALLY J. ROGERS, RHEA PAUL,  
AND KEVIN A. PELPHREY

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# Preface

The pace of autism research has increased dramatically since the previous edition of this *Handbook* appeared. In that year, 2005, there were approximately 800 peer-reviewed scientific papers on autism, while in 2012 this number had increased to over 2,600. This marked increase in research productivity poses important challenges for editors of a comprehensive handbook devoted to autism. Inevitably, some difficult choices have to be made in balancing coverage of research, intervention, theory, and social policy.

In the 70 years since Kanner's initial description of autism, the condition has attracted interest from clinicians and researchers alike. As a disorder that impacts core aspects of socialization, it has posed important challenges for theories of developmental psychology and neurobiology as well as for clinical practice in diagnosis and intervention, and studies of diagnostic validity and treatment. Essentially every theory relating to child development—cognitive, social, behavioral, affective, neurobiological—has been applied to understanding this enigmatic condition. Autism has served as a paradigmatic disorder for research on the essential preconditions for normal social-cognitive maturation—expression and recognition of emotions, intersubjectivity, sharing the focus of interest with other people, the meaning and uses of language, forming attachments, and relating empathetically to others.

In developing this new edition, we have been mindful of the considerable progress made in the field as well as areas where knowledge remains limited. Great advances have been made, for example, in understanding the social brain, in genetics, and in basic aspects of neurobiology. Other advances have also been made in the areas of intervention and there is a new and growing convergence between research findings and evidence-based practice. On the other hand, there are many areas where knowledge remains limited—for example, work on aging in autism is almost nonexistent.

As with other areas of science, we believe that autism scholarship and service will advance when we adopt, as much as possible, rigorous standards of scientific research. Our aim with this fourth edition is to provide a comprehensive account of current work in the field. In many instances, authors have kindly revised earlier contributions in light of current research; in other cases, we have solicited new contributors and chapters. Our goal for these volumes is to provide timely overviews in key areas that can help researchers, clinicians, and policy makers.

We are acutely aware that investigators and clinicians, working alongside families and advocates, have learned so much, often with limited resources. The knowledge summarized in these volumes speaks to the commitment of these individuals in understanding and caring for children

with autism. We hope that these volumes document their achievements and inspire their future efforts.

We thank a number of colleagues who have critiqued early versions of chapters or who helped us select chapter authors or focus chapter topics. These include Brian Reichow, Roger Jou, William Nordhaus, Peter Doehring, Abha Ghupta, Carlisle Runge, Iain McClure, Christopher McDougle,

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## SECTION IV

# Assessment

The assessment of individuals with autism spectrum disorder (ASD) calls on the expertise of a variety of disciplines, including pediatrics, neurology, psychiatry, psychology, special education, speech-language pathology, and physical rehabilitation, to name a few. In this section, we ask expert clinicians from these disciplines to discuss the assessment process from their point of view. Our authors address:

- Major goals of assessment, including:
  - screening to determine the need for further assessment;
  - diagnostic evaluation that establishes eligibility for services;
  - differential diagnosis that distinguishes ASD from other neuropsychiatric syndromes;
  - identifying baseline function in a range of developmental areas, against which progress in intervention can be measured;
  - characterization of strengths and needs of the individual, in order to guide the development of intervention objectives and procedures; and
  - detailed description of functioning across a range of developmental areas, in order to characterize the range of phenotypic expression within the syndrome.
- Methods available for rigorous assessment of core symptoms associated with ASD, including:
  - standardized instruments,
  - observational protocols,
  - criterion-referenced probes, and
  - caretaker and teacher questionnaires and interviews.
- The application of evidence-based practice to assessment.

These issues not only impact clinical practice in ASD, but also affect the conduct of research. Until recently, there have been few well-standardized, validated, and reliable measures that provide diagnostic and assessment information about individuals with ASD, making both creditable diagnoses and replicable research problematic. In the area of screening and diagnostic assessment, great strides have been made since the previous edition of this handbook in the development and validation of measures designed specifically to determine the need for assessment as well as the diagnosis of ASD. This progress has come as a result of intensive research efforts to assess the sensitivity, specificity, and validity of screening and diagnostic measures. Still, issues and controversies remain regarding the construction, implementation, and interpretation of these measures, many of which are discussed in the chapters in this section.

Differential diagnosis within the autism spectrum and among ASD and other disorders remains stubbornly difficult, particularly for the youngest children, for whom early identification is so crucial to optimal outcomes. Recent changes in *DSM-5* highlight this issue, and heated debate continues about the propriety of moving from older systems identifying subgroups within the autism spectrum to a system of treating it as an undifferentiated continuum. As chapters in this section demonstrate, assessment contributes to this debate by providing the opportunity to answer questions on the basis of data rather than theory or anecdotal experience.

An important goal of assessment is to move beyond global descriptions to more fine-grained, precise documentation of functioning across domains, including cognitive, linguistic, communicative, social, motor, and adaptive behaviors. These fine-grained descriptions of individual patterns of behavior and ability contribute in important ways to the identification of an individual's baseline function for gauging progress in intervention and of the profile of strengths and needs that guide the development of educational goals. In addition, though, they provide the opportunity to explore patterns across individuals. The discovery of consistent patterns of behavioral and cognitive functions provides an empirical basis for testing hypotheses about the existence and validity of subgroups within the broad autism spectrum, and the possibility of finding biological correlates, including those at genetic, neuroanatomical, neurophysiological, or neurochemical levels. The identification of subgroups with such biomarkers holds out the promise that specific medical or pharmacological interventions may one day be devised to address specific elements of the syndrome within specific subgroups. The fulfillment of this promise depends to a great degree on the precision of assessment information collected, and on the accumulation of this information in research based in psychometrically sound clinical instruments and structured observation.

An additional message that emerges from this section is the importance of seeing ASD within a developmental framework. Despite the unique symptoms and uneven skills often seen in individuals with ASD, many strands of their development nonetheless follow the normative sequence. This normative aspect of development is a crucial consideration in determining the needs of individuals with ASD, in terms of focusing on developmentally appropriate social, academic, self-help, and motor skills. It is incumbent upon clinicians not to be diverted by the many atypical behaviors of people with ASD into ignoring the aspects of their function that will allow them to take advantage of interactions with peers and other members of

their community. Detailed assessment information collected within a developmental framework, including well-constructed instruments designed specifically for individuals with ASD as well as psychometrically sound instruments that take a broader developmental spectrum into account, is essential for optimizing these opportunities. Many chapters in this section provide guidelines and methods for achieving these developmentally situated evaluations.

Another point made clear in this section is the degree of experience, expertise, and teamwork needed to accomplish the kind of multidimensional assessment that will both deeply characterize an individual's diagnostic and developmental status and provide the fine-grained data that will inform and advance research on ASD. Individuals with ASD can show unusual preferences for reinforcement, attentional, and motivational characteristics, and uneven profiles across domains. These differences can make it challenging for them to participate in assessment activities, and to demonstrate their optimal level of competence. Clinicians performing assessments need more than knowledge of their instruments; they need understanding of the particular challenges individuals with ASD face in the assessment process, insight and empathy with their struggles, and patience and flexibility to elicit the best performance. They need, too, to work closely with colleagues from other disciplines and to think creatively about planning the overall assessment experience to maximize the client's opportunities for success. No one discipline has a monopoly on the diagnostic process, and the most thorough and effective assessments will involve interprofessional collaboration in planning, administering, and interpreting assessment data.

Finally, the results of assessments must be placed within the context of the opportunities the individual has had for social relations, academic achievement, recreation, and self-advocacy. We can anticipate that children who had consistent, intensive educational programming since early childhood will appear quite different on assessment than those with more restricted experiences.

Moreover, contextually based assessments can help to locate ways in which the environment can be engineered to enhance appropriate experiences that will enable the acquisition of a range of academic and practical skills. Chapters in this section provide examples of the ways in which this kind of ecological assessment can round out the picture of the skills and needs of individuals with ASD.

The results of careful and comprehensive assessment are a function of the individual's congenital biological endowment, maturation, personal experiences, and community opportunities. Used appropriately, objective, rigorous assessment provides both the best guide to comprehensive, effective intervention and the most direct path to advancing research on this complex syndrome.



CHAPTER 24

Screening for Autism  
in Young Children

LISA V. IBAÑEZ, WENDY L. STONE, AND ELAINE E. COONROD

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Evidence from early intervention research clearly indicates that participation in specialized behavioral intervention programs at young ages can optimize the social-communicative and cognitive outcomes of children with autism and autism spectrum disorders (ASDs; Dawson et al., 2010; Ingersoll, 2010; Kasari, Gulsrud, Wong, Kwon, & Locke, 2010; Landa, Holman, O'Neill, & Stuart, 2010), and may even normalize patterns of brain activity (Dawson et al., 2012). Although parental concerns about their child's development are often present by 17–19 months (Coonrod & Stone, 2004; De Giacomo & Fombonne, 1998), the average age of an ASD diagnosis in the United States is 4.5 years (Centers for Disease Control [CDC], 2012) and the median age is 5.7 years (Shattuck et al., 2009). As a result, many children miss the opportunity to benefit from early intervention services. Screening for autism in young children has the potential to promote earlier diagnosis and more widespread,

systematic referrals to appropriately specialized intervention programs. This chapter addresses several topics related to the screening of young children for autism and ASD, including the early characteristics of autism, early screening practices and models, and the current state of the science regarding early screening measures for autism.

**CHARACTERISTICS OF AUTISM  
IN YOUNG CHILDREN**

Autism is a neurodevelopmental disorder that emerges early in life. The past 15 years have seen a dramatic increase in research focused on identifying the earliest signs and symptoms of the emerging disorder. Underlying the push for earlier diagnosis is the hope of preventing or mitigating some of the symptoms of autism by providing targeted interventions during a period of rapid brain growth

and development that occurs in infancy and toddlerhood. Behavioral studies have revealed that the social-emotional and social-communicative impairments that are well established in preschool-aged children with autism are also present by the second year of life in children later diagnosed with autism. For example, behaviors such as socially directed gaze, motor imitation, social smiling, response to adult social bids and expressions of distress, and initiation of joint attention by pointing to and showing objects differentiate infants with and without autism using both retrospective (Adrien et al., 1993; Baranek, 1999; Osterling, Dawson, & Munson, 2002; Werner, Dawson, Osterling, & Dinno, 2000) and prospective research designs (Charman et al., 1997; Hutman et al., 2010; Landa, Holman, & Garrett-Mayer, 2007; Ozonoff et al., 2010; Rozga et al., 2011; Yoder, Stone, Walden, & Malesa, 2009). In a similar vein, repetitive motor behaviors and atypical object use have also been found in children with autism by the second year of life (Ozonoff, Macari, Goldring, Thompson, & Rogers, 2008; Watt, Wetherby, Barber, & Morgan, 2008).

Behavioral findings such as these have informed the development and refinement of many screening tools currently used for the early detection of autism risk. However, the identification of this pattern of symptom expression in a young child can be challenging for several reasons. First, social-communication impairments, often considered to be the core feature of autism, represent negative symptoms, or the absence or reduced frequency of behaviors expected for a child's developmental level (Filipek et al., 1999). It is very difficult to interpret the *absence* of a behavior in young children, whose moment-to-moment behaviors are more vulnerable to the influence of internal state and setting factors. For example, the failure to observe social smiling in an 18-month-old during a clinic visit may represent a red flag for autism, but may also reflect fatigue, hunger, or a host of other contributing causes. Second, social-communicative behavior is not an all-or-none phenomenon. It is rarely the case that young children with autism *never* make eye contact, or *never* imitate the actions

of others. Rather, the differences between children with and without autism tend to be in the *consistency* with which these behaviors are exhibited and the *effort* required to elicit them (Baranek, 1999), both of which can be difficult to measure or assess. Third, there are no established norms or milestones for social behaviors in the same way they exist for motor or language development. What percentage of time is a child expected to look at a parent who calls his name, and how does one quantify social reciprocity during everyday interactions? There is much greater ambiguity in the definitions and expectations for social behaviors than for other developmental milestones.

## IMPORTANCE OF EARLY SCREENING FOR AUTISM

For over a decade, several professional groups and consensus panels, including the American Academy of Neurology (Filipek et al., 1999; Filipek et al., 2000) and the American Academy of Pediatrics (AAP Committee on Children with Disabilities, 2001), have advocated for early and regular screening for autism. Specific recommendations from the American Academy of Pediatrics in 2007 include providing surveillance at every well-child visit, with special attention to subtle red flags and the infant siblings of children with autism (high-risk siblings); conducting autism-specific screening for all children at 18 and 24 months of age; scheduling a targeted clinic visit when parent or physician concerns remain after a negative screen; and acting on a positive screen, or on the presence of two or more autism risk factors, by referring for an autism evaluation and/or early intervention (Johnson & Myers, 2007). Although these guidelines provide concrete steps and recommended tools for autism-specific screening, compliance with the guidelines is by no means universal. A recent survey conducted across six states revealed that 60% of pediatricians conduct formal screening for autism at 18 months and 50% at 24 months (Arunyanart et al., 2012). While these rates are substantially higher than the 8%

reported in an earlier study of pediatrician practices (Dosreis, Weiner, Johnson, & Newschaffer, 2006), there is much room for improvement.

Several recent studies have provided additional support for the importance of early formal screening for autism. For example, one study conducted in a large, community-based pediatric practice found that the use of formal autism screening tools was more effective in identifying ASD than was pediatrician's clinical judgment alone (Miller et al., 2011). Other studies have found that training health care workers in the use of autism screening instruments is not only associated with increased knowledge about early social and communication markers of autism, but also contributes to significant practice change (Charman et al., 2001; Oosterling et al., 2010; Swanson et al., in press; Warren, Stone, & Humberd, 2009). Perhaps the most compelling support, however, comes from an early detection program conducted in the Netherlands (Oosterling et al., 2010), in which health care providers in a certain region were trained in the use of a formal autism screening tool, the Early Screening of Autistic Traits Questionnaire (ESAT; Dietz, Swinkels, van Daalen, van Engeland, & Buitelaar, 2006; Swinkels et al., 2006). The mean age of diagnosis in the region participating in the program dropped from 82.9 months to 63.5 months, whereas no change was observed in a region not participating in the program. In addition, children in the targeted region were over nine times more likely to be diagnosed before 36 months relative to those in the comparison region. Thus, the routine use of formal screening tools has been shown to increase providers' knowledge about early red flags, reduce bias in referrals for further clinical assessment, and lower the age of autism diagnosis.

## THE SCREENING PROCESS

Screening is designed to be a brief assessment for identifying children in need of a more comprehensive diagnostic evaluation due to risk of delay or disability (Meisels, 1985). As such, screening is the first of a multistep process that may also include

rescreening, referral to a diagnostic center for further assessment, and referral to early intervention programs (Aylward, 1997). Screening measures differ from diagnostic measures in that they typically require less time, training, and experience to administer, and the results of screening measures indicate levels of risk for disability rather than provide a diagnosis.

## Dimensions of Screening Measures

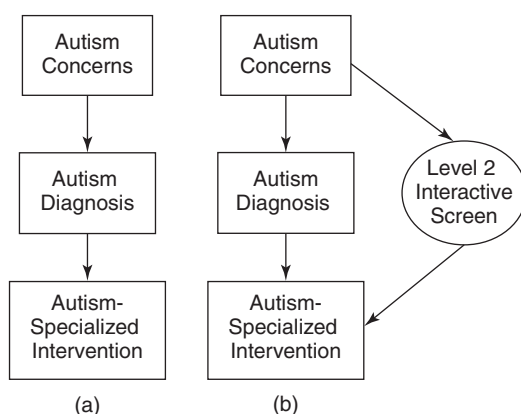
Screening measures can vary across several different dimensions, which impact their suitability for use in different practice settings (Zwaigenbaum & Stone, 2006). Level 1 screening (i.e., universal screening) is conducted for the purpose of identifying children at risk for developmental disorders from the general population of unselected, presumably low-risk children. Accordingly, Level 1 screening measures are used most commonly in pediatric or other primary health-care settings, where they can be administered routinely to all children during well-child visits, regardless of whether developmental concerns are present. For use in these settings, Level 1 screeners need to be quick and easy to administer, score, and interpret. In contrast, the purpose of Level 2 screening is to identify children's risk for a specific disorder after a developmental concern has already been identified. Thus, Level 2 screening measures can help differentiate children at risk for autism from those at risk for other developmental disorders, such as global developmental delay or language impairment. Level 2 screening measures are used more often in community settings such as child-find agencies, early intervention programs, or evaluation centers serving children with a variety of developmental challenges. Many of these settings do not have the same types of time pressures as pediatric practices and can accommodate somewhat more involved screening measures and approaches.

Another dimension on which screening measures differ is their format, which can be informant report, observational, or interactive. Each format is associated with specific strengths and liabilities. Informant-report measures, which often involve

parental report, have the advantage of capitalizing on caregivers' knowledge about multiple areas of the child's behavior over time and across diverse situations and contexts, but may be compromised by reporting bias. In contrast, observational measures that employ ratings of children's behaviors in the immediate context can benefit from the rater's training and expertise regarding age-specific norms and expectations, but are restricted in the breadth of information that can be acquired at a single point in time. As well, screening measures involving structured interactions with the child provide a more direct experience of his or her social-communicative behaviors and interaction style, but tend to be more time and training intensive. The selection of screening measures thus needs to be guided by considerations such as the type of information desired, the demands of the screening context, and the background and training of the user. Given the availability of different types and levels of screeners, it is feasible that using combinations of screening tools and multilevel models of screening could be more effective than using a single screening measure at a single point in time. In fact, several recent studies exploring screening models have successfully used combinations of screening measures as well as serial approaches to screening (Miller et al., 2011; Roux et al., 2012) for young children with autism.

The flexible use of screening tools may also serve the ultimate goal of improving access to early intervention for young children with autism. In many communities, the traditional diagnosis-intervention model can pose some serious challenges in access to early intervention services, particularly for young children with autism. This model (see Figure 24.1a) requires that children receive a formal diagnosis of autism before they can obtain autism-specialized services. However, there are several common roadblocks that occur between the time of initial concerns and the time that specialized intervention is initiated. First, primary care providers may be reluctant to make early referrals for diagnostic evaluation for reasons including a lack of familiarity with the early signs of autism, lack of knowledge regarding the use

of autism screening tools, and lack of comfort speaking with families about autism concerns (Dosreis & Weiner, 2006; Tomlin, Koch, Raches, Minshawi, & Sweizy, 2013). Once the referral is made, families may often discover extensive waiting lists for diagnostic evaluations, resulting in long delays in obtaining a confirmatory diagnosis of autism (Barton, Dumont-Mathieu, & Fein, 2012; Young, Brewer, & Pattison, 2003). Finally, after the child receives an autism diagnosis, families may be faced with a shortage of autism-specialized service providers (Tomlin et al., 2013; Wise, Little, Holliman, Wise, & Wang, 2010). In the meantime, many children have aged out of eligibility for early intervention services. In contrast, a risk-prevention model may facilitate earlier access to specialized intervention by using interactive Level 2 screening measures to confirm autism risk as well as identify targeted treatment goals and activities that can be initiated immediately (see Figure 24.1b). In this way, specialized intervention can begin earlier, prior to the formal diagnosis, thus capitalizing on early brain plasticity and the possibility of mitigating symptoms and improving outcomes (Dawson et al., 2010; Dawson et al., 2012; Kasari et al., 2010; Landa et al., 2010).



**Figure 24.1** Potential role of screening in expediting autism-specialized intervention. (a) Traditional diagnosis-intervention model. A formal autism diagnosis is required before specialized intervention is provided. (b) Risk-prevention model. A Level 2 interactive screen provides information about risk status and child-specific behavioral needs so that specialized intervention can begin while waiting for the formal diagnosis.