INTRODUCTION

The Pervasive Developmental Disorders represent a diagnostic category of severe psychopathology in childhood. The *Diagnostic and Statistical Manual of Mental Disorders, 4th ed.* (DSM-IV; American Psychiatric Association [APA], 1994), differentiates five disorders under this category, of which Autistic Disorder is the most severe. Other disorders include Asperger’s Disorder (often not differentiated from “high-functioning” autism), Pervasive Developmental Disorder, Not Otherwise Specified (PDD-NOS), Rett’s Disorder, and Childhood Disintegrative Disorder. This chapter is primarily concerned with assessment issues for Autistic Disorder (autism), PDD-NOS, and, to some extent, Asperger’s Disorder.
Though the assessment of autistic symptoms in Rett’s Disorder and Childhood Disintegrative Disorder follows the same general guidelines discussed here, these disorders will not be discussed due to their relative rarity and the differences in onset and course from those of the other pervasive developmental disorders.

Autism is a neurodevelopmental disorder characterized by core impairments in social interaction and communication and the presence of repetitive behaviors and restricted interests. In the social domain, these children are characterized by a failure to interact appropriately with peers, social avoidance and detachment, and general nonresponsiveness to the social environment. These children also either fail to develop functional communication or are severely delayed and/or deviant in communicative behavior. Typically they fail to use instrumental gestures such as pointing and waving bye-bye and do not use eye gaze to share experiences (“joint attention”). If vocal language develops it is likely characterized by specific speech anomalies, including echolalia, neologisms, idiosyncratic language, and dysprosody. Repetitive behaviors may include stereotyped body movements (e.g., body rocking, hand or arm flapping) and repetitive vocalizations. Restricted interests are noted when the child lines up objects in a ritualistic manner, speaks about only one narrow subject, or otherwise is inflexible about his behavior or the environment.

As with any disorder, assessment is critical and serves many purposes. Autistic Disorder, Asperger’s Disorder, and PDD-NOS are now more commonly seen as a “spectrum” of disorders, which vary in the severity of social/communication difficulties and language outcome (Lord & Bailey, 2002). Diagnostic accuracy has been an important area of investigation for autism researchers for a number of years. Diagnostic precision is critical for research aimed at uncovering the underlying biological causes, but the heterogeneity and overlap of the behavioral phenotype make characterization within the autism spectrum difficult (Akshoomoff et al., 2004; Akshoomoff, Pierce, & Courchesne, 2002; Lord, Leventhal, & Cook, 2001). Proper diagnosis is critical for epidemiological research to accurately report the prevalence of pervasive developmental disorders and also to address issues related to diagnostic distinctions within the autism spectrum. An accurate diagnosis is also crucial for access to appropriate intervention, treatment planning, information regarding the developmental course of the disorder, and caregiver understanding of the disorder as well as providing a common language for researchers. Good assessment is also necessary for the identification, design, and implementation of appropriate, effective treatment strategies.

ASSessment STRATEGIES

Use of the DSM-IV criteria to make a diagnosis of a pervasive developmental disorder requires an experienced clinician as well as extensive information about a child’s history, developmental level, behavior in a variety of settings, and
medical status (Gillberg et al., 1990; Lord, Storoschuk, Rutter, & Pickles, 1993). Impairments in social interaction and communication and a restricted repertoire of interests, behaviors, and activities are the core domains required for diagnosis, but several additional domains can be affected and influence manifestation of symptoms. It is therefore often recommended that an evaluation for a pervasive developmental disorder be conducted by a team of professionals experienced with these disorders and include a formal multidisciplinary evaluation of social behavior, language and nonverbal communication, adaptive behavior, motor skills, atypical behaviors, and cognitive status (Charman & Baird, 2002; Filipek et al., 2000; National Research Council, 2001; Shriver, Allen, & Matthews, 1999). The evaluation team will typically include an experienced clinical psychologist or school psychologist, a speech/language pathologist, and an occupational therapist. Many children with an Autism Spectrum Disorder (ASD) experience difficulties with fine motor coordination, low muscle tone, difficulties with behavior control and aggression, and/or the presence of a seizure disorder, warranting a consultation with an experienced pediatric neurologist or child psychiatrist.

Several detailed guidelines for diagnosis of ASD have been developed. The most comprehensive of these is the Practice Parameter for the Screening and Diagnosis of Autism (Filipek et al., 2000, 1999). These guidelines were developed by a team that included members from nine professional organizations, four parent organizations, and liaisons from the National Institutes of Health. The multidisciplinary team’s comprehensive examination of the scientific literature on autism resulted in a multitiered approach to diagnosis that includes developmental surveillance, screening, and varied levels of assessment, depending on specific symptomatology. Recommendations for assessment procedures for a variety of fields, expanded medical tests, and referrals were provided. The California Department of Developmental Services (2002) also developed guidelines for the evaluation process for young children suspected of having an ASD in order to provide appropriate intervention planning.

The five areas of evaluation recommended in these two guidelines will be used here to outline our general discussion of appropriate assessment in autism. An evaluation for an ASD should include (at minimum) a parent/caregiver interview, a medical evaluation, direct behavioral observation, a cognitive assessment, and an assessment of adaptive functioning. No assessment instruments are available that can be used in isolation to make a diagnosis of autism, but the combined use of evidence-based, standardized, objective measures is recommended for providing information relevant to making an appropriate diagnosis. Formal clinical measures (e.g., the Autism Diagnostic Interview—Revised) are often best for determining risk for autism rather than determining which specific pervasive developmental disorder most accurately describes the child (Stone et al., 1999). Clinical judgment by an experienced diagnostician using the DSM-IV is necessary for determining the specific diagnosis.

The first step in making a diagnosis is the parent/caregiver interview, which should include information about a child’s medical and developmental history, a
description of past and current functioning, behavioral and social issues, and a family history. This can be conducted using informal interview techniques and/or a structured interview. Several standardized interviews are available for assisting with diagnosing an ASD.

The Autism Diagnostic Interview—Revised (ADI-R; Lord, Rutter, & Le Couteur, 1994; Rutter, Le Couteur, & Lord, 2003) is a standardized instrument administered via a semistructured interview with the parent or caregiver, with questions in each of the diagnostic areas of social relatedness, communication, and ritualistic or perseverative behaviors. The respondent is asked about the child’s current behavior and, for older individuals, probed for behavior at ages 4–5, when autistic symptoms tend to be most prominent. Assessed individuals can be of any age, as long as mental abilities are at a developmental level of at least 18–24 months. Diagnostic decisions are based on algorithm items and correspond with both DSM-IV and ICD-10 diagnoses. While the use of this instrument is considered part of the current “gold standard” for diagnosis in the research arena (Filipek et al., 1999), its length (approximately 2 hours) and the level of training needed to reliably conduct the assessment may limit its use in clinical settings.

The Social Communication Questionnaire (SCQ; Rutter, Bailey, & Lord, 2003) is a brief instrument that helps evaluate communication skills and social functioning in children who may have autism. This instrument, formerly known as the Autism Screening Questionnaire, has good discriminate validity with respect to the separation of ASD from non-ASD diagnoses at all IQ levels (Berument, Rutter, Lord, Pickles, & Bailey, 1999; Bishop & Norbury, 2002). It can be used with any individual over 4 (with a mental age exceeding 24 months). The form can be given to the parent or caregiver and is available in Spanish as well as English.

The Gilliam Autism Rating Scale (GARS; Gilliam, 1995) and the Gilliam Asperger's Disorder Scale (GADS; Gilliam, 2001) are questionnaires completed by parents, teachers, or professionals. These instruments were normed on individuals with autism and Asperger’s disorder, respectively. The items, based on DSM-IV criteria for each disorder, also offer an optional subtest describing development during the first three years of life. These tools are appropriate for individuals ages 3–22 and provide a global rating of the probability that an individual has the disorder. The GARS appears to have limited use for diagnostic purposes and to be better used as a screening device (California Department of Developmental Services, 2002; South et al., 2002).

Other interviews or questionnaires include the Autism Behavior Checklist (ABC; Krug, Arick, & Almond, 1980), which is completed by a parent or teacher and includes questions in the areas of sensory, relating, body and object use, language and social/self-help skills. It can be used with children age 3 years and above. The Pervasive Developmental Disorders Screening Test—Stage 2 (PDDST; Siegel, 2004) is part of a three-stage assessment, which begins with an initial short screening for autistic symptoms. This tool can be used with children
as young as 18 months of age and has cutoffs for further consideration of a diagnosis of an ASD.

A medical evaluation is recommended in order to rule out other specific conditions that may cause symptoms similar to autism (e.g., fragile X syndrome; fetal alcohol syndrome; tuberous sclerosis; and congenital infections) as well as comorbid medical conditions, such as seizures. Genetic testing may be needed if there is a family history of autism, mental retardation, fragile X syndrome, or tuberous sclerosis (Filipek et al., 1999). Additionally, Rett’s Disorder is now identifiable through genetic testing. The American Academy of Pediatrics recommends that assessment of every child with autism include laboratory tests such as audiologic and vision assessments, a lead screening, genetic testing, and a neurological evaluation. Additional testing can be conducted based on symptomatology, for example, allergy testing or gastrointestinal testing.

A direct behavioral observation is paramount to an appropriate diagnosis because it provides the opportunity for the clinician to observe the child directly and to obtain information that may not be readily reported by parents or caregivers. Parents may also compensate for behavioral deficits that can be more easily identified when a child interacts with a clinician. The behavioral observation can be an informal play-based assessment or can include more formal, standardized behavior assessment. Behavioral observations of social behaviors, communicative skills, and stereotyped behaviors should be included. Ideally, observation should take place in more than one setting, including observing the child interacting with peers.

Some professionals contend that naturalistic behavioral observations provide the best source of information for a diagnosis for very young children with autism, above and beyond what can be obtained with standardized assessments. Several assessments are not specific to diagnosing autism, such as the Transdisciplinary Play-Based Assessment (Linder, 1993) and the Communication and Symbolic Behavior Scales (CSBS; Wetherby, 1993), which allow coding of a variety of functioning areas (e.g., play, communication, reciprocity, symbolic behavior, social-emotional development) through structured- and unstructured-play observations. Although these assessments do not provide information regarding a specific diagnosis, they can be used to examine characteristics useful for determining a child’s functioning in a variety of areas helpful to determining a diagnosis.

There are also standardized observational scales specific to autism. For example, The Childhood Autism Rating Scale (CARS; Schopler, Reichler, & Rochen Renner, 1988) is used by experienced professionals to rate a child’s behavior. The CARS consists of 15 four-point scales, based on DSM-III-R criteria. It requires direct observation of the child and an interview of the child’s caregiver, but it does not provide guidelines on a standardized method of observation. The CARS has fair agreement with the ADI-R (Saemundsen, Magnusson, Smari, & Sigurdardottir, 2003). Some argue that the CARS may be best used as a screening measure (Shriver et al., 1999). The CARS is useful for children over the age of 2 years and is widely used in the clinical diagnosis of autism.
The Autism Diagnostic Observation Schedule (ADOS) is a standardized observation of social behavior in naturalistic and communicative contexts. It has four different modules, with corresponding tasks for individuals of different ages and language levels (DiLavore, Lord, & Rutter, 1995; Lord et al., 2000; Lord, Rutter, DiLavore, & Risi, 2001; Lord et al., 1989). Each module includes standardized activities, or “presses,” that allow the evaluator to assess communication, social interaction, play, repetitive behaviors, and other autistic features in individuals with autism from 24 months through adulthood. The ADOS yields scores that fall within a range from autism to autism spectrum disorder, and so may be particularly helpful with difficult-to-diagnose cases. The ADOS can be used with children with cognitive skills as young as 18–24 months through adulthood. The assessment takes between 30 and 60 minutes to complete.

The ADI-R (described earlier) and the ADOS are complementary diagnostic instruments originally created for research studies but now available for clinical purposes. Both the ADI-R and the ADOS operationally define current DSM-IV and ICD-10 criteria in the three domains that define autism spectrum disorders: social reciprocity, communication, and restricted, repetitive behaviors and interests. This can be very helpful in increasing parents’ understanding of their children’s disabilities and in setting goals. Training and practice in observation, administration, and scoring is necessary. Interrater reliability within a clinic or through the use of videotapes (available from the test publisher) is desirable. Individuals using the ADOS and/or the ADI-R in research studies should attend specific research training workshops and obtain reliability with workshop leaders and with researchers from other sites.

Most children with an ASD are mentally retarded. A cognitive assessment is essential to understanding a child’s behavior in the context of his or her functioning level and is crucial to the differential diagnosis of ASD from other developmental disabilities. Information about functioning level can also provide an understanding of prognosis. Standardized cognitive assessments can be used to determine a child’s ability level in a structured setting, but they should be interpreted with caution, particularly before intervention has been attempted. Motivation can affect test results, so it is important to enhance motivation as much as possible without affecting standardized procedures of the assessment (Koegel, Koegel, & Smith, 1997).

Children with ASD tend to perform better on rote, mechanical, or perceptual tasks and more poorly on complex, abstract tasks. While it was assumed that children with autism were more likely to have higher nonverbal than verbal skills (e.g., Lincoln, Courchesne, Kilman, Elmasian, & Allen, 1988), recent studies with larger and more diverse samples suggest that it is more common for cognitive development to be uneven in children with ASD rather than following a “typical profile” (Joseph, Tager-Flusberg, & Lord, 2002; Siegel, Minshew, & Goldstein, 1996). Assessing intelligence levels in younger children with ASD can be particularly challenging (Akshoomoff, submitted). The Mullen Scales of Early Learning (Mullen, 1995) and the Bayley Scales of Infant Development—II
Bayley, 1993) can provide an estimate of the child’s current developmental level. Higher-functioning children can be tested using the Differential Ability Scales (DAS; Elliott, 1990) or the Stanford–Binet IV (Thordike, Hagen, & Sattler, 1986). The Wechsler Intelligence Scale for Children (WISC-IV; Wechsler, 2003) is typically reserved for higher-functioning children with good verbal skills (Filipek et al., 1999). Neuropsychological, behavioral, and academic assessments should be performed as needed, particularly in conjunction with the child’s IEP team.

In addition to information provided about the child’s receptive and expressive language skills from a standardized intelligence test, it is important to obtain more in-depth information about the child’s language and communication skills using the most appropriate standardized test. Typical instruments include the Peabody Picture Vocabulary Test—III (Dunn & Dunn, 1997), the Reynell Developmental Language Scale (Reynell & Grueber, 1990), the Clinical Evaluation of Language Fundamentals—4th Edition (Semel, Wiig, & Secord, 2003), or the CELF-Preschool (Wiig, Secord, & Semel, 1992). For young children with minimal functional language, the caregiver can be asked to complete the MacArthur Communicative Development Inventory (Fenson et al., 1993).

Finally, assessment of adaptive functioning can provide information about how a child is functioning in his or her environment and may be used to augment cognitive assessments. Such information is critical for determining whether an individual has mental retardation assists in treatment planning. The Vineland Adaptive Behavior Scales (Sparrow, Balla, & Cicchetti, 1984) are typically a preferred measure for children with autism (e.g., Volkmar, Klin, Marans, & Cohen, 1996). This is a caregiver interview that provides standard scores and age equivalents for four domains, including communication, social skills, daily living skills, and, for children under age 6, motor skills. Caregivers are asked to describe what their child actually does in each of these areas. The assessment can be used for individuals of any age.

**RESEARCH BASIS**

Although a biological marker for autism has not yet been identified, autism is one of the most reliably diagnosed behavioral disorders (Bristol-Power & Spinella, 1999). As already discussed, several standardized measures can be used to assist in making an autism diagnosis. However, at all ages, experienced clinical judgment using information from a variety of sources is more reliable for determination of diagnosis than the use of standard assessment instruments alone (Chakrabarti & Fombonne, 2001; Charman & Baird, 2002; Lord, 1995). Currently, the most controversial topic in autism is the accuracy of early diagnosis, especially at very early ages.

In the past few years, progress has been made in the early identification of children with autism, so most children are identified in the preschool period.
Part of this is due to improvements in the recognition of the early features of autism among primary health care providers and other professionals who interact with very young children, the development of appropriate screening tools, and the availability of early intervention services (Baird et al., 2000; Robins, Fein, Barton, & Green, 2001; Siegel, 1999). Research has demonstrated that the use of standardized test instruments by experienced clinicians results in a relatively stable early diagnosis in children as young as 2 (Lord, 1995). Recent research also suggests that identification of the disorder may be made as early as 8–12 months (Mars, Mauk, & Dowrick, 1998; Teitelbaum, Teitelbaum, Nye, Fryman, & Maurer, 1998; Werner, Dawson, Osterling, & Dinno, 2000), although the clinical implications of these findings are not yet clear.

The National Research Council’s Committee on Educational Interventions for Children with Autism (NRCA) recommended that early diagnosis be emphasized; however, children under the age of 4 who appear to have an ASD should be given a “provisional diagnosis” (Lord & Risi, 1998; National Research Council, 2001). A proportion of the children identified with possible autism before age 3 may not meet criteria for DSM-IV Autistic Disorder at later follow-up but are highly likely to meet criteria for PDD-NOS, a less severe form of autism (Cox et al., 1999; Lord, 1995; Stone et al., 1999). Alternatively, a proportion of children under the age of 3 who do not meet criteria for autism on a standardized parent report measure, such as the ADI-R, may nonetheless receive a clinical diagnosis of Autistic Disorder at a later follow-up. Therefore, a clinical diagnosis of autism is often sensitive and stable over time, and stability increases when an autism spectrum approach is used. It is clear that behavior-based diagnostic distinctions and long-term outcome for children with ASD are more reliable and predictable when diagnostic and functional outcomes are ascertained after age 5 (Coplan, 2000; Lord & Risi, 2000; Venter, Lord, & Schopler, 1992).

Longitudinal research studies of young children also have demonstrated that the use of a standardized observation of social and communicative behavior and play, such as the ADOS, may be more sensitive and stable over time than results from a standardized parent report measure alone. Children under age 4 may not show significant evidence of repetitive and stereotyped behaviors and restricted patterns of interest, as required to meet the cutoff for autism on the ADI-R or according to DSM-IV criteria. In one study of 2-year-olds suspected of having autism, use of one of two instruments that rely on the clinician’s ratings of the child, the ADOS or CARS, instead of the ADI-R alone, identified children who appeared to meet the social and communication criteria for autism but did not yet show significant evidence of restricted or repetitive behaviors (Lord & Risi, 2000). A follow-up assessment confirmed the diagnosis of autism in the vast majority of these children. It is not known how these research findings translate into everyday clinical practice or clinical practice in the schools, where the mix of developmental problems is wide compared to specialty clinics or research studies targeted toward children with ASD. Additional research is needed to
examine the reliability of diagnoses made in community settings outside of research programs.

One major area of difficulty in autism research is the inconsistent use of assessment tools across different intervention programs. When looking at many of the model programs for young children with autism, Handleman and Harris (2001) found that while all of the programs assessed children in the multiple areas discussed earlier, the specific tests used often varied across the programs, thus making comparisons difficult. A majority of programs reported using the Vineland Adaptive Behavior Scales to measure adaptive behavior. A wide variety of communication and cognitive assessments were used and often varied, depending on the age and functioning level of the child. For diagnostic purposes, the CARS was used most often, followed by the ADOS and then the ADI-R (programs using the ADI-R always used the ADOS as well). Many programs used idiosyncratic behavioral measures to examine changes in social, sensory, play, and communicative behavior as well. It is clear from this examination of model programs, which often include a research component, that no battery of specific assessments established for providing a diagnosis or examining program progress is yet preferred. This is very important for future understanding of the effects of different interventions and consistent diagnosis of this population (e.g., Lord et al., in press).

**CLINICAL UTILITY**

In addition to beginning intervention as soon as possible, it appears that the outcome of children with ASD is dependent, to some degree, on the type of intervention prescribed. Therefore in order for assessment to lead to appropriate clinical treatment, what is required are both careful early diagnosis and accurate determination of which intervention methods are effective for the various needs of children with ASD. The progress of the children needs to be monitored carefully, both across time for an individual child and across children in different intervention programs. This requires comparable assessment protocols (California Departments of Education and Developmental Services, 1997; Martin, Bibby, Midford, & Eikeseth, 2003). An appropriately written, individualized family service plan (ages 0–3 years), individualized education program (ages 3–21 years) or intervention plan (all ages) needs to be based on knowledge of current, relevant research, effective practices, and recognition of the wide range of characteristics that are classified as symptoms of various ASDs (California Departments of Education and Developmental Services). This means that professionals responsible for assessment need to be knowledgeable in the area of autism and that appropriate assessments need to be utilized. As is true for other best-practices guidelines, two “best practices” guidelines from California present a list of instruments for diagnostic and educational assessment (California Department of Developmental Services, 2002; California Departments of Education and
Developmental Services). Limited specific information is provided about reliability, validity, and training requirements for each instrument. It is also important to note that information is limited about the utility of these instruments in educational or community mental health settings (Shriver et al., 1999). This type of “best practices” guide therefore has limited practical value for professionals responsible for assessment in the schools or clinicians who are asked to provide assessment information and recommendations for the child that will be utilized by the school.

CLINICAL UTILITY IN EARLY SCREENING

As already mentioned, we are now seeing children with autism accurately diagnosed as early as 18 months of age (e.g., Lord, 1995; Stone et al., 1999). However, in order to obtain a diagnosis, a child must first be identified as being in need of an evaluation. Because pediatricians and other health care professionals maintain the earliest contact with the children, they are the most likely to detect and refer young children with developmental delays. However, a recent survey of pediatric physicians found that while they agreed that primary care providers should inquire about a child’s development, two-thirds did not feel adequately trained to conduct developmental assessments (American Academy of Pediatrics, 2000; Halfon, Regaldo, McLearn, Kuo, & Wright, 2003). A majority of these doctors (70%) identified children without formal screening tools, and 62% did not use any form of parent interview.

The practice parameters developed by Filipek et al. (1999) specify clear criteria for ASD screening, which begins with routine developmental surveillance at all well-child visits. Failure at this stage would lead to audiological assessment and lead screening and a specific screening for autism. Several screening tools are recommended in the practice parameters. The Checklist for Autism in Toddlers (CHAT; Baron-Cohen, Allen, & Gillberg, 1992; Baron-Cohen et al., 1996) was developed for use in the primary care setting at 18–24 months and consists of a short interview with the parents as well as five items to be observed or administered by the provider. It is easy to administer; however, it will fail to identify children who are higher functioning or who have milder symptoms, such as those associated with PDD-NOS. The PDDST—Stage 1 (Siegel, 2004) is the first part of a staged screening assessment designed for use in primary care settings. This assessment has a wider range of questions than the CHAT and rates both positive and negative symptoms of autism. The Modified Checklist for Autism in Toddlers (M-CHAT; Robins et al., 2001) is a 23-item parent questionnaire with no behavioral component. Preliminary findings indicate that the M-CHAT evinces improved sensitivity from the original CHAT without significantly compromising specificity (Robins, 2003); however, further studies with larger samples are currently under way.

The literature indicates that rather than using screening and/or assessment tools, most primary care providers use their clinical judgment when evaluating a child for developmental problems. This may seriously reduce the number of chil-
dren who are appropriately identified (Glascoe, 2000). Reasons for not screening may include lack of time, limited staffing, and poor reimbursement as well as lack of clinical expertise in the area of autism and developmental delay (American Academy of Pediatrics, 2000). Education of primary care providers in the use of screening tools as well as policy changes that would allow for appropriate reimbursement are essential to early identification and treatment of this disorder.

**CLINICAL UTILITY IN EDUCATIONAL SYSTEMS**

There can be significant differences between the school and mental health agencies in their practices related to identification, assessment, diagnosis, and treatment of children with ASD. The role of the school psychologist is exponentially expanding as reform movements in education, health care, and developmental services converge on providing services in the schools. Assessments conducted by school psychologists may include testing in the areas of cognition, academic achievement, learning modalities, and socio-behavioral functioning. Tools used are both norm referenced and idiographic in nature (e.g., direct observation, achievement tests, functional assessment, curriculum-based measurement) and focus on educational variables relating to school performance. The purpose of the assessment is to provide reliable and valid information to assist in classification for special education services, placement decisions, and intervention planning (Shriver et al., 1999). The educational classification system used by the schools is derived from the federal guidelines of IDEA, most recently amended in 2002. Based on assessment data, schools can classify students into one of 13 federal handicapping categories. Autism was not recognized as a disability under the IDEA until 1990. Congress found that before the introduction of this category, children with autism were typically classified as “other health impaired” or “multihandicapped.” The federal handicapping code for autism states, “A child is classified as having autism when the child has a developmental disability that significantly affects verbal and nonverbal communication and social interaction, that is generally evident before age 3, and that adversely affects educational performance.” This definition is fairly broad, in comparison to the specific criteria in the *DSM-IV* (APA, 1994). One may assume that the majority of children would either meet criteria for Autistic Disorder, PDD-NOS, or Asperger’s Disorder. However, it is possible that differential diagnoses may not be adequately taken into consideration, leading to misclassification (e.g., inclusion of children with severe-to-profound mental retardation, emotional disturbance, ADHD, or specific learning disability). Other factors may also result in false positives, such as parental desire for the more intensive and specialized services associated with autism programs.

While many schools or school districts may have “resident ASD experts,” the majority of educators and professionals have a limited understanding of ASD. Many researchers and clinicians agree that optimal diagnosis of an ASD requires that experienced professionals utilize a clinical best-estimate approach using
evidence-based standardized test instruments (Ozonoff, Rogers, & Hendren, 2003). Noland and Gabriels (2004) suggested a model process for ASD diagnosis in schools that included training in screening for ASD as well as the development of a team with increased knowledge and experience with ASD to perform evaluations. Although this is a start, research is needed to determine what the “best practices” approach for school districts should be, given personnel and budgetary limitations.

CLINICAL DIAGNOSIS IN COMMUNITY MENTAL HEALTH PROGRAMS

The *DSM-IV* (APA, 1994) remains the most frequently utilized diagnostic system by mental health professionals for diagnosis of developmental disorders, including autism. However, methods used by even experienced community mental health professionals for assessment of ASD vary a great deal. For example, interviews and observations are typically unstructured, particularly among experienced clinicians, and the format can vary according to theoretical orientation and training. While written reports include information obtained through the use of standardized tests, the context surrounding the test results may not be explicitly stated. It is typically unclear how to determine the accuracy of an assessment conducted with a child suspected to have autism. The autistic symptoms and developmental delays associated with ASD are more commonly identified at age 3 by mental health professionals and developmental service agencies, while fewer children with mild delays are identified before kindergarten.

Differences in assessment methods, experience, and philosophy appear sometimes to lead to different conclusions about the needs of the child and how they should be served among the various professionals who have evaluated the child. Differences in classification/diagnosis guidelines and resources also appear to lead to differences in decisions about eligibility for services. A multidisciplinary approach, where mental health, medical, and school professionals integrate assessment findings and design a comprehensive plan, along with the use of standardized autism assessments, is often a more optimal approach. But practical, economical, and political barriers make this approach difficult to implement.

DEVELOPMENTAL CONSIDERATIONS

The importance of understanding a child’s developmental level when making a diagnosis of autism cannot be overestimated. Many of the characteristics of autism include delayed rather than deviant development, and no single characteristic can be used to identify a child with autism. Some behaviors seen in autism, such as echolalia, tantrums, and repetitive play, may be observed in typically developing children as well as children with other disorders, including developmental delay. Therefore, when assessing a child suspected of having autism, the diagnostician must often determine whether the frequency of a certain behavior
is unusual or the intensity or quality of a specific behavior is distinct from what a typical child at the same developmental level might exhibit (Campbell, 1990).

In order to obtain an estimate of developmental level in young children with autism, both a standardized cognitive assessment and behavioral observations are necessary. Because many children with autism have behavioral issues, such as difficulty adjusting to new environments and tantrum behavior, they may be uncooperative during standard cognitive assessment. While this in itself may be somewhat diagnostic, obtaining estimates of developmental skills from caregiver interview and observations of naturalistic skills will assist in providing baseline expectations for social and communicative skills.

There is no standard for presence or absence of any specific behavior in the DSM-IV criteria for autism, so all of the behaviors must be examined developmentally. For example, impaired peer interaction will be very different for a 5-year-old child functioning at the 4-year-old level and a 5-year-old child functioning at the 18-month level. For the former, we would expect to hear reports of peer interaction involving symbolic play, the ability to perform basic adaptive skills such as potty training and dressing, etc. For the latter child, lack of symbolic play or continence would not be diagnostic of autism, but poor eye contact, sensory sensitivities, and unusual affect might be. That is, the diagnostician must determine whether the child’s social skills are delayed even further than the child’s cognitive level. In addition, children with intellectual and adaptive abilities in the severe-to-profound level of mental retardation (IQ < 35 or MA < 18 months) are not appropriately assessed by the diagnostic measures for autism. Therefore a primary diagnosis of autism must be made with caution in these individuals.

It is important to note that there are significant developmental changes in autistic symptoms that may be independent of age or IQ level (Fecteau, Mottron, & Burack, 2003). For example, recall that repetitive behaviors may not be evident in very young children with autism (Lord & Risi, 2000) and may decrease at older ages in individuals with higher IQs (Collacott, Cooper, Brandford, & McGrother, 1998; Murphy, Hall, Oliver, & Kissi-Debra, 1999). In a comparison of verbal children with Autistic Disorder using the ADI-R, Fectau et al. found improvement in all three domains (social, communicative, and restricted and repetitive behaviors) with age for children with a range of IQ levels. They posit that these improvements may be part of the natural progression of autism and that symptoms of autism are dependent on developmental age.

**ASSESSMENT, CONCEPTUALIZATION, AND TREATMENT PLANNING**

Assessment data need to be in place for determining treatment strategies. The various standardized assessments described earlier are necessary to determine cognitive, language, social, and adaptive functioning and to provide specific
information for deciding on treatment targets and thus the curriculum of an intervention. However, other forms of assessments are available and important in the design of treatment interventions.

We know that the only form of treatment empirically validated as effective for children with autism is treatment based on a behavioral model (e.g., National Research Council, 2001). Specifically, we know that the systematic application of the principles of learning (particularly when the child is very young) can lead to substantial gains in many of these children. Highly structured discrete trial training (DTT, sometimes referred to as applied behavior analysis) and naturalistic behavioral strategies are most often utilized. Both of these forms of treatment are based on the behavioral model. Additionally, augmentative teaching strategies, such as sign language, communication keyboards, and the Picture Exchange Communication System (PECS; Bondy & Frost, 2001) are frequently employed to assist these youngsters in acquiring communication skills.

We can say that behavioral treatments have been empirically validated as effective in treating these children, since one feature of the behavioral approach is the continuous collection of objective data to determine treatment effects and limitations. Data are frequently collected not only with standardized assessments, but also via behavioral observation of the child in a variety of environments. These data are used to decide if the present course of intervention is effective or whether changes are indicated. Thus, treatment decisions are based on objective evaluation rather than subjective impressions.

A very important type of assessment used in the design of behavioral treatments is functional assessment, which involves a systematic evaluation of controlling variables for behavior. It is the understanding of these controlling variables that allows for an informed choice of treatment strategy. For example, Iwata, Dorsey, Slifer, Bauman, and Richman (1982) demonstrated how the challenging behaviors (e.g., self-injurious behavior, or SIB) of developmentally disabled children, while topographically similar, may indeed be under the control of very different environmental events. Thus, one child may engage in self-injury for the purpose of escaping an aversive situation, while another child may engage in self-injury to obtain social attention. Conducting brief analogue assessments of varying environmental events while observing the effects of the events on the target behavior allows the clinician to understand, on an individual basis, the controlling events for the behavior. Knowledge of these events allows for the design of specific treatment strategies that address the events. For one child, effective treatment for SIB would be not to allow the child to escape the aversive situation but rather to try to make the situation less aversive. For the second child, it would be appropriate not to provide social attention contingent on the SIB.

Along these same lines, Carr and colleagues (e.g., Carr and Durand, 1985) demonstrated that a functional analysis of disruptive behaviors allowed one to understand the communicative properties of the behavior, which would allow for training another, more appropriate but functionally similar behavior. For example, if a child engaged in aggression when educational tasks were too difficult, the
clinician could teach the child another response that would allow escape from the
task. The child might be taught to say, sign, or otherwise communicate, “Help
me!” In such cases the child typically uses the more appropriate, but function-
ally equivalent, response.

While debates often occur over which type of behavioral strategy is overall
superior, the fact is that no matter which of these strategies are employed, there
is quite a bit of variability in treatment outcome. Thus, some of the children may
improve a great deal, while others may improve minimally or not at all. This vari-
ability in treatment effect speaks to the action of other variables that are deter-
mining outcome. In fact, it is the case that the debate about which treatment is
superior is ultimately of little help, since no one treatment is best for all children.

To address this issue, the behavioral treatment community is now focusing
more on how to individualize treatments. Important child variables have been
studied to determine a priori which treatments may in fact be most effective for
a specific child. Sherer and Schreibman (in press) identified a behavioral profile
that predicted the effectiveness of a particular naturalistic behavioral treatment,
pivotal response training, for individual autistic children. While much more
research will be required before we can prescribe specific treatments for the wide
range of symptom presentation in autism, this is a start. This information is impor-
tant since it essentially allows for treatment providers to be “right” the first time
when providing treatment. Given the importance of early intervention, one cer-
tainly does not want to waste precious time providing an ineffective treatment.
The overall goal is essentially to have a program of prescriptive treatments
wherein we can conduct behavioral assessment of individual children and, based
on this assessment, provide the best treatment. Frequent and comprehensive
behavioral assessment will be essential because as the child’s behaviors change,
different treatments may be indicated.

**CASE STUDY**

**IDENTIFICATION**

Spencer’s parents first voiced concern to their pediatrician at the 18-month
well-child checkup. While Spencer had always been a fussy baby who had diffi-
culty with new people and environments, this was becoming more obvious as
they attempted to place him in toddler gym courses and other activities. He
became upset in these settings, and did not appear to enjoy playing with other
children his own age. Additionally, although at the 12-month visit they had
reported the use of a few single words, these verbalizations had ceased by 18
months. Now Spencer used babbling and hand leading to show his parents what
he wanted. He was a happy child much of the time and enjoyed playing on his
own with his trains or videos. The pediatrician felt that Spencer was probably not
interacting because of his lack of experience with other children, that he would
be likely to gain language by age 3, and, though crying often during the visit, that he did look at the doctor. Spencer’s parents attempted to provide their son with more opportunities to be around other children by enrolling him in a local preschool. At age 20 months his teachers suggested that a screening might be appropriate for Spencer because he did not like to join the group activities, spent a great deal of time wandering or playing with just a few specific toys, and was not yet talking or trying to communicate with the teachers. Although he was compliant and seemed happy, they felt that he was not as engaged as the other children and would become upset if a teacher or child tried to interact with him. At this time his parents requested a developmental evaluation with a psychologist knowledgeable in the area of autism.

PRESENTING COMPLAINTS

Spencer’s parents were most concerned with his failure to develop language and with the loss of his first few words. They also had concerns about his difficulty in new environments, unusual sleep patterns, and apparent lack of interest in other children. According to his parents, Spencer’s strengths included his attention to detail, as evidenced by his ability to play with a toy for extended periods and to find very small items hidden on the floor, his happy nature when he was home with his family, and his ability to identify letters and numbers at an early age.

HISTORY

Spencer had no siblings. He had an unremarkable birth history. He was born at 40 weeks with no complications, and the pregnancy had been normal. Spencer had been a difficult baby, not sleeping well and not easily comforted. He did enjoy music and movement as an infant, more than he enjoyed being held. He reached his motor skills milestones at typical ages, sitting up at 6 months and walking at 11 months. He became a very independent toddler, doing most things for himself when he could. He said his first word, “doggie,” at 12 months and used it inconsistently. He used about five other single words, but by 18 months he was no longer using words to communicate. Parents reported no history of autism or mental retardation in the family; however, the paternal grandfather was described as an “eccentric loner.” Spencer’s mother reported having a 6-year-old niece who was receiving speech therapy for language delays. Spencer had a recent visit to the audiologist. He was unable to complete the behavioral assessment; however, the sedated BAER indicated normal hearing.

DEVELOPMENTAL ISSUES

Spencer was 22 months old when he arrived for his developmental evaluation. The parent interview and ADI-R portion of the evaluation were conducted prior
to seeing him. This provided the psychologist with an understanding of his behavior at home and in other community environments. The child portion of the evaluation involved a cognitive assessment, an ADOS, and an additional play-based assessment. Spencer was assessed using the Mullen Scales of Early Learning in order to obtain separate scores for visual reception, fine motor skills, and receptive and expressive communication. Because of his young age, and difficulty with new environments, completing a standardized assessment was challenging. The psychologist conducted much of the assessment on the floor of the office, interspersing play and alone time between tasks. Spencer had a very uneven cognitive profile, which was to be interpreted with caution due to his age and attention level. He had the most difficulty in the area of expressive language, with an age equivalent of approximately 10 months. His receptive skills were slightly better, at the 15-month level. Spencer was much more willing to complete tasks that did not have a verbal component. He obtained an 18-month age-equivalent score on the visual task and was at age level in his fine motor skills. Although the ADOS can be used with children 18–24 months of age, Spencer’s developmental level was younger than that in some areas. The psychologist chose to use the ADOS in order to obtain a sample of the Spencer’s behavior that would allow for an assessment of an ASD; however, results would be interpreted with caution. Spencer did meet criteria for ASD on the ADOS. Spencer’s communication and social skills were limited during the course of the ADOS activities. He did tend to play repetitively with specific toys, but no motor or verbal stereotypes were observed. Because of Spencer’s young age and developmental delay as well as his lack of stereotypy, he was given a provisional diagnosis of autism, to be confirmed after age 4. It was recommended that services appropriate for children with autism be provided through early intervention.

PEER AND SCHOOL ISSUES

Spencer was referred to an early-intervention program. Goals included increasing his communication skills, increasing his ability to interact with peers, and reducing behavioral issues such as poor sleep patterns, difficulty in new environments, and resistance to demands. Spencer’s visual/nonverbal skills and ability to engage in some cause-and-effect play on his own qualified him for an inclusion program. Spencer’s parents felt this would enhance his peer interaction skills. Because of Spencer’s young age, his peers in the program were relatively accepting of him. He did become somewhat aggressive if they approached in the beginning, and they began to shy away from him. His teachers in the program worked with him and the other children to gradually help Spencer tolerate having other children nearby. Additionally, the program used visual cues and routine to assist Spencer in participating in classroom activities. With the support of visual cues he was able to follow the routine. He learned to imitate, and when he understood the expectations he was able to complete activities. To improve his play the teachers gradually introduced new toys, rewarding that play with Spencer’s
favorite objects. As he became better able to play, his peers were more likely to join him, and he was also beginning to join in large motor imitative play. Spencer had begun to use single words and sometimes two-word phrases to communicate; however, he needed assistance to use his language.

Spencer’s parents next needed to work with his school district to develop an appropriate plan for his transition at 36 months. The district did not offer a similar program, and his parents were concerned that Spencer might not obtain the structure and peer engagement that he needed to succeed. The district and the parents developed an individualized program specific to Spencer’s needs that included highly structured learning time as well as time in a typical preschool, with an inclusion assistant to help Spencer with interaction and engagement. These issues would again need to be addressed at kindergarten, and solutions would vary based on Spencer’s skill level, behavior and, symptomatology.

**BEHAVIORAL ASSESSMENT RESULTS**

Program personnel soon realized that some of Spencer’s behavior problems were interfering with his progress in the educational program. His resistance to new tasks, tantrums, and aggression made working with him a challenge. Since it was felt he had good potential to do well in the program, the early-intervention team conducted various behavioral assessments to inform specific interventions aimed at reducing these behaviors. After objectively defining the behaviors and structuring an observation plan, program providers observed Spencer across several periods during the day and recorded his disruptive behaviors across the various activities. Results of these observations indicated that Spencer was most likely to tantrum or engage in aggression when confronted with tasks that he found difficult or if too many other children were close to him. In fact, the observational data suggested that the presence of other children was correlated with a decrease in teacher attention to Spencer.

Based on this information, the program personnel chose two specific interventions to implement. The first intervention was to give Spencer a functionally equivalent response that he could use to communicate that a task was too difficult for him and that he needed assistance (e.g., Carr & Durand, 1985). Thus, rather than tantrum and aggression when confronted with a new and difficult task, Spencer was first taught to sign and later to say, “I need help.” As expected, when he was now confronted with a difficult task, he used the more appropriate, and functionally equivalent, response rather than disruptive behavior to communicate his needs.

The second intervention was aimed at reducing Spencer’s tantrum and aggressive behavior when other children were present. Since the observational assessment indicated that such situations were associated with a loss of teacher attention, the teachers decided to ensure that Spencer received as much teacher attention as possible when other children were present. Over time, as Spencer
tolerated the situation well, the teachers gradually reduced the amount of attention specifically aimed at Spencer.

ETHICAL AND LEGAL ISSUES

Due to Spencer’s young age, a provisional diagnosis of autism was initially provided. As he continued to do well in his early-intervention program, there was the possibility that when he would leave the early-intervention program at age 3, he might not meet criteria for an autism diagnosis but rather a less severe diagnosis, such as PDD-NOS. Knowing that an autism diagnosis would likely lead to the availability of more intensive services than the PDD-NOS diagnosis, autism may be the “preferred” diagnosis. Certainly diagnosticians are aware of this, and the temptation to shade the diagnosis based on treatment availability may be an ethical issue that must be confronted.

SUMMARY

The pervasive developmental disorders are behaviorally defined syndromes characterized by specific patterns of behavioral characteristics. Given that these disorders are quite complex and affect virtually every area of functioning, it is the case that the development and utilization of assessment have proven to be most challenging. Accordingly, accurate, detailed, and comprehensive assessment has proven to be exceptionally important and has been the focus of a great deal of research. The development of diagnostic assessments has been particularly helpful, in that diagnostic precision is important for epidemiological studies, various areas of research, and the determination of appropriate services and placements. Diagnostic assessment typically includes interviews with parent or other caregiver, a medical evaluation, direct behavioral observation, cognitive assessment, and assessment of adaptive behavior. Ongoing research continues to improve our ability to diagnose these disorders accurately and at a younger age, which is essential, given the importance of early screening and early intervention. Assessments developed and used for these populations must reflect an appreciation for developmental issues that may affect their interpretation. Finally, appropriate and detailed assessment can be crucial to the identification of treatment and educational programming as well as the evaluation of such interventions.

REFERENCES


Gilliam, J. E. (2001). *Gilliam Asperger Disorder Scale (GADS)*. Austin, TX: PRO-ED.


