Assessment of Autism Spectrum Disorders

Chapter Questions

- How are autism-spectrum disorders defined by the *DSM-IV*?
- How is autism differentiated from mental retardation?
- What types of scales or strategies are most useful for the assessment of children with these syndromes?
- What is the recommended approach for the assessment of autism spectrum disorders?

Definitional Issues

Autism is believed to affect 1 in 500 children (Bertrand et al., 2001), yet it is often not recognized until after the child is 3 years of age (Filipek et al., 2000). Hence, early screening is important for devising the most appropriate intervention strategy. In addition, because of the difficulty in recognizing autism or related problems, new assessment methods for infants and toddlers are needed. However, a discussion of the development of such tools is beyond the scope of this chapter. Importantly, the array of assessment strategies available for autism spectrum assessment referrals has greatly improved and more easily translate to treatment recommendations. This chapter will give an overview of the measures and noteworthy issues in the assessment of childhood autism.

DSM-IV-TR Criteria

In the *DSM-IV-TR*, Autistic Disorder is part of a class of problems known as Pervasive Develop-mental Disorders (PDD; American Psychiatric Association, 2000).

However, the term "Autism Spectrum Disorders" (ASD) is now generally used in lieu of PDD (see Ozonoff, Goodlin-Jones, & Solomon, 2005). Other disorders that are included under the rubric of ASD include Childhood Disintegrative Disorder, Asperger's Disorder (often referred to as "Asperger's Syndrome"), Rett's Disorder, and PDD Not Otherwise Specified (American Psychiatric Association, 2000).

The prototypical ASD is, of course, Autistic Disorder, a condition that has long been of interest to psychologists. Autistic Disorder will be the primary focus of this chapter, with some discussion of other ASD issues, particularly regarding the assessment of Asperger's Disorder. The *DSM-IV-TR* describes Autistic Disorder as "the presence of markedly abnormal or impaired development in social interaction and communications and a markedly restricted repertoire of activity and interests."

Autistic Disorder is also known by other terms such as *autism* or *early infantile autism*. Autistic Disorder is known to be frequently comorbid with mental retardation (American Psychiatric Association, 2000). With co-morbidity estimates ranging as high as 75%, the differential diagnosis of autism and mental retardation can be challenging.

The *DSM-IV* emphasizes three classes of symptoms that are central to the disorder: social interaction problems, communication problems, and repetitive and stereotyped behaviors. The onset of these symptoms must occur by age 3. The *DSM* criteria require that a total of six symptoms with a minimum of one from each of the three classes of problems be present in order to make a diagnosis. Furthermore, at least two of the symptoms from the social interaction class of problems must be present.

The social interaction symptoms include:

1. Failure to engage in appropriate non-verbal behaviors such as appropriate eye contact, facial expressions, body postures, and social gestures

2. Poorly developed peer relationships

3. Failure to share pleasurable interests, activities, or achievements with others

4. Lack of social reciprocity

Communication symptoms include:

1. Delayed development of spoken language

2. When speech is present, inability to begin or maintain a conversation

3. Stereotyped or repetitive use of language

4. Lack of imaginative play

Problems with repetitive or stereotyped play include:

1. Preoccupation with one or more behavior patterns

2. Preoccupation with nonfunctional routines or rituals

3. Inappropriate motor movements

4. Preoccupation with specific objects

Characteristics of Autism

Autism Spectrum Disorders are often described as etiologically diverse disorders. Evidence points to genetic (e.g., Bailey et al., 1995) and neurological (e.g., Courchesne et al., 2001) underpinnings of ASDs; however, specific etiological agents have not been identified. Much remains to be learned about risk factors that may be etiologically involved in autism. The lack of scientific clarity implies that clinicians should not place undue importance on etiological agents when conceptualizing cases of autism or when providing feedback to others. Instead, the focus of assessment should be on symptomatology, developmental history (e.g., language development), strengths, and impairments.

Differentiation of autism from other ASDs and from Mental Retardation can be

quite difficult. One study found that children with language disorder could be more easily differentiated from children with autism, but autism and PDD-NOS were more difficult to differentiate (Mayes, Volkmar, Hooks, & Cicchetti, 1993). Similarly, differentiation of high functioning children with autism (i.e., those with average or higher intelligence) from children with Asperger's Syndrome can be quite difficult in that such youth with autism may not appear to have communication difficulties (Howlin, 2003).

Some of the assessment tools discussed in this chapter may provide useful information in making distinctions among ASDs as well as related problems. However, there remains a relative lack of research on this issue and no measure to date has clearly shown the ability to differentiate within ASDs in meaningful ways (Ozonoff et al., 2005). Therefore, it is incumbent on the clinician to use a variety of methods to gain a comprehensive picture of the client's difficulties and history such that the most appropriate interventions can then be sought.

Comorbidity

The most frequent comorbid problem for autism is mental retardation, with the majority of children with autism also meeting criteria for mental retardation (American Psychiatric Association, 2000). On the other hand, the majority of individuals with mental retardation do not meet criteria for autism or another ASD. Needless to say, the inclusion of cognitive functioning in assessments of ASDs is critical for case conceptualization and treatment planning. The same, then, can be said for the inclusion of a measure of adaptive functioning in the assessment battery.

As noted by Ozonoff et al. (2005), new difficulties may emerge over the course of development for youth with ASDs such that initial diagnosis as well as treatment planning and progress monitoring are complicated. A common comorbid area of concern, particularly for high-functioning individuals with autism, is in the internalizing problem domain (e.g., Kim, Szatmari, Bryson, Streiner, & Wilson, 2000). However, the validity of commonly used measures of depression and anxiety – such as those discussed in the preceding chapter – for individuals with ASDs is unknown (Ozonoff et al., 2005).

Regular, comprehensive assessment across domains of functioning will aid in tracking treatment gains as well as other important areas of difficulty apart from the primary problems associated with ASDs. For example, many children with ASDs may also present with significant externalizing behavioral problems that occur when expectations are not met, routines change, or due to frustration from communication difficulties. These behaviors may themselves be a primary focus of treatment. In addition, sleep difficulties that may accompany ASDs may warrant specific interventions (Ozonoff et al., 2005).

Specialized Measures of Autism

Infant Behavioral Summarized Evaluation (IBSE)

The IBSE (Adrien, Barthelemy, Perrot, & Roux, 1992) is a unique rating scale in that it is appropriate for infants and preschoolers. One study evaluated some psychometric properties of the scale for a sample of 39 children with autism, 33 with Mental Retardation, and 17 with other handicaps (Adrien et al., 1992). Good inter-rater reliability was found. A factor analysis of 31 items found two factors, with the first factor accounting for most of the items. Adrien et al. also concluded that first factor scores were capable of differentiating the group of children with autism group from the other two groups. The IBSE was

also able to differentiate among preschoolers with autism and other children with developmental delays by age 26 months (Desombre et al., 2006).

Autism Diagnostic Interview-Revised (ADI-R)

The ADI-R is a semi-structured diagnostic interview designed to be used with a child's primary caregiver and can be used for anyone with a mental age of 2 years or higher (Lord, Rutter, & Le Couteur, 1994). The ADI-R assesses behaviors relevant to the differential diagnosis of pervasive developmental disorders in individuals from 18 months to adulthood. The ADI focuses on three domains of behavior that are largely consistent with the *DSM-IV* criteria: reciprocal social interaction; communication, and repetitive, restricted, or stereotyped behavior. Scores on the ADI-R have been found to differentiate children with autism from children with other forms of delay (Mildenberger, Sitter, Noterdaeme, & Amorosa, 2001). Another study again found the ADI-R to reliably differentiate between samples of children with autism and children with mental retardation (Lord, Storoschuk, Rutter, & Pickles, 1993). This investigation, however, identified difficulties when trying to differentiate these samples among children with mental ages of less than 18 months, reflecting the continuing dilemma of diagnostic accuracy with low-functioning children.

One study evaluated inter-rater reliability of the ADI-R across seven examiners for one case (Cicchetti, Lord, Koenig, Klin, & Volkmar, 2008) and found perfect agreement for 74% of the items and "poor" agreement on less than 10% of the items. A large scale study of the ADI-R found support for a two-factor model (i.e., social communication and stereotyped behaviors) as well as a three-factor model (i.e., social communication, peer relationships/play, and stereotyped behaviors; Frazier, Youngstrom, Kubu, Sinclair, & Rezai, 2008).

The strength of the ADI-R is its strong research base, including the validity evidence of the current version and its predecessor which goes back to two decades (Le Couteur et al., 1989). However, the ADI-R is quite lengthy, taking anywhere from 90 min to 3 h to administer and score (Ozonoff et al., 2005). Therefore, it may be less practical than other tools in many clinical settings.

Parent Interview for Autism (PIA)

The PIA (see Stone, Coonrod, Pozdol, & Turner, 2003) is a newer alternative to the ADI-R. It is unique in its focus on tracking changes in symptoms over time, with parents rating the frequency of symptoms on a five-point scale. Research has shown good internal consistency and differential validity for the PIA. In addition, changes in PIA ratings, particularly in the areas of social and communicative functioning, were related to changes reflected in other ratings of the child symptomatology (Stone et al., 2003). While generally based on the three core dimensions of autism, the PIA has items that were developed and rationally/theoretically grouped into the following scales (Stone & Hogan, 1993):

- Social Relating Affective Responses Motor Imitation
- Peer Interactions Object Play
- Imaginative Play Language Understanding
- Nonverbal Communication
- Motoric Behaviors
- Sensory Responses Need for Sameness

While the PIA has shown some promise, research is limited, and the validity of the 12 subscales is not documented.

Childhood Autism Rating Scale (CARS)

The CARS (Schopler, Reichler, & Renner, 1988) is a rating form that is typically completed by an observer of the behavior of a child who has reached a developmental age of approximately 2 years or higher. In some cases, an observation period of only about 30 min is used (Sevin, Matson, Coe, & Fee, 1991). Items are rated on a 7-point continuum for the 15 subscales. The CARS is composed of nine portions. It includes items such as a puzzle-like task and a set of toy objects designed to assess make-believe play activity.

The CARS produces a moderately high correlation of .67 with the ABC (Eaves & Milner, 1993). Although this correlation is significant, the two instruments did classify children at differing rates. The CARS correctly identified 98% of the children with autism, whereas the ABC did so for 88% of the sample (Eaves & Milner, 1993).

In an investigation by Sevin et al. (1991), 24 children were assessed with the CARS. The inter-rater reliability of the CARS for these subjects was found to be highly variable. Coefficients were as low as 0.10 (Activity Level) and 0.14 (Intellectual Response), and as high as 0.85 (Relating to People). The inter-rater reliability coefficient for the total score was 0.68.

In spite of such low to modest reliability coefficients, the CARS results showed fairly good concordance with clinician diagnoses of autism (Sevin et al., 1991). The CARS classified 19 of the 24 subjects with autism correctly. Only two of the subjects were incorrectly classified with autism, although this study provided a weak test of differential validity because of the small sample of subjects without autism. Subsequent research has shown that the total score on the CARS correlates highly with the ADI-R but that it also may overidentify autism among chil-

dren with mental retardation (Saemundsen, Magnusson, Smari, & Sigurdardottir, 2003).

The CARS is a well-known, widely used assessment tool for autism; however, Ozonoff et al. (2005) caution that the content is based on conceptualizations of autism dating prior to *DSM-IV*.

Autism Diagnostic Observation Schedule (ADOS)

The ADOS (Lord, Rutter, DiLavore, & Risi, 2002) is designed to assess symptoms of ASDs in a wide rang of individuals based on age and language skills. The ADOS consists of four modules, with the module selected based on the child's current expressive language and developmental level (i.e., Module 1 for no speech; Module 2 for phrase speech; Module 3 for verbally fluent children and young adolescents; Module 4 for verbally fluent adolescents and adults; Lord et al., 2002). Module 2 is described in Box 19.1.

The ADOS emphasizes the assessment of reciprocal social interaction and communication rather than restricted or repetitive behavior, and it is structured in that the environment for the observation is structured in a standardized way, and the examiner presents predefined tasks to the child in this structured setting. In this way, the examiner serves as both the stimulus for interaction in try to elicit particular responses from the subject and as the recorder of behavior.

A study on the development of the current version of the ADOS revealed strong interrater reliability, internal consistency, and (Lord et al., 2000). The differential validity of the ADOS for distinguishing children with autism vs. other delays was also good. Another study found substantial agreement between the ADOS and ADI-R in the classification of children as having autism or not in children younger

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Box 19.1

A Closer View of the Autism Diagnostic Observation Schedule (ADOS)

Together with the ADI-R, the ADOS has been referred to as the current "gold standard" for the diagnosis of ASDs (Ozonoff et al., 2005, p. 524). The ADI-R, of course, allows the clinician to gain a detailed history of the child's development and symptomatology in a semi-structured interview format. This approach is not particularly unique among assessment practices. However, the structured observation format of the ADOS is unique to child assessment in that there are no well-established analogous procedures for assessment of internalizing or externalizing problems.

To further illustrate the content of the ADOS, Module 2, designed for children who speak in phrases, is described below. Module 2 consists of 14 tasks as follows (see Lord et al., 2002):

1. *Construction task*: Designed to assess how the child communicates a need for more objects to complete the task. For example, some children with ASDs may grab the examiner's hand to reach for more objects rather than making a verbal request

2. *Response to name*: Evaluates how readily the child responds to his/her name as said by the examiner or a parent or other stimuli directed to the child (e.g., phrases, touching). Children with ASDs may require more direct stimuli or prompting to response

3. *Make-believe play*: Assesses whether child's play includes imaginative use of objects beyond their usual purpose and the extent to which dolls are used to depict social interaction

4. *Joint interactive play*: Assesses the extent to which the child initiates interaction with the examiner during joint play above and beyond responding to the examiner's statements or requests

5. *Conversation*: Evaluates extent to which the child responds to the examiner's statements or questions in a way that leads to further back-and-forth conversation

6. *Response to joint attention*: The examiner shifts his/her gaze and observes the extent to which the child follows that shift (with or without pointing). Children with ASDs may have difficulty engaging in joint attention in this manner, particularly without other prompts such as pointing

7. *Demonstration task*: Designed to assess how well the child demonstrates common activities (e.g., brushing teeth, getting dressed) without the use of objects.

8. *Description of a picture*: For this task, the examiner attempts to elicit spontaneous language from the child and to observe what kinds of stimuli (from pictures) are of interest to the child

9. *Telling a story from a book*: In addition to assessing the child's spontaneous language and interest in a story, this task, in requiring the child to tell a story from a picture book, evaluates whether the child can provide continuity in the story by sequencing events in the story in a sensible manner

10. *Free play*: This task is designed to assess whether or not the child seeks interaction or involvement from the examiner during free play. In addition, the extent to which the child maintains attention to one task for an appropriate interval is observed. Repetitive behaviors – a symptom of ASDs – may also be evident during this task (Lord et al., 2002)

11. *Birthday party*: This task evaluates the child's ability to participate in a common-scripted event (i.e., birthday part for a doll). Children with ASDs may not engage in the make-believe of imagining the doll as a child or may have trouble participating, including with prompting

12. *Snack*: Assesses how readily the child communicates a preference from a choice of snacks. Other social interaction skills (e.g., gaze, facial expression) are also observed during this task.

13. *Anticipation of a routine with objects*: This task is designed to assess how well a child anticipates a routine (e.g., the response of a balloon when it is deflated or let go) and whether or not the child participates in the routine

Box 19.1 (Continued)

14. *Bubble play*: This task allows the examiner to observe the child's enjoyment of a play activity, social interaction skills, and motor skills in another play context

On an achievement test, Corin's performance on all areas of achievement were in the average range, indicating that her academic achievement is consistent with what would be expected for her age.

Several measures were given to assess Corin's behavioral and emotional functioning. Rating scales were completed by Mrs. Jacobs, two of Corin's teachers, and Corin. Corin's mother and a teacher completed the Achenbach Child Behavior Checklist (CBCL) and Teacher Rating Form (TRF), respectively. This teacher rated Corin as having significant attention problems, delinquent behaviors, and somatic complaints. Mrs. Jacobs did not indicate any significant problems on the CBCL. Despite the reports of attention problems, Corin's teachers stated that they do not believe that Corin has ADHD.

Corin completed several self-report measures that were used to determine her self-perceptions. She was given the Piers-Harris Self-Concept Scale (PHCSCS), and the YSR. On the PHCSCS, Corin rated herself high on anxiety, depression, somatization, and (external) locus of control. On the YSR, Corin's responses were similar to the other self-report measures. Corin also endorsed items that indicate problems with impulse control and compliance.

On the self-report measures, Corin reported some positive qualities for herself. She described herself as being good looking and has having good peer relationships. She reported that all of her friends like her because she is funny. Corin also indicated that her peer relationships and social life at school are the areas in her life that are not currently stressful for her.

As a follow-up measure, Corin was given a structured psychiatric interview on which Corin endorsed all of the items in the area of major depression with the exception of suicidal ideation. Corin described herself as being anxious, and she told the examiner that she often has stomachaches and dizzy spells that she associates with stress. Also, according the structured interview, Corin meets the *DSM* criteria for alcohol abuse. She stated that she frequently drinks large quantities of alcohol, and occasionally, she has blackouts. Corin also admitted to the examiner that she smokes marijuana quite a bit.

From the information gathered a diagnosis of ADHD does not seem appropriate. Corin's acting-out behaviors are more than likely caused by the stress and depression that she currently feels. Current diagnostic impressions are major depression, single episode, moderate, and alcohol abuse.

Recommendations for Corin include:

1. Consultation with a psychiatrist to help determine the most appropriate treatment strategies for Corin's depression.

2. It is also recommended that Corin continue receiving counseling services.

3. Corin is referred to an addictions counselor who works with adolescents who are abusing alcohol.

4. Corin may benefit from group counseling for her alcohol abuse. The best group would be one made up of other teenagers.

5. The Jacobs family should seek family counseling to improve the home situation, particularly in regards to communication and parenting monitoring. Mrs. Jacobs may also benefit from

(Continues)

Box 19.1   (Continued)

individual counseling to help alleviate some of the stress in her life.

6. Corin's teachers reportedly enjoy having Corin in their classroom and seem eager to do what they can to help her. The school psychologist can devise behavior modification plans to be implemented by Corin's teachers to increase Corin's appropriate classroom behaviors. Corin should take part in the development and implementation of the plans.

7. Communication between the school and home is necessary. Weekly reports of Corin's behaviors should be provided. Mrs. Jacobs is encouraged to work with Corin's teachers to devise solutions to any problems that may occur.

8. After six months to a year of intervention, Corin needs to be reevaluated to see if there are still issues of attention problems in the classroom.

9. Corin would benefit from tutoring in algebra.

than age 8. However, the agreement was lower for older individuals (de Bildt et al., 2004). Still, these authors suggested that an assessment battery that includes both the ADOS and ADI-R is suitable, and perhaps the best available, for the assessment of autism.

Gilliam Autism Rating Scale – 2nd Edition (GARS-2)

The GARS-2 (Gilliam, 2008) is a norm-referenced rating scale that can be completed in approximately 5–10 min by parents. The GARS-2 includes 42 items, three scales (i.e., Stereotyped Behaviors, Communication, and Social Interaction) and a total score (Autism Index). Norm-referenced scores are available for the GARS-2, and initial research indicates good internal consistency and differential validity (Gilliam, 2008).

The previous version of the GARS (Gilliam, 1995) has been the subject of much more research. A consistent finding from this research is that many youth otherwise indicated as having autism scored lower on the GARS than on other measures of autism symptoms (Mazefsky & Oswald, 2006; Sikora, Hall, Hartley, Gerrard-

Morris, & Cagle, 2008; South et al., 2002). This set of findings may indicate some serious drawbacks of the GARS, although it is unclear whether or not this issue applies to the current version of the GARS. Because the GARS-2 is geared toward screening for symptoms of autism, the clinician may want to use a low threshold of reporting of symptoms on the GARS-2 to initiate further follow-up.

Functional Analysis

In the context of the assessment of ASDs, functional analysis helps the clinician determine "what the child is trying to communicate through the behavior" (Ozonoff et al., 2005, p. 534), which takes on added importance in light of the behavioral problems and communication difficulties that present with ASDs. It is difficult to imagine a comprehensive assessment of ASDs that does not include some form of behavioral observation and functional analysis as a means to determine targets of intervention. Direct observation, coupled with functional analysis, allows the clinician to also confirm or disconfirm the notions of parents, teachers, or other caretakers as to the communicative intent

of the child's behavior and on appropriate ways to reduce inappropriate communicative behaviors (e.g., using another's hand to obtain a desired object; biting oneself from frustration). Functional analysis, then, is conducted squarely with behavioral interventions in mind. It is not a tool to differentially diagnose ASDs from other problems.

An Assessment Strategy for Autism

ASDs, including autism specifically, are recognized as having heterogeneous etiologies and highly variable symptomatology among those affected (Campbell et al., 1991). Such within-syndrome variability suggests that children who are either suspected of or diagnosed with autism or other ASDs should have access to multidisciplinary assessment procedures. The severity of autistic symptoms, as demonstrated by the overlap with mental retardation, further emphasizes the need for a range of professionals to be involved in assessing the affected child. Such interdisciplinary work, however, can be challenging if there are no adequate structures for encouraging interdisciplinary practice. Consequently, the psychologist may have to make a concerted effort to go beyond the typical practice regimen and communicate more frequently with colleagues who practice related specialties.

Marcus, Lansing, and Schopler (1993) described one of the better methodologies for fostering multidisciplinary assessment of autism. They described the State of North Carolina TEACCH evaluation system as follows:

> This process includes a developmental/psychoeducational assessment of the child, psychological assessment, detailed parent interviewing including assessment of adaptive functioning, and a medical screening. This integrated and multiperspective approach generates comprehensive data on diagnosis, intellectual and adaptive functioning, motor, language, and social functioning, behavior problems, medical factors, family functioning and school or community factors. The data are sufficiently detailed and objective to be organized into dimensions or axes that both overlap with and extend beyond the DSM-III-R system (p. 350).

In situations in which interdisciplinary assessment and intervention teams are not as readily available, it is still incumbent on the clinician to utilize methods that assess ASDs comprehensively and specifically, rather than rely on subjective clinical opinion or measures (e.g., IQ tests) that do not differentially diagnose ASDs from other developmental delays. Having said that, the incremental validity and clinical utility of specific ASD measures are largely unknown (Ozonoff et al., 2005). As with other areas of child assessment, more research is needed as to the most sound, parsimonious battery that would address referrals for ASDs and lend itself to useful recommendations.

Nevertheless, the severity and frankness of the symptomatology of ASDs require us to emphasize different aspects of our five-stage paradigm: screening, classification, comorbidities, alternative causes, and treatment considerations (see Table 19.1).

The screening process for ASDs is aimed primarily at the population of children with developmental delays as opposed to the general population. We advise that clinicians consider the possibility of ASDs in all samples of young children with developmental disabilities. Because the nature of ASDs usually does not allow the child to serve as a source of screening information, parent and teacher ratings are likely to be the most fruitful. The time-efficiency of such ratings

TABLE 19.1   Assessment Questions Related to Childhood Autism Spectrum Disorders and Implications for Assessment

Characteristic	Implications for Assessment
Screening	Administer screening measures; target young children with signs of developmental delay
	Determine need for further assessment
Classification	Assess for presence of symptoms that meet *DSM-IV* criteria
	Determine stability and duration of symptoms
	Determine age of onset
Comorbidities	Assess for presence of mental retardation
	Determine the influence of autism on school performance, adaptive behavior, development, etc.
	Assess social relationships and peer social status
Alternative causes	Obtain developmental and medical histories
	Differential diagnosis/rule out of Rhett's Disorder, Asperger's Syndrome, language disorders, mental retardation, and hearing impairment
Treatment considerations	Assess adaptive behavior assets and deficits
	Identify behavior problems that require intervention
	Assess caregiver stress and caregiver ability to provide adaptive behavior instruction and behavioral problem management
	Evaluate response to previous interventions

argues for their routine use with these populations.

Classification of the child as having ASDs requires meeting the *DSM-IV-TR* criteria outlined earlier. The classification process will depend heavily on caretaker information such as detailed histories/interviews, and possibly child behavior ratings. Furthermore, medical, language, and other assessment data will need to be integrated in order to make differential diagnoses.

The most likely comorbid condition for autism is mental retardation. An in-depth assessment of intelligence and adaptive behavior development is, therefore, required in every comprehensive study of a child suspected of autism or a related disorder. Sensory impairments must also be ruled out by other clinicians.

The process of ruling out alternative causes is a lengthy one requiring full participation by medical and other professionals in the assessment process. Neurological problems, in particular, should be ruled out as primary etiologies for the child's behavior. As noted above, the differentiation within types of ASDs is also often quite difficult (see Box 19.2 for a specific discussion of the assessment of Asperger's Syndrome).

A central aspect of psychological intervention for children with ASDs is skill development in a variety of domains. A structured behavioral observation (e.g., ADOS, functional analysis) and a comprehensive measure of adaptive behavior are typically very useful for defining needed skills and evaluating the effectiveness of intervention.

In Box 19.1, we provide a case example of this assessment approach for a child with autism.

Box 19.2

Issues in the Assessment of Asperger's Disorder

The most straightforward distinction between Asperger's Disorder and autism is the lack of language difficulties seen in the former (American Psychiatric Association, 2000). However, this difference is hard to pinpoint for youth who have average- to above-average intellectual functioning (and thus, typically demonstrate no impairments in verbal communication). A careful, detailed history of developmental delays is critical in differentiating ASDs from other forms of delays and for differentiating among ASDs. For example, past and present impairments in social skills and the presence of stereotypical behaviors in the absence of a history of language delays would be more indicative of Asperger's Disorder than autism. There has been an increased availability of specific screening tools for Asperger's Disorder and other ASDs. The Gilliam Asperger's Disorder Scale (GADS; Gilliam, 2001) is a 32-item screener that is meant to be completed by a parent, teacher, or clinician. Items load on to four scales: Social Interaction, Cognitive Patterns, Restricted Behavioral Patterns, and Pragmatic Skills. The Asperger Syndrome Diagnostic Scale (ASDS; Myles, Bock, & Simpson, 2001) consists of 50 items to be completed by a caretaker, teacher, or clinician with five scales: Cognitive, Language, Social, Maladaptive, and Sensorimotor. Another example is the Krug Asperger's Disorder Index (KADI; Krug & Arick, 2003) which consists of 32 items and yields a total score. Research on the differential validity is limited.

An exception is Campbell's (2005) study that compared these rating scales and two others that had been used in research. Campbell cited concerns regarding each of these measures. For the ASDS, Campbell noted that the standardization sample was weak, particularly due to the lack of there being no independent diagnosis of Asperger's Disorder in that sample. The GADS was described as having a stronger standardization sample, although the Asperger's Disorder diagnoses in this sample were unconfirmed. In addition, internal consistency was less-than-desirable (Campbell, 2005). The KADI was described as the best of these measures overall in terms of reliability (i.e., internal consistency, stability, and interrater agreement) as well as in content validity. However, the standardization of the KADI also lacked information on independent diagnoses. Additionally, for all three of these scales, the cognitive functioning of individuals in the standardization sample with autism was not provided, which is important in determining how well a measure of Asperger's Disorder helps distinguish between children with Asperger's Disorder *vs.* high functioning children with autism (Campbell, 2005). Therefore, at present, such measures should be used as one potential component of assessments for ASDs but in no way replace detailed histories obtained through interviews and behavioral observations in determining the child's specific impairments.

A Sample Case of Autism in a Child with Neurological Impairment

Julie was a 5-year, 1-month-old girl who was referred by her parents.

Referral Information

Julie was referred for a psychological evaluation by her parents. Original referral questions included concern about delayed language development, short attention span, difficulty in her kindergarten class, and a possible learning disability. Subsequently,

however, Julie had two seizures and was diagnosed as having tuberous sclerosis and seizure disorder. On learning that tuberous sclerosis often affects a child's intelligence, her parents requested a thorough evaluation to determine Julie's current level of functioning.

Background Information

Julie is a 5-year-old girl who lives with both parents. Her mother reported that she had no serious difficulties when she was pregnant with Julie. Julie was reportedly born full-term and weighed 7 pounds, 0 ounces. Both Julie and her mother were reportedly in good condition at the time of birth. Julie did, however, have an open sore on her back that was surrounded by a purple mark. The doctor remarked at the time that this type of wound was very unusual.

According to her mother, Julie has had two seizures. The first was reportedly about 6 weeks prior to this evaluation. Her mother describes these seizures as lasting about a minute and not involving severe convulsions. Julie was seen by a neurologist. According to Julie's medical reports, she was somewhat difficult to understand and hyperactive during that medical examination. Her doctor had difficulty obtaining her cooperation. Her physical condition appeared to be normal, except for a large scar on her right hip and skin lesions on her face and extremities. Based on Julie's physical condition, recent seizures, EEG results, and CAT scan results, she was diagnosed as having seizure disorder and tuberous sclerosis, a genetic disorder associated with tumors in the brain and internal organs and skin lesions on the face and body. Her doctor prescribed Tegretol for seizure control.

According to her mother, Julie has also had frequent ear infections, beginning at 8 months of age and continuing until 3 months ago. At that time, she had tubes placed in her ears. She has reportedly had no difficulties since then. She had a hearing examination 2 months ago that indicated a slight hearing loss in the right ear. Julie has also had frequent colds, according to her mother. Julie's vision is reportedly normal.

Julie's mother described Julie's development as inconsistent. She seemed to learn gross motor skills at a normal rate, but her fine motor and language development appeared to be delayed. She reportedly spoke her first words at 9 months, but by 18 months, she could still speak only four words. Her mother states that Julie did not speak in sentences until she was 2½ years old. Her speech articulation is reportedly clear, but her language is still delayed. She was reportedly in speech therapy until recently.

Her mother stated that Julie is sweet, has a good sense of humor, and enjoys singing. Julie, however, can also be stubborn and sometimes does not seem to listen to or obey her mother. Her mother noted that Julie likes to play by herself rather than with other children. She also reported that Julie can be easily overstimulated in that she seems uncomfortable in crowded or noisy places, is very energetic and active, has a short attention span, and is impulsive (e.g., not waiting for her turn, grabbing objects at stores without permission). She added that Julie seems to require a great deal of parental attention.

Julie has reportedly been in a preschool program since she was 2 years old. Her mother stated that Julie's teachers have been concerned because Julie did not communicate in school, had difficulty doing age-appropriate work, required much teacher attention, and seemed to lack self-esteem and confidence. Julie is now enrolled in a kindergarten class. Her current teacher reported that Julie is a sweet child and seems to want to please others. Julie reportedly memorizes well and knows many songs.

Julie's teacher also stated, however, that Julie shows many behaviors that make it difficult to teach her. She reportedly spends most of the day by herself, talking only to herself or inanimate objects. She seems to repeat, over and over, phrases that she has heard adults say. According to her teacher,

Julie does not interact with the other children. When called on in class, she seems embarrassed and then blurts out any answer. She reportedly has a very short attention span and also sometimes leaves the room without teacher permission. Her teacher stated that she is teased by the other children because of her behavior, which includes chewing on her mat and her clothes. According to her teacher, Julie has not learned many academic skills. She seems to have learned a few basic concepts, such as shapes. She can also make a capital "A," but it is frequently upside down. She reportedly writes and works with other objects upside down frequently and does not seem to recognize that she is doing so. She reportedly cannot complete worksheets, as she just draws lines up and down the page or colors the whole page one color. According to her teacher, Julie sometimes does better with one-on-one assistance, but at other times, she will not accept help from her teacher.

Julie was briefly observed at school during lunch. She was sitting at the end of the table by herself and did not interact with the other children. Although she had talked with the observer previously, she showed little response to her at this time. When asked if she remembered the observer, she said that she did, but she still did not interact with her. She just continued eating.

Behavioral Observations

Julie was tested over a 2-day period. Three examiners participated in her evaluation. She was brought to the first testing session by her mother. She seemed very uncomfortable meeting strangers and clung to her mother. Her mother carried her to the testing room and stayed for a while until Julie was more comfortable. Julie did not become relaxed with the examiners for some time. Adequate rapport for testing purposes was finally established.

During testing, Julie was very active and distractible. The examiners had difficulty keeping her attention on the test materials. She required much direction and attention from the examiners to stay on task. She frequently wanted to play with the other toys. At one point, she sat on the floor, facing the wall. When asked what she was doing, she said she was in time-out. On further questioning, she responded that she was put there because she did not pay attention. Later, she again sat on the floor, this time repeating "Stephanie, it's time to go to school." The examiner had difficulty redirecting her from this behavior. This type of behavior seemed to occur most when Julie was being asked to perform a task that was difficult for her. After this last time, Julie could not be enticed to pay any more attention to the test materials. She got up and left the room without the examiner's permission.

Julie was more cooperative during the second testing session. She seemed much more comfortable with the examiners and accompanied them readily to the testing room. She was, however, still very distractible and active, requiring much examiner attention for her to stay on task.

Test Results and Interpretations

Intellectual Functioning

Julie's intellectual functioning was far, to well below, that of her same-aged peers. This level of functioning is consistent with her teacher's and mother's reports of her ability and with her current school performance. Her performance across subtests was consistent, showing no relative strengths or weaknesses.

Visual Motor Integration

On a test of visual motor integration, Julie's performance was at or above that of 8% of children of her age, suggesting that her visual motor integration and fine motor skills are well below average. Her mother and teacher also reported difficulty with fine motor tasks, such as drawing and writing.

Academic Achievement

On a standardized test of academic achievement, only two subtests were able to be administered. Her performance on the subtests administered was well to far below average. On these subtests and informal assessment, Julie showed the ability to sing the alphabet and count objects with one-to-one correspondence.

Adaptive Behavior

The Vineland-2 is a measure of Julie's ability to take care of herself, get along with others, and live in the community appropriately for her age. It includes four domains: Communication, Daily Living Skills, Socialization, and Motor Skills. On the Vineland-2, Julie's mother indicated that Julie's overall ability in these domains is slightly below average for her age. Most of her scores were consistent with her overall Adaptive Composite score. Her score in the Socialization domain was slightly higher than the others. This score, however, is not consistent with teacher and parent reports or behavioral observations.

Julie's teacher completed the Vineland-2, Classroom Edition. Her teacher indicated that Julie's adaptive behavior is variable. Julie's score on the Daily Living Skills domain from her teacher's report is similar to that given by her mother and is in the Below-Average range. However, her other scores are in the Well Below-Average range, more consistent with her intelligence test scores. Her Socialization domain score is inconsistent with that of her mother's rating but more consistent with other assessment findings. It indicates far below-average socialization skills for Julie at school relative to same-aged peers.

Overall, the report of Julie's mother and teacher on the Vineland-2 indicates that Julie's adaptive behavior is below what would be expected for her age but is somewhat above her intellectual ability as assessed in this evaluation. However, it does not appear that a diagnosis of Mental Retardation is appropriate at this point, as Julie's adaptive functioning is not far enough below what would be expected for her age to warrant such a diagnosis.

Rating Scales

Julie's mother and father completed the Achenbach CBCL, whereas her teacher completed the TRF. This rating scale assesses behavioral and emotional problems of children. Although the raters reported similar behavioral patterns, only Julie's father indicated that Julie has any serious problems. He rated Julie as having problems in the areas of social withdrawal and hyperactivity. Julie's mother and teacher also rated her high in these areas, but not significantly so. These findings are consistent with teacher and parent report and behavioral observations in that Julie has some incidents of apparent overactivity in the classroom and consistently seems uncomfortable interacting with others. Based on Julie's current emotional, behavioral, social, intellectual, and adaptive functioning, as well as her history of communicative delays, a diagnosis of Pervasive Developmental Disorder, Not Otherwise Specified seems appropriate.

Summary and Conclusions

Julie is a 5-year-old girl referred by her parents to determine her current level of functioning. She has been diagnosed as having seizure disorder and tuberous sclerosis. Her mother reported that her language and fine motor development were delayed. Her teacher reported that she made little progress in adjusting to kindergarten or learning basic academic skills. Parent and teacher reports indicate that she is active and inattentive and requires much adult attention and supervision. These behaviors were also observed in the testing situation, in which examiners had much difficulty getting Julie to cooperate and attend to the tasks. She was very active and distractible. Parent and teacher reports, as well as observation during testing, also suggest

that Julie displays several unusual behaviors, such as talking to herself or inanimate objects, repeating the same phrases or motions, panting heavily at times, chewing on clothes, preferring to stay by herself, and not interacting with other children.

Most of Julie's test results, including intellectual, achievement, visual motor, and some adaptive behavior areas, are in the Well Below-Average range. Other adaptive behavior scores, however, were only slightly below average for her age. Information from rating scales indicates that Julie tends to be socially withdrawn, hyperactive, distractible, slow to learn or adapt to new situations, and sometimes fussy too.

Taking all of the assessment information together, the diagnosis of Pervasive Developmental Disorder–Not Otherwise Specified seems appropriate. At this time, a diagnosis of mental retardation does not seem applicable. Although her intelligence test scores are within the mild mentally retarded range, her adaptive behavior scores lie outside the mental retardation range. Both of these areas of functioning must be significantly below average to warrant a diagnosis of Mental Retardation.

Recommendations

Julie should be evaluated again at the end of this academic year to assess her progress. At this time the following recommendations are made for Julie:

1. Julie would benefit from a highly structured educational environment where she can get the attention and supervision, she needs, to learn. Her parents should consult school personnel in order to determine the most appropriate placement for her

2. Julie will need much individual instruction, gradually moving to small-group instruction

3. Julie's classroom assignments should be within the range appropriate for her intellectual and academic levels

4. Julie should be allowed to learn and work at her own pace

5. Instructional tasks should be organized into short, structured units

6. Julie will need to be taught at a very concrete and practical level, using many manipulatives and teaching aids

7. Skills and concepts will need to be repeated and reviewed often for Julie to master them

8. Julie may be helped by being tutored by someone who has been trained in tutoring children with her set of difficulties

9. Julie's parents and teachers should continue to search for activities that she does well and enjoys and encourage her in these activities

10. Julie should be provided with increased opportunities to learn and practice age-appropriate self-care and socialization skills

11. Julie's parents and teachers should continue to use behavioral management strategies, such as positive reinforcement and time-out, to help her learn appropriate behavior. Her parents may wish to attend sessions with a mental health specialist to become more facile with these techniques

12. Inappropriate behavior should be ignored as much as possible, while appropriate behavior is rewarded with praise and other appropriate reinforcers

13. Communication between school and home should be maintained. A home-school note, in which Julie is rewarded at home and for appropriate behavior at school, may be helpful

14. Julie should be allowed as much as possible to be around other children her own age, so that she can learn socialization and develop behavioral skills by observation and interaction with them

15. Julie's parents should closely monitor her physical functioning and symptoms and maintain regular contact with her physicians regarding her seizures

16. Julie should be evaluated in approximately 1 year to determine her level

of functioning, particularly after the above strategies have been implemented.

Conclusions

Autism and its related disorders are among the most difficult of the developmental disorders to reliably classify, yet classification is central to research efforts aimed at prevention and intervention. Considerable progress has been made in defining the three core dimensions of impairment that separate this condition from other developmental disabilities and in developing assessment tools geared toward evaluating these dimensions. Many of these tools appear to be useful in devising intervention strategies for individuals with ASDs.

Many of the available instruments also differentiate ASDs from other developmental disabilities, but this differentiating is particularly difficult for very young children and those with more severe developmental delays. While new methods of assessment have made strides in terms of differential validity, considerably more progress is needed. The most promising method for assessing and classifying autism at this time is a thorough and standard interview of the child's primary caregiver along with either a structured observation that systematically evaluates symptoms of ASDs and/or a functional analysis that evaluates the communicative intent of a child's behavioral problems. Complementing the diagnostic process is the use of intelligence and adaptive behavior scale such as the Vineland-2.

In summary, current recommendations (e.g., de Bildt et al., 2004; Ozonoff et al., 2005) call for a combination of a detailed developmental history (e.g., ADI-R), behavioral observation (e.g., ADOS), assessment of cognitive functioning, and assessment of adaptive functioning.

Chapter Summary

1. Autistic Disorder is part of a class of problems known as Pervasive Developmental Disorders (PDD) or Autism Spectrum Disorders (ASDs)
2. The *DSM* emphasizes three classes of symptoms that are central to the disorder: social interaction problems, communication problems, and repetitive and stereotyped behaviors
3. Much remains to be learned about risk factors that may be etiologically involved in autism
4. Differentiation within ASDs and of autism from Pervasive Developmental Disorder – Not Otherwise Specified (PDD-NOS) and Mental Retardation is difficult
5. The most frequent comorbid problem for autism is mental retardation
6. The Autism Diagnostic Interview – Revised (ADI-R) is a semi-structured diagnostic interview that is designed to be used with a child's primary caregiver. It provides for a detailed history of the domains of functioning relevant to ASDs
7. The Autism Diagnostic Observation Schedule (ADOS) is designed for the assessment of autism through structured observation in a classroom or clinical setting. Four modules are available based on the individual's expressive communication skills and developmental level
8. Assessment strategies such as functional analysis can be useful in determining the communicative intent of problem behaviors in children with ASDs and may directly translate to intervention plans
9. There has been an increase in rating scales aimed at screening for Asperger's Disorder. However, more research on the psychometrics and utility of these measures is needed
10. The within-syndrome variability associated with autism suggests that children who are either suspected of, or diagnosed with, the disorder should have access to multidisciplinary assessment procedures