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Handbook of Assessment and Diagnosis of Autism Spectrum Disorder

Springer

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Contents

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History and Purpose of Assessment and Diagnosis of Autism

1

Hilary L. Adams and Johnny L. Matson

Introduction to History and Purpose of Assessment and Diagnosis

Assessment is a broad term that encompasses evaluation of a variety of types. When considering assessment of autism, diagnostic assessment is typically the first to come to mind. However, assessment of individuals with autism frequently extends beyond diagnosis; professionals may assess challenging behavior (e.g., self-injurious behavior, aggression), intellectual functioning, adaptive skills, etc. among this population. Nonetheless, the current chapter covers the history of the assessment and diagnosis of autism in particular. In later chapters, authors discuss the other aforementioned types of assessment, as well as current diagnostic criteria and assessment practices.

The diagnosis of autism spectrum disorders (ASD) has changed substantially since its inception, with screening, assessment, and monitoring techniques continuing to evolve. In the recent past, children with autism were frequently identified and diagnosed when they entered school. This practice is changing rapidly for a variety of reasons: increased autism awareness, widespread screening requirements, recognition of the importance of early intervention, etc. (Fountain, King, & Bearman, 2011). At present, reliable identification is possible as early as infancy (Dover & Le Couteur, 2007; Klaiman, Fernandez-Carriba, Hall, & Saulnier, 2015; Zwaigenbaum, Bryson, & Garon, 2013). Reliable diagnosis at this age is crucial for access to early intervention, which leads to greatest developmental gains and best prognosis for most individuals (Bryson, Rogers, & Fombonne, 2003). Early diagnosis is also reportedly responsible for a variety of other positive results, including lessening family stress, decreasing societal costs, and earlier recognition of medical, developmental, and psychiatric conditions that may co-occur with core symptoms of autism (Dover & Le Couteur, 2007; Klaiman et al., 2015).

Despite the ability to diagnose reliably in infants, the average age of diagnosis in the United States remains later (e.g., average of 38 months in a study sampled by Valicenti-McDermott, Hottinger, Seijo, & Shulman, 2012). This trend may be due to the finding that early diagnosis is not uniform across groups. That is, variables such as race, access to relevant healthcare, and severity of symptoms influence the age of the individual when he or she is diagnosed (Wiggins, Baio, & Rice, 2006). Further, being male, having an IQ below 70, and experiencing developmental regression have all been associated with earlier

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diagnosis (Shattuck et al., 2009). With increased focus on screening, which allows for the determination of need for further, comprehensive assessment, diagnosis is likely to continue to occur earlier in development. Further, recent efforts have included the goal of determining "at-risk" symptomatology (i.e., signs even earlier in life that autism may develop later) (Klaiman et al., 2015), which has the potential to allow intervention to start before further symptoms develop.

Kanner's Autism

Although Leo Kanner, an American child psychiatrist, is commonly credited with "discovering" autism in the 1940s, individuals who exhibited symptoms of ASD had long been recognized as evincing atypical development. Before Kanner's *Autistic Disturbances of Affective Contact* in 1943, such persons were frequently considered to have an emotional disturbance or intellectual disability (Wing, 1997). The symptoms he identified among his patients represented the core domains we recognize today as characteristic of autism: communication deficits, difficulty with social interaction and forming relationships, and the presence of restricted and repetitive behavior and interests. He used observations of behavioral symptoms as well as parent-reported family, medical, and developmental history to make his classifications. His method was based on clinical presentation and predominantly atheoretical, a departure from the popular psychoanalytic thinking of his era (Blacher & Christensen, 2011).

Kanner coined the term "early infantile autism" to describe the constellation of symptoms exhibited by the children he studied (Kanner, 1951). With his publication of detailed case studies (Kanner, 1943), he was considered the first to recognize the denoted behavioral phenotype as disparate from childhood psychosis (Blacher & Christensen, 2011). Nevertheless, his first work on the subject did not specify diagnostic criteria in 1956, Kanner and Leon Eisenberger delineated specific symptoms required for classification (Eisenberger & Kanner, 1956). This development of diagnostic criteria based on observations of child clients was unusual for the time period, when criteria for disorders among children were simply modifications of criteria for syndromes seen in adults (Rutter & Schopler, 1988).

Deviations in Conceptualizations and Criteria

In the late 1950s and early 1960s, diagnostic criteria and terminology for autism remained controversial. From Kanner's original observations, other diagnostic criteria were created but with notable changes. For instance, Polan and Spencer (1959) published the 30-item *Checklist of Symptoms of Early Infantile Autism*, which included language distortion, social withdrawal, lack of integration in activities, obsessiveness and nervousness, and family characteristics. These criteria aimed to evaluate the "perceptual apparatus" and "psychogenic factors related to deviant styles of interpersonal relatedness" (Ward, 1970).

In 1958, a "Social Psychiatry Research Unit" was opened due to the British Government's impending enactment of the Mental Health Act. There, Hans Eysenck and other influential scientists led the charge for experimental psychology, including the use of statistical analyses and behavioral measures. Eysenck was a strong proponent of direct observation rather than psychoanalytic theory, arguing against Freudian speculative impressions (Evans, 2013). In particular, the psychoanalytic theory of the time suggested that autism was a "reaction to an overwhelming inner or outer assault at a vulnerable developmental stage" (Garcia & Sarvis, 1964, p. 530).

This shift in thinking toward an empirical-based study of psychology helped influence Mildred Creak, a British child psychological professional who studied psychopathology in infancy, to unite prominent members of the field to identify specific features of childhood schizophrenia. Her purpose in forming the work group

was to help establish quantitative, reliable research of childhood psychopathology, which included creating criteria that all psychiatrists could agree on in order to enable population-based studies (Evans, 2013). The work group's efforts resulted in a set of nine key features: impairment of emotional relationships with people; unawareness of personal identity; preoccupation with particular objects; resistance to environmental change; abnormal perceptual experience; acute, excessive, illogical anxiety; a lack of or delay in language ability; distortion in motility patterns; and impaired cognitive function that sometimes occurs with savant skills (Creak, 1961).

Another example of criteria appearing in that era was that by Schain and Yannet (1960). Their criteria for autism included children who displayed "an extreme preoccupation with self and unrelatedness to people" and who thus failed to develop relationships with caregivers as expected by age 2 years (p. 561). These authors noted that they might have included cases that other professionals would not consider to have infantile autism but that they had required Kanner's "common denominator" of difficulty with social relationships. Their criteria, therefore, did not include display of insistence on sameness or similar symptomatology included in Kanner's original description.

Unlike the others originating at the time, the criteria authored by Ornitz and Ritvo (1968) emphasized perception issues, considering them fundamental to the other problems in autism. Their criteria encompassed symptoms in the areas of perceptual integration, motility patterns, capacity to relate, language, and developmental rate. That same year, an additional conceptualization was published by Rendle-Short and Clancy. Their "screening test" included 14 symptoms, of which a child needed to exhibit half or more per caregiver report, that the authors considered most representative of the essential characteristics of autism (Rendle-Short & Clancy, 1968). These symptoms were: difficulty engaging with other children, acts as though deaf, resists learning, no fear of real dangers, resists routine change, indicates needs by gestures, inappropriate laughing, not cuddly, marked physical overactivity, no eye contact, inappropriate attachment to objects, spins objects, sustained odd play, and standoffish manner. With the continual development of varying definitions, the boundaries of the disorder remained unclear.

Despite a lack of agreement in the field as to what exactly constituted autism, Dr. Victor Lotter published the first paper to give the results of an epidemiological study of autism among a population of children of varying intellectual function in 1966. To meet his criteria and be considered to have autism, a participant had to have a profound lack of affective contact and elaborate repetitive, ritualistic behavior, whereas early age of onset was not included (Feinstein, 2010). Results suggested a prevalence rate of 4.5 per 10,000 (Lotter, 1966).

Beginnings of Diagnostic Assessment of Autism

In the 1960s, the practice of the family physician completing screening for developmental issues including autism was already in place in a less formal variation than today (Fotheringham, 1969). At that time, the physician might compare the child's development to established milestones (e.g., motor, communication) and gather more in-depth developmental history from caregivers (e.g., age at first concern, significant biological or social events that affected functioning). If the child was school-aged, a sampling of schoolwork or a brief achievement test may be administered. Nonetheless, in Wing and Wing's "Early Childhood Autism" (1976), contributor Dr. P. H. Connell noted the deficiency of adequate comprehensive assessment measures for diagnosis, not just screening, of autism.

The aforementioned *Checklist of Symptoms of Early Infantile Autism* by Polan and Spencer (1959) was considered one of the pioneers of standardized autism assessment. This measure required that each respondent endorses or denies the presence of a specific list of symptoms for the child being evaluated (Rotatori, Obiakor, & Bakken, 2011). In 1964, Rimland, inspired by the

aforementioned checklist, attempted to translate Kanner's definition into an empirical rating scale to identify early infantile autism in children up to age 7 years. The *Diagnostic Form E-1* (Rimland, 1964b) was a parent-report measure that included 76 questions inquiring about birth history and onset and characteristics of symptoms. The form was subsequently revised to reflect the need for information about children before age 5 years. Thus, the *Diagnostic Checklist for Behavior-Disturbed Children*, *Form E-2* (Rimland, 1964a) included questions about early development (i.e., from birth through age 5 years). The form included characteristics of autism described by Kanner and symptoms of childhood schizophrenia described by experts in that field. According to Rimland, 31 children had been diagnosed by Kanner prior to their completion of Form E-2, and the E-2 scores correlated strongly with these diagnoses (Rimland, 1971). In addition, he found that the parent-reported presence of "autistic speech symptoms" among children with and without classification of early infantile autism, indicating language issues alone, was insufficient for an autism diagnosis (Rimland, 1971). Although reliability of parent-report measures had been questioned in terms of reliability and accuracy, Rimland argued that diagnosis should require retrospective information, making caregiver report a necessity (1971). To further justify his use of parent report rather than direct observation, he also suggested that behaviors may differ within and outside of the diagnostic session (Rimland, 1971).

Soon after the publication of Rimland's checklist, Ruttenberg and colleagues published the *Behavior Rating Instrument for Autistic and Atypical Children* (Ruttenberg, Dratman, Fraknoi, & Wenar, 1966). Reportedly this measure was unable to accurately differentiate between autism and intellectual disability (Parks, 1983). Despite this, teachers and therapists found the measure useful for goal formulation and in predicting future development among children exhibiting atypical development (Feinstein, 2010).

Both Creak's (1961) criteria and Rimland's (1964b) original checklist lacked consideration of symptoms among very young children. To correct for this exclusion, Reichler and Schopler developed a 15-scale rating system, initially named the *Childhood Psychosis Rating Scale* (CPRS), in 1971. Their aim was to incorporate Kanner's original description, less common characteristics of autism noted by Creak, and symptoms of autism common in younger children. The observational scale required each of the 15 included domains to be considered in terms of atypicality, frequency, and duration and given a corresponding rating from 1, which represented behavior within normal limits, to 4, which represented severely abnormal behavior (Schopler, Reichler, DeVellis, & Daly, 1980). This measure was later renamed the *Childhood Autism Rating Scale* (CARS). An updated version of the CARS is commonly used for assessment at present.

Clarifying Distinct Definitions

Kanner's purpose for his descriptions of autism as a syndrome was to recognize a constellation of certain behaviors that differed from symptoms of other mental health issues (Rutter & Schopler, 2012). To clarify the definition, work was needed to establish which symptoms could potentially occur in autism and which were characteristic of autism and therefore requisite behaviors for such a classification. Renowned psychiatrist Sir Michael Rutter was extremely influential in this endeavor. He found three primary types of symptoms evinced by almost all children with autism and that occurred much less frequently among children with other disorders. These symptoms confirmed Kanner's work and are the same as those core domains we recognize in the field today: difficulty developing and maintaining social relationships, problems with language development and use, and ritualistic or compulsive behavior (Rutter, 1970, 1971). Additional symptoms that occurred frequently among children identified as having autism included stereotypy (e.g., repetitive motor movements), self-injury, poor attention span, and delayed bowel control (Rutter, 1970, 1971).

Most researchers in Britain, Australia, Canada, and the United States supported autism and childhood

schizophrenia as discrete syndromes by the 1970s (Green et al., 1984). In 1971, DeMyer and colleagues made an empirical comparison of five diagnostic systems for differential diagnosis between the disorders. The diagnostic systems they used included Polan and Spencer (1959), Rimland (1964b), Lotter (1966), Rendle-Short and Clancy (1968), and Creak/British Working Party (1964). The authors administered all of the checklists to each of the 44 participants. Results indicated overlap of only 35 % across all five systems, reflecting the great disparity in definitions of schizophrenia and autism that existed in that era despite the recognition that the disorders were distinct. Furthermore, the authors noted that all of the checklists lacked rigorous validity studies at the time the study was conducted and, as such, could only serve as screening instruments of relatively equal value (DeMyer, Churchill, Pontius, & Gilkey, 1971). That is, any one of the checklists studied could differentiate early schizophrenic and autistic children from nonpsychotic children, but not necessarily to differentiate within the "psychotic" group. To excuse the low amount of overlap, DeMyer and colleagues pointed out that professionals in close collaboration (e.g., working at the same facility) are much more likely to experience agreement on diagnosis than those experts who do not engage in constant feedback and comparison of diagnoses, despite the use of standardized or structured assessment instruments.

In the late 1970s, two definitions of autism that were evidence based rather than strictly theoretical were most prominent (i.e., those by Rutter (1978) and Ritvo and Freeman (1978)). The definitions were similar in that they both included impairments in social development, problems with language and cognitive function, and early onset of symptoms. Additionally, both recognized that although these core symptoms were required, variation among individuals was extensive (Schopler et al., 1980). However, whereas Rutter (1978) included behavioral rigidity (e.g., insistence on sameness) and stereotyped behavior (e.g., play), Ritvo and Freeman (1978) highlighted sensory issues and added disturbances in developmental rates or sequences. Rutter recognized and noted several flaws in his 1987 formulation; his four diagnostic criteria did not include consideration of distinct subtypes of autism, nor how to classify individuals who exhibited only some of the features he delineated (Feinstein, 2010).

Further Progress for Assessment and Toward Consensus on Definition

Recognizing the need for objective diagnostic criteria and normative behavioral data that would allow for accurate comparisons across individuals, Freeman, Ritvo, Guthrie, Schroth, and Ball (1978) developed a systematic way to code behaviors among children with developmental disabilities as well as their typically developing peers. Their measure was named the *Behavior Observation Scale*. In their factor analysis of the measure, the authors found that the group with autism was best characterized by symptoms of inappropriate interaction with people and objects. This was in contrast to their group of individuals with intellectual disability, who exhibited solitary behaviors (Freeman, Schroth, Ritvo, Guthrie, & Wake, 1980). Later, they further differentiated between high- and low-functioning autism; "relation to examiner" best differentiated the children with low-functioning autism, whereas "solitary stereotypic" and language behavior best differentiated the children with high-functioning autism (Freeman, Ritvo, & Schroth, 1984).

In 1980, the authors of the CARS compared their measure to the aforementioned Rimland checklist and the existing definitions to evaluate correspondence among these options (Schopler et al., 1980). They found that their classifications, based on behavioral observations, differed substantially from those that used the Rimland checklist, which were based on parent report. Their study also indicated significant overlap in the Rutter and Rivto and Freeman criteria, with those individuals meeting both criteria evincing higher scores on the CARS (i.e., more likely to be in the severely autistic range according to the measure). Schopler and colleagues (1980)

emphasized that although the CARS was helpful for classification purposes and to provide a "descriptive summary of a child's pathological behavior" (p. 102), the measure was not intended to replace the gathering of information from multiple sources (e.g., developmental history, behavior across settings).

The same year, the third edition of the DSM was released (1980, American Psychiatric Association). In DSM-III, childhood schizophrenia was excluded, and "infantile autism" was included for the first time (DSM-III, American Psychiatric Association). Infantile autism was included in the pervasive developmental disorder category and was clearly distinguished from childhood-onset schizophrenia. These criteria were based on Kanner's original descriptions (Kanner, 1943), his more specific delineation with Eisenberger (Eisenberger & Kanner, 1956), and Rutter's later description of behavioral manifestations of Kanner's proposed core symptoms (Rutter, 1978).

Empirical comparisons supported the differentiation between autism and schizophrenia. For instance, in their comparison of DSM-III-diagnosed children with schizophrenic disorder versus DSM-III-diagnosed children with infantile autism, Green and colleagues (1984) found that the disorders differed in terms of age of onset, behavioral symptom profile, intellectual functioning, pregnancy and delivery complications, and socioeconomic status (Green et al., 1984). Further, the groups remained distinguishable as the children developed, despite some overlap in behavioral profiles (Green et al., 1984).

In the late 1980s, Rutter's (1978) four criteria and Ritvo and Freeman's (1978) criteria were most commonly used, but there was still difficulty formulating criteria that would delineate a clinically homogeneous group (Fein, Pennington, Markowitz, Braverman, & Waterhouse, 1986). As the field worked on a neurophysiological model of the disorder, some researchers suggested autism was a neurological disorder that primarily affected social and emotional development (Fein et al., 1986). Nevertheless, focus remained on behavioral observations and caregiver-reported developmental history, with standardized ways of measuring both emerging out of necessity to compare across populations. Behavior checklists were fairly common (e.g., Behavior Rating Instrument for Autistic and Atypical Children by Ruttenberg, Kalish, Wenar, & Wolf (1974); Autistic Behavior Checklist by Krug, Arick, & Almond (1980)), but more comprehensive standardized assessment measures were just being formulated.

For instance, the *Autism Diagnostic Observation Schedule* (ADOS) and the *Autism Diagnostic Interview* (ADI) were both published in 1989 (Le Couteur et al., 1989; Lord et al., 1989). The ADOS was described as a standardized protocol to observe and code social and communicative behaviors by way of structured and semi-structured cues for interaction (Lord et al., 1989). The purpose of this observational measure was to acquire a quantifiable sampling of a client's behavior in the clinic, to which other information (e.g., observations in familiar settings, caregiver interviews) about the child's behavior are incorporated in the clinical synthesis of the case. The) ADI was described as a standardized investigator-based interview of the primary caregiver (Le Couteur et al., 1989). The authors aimed to create a measure that captured a lifetime range of behaviors in order to differentially diagnose pervasive developmental disorders in individuals beginning at 2 years of age. Questions cover reciprocal social interaction, communication and language, and repetitive, restricted, and stereotyped behavior, as well as symptoms not required for diagnosis but that frequently occur among individuals with autism and related disorders. These included self-injury, pica, aggression, and overactivity. The authors created the measure to fill the need for a standardized interview that covered the symptoms of autism across levels of cognitive functioning. As with the CARS, more recent versions of both measures are still being used today; updates and clinical uses are discussed in depth in later chapters.

In the later revision of the DSM-III, DSM-III-R, the criteria for autistic disorder were expanded in an attempt to include a broader range of ages and developmental levels (Volkmar,

Cicchetti, Bregman, & Cohen, 1992). In their study, Volkmar et al. (1992) found that the ICD-10 was the closest official diagnostic system to clinical diagnosis. Additionally, there was evidence that DSM-III-R overdiagnosed autism when compared to DSM-III or clinical diagnosis; DSM-III-R diagnosis was found to be highly sensitive but less specific than clinical diagnosis (Volkmar et al., 1992). Indeed, the DSM-III-R criteria identified clinically diagnosed atypical pervasive developmental disorder as autism (Volkmar et al., 1992). Nevertheless, Volkmar and colleagues noted that since there was no "gold standard" for diagnosis, there was no reliable way to tell whether over- or underdiagnosis was "correct," only that it was problematic for research efforts that official diagnostic systems of that time differed so widely in their criteria.

The Last Decade

In both ICD-10 and DSM-IV-TR (APA, 2004), the diagnosis of autism required evaluation of current behaviors and cognitive and language abilities, as well as consideration of developmental history. Evaluation was advised to take place across multiple settings and could involve standardized measures. Clinical judgment of several experienced professionals was recommended.

Publication of the DSM-V in 2014 enacted substantial changes for the criteria of autism with significant results (APA, 2014). The new autism spectrum disorder (ASD) would drop its previous subcategories and become a one-dimensional category. Additionally, the triad of symptom categories was reduced to just two: social communication/interaction and restricted and repetitive interests. Prior to the publication of the new criteria, the work group responsible for its development claimed the result would be increased specificity while maintaining sensitivity. Nevertheless, there was a concern that individuals with less severe symptoms of autism would no longer meet criteria and subsequently lose access to valuable services (Matson, Kozlowski, Hattier, Horovitz, & Sipes, 2012; McPartland, Reichow, & Volkmar, 2012; Worley & Matson, 2012). Indeed, several research groups suggested relaxed diagnostic algorithms following research studies that found many individuals with severe, interfering symptoms would be missed (Frazier et al., 2012; Matson et al., 2012; McPartland et al., 2012). Nevertheless, the DSM-V criteria for ASD were published as originally conceptualized. As such, controversy continues about the most accurate definition of autism; it is yet unclear which diagnostic system will be most widely used in the future (Volkmar & McPartland, 2014). Additional information about these most recent changes and their implications is provided later in this book.

At present, practice parameters indicate the necessity of screening for core symptoms of ASD, particularly issues with social relatedness and display of repetitive or unusual behaviors (Volkmar et al., 2014). A follow-up comprehensive diagnostic assessment is recommended if the screening indicates the presence of significant symptomatology. Information should be gathered from the child, the child's caregivers (e.g., parents, legal guardians), and the child's service providers (e.g., classroom teachers, therapists). Because genetic factors and biological markers have not yet been established for the diagnosis of ASD, assessment primarily consists of behavioral observation of the client (McCray, Trevvett, & Frost, 2014; Volkmar et al., 2014). The use of standardized measures is helpful in information collecting for both clinical observation and caregiver report, as data can be compared across children, allowing for more accurate assessment of development and functioning. After diagnosis of autism by a qualified professional, a multidisciplinary evaluation is suggested, which may include a medical examination, genetic testing, and/or neurological assessment (Volkmar et al., 2014). Further assessment of psychological components (e.g., cognitive abilities, adaptive behavior) and communication, occupational, and physical evaluations provide valuable information for treatment planning individualized to the client (Volkmar et al., 2014).

Although autism has a long, oftentimes controversial history in terms of diagnosis and evaluation, the above history provides a glimpse into

what was the foundation for our current practice. The early criteria and assessment measures provided a basis for our current diagnostic process, although most components have been refined, empirically tested, and standardized. As briefly discussed, current goals of assessment include quantifying symptoms as much as possible through both live observation and caregiver report. More in-depth information regarding current assessment practices and commonly used, psychometrically sound measures is provided in the following chapters.

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Types of Assessment

2

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Introduction

Assessment is an area of psychology that has been the subject of tremendous research and development activity, since the beginning of the discipline. Accordingly, it is not surprising that a very large array of types of assessments have been created. Especially with the information technology revolution continuing to explode, it is anticipated that the large variety of types and formats of assessment that already exist will only grow. In this chapter, we review the major general types of assessments as they relate to assessment of individuals with autism spectrum disorders (ASD). With a topic as broad as this one, it will of course be impossible to achieve an exhaustive coverage. Instead, we attempt a broad-level survey and discussion of most major types of assessments. To illustrate our points, we discuss particular examples of each type of assessment and we focus on assessments that have good psychometric research support and which we have found to be useful for research and practice with individuals with ASD. Although there are many different domains in which individuals may need to be assessed, for the sake of space, it is not possible to cover all. This chapter is organized first by discussing each major type of assessment (e.g., indirect, direct, etc.). Within each section on each major type of assessment, further discussion of individual diagnostic, adaptive, cognitive, and functional assessments are included as illustrative examples.

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Types and Formats of Assessments

Obtaining a History with an Unstructured Interview

Obtaining a thorough clinical history through an unstructured interview is the most basic and fundamental of assessment processes. This is generally the very first thing the assessing clinician does when meeting with the client and/or his/her guardians. The purpose of this interview is to gain relevant information regarding all major medical and psychosocial variables that might be relevant, including the client's pre- and postnatal periods, developmental milestones and achievements, health and medical background, social and play development, adaptive functioning, psychological and psychiatric care, and academic/work histories. Interviews

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should ascertain historical information regarding previous diagnoses, treatment interventions and evaluations, and behavioral presentations. This initial interview also serves the very important function of establishing rapport between the clinician and the individual being assessed and/or his/her caregivers. Interviews can be conducted with the referred individual and his/her primary caregivers (e.g., parents, family members, legal guardians) depending on the client's age and level of functioning. In addition, teachers, intervention providers, and childcare workers may be interviewed.

Diagnostic

The purpose of the diagnostic interview is to obtain narrative information from caregivers and/or the client regarding areas of functioning that are relevant to the diagnostic criteria of ASD. For very young children, this will primarily consist of interviewing the parents. For older and more verbal children, direct conversations with the client are highly valuable. According to Jerome Sattler (2001), an unstructured interview with a child, depending on the child's age, can be useful in understanding how the child views the referral and his/her family, teachers, and peer group. When considered for an ASD diagnosis, an intake with the child may assist in determining the level of severity of the diagnosis if ASD criteria are met.

When conducting a diagnostic interview with adolescents or adults who perhaps never received a childhood diagnosis of ASD, a new diagnosis may be dependent on specific criteria of communication, socialization, and restricted, repetitive patterns of behaviors being met through historical recall of the client's behaviors during his/her early developmental period, the typical onset of pervasive symptomology (American Psychiatric Association, 2013). In addition, interviews should obtain information regarding the client's current presenting problem and behavioral concerns in order to develop a referral question for the purpose of conducting a thorough evaluation, incorporating one's clinical impressions with formal testing results in the form of a written report and in-person feedback, and providing comprehensive recommendations to the individual or family.

Clinical interviews can range in structure from informal, open-ended interviews to structured interviews, designed as standardized measures that are coded and scored to align with the diagnostic criteria of ASD. Multiple interviews across interviewees and designs can be utilized in constructing the most appropriate and comprehensive battery aimed at addressing the referral question of the client. More specifically, a structured diagnostic interview with a parent may be supported at the conclusion of a semi-structured intake interview with the same parent.

The unstructured clinical interview offers a free-flowing and less rigid approach which is ideal for building rapport with the interviewee. Although this approach is less direct, it is a good idea to have an idea going into the interview of specific topics to discuss. Information gathered in an ASD clinical interview will focus on the client's presenting concerns, development, and behavioral functioning across contexts (e.g., home, school, community), with specific attention paid to typical ASD symptomatology. More specifically, information should be gathered in the following domains, with ideas for subtopics listed:

- Presenting Concerns
  - Description of the Problem
  - Onset of Symptoms
- Developmental History
  - Milestones: Single Words, Sentences, Sitting, Crawling, Walking, Toileting, Riding a Bicycle, Dressing, Eating
  - Hobbies/Interests
  - Reaction to Puberty
  - Periods of Regression in Development
- Medical History
  - Current Diagnosis/Diagnoses
  - Medication History
  - Sleep
  - Feeding and nutritional history
- Psychological, Psychiatric, and Treatment History
  - Current Diagnosis/Diagnoses
  - Previous Evaluations

  - Treatment History
  - Suicidality/Homocidality
- Social Development
  - Engaged or Parallel Play
  - Current Play Behaviors
  - Peer Interests
- Academic and/or Work History
  - IEP services
  - Classroom Type
  - Part-Time/Full-Time Aid
  - Work History
  - Current Volunteer or Paid Employment
- Family History
  - Current Living Arrangements/Family Constellation
  - Married/Separated/Divorced
  - Language(s) Spoken in the Home, etc.
  - Family Medical/Psychological/Psychiatric History
  - Cultural Background
- Behavioral Presentation
  - Restricted/Repetitive Interests
  - Echolalia
  - Idiosyncratic Speech
  - Attention/Hyperactivity
  - Atypical Behaviors

Unstructured interviews are recognized for helping examiners establish a high level of rapport with the interviewees. In addition, they facilitate a broad and flexible exploration of the client's background. However, unstructured interviews have potential limitations, including subjectivity and potentially low reliability and validity. For these reasons, most clinicians prefer to supplement the interview process with structured and/or semi-structured interview procedures.

The semi-structured interview is more goal-oriented than the unstructured interview, in that it provides a list of questions, yet it can be manipulated as needed. It is less rigid than the structured interview. Semi-structured interviews address domains similar to those listed above in the unstructured interview section. In addition, interviewers may construct semi-structured formats by converting relevant areas of functioning into specific questions (Groth-Marnet, 2009). More specifically, utilizing an expanded version of the subtopics included in the unstructured interview section and utilizing inquiries of frequency, duration, onset, description, importance, antecedent, and consequence, the interviewee can construct an elaborate, yet fluid, series of questions:

- "What are some of your concerns?"
- "Please describe the most important concern you have"
- "How often does this behavior occur?"

Overall, if administration time is a concern, a semi-structured interview may be the best choice. The interviewer can accomplish an established design of questions in a short period of time and the structured nature of the interaction tends to keep both clinician and caregiver on-track and on-time. If the client is demonstrating symptoms of multiple and conflicting diagnoses, an open-ended and unstructured interview may be appropriate in that it offers the interviewee the flexibility to probe distinct elements of the client's presentation that may be otherwise missed with the more agenda-like approach of a structured interview. Many clinicians prefer a combination of the two, particularly if time allows.

Functional Assessment

Unstructured clinical interviews are a crucial and foundational part of the process for conducting a functional assessment of challenging behavior in individuals with ASD. Many of the points discussed above also pertain to the functional assessment process and those points will not be repeated here. Instead, we will briefly summarize some of the points that are unique to conducting unstructured functional assessment interviews.

After obtaining a basic description of the problem and the main reasons for concern, the clinician will begin asking open-ended questions that attempt to identify the common antecedents (events in the environment that immediately precede challenging behavior) and common consequences (events in the environment that immediately follow challenging behavior), in order to obtain information about environmental events that may contribute to maintaining the

behavior. Researchers have shown that the vast majority of challenging behavior displayed by individuals with developmental disabilities is maintained by one or more of the following four basic functions: (1) access to attention (aka, "attention function"), (2) escape from non-preferred task or demands (aka, "escape function"), (3) access to preferred items or activities (aka "tangible function"), or (4) automatic reinforcement (aka "self-stimulatory") (Iwata et al., 1994). Therefore, when conducting an interview, it is wise to direct your questions and conversation toward obtaining information that will provide evidence for and against those primary four functions.

Some generic, open-ended questions that can be useful include:

- What time of day does the behavior usually occur?
- In what settings does the behavior usually occur?
- What are some common triggers for the behavior?
- What do you or other caregivers do that is likely to provoke the behavior?
- What reactions do you and other caregivers usually have to the behavior?
- How do you usually manage the behavior?
- Does the behavior occur when the individual is not receiving very much attention?
- Does the behavior occur when a caregiver asks the individual to do something he/she doesn't want to do?
- Does the behavior occur when a caregiver does not give the individual an item or activity that the individual wants?
- Does the individual do the behavior at a high rate, across settings and contexts, regardless of how caregivers respond?

Other less common functions, such as escape from attention, access to control over the environment, and access to stereotypy/rituals/routines have also been identified (Hanley, Iwata, & McCord, 2003). Although there is initial evidence that these functions exist, research has generally suggested that they are less common. Still, if the initial interview does not conclusively point to one of the more standard four functions described earlier, the clinician can ask questions such as these, in order to assess for the less common functions:

- Does the individual always need to be in control? Does he/she seem to be using his/her challenging behavior to be in control of the situation?
- Is he/she perfectly happy to be alone? Does he/she seem to be using his/her challenging behavior to get you to leave him/her alone?
- Does he/she engage in the challenging behavior when you interrupt him/her from engaging in his/her repetitive behavior/rituals/routines? Is he/she highly insistent that certain things or routines be done exactly the way they are supposed to? Is he/she particularly inflexible?

Because the interview is unstructured, the caregiver is encouraged to provide as much information as they can regarding the conditions in which the challenging behavior occurs. As the caregiver begins to specify particular events that might suggest one particular behavioral function or another, the clinician adjusts his/her questions to further pinpoint a likely function and to rule out other possible functions. It is often useful for the clinician to ask questions about whether the behavior occurs in conditions that one would expect it *not* to occur, given particular functions. For example, "Does the behavior occur when the individual is already receiving lots of attention?" If the answer is yes, then that would lend evidence against an attention function. Similarly, it is often useful in helping to rule out an escape function to ask whether the individual engages in the behavior when no one is asking him/her to do anything. If the answer is yes, an escape function seems unlikely, as there is nothing for him/her to be escaping from at such times. Another useful question to ask is "When the individual is engaging in the behavior, what is a sure way to get him/her to stop?" Answers to this question often identify the reinforcer for the behavior. For example, if the answer is something like "Stop asking him to do something," then that might point to an escape function, whereas an answer such as "Just give him the thing he wants," might point to a tangible function.

Records Review

Requesting formal records can be a useful means of obtaining a detailed history of a client's background. Thus, there is general consensus that any assessment process includes a records review early on.

Diagnostic

In order to obtain relevant background information for the diagnostic assessment process, medical, psychological, psychiatric, academic, speech and language, physical and occupational therapy, and other forms of documented records may be requested to supplement information acquired through clinical interviews, screening measures, and parent surveys. Information provided in previous diagnostic evaluations, Individual Education Program (IEP) triennial reviews, genetic testing lab reports, and other records may indicate concerns in specific domains for the client you are evaluating or provide evidence ruling out concerns in other areas. Overall, reviewing client records can assist in answering the client's referral question with a more inclusive and supported interpretation of results.

Functional

When conducting a functional assessment of challenging behaviors displayed by an individual with ASD, the clinician should review what relevant functional assessment activities have been done in the past. In theory, if a good-quality functional assessment has been done on the same behavior relatively recently and that assessment produced what appear to be conclusive results, it may not be necessary to repeat a comprehensive assessment. Indeed, doing so may be a waste of the client and clinician's time. However, it is important to note that the functions of challenging behaviors often change over time, so if the previous functional assessment is more than a few months old, conducting a new one—particularly a brief one, such as an indirect assessment—may well be warranted. It is also worth noting that it is impossible to determine from a records review whether existing functional assessments succeeding in addressing all relevant environmental variables and settings. In other words, in a records review, you do not know what you do not know.

Limitations

Several drawbacks of record reviews are worth discussing. Depending on the nature of the request for information (e.g., client request versus agency to agency request), applicable privacy laws (i.e., Health Insurance Portability and Accountability Act of 1996 (HIPAA)) may come into effect and must be abided by. In such instances, a written authorization to disclose the requested protected health information (PHI) must be received by the releasing agency. If interagency communications regarding the care of the client are to be conducted, both agencies must obtain written authorization to disclose PHI. An additional limitation with record reviews is that records may not always be accurate or may be incomplete. Therefore, caution in interpreting records is warranted.

Formal Indirect Assessments

Indirect assessments are formal assessments that do not require direct contact between the clinician and the client to complete the assessment. Instead, the clinician has contact with parents, staff, or other caregivers. Indirect assessments include both instruments that are completed independently by an informant (e.g., inventories, rating scales) and those that are completed by the examiner, in a structured or semi-structured interview style with the respondent (e.g., questionnaires, checklists). Respondents typically include parents and caregivers, but other individuals may also be incorporated in the process, such as teachers.

Independent Measures

Independent measures, such as parent inventories and checklists, encompass a variety of developmental domains, which may include a client's functioning in the areas of diagnostic characteristics, adaptive abilities, social skills, executive processes, socio-emotional capacity, and many

more. These measures generally take 15–60 min to complete and can be completed by the caregiver while the examiner is working with the client directly.

The Vineland Adaptive Behavior Scales, Second Edition (Vineland-II), is a measure of an individual's adaptive skills, specifically in the areas of communication, socialization, daily living, and motor skills. The Vineland-II also assesses an individual's level of maladaptive behavior. The Vineland-II is conducted using two different methods, which include the Survey Interview Form and the Parent/Caregiver Rating Form. The rating scale format is an independent method of gaining insight into a client's behavior by having a respondent who is familiar with the client rate their behavior (Sparrow, Cicchetti, & Balla, 2005). This method may be susceptible to biased responses for various reasons. Therefore, it is preferred that the interview format be administered (Sparrow et al., 2005).

The Vineland-II was standardized on males and females ranging from birth to 90 years old and of various race/ethnicity, socioeconomic status, and geographic region (Sparrow et al., 2005). Furthermore, the Vineland-II gathered data from specific clinical groups in order to identify deficits in adaptive behavior, such as "attention- deficit/hyperactivity disorder, autism-nonverbal, autism- verbal, emotional or behavioral disturbances," etc. (Sparrow et al., 2005, p. 91).

The internal consistency reliability calculated for the Vineland-II, interview form and rating scale form, utilized the split-half method. Overall, the Vineland-II subdomain has a "reliability estimate … subdomain reliabilities", using the Spearman-Brown Prophecy, indicate more than half are 0.90 or greater, and only six are below 0.80" (Sparrow et al., 2005, p. 95).

The Gilliam Autism Rating Scale-3 (GARS-3; Gilliam, 2006) is a commonly used independent indirect diagnostic tool. The GARS-3 is a 56-item rating scale that can be completed by a parent, teacher, or clinician. The GARS-3 has been shown to have good internal consistency, test-retest reliability, and inter-rater reliability.

The Baby and Infant Screen for aUtistIc Traits (BISCUIT; Matson, Boisjoli, & Wilkins, 2007) is an informant-based behavior checklist that assesses ASD symptoms in children 17–37 months of age. In addition to screening for ASD traits and symptoms, the BISCUIT contains subscales that assess for comorbid symptomology, as well as challenging behavior. The BISCUIT has strong demonstrated reliability and validity (Matson et al., 2009).

Directly Administered Measures

Indirect measures that are conducted between the examiner and a respondent exist for assessing a large variety of areas of functioning. Since these measures are administered and led by the examiner, the duration of time spent may be longer than with independent measures, as the examiner may pose further questions to clarify responses or if the respondent requires an explanation of questions they are being asked. In addition, many of these measures are simply more comprehensive and therefore require more time to administer, as well as more prior training and experience on the part of the examiner.

The Autism Diagnostic Interview-Revised (ADI-R; Lord, Rutter, & Le Couteur, 1994) is considered a "gold standard" assessment tool and is a 93-item standardized, semi-structured interview that is designed to assess for potential ASD diagnosis. The ADI-R can be used with children with a mental age of at least 2 years. Administration takes 90–150 min, including scoring time. The assessment produces categorical scores in three domains: (1) Language/Communication, (2) Reciprocal Social Interactions, and (3) Repetitive Behaviors/Interests. The ADI-R has been found to have good reliability and validity (Lord et al., 1994). Advantages of the ADI-R include the fact that it is highly detailed and widely respected. A disadvantage is that it is time-consuming and requires advanced training to administer.

Indirect Functional Assessments

A variety of structured, examiner-administered indirect functional assessments have been developed and researched. All indirect functional assessments probe knowledgeable caregivers for information regarding the common antecedents and consequences of the challenging behavior.

For example, the Questions About Behavioral Function (QABF; Matson, Bamburg, Cherry, & Paclawskyj, 1999) consists of 25 questions that caregivers rate in terms of frequency, by answering a Likert-type scale of "never," "rarely," "some," or "often." The QABF yields results that suggest one or more of the following potential functions: attention, escape, tangible, physical, and nonsocial. The QABF has been shown to have good psychometric properties, including good validity (Matson et al., 1999), test-retest reliability (Paclawskyj, Matson, Rush, Smalls, & Vollmer, 2000), inter-rater reliability (Nicholson, Konstantinidi, & Furniss, 2006), internal consistency (Shogren & Rojahn, 2003), and convergent validity with experimental functional analyses (Tarbox et al., 2009).

Indirect functional assessments enjoy many of the same strengths as diagnostic and other indirect assessments. For example, they are generally the lowest cost, both in terms of time and financial resources. They are entirely safe, in that they do not require direct contact with challenging behavior. Finally, they are often the only viable choice for bringing functional assessment to scale in the broader community. For all of these reasons, indirect functional assessments have become a standard part of a best practices approach to functional assessment of challenging behavior in individuals with ASD.

Despite their many strengths, indirect functional assessments, like other indirect assessments, also suffer from a number of weaknesses. First, they depend on the recall capability of the caregivers who answer the questions on the assessment. Caregiver recall can be inaccurate, exaggerated, or unreliable. Second, since the clinician does not directly observe the behavior and the environment in which it occurs, many relevant variables may be missed, that otherwise might be apparent from direct observation. Finally, even at best, the relations that indirect assessments suggest between behavior and environmental variables are only correlational. Even if caregiver recall was perfect, merely noting that a particular consequence frequently follows behavior (e.g., attention) does not guarantee that attention is the maintaining consequence of the behavior. It is common for caregivers to reprimand individuals when they engage in challenging behavior, so it is quite common for attention to be the most common consequence of challenging behavior, even when attention is in no way relevant to maintaining the behavior. For all of these reasons, best practices generally suggest that indirect functional assessments be supplemented with descriptive and experimental analyses, which will be discussed later in the chapter.

Direct Assessments

Direct assessments are standardized tools conducted with the client and are used to measure an array of functioning (e.g., cognitive, language, achievement, executive functioning, etc.). Direct assessments provide an opportunity for the examiner to observe and document the client's performance in specified areas of functioning, as well as behavior toward test—taking and compliance in a novel situation, with a novel individual. Direct assessments vary in the degree of structure and demand placed on the client. For instance, some direct measures require a client to sit at a table with the examiner for a specific duration of time (e.g., WISC-IV), while others include more naturalistic efforts (e.g., ADOS-2; Lord, Rutter, DiLavore, & Risi, 2008).

Semi-Structured Administrations

Semi-structured direct assessments involve procedures that specify some part of the interaction between the clinician and client but do not structure the entire interaction. A classic example in diagnostic assessment is the Autism Diagnostic Observation Scale, Second Edition (ADOS-2; Lord et al., 2008). The ADOS-2 consists a "gold standard" diagnostic assessment and consists of a semi-structured direct assessment, wherein the assessor and client engage in scenarios that assess communication, social interaction, play, and restricted repetitive behaviors. Scenarios are conducted in a standardized manner and a standardized scoring rubric is used to score the client's responses. Five different modules of scenarios are available for the assessor to implement,

depending on the age and communication level of the client. The time required to administer the ADOS-2 ranges from 40 to 60 min. Advantages of the ADOS-2 include that it is widely respected and that directly observing the client engage in social interactions helps give the clinician information that they may miss when only interviewing caregivers. A major disadvantage is that extensive training is required to administer the ADOS-2 in a reliable manner.

Structured Administrations

Structured assessments are more commonly used than semi-structured ones and comprise much of an assessment battery, be it developmental, cognitive, or other. Among the most commonly used structured assessments is the Wechsler series of intelligence tests. The Wechsler Preschool and Primary Scale of Intelligence, Third Edition (WPPSI-III; Wechsler, 2002), is a test of cognitive ability for children ages 2:6–7:7. The test requires 30–60 min to administer, depending on age, and yields full-scale IQ scores, as well as primary and ancillary index scores. The Wechsler Intelligence Scale for Children, Fourth Edition (WISC-IV; Wechsler, 2003) is designed for older individuals, ages 6 through 16. The WISC-IV requires 60–90 min to administer and yields full-scale IQ scores, index scores, and subtest scaled scores. Both Wechsler tests are very widely respected and have well-established psychometrics.

Direct Descriptive Functional Assessment Methods

A variety of direct functional assessment methods are commonly used to assess the challenging behavior of individuals with ASD. Since space does not permit an exhaustive review of the various methods, we will briefly discuss the most common two types: structured and unstructured antecedent-behavior-consequence recording (ABC recording). In both types of ABC recording, the clinician observes the client in his/her natural environment and, each time the target challenging behavior occurs, the clinician records the antecedents and consequences of the behavior. It is important for the clinician to observe the client across a variety of settings in which the challenging behavior is likely. It is also important for the clinician to observe the client across a variety of settings that allow for the opportunity of behaviors of various functions to occur. For example, if the client is always receiving large amounts of attention during the observation, attention-maintained behavior may never occur, and therefore, attention may not be identified as a function, yielding a potential false-negative result for attention. Similarly, if the client is never asked to complete non-preferred task demands during the observation, it is unlikely that he/she will engage in escape-maintained behavior, and therefore, escape would likely not be identified as a function, again potentially yielding a false-negative result for escape.

In unstructured ABC recording, the clinician records narrative data of the antecedents and consequences. When the observation is complete, the narrative data are then coded in terms of the categories of antecedents and consequences that they indicate and the data are summarized, according to function. In structured ABC recording, the clinician uses a datasheet that contains prespecified categories for antecedents and consequences and he/she indicates all categories that were observed each time the target behavior occurs. Table 2.1 is a sample structured ABC recording datasheet.

Unstructured ABC data have the advantage of allowing the clinician to record anything that might be relevant and to then analyze the relevance of each detail later. Disadvantages of unstructured ABC data are that it can be time-consuming and effortful to write the narrative and it may not be possible to write fast enough when observing particularly high-rate behavior. In addition, the necessity for interpreting the narrative after the observation introduces an additional source of potential subjectivity in the process. Structured ABC recording enjoys the advantages of being faster and easier to record in the moment and being relatively less subjective. A disadvantage is that the prespecified categories on the datasheet may fail to capture all relevant variables that the clinician observes. However, the clinician can always jot down any other anecdotes in the margin of the datasheet or

Table 2.1 Sample structured antecedent-behavior-consequence (ABC) recording datasheet. The clinician uses structured categories to record behaviors, as well as events that occur immediately before and after them.

Antecedents:
LA = Low attention, Dem = Demand given, Tang = Preferred item removed, None = None of the above
Behaviors:
(1) _____ (2) _____ (3) _____ (4)_____
Consequences:
Att = Attention given, Esc = Escape given, Tang = Preferred item given, None = No consequence

Antecedent	Behavior	Consequence
LA/Dem/Tang/None	1/2/3/4	Att/Esc/Tang/None
LA/Dem/Tang/None	1/2/3/4	Att/Esc/Tang/None
LA/Dem/Tang/None	1/2/3/4	Att/Esc/Tang/None
LA/Dem/Tang/None	1/2/3/4	Att/Esc/Tang/None
LA/Dem/Tang/None	1/2/3/4	Att/Esc/Tang/None
LA/Dem/Tang/None	1/2/3/4	Att/Esc/Tang/None
LA/Dem/Tang/None	1/2/3/4	Att/Esc/Tang/None

in a section of the datasheet that is designed for additional comments.

Regardless of whether data are collected via structured or unstructured ABC recording, the clinician must then summarize the data and interpret the results according to function. It is worth keeping in mind that, as discussed in the section on indirect functional assessments above, the vast majority of research has shown that more than 90 % of challenging behaviors displayed by individuals with developmental disabilities are maintained by attention, escape, tangible, automatic reinforcement, or some combination. Therefore, it is prudent for the clinician to look for these potential functions first, before becoming overly creative with potential interpretations of the descriptive data.

Direct descriptive functional assessments have several strengths and limitations worth noting. One strength is that they allow the clinician to directly observe behavior, so it is possible that he/she will identify important environmental variables that would be missed in an indirect assessment. Another strength is that they are relatively easy to implement and only require sound observational data collection procedures. Finally, a strength of descriptive assessments is that they are safe, in that the clinician need not interact with the individual engaging in challenging behavior, they need only observe. Like any other assessment, descriptive assessments also suffer from limitations. First, like indirect assessments, the information they produce is only correlational. It is possible that the relations observed between behavior and environment during the assessment are mere correlation and do not actually point to the maintaining variables for the behavior. Perhaps the most concerning limitation is that several studies have shown that a large proportion of descriptive assessments produce either invalid or inconclusive results (Lerman & Iwata, 1993; Tarbox et al., 2009).

Experimental Functional Analyses

In particularly severe or perplexing cases, or when indirect and descriptive functional assessments produce inconclusive results, best practices often call for simpler functional assessments to be supplemented by experimental functional analyses (EFA; Iwata, Dorsey, Slifer, Bauman, & Richman, 1982). An EFA is a procedure where antecedents and consequences for challenging behavior are intentionally manipulated to determine which antecedents reliably evoke the behavior and which consequences reliably reinforce the behavior. The classic procedure involves randomly alternating five analogue conditions: (1) attention, (2) escape, (3) tangible, (4) alone or no interaction, and (5) a control or play condition. Each of the first four experimental conditions test one putative function of challenging behavior by setting up antecedent conditions that

Table 2.2 Conditions of an experimental functional analysis for challenging behavior

Condition name	Potential function	Antecedent	Consequence for challenging behavior
Attention	Social attention	Pay no attention to client	Brief social attention
Escape	Escape from or avoidance of demands	High rates of low-preferred task demands	30-s break from task demands
Tangible	Access to preferred items of activities	Denied access to preferred items or activities	30-s access to preferred items or activities
Alone/ no interaction	Automatic reinforcement/ self-stimulation	No items or activities, no demands, no social contact	None
Play/control	N/A	High attention, no demands, continuous access to preferred items and activities	None
	Serves as a control for other conditions		

are likely to evoke the behavior, if indeed it has that particular function, and consequences that are likely to reinforce the behavior, if indeed it has that particular function. The fifth condition serves as a control condition, wherein none of the antecedents are in place and none of the consequences are delivered. Table 2.2 depicts the conditions and the antecedents and consequences that are presented in each. Sessions of each condition are repeated in a random order until differentiation in the rate of challenging behavior between conditions is observed or until it becomes apparent that the analysis is not producing interpretable results.

Experimental functional analyses have several advantages. First, substantial research has shown that they produce interpretable results in a large percentage of cases. For example, a large-scale review of research on EFAs found that 95.9 % of EFAs produce differentiated results (Hanley et al., 2003). However, it should be noted that this was a review of EFAs published in research, not a review EFAs actually done in real-life settings, so it is possible that the actual real-life success rate of EFAs is lower. A significant disadvantage of EFAs is that they require specialized training to administer and very few clinicians are available who possess that training. Even among Board Certified Behavior Analysts, the population of clinicians who possess the greatest training and expertise in functional assessment, only a very small minority possess the skills to safely and validly conduct EFAs. The unfortunate result is that EFAs are very rarely done in real clinical practice, despite their being considered the "gold standard" for functional assessment in research.

Clinical Judgment in the Assessment Process

As has been discussed throughout this chapter, clinicians use a wide variety of tools and procedures when assessing an individual with ASD. Some tools and procedures have come to be referred to as "gold standard" procedures. For example, the ADOS and ADI-R are often referred to as gold standard diagnostic procedures. Similarly, EFAs are often referred to as gold standard functional assessment procedures. However, in both diagnostic and functional assessments, it is worth noting that gold standard procedures tend to be more costly and labor intensive and require specialized training that a very small percentage of the population of clinicians possess. Even when a clinician does possess the resources and expertise required to implement gold standard procedures, it is critical to remember that no one modality or instrument is more valuable than clinical judgment. It is important to remember that results from any one modality (e.g., cognitive evaluation, diagnostic observation, functional assessment, etc.) comprise only a single component of the full evaluation process. For example, results of a single measure may indicate strengths and weaknesses in domains of intellectual functioning, but not account for possible delays in the realm of social development or

compensatory adaptive skills. While findings may provide insight to a particular observed behavior, they may be based on a limited sample of time or a novel setting. Parental endorsements may suggest a high or low frequency of a behavior in one setting that is not observed as generalizing to other settings. Similarly, even though an EFA is likely to produce the most reliable and valid functional assessment results, it is, by definition, analogue and contrived and therefore may produce behavior that occurs in reaction to clinician-contrived circumstances, rather than behavior that is representative of the client's real behavior in everyday life. Although little or no research has demonstrated it, it is hypothetically possible to "shape up" a new function for challenging behavior that was never before present, merely by systematically giving a particular consequence for a behavior during an EFA. Put differently, it is possible that a client may actually learn for the first time that a particular challenging behavior can earn him/her access to preferred items or activities.

Overall, no measure should be considered in isolation for the purpose of diagnosis or determining eligibility for services. In addition, measures should be evaluated and interpreted against one another in the evaluation process. A caregiver report should be evaluated against the clinician's direct observation and subsequent findings. It is clinical judgment that incorporates the individual modalities of testing together and produces a cohesive evaluation. Clinical opinion is invaluable in the diagnosis of ASD and functional assessment of challenging behavior and cannot be substituted, only strengthened, with carefully considered and administered measures of development, cognition, language, and executive functioning; diagnostic observations and structured interviews; surveys, questionnaires, and inventories related to social skills, behavioral, emotional, and adaptive functioning; review of psychological and medical records; functional assessment tools; and detailed histories obtained by caregivers and teachers. Furthermore, a clinician has the ability to draw from the findings of one measure to inform his/her decision to administer additional measures as he/she attempts to answer the referral question. During the interpretation of data, an individual's test performance in one domain of functioning can assist in the understanding of another domain. More specifically, a clinician can utilize an individual's performance in the areas of cognition and language to support his/her interpretation of that individual's functioning in the areas of social and communication abilities (Lord et al., 2012).

Behavioral Observations Impacting Interpretations

The behavioral observation section of an ASD evaluation focuses on the behaviors witnessed throughout the testing session(s). The behaviors exhibited by the client are described in an objective manner and can support the clinical judgment of the clinician in his/her determination or ruling out of a diagnosis. Often, the behaviors described in the behavioral observation section will be referenced in subsequent areas of the report, including the summary and diagnostic section, in which in vivo observations in combination with parent interview and behavioral questionnaires play a large role in supporting diagnostic criteria.

Observations to be Considered

- Effort
- Basic sustained attention
- Cooperation
- Speech—volume, intonation, articulation, rhythm
- Frustration tolerance
- Compliance
- Rapport
- Handedness, pencil grip
- Restless motor behaviors
- Balance/Gait
- Vision and hearing

Observations Prevalent in ASD

- Speech (e.g., one-word labels, 3–4 word phrases, fluent speech), topic flexibility
- Eye contact
- Distractibility
- Toleration of task demands
- Task initiation
- Perseveration/Rigidity
- Repetitive and stereotyped behaviors
- Self-monitoring/Self-correcting
- Transitioning between tasks

Assessment Results Versus Actual Everyday Functioning

When completing any assessment, be it diagnostic, functional, or otherwise, it is critical to consider that the client may perform different in structured assessment situations than he/she does in the course of his/her everyday life. There are many variables that may result in performance under testing conditions diverging from everyday performance. First, controlled assessment environments generally have less distractions and extraneous stimuli than real life. Particularly since many individuals with ASD have difficulty with complex, overstimulating environments, the quiet assessment environment may produce performance that is higher than that which actually occurs in real life. However, the demands of test-taking situations may have the opposite effect for some individuals with ASD. For example, some individuals may be frightened by novel environments or novel clinicians. In addition, individuals with ASD who have difficulty with language may score lower on a test that is highly verbal than what their true functioning ability may be in real life, where ample, nonvocal cues and feedback may be available. In the case of EFAs, if the assessment is conducted in a novel, empty room, with an unfamiliar clinician and no parents present, novel challenging behaviors may be evoked, such as those aimed at escaping the room. Such behaviors may appear severe to the clinician but may not actually represent the real challenging behaviors displayed by the individual in their daily life. It is of course not possible to determine a priori all of the variables that may enhance or worsen client performance under assessment conditions. Rather, it is important for clinicians to remain apprised of the potential for such problems and so supplement structured testing conditions with thorough caregiver interview and observations in the natural environment.

Progression Through Assessment Process

Each assessor and each clinic possesses traditions and preferences regarding how to progress through the entire assessment process. Each purpose for assessment will also largely dictate how the clinician progresses through the assessment process. For example, if the only purpose of assessment is to identify a diagnosis, then primarily diagnostic assessments may be administered, with other areas of functioning done in a supporting manner. However, if the purpose of assessment is to confirm diagnosis and conduct a comprehensive workup of a child's overall development and functioning, for example, then a much larger battery of assessments will likely be done. Finally, if the purpose of assessment is only to identify the function of a single challenging behavior, then the process will be much narrower and focus almost exclusively on functional assessments.

Regardless of the purpose of assessment, some clinicians resort immediately to effortful, time-consuming, costly assessment batteries, while others may attempt to use only low-cost, rapid methods. We suggest a third route, that is, progressing gradually from less to more intrusive, depending on the purpose of assessment and on the ongoing data produced during the assessment process. For example, when diagnosing a child with autism, an experienced diagnostician may find that, in some cases, merely conducting a thorough interview and completing one or two indirect diagnostic tools with the child's parent, plus a brief in-person observation of the client in the clinician's office, may suffice to confirm an ASD diagnosis and rule out other possible diagnoses.

However, in cases where these low-cost, rapid approaches do not yield conclusive results, something requiring more time and expertise, such as an ADOS, may be needed. Finally, conducting a lengthy and costly structured interview, such as the ADI-R, may be needed in cases that are not entirely clear. All of these options may well need to be supplemented by observing the client in their natural environment.

Taking a least-to-most intrusive and costly approach is also common in functional assessment of challenging behavior. In relatively straightforward and less severe cases, a simple interview with caregivers and completion of an indirect assessment, such as the QABF, might suffice to produce a clear hypothesis regarding behavioral function. If this is the case, the clinician might be wise to move directly to a rapid treatment analysis to confirm the results of the assessment. In cases where indirect assessments produce inconclusive or conflicting results and/or in cases where the behavior is of sufficient severity, progressing to a descriptive functional assessment is often warranted. Furthermore, when a descriptive assessment does not produce conclusive results, progressing to an EFA may be warranted. Another occasion upon which an EFA may be warranted is when treatments have been attempted on the basis of the results of indirect or descriptive functional assessments and the treatments have failed, suggesting that the results of those assessments may have been incorrect or incomplete. Interestingly, although EFAs are generally considered more labor intensive and time-consuming than descriptive assessments, that is not always the case. For example, Tarbox et al. (2009) spent approximately the same amount of time on ABC and EFA assessments and found that EFAs produced interpretable results in 100 % of cases, whereas ABC assessments produced interpretable results in only 57 % of cases. Therefore, at least in that study, EFAs were arguably more efficient and less costly than descriptive assessments because they required about the same amount of time but produced conclusive results, whereas almost half of the descriptive assessments still required additional assessment to be done afterward, in order to produce interpretable results.

Although ample research has demonstrated the utility of EFAs, the current reality is that very few clinicians are actually trained to conduct them. Therefore, the vast majority of behavior analysts, psychologists, and school districts simply are not equipped to conduct EFAs and therefore conduct only indirect and descriptive functional assessments. In these cases, the choice of indirect and descriptive is not based on a rational clinical decision making process, it is the only choice available.

Troubleshooting

No matter how experienced the clinician or how well-validated the assessment tools are, mistakes can happen and, even in the absence of any mistakes, some amount of inconsistency between and within various assessments is possible. Therefore, when interpreting the results of assessments, it is often necessary for clinicians to engage in various troubleshooting strategies. One important option is to reinitiate contact with caregivers to ask for additional follow-up information that may serve to clarify information and/or help to resolve inconsistencies in how the assessment data can be interpreted. In addition to following up with caregivers, conducting additional naturalistic observations is always a good option. In reality, traveling to the client's natural environment to observe again may be prohibitively expensive or time-consuming but there is often no substitute for the wealth of information that direct observation in the natural environment can provide. Finally, no matter how well trained and experienced a clinician may be, he/she will someday encounter a client for whom the clinician does not possess all the needed skills to complete the assessment satisfactorily. In cases such as these, the clinician has an ethical responsibility to either seek consultation from colleagues or refer the client out to another clinician who has a greater degree of competence in the particular specialty the client requires.

Additional Considerations

While taking a multifaceted approach to ASD evaluation (e.g., clinical interview, clinical observation of the child in a natural environment, indirect questionnaires, standardized testing, reviewing of previous test records) is preferred and may be regarded as "best practice," the clinician ought to be thoughtful about how many and which direct measures to administer. When previous test records are available, the clinician is encouraged to minimally review the types of tests that the child was given in order to safeguard against practice effect and, in contrast, may consider the entire report at the clinician's discretion. For example, it is commonly agreed upon that most IQ tests should not be readministered within a year because of practice effects. However, IQ scores are often used for diagnostic and treatment intervention purposes, in which case, the clinician must exercise caution when choosing when to readminister such tests. Some authors suggest using a different intelligence test and then compare the results from both tests (Prifitera, Weiss, & Saklofske, 1998). Some clinicians prefer to approach the evaluation with a blank state, thus, form their own hypothesis about the client's presenting concerns. Nonetheless, being fully aware of all assessment that has been done in the past allows the clinician to fully appreciate the client's diagnostic profile and would typically help enhance the diagnostic formulation.

Evaluating Adults with Suspected ASD

Due to increased public awareness of ASD within the past decade, more adult clients are self-referred to clinicians for an evaluation of ASD. These clients typically present with a complex clinical picture. They may seek a differential diagnosis of higher-functioning autism or they may experience social and behavioral difficulties due to other mental health conditions. Many of them are reportedly higher functioning and were able to navigate academic, vocational, and social demands in their primary years until those demands exceeded their personal resources to cope. Others sought an ASD evaluation in search for an answer to the challenges confronting them in various arenas of life that are not better accounted for by other mental health conditions such as depression, anxiety, attention-deficit hyperactivity disorder, and so on.

In order to qualify for an ASD diagnosis per the *Diagnostic and Statistical Manual of Mental Disorders* (DSM-5), one of the criteria is that "symptoms must be present in the early developmental period." For clinicians, establishing that the symptoms were present in the early developmental period for an adult client can be a highly challenging task. Establishing a developmental history relies upon gathering information from the client's caregivers. Instruments such as the ADI-R can be excellent tools for such use and are widely used by clinicians. However, such an interview with caregivers may be unobtainable due to practical reasons such as the caregiver not being available to participate in the evaluation either by choice or by circumstance (e.g., caregivers are deceased).

Other Considerations That Dictate Types of Assessments

ASD evaluation is a multifaceted process and there are many additional factors that may affect the assessment process. Ultimately, it is the clinician's responsibility to select the appropriate measures for the client while being cognizant of the client's culture, language, mobility, education, and so on. Funding source is another factor that may influence the type of test the clinician employs. In an ideal world, the choice of assessments would be dictated solely by what is deemed best clinical practices. In the real world, third-party funding agencies may require certain assessments to determine eligibility for initial or continued treatment funding, even when those assessments are not the best options clinically. In other cases, third-party funding agencies may provide insufficient funding to cover a sufficiently comprehensive battery of assessments. In such cases, the clinician is left with the unfortunate

choice of doing what they deem to be clinically necessary and not billing for the cost overruns, or attempting to conduct a clinically adequate evaluation in a shorter-than-ideal amount of time.

Technological Advances

The future of psychological assessment in general and ASD evaluation more specifically is going to evolve in parallel with advances in technology such as computerized assessment and long-distance service delivery through telehealth. Computerized assessment is predicted to help increase test administration efficiency. For example, computer programs may be able to generate specific test items utilizing a complex decision rule, thus, eliminating unnecessary items (Lichtenberger, 2006). It will also help immediately score each item, hence enabling the clinician to attend better to relevant factors such as client's dynamics (e.g., test-taking behaviors, pattern of responses, reaction to specific type of task, reaction to the examiner). Leading test publishing companies such as Pearson have launched Q-interactive, making numerous tests available through the iPad. This may be a welcome frontier given that current and future generations grow up with increased familiarity, access, and affinity for computers and tablets. Research will be needed to identify the ways in which technological advances make assessment of individuals with ASD more reliable, valid, and efficient.

Conclusion

Assessing individuals with ASD is a complex process that is affected by myriad variables. Among the most important variables is the choice of type and format of assessment tools and procedures to include in the overall assessment process. This chapter has provided a broad overview of the most common types of assessment, with discussions of strengths and limitations of each type, as well as illustrative examples of each type of assessment that have been found to have good psychometric properties, as well as being useful in clinical practice. Overall, it is generally the case that less structured, indirect assessments tend to be less costly, more efficient, and more flexible, but less valid and reliable. More structured, "gold standard" assessments tend to be more reliable, more valid, but require a large amount of training and experience that most clinicians simply do not possess. In the end, the strengths and limitations of each type of assessment must be weighed against one another when creating an individualized, customized evaluation for each individual with ASD, and it is important to keep in mind that no amount of standardization or professional consensus will ever supplant the critical role of clinical judgment in the assessment process.

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Purposes of Assessment

3

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The purpose of this chapter is to provide information to individuals involved in the assessment of autism spectrum disorder (ASD). The assessment process can serve a variety of purposes, and there are a number of important concepts involved in the assessment of ASD. These concepts include the surveillance of symptoms to identify children who may be at risk, screening when concerns are raised in the surveillance process, comprehensive diagnostic evaluations for ASD, determination of co-occurring disorders, and identifying areas for intervention. This chapter will provide an overview of each of these constructs, which will provide discussion of specific strategies and implications for enhancing service and care to children with ASD and their families.

Autism Spectrum Disorders

Autism spectrum disorder is a neurodevelopmental disorder that affects individuals across their lifespan. The core symptoms of ASD are often present in early development and include deficits in social communication and restricted and repetitive patterns of behavior. Although these symptoms are common among individuals diagnosed with ASD, the presentation of symptoms and prognoses are diverse, varying from one individual to the next. The behavioral symptoms characteristic of ASD typically becomes apparent between ages 1 and 2 (Courchesne et al., 2007; Kozlowski, Matson, Horovitz, Worley, & Neal, 2011), and it is broadly agreed that developmental deficits in communication and social behavior in children with ASD can be observed towards the second year of life, if not sooner (McConnell, 2002; Webster, Feiler, & Webster, 2003; Woods & Wetherby, 2003). Deficits in nonverbal social communication, lack of social or emotional reciprocity, and speech/language delays are the most prevalent diagnostic characteristics for children under 3 years of age (Stone et al., 1999). The current prevalence rates from the Center for Disease Control and Prevention estimate that one in every 68 eight-year-old children is diagnosed with ASD, with rates of diagnosis approximately four to five times higher in males than females. The median age of earliest diagnosis is 4 years, 5 months of age, which does not differ by sex or race/ethnicity (Autism and Developmental Disabilities Monitoring Network Surveillance Year 2008 Principal Investigators, 2012). Cognitive levels vary widely among children with ASD and have been identified as an early predictor of later outcomes (Ben Itzchak & Zachor, 2007). There are currently no definitive medical

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tests to diagnose ASD, and diagnostic criteria rely on the presence of certain behaviors and the absence of others. The cause of ASD remains unknown. Despite the fact that ASD has a high heritability component, science has yet to understand the complexity of the genetics involved.

Surveillance

In the United States, the current prevalence of children receiving a diagnosis of a developmental disability (e.g., attention-deficit/hyperactivity disorder, ASD, cerebral palsy, learning disability, intellectual disability) is one in six, which suggests that developmental disabilities are relatively common (Boyle et al. 2011). While there is some debate that the rising prevalence of ASD is due to recent changes in diagnostic criterion rather than an actual increase in prevalence (Hansen, Schendel, & Parner, 2015), it is clear that the development of all children should be monitored, with screening and evaluation occurring as soon as developmental delays are suspected. Although children can be diagnosed with ASD as early as 2 years old, most children do not receive a diagnosis of ASD until almost two and a half years later (Autism and Developmental Disabilities Monitoring Network Surveillance Year 2010 Principal Investigators, 2014). As such, surveillance, "the ongoing process of identifying children who may be at risk of developmental delays" (Bright Futures Steering Committee, & Medical Home Initiatives for Children With Special Needs Project Advisory Committee, 2006, p. 406) is an essential component in the care of all young children. Possible desired outcomes of developmental surveillance include triaging referrals based on data collected, providing families with necessary education to support on-target development, and determining the effectiveness of surveillance efforts through early intervention and treatment (Bright Futures Steering Committee and Medical Home Initiatives for Children with Special Needs Project Advisory Committee).

In order to conduct developmental surveillance, it is important to have an appropriate fund of knowledge related to early symptoms associated with ASD. Common early signs and symptoms of ASD that are well established in preschool-aged children include lack of social gaze, delayed motor imitation, deficits in joint attention skills, atypical object use, and the presence of repetitive behaviors (McConnell, 2002; Stone, Coonrod, & Ousley, 2000; Webster et al., 2003; Woods & Wetherby, 2003). However, one barrier to effectively identifying these deficits in social communication is the lack of established developmental milestones related to these skills, which further underscores the importance for healthcare providers to be knowledgeable of these early ASD symptoms (Ibanez, Stone, & Coonrod, 2014). Further, another challenge in the early identification of skill deficits is that some characteristics of ASD require an absence of behaviors expected for a child's developmental level, which can be hard to determine. While a child may display social communication behaviors, he or she may not perform them with the same consistency or ease that would be expected based on their developmental level (Ibanez et al., 2014). Early symptoms of ASD will be discussed in more detail later in this chapter; in general, healthcare providers need to be well informed about typical and atypical developmental progression in order to be effective in conducting developmental surveillance.

According to Johnson and Myers (2007), the medical home represents an important setting for surveillance and screening for ASD and other developmental disorders. More specifically, a discussion of developmental concerns is a necessary component of all well-child appointments until a child is 5 years old (Bright Futures Steering Committee, & Medical Home Initiatives for Children With Special Needs Project Advisory Committee, 2006). Taken together, developmental surveillance should encompass both concerns expressed by parents and healthcare professionals in determining if a child is at risk for developmental delays. The following components should be encompassed as part of general developmental surveillance: "eliciting and attending to the parents' concerns; maintaining a developmental history; making accurate and informed observations of child; identifying the presence for risk and protective factors; and documenting the process

and findings" (Johnson & Myers, 2007, p. 1195). In obtaining information regarding the child's progress from parents, healthcare professionals are encouraged to ask about the child's development, learning, and behavior. Glascoe (2000) indicted that using parents as informants is an efficient, effective, and accurate way to aid in comprehensive developmental surveillance. Further, as part of maintaining a developmental history, healthcare providers must ask specific questions regarding age-appropriate milestones to determine if a child's development is delayed or advanced or presents with any regression in development (Bright Futures Steering Committee and Medical Home Initiatives for Children with Special Needs Project Advisory Committee).

During preventative well-child appointments, healthcare providers should conduct a thorough examination of both physical health and developmental progression (Bright Futures Steering Committee and Medical Home Initiatives for Children with Special Needs Project Advisory Committee, 2006), which also gives the opportunity for the provider to directly observe the child's progress (e.g., engaging the child in conversation could yield information regarding social interaction skills and language development). Another key component of developmental monitoring is determining the presence of both risk (e.g., environmental, genetic, demographic) and protective factors (e.g., supportive family, opportunities to interact with same-age peers; Bright Futures Steering Committee and Medical Home Initiatives for Children with Special Needs Project Advisory Committee). Finally, healthcare providers must ensure that surveillance activities, along with any specific plans completed or expected (e.g., scheduling an earlier follow-up appointment, referral to early childhood specialist), are carefully documented in the child's medical chart.

Surveillance for ASD

Within the framework of general developmental surveillance, Johnson and Myers (2007) highlight additional components specific to ASD. Specifically, in obtaining additional information regarding risk factors, they suggest asking parents if there is a family history of ASD—in particular, if the child has a sibling diagnosed with an ASD, which increases the risk tenfold for the child of having symptoms of ASD. Further, healthcare providers are encouraged to ask open-ended questions regarding the child's behavior and development including age-specific developmental milestone questions related to early symptoms of ASD (e.g., verbal and nonverbal communication, reciprocal social interaction, or pretend play skills; Johnson & Myers, 2007). In particular, the American Academy of Neurology (2000) has developed practice parameters regarding the screening and diagnosis of ASD. As such, if a parent or healthcare provider endorse or observe any of the following, the child should be referred for an immediate ASD evaluation:"no babbling by 12 months; gesturing (e.g., pointing, waving bye-bye) by 12 months; single words by 16 months; two-word spontaneous (not just echolalic) phrases by 24 months; loss of any language or social skills at any age." (American Academy of Neurology, p. 471)During the context of the well-child visit, the healthcare provider may interact and directly assess the child's attainment of specific developmental skills. For example, at a 12-month visit, the healthcare provider could observe the child's responsiveness to his or her name being called (Johnson & Myers, 2007). In a typically developing child, the healthcare provider would expect the child to orient to him or her and engage in eye contact. However, in a child presenting with symptoms of ASD, he or she may appear oblivious to the healthcare provider's statement (e.g., does not look at healthcare provider or reference his or her caregiver for guidance as to how to respond) even with repeated attempts by the healthcare provider to obtain the child's attention through calling his or her name. Accordingly, information observed and obtained by the healthcare provider, as well as concerns shared by caregivers in the context of this preventative well-child visit, should drive the follow-up plan of care developed. Developmental surveillance differs from developmental screening in that surveillance is an ongoing process of monitoring development, while screening may result as a consequence of surveillance.

Screening

Screening is defined as "the prospective identification of unrecognized disorder by the application of specific tests or examinations" (Baird et al., 2001, p. 468). The basic process of screening involves the administration of a screening instrument or procedure to a large group of individuals, which is subsequently followed by a "gold standard" instrument or diagnostic method when the screen is positive. Screening is built on the notion that earlier identification and diagnosis of previously undetected problems will result in improved outcomes for individuals with various disorders and disabilities. Early screening for ASD has garnered considerable attention, due to consensus that children with ASD identified and enrolled in early intervention programming evince improved outcomes. The importance of screening for ASD has been emphasized in guidelines published by the American Academy of Pediatrics (AAP), which recommend ASD screening for 18- and 24-month-olds (Johnson & Myers, 2007).

The overall goal of screening is to identify individuals from otherwise healthy populations who may be deemed at risk for the presence of disorder. It is important to understand that screeners do not yield diagnostic decisions, but rather indicate whether an individual may be at risk for a disorder. The general goal of screening is to be differentiated from *case finding*, which refers to the detection of disorder in individuals who are diagnosed with another disorder. For example, one may engage in case-finding activities to ascertain the degree of depression within a sample of individuals with intellectual disability.

Screeners are also characterized generally as Level I or Level II depending on the scope of use and purpose of the screener. Level I screeners are measures designed for use within the general population and serve as a first screening point. Level I screeners for ASD are designed for use with all children within a defined population or particular service setting, such as pediatric primary care. As such, Level I screeners should be designed to be convenient to use, inexpensive, easy to administer and score, and completed by persons with minimal levels of expertise (Robins, 2008). Level II screeners are designed to be used with groups of individuals who have already come to the attention of professionals through referral by other means, such as clinical concern or results from a Level I screener. The goal of the Level II screener is to assist in differentiating individuals with ASD from larger groups of individuals with other disorders. A Level II screener is utilized typically within more specialized practice settings, such as developmental pediatrician offices, Child Find screening programs, or diagnostic evaluation centers.

Guidelines for Evaluating Screeners

Ideal screening instruments are those that are brief, inexpensive, and utilized by lay respondents and demonstrate strong psychometric properties. As with any assessment procedure, screening measures should demonstrate evidence of reliability and validity. Screening measures should demonstrate internal consistency reliability and temporal stability reliability; that is, screeners should feature items that share some relationship with one another and produce similar results over test administrations.

Psychometric validation of screeners typically takes the form of criterion-related (or predictive) validity with the screener serving as the predictor and the diagnostic outcome the criterion. As such, the general approach for evaluating the utility of a screener is often undertaken within a "basic epidemiologic screening model" (Derogatis & Lynn, 1999, p. 43). As shown in Table 3.1, the general model crosses the result of the screening measure, either positive or negative, with the results of a "gold standard" diagnostic measure, either positive or negative. The crossing of test results yields a two by two matrix that sorts cases into separate cells corresponding to correct and incorrect screening results. A positive screening result confirmed by accurate identification of disorder is a *true positive*; a negative screening result confirmed by accurate exclusion of disorder is a *true negative*. In contrast, a positive screening result that is disconfirmed via diagnostic evaluation is

Table 3.1 Outcomes for screening decisions and diagnostic decisions

	Diagnostic decision		
		Positive	Negative
Screening result	Positive	True positive (*a*)	**False-positive (Type I error) (*b*)**
	Negative	**False-negative (Type II error) (*c*)**	True negative (*d*)

Note. Sensitivity = $a/(a+c)$; specificity = $d/(b+d)$; positive predictive value = $a/(a+b)$; negative predictive value = $d/(c+d)$; false-negative rate = $c/(a+c)$; false-positive rate = $b/(b+d)$

termed a *false-positive*; a negative screening result that is followed by positive diagnostic test result is termed a *false-negative*.

The basic epidemiologic screening model yields statistical information about various aspects of the accuracy (i.e., validity) of the screener (see Table 3.1). A screener's *overall accuracy* or "hit rate" is the proportion of all children correctly identified by the screener and calculated by summing true positives plus true negatives and dividing by the total number of individuals screened. A screener's *sensitivity* refers to the proportion of individuals correctly detected as having the disorder within a sample and is calculated by dividing the number of true positives by the total number of individuals diagnosed in a sample. A screener's *specificity* refers to the proportion of individuals correctly excluded as not having the disorder within a sample and is calculated by dividing the number of true negatives by the total number of individuals without disorder in a sample.

Two additional pieces of statistical information yielded in the basic screening evaluation model correspond to the value of screening positive or negative. A screener's *positive predictive value* (PPV) refers to the proportion of individuals who screen positive who are identified with the disorder; PPV is calculated by the number of true positives divided by the total number of individuals identified as at risk by the screener. A screener's *negative predictive value* (NPV) refers to the proportion of individuals who screen negative who are excluded from having the disorder; NPV is calculated by the number of true negatives divided by the total number of individuals screening negative. Various guidelines exist in the screening literature regarding what constitutes acceptable levels of overall test accuracy, sensitivity, specificity, PPV, and NPV. For example, Carran and Scott (1992) suggest that sensitivity, specificity, and hit rate values should minimally meet or exceed 0.80.

Screening for ASD

To date, no universal biological (e.g., genetic) or behavioral (e.g., response to name) marker for ASD has been identified that meets all standards of sensitivity, specificity, PPV, and NPV (Barton, Dumont-Mathieu, & Fein, 2012). Until a universal marker has been identified for ASD, a combination of surveillance and screening practices is recommended for detecting ASD in the general population. For children with ASD, parents often identify first concerns about language development within the first 2 years of life. Language delay, however, is not specific to ASD; early social-communicative behaviors consistently predict ASD diagnosis in young children. For example, an early indicator of ASD includes lack of social responsiveness (e.g., child does not respond when name is called). Indeed, early in development, many parents question whether their child may be deaf or have a hearing impairment. Other social-communicative behaviors predictive of ASD diagnosis early in development (i.e., by around 18 months) are lack of response to name, lack of protodeclarative pointing (i.e., pointing out objects for the purpose of sharing interest with others), no pretend play, and poor response to joint attention (e.g., following another's gaze to an object or person of interest). Recommended ASD screeners are those that sample such social-communicative behaviors and play, such as the Modified Checklist for Autism in Toddlers-Revised (MCHAT-R/F; Robins, Fein, & Barton, 2009). The MCHAT-R/F is designed for use with 16–30-month-olds and recommended for ASD screening in primary care.

Chapter 5 of the present volume provides a review of various methods and strategies for screening for ASD using both Level I and Level II screeners. Several general points warrant inclusion in this chapter, however. First, ASD screeners may be incorporated in various service delivery settings, such as primary care and preschools. Second, despite repeated calls for screening within primary care settings, many pediatricians do not routinely screen for ASD according to the recommendations published by the AAP (e.g., Arunyanart et al., 2012). As such, ASD screening efforts will likely need to extend to nontraditional settings and be administered by individuals outside of the traditional parameters of healthcare, such as individuals working in daycare settings. Third, although the focus of this section of the chapter is on young children, older children who show age-appropriate language and cognitive development accompanied by mild ASD symptomatology may not come to clinical attention to service providers early in development. Therefore, surveillance and screening efforts are also appropriate for children in kindergarten and elementary school. Several measures exist for screening older individuals, such as the Social Responsiveness Scale, Second Edition (Constantino & Gruber, 2012). Although the field has yet to identify a universally appropriate screening measure, sound measures and methods exist to identify risk of ASD for younger and older children.

Diagnosis

When concerns are raised in the surveillance and screening process, a comprehensive diagnostic evaluation should be conducted. A diagnosis of ASD is made based on the presence of certain behaviors and the absence of others. The new diagnostic criteria for ASD, as presented in the *Diagnostic and Statistical Manual of Mental Disorders*, *Fifth Edition* (DSM-5; APA, 2013), requires that during the early developmental period, a child demonstrates impairments in social communication and interaction and restricted and repetitive patterns of behaviors. Examples of social communication deficits that may be present include difficulties in social-emotional reciprocity, impaired nonverbal communication skills, and difficulties building and maintaining relationships with others. Restricted and repetitive behaviors (RRBs) that may be observed in individuals who meet criteria for an ASD diagnosis include stereotyped repetitive movements, object use, or speech; rigidity; highly fixated interests; and over or under reaction to sensory input. Although these core symptoms are common behaviors among individuals diagnosed with ASD, as a spectrum disorder, the presentation of symptoms are diverse. Prognoses vary from one child to the next based on the severity of the symptoms displayed. The best indicators of prognosis include cognitive ability (e.g., IQ), joint attention skills by age 4, and functional spoken language by age 5 (Johnson & Myers, 2007).

Early Behavioral Features of ASD

It is widely accepted that early diagnosis of ASD is imperative given the considerable effect early intervention has on later outcomes. The behavioral symptoms characteristic of ASD appears during the early developmental period, typically before age 3 (APA, 2013). Research has indicated that the core impairments associated with ASD are present and identifiable during the second year of life (Pierce, Carter, Weinfield, & Desmond, 2011), if not sooner (Kozlowski et al., 2011). From an early age, children with ASD often exhibit developmental delays in orienting to social stimuli, play skills, motor imitation, and joint attention skills (McConnell, 2002; Stone et al., 2000; Webster et al., 2003; Woods & Wetherby, 2003). Most commonly, parents of children later diagnosed with ASD identified concerns with speech/language development, social responses, and medical concerns within the first 2 years of their child's development (De Giacomo & Fombonne, 1998). A study by Kozlowski et al. (2011) found that delays in communication are not necessarily ASD specific, although parents of children later diagnosed with

ASD noted these concerns significantly earlier in their child's development than parents of children with non-ASD-related developmental delays. Further, there was a significant positive correlation between the age at which parents first noted communication delays and age of evaluation. Thus, parental knowledge of delayed developmental milestones related to communication resulted in their children receiving evaluations at younger ages.

In addition to the social and communication impairments associated with ASD, the importance of RRBs in facilitating early diagnosis has been emphasized as well. More specifically, Kim and Lord (2010) demonstrated diagnostic differences in the prevalence and severity of RRBs among young children with ASD, developmental delays, or typical development. Utilizing semi-structured observation methods to assess for RRBs *and* social and communication deficits has been shown to increase the likelihood of a stable ASD diagnosis over time (Kim & Lord, 2010).

Diagnostic Criteria for ASD

The new diagnostic criteria for ASD provided within the DSM-5 differ significantly from the previous versions of the manual. Likely, the most significant change to DSM-5 is the elimination of the separate diagnostic categories for the subtypes of pervasive developmental disorders (e.g., autistic disorder, Rett's disorder, childhood disintegrative disorder, Asperger's disorder, and pervasive developmental disorder, not otherwise specified (including atypical autism)). Instead, within the neurodevelopmental disorders, the DSM-5 provides a single diagnostic category of ASD.

When comparing the DSM-5 diagnostic criteria for ASD to the DSM-IV-TR (APA, 2000) diagnostic criteria for autistic disorder, there is a notable change to the required age of onset for the disorder. Previously, a child had to display symptoms prior to age 3; DSM-5 requires symptoms be present in the early developmental period. Furthermore, the previous diagnostic criteria for autistic disorder included three domains (i.e., impaired social interaction, impaired communication, and restricted repetitive and stereotyped behaviors). DSM-5 reorganizes the social communication/interaction domain by combining the previous versions social interaction and communication domains and omitting the first DSM-IV-TR criteria for autistic disorder, which required a delay/absence of speech accompanied by failure to compensate. In DSM-5, a child's failure to speak in itself no longer serves as a diagnostic criteria for ASD. In comparison with previous diagnostic criteria for Asperger's disorder, the presence or absence of language delays no longer preclude diagnosis of ASD in any way. Although understanding the role of delayed or disordered language is important in the interpretation of an individual's specific features of ASD, language delays in themselves are not included in the diagnostic criteria of ASD. Another new addition to the diagnosis of ASD is the inclusion of sensory symptoms in the list of illustrative examples provided for repetitive behaviors.

The DSM-5 also includes specifiers for associated features of ASD by individual. This provides information regarding other disorders that may also be present (e.g., intellectual impairment, language impairment) and allows for the diagnosis of ASD in individuals with genetic conditions (e.g., Rett syndrome, fragile X syndrome) or other neurodevelopmental, mental, or behavioral disorders. Thus, the clinician does not have to choose between a genetic descriptor or a behavioral diagnosis, but can apply both when appropriate.

The changes to the diagnostic criteria presented in DSM-5 are not without controversy. Initial research has demonstrated that the DSM-5 diagnostic criterion for ASD results in increased specificity when compared with DSM-IV-TR, which may reduce the number of children who are diagnosed as having ASD when they do not (Frazier et al., 2012). However, there has also been concern that the new criteria may significantly alter the population of individuals diagnosed with ASD moving forward. Research has demonstrated that individuals previously diagnosed with PDD-NOS and Asperger's disorder

are less likely to exceed the diagnostic threshold required to receive an ASD diagnosis per the DSM-5 criteria (McPartland, Reichow, & Volkmar, 2012). Other studies have demonstrated that the prevalence of ASD would decrease only to the extent that the majority of children who no longer meet the diagnostic criteria for ASD would meet criteria for social (pragmatic) communication disorder (SCD), which is a new diagnosis in the DSM-5. A diagnosis of SCD is appropriate for those individuals who demonstrate deficits in the use of verbal and nonverbal communication for social purposes. A diagnosis of SCD differs from ASD in that a diagnosis of ASD requires symptoms related to social communication *and* the presence of restricted, repetitive patterns of behavior, interests, or activities. Before diagnosing SCD, ASD must first be ruled out.

Kim et al. (2014) compared clinical diagnoses made with DSM-IV-TR criteria for subtypes of autistic disorder, Asperger's disorder, and pervasive developmental disorder not otherwise specified (PDD-NOS), to that of DSM-5 diagnostic criteria for ASD and SCD. Overall, results indicated that 83 % of the children who received a diagnosis of autistic disorder using DSM-IV criteria would still receive a diagnosis of ASD using the new DSM-5 criteria. Specific results by diagnostic subtype indicated that, of the children previously diagnosed with autistic disorder, 99 % met criteria for ASD and 1 % met criteria for SCD. Of the children previously diagnosed with Asperger's disorder, 91 % met criteria for ASD, 6 % met criteria for SCD, and the other 3 % were diagnosed with a non-autism spectrum disorder. Regarding children previously diagnosed with PDD-NOS, 71 % met criteria for ASD, 22 % met criteria for SCD, and 7 % were diagnosed with another non-autism spectrum disorder. Thus, the large majority of children previously diagnosed with autistic disorder and Asperger's disorder using the DSM-IV-TR autism subtypes would still be diagnosed with ASD using the DSM-5 criteria. Those children who previously had received a diagnosis of PDD-NOS are more likely to receive the new diagnosis of SCD, as these children may not demonstrate high levels of the core symptoms associated with ASD, or may demonstrate significant language deficits, but, few to no RRBs. Currently, there are no treatment recommendations for SCD. Kim et al. suggests that treatment for ASD and SCD should be the similar or the same until future research indicates otherwise.

Although, it is possible to reliably diagnose children with ASD as young as 24 months of age (Johnson & Myers, 2007), the CDC established Autism and Developmental Disabilities Monitoring (ADDM) Network reported a much later median age (i.e., 4 years, 5 months) for earliest ASD diagnosis. While a diagnosis of ASD may be clear for some, it may be more difficult for other individuals given the presentation of behaviors and/or presence of comorbid disorders. ASD is a spectrum disorder, and, as such, it is associated with a broad range of symptoms that can affect individuals to varying degrees in severity, with the presentation of symptoms potentially changing over time (Lord, Corsello, & Grzadzinski, 2014). Further, barriers that families face when seeking a diagnostic evaluation for ASD may include a lack of access to highly qualified professionals, increased levels of parental stress and anxiety, and financial barriers (Matson & Goldin, 2014).

The "gold standard" for a diagnostic evaluation of ASD involves the clinical judgment of a qualified interdisciplinary team to determine diagnosis, which includes utilizing empirically—sound diagnostic instruments, clinical assessment, caregiver report, and behavior observations. Although a diagnosis made by an interdisciplinary team is the ideal, this is not always feasible due to availability in a given location and extensive waitlists for such evaluations. Individuals with expertise in ASD can also conduct evaluations independently. The core features of an evidence-based assessment for ASD in children and adolescents include caregiver reporting on interviews and questionnaires, autism-specific diagnostic tools and observation instruments, standardized assessment of intellectual functioning, speech/language assessment, and adaptive behavior assessment (Ozonoff, Goodlin-Jones, & Solomon, 2005).

ASD-Specific Diagnostic Tools and Observation Measures

The use of accurate, reliable, and valid diagnostic instruments is an essential part of the assessment process to identify and diagnose ASD. ASD-specific assessment measures differ in the degree to which they emphasize the presence of observable behavioral abnormalities and lack of typical-developing features (Lord et al., 2014). When diagnosing an individual with ASD, quantifying the presentation of social communication and RRB symptoms is important to determine the level of severity and support they may benefit from in each of these respective areas. For instance, the DSM-5 allows practitioners to delineate between three levels of support (i.e., very substantial support, substantial support, or support) for social communication deficits and RRBs. These designations will hopefully aid in the identification of areas of relative strengths and weaknesses as they relate to ASD core symptomology and facilitate individualized intervention planning.

There are a variety of autism scales available that clinicians may utilize to aid in the assessment and diagnosis of ASD (Matson, Nebel-Schwalm, & Matson, 2007). A systematic review of accuracy, reliability, validity, and utility of diagnostic tools and assessments conducted by Falkmer, Anderson, Falkmer, and Horlin (2013) found the Childhood Autism Rating Scales, Second Edition (CARS-2; Schopler, Van Bourgondien, Wellman, & Love, 2010), Autism Diagnostic Interview-Revised (ADI-R; Le Couteur, Lord, & Rutter, 2003), and Autism Diagnostic Observation Schedule (ADOS; Lord, Rutter, DiLavore, & Risi, 2002) were the three instruments that had the strongest evidence base and highest levels of sensitivity and specificity when diagnosing autism. Although the CARS-2 was found to have the overall strongest correct classification for ASD diagnosis (0.86), it is a measure that is not administered in isolation. As the CARS-2 is a rating form completed by the clinician, clinical observations, caregiver reporting, and the child's performance on other testing measures also inform ratings. Although an in-depth review of these diagnostic measures is beyond the scope of this chapter, a brief description of the Autism Diagnostic Observation Schedule, Second Edition (ADOS-2; Lord et al., 2012) and the ADI-R (Le Couteur et al., 2003) is provided here.

Autism Diagnostic Observation Schedule, *Second Edition* (ADOS-2: Lord et al., 2012). The ADOS-2 is a play-based assessment that incorporates standardized social interactions and activities that enable examiners to observe behaviors that are considered to be integral to the diagnosis of ASD. The ADOS-2 is a semi-structured standardized assessment that typically takes at least 45 min to administer. The ADOS-2 consists of five different modules; the module chosen is determined by development and language level of the child. This instrument should not be used in isolation, but does provide examiners the opportunity to elicit and directly observe behaviors typically associated with ASD. The ADOS-2 should be always used in conjunction with developmental history, caregiver report, other standardized testing, and clinical observation to determine a diagnosis of ASD.

Autism Diagnostic Interview-Revised (ADI-R; Le Couteur et al., 2003). The ADI-R is a semi-structured interview for caregivers of children and adults. The interview focuses on behaviors that align with the three diagnostic domains of the DSM-IV-TR ASD diagnosis (e.g., quality of social interaction, language and communication, and restricted repetitive and stereotyped behaviors). The measure typically takes about 90 min or more to administer and includes 94 questions regarding the individual's current functioning, with the exception of certain items that specify age restrictions for the assessed behavior. For example, questions that assess group play are coded for behavior displayed between the ages of 4 and 10 years; items that assess reciprocal friendships are scored for children who are ages 5 and older; and questions related to circumscribed interests are scored only for children ages 3 and above. In addition to asking about current behavior, each question focuses on the

developmental time period between the ages of 4 and 5 years, when these behaviors were likely to be the most pronounced.

Falkmer et al. (2013) found that when the ADOS (Lord et al., 2002) and ADI-R (Le Couteur et al., 2003) were used in combination, they yielded the strongest accuracy in classification of ASD as compared to using the current "gold standard" team diagnosis approach. It should be noted that when used independently, the ADOS demonstrated stronger utility for an autistic disorder diagnosis than an ASD diagnosis, and the ADI-R provided more accurate classification for children older than 3 years old. Thus, during the assessment process, these instruments were more effective at identifying the presence of ASD in those children who were older than 3 years old and who presented with symptomology more indicative of DSM-IV-TR's diagnostic subcategory of autistic disorder (APA, 2000), a category distinction that is no longer made given the diagnostic criteria in DSM-5.

Mazefsky, McPartland, Gastgeb, and Minshew (2013) conducted an analysis to determine how well an individual's performance on the ADI-R and ADOS predicted a diagnosis of ASD using the DSM-5 criteria. The research sample consisted of a large number of research participants who were verbally fluent and considered to be "high functioning" on the autism spectrum (i.e., those who using the previous DSM-IV-TR criteria had received diagnoses of PDD-NOS or Asperger's disorder). Within this population, results indicated that when using the ADOS alone, there were a disproportionately lower number of individuals who met diagnostic criteria versus using the ADI-R alone (33 % and 83 %, respectively). However, when the ADOS and ADI-R were used in combination, 93 % of the participants in this study met diagnostic criteria for an ASD diagnosis in all categories. These results indicate that for those individuals who demonstrate repetitive behaviors at lower rates of frequency/intensity, additional assessment measures will be required to capture the range of repetitive behaviors included in the DSM-5 criteria. Thus, Mazefsky et al. supported the use of both the ADOS and the ADI-R as part of the interdisciplinary team's assessment process.

Disorders that Commonly Co-occur with ASD

Although ASD is a uniquely recognized disorder (APA, 2013), it shares characteristics with other neurodevelopmental and psychiatric disorders that are manifested during the developmental years. Further, there are a variety of disorders that commonly co-occur with a diagnosis of ASD. The DSM-5 diagnostic criteria for ASD includes specifiers for associated features of ASD, allowing clinicians to provide information regarding other disorders that may also be present (e.g., intellectual impairment, language impairment) and allows for the diagnosis of ASD in individuals with genetic conditions (e.g., Rett syndrome, Fragile X syndrome), or other neurodevelopmental, mental, or behavioral disorders. Thus, differential diagnosis should include assessment for commonly occurring comorbid diagnoses such as intellectual disability (ID), language disorders, genetic conditions, and other neurodevelopmental or behavioral disorders.

Intellectual Impairment

The assessment process should also include an appropriate measure of cognitive functioning, with an evaluation of both verbal and nonverbal intelligence. Prior to administering a standardized measure of intelligence with a child who is suspected of having ASD, the clinician should first assess the child's ability to engage in appropriate test taking behaviors (e.g., remain seated, attend to the test administrator, respond to verbal prompts, etc.), determine reinforcement preferences, and assess the individual's knowledge of the basic concepts required by the selected measure of intelligence (Brassard & Boehm, 2007). Although the most recent report by the Autism and Developmental Disabilities Monitoring (ADDM) Network indicated that the majority (62 %) of children identified as having ASD did not have co-occurring intellectual disability (ID), ID and ASD do covary at high rates. The needs of individuals who have both ID and ASD are different than those who have ID or ASD alone (Ben Itzchak, Lahat,

Burgin, & Zachor, 2008; Galli Carminati, Gerber, Baud, & Baud, 2007; Matson & Shoemaker, 2009). A review by Matson and Shoemaker (2009) highlighted areas in which those diagnosed with both ASD and ID demonstrate greater deficits than those with ASD or ID alone. Those with ASD and ID showed greater deficits in adaptive behaviors, social skills, challenging behaviors, and comorbid mental health disorders. Furthermore, Ben Itzchak et al. found that young children with ASD who also had IQs below 70 presented with greater deficits in social, play, and stereotyped behaviors than children at the borderline or average intellectual functioning level. Cognitive deficits represent a critical factor in prognosis; however, early intensive treatment has been associated with improved outcomes for children of varying cognitive levels with ASD (Ben Itzchak et al. 2008; Harris & Handleman, 2000).

A standardized assessment of adaptive functioning is also important to determine individual patterns of strengths and weaknesses and informs the diagnosis of ASD and ID. The adaptive behavior profiles of children with ASD evidence a wider range in performance by domain (e.g., communication skills, motor skills, daily living skills, socialization skills) when compared to typically developing peers, this scatter is even more pronounced in children with ASD and ID. Children with ASD demonstrate a pattern of adaptive skills that include deficits in socialization, moderate communication skills, and relative strengths in activities of daily living (Carter et al., 1998). The assessment of adaptive functioning is important not only for diagnosing or ruling out ID but also in the determination of individualized educational and vocational planning for children with ASD across the range of intellectual functioning. Even children with ASD who have an IQ within the average range or above generally demonstrate adaptive skill deficits, particularly in the area of socialization. The Vineland Adaptive Behavior Scales—Second Edition (Vineland-II; Sparrow, Cicchetti, & Balla, 2005) is a semi-structured parent interview that evaluates adaptive functioning across four domains: communication, daily living skills, socialization, and motor skills. This measure also provides an overall Adaptive Behavior Composite score. The Vineland-II includes norms for two groups of individuals with ASD: (a) those who used fewer than five words functionally each day and (b) those who used more than five words with purpose and meaning on a daily basis. Results indicated similar patterns of performance across domain and subdomains for both groups of individuals with ASD. More specifically, both groups demonstrated significant deficits across all domains of adaptive skills, with interpersonal relationships, play and leisure time, and expressive subdomains representing the areas of most significant skills deficits.

Language Impairment

Absent, delayed, or atypical development of language is often one of the first early-recognized signs of ASD. Although language deficits are no longer a criteria for ASD under the DSM-V, the presence or absence of an accompanying language impairment should be specified when an ASD diagnosis is indicated. As with cognitive and adaptive skill delays, the language profiles of individuals with ASD are highly variable. Among all individuals with ASD, approximately 25 % will remain nonverbal (Lord, Risi, & Pickles, 2004; Sigman & McGovern, 2005), while others may develop language skills in line with typical peers. Kjelgaard and Tager-Flusberg (2001) examined language development in a sample of 89 children previously diagnosed with ASD who were also verbal. Across a battery of commonly used language assessments, 76 % demonstrated characteristics of language impairments, while the remaining children displayed typically developed language skills. Although it is clear that ASD and language deficits co-occur at high rates, the exact nature of their etiology and relationship remains unknown. In addition to language impairments, children with ASD may exhibit additional speech and/or communication difficulties, including repetitive or rigid language (i.e., echolalia), atypical pitch or tone of voice, narrow conversational interests or exceptional abilities, and poor nonverbal communication skills (U.S. Department of Health and Human Services, Health, and National Institute on Deafness and Other Communication Disorders, 2014).

As speech, language, and communication difficulties are prevalent among children with ASD, a comprehensive assessment by a qualified speech-language pathologist is an essential component of an interdisciplinary evaluation. Prior to a speech and language evaluation, however, an audiological evaluation should be conducted to ensure that the child's hearing is within normal limits and to rule out hearing loss as a potential contributor to communication delays. The two primary approaches to assessing communication skills in children with ASD are standardized testing and parent report, which tend to provide close agreement. Psychological testing and behavioral observation may also inform language assessment, particularly with younger children, as nonverbal cognitive ability and use of gestures have been shown to be significant predictors of early language development (Luyster, Kadlec, Carter, & Tager-Flusberg, 2008).

Associated Neurodevelopmental, Mental, or Behavioral Disorders

Accurate and reliable diagnosis of comorbid disorders associated with ASD is an imperative component of the assessment process given the significant additional clinical impairment these disorders may present to the individual (Leyfer et al., 2006). Commonly, individuals with an ASD diagnosis present with challenging behaviors (e.g., aggression towards self and others, tantrumming, feeding difficulties, sleep issues, etc.), difficulties with attention, and older, higher functioning individuals are at increased risk for anxiety and mood disorders (Leyfer et al., 2006; van Steensel, Bögels, & Perrin, 2011). Determining the presence of additional diagnoses such as obsessive-compulsive disorder, attention-deficit/hyperactivity disorder (ADHD), anxiety, and depression in individuals with ASD presents implications not only for the assessment process but in treatment planning as well (Matson, 2007).

Assessing for additional psychiatric or behavioral difficulties in individuals with ASD commonly utilizes clinical judgment, which is informed through gathering and synthesizing information from a variety of sources, including consideration of detailed background information, self-report and parent report of symptomatology, and a careful review of DSM-5 criteria. However, accurately and reliably diagnosing comorbid disorders in children and adults with ASD can be difficult for a number of reasons. In some instances, it may remain unclear the extent to which certain symptoms warrant a separate diagnosis or if they may be viewed as features of an ASD diagnosis (Matson & Nebel-Schwalm 2007). Furthermore, the social communication impairments that are core features of ASD make it difficult for the individual with ASD to describe symptomology related to psychiatric disorders, which further complicates the identification of psychiatric comorbidity (Leyfer et al., 2006). In addition, although structured instruments that have been created to assess for behavioral difficulties and comorbid psychiatric disorders in the general population have been used with individuals with ASD, many of these instruments have not been tested for reliability or validity with individuals with ASD. Thus, identifying comorbid diagnoses for individuals is hampered by a variety of factors, which include overlapping symptomology with other diagnoses, impaired communication between the clinician and patient, and lacking diagnostic tools.

More recently, instruments specifically designed to assess for symptoms of comorbid disorders in individuals with ASD are being developed and researched. The Psychopathology in Autism Checklist (PAC; Helverschou, Bakken, & Martinsen, 2009) and the Autism Spectrum Disorders—Comorbidity for Adults (ASD-CA; Matson, Terlonge, & Gonzalez, 2006)—are two instruments that are designed for assessing comorbidity in adults with ASD. Instruments assessing comorbidity in children are still newer and present their own challenges, as comorbidity is more difficult to detect among younger children (Mannion & Leader 2013). Instruments assessing comorbidity among children with ASD include the Baby and Infant Screen for Children with Autism Traits, Part II (BISCUIT; Matson, Boisjoli, & Wilkins, 2007), the Autism Spectrum Disorders Comorbidity-Child Version (ASD-CC;

Matson & Gonzalez, 2007), and the Autism Comorbidity Interview-Present and Lifetime Version (ACI-PL; Leyfer et al., 2006). Research examining these new instruments has primarily established internal consistency, establishment of cutoff scores, and validity; however, additional studies are needed to establish replication (Neil, Moum, & Sturmey, 2014).

In light of these limitations to the differential diagnosis process, several studies have documented the commonality of comorbid psychopathology in ASD, although the exact rate of prevalence remains debated. Research examining rates of comorbidity among individuals with ASD have reported widely varied results depending upon the age range of individuals sampled and the method of assessment. For example, in a sample of children with ASD, Joshi et al. (2010) found that 95 % had three or more comorbid diagnoses, while Mannion, Leader, and Healy (2013) calculated that 46 % of the children in their sample experienced at least one comorbid disorder in addition to ASD. Furthermore, comorbid conditions have been found to be more prevalent among adolescents and adults with ASD. More specifically, disorders that have been found to have the highest level of overlap with ASD include depression, anxiety disorders, ADHD, intellectual disabilities, and language disorders. The section of the present volume dedicated to the assessment of comorbid disorders will provide the reader with a more thorough and in-depth review of these, and other additional disorders that commonly co-occur with ASD.

From Assessment to Intervention

A final and crucial component of the assessment process is providing caregivers with the results of the diagnostic evaluation. Ideally, a feedback session should be held with caregivers immediately following the evaluation or soon thereafter. Results should be shared in a setting and manner that encourages caregivers to engage in an active discussion about the findings and voice any questions or concerns that arise during the informing process. Depending on the age and level of understanding of the child, it may be beneficial and appropriate to have him or her participate in the feedback session. The final comprehensive report provided to the caregivers should provide the assessment results in clear, easy to understand terms, emphasizing the individual's unique strengths and areas of difficulties. Assessment results should be directly tied to the intervention and follow-up recommendations provided within the report (Volkmar, Langford Booth, McPartland, & Wiesner, 2014).

The National Professional Development Center (NPDC) on ASD and the National Standards Project (National Autism Center 2009) reviewed literature and established evidence-based practices (EBP) for individuals with autism from birth to 22 years of age. Both groups included reviews of the research literature through 2007 and applied criteria for determining which studies provided evidence of efficacy for intervention practices. At the time of the initial review, the NPDC identified 24 intervention modalities that met criteria for EBP for individuals on the autism spectrum. From the analysis conducted by NSP, 11 "established" treatments (i.e., treatments with sufficient evidence to confidently determine that the intervention produces benefits for a child on the autism spectrum) were identified. The results of recommended EBP for individuals with ASD provided by the two analyses were remarkably similar. The NPDC provided an updated review of EBP for individuals with ASD in 2014, which broadened the previous NPDC review by incorporating intervention literature that had been published subsequent to the initial review, expanding the timeframe previous to the initial review, and utilizing a more rigorous review process. The updated review of EBP for individuals with ASD included 27 intervention practices and is comprised of a variety of intervention techniques including fundamental components of applied behavior analysis, assessment tools for analyzing behavior to inform intervention, and systematic behavioral practices used to facilitate skill acquisition.

The results of the diagnostic assessment can be used to inform an individual's intervention plan by identifying areas of relative strengths and

difficulties and targeting areas of difficulty with appropriate EBP intervention techniques. Quantifying the presentation of social communication and RRB symptoms by level of severity and specifying the level of support needed are included within the DSM-5 diagnostic criteria for ASD. This information is important to determine the level of severity and support an individual may benefit from in intervention planning. For instance, the DSM-5 allows practitioners to delineate between three levels of support (i.e., very substantial support, substantial support, or support) for social communication deficits and RRBs. These designations will hopefully aid in the identification of areas of relative strengths and weaknesses as they relate to ASD core symptomology and facilitate individualized intervention planning.

Summary

This chapter has discussed a number of considerations that are involved in the assessment of ASD. There are many important factors for clinicians to consider throughout the course of the assessment and diagnosis process which begins long before an individual receives a diagnostic assessment. The initial stages of the assessment process include the surveillance for ASD symptoms in the general population. Assessment continues for those children who are determined to be at risk for developmental delays, utilizing ASD-specific screenings to identify those children who may benefit from a comprehensive diagnostic evaluation. The assessment and diagnosis of ASD is complicated by the nature of the disorder (e.g., the diverse presentation of symptoms and varying levels of severity) and high rates of comorbid psychopathology. To assure appropriate services are provided to individuals with ASD, the assessment process also necessitates individualized intervention planning. This chapter has provided the reader with an introduction to the purposes of assessment and specific strategies for enhancing service and care to children with ASD and their families.

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Report Writing for Autism Spectrum Disorder Evaluations

4

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Introduction

Autism spectrum disorders (ASD) are developmental disorders that include social and communication impairments as well as restricted and repetitive patterns of behavior (RRB; Chowdhury, Benson, & Hillier, 2010; Fodstad, Matson, Hess, & Neal, 2009). ASD affects approximately 1 % of children (Baird et al., 2006), with a more recent prevalence rate estimating that 1 in 68 children aged 8 years old is diagnosed with ASD (Centers for Disease Control and Prevention [CDC], 2014). Therefore, a comprehensive assessment and, in turn, a well-written report are needed to enhance treatment, guide and inform instruction specific to the individual's needs, and provide information to the referral source and others involved in the individual's treatment and/or care (Lichtenberger, Mather, Kaufman, & Kaufman, 2004). A psychological report should be integrative and includes results from all parties involved in the evaluation. Components that are commonly included in a comprehensive assessment report include background information, behavioral observations, psychometric testing results and interpretation, summary/diagnostic formulation, and recommended resources for parents and professionals (Lichtenberger et al., 2004; Saulnier & Ventola, 2012). Outlined below is further detail concerning these common components of an ASD-focused psychological evaluation.

Background History

When conducting a comprehensive neurodevelopmental evaluation for an individual suspected to have an ASD, it is important to conduct a thorough background history (Matson & Golden, 2014). Considering the limited amount of time most professionals have to gather information as well as the sheer breadth of relevant information that informs a diagnosis of ASD, practitioners must use their

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time efficiently by asking germane questions (Andersson, Miniscalco, & Gillberg, 2014). The following sections describe the critical areas of information that should be gathered and the rational for inquiring about each area. A caveat in writing the background history section is that the clinician should be diligent to include all relevant information while writing concisely and, clearly, keeping the audience of the report in mind.

Identifying Information

The identifying information section orients the audience of the report to the individual characteristics of the person being evaluated. In this section, the clinician should include the child's first name and last name, age (reported in years and months [e.g., 4 years and 10 months old]), race and ethnicity, and gender. Also, information should be included about the individual's parents or guardians and other individuals who live in the household. Finally, information should be included concerning the location where the individual resides (i.e., city and state). If the individual spends time at different residences (e.g., divorced parents with shared custody) or has visitation with parents, report the schedule when the individual lives with different caregivers (e.g., every other weekend with father).

Early Development

This section should present information on prenatal development, birth history, behavior as an infant, and developmental milestones (Easson & Woodbury-Smith, 2014). Regarding prenatal development, the clinician should include information concerning use of fertility drugs, complications during pregnancy to the individual or mother (e.g., gestational diabetes, hemorrhaging), exposure to teratogens (e.g., drugs, alcohol, and tobacco), and any prescription medications (Mamidala et al. 2013). When reporting birth history, include information about labor and delivery (e.g., Cesarean section, vaginal birth), use of epidural, gestational age, and birth weight. If the individual was born prematurely (i.e., the organs were not completely developed) or preterm (i.e., before 38 weeks), describe the type of neonatal care provided (e.g., neonatal intensive care unit), the amount of time spent in neonatal care, and any neonatal condition (e.g., jaundice). Also, describe the behavior of the infant and provide relevant information regarding any medical conditions.

After reporting on the birth history and behavior as an infant, the clinician should describe the individual's achievement (or delay) of his/her developmental milestones (Kenworthy et al., 2012). These milestones include motor, toilet training, and language. Motor milestones that should be considered include the age at which the child first began sitting without support and walking without assistance. Fine and gross motor skills, which pertain to precise motor movement of the hands and fingers (e.g., holding a pencil, coloring, opening objects) and large movements and body control (e.g., sitting, crawling, walking), respectively, should also be reported. Regarding toilet training, the clinician should describe the age at which toilet training was mastered and any difficulty with toileting training such as incontinence (i.e., enuresis and encopresis) or constipation. If the individual was incontinent, the clinician should describe the time of day that the individual was incontinent (i.e., nocturnal or diurnal).

Language Development and Communication

Considering language and communication skills are core deficits in individuals with ASD (Kwok, Brown, Smyth, & Cardy, 2015), special attention should be paid to this section in the report. It is important to note that some caregivers might have difficulty remembering specific details about their child's early language development; however, estimates of the following details are acceptable and because of their critical impact on the diagnostic formulation (Nordahl-Hansen, Kaale, & Ulvund, 2014). The communication section should include information concerning the age at which the individual began babbling, spoke his/her first words and phrases, and spoke in complete sentences. This section should also include information about receptive language

skills, specifically the complexity of directions that the individual follows (i.e., single-step instructions, multistep instructions, etc.; Kjellmer et al., 2012). Next, information about the individual's use of nonverbal communication, such as gestures, should be reported. Regarding gestures, the clinician should distinguish which type(s) of gestures the individual uses (Lambrechts, Yarrow, Maras, & Gaigg, 2014), including descriptive (e.g., holding one's hands apart to show how big something was), conventional (e.g., shaking one's head to indicate no), and instrumental (e.g., holding one's hand out, like begging, to obtain something) gestures. Moreover, the clinician should report if the individual currently or previously used other people as a tool to communicate their needs or convey information (e.g., grapping the hand of a parent and using it to point to a picture in a book or taking them to the refrigerator to access juice).

Beyond gestures, clinicians should gather information about potential unusual communication problems that are part of the diagnostic criteria for ASD (Hattier & Matson, 2012). This includes echolalia, undirected repetitive vocalizations, difficulty understanding metaphorical language and/or jokes, and idiosyncratic speech. When gathering information related to idiosyncratic speech, the examiner should consider quality, rate, rhythm, tone, volume, and any pronoun reversals or atypical language use. Finally, in this section, a clinician should include information about alternative modes of communication (e.g., American Sign Language, picture exchange communication system, augmentative communication devices). Language regression is also an important consideration, and the clinician should include the age of regression in the report (van der Meer, Sutherland, O'Reilly, Lancioni, & Sigafoos, 2012). Other information about social communication should be reported in the following section, social skills.

Social Skills

Similar to communication skills, social skills are a core deficit of individuals with ASD and a critical component of the background information section (Cervantes & Matson, 2015; Hanley et al., 2014). As such, this section should clearly articulate the specific social strengths and weaknesses of the individual. The clinician should begin by reporting early social skills including eye contact, social smiling, responding to name, and joint attention. Eye contact should be discussed in terms of the individual's ability to use eye contact to facilitate nonverbal social communication (Louwerse et al., 2013), as well as in response to stimuli in the environment (e.g., looking at a parent/caregiver after hearing a loud noise). Social smiling should be noted as it relates to the individual's directed response (i.e., smiling toward a parent/caregiver) to smiles emitted by a parent/caregiver. In addition, responding to an individual's name should be reported in terms of the frequency of responding and the quality of the response.

Joint attention, which is defined as sharing experiences between two individuals, is a pivotal social skill in young children (Jones & Carr, 2004). Joint attention includes a variety of gestures (e.g., giving, showing, and pointing) and integrated eye contact. In the report, a clinician should report if the individual previously or currently engages in joint attention, the types of behaviors they emit as part of their joint attention repertoire, and if they initiate and/or respond to joint attention (Krstovska-Guerreo & Jones, 2013).

After reporting information about early social skills, the clinician should describe the individual's social interactions with peers (Deckers, Roelofs, Muris, & Rinck, 2014). This information is dependent on the individual's age and social functioning. Important aspects of social interactions with peers include how the child engages in group settings, whether he/she has preferred friends, whether the child engages in collaborative/interactive play with peers, and whether the individual is responsive when peers approach him/her to engage in play. In addition, how peers respond to the child is an important consideration. For older children, details about any romantic relationships may be appropriate to include.

Additional information about social communication skills is important to include in this section

(Radley et al., 2014). Specific social communication skills include initiating/responding in conversations, reciprocal communication skills (e.g., back-and-forth comments), understanding social relationships, and social pragmatics.

Play Skills

During early childhood, play skills are particularly important because they allow children to access and learn from their environment; moreover, they facilitate social interactions and communication with others (Morrison, Sainato, Benchaabane, & Endo, 2002). Gathering information related to the child's play yields important diagnostic information. More specifically, it is in play that delays in social communication and RRB are often observed. It is important to report whether the child engages in any atypical play behaviors (i.e., playing with parts of objects or playing with toys in a nonfunctional manner), exhibits intense/restricted interests in certain play materials, and displays imaginative/pretend play and the extent to which the child includes others in his/her play. Examples of functional and pretend play include rolling a car on a table and brushing a doll's hair with a spoon, respectively. Finally, the clinician should report if the individual currently or previously engaged in imitation of others' play.

Emotional Skills

Broadly, individuals with ASD have difficulty interpreting and expressing emotions (Dapretto et al., 2006). Clinicians should report on the individual's emotional understanding, emotional expression, and emotional regulation. Additionally, the clinician should describe the individual's ability to identify emotions in others and empathize with them. The clinician should also describe the individual's proclivity to be affectionate toward others (e.g., initiates giving hugs to others) and their desire to receive affection (e.g., asks others for a hug or kiss). It is in this section that the examiner should comment on the child's typical mood. The child's mood is particularly relevant to any differential diagnoses that might be present, such as anxiety.

Sensory Issues

Individuals with ASD often exhibit hyperreactivity to sensory stimuli and/or have idiosyncratic sensory interests (Tomchek, Huebner, & Dunn, 2014). As sensory seeking behavior or sensory sensitivities are part of the diagnostic criteria for ASD, it is important to gather this information across all senses. The clinician should differentiate whether sensory sensitivities are hyperreactive (e.g., adverse reaction to noises) or hyporeactive (e.g., seemingly under reactive response to painful stimuli).

Behavioral Concerns

Individuals with ASD evince behavioral concerns that vary in their topography and encompass different functions (Lane, Paynter, & Sharman, 2013). In regard to behavioral concerns, a clinician should report information across each of the following areas: RRB, disruptive behavior (e.g., aggression, tantrums, noncompliance, and self-injury), substance use or abuse, sexual behavior, and adaptive behavior skills. The clinician should report on each area that the individual or their parent endorsed. Specifically related to RRB, whether behaviors (e.g., body rocking, hand flapping, toe walking, pattern running, tics), interests (e.g., frequently and acutely discussing Pokémon, entomology, or "Dr. Who"), or activities (e.g., navigating the grocery story in the same way) are endorsed, the clinician should clearly describe RRB, providing examples and discussing how the behaviors cause dysfunction for the individual. Additionally, the clinician should report what happens when others attempt to disrupt or interrupt the individual while he/she is engaged in RRB.

Next, the clinician should report any concerns related to disruptive behavior (Kaat & Lecavalier, 2013). Within this area, specific information

should be discussed regarding aggression, noncompliance, tantrums, and self-injury. The clinician should clearly convey the type of behavior (e.g., hitting, hand banging, eloping, dropping to floor), antecedents of the behavior, and how others respond to those behaviors. Should this yield any clinician or parent safety concerns for the child, the report should include relevant portions of the safety assessment that the clinician conducts with the family. If the individual being evaluated has a history of or currently uses drugs or alcohol, the clinician should include that information in this section as well. Substances of the individual used/uses and the frequency and duration of the substance use would be important to outline. Prescription medication that has been prescribed by a physician should be reported later in the report; however, if the individual being evaluated reports abuse of prescribed medications, the clinician should include that information in this section. Likewise, in this section, the clinician should discuss if the individual engages in sexual behavior, if developmental appropriate. If so, the clinician should inquire if the individual is engaging responsible sexual activity (e.g., uses protection and understands the potential contraction of a sexually transmitted disease).

Finally, the clinician should discuss the individual's adaptive behavior. Adaptive behaviors (i.e., skills of daily living) are useful for people to conduct themselves safely and responsibly (MacDonald, Lord, & Ulrich, 2013). They encompass a broad domain of skills (e.g., toileting, cleaning, dressing, navigating in the community, etc.). Particular attention should be placed on toileting skills, especially for young children. If issues with toileting exist, the clinician should describe the frequency of enuresis/encopresis, the time of day that they typically occur, and any consequences for incontinence. Within the report, the clinician should describe the individual's ability to perform these skills; however, as part of a comprehensive ASD evaluation, more information about adaptive skills is reported through standardized measures of adaptive functioning.

Eating

Individuals with ASD commonly have feeding problems (Luiselli, 2006). Feeding difficulty includes food selectivity, food refusal and avoidance, and specific problem behaviors associated with instructions to eat certain foods. In this section, the clinician should report the individual's eating habits. Additionally, the clinician should describe if the individual is able to self-feed or needs assistance or if the individual requires any artificial feeding (e.g., tube feeding). Finally, the clinician should report if the individual has any motor difficulties with feeding (e.g., oral-motor skills, chewing, swallowing) and if the individual engages in any incompatible feeding behaviors such as chocking, gaging, or vomiting.

Sleeping

Research indicates that children with ASD have sleep difficulties, with prevalence rates ranging from 44 to 83 % (Richdale, 1999). Considering these data, particular attention should be placed on gathering and reporting information about the individual's sleep. Specifically, the clinician should include information about any difficulties with falling and remaining asleep, night terrors/nightmares, early waking, naps, and sleep hygiene. If any problems exist within the previously mentioned areas, the clinician should discuss the dysfunction and how the family responds to those sleep issues.

Educational and Employment History

The Individuals with Disabilities Education Act (IDEA, 2004) ensures that all children with qualifying disabilities, including children with ASD, receive a free and appropriate education in a setting as similar to their typically developing peers as possible. The clinician should begin this section by reporting the names of the school and current grade. Also, a list of the previous schools, grades attended at those schools, and

grade retentions or promotions should be provided. Next, the clinician should discuss the type of setting in which the individual receives his/her education. This setting should be discussed in terms of the level of inclusion (e.g., substantially separate classroom, self-contained classroom, inclusion classroom). The clinician should also discuss if the individual has an Individualized Education Program (IEP) and report the individual's educational classification. The clinician should report specific services that the individual receives under the IEP (e.g., speech and language service, occupational therapy, Applied Behavioral Analysis Therapy, adapted physical education, etc.).

If applicable, the clinician should report the individual's current job status and/or job history. In this section of the report, the clinician should discuss the types of jobs the individual currently or previously held, his/her responsibilities at that job, and any information about difficulties performing his/her job or terminations (Gal, Landes, & Katz, 2015). For individuals with ASD who are able to attend college, this section of the report should also reflect information about current or previous postsecondary education and any difficulties the individual had in those settings or while obtaining entrance into those settings.

Intervention History

There are a variety of interventions that an individual with ASD may have received. These interventions range from behavioral treatments for skill acquisition to special diets. Considering the variety of interventions and their empirical support, it is important to report the types of interventions the individual being evaluated currently or previously received and their effectiveness. First, the clinician should use this section to discuss enrollment in early intervention (EI) services before age three (MacDonald, Parry-Cruwys, Dupere, & Ahearn, 2014). Specifically, the clinician should report which type of services the individual received (e.g., speech and language therapy [SLT], occupational therapy [OT], physical therapy [PT], applied behavioral analysis [ABA] therapy, etc.), the frequency and duration of each service, and each therapy's effectiveness. Next, information concerning interventions the individual received after age three should be noted. These could be services received in school (e.g., SLT, OT, PT, ABA therapy, social skills groups) as well as services outside of school. Other interventions could include job coaching, community vocational training, or alternative interventions (e.g., special diets).

Medical History

Individuals with ASD, like those who are typically developing, experience a variety of comorbid medical conditions (e.g., sleep problems, hormone dysfunction, metabolic disorder, gastrointestinal disorders, and seizure disorders). Considering the potential for comorbid medical conditions, clinicians should obtain thorough information from the individual's family (or the individual, if appropriate). Relevant medical information includes chronic concerns, allergies, medications, surgeries, or hospitalizations. Of particular relevance are seizure disorders, gastrointestinal problems, traumatic brain injury, and exposure to lead. Finally, the clinician should report if the individual received genetics testing, electroencephalography (EEG), or magnetic resonance imaging (MRI) as well as the results of those procedures.

Psychiatric and Trauma History

Although not unique to an evaluation for an individual with ASD, psychiatric and trauma history are essential elements of the report (Mehtar & Mukaddes, 2011). Trauma could include abuse, neglect, witnessing or experiencing violence in the community or home setting, or traumatic loss of a loved one. If trauma is endorsed, the clinician should include any agency involvement including the Department of Social Services, Department of Children and Families, or Department of Protection for Persons with Disabilities. Each state has their own agency for

the previously described departments and clinicians should be familiar with their respective state agencies. If the individual being evaluated was followed by any agency, a description of the services they received should be included.

The clinician should also report any psychiatric history for the individual being evaluated. The psychiatric history should include psychiatric hospitalizations, the date and length of hospitalization, and the reason for the hospitalization. Besides hospitalization, the clinician should report if the individual being evaluated receives services from a psychiatrist. If so, the clinician should report the psychiatrist name, duration and frequency of visits, and name of prescribed medications (including frequency and dosage). This section should also include the individual's risk for suicide.

Family History

In this section of the background history, the clinician should discuss the family history of psychopathology for the individual being evaluated. It is considered proper etiquette to report this information in a somewhat vague manner (i.e., there is a history of bipolar disorder in the immediate family). In this way, the report maintains its focus on the child, and the inclusion of family history does not present a barrier to families who might not wish to share this information with outside sources, such as the school.

In addition to the family history of psychopathology, the clinician should also discuss the relationship of the individual's parents, the family support system (e.g., help from extended family or neighbors), community/religious involvement, and any recent family or socioeconomic stressors.

Previous Psychological Testing

The review of written records is often an important component of collecting adequate background information. These sources likely contain information (e.g., test results, diagnoses, etc.) pertinent to the new report, as they provide details that may inform the interpretation of current test results and document previous levels of functioning that affect diagnostic conclusions. However, it can be difficult to decide what information from these reports to include and how to incorporate it into the background information section in a clear and concise manner.

As with all sections of the diagnostic report, the writer should always keep the referral question at the forefront of his/her mind when deciding what information to omit or include (Lichtenberger et al., 2004). Asking oneself "how does this detail help me answer the referral question?" can aid in the decision of whether to include specific information from previous evaluations. Necessary information will likely provide some context for the previous evaluation, provide support for differential/comorbid diagnoses, inform the reader's understanding of the client's course of development, and highlight progress that has been made over time (Saulnier & Ventola, 2012).

As a general guideline, when summarizing the results of previous evaluations, it is important to include the month/year of testing, referral question at the time of testing, an overview of test results, diagnoses given, and the family's follow-up with recommendations (Lichtenberger et al., 2004). It is also important to note the previous examiner's conclusions concerning the validity of the results. If the assessment was thought to be invalid, it may be misleading to include the test results (i.e., a Full Scale IQ, etc.) and is more appropriate to emphasize the evaluator's conclusions. This general guideline can also be applied to the review of other records, such as medical records or Individualized Education Programs (IEPs).

The information should be summarized briefly and may be sufficiently captured in a few sentences. It is not necessary to include the level of detail that the writer will use in his/her own interpretation of test results (e.g., presenting test results in charts, full analysis of a profile, etc.). However, there may be unique circumstances in which it is appropriate to go into further detail. For example, if the writer finds that previous test results conflict

with the results of the current evaluation, there may be cause for a more thorough summary of the previous testing in order to highlight these differences. In this situation, a higher level of detail in the background information section will enable the writer to interpret and/or create hypotheses about these discrepancies later in the report.

Behavior Observations

Behavior observations are essential to any ASD evaluation. The reader may notice that the format of the behavioral observation section reflects the background history section. However, in this section, the focus shifts from reported diagnostically relevant information to observed diagnostically relevant information. This section, in particular, allows the clinician to provide readers with a picture of the client's presentation and ultimately provides an initial illustration of the diagnostic conclusion. As with other sections, the key to writing the behavior observation section is to determine which information is most relevant to the referral question (i.e., "Does this child have ASD?") and if the information adds anything to the overall evaluation of the individual. Saulnier and Ventola (2012) note that any observations should have a clear purpose for inclusion. It is wise to avoid rehashing every detail that occurred during the observation.

This section includes observations from the totality of the evaluation, beginning in the waiting room through saying goodbye. For some clinicians, such as school providers or those who provide in-home services, observations in other settings, such as the classroom, may be beneficial. In order to accurately and concisely present behavioral observations to the reader, one must develop a strong foundation in basic behavioral observations, as well as be familiar with ASD diagnostic criteria, common features of the disorder, and differential diagnoses.

General Considerations

According to Morrison (2008), a mental status exam is the clinician's appraisal of an individual's current level of functioning. This is predominately comprised of behavioral observations, as well as assessment of cognitive aspects (i.e., delusions, hallucinations, insight; Morrison, 2008). It should be noted that these cognitive aspects may be difficult to assess in young children, nonverbal, or lower functioning individuals who may not be able to answer questions about the content of their thoughts or indicate they are oriented to person, place, time, and situation. However, behavioral observations about the individual's mood, affect, and speech provide a glimpse into other aspects of the individual's internal world. For the purposes of this text, formal mental status tasks will not be described, rather, behavioral observations that are particularly relevant to an assessment of ASD will be provided. Three areas of general behavioral observations include the individual's appearance and physical behaviors, mood and affect, and the presentation of speech, or lack thereof (Morrison, 2008). These three areas require simple observation during interview, testing, or other planned observations.

Appearance

Physical appearance gives the clinician more information regarding the individual's level of functioning, the care being provided to him/her, information regarding culture and socialization, and physical abilities. When assessing an individual, clinicians make note of the client's ethnicity (Morrison, 2008). The best way to complete this task during the evaluation is to ask the individual and/or his/her caregivers, regarding the individual's cultural and ethnic heritage. This information gives the clinician and the report-reader information regarding treatment and social concerns, as the effects of a diagnosis of ASD may vary from culture to culture.

In addition to identifying ethnicity, a clinician should include information regarding the client's dress and general appearance. An adult seeking an evaluation for ASD who has disheveled clothing, unkempt hair, and presents with an odor has a different level of functioning as compared to an

individual who is impeccably dressed, with starched clothing, and well-combed hair. These two individuals may also be presenting with different symptomatology. In addition, appropriateness of dress is worth noting. For instance, an individual who is wearing a tank top and sandals during a snowstorm is displaying difficulty with self-care and judgment.

Mood and Affect

According to Morrison (2008), mood is the individual's reported emotional state, whereas affect is the way one shows their emotional state. Although nonverbal and/or lower functioning individuals may not be able to describe their mood, it may be inferred from their behavior (e.g., throwing items, stomping on the floor, and various facial expressions may indicate an individual is angry). In cases where a verbal indication of current mood is not available, one may include a brief statement indicating why mood was perceived this way. For example, "the client's mood was angry throughout the evaluation, as evidenced by throwing items, screaming, clenching fists, and frequent frowning" would give a reader a glimpse of why the assumption of angry mood was made.

Following a statement regarding the client's mood, it is important to indicate if the affect was congruent with the stated mood. For instance, in a report, one may write, "the reported mood was 'happy', with incongruent affect. The client often frowned, buried his hands in his face, and became teary during the evaluation." In addition, one may note if the affect is "blunted" (i.e., decreased facial expression of emotion) or "flat" (i.e., no facial expression of emotion).

Speech/Language

Speech difficulties and language delays are common among individuals with ASD (Matson, Kozlowski, & Matson, 2012). Children may lack speech, speak only in single words or short phrases, and/or use little pragmatic speech. These speech disturbances, or use of fluent speech, should be noted in the behavior observations of the report. Furthermore, note if there is an unusual tone, rate, volume, or pitch (Gebauer, Skewes, Horlyck, & Vuust, 2014). Individuals with ASD may also present with unusual, idiosyncratic speech. It is also important to note whether the client's vocalizations were socially directed or self-directed and whether there was any atypical language use (e.g., scripted, repetitive, echolalic speech).

Social Communication

Social communication is an aspect of language that refers to deficits in nonverbal communication (Konst, Matson, Goldin, & Williams, 2014). This includes difficulty integrating nonverbal and verbal communication, poor eye contact, difficulties using nonverbal communication (i.e., gestures), and diminished use of facial expressions (Lambrechts et al., 2014). Statements about the client's use of the above-listed nonverbal communicative behaviors should be included.

Social Interactions

Social strengths and deficits should be noted in the behavior observation section of the report. For instance, children with ASD may have difficulty initiating or maintaining to-and-fro conversations, sharing interests with others, or attending to the interests of others. Additionally, they may exhibit difficulties in sharing emotions, presenting with a socially appropriate affect, or have difficulties with beginning or replying to social interactions (Mahoney, Breitborde, Leone, & Ghuman, 2014; Wang & Tsao, 2015). During the observation, it would be prudent to attend to how the client responds to small talk, the content of their speech, and their interests during the evaluation. Important questions to inquire about include the following: Does the client respond to probes such as "How are you?" and reciprocate by asking the examiner questions? Does the client talk exclusively about his/her interests or is he/she able to discuss other topics or the interests

of other individuals? Does the individual respond to probes to initiate a conversation?

Including observations of play is also relevant to social interactions and should be included in this section. Use of imitation, imagination, and functional play should be noted. Examples of questions to address in this section include the following: Does the child use miniatures as figures that interact with each other? Does he/she use objects to represent other items (e.g., using a box as a house)? Does the child play with toys in an immature manner by just banging, spinning, or mouthing?

Behavior

Observations related to the client's psychomotor behavior are important to note in the behavior observations section. This information will help illustrate the child's engagement in the activities that were presented and ultimately informs considerations regarding the validity of the assessment session. Psychomotor observations may include fidgeting, level of activity, movement around the room, and speed of movement. Other relevant motor activities include picking at skin, inappropriate touching (e.g., touching privates), the inability to move as would be expected (e.g., movement disorders), or falling asleep or difficulty concentrating on the task at hand (Morrison, 2008).

Restricted and Repetitive Behaviors (RRB)

RRB may be very easy or very difficult to observe, depending on the frequency and the presentation of the behavior in question. These behaviors may include repetitive/unusual motor movements such as hand flapping, rocking, jumping, spinning, or walking on toes (Bodfish, Symons, Parker, & Lewis, 2000). Some repetitive movements may be more difficult to observe such as rubbing or eye rolling. RRB may also include inappropriate use of object, such as lining up, banging, or spinning toys (Maestro et al., 2005). Children with ASD may be resistant to changes in their routine, be resolute in their attempts to keep things the same, or insist on engaging in behavioral rituals (Stoner, Angell, House, & Bock, 2007). When observing the client, look to see how he/she responds to transitions and small changes in his/her routine. Typically, being present for an evaluation means a break in the routine, so one may have an idea of how the client reacts to changes simply by having them come to the evaluation. In addition, the clinician should note if the client displays any rituals or exhibits distress when something changes during the evaluation (e.g., taking away items and moving to a different room).

Restricted interests in very specific topics are also important to note (Szatmari et al., 2006). This can be observed by noting the content of the client's speech such as experiencing difficulties in switching topics of conversation and/or providing detailed information about a certain topic that is inappropriate to the setting. In addition, a clinician may attend to the individual's interest in objects presented in the evaluation, as well as insistence on keeping an object from home nearby. Individuals with ASD may also exhibit intense interest with topics that are unusual for their age or cognitive level. For instance, a 4-year-old boy may be highly interested in washing machines, to the extent that he can name different models of washing machines among other details.

Finally, hyper- or hyporeactivity to sensory input or unusual interest in sensory aspects of the environment (Tomchek & Dunn, 2007) should also be included in the behavior observation section. For example, a clinician should take note of how the client responds to sensory experiences in the environment such as sounds, lights, and textures.

Implications for Validity of the Evaluation

The final portion of the behavioral observation section should address the validity of the evaluation based on what was observed by the examiner (e.g., client level of engagement in activities) and whether this behavior was representative of the client's typical functioning. If the caregiver

or client indicates illness, fatigue, or discomfort, that may affect their performance during the evaluation and it is important to note in the report.

Assessment Instruments: ASD-Specific Assessment

An ASD evaluation must include information obtained by one or more measures designed specifically to assess for symptoms of ASD. These measures provide caregiver, teacher, or self-report and/or direct assessment of an individual's social communication and RRB. In the report, presentation of the assessment results, as well as interpretation of the results, is important in order to further illustrate what the reader will later see in the diagnostic formulation. Assessment measures that look specifically at ASD signs and symptoms may consist of parent report measures and measures designed for direct assessment and observation of ASD behaviors. Due to the limited time an evaluator has with a client, parent/caregiver report measures may be beneficial to assess for behaviors that one may not see during the formal assessment. However, due to the parents' lack of formal training in assessment and diagnosis and to provide an objective measurement of reported deficits, parent report should not be sufficient in diagnosing ASD (Ozonoff, Goodlin-Jones, & Solomon, 2005). Formalized observational data should accompany parent/caregiver rating scales in arriving at an ASD diagnosis.

Other Important Instruments to Consider

In addition to ASD-specific measures, it is important to consider other test instruments that may be helpful in considering diagnosis. These measures include caregiver, teacher, or self-report and/or direct assessment of an individual's intellectual, language, adaptive, sensory, and behavioral patterns which are all important to consider when assessing for an ASD. Similar to the ASD-specific measures, it is important to also include examples of specific behaviors observed or endorsed to support diagnoses.

Measures of Cognitive/Developmental Functioning

Ozonoff et al. (2005) note that one's level of intellectual functioning is associated with severity of ASD symptoms, ability to learn new skills, and level of adaptive functioning. Additionally, level of intellectual functioning is one of the best predictors of later outcome for individuals with ASDs (Harris & Handleman, 2000). Reasons to assess for intellectual functioning would be to obtain the individual's strengths and weaknesses and determine appropriate educational placements and treatment recommendations.

Adaptive Functioning Scales

According to Ozonoff et al. (2005), there are several reasons to use an adaptive measure when assessing for ASD. Intellectual disability is very common among individuals diagnosed with ASD, and intellectual disability cannot be diagnosed without a measure of an individual's adaptive functioning. Similar to intellectual functioning, adaptive functioning level is important for treatment recommendations as reasons can indicate skills to target in therapy.

Behavior Scales

Individuals of all ages with an ASD may exhibit behavioral difficulties. These difficulties can range from a variety of topographies and functions. A robust evaluation should include data from a behavioral scale from multiple sources such as parents and teachers. Results from these scales can inform decisions regarding comorbid diagnoses as well as treatment recommendations.

Summary, Diagnostic Impressions, and Recommendations

Summary

The purpose of the summary section of the report is to concisely synthesize all of the previous information into succinct description of the

individual being evaluated and the obtained results. This section is important due to the fact that it is often the first section that the consumer reads. The author should write this section so that it builds a convincing case for the diagnosis given. The clinician should begin by summarizing identifying information about the individual being evaluated, including information about age, gender, current grade and name of school (or place of employment), and any previous diagnoses. Next, it is important to include a brief description of any services that the individual being evaluated currently receives (e.g., EI, SLT, etc.). This section should also include a brief summary of particularly relevant behavioral observations.

Once the clinician has adequately described the individual being evaluated, they should systematically report the findings from each of the measures given in the evaluation. The data from these measures should be synthesized and reported in one to two sentences, with performance ranges and strengths/weakness highlighted.

Diagnostic Impressions

After summarizing the individual's identifying information and the results of each measure, the clinician should integrate all of the information from the report, including the background history, to formulate a case conceptualization. The clinician should state if the individual meets the diagnostic criteria for ASD and provide supporting information (from background information and testing results) about the nature and severity of the disorder in terms of the core deficits (i.e., social communication and RRB).

Individuals with ASD commonly have comorbid diagnoses, and the clinician should follow the previously outlined method for reporting other diagnoses the individual meets, if applicable. When reporting comorbid diagnoses, it may be helpful to separate each disorder into an individual paragraph that includes all supporting information for the respective diagnosis.

Recommendations

The recommendations inform next steps that are relevant for the individual being evaluated. Moreover, the recommendation section allows the individual and/or their caregivers to understand specific interventions, treatment providers, and resources that are suggested to improve outcomes. The following information highlights the recommendation areas that clinicians might focus on and provides examples of specific services that individuals with ASD are commonly given (i.e., evidence-based practices), as based on the needs of the specific individual.

Education and Employment

The recommendations in this section vary depending on the age of the individual being evaluated. If the individual is very young (i.e., between birth to 3 years old), he/she may benefit from a comprehensive early intervention (EI) program that is supervised by a Board Certified Behavior Analyst (BCBA) or a licensed professional for at least 25 h per week (National Research Council, 2001). A program supervised by a BCBA or licensed professional will ensure that the individual receives applied behavioral analytic services, which are evidence based (Wong et al., 2013) and supported by many insurance providers nationally. These services typically are available in the individual's home or in outpatient clinic settings. Critical aspects of an EI program include a baseline skill assessment to determine goals (e.g., Assessment of Basic Language and Learning Skills, Revised or the Verbal Behavior Milestones Assessment and Placement Program), continual data collection for progress monitoring, updates to the treatment program as indicated by the data, frequent assessment of preferred items and activities, use of reinforcement strategies, and generalization of skills to different settings, with different people, and using different materials.

Once the individual no longer qualifies for EI (i.e., after age three), the individual's local school district is responsible for providing educational services. The previously described BCBA or

licensed professional supervised services may be provided by the school district as well; however, some districts may not have the capacity to provide these services, and parents would likely have to work with the school district to obtain those services for their child. Once the individual begins preschool at the local school district, they could be evaluated for eligibility in special education. However, the individual's eligibility for special education is based on criteria provided by the Individuals with Disabilities Education Act (IDEA; Individuals with Disabilities Education Act, 2004). Clinicians should be familiar with their state's IDEA mandates since there are state-specific applications. If the individual qualifies for special education under IDEA, they will receive an individualized education program (IEP).

The IEP may emphasize social, communication, and behavior goals (Torana, Yasina, Chiria, & Tahara, 2010). Within each IEP goal, the objectives should be criterion based and outline when and under what conditions the individual should engage in each skill (e.g., in group work, during transitions, when given visual cues, etc.). Additionally, the IEP objectives should state the expected criterion (e.g., 85 % of opportunities, with 85 % independence) and the mastery criteria for each criterion (e.g., 3 out of 4 days, 4 consecutive days). If the individual has behavior problems, the IEP should incorporate a positive behavior support plan (PBSP) that is informed by a functional behavior assessment (FBA).

The FBA should be conducted by a psychologist, BCBA, or adequately trained behavior specialist and assesses the antecedents and consequences of the individual's problems behavior. O'Neill, Albin, Storey, Horner, and Sprague (2014) provide comprehensive resource for implementation of FBA in school settings. The information from the FBA may be used to formulate a plan that can be implemented in the school and home setting, which will improve continuity. When creating the PBSP, the professional can target reductions of unwanted disruptive behavior (e.g., tantrums, noncompliance, self-injurious behavior) and increases in positive, adaptive replacement behaviors (e.g., raising hands to speak, improving social skills, improving coping around change and transitions), which are considered consequence interventions. They may also develop antecedent interventions that provide changes in the environment (e.g., visual schedules, warning, noncontingent breaks, etc.). In addition to antecedent and consequence procedures, the PBSP can include explicit teaching strategies of the replacement behaviors as well as an outline of the reinforcement schedule and data collection procedures.

Regarding the IEP and PBSP, school staff, BCBAs, teachers, and other professionals should meet regularly to discuss the student's progress and take particular measures to ensure that the IEP and PBSP are being implemented as planned (i.e., treatment integrity). The individual's family may also be included in these meetings. Parent involvement is an essential component for the success of the student, and these meetings provide an excellent opportunity to foster a strong home-school collaboration. Another aspect to consider for the IEP is the level of support and placement that the individual needs.

The clinician may recommend the appropriate placement for the individual being evaluated (e.g., self-contained classroom, inclusion classroom, out of district school). Also, the clinician may recommend if the individual needs support from a paraprofessional (which would be indicated by improved performance working one-on-one during the evaluation). The placement and supports that are needed will greatly depend on the individual's level of symptom severity. However, regardless of the individual's level of impairment, the clinician may recommend that the individual with ASD have the opportunity to interact with typically developing peer models to bolster his/her language, play, and social skills development (Wang, Cui, & Parrila, 2011).

Like all children with an IEP, once the individual with ASD reaches age 14, the school is responsible for developing a transition plan. The transition plan should initially focus on prevocational skills and develop into a comprehensive plan that helps identify potential career opportunities and skills needed to live independently. Once career opportunities and required skills are identified, the school staff may create individualized

learning opportunities that allow the individual with ASD to reach their postsecondary goals. Specific recommendations can include a variety of adaptive behaviors including responsible management of money, domestic skills, and successfully interacting in the community. The transition plan is part of the individual's IEP and should be developed and implemented with the same considerations as described previously in this section. Although specific recommendations regarding school accommodations and placements will likely be useful to the schools, it is important to note that it is ultimately up to the school to determine the accommodations that they will provide the individual. Referrals to advocates can support families in working with schools to ensure that the individual's needs are being met.

Regarding employment, if the individual has difficulty obtaining or maintaining a job, the individual or his/her family may wish to contact agencies in the community that can provide a variety of job-related assistance. Some of the services these agencies provide are job coaching, interview preparation, and job previewing. Typically, these agencies are state run or nonprofit, so services may be free or at a reduced price (depending on qualification for services).

Sleep and Feeding Assessment and Intervention

Individuals with ASD typically require interventions for sleep and feeding problems (Beighley, Matson, Rieske, & Adams, 2013; Hodge, Carollo, Lewin, Hoffman, & Sweeney, 2014). Clinicians should make appropriate recommendations for feeding and/or sleep, if applicable. For feeding problems, the clinician may refer the individual or his/her caregivers to a local interdisciplinary feeding clinic or their primary care provider. Regarding sleep problems, clinicians can recommend that the individual or their caregiver follows up with their primary care provider or local sleep clinic. If the sleep or feeding problems appear to be behavioral in nature, the clinician could recommend outpatient behavior management or parent training (these will be discussed further in the next section); however, an appropriate practitioner (e.g., speech-language pathologist, physician, etc.) can evaluate these presenting problems first to rule out any medical or physiological basis of the problem. The clinician may include the names, locations, contact numbers, and website for each referral source.

Behavior

Any difficulties with behavior management that were endorsed during the evaluation should be addressed in this section. Behavior management spans an array of areas including compliance, reduction of problems behavior, toileting, organization and study skills, and others (Carroll et al., 2014). Similar to school, the clinician may recommend that caregivers meet with a psychologist, social worker, or other professional with expertise in behavior management for individuals with ASD. The focus of the outpatient parent training sessions may be behavior management, conducted through manualized evidence-based parent training programs.

To improve responsibility and organizational skills, the clinician may recommend that the individual or his/her caregivers create lists of responsibilities at home and, if applicable, a planner for school. Being able to create lists and check items off the list as he/she accomplishes tasks will promote organizational skills and self-monitoring. In addition to self-monitoring, the individual with ASD may benefit from having a place at home to relax when upset. This spot should be used to calm down or deescalate his/her behavior when feeling elevated levels of frustration or anxiety. This strategy is unique from time-out procedures that may be implemented as part of behavioral parent training. Moreover, the relaxation area should not be used as a discipline strategy; rather it should be used as a way to facilitate effective coping skills. Also, the clinician can recommend that that relaxation area is collaboratively identified with the individual being evaluated and their caregivers, and only certain items should be available (i.e., not free access to toys). To ensure successful use of the relaxation area, the clinician may recommend that the individual and his/her caregivers practice using the area when calm, so that the individual can request for it when feeling upset.

Finally, if available through the individuals insurance, some behavioral services are home based. If so, this opportunity allows many of the previously described services to occur in-home, increasingly the generalization of skills in that setting (Roberts et al., 2011). The clinician should be familiar with local home-based behavioral and outpatient behavioral services and provide the individual or their caregivers with the names, locations, contact numbers, and website for each referral source.

Community

A variety of agencies provide services for individuals with ASD in the community setting. Clinicians should be familiar with the different agencies within their state and particular services. Recommendations for community supports for individuals with ASD include support groups for individuals and their family, job-related services (as described previously), vocational training, community activities, respite for families, and therapeutic mentors who can work one-on-one with the individual to improve adaptive skills. As mentioned in previous sections, the clinician should be familiar with community services and provide the individual or their caregivers with the names, locations, contact numbers, and website for each referral source.

Medical

Clinicians should be prepared to make recommendations for referrals to various medically related services. If the individual being evaluated or his/her caregivers endorsed anxiety or depression, the clinician may recommend that the individual or his/her caregiver schedule an appointment with a psychiatrist (or their primary care provider) for medication management.

If significant sleep difficulties, motor mannerisms, or seizures are present, the clinician may recommend that the individual receive an evaluation by a pediatric neurologist. This recommendation should encourage the individual and/or his/her family to pursue a referral through his/her primary care provider. The clinician should be familiar with local pediatric neurologists and provide the names, locations, contact numbers, and website for each referral source.

As mentioned earlier in the chapter, ASD tends to occur more frequently in people who have certain genetic or chromosomal conditions. ASD also commonly cooccurs with other neurological diagnoses. Considering this information, the clinician may recommend that the individual being evaluated receives an evaluation to determine the presence of related conditions from a developmental pediatrician or pediatric neurologist.

Social Skills

The clinician should provide recommendations that enhance the individual's opportunity to socialize with peers and develop appropriate social skills. Play dates can be highly recommended, and these play dates may be structured and facilitated by an adult. If available in the community, the clinician can recommend that individual participates in a peer training program in which typically developing peers are taught ways to interact with individuals with social skills deficits. The benefits of a peer-tutoring program include opportunities for the individual learn the appropriate social skills through modeling and successful social interactions with peers (DiSalvo & Oswald, 2002). Additionally, the clinician may recommend that the individual being evaluated has a specific IEP goal addressing social skills, with a focus on peer interaction skills.

To address social skill goals in the IEP, the clinician may recommend that the school use a structured social skills assessment, such as the Social Skills Improvement System-Rating Scale (Gresham & Elliott, 2008), to help identify specific, measurable social goals for the IEP. Moreover, the clinician can recommend that the individual receives structured social skill instruction in a small group setting (this could occur at school or in an outpatient clinic setting). Social skill groups can focus on social pragmatics, initiating and terminating interactions, responding to others, improving flexible play skills, and reading social cues and body language. Older individuals may work on developing and

maintaining peer interactions. Regardless of age, the clinician can also recommend that individuals with ASD receive structured social skills training, which includes direct instruction, modeling (live or video modeling), feedback, role-playing, and social narratives.

Finally, if the individual with ASD is shy or withdrawn, the clinician can recommend that the individual receive interventions to promote self-advocacy and assertiveness skills. These skills will promote communication with teachers, staff, and peers and help the individual with completing tasks, understanding directions, and asking for help.

Communication Skills

If indicated in the evaluation, the clinician may recommend that the individual receive a speech and language assessment and therapy. Although the individual may receive these services in the school setting, these services are also available in outpatient clinical settings. SLT services for young children can focus on developing pragmatic language and conversation skills (e.g., making eye contact, asking/answering questions, taking turns, sustaining back-and-forth exchanges, staying on topic, listening to speaker, understanding humor/sarcasm/nonliteral language) and teaching skills around nonverbal language (e.g., reading body language and social cues). SLT services may also focus on decreasing scripted or idiosyncratic speech, if applicable.

If the individual has a limited verbal repertoire, an assistive augmentative communication (AAC) system may be recommended. The AAC system may be used to promote easily performed communication skills. The speech-language pathologist can assess to determine the most appropriate communication system. Examples of AAC systems include picture exchange communication system, American Sign Language, and microswitches. The clinician can recommend that the individual's caregiver consult with a speech pathologist and other service providers to determine which system to use and strategies to implement the system consistently across settings.

Sensory and Motor Difficulties

If the individual with ASD has not received an evaluation for their sensory and/or motor impairments, the clinician may recommend that he/she receive a referral from his/her primary care provider for an OT and/or PT evaluation. These providers can make specific treatment recommendations after assessing the individual's deficits in each of these areas. The clinician should be familiar with OT and PT service providers and make specific suggestions; however, the individual's insurance provider may ultimately dictate service providers on the basis of coverage. The clinician should provide the individual or their caregivers with the names, locations, contact numbers, and website for each referral source.

Miscellaneous

Aside from the domain-specific recommendations that a clinician could provide, there are a variety of miscellaneous recommendations that a clinician should consider. If the individual has social-emotional needs, the clinician may include recommendations for school (e.g., scheduled meetings with school adjustment/guidance counselor, noncontingent breaks, check-in system when experiencing elevated anxiety) and in the community. Community-based social-emotional recommendations may include outpatient individual psychotherapy. Therapy can focus on developing social skills, increasing coping skills, and regulating mood. Specifically, cognitive-behavioral therapy using workbooks such as *Coping Cat Workbook*, *Second Edition* (Kendall & Hedtke, 2006) may be beneficial.

Regardless of the program, the focus of therapy can include discussing and identifying emotions, empathizing with others, and relaxation techniques (e.g., progressive muscle relaxation, diaphragmatic breathing). For higher functioning individuals, therapy can include cognitive strategies including visualization, thought challenging, and cognitive restructuring. The clinician may recommend that the individual's therapist provide ongoing progress monitoring of anxiety or depression. In addition to the symptoms of anxiety, if the individual endorsed compulsive behaviors,

the clinician can include recommendations for compulsions as well. These recommendations include the previously described coping skills and response prevention and exposure. If the individual being evaluated experiences bullying, the clinician may provide recommendations for outpatient therapy that help with assertiveness and social skills.

Finally, depending on the results of the evaluation, the clinician can recommend a reevaluation. The clinician may recommend that young children be evaluated during pivotal transitions (e.g., entry into kindergarten or other large transition). The clinician should convey that the reevaluation will update assessment results and treatment recommendations.

Conclusion

The increase in the number of individuals diagnosed with ASD has implications for the delivery of appropriate diagnostic, intervention, and support resources. A National Research Council (2001) committee estimated that 10 years ago, fewer than 1 in 10 children were receiving appropriate treatment. Therefore, a comprehensive and well-written report is essential for an individual to receive appropriate treatment and interventions in a variety of settings (Saulnier & Ventola, 2012). Comprehensive assessment reports are the summation and culmination of psychological evaluations (Lichtenberger et al., 2004) and should include results from all perspective involved in the evaluation, allowing for a comprehensive formulation to exist in a single document. Overall, a comprehensive psychological report for individuals with suspected ASD is essential in order to provide accurate diagnosis and convey relevant recommendations for treatment.

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Screening Methods

5

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Introduction

As discussed in Chap. 3 of the present volume, the form and function of assessment depends on the intended purpose of the assessment. Assessment may be conducted for the purpose of diagnostic evaluation, intervention planning, progress monitoring, or screening, among others. The goal of our chapter is to provide a general introduction to the purpose and methodology used for screening individuals for the presence of autism spectrum disorder (ASD). We situate screening within a larger process of diagnostic evaluation and provide an overview of approaches to evaluating screening instruments, in general. We briefly review symptoms that have shown to be predictive of a diagnosis for ASD for young children, and then we selectively review various screening instruments available for clinical practice. Screening approaches and measures are then introduced for older children, including those of school age. The chapter emphasizes the impact of base rate on screening accuracy and identifies several possible approaches to counter the problem of low base rate. Our chapter concludes with general recommendations for screening for ASD.

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General Purpose and Methods for Screening

Our working definition of screening is "the prospective identification of unrecognized disorder by the application of specific tests or examinations" (Baird et al., 2001, p. 468). As further explained in Chap. 3, screening is differentiated from surveillance, developmental monitoring, and diagnostic evaluation. ASD-specific screening involves application of specific procedures as opposed to general developmental monitoring or general developmental screening, which may be conducted through informal interviewing or application of a general developmental checklist. It is also critical to understand that screening methods and procedures yield data about *risk* for the presence of a disorder as opposed to rendering a diagnosis.

The utility of a screener is determined by a variety of factors, such as its usability with large groups and degree of specialized knowledge required to administer and score. From a psychometric perspective, screeners are judged by the degree of predictive validity or the screener's capacity to accurately discriminate between the presence and absence of a disorder. Various indices exist to capture the accuracy of a screener and a few are introduced here (see Chap. 3 for more detailed description and illustration). Overall accuracy is the total number of correct outcomes

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produced by a screener. Sensitivity refers to the proportion of those with the disorder correctly detected by the screener; specificity refers to the proportion of those without the disorder correctly excluded by the screener. Positive Predictive Value (PPV) refers to the proportion of individuals who screen positive whopare correctly diagnosed with the disorder. Negative Predictive Value (NPV) refers to the proportion of individuals who screen negative who are correctly excluded from having the disorder. A psychometrically sound screener is one that consistently produces sensitivity, specificity, PPV, and NPV values that meet or exceed 0.80.

An Example of Screening

Table 5.1 provides an illustrative example of how screeners may be evaluated and the unique types of information produced within a generic screening evaluation model. In our ideal example, assume that a screener is administered to a sample of 1000 young children who subsequently receive a comprehensive evaluation for the presence or absence of ASD. The example also assumes that the prevalence rate of ASD in this sample is 5 %, which exceeds prevalence rates reported in the literature, yielding a total number of 50 children diagnosed with ASD. Based upon the results, the screener produces 135 positive screens from the sample and correctly identifies 40 of 50 children with autism, i.e., sensitivity of 0.80. The screener produces 865 negative screens and correctly excludes 855 of 950 individuals, thereby yielding a specificity of 0.90. Of the 135 children screening positive, 40 are diagnosed with autism which yields a PPV of only 0.30. Conversely, of the 865 children screening negative, 855 are not diagnosed with autism which yields a NPV of 0.99. In this example, the screener yields minimally acceptable sensitivity, specificity, and overall hit rate; however, the screener produces an unacceptably poor PPV. In our ideal example, *all children are screened and subsequently evaluated*, a situation that yields a complete set of accuracy statistics, e.g., all screen negative cases complete a diagnostic evaluation despite "passing" the screener. In applied research, particularly investigations involving large sample sizes, follow-up evaluation is cost prohibitive; therefore, most accuracy statistics are known to be inaccurate. Applied research is also consistently limited by lack of follow-up of children over time, a problem that often affects sensitivity values as more children are subsequently identified with ASD as they grow older.

Within the screening paradigm, two errors result: false positives and false negatives. Each is associated with untoward outcomes. For false negatives, the screening error does not allow for detection of a condition and receipt of appropriate intervention and may produce a misleading assumption that additional screening is unnecessary in the future. For false positives, the screening error wastes time and resources for individuals who do not need assessment and interventions. False positives may also produce undue stress for those undergoing additional assessment. Given the general purpose of screening, however, false positives are typically viewed as more acceptable errors.

Table 5.1 An example of screening 1000 individuals with base rate of 0.05

	Diagnostic result			
Screening result		Disorder	No disorder	
	Positive	True positive 40	**False positive 95**	PPV 40/135 = 0.30
	Negative	**False negative 10**	True negative 855	NPV 855/865 = 0.99
		Sensitivity 40/50 = 0.80	Specificity 855/950 = 0.90	Hit rate 40 + 855/1000 = 0.90

Note. Sensitivity of test is 0.80. Specificity of test is 0.90. PPV = Positive predictive value; NPV = Negative predictive value

Screening for Autism in Young Children

Presently, ASD is a neurodevelopmental disorder defined by (a) social-communicative (SC) impairments and (b) impairing restrictive/repetitive behaviors or interests (RRB) present early in development. Parents often identify concerns about their children's development in the first 2 years of life. Concerns are often shared with healthcare providers when children are 14–18 months old, with some concerns being conveyed as early as 11 months (Chawarska, Klin, Paul, & Volkmar, 2007; Coonrod & Stone, 2004). First symptoms often involve language delay accompanied by social communication delays or deficits. For example, infants and toddler with ASD are often less responsive to their name being called; have difficulties with eye contact; demonstrate less social smiling; show poor imitation skills; or lack imitation skills altogether. During children's early development, caregivers often report concerns that their child may be deaf due to the lack of social response to their name being called. Early symptoms of ASD also include poor pretend play skills and impairments in joint attention, both in its initiation and appropriate response. The social communicative and play difficulties exhibited by many young children with ASD are part of the repertoire of typically developing children by the age of 18 months. The presence of these symptoms also discriminates between young children with ASD and those with language and developmental delays.

Early symptoms of RRB include unusual toy play (e.g., repetitive play with toys; lining up toys), repetitive interests (e.g., watching same videotape or video clip), and repetitive movements (e.g., hand flapping). Approximately one third of those with ASD experience a period of developmental regression, whereby acquired skills are lost. Regression is most often reported in the area of language development and most often during the ages of 20–24 months (Barger, Campbell, & McDonough, 2013). Despite the presence of early parental concerns and symptoms, the average age of diagnosis for ASD diagnosis in the United States is often reported at 4–5 years of age (e.g., Centers for Disease Control [CDC], 2012). Wiggins, Baio, and Rice (2006) further documented that the average time delay between initial evaluation for developmental concerns and diagnosis of ASD was 13 months. Given these findings, it is important that research and clinical practice continue to focus on reducing the time between initial parental concerns, age of initial evaluation for ASD, and age of diagnosis. By screening for ASD in young children, clinicians have the opportunity to promote earlier evaluation, diagnosis, and access to specialized interventions, which have been shown to improve social, emotional, cognitive, and behavioral functioning in young children with ASD (Dawson et al., 2010; Eaves & Ho, 2004).

Overview of Screening Measures for Early Childhood

Due to the importance of early assessment and targeted interventions for young children with ASD, the field has developed and validated, with some success, screening measures designed to identify autism-specific symptoms in young children. By utilizing screening tools with young children, clinicians are better able to identify children at risk for developmental delays and ASD in order to refer them for more comprehensive evaluations (Meisels, 1985). The current section reviews Level 1 screeners, which are designed to identify children at risk for developmental disorders from unselected, generally low-risk populations, as well as Level 2 screeners, which are used to differentiate children at risk for autism versus those at risk for other developmental disorders.

Screening measures differ in purpose and usability across settings (Zwaigenbaum & Stone, 2006). Specifically, Level 1 screeners tend to be used commonly in pediatric or primary healthcare settings at well-child visits, thus suggesting that these screeners should be quick and easy to administer and score given the limited time clinicians can typically spend with each child. On the other hand, Level 2 screeners are used more

frequently in community settings that serve children with a range of disabilities such as early intervention programs or diagnostic centers, which tend to have more time to conduct more interactive, time-consuming evaluations. Despite the differences in the types of screeners, researchers have suggested that multilevel models of screening and a combination of screening tools may be more effective than a single screener in some cases (Miller et al., 2011; Roux et al., 2012). For example, a risk-prevention model, in which Level 2 interactive screeners are used to assess children identified as at risk for autism during Level 1 screening, is designed to increase children's access to earlier, specialized interventions (Ibañez, Stone, & Coonrod, 2014).

Level 1 Screening Measures

In order to identify children at risk for ASD within the general population, two approaches can be used. One strategy, referred to as general developmental screening, identifies children at risk for a variety of developmental problems including ASD. In contrast, Level 1, autism-specific screeners are used to screen the general population to identify ASD symptoms within a child's overall developmental profile. In the following section, both types of Level 1 screening measures are described, including brief overview of validity and reliability information presented in peer-reviewed publications.

General Developmental Screening

Researchers have found that most (82 %) of pediatricians screen for general developmental delays; however, less than half of these pediatricians utilized validated procedures (dosReis, Weiner, Johnson, & Newschaffer, 2006; Self, Parham, & Rajagopalan, 2014). It is crucial for healthcare providers who service young children to use general developmental screeners in order to identify children with cognitive, language, or social delays. By using general developmental screening measures, healthcare providers can make referrals to specialty clinics or early intervention centers if children are identified as at risk for a developmental delay or disorder. Many broad developmental screeners play a role in the early identification process; three measures are briefly reviewed in this section. Two widely used general developmental measures are the Ages and Stages Questionnaire, Third Edition (ASQ-3; Squires & Bricker, 2009) and the Parents' Evaluation of Developmental Status (PEDS; Glascoe, 2003). A third tool, the Infant/Toddler Checklist (ITC) component of the Communication and Symbolic Behavior Scales Developmental Profile (CSBS DP; Wetherby & Prizant, 2002), focuses more specifically on children's communication and symbolic functioning.

Ages and Stages Questionnaire, Third Edition

The Ages and Stages Questionnaire, Third Edition (ASQ-3) is a 30-item parent-report measure designed to examine developmental functioning in children ages 1–66 months in the following five domains: communication, fine motor, gross motor, personal-social, and problem solving (Bricker & Squires, 1999; Squires & Bricker, 2009). The ASQ-3 includes age-specific questions and identifies children as "at risk," "not at risk," or in the "monitoring zone," which indicates their development should continue to be monitored over time. For risk classification, the ASQ-3 has high test-retest reliability (0.92) and inter-rater reliability (0.93). Sensitivity ranges from 0.83 to 0.89 and specificity ranges from 0.80 to 0.92 across ages (Squires & Bricker, 2009). Overall, the ASQ-3 seems to screen appropriately for overall general developmental functioning; however, it will not identify specific cases of ASD or ASD symptoms, such as joint attention or interest in peers.

Parents' Evaluation of Developmental Status

The Parents' Evaluation of Developmental Status (PEDS is a brief, 10-item yes/no parent questionnaire that assesses developmental concerns for children ages 1–95 months in the following five domains: global/cognitive, expressive language, receptive language, social-emotional, and other (Glascoe, 1998, 2003). Responses to the PEDS

are divided into "predictive" or "non-predictive" concerns. The PEDS was validated on a sample of 771 children ages 0–8 from urban, rural, and suburban areas across the United States. Sensitivity ranges from 0.74 to 0.79 while specificity ranges from 0.70 to 0.80. Currently, mixed findings have been reported regarding the PEDS' ability to identify children at risk for ASD among the general population. One group of researchers found that the PEDS failed to identify a large portion of children who were identified using the Modified Checklist for Autism in Toddlers (M-CHAT; Robins, Fein, Barton, & Green, 2001), which is an autism-specific screener. In conclusion, the PEDS meets the recommended psychometric properties for a general development screener, and it has been standardized and validated as well as used commonly in settings that serve young children. Future research should continue to explore the usability and psychometric properties of the PEDS as it relates to the identification of ASD.

Infant Toddler Checklist

Another tool focused on identifying children at risk for language, social communication, and general developmental delays is the Communication and Symbolic Behavior Scales Developmental Profile (CSBS DP; Wetherby et al., 2004; Wetherby & Prizant, 2002). Based on Wetherby and Prizant's (1993) work, the CSBS DP is comprised of three separate measures that can be used for a variety of purposes depending on the setting and particular needs of the population. The Infant/Toddler Checklist (ITC) is reviewed here as it is considered to be a broad, population screener, and the other two tools, the CSBS DP Caregiver Questionnaire and the CSBS Behavior Sample, are follow-up assessment measures typically employed after children have been previously identified. For a comprehensive review of these two measures, refer to Wetherby and Prizant (2002). Based on standard scores across a 4-month interval for a normative sample, the CSBS DP has internal consistency ranging from 0.86 to 0.92 and good test-retest reliability (Wetherby, Brosnan-Maddox, Peace, & Newton, 2008).

The ITC component of the CSBS DP is a standardized instrument, consisting of 24 yes/no parent-report items and one open-ended parent concern question. Specifically, parents are asked to describe their child's developmental concerns if they answer "yes" to the following question: "Do you have any concerns about your child's development?" The ITC screens for deficits in communication and symbolic skills among 6–24-month-old infants (Wetherby et al., 2008; Wetherby & Prizant, 2002). The ITC not only features screening cutoff scores but also has related standard scores at monthly intervals based on a normative sample of 2188 children ages 6–24 months (Wetherby & Prizant, 2002). In one study, Wetherby et al. (2004) examined the validity of the ITC in detecting communication delays in over 3000 children ages 6–24 months who were screened from a general population sample as part of the FIRST WORDS® Project. The following two samples were asked to receive further evaluation using the CSBS DP Behavior Sample after they were initially screened with the ITC: (a) children who scored in the bottom tenth percentile on the ITC and (b) randomly selected children functioning within normal limits on the ITC. After further evaluation, children were diagnosed with ASD, diagnosed with developmental delay, or identified as typically developing.

When the ASD and DD groups were combined together and compared to the typically developing group, sensitivity was estimated to be 88.9 %. However, sensitivity increased to 94.4 % when the ASD group was solely examined with the typically developing group. Overall specificity was 88.9 %. Thus, the ITC had good sensitivity and specificity to be used as a general population screener for developmental abnormalities, including ASD and other DDs. More recently, researchers used similar procedures as Wetherby et al. (2004) to further validate the ITC. Results suggested that the ITC is valid for screening children ages 9–24 months, but it fails to accurately assess parental concerns at 6–8 months (Wetherby et al., 2008). Specifically, the PPV and NPV, which were above 70 %, both support validity of the ITC for children 9–24 months; however, the false negative rate

was high for 6- to 8-month-old infants. Additionally, less than half of the parents in the sample reported concerns between 6 and 15 months; however, 75 % reported concerns between 21 and 24 months.

Currently, a positive screen on the ITC does not necessarily differentiate children with ASD from those with other developmental problems; however, some researchers suggest the ITC is more capable of screening a heterogeneous sample of children with ASD that is more inclusive of high-functioning individuals. Specifically, the ITC was able to identify children with higher composite scores and greater variability on the Mullen Early Learning Scales (Wetherby et al., 2008) than were identified in a lower-scoring sample screened using another parent-rated screener (Kleinman et al., 2008). If children screen positive on the ITC screener, then clinicians may consider referral for further communication evaluation using the CSBS Behavior Sample or an autism-specific Systematic Observation of Red Flags for Autism (SORF). If children screen negative on the ITC, then they should consistently participate in developmental screening every 3 months until age 24 months (Wetherby et al., 2008). Future research should continue to examine the validity of the ITC in determining which children should receive ASD diagnoses within a large, general sample.

Summary

Although differences in population makeup and sampling may explain various results, general consensus suggests that broad-based measures do not sufficiently identify all children who may be at risk for ASD. Thus, general developmental screeners should be utilized in pediatric primary care settings to identify children for a range of developmental concerns; however, they do not seem to replace first-stage, autism-specific measures. If general developmental measures are to be used as first-stage screeners, further research is needed to validate their use in detecting children with ASD and other DDs. Currently, the most accurate approach is to use a broadband measure followed by an ASD-specific tools when screening children ages 18–24 months in the general population (Ibañez et al., 2014).

Level 1 Autism-Specific Screening

In order to identify unique behavioral symptoms indicative of ASD, Level 1, autism-specific measures have been developed for screening general populations. The American Academy of Pediatrics (AAP) recommends that these measures be used at 18- and 24-month preventive pediatric healthcare visits (Johnson & Myers, 2007); however, pediatricians often do not screen for ASD and, if they do, they often do not adhere to the AAP guidelines (e.g., Self et al., 2014). Comprehensive reviews of published autism-specific screeners are available to supplement our review (Mawle & Griffiths, 2006; Robins & Dumont-Mathieu, 2006); select peer-reviewed Level 1 autism-specific screeners are reviewed in the following section.

Checklist for Autism in Toddlers

Over two decades ago, Baron-Cohen, Allen, and Gillberg (1992) developed the Checklist for Autism in Toddlers (CHAT), which was the first autism-specific measure designed for general population screening during 18-month-year olds' routine healthcare visits. The CHAT is a nine-item parent-report measure combined with five items to be observed by health professionals. The CHAT samples children's functioning in several areas, with particular focus on early signs of ASD, such as gaze monitoring, use of protodeclarative pointing (i.e., initiating joint attention), and pretend play (Baron-Cohen et al., 1992). In the first publication establishing the CHAT's psychometric properties, the measure was used to screen 50 infants during routine, 18-month checkups as well as a sample of 41 young siblings of children with autism, a high-risk sample (Baron-Cohen et al., 1992). Using a cutoff criteria of failing two or more skill areas, the CHAT correctly identified four children who were later diagnosed with ASD while none of the typically developing siblings were identified using the CHAT.

A later study used the number of passes and failures within each of the three domains to place 16,000 18-month children into one of three groups: Autism, Developmental Delay (DD), or Typically Developing (Baron-Cohen et al., 1996). Out of the 12 children placed in the Autism

group, ten later received a diagnosis of autism and two received a diagnosis of DD, which were confirmed 3.5 years after initial evaluations. A follow-up study conducted 6 years later rescreened the sample and established scoring thresholds for groups identified as either high or medium risk for autism (Baird et al., 2000). The high-risk criteria required children to fail items about protodeclarative pointing and pretend play on both parent and observer portions of the CHAT as well as gaze monitoring items when observed by the clinician. However, the medium-risk criteria required children to fail the protodeclarative pointing parent and observer portions but pass one of the other items.

Using the high-risk criteria, the CHAT identified 10 of 50 children with ASD in the population sample of 16,235. As such, the CHAT produced a sensitivity of 0.20 and specificity of 0.998. Using medium-risk criteria, sensitivity was 0.38, specificity was 0.98, and the PPV was 0.05. When children were screened twice using the CHAT, the PPV increased to 0.75 and the sensitivity decreased to 0.18 (Baird et al., 2000). Although the CHAT identified some children who later received diagnoses of ASD, it did not identify a majority of the children. Overall, the poor sensitivity and high false negative rates associated with the CHAT suggest that future research is needed to determine its effectiveness in screening for ASD symptoms in 18-month-old infants. Additionally, the CHAT may not represent the ideal screening tool for all settings as it requires both clinician observation of children's behaviors and parental report.

Modified Checklist for Autism in Toddlers

The Modified Checklist for Autism in Toddlers (M-CHAT) is a modified version of the CHAT adapted for use as a Level 1 screener in pediatric settings in the United States (Robins et al., 2001). The M-CHAT consists only of parent-rated items; however, physicians can "flag" the screener when they suspect autism despite responses on the parent checklist. The M-CHAT is comprised of 23 questions, including nine items from the parent-report CHAT and 14 other items specifically related to symptoms of autism present in young children such as repetitive behaviors, which are not included on the CHAT. The following six critical items are included on the M-CHAT: protodeclarative pointing, following a point, showing objects, imitation, interest in other children, and response to name (Robins et al., 2001). Internal consistency reliabilities for the entire screener ($a = 0.85$) and six critical items ($a = 0.83$–0.84) are adequate (Kleinman et al., 2008; Robins et al., 2001). A Chinese version of the M-CHAT, known as the CHAT-23, has recently been developed; however, the measure should continue to be examined for its utility across settings and in other countries (Wong et al., 2004). The English version of the M-CHAT is reviewed in the following section.

To examine initial psychometric properties of the M-CHAT, 1122 children were screened in primary care settings and 141 children in early intervention sites using the M-CHAT screener (Robins et al., 2001). Robins et al. (2001) utilized follow-up interviews to confirm the presence of symptoms in children who met the cutoff criteria, which were either failing two or more critical items or failing any three items. Children who failed the screener after the interview participated in further evaluation. In this sample, 58 children received evaluations, 74 parents completed follow-up interviews that did not end in their children failing the M-CHAT, and 1161 children did not require follow-up interviews.

Most children diagnosed with ASD were referred from early interventionists, indicating the sample was initially a high-risk group. Results varied depending on the cutoff criteria (i.e., failing two critical items or three total items) as well as whether or not children who passed after follow-up interviews were labeled as false positives. Initial results, which examined the checklist and follow-up interview combined, revealed sensitivity ranging from 0.95 to 0.97, specificity ranging from 0.95 to 0.99, PPV from 0.36 to 0.80, and NPV reported at 0.99 (Robins et al., 2001).

Another study examined the M-CHAT by screening 3309 children in a low-risk sample at well checkups and 484 children in a high-risk sample who were either referred by specialists for further evaluation or screened by early

intervention providers (Kleinman et al., 2008). Identical to Robins et al. (2001) initial results, the PPV of the entire sample was 0.36; however, the PPV of the low-risk sample alone was 0.11 compared to 0.60 for the high-risk sample. When examining the children whose initial failed screens were confirmed during follow-up interviews, the PPV of the entire sample rose to 0.74. Similarly, the PPVs of both groups (low risk—0.65; high risk—0.76) also increased when solely including the children whose responses on the screener were confirmed via interview. When children were rescreened and re-evaluated at around age 4, seven children were diagnosed with autism who did not fail the M-CHAT screen at a younger age (Kleinman et al., 2008). Thus, seven false negatives were identified out of the total sample of 1416 from combined low- and high-risk samples when children's symptoms were monitored in longitudinal studies.

In a large, recent follow-up study, 18,989 toddlers between the ages of 16 and 30 months were screened during well-child visits (Chlebowski, Robins, Barton, & Fein, 2013). Of the 1737 children who screened positive on the initial M-CHAT, 74.6 % participated in the follow-up interview, and 1023 children screened negative after the interview. However, 272 continued to screen positive after the phone interview and were referred for further evaluation. The PPV for the initial M-CHAT screening alone was 0.06, and the PPV was 0.53 for the M-CHAT combined with the follow-up phone interview. Overall, results indicate that it is crucial to combine the M-CHAT screener with a follow-up telephone interview to reduce false positive and avoid unnecessary referrals and parent concerns (Chlebowski et al., 2013; Kleinman et al., 2008). This factor is especially important in settings that serve large numbers of families, thus leaving healthcare providers with limited time and resources to spend on each child.

The use of a brief, follow-up interview, either on the phone or in person at a healthcare provider's office, improves accurate referral for further diagnosis and screening for suspected ASD. Recently, a revised version, referred to as the Modified Checklist for Autism in Toddlers—Revised, with Follow-Up (M-CHAT-R/F; Robins, Fein, & Barton, 2009), was developed to allow physicians to review responses on the M-CHAT-R checklist with parents in greater detail. The follow-up interview serves as a Level 2 screener within the M-CHAT-R/F screener and it is discussed in the Level 2 screening section. In conclusion, mixed results regarding the sensitivity and specificity of the M-CHAT suggest that future research should continue to provide support for the utility, reliability, and validity of this common autism-specific Level 1 screener. However, the M-CHAT is the most commonly used and researched tool for screening for ASD in the general population.

Pervasive Developmental Disorders Screening Test, Second Edition

The Pervasive Developmental Disorders Screening Test, Second Edition (PDDST-II) is a parent-report screening measure for autism and other pervasive developmental disorders designed for children ages 12- to 48-months old (Siegel, 2004). The PDDST-II is comprised of three forms that include both Level 1 and Level 2 screeners as well as an additional form; the appropriate form is selected depending on the proposed purpose of the screener. Depending on clinical use, three PDDST-II forms exist: (a) a Stage 1—Primary Care Setting form, (b) a Stage 2—Developmental Clinic Setting form, and (c) a Stage 3—Autism Clinic Severity Setting form. Each stage is associated with varying cutoff scores and can be used in conjunction or individually.

The Primary Care Setting (PCS) form, which consists of 22 parent-report items, is most likely to be utilized by general pediatricians and primary care physicians to identify 12- to 48-month-old infants at risk for autism (Siegel, 2004). When 681 children at risk for ASD and 256 children with other developmental disorders were screened using the PCS, sensitivity and specificity were found to be 0.92 and 0.91 (Siegel, 2004). The Developmental Clinic Setting (DCS) form includes 14 items that can be used to identify children in specialized developmental settings who are more likely to have autism than a range of other developmental disorders. When the DCS

form was used to compare functioning of 490 children diagnosed with ASD to 194 diagnosed with other disorders, sensitivity and specificity were found to be 0.73 and 0.49, respectively, when an associated cutoff score of 5 was utilized (Siegel, 2004).

Lastly, the Autism Clinic Severity Setting (ACSS) form consists of 12 items that assess early symptoms to predict severity levels of ASD. When the ACSS form was used to compare 355 children with ASD to 99 children with either PDD-NOS or Asperger's disorder, sensitivity and specificity were found to be 0.58 and 0.60, when an associated cutoff score of eight was utilized. The Level 1 PCS form correctly classified over 90 % of cases; however, the sample presented in the manual was a selected sample of children at high risk at the time of screening. Thus, the PCS form of the PDDST-II should be validated by screening children in the general population rather than those who have already been identified as at risk to be fully endorsed as an appropriate Level 1 screener. Additionally, the sensitivity and specificity of the DCS form fall below generally acceptable levels for a screener; therefore, the DCS needs additional validation before it is recommended as a Level 2 screener. Overall, additional studies exploring the psychometric properties and usability of the entire PDDST-II rating system are needed prior to its endorsement.

Summary

Many children falsely identified by autism-specific screeners meet criteria for other developmental delays; therefore, children without ASD but other delays may benefit from early screening using ASD-specific or broad-based tools. Young children should be screened for ASD at 18- and 24-month checkups as well as whenever parental concerns are expressed. When examining sensitivity and specificity, some of the measures (i.e., M-CHAT and M-CHAT-R/F) appear promising; however, results of many studies are difficult to generalize. For example, some studies included high-risk samples when assessing general population screeners, failed to validate cutoff criteria before conducting studies, and refrained from following up with children who passed the screeners after their initial screening. Even for measures, such as the M-CHAT, that have generated promising psychometric support, there are limitations associated with imperfect measures designed to identify relatively low base rate disorders, such as ASD. The impact of low base rate is discussed further in subsequent sections of the chapter.

To address potential concerns and reduce false positives, healthcare providers should follow-up with parents whose children fail the screening by reviewing any flagged items or concerns. Additionally, clinicians should continue to screen children for developmental concerns that may arise in the future despite passing an initial screening. Overall, the M-CHAT and M-CHAT-R serve as the strongest Level 1 autism-specific tool; however, the Level 2, follow-up interview (i.e., M-CHAT-R/F) should be included as part of the initial screening to confirm positive screens. The follow-up interviews can take place over the phone or in physicians' offices, especially if an electronic version of the M-CHAT is utilized. The electronic version of the M-CHAT, which has been researched preliminarily in a primary care setting (Harrington, Bai, & Perkins, 2013), is unique in that it can be scored instantly, enabling physicians to conduct follow-up questioning at the same time as the developmental screening and well-child visits.

Level 2 Screening Measures

The following section contains a brief overview of measures designed to identify children with autism after developmental concerns have already been noted. Level 2 autism-specific screeners are most commonly used in community settings, such as early intervention centers or evaluation clinics, to help differentiate children at risk for autism from those at risk for other disorders. Peer-reviewed, published measures that utilize a variety of formats (i.e., follow-up interviews, standardized observations, rating scales) are reviewed in this section. The rating scales are relatively easy to score and administer while standardized observations tend to be more time-consuming and require a higher level of clinician training.

Modified Checklist for Autism in Toddlers: Revised/Follow-Up

As discussed above, the M-CHAT is one of the most commonly used Level 1 screeners; however, research suggests clinicians should utilize the follow-up interview to reduce false screens using the M-CHAT alone (Chlebowski et al., 2013). The Modified Checklist for Autism in Toddlers—Revised/Follow-up (M-CHAT-R/F) is a two-step screener for detecting symptoms of ASD in children ages 16 to 30 months. Although the M-CHAT-R/F is similar to the M-CHAT (Robins et al., 2001), several changes have been incorporated including dropping three items that performed poorly, reorganizing the placement of items, simplifying language, and clarifying items by using examples and adding context. In present form, the M-CHAT-R/F has 20 items and classifies children at low (total score <3), medium (total score 3–7), or high risk (total score ≥ 8) for autism based on parental responses (Robins et al., 2009). If children are classified as medium risk at initial M-CHAT-R/F screening, the follow-up interview can be completed via telephone or in person to confirm failed items (Robins et al., 2009). Children who continue to be classified as medium risk after interviews should be referred for further diagnostic evaluation. However, children initially classified as high risk should immediately be referred for further evaluation and/or early intervention services.

Robins et al. (2014) report that 7 % of 16,071 children fell into medium or high risk compared to 9 % of children on earlier versions of the M-CHAT. The overall autism detection rate was higher for the M-CHAT-R/F (67 cases per 10,000 screened) than for the earlier version (45 cases per 10,000 screened). Overall, the modified instrument seems to have several advantages over the earlier versions; however, preliminary data suggest that the screening performance of the M-CHAT-R/F does not differ significantly from the original version as long as the follow-up interview is utilized (Robins et al., 2014). Future research is needed on the M-CHAT-R/F if it is intended to replace the original M-CHAT in primary healthcare settings. The M-CHAT-R/F rating form, follow-up interview, and scoring software are also freely available at: www.mchatscreen.com.

Screening Tool for Autism in Toddlers

The Screening Tool for Autism in Toddlers (STAT) is a Level 2 screener involving a 20-min, play-based interactive session with children ages 24 to 36 months (Stone, Coonrod, & Ousley, 2000; Stone, Coonrod, Turner, & Pozdol, 2004). The 12 items administered during the session assess the four following domains of social communication: play (two items), motor imitation (four items), directing attention (four items), and requesting (two items). Assessment of the four domains does not require language comprehension, and the domain scores are equally weighted and combined to derive a total score ranging from 0 to 4, with higher scores representing more impairments and a cutoff score of 2 indicating "risk for ASD."

To assess the validity of the STAT, Stone et al. (2000) randomly assigned 24- to 35-month-old children to one of two groups: (a) a development sample and (b) a validation sample. The development sample consisted of seven children with ASD and 33 with disorders other than ASD while the validation sample included 12 children with ASD and 21 with other disorders. When diagnosis based on DSM-IV criteria was used as the standard, the sensitivity and specificity of the development sample were 1.00 and 0.91, respectively. Examination of the validation sample alone yielded sensitivity and specificity of 0.83 and 0.86, as well as PPV of 0.77 and NPV of 0.90. When subgroups of children with and without autism were created and matched on mental age, the sensitivity and specificity were both 0.83.

Using a similar approach as above, Stone et al. (2004) matched two groups consisting of 26 children with autism and 26 children with other developmental delays or language impairments. These children were randomly assigned to either a developmental sample or validation sample to further examine the validity of the STAT. The authors used clinical diagnosis as the standard to

create cutoff scores for the development sample before testing the cutoff criteria on the validation sample. Using this approach, the validation sample produced a sensitivity of 0.92, specificity of 0.85, PPV of 0.86, and NPV of 0.92. Concurrent validity of the STAT was examined through agreement with the Autism Diagnostic Observation Schedule—General by comparing STAT risk category (i.e., ASD risk/no risk) to ADOS-G diagnosis (i.e., ASD/no ASD). The resulting Cohen's kappa of 0.77 and 89 % agreement between the measures provided support for the validity of the STAT. Inter-rater agreement, as measured by Cohen's kappa, was 0.88 for risk category when 30 children were assessed. Additionally, test-retest reliability was 0.88 when 18 children were screened by two different examiners 2–3 weeks apart, and the correlation between the STAT scores across both times was 0.85 (Stone et al., 2004).

Although the STAT was initially developed and validated on children ages 24 to 36 months of age, exploratory research suggests that the STAT may be suitable for children under the age of 2 (Stone, McMahon, & Henderson, 2008). Researchers examined the validity of the STAT for screening 71 children in a high-risk sample below 24 months of age, of which 59 had an older sibling with ASD and 12 who were referred for evaluation for suspected ASD. In this study, the original STAT cutoff score of 2 for "at risk" was increased to 2.75 in order to maintain adequate sensitivity and specificity for children 12–23 months. The revised cutoff score produced a sensitivity of 0.95, specificity of 0.73, PPV of 0.56, and NPV of 0.97. When 12–13-month-olds were removed from the sample due to high false positives rates (38 %), the sensitivity was 0.93, specificity was 0.83, PPV was 0.68, and NPV was 0.97. Thus, the PPV and specificity improved when younger infants were excluded from the sample while the NPV and sensitivity remained acceptable. Preliminary evidence suggests that the original STAT may be used to screen children under 2 years old; however, results need to be validated in larger samples and cutoff scores need to be validated for younger children.

Other Level 2 Measures

Two measures are briefly reviewed in this section; more information on their psychometric properties and use can be found in Ibañez et al.'s (2014) review. The Childhood Autism Rating Scale (CARS; Schopler, Reichler, DeVellis, & Daly, 1980; Schopler, Reichler, & Renner, 1988) is a 15-item behavioral rating scale that can be completed via combinations of three methods: (a) direct observation, (b) caregiver report, and/or (c) review of charts and records. The CARS was developed using a sample of 1500 children of which more than half were under the age of 5 (Schopler et al., 1988). A CARS total score is calculated by summing scores for each item, which are on a seven-point scale, with midpoints, ranging from normal behavior (1) to severely abnormal behavior (4). Total scores on the CARS place children into one of three groups: autism range (≤30), mild to moderate autism (30–36.5), and severe autism (37–60). For children and adults with severe autism, the sensitivity of the CARS ranges from 0.92 to 0.98 (Eaves & Milner, 1993; Sevin, Matson, Coe, & Fee, 1991). However, less is known about the psychometric properties of the CARS when screening young children for ASD. For example, one study found sensitivity and specificity to be 0.94 and 0.85, respectively (Perry, Condillac, Freeman, Dunn-Geier, & Belair, 2005). Another group of researchers suggested that increasing the cutoff score from 30 to 32 when assessing children as young as 2 years old improved specificity from 0.49 to 0.81 while sensitivity, PPV, and NPV values remained acceptable at 0.79, 0.85, and 0.73, respectively.

The new CARS-2 includes a form identical to the initial CARS referred to as the CARS-2-ST as well as a high-functioning version (CARS-2-HF) for children over the age of 6 with an IQ of 80 or above (Schopler, van Bourgondien, Wellman, & Love, 2010). Using a cutoff score of 28, the CARS-2-HF had a sensitivity of 0.81 and a specificity of 0.87. The internal consistency of the CARS-2-ST and CARS-2-HF is 0.93 and 0.96, respectively. Further research is needed to determine the psychometric properties of the

newly developed CARS-2 forms for Level 2 screening. The CARS-2-HF form is of particular interest as this is designed for higher functioning individuals.

Another measure that has the potential to serve as an interactive, Level 2 autism screener is the Systematic Observation of Red Flags (SORF), which is a component of the CSBS DP (Wetherby et al., 2004; Wetherby & Prizant, 2002). As part of the CSBS DP, the ITC identifies children who are at risk for communication delays, and these children may complete the CSBS DP Behavior Sample, which involves a 10-min warm-up before the 30–40 min videotaped, interactive session. While reviewing recorded behavior samples, clinicians can complete the 29 items of the SORF that assess children's social, emotional, and communication functioning as well as repetitive behaviors and restricted interests. Items require clinicians to use a 3-point scale to rate the presence of atypical behaviors and absence of typical behaviors, and the total SORF score is determined by adding the ratings for each item. Thus, higher scores indicate more red flags for ASD.

To assess psychometric properties and usability of the SORF, researchers assessed 54 children ages 25–65 months who later fell into one of three categories: children with ASD ($n=18$), children with developmental delays (DD) ($n=18$), or typically developing (TD) children ($n=18$) (Wetherby et al., 2004). Inter-rater reliability was calculated for each of the 29 items, and mean percentage agreement was 97.1 %. Initial research identified nine items on which children with ASD differed from those with DD or TD. A more recent study used the SORF to reanalyze archived video samples from 150 children who were diagnosed with ASD ($n=60$), DD ($n=30$), or were TD ($n=60$), including the 54 children from the previous study (McCoy, Wetherby, & Woods 2009). Children with ASD differed from DD and TD counterparts on 20 behaviors, with medium to large effect sizes documented, compared to the nine items identified in previous research. Using a cutoff score of 8, sensitivity was 0.87 and specificity was 0.84. Further validation of cutoff scores and critical red-flag items is necessary to further support that the SORF is a useful interactive, Level 2 ASD-specific screener. Currently, preliminary findings suggest that the SORF could serve as a physician-administered screener to further screen young children who have already been identified as at risk using general population screeners such as the ITC. The length of time to complete the observation and scoring, however, may make the SORF time prohibitive.

Summary

While Level 1 autism-specific screeners are intended to screen infants and toddlers under 30 months, many Level 2 screeners focus on slightly older children. In particular, the STAT and the SORF exist as interactive, Level 2 screeners that provide clinicians with the opportunity to directly observe young children's language, communication, and social skills. By utilizing direct observation rather than relying solely on parent checklists, clinicians can supplement parent report with clinical observation. Clinicians can use their assessment of children's strengths and weaknesses to help inform potential diagnosis and future targeted interventions. However, these interactive measures require clinician training in administration and scoring, which can be cost prohibitive for clinics that serve a large number of children and families.

Research supports the combined use of parent-report screeners and interactive tools to help identify at-risk children and yield referral for comprehensive evaluation. When choosing screening measures, clinicians should consider a variety of factors such as service delivery setting, level of training necessary to administer the screener, cultural and linguistic needs of their population, and appropriate planning for handling referrals in the presence of positive screens, among others. Using combinations of Level 1 and Level 2 screening tools when assessing children is generally more effective than utilizing one single measure at a single point in time. Further research should be conducted on Level 2 screeners as most have recently been developed and limited published psychometric data exists on the measures. Also, there is only limited evidence

available regarding how different screeners compare with each other as well as how screeners may be utilized with various groups, such as families from low socioeconomic status, parents with low literacy levels, and families whose primary language is not English.

Screening for Autism Spectrum Disorder in Middle Childhood and School-Age Children

Despite increased efforts toward identification of ASD in early childhood, there are many children who will not be identified with ASD until they reach middle childhood and school age. For example, recent data from a large study in the Netherlands indicated that 20 % of children were first identified by school professionals (Burke, Koot, & Begeer, 2015). Age of diagnosis has been somewhat dependent on level of functioning (e.g., with more cognitively able individuals diagnosed later); however, Mandell et al. (2010) reported that the average age of ASD diagnosis was 5 years. Research has also documented that children from impoverished or minority backgrounds are more likely to be diagnosed later when compared to their counterparts (e.g., Lipatk et al., 2008). Thus, the need for efficient and reliable screening measures is crucial with this age group, particularly in light of the missed opportunity to benefit from specialized interventions in early childhood. In contrast to the early childhood screening literature, less is known and available related to screening for ASD in older children and school-age children. Due to the concerns of later diagnoses for children from minority or low income backgrounds, Burke et al. (2015) also noted, "as a first and frequent point of contact for children, their [school professionals'] objectivity and accuracy is imperative in early identification of ASDs and specifically amongst children from ethnic minority groups" (p. 113). Therefore, it is important for practitioners to be aware of ASD screeners available for use with school-age children.

AAP guidelines recommend ASD screening until 24 months (i.e., both 18 and 24 months) and general developmental screening until 30 months (i.e., 9, 18, and 30 months). As children enter preschool and formal education, schools become more central to the screening process. Although academic attainment is typically considered the primary role of schooling, social-emotional and behavioral adjustment, particularly as difficulties with adjustment affect children's educational performance, also falls under the responsibility of schools. The rationale for screening holds true within school settings as well, chiefly, that earlier detection of unidentified problems leads to earlier access to services and, ultimately, outcomes. Screening for ASD in school settings is possible through various routes and service delivery models. For example, federal law requires that schools engage in child find procedures to identify students with developmental, educational, language, and behavioral difficulties. Further, schools are moving toward implementing service delivery models, such as Response to Intervention (RTI), which incorporate tiered levels of intervention for academic and behavioral concerns.

Universal screening is a key component for RTI models and is defined as the systematic assessment of all children within a class, grade, school, and/or district on academic and behavioral areas identified as important by the school and community at large (Ikeda, Neessen, & Witt, 2008). Typically, universal academic screeners are used more frequently than behavioral screeners, due, in part, to concerns with potential overidentification of various behavioral problems that may overwhelm existing resources (see Campbell & Hammond, 2014). To our knowledge, proactive ASD screening does not typically occur within schools. Even so, ASD screeners could be implemented within a multi-tiered framework, although the utilization of general autism screeners with school populations (i.e., akin to Level 1 screening) has not been widely studied. Williams and Brayne (2006) concluded that no ASD screening test has been fully validated for the general population of school-age children.

Hammond, Campbell, and Ruble (2013) described a basic model which could be integrated into the existing screening or tiered intervention process in the school to identify students

with ASD. Noland and Gabriels (2004) also articulated a model for screening and identifying children with ASD within public school settings. Noland and Gabriels' model involves a seven-step process that includes a nonstandardized teacher form, a "developmental red flag" form, which describes social, communicative, and behavioral symptoms of ASD. At the initial stage of any student referral process, the "developmental red flag" form is available for teachers to complete, which serves as a Level 1 screener in the model. In the presence of initial concerns, school professionals may complete a Level 2 screener, such as several described in the next section.

Due to the difficulties with screening all children within schools for ASD, child find screening programs notwithstanding, the "de facto" Level 1 screen for ASD within school settings is often teacher referral. Capitalizing on teachers' observation of student behavior, the use of a streamlined ASD screening procedure involving a teacher nomination procedure has been piloted. The rationale for utilizing such a procedure is based, in part, upon the ecological validity of teacher observations, including peer interactions that occur within various school contexts. Hepburn et al. (2008) evaluated the validity of such a procedure by asking 60 elementary school teachers to use a Teacher Nomination Form (TNF) to identify one or two students in their classroom who best fit a list of ASD characteristics. Teachers also completed a Level 2 ASD screener for all children ($n = 1323$) and agreement between teacher nomination and screener outcome was calculated; the TNF and ASD screener were administered in counterbalanced order. Results documented an overall agreement of 93 %, sensitivity of 0.61, specificity of 0.95, PPV of 0.50, and NPV of 0.97 for TNF nomination and ASD Level 2 screener result. Although the findings do not reach accuracy guidelines introduced earlier in the chapter, the teacher nomination strategy is worthy of further study as this procedure could save time and potentially identify those children who have not been identified in early childhood. Within this particular framework, additional study is needed to identify how many children nominated actually meet criteria for ASD after formal diagnostic evaluation. Additional research is needed on issues of potential bias and under identification of ethnic minorities, gender, and those from low income backgrounds. Regardless, awareness of ASD in school professionals should continue to be targeted, both regarding characteristic symptoms and the variety of their manifestation in older children.

Screening Instruments for Middle Childhood and School-Age Children

Several Level 2 screening instruments are reviewed in the next section that may be utilized within various service delivery settings, such as preschools, early intervention programs, elementary schools, and older groups. The screeners included in the brief review vary in terms of the age of the individual rated (e.g., some are appropriate for children to adulthood while others are designed only for school-age children), the number of items involved in the rating, the time period rated, and the availability of teacher and parent forms. For more comprehensive reviews and detailed information for Level 2 screeners, the reader is referred to Campbell (2005) and Campbell, James, and Vess (2014).

Social Communication Questionnaire

Previously referred to as the Autism Screening Questionnaire (ASQ; Berument, Rutter, Lord, Pickles, & Bailey, 1999), the Social Communication Questionnaire (SCQ; Rutter, Bailey, & Lord, 2003) is a 40-item parent questionnaire derived from a "gold standard" ASD diagnostic instrument, the Autism Diagnostic Interview-Revised (Rutter, LeCouteur, & Lord, 2003). The SCQ assesses functioning in children 4 years of age and older in the following domains: reciprocal social interaction, language and communication, and stereotyped behaviors. A total score, based on the domains, is then compared to a specific cutoff score. Caregivers complete one of two forms (i.e., Current Form or Lifetime

Form), which asks about the presence or absence of symptoms associated with ASD over different time periods.

Initially, the SCQ was examined in a sample of 200 individuals ages 4–40 who consisted of 160 individuals with ASD and 40 with disorders other than ASD (Berument et al., 1999). All individuals had received the ADI or ADI-R, and the correlations between ADI/ADI-R and SCQ total scores and individual domains were significant, ranging from 0.55 to 0.71. For the total SCQ scale, the internal consistency was 0.90. When a cutoff score of 15 was used to differentiate individuals with ASD from those with other disorders, sensitivity was 0.85, specificity was 0.75, PPV was 0.93, and NPV was 0.55. When children with intellectual disabilities were removed from comparisons, the sensitivity and specificity increased to 0.96 and 0.80. However, specificity dropped to 0.67 when the ASQ was used to differentiate autism from intellectual disabilities, but sensitivity remained high (0.96). Despite these promising results, it is important to note that the ADI-R was used as part of the diagnostic process, and the SCQ items were developed from the ADI-R. Therefore, agreement between the SCQ and ADI-R is expected; however, the results of Berument et al.'s (1999) study presented promising initial results for the SCQ.

Additional studies have found mixed results when using the SCQ with children across a wide age range using a variety of cutoff scores (Corsello et al., 2007; Eaves, Wingert, Ho, & Mickelson, 2006; Wiggins, Bakeman, Adamson, & Robins, 2007). When a cutoff score of 15 was utilized, Corsello et al. (2007) found that the SCQ had lower sensitivity for children 7 years and younger (0.63–0.68) than for those between the ages of 8 and 16 (0.71–0.80). Similarly, Wiggins et al. (2007) found the SCQ was less effective at identifying at-risk children between 17 and 45 months. Specifically in this sample, sensitivity was 0.47 and specificity was 0.89 using cutoff score of 15. However, sensitivity was maximized (0.89) and specificity remained stable (0.89) when a cutoff score of 11 was used.

Eaves et al. (2006) performed similar analyses by examining psychometric properties when cutoffs of 11 and 15 were applied. When a cutoff score of 15 was used, sensitivity was 0.71, specificity was 0.79, and PPV was 0.65; however, specificity dropped to 0.35 and sensitivity increased to 0.91 when a cutoff score of 11 was utilized. Due to its higher associated sensitivity, overall findings suggest that a cutoff score of 11 should be utilized on the SCQ despite lower specificity than using a cutoff score of 15. Thus, the SCQ serves as a useful Level 2 measure if cutoff scores are adjusted depending on the population clinicians intend to screen. Additionally, evidence suggests the SCQ is not as accurate for children ages 2 to 3; however, it appears particularly useful for older children, especially those over the age of 7.

Autism Spectrum Screening Questionnaire

The Autism Spectrum Screening Questionnaire (ASSQ; Ehlers, Gillberg, & Wing, 1999), formerly known as the Asperger Syndrome Screening Questionnaire, has been utilized in school-based screening research. The ASSQ includes 27 questions, with a yes, no, or sometimes response format. The ASSQ consists of parent and teacher forms, for children ages 6–17 (parent) and 6–16 (teacher form). Overall, Posserud, Lundervold, and Gillberg (2009) found that the ASSQ possessed good screening properties across a total population sample, specifically high sensitivity and high specificity. In their comparison to the general population, Posserud et al. (2009) also found that although the form was designed for higher functioning children, the ASSQ was efficient in detecting lower functioning children as well. Initial research from Mattila et al. (2009) cautioned against the use of the ASSQ as a singular instrument, noting combined parent and teacher ratings provided higher sensitivity and specificity more consistently as compared to parent or teacher ratings alone.

Childhood Autism Spectrum Test

The Childhood Autism Spectrum Test (CAST; Scott, Baron-Cohen, Bolton, & Brayne, 2002), formerly the Childhood Asperger Syndrome Test, is a 37-item parent form; 31 items are summed to produce an overall score while six items sample general development and do not contribute to the total score. The CAST has shown good initial sensitivity and specificity; however, Posserud et al. (2009) reported several initial concerns related to the CAST, specifically in item content and moderate test-retest reliability. Williams et al. (2008) investigated whether the CAST produced different findings for males and females, and the authors found significantly higher scores for males than females. Williams et al. (2008) proposed that gender differences could be due to preferences rather than abilities and difficulties. For the CAST, and potentially other screeners, questions have arisen regarding whether the measures are sensitive enough to detect more subtle difficulties potentially displayed by girls (e.g., management of social groups).

An Illustration of Problems Encountered when Detecting Low Base Rate Disorders

An important statistical reality deserves consideration when discussing the use and evaluation of screeners designed to detect low base rate disorders, such as ASD. The prevalence of disorder in a population or sample of interest will contribute to how well a screener will perform, and PPV (the predictive value of screening positive) is particularly vulnerable when the base rate is low. Derogatis and Lynn (1999), for example, demonstrated that prevalence rates of less than 10 % result in PPVs that fall at 0.50 or less, even in instances where sensitivity and specificity values of a screening are excellent (i.e., 0.95). Similarly, Clark and Harrington (1999) showed that the PPV of screening instruments with acceptable sensitivity and specificity (i.e., 0.80) will not exceed 0.50 until the base rate of disorder falls at or above 0.25. More recently, Groen, Swinkels, van der Gaag, and Buitelaar (2007) also discussed the low base rate problem with respect to the accuracy of ASD screeners.

To illustrate the impact of prevalence on PPV, consider our initial screener example again. If sensitivity and specificity values are held constant, and the screener is used with a sample with a prevalence rate of 0.50, the screener produces an excellent PPV of 0.89 while the NPV falls to 0.82 and the overall hit rate drops slightly to 0.85 (Table 5.2). Next, assume that the sensitivity and specificity values remain constant, but that the prevalence rate falls to 0.01 (i.e., 1 in 100), lower than 0.015 (i.e., 1 in 68), a frequently cited prevalence rate for ASD in 8-year olds in the United States (CDC, 2014). In this instance, the screener produces a PPV of 0.07 while the NPV rises to 0.99 and the overall hit rate remains at 0.90 (Table 5.3).

The relationship between the base rate and PPV is an important one to consider because ASD screeners are often developed and initially evaluated within clinic settings and subsequently evaluated with larger community samples. Clinic settings feature artificially higher base rates of ASD disorder which artificially

Table 5.2 An example of screening 1000 individuals with base rate of 0.50

	Diagnostic result			
Screening result		Disorder	No disorder	
	Positive	True positive 400	**False positive 50**	PPV 400/450 = 0.89
	Negative	**False negative 100**	True negative 450	NPV 450/550 = 0.82
		Sensitivity 400/500 = 0.80	Specificity 450/500 = 0.90	Hit rate 400 + 450/1000 = 0.85

Note. Sensitivity of test is 0.80. Specificity of test is 0.90. PPV = Positive predictive value; NPV = Negative predictive value

Table 5.3 An example of screening 1000 individuals with base rate of 0.01

	Diagnostic result			
Screening result		Disorder	No disorder	
	Positive	True positive 8	**False positive 99**	PPV 8/107 = 0.07
	Negative	**False negative 2**	True negative 891	NPV 891/893 = 0.99
		Sensitivity 8/10 = 0.80	Specificity 450/990 = 0.90	Hit rate 8 + 891/1000 = 0.90

Note. Screener sensitivity is equal to 0.80. Screener specificity is equal to 0.90. PPV = Positive predictive value; NPV = Negative predictive value

Table 5.4 An example of sequential screening with 30,000 individuals and base rate of 0.05

First screen of **30,000** (Prevalence rate = 0.05)			
	Disorder	No disorder	
Positive	True positive 1200	**False positive 2850**	PPV 1200/**4050** = 0.30
Negative	**False negative 300**	True negative 25,650	NPV 25,650/25,950 = 0.99
Second screen of **4050** (Prevalence rate = 0.30)			
	Disorder	No Disorder	
Positive	True positive 960	**False positive 285**	PPV 960/1245 = 0.77
Negative	**False negative 240**	True negative 2565	NPV 2565/2805 = 0.91

Note. Screener sensitivity is equal to 0.80. Screener specificity is equal to 0.90

inflates PPV values and sensitivity values for screeners. Due to the precipitous fall in prevalence once screening moves from clinic to community, PPV values also decrease. As such, some screenings with sound sensitivity and specificity characteristics during development are likely to yield poorer accuracy values as they are utilized in community settings.

The Potential Value of Sequential Screening

A proposed method for improving detection of a relatively low base rate phenomenon, such as ASD, is to engage in sequential (Derogatis & Lynn, 1999) or two-stage screening (e.g., Groen et al., 2007). *Sequential screening* involves the use of an initial screener to rule out a large portion of a population who screens negative for a disorder. Excluding a large number of true negatives raises the base rate of the disorder of interest in the second screening group. A second screening procedure is applied to the remaining sample which results in a corresponding increase in PPV. The initial screen will still produce a fairly large number of false positives who will receive a second screen.

Consider the use of two distinct screeners in a sequential screening format, with the first screener consisting of a small number of items such as might be used for surveillance purposes. The potential value for sequential screening is illustrated using our hypothetical screening instrument. Again, assume the base rate for disorder remains 0.05 and sensitivity (0.80) and specificity (0.90) values remain constant for the two screeners; however, the number of children screened is 30,000, a number which has been reported in several population-based screening investigations for ASD. Using the initial abbreviated screener results in referral of 4050 individuals and a PPV of 0.30 (Table 5.4), which becomes the "new" base rate for disorder for the second screener. The first screen will also produce a large number of false positives (i.e., 2850/4050 = 0.70). When the second screener is used, the PPV improves to 0.77 which results in significant added value of a positive test result at the second stage of screening.

Barriers to Screening

Pediatric primary health care is often considered the service setting where young children with ASD will be identified by professionals who constitute the "first line of defense" (Crais et al., 2014, p. 2312). Despite repeated calls and published recommendations, many pediatric healthcare professionals do not screen for ASD, although the percentage of pediatricians screening for ASD appears to have increased from 8 to 50 % over the past few years (Arunyanart et al., 2012; dosReis et al., 2006; Gillis, 2009). Barriers to implementing ASD screening in pediatric primary care include lack of knowledge of ASD, lack of knowledge of ASD screening instruments, and lack of time and resources available within the practice. Crais et al. (2014) found that pediatric healthcare professionals identified the following needs: (a) availability of ASD screeners that were sensitive to social-cultural differences; (b) access to effective early intervention programs for young children with ASD, once identified; (c) continuing education; and, (d) access to systems that would be able to handle an increase of ASD referrals.

The consistently low percentages of pediatricians actively screening for ASD have led to calls for allied health professionals to proactively screen for ASD, such as speech-language therapists and early interventionists. Within other settings, such as early intervention services, however, providers also identify barriers to screening for ASD. Early intervention professionals, for example, report that they feel unprepared to talk with families about concerns related to the presence of an ASD and that they are not adequately prepared to utilize various ASD screeners (Tomlin, Koch, Raches, Minshawi, & Swiezy, 2013). Early intervention providers, however, reported that they were eager to receive training in conducting ASD-specific screening (Tomlin et al., 2013). Federal public health campaigns such as the CDC's "Learn the Signs. Act Early" campaign have been developed and targeted to various providers, including pediatricians and early childhood education professionals to address some of the barriers identified.

Summary

A variety of ASD-specific screeners are available for use in various settings, including pediatric primary care, early intervention programs, preschools, and schools. Although psychometrically sound Level 1 and Level 2 screeners have been developed within clinical samples, they produce poorer results when used with larger populations, such as community screening programs. Despite the availability of established screeners and published professional guidelines for pediatricians to screen for ASD at ages 18 and 24 months, many young children are not being screened. Indeed, recent data reveals that roughly 50 % of pediatricians adhere to the AAP ASD screening guidelines. Many barriers to ASD screening have been identified within primary care settings, including limited time, expertise, and familiarity with ASD screeners, among others. Barriers encountered in pediatric primary care settings, and many others, result in many children with ASD going unidentified until 4 or 5 years of age.

As ASD screeners are developed and scaled up for use within communities, their psychometric properties become less favorable, with the predictive value of a positive screening result often vulnerable. The goal of an ASD screening program, however, is to identify those who have previously gone unidentified; therefore, the generation of false positive screening results is often more desirable than false negatives. As such, it may be acceptable for a Level 1 screening to produce a referral rate that significantly exceeds the base rate to improve sensitivity. Any ASD screening program must be implemented with appropriate planning, including staff training and identification of appropriate follow-up referrals and services in the presence of a positive screen.

Until a highly reliable and valid behavioral or medical marker is identified, available screeners will produce errors, in part, due to the relatively low base rate of ASD in general populations. One potentially viable approach to conducting pediatric, school, or community-based screening to counter the low base rate problem is to combine results from two brief screening measures, i.e., a simultaneous screening approach. In this

approach, various thresholds for screening decision-making are possible with (a) liberal referral decisions based on screening positive on either measure or (b) conservative decisions based on screening positive on both measures. Brief measures are available for administration and scoring in such an approach.

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Monitoring Progress in Autism Spectrum Disorder

6

Valsamma Eapen, Katrina Williams, Jacqueline Roberts, Nicole Rinehart, and Jane McGillivray

Overview

The consensus of most professionals is that autism is a lifelong condition but with abilities and difficulties, associated problems, function and participation, as well as management issues, changing over time. Thus, while identification and accurate diagnosis constitute a first step, ongoing monitoring is essential for helping the individual with ASD to reach their potential and manage developmental challenges that arise throughout the life course. This chapter highlights the key issues in the process of monitoring and how this can be achieved along with current opportunities and pitfalls, where they exist.

Context

Heterogeneity and Complexity

The landscape of autism spectrum disorder (ASD) is diverse and complex; each individual diagnosed with ASD varies in the severity of impairment across behavioural, social, and cognitive dimensions, and each individual's behaviours or interests may be idiosyncratic. As ASD frequently co-occurs with other problems or difficulties such as epilepsy, intellectual disability, and other mental health diagnoses (Simonoff et al., 2008), ASD features may not be the focus of interventions or strategies to improve well-

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being, function, and participation. For example, anxiety, irritability, aggression, learning disability, and self-injurious behaviour (Maskey, Warnell, Parr, Le Couteur, & McConachie, 2013) often occur and require management. Individuals with multiple coexisting problems or difficulties will require closer monitoring over time compared to individuals who present with few or no comorbidities that impair occupational function. These factors result in a unique presentation in each individual, and unique challenges for intervention and other strategies and useful and relevant monitoring. Add to this the different values that each individual and their family bring and it becomes apparent that the goals of each individual, and hence the things that should be monitored will be as different as they are the same. Due to this intrinsic clinical variability, measuring changes in symptomatology and monitoring progress is necessarily complex, but also crucial to improving the lives of each individual.

Validity, Utility, and Appropriateness of Tools

There are significant challenges in monitoring the impact of interventions in the context of ASD (Eldevik et al., 2009; Howlin, Magiati, & Charman, 2009), and one of the main difficulties involves the lack of reliable and valid tools that measure change and that can be repeated at different time points. As a result, evaluators have resorted to using measures that are primarily diagnostic instruments but typically these are not sensitive to change. Further, most longitudinal studies have focused on overall developmental trajectories using standardised developmental instruments. These measures have significant limitations as they are primarily developed for typically developing children and therefore delayed and different developmental patterns observed in ASD are difficult to track over time. Although there are some exceptions, most of these instruments do not allow measurements spanning the age range from preschool to adolescence and beyond.

Recent reviews of assessment tools have identified problems with validity and utility, including their appropriateness for measuring change over time and the need for measure of health-related quality of life to allow evaluation of economic impacts of interventions and management approaches (McConachie & Fletcher-Watson, 2014; Payakachat, Tilford, Kovacs, & Kuhlthau, 2012). Also identified is that individuals with neurodisability, including autism, and their families value different outcomes to those commonly measured (Allard et al., 2014).

International Classification of Functioning, Disability, and Health

The development of the International Classification of Impairments, Disabilities and Handicaps (World Health Organization, 1980), now the International Classification of Functioning, Disability, and Health (World Health Organization, 2001), provides a useful structure for assessing or monitoring individuals with autism and other disabilities, with a focus on impairment, function, and participation within a framework of children's rights and the application of the biopsychosocial model. This approach has several advantages including that disability is understood as the consequences of underlying health conditions attributable to disease or injury and that the consequences are detailed as having a distinct impact on human experiences at the levels of body, person, and society. In addition by differentiating these terms conceptually and semantically, it is emphasised that disability is not uni-dimensional but rather manifested at different levels of human functioning in the form of impairments, performance limitations, and the experience of disadvantage. It also provides a taxonomy with numeric codes that can be used to document the elements unique to each of the three levels, with applicability for clinical and administrative purposes (Simeonsson et al., 2003).

The ICF allows the classification of functioning as universal human experiences involving 'body function and body structures' which can be conceptualised as well-being, 'personal activities and

performance' such as mobility and self-care that can be conceptualised as function and 'participation in community' such as school, work, and civic life. Since the barriers and facilitators within the environment at each of these three levels can also be recognised through the 'environmental factors qualifiers' option, this classification offers a distinct advantage in terms of assessing eligibility and prioritisation of interventions as well as in monitoring progress. However one limitation is the application to and coverage of child characteristics and hence additional considerations are required during the early developmental years. For example, there are issues relating to assessing children with limited cognitive and language abilities resulting in a reliance on parental and caregiver reports. It would be important to include, wherever possible, reports of children through interview, play, or other direct observations.

Individualised Planning

Good practice dictates that intervention, management, or care plans for ASD must be tailored to the individual's needs and goals, have research evidence supporting their effectiveness, and that goals must be measurable, continuously monitored, and frequently revised (National Institute for Health and Care Excellence, 2013; Prior, Roberts, Rodger, Williams, & Sutherland, 2011). Yet as young children with ASD mature into adolescents and young adults, delivery of best practice becomes more challenging as the context and circumstances of individuals diverge (National Institute for Health and Care Excellence, 2012). Even during the school years while some children with an ASD are schooled entirely in autism-specific or special education schools, the majority are included to some degree in general education programmes. After school the diversity of possible environments increases further, ranging from university education, to the work place to supported employment options and accommodation arrangements. Individual plans should incorporate as much input from the individual with autism as possible and include all of those involved with their care such as the family, therapists, and educators in a collaborative process. Although the specifics of an IP must necessarily change as each individual progresses through their development, educational, and other settings, the main guiding principles of an effective individual plan remain the same. These principles are seen as best practice and they also govern recommendations from different developed nations such as the United States (Individuals with Disabilities Education Improvement Act of 2004), the United Kingdom (Children and Families Act, 2014), and Australia (The Australian Advisory Board on Autism Spectrum Disorders, 2014). Accordingly, the individual plan should be re-evaluated at least every 6 months and the emphasis of this approach should be on accurate and objective measurement of progress in accordance with the set goals that address individual strengths and needs as detailed in Table 6.1.

Table 6.1 Key items needing attention in an individualised plan (IP) for children with ASD

Overarching long-term goal(s) for the person with ASD incorporating planning for transition
A thorough assessment of current performance in key developmental and academic/employment/adaptive skills areas
Measurable goals for each specified period (minimum six monthly interval)
A strategy for measuring progress and outline of when periodic progress reports will be provided
Assessment of resources and consideration of which services and educational strategies are to be provided by whom in order to reach, monitor, and assess the goals
A process for the collaborative review and revision of the IP at least on a 6-monthly basis

Goal Setting as a Core Element of Monitoring Progress and Transitions

Intervention and management vary over time, as do their goals and tools that would be used to measure whether goals have been achieved.

Key Ages and Stages

Four main stages in life can be identified that are likely to bring different goals, because of the changing environment, the change in ability, and different priorities of individuals and families. The first is the preschool years, the second the primary years, the third the high school years, and the fourth the adult years. Of course within these stages there are further important divisions, but for ease we will focus on these four in the hope that individual variation due to, for example, ageing can be catered for because of the flexibility of the approach that is being presented.

In the early years the focus will be on developmental impairments in the areas of receptive language, expressive language, social interaction, fine/gross motor skills, cognition, play skills, and adaptive behaviour/personal independence. However, over time, there will be a shift from assessing specific developmental domains and abilities to assessing participation in education, employment, or civic life. Time points for assessments would also deserve special attention in the monitoring process. For example there are well-identified points of stress for the individual with autism and their families when goal-specific assessment and planning would be critical and such time points may include immediately after diagnosis in terms of choice of early intervention, start of school or other educational programmes, transition from one educational setting to another and in particular transition to high school, and then post high school as they move into vocational or career/employment related placements. Issues relating to life skills, personal, social and sexual relationships, driving, and independent living as well as mental health would also deserve due consideration. Further, any other major life event in the life of individuals with autism will create additional needs for themselves and their families, over and above those experienced by the general population. Since it will be difficult to initiate contact with services and agencies for the first time during such times of crisis, specific attention to how families and individuals could easily connect with appropriate agencies at these times needs to be built in to the monitoring framework. Further, monitoring information should always cause professionals to pause and reflect on what could be creating the patterns that are being observed, and how that information would assist in decision making on any changes that needs to be made to the ongoing management plan. Things that might need modification could include the nature, frequency or setting of interventions, the way treatment plan is being coordinated and provided, or the environment, community supports, or other aspects of care. Ongoing monitoring and assessing progress is central to intervention, education and social programmes in ASD, and fundamental to all programmes that include goals.

Fit-for-Purpose Monitoring

An approach that can add value to what we know about appropriate monitoring for different ages and stages of children with autism is consideration of the purpose of monitoring. In this approach, monitoring can be to identify autism, to assess autism interventions, to identify common problems early, or to ensure that ongoing management is maximising opportunities for an individual with autism and their family. Embedding the international classification of functioning, disability, and health with this approach ensures monitoring that includes information about the impairment or well-being, function, and participation as relevant.

Identifying Autism

Monitoring for early signs and symptoms of ASD can assist timely identification and opportunities for early intervention. Although some of these symptoms may be evident from as early as the first year of life, ongoing surveillance is the key to monitoring these symptoms to determine their developmental course and accurate diagnosis. Studies based on the siblings of children with an affected older sibling have indicated delay or differences in early attentional control, emotion regulation, social orienting/approach,

and communication development (Brian, Bryson, & Zwaigenbaum, 2015). These domains may also be appropriate targets for early intervention. Some of the main domains of ASD that are relevant to monitoring for symptoms suggestive of autism are described below.

Social communication: It has been suggested that early abnormalities in brain development in autism lead to early low-level deficits in recognition and orientation towards social stimuli which then cascades to lack of social engagement with primary caregivers during infancy and resulting in decreased exposure to the reciprocal social interactions critical for development of typical social behaviour. There is substantial evidence to support the presence of these types of deficits which in turn suggests a need for intervention to support the development of early social engagement and reciprocity designed to minimise divergence from a typical developmental trajectory (Webb, Jones, Kelly, & Dawson, 2014). Emerging evidence indicates that interventions that address early deficits in joint attention and social reciprocity using strategies that involve interpersonal exchange and positive affect, shared engagement with real-life materials and activities, sensitivity to child cues and adult responsivity etc. facilitate the development of age appropriate socio-communicative behaviours.

Restricted Repetitive Behaviours (*RRB*): As repetitive and restrictive behaviours are a core symptom of ASD, and can be a significant cause of impairment affecting multiple facets of life, these specific behaviours are frequently targeted by intervention programmes. However, while other core ASD symptoms are strongly related to general developmental level and correlate with cognition and IQ, insistence on sameness does not share this relationship with these variables (S. L. Bishop, Richler, & Lord, 2006; Richler, Huerta, Bishop, & Lord, 2010). Further, RBBs are not unique to ASD but can also occur in other psychiatric and neurological disorders such as obsessive compulsive disorder and Tourette syndrome. In OCD this is driven by a need to relieve anxiety and intrusive thoughts, while in Tourette syndrome this follows a need to relieve a premonitory urge, and in ASD these behaviours are characterised largely by an insistence on sameness and unwavering rigidity in routine. Despite being a major target for therapy, repetitive behaviours and restrictive interests appear to persist in severity over time, even when children show progress in other areas of their symptomatology (Dawson et al., 2010; Vivanti et al., 2014).

Sensory sensitivities: Previously, researchers have shown that there are distinct sensory profiles in autism relating to behaviours associated with sensory reactivity (the intensity of the response to a sensory stimulus) and multisensory integration (combining information from multiple sensory stimuli) which links with specific patterns of behaviours (Lane, Molloy, & Bishop, 2014). This would suggest that specific intervention strategies matching the sensory difficulties in those affected would be beneficial.

Evaluating Interventions

Although it is outside the scope of this chapter to discuss the various behavioural and developmental interventions available, some background is necessary for an understanding of how the success of such interventions and management strategies may be measured.

Current clinical guidelines advise focussing on improvements in the core ASD characteristics, especially social interaction and reciprocal communication, by including techniques to expand the child or young person's communication, interactive play and social routines, and working with parents, carers, teachers, or peers to facilitate greater understanding of, and responsiveness to, the child or young person's patterns of communication and interaction (National Institute for Health and Care Excellence, 2013). For the preschool age group some recommended techniques include the integration of play-based strategies with parents, carers, and teachers with therapist modelling and video-interaction feedback to increase joint attention and engagement. Additionally, clinicians, educators, and carers may employ techniques such as pivotal response

training, prompting, reinforcement, and discrete trial teaching (Odom et al., 2003) over a short period of time to enact a change in a specific behaviour or to develop a targeted skill.

Typically, in efficacy studies each individual's developmental skills, cognitive ability, and behaviours that challenge or are unwanted will be assessed at the start and end of intervention. The monitoring tools, also called outcome measures in this context, selected will also reflect the form of intervention chosen. For example, if a child is undergoing a comprehensive treatment model (CTM) which is designed to elicit a broad developmental response, progress may be monitored across autism severity and developmental milestones using treatment-specific tools as well as other assessment tools for autism-specific symptoms such as the Social and Communication Questionnaire (SCQ) and Autism Diagnostic Observation Schedule (ADOS), in addition to using additional measures such as the Mullen Scale of Early Learning (MSEL) and Vineland Adaptive Behaviour Scale (VABS) to monitor overall development and adaptive functioning (Dawson et al., 2010; Eapen, Crncec, & Walter, 2013; Vivanti, Dissanayake, Zierhut, & Rogers, 2013). The measures commonly used in these instances to assess and monitor progress would change over time, and some of the commonly used measures are detailed in Table 6.2. When establishing intervention goals in practice domains as described above, it is important to include, along with overall development, other aspects of functioning, participation, and quality of life, for the individual with autism and their family. In this section we will focus on autism characteristics, development, and abilities and will discuss other key elements of expected outcomes from intervention in later sections.

Autism Features

Autism Diagnostic Observation Schedule (ADOS)

The *Autism Diagnostic Observation Schedule* (ADOS; Lord et al., 2000) is a standardised tool for the direct observation and measurement of autistic symptomatology. The ADOS consists of a series of investigator-led processes designed to elicit naturalistic social and communicative behaviours from the child. The investigator thus builds a profile of the child's social communication, social relatedness, play and imagination, and restricted and/or repetitive behaviours. Despite its reputation as the 'gold standard' measure of autistic severity, the ADOS was designed as a diagnostic tool to measure relatively stable traits in ASD which are not anticipated to vary greatly over a lifetime. Longitudinal studies have demonstrated the stability of these standardised scores throughout childhood (Chawarska, Klin, Paul, & Volkmar, 2007; Gotham, Pickles, & Lord, 2009; Hedvall et al., 2014). Indeed, even when children demonstrate vast gains in other domains such as expressive and receptive language and adaptive behaviours as a result of an autism-specific intervention, their ADOS scores did not significantly improve (Dawson et al., 2010; Vivanti et al., 2014). While improvements in such measures would undoubtedly indicate robust changes to behaviour, a lack of improvement may indicate insensitivity to subtle improvements and treatment effects, especially when the aim of an intervention does not broadly target ASD, but rather a specific behaviour or outcome. Hence, while the ADOS may help assess the progress of a CTM with limited sensitivity, it is unlikely to accurately reflect progress relating to specific tasks or behaviours. However it can be useful if such progress results in the child no longer reaching a diagnostic status on the repeat ADOS assessment.

Social Responsiveness Scale (SRS)

The Social Responsiveness Scale (Constantino & Gruber, 2005) is a brief quantitative measure of autism severity in children and teenagers. It focuses on the degree of impairment in the core ASD domains of social awareness, social information processing, reciprocal social communication, social anxiety/avoidance, and stereotypic behaviour/restricted interests. The SRS compares favourably with the ADI-R (Constantino et al., 2003); however it is scored based on the observations of parents or teachers, and hence has the limitation of lacking clinician input.

Table 6.2 Commonly used assessment tools for monitoring progress throughout life

	Type of change	Toddlers	Preschool age group	Primary school age	Secondary school age	Adults
Evaluating interventions	Autism characteristics	ADOS—toddler version	ADOS-1 to 4 depending on level of language	ADOS-1 to 4 depending on level of language	ADOS-1 to 4 depending on level of language	ADOS-1 to 4 depending on level of language
			SRS	SRS	SRS	Social Responsiveness Scale-Adult version (SRS-A)
			RBS-R	RBS-R	RBS-R	RBS-R
		ESCS				
			CARS-2	CARS-2	CARS-2	
			SCQ	SCQ	SCQ	SCQ
			AIM	AIM	AIM	
			ATEC	ATEC	ATEC	ATEC
	Development and abilities	ASQ and ASQ:SE				
		BSID-III				
		CBCL 1.5–5	CBCL 1.5–5	CBCL 6–18, TRF 6–18, and YSR 11–18	CBCL 6–18, TRF 6–18, and YSR 11–18	ASR/ABCL
			DBC	DBC	DBC	
		GMDS	GMDS	GMDS		
		MSEL	MSEL			
		SB5	SB5	SB5	SB5	SB5
		WPPSI	WPPSI	WPPSI or WISC-IV	WISC-IV	
	Communication			CCC-2	CCC-2	
			CELF-P	CELF-4	CELF-4	CELF-4
		CSBS-DP	CSBS-DP			
		MacArthur-Bates CDI				
		NRDLS	NRDLS	NRDLS		
		PPVT-4	PPVT-4	PPVT-4	PPVT-4	PPVT-4
		Pragmatics profile	Pragmatics profile	Pragmatics profile	Pragmatics profile	Pragmatics profile
		PLS-5	PLS-5	PLS-5		
	Adaptive ability	BASC-2	BASC-2	BASC-2	BASC-2	BASC-2

(continued)

Table 6.2 (continued)

	Type of change	Toddlers	Preschool age group	Primary school age	Secondary school age	Adults
		CBCL 1.5–5	CBCL 1.5–5	CBCL 6–18, TRF 6–18, and YSR 11–18	CBCL 6–18, TRF 6–18 and YSR 11–18	
		SDQ	SDQ	SDQ	SDQ	
		VABS II	VABS II	VABS II	VABS II	VABS II
Early identification of associated conditions	Maladaptive behaviours		DBC	DBC	DBC	
			ABC	ABC	ABC	ABC
	Sleep problems		CSHQ	CSHQ		
			Sleep diary	Sleep diary	Sleep diary	Sleep diary
Maximising potential: individual	Function			PEP3	PEP3	
				TRSSA	TRSSA	
	Participation			CAPE		
				CHORES		
				PICO-Q		
Maximising potential: family	Stress					DASS
						PSOC
						PSI/SF
	Quality of life	PedsQL	PedsQL	PedsQL	PedsQL	
		QoLA—parent/carer report	QoLA—parent/carer report	QoLA—parent/carer report	QoLA—parent/carer report or self-report version depending on language ability	QoLA—self-report

Repetitive Behaviour Scale—Revised (RBS-R)

The Repetitive Behaviour Scale—Revised is a parent-completed questionnaire which characterises the severity of repetitive behaviours across six subdomains: stereotyped behaviour, self-injurious behaviour, compulsive behaviour, ritualistic behaviour, sameness behaviour, and restricted behaviour (Bodfish, Symons, Parker, & Lewis, 2000).

Early Social Communication Scales (ESCS)

The Early Social Communication Scales (Mundy et al., 2003) is used to measure social behaviour and joint attention skills in a structured setting. During the ESCS, the child is seated at a table while an experimenter presents a range of standardised probes assessing social responsiveness and communication skills, including initiation and response to joint attention, as reflected in frequencies of child alternating gaze, showing, and pointing to share. The ESCS has shown good reliability and validity and has been used in studies of children with ASD, including treatment studies (Kasari, Freeman, & Paparella, 2006; Remington et al., 2007; Salt et al., 2002).

Childhood Autism Rating Scale (CARS)

Childhood Autism Rating Scale (Schopler, Reichler, & Renner, 1986) and the revised version, CARS2 (Schopler, Bourgondien, Wellman, & Love, 2010), can be completed by a parent, teacher, or a clinician, based on subjective observations of the child's behaviours. Based on the findings of a bimodal distribution among these scores, the scale includes criteria to differentiate between those with mild to moderate autism and those with severe autism (Schopler, Reichler, DeVellis, & Daly, 1980).

Social Communication Questionnaire (SCQ)

The Social Communication Questionnaire (SCQ) (Berument, Rutter, Lord, Pickles, & Bailey, 1999), formerly known as Autism Screening Questionnaire, is based on a well-validated parent interview, the original Autism Diagnostic Interview (ADI; Rutter, Le Couteur, & Lord, 2003). The SCQ covers the areas of communication, reciprocal social interaction, and restricted and repetitive behaviours and interests, which are core diagnostic criteria for autism. There are two versions: a 'current' version designed for children under 5 years and a 'lifetime' version designed for children ≥5 years. The current version is helpful for treatment/planning in that it indicates the type and severity of the characteristics of autism in individual children. The items can be used for setting treatment goals for example, if the child has no ability to take turns in a conversation, conversational turn taking can be targeted in the intervention programme. The SCQ can be used for monitoring purposes as it can measure change over time.

Autism Treatment Evaluation Checklist (ATEC)

The Autism Treatment Evaluation Checklist (ATEC) (Rimland & Edelson, 1999) is another tool that can be used by clinicians and parents to evaluate treatment outcomes and to monitor progress in ASD. The ATEC can be accessed and scored online by parents, teachers, and/or other primary carers (http://legacy.autism.com/ari/atec/atec_report.htm). The scale covers 77 items in the areas of communication, sociability, sensory and cognitive awareness, and health and physical behaviour, and also provides a total score.

Autism Impact Measure (AIM)

The Autism Impact Measure (AIM) (Kanne et al., 2014) is a 25-item questionnaire that has been specifically designed to have greater sensitivity detecting changes in core ASD symptoms. It asks respondents to recall a 2-week period with items rated on two corresponding 5-point scales of frequency and impact of core ASD symptoms. Using exploratory factor analysis, four factors were found namely (1) repetitive behaviours, (2) odd/atypical behaviours, (3) communication/language, and (4) social/emotional reciprocity, and these were observed to concur with the reports of symptom severity/impact.

General Development and Ability

In infants and toddlers, the symptoms of an ASD may only be starting to become apparent, and any differences between an affected child and their peers may not seem too extreme. However, over time the differences may become more pronounced and a child with ASD may lag further behind their peers. This is one of the greatest opportunities for an early intervention, as it provides intensive support for young children to make more early gains, potentially before their developmental trajectories uncouple from those of their peers. To focus on improving developmental outcomes in young children, it is essential to accurately monitor and measure progress in the five developmental domains of early childhood: physical, social, emotional, language, and cognitive skills. A child with ASD may experience general or specific impairments in any or all of these domains and associated subdomains, from a particular sensory processing abnormality to pervasive intellectual impairment.

In addition to monitoring core symptoms and psychopathology in children with ASD, it is also important to take into consideration a child's motor profile in their overall management plan. In a study by Papadopoulos et al. (2011) of fifty-three 7–12 year old children with ASD, a significant positive correlation between impairments in motor proficiency (in particular ball skills and balance) and DBC measures of emotional/behavioural disturbance, autistic symptoms, and communication disturbance was reported. These authors suggest that adjunct motor measures (in particular balance) may be a useful objective measure to help monitor the overall developmental profile of a child with ASD over time (Papadopoulos et al., 2011). For children with ASD who have significant motor impairment that might range from problems with clumsiness, difficulty with motor planning, handwriting difficulties, and dystonia, there is a need for clinical planning around whether motor symptoms should be directly addressed, for example, through intensive occupational therapy, or whether these difficulties should be 'monitored' over time. This is particularly relevant in the primary school years. Given that motor impairment is associated with reduced physical activity and participation, there are health as well as psychological benefits for ongoing monitoring of a child's motor development. By monitoring a child's functioning in relation to their individual motor profile and potential limitations, a holistic management approach can be put in place that includes the optimisation of activity and participation (Emck, Bosscher, Beek, & Doreleijers, 2009).

The Mullen Scales of Early Learning

The Mullen Scales of Early Learning (MSEL; Mullen, 1995) is a standardised, normed developmental assessment for children aged birth through 68 months. It provides an overall index of ability, the Early Learning Composite, and subscale scores of Receptive Language, Expressive Language, Visual Reception, and Fine Motor skill.

Ages and Stages Questionnaire

The Ages and Stages Questionnaire (ASQ; Squires, Bricker, & Twombly, 2009): Parents or caregivers can use the ASQ questionnaires to check a child's general development and the ASQ:SE (socio-emotional) questionnaire to check a child's social emotional development.

The Bayley Scales of Infant Development

Bayley (1993): The Bayley Scales of Infant Development (BSID-III is the current version) is a standard series of measurements used to assess the motor (fine and gross), language (receptive and expressive), and cognitive development of children aged 0–3 years.

Griffiths Mental Developmental Scale

Griffiths Mental Developmental Scale (third edition; Griffiths, 2006): The six subscales include Locomotor (gross motor skills including the ability to balance and to co-ordinate and control movements); Personal-Social (proficiency in the activities of daily living, level of independence, and interaction with other children); Language (receptive and expressive language); Eye and Hand Co-ordination (fine motor skills, manual dexterity, and visual monitoring skills); Performance (visuospatial skills including speed of working and precision), and Practical

Reasoning (ability to solve practical problems, understanding of basic mathematical concepts, and understanding of moral issues).

Cognitive Ability and Intelligence

There is considerable variability in levels of cognition in individuals with ASD and therefore accurate intelligence assessment is important in treatment planning.

Stanford-Binet Intelligence Scales: Fifth Edition

The Stanford-Binet Intelligence Scales: Fifth Edition (SB5) (Roid, 2003) is a widely used standardised intelligence scale which assesses multiple components of intelligence. It includes ten subtests, five verbal and five nonverbal, which can be used to determine verbal intelligence (VIQ), nonverbal intelligence, and full-scale or abbreviated intelligence. Although it was originally thought that most people with ASD also suffered comorbid intellectual disability (ID; i.e. IQ < 70), more recent estimates have reduced this co-occurrence to approximately one third to one half of cases (Centers for Disease Control and Prevention, 2014). Additionally, epidemiological studies indicate that more than a quarter of participants with ASD have average or above average intelligence (i.e. IQ > 85) (Charman et al., 2011).

WISC/WPPSI and Other Tests of Intelligence

Wechsler Pre-school and Primary Scale of Intelligence (WPPSI; Wechsler, 1989, 2002) or the Wechsler Intelligence Scale for Children (WISC-IV; Wechsler, 2003) as appropriate; for those unable to be tested or those not reaching standardised T scores to derive an IQ score, an IQ estimate, a best estimate of the Developmental Quotient (DQ) can be calculated using any of the general developmental tests as above using the equation Mental Age (MA) divided by the chronological age and multiplied by 100.

Communication

Autism is unique in that essentially the development of communication may not be directly linked to the development of language. More than in any other condition, in autism, language development may occur separately from communication development (Jordan & Jones, 2012). Very young children with autism usually show divergent communication development with differences in the development of joint attention and early engagement with others (Charman & Stone, 2008; Toth, Munson, Meltzoff, & Dawson, 2006). Also, young children with autism are less interested in people than in objects (Kasari et al., 2006) and primarily, as a result of paying less attention to other people in their environment, have poor early social communication development. This extends to the development of language; for example at the most basic level the learning of the names for things is highly dependent on joint attention and interaction with primary caregivers. Assessment of communication in autism needs to be broad and address all aspects of communication including language development and the structure and function of language and communication. For preverbal, nonverbal, and verbal individuals with autism, assessment of communication as well as of language development is essential. Accurate assessment of receptive and expressive communication is also important because unlike other condition, in autism receptive language is often more impaired than expressive language (Hudry et al., 2010). This can be misleading when those around the child or adult with autism assume, not unreasonably, that they understand at the same level at which they speak. Children with autism appear to learn language primarily through a process of rote learning chunks of language, which they associate with particular internal and external contexts. Speech often gives a stereotyped impression and echolalia is common. It is important to assess exactly what the child understands and what cues they follow. They may be expert at interpreting visual cues and contextual information while understanding very little of what is actually being said to them.

Children's Communication Checklist (CCC)

Children's Communication Checklist (CCC-2; D. Bishop, 2003) is a 70-item questionnaire completed by a caregiver and screens for communication problems in children aged 4–16 years. The test evaluates a broad range of language skills such as recalling and formulating sentences, word classes, and word definition and understanding

spoken paragraphs and semantic relationships. There is also a version for older adolescents and adults.

Clinical Evaluation of Language Fundamentals (CELF)

There are preschool and 5–22 years version of this assessment (CELF-P; Elisabeth H. Wiig, Secord, & Semel, 2004), for preschool to early school age children. Subtests include basic concepts, sentence and word structure, formulating labels, recalling meaning, and linguistic concepts.

CELF-5 (E. H. Wiig, Semel, & Secord, 2013) is a quick and accurate assessment for ages 5–22 years to assess for a language disorder. The test evaluates a broad range of language skills such as recalling and formulating sentences, word classes, and word definition and understanding spoken paragraphs and semantic relationships. The current battery of tests provides a comprehensive language assessment including a robust assessment of pragmatics using observations and interactive activities.

Communication and Symbolic Behaviour Scales Developmental Profile

Communication and Symbolic Behaviour Scales Developmental Profile (CSBS-DP; 6 months–6 years) (Wetherby & Prizant, 2002): This assessment is a combination of parent report and face-to-face evaluation of the child. The assessment measures seven language predictors: emotion and eye gaze, communication, gestures, sounds, words, understanding, and object use and is sensitive to early delays in social communication, expressive speech/language, and symbolic functioning.

MacArthur-Bates Communication Development Inventories

The MacArthur-Bates Communication Development Inventories (Fenson et al., 2007) (1–3), 3–37 months: The assessment consists of three inventories using parent report to probe use of gestures, words, and sentence.

Reynell Developmental Language Scales

The New Reynell Developmental Language Scales (NRDLS; Edwards, Letts, & Sinka, 2011): This is a direct assessment of the child designed to identify speech and language delays and impairments in very young children, from 2 to 7 years 5 months.

Peabody Picture Vocabulary

The Peabody Picture Vocabulary Test 4 (PPVT-4; L. M. Dunn & Dunn, 2012): Measures listening comprehension of vocabulary in standard English from 2.5 years.

Pragmatics Profile of Everyday Communication Skills in Children

The Pragmatics Profile of Everyday Communication Skills in Children (Dewart & Summers, 1996): Version for preschool aged children 0–4 years, school aged children 5–10 years, and adolescents/adults. The assessments are structured interviews with a primary carer designed to assess child communicative functions, response to communication, interaction and conversation, and contextual variation.

Preschool Language Scale

The Preschool Language Scale fifth ed (PLS5) (Zimmerman, Steiner, & Evatt Pond, 2011), birth to 7 years: This is a direct assessment of the child designed to evaluate maturational lags, strengths, and deficiencies by testing auditory comprehension and verbal ability.

Adaptive Functioning

There is some evidence to suggest that there is a cognitive advantage over adaptive functioning in children with ASD, and similar results have been found in a recent study in an older sample (Matthews et al., 2015). Compared to communication and socialisation skills, adults with ASD showed relative strength in daily living skills although this was not true for adolescents. However, all standard scores were well below average, regardless of their level of cognitive functioning which suggests the need for interventions that target adaptive functioning across the lifespan.

Vineland Adaptive Behaviour Scale (VABS)

One critical indicator of an individual's functioning and progress is their ability to translate their theoretical intelligence to practical intelligence, or their cognitive potential into real-life skills, hereafter defined as adaptive behaviour.

The Vineland Adaptive Behaviour Scales (Sparrow, Balla, & Cicchetti, 1984) and (VABSII; Sparrow, Cicchetti, & Balla, 2005) assesses social, communication, motor, and daily living skills reflective of an individual's ability to navigate life in the community. It is administered by parent interview and provides both age-equivalent and standardised scores.

Behaviour Assessment System for Children (BASC)

The Behaviour Assessment System for Children (second ed.) (BASC-2; 2004) can be used to measure adaptive functioning across core domains including adaptive/functional skill development and to monitor change. The assessment focuses on the measurement of adaptive and maladaptive behaviour, which are important outcomes for intervention programmes. It is standardised (valid and reliable) for age range 2–21 years. For those in the 2–5 year age range, the 134–160 items cover the key areas of activities of daily living, adaptability, aggression, anxiety, attention problems, depression, functional communication, hyperactivity, social skills, somatisation, and withdrawal. There is a parent rating form and a teacher form (except activities of daily living scale) and the parent and teacher observation forms can be used to measure change following an intervention programme or over time.

Child Behaviour Checklist (CBCL)

The Child Behaviour Checklist (Achenbach & Rescorla, 2001) version 1.5–5 years (CBCL 1.5–5) or version 6–18 (CBCL 6–18) can be completed by parents and others who see the children in home-like settings. It obtains parents' reports of children's competencies and problems.

The Teachers Report Form 6–18 (TRF 6–18) is completed by teachers and other school staff who have known the child in school settings for at least 2 months. It obtains teachers' ratings of many of the problems rated on the CBCL 6–18, plus additional items appropriate for teachers.

The Youth Self-Report 11–18 (YSR 11–18) is completed by 11–18 year olds to describe their own functioning. It has most of the same competence and problem items as the CBCL 6–18, and open-ended responses to items covering physical problems, concerns, and strengths.

All forms have parallel Internalising, Externalising, and Total Problems scales. The TRF also includes Inattention and Hyperactivity-Impulsivity subscales. The following cross-informant syndromes can be derived from the forms: Anxious/Depressed; Withdrawn/Depressed; Somatic Complaints; Social Problem; Thought Problems; Attention Problems; Rule-Breaking Behaviour; Aggressive Behaviour.

Strengths and Difficulty Questionnaire (SDQ)

The Strengths and Difficulty Questionnaire (SDQ; Goodman, 1997) is a brief 25-item parent report measure to elicit emotional and behavioural attributes of children and adolescents ages 2 through 17 years. The SCQ has five subscales namely emotional problems, conduct problems, hyperactivity/inattention, peer relationship problems, and prosocial behaviours and there is also a total difficulty score based on 20 items.

Early Identification of Associated Conditions

Maladaptive or Disruptive Behaviours

The presence of maladaptive behaviours in young people with ASD can significantly limit engagement in treatment programmes, as well as compromise future educational and vocational opportunities (Fulton, Eapen, Črnčec, Walter, & Rogers, 2014). Therefore decreasing such behaviours or replacing these with alternative adaptive behaviours will be a critical focus for interventions and subsequent monitoring. Dominick, Davis, Lainhart, Tager-Flusberg, and Folstein (2007) reported aggressive behaviours including hitting, kicking, and pinching and self-injurious behaviours (SIB) such as head banging, hitting oneself, and biting oneself, in around a third of children with ASD. More than three-quarters of children with these behaviours showed aggressive behaviours both at home and outside the home. Furthermore, around 70 % had experienced a period of severe temper tantrums and for

60 % of children with tantrums these occurred on a daily basis and were a constant, rather than episodic. Several authors have suggested that there is a relationship between inability to communicate and the prevalence of maladaptive behaviours (Dominick et al., 2007) and self-injurious behaviours (Vismara & Rogers, 2010). Both internalised behaviours (e.g. self-injurious behaviour) and externalised behaviour (e.g. aggression to others) may also be a response to environmental stress (Bartak, Bottroff, & Zeitz, 2006). Thus disruptive and challenging behaviours and their appropriate management and ongoing monitoring have significant implications for integration in educational settings and for the overall functioning of the person with ASD.

Developmental Behaviour Checklist (DBC)

The Developmental Behaviour Checklist (DBC)-Parent/Caregiver or Teacher Version (DBC-P and DBC-T; Einfeld & Tonge, 2002) is a 96-item checklist of behavioural and emotional problems in children aged between 4 and 18 years with developmental difficulties.

The DBC provides an excellent measure of emotional and behavioural problems in both children and adolescents with developmental conditions (Einfeld & Tonge, 1992, 1995, 2002). The DBC can be used for children with intellectual disabilities as well as for children who are cognitively able (Brereton, Tonge, Mackinnon, & Einfeld, 2002; Einfeld & Tonge, 2002). The DBC has 96 items providing quantitative measures of behavioural and emotional disturbance. Each item is scored on a scale ranging from 0- 'not true as far as you know' to 3- 'often true or very true'. The total score of the DBC provides a measure of overall psychopathology. There are five subscales: Disruptive/Antisocial, Self-absorbed, Communication Disturbed, Anxiety, and Social Relating (Dekker, Nunn, & Koot, 2002). In addition to measuring psychopathology, the DBC can be used as an autism screening tool (the DBC-ASA) in children as young as 4 years of age (Brereton et al., 2002).

The DBC also has screening measures that are able to identify and monitor individuals at risk of developing comorbidities. One example of use of the DBC is to monitor comorbid ADHD symptomology (see Gargaro et al., 2014). Boys with ASD may be particularly at risk for ADHD comorbidity and require further monitoring, than age, IQ, and cognitively and academically matched girls with ASD (May, Cornish, & Rinehart, 2014).

Aberrant Behaviour Checklist (ABC)

The Aberrant Behaviour checklist (ABC; Aman, Singh, Stewart, & Field, 1985): This scale was primarily developed to assess drug and other treatment effects on severely mentally retarded individuals. Factor analysis of the 58 item has yielded five factors namely (1) Irritability, Agitation, Crying; (2) Lethargy, Social Withdrawal; (3) Stereotypic Behaviour; (4) Hyperactivity, Noncompliance; and (5) Inappropriate Speech.

Adult Behaviour Checklist (ABCL)

The Adult Self-Report (ASR/18–59) and Adult Behaviour Checklist (ABCL/18–59); (Achenbach & Rescorla, 2003): The ASR is used to obtain self-reports from adults on aspects of their adaptive functioning and problems. The ABCL on the other hand is used to obtain reports from people who know the adult person with problems well. There are normed scales for adaptive functioning, as well as empirically based syndromes such as Anxious/Depressed, Attention Problems, Withdrawn, Aggressive Behaviour, Somatic Complaints, Rule-Breaking Behaviour, Thought Problems, and Intrusive problems as well as Internalising and Externalising problems. The profiles also include a Critical Items scale consisting of items of particular concern to clinicians and a total score.

Tics

Available evidence from the literature suggests that tics occur in around 20–40 % of individuals with ASD, although there is significant variability in the extant research (Eapen, Črnčec, McPherson, & Snedden, 2013). Perhaps the largest and best controlled study to date has reported a rate of 6.5 % for the occurrence of Tourette syndrome in ASD (Baron-Cohen, Scahill, Izaguirre,

Hornsey, & Robertson, 1999) with considerably higher rates of up to 50 % for tics when individuals with intellectual disability and ASD are considered (Eapen, Robertson, Zeitlin, & Kurlan, 1997). Awareness of tic disorders will allow for tics to be sensitively managed and possible comorbidities anticipated and differentiated from tics, which in turn can lead to the minimum possible disruption to the young person. For example, tics may be mistaken for fidgetiness that can occur with ADHD, and coprolalia may attract negative consequences such as disciplinary action in children and stigma and social embarrassment in adults. Pharmacological treatment for tic disorders may include clonidine, especially when ADHD presents comorbidly, or antipsychotic agents such as risperidone when there are tics and comorbid behavioural problems such as irritability, aggression, and insomnia (Eapen & Gururaj, 2005). The presence of comorbid OCD would need attention and may necessitate treatment with specific serotonin reuptake inhibitors, while comorbid ADHD would necessitate the use of stimulants (with caution, monitoring for tic exacerbation) or atomoxetine. The risk of drug interactions and side effects may be increased in those with brain damage or epilepsy, and gradual increase in dosage with close monitoring is recommended in these situations (Eapen & Črnčec, 2009). Psychotherapeutic techniques such as cognitive-behaviour therapy for OCD or comprehensive behavioural intervention for tics (CBIT) have established efficacy (Piacentini et al., 2010; Watson & Rees, 2008); however, outcomes may be constrained in individuals where poor cognitive and learning abilities, and hyperactivity, are a factor. Yale Global Tic Severity Rating Scale (YGTSS; Leckman et al., 1989) can be a useful tool in monitoring progress following intervention for tics.

Sleep Problems

It is also important to monitor common comorbidities such as sleep disturbances which left untreated can have significant impact on a child's cognition, academic functioning, behaviour, and mental health. Although sleep problems in children with ASD are similar to those of the general population, they occur at markedly higher rates. Approximately 73–86 % of children with ASD experience problems with sleep onset and maintenance (e.g. long sleep onset latency, short sleep duration, early morning waking (Liu, Hubbard, Fabes, & Adam, 2006; Polimeni, Richdale, & Francis, 2005)). May et al. recently found that 78 % of children with ASD had parent-reported sleep problems compared to 29 % of typically developing controls, with 65 % of children with ASD having persistent sleep problems 1 year later ($n = 84$; 5–12 years) (May, Cornish, Conduit, Rajaratnam, & Rinehart, 2013). This study also showed that children with ASD who were poor sleepers were more aggressive, hyperactive, and experienced greater social problems. Papadopoulos et al. (2015) recently showed that a brief, behaviourally focussed intervention delivered to parents resulted in significantly improved sleep problems and behavioural problems for children with ASD. In addition, parents reported improvements in their own mental health after participating in this programme. This is an important finding given sleep problems in children with ASD have a pervasive impact on the family, including elevated risk for parental stress and poor mental health (Doo & Wing, 2006).

Children's Sleep Habits Questionnaire (CSHQ)

A useful tool for monitoring sleep in children with ASD is the Children's Sleep Habits Questionnaire (CSHQ; Owens, Spirito, & McGuinn, 2000). The CSHQ is 33-item, behaviour parent-reported validated measure of disorders of initiating and maintaining sleep that can distinguish clinical from community samples. Eight subscale scores reflect major behavioural sleep disorders (bedtime resistance, sleep onset delay, sleep duration, sleep anxiety, night wakings, parasomnias, sleep disordered breathing, daytime sleepiness).

Sleep Diary

Sleep diaries are also commonly used to monitor sleep disturbances in children with ASD. Sleep diaries typically involve parents recording the time their child gets into bed at night, falls asleep, any

awakenings, and morning wake time, permitting the calculation of sleep duration, sleep onset latency, and number and duration of night wakings.

Eating Problems

Children with ASD have been described to have atypical eating behaviours and food selectivity is the most frequent of these problems. The everyday management of mealtime behaviours among children with ASD can have a negative impact on family routines and become a significant stressor for families. In a recent study Postorino et al. (2015)investigated the clinical and behavioural features in individuals with ASD with the aim of identifying distinctive clinical profiles in children with and without food selectivity. These authors observed that, while there was no statistically significant difference on gastrointestinal symptoms and growth adequacy between those with and without food sensitivity, parents of those with food sensitivity reported significantly higher levels of parental stress and attributed a larger degree of their children's behavioural problems to this. These findings suggest that early identification and appropriate intervention coupled with ongoing monitoring of distinctive clinical and behavioural patterns linked to food sensitivity should be an important consideration in children with ASD.

Anxiety and Obsessive Compulsive Behaviours

High levels of anxiety are observed in around 40 % of children with ASD with a recent meta-analysis revealing that the most common type of anxiety is specific phobia (30 %), followed by Obsessive Compulsive Disorder (OCD; 17 %), social anxiety disorder and agoraphobia (17 %), generalised anxiety disorder (15 %), separation anxiety disorder (9 %), and panic disorder (2 %) (van Steensel, Bögels, & Perrin, 2011). Early identification and appropriate management of anxiety symptoms should form a critical component in the comprehensive management of ASD.

Depression, Self-Harm, and Suicidality

Low mood, self-harm, and suicidal behaviours are higher in individuals with ASD as compared to the general population with one recent study reporting that over 35 % of individuals with Asperger syndrome diagnosis had attempted suicide in the past, making it much higher than the 4.6 % lifetime prevalence seen in the general population (Paquette-Smith, Weiss, & Lunsky, 2014). However, identifying those at risk may be difficult due to the challenges in obtaining accurate history from individuals with ASD and careful informal and formal enquiries with the young person as well as corroborative evidence from parental or caregiver reports would be crucial in assessing for depression and suicidal behaviours.

Bullying and Victimisation

Bullying and victimisation are more prevalent among youth with ASD than in the general population. The role of anxiety in these situations is complex with a recent study observing that parenting stress moderates the association between bullying victimisation and anxiety (Weiss, Cappadocia, Tint, & Pepler, 2015). This study also found that when mothers reported high levels of stress, the severity of anxiety was most strongly associated with bullying victimisation, which has implications for the management of both child anxiety and parental stress in addressing bullying and victimisation.

Psychosis and Catatonia

Co-occurrence of psychotic symptoms in patients with ASD can be challenging as some of the core features of ASD such as deficits in social reciprocity and communication, as well as restricted behaviours and interests, can be mistaken for psychosis. There are also instances of misdiagnosis or missed diagnosis of psychosis in ASD as there is a subset of patients who present with a complex neurodevelopmental disorder with impairments that cross diagnostic categories (Cochran, Dvir, & Frazier, 2013). Further, symptoms of catatonia are being increasingly recognised at a rate of 4–17 % in adolescents and adults with ASD (Dhossche, 2014). However it is to be noted that behaviours such as repetitive movements, mutism, posturing, and frantic agitation can occur in autism, and hence caution should be exercised and a diagnosis of catatonia should not be made unless there is a sharp and

sustained increase of these symptoms persisting for several days or weeks. DeJong, Bunton, and Hare (2014)in a recent review reported 22 papers that described the treatment of catatonic symptoms in a total of 28 children and adults with ASD using electroconvulsive therapy (ECT), high-dose lorazepam, and behavioural therapy.

Pharmacotherapy and Monitoring to Evaluate the Outcome of Medication Use

No drug is currently known to improve autism characteristics. A key principle is to identify target symptoms and medication choice is matched to those goals. For example risperidone has been found to reduce disruptive behaviour disorder symptoms including aggression and conduct problems in children aged 5–18 in the short term and on follow-up over 6 months (Loy, Merry, Hetrick, & Stasiak, 2012), measuring outcomes with the irritability subscale of the Aberrant Behaviour Checklist (ABC; Aman et al., 1985) and Conduct Problem subscale of the Nisonger Child Behaviour Rating Form (NCBRF-CP; Aman, Tassé, Rojahn, & Hammer, 1996). Thus whether using second generation antipsychotics including risperidone and aripiprazole for severe behavioural disturbance such as tantrums, aggression, self-injury, etc.(Stigler, 2014), stimulants for ADHD, melatonin for sleep problems, or selective serotonin reuptake inhibitor (SSRI) for anxiety, OCD, or depression, both careful assessment of baseline symptoms and any change in symptoms following treatment will need to be carefully monitored using relevant scales that are specific to each of these conditions and symptom profiles as well as measures of overall improvement such as the Clinical Global Impression Severity Scale (Busner & Targum, 2007). CGI-S is a widely used clinical rating scale of the severity of symptoms, and it is treatment sensitive. Similarly there is a need to include monitoring for adverse events of medication use. It is essential to monitor the side effects of individual medication using specific questionnaires to elicit the relevant side effects as applicable to each drug. There are also some general principles of monitoring that would be in order in certain situations. One such example is the need for monitoring weight gain and metabolic abnormalities when using second generation antipsychotics (SGAs) such as risperidone as these drugs are commonly used in ASD. Given that the current evidence points to the occurrence of the key antecedents of metabolic syndrome soon after initiation of the medication, suggested practice guideline for cardiometabolic monitoring in young people on antipsychotic medication includes 3-monthly in the first year and biannually thereafter (Eapen, Shiers, & Curtis, 2013).

Maximising Opportunities: Well-Being, Function, and Participation

Individual with Autism

Learning and Adjustment in School

Programming and progress monitoring is particularly complex in this context as many core aspects of an individualised plan may not align to a prescribed curriculum and may focus instead on non-academic skills. For example, skills such as communication, socialisation, and independence, which underpin success in all areas of learning and are associated with positive outcomes, are intrinsically difficult to measure and incorporate into a curriculum. Individualised plans must include measurable academic and functional goals that are not merely restatements of curriculum, standards, or expectations, but are observable, relevant, and assessable objectives intended to facilitate specific gains in academic standards and life skills.

The usual approach to measuring achievement in school is standardised testing. Administering a standardised test to a child with ASD can be difficult, and the results somewhat misleading. Students with ASD may demonstrate challenging behaviour during the assessment, and research shows that test scores may improve significantly if specialised procedures are implemented to increase the student's engagement in the assessment task (Koegel, Koegel, & Smith, 1997). Further, although criterion-based or observation-based assessments

often provide valuable complementary information, numerous studies have shown that contextual variables such as the amount of attention given to the student prior to the assessment (McComas, Thompson, & Johnson, 2003; Roantree & Kennedy, 2006), the environment (Lang et al., 2009), the person implementing the assessment (Ringdahl & Sellers, 2000), and the motivation of the person with autism and interest in the test materials can all affect the outcome.

It is important to consider what data will need to be collected to document student progress towards IP goals, which tools will be used to generate the data, and how frequently and who will collect data and report progress. Popular methods employed by educators include direct methods, indirect methods, and authentic methods. As has been discussed, each of these approaches in isolation may not be effective in assessing the child with ASD. Direct methods include behaviour observation, such as frequency, duration and interval recording, and curriculum-based assessment. Indirect methods are often auxiliary and include rubrics, which describe performance in qualitative or quantitative terms, attainment scaling, in which the educator rates the student responses on a best-to-worst scale, and student self-monitoring. Authentic methods such as anecdotal notes of informal interviews with students and portfolios of student work involving relevant skills as appropriate for the age.

PEP3

The Psycho Educational Profile 3 (PEP3; Schopler, Lansing, Reichler, & Marcus, 2005) is designed to provide information to inform educational programming (IEP) by evaluating uneven learning strengths and weaknesses that characterise ASD, and provide information on developmental skill levels. The test also provides a measure of severity, establishes developmental/adaptive levels, and serves as a research tool in outcome research and learning. This is particularly useful for programme development and targets social communication and adaptive behaviour. It can be administered by competent and experienced staff and is norm referenced, and provides a measure across core domains of communication, motor, and adaptive/maladaptive behaviour, and collects information from a variety of sources: parents, teachers, and direct observation (enabling triangulation of data).

Teacher Rating Scale of School Adjustment

Teacher Rating Scale of School Adjustment (TRSSA; Betts & Rotenberg, 2007) has been demonstrated to have acceptable internal consistency and stability and can be used to evaluate school adjustment and participation across different time points. An exploratory factor analysis of the TRSSA has yielded three associated factors namely On-Task Classroom Involvement, Positive Orientation, and Maturity.

Function

One of the important considerations in monitoring progress following intervention in ASD involves reduction of characteristics that have a functional impact. While reduction in ASD characteristics has been extensively studied, the improvement in functioning has not been sufficiently addressed in ASD. While some characteristics may be persistent, pervasive, or occur frequently but have limited impact on day-to-day functioning, others although infrequent may have a more profound functional impact. Also, it has been suggested that functional impairment may be independent of the presence and frequency of the characteristics as is the case with psychiatric disorders, where the course and outcomes are different based on the presence or not of functional impairment (Bird et al., 1996). Evidence that indicates the relationship between autism characteristics and function is not straightforward but is now emerging (Szatmari et al., 2015). Further there are issues pertaining to inconsistencies with the operational definition as well as the measurement of functional impairment (Canino, Costello, & Angold, 1999). While assessment of overall improvement is the focus with measures such as the Children's Global Assessment of Functioning (Shaffer et al., 1983), others such as the Vineland-II (Sparrow et al., 2005) have a focus on specific aspects of adaptive functioning and

activities of daily living. Both these methods have distinct advantages and disadvantages and further these measures do not link the functioning with specific characteristics in that they do not consider the impact of individual problems on functioning. Measures such as the AIM hold promise in this regard by linking the frequency, impact, and interference of each symptom with overall functioning that would have significant advantage in assisting with treatment planning and outcome assessment (Kanne et al., 2014).

Participation

School

For all children the crudest measure of participation in school is attendance. Attendance includes participation in the academic curriculum that can be achieved at a school campus or in the home environment. Unfortunately today many children with autism do not participate in the school curriculum either because they have been excluded from it or because they refuse to go to school. The former indicates problems with ability to manage the types of problems that can occur in children and young people with autism and the latter a failure in addressing issues or concerns to minimise the risk of refusal.

Participation in the social curriculum (sometimes called the 'hidden curriculum') is also important. It is not as immediately available to children and young people in home schooling. Attendance at a school campus is not sufficient to ensure participation in the social curriculum. As such monitoring is needed to ensure it is occurring. For children who are attending school monitoring of participation should include information from the classroom and outside the classroom. Monitoring should be linked to specific programme goals designed to enable the student to participate in non-academic aspects of school life. Assessments such as the Participation and Environment Measure for Children and Youth (PEMCY) (Coster et al., 2011) may also be useful.

After School

Post-school participation is typically conceptualised along three dimensions: employment, independent living, and participation in post-secondary education. For a student with ASD, the high school years and IP should be catered to maximising these outcomes, and their educational focus shifts from aiming to fill in missing gaps in the student's developmental profile to optimise their post-school lifestyle and opportunities preparation for independence. In the United States, for example, students with disabilities are generally required to develop a transition plan as the driving force of their IP at age 14. Hence, while progress in ASD may still be measured broadly in regard to cognition and adaptive functioning at this stage in life, there will also be a greater emphasis on the attainment of specific practical skills. Overall, in terms of assessment and monitoring of progress, instead of continuing to assess what the student cannot do and working towards improvements in those areas, the IP must be based on student interests, preferences, strengths, and work habits and describe the supports and modifications necessary for their future success.

At this stage, evaluation of ability should comprise both formal assessment tools and more of the auxiliary methods previously described, such as structured observations and grading and feedback of work samples. It should include assessment of student interests and preferences, career awareness, cognitive development, academic achievement, adaptive behaviour, self-determination, interpersonal relationship and social skills, communication skills, emotional development and mental health, employment and community skills, and community participation and independent living skills. In this regard, age appropriate, specific and measurable goals as detailed in Table 6.3 must be set relevant to school and post-school participation in education, employment, and independent living skills.

Community

With regard to participation in community activities, available evidence from the literature suggests that children with ASD participate in activities less frequently and with less variety compared to children with other developmental disabilities as well as those who are developing normally (LaVesser & Berg, 2011). Measures

Table 6.3 Examples of target goals, measurement of such goals, and relevant interventions in ASD

Skill area	Targeted behaviour	Measurement	Intervention	Reference
Academics	Essay writing—total words written and function essay elements included	Number of words and elements	Video modelling and self-monitoring	Delano (2007a)
	Essay writing—total words written, number of unique verbs, adverbs, and adjectives	Number of target elements	Instruction, modelling, practice, and feedback	Delano (2007b)
Adaptive skills	Setting the table and putting away groceries	Percentage of tasks performed correctly	Task analysis and video prompting	Cannella-Malone et al. (2006)
	Packing and unpacking bag, brushing teeth	Percentage of tasks performed correctly	Task analysis and video prompting	Rayner (2010)
	Washing dishes	Percentage of tasks performed correctly	Task analysis and video prompting	Sigafoos et al. (2007)
Problem behaviour	Disruptions, physical and verbal aggression, and straightening (obsessive) behaviour	Problem behaviour per minute and percentage of items straightened	Functional communication training with extinction	Kuhn, Hardesty, and Sweeney (2009)
	Physical aggression and destructive behaviour	Frequency of aggressive behaviour	Mindfulness exercise	Singh et al. (2011)
Social skills	Conversational basics; providing positive feedback to a speaker and answering open-ended questions	Percentage of steps performed correctly	Group instruction, modelling, role play, and feedback	Dotson, Leaf, Sheldon, and Sherman (2010)
	Initiation to peers and responses to peers	Frequency of behaviour	Script and prompting	Krantz and McClannahan (1993)
Vocational skills	Prepare folders with advertising material, prepare folders and information notebooks	Percentage of tasks completed successfully and independently	Simulation training: most-to-least prompting and task instruction	Lattimore, Parsons, and Reid (2008)
	Cleaning of sinks and mirrors in a company bathroom, and washing up in the break room	Percentage of tasks completed successfully and independently	Simulation training: most-to-least prompting and task instruction	Lattimore et al. (2008)

that have been used in this context include assessments based on self-reports such as the Child Assessment of Participation and Enjoyment (CAPE; King et al., 2006) although children with ASD would find this difficult to undertake and assessors would find it difficult to interpret the responses due to the child's limited social communication abilities. Measures that use interview with a caregiver such as the Preschool Activity Card Sort (Berg & LaVesser, 2006) are difficult to administer as they are resource intensive and require considerable amount of interviewer time. While there are some measures that focus on specific activities as is the case with Participation in Childhood Occupations Questionnaire (PICO-Q; Bar-Shalita, Yochman, Shapiro-Rihtman, Vatine, & Parush, 2009) or in specific contexts such as the Child Routines Inventory (Sytsma, Kelley, & Wymer, 2001); Children Helping Out: Responsibilities, Expectations, and Supports (CHORES; L. Dunn, 2004), etc., valid general measures of activity participation for use in ASD population are lacking. In a recent study, Little, Sideris, Ausderau, and Baranek (2014) investigated the use of Home and Community Activities Scale (HCAS; adapted from Dunst, Hamby, Trivette, Raab, and Bruder (2000)) in a large cohort of 713 children with ASD and found that activity participation of school-age children fell into six dimensions, namely Parent–Child Household Activities, Community Activities, Routine Errands, Neighbourhood–Social Activities, Outdoor Activities, and Faith-Based Activities (Little et al., 2014).

Families: Parents, Carers, and Siblings

Families of children with ASD face unique challenges, and as a result ASD families experience higher levels of stress (Hoffman, Sweeney, Hodge, Lopez-Wagner, & Looney, 2009) which can have a significant impact on their quality of life. Siblings can also experience significant challenges and a number of factors may affect the dynamic of the relationship, continually evolving and changing across the course of life (Orsmond & Seltzer, 2007). Monitoring progress in ASD would therefore need to include family adjustment and quality of life, stress, and coping as well as parental satisfaction, competence, and confidence to manage their child as well as parental perception of their capacity to participate in their community.

The interactions between brothers and sisters provide them with opportunity to experience sharing, companionship, rivalry, and other outcomes. Researchers who study ASD do not have a clear understanding of why some sibling pairs experience warm, supportive relationships, whereas others experience conflict and isolation (Rivers & Stoneman, 2003). Many individuals with ASD have behaviour repertoires that might be expected to affect sibling relationships and the social, behavioural, and psychological adjustment of their typically developing siblings. Findings regarding the effects of having a sibling with ASD have been mixed and inconsistent (Macks & Reeve, 2007; Mascha & Boucher, 2006; Verté, Roeyers, & Buysse, 2003). Some researchers (e.g. Hastings, 2003b; Ross & Cuskelly, 2006) (e.g. Hastings, 2003b; Ross & Cuskelly, 2006) have reported negative outcomes (e.g. loneliness, behavioural difficulties, depression) for the typically developing siblings, whereas other researchers (e.g. Kaminsky & Dewey, 2001; Mascha & Boucher, 2006) have found positive outcomes (e.g. less conflict within the relationship, high self-esteem and self-concept) or no evidence of negative effects (Hastings, 2003a; Orsmond & Seltzer, 2007). Orsmond and Seltzer investigated adult siblings of individuals with ASD and DS and found that typically developing adult siblings of individuals with ASD reported significantly less contact and less positive effect in the relationship with their sibling with ASD than did the DS group. Pilowsky, Yirmiya, Doppelt, Gross-Tsur, and Shalev (2004)reported that most siblings of individuals with ASD were well adjusted, but emphasised that the stress of having a sibling with ASD cannot be overlooked.

Comprehensive monitoring of outcomes should include the well-being of parents, siblings, and carers involved in the life of a young person with ASD. Thus, for the overall

improvement, independent living outcomes, maladaptive behaviours as well as general well-being, family stress, coping and quality of life, and other relevant measures are indicated. Examples include Autism Treatment Evaluation Checklist (ATEC; Rimland & Edelson, 1999), Parent Stress Index (PSI: Abidin, 1990a), and Quality of Life in Autism (QoLA: Eapen, Črnčec, Walter, & Tay, 2014).

The Depression Anxiety Stress Scales

The Depression Anxiety Stress Scales (DASS; Lovibond & Lovibond, 1995) is a 21-item self-report measure that assesses negative affect, generating separate scores for the subscales of Depression, Anxiety, and Stress. The Anxiety scale assesses what causes arousal, what situations cause anxiety, and what experiences have led to this effect. The Stress scale assesses whether the person has difficulty relaxing, nervous arousal, and being easily upset/agitated, irritable/over-reactive, and impatient. Higher scores indicate greater symptomatology. The DASS-21 has been shown to have excellent psychometric properties (Antony, Bieling, Cox, Enns, & Swinson, 1998; Henry & Crawford, 2005; Lovibond & Lovibond, 1995).

The Parenting Sense of Competence Scale

The Parenting Sense of Competence scale (PSOC; Johnston & Mash, 1989) includes 17 items designed to measure parental self-efficacy. Based on the factor structure found in Australian populations (Rogers & Matthews, 2004), the scale generates scores on three subscales: Satisfaction, Efficacy, and Interest, with higher scores indicative of higher levels of parental satisfaction and self-efficacy. The PSOC has been found to have strong psychometric properties (Rogers & Matthews, 2004).

Parenting Stress Index

Parenting Stress Index Short Form (PSI-SF) (Abidin, 1990b): The PSI Short Form (PSI/SF) has 36 items written at a fifth-grade reading level, for parents of children 12 years and younger. The PSI/SF yields a Total Stress score from three scales: Parental Distress, Parent–Child Dysfunctional Interaction, and Difficult Child.

Paediatric Quality of Life Inventory (PedsQL)

The Paediatric Quality of Life Inventory (PedsQL) (Varni, Seid, & Rode, 1999) follows a modular approach to measuring health-related quality of life (HRQOL) in healthy children and adolescents and those with acute and chronic health conditions. The PedsQL Measurement Model integrates seamlessly both generic core scales and disease-specific modules into one measurement system and different developmentally appropriate (Ages 2–18; Child Self-Report Ages 5–7, 8–12, 13–18; Parent Proxy-Report Ages 2–4, 5–7, 8–12, 13–18) forms are available. While disease-specific modules are available for some of the chronic health conditions, there is no specific module for autism.

The Quality of Life in Autism

The Quality of Life in Autism (QoLA) contains two subscales to be completed by the parent or carer: Part A, with questions pertaining to overall quality of life, and Part B, with questions asking parents to rate the impact of autism-specific symptoms of their child on parental daily activities. A preliminary study showed good psychometric properties with strong internal consistency and convergent validity (Eapen et al., 2014) and self-report version is also available.

Conclusions and Directions for Future Research

Fit-for-purpose monitoring of individuals with ASD and their families offers the opportunity to individually tailor interventions, with timely adaptations based on emerging skills and difficulties, identify commonly occurring problems early, with the hope of preventing or minimising any negative impact, and to ensure that every individual with autism and their family are reaching their potential for function and community participation. Along the way we are likely to also discover new information about how to build on the strengths of individuals with autism and how the environment and community can accommodate difference to minimise avoidable disability.

We are not yet equipped with tools that are ideal for these tasks, and so tools development is needed. In particular, appropriate measures to evaluate participation and functional impact are needed. Although Home and Community Activities Scale (HCAS) has been recently adapted for use in ASD, further research is needed to validate the HCAS factor structure and to expand the responses to be more sensitive to a range of frequency options as well as ratings of enjoyment. In addition, studies are needed to better address questions such as with whom participation occurs and level of functioning and activity participation as individuals with ASD transition from preschool to school and to post-school options and adult life. Nor do we have services that value monitoring or that make it easy for this to be integrated across different types of services that are accessed by individuals with autism and their families. Seamless monitoring across the lifespan of developmental progress, scholastic achievement, and also functional impact and participation in activities and civic life is the exception rather than the rule. A greater understanding of the link between and relative importance of the characteristics of autism and function and participation is also needed, from the perspective of individuals with autism and their families. Only this will ensure that monitoring is fit-for-purpose and relevant.

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Implications of *ICD* and *DSM* on Screening, Diagnosis, and Monitoring

7

Sarah J. Carrington

General Introduction

As outlined in earlier chapters of this volume, our understanding of autism has continued to evolve since the original description of the condition by Leo Kanner in 1943. Once considered to be a form of childhood schizophrenia, autism was only recognised as a distinct clinical condition by the World Health Organisation (WHO) in 1979, in the ninth edition of the *International Classification of Disease* (*ICD*). Similarly, in the third edition of the *Diagnostic and Statistical Manual of Mental Disorders* (*DSM-III*), the American Psychiatric Association (APA) described infantile autism as being characterised by a lack of responsiveness to others, absent or abnormal language, and unusual responses to aspects of the environment (including resistance to change or attachment to objects), all of which would manifest within the first 30 months. Around this time, Lorna Wing and Judith Gould proposed that autism could be characterised by a triad of social impairments, affecting social interaction, social communication, and social imagination (Wing & Gould, 1979). The notion of a triad of impairments, although subtly different to the Wing and Gould triad, was included in subsequent editions of both *ICD* (*ICD-10*) and *DSM* (*DSM-IV* and *DSM-IV-TR*). In 2014, the latest edition of *DSM* (*DSM-5*) was published and introduced a number of changes relative to both its previous edition (*DSM-IV-TR*) and the current edition of *ICD* (*ICD-10*). Any change to the diagnostic criteria can have implications for the diagnosis and assessment of autism; for example, it can affect which behaviours contribute towards a diagnosis and, therefore, who meets criteria for a diagnosis. The changes introduced in *DSM-5* have proved to be particularly controversial, with concerns over a narrowing of the criteria, which could potentially result in under-diagnosis compared with *DSM-IV-TR*, and concerns that there may be a loss of support for those with *DSM-IV-TR*, but not *DSM-5* diagnoses. Furthermore, these changes may also influence revisions to *ICD-10*, which are expected to be published in 2017. This chapter lays out the current situation as it applies to differential diagnosis. The implications of new changes in diagnostic criteria will be discussed in the context of the assessment process.

Current Descriptions and Diagnostic Criteria

Until relatively recently, the descriptions and diagnostic criteria for autism included in both *ICD* and *DSM* were almost identical, differing

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primarily in the terms used; while *ICD-10* (WHO, 1993[1]) refers to childhood autism, *DSM-IV-TR* (APA, 2000) referred to autistic disorder. In this chapter, the term autism will be used to refer to both autistic disorder and childhood autism. In both *ICD-10* and *DSM-IV-TR*, autism fell within the category of pervasive developmental disorder (PDD) and the descriptions were based on a triad of impairments, which partially overlapped with the triad described by Wing and Gould. The triads in both *ICD-10* and *DSM-IV-TR* described impairments in social interaction and social communication, but rather than the social imagination impairment described by Wing and Gould, *ICD-10* and *DSM-IV-TR* specified the presence of restricted, repetitive, and stereotyped patterns of behaviour, interests, or activities. Although impairments in imagination were included in the *ICD-10*/*DSM-IV-TR* descriptions—within the communication domain (see Fig. 7.1)—they were not considered to be essential for diagnosis; unlike the Wing and Gould triad, it would be possible to receive a diagnosis according to *ICD-10*/*DSM-IV-TR* without impaired imagination. Each domain of the *ICD-10*/*DSM-IV-TR* triad is associated with a number of subdomains, or subcategories of behaviour, and impairment is required in at least six subdomains to qualify for a diagnosis (Fig. 7.1). Moreover, the criteria specify that impairment must be evident within the first 36 months in either social interaction, language as used for social communication, or symbolic or imaginative play.

In addition to autism, *ICD-10* and *DSM-IV-TR* described separate subgroups within PDD for Asperger syndrome,[2] childhood disintegrative disorder, Rett's disorder, and PDD not otherwise specified (PDD-NOS). The latter category in *DSM-IV-TR* included presentations of autism that were atypical in the age of onset or had atypical or subthreshold symptomatology. In *ICD-10*, however, there are three diagnoses intended to capture these individuals: atypical autism (in both age of onset and symptomatology), other PDDs, and PDD unspecified.

The latest edition of the *DSM* (*DSM-5*) has introduced changes to the clinical description and diagnostic criteria for autism. First, *DSM-5* has moved away from the triad of impairments and now defines just two domains: impaired social communication behaviour and the presence of restricted and repetitive patterns of behaviours, interests, or activities (RRBs). In reality, this is more complex than simply combining the social and communication domains from *DSM-IV-TR*, as more repetitive aspects of communication such as stereotyped or repetitive speech, or ritualised greetings would be included within the RRB domain of the *DSM-5* dyad. There is evidence supporting the move from a triad to the dyad, with confirmatory factor analysis indicating that two-factor models emulating the *DSM-5* model fitted the data better than models based on the *DSM-IV-TR* triad (Guthrie, Swineford, Wetherby, & Lord, 2013; Harstad et al., 2015; Mandy, Charman, Puura, & Skuse, 2014; Mandy, Charman, & Skuse, 2012). As with *DSM-IV-TR*, both of the *DSM-5* domains have a number of associated subdomains or subcategories of behaviour; for example, social communication impairments are characterised by a lack of social emotional reciprocity, impaired non-verbal communication, and difficulties in developing and maintaining relationships (Fig. 7.2). *DSM-5* specified that an individual would need impairments in all three of the social communication subdomains and at least two of the four restricted and repetitive patterns of behaviour subdomains.

[1] The WHO published a set of clinical descriptions and diagnostic guidelines (1992) and a set of diagnostic criteria for research (1993). The diagnostic criteria for research were derived from the clinical guidelines and were intentionally more restrictive, to allow the identification of groups of individuals with relatively homogeneous symptom profiles. Due to the restrictive nature of the criteria, in clinical practice they were intended to be used alongside the more descriptive clinical guidelines to allow the identification of more atypical, yet still clinically significant cases. The significance of clinical judgement will be considered in the discussion section of this chapter.

[2] *DSM-IV-TR* referred to Asperger's disorder, while in *ICD-10* the term Asperger's syndrome is used. In this chapter, the term Asperger syndrome will be used to refer to both.

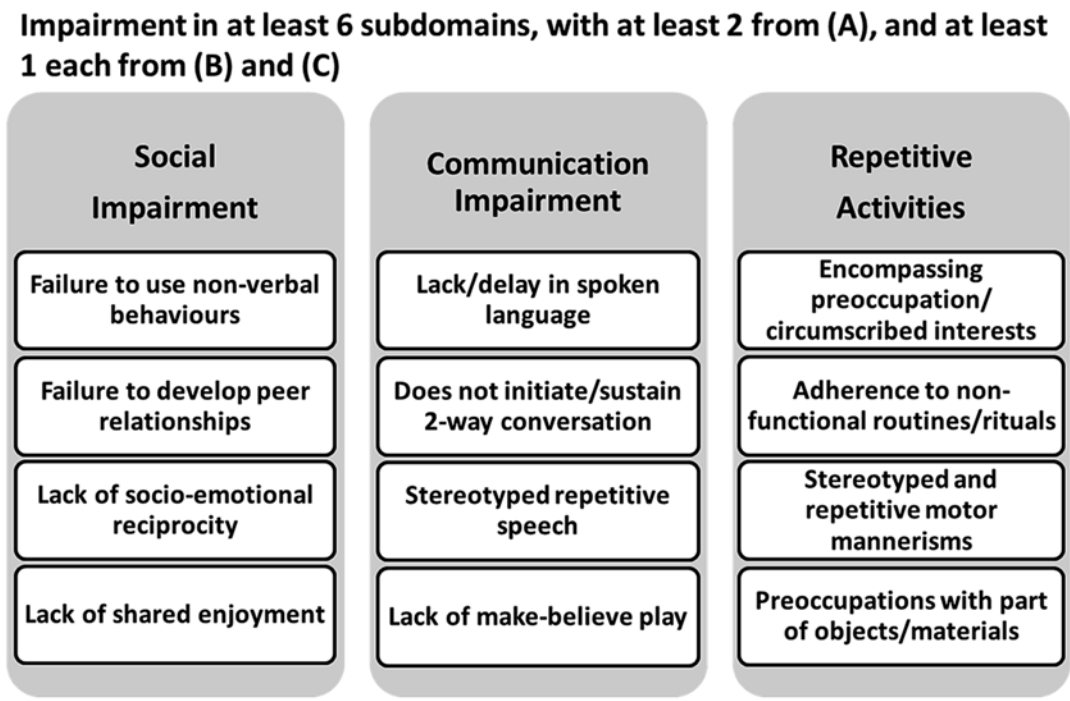

Fig. 7.1 The *ICD-10* and *DSM-IV-TR* triad of impairments

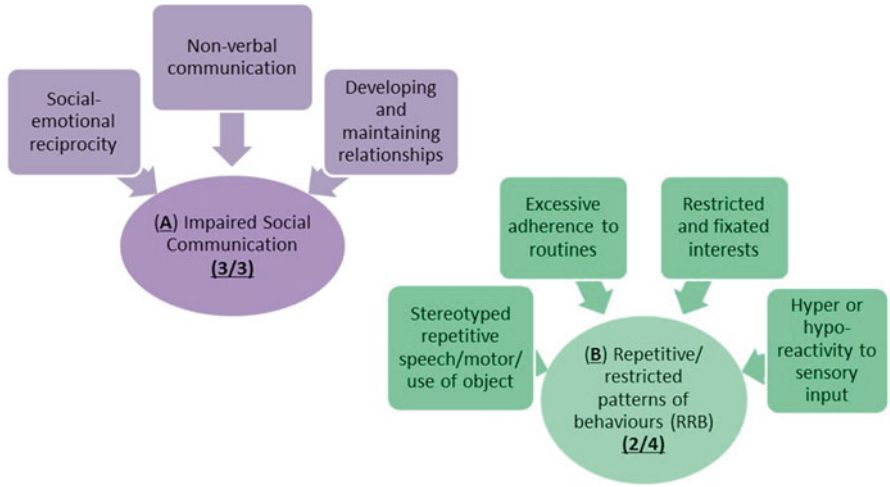

Fig. 7.2 The *DSM-5* diagnostic criteria for autism spectrum disorder (ASD)

DSM-5 has a somewhat more flexible approach to the age at which symptoms would need to be present for diagnosis. The new criteria specify that symptoms must be present in the early developmental period, but acknowledge that in some individuals, certain symptoms may not be evident until the demands of the social environment placed on an individual (e.g. school, college, or work) exceed their level of functioning. The new criteria also include a three-level rating of severity for each of the two domains, which can be used to

describe an individual's current symptomatology. Level one is assigned for individuals requiring support, level two for those who require substantial support, and level three for those requiring very substantial support. It is recognised that these severity ratings may vary over time and across contexts, and that an individual may in fact score below level one. Finally, clinicians are asked to specify whether there is accompanying intellectual or language impairment.

Perhaps one of the most controversial changes has been that in *DSM-5*, the previously distinct diagnostic categories of autistic disorder, Asperger syndrome, childhood disintegrative disorder, and PDD-NOS are now included under the single umbrella term autism spectrum disorder (ASD). Rett syndrome is no longer included in *DSM-5* as it is considered as having a known genetic aetiology. Wing, Gould, and Gillberg (2011) suggested it may be helpful to retain a list of subgroup names that had existed in *DSM-IV-TR* along with a brief description. While this concept was not adopted in the final *DSM-5* criteria, the severity rating may have been intended to help identify the level of need an individual may have, thus facilitating provision of appropriate support. The potential implications of the removal of the subgroups, and particularly for Asperger syndrome, will be discussed in more detail below.

DSM-5 has also seen the introduction of a new category: social (pragmatic) communication disorder (SCD). SCD is described in *DSM-5* as being characterised by a difficulty in the 'pragmatics, or social use of language and communication'. It is primarily differentiated from ASD by the presence of restricted and repetitive behaviours in ASD and their absence in SCD; however, the condition is not simply characterised by the social communication domain of the *DSM-5* ASD dyad. Instead, SCD is characterised by persistent difficulties in (1) using communication for social purposes, (2) the ability to change communication to match the context or needs of the listener, (3) following the rules of conversation or storytelling, and (4) understanding non-literal, ambiguous, or inferred meanings. Deficits must limit communicative and social functioning, with potential effects on academic achievement, and onset of symptoms in the early developmental period. Given the higher-order nature of these deficits, language must be sufficiently developed to allow their detection; consequently, SCD would not typically be diagnosed before four years. The inclusion of non-verbal communication in the descriptions is an expansion on the traditional definition of pragmatic language disorder, although there is still likely to be overlap between these conditions.

Each of the changes introduced in *DSM-5* has the potential to impact on who will receive a diagnosis, as well as the assessment process and provision of services and support. Indeed, there has been much concern that *DSM-5* represents a narrowing of the diagnostic criteria that will lead to under-diagnosis and a subsequent loss of support for individuals who currently have a diagnosis. In this chapter, the research exploring the efficacy of the *DSM-5* criteria will be reviewed and the potential impact of changes to the criteria on the use of standardised diagnostic assessments will be discussed. The implications of the loss of the *DSM-IV-TR* subtypes such as Asperger syndrome and PDD-NOS will be discussed together with the introduction of the new diagnostic category of social (pragmatic) communication disorder. Finally, dimensional versus categorical approaches to diagnosis (and research) will be considered.

Who Will Get a Diagnosis of *DSM-5* ASD?

The publication of the draft criteria for *DSM-5* generated considerable research investigating the efficacy of the proposed guidelines. For diagnostic criteria to be effective, they must provide good levels of both sensitivity and specificity. Sensitivity refers to the ability of the criteria to accurately identify individuals who should qualify for a diagnosis; thus for *DSM-5* to have good sensitivity relative to *DSM-IV-TR*/*ICD-10*, it would be expected that the majority of individuals who met criteria for a diagnosis according to *DSM-IV-TR*/*ICD-10* would also meet the criteria for *DSM-5* ASD. Specificity on the other hand

refers to the ability of the criteria to exclude individuals who should not receive a diagnosis; if individuals who met criteria for *DSM-IV-TR*/*ICD-10* conditions other than PDD or indeed individuals who had no clinical diagnoses met criteria for *DSM-5* ASD, the criteria would have low levels of specificity. Sensitivity and specificity can vary between 0 and 1, with higher values indicating greater accuracy. Initial concerns regarding *DSM-5* have largely been about the sensitivity of new criteria.

Evidence of Reduced Sensitivity

Early studies focusing on the *DSM-5* criteria largely found a concerning loss of sensitivity compared with the *DSM-IV-TR* criteria. Typically this drop of sensitivity was found in the context of good levels of specificity (between 0.94 and 1.0). For example, Mattila et al. (2011) and Gibbs, Aldridge, Chandler, Witzlsperger, and Smith (2012) reported that strict application of the draft *DSM-5* criteria resulted in reduced diagnostic sensitivity for children (a loss of 54 % and 23 % respectively) when compared with *DSM-IV-TR*. Other studies that applied the two sets of criteria to the same individuals similarly found reduced sensitivity in at-risk toddlers (Matson, Kozlowski, Hattier, Horovitz, & Sipes, 2012) and adults with intellectual disability (Matson, Belva, Horovitz, Kozlowski, & Bamburg, 2012). A more recent study explored this further and reported a loss of 23 % sensitivity for *DSM-5* compared with *DSM-IV-TR* in a sample of children aged between 16 months and 18 years, but with some preliminary evidence suggesting that sensitivity may be lower for those children under the age of 30 months (Harstad et al., 2015). Importantly, this study also suggested that children who met criteria for *DSM-IV-TR* autistic disorder were significantly more likely to meet criteria for *DSM-5* ASD than those who met *DSM-IV-TR* criteria for PDD-NOS or Asperger syndrome.

The finding of comparatively reduced sensitivity of the *DSM-5* criteria to PDD-NOS and Asperger syndrome compared with 'core' autism is consistent with previous evidence suggesting that the descriptions may be too narrow to capture the full autism spectrum. For example, a study by Mayes, Black, and Tierney (2013) reported excellent sensitivity of the *DSM-5* criteria for both high and low functioning autism groups in two samples of children, but poor sensitivity (between 0.20 and 0.28) for children who met *DSM-IV-TR* criteria for PDD-NOS. In a similar study, Gibbs et al. (2012) reported that the majority of children in their sample who did not meet criteria for *DSM-5* ASD had received a diagnosis of *DSM-IV-TR* PDD-NOS, while McPartland, Reichow, and Volkmar (2012) reported low levels of sensitivity for children meeting *DSM-IV-TR* criteria for Asperger syndrome or atypical autism (including PDD-NOS). This was explored further in a study of data collected with both children and adults conducted by Young and Rodi (2013). They reported that none of the individuals who had received a *DSM-IV-TR* PDD-NOS diagnosis and just 56.1 % of individuals with Asperger syndrome met criteria for *DSM-5* ASD, compared with 73.7 % of those with autistic disorder.

As well as varying according to diagnostic subgroup, research has also looked at the sensitivity of the new criteria in individuals with different ability levels. This work has suggested that the sensitivity of the *DSM-5* criteria may vary as a function of IQ. In the study previously described by McPartland et al. (2012), only 46 % of those who met criteria for *DSM-IV-TR* PDD with an IQ above 70 met the *DSM-5* criteria for ASD. In another example, Taheri and Perry (2012) found that while only 22.2 % of their sample who had an IQ above 70 met criteria for *DSM-5* ASD, 89.7 % of individuals with an IQ below 40 met the criteria. Not all studies investigating IQ, however, have found a significant effect; while Harstad et al. (2015) reported only a trend indicative of lower sensitivity for higher ability individuals, Young and Rodi (2013) found no significant relationship between IQ and meeting criteria for *DSM-5* ASD. Moreover, a recent meta-analysis found that while the sensitivity of the *DSM-5* criteria may be reduced for *DSM-IV-TR* autistic disorder and PDD-NOS, it was not

significantly reduced for individuals who met the *DSM-IV-TR* criteria for Asperger syndrome (Kulage, Smaldone, & Cohn, 2014).

According to *DSM-IV-TR*, a diagnosis of PDD-NOS is given when an individual has either (a) impairments in reciprocal social interaction together with impaired communication or (b) impairments in reciprocal social interaction and the presence of repetitive or restricted interests. However, based on a study of 66 individuals who met criteria for PDD-NOS, Mandy, Charman, Gilmour, and Skuse (2011) found that the majority of people (64 of the 66 cases seen) had impaired social interaction and communication in the absence of repetitive and restricted behaviours and interests (type (a), above). Given that *DSM-5* required the presence of RRBs for a diagnosis of *DSM-5* ASD, and assuming that the majority of individuals with PDD-NOS do not have these behaviours, as described by Mandy et al., it is perhaps not surprising that so many studies have reported reduced sensitivity of the *DSM-5* criteria for PDD-NOS. One suggestion emerging from the *DSM-5* field trials was that the apparently reduced prevalence of *DSM-5* ASD compared with the combined prevalence of *DSM-IV-TR* autistic disorder, Asperger syndrome, and PDD-NOS may be accounted for by movement into the newly defined social (pragmatic) communication disorder (SCD) category (Regier et al., 2013). However, this was not universally accepted, and Bishop and Norbury (2002) noted that the majority of children they identified with a pragmatic language impairment[3] used stereotyped language, with a minority also reporting unusual sensory interests. Both sensory symptoms and the more repetitive and stereotyped aspects of communication impairments are included within the RRB domain of *DSM-5* ASD; Norbury, therefore, suggested that some children with PDD-NOS may continue to receive an ASD rather than SCD diagnosis (Norbury, 2014; Swineford, Thurm, Baird, Wetherby, & Swedo, 2014). Whether individuals with *DSM-IV-TR* PDD-NOS best meet the *DSM-5* criteria for ASD or SCD—or neither—remains to be seen as further research is conducted following the publication of the *DSM-5* guidelines. However, the potential implications should these individuals qualify for the SCD diagnosis will be discussed below.

Overall, the findings reviewed so far in this chapter lend support to the view that the *DSM-5* descriptions may be too narrow to capture the broad range of subgroups included within *DSM-IV-TR*. While some researchers may argue that this could in fact reflect the overly inclusive nature of *DSM-IV-TR* rather than an overly restrictive approach by *DSM-5*, several studies have indicated that those individuals missed by *DSM-5* had significantly higher autism symptom severity than individuals with non-autism clinical diagnoses and individuals with no clinical diagnoses (Matson, Belva, et al., 2012; Matson, Hattier, & Williams, 2012; Matson, Kozlowski, et al., 2012; Mayes et al., 2013; Worley & Matson, 2012). The studies presented so far are, therefore, consistent with the idea that *DSM-5* may underdiagnose individuals with significant clinical need consistent with autism, although some of those who do not meet criteria for ASD may meet criteria for SCD. It is important to note, however, that not all studies have found reduced sensitivity for the *DSM-5* criteria, and this literature will be reviewed in the next section.

Evidence of Good Sensitivity, but Poor Specificity

Following the release of the draft *DSM-5* criteria, the earliest research findings suggested that the new criteria may lack sensitivity whilst maintaining good levels of specificity. In the following years, additional large-scale studies were conducted that reported the opposite pattern; that is good levels of sensitivity but poor specificity. The three studies that first reported good levels of sensitivity for *DSM-5* ASD mapped items from two

[3] For discussion of the overlap between SCD and more traditionally defined pragmatic language impairments, see Norbury (2014) Practitioner Review: social (pragmatic) communication disorder conceptualization, evidence, and clinical implications. *Journal of child Psychology and Psychiatry*, *55*(*3*), 204–216.

well-established clinical tools onto the *DSM-5* criteria (Barton, Robins, Jashar, Brennan, & Fein, 2013; Huerta, Bishop, Duncan, Hus, & Lord, 2012; Mazefsky, McPartland, Gastgeb, & Minshew, 2013). The tools that they used were the *Autism Diagnostic Interview* (*ADI-R*; Lord, Rutter, & Le Couteur, 1994) and the *Autism Diagnostic Observation Schedule* (*ADOS*; Lord et al., 2000), both of which were developed specifically to help guide diagnosis according to the *DSM-IV-TR* criteria for autism and PDD. Both the *ADI-R* and the *ADOS* include diagnostic algorithms, which can be run to determine whether an individual meets the criteria for autism, and the *ADOS* includes an additional classification of autism spectrum, which relates to the broader category of PDD. When using information collected with both tools, Mazefsky et al. (2013) found sensitivity of 0.88 in a sample of 498 children and adults with clinical *DSM-IV-TR* autism (or PDD) diagnoses. This high level of sensitivity could be further improved (to 0.93) by including additional items measuring repetitive behaviours that were not included in the diagnostic algorithm. Despite these excellent levels of sensitivity, it was not possible to assess the true efficacy of the *DSM-5* criteria in this study; this was because the specificity of the criteria could not be explored as the sample did not include individuals with non-PDD diagnoses. In this study, therefore, it was not possible to be certain that the high levels of sensitivity reported did not reflect a tendency for individuals with any form of developmental disability—or indeed typical development—to meet the criteria.

Huerta et al. (2012) conducted a large-scale study of three samples of children, which included a total of 4,453 children with *DSM-IV-TR* PDD clinical diagnoses as well as 690 with non-PDD diagnoses. When analyses were based on parent-report (*ADI-R*) data only and using the rule that an individual would need impairment on one item in all three of the social communication subdomains and in at least two of the four RRB subdomains, sensitivity of the *DSM-5* criteria was 0.91 for the sample as a whole. Sensitivity was generally lower for non-autism PDD and Asperger syndrome when explored in the three samples independently (varying between 0.76 and 0.94). The inclusion of data collected using the *ADOS* largely resulted in improved sensitivity. Specificity, however, was unacceptably low, both for the sample as a whole (0.53) and in the two samples where these data were available (0.49 and 0.63). In a similar study of toddlers (Barton et al., 2013), sensitivity of the combined *ADI-R* and *ADOS* data was 0.84 when applying the same principles reported by Huerta et al. (2012), but specificity was again unacceptably low (0.55). These two studies, therefore, reflect a tendency to over-diagnose ASD.

One way in which the diagnostic performance of *DSM-5* could be adjusted would be to change the rules governing both the pattern of symptoms needed for a diagnosis (the symptom profile) and how many symptoms are needed. Both Huerta et al. (2012) and Barton et al. (2013) explored whether adjusting these rules could improve the diagnostic performance of the *DSM-5* criteria relative to *DSM-IV-TR*. Huerta et al. investigated the effect of increasing the number of items an individual would need to score on in each subdomain of the *DSM-5* criteria from one to two. This adjustment would be expected to improve specificity, but could at the same time reduce sensitivity, and indeed this was what was found; sensitivity dropped from 0.91 to 0.88 and although specificity was improved, this improvement was only marginal (from 0.53 to 0.66). In a second adjustment focusing more on the symptom profile, Huerta et al. explored the effect of decreasing the total number of subdomains in which an individual needed impairment, so that an individual would need a minimum of two symptoms in either (a) all three social communication subdomains and at least one or more of the RRB subdomains or (b) at least two of the three social communication subdomains and at least two of the four RRB subdomains. This adjustment increased sensitivity to 0.99 but further reduced specificity to 0.42.

Barton et al. (2013) conducted more detailed investigation of the impact of varying the *DSM-5* rules, exploring different combinations of thresholds for the individual subdomains (the number of symptoms) and also the number of subdomains

required (the symptom profile). The solution that they found to achieve the best combination of sensitivity (0.93) and specificity (0.74) required toddlers to score on at least one item in one of the RRB subdomains and above a statistically defined threshold in at least two of the social communication subdomains. The most frequent adjustment to the *DSM-5* rules that has been explored, however, has been the requirement that individuals need exhibit impairment in just two rather than all three of the social communication subdomains (symptom profile). This adjustment has typically been reported to improve sensitivity (Frazier et al., 2012; Huerta et al., 2012; Matson, Hattier, et al., 2012; Mayes et al., 2013; Wilson et al., 2013) with only a minimal loss of specificity (Matson, Hattier, et al., 2012; Mayes et al., 2013).

As outlined earlier in this chapter, effective diagnostic criteria should have good levels of both sensitivity and specificity. Although alterations to the *DSM-5* rules should certainly be considered if research supports the need to do so, the next section will review evidence suggesting that it may be possible to achieve good levels of sensitivity and specificity using the *DSM-5* rules as they currently stand.

Evidence of Good Sensitivity AND Specificity

Two studies to date have reported good levels of sensitivity and specificity of the *DSM-5* criteria without adjustment to the rules. Using questionnaire data collected from a large registry of siblings where at least one child in the family has an autism diagnosis, Frazier et al. (2012) reported that the sensitivity of the *DSM-5* criteria relative to clinical judgement was 0.81 with specificity of 0.97. Although this sensitivity value is commonly accepted as good, the authors noted that adjusting the *DSM-5* rules as described above (i.e. impairment in two rather than all three social communication subdomains) further improved sensitivity to 0.93 with only a minimal decrease in specificity (0.95 rather than 0.97). The improved level of sensitivity was attributed to the identification of more individuals with Asperger syndrome. One potential limitation of this study, however, was that the comparison group included siblings of children with autism who had typical development as well as those with non-autism clinical diagnoses. As such, this sample was not a typical *clinical* comparison group, and this may have somewhat inflated the reported specificity in comparison with other studies.

Using a diagnostic instrument called the *Diagnostic Interview for Social and Communication Disorders* (*DISCO*; Leekam, Libby, Wing, Gould, & Taylor, 2002; Wing, Leekam, Libby, Gould, & Larcombe, 2002), researchers and clinicians developed an algorithm based on the draft *DSM-5* criteria that had good levels of sensitivity (0.85) and specificity (0.89) for autism in comparison with an entirely clinical control group, which included children with either language impairment or intellectual disability (Kent, Carrington et al., 2013). When typically developing children were also included in the comparison sample, sensitivity and specificity was 0.85 and 0.95 respectively, which is comparable to the figures reported by Frazier et al. (2012). Kent, Carrington et al. (2013) also explored the effect of relaxing the *DSM-5* rules so that an individual needed impairment in two of the three social communication subdomains. As in other studies, improved sensitivity was found (0.96 compared with 0.85); however, this improvement was not statistically significant. Moreover, specificity was decreased (0.69 compared with 0.89 when only clinical controls were included), although this was again not significant. Finally, the sensitivity of the algorithm did not vary as a function of age or ability level in a sample of 200 children ($n = 112$; 68 higher ability (HFA); 44 lower ability (LFA)), adolescents ($n = 33$; 19 HFA; 14 LFA), and adults ($n = 45$; 33 HFA; 12 LFA). Although the results from this study support the *DSM-5* criteria for ASD, it is important to note that the analyses were conducted on relatively small, well-defined research samples in which the majority of individuals in the autism group had diagnoses of childhood autism. A clear test of their validity will be to investigate their accuracy when used in standard clinical care pathways.

Summary

In summary, research focusing on the impact of revisions made in *DSM-5* has raised concerns that the new criteria may be overly restrictive, with a lack of sensitivity particularly for those who met criteria for the non-autism PDD subgroups within *DSM-IV-TR*. The majority of studies have provided evidence supporting this concern, and there has been some discussion as to whether the difference between the two sets of criteria may be due to overly inclusive descriptions in *DSM-IV-TR* rather than overly restrictive descriptions in *DSM-5*. Evidence of higher symptom severity in those missed by *DSM-5*, however, may suggest the apparent loss of sensitivity of *DSM-5* should not be disregarded, regardless of whether this loss reflects 'over-diagnosis' by *DSM-IV-TR*. There are studies, however, that have reported good levels of sensitivity. Although these studies typically reported poor specificity and, therefore, still indicated less than optimal performance of the *DSM-5* criteria, there is some preliminary evidence that it may be possible to achieve good levels of both sensitivity and specificity.

The variability in the research findings to date is not reassuring at a time when families and clinicians are looking for resolution of the concerns regarding the diagnostic criteria. One explanation for the different findings in these studies may be that the potential to fully investigate the accuracy of the *DSM-5* criteria may be limited by the diagnostic tools that are used to gather information about individuals within the sample. This possibility will be explored in the next section.

The Impact of Diagnostic Tools on the Reported Sensitivity and Specificity of *DSM-5*

In response to one of the earlier studies raising concern regarding the new *DSM-5* criteria (McPartland et al., 2012), the *DSM-5* Workgroup for Neurodevelopmental Disorders published a commentary in which they raised a number of potential limitations of the paper (Swedo et al., 2012). One limitation in particular that may be relevant to on-going diagnosis and assessment was that the data studied by McPartland et al. may not have included a sufficient range of information to fully map the *DSM-5* criteria. McPartland et al. analysed data that were collected during the field trials for *DSM-IV-TR*. These data, therefore, were based on the *DSM-III-R* and *DSM-IV-TR* descriptions, and consequently, were limited to the information included in those criteria. While there is indeed considerable overlap in the content of the descriptions in *DSM-IV-TR* and *DSM-5*, there are discrepancies; for example, *DSM-5* includes an additional focus on sensory symptoms, which form an entire subdomain of the RRB domain.

The criticism levelled at the McPartland et al. study can, to varying degrees, be applied to several of the studies reviewed above. For example, Matson, Belva, et al. (2012) acknowledged that in their study of adults with intellectual disability, they did not have sufficient data to fully map the *DSM-5* criteria; more specifically, they did not have information regarding hypo- and hyper-reactivity to sensory input. Studies in which items were mapped from the *ADI-R* and *ADOS* onto the *DSM-5* criteria may have faced similar limitations. As described above, both the *ADI-R* and *ADOS* were developed to guide diagnosis according to the *ICD-10*/*DSM-IV-TR* criteria. Although Huerta et al. (2012) reported that there were sufficient *ADI-R* items to fully map the *DSM-5* criteria, the same was not true of the *ADOS*; there were no *ADOS* items that fit with the descriptions of hypo- or hyper-reactivity to sensory input, and just one item that mapped to the subdomain regarding highly restricted, fixated interests. Both Huerta et al. (2012) and Mazefsky et al. (2013) found better sensitivity when *ADOS* and *ADI-R* data were pooled, and Mazefsky et al. found that sensitivity could be further improved by including additional items from the *ADI-R* measuring RRBs that were not included in the diagnostic algorithm. Thus, these two studies indicated that the combination of *ADI-R* and *ADOS* data was necessary to best map the *DSM-5* criteria, and in so doing, demonstrate good levels of sensitivity.

The two studies that reported the best balance between sensitivity and specificity were arguably able to do so as the data they used were not so constrained by *DSM-IV-TR* (Frazier et al., 2012; Kent, Carrington et al., 2013). Frazier et al. (2012) mapped items from two parent-report questionnaires—the *Social Responsiveness Scale* (*SRS*; Constantino, 2002; Constantino et al., 2003) and *Social Communication Questionnaire* (*SCQ*; Rutter, Bailey, & Lord, 2003)—to the *DSM-5* criteria. Although the *SCQ* was developed as a companion measure for the *ADI-R* (Lord et al., 1994) and may, therefore, face the same limitations as the *ADI-R*, the *SRS* primarily measures reciprocal social behaviours; items relating to communication and restricted or stereotyped behaviours or interests are included, but those items emphasise the impact of those behaviours on social behaviour. The *SRS*, therefore, is less closely tied to the *DSM-IV-TR* triad of behaviours than the *SCQ*, although scores on the *SRS* correlate significantly with the *ADI-R* (Constantino et al., 2003). Importantly, when mapping items from the two measures to the *DSM-5* criteria, Frazier et al. predominantly used items from the *SCQ* specifically because the measure was more closely tied to the *DSM-IV-TR* criteria. They argued that this provided a stronger test of the efficacy of *DSM-5* than would be gained by relying on a tool (the *SRS*) that was not developed according to any specific diagnostic criteria.

In contrast, Kent, Carrington et al. (2013) argued that the high levels of sensitivity and specificity of the *DSM-5* criteria found using an algorithm developed from the *DISCO* were achieved precisely because the development of the *DISCO* was not based on specific diagnostic criteria. The *DISCO* is a 320-item clinical interview tool that, like the *ADI-R*, is typically conducted with a parent or a carer. The interview was developed based around the concept of an autism spectrum, and due to the wide range of behaviours it assesses, it is possible to run a range of algorithms, including those to guide in the diagnosis of Wing and Gould's ASD and Gillberg's Asperger syndrome as well as *DSM-IV-TR*/*ICD-10* autistic disorder and Asperger syndrome. When developing a new *DISCO* algorithm according to the *DSM-5* ASD criteria, items from the *DISCO* were mapped to the descriptions offered by *DSM-5*. All items from the interview that were considered relevant were included and their inclusion was reviewed by independent clinicians. The number of *DISCO* items included in each subdomain varied between six and 14, with ten items included in the subdomain measuring reactivity to sensory input. The number of items within each subdomain allowed for a relatively large degree of variability in the clinical presentations that could still meet criteria for a diagnosis of *DSM-5* ASD. Unlike the majority of studies, the threshold for each subdomain was determined statistically. The only other study that adopted a statistical approach to setting the thresholds was Barton et al. (2013), who used receiver operating characteristic (ROC) curves to identify the highest threshold that maintained sensitivity at or above 0.9. A similar approach was adopted by Kent, Carrington et al. (2013); ROC curve analyses were conducted to identify the threshold that maximised specificity while maintaining the highest possible sensitivity for that threshold. It was argued that the inclusion of sufficient items to enable a variety of clinical presentations to be represented, together with the use of statistically defined thresholds, allowed good levels of sensitivity and specificity to be achieved.

Overall, the studies reviewed above highlight that accurate diagnosis of *DSM-5* with good levels of both sensitivity and specificity may be dependent on the use of appropriate diagnostic instruments. More specifically, instruments with scope to assess behaviours beyond those described in *DSM-IV-TR* will best enable accurate measurement of the *DSM-5* criteria. These findings, therefore, have important implications for diagnosis and assessment. While early studies suggest that the *DISCO* may provide sufficient information to enable detailed mapping of the *DSM-5* criteria resulting in good sensitivity and specificity, further validation of the diagnostic algorithm for *DSM-5* in clinical samples is essential. The *Developmental, Dimensional, and Diagnostic Interview* (*3Di*; Skuse et al., 2004) is

another well-established clinical interview tool that has been used to investigate the *DSM-5* criteria. Specifically, data collected using the *3Di* has been used to explore the dyadic domain structure described in *DSM-5* (Mandy et al., 2012). The *3Di* consists of 120 items that form 12 scales, corresponding to the 12 *ICD-10*/*DSM-IV-TR* subdomains. Confirmatory factor analysis indicated a better fit for a two-factor model compared with the triadic model in *DSM-IV-TR*, with evidence of stronger factor loading in autism compared with broader autism phenotype groups. Moreover, the inclusion of an additional sensory scale consisting of five items from within the interview did not decrease the fit of the model, supporting the inclusion of these symptoms in the restricted and repetitive pattern of behaviour domain (Mandy et al., 2012). However, there have as yet been no studies exploring the sensitivity and specificity of the *DSM-5* criteria using the *3Di*, and therefore the potential use of the *3Di* in diagnosing *DSM-5* ASD is not yet known. It is clear from studies using the *ADI-R* and *ADOS* that the combination of these instruments may provide good sensitivity, although relatively limited specificity, and the potential benefits of including information from other sources in order to improve specificity must be investigated.

Impact of the Changes for Screening and Guiding Diagnosis

The previous section detailed how current diagnostic instruments may be limited in their ability to gather sufficient information to fully map the profile of *DSM-5* ASD, and that this in turn could limit their utility in diagnosis according to these criteria. However, none of these instruments were designed to be used in isolation and none should over-rule clinical judgement; consequently standardised clinical tools could continue to guide diagnosis with clinicians including additional information to ensure all aspects of the *DSM-5* criteria can be considered. Measures used at early stages of the assessment pathway may be less informed by clinical judgement and their efficacy may, therefore, be more vulnerable to changes in the diagnostic criteria. The following paragraph provides an overview of the range of questionnaires and interviews which can be used to prospectively identify ASD behaviours.

A number of questionnaire and checklist measures have been designed to prospectively detect traits and signs early in childhood, before a full diagnosis of ASD is made. These include the *Checklist for Autism in Toddlers* (*CHAT*; Baron-Cohen, Allen, & Gillberg, 1992), the *Modified CHAT* (*M-CHAT*; Robins, Fein, Barton, & Green, 2001), and the *Early Screening for Autistic Traits Questionnaire* (*ESAT*; Swinkels et al., 2006). Similarly, screening questionnaires have been developed for older children and adults, such as the *SRS*, and the *Ritvo Autism Asperger Diagnostic Scale-Revised* (*RAADS-R*; Ritvo et al., 2011). Moreover, brief, age-specific ten-item 'red flag' questionnaires have been developed from the *Autism Spectrum Quotient* (*AQ*; Baron-Cohen, Wheelwright, Skinner, Martin, & Clubley, 2001) to help guide the referral of cases for full diagnostic assessment (*AQ-10*; Allison, Auyeung, & Baron-Cohen, 2012). Although these measures were not typically developed based solely on the *ICD-10*/*DSM-IV-TR* criteria in the same way as the *ADI-R* for example, the sensitivity and specificity of these measures according to the *DSM-5* criteria has not been explored. One exception to this is a recent study of the *DISCO*, in which a set of 14 items were identified that had excellent sensitivity and specificity according to both the *DSM-IV-TR*/*ICD-10* and *DSM-5* criteria; it was suggested, therefore, that similarly to the *AQ-10*, this short interview set (the *DISCO Signposting Interview*) had the potential to help guide referral for further assessment (Carrington et al., 2015).

Assuming that the primary aim of screening measures (such as the *ESAT*) or brief measures intended to guide referrals (e.g. the *AQ-10* and the *DISCO Signposting Interview*) is to highlight cases in need of more detailed assessment, it could be argued that agreement with specific diagnostic criteria is not essential. Given evidence from studies using more comprehensive diagnostic assessments that *DSM-5* is likely to

lack sensitivity compared with *DSM-IV-TR*, it seems likely that screening measures with demonstrable reliability and validity according to earlier versions of the diagnostic criteria will lack specificity rather than sensitivity for *DSM-5*. While the identification of false positives is clearly not a benefit, those individuals identified by these measures but who do not meet criteria for *DSM-5* ASD are still likely to need further assessment and support. Moreover, clinical guidelines such as the National Institute of Clinical Excellence in the UK do not recommend relying on the use of screening measures for the purpose of diagnosis. Arguably, the impact of the changes to *DSM-5* on the use of these screening or signposting instruments will therefore be greatest in research, where such instruments are often used to 'confirm' clinical diagnosis when defining an autism participant sample.

Differential Diagnoses/Subgroups

No chapter exploring the impact of changes to the diagnostic criteria could not comment on the potential impact of removing the *DSM-IV-TR* PDD subgroups in *DSM-5* ASD. In order to do so, the history of the addition of subgroups to the criteria will be reviewed along with the research evidence that supports the addition and removal of these diagnostic groups. In particular, the removal of the diagnosis of Asperger syndrome has been highly controversial. In his original description of what later came to be known as Asperger syndrome, Hans Asperger considered the cases he saw to be distinct from those with Kanner's early infantile autism; he felt that the condition described by Kanner was a form of psychosis, while the characteristics he described represented a stable personality trait. Lorna Wing, however, argued that although the term Asperger syndrome could be helpful in explaining the particular difficulties experienced by individuals with the condition, it should be considered as part of the autism spectrum (Wing, 1981). In *DSM-IV-TR*/*ICD-10*, Asperger syndrome is primarily differentiated from autism by a lack of clinically significant delay in language or cognitive development. However, given growing recognition that autism often occurs with 'normal' intelligence (i.e. IQ above 70), the distinction is typically made based on the presence or absence of language delay.

The removal of the *DSM-IV-TR* subtypes in *DSM-5* was based on a large body of research investigating whether these categories could be reliably distinguished. Studies using cluster analysis techniques have typically concluded that although subgroups can be defined within samples of individuals with PDD diagnoses, these subgroups—or clusters—were based on factors such as symptom severity and IQ rather than the subtypes described in *DSM-IV-TR*/*ICD-10* (e.g. Kamp-Becker et al., 2010; Prior et al., 1998; Ring, Woodbury-Smith, Watson, Wheelwright, & Baron-Cohen, 2008). The literature more specifically investigating potential differences between autism and Asperger syndrome has been comprehensively reviewed elsewhere, with the majority of reviews concluding that there was not sufficient evidence to reliably confirm or refute the differentiation between the two conditions (e.g. Howlin, 2003; Macintosh & Dissanayake, 2004; Sanders, 2009). It is important to note, however, that not all research has supported the notion of a single diagnostic category. For example, in a recent review, Tsai and Ghaziuddin (2014) concluded that the evidence reviewed did not support the view of the *DSM-IV-TR* subtypes as a single concept. However, studies that do not use the cluster-based analyses described above are subject to possible issues of circularity; that is, they are investigating whether groups that have been differentially diagnosed on the basis of behaviour can then be distinguished on the basis of that same behaviour. This is something of a simplification of a rather complex issue, but it does raise another point regarding the mechanisms by which a particular diagnosis is decided upon.

In a multi-site study, Lord et al. (2012) reported that differential best-estimate clinical diagnoses of the different PDD subtypes—including autism and Asperger syndrome—varied significantly from site to site, despite relatively consistent scores on standardised diag-

nostic instruments. Although the use of diagnostic terms within sites was clearly not random, being based primarily on severity of observed social communication difficulties, the finding of variability between sites raised questions as to how the different diagnostic terms were applied. One potential explanation proposed by Lord et al. was that the use of diagnostic terms may have varied due to regional differences in available post-diagnostic support. The resulting variability in how particular diagnoses are given would inevitably impact on research studies investigating whether diagnostic subgroups can be reliably differentiated.

Although research evidence largely supports the removal of the *DSM-IV-TR* subtypes, as described above, several studies raised concerns that *DSM-5* may underdiagnose individuals who received a *DSM-IV-TR* diagnosis of Asperger syndrome, PDD-NOS, or individuals with autism and an IQ above 70. However, a meta-analysis of these studies concluded that while *DSM-5* may lack sensitivity for autism and PDD-NOS, sensitivity was not significantly reduced for Asperger syndrome (Kulage et al., 2014). Moreover, the results for studies exploring the sensitivity of *DSM-5* as a function of IQ are mixed. The true impact of the changes in *DSM-5* on the diagnosis of individuals with 'non-core' autism presentations, such as Asperger-like or atypical presentations, remains to be seen and is dependent on the collection of new research data using appropriate diagnostic tools and techniques, as discussed above. If it were found that *DSM-5* did have good sensitivity across the subgroups, Vivanti et al. (2013) argued that there was no reason to anticipate that the loss of the subtype labels would cause problems with the delivery of interventions, as there has been no evidence that the type of intervention advocated should be based on the *DSM-IV-TR* subtype. This is not to say that the support offered to individuals may not be affected, and indeed, this has been raised as a serious concern. Services offered to individuals can vary according to their diagnosis, and indeed, there is regional variation in how this is actioned, a fact that Lord et al. (2012) indicated may have influenced the best-estimate clinical diagnoses given at different sites. As described above, it has been suggested that individuals who previously met criteria for *DSM-IV-TR* PDD-NOS may qualify for a *DSM-5* diagnosis of social (pragmatic) communication disorder (SCD) rather than *DSM-5* ASD (e.g. Regier et al., 2013; Swineford et al., 2014). As such, these individuals may no longer be eligible for support that is delivered specifically for those with an ASD diagnosis, despite clear overlap in the social communication impairments of the two conditions. It will, therefore, be important to review the provision of services for individuals receiving the new SCD diagnosis. It is important to note, however, that *DSM-5* explicitly states that individuals with a well-established *DSM-IV-TR* diagnosis of any of the PDD subtypes should receive a diagnosis of ASD and thus, the provision of services should not, in theory, be affected.

Despite concerns raised regarding PDD-NOS and evidence from meta-analysis (Kulage et al., 2014) that this group rather than those with Asperger syndrome may be most at risk of underdiagnosis by *DSM-5*, it is the exclusion of the diagnostic category of Asperger syndrome that has received the most attention, particularly in the mainstream media. There is a strong cultural identity associated with Asperger syndrome, with many referring to themselves as 'Aspies'. Many individuals with Asperger syndrome consider the differentiation from autism to be important in defining their abilities, and consider the condition as a way of being, not a disability (Vivanti et al., 2013). The potential impact of the removal of the diagnostic category on this community should not be overlooked. Some clinicians may continue to use the term descriptively, and Wing et al. (2011) suggested that maintaining the *DSM-IV-TR* subtype 'labels' may help describe an individual's ASD profile. The approach adopted by *DSM-5* was to include a number of specifiers and severity ratings, such that an individual may have an individualised description. Thus, someone with an Asperger-like presentation could be diagnosed as 'ASD, with no intellectual or language impairment. Requires support for social communication and restricted and repetitive behaviours'. Clinicians

could further specify the areas in which support was needed. Although the cultural impact of the loss of the 'Aspie' identity should not be overlooked, this move towards a more individualised diagnostic approach may be seen as a step towards ensuring that each individual's profile of strengths and difficulties can be adequately described in order to best meet their needs, both in terms of clinical and social—including occupational—support. How such an approach could be best implemented remains to be seen.

Implications for Research

Changes to the diagnostic criteria for autism will also impact on the research community, and this impact is likely to be felt in a number of ways. First, the changes introduced in *DSM-5* will affect the comparability of findings from studies conducted before the change and those conducted after. If, as suggested by some of the studies reviewed above, *DSM-5* is likely to miss some people who would previously have received a diagnosis of *DSM-IV-TR* Asperger syndrome or PDD-NOS, then it could be argued that the findings from research that recruited people with *DSM-IV-TR* PDD diagnoses would not be specific to *DSM-5* ASD. For example, some of the people who met *DSM-IV-TR* criteria for PDD-NOS may receive a *DSM-5* diagnosis of SCD rather than ASD and thus the findings from studies based on the *DSM-IV-TR* criteria may reflect a broader range of symptom profiles than those encompassed by *DSM-5*. This discrepancy may be particularly important when attempting to track changes in prevalence rates over time. If prevalence was found to plateau—at least temporarily—or even decrease following the introduction of *DSM-5*, the trend could reflect the changes to the diagnostic criteria rather than a true difference in the number of individuals with clinically significant symptoms who would previously have been diagnosed according to *DSM-IV-TR*. Another concern is the potential for on-going differences in the international classification systems. The revisions that were introduced in *ICD-10* and *DSM-IV-TR* brought the two classification systems into almost perfect agreement, resulting in consistent diagnostic criteria for PDDs internationally. Should the anticipated revisions to *ICD-10* diverge from the changes introduced in *DSM-5*, particularly with regard to the inclusion/exclusion of the PDD subgroups, the comparability of research internationally will be hindered. It should be noted, however, that the groups overseeing the revisions to *DSM-IV-TR* and *ICD-10* shared the common goal of harmonising the two systems as far as possible, an aim that is described in the introduction to the *DSM-5* manual.

The use of standardised assessments may at least partially address each of the issues raised here. Symptom severity scores can be calculated from measures such as the *ADI-R*, *ADOS*, *DISCO*, or *3Di*. However, it is important to note that having a high number of symptoms does not necessarily qualify an individual for a diagnosis, and it is also the pattern or profile of impairment that is significant. For example, two individuals may have the same number of symptoms, but while one may have both social communication impairments and restricted and repetitive behaviours, the second may only have impairment in social communication behaviours and may, therefore, meet criteria for SCD rather than ASD. Moreover, as discussed above, the development of some of the most widely used standardised assessments was based on the *DSM-IV-TR* criteria and may not, therefore, adequately measure all of the behaviours described by *DSM-5*. There is a risk, therefore, that in using such standardised measures to try and ensure the continuity of research in this area, research may in fact be biased more towards the *DSM-IV-TR* criteria.

The removal of the *DSM-IV-TR* subtypes has largely been supported by research, as reviewed above. Moreover, due to the lack of definitive evidence supporting a distinction, the use of the terms Asperger syndrome and high functioning autism has overlapped to some extent in recent years. On-going research into potential endophenotypes within the autism spectrum will remain important, however (e.g. Vivanti et al., 2013). Given the broad range of variation within the

autism spectrum, better understanding of individual differences could eventually help guide more targeted intervention. The aim of identifying how particular symptoms or patterns of symptoms are related to the underlying genetics and/or neurobiology is a common goal of much research focusing on neurodevelopmental disorder. However, it has been suggested that this goal may have been hindered rather than aided by categorical diagnoses such as those included in *DSM* and *ICD*. Moreover, there is evidence indicating that the *DSM* and *ICD* categories do not map well onto the emerging research evidence, including evidence from neuroscience and genetics studies. The Research Domain Criteria framework (RDoC; Casey, Oliveri, & Insel, 2014; Insel et al., 2010) from the National Institute of Mental Health (NIMH) proposed that a dimensional approach could better advance our understanding of the relationship between brain (or genes) and behaviour, including how that relationship was linked with clinical phenomenology. It was suggested that common constructs (such as anxiety or attention deficits) could be found underlying multiple mental health diagnostic categories. As such, the starting point for research should not be a top-down approach beginning with the clinical diagnoses, but rather a bottom-up investigation of the relationship between these constructs (or behaviours) and the brain (or genes) across the full spectrum of 'normal to abnormal'. The RDoC framework, therefore, extends beyond the investigation of endophenotypes within the *DSM-5* ASD category; however a similar dimensional approach could also be adopted to better understand variation within ASD.

A Dimensional Rather Than Categorical Approach: An Alternative to *ICD*/*DSM*?

Although the RDoC framework is intended, at least at this stage, as a research guide, the idea of a more dimensional approach has also been considered from a clinical angle, not least by Lorna Wing and colleagues, who have long argued that autism is best represented as a spectrum rather than a set of categorically defined subtypes. Moreover, in recognition of the 'growing realisation that co-existence of disorders and sharing of symptoms across disorders … is the rule rather than the exception', Christopher Gillberg coined the term ESSENCE: Early Symptomatic Syndromes Eliciting Neurodevelopmental Clinical Examinations (Gillberg, 2010). ESSENCE refers to a collection of symptoms presenting within the first three years of life that are considered as markers of potential neurodevelopmental disorder such as ASD or PDD, ADHD, oppositional deviance disorder, specific language impairment, learning disability (verbal and non-verbal), tic disorder/Tourette's syndrome, bipolar disorder, behavioural phenotype syndromes (including 22q11 deletion syndrome and Fragile X syndrome), rare epilepsy syndromes, and reactive attachment disorder. These syndromes are all characterised by problems in the areas of general development, communication and language, social inter-relatedness, motor coordination, attention, activity, behaviour, mood, and sleep. Given the organisation of services into discrete specialities, Gillberg argued that the precise diagnosis given to young children may depend to some extent on the clinician who saw them. Moreover, the symptom profile may change over time. However, due to the overlap of symptoms between the ESSENCE conditions, Gillberg suggested that even if an initial diagnosis may no longer apply, the majority of children would continue to meet criteria for one of the other ESSENCE conditions. For example, in his 2010 paper, Gillberg described how 75 % of children who had received ASD diagnoses before the age of three years still met criteria for ASD at follow-up a few years later. Of the 25 % who no longer met the criteria for ASD, all met criteria for another developmental disorder.

The structure of the ESSENCE framework is, therefore, somewhat comparable to RDoC, with the idea of common constructs (or symptoms) underlying multiple clinical diagnoses. Moreover, Gillberg also suggested that differences in brain function could contribute to the symptoms of ESSENCE and, therefore, overlap in multiple conditions. The ESSENCE framework does not

suggest that the diagnostic categories are redundant; indeed, while Gillberg and Fernell (2014) recognised the potential of a more dimensional research approach such as RDoC, they highlight the need for diagnostic categories in clinical practice. However, Gillberg argued that the definition of these clinically meaningful categories should be subject to review as our understanding of the conditions evolves. This is a view that is shared by the APA, and in the introduction to *DSM-5*, the task force recognised that '… research advances will require careful, iterative changes if *DSM* is to maintain its place as the touchstone classification of mental disorders' (APA, 2013, p. 5). Thus, in *DSM-5* the diagnostic criteria for autism have shifted based on research evidence; for example, in addition to the move from a triad of impairments to a dyad, the co-occurrence of ASD and ADHD has been recognised such that the presence of ADHD is no longer an exclusion criterion for ASD. The recognition of co-existing conditions such as ADHD, or even overlap in symptoms rather than the full-blown condition is important to allow the development of appropriate interventions. Gillberg suggested that the lessons to be learned from the ESSENCE framework may be the importance of ensuring that early assessment services are able to assess the full range of early symptoms associated with developmental disorder, in order to facilitate more accurate diagnosis and the provision of more targeted intervention.

So, could it be argued that the ESSENCE and RDoC frameworks represent an alternative, more dimensional approach to *DSM*/*ICD*? Although in comparison with *DSM-IV-TR* and *ICD-10* the answer to this question would be yes, in *DSM-5* there appears to have been a clear shift in thinking. The introduction to *DSM-5* describes growing recognition that the categorical system doesn't adequately capture either clinical experience or research findings, as well as the understanding that symptoms may be shared across diagnostic boundaries, which may change across the life course. Moreover, there is recognition that there may be shared environmental and genetic risk factors as well as potentially shared neural substrates across neurodevelopmental disorders. As stated by the authors, 'In short, we have come to recognise that the boundaries between disorders are more porous than originally perceived' (p. 6). The organisation of *DSM-5* has been approved by the leaders of the RDoC framework, although from a research point of view the NIMH encourages research that crosses rather than conforms to the *DSM-5* diagnostic categories. While recognising the limitations of the categorical approach, the *DSM-5* Task Force argued that due to the need for all revisions to be evidence-based, scientifically, it was too early to propose new definitions for the majority of disorders. Consequently, the current edition of *DSM-5* should be viewed as a bridge, with on-going research driving future revisions and updates.

Discussion

This chapter has provided a general overview of the implications of *ICD* and *DSM* on the screening and assessment of autism by focusing on the potential impacts of changes to these international classification systems. More specifically, the impact of the changes introduced in *DSM-5* has been considered in the areas of diagnosis and assessment, as well as research. In addition, there has been discussion of whether categorical or dimensional approaches may be most appropriate or effective. So the question remains, what are the implications of *ICD* and *DSM* for the screening, diagnosis, and monitoring of autism?

We have seen that changes to the international classification systems may affect both their sensitivity and specificity; that is, there is evidence suggesting that there may be changes in who receives a diagnosis of ASD. However, the results from research studies have been mixed, and there is some evidence to suggest that reported differences in sensitivity and specificity may be at least partially attributable to the way in which information is collected. More specifically, good levels of both sensitivity and specificity may be dependent on the collection of sufficient information to fully capture the description of ASD in *DSM-5*. This evidence, therefore, has implications for both assessment and screening, as the tools used in these processes should elicit information that informs clinicians about the specific behaviours included in the diagnostic criteria.

As discussed above, some of these tools were developed based on the *DSM-IV-TR* criteria and may not, therefore, elicit sufficient information in areas such as sensory sensitivity. Revisions to the criteria that affect who receives a diagnosis will also clearly affect our ability to monitor the prevalence of autism over time, as well as monitoring the stability of each individual's diagnostic 'status' over their lifetime.

These findings seem to indicate significant implications of *ICD* and *DSM* for the screening, diagnosis, and monitoring of autism. However, it is important to remember two points. First, the findings from studies have been mixed and further research is essential to fully understand the impact of the changes in *DSM-5*. Second, it is important to remember how the *ICD* and *DSM* systems were intended to be used. The APA (2013) highlighted that the descriptions offered in the international classification systems are not intended as comprehensive definitions and that other factors that may have contributed to an individual's symptom profile should be considered, including social, emotional, and biological factors. Moreover, the *ICD-10* diagnostic criteria for research (WHO, 1993) are intended to be used alongside the clinical descriptions and guidelines (WHO, 1992), which better facilitate the identification of more atypical presentations. The *DSM* and *ICD* criteria are not, therefore, simple checklists; rather they are descriptions to supplement and inform, but not replace clinical judgement. Similarly, the need for treatment or intervention is not assessed purely on the basis of whether an individual ticks sufficient boxes to meet the diagnostic criteria, but should also involve consideration of the severity of an individual's symptoms as well as the associated disability and distress. Thus, an individual who does not meet all the criteria for a clinical diagnosis may still exhibit a clear need for care. The APA states that 'the fact that some individuals do not show all symptoms indicative of a diagnosis should not be used to justify limiting their access to appropriate care' (APA, 2013, p. 20). Moreover, individuals with well-established *DSM-IV-TR* PDD diagnoses should receive a *DSM-5* diagnosis of ASD. In reality, access to services and care is determined relatively locally and not by the *DSM-5* or *ICD-11* task forces. The implications of *DSM* and *ICD* in this sense are, therefore, to some extent, dependent on how the guidelines are viewed and implemented by the bodies who govern the provision of services.

The implications of *DSM* and *ICD* for our understanding of autism is perhaps a simpler question. These guidelines are intended to be driven by our evolving understanding of the nature of the condition, and the various editions of *DSM* and *ICD*, therefore, reflect the nature of autism as it was understood at discrete time points. As such, it is to be hoped that these descriptions do have implications on diagnosis and assessment, as well as research, as each of these processes should be based on a good understanding of the condition. However, diagnosis, assessment, and research should not be limited by *DSM* and *ICD*, as our understanding and knowledge of autism does not remain static between editions. As our understanding continues to evolve, the importance of clinical judgement in how to best apply the guidelines and meet the needs of individuals is paramount.

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Stress and Satisfaction in the Diagnostic Process

8

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Satisfaction and Stress in the Diagnostic Process

Autism spectrum disorder (ASD) is a neurodevelopmental disability characterized by impairment in social-communication skills and the presence of restricted or repetitive behaviors (American Psychiatric Association, 2013). According to the Centers for Disease Control and Prevention (CDC), ASD affects approximately 1 out of 68 children in the USA (CDC, 2014). Even more, the global prevalence of ASD has increased nearly 20–30 times since the 1960s (CDC, 2014) and is estimated at approximately 1 out of 160 children (Elsabbagh et al., 2012). These rising rates of ASD combined with the importance of early intervention (Boyd, Odom, Humphreys, & Sam, 2010; Lord & Richler, 2006) have led to a greater awareness for increased screening and surveillance (Johnson & Myers, 2007; Nadel & Poss, 2007; Oosterling et al., 2010). In those cases where formal assessment is pursued, the process of diagnosing ASD can be a complex and challenging experience for both professionals and families. Professionals may feel overwhelmed by time or resource constraints (Moh & Magiati, 2012), or by individuals exhibiting complex clinical presentations (Nissenbaum, Tollefson, & Reese, 2002). Most importantly, parents and the individuals being assessed may be confused by the assessment process, overwhelmed by the amount of information available to them, or unsure of what their next steps should be. Therefore, it is crucial to explore the experiences and perspectives of families who are at the center of the diagnostic process.

The examination of patient satisfaction has been a focus of health care systems for several decades. This concept, which reflects the type and quality of services, as well as overall experience, is often considered a global indicator of health care quality and a significant factor in improving service delivery (e.g., Gonzalez et al., 2005; Turris, 2005). One particular area of focus in assessing patient satisfaction in ASD is in the diagnostic process specifically. In 1994, Smith and colleagues launched a comprehensive evaluation to assess whether the diagnostic process for ASD had improved during the previous decade for families. Participants included 127 families of children aged 19 years and younger with ASD diagnoses. Outcomes of their investigation yielded a lack of significant progress in diagnosis, support, and early intervention among those

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families surveyed (Smith, Chung, & Vostanis, 1994). Since that time, research has continued to investigate parental and individual/adult perspectives of the diagnostic process. Although several consistencies have been identified in the literature, numerous discrepancies still exist. Overall, the quality of the research in this area is still emerging. Rich information has been gained from qualitative studies, which have identified meaningful themes that aid in understanding the parent and/or professional experience through the diagnostic process. However, due to methodological limitations including inconsistency in measurement and a lack of rigorous quantitative studies, the ability to generalize on a larger scale is limited. This is especially significant given the heterogeneity of ASD, and the likely impact upon the diversity of parent perspectives.

The focus of this chapter is to explore the reactions and perspectives of parents, and in some cases the individuals themselves, regarding the process of diagnosing ASD. First, the most common pathways to diagnosis will be presented and integrated with the factors that can impact stress and satisfaction among families. Within these common steps of the diagnostic process, current research will be discussed in order to highlight strengths and areas that require continued focus. Next, the chapter outlines best practices for working efficiently and effectively with families during the assessment and diagnostic process. Finally, future directions for research are also discussed.

Diagnostic Pathway

Development of Parental Concerns

Developmental milestones are important indicators for parents that their child is progressing as expected. When parents begin to notice that their child is not engaging in typical behaviors expected for his or her age, worry or anxiety may develop. Among children with ASD, most parents' concerns regarding development occur between 18 and 24 months of age (Chamak, Bonniau, Oudaya, & Ehrenberg, 2011; McConkey, Truesdale-Kennedy, & Cassidy, 2009; Molteni & Maggiolini, 2014; Siklos & Kerns, 2007). Several studies have examined the types of early concerns identified by parents or caregivers. Results consistently indicate that the majority of parents first recognize delays or abnormalities in language development (Howlin & Moore, 1997; McConkey et al., 2009; Moh & Magiati, 2012) and/or social skills (Chamak et al., 2011; Daley, 2004; Jones, Goddard, Hill, Henry, & Crane, 2014; Molteni & Maggiolini, 2014). Additional concerns include behavioral disturbances (Chamak et al., 2011; Moh & Magiati, 2012; Molteni & Maggiolini, 2014), limited imaginative play (Moh & Magiati, 2012), restricted/repetitive behaviors (Chamak et al., 2011; Moh & Magiati, 2012), sleep or feeding difficulties (Chamak et al., 2011; Molteni & Maggiolini, 2014), and general delays in motor development (McConkey et al., 2009).

Previous research has highlighted slight differences in these early concerning symptoms based upon ASD subtype/severity (Howlin & Asgharian, 1999) and country of origin (Moh & Magiati, 2012). Within a sample of 770 families, Howlin and Asgharian (1999) investigated differences in the diagnostic experiences between parents who received diagnoses of Asperger's disorder versus autistic disorder. Regarding the age of initial concern, parents of children with autistic disorder first identified warning signs at 18 months of age compared to 3 years of age for parents of children with Asperger's disorder. These findings, also confirmed in later studies (e.g., Wiggins, Baio, & Rice, 2006), suggested that individuals with higher functioning ASD initially may exhibit more subtle symptoms that are not identified until later years.

For many individuals and families, the journey to receiving an appropriate diagnosis can be lengthy and challenging. The average period of time between age of initial concerns and diagnosis has varied among studies. Most researchers have cited a length of time between 1 and 4 years for the diagnostic process, with the typical age of diagnosis ranging from 3 to 6 years among children (CDC, 2014; Daley, 2004; Daniels & Mandell, 2014; Goin-Kochel, Mackintosh, &

Myers, 2006; Howlin & Moore, 1997; Mansell & Morris, 2004; McMorris, Cox, Hudson, Liu, & Bebko, 2013; Moh & Magiati, 2012; Siklos & Kerns, 2007; Wiggins et al., 2006). It is noted that results have varied and some investigators found children diagnosed at younger ages and in a more expedited process (e.g., Harrington, Patrick, Edwards, & Brand, 2006). This is encouraging given that rates of satisfaction have been found to be higher among parents whose children were diagnosed at younger ages (Goin-Kochel et al., 2006; Siklos & Kerns, 2007). However, even a wait of only a few months can still be considered a prolonged period of uncertainty and stress in the lives of families.

Encounters with Professionals

It is not uncommon for a lag time to exist between the period that initial concerns are identified and the point at which families pursue further assessment. Prior studies have indicated that parents wait between 7 and 8 months prior to scheduling an initial appointment with a professional (Daley, 2004; Howlin & Moore, 1997). It is possible that these delays occur due to familial beliefs that the symptoms will subside over time. Alternately, families or individuals may be uncertain if their concerns are valid. During this pre-diagnostic period, worry and anxiety may continue to develop in the family as decisions are eventually made to pursue further evaluation.

Initial Visit. There are a variety of professionals who serve as the initial point of contact for families to discuss their concerns. These individuals include pediatricians, psychiatrists, psychologists, educators, and other medical or mental health providers. However, the first consultation is often the primary care provider (PCP) or general practitioner/pediatrician (Johnson & Myers, 2007). A variety of outcomes can result from this initial consultation. Families may either receive a formal ASD diagnosis, a diagnosis of a different condition (e.g., language delay, intellectual disability, behavioral problems), referral for additional assessment, or assurance that there is no cause for concern.

Parent reactions to this initial contact with professionals can vary. Some parents cite confidence in the consulted professional's assessment abilities and feel respected and valued during evaluation appointments (Hackett, Shaikh, & Theodosiou, 2009). Other families may be told by professionals that there are no significant issues of concern. In these situations, feelings of stress and frustration can develop, especially for parents who believe that there are clear abnormalities occurring in their child's behavior or development. In fact, some parents believe that their initial concerns were not taken seriously by professionals, or that they were unable to accurately describe their worries to their PCP or general practitioner (Braiden, Bothwell, & Duffy, 2010). Perhaps unintended, professionals' responses to parental concerns sometimes can be perceived as curt and dismissive (Bailey, 2008; Carbone, Behl, Azor, & Murphy, 2010). This is particularly worthy of focus given that many of parents in the cited studies (e.g., Braiden et al., 2010; Carbone et al., 2010) had children who eventually received ASD diagnoses. Certainly, this is not to imply that all children with delays in their language or social skills eventually receive diagnoses of ASD. However, of those children with ASD diagnoses, a portion of parents indicated that their initial concerns were not validated by professionals (Braiden et al., 2010; Carbone et al., 2010).

The extent to which professionals are attentive and proactive with early warning signs is varied, and the issue is complex. Some health and mental health professionals may be insufficiently trained in ASD to accurately identify subtle symptoms or various presentations of behaviors. In some cases, parents lack confidence in their PCP's skills to identify ASD (Carbone et al., 2010; Harrington et al., 2006). Many times, families simply wait until additional or more significant concerns develop in their child. In a subsequent investigation by Carbone and colleagues (2013), 144 parents of children with ASD completed a questionnaire assessing perceptions of their PCP's abilities to address specific needs and conditions related to their children's diagnoses. Additionally, 144 PCPs (unmatched to family participants) completed a similar questionnaire

regarding self-perceptions of their own abilities in the same areas. Participating PCPs rated their abilities in addressing early behavioral or developmental concerns more favorably (i.e., 78 % rated as "good") than parents (i.e., 62 % rated as "good"). Additionally, Carbone and colleagues identified that one of the most discrepant areas between parents and PCPs was in the ability to make appropriate referrals during the diagnostic process. Approximately 80 % of PCPs perceived that they had "good" abilities to make appropriate referrals, compared to only 50 % of parents (Carbone et al., 2013). These discrepancies suggest that there may be a gap between professionals and families related to needs and expectations during the initial contact and subsequent rendered services.

Researchers have also evaluated PCPs' self-ratings of perceived difficulty in identifying early warning signs and symptoms of ASD within minority children (Zuckerman et al., 2013). Among 500 PCPs, approximately 60 % reported difficulty in identifying ASD symptoms and warning signs in Spanish-speaking Latino families. Approximately 37 % of PCPs reported the same difficulty for African-American children. These ratings were found to be significantly different from those of Caucasian children (Zuckerman et al., 2013). Overall, these outcomes reflect the ways in which cultural and language variables can impact the assessment of ASD and perhaps the screening and diagnostic experiences of those families.

Subsequent Referrals. When parents and professionals are in agreement about initial concerns, research has demonstrated that 50–55 % of families are then referred to subsequent providers (Howlin & Moore, 1997; Jones et al., 2014; Moh & Magiati, 2012). During this next stage of the diagnostic process, psychiatrists, psychologists, and multidisciplinary teams are common providers of additional specialized assessment. Even after referrals to these specialists, it is not unusual for some families to be further referred to other professionals for additional evaluation. Although identified estimates have varied, families typically visit an average of four to five professionals before receiving a final ASD diagnosis (Goin-Kochel et al., 2006; Moh & Magiati, 2012).

A factor that contributes greatly to this high number of referrals is that access to quality services (i.e., ASD-specific diagnostic centers, specialized professionals) is sometimes limited due to the high demand for these services and small number of specialists (Zwaigenbaum & Stone, 2006). However, these referrals and multiple appointments can take a toll on a family. Goin and colleagues (2006) found a significant inverse relationship between the number of professional encounters and overall satisfaction. Specifically, increased satisfaction was associated with fewer visits to professionals and decreased satisfaction associated with more professional visits. Levels of satisfaction and stress among families also can be influenced by the quality of the relationship with professionals. Among families who consult a high number of professionals, those who identify a highly collaborative relationship experienced less stress and more satisfaction compared to those families with lower rated levels of collaboration (Moh & Magiati, 2012).

Variables Impacting Diagnosis

The length of the diagnostic process may be influenced by several variables including level of severity, race/ethnicity, and socioeconomic status. These variables can introduce complexity to the evaluation process, which potentially may lead to delays in final diagnoses. Taking into consideration the association between age of diagnosis and parental satisfaction (Goin-Kochel et al., 2006; Siklos & Kerns, 2006), it is important to understand how these additional variables impact parental experiences of the diagnostic process.

In a critical review of 42 studies published between 1990 and 2012, Daniels and Mandell (2014) analyzed discrepancies between age of diagnosis and other related variables. Within ASD subtypes/severity, children with Asperger's disorder were consistently diagnosed at later ages than children with PDD-NOS or autistic disorder. Additionally, PDD-NOS diagnoses

were generally identified later than diagnoses for autistic disorder. Many of these studies suggested that those children with more severe ASD symptoms received earlier diagnoses (Daniels & Mandell, 2014).

Symptom severity was also found to impact the number of encounters with professionals. For example, Moh and Magiati (2012) found a negative correlation between the degree of ASD severity and the number of professional consultations, such that individuals with more severe symptomology visited fewer professionals in order to obtain a diagnosis. This finding is likely due to a clearer presentation of diagnostic criteria. There are also specific deficits or clinical presentations associated with parental stress and satisfaction. Siklos and Kerns (2007) found that families of children with more impaired communication reported lower levels of stress and higher rates of satisfaction during the diagnostic process. Conversely, parents of children with greater behavioral difficulties report less satisfaction with their diagnostic experiences. Their research suggested that communication deficits may be identified more efficiently by professionals, leading to quicker referrals, evaluation, and access to services (Siklos & Kerns, 2007).

Furthermore, ethnic/racial disparities have been identified related to diagnostic instability, which is the likelihood of individuals receiving other psychological or medical diagnoses prior to their final ASD diagnosis (McMorris et al., 2013). For instance, African-American children were found to be three times more likely than Caucasian children to receive an alternate diagnosis before their ASD diagnosis (Mandell, Ittenbach, Levy, & Pinto-Martin, 2007) and were diagnosed at overall older ages (Mandell et al., 2009). These identified variables (i.e., ASD subtype/severity, ethnicity) are important to consider due to the potential impact upon diagnostic age and overall parental stress and satisfaction. If individuals with a specific functioning level or impairment and/or those of identified cultural backgrounds are prone to receiving diagnoses at later ages, it is possible that these factors may impact the stress/satisfaction of family members during the diagnostic process. Certainly, research would need to further investigate these issues more directly.

As noted prior, diagnostic instability can be even more common among specific demographic groups. Researchers have found increased delays in ASD diagnosis with families of lower socioeconomic status, members of certain racial/ethnic groups, and those living in underserved/rural areas (Daniels & Mandell, 2014). Among young children (less than 6 years of age), decreased ASD prevalence rates have been found in children with low socioeconomic status (Liptak et al., 2008). Researchers have also found lower prevalence of ASD among Latino children compared to other races/ethnicities (Liptak et al., 2008; Mandell et al., 2009). Although the overall research on racial/ethnic and economic disparities is inconsistent, it is possible that the cited differences reflect a greater trend in missed early diagnosis in these populations (Palmer, Walker, Mandell, Bayles, & Miller, 2010). When acknowledging the identified correlation between diagnostic age and parental stress and/or satisfaction (Goin-Kochel et al., 2006; Howlin & Moore, 1997; Siklos & Kerns, 2007), implications may also exist for the impact of culture and/or socioeconomic level on outcome variables.

Past researchers (Brogan & Knussen, 2003; Howlin & Moore, 1997) also found that higher parental satisfaction was associated with receiving a definitive rather than tentative diagnosis. Several researchers have made note of participants with diagnoses of "autistic traits, tendencies, or features" (e.g., Brogan & Knussen, 2003; Howlin & Moore, 1997; Siklos & Kerns, 2007; Smith et al., 1994). These descriptors were often defined as tentative diagnoses in the above studies and identified those individuals who did not meet full diagnostic criteria for autistic disorder or Asperger's disorder. When professionals provide a tentative diagnosis, it may be due to their caution or hesitancy in assigning a false-positive outcome (Zwaigenbaum & Stone, 2006) or later misdiagnosis (Nissenbaum et al., 2002). However, it is important for professionals to be aware that tentative diagnoses have been associated with

lower rates of satisfaction from parents and families (Brogan & Knussen, 2003; Howlin & Moore, 1997).

Overall, parental satisfaction with the evaluation process can correlate with a child's diagnostic age. Fortunately, the outcomes from a literature review on age of ASD diagnosis by Daniels and Mandell (2014) yielded a consistent trend for younger groups of children to be diagnosed at earlier ages compared to the ages at which older groups of children were diagnosed. This may reflect a recent trend toward increased screening and surveillance for ASD among younger children leading to further evaluation (Brian et al., 2008; Johnson & Myers, 2007; Nadel & Poss, 2007). Timely diagnosis can allow children access to earlier intervention services (Boyd et al., 2010; Lord & Richler, 2006) which may positively impact upon their long-term prognosis (Klintwall, Eldevik, & Eikeseth, 2015; Osborne, McHugh, Saunders, & Reed, 2008) and also serve to decrease rates of parental stress (Wong & Kwan, 2010).

Disclosure of Diagnosis. The delivery of a diagnosis has the potential to be one of the most stress-producing periods in the diagnostic process for both families (Abbott, Bernard, & Forge, 2013) and professionals (Nissenbaum et al., 2002). At this delicate juncture, many parents or family members have personally identified significant concerns in their child's behaviors, met with numerous professionals, and may have endured long waiting periods. Given all of these factors, families often present to the feedback/disclosure appointment with heightened anxiety and worry and a variety of contradictory emotions about potential diagnostic outcomes (Molteni & Maggiolini, 2014). Research is somewhat discrepant regarding parent/family satisfaction with the actual delivery of diagnosis. In an examination of 102 parents of children with ASD, Moh and Magiati (2012) found that the majority of participants reported satisfaction with the manner in which diagnostic information was shared with them. Overall satisfaction in this study was determined by parental ratings of six components of the diagnostic process, including the way in which the diagnosis was communicated. Scores ranged from 1 (not satisfied at all) to 5 (very satisfied). The mean score for the style in which diagnosis was shared was 3.42 (SD = 0.93). These parents were also moderately satisfied with their relationships with professionals (i.e., $M = 3.34$, SD = 0.96). In fact, parents were most satisfied with the overall diagnostic experience when they believed that they were provided with helpful information by professionals and when they experienced valuable collaboration (e.g., sharing of information, incorporation of parents in decision making, genuine validation of concerns) (Moh & Magiati, 2012). A particular aspect of collaboration, specifically the acknowledgement of initial parental concerns, has also been associated with increased rates of satisfaction during the delivery of diagnosis (Brogan & Knussen, 2003). Additionally, Punshon, Skirrow, and Murphy (2009) emphasized that receiving an ASD diagnosis should be viewed as a process over time rather than an isolated experience. Although this research focused solely on adults diagnosed with Asperger's disorder, there may be shared pathways in the experiences of parents/families adjusting to an overall ASD diagnosis.

Researchers have also examined the perspectives of parents related to the positive and negative factors associated with the delivery of diagnosis. Results have identified overall strengths as parental belief in the expertise of the professional (Molteni & Maggiolini, 2014), and the overall relief, increased knowledge, and acceptance of the diagnosis (Mansell & Morris, 2004; Osborne & Reed, 2008). Undesirable factors include the professional's inability to provide a prognosis when delivering diagnosis (Molteni & Maggiolini, 2014), incomplete or tentative diagnoses (Brogan & Knussen, 2003), and confusing conversation or discussion (Mansell & Morris, 2004; Molteni & Maggiolini, 2014).

Post-diagnosis. The period immediately following the disclosure of a diagnosis is also considered emotionally intense for many individuals and families. For some parents, the shock or

stress of receiving a formal ASD diagnosis can interfere with their ability to effectively hear and understand post-diagnostic feedback from professionals (Abbott et al., 2013). Many of the participants in Abbott and colleagues' investigation reported feeling overwhelmed by the amount of information provided at the disclosure or feedback session. Outcomes from other studies (Jones et al., 2014; Osborne & Reed, 2008; Siklos & Kerns, 2007) indicated that individuals and family members identified dissatisfaction due to a lack of post-diagnostic support or because information was not described as efficiently or effectively as possible. Considering these findings, it appears crucial to enact a careful balance in the type and quantity of information provided at this sensitive stage of the diagnosis process.

Although the majority of researchers have assessed the experiences of parents during the diagnostic experience, it is also important to consider the experiences of the individuals themselves. Jones and colleagues (2014) evaluated the perceptions of 134 adults with ASD diagnoses. Participants were high functioning and able to report on their diagnostic process, occurring either in childhood or adulthood. Five predictors of overall satisfaction (i.e., time/delay in diagnosis, numbers of professional encounters, manner of professional providing diagnosis, quality of information provided at diagnosis, and support offered post-diagnosis) were identified. Participants completed a detailed questionnaire assessing these variables. Results indicated that the most significant predictor of overall satisfaction was the quality of information provided at diagnosis, followed by the time/delay in diagnosis (Jones et al., 2014). Other researchers (Punshon et al., 2009) have also identified delays in diagnosis among high-functioning adults with ASD. Collectively, these findings are generally consistent with experiences of stress and satisfaction of parents during the diagnostic process (e.g., Brogan & Knussen, 2003; Goin-Kochel et al., 2006; Howlin & Moore, 1997; McMorris et al., 2013; Siklos & Kerns, 2007).

In sum, several variables (i.e., number of professional encounters, diagnostic age/wait time, quality of professional relationship) have been associated with levels of stress and satisfaction of families and individuals during the diagnostic period. The identification and assessment of these variables are essential in order to increase the knowledge and awareness of professionals who are engaged in service delivery. With greater understanding of family and patient experiences during the diagnostic process, professionals can strive to implement best practice strategies aimed at improving satisfaction and overall experiences.

Improving the Diagnostic Process

As indicated earlier, it may take several years for a child to obtain an ASD diagnosis. The child may be placed on waiting lists (Connolly & Gersch, 2013) or referred to multiple providers before he/she receives a diagnosis (Goin-Kochel et al., 2006). Waiting for a diagnosis is anxiety provoking for parents (Osborne & Reed, 2008). As providers, there are a number of things that we can do to help attenuate the stress that parents experience during the evaluation process and thereby hopefully increase their satisfaction with services.

Preparing Families for the Process

Although parents would like the diagnostic process to take less time, this is not always possible for clinics. To reduce parental distress during this time period, parents find it helpful if professionals inform them about the length of the diagnostic process beforehand (Abbott et al., 2013; Connolly & Gersch, 2013). If the child is completing a multidisciplinary assessment, parents prefer being informed that several different professionals will be completing the exam. This information helps parents understand why the diagnostic process takes a significant amount of time and also helps relieve parental frustration (Abbott et al., 2013).

While waiting for an ASD diagnosis, parents may experience fear and anxiety because they have either inaccurate or no information about

ASD. Parents can find an overwhelming amount of information on the Internet. Additionally, they may only obtain information about the most severe cases (Connolly & Gersch, 2013). To reduce parental fear and anxiety, professionals should provide parents with information about ASD while they are waiting for their diagnostic assessment. Professionals could provide parents with pamphlets and/or handouts on ASD, along with a list of reputable websites and books. This information could be provided to the family via a letter in the mail or be posted on the agency's website. When professionals provide this information to the family, they should clearly state that they do not know if the child meets criteria for ASD. Professionals should state that they are providing this information because many parents report that receiving accurate information on ASD helps alleviate parental anxiety during the diagnostic process. These statements could be provided in a letter to the family and/or verbally when the family schedules the ASD evaluation.

The Feedback Session

Since parents often wait a significant amount of time to obtain a diagnostic evaluation, feedback should be delivered to parents as soon as possible (Hasnat & Graves, 2000). Unfortunately, researchers have not indicated how quickly feedback should be delivered to families. As providers, it is important to keep in mind the gravity of the information being provided from the family's perspective. With this in mind, professionals should work to ensure that the delivery of a diagnosis is given ample consideration in terms of the setting and structure of the feedback session, as well as the information provided in the written report.

When planning feedback sessions, consideration should be given to the time and setting. Professionals should allocate a sufficient amount of time to the feedback session (Mulligan, MacCulloch, Good, & Nicholas, 2012). Research suggests allocating between 75 and 90 min to the feedback session (Pruett, 2013). Feedback should be provided in a private setting, where the professional and family will not be disturbed (Baird, McConachie, & Scrutton, 2000). Since receiving diagnostic feedback can be a stressful experience for parents, it should be delivered in a family-friendly setting. It is recommended that professionals have comfortable chairs or tables in their office (Nissenbaum et al., 2002) and the room be arranged in a manner that is conducive to conversation (Shea, 1993). Since parents can have negative emotional reactions to the diagnosis, it is beneficial to have tissues available (Shea, 1993). While potentially sounding minor to providers, a warm and comfortable environment for delivering feedback may reduce some of the external stress experienced by the parents and therefore allow them to more effectively listen to the information being provided.

Beyond location and duration, another factor to consider is the people present in a feedback session. During an ASD evaluation, families may be assessed by several professionals on a multidisciplinary team or one professional (Mulligan et al., 2012). When a multidisciplinary team completes the evaluation, the team should meet prior to the feedback session in order to discuss the data and results. Together, the team should decide who from the team will be present for the feedback session and how information, results of the assessment, and the diagnosis will be disseminated (i.e., who will speak, lead the session, and deliver the diagnosis). Frequently, it is the psychologist on the team who delivers the diagnosis (Nissenbaum et al., 2002). Additionally, the team should designate one main professional for the family to contact with questions (Cottrell & Summers, 1990). Whether a single professional or multidisciplinary team completes the evaluation, the professional who delivers feedback should have a prior relationship with the family. Parents prefer receiving feedback from someone who has interacted with their child and has first-hand knowledge of his/her skills and behavior (Shea, 1993).

In addition to ensuring that the appropriate professionals are present for feedback, parents have indicated that they do not like being informed of a diagnosis when they are alone and do not have any support. If the child comes from

a two-parent home, then professionals should inform parents of the diagnosis when they are together (Baird et al., 2000; Poehlmann, Clements, Abbeduto, & Farsad, 2005). If the child comes from a one-parent household, then professionals should ask the parent if they would like to bring another individual to the feedback session for support (Baird et al., 2000). If other family members (e.g., grandparents, aunts, uncles) also live in the home or are significantly involved in the child's life (e.g., provide childcare), then it may also be beneficial to invite them. Consideration must be given to parents who are divorced or separated. It is best practice to have all interested parties in the room, which includes all parents and stepparents. However, if parents do not live near each other or have a hostile relationship, then it may be best to have two separate feedback sessions (Tharinger et al., 2008).

Research is inconsistent about whether children should be present in the room during feedback. Cottrell and Summers (1990) indicate that parents prefer being informed of a diagnosis with the child present. Nissenbaum et al. (2002) interviewed parents and asked them if their child was present during feedback. The majority of parents indicated that their child was not in the room during feedback. Parents who preferred having their child out of the room indicated that their child would not have understood the information and/or that they needed time to grieve the diagnosis without their child present. Tharinger et al. (2008) suggest having a second feedback session with the child and his/her parents after the professional has completed a separate feedback with the parents. It is recommended that this session occur days or weeks after the initial parent feedback session to allow parents time to process their initial emotional reactions to the diagnosis. When delivering feedback to children, information should be provided in a developmentally appropriate manner. Children with ASD often have poor insight into their psychological self (Williams, 2010). Therefore, they may be unable to recognize their symptoms. It may be beneficial for professionals to give concrete examples of the child's symptoms when informing the child of his/her diagnosis. Professionals could also use visuals and/or social stories to assist the child in understanding his/her symptoms. Additionally, professionals should use simple language that the child will understand.

It is recommended that parents have the opportunity to ask questions throughout the feedback session (Abbott et al., 2013; Mulligan et al., 2012). When parents ask questions, professionals should do their best to answer all of them. Subsequently, professionals should be knowledgeable about symptoms of ASD and efficacious treatments prior to the feedback session (Nissenbaum et al., 2002). If the professional does not know the answer to the parents' question(s), he/she should inform the parents that he/she is "not sure" or "does not know." Professionals should acknowledge their limitations rather than avoid the question or give an incorrect response (Shea, 1993).

Structuring the Feedback Session

In addition to thinking about all of the various factors outlined above that influence the nature of a feedback session, clinicians should also give prior consideration to the way that information is being delivered. Feedback sessions should be a structured session that is outlined and planned beforehand (Abbott et al., 2013). At the beginning of the feedback session, it is beneficial for professionals to check in with the parents and assess their feelings about the assessment process (Tharinger et al., 2008). Next, professionals should review the purpose of the evaluation (Groth-Marnat, 2003) and provide an outline for the session (Tharinger et al., 2008). At this point, it is important that professionals emphasize the importance of collaboration during feedback. Parents must be encouraged to offer their opinions, thoughts, and disagreements. Moreover, professionals should encourage parents to ask questions throughout the feedback session. In addition, it is recommended that professionals thank parents for their participation and validate their feelings about the evaluation process. It is also beneficial if professionals acknowledge the

time and energy that parents dedicated to the evaluation (Tharinger et al., 2008).

When professionals inform parents of their child's diagnosis, it is beneficial if he/she reviews the diagnostic criteria of ASD (Osborne & Reed, 2008) and states which symptoms the child exhibits (Nissenbaum et al., 2002). After the diagnosis is rendered, professionals should provide information regarding the child's prognosis (Mansell & Morris, 2004; Mulligan et al., 2012; Nissenbaum et al., 2002) and recommendations (Tharinger et al., 2008). With regard to the child's prognosis, professionals should educate parents on the child's future development and the impact of early intervention (Nissenbaum et al., 2002). When reviewing recommendations, it is beneficial if professionals adequately explain treatment options (Mansell & Morris, 2004) and provide information regarding local resources (Mulligan et al., 2012). All recommendations should be specific and individualized to the child.

Overall, feedback should be provided in a manner that is honest (Mulligan et al., 2012; Nissenbaum et al., 2002), clear (Abrams & Goodman, 1998; Baird et al., 2000; Mulligan et al., 2012), and easy to understand (Mulligan et al., 2012; Nissenbaum et al., 2002; Shea, 1993). Professionals should be honest regarding the child's strengths, needs, weaknesses, and future prognosis (Shea, 1993). At times, professionals avoid using labels during feedback sessions (Abrams & Goodman, 1998; Chamak et al., 2011). They may inform parents that the child has communication problems, a developmental delay, or language problems (Chamak et al., 2011). Instead of avoiding diagnostic labels, which can lead to confusion on the part of the parents, professionals should clearly state that the child meets criteria for ASD (Abrams & Goodman, 1998).

Additionally, many parents report that information provided during feedback was not clear (Keenan, Dillenburger, Doherty, Byrne, & Gallagher, 2010). Therefore, information should be conveyed in simple language that is easily understandable (Abbott et al., 2013; Nissenbaum et al., 2002; Shea, 1993; Watermeyer, Kanji, & Cohen, 2012). To assist with comprehension, professionals should repeat information, have visual aids, and use examples when explaining concepts. Professionals should be aware of parental verbal and nonverbal cues that indicate if they understand the information being presented. Research suggests that parents who do not spontaneously ask questions, appear unwilling to engage in the discussion, and provide minimal verbal (e.g., yes, no, okay, uh huh) and nonverbal responses (e.g., head nod) likely do not understand the information or may be confused (Watermeyer et al., 2012).

Professionals should focus on the child's strengths and provide hope for the family during feedback (Abbott et al., 2013; Mulligan et al., 2012; Nissenbaum et al., 2002). Parents report being more satisfied with feedback when professionals discuss positive attributes of their child (Abbott et al., 2013). When professionals focus on the child's strengths, it provides hope for the parents (Mulligan et al., 2012), which in turn provides motivation for parents to handle the child's behavior and other challenging symptoms of ASD. It is recommended that professionals discuss the child's strengths at the end of the feedback session so it ends on a "positive note" (Nissenbaum et al., 2002). Research suggests that parents enjoy hearing optimistic statements about their child's future (Abbott et al., 2013; Nissenbaum et al., 2002). Specifically, parents want to hear that there is hope for improvement and that there are effective interventions that could improve the child's deficits (Cottrell & Summers, 1990; Mulligan et al., 2012). Although professionals should offer hope and focus on the strengths of the child, it is important that he/she provides accurate and honest information (Shea, 1993). In other words, professionals should not provide false hope to the family.

Professionals should be supportive, warm, and empathetic during feedback (Baird et al., 2000). Failure to do so may negatively impact parents' abilities to cope with their child's diagnosis. In fact, parents who perceive their medical professional as being insensitive and lacking empathy

indicate that these characteristics negatively impacted their emotional response to their child's diagnosis (Poehlmann et al., 2005). Research suggests that having a supportive relationship with professionals assists parents in accepting their child's diagnosis (Abbott et al., 2013).

Written Feedback

Due to the large amount of information provided and the emotional nature of feedback sessions, parents may have difficulty retaining and understanding the information presented (Abbott et al., 2013; Mulligan et al., 2012). Thus, written information should be provided to families at the feedback session so they can revisit information discussed (Braiden et al., 2010; Brogan & Knussen, 2003; Mulligan et al., 2012). Specifically, the family should be provided with a written report regarding the diagnostic process (Shea, 1993). It is suggested that professionals inform parents at the beginning of the feedback session that they will be receiving a report in order to relieve their anxiety of having to remember all of the information presented (Tharinger et al., 2008).

In addition to a written psychological report, parents find it beneficial if they receive pamphlets, booklets, and/or websites on ASD (Mulligan et al., 2012; Osborne & Reed, 2008), along with a reading list (Braiden et al., 2010; Mansell & Morris, 2004; Mulligan et al., 2012). Written information about local resources and treatment should also be provided to parents (Mansell & Morris, 2004; Nissenbaum et al., 2002). It is helpful if professionals include the phone number and name of the contact person in this information (Baird et al., 2000; Nissenbaum et al., 2002). All written materials provided to parents should be written using simple language; parents must be able to understand the information (Braiden et al., 2010; Nissenbaum et al., 2002).

In summary, a variety of factors must be considered when providing feedback to parents. Professionals should be knowledgeable about how to prepare for the feedback session, structure the feedback session, deliver feedback, and provide written information. While it can be quite time consuming to do so, research has demonstrated that parents' reaction to receiving an ASD diagnosis is impacted by the quality of the assessment and feedback they receive. A summary of the feedback session is provided in Table 8.1.

Table 8.1 Strategies for effective feedback sessions

The feedback session
Preparing for the feedback session
• Have comfortable chairs and tables
• Have tissues available
• Arrange chairs in a manner that is conducive to conversation
• Schedule the feedback session for 60–75 min
• Ask the parent(s) if he/she would like to bring another adult to the interview (i.e., spouse, partner, family member(s), and/or family friend)
• Have the parent(s) decide if he/she would like the child present during the feedback session
Structuring the feedback session
• Check-in with the parents and evaluate their feelings about the assessment process
• Review the purpose of the evaluation
• Invite parents to share their thoughts and opinions
• Encourage parents to ask questions at any point
• Review the diagnostic criteria of ASD and state which symptoms the child demonstrates
• Clearly state that the child meets criteria for ASD
• Discuss the child's strengths
• Provide information regarding the child's prognosis (i.e., child's future development and the impact of early intervention)
• Provide recommendations
• Allow additional time at the end of the session for questions
How to deliver feedback
• Use language that the parents will understand
• Be honest, supportive, warm, and empathetic
• Provide hope for the family
Written information provided at feedback
• Written psychological report
• Pamphlets, booklets, and/or handouts on ASD
• List of books and websites on ASD
• The name, telephone number, and/or website for local resources
• The name and telephone number for local treatment providers

Parent Experiences Following a Diagnosis

Following the diagnosis, parents may experience either positive or negative emotional reactions. Research indicates that parents experience the following negative reactions to receiving an ASD diagnosis: shock, anger, hopelessness, denial, grief, sadness, frustration, anxiety, and confusion (Cameron, Snowdon, & Orr, 1992; Goff et al., 2013; Graungaard & Skov, 2007; Hasnat & Graves, 2000; Mansell & Morris, 2004; Mitchell & Holdt, 2014; Poehlmann et al., 2005). Following a diagnosis of ASD, parents may experience grief that their child will never be "normal" (Cameron et al., 1992; Poehlmann et al., 2005). They may experience a sense of loss, as they have to alter their image of the child (Goff et al., 2013). Additionally, parents may worry about their child's future (Mansell & Morris, 2004). Specifically, parents worry about the amount of care and support their child may need during their life and how to provide this (Mitchell & Holdt, 2014).

Though some parents may react negatively to their child's diagnosis, the majority of parents report experiencing a sense of relief (Mansell & Morris, 2004; Osborne & Reed, 2008). They feel relieved because their concerns regarding their child's development and/or behavior were validated (Avdi, Griffin, & Brough, 2000; Mulligan et al., 2012; Watson, 2008). Parents also report experiencing a sense of relief because a diagnosis allows them to obtain services for their child (Osborne & Reed, 2008).

Prior to a diagnosis of ASD, parents may blame themselves and question if their parenting caused the child's delay or behavior (Mulligan et al., 2012; Watson, 2008). Mothers may question if they did something wrong during their pregnancy or immediately after their child's birth. For instance, mothers have reported that they worried that their illnesses or infections during pregnancy caused their child's behavioral problems (Watson, 2008). A diagnosis helps alleviate parental guilt and personal blame (Mansell & Morris, 2004; Midence & O'Neill, 1999; Watson, 2008). It is vital that professionals allow time for parents to express these concerns and provide information to reduce these concerns and correct misbeliefs, especially pertaining to the causes of ASD.

Accepting the Child's Diagnosis

Accepting their child's diagnoses may be harder and take more time for some parents than others (Cameron et al., 1992; Mitchell & Holdt, 2014). However, the majority of parents report reaching this stage at some point of time (Mitchell & Holdt, 2014; Poslawsky, Naber, Van Daalen, & Van Engeland, 2014). Parents may initially be in denial of their child's diagnosis, limiting their ability to accept the diagnosis (Mitchell & Holdt, 2014; Nissenbaum et al., 2002). Parents must process their negative emotional reactions before they are able to accept their child's diagnosis (Mitchell & Holdt, 2014). Some parents indicate that in order to accept their child's diagnosis, they had to alter how they viewed their child. Instead of focusing on how the child "should be," they began thinking about how "the child is" (Avdi et al., 2000).

Poslawsky et al. (2014) examined parental acceptance of their child's ASD diagnosis. Parents were defined as adequately adapting and coping with the diagnosis if they were action, thinking, or feeling oriented. Parents who were action oriented took steps to obtain resources for their child and adjust their child's routine to account for the diagnosis. Thinking-oriented parents obtained information about their child's diagnosis in order to assist their understanding of ASD. Feeling-oriented parents experienced both positive and negative emotions about their child's diagnosis. Poslawsky and colleagues found that most parents who accepted their child's diagnosis were action oriented. The study indicated that parents who were unable to accept their child's diagnosis, were angry, emotionally overwhelmed, depressed, or neutral to their child's diagnosis. The outcomes of Poslawsky and colleagues investigation indicated that it was harder for parents to accept their child's diagnosis if he/she had more severe symptoms of ASD.

Support and Resources

Despite the parents' initial reaction to their child's diagnosis, having a child with ASD frequently causes parental stress (Dillenburger, Keenan, Doherty, Byrne, & Gallagher, 2010). Therefore, support throughout the child's life is needed in order to assist the parent with his/her stress. It is important to note that studies regarding parental support are primarily based in the UK. Thus, access to services and availability of services may vary from the USA.

Studies indicate that over half of parents have been offered help or are currently receiving services for their child (Osborne & Reed, 2008; Renty & Roeyers, 2006). Despite the number of parents receiving professional assistance, many parents report that they have never received support (Braiden et al., 2010; Osborne & Reed, 2008). Furthermore, parents report a time lapse between receiving the diagnosis and obtaining services (Braiden et al., 2010).

Mulligan et al. (2012) interviewed parents, who had children diagnosed with ASD, regarding their service utilization. Parents reported that services were often limited and difficult to obtain. Many services had strict admission criteria, long wait lists, and/or provided few resources. Additionally, professionals did not assist parents in obtaining services for their child. Following the diagnosis, the professional informed the parent of services he/she would need to obtain for the child; however, they did not provide any referrals.

Several studies have examined which services parents would like to receive. Overall, parents want to receive more support and services for their child (Bromley, Hare, Davison, & Emerson, 2004). Therefore, professionals should provide information regarding supports and services to parents throughout their lifetime. Many parents feel that they do not have enough knowledge about ASD and would like more information regarding the disorder (Dillenburger et al., 2010; Osborne & Reed, 2008; Renty & Roeyers, 2006). Respite services for children can be limited, as many are only available once a month or do not accept adolescents (Hall & Graff, 2010). Therefore, many parents have expressed a need for more respite services (Baile & Costantini, 2013; Bromley et al., 2004; Dillenburger et al., 2010; Osborne & Reed, 2008). Parents want more programs for children with ASD that they could attend after school, on the weekends, or during school breaks (Siklos & Kerns, 2006). Parents also express a desire to have more training in applied behavior analysis (ABA) or behavior therapy in order to better manage their child's behavior (Bromley et al., 2004; Dillenburger et al., 2010; Osborne & Reed, 2008).

Furthermore, parents suggest that professionals provide them with referrals to individual therapy for themselves to assist them in coping with the diagnosis (Mansell & Morris, 2004). Whole family supports such as group or family therapy are also recommended by parents to assist the family with stressors related to their child's diagnosis (Hall & Graff, 2010; Osborne & Reed, 2008). Additional services parents would like to receive include childcare (Bromley et al., 2004; Hall & Graff, 2010), a case manager to assist with the coordination of services (Mulligan et al., 2012), educational support, support groups, a professional to assess their child on a regular basis (Osborne & Reed, 2008), a family advocate, ABA schools/centers, multidisciplinary support (Dillenburger et al., 2010), and transportation (Bromley et al., 2004).

Parents who have children with ASD may experience financial strain. A parent may be unable to work due to the amount of time he/she has to dedicate to obtaining services for the child (Mitchell & Holdt, 2014). Insurance companies may not cover behavior therapy and/or diagnostic evaluations (Hall & Graff, 2010). Additionally, parents need financial assistance for other treatments (Siklos & Kerns, 2006). Overall, parents want more financial support for their children (Bromley et al., 2004; Hall & Graff, 2010; Renty & Roeyers, 2006).

Many parents experience distress over their child's future (Siklos & Kerns, 2006). Parents worry about their child's ability to financially support themselves when he/she is an adult (Hall & Graff, 2010). Thus, parents need assistance

planning for their child's future income. Other future concerns include medical support, obtaining employment as an adult, and the child's ability to live independently as an adult (Renty & Roeyers, 2006). Due to these future concerns, parents need services to assist with their child's transition to adulthood.

Limitations of Current Research and Issues Requiring Further Study

In order to continually identify best practice strategies to implement during the diagnostic process, professionals must have an empirically based understanding of the variables that influence parent and caregiver levels of satisfaction and stress. One area of focus within the literature base is the diversity of participants from several different countries. A significant portion of the research is from the UK followed by the USA, with other investigations based in regions such as Canada, France, Australia, India, Italy, and Singapore. This diversity of participants is desirable because the global experiences of families can be evaluated, potentially leading to large-scale generalizability. However, this regional diversity can also create further discrepancies within a developing research base. Given some of the likely differences in health care systems related to service delivery and overall patient satisfaction (Thomson, Osborn, Squires, & Jun, 2013), the ability to generalize specific results among countries may be somewhat limited.

Although it appears likely that shared experiences (i.e., satisfaction/dissatisfaction with diagnostic process) may occur regardless of country of origin, it is possible that other cultural/regional factors specific to systems of care could have an influence on outcomes. For example, Daley (2004) described that families in India often experience limited access to health care providers who are qualified to diagnose ASD. As a result, some individuals seeking evaluations travel several days to receive care (Daley, 2004). Certainly, in the time since this study, greater access to professionals specializing in ASD may have occurred. However, the availability and/or quality of specialized services in non-Western countries can be different than those in Western countries. Furthermore, in a review of health care system performance indicators among 14 industrialized countries, UK citizens had notably more favorable views of their public health system. In contrast, US citizens had the least favorable views compared to the other assessed countries. Although the association between global perspectives and more specific clinical/health experiences is unknown, it is worthwhile to consider the potential implications regarding the countries who have contributed most readily to the research base. Going forward, research should continue to explore both the global and cultural/regional-specific experiences of individuals navigating the ASD diagnostic process. In this pursuit, researchers may need to delve further into the complexities and norms of health care systems within and between countries in order to better understand the variables that could influence diagnostic perceptions. Further evaluation of the extent to which these regional and cultural differences impact upon overall diagnostic experiences could provide greater conceptual clarity.

In addition to some of the previously identified correlates of overall satisfaction (e.g., age at diagnosis, wait time, number of professional encounters, relationship with professionals), future investigations should also explore the potential impact of additional variables. Numerous studies have examined stress (e.g., Baker-Ericzén, Brookman-Frazee, & Stahmer, 2005; Hayes & Watson, 2013; Ritzema & Sladeczek, 2011; Rivard, Terroux, Parent-Boursier, & Mercier, 2014) and psychological functioning (e.g., Harper, Dyches, Harper, Roper, & South, 2013; Minnes, Perry, & Weiss, 2015) in parents of children with ASD, and it would be noteworthy to assess the impact of these variables on ratings of overall satisfaction. It is possible that extraneous factors such as family stressors or general parenting stress may impact perceptions of the diagnostic process. Similarly, further study of child-specific variables could better inform practice. Considering that the level of ASD severity has been found to be a significant predictor of

parental stress (Lyons, Leon, Phelps, & Dunleavy, 2010), future studies could explore the possible moderating impact of disability severity on parental stress and overall satisfaction during the diagnostic process. Further investigation of these parent and child variables may help professionals to better understand, predict, and plan for future diagnostic experiences.

Additionally, many of the core studies in this area have included qualitative (e.g., Abbott et al., 2013; Goin-Kochel et al., 2006; Howlin & Asgharian, 1999; Osborne & Reed, 2008; Punshon et al., 2009), quantitative (e.g., De Alba & Bodfish, 2011; Harrington et al., 2006; Howlin & Moore, 1997; Jones et al., 2014; Siklos & Kerns, 2007; Smith et al., 1994), and mixed-method research designs (e.g., Chamak et al., 2011; Mansell & Morris, 2004; Molteni & Maggiolini, 2014). Many qualitative studies have provided rich information that assists in understanding the themes and experiences of parents and families who encounter the ASD diagnostic process. Quantitative studies have also explored a range of issues related to satisfaction with the diagnostic process. In the Daniels and Mandell (2014) review of literature that assessed disparities in age at ASD diagnosis, they suggested that many of the identified disparities may be associated with methodological inconsistencies. For example, archival or administrative data (i.e., insurance claims or school/health records) were utilized in numerous studies whereas other researchers pursued primary data collection. Among those researchers who engaged in primary data collection, sampling techniques varied. Overall, it appears important to build upon the methodological rigor of future research both quantitatively and qualitatively. One particular emphasis should be on further development of the constructs of satisfaction and stress for individuals navigating the ASD diagnostic process.

As noted, many variables (e.g., age of diagnosis, wait time, professional response to initial concerns, professional relationship, diagnostic severity/subtype) have been examined related to overall satisfaction. Further, several other variables have been posited as additional correlates of overall satisfaction with the diagnostic process. Assessing the contribution of each of these factors within the overall construct of satisfaction will enhance conceptual and theoretical understanding. Several studies (e.g., Brogan & Knussen, 2003; Jones et al., 2014; Moh & Magiati, 2012; Siklos & Kerns, 2007) have explored predictors and correlates of satisfaction through multivariate analysis. Continued exploration and confirmation of findings are necessary to further develop and refine theory.

As the constructs of stress and satisfaction are further explored, implications for the assessment and measurement of related variables are relevant. In the reviewed studies, many investigators created their own questionnaires/surveys to assess perceptions of stress and satisfaction (e.g., Harrington et al., 2006; Jones et al., 2014; Mansell & Morris, 2004; Smith et al., 1994). The measurement of these variables in other studies (e.g., Brogan & Knussen, 2003; Howlin & Asgharian, 1999) was based on different questionnaires used during previous investigations (i.e., Howlin & Moore, 1997; Sloper & Turner, 1993). When a range of questionnaires/surveys are used with limited or no reported psychometric qualities, it is difficult to condense outcomes and determine the reliability of measurement. Additionally, inconsistencies also exist among scales in the way in which overall satisfaction is measured. Some satisfaction scores were derived from a single item, often based upon a four- or five-point Likert scale. Other scores were based upon multiple aspects of a questionnaire or responses to several different items. If researchers are acknowledging the multidimensionality of stress and satisfaction, it is unknown if single-item questions can accurately reflect the overall experience and construct of these variables. A more comprehensive emphasis on multidimensional assessment may be warranted. As a result, future research should explore scale development and refinement with specific measurement tools. Researchers are encouraged to extend beyond the face validity of questionnaires and continue to examine construct and content validity. Enhanced understanding of the variables

primarily contributing to the constructs of stress and satisfaction could assist in more efficient and effective identification of best practice strategies for professionals.

Finally, investigations should strive to narrow the research-to-practice gap that can be common in the health and mental health fields. This gap between the identification of empirically based strategies and their use in regular clinical practice has been discussed related to ASD intervention research (e.g., Dingfelder & Mandell, 2011; Stahmer, 2007; Stahmer & Aarons, 2009), and it is possible that similar challenges may be present within ASD assessment/diagnostic research. One reason for the disconnect between researchers and practitioners might occur due to a lack of attention or acknowledgement of systemic issues and contextual factors in different practice settings (Jensen & Foster, 2010). For example, practitioners may attempt to implement best practice strategies, but find themselves burdened by the realities of limited (or absence of) insurance payment for additional feedback appointments. Additionally, spending increased time with some families in attempts to increase satisfaction and reduce stress may inevitably increase the diagnostic wait time for other families, a factor known to increase stress and decrease satisfaction. This dichotomy, in which research-based strategies may be beneficial for one group of individuals but not another, may lead to inconsistent or limited adoption of the recommendation practice.

To improve effectiveness and consistency of practice, researchers should explore the extent to which implementation of the recommended strategies actually affects overall experiences and satisfaction during the diagnostic process. There are numerous variables that may influence an individual's experiences during this time. As a result, it may be helpful to begin isolating specific strategies (e.g., number of feedback sessions, type of information provided during disclosure) to explore the extent to which implementation impacts ratings of overall stress and satisfaction. This information may be able to better shape the practices of professionals working with families and individuals.

Conclusion

Navigating the diagnostic process for ASD can be a highly stressful period for parents and caregivers. Despite some limitations, the growing body of research in this area contributes to a better understanding of the experiences and perspectives of families and individuals. The current literature provides several implications for professionals who are providing health and mental health services to children, families, and/or adults. As research continues to inform practice, professionals should strive to provide high-quality services to individuals and families that are efficient, comprehensive, collaborative, and respectful.

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Diagnosing ASD in Very Early Childhood

9

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Diagnosing ASD in Very Early Childhood

Autism spectrum disorder (ASD) is a common, neurodevelopmental disorder defined by deficits in social and communication skills as well as the presence of restricted, repetitive, and stereotyped behaviors, interests, or activities (American Psychiatric Association [APA], 2013). According to the most recent Autism and Developmental Disabilities Monitoring (ADDM) Network study, the current prevalence of ASD is estimated at 1 in 68 children in the USA (Centers for Disease Control and Prevention [CDC], 2014). The *Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition* (*DSM-5*) criteria, frequently used in the diagnosis of autism, conceptualizes ASD based on the presentation of symptoms in two domains: social communication and social interaction, and restricted, repetitive patterns of behaviors, interests, or activities. Items within the social communication and social interaction domain include (1) deficits in social-emotional reciprocity, (2) deficits in nonverbal communication, and (3) deficits in forming, maintaining, and understanding social relationships. Individuals being evaluated for ASD must evince all three items to be considered for diagnosis. The restricted, repetitive patterns of behavior, interests, or activities domain includes (1) stereotyped and repetitive language use, motor movements, or object manipulations; (2) strict adherence to routines, ritualized patterns of verbal or nonverbal behavior, and/or resistance to change; (3) restricted, fixated interests that are atypical in intensity or focus; and (4) aberrations in sensory reactivity or abnormal interest in sensory input from the environment. Diagnosis requires evidence of at least two of these four symptoms. Symptoms from both domains must be present early in life (APA, 2013).

Currently, formal diagnosis of ASD is rarely made before 3 or 4 years of age in the USA. However, researchers have shown that most parents recognize signs and symptoms of ASD in their children during the first or second year of life (De Giacomo & Fombonne, 1998; Goin-Kochel, Mackintosh, & Myers, 2006; Landa & Garrett-Mayer, 2006; Rogers, 2009; Wetherby et al., 2004; Zwaigenbaum et al., 2007). Research findings indicate that behavioral markers of ASD are apparent before 2 years of age and that diagnosis at 2 years old can be made reliably. ASD diagnoses made in children at 2 years old are stable and have been found to persist a year later in 90 % of cases studied (Lord, 1995; Wetherby, Watt, Morgan, & Shumway, 2007; Zwaigenbaum et al., 2007).

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Although nearly a decade of research supports the reliability of identifying ASD at 2 years of age, there are several factors that contribute to the lag in formal diagnosis we are experiencing. The first involves a lack of knowledge and experience in both parents and professionals. Parents may be limited in their knowledge about typical development in young childhood, particularly if the child experiencing developmental delays or atypicalities is their firstborn. Parents may also dismiss any developmental concerns as problems their child will "grow out of" with time (De Giacomo & Fombonne, 1998). This outlook would be responsible for delaying professional consultation. De Giacomo and Fombonne (1998) found that the mean age of parental concern for children who are later diagnosed with ASD was 19 months but that it took approximately 5 months after that concern for parents to seek professional advice.

Further, pediatricians and general practitioners are typically the first professionals to be consulted with these developmental concerns (De Giacomo & Fombonne, 1998; Wetherby et al., 2004). These primary care providers may not have the expertise necessary to distinguish parental concerns as emerging ASD symptoms (De Giacomo & Fombonne, 1998; Goin-Kochel et al., 2006). For instance, Shah (2001) studied medical students' understanding about various aspects of ASD using a ten-item questionnaire addressing diagnostic criteria, causes, symptomology, treatment, and outcome. Results indicated that fourth-year students averaged fewer than half correct responses on the questionnaire. Lack of information about autism may contribute to professional hesitation in addressing concerns about child development (Goin-Kochel et al., 2006; Shah, 2001).

Another obstacle for establishing earlier diagnosis is the heterogeneity in symptom presentation and symptom onset in children with ASD (Zwaigenbaum, 2010). Individuals with ASD vary in severity of symptom presentation; those children with a milder presentation often are not diagnosed until later in life when social demands increase and their deficits become more pronounced (Goin-Kochel, 2006; White, Keonig, & Scahill, 2007). Using the *Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition, Text Revised* (*DSM-IV-TR)* autism subtypes, Goin-Kochel and colleagues (2006) found that mean age of ASD diagnosis differed according to diagnosis; while the mean age of autistic disorder diagnosis was 3.4 years, children with PDD-NOS and Asperger syndrome were diagnosed significantly later ($M = 4.2$ and 7.5 years, respectively). Variability of onset and presentation creates complexities in the early detection of ASD. Finally, the existing ASD diagnostic criteria may not be appropriate when diagnosing very young children, and criteria specifically for infants and toddlers has not been established (Goin-Kochel et al., 2006; Zwaigenbaum et al., 2007). The behavioral repertoire of infants and toddlers who are later diagnosed with ASD may be too limited to evaluate for the symptoms illustrated in the diagnostic criteria of the *DSM* (De Giacomo & Fombonne, 1998).

Goin-Kochel and colleagues (2006) reported that over 40 % of parents of children with ASD were unsatisfied with the diagnostic process. Delays in diagnosis have been found to increase parental distress and coping difficulties. Delayed diagnosis would also postpone child enrollment into early intervention services (De Giacomo & Fombonne, 1998; Goin-Kochel et al., 2006). This is particularly problematic, as researchers have shown that early intervention has a greater benefit when provided before 3.5 years of age compared to after age 5. Early intervention beginning before 4 years of age has been associated with greater language, social, and cognitive improvements (De Giacomo & Fombonne, 1998; Wetherby et al., 2004). Working to improve the diagnostic process is essential for bettering the prognosis for both children with ASD and their families.

Studying ASD in Young Childhood

In order to improve early identification and diagnosis of autism in young childhood, we must first understand autism onset and presentation in this age population. Researchers and clinicians have employed several different retrospective and prospective strategies to study the emergence of ASD in infants and toddlers. It is from this line of

research where early diagnostic measures, practices, and procedures arise. In this section, these strategies are discussed.

Retrospective Studies

Parent Report

Obtaining information regarding early autism emergence via parent report is a common method used in research and clinical practice. Retrospective parent report is efficient in collecting early history. Parents and caretakers observe their child's behavior across time and across various settings allowing for a wide range of information to be gathered (Ozonoff, Heung, Byrd, Hansen, & Hertz-Picciotto, 2008; Zwaigenbaum et al., 2007).

Several limitations to studying ASD onset and early symptomology by parent report exist. First, parent report is prone to errors of memory and affected by the passage of time (Ozonoff et al., 2008; Rogers, 2009; Zwaigenbaum et al., 2007). The level of parental knowledge about typical child development also affects parent report. Parent ability to recall and recognize subtle social and communication atypicalities may be limited compared to clinicians or researchers specialized in ASD (Rogers, 2009; Zwaigenbaum et al., 2007). Recognition of symptom onset has been found to be particularly difficult for parents (Ozonoff et al., 2008). Parent report is subject to bias caused by knowledge of their child's later diagnosis; parents may report more early behaviors and symptoms consistent with the diagnosis (Ozonoff et al., 2008; Zwaigenbaum et al., 2007). Last, assessors conducting parent report interviews must be trained to ask questions that are clear and full but are not leading. They must also be trained to provide probes when necessary, as parents often do not conceptualize symptoms in the same way as professionals in the field (Ozonoff et al., 2008).

Despite the limitations of parent report, studies have shown moderate consistency between the behaviors and symptoms parents report and those seen on videotape footage. Therefore, parent report is a relatively valid method of studying early onset and symptomology of ASD (Ozonoff et al., 2008).

Home Videos

Studying home videos offered the first opportunity for objective examination of the early behaviors exhibited by children who were later diagnosed with ASD (Rogers, 2009; Saint-Georges et al., 2010; Zwaigenbaum et al., 2007). Compared to parent report methods, studying home videos allows for more objective assessments by trained and unbiased viewers of early behaviors in children with ASD (Zwaigenbaum et al., 2007).

Several concerns regarding the representativeness and standardization process in the home video method have been raised (Ozonoff et al., 2008; Rogers, 2009; Saint-Georges et al., 2010; Zwaigenbaum et al., 2007). Rather than collecting random samples of behavior, home videos are filmed for particular reasons in specific settings and may not represent behavior across all settings (Rogers, 2009). Further, it is possible that parents stop filming when children behave inappropriately or undesirably (Zwaigenbaum et al., 2007). Because of this, collecting data regarding ASD-specific behaviors (e.g., interaction patterns, object exploration, sensory response) may require additional parent report methods. Another issue involves the variability across families in the amount, content, and quality of home videos. Some families do not videotape their children at all, raising concerns of the generalizability of findings across the ASD population. Because home videos are made to preserve family memories, each family will have varying activities filmed in varying settings. This variability makes standardization difficult and time intensive (Ozonoff et al., 2008; Zwaigenbaum et al., 2007).

Despite limitations, the home video method has led to significant findings regarding the early distinguishability of ASD symptoms in infants (Rogers, 2009). Further, results from recent prospective studies have supported the findings

of home video research. Therefore, home video analysis is viewed as a valid and reliable method of studying ASD emergence in infancy and toddlerhood (Saint-Georges et al., 2010).

Prospective Studies

Prospective studies test specific hypotheses utilizing experimental methods. These studies are designed to explore particular behavioral or biological constructs in a standardized manner (Zwaigenbaum, 2010). Multiple assessments are conducted across a long period of time on the same sample of infants and toddlers. This often involves frequent naturalistic assessments of participant development and less frequent "landmark" evaluations using standardized measures of language, cognition, and adaptive functioning. The developmental progression of high-risk (e.g., siblings of children with ASD) and low-risk children is compared. An endpoint of at least 3 years old is most often employed (Landa & Garrett-Mayer, 2006).

There are several advantages of employing a prospective design. Prospective studies are not subject to the same biases seen in parent report and home video research (Landa & Garrett-Mayer, 2006; Ozonoff et al., 2008). Prospective methods provide uniform data points and methods of data collection across participants. The longitudinal nature of prospective designs also allows for improvement in the understanding of developmental trajectories of individuals with ASD (Landa & Garrett-Mayer, 2006).

Several populations have been used to study ASD onset and symptom emergence prospectively. Among these populations are children with a sibling with ASD, children who fail population screeners, and children who have specific medical or genetic diagnoses that often co-occur with ASD (Landa & Garrett-Mayer, 2006). Using siblings of children with ASD in prospective studies offers a great deal of feasibility (Landa & Garrett-Mayer, 2006; Zwaigenbaum, 2010). ASD has among the highest recurrence risk of all neuropsychiatric disorders; the risk of having a child who will develop ASD when one child in the family has ASD is as high as 8 % and 35 % when the family has two children with ASD (Landa & Garrett-Mayer, 2006). Because of this, prospective studies on high-risk siblings can begin as early as prenatal periods offering unique opportunities to study neurobiological underpinnings of ASD (Landa & Garrett-Mayer, 2006; Zwaigenbaum, 2010). Studying siblings is not without limitations, however. The characteristics of the older sibling with ASD (e.g., severity level) may influence the likelihood of participation. Further, generalizability of results may be limited due to possible genetic differences in single-incidence versus multiple-incidence families (Landa & Garrett-Mayer, 2006; Zwaigenbaum, 2010).

Utilizing children who screen positive for delays in development offers the opportunity to study children with no family history of ASD; however, these studies rarely begin before the first year of life when delays cannot be reliably identified (Zwaigenbaum, 2010). Sampling biases may occur when using this high-risk sample because parents with concerns may be more likely to participate. Further, data collection beginning after the first screening restricts the age range that can be studied (Landa & Garrett-Mayer, 2006). Young children at a heightened risk for ASD due to a preestablished medical or genetic disorder may also be used in prospective studies. Among these disorders are fragile X syndrome, chromosomal aberrations, and tuberous sclerosis. However, these medical conditions are rare and are associated with unique presentation differences in ASD, making this population difficult to study and results difficult to generalize (Landa & Garrett-Mayer, 2006).

Weaknesses of prospective designs can be found in both the age of enrollment and the age of endpoint. Results may vary based on age of enrollment. If participants are enrolled at or after 1 year of age, there is a heightened risk of sampling bias because parents may be observing and may be concerned about behaviors consistent with ASD (Rogers, 2009). Variation may also stem from the determined endpoint of the study. Studies using a later endpoint (e.g., 60 months) may have higher rates of ASD compared to those

using earlier endpoints. This would result from misclassification into the "typical development" group of children who have milder presentations of ASD such as those individuals who would have been classified as having PDD-NOS or Asperger syndrome in the *DSM-IV-TR* (Landa & Garrett-Mayer, 2006; Rogers, 2009). These milder cases of ASD are often diagnosed later when social demands increase and atypicalities become more pronounced.

Despite these weaknesses, prospective studies of high-risk infants offer increased objectivity in studying infants and toddlers with ASD. Prospective studies also present a new opportunity to study behavioral and biological markers of ASD and have helped to improve the understanding of the neurobiology of ASD, the available early detection measures, and hold implications for early intervention.

ASD Symptom Emergence

Results from retrospective and prospective studies indicate that the most common onset pattern noted in children with ASD is gradual, where parents become increasingly aware of certain atypical symptoms or lack of progression through developmental milestones during the child's first 2 years of life (Werner, Dawson, Munson, & Osterling, 2005). Though a third of parents recognize atypicalities before their child's first birthday, most parental concerns begin between the first and second year of their child's life (De Giacomo & Fombonne, 1998). A later diagnosis of ASD is associated with increasing concerns from 12 to 18 months of age, but not concerns at 6 months of age (Zwaigenbaum, 2010). Significant differences between infants and toddlers who are typically developing, developmentally delayed, and who later receive a diagnosis of ASD have been found at 13–15 months for socialization deficits, 16–18 months for repetitive behaviors, and 19–21 months for communication symptoms (Wetherby et al., 2007). This section describes specific symptoms across several developmental domains that characterize infants and toddlers who are later diagnosed with ASD.

Communication

Speech and language problems are the most common first concern for parents of children who are later diagnosed with ASD (De Giacomo & Fombonne, 1998). Researchers have shown that deficits in both verbal and nonverbal communication begin at 12 months of age in infants who develop ASD (Rogers, 2009). Verbal communication deficits can present as delayed development of language, abnormal use of language, or a complete lack of verbal language (Inglese & Elder, 2009). Although considered a part of typical language development, echolalia, or repeating words or phrases previously heard, is often observed beyond normal time limits in young children with ASD. Abnormal voice intonation when speaking is also seen (Chawarska, Klin, Paul, & Volkmar, 2007; Rogers, 2009). Infants and toddlers with ASD have difficulty expressing their wants, display more stereotyped vocalizations, produce less vocalizations directed towards other people, and have a reduced number of words and sentences compared to their peers. Receptively, young children with ASD present with deficits in following directions and have an inconsistent response to their name being called (Saint-Georges et al., 2010; Wetherby et al., 2004; Zwaigenbaum, 2010). In regard to nonverbal communication, infants and toddlers who are diagnosed with ASD engage in less or no communicative gestures (e.g., pointing; Saint-Georges et al., 2010; Wetherby et al., 2004).

Socialization

In cases of early ASD onset, social symptoms can be observed from several months after birth. Infants who are later diagnosed with ASD often do not assume an anticipatory posture before being held by an adult. Infants with ASD may show little social interest and a lack of responsiveness to social stimuli. This population shows deficits in interaction, and higher nonsocial attention, and demonstrates less appropriate emotions and facial expressions. Behaviors predictive of a later diagnosis of ASD in 12-month-old children include

deficits in eye gaze, little social smiling, and delays in play skills and imitation (Wetherby et al., 2004; Zwaigenbaum et al., 2007; Zwaigenbaum, 2010). Joint attention, a behavior typically developed by age 12 months, is rarely observed in infants who develop ASD (Saint-Georges et al., 2010; Zwaigenbaum et al., 2007). Young children with ASD rarely share their interests and enjoyments with caretakers and show a lack of interest in their peers (Saint-Georges et al., 2010; Wetherby et al., 2004). Researchers have found that children who later receive an ASD diagnosis are less likely to attend to an adult feigning distress (Zwaigenbaum et al., 2007). By 2 years old, social symptoms become more pronounced. At 2 years of age, children with ASD interact poorly with other people, spend less time looking at others, show poor eye contact, demonstrate deficits in imitation, and express less positive affect (Saint-Georges et al., 2010; Werner et al., 2005).

Restricted and Repetitive Behaviors

Restricted and repetitive behaviors are rarely seen before 12 months of age. In fact, several researchers have found that stereotypies and self-stimulatory behaviors in children who later develop ASD did not significantly differ from typically developing peers in the first year of life (Saint-Georges et al., 2010; Wetherby et al., 2004). By 12–18 months of age however, young children with ASD display aberrations in toy play such as less functional use and atypical exploration (e.g., spinning, rotating, repetitive actions, unusual visual regard; Rogers, 2009; Zwaigenbaum, 2010). Atypical reactions to sensory input may also be present in this age group (Zwaigenbaum, 2010). Though repetitive motor movements may be less prevalent in infant and toddlerhood, these behaviors may also be more difficult to differentiate from age-appropriate movements observed in typically developing infants. When assessing an infant for ASD, Zwaigenbaum and colleagues (2007) suggest looking at not only the type of repetitive behaviors present, but also the persistence, quality, frequency, and contexts under which the behavior occurs.

Other

Beyond the deficits observed within the core domains of autism, ASD has been found to affect several areas of development early in life (Zwaigenbaum, 2010). These associated symptoms include impairments in attention regulation, cognitive deficits, and hypoactivity (Saint-Georges et al., 2010; Zwaigenbaum, 2010). Temperamental difficulties are also seen in young children who later receive an ASD diagnosis (Rogers, 2009; Saint-Georges et al., 2010). Significant differences in motor development have been observed in young children with ASD. Researchers have found that infants and toddlers who develop ASD show signs of hypotonia as well as deficits in fine and gross motor skills in the first 2 years of life (Landa & Garrett-Mayer, 2006; Rogers, 2009; Saint-Georges et al., 2010).

Variability in Onset

From its first description (Kanner, 1943), autism has been conceptualized as a disorder present from birth; however, results from several longitudinal studies have shown that the course and presentation of ASD can vary tremendously between individuals, or even within the same individual over time (Saint-Georges et al., 2010; Volkmar, State, & Klin, 2009). Though most young children who are diagnosed with ASD present with the early symptom emergence discussed above, researchers have indicated that around 30 % of children experience late onset of ASD (Ozonoff et al., 2008). Of particular interest in this onset variability research is autistic regression. Regression can be loosely defined as a loss of previously acquired skills before age 3 years (Kalb, Law, Landa, & Law, 2010; Ozonoff et al., 2008). While some researchers require a loss of language skills to characterize regression, a child can experience regression over several different developmental domains (i.e., social, motor, and potentially cognitive skills). Researchers have found that approximately half of children who experience regression have both social and

language skill losses, and up to one-third of children experience social losses only (e.g., loss of eye-to-eye gaze, decreased response to name; Kalb et al., 2010; Ozonoff et al., 2008).

The traditional conceptualization of regression involves a loss of skills following typical development. At 1 year old, children who experience this onset pattern have been found not to differ from typically developing peers in social-communication behaviors (e.g., eye gaze, social smiling, responding to name, vocalizing to others, points). However, by 2 years of age, these children show no differences from early-onset ASD cases in pointing, social gaze, response to name, and language development (Saint-Georges et al., 2010).

While it was previously thought that autism onset occurred either early or as part of a regression from typical development, recent research indicates that there may be several different onset patterns that are more prevalent than traditional regression (Ozonoff et al., 2008). For example, several young children with ASD experience typical developmental milestone progression before a "developmental plateau." These children may display intact early social development and mild nonspecific delays until 2 years of age when progression stops. These children may exhibit mutual attention, emotional reactions, and social interest in games like peek-a-boo the same as children who develop typically. Differentiation in skills, however, becomes clear around 24 months of age (Saint-Georges et al., 2010; Tager-Flusberg, 2010). Some researchers have theorized that this trend represents an inability for children with ASD to transform basic social behaviors into more complex and multifaceted skills necessary for interpersonal competency (Kalb et al., 2010; Ozonoff et al., 2008; Saint-Georges et al., 2010). Another onset pattern identified in the research may actually be the most common of the late-onset patterns. A majority of children with regression demonstrate subtle developmental atypicalities prior to the loss of skills. Several researchers have characterized this pattern as a mixed onset showing both delays and losses (Ozonoff et al., 2008).

Differences in presentation and prognosis between children who experience varying onset patterns are unclear. Some researchers have suggested that children with regression have worsened communication, social, and behavioral outcomes compared to those with early-onset ASD. However, several researchers have found no significant differences in presentation or prognosis between individuals with early and late onsets (Kalb et al., 2010; Werner et al., 2005). What is clear is that ASD symptom emergence can occur as part of a later onset pattern; thus, conducting multiple assessments over the span of infant and toddlerhood is imperative for the early identification and diagnosis of ASD in young children (Kalb et al., 2010; Ozonoff et al., 2008; Rogers, 2009).

Differential Diagnosis

One of the most difficult aspects of the early ASD diagnostic process is differentiating symptoms that indicate autism versus symptoms consistent with delay in general. Of particular importance in early identification assessment is identifying signs and symptoms to discriminate ASD from other developmental, intellectual, or language disorders (Gillberg et al., 1990; Howlin, 2006). Several measures have been developed to aid in differential diagnosis and will be discussed in later sections.

Researchers have indicated that it is much more difficult to differentiate ASD from intellectual or developmental disabilities (IDDs) early in life. In fact, parents of children with ASD reported significantly higher social, communication, repetitive behavior, and regulatory (i.e., eating, sleeping difficulties) symptoms than parents of typically developing infants by the end of the first year of life. However, ASD parents did not report significantly more symptoms compared to parents of children with developmental disorders (DD) until 13–24 months of age. Socialization differences were the first to differentiate ASD and DDs at 13–15 months old while communication, regulatory, and repetitive behavior symptoms

did not differ until closer to 2 years of age (Ozonoff et al., 2008; Werner et al., 2005). Symptoms that appear nonspecific to ASD include deficits in symbolic play skills and functional toy use, repetitive behavior and object play, unusual posturing, problems in motor activity, and diminished looking at objects held by others (2007; Saint-Georges et al., 2010, Wetherby et al., 2004). Rather than reflecting ASD, these symptoms likely reflect cognitive delay and are experienced by children with IDDs at similar rates (Wetherby et al., 2004).

Though there is significant symptom overlap in infants and toddlers with ASD and children with intellectual disability (ID) or DD, a greater number of behaviors can be used to distinguish ASD from IDDs in the second year of life when social behavior is expected to become more complex and the atypicalities of ASD become more pronounced (Gillberg et al., 1990; Saint-Georges et al., 2010; Werner et al., 2005; Wetherby et al., 2004, 2007; Zwaigenbaum et al., 2007). These distinguishing symptoms include deficits in gaze shifts, lack of joint attention behaviors, use and comprehension of gestures, eye contact, decreased interest in interaction, less positive affect, lack of shared enjoyment or interests, appropriate facial expression, and lack of orientation to name. Restricted and repetitive behavior symptoms shown to distinguish ASD and IDDs include unusual arm, hand, or finger movements, unusual sensory behavior, and repetitive movements with objects; however, these symptoms may lack specificity as many individuals with IDDs also engage in these behaviors (Gillberg et al., 1990; Saint-Georges et al., 2010; Werner et al., 2005; Wetherby et al., 2004, 2007; Zwaigenbaum et al., 2007). Researchers have posed that response to name in addition to quality of eye contact and affect, and interest in interaction, may be the best predictors of a later ASD diagnosis (Saint-Georges et al., 2010).

Of note, it is not uncommon for ASD to co-occur with ID. When children have both ASD and ID, age of first concern, first evaluation, and eventual diagnosis is significantly younger than children with ASD without ID. Similar results have been found for children with co-occurring ASD and medical problems (Baghdadli, Picot, Pascal, Pry, & Aussilloux, 2003; De Giacomo & Fombonne, 1998).

Language disorders can also be difficult to differentiate from ASD. Impairments in verbal communication and comprehension occur in both ASD and language disorders; however, these deficits in addition to social communication impairments can distinguish ASD from language delays (Saint-Georges et al., 2010). Wetherby and colleagues (2007) indicated that assessing the child's range of facial expression, use of gestures, and pointing to items of interest discriminates children with ASD from children with language delays.

Tools Used in the Diagnosis of ASD

Researchers and clinicians in the field have developed a number of measures designed to assess ASD with good reliability and validity. Accurate assessment is recommended to first begin with a detailed account of developmental history, gathering information on the development of communication and social skills, as well as the presence of odd or abnormal behaviors or interests, and repetitive behaviors (Howlin, 2006). Subsequently, three main methods of diagnosis are used including observational measures, diagnostic interviews, and informant-based behavior checklists. Comprehensive ASD evaluation often consists of a battery of measures utilizing several of these methods for assessment. Additional measures of associated constructs (e.g., developmental progression, adaptive behavior skills, cognitive functioning, psychopathology) are often used and provide diagnostic utility. Each method of assessment offers its own strengths and weaknesses, which will be discussed in this section of the chapter.

Observational Methods

Observational methods for assessing ASD are based on clinician ratings and can be implemented in a range of settings (e.g., clinic/office,

the child's natural environment, school/daycare). Some observational methods are highly structured and require the use of specific toys and objects, while others are less standardized and allow the clinician to elicit behaviors with a variety of methods. During an observational session, the child should be provided opportunities to play alone as well as interact with others. Core features of ASD should be assessed to determine if symptoms are present and identify the context (e.g., settings, time of day) under which the behaviors and symptoms occur. An advantage of observational methods is the opportunity for a clinician trained in child development to compare behavioral observations with developmental norms. This allows the clinician to make an informed decision about the course of the child's development. Limited observation time however is a major weakness, as low-frequency behaviors may be missed. Parent-reported behaviors such as repetitive behaviors or restricted interests may not occur if they are not elicited during the observation period. Therefore, it is imperative to use a variety of diagnostic techniques when conducting an ASD evaluation. Two frequently used observational measures include the *Childhood Autism Rating Scale, Second Edition (CARS-2)* and the *Autism Diagnostic Observation Schedule, Second Edition (ADOS-2)* discussed below.

Childhood Autism Rating Scale, Second Edition (CARS-2)

The *CARS-2* (Schopler, Van Bourgondien, Wellman, & Love, 2010) is an observational assessment comprised of 15 items (relating to people; imitation; emotional response; body use; object use; adaptation to change; visual response; listening response; taste, smell, and touch response and use; fear/nervousness; verbal communication; nonverbal communication; activity level; level and consistency of intellectual response; and general impressions). The measure is completed by a clinician after observation of a child's behavior and review of developmental history. Items are rated on a scale of 1 to 4, ranging from normal to severely abnormal. Cutoffs are reported for children and adolescents/adults separately and include three categories, no-to-minimal symptoms of ASD, mild-to-moderate symptoms of ASD, and severe symptoms of ASD.

The *CARS-2* is widely used with reported high internal consistency and inter-rater reliability (Schopler et al., 2010). The measure is appropriate for use with individuals 2 years of age and older, and is based on comparisons with same-aged, typically developing peers. Currently the measure is utilized in both research and clinical settings (Chlebowski, Green, Barton, & Fein, 2010; Mayes et al., 2009). Strengths of the measure include brief and easy administration; the measure takes approximately 15 min to administer. The *CARS-2* requires less training than some other observational measures and has been translated into several languages. The measure however is limited in that the *CARS* was developed prior to the publication of the *DSM-IV-TR* and *DSM-5*. Therefore, social deficits are not weighted as the most pervasive impairment of ASD (Lord & Risi, 1998). Despite this limitation, the measure is still well regarded (Inglese, 2009).

Internal consistency for the *CARS-2* was found to be robust (0.93; Schopler et al., 2010). Good inter-rater consistency was reported for individual items (0.55–0.93), and good test–retest reliability was also reported (0.78–0.90; Hedley et al., 2015). Schopler and colleagues (2010) evinced a sensitivity of 0.88 and a specificity of 0.86 for identifying those with ASD from those without ASD. As the current version of the measure was recently released, further research is required to confirm these findings; however, the findings suggest that the measure is useful for differential diagnosis.

Autism Diagnostic Observation Schedule, Second Edition (ADOS-2)

The *ADOS-2* (Lord, Luyster, Gotham, & Guthrie, 2012; Lord, Rutter, et al., 2012) is a semi-structured, standardized observational assessment. The measure takes approximately 30 min to conduct. Substantial training is required for reliable administration. The *ADOS-2* includes five different

modules; each module is designed to assess individuals with differing levels of language. A module is selected before administration depending on the child's expressive language capacities (Bertoglio & Hendren, 2009). The *Toddler Module* (*ADOS-T*) was specifically developed for children between 12 and 30 months of age who do not consistently use phrase speech. The *ADOS-T* targets social affect and restricted and repetitive behavior through 11 primary activities and 4 secondary tasks. Parent involvement may be used to help the child engage with the prompts provided (Luyster et al., 2009).

Items are rated on a four-point scale ranging from no evidence of abnormality related to autism to definite evidence. For the *ADOS-T*, a total score is calculated to determine range of concern: little-to-no concern, mild-to-moderate concern, and moderate-to-severe concern (Guthrie, Swineford, Nottke, & Wetherby, 2013). The *ADOS-T* boasts good inter-rater reliability at 0.84 (Guthrie et al., 2013; Luyster et al., 2009). In terms of differential diagnosis, the *ADOS-T* appears to sufficiently distinguish between ASD and non-ASD. The measure has a reported sensitivity of 0.90 and specificity of 0.71 (Guthrie et al., 2013; Luyster et al., 2009). A major limitation of the measure is that behavior observed and scored during the assessment only allows the examiners to rate current level of functioning. The measure is unable to assess development over time which has been deemed important in accurate assessment (Howlin, 2006).

Diagnostic Interview

Diagnostic interviews rely on informants, typically parents or caregivers, to provide detailed information in response to interview questions. Diagnostic interviews differ from informant-rated behavior checklists in that the clinician is able to gather more precise information from informants; clinicians may prompt caregivers to elaborate on their responses and/or ask follow-up questions when needed. The ability of a clinician to obtain detailed information is a major benefit of diagnostic interviews. Clinicians can also clarify informant responses to ensure that they are receiving the most accurate information upon which to make clinical judgments. Limitations of diagnostic interviews include lengthy administration times and extensive training requirements. The *Autism Diagnostic Interview-Revised (ADI-R)* is a structured, diagnostic interview commonly used in ASD evaluations and is detailed below.

Autism Diagnostic Interview-Revised

The *ADI-R* (Lord, Rutter, & LeCouteur, 1994; Rutter, LeCouteur, & Lord, 2003) is a structured interview administered by a trained clinician to a primary caregiver. The *ADI-R* is appropriate for children with a mental age of 2 years and older (Cox et al., 1999; Lord, 1995). The interview consists of five sections: opening questions; communication; social development and play; repetitive and restricted behaviors; and general behavior problems. It is often recommended that the *ADI-R* be given in conjunction with the *ADOS-2* in order to collect information on current behavior through observation and early development through the interview.

The interview consists of 93 questions related to current behavior as well as developmental history. Eight specific areas are targeted through questioning including the child's background, early development and developmental milestones, language acquisition or regression, current language and communication functioning, social development and play, interests and behaviors, and other clinically relevant behaviors. Responses for each question are coded and entered into either a diagnostic algorithm or a current behavior algorithm. The measure can be used to diagnose autism only based on the *DSM-IV-TR* and *International Classification of Diseases, Tenth Edition* (*ICD-10*).

Examination of psychometric properties by the authors indicated good inter-rater reliability and test-retest reliability ranging from 0.62 to 0.89 (Lord et al., 1994). High internal consistency for each domain, social (0.95), restricted and repetitive behaviors (0.69), and communication

(0.84), was reported (Lord et al., 1994). Sensitivity ranged from 0.86 to 1.00 and specificity ranged from 0.75 to 0.96 in distinguishing ASD from other developmental disabilities (Lord et al., 1997). Weaknesses of the interview include a lengthy administration time at approximately 2 h; findings are based solely on parent report; and extensive training is necessary to administer the measure.

Rating Scales

Rating scales are similar to diagnostic interviews in that information about the child is collected directly from his or her primary caregivers. Caregivers rate items measuring behavior and symptoms on a Likert scale. Ratings are used to determine the presence of certain behaviors and symptoms, as well as the intensity or level of the symptoms. Rating scales offer the advantage of efficiency as they are often brief to complete and easy to administer. Furthermore, limited training is required to score and interpret results. Rating scales can also be completed by more than one caregiver, allowing for consistency in reporting to be compared. Rating scales are not without limitations as accuracy of caregiver reporting is more difficult to ensure. Caregivers may over- or underreport symptoms due to lack of knowledge about typical development, since many rating scales ask caregivers to compare their child's behavior against that of a same-aged peer. Discussed below are two frequently administered rating scales: the *Baby and Infant Screen for Children with aUtIsm Traits* (*BISCUIT)* and the *Modified Checklist for Autism in Toddlers (M-CHAT).*

Baby and Infant Screen for Children with aUtIsm Traits (*BISCUIT)*

The *BISCUIT* is an informant-rated measure designed to aid in early detection of ASD in children 17–37 months of age (Matson, Boisjoli, & Wilkins, 2007). The measure is comprised of three parts assessing ASD symptomatology, comorbid psychopathology, and challenging behaviors. Demographic information is also collected including variables such as gender, ethnicity, age of parental first concern, additional diagnoses, and family history of ASD. In Part 1 of the *BISCUIT*, informants rate their child compared to same-aged peers on a Likert scale ranging from 0 to 2. A score of 0 corresponds to "not different; no impairment," 1 corresponds to "somewhat different; mild impairment," and 2 corresponds to "very different; severe impairment" from same-aged peers. Factor analysis of the items revealed three distinct factors: socialization/nonverbal communication, repetitive behaviors/restricted interest, and communication (Matson, Boisjoli, Hess, & Wilkins, 2010). Total scores are calculated to determine the range of impairment: no autism/atypical development, possible ASD, and probable ASD (Horovitz & Matson, 2013; Matson, Wilkins, Sharp, et al., 2009).

The *BISCUIT-Part 1* is reported to have sound internal reliability (0.97) and an overall correct classification rate of 0.89 (Matson, Wilkins, Sevin, et al., 2009). Internal consistency of all factors was also found to be sufficient. Internal consistency is $\alpha = 0.93$ for the socialization/nonverbal communication factor, $\alpha = 0.90$ for the repetitive behaviors/restricted interest, and $\alpha = 0.87$ for the communication factor (Matson et al., 2010). When differentiating children without ASD from those with PDD-NOS, the measure has high specificity (0.83) and sensitivity (0.90; Matson, Wilkins, Sharp, et al., 2009).

Modified Checklist for Autism in Toddlers

The *M-CHAT* (Robins, Fein, Barton, & Green, 2001) is a parent report measure designed to screen toddlers 16–30 months of age. The measure contains 23 items that can be completed in approximately 5–10 min. Six of the 23 items are considered critical items. A child that fails to pass 3 or more of the 23 total items or 2 or more of the 6 critical items warrants a referral for the child to have a true diagnostic evaluation. A supplementary follow-up interview is available if parental responses suggest the possibility of

ASD. The follow-up interview probes for further clarification and information on failed items. The *M-CHAT* is quick to administer and easy to access as it is available free of charge on the Internet.

Internal consistency has been found to be adequate ($\alpha = 0.85$ for the entire measure and 0.83 for critical items; Robins et al., 2001). A sensitivity of 74.1, a specificity of 87.5, and a classification rate of 83.0 have been reported (Matson, Wilkins, Sharp et al., 2009). Accurate identification of children later diagnosed with an ASD is estimated to be approximately 85 % (Martínez-Pedraza & Carter, 2009).

Additional Measures for Diagnosis

When conducting diagnostic evaluations for ASD, assessing for delays in milestones across multiple developmental domains can provide additional diagnostic utility. Developmental inventories can be an important first step in identifying children at risk for ASD. Developmental inventories provide information regarding a child's developmental strengths and weaknesses compared to same-aged typically developing peers. Additionally, evaluating cognitive functioning in very young children using tests that yield an IQ is difficult as these tests focus on verbal, conceptual, and problem-solving skills. Results from IQ tests in young children are generally considered unstable (Fombonne, 2003). Therefore, measuring cognitive abilities in regard to developmental milestones with developmental inventories may be more informative in this population. Such information is important for determining the level of overall impairment as well as informing intervention strategies and prognosis. Further, developmental inventories can assist clinicians in differential diagnosis, particularly with regard to IDs.

A widely used measure, the *Battelle Developmental Inventory, Second Edition* (*BDI-2*; Newborg, 2005), evaluates personal/social, adaptive, motor, communication, and cognitive development in children from birth through age 7. Administrators rate the quality of aspects of a child's development from 0 to 2 (based on observation or informant report). A score of 0 corresponds to "no ability," 1 corresponds to "emerging ability," and 2 corresponds to "ability present." The measure yields developmental quotients that serve as indicators for overall developmental growth in young children. Developmental quotient scores provide insight into where a child's development lies on a continuum compared to other children. The *BDI-2* has been found to have acceptable test-retest reliability of $\alpha = 0.80$, as well as excellent internal consistency of 0.98–0.99 (Bliss, 2007; Newborg, 2005).

The *Bayley Scales of Infant Development-Third Edition* (*Bayley-III*; Bayley, 2006) is designed to identify children with developmental delays and provide information that is useful for intervention planning. The measure is normed for use with children 1 month to 42 months of age. Three scales examining cognitive, language, and motor skills are administered to the child while information about the child's social-emotional functioning and adaptive skills are obtained from the child's caregiver (Michalec, 2011). Results are provided in the form of scaled scores, percentile ranks, growth score equivalents, and developmental age scores in months and days. These results can be used to determine if impairments are exhibited in all areas of development or in particular isolated areas. Clinicians may use this information to rule out certain diagnoses or guide how they conduct the rest of their evaluation. The *Bayley-III* has been found to have acceptable test-retest reliability of $\alpha = 0.80$ for the cognitive, language, motor, and adaptive skills domains. Internal consistency for the social-emotional items has been found to range from 0.83 to 0.94, and 0.76 to 0.91 for the sensory processing items (Albers & Grieve, 2007).

Along with information on developmental functioning, information on adaptive functioning can be useful in the diagnosis of ASD. Adaptive functioning refers to the ability of a child to complete developmentally appropriate daily activities. Since it is difficult to acutely measure IQ in young children, adaptive functioning provides another means to estimate a child's intellectual functioning. Level of intellectual functioning

may be important for differential diagnosis as well as in determining the severity of ASD and prognosis for a child.

One of the most commonly used measures of adaptive skills is the *Vineland Adaptive Behavior Scales-Second Edition (VABS-II*; Sparrow, Cicchetti, & Balla, 2005). The *VABS-II* relies on informant report to assess communication (i.e., receptive, expressive, written communications), social interactions (i.e., personal, domestic, community), daily living skills (i.e., interpersonal play, relationship play, leisure time), motor skills (i.e., gross motor skills, fine motor skills), and maladaptive behaviors (i.e., internalizing and externalizing problem behaviors). Items are rated with either a score of 2 "usually," 1 "sometimes," or 0 "never." Scores can be converted into percentile ranks, stanines, adaptive levels, and age equivalents. The *VABS-II* was normed for use with individuals from birth through 18 years old. Inter-rater reliability has been found to range from the low 0.70s to high 0.80s, whereas test-retest reliability ranges from 0.80s to 0.90s (Sparrow, 2011). A significant strength of the measure is the number of adaptive areas it captures. Clinicians can get a comprehensive look at relative strengths and weaknesses of the child, which may be used to rule out certain disorders or highlight areas that require further assessment through observational measures, diagnostic interviews, and/or rating scales.

Finally, assessing for psychopathologies in young children can be beneficial in achieving an accurate diagnosis and planning for intervention. The *Behavior Assessment System for Children, Second Edition* (*BASC-2;* Reynolds & Kamphaus, 2004) is a parent rating scale designed to evaluate for the presence of psychopathology in individuals 2–25 years of age. Information is gathered on how often behaviors and symptoms occur on a four-point rating scale ranging from never to always. Responses are scored and results are provided regarding several clinical aspects of behavior including aggression, conduct problems, anxiety, depression, somatization, attention problems, hyperactivity, atypicality, and withdrawal. The measure serves a dual function as it is designed to assess for adaptive functioning (i.e., adaptability, activities of daily living, leadership, functional communication, social skills) in addition to emotional and behavioral symptoms. The *BASC-2* also contains a Developmental Social Disorders content scale that evaluates the presence of behaviors commonly associated with pervasive developmental disorders (e.g., poor socialization, self-stimulation). This scale in particular can be useful in differentiating children with ASD from those without.

Researchers studying the validity of the *BASC-2* have shown that compared to typically developing peers and children with general developmental disabilities, young children with ASD exhibit more clinical symptoms in domains like hyperactivity, attention problems, anxiety, depression, atypicality, and withdrawal. Further, children with ASD have been found to exhibit greater impairments in nearly all of the adaptive functioning domains (Goldin, Matson, Konst, & Adams, 2014; Volker et al., 2010). These findings highlight the ability of the measure to be utilized for differential diagnosis when the child's symptoms and behaviors are complex. Internal consistency of the *BASC-2* is adequate ranging from 0.67 to 0.97 and the test-retest reliability is good, ranging from 0.56 to 0.99 (Reynolds & Kamphaus, 2004).

Chapter Conclusions and Future Directions

ASD is a very complex, heterogeneous disorder with substantial variability in symptom onset, presentation, and prognosis across those affected. However, diagnosis of ASD at 2 years of age is possible, reliable, and stable (Lord, 1995; Wetherby et al., 2007; Zwaigenbaum et al., 2007). As discussed, a variety of symptoms across multiple domains of development are apparent early in life. Researchers have shown that within the first 2 years of life, several social, communication, and restricted and repetitive behaviors and symptoms can reliably differentiate infants and toddlers with ASD from typically developing children and infants and toddlers with other developmental difficulties (e.g., IDDs,

language delays; De Giacomo & Fombonne, 1998; Goin-Kochel et al., 2006; Landa & Garrett-Mayer, 2006; Rogers, 2009; Wetherby et al., 2004; Zwaigenbaum et al., 2007). However, most children with ASD are not diagnosed until 3–4 years of age. This trend holds negative consequences for both the child with ASD and his or her family (De Giacomo & Fombonne, 1998; Goin-Kochel et al., 2006; Wetherby et al., 2004). Improvements in identifying at-risk children and encouraging them to pursue a comprehensive ASD assessment are necessary. Currently, comprehensive ASD diagnostic processes are conducted by qualified clinicians with extensive experience and training, and involve a battery of assessment methods including gathering a detailed developmental and medical history, utilizing reliable and valid observational tools, structured interviews, and rating scales, and administering measures of associated constructs to aid in differential diagnosis.

Though our understanding of ASD emergence and available methods to assess ASD in infant and toddlerhood has developed tremendously in the past decade, it is essential that we continue to make strides to improve early diagnosis. This must begin with enhancing our ability to identify infants and toddlers in need of more comprehensive ASD evaluation processes. The American Academy of Pediatrics recommends utilizing a multilevel screening process beginning with universal ASD screening for all children aged 18–24 months. In order to pursue this recommendation, we should make use of primary care professionals who see young children frequently and regularly for checkups (De Giacomo & Fombonne, 1998; Ozonoff et al., 2008; Wetherby et al., 2007; Zwaigenbaum, 2010). Those children scoring in the at-risk range on these screeners should be referred for a more comprehensive evaluation (Ozonoff et al., 2008; Zwaigenbaum, 2010). Because of the variability in ASD symptom emergence and onset, it is essential that screenings occur repeatedly through young childhood until 3 years of age. This would help identify those children experiencing later onset or milder presentations of ASD (Ozonoff et al., 2008; Rogers, 2009). ASD screening in the general pediatric setting however has been limited and it is imperative that we identify and rectify the obstacles to implementation of universal screening (Zwaigenbaum, 2010). Also important is bringing caregivers' attention to the symptoms present when a child fails a screener. This may foster a consensus with the family and prepare the caregivers to consider an ASD diagnosis. It may also help shorten the time it takes the family to seek a comprehensive evaluation (De Giacomo & Fombonne, 1998; Wetherby et al., 2007).

The future of assessment for ASD may lie in the neurobiological underpinnings of the disorder. Some researchers suggest that assessing underlying developmental and biological constructs (i.e., attentional control, executive functioning, orientation to social stimuli, visual fixation, face processing) may help better identify ASD in very young children (Klin & Jones, 2008; Klin, Lin, Gorrindo, Ramsay, & Jones, 2009; Ozonoff et al., 2008; Rogers, 2009; Zwaigenbaum et al., 2007). These constructs show promise in serving as biological markers that predict the presence of ASD before behavioral symptoms arise (Ozonoff et al., 2008). However, this line of research requires further development, including evidence of sensitivity and specificity. Identifying neurobiological markers for ASD, such as potential endophenotypes or brain abnormalities, remains difficult due to the heterogeneity of the disorder and complex etiology involved (Volkmar et al., 2009).

Evidence-based treatment for ASD in young children is available and has been shown to improve language, social, and cognitive skills more when provided before 4 years old (De Giacomo & Fombonne, 1998; Wetherby et al., 2004). This highlights the importance of early diagnosis. To aid in early enrollment, some researchers have posed that young children should be referred for early intervention services at the time of suspicion of ASD rather than waiting for an official diagnosis. Further, while there is extensive evidence for the effectiveness of early intensive behavioral intervention beginning in toddlerhood, research on and development of interventions appropriate for infants is needed

(Werner et al., 2005). Great improvements in identification and treatment of ASD in young childhood have been achieved in the past several years; however, our understanding will continue to grow as more research is conducted on early identification of behavioral and neurobiological markers and effective interventions for infants and toddlers with ASD.

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Preschool, Early Childhood, and Adolescence

10

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As the prevalence of autism spectrum disorder (ASD) has increased markedly over the past two decades, rising from 2 per 10,000 in 1990 to 1 in 68 children and 1 in 42 boys by age 8 today (Blumberg et al., 2013; Centers for Disease Control and Prevention, 2014) screening, evaluating, and diagnosing children with ASD as early as possible are important for ensuring that these children access the services and supports they need (CDC, 2014; Eikeseth, Smith, Jahr, & Eldevik, 2007). Diagnosis occurs when a psychologist or other professional conducts a comprehensive evaluation to determine if a child has ASD based on the criteria in the *Diagnostic and Statistical Manual of Mental Disorders* (*DSM-5*, APA, 2013). According to the *DSM-5*, ASD diagnosis requires (a) persistent deficits in social communication and social interaction across multiple contexts and (b) restricted, repetitive patterns of behavior, interests, or activities. Therefore, the focus of assessment is on identifying language delays, social skill deficits, and restricted, repetitive, and stereotyped patterns of behavior. In addition, as there is a great deal of heterogeneity of features in individual children with ASD (Johnson & Myers, 2007) observation and functional assessment of behavior are essential in order to link assessment and subsequent intervention. Although diagnosis of ASD is possible in children as young as 14 months of age (Johnston et al., 2009), factors such as autistic regression and difficulty in identifying symptoms of ASD in very young children, results in most children with ASD not being diagnosed until after 3 years of age, especially those with average or above-average language and cognitive abilities (Mandell, Novak, & Zubritsky, 2005; Mandell et al., 2010; Manning et al., 2011; Pinto-Martin & Levy, 2004). Thus, the period from 3 to 18 years of age represents an important period for detection and diagnosis. This chapter covers evidence-based assessments used for this age group.

Diagnosing Autism

Within the latest addition of the *DSM* (*DSM-5*, APA, 2013) several previous separate disorders, autistic disorder, Asperger's disorder, pervasive developmental disorder-not otherwise specified (PDD-NOS), Rett syndrome, and childhood disintegrative disorder, have been placed under one umbrella. To be classified ASD in the *DSM-5* a child must present with symptoms in early childhood, which cause impaired ability for the child to

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function in daily life activities. These symptoms may not fully manifest until social demands exceed capacity, for instance in middle school, later adolescent, and young adulthood (Casey et al., 2013). ASD is characterized by two core domains dealing with significant difficulties in practical verbal and nonverbal social communication and repetitive patterns of behavior interest and activities. The child must present in all three deficits in the social communication domain (APA, 2013, p. 50): (a) deficits in social-emotion reciprocity, ranging, for example, from abnormal social approach and failure of normal back and forth conversation to reduced sharing interests, emotions, or affect and to failure to initiate or respond to social interactions; (b) deficits in nonverbal communicative behaviors used for social interaction, ranging, for example, from poorly integrated verbal and nonverbal communication to abnormalities in eye contact and body language or deficits in understanding and use of gestures and to a total lack of facial expressions and nonverbal communication; and (c) deficits in developing, maintaining, and understanding relationships, ranging, for example, from difficulties adjusting behavior to suit various social contexts to difficulties in sharing imaginative play or in making friends and to absence of interest in peers.

In addition, a minimum of two of the four criteria in the restricted and repetitive patterns of behaviors domain are required for an ASD diagnosis (APA, 2013, p. 50): (a) stereotyped or repetitive motor movements, use of objects, or speech (e.g., stereotypies, lining up toys or flipping objects, echolalia, idiosyncratic phrases); (b) insistence on sameness, inflexible adherence to routines, or ritualized patterns of verbal or nonverbal behavior (e.g., extreme distress at small changes, difficulties with transitions, rigid thinking patterns, greeting rituals, need to take same route or eat same food every day); (c) highly restricted, fixated interests that are abnormal in intensity or focus (e.g., strong attachment to or preoccupation with unusual objects, excessively circumscribed or perseverative interests); and (d) hyper- or hypo-reactivity to sensory input or unusual interest in sensory aspects of environment (e.g., apparent indifference to pain, temperature, adverse response to specific sounds or textures, excessive smelling or touching of objects, visual fascination with lights or movement).

Symptoms must also be present in early development, cause clinically significant impairment in current functioning, and are not better explained by intellectual disability or global developmental delay. The *DSM-5* identifies three severity levels, based on support needed within two domains: (a) social communication and (b) restricted repetitive patterns of behavior. Symptom severity is classified as Level 1 (requiring very substantial support), Level 2 (requiring substantial support), or Level 3 (requiring support).

The behaviors associated with ASD vary in range. Some individuals may have verbal capabilities and still be unable to use language in a socially meaningful manner, whereas others may have no verbal ability whatsoever. Some may engage in self-stimulatory behaviors such as rocking or twirling their bodies, and flapping their hands, whereas others diagnosed with an ASD may not. Individuals diagnosed with an ASD typically do not engage in pretend play, although some may engage in some pretend play at some level that is less than that of same-aged typically developing peers (Strock, 2004).

Autism Assessment: Screening and Comprehensive Evaluation

As previously mentioned, early identification of autism is crucial as it enables early intervention. Early identification and intervention of autism in children as young as age 2 has not only been found to be reliable, valid, and stable; it has been found to promote positive long-term outcomes (Conrood & Stone, 2005). Nevertheless, many children do not receive a definitive diagnosis until much later, which means they miss out on the long-term benefits of early intervention (Conrood & Stone).

Although autism cannot be detected with any one medical test, Volker and Lopata (2008) discussed various medical evaluations that are components of the overall ASD assessment

process. There are tests used to rule out speech and hearing problems, which may account for the symptoms of language problems common in ASD. Neurological tests are used to assess for seizure activity or other brain abnormalities that may occur either in the presence of ASD or as an exclusion. Genetic testing identifies chromosomal abnormalities and other tests assess for allergies and other medical conditions that may be comorbid with an ASD. However, none of these medical procedures can ascertain whether an individual has an ASD. Rather, assessment relies on behavioral observations and comparison to criteria set forth by diagnostic systems such as the *DSM-5* (APA, 2013).

ASD assessment consists of two stages; the first is screening and the second is a comprehensive diagnostic evaluation (Strock, 2004). Screening is a brief assessment that is conducted to identify children with developmental difficulties who exhibit symptoms typical of ASD and are therefore in need of a more comprehensive evaluation. Screening, which requires less time and expertise than a full evaluation, often begins with the pediatrician or family physician during the child's routine visits; however, schools, child-find agencies, and early intervention programs also screen for ASD (Conrood & Stone, 2005). Screening involves behavioral observations and may also include screening instruments such as checklists and parent and/or teacher questionnaires. Screening tools help provide information regarding developmental delays in cognitive development, language, and motor movements/skills; however, they should not be used in isolation to make a diagnosis. On the contrary, screening paves the way for referrals, which may then lead to a formal diagnosis from which intervention can be planned and financed.

Conrood and Stone (2005) described several commonly used instruments that are employed for varying purposes in the screening process. Level 1 screening measures are offered to all children, typically at pediatrician offices. Some of these are specifically designed to identify ASD; however, most are used to identify nonspecific developmental problems, such as cognitive, motor, or language problems. Level 2 autism-specific measures are designed to differentiate children who are more likely to have ASD than other developmental problems.

Although several individuals may be involved in the screening process, a formal diagnosis can only be rendered by a medical doctor, a psychologist, or a multidisciplinary team which includes one or both of the aforementioned professionals. School counselors, teachers, speech therapists, occupational therapists, parents, and others who are not psychologists or physicians cannot diagnose autism even though they may indeed recognize the presence of autistic symptoms (Waltz, 2002) and may play an important role in the assessment process. A formal diagnosis is typically rendered by way of a comprehensive diagnostic evaluation (Strock, 2004).

A comprehensive diagnostic evaluation is the second step in the process toward diagnosis. This thorough evaluation also includes the use of parent/caregiver questionnaires; however, it also involves clinical observations, including an FBA, and parent/caregiver interviews. The CDC (2015) has advised that no single source of information should serve alone for diagnostic purposes and one or more diagnostic scales may be used. The CDC identified the following as examples of screening tools for children aged 3 and older: *Ages and Stages Questionnaire* (*ASQ*), *Communication and Symbolic Behavior Scales* (*CSBS*), and *Parents' Evaluation of Developmental Status* (*PEDS*). The CDC identified the following as examples of ASD diagnostic tools: *Autism Diagnostic Interview-Revised* (*ADIR-R*), *Autism Diagnostic Observation Schedule* (*ADOS*), Childhood Autism Rating Scale (*CARS*), and the *Gilliam Autism Rating Scale, Second Edition (GARS-2)*. All of these are discussed in more detail later in this chapter.

Autistic Regression

Most children who receive an ASD diagnosis demonstrate a gradually unfolding pattern of symptoms during their first 2 years of life (Stefanatos, 2008; Zwaigenbaum et al., 2005). Not all children with ASD demonstrate this

pattern of symptoms however. Various sources report that from 15 to 56 % of children with ASD display a pattern characterized by regression in one or more domains of behavior (Lord, Shulman, & DiLavore, 2004; Rogers, 2004) or the worsening of previously reported ASD features (Ekinci, Arman, Melek, Bez, & Berkem, 2012). Stefanatos (2008) identifies three types of autistic regression. The most common type of autistic regression involves symptoms of ASD emerging during the first year of life but the saliency of these delays or deviations in behavior increases do not trigger parental concern until later in the developmental period (Dawson et al., 2007). In the second type, children demonstrate normal or near-normal early development but then exhibit an unexpected arrest or expansion in development, usually in their second year of life (Landa & Garrett-Mayer, 2006; Landa, Holman, & Garrett-Mayer, 2007). The third type is illustrated by developmental regression or reversal of behavioral functioning in one or more domains (Lord et al., 2004). In this type, not only is there a cessation of skill acquisition but there is also a loss of previously acquired skills. This usually occurs between 15 and 30 months of age (Hoshino et al., 1987). Ekinci et al. (2012) reported that 56 % of children with ASD in their clinically referred sample demonstrated some indicators of autistic regression while Davidovitch, Glick, Holtzman, Tirosh, and Safir (2000) reported a rate of 47.5 % in a similar sample. Overall, most studies report rates between 20 and 49 % (Bernabei, Cerquiglini, Cortesi, & D'Ardia, 2007) illustrating the importance of ASD assessment in children aged 3 and above.

ASD Screening Instruments

Ages and Stages Questionnaire (ASQ)

The *Ages and Stages Questionnaire, Third Edition* (*ASQ-3*, Squires, Twombly, Bricker, & Potter, 2009) is a 30-item parent/caregiver-completed questionnaire designed to screen young children for developmental delays. With an age range from 1 to 5½ years, scores are provided on five dimensions: communication, gross motor, fine motor, problem solving, and personal-social. According to the test's authors it is intended to be a first step screening measure intended to assess the need for intervention services. While the measure is not designed specifically for autism screening, it has utility as an autism screener (Hanig, 2010), especially the communication and personal-social dimensions. Reviews of the psychometric qualities on the *ASQ-3* conclude that it is generally sound with adequate support for its reliability and validity (Hanig, 2010, Valleley & Roane, 2010). In addition to its use as a screening tool it can also be useful in progress monitoring.

Parents' Evaluation of Developmental Status

The *PEDS* (Glascoe & Robertshaw, 2013) is a brief screening tool completed by parents/caregivers to identify concerns about children's language, motor, self-help, early academic skills, behavior, and social/emotional/mental health. The age range of the instrument is birth to 8 years. The *PEDS* can be used either as a screener or, in repeated administrations, to track progress. While the most recent version of the *PEDS* has yet to be reviewed, the previous edition was judged to be a useful screener with adequate reliability and validity (Bischoff, 2001; Roberts, 2001).

PDD Behavior Inventory-Screening Version

The *PDD Behavior Inventory-Screening Version* (*PDDBI-SV*; Cohen, 2011) is an 18-item abbreviated version of the *PDD Behavior Inventory* (*PDDBI*; Cohen, 2005) designed as an ASD screen for children aged 18 months to 12 years, 5 months. The *PDDBI-SV* provides scores in two domains: social pragmatic problems and social approach behaviors as well as a composite score: social defi-

cits. The author stresses that this measure is designed solely as a screen to help clinicians decide whether to pursue a more comprehensive assessment and should never be used for diagnostic purposes (Cohen). The *PDDBI-SV* was designed based on *DSM-IV-TR* criteria, not *DSM-5* criteria, and it assesses only the socialization component of ASD and the standardization and technical characteristics or the scale are limited which led to Barnard-Brak and Richman (2014) to recommend against its use. Shaw (2014a), however, concluded that it could be useful as an early identification screen, especially if used as a universal screen.

ASD Diagnostic Instruments

Autism Spectrum Rating Scales

The *Autism Spectrum Rating Scales* (*ASRS*; Goldstein & Naglieri, 2010) is a 70-item behavior rating scale designed to be easily administered to parents or teachers. In addition there is a 15-item short form which can be completed by informants in approximately 5 min. With an age range from 2 to 18, the *ASRS* yields a total score, two (social/communication and unusual behaviors for ages 2–5) or three (social/communication, unusual behaviors, and self-regulation for ages 6–18) subscales, a *DSM-IV-TR* scale, and eight treatment subscales (peer socialization, adult socialization, social/emotional reciprocity, stereotypy, behavioral rigidity, sensory sensitivity, and attention/self-regulation for ages 2–5 or attention for ages 6–18) intended to aid in treatment planning and evaluation (Kluck, 2014). The intended purpose of the *ASRS* is to measure behaviors associated with autism spectrum disorders (Goldstein & Naglieri). One positive feature of *ASRS* development is that the standardization of the *ASRS* included both ASD and normally developing children. Overall the test appears to be well developed with a good standardization sample, and strong reliability and validity (Shaw 2014b). While the authors of the scales indicate that the *ASRS* can help guide diagnostic decisions as well as be used in treatment planning, ongoing monitoring of response to intervention, and program evaluation, Shaw concluded that while the short form can be useful as an ASD screener, the full *ASRS* is not a significant improvement in providing diagnostic information compared to the *Autism Diagnostic Interview-Revised* (ADI-R) (Rutter, Le Couteur, & Lord, 2003), *Autism Diagnostic Observation Schedule* (Lord, Rutter, DiLavore, & Risi, 1989), and *Childhood Autism Rating Scale* (Schopler, Reichler, & Renner, 1980). He also points out that norm-referenced measures such as the ASRS are insensitive to change over time reducing their utility in monitoring behavior change.

Autism Diagnostic Interview-Revised

The *ADI-R* (Rutter et al., 2003) is a semi-structured interview conducted with parents of individuals being evaluated for ASD. The interview can be used for diagnostic and treatment planning purposes for individuals aged 2 through adulthood (Rutter et al.). It consists of 93 questions that are based on DSM-IV TR diagnostic criteria. Scores are provided in three domains: language/communication, reciprocal social interactions, and repetitive behaviors/interests. The authors report excellent test-retest and inter-rater reliabilities (>0.9) and support for the validity of the scale, including the three factors identified above (Kim & Lord, 2012; Kim, Thurm, Shumway, & Lord, 2013). Falkmer, Anderson, Falkmer, and Horlin (2013) concluded that the *ADI-R* is one of only three instruments with strong supporting evidence for its diagnostic accuracy. The *ADI-R* requires specific training for those administering the instrument but has been identified as a "gold standard" instrument in the assessment and diagnosis of ASD (Magaña & Smith, 2013) despite its lengthy administration time and high cost. The *ADI-R* has been translated into other languages (e.g., Spanish, Chinese, Japanese) and found to be generally equivalent to the English version in the assessment and diagnosis of ASD (e.g., Magaña & Smith, 2013; Sun et al., 2013; Tsuchiya et al., 2013). The *ADI-R* is

not recommended as a diagnostic tool for children below age 2 because of its poor ability to identify ASD at this age (Cox et al., 1999).

Autism Diagnostic Observation Schedule, Second Edition

The Autism Diagnostic Observation Schedule, Second Edition (ADOS-2) (Lord et al., 2012) is a play-based standardized instrument that assesses ASD symptomology (communication, social interaction, play, and restricted and repetitive behaviors) during a semi-structured interaction with an examiner. The *ADOS-2* includes five modules, each requiring just 40–60 min to administer. The individual being evaluated is given only one module, selected on the basis of his or her expressive language level and chronological age. Module 1 is for children of 31 months and older who do not consistently use phrase-based speech. Module 2 is for children of any age who use phrase-based speech but lack verbal fluency. Module 3 is for verbally fluent children and young adolescents. Module 4 is for verbally fluent older adolescents and adults. In addition, there is a toddler module for children of 12–30 months of age who do not consistently use phrase-based speech. Each module engages the examinee in a series of activities involving interactive stimulus materials. Scores for each individual assessed are compared with cutoff scores to yield one of the three classifications: autism, ASD, or non-ASD. The difference between the autism and ASD classifications is one of severity, with the former indicating more pronounced symptoms (i.e., *DSM-5* Level 1). *ADOS-2*-specific training is recommended before administering this instrument. Translations are available in Czech, Danish, Dutch, Finnish, French, German, Italian, Norwegian, and Swedish. While the authors of the *ADOS-2* report acceptable levels of reliability and validity, little independent research has been conducted on this instrument. The *ADOS* is well studied and the consensus is that it is a reliable and valid instrument to assess the presence of ASD (e.g., Bastiaansen et al., 2011; Falkmer et al., 2013; Gray, Tonge, & Sweeney, 2008) with Falkmer and colleagues concluding that it was one of the only three instruments with strong supporting evidence for its diagnostic accuracy and Kanne, Randolph, and Farmer (2008) recommending it as one of the gold standard measurement tools for diagnosing ASD.

Childhood Autism Rating Scale, Second Edition

The *Childhood Autism Rating Scale, Second Edition* (*CARS-2*, Schopler et al., 2010) is a questionnaire used to identify behavioral symptoms of autism as part of the diagnostic process. Designed for ages 2 and higher, the *CARS-2* includes three forms: (a) Standard Version (CARS-2, ST, ages 2–5, or older if estimated IQ 79 or lower), (b) High-Functioning Version (CARS-2 HF, ages 6 and over with estimated IQ 80 or above), and (c) Questionnaire for Parents or Caregivers (unscored scale to assist in making ratings on the two other scales). For the ST and HF versions clinicians rate the individual on 15 items, using a 4-point scale. Ratings are based on frequency, intensity, peculiarity, and duration of the behavior in question. The ST and HF versions each addresses the following functional areas: (a) relating to people, (b) imitation (ST), (c) social-emotional understanding (HF), (d) emotional response (ST), (e) emotional expression and regulation of emotions (HF), (f) body use, (g) object use (ST), (h) object use in play (HF), (i) adaptation to change (ST), (j) adaptation to change/restricted interests (HF), (k) visual response, (l) listening response, (m) taste, smell, and touch response and use, (n) fear or nervousness (ST), (o) fear or anxiety (HF), (p) verbal communication, (q) nonverbal communication, (r) activity level (ST), (s) thinking/cognitive integration skills (HF), (t) level and consistency of intellectual response, and (u) general impressions.

The reliability and validity of the *CARS* and *CARS-2* have been favorably evaluated by multiple researchers (e.g., Breidbord & Croudace, 2013; Chlebowski, Green, Barton, & Fein, 2010; Malcolm, 2014; Magyar & Pandolfi, 2007;

McLellan, 2014; Reszka, Boyd, McBee, Hume, & Odom, 2014) with Falkmer, Anderson, Falkmer, and Horlin (2013) concluding that it is one of the only three instruments with strong supporting evidence for its diagnostic accuracy.

Diagnostic Interview for Social and Communication Disorders

The *Diagnostic Interview for Social and Communication Disorders* (*DISCO*: Wing, Leekam, Libby, Gould, & Larcombe, 2002) is a diagnostic tool developed in the UK and is designed for people at high risk of ASD. The *DISCO* is suitable for use at all age levels. The *DISCO* systematically records a wide range of behavior and developmental skills needed by clinicians to make a diagnosis and recommendation relating to ASD. The *DISCO* uses a standardized, semi-structured interview, each question which reflects a specific example of behavior seen in ASD based on both the *DSM IV-TR* and *ICD-10* (Leekam, Libby, Wing, Gould, & Taylor, 2002; Leekam, Nieto, Libby, Wing, & Gould, 2007). The psychometric properties of the *DISCO 9* and *DISCO 10* have been examined using samples of participants from the UK, Sweden, and the Netherlands (Leekam et al., 2002; Maljaars, Noens, Scholte, & van Berckelaer-Onnes, 2012; Nygren et al., 2009) and have been found to have high sensitivity, moderate specificity, and sufficient validity when compared to the *ADOS* and *SCQ*. Limitations of the *DISCO* include a lengthy administration time (120–180 min); however, it is currently the only scale consistent with *DSM-5* criteria (Carrington et al., 2014; Kent et al., 2013).

Gilliam Autism Rating Scale, Second Edition

The *Gilliam Autism Rating Scale, Second Edition* (*GARS-2*, Gilliam, 2006), a revised version of the original *Gilliam Autism Rating Scale* (*GARS*) Gilliam, 1995), is a behavioral checklist designed to identify persons with autism. The *GARS* and the *GARS-2* were constructed based on definitions of autism from the Autism Society of America (1994) and from *DSM* definitions in place at the time (APA, 1994, 2000). It is designed to be completed by a parent, parents, or other caregivers/professionals familiar with the child's behavior and can be completed in 5 or 10 min and requires no professional training to administer (Lord & Corsello, 2005).

The *GARS-2* (Gilliam, 2006) consists of 42 items divided into three subscales: stereotyped behaviors, communication, and social interaction. It provides scaled scores for each of the subscales ($M = 10$, $SD = 3$), an overall autism composite standard score (autism index, $M = 100$, $SD = 15$), and percentiles for each of these. Respondents are asked to rate the frequency of the examinees behavior on a 4-point Likert scale, ranging from "Never Observed" to "Frequently Observed." The *GARS-2* was normed on 1,107 participants with autism from 48 states and is designed to be used to assess persons from age 3 to 22. It has also been translated into Spanish (Jackson, Little, & Akin-Little, 2013).

The *GARS-2* (Gilliam, 2006) reports internal consistency alphas from 0.84 to 0.88 for subscales and 0.94 for the total test. Test-retest coefficients ranged from 0.70 for the communication subscale to 0.90 for the stereotyped behaviors subscale and 0.88 for the autism index. With regard to validity, Gilliam (2006) provides evidence of content validity, criterion-related validity, and construct validity. While independent reviewers and researchers have generally concluded that the GARS-2 has adequate reliability (Fairbank, 2007; Garro, 2007) its factor structure has been criticized (Pandolfi, Magyar, & Dill, 2010).

The latest version of the *GARS* is the *Gilliam Autism Rating Scale, Third Edition* (*GARS-3*; Gilliam, 2013). However, no psychometric studies related to the *GARS-3* are currently available. Minimal information on the *GARS-3* exists on commercial websites (e.g., Pearson, MHS), where high reliability and validity are reported, as well as good sensitivity and specificity. In addition, the commercial websites mentioned above both indicated that the items on the *GARS-3* were developed

based on *DSM-5* criteria (Pearson: http://www.pearsonclinical.com/psychology/products/100000802/gilliam-autism-rating-scale-third-edition-gars-3.html#tab-details. MHS: http://www.mhs.com/product.aspx?gr=cli&prod=gars3&id=overview).

PDD Behavior Inventory

The *PDDBI* (Cohen & Sudhalter, 2005) is designed to assess children aged 18 months to 12 years, 5 months. The *PDDBI* has parent and teacher forms and comes in standard (124 item) and extended (180 items) forms. The *PDDBI* standard rating form consists of six domains and the extended rating form consists of ten domains (six maladaptive and four adaptive). Domain scores are divided into two sections: (a) approach/withdrawal problems and (b) receptive-expressive social communication abilities. Domain scores are grouped into five composite scores: (a) repetitive, ritualistic, and pragmatic problems; (b) approach/withdrawal problems (extended form only); (c) expressive social communication abilities; (d) receptive/expressive social communication abilities (extended form only); and (e) autism composite. While based on the *DSM-IV* criteria for pervasive developmental disorders, the majority of items cover *DSM-5* criteria for the most part. The standardization of the *PDDBI* is limited in size and diversity and there is some question as to the reliability and validity of the instrument (Hoff & Tobin, 2007). A strength of the *PDDBI* is that it provides measures of both adaptive and maladaptive behaviors. While the authors indicate that the *PDDBI* can be useful in diagnosis and assessing response to intervention (Carey, 2007), its limitations suggest that other instruments (e.g., *CARS*) may be a better alternative.

Other Assessment

While ASD-specific measures are an essential element in the assessment and diagnosis of an ASD, they are by no means comprehensive if used as the sole measure. It is important that assessment leads not just to diagnosis but also to efficacious intervention and a variety of other measures may be needed on a case-by-case basis.

Functional Behavior Assessment

Functional behavior assessment (FBA) is essential to the link between assessment and intervention. An FBA attempts to identify the relationship between events in a person's environment and the occurrence of challenging behaviors in order to develop an effective intervention (Cooper, Heron, & Heward, 2007). The main outcomes of an FBA are a clear definition or description of the behavior(s); predictions as to the times and situations in which the behavior might or might not occur; and identification of what function the behavior(s) may serve (Rogers, 2001). The logic behind an FBA is that behavior occurs within a particular context and serves a specific purpose (i.e., positive reinforcement, negative reinforcement, self-stimulation). Individuals engage in behaviors which maximize the likelihood that a desired outcome will result. Identifying the function of specific behaviors provides information that is essential to developing instructional strategies and supports to reduce or eliminate maladaptive behaviors and increasing the frequency of adaptive behaviors.

Functional assessment has been classified into three categories: indirect, descriptive, and experimental. Indirect FBA involves conducting an interview with parents/caregivers and/or the client to hypothesize the function of a behavior. The *Questions About Behavioral Function* (*QABF*) (Matson & Vollmer, 1995) is an indirect assessment tool with a significant amount of research supporting its use (Tarbox et al., 2009). Descriptive FBAs involve direct observation and measurement of the target behavior and environmental variables which are presumed to be functionally relevant (Cooper et al., 2007). The most common descriptive measure is an antecedent-behavior-consequence (ABC) observation. After data collection, antecedents and consequences are analyzed and summarized to hypothesize the potential function of the behavior. Experimental

functional assessments, also referred to as "functional analyses," involve direct manipulation of antecedents and consequences to the target behavior, in order to experimentally demonstrate a functional relationship between behavior and the environment. Tarbox et al. (2009) compared indirect, descriptive, and experimental functional assessments using seven children with autism. Results suggested that descriptive assessment did not produce conclusive results, whereas the indirect and experimental assessments generally did.

Cognitive Functioning

A significant subset of children with ASD also have an intellectual disability (ID; Saunders et al., 2015). In addition, ASD and ID can present similarly, as children with either disorder may demonstrate difficulty with communication, social skills, and behavior (Johnson & Walker, 2006). Therefore, it is frequently important to get a measure of cognitive ability as part of a comprehensive ASD assessment. The *Wechsler Intelligence Scale for Children-Fourth Edition* (*WISC-IV*) and other Wechsler test (e.g., *Wechsler Preschool and Primary Scales of Intelligence-Fourth Edition*, *WPPSI-IV*) have been used in the ASD assessment process for many years, particularly for higher functioning individuals (Campbell, Ruble, & Hammond, 2014). Other commonly used cognitive assessment measures include the *Woodcock-Johnson III Tests of Cognitive Ability* (*WJ-III*) and the *Stanford-Binet Intelligence Scales, Fifth Edition* (*SB-5*). Due to communication deficits fundamental to an ASD diagnosis, language-related subtests on these scales may be depressed. Therefore caution should be used in interpreting any global measure of cognitive ability generated by these instruments. Cognitive measures that are less reliant on language, such as *the Leiter International Performance Scale-Revised* (*Leiter-R*) or the *Universal Nonverbal Intelligence Test* (*UNIT-2*), should be considered when individuals with ASD present with significant language deficits (Campbell et al., 2014).

Adaptive Behavior

In addition to deficits in intellectual functioning, an ID diagnosis also requires deficits in adaptive functioning (APA, 2013). The *DSM-5* defines adaptive functioning as "how well a person meets community standards of personal independence and social responsibility …" and "involves adaptive reasoning in three domains: conceptual, social, and practical" (p. 37). Measures such as the *Vineland Adaptive Behavior Scales, Second Edition* (*Vineland-II*) or the *Adaptive Behavior Assessment System, Second Edition* (*ABAS-2*) should also be considered. Tomanik, Pearson, Loveland, Lane, and Shaw (2007) found that, even in the absence of ID and a cognitive measure, including a measure of adaptive behavior (*Vineland*) improved diagnostic accuracy from 75 to 84 % from using the *ADI-R* and *ADOS* alone. A measure of adaptive behavior may also prove useful in program planning.

Communication

Assessment of communication skills is a fundamental component of any ASD assessment. The scales discussed above under both screening and diagnostic assessment all contain a language/communication component as do measures of adaptive behavior (e.g., *Vineland*). As the goal of any assessment should be to not only diagnose but also direct subsequent interventions, a more detailed language assessment is recommended. In most cases this will be conducted by a speech-language pathologist (SLP) and include an assessment of receptive, expressive, and pragmatic language skills. An example of a standardized test that may be administered by an SLP is the *Clinical Evaluation of Language Fundamentals-Fifth Edition* (CELF-5; Wiig, Semel, & Secord, 2013). This instrument provides a comprehensive evaluation of language, is helpful in determining eligibility for language services in schools, and provides information which is useful in developing language-based interventions.

Social Skills

Another common area in which additional assessment may be needed for diagnostic and intervention planning purposes is social skills. As with communication deficits, social skill deficits are a core feature of autism and assessed on the screening and diagnostic measures discussed above. A more detailed assessment of social skills may be warranted in order to get a more in-depth understanding of the social functioning of the individual and as an aid to intervention development. Two common measures of social skills are the *Social Skills Rating Scale* (*SSRS*), now part of the *Social Skills Improvement System* (*SSIS*), and the *Preschool and Kindergarten Behavior Scale* (*PKBS*). Wang, Sandall, Davis, and Thomas (2011) examined the usefulness of these scales with children with ASD. Results indicated that both measures were predictive of observations of behavior in the natural setting. However, their usefulness in detecting social skill progress over time or intervention outcomes was not satisfactory.

Summary and Conclusions

The assessment of autism spectrum disorders serves multiple purposes in preschool, early childhood, and adolescence (ages 3–18). First and foremost is diagnosis. While it is ideal for ASD to be diagnosed as early as possible, diagnosis prior to the age of 3 is not always possible. Factors such as autistic regression, cognitive development, and social emotional development may limit the manifestation of ASD symptomology until into the preschool and elementary school years. This is particularly evident with those children higher on the spectrum (ASD-Level 3). In addition to diagnosis, ASD assessment plays an important role in selecting intervention methodology and monitoring intervention effectiveness. The focus of diagnostic assessment is on identifying language delays, social skill deficits, and restricted, repetitive, and stereotyped patterns of behavior as these are the areas of functioning specified in the *DSM-5*.

Assessment relies on behavioral observations by psychologists or reports on behavior by parents, teachers, or other caregivers. ASD diagnosis involves a comparison of these behaviors to criteria set forth by diagnostic systems such as the *DSM-5* (APA, 2013) and consists of two stages: screening and comprehensive evaluation (Strock, 2004). Screening is a brief assessment that is conducted to identify children with developmental difficulties who exhibit symptoms typical of ASD and are therefore in need of a more comprehensive evaluation. Screening frequently involves behavioral observations and the use of screening instruments such as checklists and parent and/or teacher questionnaires. This chapter reviewed a number of screening instruments including the *ASQ-3* (Squires et al., 2009); the *PEDS* (Glascoe & Robertshaw, 2013); and the *PDDBI-SV* (Cohen, 2011). In addition to screening for diagnosis, each of these screening instruments can also be used to track an individual's response to intervention although these measures may not be sensitive enough to evaluate small increments of progress. Identifying and operationally defining specific target behaviors and conducting systematic behavioral observations would generally be considered a more sensitive response to intervention monitoring procedures.

This chapter also reviewed a number of diagnostic scales. These included the *Autism Spectrum Rating Scales* (*ASRS*; Goldstein & Naglieri, 2010), the *ADI-R* (Rutter et al., 2003), the *ADOS-2* (Lord et al., 2012), the *CARS-2* (Schopler et al., 2010), the *DISCO* (Wing et al., 2002), the *GARS-2* (Gilliam, 2006), and the *PDDBI* (Cohen, 2005). Of these, the *ADI-R*, the *ADOS-2*, and the CARS-2 have been identified as either "gold standard" instruments (Kanne et al., 2008; Magaña & Smith, 2013) or instruments with strong supporting evidence for their diagnostic accuracy (Falkmer et al., 2013). As with the screening instruments, these scales can be used for monitoring response to intervention/progress and assisting in program planning.

While ASD-specific measures such as the screening and diagnostic instruments mentioned above are an important element of ASD assessment, they should not be considered sufficient as

Table 10.1 Autism rating scales

Title	Age range	Publication date	Author(s)	Purpose	Scales/scores	Publisher
Ages & Stages Questionnaire (ASQ-3)	1–5–6	2009	Squires, Twombly, Bricker, & Potter	• Screening	• Communication • Gross motor • Fine motor • Problem solving • Personal-social	Western Psychological Services
Autism Diagnostic Interview-Revised (ADIR-R)	2–Adult	2003	Rutter, Le Couteur, & Lord	• Diagnosis • Program planning	• Language/communication • Reciprocal social Interactions • Repetitive behaviors/interests	Western Psychological Services
Autism Diagnostic Observation Schedule, Second Edition (ADOS-2)	12 months −adult	2012	Lord et al.	• Assessment • Diagnosis	• Five modules, selected on the basis of expressive language and age	Western Psychological Services
Autism Screening Instrument for Educational Planning (ASIEP-2)	18 months +	1993	Krug, Arick, & Almond	• Evaluation • Develop instruction • Monitor progress	• Autism behavior checklist • Sample of vocal behavior • Interaction assessment • Educational assessment • Prognosis of learning rate	PRO-ED
Autism Spectrum Rating Scales (ASRA)	2–18	2010	Goldstein & Naglieri	• Screening • Diagnosis • Progress monitoring	• Total score • Social/communication • Unusual behaviors • Self-regulation • Short form score	Multi-Health Systems, Inc. (MHS)
Checklist for Autism Spectrum Disorder (CASD)	1–16	2012	Mayes	• Screening • Diagnosis • Research	• Total score only	Stoelting
Childhood Autism Rating Scale (2nd ed.) (CARS-2)	2+	2010	Schlopler, Van Bourgondien, Wellman, & Love	• Identification • Determine functional capabilities	• Standard version • High-functioning version	Western Psychological Services
Diagnostic Interview for Social and Communication Disorders (DISCO)	All ages	2002	Wing, Leekam, Libby, Gould, & Larcombe	• Diagnosis • Program planning	• “Picture of the whole person”	Lorna Wing Centre for Autism

(continued)

Table 10.1 (continued)

Title	Age range	Publication date	Author(s)	Purpose	Scales/scores	Publisher
Gilliam Autism Rating Scale (3rd ed.) (GARS-3	3–22	2014	Gilliam	• Identification • Symptom severity	• Restrictive and repetitive behaviors • Social interaction • Social communication • Emotional responses • Cognitive style • Maladaptive speech	PRO-ED
Parents' Evaluation of Developmental Status (PEDS)	Birth–8	2013	Glascoe & Robertshaw	• Screening	• Language • Motor • Self-help • Early academic skills • Behavior • Social/emotional/mental health	Ellsworth & Vandemeer Press, LLC
PDD Behavior Inventory (PDDBI)	18 months –12-5	2005	Cohen & Sudhalter	• Diagnosis • Assessing response to intervention	• Repetitive, ritualistic, and pragmatic problems • Approach/withdrawal problems (extended form) • Expressive social communication abilities • Receptive/expressive social communication abilities (extended form) • Autism composite	PAR
PDD Behavior Inventory-Screening Version (PDDBI-SV)	18 months –12-5	2011	Cohen	• Screening	• Social pragmatic problems • Social approach behaviors • Composite score	PAR
Pervasive Developmental Disorders Screening Test (2nd ed.) (PDDST-II)	12–48 months	2004	Siegel	• Screening	• Social pragmatic problems • Social approach behaviors	Pearson Assessment
Social Responsiveness Scale (2nd ed.) (SRS-2)	2–6+	2012	Constantino & Gruber	• Screening	• Social awareness • Social information processing • Capacity for reciprocal social communication • Social anxiety/avoidance • Autistic preoccupations and traits	Western Psychological Services

the sole measure of ASD diagnosis. It is also important that assessment leads not just to diagnosis but also to efficacious intervention. Therefore, other instruments and procedures as well as input from other professionals are an important component of ASD assessment and diagnosis. It is also recommended that ASD diagnosis and program planning not be made by a sole professional but rather by a multidisciplinary team which may include professionals such as a pediatrician, psychologist, speech pathologist, and occupational therapist as needed based on the specific needs of the individual being assessed (Robertson, Stafford, Benedicto, & Hocking, 2013). Information gathered from an FBA and assessment of cognitive, communicative, adaptive, and social/emotional functioning can all add to both diagnosis and program planning (Table 10.1).

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Assessment in Adulthood

11

Iliana Magiati

Overview

Much research and clinical focus in recent decades has been directed towards assessing, diagnosing, and supporting children with ASD, aiming to facilitate earlier identification and support in order to improve future outcomes. Although ASD is a lifelong neurodevelopmental disorder and similar rates of diagnosis of ASD have been reported in adults as in children (approximately 1 % of the population; see Brugha et al., 2011), considerably less emphasis has been given to understanding, monitoring, and supporting the development of individuals with ASD throughout later adolescence and adulthood.

Recent reviews of research studies evaluating outcomes of individuals with ASD in adulthood have so far reported overall poor, although highly variable, outcomes. Many individuals with ASD in adulthood remain unemployed, depend on their families or services for many of their needs, have few meaningful friendships, have low levels of social participation, and experience high rates of associated mental health, emotional and behavioural challenges, although a significant minority achieve college or university education, are employed, and have meaningful social relationships (see Farley & McMahon, 2014; Henninger & Lounds Taylor, 2012; Levy & Perry, 2011; Magiati, Tay, & Howlin, 2014). Research is scarce on adult services (Shattuck et al., 2012), psychosocial interventions for adults (Bishop-Fitzpartick, Minshew, & Eack, 2013), and virtually nonexistent on ageing in ASD (see Happe' & Charlton, 2012; Piven & Rabins, 2011; Wright et al., 2013). Currently, little is known about the developmental trajectory of ASD in middle and older adulthood and about how these individuals can be supported to achieve increased independence and quality in their adult lives. For these reasons, assessment of adults with ASD for clinical and research purposes needs to become a priority.

Why Assess Adults with ASD?

One important reason for assessment in adulthood is the diagnosis of ASD in previously unidentified adults, who typically fall in one of two groups: those without intellectual impairments who were never identified in childhood (Nylander & Gillberg, 2001; see Shea & Mesibov, 2009), and those who already have other existing diagnoses (primarily intellectual disability), for whom a dual diagnosis of ASD may be suspected, mainly in learning disability or residential settings.

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At the same time, many individuals with childhood diagnoses of ASD are now adults or will soon be entering adulthood. Thus, the second important aim of assessment in adulthood is the monitoring of their development, functioning, strengths, needs, and preferences, so as to facilitate individualized provision and support throughout their lives.

With these key purposes of assessment in mind, this chapter is organized by reviewing:

1. Current approaches to assessment and diagnosis of yet-unidentified adults with ASD with and without intellectual disability in the following domains: autism symptomatology and severity; intellectual functioning; adaptive functioning; language/verbal skills; and emotional, behavioral, and psychiatric comorbidity.
2. Ways in which continuous monitoring or reassessment in adulthood can be carried out to facilitate individualized planning for support and services in individuals with an existing diagnosis.

The assessment process and content are reviewed and the measures available to facilitate assessment in adulthood are summarized. Existing gaps in the assessment of adults with confirmed or suspected ASD are identified and recommendations are made for improvements in the assessment process.

Guidelines for the Identification and Assessment of Adults with Suspected ASD

The National Institute of Clinical Excellence guidelines for the recognition, diagnosis, and management of adults with ASD (NICE, 2012) recommends that assessment for possible ASD in adulthood should be considered when:

(a) An adult has persistent difficulties in *either* social interaction, social communication, *or* rigid and inflexible behaviors, resistance to change, and restricted interests; and

(b) One or more of the following: (1) difficulties obtaining or sustaining education or employment or pervasive social relationship difficulties; (2) a history of a neurodevelopmental condition or mental disorder; and/or (3) past or present contact with mental health or learning disability services.

To improve the validity and experience of the diagnostic process, a comprehensive assessment needs to be carried out by a specialist multidisciplinary professional team with specific expertise in ASD (NICE, 2012). The assessment should involve a range of information gathering methods, including:

- Interviewing and observing the individual
- Obtaining historical and current information from the adult, significant others, and/or from past documentation (i.e., school reports; previous assessments if any)
- Using evidence-based diagnostic procedures with adults, and self- and other-report checklists
- Comprehensively assessing co-occurring intellectual, adaptive, language, health, emotional, social, and behavioral functioning.

Diagnostic Assessment and Assessment of Autism Symptom Presentation and Severity

Cognitively Able Adults

Adults without associated intellectual impairments referred for assessment of suspected ASD may face a complex and lengthy diagnostic process. Diagnosis may be particularly delayed for those with average or high intellectual abilities, whose autism symptoms may be more subtle and coping strategies better developed than is the case for individuals with ASD diagnosed in childhood (Eriksson, Andersen, & Bejerot, 2014; see also Jones, Goddard, Hill, Henry, & Crane, 2014). Often, the initial diagnostic referral may be prompted by a deterioration in emotional or mental health, loss of employment, breakdown of

a significant relationship, or a related crisis. Often too, adults with undiagnosed ASD are initially referred to mental health or forensic professionals for primary concerns not relating to ASD, such as depression, anxiety, stress, relationship problems, anger, aggression, or, in a small number of cases, other law-breaking behaviors; and it is during their initial assessment for these concerns that a history highly suggestive of ASD begins to emerge (Jones et al., 2014).

To facilitate screening and initial identification of cognitively able adults suspected of ASD, a number of self-report measures have been developed, including the Autism Quotient (AQ; Baron-Cohen, Wheelwright, Skinner, Martin, & Clubley, 2001), the Empathy Quotient (EQ; Baron-Cohen & Wheelwright, 2004), the Social Responsiveness Scale for Adults (SRS-A; Constantino, 2012), the Broad Autism Phenotype Questionnaire (BAPQ; Hurley, Losh, Parlier, Reznick, & Piven, 2007), and the Ritvo Autism and Asperger Diagnostic Scale-14 Screen (RAADS; Eriksson et al., 2013; for a summary of all measures discussed in this chapter, please see Table 11.1). The AQ and the RAADS-R also have abridged shorter versions (i.e., AQ-10; Allison, Auyeung, & Baron-Cohen, 2012; Eriksson et al., 2013). All have been employed for research and screening purposes to varying degrees and can facilitate initial identification and referral for a more comprehensive assessment. However, they are not, in themselves, diagnostic tools. Little evidence exists as to the comparative strength of these instruments, but Ingersoll et al. (2011) compared the AQ, BAPQ, and SRS-A as a dimensional measure of autistic traits in an unselected sample of undergraduate students without ASD. They found that the BAPQ and SRS-A had better internal consistency, better replicated factor structures, and higher predictive validity than the AQ.

More than 80 % of cognitively able adults referred for possible ASD present with social interaction or relationship problems as their primary initial concern and about 50 % are primarily concerned about the presence and impact of ritualistic and inflexible behaviors or interests (Jones et al., 2014). Thus, both social/communication and behavioral ASD symptoms need to be comprehensively assessed. Clinicians need to obtain detailed information on the history and current presentation of the core ASD symptoms from the individual themselves. Should a caregiver or adult sibling be available, their participation in the assessment process can be encouraged, although it is acknowledged that their involvement may not always be feasible or appropriate.

Important areas of enquiry in relation to social/communication functioning should focus on past and current peer and romantic relationships in school, college/university, and the workplace; past and current employment and relationships with colleagues/employers; social participation and interactions with others; pragmatic language and conversational skills; and understanding of social cues, rules, and expectations in varying settings and situations. Inviting the adult to complete a measure of social skills or peer relationships, such as the Social Skills Inventory (Riggio, 1989), the Index of Peer Relations (Hudson, 1993; Klein, Beltran, & Sowers, 1990), or the Communication Skills Questionnaire (Takahashi, Tanaka, & Miyaoka, 2006), may be useful in providing preliminary information, following which a more thorough assessment of social abilities and difficulties can be completed as necessary.

With regard to circumscribed behaviors and interests, the clinician should establish the nature, pervasiveness, intensity, and impact of circumscribed or rigid behaviors and interests on social functioning and relationships, eliciting specific past and recent examples. Both the positive and negative impact of the individual's interests and behaviors need to be investigated, as many adults with ASD have special interests that are often a particular strength of theirs and which may positively influence their choice of studies, career, or social participation. A self-report scale, such as the Repetitive Behavior Scale (RBS; Bodfish, Symons, Parker, & Lewis, 2000), can be helpful in identifying the range and severity of stereotyped and repetitive behaviors. Sensory over- or under-sensitivity should also be explicitly enquired about in the clinical interview and this can be facilitated by completion of self-report

Table 11.1 Summary of assessment measures to consider in the assessment of adults with ASD by domain of functioning

Domain of functioning assessed	Assessment of cognitively able adults with ASD	Assessment of adults with ID and ASD
Screening for ASD/ASD symptomatology	Autism Quotient (AQ; Baron-Cohen et al., 2001)[a]	ASD screen of the Mini Psychiatric Assessment Schedule for Adults with Developmental Disabilities (Mini PAS-ADD; Moss, 2002a)[b]
	Empathy Quotient (EQ; Baron-Cohen & Wheelwright, 2004)[a]	
	Social Responsiveness Scale for Adults (SRS-A; Constantino, 2012)[a]	
	Broad Autism Phenotype Questionnaire (BAPQ; Hurley et al., 2007)[a]	
	Ritvo Autism and Asperger Diagnostic Scale-14 Screen (RAADS; Eriksson et al., 2013)[a]	
Diagnostic measures/ assessment of severity of ASD symptomatology	Royal College of Psychiatrists (2011) structured diagnostic interview guide[b]	Diagnostic Behavioral Assessment for ASD-Revised (di-BAS-R; Sappok et al., 2014)[b]
	Ritvo Autism Asperger Diagnostic Scale-Revised (RITVO-R; Ritvo et al., 2011)[b]	
	Adult Asperger Assessment (AAA; Baron-Cohen et al., 2005)[b]	
	Asperger Syndrome Diagnostic Interview (ASDI; Gillberg et al., 2001)[b]	
	Autism Diagnostic Observation Schedule (ADOS-2; Lord et al., 2012)[b]	
	Autism Diagnostic Interview-Revised (ADI-R; Lord et al., 1994)[b]	
	Diagnostic Interview for Social and Communication Disorders (DISCO; Wing et al., 2002)[b]	
Social functioning/skills	Social Skills Inventory (Riggio, 1989)[a]	Direct Observations, Information from Caregivers and Carers
	Index of Peer Relations (Klein et al., 1990)[a]	
	Social Communication Skills Questionnaire (SCSQ; Takahashi et al., 2006)[a]	
Repetitive/circumscribed behaviors and interests/sensory issues	Repetitive Behavior Scale (RBS; Bodfish et al., 2000)[a]	
	Adolescent/Adult Sensory Profile (Brown & Dunn, 2002)[a]	
	Sensory Perception Quotient (SPQ; Tavassoli et al., 2014)[a]	
Intellectual functioning	Kaufman Adolescent and Adult Intelligence Test (Kaufman & Kaufman, 1993)[b]	Leiter international performance scale, 3rd edition (Roid et al., 2013)[b]
		Test Of non-verbal Intelligence (TONI-4; Brown et al., 2010)[b]
		Peabody Picture Vocabulary Test-3 (PPVS-3; Dunn & Dunn, 2007)[b]
	Wechsler Adult Intelligence Scale (WAIS; Wechsler, 2008)[b]	
	Wechsler Abbreviated Scale of Intelligence (WAIS; Wechsler, 1999)[b]	
	Stanford Binet scales-5th edition (SB5; Roid, 2003)[b]	
Executive functioning	Delis-Kaplan Executive Functions System (D-KEFS; Delis et al., 2001)[b]	
	Wisconsin Card Sortin Test (WCST; Hudson, 1993)[b]	

Adaptive functioning		Waisman activities of daily living scale (Maenner et al., 2013)[a]
		Matson Evaluation of Social Skills for Individuals with Severe Retardation (MESSIER; Matson et al., 1998)[a]
	Vineland Adaptive Behavior Scales (VABS-II; Sparrow et al., 2005)[a,b]	
	Adaptive Behavior Assessment System-II (ABAS-II; Harrison & Oakland, 2003)[a]	
	Scales of Independent Behavior-Revised (SIB-R; Bruininks et al., 1996)[a]	
Language/verbal skills and communication	ADOS	Informal or structured observations of communication/information from caregivers/carers
	Woodcock language proficiency battery (Woodcock, 1991)[b]	
	Clinical Evaluation of Language Fundamentals (CELF-5; Wiig, Semel, & Second, 2013)[b]	
	Test of Language Competence-Expanded (TLC-Expanded; Wiig & Second, 1989)[b]	
	Peabody Picture Vocabulary Test-3 (PPVS-3; Dunn & Dunn, 2007)[b]	
	Expressive Vocabulary Test (EVT; Williams, 1997)[b]	
Mental health, psychiatric comorbidity; emotional and behavioral functioning	Achenbach System of Empirically Based Assessment (ASEBA; Achenbach & Rescorla, 2003) for adults[a]	Developmental Behavior Checklist-Adult version (DBC-A; Mohr et al., 2004)[a]
	Structured Clinical Interview of DSM disorders-clinician version (SCID-CV; First et al., 1996)[b]	Psychiatric Assessment Schedules for Adults with Developmental Disabilities Checklist (PAS-ADD; Moss, 2002b)[b]
	Other self-report or clinician rated measures employed for people with mental health problems without ID/ASD	Aberrant Behavior Checklist (ABC; Aman & Singh, 1986)[a]
		Autism Spectrum Disorders-Comorbidity for Adults (ASD-CA; LoVullo & Matson, 2009)[a]
		Diagnostic Assessment for the Severely Handicapped-II (DASH-II; Matson, 1995)[b]
		Diagnostic Criteria for use with adults with Learning Disabilities (DC-LD; Royal College of Psychiatrists, 2001)[b]
		Diagnostic Manual Intellectual Disability (Fletcher et al., 2007)[b]
		Self-report Depression Questionnaire (SRDQ; Reynolds & Baker, 1988)[a]
		Mood, interest and pleasure questionnaire (Ross & Oliver, 2003)[a]
		Zung self-rating anxiety scale (Lindsay & Michie, 1988)[a]
		Fear survey for adults with mental retardation (Ramirez & Lukenbill, 2007)[a]

[a]Self- or informant report
[b]Clinician administered

measures, such as the Adolescent/Adult Sensory Profile (Brown & Dunn, 2002) or the Sensory Perception Quotient (SPQ; Tavassoli, Hoekstra, & Baron-Cohen, 2014).

To aid clinicians, the Royal College of Psychiatrists in the UK (Berney, Brugha, & Carpenter, 2011) has produced a useful structured diagnostic interview guide. To facilitate and inform the diagnostic process, a number of semi-structured diagnostic measures can also be employed with cognitively able adults. Module 4 of the Autism Diagnostic Observation Schedule (ADOS-2; Lord, Rutter, & DiLavore, 2012), a semi-structured observation of an individual's current social communication, interaction, and behavior when interacting with a trained clinician, has been specifically developed for verbally fluent adults. There is emerging evidence that the use of the ADOS, together with information obtained from a caregiver using the semi-structured Autism Diagnostic Interview-Revised (ADI-R; Lord, Rutter, & Le Couteur, 1994), can facilitate and improve the diagnostic process of ASD in adulthood (Bastiaansen et al., 2011). The Diagnostic Interview for Social and Communication Disorders (DISCO; Wing, Leekam, Libby, Gould, & Larcombe, 2002) can also be considered in more complex diagnostic assessments (NICE, 2012). Other structured or semi-structured diagnostic measures considered by NICE (2012) include the Ritvo Autism Asperger Diagnostic Scale-Revised (RITVO-R; Ritvo et al., 2011), the Adult Asperger Assessment (AAA; Baron-Cohen, Wheelwright, Robinson, & Woodbury-Smith, 2005), and the Asperger Syndrome (and high functioning autism) Diagnostic Interview (ASDI; Gillberg, Gillberng, Rastam, & Wentz, 2001). Of those, the ADOS-2, ADI-R, and DISCO require extensive training and practice to administer.

Adults with Intellectual Disabilities

It can be difficult to determine whether adults with intellectual disabilities, especially those with severe and profound ID, also have ASD. Because individuals with ID and those with ASD often present with repetitive or circumscribed behaviors and interests, it is the assessment of social interests, functioning, relationships, and skills that is likely the most critical in differential diagnosis. Key social behaviors present in young children from the first few months or years of life (such as social eye contact, sharing enjoyment, use of gestures and facial expressions to communicate and share) are considerably more limited and impaired in those with mild or moderate ID and ASD compared to individuals with ID only.

It is important to assess social and communication behaviors relative to the adult's level of intellectual functioning and skills: Are their interactions one sided or primarily geared towards fulfilling needs only? Does their social behavior show flexibility in different settings or with different people? Do they show reduced or absent empathy or facial expressions and limited response to others relative to their developmental level? However, in individuals with severe or profound ID, it is often very difficult to differentiate between profound developmental delays in social functioning and social limitations due to ASD.

In terms of possible measures, the Mini Psychiatric Assessment Schedule for Adults with Developmental Disabilities (Mini PAS-ADD; Moss, 2002a) also includes a screen specifically for ASD and could be used in the differential screening process, as can the Diagnostic Behavioral Assessment for ASD-Revised (di-BAS-R; Sappok et al., 2014). To aid differential diagnosis, the NICE guidelines (2012) also suggest the use of the ADOS and ADI-R in complex cases (see also Sappok et al., 2013). However, ADOS Modules 1 (for pre-verbal children or children using only single words) or 2 (for children with phrase speech) may need to be used, as Modules 3 and 4 are intended for verbally fluent adolescents and adults and will likely not be suitable for individuals with moderate to profound intellectual disabilities and limited speech.

Assessment of Intellectual Functioning

Cognitively Able Adults

Even in individuals who have successfully completed mainstream education, college, or university, an assessment of intellectual functioning can provide valuable information about their relative cognitive strengths and weaknesses. People with ASD often have uneven cognitive profiles and it may be useful to ascertain whether there are large discrepancies between visuospatial and verbal processing skills or between different subtests, as variability in different skill domains may help to explain everyday challenges.

A comprehensive assessment of intellectual abilities can be completed as part of the diagnostic assessment using well-established measures with adult norms. These include the Wechsler Adult Intelligence Scale (WAIS; Wechsler, 2008), the briefer Wechsler Abbreviated Scale of Intelligence (WASI; Wechsler, 1999), the Stanford Binet Scales-fifth edition (SB5; Roid, 2003), or the Kaufman Adolescent and Adult Intelligence Test (Kaufman & Kaufman, 1993). In cognitively able adults, it may also be informative to assess their executive functioning, including problem solving, response inhibition, mental flexibility, and planning. Measures that can be administered for this purpose include the Delis-Kaplan Executive Functions System (D-KEFS; Delis, Kaplan, & Kramer, 2001) and the Wisconsin Card Sorting Test (WCST; Grant & Berg, 1981).

Adults with Intellectual Disabilities

Many individuals with ID and ASD tend to have more uneven profiles of intellectual functioning compared to those with ID only, who often present with more uniform profiles. Thus, more detailed assessment of intellectual functioning may further aid differential diagnosis of ASD in those with ID (see Wolf & Ventola, 2014). The Stanford-Binet and Wechsler scales can be employed to assess cognitive skills in those with mild or moderate ID, but they may be less appropriate for some individuals with severe or profound ID and/or very limited or no speech. In such cases, the Leiter International Performance Scale (3rd Edition; Leiter-3; Roid et al., 2013), the Test Of Non-verbal Intelligence (TONI-4; Brown, Sherbenou, & Johnsen, 2010), or the Peabody Picture Vocabulary Test-4 (PPVT-4; Dunn & Dunn, 2007) can be attempted.

Assessment of Adaptive Functioning/Independence and Life Skills

Cognitively Able Adults

Many individuals with ASD present with discrepancies between their often higher intellectual skills and their comparatively reduced ability to care for themselves, communicate, or relate to others in everyday life. Such difficulties, despite at least average intellectual abilities, can contribute to adjustment or emotional difficulties or the breakdown of studying, work, living arrangements, or relationships. Thus, it may be helpful to assess adaptive functioning skills of cognitively able adults, especially those who present with or report difficulties living independently.

Measures that can be employed to evaluate adaptive behavior skills include the Vineland Adaptive Behavior Scales (VABS-II; Sparrow, Cicchetti, & Balla, 2005), the Adaptive Behavior Assessment System-II (ABAS-II; Harrison & Oakland, 2003), the Scales of Independent Behavior-Revised (SIB-R; Bruininks, Woodcock, Weatherman, & Hill, 1996), and the Waisman Activities of Daily Living Scale (Maenner et al., 2013). The adults themselves and/or their caregivers can act as informants and the measures can be administered using either a structured interview or a checklist format.

Adults with Intellectual Disabilities

Individuals with ID and ASD present with significantly more impaired scores in the communication

and social domains and higher maladaptive behaviors in the VABS when compared to adults with ID only matched for gender and IQ, but there are no differences in self-help, daily living, or gross motor skills (see Alim, Paschos, & Hearn, 2014). The measures discussed earlier for use with cognitively able adults are also appropriate for use with those with ID. In addition, the Matson Evaluation of Social Skills for Individuals with Severe Retardation (MESSIER; Matson, Carlisle, & Bamburg, 1998) may be useful for those with severe and profound ID.

Assessment of Language/Speech/Verbal Communication

Cognitively Able Adults

Although vocabulary and grammar are likely to be commensurate with cognitive abilities in most intellectually able adults with ASD, there may be impairments in other language domains, such as in prosody (the quality and intonation of speech) and in semantic and pragmatic language (i.e., the ability to initiate, organize, structure, select, and interpret social communication through language). Paul, Landa, and Simmons (2014) recommend exploring discrepancies between higher syntax/vocabulary skills and lower pragmatic language skills, by observing the individual's social communication in less formal, more naturalistic settings. Similarly, the American Speech-Language-Hearing Association's 2006 guidelines in the diagnosis, assessment, and treatment of ASD across the life-span also recommend observing the individual in their natural social contexts, gathering information from the individual's communication partners and "staging" communication contexts during the assessment to provide opportunities for communication strengths and needs to be demonstrated (Wetherby et al., 2006). The individual's ability to initiate, understand, reciprocate, and maintain social communication through verbal and nonverbal means (i.e., gestures, speech, facial expressions) should be assessed in less formal, observational ways and documentation of the clinician's observations and judgment is important (Wetherby et al., 2006). Observations of the adult's social communication and conversation skills during the ADOS interactions, for example, is one useful semi-structured way to observe pragmatic language skills during clinical assessment.

In terms of selecting specific measures, very few, if any, standardized structured language tools assessing pragmatic language skills are available extending well into the adulthood years. The Woodcock Language Proficiency Battery (Woodcock, 1991) assesses oral language, vocabulary, antonyms, and synonyms, but provides little information on the more complex aspects of social language. Similarly, the PPVS and the Expressive Vocabulary Test-2nd edition (Williams, 2007) have norms up to the age of 90 years, but assess single-word receptive and expressive vocabulary, respectively. The 5th edition of the Clinical Evaluation of Language Fundamentals (CELF-5; Wiig, Semel, & Second, 2013) has an extended age range up to 22 years and may be useful in assessing social language skills in young adults. Similarly, the Test of Language Competence-Expanded (TLC-Expanded; Wiig & Second, 1989) assesses higher level functioning (i.e., understanding ambiguous language, listening comprehension, and making inferences) in young people up to the age of 18 years.

Adults with Intellectual Disabilities

The PPVS and the EVT can assess single-word receptive and expressive vocabulary, respectively, in adults with ID and suspected ASD, but it is the assessment of the social use of verbal communication, even if this is rather limited, via direct observations and information from caregivers, that is more likely to be useful in assisting the process of differential diagnosis of ASD in adults with intellectual disabilities.

Assessment of Emotional and Behavioral Functioning/ Psychiatric Comorbidity

Cognitively Able Adults

Individuals referred for suspected ASD for the first time in adulthood often initially present to professionals with mental health problems, primarily depression and anxiety (Hofvander et al., 2009; Lugnegard, Hallerback, & Gillberg, 2011). Symptoms of ADHD are also common. Although most of the existing literature has so far focused on children and adolescents, considerable efforts have been made in the last few years in order better to understand the comorbidity between ASD and other psychiatric disorders (for work with adults, see Buck et al., 2014; Joshi et al., 2013; Takara & Kondo, 2014).

A comprehensive assessment should therefore focus on identifying and understanding common emotional and behavioral difficulties, including low mood and self-esteem, anxiety, aggression towards self or others, self-neglect, and abuse (NICE, 2012). At the symptom level, the clinician needs to identify co-occurring psychiatric problems and to try to disentangle core autism from associated psychiatric symptoms as much as possible. For example, common areas of "diagnostic over-shadowing" involve social avoidance and repetitive behaviors, which could be a presenting concern in both ASD and social anxiety or OCD, respectively. Careful consideration of similarities and differences between core ASD and psychiatric symptoms is important, for example considering whether social avoidance is primarily due to a limited interest in social interactions, limited social skills, or excessive anxiety. Similarly, behaviors described as "obsessive" or "ritualistic" in ASD tend to be qualitatively different and to serve different purposes from OCD obsessions and compulsions (i.e., see Kerns & Kendall, 2013).

The assessment should also include a careful exploration of environmental factors that may trigger or exacerbate mental health difficulties (i.e., family and other social relationships and support systems, life events, recent changes or breakdown of family, employment, or living arrangements). When adult clients present with mental health concerns as their primary concern, but ASD is suspected, the clinicians should examine the client's developmental and psychiatric history in order to explore evidence of *pervasive* social, communication, and behavioral impairments associated with ASD throughout the individual's life.

Few ASD-specific measures exist to assess psychiatric comorbidity, but several measures developed for adults without ASD can be used, even though their content and standardization data are not always entirely relevant for individuals with ASD. For example, the Achenbach System of Empirically Based Assessment (ASEBA; Achenbach & Rescorla, 2003), which includes self- and caregiver/informant-completed checklists for adults, can be employed. To aid differential diagnosis, the Structured Clinical Interview of DSM Disorders Clinician Version (SCID-CV; First, Spitzer, Gibbon and Williams 1996) can aid in obtaining detailed information about a range of psychiatric conditions from the adult or their caregiver/significant others. Two broad important adaptations need to be taken into consideration when such measures are used. Firstly, clinicians may need to modify the way the interview or self-rating form is presented. For example, many adults with ASD have difficulties talking about and describing emotions and it may be necessary to provide concrete definitions or explanations of items and/or to include visual aids, such as the use of an emotion "thermometer" or "volume" scale to describe emotions. Secondly, clinicians are encouraged to probe for both typical and less typical presentations of emotional difficulties, as there is evidence that people with ASD present with some symptoms which are very similar to those experienced by psychiatric populations, but also with atypical presentations of more ASD-specific fears, worries, or anxiety (i.e., Kerns et al., 2014; Ozsivadjian, Knott, & Magiati, 2012).

Adults with Intellectual Disabilities

The assessment of mental health in those with ID and ASD needs to be modified to take intellectual

disability, more limited verbal skills, and additional impairments into consideration (see Alim et al., 2014). One of the most clinically useful ways in identifying the potential onset of a psychiatric concern in this population is to look for *changes* in behavior compared to earlier, premorbid functioning, instead of focusing on current behavior only (see also Deprey & Ozonoff, 2009). When an individual shows significant changes in their behavior (i.e., becomes more socially withdrawn, shows increased aggression/irritability, or presents with decreased engagement in activities) compared to their earlier functioning, this may indicate the onset of co-occurring physical or mental health problems requiring further assessment. The onset of *new* behaviors may also be indicative of the need to further evaluate emotional well-being. It is important to assess predisposing, precipitating, maintaining, and protective psychosocial and environmental factors (i.e., change in residential setting or carer, illness in the family, a supportive sibling), not merely individual or organic factors (see Magiati, Tsakanikos & Howlin, 2014).

Because challenging behaviors (i.e., self-injurious, aggressive or inappropriately sexualized behaviors) can be common in individuals with ID, the NICE guidelines recommend functional analysis assessment of individual and environmental factors triggering or maintaining specific problem behaviors (NICE, 2012; see also Alim et al., 2014) in order to guide the development of specific behavioral intervention programs.

In terms of measures, few have been developed specifically for individuals with ASD. However, a number has been developed for individuals with ID, which may also be employed in the psychiatric assessment of people with ID and ASD. These tend to rely mainly on information obtained from significant others and/or direct behavioral observations. For checklists completed by carers who know the adult well, the Developmental Behaviour Checklist-Adult version (DBC-A; Mohr, Tonge, Einfeld, & Gray, 2004) is a comprehensive and well-established screening measure of problem behaviors for individuals with ID and developmental disabilities. The Psychiatric Assessment Schedules for Adults with Developmental Disabilities checklist (PAS-ADD; Moss, 2002b) is a 25-item questionnaire also completed by care staff or families. The Aberrant Behavior Checklist (ABC; Aman & Singh, 1986) is a reliable and valid caregiver- or clinician-completed checklist measuring a range of problem behaviors with participants with ID and ASD. The Autism Spectrum Disorders-Comorbidity for Adults (ASD-CA; LoVullo & Matson, 2009) is another measure that can aid the assessment of comorbid difficulties in this population. For individuals with severe and profound ID, the informant-rated Diagnostic Assessment for the Severely Handicapped-II (DASH-II; Matson, 1995) can also be useful. The diagnostic process of establishing psychiatric comorbidity in individuals with ID and ASD can also be facilitated by the use of standardized instruments such as the Diagnostic Criteria for use with adults with Learning Disabilities by the Royal College of Psychiatrists (DC-LD; Szymanski, 2002) and the Diagnostic Manual-Intellectual Disability (DM-ID; Fletcher, Loschen, Stavrakaki, & First, 2007).

A small number of self-report measures has also been developed, which may be helpful with those who can respond to simplified items administered verbally. These include the Self-Report Depression Questionnaire (SRDQ; Reynolds & Baker, 1988), the Mood, Interest and Pleasure Questionnaire (Ross & Oliver, 2003), the Zung Self-Rating Anxiety Scale (Lindsay & Michie, 1988), and the Fear Survey for Adults with Mental Retardation (Ramirez & Lukenbill, 2007).

For all clients with a presentation of depression, severely debilitating anxiety, self-harm, or suicidal ideation, irrespective of their intellectual or verbal skills, a careful risk assessment and management plan needs to be developed. This risk assessment should also take into account any past, current, or likely future trouble with the criminal justice system (Cheely et al., 2012; see Woodbury-Smith, 2014).

Assessment for Life: Ongoing Assessment in Adults and Older Adults with ASD

Many, although not all, adults with ASD will need varying levels of support, services, and resources at different points in their lives, depending on their skills, strengths, and needs and the social and environmental resources available to them. The few systematic studies of individuals with ASD in older adulthood suggest that opportunities for development throughout the lifespan need to be provided, as they can lead to increased skills and improved quality of life and social participation even in later stages of life (i.e., Donovan & Zucker, 2010). Ongoing assessment in adults and older adults with ASD with or without ID thus serves a number of potential functions.

Assessment to Aid Transition Planning and Support

Many adults with ASD share similar hopes and expectations about their adult lives as individuals without ASD or ID, but may require improved understanding and acceptance of their condition and/or additional support at vulnerable or stressful times to achieve their life goals. For this reason, a comprehensive psychosocial assessment needs to be carried out during late teenage or young adult years to facilitate a better understanding of the individual's strengths, needs, challenges, and preferences. Gathering information can be achieved through interviews with the adult themselves, reports from caregivers, siblings, partners, significant others, and/or professional carers, as well as through direct observation. Particularly important time points for an individualized assessment are prior to major transitional periods (i.e., from school to post-school education or vocational training; from living with family members to living with peers, alone, or in residential settings; before and during the adult's first employment; when changing jobs; or when anticipating a significant change in social support, such as ill health or ageing of family member).

Structured assessments, such as the TEACCH Transition assessment Profile (TTAP; Mesibov, John, Thomas, Chapman, & Schopler, 2007) and the Transition Planning Inventory-Updated Version (TPI-UV; Clarm & Patton, 2006), have been developed to enable a more systematic evaluation of skills at home, education, and/or work. In 2014, Autism Speaks, together with Virginia Commonwealth University's Rehabilitation Research and Training Center, developed a comprehensive Community based Skills Assessment (CSA) to facilitate a successful transition process. The CSA assesses eight functional life skill areas (career path and employment, self-determination, health and safety, peer relationships, community participation and finances, transportation, leisure, and home living skills) in individuals aged 12 years or older using both criterion-based observations and interviews.

Assessment to Support Vocational Training and Employment

Employment has been found positively to affect the well-being and quality of life of adults with ASD (Walsh, Lydon, & Healy, 2014), although little is currently known about how best to enable and support individuals with ASD to seek and maintain employment (see Lounds-Taylor & Mailick Seltzer, 2012; Chen et al., 2015, for reviews).

The very few studies that have been carried out examining predictors of successful employment in adults with ASD (see Walsh et al., 2014 for a review) highlight that assessment for employability and employment purposes needs to gather information about:

- Individual characteristics and skills (i.e., communication and interpersonal skills, educational level, decision making and problem solving, flexibility and ability to prioritize, mental health or behavioral challenges, ability

to ask for help, motivation, interests, and skills)
- Family and social factors (i.e., amount and quality of family support, family's socioeconomic and educational standing)
- Employment characteristics (i.e., environmental modifications, autism awareness, supervision and implementation of behavioral contracts, utilization of employment support services)

Therefore, the assessment may need to examine whether there are individual risk factors that may limit employment success and to measure the extent to which the employment environment is well suited (or can be adapted) for the person with ASD.

For cognitively able adults with ASD, traditional psychological and achievement assessments may be used to better understand the individual's needs, strengths, and challenges in different employment settings. The extent to which the individual might benefit from supported employment schemes or other workplace accommodations also needs to be assessed. For adults with ASD and ID, the Adolescent and Adult Psychoeducational Profile (Mesibov, Schopler, & Caison, 1989) is a structured assessment for adults with severe developmental disabilities that assesses vocational, adaptive, leisure, communication, and interpersonal skills—it can provide helpful recommendations for future education, vocational training, or living arrangement planning. For all individuals with ASD, emphasis should be placed on assessing adaptive, rather than cognitive, skills, as these are more likely to affect employability and employment prospects.

Assessment to Aid Independent or Supported Living

Most adults with ASD continue to live with their families well into their adult years, although an increasing number live on their own or with peers. When caregivers grow older or become frailer, there may be a need for alternative living arrangements. Thus, assessment, ideally in a planned and systematic way well before the caregivers are no longer available, can support decision making regarding optimal care and living arrangements. This assessment should be strength based and focus on community-based living and adaptive skills; the adult's wishes and preferences should also be taken into consideration.

Assessment to Improve Quality of Life and Mental Well-Being

Individuals with ASD with or without ID are vulnerable to experiencing emotional and behavioral difficulties that can significantly impact on their quality of life. Thus, ongoing screening and enquiring about their mental health should be incorporated into routine follow-up assessments, especially at stages of their adult lives when challenges or stressful life events may be anticipated (see earlier sections for more on how to assess psychopathology in adults with ASD with or without ID).

Assessment to Monitor Response to Interventions or Care Plans

There is a limited, but growing, literature examining whether pharmacological or psychosocial interventions for core symptoms of ASD or associated comorbidities are effective when implemented in adults (i.e., Bishop-Fitzpartick et al., 2013). Thus, assessment of pharmacological, psychological, or environmental interventions is necessary to determine their relative effectiveness and to identify key "ingredients." Assessing progress is also needed to ensure that treatment programs or care plans are appropriately modified and tailored to individual needs.

Assessment of Older Adults with ASD

"The aging process in ASD remains … underinvestigated and thus poorly understood" (Mukaetova-Ladinska, Perry, Baron, & Povey,

2011). Happe and Charlton (2012) also highlighted the fact that very little empirical work has been carried out relating to ASD in old age. Dementia, for example, is more common in people with ID, particularly in those with Down's syndrome, than in people without ID, but little is known about the rates and presentation of dementia or other ageing-related conditions in older adults with ASD.

Assessment to Improve Knowledge of Developmental Trajectories of ASD Across the LifeSpan

The few long-term follow-up studies of adults who were diagnosed with ASD in childhood (see Overview, this chapter) generally report poor, although highly variable, outcomes. However, many of the participants included in these studies were diagnosed as children in the 1960s, 1970s, or early 1980s, and in all likelihood these "older" samples included people with more "classic" autism who received no or very little early intervention or education. Little is known about the adult outcomes of individuals with ASD who were diagnosed as children in the 1980s and 1990s, who were more likely to receive early intervention and specialist education. Thus, it is imperative that assessment of these individuals in young and later adulthood continues in order to improve our understanding of their developmental trajectory across the spectrum. So far, many longitudinal studies have focused mainly on cognitive and language functioning in adulthood, although more recent studies have also assessed more socially relevant areas of functioning, such as independent/adaptive behavior skills, relationships and social participation, emotional well-being, and quality of life (see Magiati et al., 2014 for a review).

Assessment of and for Families of Adults with ASD

The strengths and needs of the family, partner, or carer(s) of the adult with ASD need to be evaluated and taken into consideration when care plans are developed (NICE, 2012). Families are often important informants in the assessment process; however their own needs also need to be assessed and met. Specifically, clinicians need to assess the support and resources that would help families in their ongoing caring responsibilities and to include these in planning for the future care of the adult with ASD (NICE, 2012). Families, partners, or carers may require advice, education, training, and/or support to meet the complex needs of their adult with ASD and may also need support to meet their own needs.

Assessment in Adulthood: Summary, Recommendations, and Conclusions

Currently, little is known about how best to assess and support individuals with ASD in adulthood. We also know little about the developmental nature of the condition beyond young or middle adulthood. Although assessment of adults with ASD should be comprehensive and lead to specific recommendations for support, provisions, and interventions, there are currently very few professionals with the required expertise and skills working with adults with ASD who can actually implement these recommendations, while adult services continue to be scarce in most countries. This creates considerable challenges for assessment in adulthood, as often helpful recommendations simply cannot be implemented following assessment, because the resources and supports required are nonexistent or extremely limited.

Another considerable challenge in assessment in adulthood is the limited range of suitable standardized measures available that extend into the older adult years and have some evidence of sound measurement properties when employed with individuals with ASD. Thus, another research and clinical priority is the evaluation of existing measures when used with adults with ASD and/or the development of measures suitable to assess their skills and needs.

Assessment of adults with ASD also needs to include the immediate, proximal, and more distant

systems around the individual. Thus, in addition to assessing the individual's skills and needs, we should also evaluate the quality, amount, and role of family, peer, employment, and community support (see also Henninger & Taylor, 2012, who advocate for a need to measure success and progress in adulthood in a dynamic integrated person-environment framework). In order for any assessment at this developmental stage to be meaningful, we need to concentrate on the translation of the assessment findings into the "real" world and the extent to which we can implement the recommendations derived from the assessment. Our assessment findings should first and foremost identify needs to be met and skills or qualities to be strengthened, but policy makers, governments, and health organizations need to seriously catch up, so that improvements in the assessment process can be put in good use to improve the lives and outcomes of adults with ASD.

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Challenging Behaviors

12

Geraldine Leader and Arlene Mannion

Introduction

Comorbidity is an area of great importance in autism research. One of the most common co-occurring problems with autism spectrum disorder (ASD) is challenging behaviors. The aim of this chapter is to discuss challenging behaviors in the context of ASD. We need to define challenging behaviors to better understand what constitutes a challenging behavior. One of the difficulties in assessing challenging behaviors is in deciding what is a challenging behavior and what is not a challenging behavior. Often challenging behaviors are subjective. They cause problems to an individual themselves or others around them, and then become challenging. One behavior may constitute a challenging behavior for one individual with ASD or their caregivers and may not be a behavior of concern for another individual with ASD and their caregivers. In order to provide the best treatment for individuals with ASD, it is imperative that a thorough assessment is conducted. Many methods have been developed in order to assess challenging behaviors. This chapter reviews the measures that have been used to assess the maintaining variables of challenging behaviors. These are the measures used for the functional assessment of challenging behaviors. An additional aim of this chapter is to provide a review of the types of scales that are available to identify whether challenging behaviors are present.

Definition of Challenging Behaviors

Challenging behavior is defined as "culturally abnormal behavior(s) of such intensity, frequency or duration that the physical safety of the person or others is likely to be placed in serious jeopardy, or behavior which is likely to seriously limit or delay access to and frequent use of ordinary community facilities" (Emerson, 2001, p.3). Challenging behavior can be a cause of difficulty for family, staff, society, and importantly the individual themselves. Challenging behaviors include self-injurious behavior (SIB), stereotypic or repetitive behaviors, aggressive behaviors towards others, destructive behaviors, and disruptive behaviors.

Challenging behaviors also include behaviors such as toileting difficulties and feeding problems. All too often these types of behaviors are ignored when considering problem behaviors. Toileting and feeding problems can be very challenging for parents and caregivers to deal with. Some individuals may have many toileting accidents a day, or may engage in behaviors such as

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smearing of feces. With regard to feeding problems, an individual may engage in food selectivity, where only certain foods or types of foods are eaten. They may also engage in mealtime problem behaviors, including food refusal, aggression, and even self-injurious behavior in mealtime situations. They are also challenging for the individual. Individuals who cannot toilet independently may find that lacking this skill may impact on their quality of life. For an individual who is engaging in pica, where they are eating inedible objects, or rumination, where they are regurgitating food, these feeding problems can severely affect an individual's physical health and well-being.

Importance of Studying Challenging Behaviors

More research is needed on challenging behaviors in individuals with ASD. Challenging behaviors can severely impact on an individual's self-esteem and their quality of life. They can interrupt one living an independent life. For some individuals, challenging behavior is maintained by environmental events, such as escape from a demand, or attention from others. At times, behavior can be maintained by physical events. Challenging behaviors can be caused by an individual experiencing pain. Challenging behaviors may be a reaction to physical pain caused by medical issues, such as gastrointestinal symptoms and epilepsy. Gastrointestinal symptoms, such as acid reflux, abdominal pain, bloating, diarrhea, nausea, and constipation, are common in individuals with ASD (Mannion & Leader, 2014; Mannion, Leader, & Healy, 2013). Gastrointestinal symptoms or other sources of discomfort could be a maintaining variable for challenging behavior that does not appear to be maintained by environmental events. It is very important to study challenging behaviors. It is important that the source of challenging behavior is identified for pain attenuation.

Individuals with ASD can experience psychological symptoms or disorders, as well as ASD. It is important to study challenging behavior in order to better understand the role that comorbid psychopathology can play in individuals with ASD. An individual with ASD may present with challenging behaviors, such as aggression, self-injurious behavior, or stereotyped behavior, due to internal events that they are experiencing. These could include depressed symptoms, anxiety symptoms, or other feelings or emotions.

Verbal ability is an important aspect to consider when investigating challenging behaviors. If an individual is nonverbal, they may communicate through challenging behaviors. If they want to get someone's attention but cannot ask for it, they may engage in an inappropriate behavior. If they want to take a break or access a tangible item, they may display challenging behaviors. It is also important to consider challenging behaviors that are communicating a person is in pain, or that a person is experiencing symptoms of anxiety. All behavior is communication, and it is up to researchers and practitioners to better understand what an individual with ASD is communicating through different types of challenging behaviors.

Treatment is a key reason why we need to research challenging behaviors. If we can understand what is causing a challenging behavior, and what increases and decreases the likelihood of a behavior occurring in the future, effective treatment packages can be designed. No two individuals with ASD are alike. Similarly, no two behaviors are exactly alike. While a behavior may look topographically similar to a behavior emitted by another individual, its function may be completely different. Functional assessment is a way in which the variables maintaining a challenging behavior can be investigated and explored. When functional assessment is accurate, the most effective treatment intervention can be provided. Therefore it is extremely important that consideration is given when choosing a measure to assess the function of a challenging behavior.

Functional Assessment of Challenging Behaviors

A variety of different measures exist that are designed to determine the maintaining variables of challenging behaviors. The function of a behavior needs to be established before an effective

treatment plan can be designed. Behaviors can be maintained by positive reinforcement, negative reinforcement, and by automatic reinforcement. Some behaviors are maintained by attention from others, whereby someone else being present or paying attention can be a variable that can maintain a behavior. Behaviors can be maintained by access to tangible items. Behaviors can be maintained where an individual wants to escape from a situation that they find aversive, such as a task demand. Behaviors can also be maintained automatically, whereby social variables do not affect the occurrence of the behavior. Individuals may receive sensory input by engaging in some typographies of challenging behavior, and thus are automatically reinforced. Behaviors can also be maintained by physical pain, whereby an individual engages in a particular behavior because of physical pain. Some challenging behaviors are maintained by multiple functions. In what follows, there is a discussion of a number of different functional assessment measures that can be used with individuals with ASD who display problem behavior.

Functional Assessment Measures

Questions About Behavioral Function (QABF)

The Questions about Behavioral Function (QABF; Matson & Vollmer, 1995) is a 25-item measure. Informants are asked to rate an individual's behavior from "X" = "Does Not Apply," "0" = "Never," "1" = "Rarely," "2" = "Sometimes," and "3" = "Often." There are five functions of behavior, including Attention, Escape, Non-social, Physical, and Tangible. Attention is scored based on items 1, 6, 11, 16, and 21 and an example of an item is "Does he/she seem to be saying "come see me" or "look at me" when engaging in the behavior?" Escape includes items 2, 7, 12, 17, and 22 and an example of an item is "Does he/she seem to be saying "leave me alone" or "stop asking me to do this" when engaging in the behavior?" Non-social includes items 3, 8, 13, 18, and 23 and an example of an item is "Does he/she seem to enjoy the behavior, even if no one is around?" Physical includes items 4, 9, 14, 19, and 24 and an example of an item is "Does the behavior seem to indicate to you that he/she is not feeling well?" Tangible includes items 5, 10, 15, 20, and 25 and an example of an item is "Does he/she seem to be saying "give me that (toy, item, food)" when engaging in the behavior?" The function that receives the highest score is deemed to be the function maintaining the behavior.

Matson, Tureck, and Rieske (2012) conducted a review on the current status of the QABF. The authors commented that the QABF can be completed and scored in 20 min. The rationale for the QABF is discussed, alongside the psychometrics, and behaviors and corresponding functions. The authors commented that "The QABF is the scale with the best psychometrics, at this point" (p.632). Paclawskyj, Matson, Rush, Smalls, and Vollmer (2000) provided psychometric data for the QABF, examining test-retest, inter-rater, and internal consistency. Test-retest reliability was examined with 34 participants with profound intellectual disability. In order to examine inter-rater reliability, an additional 23 male participants were included, who were mainly in the profound and severe levels of intellectual disability. Test-retest reliability was found to be high. Inter-rater reliability was found to be good, with total agreement ranging from 69.67 to 95.65 %. Paclawskyj et al. (2000) found that "the internal consistency and factor structure demonstrate that the QABF consists of five underlying factors that are statistically significant and clinically meaningful" (p.228). Nicolson, Konstantinidi, and Furniss (2006) examined the psychometric properties of the QABF in 40 individuals, aged between 10 and 26 years with autism and/or severe learning difficulties and severe challenging behavior. There was inter-rater agreement in primary function of the behavior for 59 % of the QABFs. Inter-rater agreement was found to be higher for higher-rate behaviors and lower for lower-rate behaviors. Internal consistency was found to be high.

Paclawskyj, Matson, Rush, Smalls, and Vollmer (2001) compared the convergent validity of the QABF and analogue functional analyses.

The agreement between the QABF and analogue functional analyses was found to be 56.3 %. In support, Watkins and Rapp (2013) examined the convergent validity of the QABF and functional analysis in six participants with ASD, aged from 9 years to 19 years. For 5 out of 6 participants, both QABF and functional analyses identified non-social reinforcement as the function of behavior.

Healy, Brett, and Leader (2013) compared the QABF with experimental functional analysis in 32 individuals with autism, ranging in age from 6 years to 19 years. The QABF and functional analysis had exact agreement for 24 participants, which was a concordance rate of 75 %. Partial agreement was found for 6 out of the other 7 participants. Through functional analysis and the QABF, it was found that self-injurious behavior was mostly maintained by automatic reinforcement and escape from demands. Stereotypy was mostly maintained by automatic reinforcement. Aggressive/destructive behavior was mostly maintained by escape and access to tangibles. The authors commented that the QABF addresses some of the disadvantages of the use of functional analysis as "it does not involve invoking a challenging behavior, it can be used to assess low-rate behaviors, it is easily administered and scored, it has demonstrated good reliability and validity" (p.80).

Matson and Wilkins (2009) examined the reliability, frequency, and related characteristics of 95 adults with intellectual disability. Functional assessment of high-rate and low-rate challenging behaviors were investigated. Inter-rater reliability was found to be higher for behaviors that occurred more frequently. The reliability of the function of a behavior appeared to be affected by frequency and type of challenging behavior. For the individual items, there was higher inter-rater reliability for aggression than self-injurious behavior.

Matson et al. (2005) assessed the behavioral function of feeding problems using the QABF in 125 adults, aged 16–84 years, who were primarily in the profound range of intellectual disability. Five different types of feeding problems were identified. These were mealtime behavior problems (e.g., aggression and self-injurious behavior), food stealing behavior, pica, rumination, and food refusal. A QABF was completed for each identified feeding problem. Participants who engaged in food refusal received significantly higher scores on the escape subscale of the QABF than those engaging in rumination, pica, and food stealing. Those who engaged in mealtime problem behaviors also had significantly higher scores on the escape subscale than those engaging in pica or food stealing, but not food refusal. Those who engaged in rumination received significantly higher escape subscale scores than those who engaged in food stealing. Participants engaging in pica received significantly higher scores on the non-social subscale than mealtime problem behaviors, food stealing, and food refusal. Participants with rumination scored significantly higher on the non-social subscale than those engaging in mealtime problem behaviors, food stealing, and food refusal, but not pica. Participants who engaged in food refusal scored significantly higher on the physical subscale than those with mealtime problem behaviors, food stealing, and pica, but not rumination. Those with rumination and mealtime problem behaviors scored significantly higher on the physical subscale than those with food stealing. Participants with food stealing behavior scored significantly higher on the tangible subscale than those engaging in pica and rumination.

Wilke et al. (2012) examined functional assessment of stereotypy using the QABF with 53 children with ASD. Out of 39 assessments that yielded interpretative results, it was found that automatic reinforcement was the primary source of reinforcement for 35 participants. Therefore, 90 % of participants displayed stereotypy that was maintained by automatic reinforcement. Automatic reinforcement was found to be the most common maintaining variable for both vocal and non-vocal stereotypy.

Adaptations have been made to the QABF. These include a shortened version and versions using different languages. Singh et al. (2009) shortened the QABF from 25 items to 15 items and investigated if a short form (QABF-SF) was psychometrically valid and reliable. The QABF-SF was administered to 75 individuals with intellectual disabilities, aged from 19 to 85 years of age. Internal consistency, test-retest

reliability, and inter-rater reliability were investigated. The short form retained the same five-factor structure as the QABF.

Simó-Pinatella et al. (2013) adapted the QABF into Spanish and validated its use with Spanish-speaking informants. Participants were 300 individuals with intellectual disabilities. The authors concluded that the Spanish version of the QABF had good psychometric properties. Similarly, other language adaptations have been made. Dixon, Jang, Chung, Jung, and Matson (2013) translated the QABF into Korean, becoming the QABF-K. Participants were 153 individuals with developmental disabilities and challenging behavior, ranging in age from 2 years to 38 years of age. The QABF-K showed good internal consistency. A total of 40 participants participated in an investigation of test-retest reliability. The QABF-K was found to have good test-retest reliability.

Questions About Behavior Function-Mental Illness (QABF-MI)

The Questions about Behavior Function-Mental Illness (QABF-MI; Singh et al., 2006) is an adaptation of the QABF for use for individuals with mental illness who engage in challenging behaviors. Singh et al. (2006) investigated the validity of the QABF-MI in 135 individuals with serious and persistent mental illness and maladaptive behavior. Diagnoses included schizophrenia spectrum disorders, depressive disorders, and anxiety disorders. The QABF-MI contains 25 items, which are the same number as the QABF. Items were reworded in the QABF-MI to apply to individuals with mental illness. Items were found to load onto five factors. Inter-rater agreement and test-retest reliability coefficients were found to be high. The authors commented on the need to use other assessments in conjunction with the QABF-MI for some individuals as "therapists will need to be careful in not relying exclusively on the QABF-MI in identifying functions of the maladaptive behavior particularly in individuals with comorbid personality disorders, such as borderline personality disorder or antisocial personality disorder" (p. 748).

Functional Assessment for Multiple CausaliTy (FACT)

The Functional Assessment for multiple CausaliTy (FACT; Matson, Dixon, & Kuhn, 2003) is a 35-item measure designed to determine the function of a behavior where two functions seem to be likely to be maintaining the behavior. These two functions could be determined from a measure like the QABF or the Functional Analysis Screening Tool (FAST; Iwata, DeLeon, & Roscoe, 2013). The informant is asked to write the letter, shown in the parenthesis that corresponds to the informant's forced choice. An example of a question would be "Engages in the behavior more (A) to get attention, or more (P) because he/she is in pain, or (N) neither?" There are five functions: Attention (A), Escape (E), Non-social (S), Physical (P), and Tangible (T). The frequency and the percentage of each function are calculated. The frequencies for each letter are totalled and graphed under the corresponding function subscale. The percentage column indicates the percentage of presentations each behavioral function was positively endorsed. The FACT is a very useful measure for use if it appears that a behavior is maintained by two or more functions. By determining what function specifically is maintaining the behavior most strongly, a more effective behavior support plan can be designed. Where a behavior is determined to be maintained by multiple functions, one function can be designated as primary, while another is designated as having a secondary function, using the FACT.

Matson et al. (2003) developed the FACT and examined its factor structure. In Study 1, participants were 297 individuals with intellectual disabilities, ranging in age from 9 years to 85 years. Internal consistency across subscales was found to be excellent. It was found that items loaded onto five factors. Study 2 was conducted to replicate the factor analysis and to reassess internal consistency. In Study 2, participants were 197 individuals with intellectual disabilities, ranging from 16 years to 85 years of age. Internal consistency was found to range from 0.88 to 0.92, which indicated good to high estimates of reliability. The authors concluded that "one may infer that the forced-choice format of

the FACT possesses good initial estimates of reliability and validity" (Matson et al., 2003, p.494).

Functional Analysis Screening Tool (FAST)

The Functional Analysis Screening Tool (FAST; Iwata et al. 2013) is a measure used to identify factors that may influence problem behaviors. It is recommended to be used for screening as part of a comprehensive functional analysis. It is also recommended that it is administered to several individuals who interact with the client on a regular basis. There are 16 items included in the FAST. Each item is rated "Yes," "No." or "N/A." There are four potential sources of reinforcement: Social (attention/preferred items), Social (escape from tasks/activities), Automatic (sensory stimulation), and Automatic (pain attenuation). Each item that is rated as "Yes" should be circled in the scoring summary and the number of items that are circled is entered in the Total column. The potential source of reinforcement that receives the highest number of "Yes" responses is indicated to be the maintaining source of reinforcement for the problem behavior.

Social (attention/preferred items) contains items 1–4, and an example of an item is "Does the problem behavior occur when the person is not receiving attention or when caregivers are paying attention to someone else?" Social (escape from tasks/activities) contains items 5–8, and an example of an item is "Does the person usually fuss or resist when (s)he is asked to perform a task or to participate in activities?" Automatic (sensory stimulation) contains items 9–12, and an example of an item is "Does the problem behavior occur even when no one is nearby or watching?" Automatic (pain attenuation) contains items 13–16 and an example of an item is "Is the problem behavior cyclical, occurring for several days and then stopping?"

Prior to the 16 items of the FAST, there is also an Informant-Client Relationship section and a Problem Behavior Information section. The Informant-Client Relationship section asks the informant to indicate their relationship to the client, the length of time that they have known the client, whether they interact with the client daily, and in what situations that they usually interact with the client. The Problem Behavior Information section asks about the type of problem behavior, the frequency, severity, the situations where the problem behavior is most and least likely to occur, what usually happens to the person right before and after the problem behavior occurs, and the current treatment.

Iwata et al. (2013) investigated the reliability and validity of the FAST. In Study 1, the authors assessed inter-rater reliability of the FAST by administering the tool to pairs of raters assessing the same client. Data was collected for 151 individuals, ages 5–53 years, with a diagnosis of intellectual disability or autism, and problem behavior. Informants were parents, relatives, teachers, teacher aides, and direct care staff. Overall inter-rater agreement for the FAST was found to be 71.5 %, which the authors found to be moderate at best, using the 80 % criterion typically considered acceptable for direct observation measures. Agreement for individual items ranged from 53.3 to 84.5 %. Outcome agreement, which is the extent to which two informants' most frequent yes answers were for the same function, was found to be 64.8 %.

In Study 2, Iwata et al. (2013) compared 59 Functional Analysis (FA) to FAST data of the individuals who participated in Study 1. Overall correspondence between FAST and functional analysis outcomes was found to be 63.8 %. The highest degree of correspondence was found when results of the functional analysis indicated that the problem behavior was maintained by social-positive reinforcement. The authors emphasized that "the FAST is not an approximation to a FA of problem behavior; it is simply one way to gather information during an interview" (p.283).

Motivation Assessment Scale (MAS)

The Motivation Assessment Scale (MAS; Durand & Crimmins, 1998) is a measure designed to access what factors are motivating a particular problem behavior. There are four areas: Sensory,

Escape, Attention, and Tangible. In each function area, there are four items. The function areas are labeled and the items for each are grouped together. An example of a Sensory function item is "Would this behavior occur continuously if your child was left alone for long periods of time (e.g., one hour)?" An example of an Escape function item is "Does this behavior occur following a command to perform a difficult task?" An example of an Attention function item is "Does this behavior occur when you are talking to other persons in the room?" An example of a Tangible function item is "Does this behavior ever occur to get a toy, food, or game that they had been told they can't have?" Items are rated on a seven-point scale from 0 to 6, including "Never," "Almost Never," "Seldom" "Half The Time," "Usually," "Almost Always," and "Always." For each function area the numbers are added. The function area with the highest score suggests the function of the behavior.

Paclawskyj et al. (2001) examined the convergent validity between the MAS and the QABF, and also compared them to analogue functional analyses in 13 participants with intellectual disabilities. The agreement between the MAS and QABF was 61.5 %. The agreement between the MAS and analogue functional analyses was 43.8 %. The authors concluded that the two checklists have similar content dimensions. Duker and Sigafoos (1998) examined the reliability and construct validity across three typographies of behaviors in individuals with intellectual disabilities. It was found that reliability and internal consistency were found to be poor. The authors suggested that the psychometric properties of the MAS may be related to the typographies of the problem behaviors involved.

Holden and Gitlesen (2008) investigated the relationship between psychiatric symptomatology and motivation of the most severe challenging behavior in adults with intellectual disabilities. It was found that automatic/sensory reinforcement was the main function of challenging behavior in 21 % of participants, while in 33.6 % of individuals, escape from demands was the main function, in 20.2 % of individuals, attention was the main function, and in 31.9 % of individuals, tangible reinforcement was the main function. Individuals who were endorsed by informants on the item "Less able to use self-care skills, such as dressing, bathing, using the toilet, and cooking," were found to be associated with automatic/sensory reinforcement. "Broken sleep, waking up for an hour or more, before falling back to sleep" was associated with escape. "Change of weight, enough to make clothing fit less well" was found to be associated with escape also, as well as tangible reinforcement. "Sad or 'down' (noticed for at least 3 days in the past 4 weeks)" was associated with attention. "Repeated actions, such as checking over and over that a door has been locked, or having to do things in a particular order" was also associated with attention, and tangible reinforcement.

Motivation Analysis Rating Scale (MARS)

The Motivation Analysis Rating Scale (MARS; Wieseler, Hanson, Chamberlain, & Thompson, 1985) is also referred to as the Contingency Analysis Questionnaire (CAQ). It consists of 6 items, ranging from "Never" to "Almost Always," and the items represent the following functions: Social and tangible positive reinforcement, social and situational escape, and self-stimulation (Rojahn, Schroeder, & Hoch, 2007). Little research has been conducted to examine its psychometric properties (Sipes & Matson, 2012). No other studies have been published besides the original Wieseler et al. (1985) article (Belva, Hattier, & Matson, 2013).

Problem Behavior Questionnaire (PBQ)

The Problem Behavior Questionnaire (PBQ; Lewis, Scott, & Sugai, 1994) is a 15-item measure designed to determine the function of a behavior. Items are rated by percent of the time and are rated 0-"Never," 1-"10 %," 2-"25 %," 3-"50 %," 4-"75 %," 5-"90 %," and 6-"Always." Informants are asked to keep in mind a typical episode of the

problem behavior, and to circle the frequency at which the statements are true. A score is then circled for each question, and scores are summed into total scores. Possible functions include Peers Escape, Peers Attention, Adults Escape, Adults Attention, and Setting Events. Peers Escape includes items 3, 10, and 14 and an example of a question is "During a conflict with peers, if the student engages in the problem behavior do peers leave the student alone?" Peers Attention includes items 4, 7, and 11 and example of an item is "When the problem behavior occurs, do peers verbally respond or laugh at the student?" Adults Escape includes items 1, 9, and 13 and an example of an item is "Does the problem behavior occur and persist when you make a request to perform a task?" Adults Attention includes items 2, 6, and 12 and an example of an item is "When the problem behavior occurs, do you redirect the student to get back to task or follow rules?" Setting Events includes items 5, 15, and 18 and an example of an item is "Is the problem behavior more likely to occur following unscheduled events or disruptions in classroom routines?"

Scales to Identify Challenging Behaviors

A number of different scales are available to identify the types of challenging behaviors an individual presents with. There are measures designed for babies and infants, children, adolescents, and adults. Some measures have been designed specifically for individuals with ASD, while other scales were developed for use with individuals with intellectual disabilities. Some scales have been developed for the general population, but have been validated for use with individuals with ASD. The following outlines a number of these scales that have been designed to identify the type of challenging behaviors that an individual presents with. Some measures identify the frequencies and severity of specific types of challenging behaviors. Others deliver mean and total scores. Some measures have clinical cut-off points. There is much choice available for researchers and it is important that researchers are adequately prepared in their knowledge about the variety of measures available in order to choose the most suitable measure for their purposes.

Baby and Infant Screen for Children with aUtIsm Traits (BISCUIT-Part 3)

The Baby and Infant Screen for Children with aUtIsm Traits (BISCUIT-Part 3; Matson, Boisjoli, & Wilkins, 2007) is a measure designed to assess challenging behaviors in toddlers between 17 and 37 months in age. It contains 15 items about stereotypic behavior, aggressive/disruptive behavior, and self-injurious behavior. Items are rated as (0) not a problem or impairment; not at all, (1) mild problem or impairment, or (2) severe problem or impairment. Items are rated as to the extent that they are a recent problem.

Matson et al. (2009) established the reliability and the item content of the BISCUIT-Part 3. Participants were 276 children ages 17–37 months who were identified as being at risk for developmental and/or physical disabilities. The internal reliability coefficient of the BISCUIT-Part 3 was 0.91. Rojahn et al. (2009) investigate the cut-offs, norms, and patterns of problem behaviors on the BISCUIT-Part 3. Participants were 312 toddlers with ASD. In Study 1, cut-offs were derived for the scale, which are No/minimal impairment, Moderate impairment, and Severe impairment. In Study 2, the frequency of challenging behaviors in toddlers was examined. A control group of atypically developing toddlers without a diagnosis of ASD was included. Total problem behaviors were greater for those with autism, followed by those with PDD-NOS, and those with no ASD diagnosis. Toddlers with autism were more likely to receive higher subscales and total scores when compared to toddlers with PDD-NOS. Toddlers with autism were more likely to receive scores in the severe cut-off range than toddlers with PDD-NOS or atypically developing toddlers.

In support, Matson, Fodstad, Mahan, and Rojahn (2010) investigated the cut-off, norms, and patterns of problem behaviors on the BISCUIT-Part 3 in 644 infants. For the total

behavior score, it was found that 6.2 % of toddlers were in the severe impairment range. For the aggressive/destructive behavior subscale, 7 % were in the severe impairment range. For the stereotypies subscale, 2.5 % of toddlers were in the severe impairment range. For the self-injurious behavior subscale, 2.8 % of toddlers were in the severe impairment range. Matson, Boisjoli, Rojahn, and Hess (2009) conducted a factor analysis of the BISCUIT-Part 3. The factor analysis yielded a three-factor structure. Matson, Boisjoli et al. (2009) also examined the differences in challenging behaviors in those with and without ASD. The ASD group were 270 participants diagnosed with ASD. The control group were 505 toddlers with developmental delays, but without ASD. Infants and toddlers with ASD scored significantly higher on all factors of the BISCUIT-Part 3 compared to children without an ASD diagnosis.

Horovitz and Matson (2013) developed age-based scoring procedures for the BISCUIT-Part 3. Separate cut-off scores were developed for individuals with ASD and for those with developmental delays but without ASD. Participants were 3022 infants and toddlers. Cut-offs were derived for three age groups: (1) 17–23 months, (2) 24–30 months, and (3) 31–37 months. The authors found that as children with ASD grow older, challenging behaviors become more frequent and severe. Fodstad, Rojahn, and Matson (2012) examined how challenging behaviors affect different age groups. Participants were divided into four age groups: 12–18 months, 19–25 months, 26–32 months, and 33–39 months. There were 297 children in the ASD group, and 327 in the non-ASD, atypically developing group. It was found that younger children engaged in less severe challenging behaviors, and the severity of challenging behaviors increased as infants and toddlers aged. There were increases in Aggressive/Destructive Behaviors and Stereotypic Behaviors beginning around 26–32 months of age.

Matson, Boisjoli, and Mahan (2009) explored the relationship between communication and challenging behaviors. Lower levels of receptive communication were associated with higher levels of stereotypic behavior, and self-injurious behavior, and to a lesser extent, aggressive/disruptive behavior. Medeiros, Kozlowski, Beighley, Rojahn, and Matson (2012) investigated the effect of developmental quotient (DQ) and diagnostic criteria on challenging behaviors in toddlers with developmental disabilities. The relationship between developmental quotient and challenging behaviors varied depending on whether a child received a diagnosis of autistic disorder, PDD-NOS, or atypical development. Toddlers with autistic disorder and PDD-NOS exhibited more challenging behaviors with higher total DQ.

Matson et al. (2011) investigated the effects of symptoms of comorbid psychopathology on challenging behaviors in infants and toddlers. Aggressive behaviors and stereotypies were significantly different for those with no/minimal impairment and moderate/severe impairment in Inattention/Impulsivity. Aggressive behaviors, stereotypies, and SIB were all significantly different in the no/minimal impairment and moderate/severe impairment in Avoidance behavior. For the anxiety/repetitive behavior scores, stereotypies were significantly lower in the no/minimal impairment group than the moderate/severe impairment group. There were significant differences in aggressive behaviors, stereotypies, and SIB between the no/minimal impairment and the moderate/severe impairment in Tantrum behavior. Participants with higher rates of eating and sleeping problems displayed greater aggressive/destructive behavior and stereotypies, than those with lower rates of eating and sleeping problems. Participants with high scores in Anxiety/Repetitive behavior displayed greater levels of stereotypy.

Cervantes, Matson, Tureck, and Adams (2013) investigated the relationship between comorbid anxiety symptom severity and challenging behaviors in 385 infants and toddlers with ASD. Participants were divided into two groups based on their Anxiety/Repetitive Behavior score, with 291 participants in the no/minimal impairment group, and 94 participants with moderate/severe impairment. Children with moderate/severe anxiety symptoms displayed significantly

more challenging behaviors than children with no/minimal impairment in anxiety symptoms. There were significant differences in 13 of the 15 challenging behaviors, with the moderate/severe anxiety group scoring significantly higher on challenging behaviors in comparison to the no/minimal impairment anxiety group. Autism symptom severity was entered as a co-variate and it was significant for the following behaviors: "repeated and unusual vocalizations," "repeated and unusual body movements," and "unusual play with objects." Toddlers in the moderate/severe impairment in anxiety symptoms scored significantly higher than the no/minimal impairment in 9 out of 10 aggressive/destructive behaviors.

Hattier, Matson, Belva, and Horovitz (2011) compared challenging behaviors in children with ASD and atypical development. It was found that toddlers in the ASD group exhibited a higher percentage of challenging behaviors than those in the atypically developing group. Sipes, Rojahn, Turygin, Matson, and Tureck (2011) used the BISCUIT-Part 3 to compare problem behaviors in atypically developing infants and toddlers. Participants were divided into five different groups: Down syndrome, developmental delay, prematurity, cerebral palsy, and seizure disorder. No significant differences were found in challenging behaviors between the groups. It was found that aggressive and destructive behaviors were more common than SIB or stereotyped behavior.

Horovitz, Matson, Rieske, Kozlowski, and Sipes (2011) investigated the relationship between race and challenging behaviors in 453 Caucasian and 409 African American infants and toddlers. Significant difference were found for the following aggressive/destructive behaviors: kicking objects, throwing objects at others, aggression towards others, pulling others' hair, and property destruction, with African American toddlers scoring higher on these items than Caucasian toddlers. No significant differences were found for SIB or stereotypic behavior. The authors concluded that cultural factors need to be taken into account when assessing challenging behaviors in infants and toddlers with ASD.

Williams et al. (2013) investigated the effect of the DSM-5 criteria on challenging behaviors in children that no longer meet the diagnostic criteria for ASD. Participants were divided into three groups: (1) 501 participants who maintained an ASD diagnosis using the DSM-5 criteria, (2) 439 toddlers who failed to meet DSM-5 criteria, but did meet DSM-IV-TR criteria, and (3) 2399 toddlers with atypical development. Large effect sizes were found between the atypical development group and the DSM-5 group on total problem behaviors, aggressive/destructive behaviors, SIB, and stereotyped behaviors. Large effect sizes were found between the DSM-IV-TR group and the DSM-5 group on total problem behaviors and stereotyped behaviors. Medium effect sizes were found between the DSM-IV-TR group and the DSM-5 group on aggressive/destructive behaviors and SIB. Those who no longer met criteria for ASD with the DSM-5 still displayed significantly more challenging behaviors than those who were atypically developing. While a toddler may no longer met criteria for ASD with the DSM-5, it is important for practitioners and researchers to recognize that challenging behaviors are occurring at higher rates in these children than other children with atypical development, who never met the DSM-IV-TR criteria for ASD.

Autism Spectrum Disorders-Behavior Problems for Children (ASD-BPC)

The Autism Spectrum Disorders-Behavior Problems for Children (ASD-BPC; Matson & González, 2007) is an 18-item scale used to determine the frequency of behavior problems in children with ASD. Informants are asked to rate each item from "0 = Not a problem or impairment; not at all," "1 = Mild problem or impairment," and "2 = Severe problem or impairment." The scale is composed of two dimensions: an externalizing scale and an internalizing scale. Examples of items included in the scale are "Poking him/her self in the eye," "Kicking objects (e.g., doors, walls)," and "Repeated and

unusual body movements (e.g., hand flapping, waving arms, etc.)."

Matson, González, and Rivet (2008) investigated the reliability and factor structure of the ASD-BPC. Participants were 218 children and adolescents aged between 2 and 16 years. An ASD group included 110 children and adolescents and a control group included 108 children and adolescents without a diagnosis of ASD. The mean inter-rater reliability was found to have fair clinical significance, with a mean agreement of 92 %, which is excellent clinical significance. Mean test-retest reliability was found good clinical significance, with a mean agreement of 92 %, which is excellent clinical significance. Items loaded onto two factors: externalizing behavior and internalizing behavior.

Mahan and Matson (2011) investigated the convergent and discriminant validity of the ASD-BPC against the Behavioral Assessment System for Children, Second Edition (BASC-2). Participants were 49 children and adolescents with ASD, aged from 4 to 16 years. The ASD-BPC externalizing scale demonstrated convergent validity with the BASC-2 hyperactivity and aggression subscales. The ASD-BPC internalizing scale demonstrated convergent validity with the BASC-2 atypicality subscale. The ASD-BPC and BASC-2 also demonstrated discriminant validity for the ASD sample.

Jang, Dixon, Tarbox, and Granpeesheh (2011) used the ASD-BPC to investigate the relationship between challenging behavior and autism symptom severity in 84 children with ASD, ranging from 29 to 218 months. All children were receiving Early Intensive Behavioral Intervention (EIBI). It was found that 94 % of participants displayed challenging behavior. The most common challenging behavior was repeated and unusual vocalizations, where 73.8 % of participants displayed this behavior. This was followed by unusual play with objects, where 57.1 % of participants emitted this behavior. Leaving the supervision of caregiver was the third most common challenging behavior, where 56 % of participants displayed this behavior. Significant differences were found in challenging behaviors, depending on autism symptoms severity. A number of items were found to be significantly different between the mild and severe autism symptoms groups. These are unusual play with objects, playing with own saliva, aggression towards others, repeated and unusual vocalizations, and repeated and unusual body movements. Smearing or playing with feces and property destruction were found to be significantly different between the severe and moderate ASD groups. It was found that the presence of challenging behavior was predicted by autism severity.

Matson, Mahan, Hess, Fodstad, and Neal (2010) examined how challenging behaviors progress as children with ASD get older, using the ASD-BPC. Participants were 167 children with ASD, aged 3–14 years. Children were divided into three different age groups: (1) young children (1–6 years), (2) children (7–10 years), and (3) young adolescents (11–14 years). No significant differences were found between the different age groups in terms of challenging behavior. Therefore, it appears that challenging behaviors are stable over time as children age and move into adolescence.

Kozlowski, Matson, and Rieske (2012) investigated gender effects on challenging behaviors in children with ASD. The ASD-BPC was conducted with 291 children, aged 2–17 years. Children were assigned to four groups: (1) male with ASD, (2) male without ASD, (3) female with ASD, and (4) female without ASD. It was found that individuals with ASD displayed more challenging behavior than individuals without ASD. In general, males and females did not differ in challenging behavior presentation. However, females with ASD were more likely to engage in yelling or shouting at others than males or females without ASD. Males with ASD did not differ from other groups in exhibiting yelling or shouting at others. Males with ASD displayed significantly more throwing objects at others than females with ASD.

Chung et al. (2012) used the ASD-BPC to examine cross-cultural differences in challenging behavior between Israel, South Korea, the UK, and the USA. The aim of the study was to examine differences between cultures in the presence and severity of challenging behaviors. Participants

were 285 children with ASD, aged between 2 and 16 years. A large degree of consistency was found between the USA and South Korea and Israel. Where there were differences, the USA had higher endorsements of the presence and severity of challenging behavior than South Korea or Israel. It was found that nearly half of the challenging behaviors differed between the USA and the UK. The UK had higher endorsements in the presence and the severity of challenging behaviors when compared to the USA.

Autism Spectrum Disorders-Behavior Problem for Adults (ASD-BPA)

The Autism Spectrum Disorders-Behavior Problem for Adults (ASD-BPA; Matson, Terlonge, & González, 2006) was designed to assess problem behaviors in adults with ASD. It contains 19 items. Items are rated as 0 (not a problem or impairment, not at all), or 1 (some problem or impairment). Items are rated as to the extent that they are a recent problem. There are four subscales, including Aggression/Destruction, Stereotypy, Self-Injurious Behavior (SIB), and Disruptive Behavior.

Matson and Rivet (2007) assessed the validity of the ASD-BPA by comparing it to the Behavior Problems Inventory (BPI-01). Participants were 27 adults with intellectual disabilities, aged from 29 to 87 years. In additional to intellectual disabilities, 8 participants had a diagnosis of autistic disorder and 10 participants had a diagnosis of Pervasive Developmental Disorder-Not Otherwise Specified (PDD-NOS). All ASD-BPA subscales were significantly correlated with the BPI-01 subscales. Moderate correlations were found for the aggression and destruction subscales. Strong correlations were found for the self-injury subscales and the stereotypic and disruptive behaviors subscales. Total scores of the ASD-BPA and the BPI-01 were strongly correlated. The ASD-BPA Disruptive Behavior subscale was strongly correlated with the BPI-01 total score. A moderate correlation was found between the ASD-BPA Self-Injurious Behavior (SIB) subscale and the BPI-01 total score. Matson and Rivet (2008b) established the psychometric properties of the ASD-BPA. Participants were 171 adults with ASD and intellectual disabilities, ranging in age from 16 to 78 years. It was found that 88 % of participants had profound intellectual disability. Inter-rater reliability was found to be moderate to good. Test-retest reliability was found to be moderate to good. Items loaded onto a four-factor model.

Smith and Matson (2010) investigated challenging behavior in adults and compared four groups: (1) Intellectual disability, (2) Epilepsy, (3) ASD, and (4) ASD and epilepsy combined. The ASD-BPA was used to investigate challenging behavior. It was found that the ASD group was significantly more impaired in self-injury than those with intellectual disability, and the additional diagnosis of epilepsy did not add to this. Those with ASD and epilepsy were more impaired on measures of disruptive behavior than those with intellectual disability alone, ASD alone, or epilepsy alone. There was also a surprising finding that epilepsy contributed more on the disruptive behavior scale than ASD did. The authors commented that this may be due to direct care staff considering seizures to be more disruptive than the disruptive behaviors of those with ASD.

Horovitz, Matson, Hattier, Tureck, and Bamburg (2013) investigated the effects of race and autism spectrum disorders on challenging behaviors in adults with intellectual disabilities and used the ASD-BPA. Participants had a diagnosis of intellectual disability, while 49.7 % of participants had a comorbid diagnosis of ASD. Participants ranged in age from 20 to 87 years of age. It was found that 75 % of participants had a profound intellectual disability. Participants were divided into four groups; (1) Caucasian with ASD, (2) African American with ASD, (3) Caucasian with no ASD diagnosis, and (4) African American with no ASD diagnosis. It was found that Caucasian participants with ASD received higher ASD-BPA scores than did African American participants with ASD. For individuals with intellectual disabilities alone, it was found that African American participants

without a diagnosis of ASD received higher ASD-BPA scores than Caucasian participants without an ASD diagnosis. Specifically, Caucasian participants with ASD received higher stereotypy scores than African American participants with ASD. African American participants without a diagnosis of ASD received higher stereotypy scores than Caucasian participants without ASD. Participants with ASD and comorbid intellectual disability displayed significantly greater rates of challenging behaviors than those with ID alone.

Matson and Rivet (2008a) investigated the characteristics of challenging behaviors in adults with ASD. Participants were 161 adults with ASD, and 159 matched control participants with ID only. Participants were divided up into groups of participants with autistic disorder, PDD-NOS, and ID only. It was found that frequency of aggression/destruction, stereotypy, self-injurious behavior, and disruptive behavior increased with severity of autism symptoms. Participants with autistic disorder had higher rates of problem behavior than those with PDD-NOS or ID only. Behaviors that showed the most differences between groups were stereotypy (repeated/unusual body vocalizations/body movements, unusual object play), self-injurious behavior (harming self, mouthing/swallowing objects), aggression/destruction (banging on objects), and disruptive behavior (elopement).

Matson and Rivet (2008c) investigated the effects of autism and PDD-NOS symptoms on challenging behaviors in adults with intellectual disabilities, using the ASD-BPA. Participants were 298 adults with intellectual disabilities, aged from 21 to 88 years. The majority (76.5 %) of participants had a profound intellectual disability. It was found that 49.7 % of participants met criteria for autistic disorder or PDD-NOS. Participants were divided up into two groups: those with severe autism symptoms and those with mild autism symptoms. Participants with severe autism symptoms had significantly higher endorsements of disruptive behavior and self-injurious behavior than participants with mild autism symptoms. There were no significant differences in aggressive/destructive behavior for those with mild or severe autism symptoms.

Turygin, Matson, MacMillan, and Konst (2013) used the ASD-BPA to investigate the relationship between challenging behavior and symptoms of depression in adults with intellectual disabilities, with and without ASD. Participants were 332 adults with intellectual disabilities, the majority (76.2 %) of which had a profound intellectual disability. Participants were divided up into three groups: (1) ASD, (2) PDD-NOS, and (3) No ASD. It was found that in participants with ASD, aggression, disruptive behavior, and self-injurious behavior were all moderately associated with depressive symptoms. Similarly, for those with PDD-NOS, aggression, disruptive behavior, and SIB were also moderately associated with depressive symptoms. It was found that the association between SIB and depressive symptoms was significantly higher in those with ASD, than in those with no pervasive developmental disorder (PDD). It is important for researchers and clinicians to be aware of the role that comorbid psychopathology can play in challenging behaviors. An individual may be engaging in challenging behaviors due to feelings of anxiety or depressive symptoms. It is important that comorbid psychopathology is screened for when designing intervention packages for individuals with challenging behaviors.

Rojahn, Wilkins, Matson, and Boisjoli (2010) compared the ASD-BPA to the BPI-01 in adults with intellectual disabilities, with and without ASD. Participants were 57 adults with intellectual disabilities, ranging in age from 23 to 81 years. The majority (49 participants) of the sample were diagnosed with profound intellectual disability. Participants were divided into two groups: ASD and No ASD. The majority (40 participants) of the sample met criteria for ASD. No significant differences were found between those with ASD and without ASD on the ASD-BPA. Significant differences were found on the BPI-01 on total frequency, SIB frequency and severity, and stereotypy frequency and severity between those with ASD and those without ASD. The convergent validity of the ASD-BPA and the BPI-01 was investigated. Total ASD-BPA scores were significantly correlated with BPI-01 total severity and frequency scores. ASD-BPA aggression/destruction was significantly correlated with BPI-01

aggression/destruction frequency and severity subscales. ASD-BPA stereotypy was significantly correlated with BPI-01 stereotypy frequency and severity subscales. ASD-BPA self-injurious behavior was significantly correlated with the BPI-01 SIB frequency and severity subscales.

Behavior Problems Inventory (BPI-01)

The Behavior Problems Inventory (BPI-01; Rojahn, Matson, Lott, Esbensen, & Smalls, 2001) is designed to assess behavior problems in individuals with intellectual and developmental disabilities. It contains 52 items and items are scored on a frequency and a severity scale. Items are rated on the five-point frequency scale from 0 (Never), 1 (Monthly), 2 (Weekly), 3 (Daily), and 4 (Hourly). Items are rated on the four-point severity scale from 0 (No problem), 1 (A slight problem), 2 (A moderate problem), and 3 (A severe problem). Informants are asked to respond as to whether the behavior occurred during the past 2 months. Items are divided into three subscales: Self-injurious Behavior (SIB), Stereotypic Behavior, and Aggressive/Destructive Behavior. There are 14 SIB items, 24 Stereotypic Behavior items, and 11 Aggressive/Destructive Behavior items. There is also a generic behavior problem definition (e.g., Other SIB) asked for each type of behavior problem.

Rojahn et al. (2001) found test-retest reliability to be good to excellent. The BPI-01 demonstrated good clinical criterion validity. The authors concluded the BPI-01 "was found to be a reliable (retest reliability, internal consistency, and between-interviewer-agreement) and valid (factor and criterion validity) behavior rating instrument" (p.577). González et al. (2009) investigated the reliability and factor validity in adults with intellectual disabilities. The internal consistency of the BPI-01 was found to be in the good to excellent range. The inter-rater and test-retest reliability were found to be adequate. Lower reliability was found for the Stereotypy subscale. González et al. (2009) confirmed that the three-factor structure of the BPI-01 was a good fit. The BPI-01 has been translated in different languages, including Swedish, Dutch, Romanian, Korean, and Chinese.

Rojahn, Aman, Matson, and Mayville (2003) investigated the convergent and divergent validity of the BPI-01 and the Aberrant Behavior Checklist (ABC), in 226 adults with intellectual disabilities. It was found that participants with high BPI-01 scores also had high ABC scores. The subscales of the BPI-01 were significantly and positively related to the subscales of the ABC. Both measures also yielded information that was not received from the other measure. In support, Hill, Powlitch, and Furniss (2008) investigated the convergent validity of the BPI-01 and the ABC. Participants were 69 children and adults with intellectual disabilities. Strong evidence of convergent validity was found between the BPI-01 and the ABC.

Rojahn et al. (2013) investigated the validity and the reliability of the BPI-01, the ABC, and the Repetitive Behavior Scale-Revised (RBS-R) in 180 infants and toddlers at risk of intellectual or developmental disabilities. High rates of convergent and discriminant validity were found across the three instruments. The authors recommended using all three measures to assess behavior problems in infants at risk of intellectual or developmental disabilities.

Murphy, Healy, and Leader (2009) used the BPI-01 to examine challenging behaviors in 157 children with ASD. It was found that 64.3 % of children displayed challenging behaviors. McTiernan, Leader, Healy, and Mannion (2011) analyzed the risk factors and early predictors of challenging behaviors in 174 children with ASD, and used the BPI-01 to investigate the prevalence of challenging behaviors in this sample. Hattier, Matson, MacMillian, and Williams (2013) investigated stereotyped behaviors in toddlers with ASD and atypical development. Stereotyped behavior was assessed using the BPI-01. The ASD group displayed significantly more stereotyped behavior than the atypically developing group.

Schroeder, Richman, Abby, Courtemanache, and Oyama-Ganiko (2014) investigated the comparison between functional analysis and

the BPI-01 in 17 infants and toddlers at risk for developmental delays. Overall agreement for functional analysis and the BPI-01 for aggression was 91 %, for stereotyped behavior was 83 %, and for SIB was 73 %. However, for less frequently occurring topographies, the overall agreement for aggression was 48 %, for stereotyped behavior was 50 %, and for SIB was 42 %. Overall, functional analysis and the BPI-01 agreed approximately 75 % of the time.

Behavior Problems Inventory-Short Form (BPI-S)

The Behavior Problems Inventory-Short Form (BPI-S; Rojahn et al., 2012a) is an informant-based behavior rating tool designed to evaluate maladaptive behaviors in individuals with intellectual disabilities. The rating scale uses the same system as the BPI-01 (Rojahn et al., 2001) but has fewer items. It consists of 30 items and has three subscales: Self-injurious behavior, Aggressive/destructive behavior, and Stereotyped behavior. The Self-injurious behavior subscale has 8 items. The Aggressive/destructive behavior subscale has 10 items. The Stereotyped behavior subscale has 12 items. Each item on the Self-injurious behavior and Aggressive/destructive behavior subscales is rated on a frequency scale and a severity scale. The Stereotyped behavior subscale is rated on a frequency scale only. Each frequency scale was rated from "Never/No problem," "Monthly," "Weekly," "Daily" to "Hourly." Each severity scale was rated from "Mild," "Moderate" to "Severe." Rojahn et al. (2012b) investigated the reliability and validity of the BPI-S. The BPI-S was found to be psychometrically sound. The internal consistency values on the BPI-S frequency subscales ranged from fair (Self-injurious Behavior) to good (Aggressive/Destructive Behavior and Stereotyped Behavior).

Williams, Leader, Mannion, and Chen (2015) used the BPI-S to investigate the relationship between anxiety and challenging behavior in 109 children and adolescents with ASD. A high prevalence of challenging behavior was found. It was found that 99 % of the sample exhibited at least one form of challenging behavior. It was found that 67 % displayed all three typographies of challenging behavior, 28 % displayed two types of challenging behavior, and only 5 % displayed one type of challenging behavior. The mean for self-injurious behavior frequency was 4.61 (SD = 4.54), and self-injurious behavior severity was 2.96 (SD = 3.19). The mean for aggressive/destructive behavior frequency was 7.05 (SD = 6.82), while aggressive/destructive behavior severity was 5.09 (SD = 5.29). The mean for stereotyped behavior frequency was 16.02 (SD = 10.30). There were no significant correlations found between anxiety and the subscales of the BPI-S. Severity of self-injurious behavior was found to be a negative predictor of anxiety.

Fragile X syndrome may be an underdiagnosed comorbid disorder in individuals with ASD. Newman, Leader, Chen, and Mannion (2015) investigated challenging behavior in children and adolescents ages 2–17 years with Fragile X syndrome using the BPI-S. It was found that 72 % of individuals displayed all three types of challenging behavior, while 21 % displayed two forms of challenging behavior, and only 6 % engaged in one form of challenging behavior. It was found that all participants displayed some form of stereotypy, while 85 % displayed aggressive/destructive behavior, and 80 % displayed self-injurious behavior. It was found that individuals with Fragile X syndrome and ASD exhibited significantly higher rates of challenging behavior than those with Fragile X syndrome and no comorbid diagnosis of ASD. No significant differences in challenging behavior were found between males and females, and between those with and without intellectual disability. Presence of ASD was found to be a significant predictor of challenging behavior. It was also found that challenging behavior and comorbid psychopathology were positively correlated, where stereotypy correlated most strongly with comorbid psychopathology.

Aberrant Behavior Checklist (ABC)

The Aberrant Behavior Checklist (ABC; Aman, Singh, Stewart, & Field, 1985) is a 58-item behavior rating scale. Items are rated on a 4-point scale from 0 (never a problem), 1 (slight problem), 2 (moderately serious problem), to 3 (severe problem). There are five subscales: Irritability (15 items), Lethargy (16 items), Stereotypy (7 items), Hyperactivity (16 items), and Inappropriate speech (4 items). Higher scores indicate more severe problems. The ABC has been shown to have high internal consistency among subscales, excellent test-retest reliability, and acceptable inter-rater reliability (Aman et al., 1985; Schmidt, Huete, Fodstad, Chin, & Kurtz, 2013).

Schmidt et al. (2013) investigated the ABC for use with children with intellectual and developmental disabilities under the age of 5 years. Participants were 97 children under the age of 5 years. It was found that 45.4 % of the children had a developmental delay or intellectual disability, while 13.4 % were diagnosed with ASD. The authors found that the five-factor structure of the ABC was not fully supported for children under the age of 5 years. The authors suggested that the factor structure of the ABC may need to be revised for the younger population.

Baeza-Velasco, Michelon, Rattaz, and Baghdadli (2014) investigated whether aberrant behavior patterns are associated with adaptive behavior in teenagers with ASD. Participants were 152 adolescents with ASD. Teenagers with high rates of aberrant behavior were found to have high rates of severity of autism symptoms. Adolescents with low rates of aberrant behavior were more likely to have functional language. It was found that most adolescents with higher scores on communication and socialization had lower/medium levels of aberrant behavior. However, adolescents with lower adaptive behavior were found across all groups of levels of aberrant behavior, from cluster (1) low scores on the ABC four domains, (2) high scores in irritability, and hyperactivity, (3) medium scores on the ABC four domains, to (4) medium level of irritability and high scores in stereotypy, lethargy, and hyperactivity.

Brown, Aman, and Havercamp (2002) investigated the factor analysis and norms of the ABC for young people in special education. Participants were 601 children and young people, aged from 6 to 22 years. Participants were divided into three age groups: 6–10 years, 11–14 years, and >14 years. It was found that boys scored higher than girls on hyperactivity. The younger groups scored higher on hyperactivity and irritability than the adolescents. Individuals in the multi-handicapped classes scored higher on Stereotypic Behavior than those in the developmentally handicapped classes. The authors concluded that for the factor structure of the ABC, "the Inappropriate Speech subscale should perhaps be considered as tentative where parent ratings of children are concerned" (p.58).

Green, O'Reilly, Itchon, and Sigafoos (2005) investigated the persistence of early emerging aberrant behaviors in 13 preschool children, aged 35–55 months when the study began, with developmental disabilities. Children were assessed every 6 months over a 3-year period. All children presented with challenging behaviors at the start of the study. Nine of the children received high scores on the ABC at the start and continued to receive high scores. Three children showed a reduction in ABC scores, and one child showed an increase in aberrant behavior.

Brinkley et al. (2007) examined the factor analysis of the ABC in individuals with ASD. Participants were 275 individuals with ASD who were between 3 and 21 years of age. The authors found that the ABC is generally robust for use with individuals with ASD and found the five-factor solution to be a moderate fit. The research found a self-injury factor to be present. More research is needed on this self-injury factor.

Kaat, Lecavalier, and Aman (2014) examined the validity of the ABC in children with ASD. Participants were 1893 individuals with ASD, aged 2–18 years. The ABC was compared to the Child Behavior Checklist (CBCL) and good convergent validity was demonstrated. The original five-factor structure of the ABC was found to be robust in children with ASD. The subscales were found to have acceptable to excellent internal consistency.

Child Behavior Checklist (CBCL)

The Child Behavior Checklist (CBCL; Achenbach & Rescorla, 2000, 2001) includes a measure for children aged 1.5–5 years. The CBCL 1.5–5 is a 100-item measure. There are six syndrome scales. These contribute to either Internalizing or Externalizing problems. Emotionally Reactive, Anxious/Depressed, Somatic Complaints, and Withdrawn contribute to Internalizing problems. Attention Problems and Aggressive Behavior contribute to Externalizing problems. Sleep problems do not contribute to either Internalizing or Externalizing problems, but is used for the Total Problems score. The CBCL 6–18 has eight empirically derived Syndrome Scales, as well as six DSM-Oriented scales. Externalizing problems contains the Rule Breaking Behavior and Aggressive Behavior syndrome scales. Internalizing problems contains Anxious/Depressed, Withdrawn/Depressed, and Somatic Complaints. The other syndrome scales do not belong to Externalizing or Internalizing problems, and these are Attention Problems, Thought Problems, and Social Problems. For both age groups, items are rated from 0 (Not True), 1 (Somewhat or Sometimes True), or 2 (Very True or Often True). Raw scores are converted to T-scores. T-scores are rated from normal to borderline to clinical ranges.

Pandolfi, Magyar, and Dill (2009) investigated the factor analysis of the CBCL 1.5–5 in 128 children with ASD. The two-factor model of Internalizing and Externalizing factors was supported in this study. Pandolfi, Magyar, and Dill (2012) investigated the psychometric properties of the CBCL 6–18 in children and adolescents with ASD. Individuals were divided into two groups: ASD and emotional and behavioral disorders (EBD), and ASD only. The ASD + EBD group had significantly higher mean scores on Total Problems, Anxious/Depressed, Somatic Complaints, Thought Problems, Withdrawn/Depressed, and Internalizing domain than those with ASD only. Factor analysis supported the Internalizing and Externalizing factor structure.

Individual scales of the CBCL can be used to look at specific problem issues or behaviors. Presmanes Hill et al. (2014) explored aggressive behavior problems in children with ASD, and used the CBCL Aggressive Behavior scale T-scores. Individuals were 400 children and adolescents aged 2–18 years with ASD. Individuals were split into two groups: those with aggressive behavior scores in the clinical range, and those with scores below the clinical range. Prevalence of aggressive behavior problems was found to be 25 %. The authors noted "In clinical settings, it may be beneficial to administer questionnaires with known psychometric properties and normative data such as the CBCL to provide parents the opportunity to rate challenging behaviors that the clinician can then use to facilitate open discussions with families" (p. 1131). Williams et al. (2015) used the DSM-Oriented Anxiety Problems Scale of the CBCL. It was found that 75 % of children and adolescents with ASD were in the clinical range for anxiety problems, while 10 % were in the borderline range, and 15 % were in the normal range.

Parental Concerns Questionnaire (PCQ)

The Parental Concerns Questionnaire (McGrew et al., 2007) contains 13 items. The severity of core developmental and psychiatric symptomatology is assessed using a 4-point scale, from 1 (No problems), 2 (Mild problems), 3 (Moderate problems), and 4 (Severe problems). Questions ask about social interaction, verbal and nonverbal communication, restrictive and repetitive behaviors, anxiety, obsessive/compulsive behaviors, aggression, SIB, mood swings, hyperactivity and attention issues, and sleep disturbances. Parents are asked to rate the concerns as to what extent that they have been a problem within the last month.

McGrew et al. (2007) investigated the validity of the PCQ in 53 children with ASD, and 48 age-matched typically developing controls. Participants were from age 4 to 10 years. For the ASD group, internal consistency was found to be high. It was not as internally consistent for the typically developing group. Test-retest reliability was found to have substantial agreement. Goldman

et al. (2011) investigated the relationship between sleep problems and problem behaviors, using the PCQ. Participants were 1784 children, ages 2–18 years with ASD. Over 60 % of children had problems with language use and understanding, attention span, and social interactions. Over 50 % of children had problems with anxiety, sensory issues, hyperactivity, and eating habits. It was found that poor sleepers had a higher percentage of behavioral problems on all PCQ scales than good sleepers.

Profile of Toileting Issues (POTI)

Toileting problems have been identified as a common challenging behavior in individuals with ASD (Mannion & Leader, 2013). The Profile of Toileting Issues (POTI; Matson, Dempsey, & Fodstad, 2010) is a 56-item checklist that is designed to screen for the diagnostic criteria for enuresis and encopresis as well as potential functions including pain, avoidance, social difficulties, noncompliance, internal cues, shame/deception, peer rejection, aversive parenting, and medical problems. The scale is completed by the individual's primary caregiver with items rated as "no problem present" (0), "problem present" (1), or "does not apply" (X). A total score is derived by summing the responses for each item, with higher scores indicating more significant toileting problems. The POTI is designed for individuals with intellectual disabilities from age 4 years throughout adulthood. Matson, Neal, Hess, and Kozlowski (2011) established that the POTI questionnaire has good internal consistency, with a Cronbach alpha coefficient reported of 0.83.

Matson, Horowitz, and Sipes (2011) investigated the prevalence of toileting problems in 153 adults with intellectual disability. The POTI was used to determine which toileting problems were the most frequent. Their analysis revealed that the most frequently reported problems were "has a toileting accident during the day," "has toileting accidents during the night," and "has had wet underwear in the past month." The least frequently reported problems were "others tease the individual about the odor" and "the individual is rejected by peers due to toileting problems." Horovitz et al. (2011) found there were significant differences in toileting problems based on scores on the POTI, in relation to verbal ability of the participant. Participants who were nonverbal scored significantly higher POTI scores, than those who were verbal. Results showed that participants who were verbal scored a mean of 7.66 on the POTI scale, in comparison to those who were nonverbal who scored significantly higher, an average of 10.31.

Belva, Matson, Barker, Shoemaker, and Mahan (2011) examined the relationship between toileting problems and adaptive functioning in individuals with intellectual disabilities. The authors hypothesized that poorer adaptive functioning would be associated with more toileting difficulties. They examined 80 individuals, ranging from 23 to 72 years with intellectual disabilities ranging from mild to profound. They concluded that higher adaptive functioning is associated with significantly fewer toileting problems. Individuals that scored highly on the POTI scored lower on the Vineland Adaptive Behavior Scales, 2nd edition (VABS-II; Sparrow, Cicchetti, & Balla, 2005).

Screening Tool of fEeding Problems (STEP)

Feeding problems are a co-occurring issue in individuals with ASD (Mannion & Leader, 2013). These feeding problems, including food selectivity, food refusal, and mealtime tantrums, can be a great source of challenging behavior for the individual themselves, parents, caregivers, staff members, and for anyone interacting with the individual during mealtimes. Matson and Kuhn (2001) developed the Screening Tool of fEeding Problems (STEP) to identify feeding problems in adults with an intellectual disability. The STEP consists of 23 items. Problems are organized into five categories. These are aspiration risk, feeding skills, selectivity, feeding skills, behavior problems, and nutrition (Kuhn & Matson, 2008). Matson and Kuhn (2001) found test-retest reliability to be 0.72, while cross-rater

reliability was found to be 0.71. Kuhn and Matson (2008) commented that the psychometric properties for the measure are modest.

Fodstad and Matson (2008) compared feeding problems in those with intellectual disabilities, with and without autism. Individuals with ASD and intellectual disability displayed more behaviorally based feeding issues like food selectivity and refusal related behaviors than those with intellectual disability alone. The ASD and intellectual disability group had more severe feeding and mealtime problems than the intellectual disability alone group (Fodstad & Matson, 2008).

Screening Tool of fEeding Problems for Children (STEP-CHILD)

As well as measures designed for adults with ASD, there are also measures designed for children with ASD. The Screening Tool of fEeding Problems for Children (STEP-CHILD; Seiverling, Hendy, & Williams, 2011) is an informant-based questionnaire, which measures feeding problems in children. The STEP-CHILD contains 15 items. Factor analysis yielded six subscales; (1) Chewing Problems, (2) Rapid Eating, (3) Food Refusal, (4) Food Selectivity, (5) Vomiting, and (6) Stealing Food. Caregivers report the number of times their child has exhibited each feeding problem using a three-point rating scale. The subscales demonstrated a mean internal validity of 0.62 (Seiverling et al., 2011). Seiverling et al. (2011) examined convergent validity and it was confirmed by expected associations with another psychometrically tested measure of feeding problems, the Children's Eating Questionnaire (CEBQ; Wardle, Guthrie, Sanderson, & Rapoport, 2001).

Conclusion

Challenging behaviors are a common co-occurring issue for individuals with ASD. This chapter has focused on challenging behaviors, such as SIB, aggressive/destructive behaviors, and stereotyped behaviors. It also included other lesser researched challenging behaviors such as toileting problems and feeding problems. These challenging behaviors need to be addressed more in future research. A review has been given of the different measures used to assess the function of challenging behaviors. More research is needed to compare these scales with experimental functional analysis in order to determine whether these scales can identify the function of challenging behaviors as effectively as functional analysis. Functional assessments are an efficient way of assessing the function of a challenging behavior, as they are much less time-consuming than functional analysis. However, their validity needs to be compared to functional analysis, in order to determine whether they are as reliable as functional analyses.

Scales used to identify challenging behaviors have also been discussed. While there are a variety of scales available to assess the presence of challenging behavior, there are a limited number of scales that have been validated for use for individuals with ASD. All too often, these scales have been used with typically developing individuals or individuals with intellectual disabilities. For some measures, they have been used with adults with ASD only. It is therefore important that these scales are validated for use with preschool-aged children and school-aged children if they are to be used with these populations. While scales may have been validated for use for individuals with ASD, measures are also available that have been specifically designed for individuals with ASD. Where possible, it is best to use measures that can distinguish between the challenging behaviors that those with ASD present with and challenging behaviors exhibited by those without ASD.

Much more research is needed on the use of these challenging behavior scales in individuals with ASD. We need to better understand how challenging behaviors present in babies and infants, preschoolers, school-aged children, and adolescents. We need to understand how challenging behaviors change as children age. We also need to understand how common challenging behaviors are in younger and older adults with ASD. Little is known about challenging behaviors in an adult population with ASD. While we know more about challenging behaviors in adults

with intellectual disabilities, research is needed in adults with high-functioning ASD, and adults with ASD alone. We need to understand how comorbid medical and psychiatric conditions, such as gastrointestinal symptoms, epilepsy, attention-deficit/hyperactivity disorder (AD/HD), anxiety, depression, and sleep problems, affect challenging behaviors in individuals with ASD of all ages. By better understanding challenging behavior, more effective interventions can be designed to treat these challenging behaviors and in turn improve an individual's quality of life and the quality of life of parents and caregivers.

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Anxiety Disorders and Obsessive-Compulsive Disorders (OCD)

13

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Introduction

Anxiety disorders and obsessive-compulsive disorder (OCD) are among the most common psychiatric comorbidities seen in youth (e.g., Joshi et al., 2010; White, Oswald, Ollendick, & Scahill, 2009) and adults (e.g., Buck et al., 2014; Hofvander et al., 2009) with autism spectrum disorder (ASD). Although prevalence estimates vary widely across studies (11–84 %; Kerns & Kendall, 2012; White et al., 2009), researchers generally agree that individuals with ASD are at increased risk of experiencing anxiety disorders and OCD. A recent meta-analysis found that approximately 40 % of children and adolescents with ASD have at least one anxiety disorder (van Steensel, Bögels, & Perrin, 2011). This rate is significantly higher than that found in the general population (Costello, Egger, & Angold, 2005; Kessler, Petukhova, Sampson, Zaslavsky, & Wittchen, 2012) and in many other clinical groups, such as learning disabilities (Burnette et al., 2005), specific language impairments (Gillott, Furniss, & Walter, 2001), and Williams syndrome (Rodgers, Riby, Janes, Connolly, & McConachie, 2012). Although the majority of research in this area has focused on youth with average or above cognitive abilities, it appears that anxiety affects a wide range of individuals with ASD, across ages (e.g., Davis et al., 2010; Joshi et al., 2013) and intellectual abilities (e.g., Helverschou & Martinsen, 2011; Moseley, Tonge, Brereton, & Einfeld, 2011).

Co-occurring anxiety or OCD can cause significant distress and impairment for individuals with ASD, negatively affecting daily living skills, school or occupational performance, peer relationships, family functioning, and parental stress (Drahota, Wood, Sze, & van Dyke, 2011; Kerns, Kendall, et al., 2015; Reaven, 2009). Anxiety problems may be particularly debilitating in the context of ASD by further exacerbating or amplifying core ASD symptoms, such as impaired social reciprocity and communication, and triggering disruptive behaviors, such as aggression, tantrums, and self-injury (e.g., Sukhodolsky et al., 2008; Wood & Gadow, 2010). Co-occurring anxiety has also been

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associated with increased loneliness, depressive symptoms, and negative automatic thoughts in individuals with ASD (Kerns, Kendall, et al., 2015; Mayes, Calhoun, Murray, & Zahid, 2011; White & Roberson-Nay, 2009).

The remarkably high rates of co-occurring anxiety or OCD, coupled with the associated impairments, highlight the importance of routinely assessing all individuals with ASD for these conditions. Unfortunately, anxiety and OCD often go unrecognized or misdiagnosed in the context of ASD (MacNeil, Lopes, & Minnes, 2009). The assessment of anxiety and OCD in this population can be problematic for multiple reasons. One source of challenge comes from overlapping symptoms, such as limited eye contact, social avoidance, and ritualistic behavior. This phenotypic overlap makes it difficult to determine whether seemingly anxious behaviors are due to anxiety or are a component of ASD. In many cases, anxiety or OCD symptoms are attributed to the diagnosis of ASD and thus overlooked as a distinct disorder. This is an example of diagnostic overshadowing (Mason & Scior, 2004), meaning that the salience of ASD overshadows the recognition of a true psychiatric comorbidity. Diagnostic overshadowing is a major concern because it detracts from learning how ASD and anxiety disorders or OCD manifest clinically, interfere with daily functioning, and complicate treatment.

A related problem is the tendency to miss atypical or unusual presentations of anxiety and OCD in individuals with ASD (Kerns et al., 2014). For example, a person with ASD may express anxiety as increased repetitive behaviors, sensory-seeking or sensory-avoiding behaviors, and aggression (Stoddart, Burke, & King, 2012), and these behaviors are not typically captured by current assessment tools. Additional diagnostic challenges include the cognitive impairments and difficulties with communication, introspective thinking, insight, and emotion identification often seen in individuals with ASD (Reaven, 2009).

Although the identification of anxiety or OCD in the context of ASD may be difficult, it is certainly possible to distinguish these disorders with a thorough evaluation and sound clinical judgment. Accurately identifying co-occurring anxiety or OCD has considerable implications for case conceptualization and treatment planning with individuals with ASD. For example, it is likely that unaddressed anxiety can undermine potential treatment gains from social skill interventions by interfering with learning and practice of social skills (White et al., 2010). Yet, there is little guidance or agreement about how to best assess anxiety and OCD in this population, which leaves many clinicians and researchers feeling uncertain and undertrained to make these distinctions.

This chapter offers a comprehensive review of current methods and procedures available to help make differential or dual diagnoses of anxiety and OCD with ASD. The first section of this chapter provides an overview of available anxiety and OCD measures for use with individuals with ASD. The second section presents practical, evidence-based recommendations for the assessment of particular anxiety disorders and OCD. Finally, avenues for future research and key clinical practice points are discussed.

The majority of previous research in this area has focused on youth without cognitive impairment. Fewer studies have examined anxiety and OCD in adults with ASD (regardless of cognitive level) or in individuals with ASD and co-occurring intellectual disability (ID). As a result, the information provided in this chapter is most representative of a higher functioning population of children and adolescents with ASD. When available, empirically based recommendations specific to adults with ASD or individuals with co-occurring ID will be discussed.

Measures to Assess Anxiety and OCD in ASD

Much research on anxiety in ASD and OCD has relied on measures developed and validated in non-ASD populations. The ability of these measures to accurately capture the constructs of anxiety and OCD in individuals with ASD is under investigation (Grondhuis & Aman, 2012; Kerns & Kendall, 2012; van Steensel et al., 2011).

Research has begun to explore the psychometric properties of current anxiety and OCD measures in ASD samples and, further, to adapt these measures to better differentiate and capture overlapping and atypical symptoms. This section will review the pros and cons of a selection of anxiety and OCD measures that have received the most empirical attention for individuals with ASD. To cover a broad range of clinical assessment needs, we review measures designed for brief and comprehensive assessment, screening and diagnosis, broad anxiety symptoms and specific diagnoses, as well as measures suitable for a varied range of ages and intellectual ability (see also: Grondhuis & Aman, 2012; Lecavalier et al., 2014; Wigham & McConachie, 2014).

Semi-structured Clinical Interviews

The *Anxiety Disorders Interview Schedule—Child/Parent Versions* (ADIS-C/P; Silverman & Albano, 1996) is a semi-structured interview that combines child and parent report with expert clinical judgment to assess anxiety and related disorders in children ages 7–18 years. Considered the "gold-standard" for assessing anxiety disorders in youth without ASD, the ADIS-C/P has empirical support as a reliable and valid tool for cognitively able youth on the spectrum. The ADIS-C/P has demonstrated inter-rater reliability (0.77–1.00; Ung et al., 2014), sensitivity to change (White et al., 2013; Wood et al., 2009), and convergent and divergent validity in youth with ASD seeking anxiety treatment (Renno & Wood, 2013). Notably, parent/child agreement on the ADIS-C/P can be poor (Storch et al., 2013), and some studies have relied on parent report alone (Keehn, Lincoln, Brown, & Chavira, 2013; Reaven, Blakeley-Smith, Culhane-Shelburne, & Hepburn, 2012). In addition, the ADIS-C/P is lengthy, often requiring upwards of 2 h to complete for children with complex clinical presentations. As such, the ADIS-C/P may be most useful when precise clinical characterization is needed for research or when determining clinical diagnoses and developing treatment plans. An adult version of the ADIS (Brown, DiNardo, & Barlow, 1994) is available and may be useful for cognitively able individuals with ASD (Maddox & White, 2014), though this version has yet to be psychometrically evaluated in an ASD sample.

In a sample of 59 non-treatment-seeking youth with ASD, Kerns et al. (2014) found convergent and discriminant validity as well as inter-rater and 2-week test-retest reliability (in a small subsample) for an expanded version of the ADIS--C/P, the *ADIS/Autism Spectrum Addendum* (ADIS/ASA). The ADIS/ASA was designed to differentiate overlapping symptoms and capture atypical manifestations of anxiety in ASD (e.g., social avoidance, repetitive behavior, fears of change or unusual stimuli). The retest and inter-rater reliability of the ADIS/ASA needs further assessment in a larger ASD sample. Further, how inclusion of the ASA items may influence hit rates for other psychiatric disorders on the ADIS--C/P requires exploration. Atypical phobias and fears of change are not exclusive to youth with ASD. Rather, it is widely acknowledged that symptoms of childhood anxiety, with or without co-occurring ASD, do not always adhere to the *Diagnostic and Statistical Manual of Mental Disorders* (DSM) criteria (Regier, Narrow, Kuhl, & Kupfer, 2009). As such, the ASA may be useful not only for youth with ASD, but also in cases where ASD is suspected, but not yet diagnosed or when atypical presentations of anxiety are endorsed. In some cases, administration of the ADIS/ASA may raise concerns for ASD in not previously diagnosed individuals.

Other semi-structured diagnostic interviews for youth with ASD include the *Autism Comorbidities Interview, Present and Lifetime* (ACI; Leyfer et al., 2006), a version of the Kiddie—Schedule for Affective Disorders and Schizophrenia (K-SADS; ages 5–17), which requires 1–3 h to complete, and the briefer, 60-min *Children's Interview for Psychiatric Syndromes-Parent Version* (P-ChIPS; Weller, Weller, Teare, & Fristad, 1999). The ACI, which relies solely on parent report, was expressly developed for youth with ASD; however, preliminary testing of the ACI established inter-rater reliability and concurrent validity for only OCD, attention-deficit/hyperactivity disorder (ADHD),

and major depressive disorder, and not the anxiety disorders (Leyfer et al., 2006). The P-ChIPS assesses 20 psychiatric disorders, including anxiety disorders, in youth ages 6–17 years. It has demonstrated inter-rater reliability for phobias, generalized, separation, and social anxiety disorders, but more limited inter-rater agreement for OCD symptoms, ADHD, and mood disorders in youth with IQ < 70 (Witwer, Lecavalier, & Norris, 2012). Further research is needed to validate the ACI and P-ChIPS for ASD research. Nonetheless, both measures offer certain advantages. The ACI measures both lifetime and current disorders, a useful aspect for epidemiological research. The P-ChIPS is considerably shorter than other semi-structured interviews, which may enhance its usability in clinical and research settings.

Though not a diagnostic tool, the *Pediatric Anxiety Rating Scale* (PARS; RUPP, 2002) combines child and parent reports with clinical judgment to provide a continuous measure of anxiety symptoms, spanning panic, phobias, separation, social, and generalized anxiety disorders in youth ages 6–17 years. The PARS was designed as a treatment outcome measure, appears sensitive to change in cognitively able children with ASD (Storch et al., 2013), and takes only 30–60 min to administer (RUPP, 2002). Its psychometric properties in youth with ASD are variable. Storch, Ehrenreich-May, et al. (2012) found moderate internal consistency ($\alpha = 0.59$) and acceptable inter-rater and 26-day retest reliability, as well as convergent validity with other anxiety measures in cognitively able youth with ASD seeking treatment; however, evidence for discriminant validity was limited. In a small sample of cognitive able youth with ASD (non-treatment seeking), Kerns, Maddox, et al. (2015) found that the PARS was an effective tool for ruling in the presence of anxiety (e.g., specificity is high), but lacked sensitivity. That is, the PARS may lead clinicians to incorrectly rule out clinically significant anxiety in youth with ASD. Further research may be needed to improve the sensitivity of the PARS, particularly in non-treatment-seeking (i.e., lower-risk) samples.

With regard to OCD assessment, the *Yale-Brown Obsessive Compulsive Scale* (Y-BOCS; Goodman et al., 1989) and *Children's Yale-Brown Obsessive Compulsive Scale* (CY-BOCS; Scahill et al., 1997) are clinician-administered interviews designed to measure the symptom severity of obsessions and compulsions in adolescents/adults (age 14+ years) and children (age 6–14 years), respectively. The Y-BOCS has demonstrated inter-rater reliability and sensitivity to change in cognitively able adults with ASD (Russell, Mataix-Cols, Anson, & Murphy, 2005, 2008), although evaluations of its retest reliability, convergent, and discriminant validity are still needed. The CY-BOCS has demonstrated internal consistency, inter-rater reliability, convergent and discriminant validity in cognitively able youth with ASD seeking treatment for anxiety (Wu et al., 2013). It has also been modified to measure repetitive behavior in youth with ASD by excluding all obsession-related items (i.e., the CY-BOCS-PDD; Scahill et al., 2006). The CY-BOCS-PDD has demonstrated reliability and convergent validity with other measures of repetitive behavior, as well as sensitivity to change (McDougle et al., 2005; Scahill et al., 2006). However, it is a measure designed to assess the severity of repetitive behaviors in ASD rather than to differentiate ASD and OCD-related behaviors per se. When differential diagnosis of ASD and OCD is the focus of evaluation, the original CY-BOCS, ACI, and ADIS/ASA may be more useful.

Informant- and Self-Report Measures for Youth with ASD

A number of informant and self-report measures of child behavior have been utilized and assessed in youth with ASD. These include general measures of psychopathology with anxiety subscales and anxiety-specific scales. Because these measures are brief, continuous in nature, and completed by youth and their caregivers, they can—when reliable and valid—provide a quicker, more efficient means to screen for anxiety problems or track symptom change over time. Below we summarize research on the reliability and validity of various anxiety questionnaires in youth with ASD.

Broad Child Psychopathology Questionnaires with Anxiety Subscales

The *Child and Adolescent Symptom Inventory* (CASI; 5–18 years, 120–163 items; Gadow & Sprafkin, 2002) and related *Early Childhood Inventory* (3–5 years; Gadow & Sprafkin, 1997) and *Child Symptom Inventory* (5–12 years; 87–97 items; Gadow & Sprafkin, 2002) have been used in several studies to assess anxiety in a wide age range of youth with ASD (Gadow, Roohi, DeVincent, Kirsch, & Hatchwell, 2010; Guttmann-Steinmetz, Gadow, DeVincent, & Crowell, 2010; Hallett, Lecavalier, et al., 2013; Roohi, DeVincent, Hatchwell, & Gadow, 2009; Sukhodolsky et al., 2008; Weisbrot, Gadow, DeVincent, & Pomeroy, 2005). The original CASI-4 asks parents or teachers to rate the frequency of various *Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition* (DSM-IV) referenced symptoms, including 26 anxiety items covering post-traumatic stress, obsessions, compulsions, specific phobia, generalized, separation, and social anxiety symptoms. Sukhodolsky and colleagues (2008) created a modified, 20-item CASI-4 anxiety scale for use in ASD. This revised subscale has demonstrated internal consistency in youth with varied intellectual functioning (Hallett, Lecavalier, et al., 2013) as well as convergent validity in youth without intellectual disability (White, Schry, & Maddox, 2012). Notably, parent/adolescent agreement for this subscale may be limited (White et al., 2012), and items involving verbal worry appear less endorsed for youth with ASD (Hallett, Lecavalier, et al., 2013). In addition, research has yet to determine whether this subscale is sensitive to symptom change, or whether it is a sensitive and specific screener for anxiety disorders in ASD. The CASI-4's DSM-based items may not correspond well with the more unusual anxiety symptoms in ASD.

The *Behavioral Assessment System for Children—Second Edition* (BASC-2; Reynolds & Kamphaus, 2004) is a 126- to 148-item self/parent/teacher rating of various childhood behaviors for youth 2–21 years (preschool, child, and adolescent versions) that includes anxiety and internalizing subscales. Rieske et al. (2013) reported convergent validity between the BASC-2 and the Worry/Depressed subscale of the Autism Spectrum Disorder—Comorbidity for Children (ASD-CC; Matson, LoVullo, Rivet, & Boisjoli, 2009) measure in children (ages 2–16 years) with ASD. Still, further research is needed to determine the reliability, sensitivity to change, and discriminant validity of the BASC-2 in youth with ASD. In a small sample of cognitively able youth with ASD (Kerns, Maddox, et al., 2015), the BASC-2 (child and parent versions) demonstrated limited sensitivity to detect anxiety disorders, a cautionary finding given that the BASC-2 is often used to screen for anxiety and may lead clinicians to prematurely rule out anxiety in a child with ASD.

The parent-reported *Child Behavior Checklist* (CBCL; Achenbach, 1991) and related *Teacher's Report Form* (TRF; Achenbach, 1991) are 118- to 120-item questionnaires of adaptive and problem behaviors, and they include internalizing and anxious/depressed subscales. Preschool, child, and adolescent versions are available for ages 1.5–18 years. Though widely used in youth without ASD, there is limited research on the psychometrics of the CBCL in samples with ASD, and several studies suggest that youth with ASD generally show elevated scores on this measure across internalizing and externalizing domains (Holtmann, Bölte, & Poustka, 2007; Hurtig et al., 2009). Initial research suggests that the CBCL may not be as reliable in youth with intellectual disability (Embregts, 2000). Pandolfi, Magyar, and Dill (2009) found support for the factor structure of the CBCL in preschoolers with ASD; however, internal consistency was lower relative to that seen in youth without ASD. Further, the CBCL's limited coverage of anxiety symptoms (14 items) may limit its use as an anxiety outcome measure in ASD (Lecavalier et al., 2014). An Adult Behavior Checklist (ABCL; Achenbach, 1997) and Adult Self-Report (ASR; Achenbach, 1997) are also available, but are just beginning to be explored as tools for adults with ASD (Gotham, Unruh, & Lord, 2014).

Child Anxiety Questionnaires

The *Multidimensional Anxiety Scale for Children* (MASC; March, 1998) is a 39-item youth/parent questionnaire of various anxiety symptoms across four domains: physical symptoms, social anxiety, harm avoidance, and separation/panic. In their recent review, Lecavalier et al. (2014) described the MASC as a potentially appropriate outcome measure for youth with ASD, with conditions. The MASC has shown sensitivity to change (Storch et al., 2013; Wood et al., 2009), as well as good internal consistency (Wood et al., 2009) and modest convergent validity with the PARS in cognitively able ASD samples ($r=0.4$; Storch, Wood, et al., 2012). However, studies also suggest differences in the factor structure of the parent-reported MASC in youth with vs. without ASD, as well as poor child/parent agreement (White, Lerner, et al., 2015; White et al., 2012). Many MASC items are dependent on child verbal ability, a potential issue for youth with ASD and intellectual or communication deficits. Research is also needed to assess the sensitivity, specificity, and retest reliability of this tool in ASD samples.

The *Spence Children's Anxiety Scale* (SCAS; Spence, 1998) is a 44-item parent/child frequency rating of physical injury fears, panic, obsessive-compulsive, separation, social, and generalized anxiety symptoms that has shown sensitivity to change in cognitively able youth with ASD (Chalfant, Rapee, & Carroll, 2007; Sofronoff, Attwood, & Hinton, 2005). Several studies suggest acceptable parent-child agreement for SCAS total scores, as well as acceptable internal consistency for the total and subscales scores in cognitively able adolescents with ASD (Farrugia & Hudson, 2006; Keehn et al., 2013; Sofronoff et al., 2005). Other studies report discrepancies in child/parent ratings (Russell & Sofronoff, 2005) and limited internal consistency for the obsessive/compulsive and physical injury subscales (Ozsivadjian, Hibberd, & Hollocks, 2014). A recent study found support for the sensitivity and specificity of the parent-reported SCAS in non-treatment-seeking samples (Zainal et al., 2014); however, the retest reliability, convergent validity, and discriminant validity of this tool in ASD samples require study.

The *Screen for Anxiety and Related Emotional Disorders* (SCARED; Birmaher et al., 1999) is a 41-item parent/youth questionnaire of panic, generalized, social, and separation anxiety symptoms. Several treatment studies suggest that the SCARED is sensitive to anxiety change in youth with ASD (Reaven et al., 2009, 2012; Weiss, Viecili, & Bohr, 2014), yet tests of its reliability and validity in this subgroup are scant. In a sample of verbally fluent children with ASD, Blakeley-Smith, Reaven, Ridge, and Hepburn (2012) found moderate to strong parent-child agreement on the SCARED total and subdomain scores. Stern, Gadgil, Blakeley-Smith, Reaven, and Hepburn (2014) found support for a similar factor structure and internal consistency for the SCARED in treatment-seeking youth with and without ASD as well as good sensitivity and specificity. However, in a non-treatment-seeking sample of cognitively able youth with ASD, Kerns, Maddox, et al. (2015) found that the SCARED demonstrated limited sensitivity and specificity. These studies underscore the importance of further exploring the performance of the SCARED in youth who are not already seeking services for anxiety.[1]

The *Revised Children's Manifest Anxiety Scale* (RCMAS; Reynolds & Richmond, 1985) asks youth to complete 37 yes/no questions across three anxiety symptom domains (i.e., physiological, worry/oversensitivity, and social concerns/concentration). Though the RCMAS has shown sensitivity to change in cognitively able youth with ASD (Chalfant et al., 2007), Mazefsky, Kao, and Oswald (2011) found the sensitivity and specificity of the tool to be limited in a small sample of youth with ASD. The retest

[1] The Dutch version of the SCARED, the SCARED-71 (Bodden, Bögels, & Muris, 2009), is an expanded, 71-item questionnaire that assesses social, separation, and generalized anxiety, panic, specific phobia, post-traumatic stress disorder, and OCD symptoms. van Steensel, Deutschman, and Bögels (2012) reported construct validity and acceptable internal consistency for total and subscales scores (except OCD) in cognitively able youth with ASD and anxiety difficulties. Discriminant validity, however, was less than that observed for youth without ASD and a raised cut-off was needed to improve sensitivity and specificity.

reliability, convergent validity, and divergent validity of the tool in ASD samples have yet to be evaluated. The RCMAS measures the presence, not the severity, of symptoms and relies solely on child self-report. As such, its use as a treatment outcome measure for youth with ASD may be limited (Lecavalier et al., 2014).

The *Social Worries Questionnaire* (SWQ; Spence, 1995) is a brief parent and child report about avoidance of social evaluation situations, with 10 and 13 items, respectively. The SWQ has shown acceptable internal consistency and sensitivity to change in studies of cognitively able youth with ASD (Russell & Sofronoff, 2005; Sofronoff et al., 2005). Gillott et al. (2001) found weak agreement between parent and youth reports ($r = 0.28$) in their sample of cognitively able children with ASD. Assessment of the retest reliability, sensitivity/specificity, convergent validity, and divergent validity of the tool in ASD is needed.

Other Anxiety Measures to Consider

In their review, Lecavalier et al. (2014) identified the *Revised Child Anxiety and Depression Scale* (RCADS; Chorpita, Yim, Moffitt, Umemoto, & Francis, 2000) as a potentially appropriate anxiety measure for youth with ASD. The RCADS is a 47-item self/informant report measure of mood, obsessive-compulsive, panic, separation, social, and generalized anxiety symptoms. Though the RCADS has been tested in only one study of youth with ASD, it demonstrated strong internal consistency for total scores and individual subscales (Hallett, Ronald, et al., 2013). Other promising measures include the *Social Phobia Anxiety Inventory for Children* (SPAI-C; Beidel, Turner, & Morris, 1995) and *Social Anxiety Scale Child—Revised* (SASC-R; La Greca & Stone, 1993), which Kuusikko et al. (2008) revised for use in cognitively able youth with ASD by removing items that might overlap with ASD itself (e.g., "I try to avoid social situations"). Internal consistency was excellent for both original and revised SPAI-C and SASC-R total scores, including the SASC-R Fear of Negative Evaluation subscale, but modest for revised subscales (e.g., Behavioral Avoidance).

Assessing fears of negative evaluation and other anxious thoughts/attributions can be an important element of anxiety assessment and treatment planning in cognitively able youth with ASD. Specifically, measures that capture anxious thoughts/attributions, such as the *Negative Affect Self-Statements Questionnaire* (NASSQ; Ronan, Kendall, & Rowe, 1994) and the *Children's Automatic Thoughts Scale* (CATS; Schniering & Rapee, 2002), may help differentiate social avoidance from social anxiety, guide the use of cognitive interventions (e.g., cognitive restructuring), and tap into a broader array of anxiety difficulties in youth with ASD, including more atypical worries and fears (Kerns et al., 2014). In cognitively able youth with ASD, the CATS has shown sensitivity to treatment effects (Chalfant et al., 2007). The NASSQ has shown acceptable internal consistency as well as moderate sensitivity (0.78) and specificity (0.59) to detect anxiety disorders (Kerns, Maddox, et al., 2015). Further research is needed to validate these potentially promising tools.

Measures of Anxiety in ASD for Adults and Individuals with ID

Research on the assessment of anxiety in individuals with ID, with and without ASD, has lagged behind that of individuals without intellectual deficits (Hagopian & Jennett, 2008). The *Autism Spectrum Disorders—Comorbidity for Children* (ASD-CC; Matson, LoVullo, et al., 2009) is a 39-item informant-rated anxiety scale designed to assess anxiety in youth (ages 2–16 years) with ASD and varied intellectual functioning. The ASD-CC Worry/Depressed subscale has shown convergent and discriminant validity with similar and dissimilar subscales of the BASC-2 (Rieske et al., 2013), but its retest reliability, sensitivity, and specificity have yet to be evaluated. In addition, the *Anxiety Depression and Mood Scale* (ADAMS; Esbensen, Rojahn, Aman, & Ruedrich, 2003) is a 28-item informant-rated scale of behaviorally based mood and anxiety symptoms that has shown promising psychometrics in youth with ID. Though untested in individuals with ASD, the ADAMS is a potentially appropriate measure for this group

given its brief nature and behavioral emphasis. Finally, the *Baby Infant Screen for Children with aUtIsm Traits—Part 2* (BISCUIT; Matson, Fodstad, & Mahan, 2009), *Diagnostic Assessment for the Severely Handicapped-II* (DASH-II; Matson, 1995), *Psychopathology in Autism Checklist* (PAC; Helverschou, Bakken, & Martinsen, 2009), and *Developmental Behavior Checklist* (DBC; Einfeld & Tonge, 1995) have been used in some studies to assess anxiety problems in youth with ASD and ID (e.g., Bakken et al., 2010; Bradley, Summers, Wood, & Bryson, 2004; Brereton, Tonge, & Einfeld, 2006; Helverschou & Martinsen, 2011). All are informant ratings designed to assess a range of behavior problems that include anxiety subscales. Such measures may be most helpful for screening or early stages of assessment, and they should be followed by a more comprehensive interview with multiple informants and behavioral observation of the individual.

Very few studies have focused on the assessment of anxiety problems in adults with ASD. Matson and Boisjoli (2008) evaluated the psychometrics of the *Autism Spectrum Disorders—Comorbidity for Adults* (ASD-CA) measure, an informant scale to assess comorbid psychopathology in adults with ASD and ID. The ASD-CA items and factors demonstrated variable inter-rater reliability (0.07–0.77) and internal consistency (0.44–0.91); however, results of the exploratory factor analysis were promising and the overall internal consistency for the scale was good (0.91). The 21-item Beck Anxiety Inventory (BAI; Beck & Steer, 1993) has also been found to be a reliable tool for assessing anxiety in adults with and without intellectual disability (Lindsay & Skene, 2007). The BAI has been used to assess anxiety in adults with ASD in several studies, though psychometric data is lacking (Cath, Ran, Smit, van Balkom, & Comijs, 2008; Lai et al., 2011). Similarly, the *Liebowitz Social Anxiety Scale* (LSAS; Heimberg et al., 1999), a 24-item self-report of social anxiety symptoms, has been used to assess social anxiety in cognitively able adults with ASD in some studies with good internal consistency (Cath et al., 2008; Dziobek, Gold, Wolf, & Convit, 2007; Kanai et al., 2011). Further research on its reliability and validity in ASD samples is needed.

Summary

Research suggests that there is both considerable overlap and also variability in the presentation of anxiety and OCD in people with and without ASD (Kerns & Kendall, 2012; Ozsivadjian, Knott, & Magiati, 2012; White, Lerner, et al., 2015). As such, existing anxiety and OCD measures have much to offer clinicians and researchers, and also considerable room for improvement. ASD-specific adaptations are needed and emerging (Kerns et al., 2014; Kuusikko et al., 2008; Leyfer et al., 2006; Sukhodolsky et al., 2008), but may limit comparisons across individuals with and without ASD (van Steensel et al., 2011). Specifically, comparisons across studies and samples may be complicated by methodological differences (i.e., use of different tools) and conceptual differences (i.e., discrepancies in how anxiety is conceptualized). In general, it is highly recommended that researchers and clinicians use multiple methods, including expert clinical judgment, direct observation, and multiple informants to accurately assess anxiety and OCD in ASD. Given that rating scales often yield higher than expected scores for people with ASD, clinicians must be cautious about interpreting scores (which may be elevated due to other difficulties associated with ASD) and should not rely on a single indicator. Multi-informant assessment may be particularly important when parent-youth reports tend to be discrepant, as in youth with ASD (e.g., Gillott et al., 2001; Russell & Sofronoff, 2005; White et al., 2012). This type of multifaceted approach will improve understanding of the constructs of anxiety and OCD in ASD, as well as the strengths and weaknesses of various individual measures.

Recommendations for Diagnosing Anxiety and/or ASD

Determining whether psychiatric symptoms in individuals with ASD are part of core ASD features or whether they represent anxiety is a complex clinical issue. This section highlights key points for differential and dual diagnostic

decision-making, in hopes of aiding the accurate identification of co-occurring anxiety disorders. Before providing recommendations for each anxiety disorder separately, several general guidelines are offered here.

Anxiety symptoms can be conceptualized along three dimensions: physiological, behavioral, and cognitive (Lang, 1968). Physiological symptoms include signs of arousal, such as tachycardia (i.e., quickened heart rate), blushing, trembling, and sweating, along with somatic complaints (e.g., nausea, headaches, muscle tension). The primary behavioral symptom of anxiety is avoidance of feared stimuli and situations. Behavioral avoidance may be obvious (e.g., running away from a bee) or more subtle (e.g., avoiding eye contact). Hypervigilance and checking are also common behavioral symptoms. Cognitive symptoms typically include catastrophic predictions and other negative thoughts. This model of anxiety provides a framework to determine whether an assessment battery covers all three domains. Given that ASD and anxiety share common features, it can be helpful to use this framework to organize an individual's different symptoms and determine whether an ASD diagnosis accounts for all presenting problems, or whether there is support across the three dimensions of anxiety to diagnose an anxiety disorder.

The *Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition* (DSM-5; APA, 2013) highlights how anxiety and fear may manifest differently in children (e.g., fear or anxiety may be expressed by crying, tantrums, freezing, or clinging). We encourage clinicians to think similarly about individuals with ASD of all ages—they may self-report and/or manifest anxiety symptoms in a different way than do individuals without ASD. For example, people with ASD may make vague statements about having "bad feelings" instead of "feeling anxious" (Kreiser & White, 2014). Based on a focus group with parents of youth with ASD, Ozsivadjian and colleagues (2012) identified five common categories for the ways that anxiety is expressed in this population: (1) challenging behaviors (e.g., tantrums), (2) avoidance or escape, (3) hyperactivity or heightened arousal, (4) increased sensory behaviors, and (5) increased repetitive behaviors. These categories highlight how, relative to typically developing individuals, anxiety in people with ASD can present similarly (e.g., avoidance, increased arousal) or differently (e.g., aggression), often amplifying the core ASD deficits (e.g., sensory or repetitive behaviors).

Diagnostic decisions are even more challenging without direct verbal expression from the individual. When assessing individuals with limited expressive language, clinicians must rely more on their assessment of behavioral and physiological symptoms of anxiety. One way to directly observe behavioral and physiological reactions to a feared stimulus is a behavioral avoidance test (BAT), an individualized task that involves gradually exposing a person to his or her feared stimulus to assess when avoidance and/or anxiety is displayed (Dadds, Rapee, & Barrett, 1994). BAT participants may also indicate their subjective experience of fear with Subjective Units of Distress Scale (SUDS) ratings and visual aids.

In order to constitute comorbidity of any anxiety disorder with ASD, the following should be established:

1. *The anxiety symptoms are not better accounted for by the ASD diagnosis*. To help tease apart anxiety symptoms from core ASD symptoms, clinicians can make a list with three columns: *ASD*, *anxiety*, and *unclear* (meaning the symptom could be due to ASD or anxiety). This list is then used to organize all available clinical information and determine which presenting concerns are not explained by ASD.
2. *The anxiety symptoms lead to additional distress and/or impairment beyond the ASD diagnosis*. According to the DSM-5, in order for an individual to meet full diagnostic criteria for an anxiety disorder, the anxiety, fear, or worry must result in impairment in at least one significant life domain (e.g., social, occupational, or academic functioning) or cause the person significant distress (APA, 2013). For a person with ASD and a co-occurring anxiety disorder, the anxiety symptoms should cause significant

negative impact on the individual's daily functioning, above and beyond the individual's baseline functioning with ASD.

3. *The individual's fear or anxiety is excessive or unreasonable relative to the actual threat posed by the feared object or situation*. According to the DSM-5, this distinction is determined by the clinician because many individuals with anxiety disorders overestimate the danger in feared or avoided situations (APA, 2013). Thus, it is important for the clinician to gather additional background information for this determination. For example, does the individual with ASD and social anxiety symptoms experience severe bullying or tormenting at school? If so, his fear of social interactions may be reasonable given the real threat in his daily environment.
4. *The onset of anxiety symptoms is marked by a change from the individual's baseline behaviors* (e.g., increase in aggressive behavior or restricted interest intensity). That is, do the anxiety symptoms represent a departure, either qualitatively or quantitatively, from the person's baseline level of functioning? Although this change from baseline is typically conceptualized as a change in behavior, it may also manifest as changes in thoughts or physiological arousal.
5. *The anxiety symptoms are not transient*. Transient anxiety occurs naturally as part of development and causes little interference in functioning. It is often associated with circumscribed events (e.g., public speaking, new situations) and ultimately dissipates with encouragement, reassurance, or habituation. Information about the specific contexts in which anxiety symptoms are experienced and are *not* experienced should be collected during the assessment to rule out transient anxiety. If the situation or object only occasionally provokes fear or anxiety, an anxiety disorder is not diagnosed.
6. *Avoidance of the object or situation is driven by anxiety or fear*. Hagopian and Jennett (2014, p. 156) distinguish between "simple avoidance" (i.e., avoidance of nonpreferred stimuli or mildly aversive situations, such as schoolwork) and "anxious avoidance" (i.e., avoidance that is associated with indicators of anxiety, such as increased physiological arousal and fearful facial expressions). Clinicians should have evidence for anxious avoidance before diagnosing an anxiety disorder. The continued display of distress after the eliciting stimulus has been avoided may suggest an anxiety disorder (Jennett, Vasa, & Hagopian, 2013). Conducting a functional analysis of the avoidant behavior can also provide helpful information during an assessment.

To provide more specific recommendations for distinguishing co-occurring anxiety symptoms from core ASD symptoms, the assessment of each anxiety disorder is described below. This information is based on the DSM-5 (APA, 2013), which takes a developmental lifespan perspective and presents anxiety disorders chronologically according to their average age of onset. As will be clear from this section, we currently know more about certain anxiety disorders in the context of ASD (e.g., Social Anxiety Disorder) than others (e.g., Panic Disorder, Agoraphobia).

Separation Anxiety Disorder

Separation anxiety disorder is characterized by developmentally inappropriate and excessive anxiety about separation from attachment figures, such as parents or caregivers (APA, 2013). Individuals with separation anxiety disorder experience persistent concerns about harm befalling attachment figures and about events that could result in separation from attachment figures (e.g., getting lost, being kidnapped). They often show reluctance or refusal to separate from attachment figures (e.g., going to school, sleeping away from home), nightmares involving the theme of separation, and physical symptoms of distress (e.g., headaches, stomachaches) when separation occurs or is anticipated. To meet diagnostic criteria for this disorder, the separation anxiety must be present for at least 4 weeks in children and adolescents, and typically lasts for at least 6 months in adults.

We recommend that clinicians pay close attention to the following considerations when assessing for possible comorbid separation anxiety disorder in individuals with ASD (Kerns et al., 2014; Leyfer et al., 2006):

Anxiety vs. rigidity. The DSM-5 notes that some symptoms of separation anxiety disorder may be better explained by ASD, "such as refusing to leave home because of excessive resistance to change" (APA, 2013, p. 191). The clinician should clarify that the individual's anxiety is due to attachment-related aspects of separation from his or her attachment figure, instead of a change in routine. If part of a routine (e.g., going to school each morning), can the person be apart from his or her attachment figure without signs of distress? Individuals with separation anxiety disorder often show anticipatory anxiety about separation from attachment figures, whereas individuals with ASD and associated rigid routines may only show distress when the change occurs. In addition, clinicians should gather information about whether the individual frequently wants to know the whereabouts of his attachment figures (e.g., frequent phone calls when apart), has difficulty staying in a room of the house by himself, and has fears of potentially dangerous situations to himself or family members (e.g., kidnappers, car accidents), all of which would increase one's confidence in the diagnosis of separation anxiety disorder.

Reality basis of fear. Due to the deficits associated with ASD, the individual may be highly dependent on his parent or caregiver for daily functioning needs. If this is the case, anxiety related to separation may not meet the DSM-5 criterion of "developmentally inappropriate and excessive fear or anxiety" (APA, 2013, p. 190).

Precipitating events. Details about the onset of separation anxiety symptoms and surrounding life events are important to collect. Research suggests that separation anxiety disorder in typically developing youth often develops after a life stress, particularly when the stress involves loss, such as the death of a family member or pet, change in schools, parental divorce, or move to a new house (APA, 2013).

Specific Phobia

Specific phobia is characterized by markedly intense and excessive fear or anxiety about a specific object or situation, leading to active avoidance or distress when the object or situation is endured (APA, 2013). The fear or anxiety is typically an immediate reaction to the specific object or situation and present for at least 6 months. There are five types of a specific phobia diagnosis: animal type (e.g., spiders, insects, dogs), natural environment type (e.g., heights, storms, water), blood-injection-injury type (e.g., needles, invasive medical procedures), situational type (e.g., airplanes, elevators, enclosed places), and other type (e.g., choking, vomiting, loud sounds, costumed characters).

For youth with ASD, specific phobia has been found in some studies to be the most common co-occurring disorder (e.g., Leyfer et al., 2006; Sukhodolsky et al., 2008; van Steensel et al., 2011), so it is likely that clinicians will encounter this comorbidity. We recommend the following considerations when assessing for possible comorbid specific phobia in individuals with ASD (Davis & Ollendick, 2014; Kerns et al., 2014; Kerns & Kendall, 2014; Matson & Nebel-Schwalm, 2007; Mayes et al., 2013):

Physiological reactions. Although physiological symptoms can be present in all anxiety disorders, they may be particularly prevalent in specific phobias, both in anticipation of or during exposure to the feared stimulus (APA, 2013). Individuals with animal, natural environment, and situational specific phobia types tend to show sympathetic nervous system arousal (e.g., increased heart rate), similar to the physiological manifestations of anxiety in other anxiety disorders. However, individuals with the blood-injection-injury type often have a vasovagal syncope (fainting) or near-fainting response because their initial increase in heart rate and blood pressure is followed by a drastic drop in both.

Unusual fears. Individuals with ASD may present with atypical fears that are not generally reported in the specific phobia literature, such as fear of vacuum cleaners or graffiti (Kerns et al., 2014; Mayes et al., 2013). Clinicians are encouraged to include open-ended questions when assessing for specific

phobia in people with ASD, given that standardized measures of fears may not capture the variety of unusual fears experienced by many of these individuals. If the presenting fear is excessive, unreasonable, distressing, circumscribed to a specific stimulus, and impairing to daily functioning, then it may meet criteria for specific phobia. Of note, typically developing youth have also been documented to experience unusual fears (e.g., buttons, mushrooms), so this type of specific phobia is not exclusive to ASD (Davis & Ollendick, 2014).

General hypersensitivity. Hypersensitivity to sensory input is part of the recently revised ASD diagnostic criteria (APA, 2013), and a specific phobia diagnosis may not be warranted if the fear is part of a generalized sensitivity. For example, an individual with hypersensitivity to most noises may show distress at the sound of a specific tone, but this distress is better accounted for by the ASD diagnosis. By comparison, an individual who does not exhibit a general sensitivity to noise but responds with excessive fear and avoidance to particular tones, noises, or other sensory stimuli (e.g., sight of men with beards) may meet criteria for specific phobia.

Restricted interests. Clinicians should consider whether the person's restricted interest is related to the stimulus endorsed by a caregiver as causing fear. For example, a child with ASD may spend hours each day researching thunderstorms and checking the weather station due to his intense interest in weather, and this type of preoccupation should be distinguished from a specific phobia of storms. If the child displays negative affect about future exposure to storms and avoids news about the weather, a diagnosis of specific phobia may be appropriate.

Stability. To meet criteria for specific phobia, the fear typically lasts for 6 months or more, meaning that it is not a transient fear following a frightening encounter or experience. This point is particularly relevant when assessing individuals with ASD because they often become "stuck" or perseverate on a negative event (e.g., choking on a piece of food, losing electricity due to a lightning storm) for longer than is expected, but perseveration with associated distress does not necessarily equate to a specific phobia and often shows a more transient pattern.

Social Anxiety Disorder

Social anxiety disorder (SAD) is characterized by an excessive and persistent fear of social scrutiny that typically lasts for at least 6 months (APA, 2013). For children to be diagnosed with this disorder, their social anxiety must occur with peers and not just with adults. An individual with SAD fears that he or she will experience embarrassment or negative evaluation by others in social or performance situations (e.g., attending a party, eating or drinking in front of others, maintaining a conversation, giving a speech), which often leads to avoidance of these situations. The DSM-5 places an increased emphasis on the role of fear of negative evaluation by others in SAD, relative to prior versions of the manual (Heimberg et al., 2014). This fear can include concerns about rejection, ridicule, or offending others.

Another change in the DSM-5 is that it now explicitly highlights the comorbidity of ASD and SAD, referring to social anxiety as a "hallmark of ASD" (APA, 2013, p. 207). Diagnostic decisions regarding ASD and SAD are likely among the most challenging for clinicians due to considerable phenotypic overlap (Tyson & Cruess, 2012). Clinicians are cautioned against "double-counting" symptoms that may overlap (e.g., poor eye contact, social avoidance) and are encouraged to look for subtle symptoms of social anxiety (e.g., diverting attention to others, over-preparing for a public speech). We recommend that clinicians pay close attention to these additional considerations when assessing for possible comorbid SAD in individuals with ASD (Kerns et al., 2014; Kreiser & White, 2014; Leyfer et al., 2006; White & Schry, 2011; White, Schry, & Kreiser, 2014):

Bidirectional relationship of social anxiety and social skill impairment. When present, social anxiety and the social deficits associated with ASD likely have a bidirectional relationship. That is, anxiety about social situations and negative evaluation by others may be magnified by an awareness of one's social difficulties, and increased anxiety may lead to inaccurate processing and interpretation of social cues, avoidance of social encounters, and fewer opportunities to

acquire new learning or practice social skills during interpersonal interactions. Understanding this relationship may help guide a clinician's assessment and inform case conceptualization.

Social motivation and theory of mind capabilities. Many individuals with ASD are acutely aware of their social difficulties, place as much emphasis on the importance of peer approval as their typically developing peers, desire more social interactions and friendships, and experience a profound sense of isolation and loneliness (Müller, Schuler, & Yates, 2008; Williamson, Craig, & Slinger, 2008). These individuals are likely at increased risk of developing SAD. Clinicians can supplement existing assessment measures with questions about social motivation (i.e., desire to interact with others and/or have friendships) and theory of mind capabilities (i.e., an awareness of others' social perceptions and intentions) or use diagnostic measures adapted for youth with ASD to assess these domains in concert with SAD (see Kerns et al., 2014). When an individual with ASD self-reports or displays limited social motivation, it is important to evaluate whether this represents a change from baseline functioning. More specifically, the apparent lack of social motivation or denial of social interest could be a coping mechanism related to social anxiety and avoidance (e.g., "I'm not going to the party because I don't care about making friends.").

Reasons behind avoidance of social situations. Avoidance of social situations can be present in both ASD and SAD, and this symptom alone is clearly insufficient for the diagnosis of SAD. To meet criteria for SAD, the avoidance of social situations must be related to social, rather than non-social, aspects of the situation, and must not be due to a lack of interest in the particular situation. Thus, it is imperative to consider the processes underlying social avoidance when determining whether symptoms are better accounted for by ASD or social anxiety. For example, avoidance of social or performance situations due to sensory overarousal or environmental stimulation (e.g., bright lights, loud crowd) does not support a diagnosis of social anxiety disorder. Similarly, avoiding social or performance situations due to general disinterest in social engagement, distress about uncertainty, or dislike of changing the routine may be better accounted for by ASD.

Fear of negative evaluation. The cognitive domain of SAD (e.g., fear of negative evaluation by others) may be especially important to assess in individuals with ASD, given that these two disorders can significantly overlap in the physiological and behavioral domains (Maddox & White, 2014; White, Maddox, & Panneton, 2015). If self-report is available, the clinician can include direct questions about the feared consequences related to social or performance situations (e.g., "What are you worried would happen if you started a conversation with someone?"). When SAD is present in ASD, the evaluative fears may not be expressed in elaborate terms, but rather in statements such as "they won't like me" or "they'll laugh at me." When the clinician hears a concern about being judged negatively (e.g., viewed as stupid, boring, or anxious), the diagnosis of SAD can be made with greater confidence.

Fear of positive evaluation. Although not yet studied in the context of ASD, the fear of positive evaluation has recently been associated with the maintenance of social anxiety (Weeks, Heimberg, Rodebaugh, & Norton, 2008). According to the bivalent fear of evaluation model (Weeks & Howell, 2012), fear of positive evaluation is an important construct within SAD because information conveying social approval (e.g., a smile or verbal praise) also conveys threat by making a socially anxious person feel conspicuous or self-conscious. Thus, clinicians are encouraged to look for concerns about positive evaluation as well.

The considerable phenotypic overlap between ASD and SAD makes differential diagnosis particularly difficult, meaning people may be inaccurately diagnosed with SAD before receiving an ASD diagnosis later in life, or vice versa. For this reason, a few additional assessment recommendations are offered here. Guidelines for differentiating ASD and SAD mostly relate to differences in the chronological course of the disorder, pervasiveness of symptoms, and quality of social skills or relationships (Tyson & Cruess, 2012; White & Schry, 2011; White, Schry, et al., 2014). Chronologically, SAD

and the associated social impairments generally begin and intensify during adolescence, whereas ASD-related social deficits are present from an early age. In addition, all individuals with ASD have social skill disability, which is pervasive across situations. They have few same-age friendships, and these relationships are usually not reciprocal in nature. Individuals with SAD may or may not demonstrate clear social skill impairment; when present, these abnormalities (e.g., not speaking, avoiding eye contact) are usually not seen across contexts, but rather are specific to anxiety-producing social or performance situations. They typically have reciprocal, although perhaps not intimate, friendships. Another area of distinction is social initiation. Individuals with ASD may demonstrate awkward, socially inappropriate attempts to initiate with others or completely avoid initiations due to not knowing what to do or say, whereas individuals with SAD avoid social initiations due to anxiety about embarrassing themselves or making a negative impression. The same patterns may also be found in social responses, with individuals with SAD often showing less responsiveness and assertiveness, and individuals with ASD displaying odd or stereotyped social responses.

Atypical manifestations of social anxiety in ASD. Research suggests that some individuals with ASD may present with excessive fear and avoidance of social situations without an accompanying fear of negative evaluation. Rather, these individuals may have worries related to theory of mind deficits and not knowing what to do or expect in social situations due to their social deficits (Ozsivadjian et al., 2012). This presentation is closely aligned with symptoms of ASD itself and does not meet diagnostic criteria for SAD, given the absence of social evaluation concerns. Nonetheless, these fears may be excessive relative to the individual's actual social difficulties and impairing, preventing the individual from improving their social skills or participating in daily life activities. In cases where such anxiety is associated with severe distress and/or impairment, a diagnosis of other specified anxiety disorder (see below) may be considered to communicate that anxiety is an important aspect of the clinical presentation and a target for treatment.

Panic Disorder

Panic disorder is characterized by recurrent (i.e., more than one), unexpected (i.e., no obvious cue or trigger at the time of occurrence) panic attacks (APA, 2013). Panic attacks are sudden surges of intense fear or discomfort that peak in intensity within minutes, with at least four physical (e.g., heart palpitations, sweating) and cognitive (fear of losing control, fear of dying) symptoms occurring (APA, 2013). Panic attack symptoms may surge from a calm state or an anxious state. Individuals with panic disorder experience persistent concern or worry (at least 1 month duration) about having more panic attacks or their consequences. They may also engage in maladaptive behavior changes due to panic attacks (e.g., avoidance of exercise).

We recommend that clinicians pay close attention to the following considerations when assessing for possible comorbid panic disorder in individuals with ASD:

Unexpected vs. expected panic attacks. Although panic attacks can occur in response to specific triggers, a panic disorder diagnosis requires that at least some of the panic attacks are unexpected (i.e., not in response to a specific object or situation). Therefore, a thorough functional assessment of the individual's panic attacks is imperative. In individuals with ASD, the surge of panic-like symptoms may be situationally bound or triggered by specific triggers. Clinicians can ask: "Did the attack seem to occur out of the blue? Do you ever experience attacks when you are relaxing, engaging in a preferred activity, or emerging from sleep?"

Other reasons for somatic symptoms. The somatic symptoms associated with panic disorder, such as pounding heart and sweating, may or may not constitute a panic attack in people with ASD. They may be physiological symptoms indicative of another anxiety disorder, and perhaps verbal report is limited to explain the associated factors. As part of the assessment, clinicians could inquire about experiences seeking medical care for panic attacks. Individuals with panic disorder often make frequent visits to their primary care physicians and the emergency room (APA, 2013), so a history of this behavior may be more suggestive of a full panic attack.

Agoraphobia

Agoraphobia is characterized by marked fear and anxiety about two or more of the following situations: using public transportation, being in open spaces, being in enclosed spaces, standing in line or being in a crowd, or being outside of the home alone. Individuals with agoraphobia are afraid of these situations because they think that escape might be difficult or help might not be available in the event of developing panic-like symptoms or other incapacitating or embarrassing symptoms (e.g., falling, incontinence, vomiting). They tend to actively avoid these situations or require a companion to be present with them. The fear is persistent, typically lasting for at least 6 months. The avoidance can become so severe that the person is homebound, meaning unable to leave his or her house.

We recommend that clinicians pay close attention to the following considerations when assessing for possible comorbid agoraphobia in individuals with ASD:

Reasons behind avoidance. Some people with ASD resist leaving their house due to the presence of their restricted interests at home, overwhelming sensory input outside of home, or rigid routines at home. Although many people with ASD may not be able to verbalize the cognitive component of agoraphobia, when possible, clinicians can focus on whether the individual worries about difficulties with escaping (e.g., "impossible to get out of there") or receiving help (e.g., "nobody would be there to help me") in the event of developing embarrassing or incapacitating symptoms away from home.

Nature of fear. If an individual with ASD is better able to confront an agoraphobic situation with a companion (e.g., parent, friend, health professional) present, then a diagnosis of agoraphobia may be more likely.

Generalized Anxiety Disorder

Generalized anxiety disorder (GAD) is characterized by excessive anxiety and worry (i.e., apprehensive expectation) about a number of events or activities, such as work and school performance, family affairs, and health (APA, 2013). The worry is difficult to control and occurs more days than not for at least 6 months. To meet diagnostic criteria for GAD, a person's worry must be regularly accompanied by at least some of the following physical symptoms (at least three are required for adults, and only one for children): restlessness or feeling keyed up or on edge, fatigue, difficulty concentrating or mind going blank, irritability, muscle tension, and sleep disturbance. Youth and adults with GAD are often described by others as "worriers."

We recommend that clinicians pay close attention to the following considerations when assessing for possible comorbid GAD in individuals with ASD (Kerns et al., 2014; Reaven, 2009):

Focus of worry. In GAD, the focus of the worry is typically about forthcoming problems or future events (even seemingly positive events such as upcoming vacations). The content of GAD worries may differ with age, with adults often worrying about routine daily life circumstances (e.g., job responsibilities, health of family members, finances) and children often worrying about their competence or quality of their performance (APA, 2013). Other common concerns for children with GAD are punctuality and catastrophic events (e.g., earthquakes, war). For an individual with ASD to be diagnosed with co-occurring GAD, the worry must be generalized and not restricted to one area (e.g., worrying about limited access to restricted interest).

Perseverative style. Individuals with ASD tend to get "stuck" on a variety of topics, which is an important aspect for differential diagnosis. It is currently unclear whether this perseverative style is a risk factor for GAD. Clinicians must determine whether the perseveration is associated with worry and physical signs of distress.

Need for reassurance. Family members and friends of individuals with ASD and co-occurring GAD often find themselves spending excessive amounts of time reassuring the individual, without much relief from the worry. An individual with GAD may report that it feels impossible to go long periods of time without feeling worried, despite reassurance from others.

Atypical worries in ASD. Individuals with ASD may also present with a number of excessive worries about novelty and change, as well as worries related to their circumscribed interests, but not other more generalized concerns. These worries appear closely related to insistence on sameness, a common feature of the ASD phenotype, but also resemble the intolerance of uncertainty frequently associated with GAD (Boulter, Freeston, South, & Rodgers, 2014; Gotham et al., 2013). The amount of anxiety and distress that surrounds insistence on sameness behaviors in ASD varies significantly across individuals (Gotham et al., 2013; Kerns et al., 2014). Further, worries about change and novelty in children with ASD have been associated with DSM-consistent anxiety disorders and anxious automatic thoughts (Kerns et al., 2014). A diagnosis of other specified anxiety disorder (see below) could be considered to capture excessive worries of this type, which appear distinct from GAD, but are also significantly interfering for the individual and deserving of intervention.

Other Specified Anxiety Disorder

The DSM-5 (APA, 2013) no longer includes an anxiety disorder-not otherwise specified (NOS) category. Instead, the new revision includes a category termed other specified anxiety disorder, which applies to presentations of predominately anxiety disorder symptoms that cause clinically significant distress or impairment in important areas of functioning, but do not meet the full diagnostic criteria for any of the anxiety disorders. When diagnosing other specified anxiety disorder, the clinician should specify the reason that the individual's presentation does not meet full diagnosis criteria (e.g., "generalized anxiety not occurring more days than not"). Based on our collective clinical experience, this category appears warranted and useful in some cases with ASD to communicate the presence of clinically significant anxiety, which is excessive (given the known deficits in ASD) and deserving of targeted treatment, but which does not fall into the traditional DSM-5 categories. As described above, other specified anxiety disorder could be diagnosed to capture social anxiety without a fear of negative evaluation, circumscribed fears of change or novelty, or other atypical and ambiguous fears that have been noted in the literature (Kerns et al., 2014). It may also be used when certain signs and symptoms that contribute to a traditional DSM-5 diagnosis cannot be evaluated in people with ASD due to language or cognitive impairments.

Recommendations for Diagnosing OCD and/or ASD

As described in the DSM-5, OCD is characterized by recurrent obsessions and/or compulsions that cause marked distress and/or functional interference (APA, 2013). Key features of OCD include (1) obsessions, which are intrusive, recurrent, and persistent thoughts, images, or impulses; and (2) compulsions, which are repetitive, purposeful behaviors or mental acts performed in response to an obsession, often according to certain rules or in a stereotyped fashion. Obsessions are generally accompanied by dysphoric affect, such as fear, disgust, doubt, or a feeling of incompleteness, and are experienced as distressing to the affected individual. Compulsions, which can be observable repetitive behaviors, such as washing, or covert mental acts, such as counting, serve to neutralize or alleviate obsessions and accompanying dysphoric affect in the short run. This functional link between obsessions and compulsions may well serve to assist clinicians in determining whether a recurrent thought or repetitive behavior is indeed an obsession or compulsion—in the absence of such a link, other phenomena should be considered.

Assessment of OCD includes a comprehensive evaluation of (1) current and past obsessions and compulsions, (2) current OCD symptom severity, (3) associated functional impairment, and (4) comorbid psychopathology. In addition, the strengths of the individual and family should be evaluated, as well as their knowledge of OCD and its treatment. Problems other than OCD identified in the assessment process become the focus

of further evaluation if it is apparent that such symptoms are prominent or perhaps even primary. It is in this context that ASD symptoms are sometimes uncovered if they have not already been raised previously by the family. At that point, it is imperative to perform a functional analysis to carefully identify the antecedents, exact behaviors, and consequences of OCD and ASD symptoms, as they may serve different affective functions that can help differentiate them from one another and help the clinician to devise treatment strategies for each. We recommend that clinicians pay close attention to the following considerations when differentiating between OCD and ASD:

Restricted interests vs. obsessions. Individuals with ASD may well present to the clinic with symptoms that are described colloquially as "obsessional," yet careful assessment of these focused areas of interest may not reveal any fear or anxiety in the presence of relevant stimuli. For example, a young boy (age 5) presented to an OCD treatment clinic with what his mother described as "obsessions about trains." Initial efforts by the therapist to interact directly with the boy were met with poor eye contact, unusual speech patterns, and an absence of reciprocity despite his being at an age in which such skills might be expected developmentally. The therapist mentioned to the boy that the office window overlooked the region's largest train station; the boy immediately sprung from his seat, dragged the chair across the room to the window and, after knocking down several piles of books and articles from the therapist's credenza to improve his view, proceeded to hone in exclusively on the arriving and departing trains, breaking eye contact with the station only occasionally to express gleefully to his mother that he was looking at the trains. His affect at the time was very positive, although his mother correctly anticipated substantial distress when he was asked to leave the office at the end of the appointment—it was this response, rather than his affect at the time he was exposed to trains, that led her to believe that anxiety was central to this picture. The evaluation was useful in that the boy's behavior in the moment allowed the therapist to explore in detail whether these were the kinds of obsessions she was alluding to, and whether she had ever noticed any anxiety in the presence of trains, which she reported only occurred when he was asked to move on with other tasks. Individuals with both OCD and ASD can have both obsessions and focused interests, but their affect at the time they are in the presence of the relevant stimuli will likely serve as the best guide to which diagnostic umbrella best applies: obsessions in OCD give rise to distress, whereas restricted interests are usually experienced as appetitive, which may be gleaned either from verbal description or from behavioral observations.

Repetitive behaviors vs. compulsions. There is no disputing that repetitive behaviors are common in ASD, but again uncovering their affective function will go a long way towards determining whether said behaviors are compulsive, part of ASD, or characteristic of other common co-occurring symptoms such as tics. Compulsions are defined in relation to obsessions: obsessions give rise to anxiety or some other form of distress and are typically experienced as intrusive, whereas compulsions are typically reported to be intentional in that they are performed in order to reduce obsessional distress. This neutralizing of negative affect associated with obsessions is the cardinal feature of a compulsion. Stereotypies, which are commonly observed in ASD, may serve a self-stimulating function rather than an anxiety reduction function per se, and the awareness of stereotypies is typically less well developed than what is seen in compulsions, in which most are able to describe a cognitive prompt and a neutralizing function to the repetitive behavior. Tics are typically performed in response to a premonitory urge rather than to a specific cognition—here again, the close relationship between negative cognition, anxiety, and repetitive behavior also helps to differentiate compulsions from tics in that tics are usually performed in response to a physical sensation rather than a thought. In the absence of adequate verbal skills or capacity for introspection about internal cues that precede behavior, such distinctions are more difficult to make in individuals with ASD who have co-occurring intellectual impairments. When the

link between obsessional anxiety and repetitive behaviors is stated or is evident behaviorally, then OCD may be the most appropriate diagnostic entity to apply.

"Not Just Right" OCD vs. behavioral rigidity. Although most individuals with OCD can articulate a specific feared consequence that they fear will occur if they do not engage in a compulsion, a subset can only describe a prevailing sense of mental and physical discomfort that they can only discharge if they engage in a compulsion. For example, patients with OCD sometimes describe discomfort that follows if one arm brushes unexpectedly against something; this experience causes discomfort that can only be neutralized by touching the other arm in the same spot to restore their sense that things are "just right." Individuals with ASD may also have to repeat behaviors in order to restore homeostasis, but the prompt for this kind of discomfort is often a deviation from usual routines (e.g., being picked up early or late for school) that typically provide comfort and assurance about sameness.

Making use of the focused interest to drive treatment of comorbid OCD. In clinical situations in which an individual suffers from both OCD and ASD, exposure-based treatments can be especially difficult to conduct. Individuals with ASD often struggle to regulate strong negative emotion, which is of course part of what is or perhaps even must be experienced in the behavioral treatment of anxiety disorders (e.g., Foa & Kozak, 1986). A comprehensive discussion of how to move exposure treatments forward in this context is beyond the scope of the current chapter, but one way to enhance motivation to engage in exposures both in and between sessions is to link compliance with procedures with time spent in session discussing the ASD patient's restricted interest. For example, one teenager treated for OCD had contamination-related fears and washing compulsions that necessitated exposure to surfaces and items the patient viewed as "repulsive." The therapist laid out a hierarchy of items to confront in treatment, but also made clear that confronting those items without washing or avoiding could be exchanged for time at the end of the session reviewing the patient's Facebook page filled with pictures related to his restricted interest in fishing, including the "Catch of the Week" photos of fish he had caught himself. This procedure helped energize and motivate the patient, and the therapist could address avoidance behaviors in session directly by suggesting that finishing the exposures without delay would allow more time for the review of the Fishing Page. We encourage clinicians to make ample use of such reinforcers during treatment, and to mine the restricted interests to generate the language and metaphors needed to help patients engage fully with the exposure procedures.

Future Directions and Conclusions

It is clear that anxiety is widespread among children, adolescents, and adults with ASD. Most of the extant research on this topic indicates that anxiety is more common, both in terms of reason for treatment-seeking and diagnostic outcome, among individuals with ASD than those without ASD, regardless of whether samples are community based or clinically derived. We cannot, however, be certain that prevalence estimates for comorbid anxiety disorders or OCD in people with ASD can be directly compared to estimates from samples without ASD. Studies using measures of anxiety developed for use with individuals who do not have ASD have often, quite rightly, cautioned that derived scores may be inflated due to the ASD itself. As previously discussed, there is considerable phenotypic overlap (e.g., social avoidance, decreased eye contact). If this overlap is not considered and adjusted for, it stands to reason that scores will be elevated, not necessarily due to elevated anxiety. On the other hand, studies that have used measures of anxiety modified to ASD issue a different cautionary tale. Is the construct being assessed the same, once the measure is modified, as it is in its unadulterated state? One cannot assume the answer is yes. In simple terms, our attempts to disentangle measurement of ASD and anxiety/OCD symptoms may yield incomplete constructs that, in effect, capture neither entity in its complete form. Can we assess social anxiety, for

instance, without considering core symptoms such as behavioral avoidance of social situations? The obvious answer is *no*.

As we continue to conduct research on how to effectively and validly assess anxiety in people with ASD, it will be important to consider how "manifest anxiety" maps onto the processes that underlie the anxiety. Examination of both the identified problem (anxiety) and its pathways (e.g., reward salience, social problems) will permit us to more deeply explore the construct validity of anxiety. If the underlying mechanisms are similar yet the "outcome" is manifested differently, then there is greater validity to considering anxiety in both forms. For example, demonstration of engagement of similar processes (e.g., social gaze patterns) across ASD and non-ASD clinical groups, in the context of differing clinical manifestations of social anxiety disorder, would support the validity of our conceptualization of an "atypical" manifestation in ASD as anxiety. It has been suggested that emotional dysregulation, for instance, may underlie the expression of a range of primary (e.g., cognitive perseveration) as well as secondary problems (e.g., repetitive checking) in people with ASD (e.g., Mazefsky, Pelphrey, & Dahl, 2012). As proposed by White, Mazefsky, and colleagues (2014), expression of the emotional dysregulation that is ubiquitous in ASD as anxiety may be moderated by a host of ASD-specific characteristics, such as sensory issues and cognitive rigidity. This type of research should inform to what extent measures of anxiety must be modified (or forgone for new measures developed specifically for ASD) and what such modification means with regard to examination of the construct of anxiety transdiagnostically.

As clinical scientists work to resolve how to best assess anxiety in this clinical population, practitioners need guidance on how to best evaluate its presence in their clients. We have offered some suggestions on this topic. It is critical to consider the temporal and configural relationship of symptoms. For example, although an unannounced fire alarm at school may trigger an initial intense negative reaction in a boy with ASD (e.g., fleeing, crying), if the behavior generalizes and he begins worrying about fires and other natural disasters and how to determine when it is a drill or a real emergency, seeking reassurance about safety from his parents, it is important to consider the possibility of a secondary disorder (e.g., generalized anxiety disorder) and not assume attribution to the ASD itself (e.g., heightened sensory sensitivity).

Second, clinicians should consider the possibility that accommodations, both overt (e.g., homeschooling) and the less obvious (e.g., a mother arranging all social and athletic activities for her unwilling son, throughout high school), may function to reduce obvious impairment owing to anxiety. Often in families of children with ASD, well-intentioned parents accommodate to help their offspring manage and succeed socially and academically. Parents, in fact, are often trained to do so. In the case of anxiety, unfortunately, such parental accommodation can unwittingly perpetuate and strengthen the problem (e.g., the phobic child never learns that he can face his fears without suffering the feared consequence). As such, in assessment it is critical to probe for obvious as well as more covert accommodations and compensations and their functions.

Finally, in attempting to differentiate between ASD and an anxiety disorder or OCD, it is imperative to consider the function(s) of the target behavior. In ASD, functions are often not obvious, which requires astute clinical observation and hypothesis testing, and often functional analysis. For example, a child with ASD may engage in a ritual that is comforting when faced with novelty. A child with ASD and OCD may have no clear trigger to use of rituals, and possibly verbalize a desire to prevent an imagined danger from occurring (or seek reassurance from a parent or attachment object, verbally or nonverbally). Additionally, just as important as considering the possibility of an anxiety disorder in a person with ASD is to be mindful of the possibility of ASD in a person referred for problems with anxiety. Although most diagnosis of ASD is in early childhood, this is not uniformly the case. Especially among higher functioning individuals, diagnosis can be considerably later—in adolescence and even adulthood. If there is no evidence of heightened rigidity, unusual rituals, or

repetitive behaviors or of social difficulties until after first report of anxiety symptoms, for instance, it is very unlikely that ASD is present. However, thoughtful history-taking and probing about early childhood social interest and skill, presence of unusual interests or behaviors, and behavioral preferences and environmental accommodations made to compensate for social or communicative difficulties may be helpful in some cases.

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The Comorbid Diagnosis of ASD and ADHD: Clinical and Neuropsychological Perspectives

14

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Introduction

Autism spectrum disorder (ASD) is a lifelong neurodevelopmental condition which is first diagnosed in childhood (APA, 2013). ASD is characterized by deficits in social reciprocity and communication as well as patterns of restricted, repetitive, and stereotyped behaviours and affects around 1 % of the population (APA, 2013). Impairments in social-communicative ability include a lack of nonverbal social behaviours, delayed or absent peer relationships, deficits in social or emotional reciprocity, delays in or lack of spoken language, difficulties initiating or sustaining a conversation, repetitive language, and deficits in spontaneous make-believe play (APA, 2013). Patterns of restricted repetitive and stereotyped behaviours and interests include preoccupation and intense focus on one or more interests or parts of objects, insistence on sameness of routines, and repetitive mannerisms such as hand flapping (APA, 2013). Around 60 % of individuals with ASD have cognitive functioning within the normal range (often referred to as 'high-functioning' or 'cognitively able') and around 40 % will have comorbid intellectual disability (referred to as 'low-functioning' or cognitively impaired) (Baio, 2012). Many more males are diagnosed with ASD than females, with male to female ratios being on average 4.3:1 but with females more prevalent in the cognitively impaired range where the ratio is around 2:1 (Fombonne, 2003).

Attention deficit hyperactivity disorder (ADHD) is a common comorbidity in the clinical manifestation of ASD (APA, 2013). ADHD is diagnosed based on a pervasive pattern of inattentive behaviour, hyperactivity, and impulsivity (APA, 2013). Similar to ASD, ADHD affects more males than females, at a ratio of 2:1 (APA, 2013). Until the release of the Diagnostic and Statistical Manual of Mental Disorders Fifth Edition (DSM-5), these two conditions were not able to be dually diagnosed (APA, 2013). Previously DSM-IV stated: 'attention-deficit/hyperactivity disorder is not diagnosed if the symptoms of inattention and hyperactivity occur

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exclusively during the course of a pervasive developmental disorder' (p. 91). DSM-5 is now in line with the growing body of research and clinical experience which suggests considerable overlap between the two conditions, with around 50 % of children with ASD having clinically significant symptoms of ADHD (Simonoff et al., 2008; Sinzig, Walter, & Doepfner, 2009). Similarly, clinically elevated levels of ASD symptoms in up to a third of children who have a primary diagnosis of ADHD have also been noted (Clark, Feehan, Tinline, & Vostanis, 1999; Grzadzinski et al., 2011; Mulligan et al., 2009; Reiersen, Constantino, Volk, & Todd, 2007). The around 50 % of children with ADHD who also fall within the autism spectrum is far higher than ADHD in the general population where around 5 % of children are affected (APA, 2013). The occurrence of ADHD within the autism spectrum is also higher than that found in other conditions such as intellectual disability where the rate of ADHD is around 6–14 % (Dekker & Koot, 2003; Paris et al., 2006).

Recent reviews considering ASD and ADHD have highlighted that the majority of clinical, cognitive, and behavioural research in the ASD and ADHD literature has generally not accounted for the comorbidity (Antshel & Hier, 2014; Gargaro, Rinehart, Bradshaw, Tonge, & Sheppard, 2011; Murray, 2010; Taurines et al., 2012). Hence, many studies that refer to a clinical population of children with ASD may in fact be referring to children with both ASD and ADHD, and vice versa.

Importantly, individuals with ASD with comorbid ADHD are likely to experience higher levels of emotional-behavioural disturbances, characterized by increased disruptive/antisocial behaviour, self-absorbed behaviour, and greater communication disturbance compared to those with autism or ADHD alone (Gargaro et al., 2014). The diagnosis of ASD can overshadow the comorbid diagnosis of ADHD, which may result in these 'at risk' children not receiving treatments appropriately tailored to their presenting difficulties (Joshi et al., 2014).

Beyond DSM-5, there are currently no internationally agreed upon guidelines for supporting clinical decision-making about the presence or absence of a comorbid diagnosis of ADHD in individuals who have a primary diagnosis of ASD (with the exception of one guideline published prior to DSM-5, see Mahajan et al., 2012). Indeed, the majority of assessment tools for ASD have not been designed to indicate whether individuals also have clinically significant levels of ADHD symptoms. The aim of this chapter is to outline the clinical presentation of ADHD, describing relevant unique and overlapping behavioural, biological, and neuropsychological findings to inform the differential diagnosis of ASD and ADHD. An approach to the clinical assessment of ADHD in individuals with a primary diagnosis of ASD will be presented, with reference to useful assessment tools which may aid in the detection of ASD + ADHD.

Overview of ADHD

Despite ADHD being thought of as a relatively recent phenomenon, first accounts of the condition can be traced to 1798 when Sir Alexander Crichton described individuals who experienced 'mental restlessness' characterized by distractibility and deficits in sustained attention (Lange, Reichl, Lange, & Tucha, 2010). Accounts of childhood hyperactivity were captured in the poetry of German physician, Dr Heinrich Hoffmann in 1865, and by Sir George Still in 1902 who detailed the characteristics of 43 children who had difficulties in the 'moral control of behaviour'. These children were reported to be aggressive, defiant, excessively emotional, resistant to punishment, and to have deficits with sustained attention (Lange et al., 2010).

Current Conceptualizations of ADHD

The DSM-5 currently defines ADHD as 'a persistent pattern of inattention and/or hyperactivity-impulsivity that interferes with functioning or development' (APA, 2013, p. 68). The disorder is characterized by behavioural disinhibition, executive dysfunction, and motivational deficits

(Barkley, 2006; Tripp & Wickens, 2009). Executive functioning deficits include impaired working memory, sustained attention, and response inhibition (Willcutt, Doyle, Nigg, Faraone, & Pennington, 2005), while motivational deficits include a high preference for immediate versus delayed rewards and atypical responses to positive reinforcement (Tripp & Wickens, 2005).

In order to fulfil DSM-5 diagnostic criteria for ADHD a minimum of six inattentive and/or hyperactivity symptoms need to be present for at least 6 months (Criterion A), see Table 14.1 (APA, 2013). Symptoms also need to have been present before the age of 12 years (Criterion B), need to be present in two or more settings (Criterion C), and there needs to be clear evidence that the symptoms are interfering with (or reducing the quality of) social, academic, or occupational functioning (Criterion E) (APA, 2013). Finally the symptoms should not be better accounted for by another mental health disorder. These criteria are largely similar to those published in the DSM-IV; however, there are some important differences. In the DSM-5 the age of symptom onset changed from 7 to 12 years reflecting the difficulty establishing the precise onset of the condition (APA, 2013). Furthermore, age-appropriate examples of symptoms have been included in the DSM-5 to be more applicable for adolescents and adults, and for those aged 17 years and above, a minimum of five symptoms are required for Criterion A.

ADHD can be summarized according to three subtypes or presentations: (1) ADHD combined type (ADHD-C): at least six inattention *and* six hyperactivity-impulsive symptoms; (2) ADHD predominantly inattentive type (ADHD-I): at least six inattention symptoms but fewer than six hyperactive-impulsive symptoms; or (3) ADHD predominantly hyperactive type (ADHD-H): at least six hyperactive-impulsive symptoms and less than six inattentive symptoms (APA, 2013). The term 'presentation' is used in the DSM-5, as opposed to 'subtype' which was used in the DSM-IV, given the fluidity of subtypes over time (Willcutt et al., 2012). ADHD-C is most commonly encountered in clinical samples, while

Table 14.1 DSM-5 diagnostic criteria for ADHD

A. A persistent pattern of inattention and/or hyperactivity-impulsivity that interferes with functioning or development, as characterized by (1) and/or (2)
1. *Inattention*: Six (or more) of the following symptoms have persisted for at least 6 months to a degree that is inconsistent with developmental level and that negatively impacts directly on social and academic/occupational activities. (For older adolescents/adults [age 17 and older], at least five symptom are required.)
(a) Often fails to give close attention to details or makes careless mistakes in schoolwork, at work, or during other activities (e.g. overlooks or misses details, work is inaccurate).
(b) Often has difficulty sustaining attention in tasks or play activities (e.g. has difficulty remaining focused during lectures, conversations, or lengthy reading).
(c) Often does not seem to listen when spoken to directly (e.g. mind seems elsewhere, even in the absence of any obvious distraction).
(d) Often does not follow through on instructions and fails to finish schoolwork, chores, or duties in the workplace (e.g. starts tasks but quickly loses focus and is easily sidetracked).
(e) Often has difficulty organizing tasks and activities (e.g. difficulty managing sequential tasks; difficulty keeping materials and belongings in order; messy, disorganized, work; has poor time management; fails to meet deadlines).
(f) Often avoids, dislikes, or is reluctant to engage in tasks that require sustained mental effort (e.g. schoolwork or homework; for older adolescents and adults, preparing reports, completing forms, reviewing lengthy papers).
(g) Often loses things necessary for tasks or activities (e.g. school materials, pencils, books, tools, wallets, keys, paperwork, eyeglasses, mobile telephones).
(h) Is often easily distracted by extraneous stimuli (for older adolescents and adults, may include unrelated thoughts).
(i) Is often forgetful in daily activities (e.g. doing chores, running errands; for older adolescents and adults, returning calls, paying bills, keeping appointments).
2. *Hyperactivity and Impulsivity*: Six (or more) of the following symptoms have persisted for at least 6 months to a degree that is inconsistent with developmental level and that negatively impacts directly on social and academic/occupational activities. (For older adolescents/adults [age 17 and older], at least five symptom are required.)
(a) Often fidgets with or taps hands or feet or squirms in seat.

(continued)

Table 14.1 (continued)

(b) Often leaves seat in situations when remaining seated is expected (e.g. leaves his or her place in the classroom, office or other workplace, or in other situations that require remaining in place).
(c) Often runs about or climbs in situations where it is inappropriate. (In adolescents or adults, may be limited to feeling restless.)
(d) Often unable to play or engage in leisure activities quietly.
(e) Is often 'on the go', acting as if 'driven by a motor' (e.g. is unable to be or uncomfortable being still for extended time, as in restaurants, meetings; may be experienced by others as being restless and difficult to keep up with).
(f) Often talks excessively.
(g) Often blurts out an answer before a question has been completed (e.g. completes people's sentences; cannot wait for turn in conversation).
(h) Often has difficulty waiting his or her turn (e.g. while waiting in line).
(i) Often interrupts or intrudes on others (e.g. butts into conversations, games, or activities; may start using other people's things without asking or receiving permission, adolescents or adults may intrude into or take over what others are doing).
B. Several inattentive or hyperactive-impulsive symptoms were present prior to age 12 years.
C. Several inattentive or hyperactive-impulsive symptoms are present in two or more settings (e.g. at home, school or work; with friends or relatives; in other activities).
D. There must be clear evidence that the symptoms interfere with or reduce the quality of social, academic, or occupational functioning.
E. The symptoms do not occur exclusively during the course of schizophrenia or another psychotic disorder and are not better explained by another mental disorder (e.g. mood disorder, anxiety disorder, dissociative disorder, personality disorder, substance intoxication, or withdrawal).
Specify whether:
Combined Presentation: If both Criterion A1 (Inattention) and Criterion A2 (Hyperactivity-Impulsivity) are met for the past 6 months.
Predominantly Inattentive Presentation: If Criterion A1 (Inattention) is met but Criterion A2 (Hyperactivity-Impulsivity) is not met for the past 6 months.
Predominantly Hyperactive/Impulsive Presentation: If Criterion A2 (Hyperactivity-Impulsivity) is met and Criterion A1 (Inattention) is not met for the past 6 months.
Specify current severity:
Mild, Moderate, or Severe.

ADHD-I is more commonly observed in community-based studies (Graetz, Sawyer, Hazell, Arney, & Baghurst, 2001).

Associated Difficulties

In addition to core symptoms of inattention, hyperactivity, and impulsivity, children with ADHD encounter significant impairments across multiple domains. They have poorer school-based functioning including academic under-achievement, absenteeism, grade retention, suspensions/expulsions, and early school drop-out (Barbaresi, Katusic, Colligan, Weaver, & Jacobsen, 2007a; Efron et al., 2014). Furthermore, children with ADHD have poorer social outcomes than non-ADHD peers including difficulties initiating and maintaining friendships, peer rejection and peer victimization (Harpin, Mazzone, & Raynaud, 2013; Sciberras, Ohan, & Anderson, 2012), and poorer quality of life (Danckaerts et al., 2010). ADHD also impacts negatively on families, with parents reporting higher levels of stress and mental health difficulties, less adaptive coping, higher levels of marital conflict, and lower parenting self-efficacy compared to children without ADHD (Cussen, Sciberras, Ukoumunne, & Efron, 2012; Harpin, 2005; Johnston & Mash, 2001).

The majority of children with ADHD meet diagnostic criteria for at least one comorbid psychiatric disorder including mood disorders (7–50 %), anxiety disorders (27–33 %), oppositional defiant disorder (ODD; 45–65 %), and conduct disorder (CD; 14–23 %) (Biederman et al., 1996; Busch et al., 2002; Ghanizadeh, Mohammadi, & Moini, 2008; Wilens et al., 2002). About one quarter of children with ADHD present with both internalizing and externalizing comorbidities (Abikoff, Jensen, & Arnold, 2002). Children with ADHD are also at elevated risk for learning and language disabilities (Biederman, Newcorn, & Sprich, 1991b; Pastor & Reuben, 2008; Sciberras et al., 2014), Tourette's disorder (Biederman, Newcorn, & Sprich, 1991a), sleep problems (Sung, Hiscock, Sciberras, & Efron,

2008), poorer physical health including overweight/obesity (Nigg, 2013), and motor coordination difficulties (Cole, Mostofsky, Larson, Denckla, & Mahone, 2008).

Given the impairments experienced by children with ADHD and their increased risk for comorbidities, it is not surprising that the condition is associated with poorer long-term outcomes (Cherkasova, Sulla, Dalena, Pondé, & Hechtman, 2013; Sciberras, Roos, & Efron, 2009). Although approximately one third of individuals with ADHD will show improvements in clinical symptom severity, the impairments associated with the condition persist over time (Cherkasova et al., 2013). For example, a number of longitudinal studies have demonstrated that children with ADHD have poorer outcomes in adulthood including poorer social (e.g. relationship difficulties, divorce) and occupational functioning, as well as elevated levels of delinquency and mental health difficulties including conduct disorder, antisocial personality disorder, and substance use (Cherkasova et al., 2013; Klein et al., 2012; Sciberras et al., 2009; Silva, Colvin, Glauert, & Bower, 2014; Spencer et al., 2006). There is mixed evidence regarding whether ADHD is associated with anxiety and/or mood disorders later in life (Cherkasova et al., 2013).

Aetiology of ADHD

The precise aetiology of ADHD is unclear; however, the disorder likely arises due to a complex interplay between genetic and environmental risk and protective factors. Imaging studies have pointed to numerous functional brain abnormalities in children with ADHD, most commonly in the prefrontal cortex and striatum (fronto-striatal circuits) and the parietal cortex (Rubia, Alegria, & Brinson, 2014; Silk et al., 2005). A number of structural imaging studies have found differences between children with and without ADHD in the prefrontal cortex, cerebellum, striatum and basal ganglia, corpus callosum, and the parietal cortex (Rubia et al., 2014). On average, children with ADHD have decreased cerebral volumes and reduced cortical thickness compared to their non-ADHD counterparts (Rubia et al., 2014; Sowell et al., 2003). Brain abnormalities identified in ADHD are non-specific and overlap with those observed in children without ADHD; therefore, brain imaging techniques are not yet useful in the diagnosis of ADHD.

Family, twin, and adoption studies demonstrate that ADHD is a highly heritable disorder, accounting for approximately 80 % of cases (Faraone, Perlis, & Doyle, 2005; Thapar, Cooper, Jefferies, & Stergiakouli, 2012). No one gene conferring risk for ADHD has been identified. Candidate gene studies have implicated a number of genes within the dopamine system including the D4 receptor (seven-repeat allele), dopamine D5 receptor, and dopamine transporter gene, and the serotonin system including the serotonin transporter (5HTT) (Thapar et al., 2012). However, the amount of variance explained by these candidate genes is small. Genome-wide association studies have yet to identify any common gene variants associated with ADHD, suggesting that multiple common variants may be implicated, each exerting a small effect (Neale et al., 2010; Thapar et al., 2012). Williams and colleagues (2010) found that rare chromosomal deletions and duplications (copy number variants) were elevated in ADHD cases, yet these were common to numerous developmental disorders including intellectual disability and ASD.

A number of environmental factors have also been associated with ADHD including exposure to maternal smoking and alcohol use during pregnancy, maternal stress and/or anxiety during pregnancy, post-natal depression, low birth weight or prematurity, lead exposure, and psychosocial adversity including low parent education and poverty (Sauver et al., 2004; Sciberras, Ukoumunne, & Efron, 2011; Thapar et al., 2012; Williams et al., 2010). There are no randomized control trials which implicate nutritional deficiencies and artificial colourings in the aetiology of ADHD (Thapar et al., 2012). Like most mental health conditions, it is suspected that multiple genetic and environmental factors interact to produce risk for ADHD.

Treatment of ADHD

Treatment guidelines emphasize that the management of ADHD should be multi-modal including both pharmacological and non-pharmacological interventions (American Academy of Child and Adolescent Psychiatry, 2007; National Health and Medical Research Council, 2012; NICE clinical guideline 72, 2008; Taylor et al., 2004). ADHD is commonly managed using psychostimulant medication including short and long acting preparations of methylphenidate and amphetamine based stimulants (Feldman & Reiff, 2014). Non-stimulants such as atomoxetine and norepinephrine reuptake inhibitor are also used to treat ADHD, although less commonly and with weaker effects than stimulant medications (Wolraich et al., 2011). Most children with ADHD (~80 %) taking stimulant medication will have short-term clinically significant reductions in hyperactivity and/or inattention without adverse side effects (Biderman et al., 2003; Faraone et al., 2002; Goldman, Genel, Bezman, & Slanetz, 1998). Common short-term side effects include reduced appetite and initial insomnia (Feldman & Reiff, 2014).

The largest study investigating the efficacy of both medication and behavioural interventions for children with ADHD aged 7.0–9.9 years is the Multimodal Treatment of ADHD Study (MTA; $N=579$) (The MTA Cooperative Group, 1999). This study found that stimulant medication was superior to behavioural therapy in reducing the core symptoms of ADHD in the short to medium term (i.e. 14 months later), and helped children function more effectively in the classroom and in the playground (The MTA Cooperative Group, 1999). Behavioural treatment added benefit to medication in improving broader functional outcomes (e.g. teacher-rated social skills, academic skills, parent-child relationships) and was just as effective at reducing inattention, hyperactive/impulsive, internalizing symptoms, overall impairment, social skills, and academic achievement as medication for those children with comorbid ADHD and anxiety (Jensen et al., 2007). The best overall outcomes were for children who received both medication and psychosocial (behavioural and educational) interventions and this was especially so for children with ADHD-I (Pfiffner et al., 2007; The MTA Cooperative Group, 1999). There is some preliminary evidence that medication use may be associated with improved educational functioning and reduced risk for substance abuse although further research is needed (Barbaresi, Katusic, Colligan, Weaver, & Jacobsen, 2007b; Groenman et al., 2013; Langberg & Becker, 2012).

Behavioural therapies are an essential component of ADHD management (Pelham & Fabiano, 2008). A recent meta-analysis found that there were small improvements in ADHD symptoms for non-pharmacological interventions including parent and teacher training, cognitive training, and dietary modifications including supplementation with essential fatty acids (Sonuga-Barke et al., 2013). However, when studies were restricted to those using blinded ratings of ADHD symptoms, no treatment effect was observed. Yet there is evidence that psychological therapies have more benefit in improving functional outcomes for children with ADHD. In a recent meta-analysis, Daley and colleagues (2014) found that behavioural interventions had benefits in promoting positive parenting and reducing child conduct problems assessed using blinded outcome measures. Effectively managing sleep problems in children with ADHD is another promising non-pharmacological intervention, with a recent large-scale randomized controlled trial reporting that a two session treatment program addressing behavioural sleep problems in children with ADHD improved not only sleep but also child ADHD symptom severity, quality of life, and broader daily functioning (Hiscock et al., 2015).

Overlap and Distinctions Between ADHD and ASD

There is a growing body of research examining the overlap and distinction between ASD, ADHD, and comorbid ASD + ADHD across biological, neuropsychological, and behavioural domains. The few studies which have directly

examined ASD, ADHD, and ASD + ADHD will be the focus of this section, rather than providing a comprehensive review of each domain.

Biological Findings

There is strong evidence of overlap between ADHD and ASD in regard to genes, brain function, and structure. Both ASD and ADHD are highly heritable conditions, with around 70–80 % of the phenotypic variance for each disorder explained by genetic factors (Faraone, Perlis, Doyle, Smoller, et al., 2005; Lichtenstein, Carlström, Råstam, Gillberg, & Anckarsäter, 2010). Studies suggest that around 50–70 % of the covariance of ASD and ADHD may be explained by common genetic influences (Mulligan et al., 2009; Reiersen, Constantino, Grimmer, Martin, & Todd, 2008; Rommelse, Franke, Geurts, Hartman, & Buitelaar, 2010; Ronald, Simonoff, Kuntsi, Asherson, & Plomin, 2008). This indicates that the two disorders may potentially be alternate manifestations of the same underlying risk factors. There are a number of recent comprehensive reviews of this area (Rommelse et al., 2010; Taurines et al., 2012).

Until recently individuals with ASD and ADHD had not been directly compared in brain imaging studies, with ADHD symptoms in ASD typically not controlled for and vice versa. In individuals with ADHD, structural studies show reduced volume and cortical thickness in the frontal, cingulate, and parietal regions of the brain (Bush, 2011; Durston, van Belle, & de Zeeuw, 2011) with abnormalities in the frontostriatal and fronto-cerebellar circuits (Durston et al., 2011). Together, studies suggest dysfunction in fronto-striato-cerebellar and frontoparietal networks in ADHD (Taurines et al., 2012). There have been inconsistent findings in individuals with ASD; however brain connectivity is atypical in ASD (Anagnostou & Taylor, 2011). Early brain overgrowth has consistently been found in at least a subset of individuals with ASD (Anagnostou & Taylor, 2011; Stanfield et al., 2008). This involves both increased volume of grey and white matter particularly in cerebral, cerebellar, and limbic structures and is followed by arrested or abnormally slow growth over time (Courchesne, 2004; Stanfield et al., 2008). In addition, there is reduced volume of the corpus callosum (Stanfield et al., 2008). Increased head circumference is a feature of a subset of those with ASD, but notably is also present to some degree in individuals with ADHD, but may be less stable over development (Gillberg & De Souza, 2002).

Studies directly comparing the two conditions are limited. One study of structural MRI compared ASD and ADHD but did not control for comorbidity with both the ASD and ADHD groups having similar levels of ADHD symptoms (Brieber et al., 2007). Structural abnormalities found in both ASD and ADHD groups compared to controls were grey matter reductions in the left medial temporal lobe and higher grey matter volumes in the left inferior parietal cortex. ASD-specific brain abnormalities consisted of increased grey matter volume in the right supramarginal gyrus (Brieber et al., 2007). Another recent study excluded participants with comorbidity but did not examine the comorbid presentation (Lim et al., 2015). Using structural MRI they found reduced grey matter in the cerebellar in ADHD relative to controls and ASD, and enlargement in the middle/superior temporal gyrus in ASD relative to ADHD (Lim et al., 2015). A recent study of fMRI in children with ASD, ADHD, and ASD + ADHD found both unique and overlapping brain regions (Di Martino et al., 2013). Children with ASD + ADHD shared ADHD-specific basal ganglia connectivity abnormalities, whereas connectivity in temporolimbic areas was atypical in ASD with or without ADHD comorbidity. These findings suggest there is an additive effect of having both conditions with brain connectivity abnormalities from both conditions implicated in the comorbid phenotype. Further work directly comparing the two disorders and their comorbid form is needed in this domain to better understand the neurobiological phenotypes.

Neuropsychological Findings

Attention/Executive Functioning

Executive function is an umbrella term for a range of attention components including the ability to switch attention between stimuli, sustain attention on the task at hand, and inhibit responses (Pennington & Ozonoff, 1996). Individuals with ASD are primarily thought to show difficulties related to perseveration impacting the ability to switch attention. In ADHD inhibition and atypical reward processing are primary areas of executive dysfunction.

When the two disorders are directly compared, there are equivocal findings. For response inhibition, some studies find children with ADHD show more inhibitory deficits than those with ASD, with comorbid ASD + ADHD falling in between the two groups but not significantly different to either (Bühler, Bachmann, Goyert, Heinzel-Gutenbrunner, & Kamp-Becker, 2011). In contrast, other studies indicate that children with ASD have similar or even greater inhibition deficits than those with ADHD (Corbett, Constantine, Hendren, Rocke, & Ozonoff, 2009). Sinzig, Morsch, Bruning, Schmidt, and Lehmkuhl (2008) found impairment in inhibition and working memory in ADHD but not ASD, with impairment in planning in ASD but no group differences in flexibility. Those with comorbid ASD + ADHD also showed more impairment in inhibition, but not working memory, compared to the ASD alone group. The authors concluded that the executive functioning profiles may not be useful in the differential diagnosis of ASD and ADHD. Notably, although these studies fail to consistently differentiate ASD and ADHD, they provide evidence for additive effects of having ASD + ADHD (Gargaro et al., 2014; Taurines et al., 2012).

In regard to sustained attention, there are similarly inconsistent findings. In a study which did not exclude comorbid ADHD symptoms in ASD, individuals with ADHD performed more poorly than ASD with the ASD group performing similarly to controls (Johnson et al., 2007). However, other studies have found children with ASD and ADHD (without excluding ADHD in ASD) were similarly impaired in regard to sustained attention (Corbett et al., 2009). Studies comparing ASD, ADHD, and ASD + ADHD are needed to further clarify whether sustained attention deficits are associated specifically with the presence of ADHD symptoms in ASD.

Intra-individual response variability is considered a measure of lapses of attention and therefore may be characteristic of ADHD. Again, there are mixed findings in this area. One study which did not exclude comorbid symptoms found only individuals with ADHD showed higher levels of response variability compared to ASD and typically developing children (Johnson et al., 2007). Another study which carefully differentiated ASD, ADHD, and ASD + ADHD found individuals with ASD or comorbid ASD + ADHD had more intra-individual variability on EF tasks than did individuals with ADHD (Geurts et al., 2008). This finding was taken to indicate that elevated response variability in ADHD was associated with comorbid ASD. In contrast, a more recent study found that ADHD whether comorbid with ASD or alone showed elevated response variability relative to ASD alone (Adamo et al., 2014).

Neuromotor Profile

There is an emerging literature showing that motor profiles may be a distinguishing characteristic of children with ASD versus children with ADHD. For example, using measures of gait and movement proficiency, Rinehart et al. (2006) and Papadopoulos, Rinehart, Bradshaw, and McGinley (2013) reported unique motor deficits for each disorder, and noted that children with ADHD who are carefully screened for ASD do not have motor problems. This contrasts with previous research showing that up to 50 % of children with ADHD (where the ASD status is unknown) experience motor problems (Buderath et al., 2009; Pan, Tsai, & Chu, 2009).

Social Processing

Emotion recognition and social processing deficits have been extensively studied in ASD. There have

been some equivocal findings, with some studies indicating intact emotion and facial recognition performance (Bar-Haim, Shulman, Lamy, & Reuveni, 2006) and others showing deficits (Baron-Cohen, Wheelwright, & Jolliffe, 1997; Dalton et al., 2005). These task performance differences may relate to compensatory mechanisms in individuals with ASD given underlying atypical processing found via brain imaging, electrophysiological, and eye gaze studies (Harms, Martin, & Wallace, 2010). Facial emotion recognition ability has been found to be similarly impaired in individuals with ASD, ADHD, and ASD + ADHD (Bühler et al., 2011; Sinzig, Morsch, & Lehmkuhl, 2008) and not associated with autistic or ADHD symptoms but may instead relate to executive functioning deficits (Sinzig, Morsch, & Lehmkuhl, 2008). Similarly, individuals with ASD have been found to show similar Theory of Mind deficits to those with ADHD and ASD + ADHD (Bühler et al., 2011). However, ASD symptoms but not ADHD symptoms have been correlated with Theory of Mind deficits (Ames & White, 2011; Geurts, Broeders, & Nieuwland, 2010). Hence, social processing deficits appear in both children with ASD and ADHD, thus not representing a useful point of difference between the two conditions.

Reward Processing

Individuals with ADHD show delay aversion, tending to prefer smaller immediate rewards compared to larger delayed rewards (Castellanos, Sonuga-Barke, Milham, & Tannock, 2006; Marco et al., 2009). When ASD and ADHD have been compared in this area, there have been inconsistent findings. In one study individuals with ADHD but not ASD showed delay aversion (Antrop et al., 2006). In contrast, another study showed both conditions have atypical reward processing (Demurie, Roeyers, Baeyens, & Sonuga-Barke, 2011).

Overall, there are inconsistent findings regarding the executive functioning profile of ASD and ADHD, and what is unique or shared between the two disorders. Currently, executive functioning profiles are not able to reliably differentiate the two conditions and there is much work to be done in this area.

Behavioural Findings

ADHD Symptoms in Populations with ASD

The onset of ADHD symptoms and their presentation in children with ASD + ADHD appear to be similar to that found for ADHD alone (Frazier et al., 2001; Joshi et al., 2014). The ADHD combined subtype is most prevalent in ASD clinical populations compared with the primary inattentive and hyperactive subtypes (Hofvander et al., 2009; Joshi et al., 2014).

ASD Symptoms in Populations with ADHD

Social-communicative and rigid repetitive behaviours also present similarly in children with ADHD as those with ASD (Frazier et al., 2001; Martin, Hamshere, O'Donovan, Rutter, & Thapar, 2014; Reiersen et al., 2007). A proportion of children with ADHD have difficulties in social interaction and communication, similar to that seen in ASD (Clark et al., 1999). This may include lack of empathy and difficulties with peer relationships, and in their communication including deficits in imaginative ability, nonverbal communication, and maintaining conversations (Clark et al., 1999). Additionally, there is some evidence that girls with ASD have fewer symptoms of hyperactivity-impulsivity than boys with ASD, and that the symptoms of hyperactivity remit over time in children with ASD, similar to the trajectory found in ADHD (May, Cornish, & Rinehart, 2012, 2014). These findings of typical ADHD symptom presentation in ASD and vice versa have been taken to indicate a true comorbidity between the two conditions, rather than a unique ASD + ADHD phenotype (Frazier et al., 2001).

Although the symptoms of each disorder present typically when occurring in the other condition, correlations between ASD and ADHD symptoms have been found. For example, associations between hyperactive-impulsive symptoms and rigid repetitive and stereotyped behaviours (Martin et al., 2014) and communication impairment (Sinzig, Bruning, Morsch, & Lehmkuhl, 2008) have been found, and repetitive

behaviours have also been correlated with inattention (Sinzig et al., 2009). Recently, Konst and colleagues (2014) examined DSM-IV-TR and DSM-5 classifications of ASD and found ADHD inattentive and impulsive symptoms correlated with the ASD symptoms as described by both DSM-IV-TR and DSM-5. Increased severity of ASD symptoms was associated with increased inattentive/impulsive symptoms, again highlighting the additive effect of the two conditions. Although one study suggested that social-communicative impairment may better differentiate the two conditions rather than repetitive and stereotyped behaviours (Hartley & Sikora, 2009), most studies have found overlap with ADHD symptoms across both social-communicative impairment and repetitive and stereotyped behaviours.

In summary, biologically shared genetic influences are indicated between the two conditions, yet emerging imaging studies suggest that unique brain structure and connectivity patterns can differentiate the two conditions with the comorbid form having additive effects. Neuropsychological testing is not able to reliably differentially diagnose the two conditions. Together, the differentiation of ASD and ADHD across biological and neuropsychological domains can be difficult. Although the symptoms of ASD and ADHD are often correlated, they are behaviourally distinct and appear to present similarly when ASD and ADHD coexist indicating true comorbidity (Frazier et al., 2001). As the following sections outline, careful examination of the presenting behavioural symptoms is necessary to differentially and comorbidly diagnose these two conditions. The next section reviews the general assessment of ADHD, followed by points of consideration in the assessment of a child with ADHD suspected of also meeting DSM-5 ASD criteria.

General Assessment of ADHD

There is no single diagnostic test for ADHD; therefore, clinicians need to rely on their clinical judgment in applying DSM-5 criteria. The key task for clinicians is to assess for the presence, duration, and impact of inattention, hyperactivity, and impulsivity symptoms on the basis of a detailed developmental and clinical history with parents and use of multi-informant standardized behaviour rating scales. Assessing ADHD symptoms can be challenging given that all children can display some of these symptoms in the context of normal childhood development; therefore, comparing the severity of symptoms to same-aged peers is essential in diagnostic decision-making, as is determining whether the symptoms are pervasive and impairing (Biel & McGee, 2011; National Health and Medical Research Council, 2012). ADHD symptoms are especially difficult to distinguish from normal development before the age of 4 years; therefore, the disorder is more commonly identified in school-aged children (APA, 2013). In particular, inattention symptoms become more observable as academic demands increase with age (APA, 2013). Agreement between parent and teacher reports can often be low; therefore, diagnosis should not be made on the basis of parent or teacher reports in isolation.

A number of clinical practice guidelines exist around the world to guide clinicians in best practice assessment for ADHD, aiming to improve the reliability of diagnosis and standardization of clinical management (American Academy of Child and Adolescent Psychiatry, 2007; National Health and Medical Research Council, 2012; NICE clinical guideline 72, 2008; Wolraich et al., 2011). Although there are some slight variations between these guidelines, key recommendations for assessment include:

(a) Only making the diagnosis when DSM criteria are fulfilled.
(b) Use of standardized behaviour rating scales.
(c) Obtaining information from multiple sources (e.g. parents and teachers).
(d) Specific assessment for comorbid developmental, medical, and mental health conditions.

The above four points form the basis for a gold standard assessment of ADHD. A comprehensive

medical, developmental, and mental health assessment should be conducted, in addition to a psychosocial assessment of the child and their family. An interview with the parent/caregiver is a crucial component of an assessment for ADHD (Biel & McGee, 2011). This interview should cover:

- Reason for referral
- Developmental history
- Detailed history of presenting inattention, hyperactivity, and impulsivity symptoms including duration and frequency
- Impact of the child's symptoms on home and school life including relationships with peers and academic/cognitive functioning
- Parent and family functioning including family history of mental health or developmental difficulties and parent-child interaction
- Assessment of broader mental health functioning including the presence of broader internalizing and externalizing symptoms
- Child strengths, talents, and interests

The clinical history should be supplemented by use of both broad and narrowband, multi-informant rating scales in order to assess both broader mental health functioning and specific ADHD symptoms. Best practice dictates that rating scales are completed by both parents and teachers. Multi-informant broadband rating scales such as the Achenbach Child Behavior Checklist, Behavioral Assessment System for Children (BASC), or the Strengths and Difficulties Questionnaire (SDQ) should be used to determine the child's overall clinical profile (see section 'Assessment Tools' for further details). This is particularly important to identify differential diagnoses and comorbid conditions that will lead to differential treatment planning. Broadband rating scales may under-estimate the presence of less common internalizing comorbidities such as major depression and panic disorder (Bekker, Bruck, & Sciberras, 2013); therefore, it is important to remember that these should be inquired about during the clinical interview. Multi-informant narrowband or ADHD-specific rating scales should be used to assess specifically for inattention and/or hyperactivity-impulsivity symptoms and may include the ADHD Rating Scale IV, Conners Rating Scales, Vanderbilt Rating Scales, or the Swanson, Nolan, and Pelham-IV Questionnaire-Revised (SNAP-IV-R). Given the lack of coverage of sleep issues in these scales, specific questions about the child's sleep patterns and behaviours (including habitual snoring and sleep apneas) should also be sought.

More detailed information from teachers can be helpful in the diagnostic process including school reports and an interview with the teacher (Biel & McGee, 2011). This information supplements standardized rating scales, by providing more qualitative descriptors of the child's symptoms and impairments in the school setting. Direct observations of the child's behaviour in the classroom can be incredibly helpful to supplement clinical history taking and standardized rating scales but is often not feasible for clinicians not working in educational environments. An interview with the child's teacher could cover:

- Current concerns including duration, frequency, examples of behaviour, and antecedents/consequences
- Impact of symptoms on classroom functioning
- The child's education history and academic performance
- Interactions with peers and teachers
- Strategies that have been implemented in the classroom—what works, what doesn't work?

No medical, psychological, or neuropsychological tests are required to make the diagnosis of ADHD given their lack of sensitivity and specificity; however, a physical examination should be undertaken to rule out potential medical causes (National Health and Medical Research Council, 2012). Standardized tests of intellectual, language, and academic abilities may be utilized in situations where there are concerns about the child's general intellectual or language ability or to assess for a comorbid learning disability (Biel & McGee, 2011) but these tests do not have the ability to confirm or disconfirm a diagnosis of ADHD. Again, neuropsychological test may be administered to help understand the nature of the

child's deficits and inform intervention strategies, but they cannot determine whether or not a child meets criteria for ADHD (National Health and Medical Research Council, 2012).

Although it is important to assess the child's perspective during an assessment, children with ADHD often present with a positive illusory bias (Owens, Goldfine, Evangelista, Hoza, & Kaiser, 2007), which means that they tend to overestimate their functioning relative to parents and teachers. For adolescents though, self-reports are particularly important in assessing inattention symptoms given that parent and teachers will have difficulty observing these symptoms (Feldman & Reiff, 2014). Adolescent's views should be specifically sought during history taking and they should also complete standardized rating scales.

Clinicians should not rely on their observations of the child's behaviour in the one-to-one clinical environment in order to make a diagnosis, given that symptoms are more likely to be more observable in naturalistic environments such as the classroom. It is quite possible that observable symptoms may be minimal or absent if the child is (APA, 2013):

- Receiving frequent positive reinforcement for appropriate behaviour
- Being closely supervised or in a one-to-one environment
- In a new setting or is engaged in particularly interesting activities.
- Has consistent external stimulation through use of electronic screens, for example.

In summary, there is no single diagnostic test for ADHD. Key components of an assessment of ADHD include a detailed developmental and psychosocial assessment and the completion of standardized behavioural rating scales. It is absolutely essential that information is collected from multiple informants in order to ensure that symptoms occur in more than one setting. Furthermore, the diagnosis of ADHD should only be made if the child meets the full criteria for ADHD, that is, that the minimum number of symptoms are present and that there is clear evidence that inattention, hyperactivity, and impulsivity symptoms are associated with impaired functioning. Finally, an evaluation for ADHD should include an assessment for developmental and mental health comorbidities, given that these predict poorer functioning over time and need to be taken into account in treatment planning (Biel & McGee, 2011; Tarver, Daley, & Sayal, 2014; Wolraich et al., 2011).

Assessment of ADHD in Children with ASD or Suspected ASD

There are a number of existing international guidelines for the clinical assessment of ASD (American Academy of Neurology, 2000; Johnson & Myers, 2007). When considering a comorbid diagnosis of ADHD in ASD, the ADHD diagnostic guidelines as previously discussed should be applied (American Academy of Child and Adolescent Psychiatry, 2007; National Health and Medical Research Council, 2012; NICE clinical guideline 72, 2008; Wolraich et al., 2011). It has been recommended that a comprehensive ADHD assessment is only undertaken in a child with ASD, if ADHD symptoms persist following the implementation of educational, speech/language, and behavioural supports which target the core ASD symptoms and language or cognitive impairment (Mahajan et al., 2012).

Potential Challenges of ADHD Assessment in ASD

There are a number of challenges faced by clinicians when considering an ADHD diagnosis in a child with, or suspected of having, ASD. A diagnosis of ASD and/or ADHD is made on the basis of observable behaviour. There are no blood tests, no single measure, no single defining symptom, and no physical characteristics that are unique to ASD or ADHD, and so clinicians must use careful observation of behaviour to determine whether a child's difficulties are related to ASD and/or ADHD, or are better described by another

condition. Importantly, clinicians conducting the assessment must have an adequate knowledge of the diagnostic features of not only ASD but also ADHD, as well as other childhood disorders. Although an individual with ASD may have symptoms of ADHD, the ADHD symptoms must be:

1. Clinically meaningful
2. Producing clinically significant impairment
3. The most likely cause of the impairment

ADHD symptoms in children with ASD must produce clinically significant impairment related to excess levels of impulsivity and hyperactivity or inattention which are beyond the impairment caused by ASD symptoms alone. This can sometimes be difficult to differentiate and may only be clear with the persistence of ADHD symptoms despite interventions targeting ASD symptoms.

Other challenges are the growing differences in the typical age of diagnosis of ASD and ADHD. The timing for when a child first undergoes an ASD assessment is slowly becoming earlier in development. The gold standard ASD measures show good reliability from 2 years of age (Lord et al., 2006) with parents noting autism-related developmental problems from around 19 months of age (De Giacomo & Fombonne, 1998). In contrast, for ADHD although caregivers typically note deviations from normality at around 3–4 years of age (Lahey et al., 2004), formal diagnosis may not occur until around 7–8 years of age, with DSM-5 allowing onset to occur up to the age of 12 years (APA, 2013). Guidelines for the assessment of ADHD recommend diagnosis only from 4 years of age given that ADHD behaviours may be difficult to differentiate from typical development prior to this (American Academy of Pediatrics, 2011). Hence, children with ASD who are diagnosed between 2 and 3 years of age may not be considered for ADHD comorbidity. Potentially, these children may not undergo another comprehensive psychological assessment during childhood resulting in their ADHD symptoms remaining undiagnosed and untreated (Joshi et al., 2014). Clinicians therefore need to be vigilant in monitoring children with ASD for ADHD symptoms throughout childhood and performing additional assessment post ASD diagnosis to examine ADHD comorbidity if indicated.

A final consideration is that of the fluidity of ADHD symptoms, particularly in children under 7 years of age (Law, Sideridis, Prock, & Sheridan, 2014). Studies show that the diagnostic stability of ADHD in children under 7 following a 2-year period is anywhere from 50 to 79 % (Law et al., 2014; Srebnicki, Kołakowski, & Wolańczyk, 2013). This again highlights the importance of ongoing review and monitoring of ADHD symptoms throughout childhood.

Assessment Considerations

The ASD assessment process will vary depending on the age of the individual and the services available in the area. Assessment will ideally involve a multidisciplinary team including a psychologist, paediatrician/psychiatrist, speech pathologist, and an occupational therapist experienced in the assessment and diagnosis of ASD. A comprehensive ASD assessment will typically include the following components:

- Gathering health, developmental, behavioural, and intergenerational family history.
- Physical examination including laboratory investigation to search for a known aetiology or coexisting condition.
- Family system assessment including understanding the roles of significant extended family, childcare/kindergarten/school, the peer group, and the wider social and cultural context.
- A developmental evaluation including formally assessing adaptive, cognitive, and speech/language functioning.
- Determining the presence of DSM-5 diagnoses using standardized interviews, observations, and questionnaires, established across multi-informants, and multiple settings.

These assessment components are similar to that for ADHD, and will therefore provide

information relevant to the differential and comorbid diagnoses of both conditions. Formal assessment of DSM-5 symptoms will be the key informative factor when making a differential or comorbid diagnosis of ASD/ADHD. As previously discussed, research suggests that ADHD symptoms present similarly in individuals with ASD + ADHD (Frazier et al., 2001). For a comorbid diagnosis of ASD and ADHD to be given, children must meet the full criteria for each disorder. Each disorder must uniquely contribute to clinically significant impairment in functioning to be dually diagnosed.

In addition to gathering a comprehensive history, the clinician should perform a detailed interview with the parent/caregiver about each of the 18 ADHD symptoms listed in the DSM-5. The clinician should determine the presence of each symptom as well as its duration, severity, and frequency. The impact of each symptom on academic, occupational, and social functioning should be determined. Clinicians will need to use clinical experience and judgment to determine whether the symptom experienced is primary due to attentional and/or hyperactivity/impulsivity issues or is related to ASD or another condition. For example, the ADHD hyperactivity and impulsivity symptom: 'Often runs about or climbs in situations where it is inappropriate' could be due to true hyperactive behaviour or may be due to failing to understand the rules of a social situation and therefore behaving 'inappropriately'. This point highlights the importance of first treating ASD-related difficulties in order to determine whether it is ASD symptoms which are responsible for apparent ADHD symptoms. Consideration of developmental level, direct observation, and further questioning of parents/teachers/caregivers will also be required to help determine the underlying drivers of these behaviours.

For ADHD to be diagnosed in ASD, a child/adolescent must have the specified number of symptoms experienced persistently over the prior of 6 months (at least six hyperactivity and impulsivity symptoms; and/or at least six inattentive symptoms for children/adolescents; and at least five of each for older adolescents and adults aged 17 years and over) (APA, 2013). Importantly, when parent questionnaires are used, gaining information from multiple informants, such as both parents/caregivers and teachers, is important to confirm that ADHD symptoms in ASD exist across more than one setting as required by DSM-5 ADHD criteria and as highlighted previously.

Using narrowband ADHD rating scales and broadband measures of psychopathology which include ADHD subscales will alert to the presence of elevated ADHD symptoms in children with ASD or suspected ASD. Similarly, narrowband ASD-specific tools and questionnaires are able to exclude the presence of ASD in children with ADHD. The following section outlines these rating scales in more detail.

Additional Considerations

Formal assessment of intellectual functioning is particularly important in an ASD assessment to determine the presence of intellectual disability, a commonly co-occurring condition (APA, 2013; Matson & Shoemaker, 2009). An assessment of intellectual functioning will also highlight areas of strengths and weaknesses including determining where individuals may need additional assistance to improve their functioning in different settings. This may involve a review of a recent assessment of intellectual functioning, or informal assessment if it is not possible to conduct a formal assessment.

Characteristic patterns of intellectual functioning are present in both ASD and ADHD on the Wechsler intelligence scales. For ASD, an uneven cognitive profile, with superior perceptual ability in autistic disorder and superior (albeit often superficial) verbal abilities in Asperger's disorder, is often noted (Mayes & Calhoun, 2003, 2008). In ADHD, deficits in aspects of working memory and processing speed may be evident which relate to the core ADHD symptoms of inattention and concentration difficulties (Ehlers et al., 1997). Individuals with both ASD and ADHD have been found to have more impaired working memory than those with ASD

alone (Ehlers et al., 1997; Yerys et al., 2009). Importantly, theses cognitive profiles are *not* consistent across individuals within the disorders and are therefore not considered to be diagnostically valid (Siegel, Minshew, & Goldstein, 1996). Formal administration of intellectual functioning tests may reveal an important opportunity for behavioural observation in the clinical setting where difficulties with ASD symptoms (for example, perseveration and restricted interests) as well as inattention, impulsivity, and hyperactivity symptoms may be readily observed and used to inform diagnosis.

Formal assessment of adaptive functioning is required in individuals suspected of having ASD. This will be necessary where IQ cannot be determined and importantly this assessment will provide critical information regarding social and adaptive deficiencies which require targeted intervention. Children with ASD can often have severe impairment in adaptive behaviour (Klin et al., 2007). Children with ADHD may also exhibit adaptive behaviour significantly below their IQ (Roizen, Blondis, Irwin, & Stein, 1994). For example, children with ADHD may show impairment in socialization, communication, and daily living skills which may be even more severe than those with ASD when IQ is taken into account (Stein, Szumowski, Blondis, & Roizen, 1995). Individuals with both ASD + ADHD have been found to have more daily living adaptive functioning deficits than those with ASD alone highlighting the 'double hit' of the two conditions (Yerys et al., 2009). Clearly, impairment in adaptive functioning is not specific to ASD and will not assist in the differential diagnosis of these conditions, but a more severe degree of difficulty in individuals with ASD may warrant the consideration of ADHD.

Summary

For an individual to be dually diagnosed with ASD and ADHD, they must meet the full DSM-5 criteria for both disorders, including having clinically significant impairment in functioning which is uniquely contributed to by both conditions. Current recommendations indicate that a child with ASD presenting with ADHD symptoms which do not improve following appropriate intervention should undergo a comprehensive ADHD assessment (Mahajan et al., 2012). Clinical assessment of ADHD in an individual with ASD should be based on current guidelines for the assessment of ADHD (American Academy of Child and Adolescent Psychiatry, 2007; National Health and Medical Research Council, 2012; NICE clinical guideline 72, 2008; Wolraich et al., 2011). Clinicians need to be experienced across the range of childhood psychopathology and not just ASD in order to dually diagnose or exclude potential comorbid conditions. Familiarity with ADHD criteria is essential. A thorough assessment which includes multi-informant interviews and questionnaires and multi-setting observations is required to dually or differentially diagnose ADHD and ASD. Those with ASD, especially very young children diagnosed with ASD prior to age 4, need to be routinely monitored throughout childhood for the onset of ADHD; otherwise, ADHD difficulties may remain undetected with lost opportunity for appropriate management which is tailored to the comorbid diagnosis.

Assessment Tools

There are a wide range of assessment tools which can be used to assist in diagnostic decision-making for ASD and ADHD. The following section outlines the research to date examining the ability of assessment tools to differentiate between ASD and ADHD.

Autism-Specific Assessment Tools

Numerous narrowband autism-specific assessment tools have been investigated to determine if they can differentiate between ASD and ADHD. Most of the studies which examined the potential for differential diagnosis were prior to DSM-5; hence there are few tools which have considered comorbid ASD + ADHD.

The Autism Diagnostic Observation Schedule 2 (ADOS), Autism Diagnostic Interview—Revised (ADI-R), and Childhood Autism Rating Scales (CARS) are the most common clinician-rated diagnostic tools for ASD. The ADOS (Lord et al., 2000) using both the original and revised algorithms has been found to incorrectly classify around 7–20 % of ADHD cases as being within the ASD range (Kamp-Becker et al., 2013; Sikora, Hartley, McCoy, Gerrard-Morris, & Dill, 2008). Children with ASD + ADHD have been found to score similarly on the ADOS compared to children with ASD without ADHD symptoms (Yerys et al., 2009). The CARS is another commonly used ASD diagnostic tool completed by clinicians based on parent report and direct observations (now revised into a second edition; Schopler, Van Bourgondien, Wellman, & Love, 2010). This tool typically has a cut-off score of 30 or higher to indicate ASD. Mayes, Calhoun, Murray, et al. (2012) examined both cognitively able and cognitively impaired individuals with ASD and those with ADHD. They found a lower cut-off score of 25.5 was better for identifying individuals with high-functioning ASD and also differentiating children with ADHD, with only 3 % of the ADHD sample scoring above this cut point (Mayes, Calhoun, Murray, et al., 2012). These instruments are able to differentiate ADHD from ASD with reasonably high specificity based on ASD symptoms. Studies examining the ability of the ADI-R (Lord, Rutter, & Le Couteur, 1994) to differentiate ASD and ADHD are notably lacking, although one study examined children with ASD + ADHD compared to those with ASD alone and found no differences in the number of symptoms across the domains of the ADI-R between the two groups (Yerys et al., 2009). Hence, it appears these clinician-rated tools can differentiate ASD and ADHD, and that the comorbid ASD + ADHD presentation does not result in elevated ratings of ASD severity.

There are a range of parent and teacher report questionnaires which have been examined in populations with ASD and ADHD. The Checklist for Autism Spectrum Disorder Symptoms (CASD) was examined by its authors in a group of children with ASD ($N = 847$, DSM-IV Autistic Disorder or Asperger's Disorder) and ADHD ($N = 158$, combined or inattentive subtype) (Mayes, Calhoun, Mayes, & Molitoris, 2012). The CASD easily differentiated between the two groups with no children with ADHD incorrectly classified as having ASD. Similarly, in a group of 190 children with low-functioning ASD, 190 children with high-functioning ASD and 76 with ADHD, the CASD, CARS, and Gilliam Asperger's Disorder Scale (GADS) were all found to have good specificity with the CASD and CARS correctly differentiating 100 % of ASD from ADHD, and the GADS only incorrectly identifying 4 % of the ADHD group as having ASD.

The parent-reported Autism Spectrum Screening Questionnaire (ASSQ) has also been shown to differentiate between those with ASD ($N = 21$) and a combined group of ADHD, conduct disorder, or oppositional defiant disorder ($N = 58$) with only 10 % false positives (Ehlers, Gillberg, & Wing, 1999). In contrast, a smaller study of the ASSQ found no difference in ASD ($N = 15$) and ADHD ($N = 20$) groups on the communication and restricted repetitive behaviours scales but the ASD group showed more impairment on the social interaction scale. The Children's Communication Checklist Second Edition (Bishop, 2003), a measure of language disturbance in children, has been explored to determine whether it can differentiate between typically development, ASD and ADHD (Geurts et al., 2004). Comorbidity between ASD and ADHD was not reported given that the study was conducted prior to DSM-5. There was significantly more language impairment in the ASD group than the ADHD group, while the ADHD group was significantly more impaired than the comparison group. Of note, both children with ASD and ADHD experienced pragmatic language difficulties. This measure was able to classify 76 % of children correctly based on parent report, and 77 % based on teacher report.

The Social Responsiveness Scale (Constantino, 2002) has both parent- and teacher-reported versions assessing social difficulties and classifies individuals into a non-ASD or ASD range. This instrument has been found to classify around one third of boys and three fourths of girls with

ADHD combined type within the ASD range (Reiersen et al., 2007). Children with ASD + ADHD have also been found to experience higher scores on the SRS than those with ASD alone (Yerys et al., 2009). Hence, the SRS has difficulty in differentiating ASD and ADHD and appears to capture some features of ADHD.

In contrast to child measures, there are very few adult assessment tools which have been validated for differentiating between ASD and ADHD. The Autism-Spectrum Quotient (AQ; Baron-Cohen, Wheelwright, Skinner, Martin, & Clubley, 2001) has been examined in adults with ADHD and ASD. Adults with ASD scored higher on all the AQ subscales than those with ADHD, with the exception of the 'Attention to detail' subscale where the two groups were similar. A cut-off score of 26 incorrectly classified a fifth of ADHD patients as ASD (Sizoo et al., 2009). Comorbidity was not considered.

Generally, most ASD narrowband clinician-rated measures (e.g. CARS and ADOS) and parent and teacher questionnaires (e.g. CASD) show good specificity in differentiating between ASD and ADHD. However, few studies have considered the comorbid condition and how this may impact on cut-off scores in regard to when a child with ASD should also be dually diagnosed with ADHD.

ADHD-Specific Assessment Tools

Rating scales to screen for ADHD include the Conners Rating Scale/Conners 3, Brown ADD Scales, and ADHD Rating Scale IV. There have only been a few studies which have attempted to determine whether these questionnaires can differentiate ASD from ADHD. The parent-reported Conners Rating Scale was not able to differentiate ASD and ADHD (although the ADHD group included participants with conduct disorder and oppositional defiant disorder) (Ehlers et al., 1999). It is possible that the ASD group included participants with undiagnosed comorbid ADHD given this study was prior to DSM-5. The ADHD Rating Scale IV was similarly found not to differentiate between children with ASD and ADHD (Hattori et al., 2006). Yerys and colleagues (2009) examined individuals with ASD or ASD + ADHD. They found additive effects of both conditions were evident with children with ASD + ADHD experiencing more severe symptoms of hyperactivity, inattention, and total ADHD symptoms than those with ASD alone on the ADHD Rating scale IV (Yerys et al., 2009).

Generally, individuals with both ASD and ADHD are likely to rate equally highly on ADHD-specific rating scales. There are a lack of studies clearly delineating ADHD, ASD, and ASD + ADHD; therefore, it is unclear whether children with ASD without ADHD have fewer symptoms than those with ADHD alone on these scales. On balance, previous studies indicate that ADHD rating scales are useful to determine if there are elevated ADHD symptoms in children with ASD but not in differentiating the two conditions.

Broadband Measures of Child Psychopathology

Assessment tools designed to assess broad psychopathology in children have also undergone some research to determine whether they can differentiate ADHD and ASD, refer Table 14.2. Gargaro et al. (2014) examined the parent-reported Developmental Behaviour Checklist (DBC) in a group of children with ASD, ADHD, and ASD + ADHD and comparisons. They found the three clinical groups could be differentiated by the Hyperactivity subscale (which includes both inattentive and hyperactive-impulsive symptoms) with two different cut points, with ASD showing the lowest scores, children with combined ASD + ADHD showing the highest scores, and children with ADHD in between. The advantage of the DBC is in also including an autism screening algorithm, and in this study children with ADHD alone scored below the cut point for this scale. Hence, the DBC has the ability to differentiate ASD from ADHD using the autism screening algorithm, and can indicate when comorbid ASD and ADHD should be considered via the Hyperactivity Index.

The Behavior Assessment System for Children (BASC) (Reynolds, 2004) domains of externalizing problems, attention problems, and hyperactivity have been found to be higher in children with ASD + ADHD than those with ASD alone, while internalizing problems, atypicality, and withdrawal did not differ between those with ASD and ASD + ADHD (Yerys et al., 2009); an ADHD alone group was not examined in this study. Individuals with ASD + ADHD have been found to have more externalizing and internalizing behaviour problems on the Achenbach Child Behavior Checklist (CBCL) (Holtmann, Bolte, & Poustka, 2007); however, the ability of this questionnaire to differentiate ASD and ADHD has not been investigated. Findings of a more impaired profile of psychiatric difficulties in the combined condition have also been documented with the DBC (Gargaro et al., 2014).

Summary

A number of narrowband ASD-specific tools are able to differentiate between individuals with ADHD (without ASD) and those with ASD. Scales such as the ADOS, CARS, and CASD can reliably classify individuals with ADHD within the non-ASD range. In contrast, ADHD measures generally show poor ability to differentiate between ASD and ADHD with both groups typically reporting similarly high scores on these measures. This may be due to comorbid ADHD symptoms not being excluded in the ASD samples in the research conducted to date. Few studies of broadband rating scales using carefully partitioned ASD, ADHD, and ASD + ADHD diagnostic groups currently exist. Those that have compared the three groups show some ability to differentiate. Generally, individuals with ASD + ADHD show more impairment than those with ADHD or ASD alone on ADHD-specific checklists, highlighting the additive effects of having both conditions (Gargaro et al., 2014). Overall, the assessment of individuals with suspected ASD and/or ADHD will be informed by careful selection and administration of measures reviewed in this section. A broadband tool such as the DBC, CBCL, or BASC will be particularly important to alert to not only ASD and ADHD symptoms, but problems in other areas.

There is a notable lack of research comparing ASD and ADHD rating scales in adult populations. With the increased recognition that ADHD persists into adulthood for around half of suffers and modified symptom criteria for adults in DSM-5, further research into this area is likely to occur (APA, 2013).

Conclusion

The ASD + ADHD clinical research field has progressed a long way over the last 10 years cumulating with DSM-5 criteria that supports an ASD + ADHD comorbid diagnosis. DSM-5 has now opened the door for clinical research to explore both the distinguishing and overlapping aspects of these two conditions, using internationally agreed upon clinical criteria. Pre-DSM-5 comorbidity studies which have included carefully described groups of ADHD, ASD, and ASD + ADHD generally indicate that children with the combined condition experience additive effects from each condition resulting in a more severe phenotype (Di Martino et al., 2013; Gargaro et al., 2014). This highlights the importance of identifying, assessing (on repeated occasions if required), and then treating the combined condition. Studies which track the comorbid form of ASD + ADHD longitudinally are needed to determine what the clinical outcomes for this more impaired group will be.

Existing clinical guidelines for the assessment of ASD and ADHD should be employed when investigating the presence of ADHD in ASD. Current guidelines recommend a comprehensive ADHD assessment is undertaken in individuals with ASD with ADHD symptoms, after intervention for ASD difficulties does not improve apparent ADHD symptoms (Mahajan et al., 2012). This is necessary given that determining whether ADHD symptoms are due to ASD- or ADHD-specific underpinnings can be difficult. There is a particular importance for clinicians to routinely screen for ADHD symptoms in suspected cases of

Table 14.2 Assessment tools for differential and comorbid diagnosis of ADHD and ASD

Measure	Format	Age range	Research re differential ADHD/ASD diagnosis	Conclusion
ASD-specific assessment tools				
ADI-R	Interview	2 years +	No	Unknown
ADOS-2	Direct observation	1 year +	Kamp-Becker et al. (2013), Sikora et al. (2008), Yerys et al. (2009)	ASD false positives in 7–20 % of ADHD
CARS	Clinician rated from direct observation and parent report	2 years +	Mayes, Calhoun, Murray, et al. (2012)	ASD false positives in 3 % of ADHD using high-functioning cut point (25.5)
Social Responsiveness Scale	Parent and teacher report	2.5 years +	Reiersen et al. (2007)	ASD false positives in 30–75 % of ADHD group; no comorbid group
Children's Communication Checklist	Parent and teacher report	4–16 years	Geurts et al. (2004)	76–77 % correct classifications; no comorbid group
CASD	Clinician rated from direct observation, parent report etc.	1–17 years	Mayes, Calhoun, Mayes, & Molitoris (2012)	ASD false positives in 0 % of ADHD group, no comorbid group
Autism Spectrum Screening Questionnaire (ASSQ)	Parent and teacher report	6–17 years	Mayes, Calhoun, Mayes, & Molitoris (2012)	ASD 10 % false positives in sample including ADHD and learning disorders; no comorbid group
ADHD-specific assessment tools				
Conners Rating Scale Revised	Parent and teacher, adolescent report	3–18 years	Ehlers et al. (1999)	ASD and ADHD cannot be differentiated
ADHD Rating Scale IV	Parent, teacher, and clinician Report	Preschool version 3–5 years; 6–16 years	Hattori et al. (2006), Yerys et al. (2009)	ASD and ADHD cannot be differentiated
Broad psychiatric assessment tools				
Developmental Behaviour Checklist	Parent and teacher report	Early screen; child (4–18) and adult version	Gargaro et al. (2014)	Shows promise for differentiating ASD, ADHD, ASD + ADHD on hyperactivity scale; and ASD from ADHD on autism screening algorithm
Achenbach Child Behaviour Checklist	Parent, teacher, youth report	1.5–18 years	Holtmann et al. (2007)	More externalizing, and internalizing problems in ASD + ADHD than ASD No research on ADHD versus ASD
Personality Inventory for Children Revised	Parent report	5–19 years	Jensen et al. (1997)	Differentiated between PDD-NOS and ADHD
Behaviour Assessment System for Children (BASC)	Teacher, parent, and student rating	2–21:11 years	Yerys et al. (2009)	More externalizing, attention, and hyperactivity problems in ASD + ADHD than ASD No research on ADHD versus ASD

ASD and conduct comprehensive ADHD assessments when elevated symptoms are present. Using only ASD-specific tools will not provide information regarding ADHD comorbidity. ADHD narrowband tools and broadband tools such as the DBC can provide clinically useful information across both ASD and ADHD symptoms with clinical cut-off points to indicate the presence of each and also the comorbid condition (Gargaro et al., 2014).

Importantly, although not the focus of this chapter, treatment options for ADHD are distinct from those for ASD. For example, psychostimulant medication has been shown to be effective in reducing symptoms of hyperactivity and inattention in individuals with ASD with ADHD symptoms (Aman & Langworthy, 2000; Handen, Johnson, & Lubetsky, 2000; Mahajan et al., 2012; Tonge & Rinehart, 2007). Hence the identification of ADHD in individuals with ASD is likely to lead to additional treatment pathways and reduce the elevated suffering of individuals with ASD + ADHD and their families.

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Depression and Autism

15

Maya Matheis and Nicole C. Turygin

Although much research has focused on psychiatric and medical conditions comorbid with depression, very little attention has been given to depression co-occurring with autism spectrum disorder (ASD). Depression has been observed to co-occur with ASD at relatively high rates (De-la-Iglesia & Olivar, 2015; Hess, Matson, & Dixon, 2010; Matson & Nebel-Schwalm, 2007). However, diagnosing depression in individuals with ASD presents several challenges, including differences in symptom presentation compared to typically developing individuals, difficulties with expressive communication, and that few standardized assessment measures have been developed for this population. Depression can negatively impact long-term outcomes for individuals with ASD, as well as their families, and has implications for intervention (Gold, 1993; Kim, Szatmari, Bryson, Streiner, & Wilson, 2000; Matson & Nebel-Schwalm, 2007). Thus, it is highly important for clinicians to consider the co-occurrence of depression with ASD in their assessments and interventions.

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Diagnostic Criteria

Autism Spectrum Disorder

ASD is a neurodevelopmental disorder characterized by difficulties with verbal communication, social interactions, and restrictive, repetitive behaviors and interests (American Psychiatric Association, 2013; Rapin & Tuchman, 2008; Volkmar & Lord, 1998). Changes in the most recent edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM-5) have seen the amalgamation of three previous autism-related diagnoses, Autistic Disorder (AD), Asperger's Disorder, and Pervasive Developmental Disorder Not Otherwise Specified (PDD-NOS), into a single diagnosis: Autism Spectrum Disorder (American Psychiatric Association, 2013).

A diagnosis of ASD should be made by a qualified professional who has experience with developmental disorders through a combination of standardized assessment and clinical observation (Matson, Nebel-Schwalm, & Matson, 2007). To meet current diagnostic criteria for ASD, an individual must demonstrate persistent deficits in social communication and social interaction across multiple domains (American Psychiatric Association, 2013; Rapin & Tuchman, 2008; Volkmar & Lord, 1998). Individuals with ASD exhibit deficits in nonverbal communication, reduced interest in peers,

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lack of eye contact, and difficulties with social-emotional reciprocity. Additionally, at least two symptoms of restricted, repetitive patterns of behaviors, activities, or interests must have been observed or currently exhibited. These include stereotyped or repetitive motor movements or speech; insistence on sameness, inflexible adherence to routines, or ritualized patterns of behavior; highly restricted interests abnormal in intensity and focus; and hyper- or hypo-reactivity to sensory input or unusual interest in sensory aspects of the environment (American Psychiatric Association, 2013; Rapin & Tuchman, 2008). The severity of ASD symptoms is indicated using a three-tier scale to inform the degree of support an individual requires in daily activities: mild, moderate, or severe.

Depression

Depression is one of the most frequently occurring psychiatric disorders, with estimates indicating that about 15–20 % of the population will develop a clinically significant depressive disorder during their lifetime (Goldman, Nielsen, & Champion, 1999; Gotlib & Hammen, 2014). Characterized by episodes of sadness and depressed mood, and loss of interest in previously enjoyed activities, depression can greatly impact physical health, interpersonal relationships, and daily life functioning (Kessler et al., 2014). There is a very high reoccurrence rate with depression; half of individuals with depression will experience more than one depressive episode (Hardeveld, Spijker, De Graaf, Nolen, & Beekman, 2013; Kessler et al., 2014).

Depression is diagnosed through the combination of clinical interview and standardized screening tools (Goldman et al., 1999; Nezu, Nezu, Lee, & Stern, 2014). Depressive symptoms span a spectrum, encompassing subclinical levels of symptoms and several clinical syndromes (Ingram, Siegle, & Steidtmann, 2014). Major depressive disorder (MDD) is the clinical diagnosis most associated with depression and is distinct from other mood disorders such as bipolar disorder and disruptive mood dysregulation disorder (American Psychiatric Association, 2013; Nezu et al., 2014). The diagnosis requires that five or more depressive symptoms (i.e., depressed mood, diminished interest in activities, significant change in weight, insomnia or hypersomnia, psychomotor agitation or retardation, fatigue, feelings of worthlessness, diminished concentration, or recurrent thoughts of death) occur nearly every day for a period of at least 2 weeks and that they cause significant distress or impairment in daily functioning.

Persistent depressive disorder, an amalgamation of the previous diagnostic categories of chronic major depressive disorder and dysthymic disorder, is diagnostically appropriate when depressive symptoms occur for most days for at least 2 years in adults or at least 1 year in children and adolescents (American Psychiatric Association, 2013; Nezu et al., 2014). Given the number of depressive disorders and the nature of the depressive symptom spectrum, it's important to clarify that the term "depression" is used in this chapter to refer to clinically significantly levels of depressive symptoms, which may not always qualify specifically as MDD.

Primary vs. Secondary Diagnosis

When assessing co-occurring disorders, the primary disorder is usually the condition with the greatest degree of impairment and requiring priority for intervention (Matson & Nebel-Schwalm, 2007). In instances in which ASD and major depressive disorder are co-occurring, clinicians must consider symptom severity, priority of intervention goals, and the pervasiveness of the conditions when identifying primary and secondary diagnoses. In most cases, ASD should be considered the primary diagnosis, as it is a pervasive developmental condition requiring intervention across multiple domains.

Prevalence of Comorbidity

Depression

Co-occurring disorders such as depression are a less-studied topic in individuals with ASD. Existing studies vary greatly with respect

to sample size, diagnostic criteria, and age of study participants, and depression is often an auxiliary focus. No population studies have been conducted to examine the prevalence, symptomatology, or treatment of depression in individuals with ASD. However, evidence suggests that depression is one of the most common psychiatric disorders affecting individuals with ASD, with estimates suggesting that between 1.4 and 24 % of this population have comorbid depression (Ghaziuddin, Tsai, & Ghaziuddin, 1992; Leyfer et al., 2006; Matson & Nebel-Schwalm, 2007; Simonoff et al., 2008). Depression may be one of the most underdiagnosed conditions, and many researchers believe that individuals with ASD have depression at greater rates than have been suggested by researchers (De-la-Iglesia & Olivar, 2015; Ghaziuddin, Ghaziuddin, & Greden, 2002; Ghaziuddin & Greden, 1998; Matson & Nebel-Schwalm, 2007). Researchers have observed that depression occurs at higher rates in individuals with ASD compared to the general population (Green, Gilchrist, Burton, & Cox, 2000; Kim et al., 2000) or amongst individual with intellectual disability (Brereton, Tonge, & Einfeld, 2006).

Estimates of comorbid depression in children with ASD range greatly. Simonoff and colleagues (2008) observed a prevalence of 1.4 % of depression in 112 children aged 10–14 with ASD. Kim and colleagues (2000) found that 16.9 % of a sample of 68 children and adolescents with ASD had clinically elevated levels of depressive symptoms. Another study found that 24 % of a sample of children and adolescents with ASD ($n=109$) met criteria for major depressive disorder (Leyfer et al., 2006).

Studies that have restricted their sample to individuals with high-functioning ASD have reported higher estimates of comorbid depression. Strang and colleagues (2012) found that 30 % of a sample of children and adolescents with ASD without intellectual disability ($n=95$) were in the clinical range for depressive symptoms while another 14 % were in the borderline range. Among a sample of 20 male adolescents with Asperger's syndrome, 30 % were found to meet criteria for dysthymia or MDD (Green et al., 2000). Another study found that 30 % of a sample of 35 adolescents and adults with Asperger's syndrome had clinical levels of depression (Ghaziuddin, Weidmer-Mikhail, & Ghaziuddin, 1998).

Suicide

Few studies have examined rates of suicidal ideation and behavior amongst individuals with ASD. Balfe and Tantam (2010) found that 15 % of a sample of 42 adolescents and adults with Asperger's syndrome reported previous suicide attempts. Storch and colleagues (2012) reported that 11 % of a sample of 102 children and adolescents with ASD had suicidal ideation associated with depression. While these findings are limited, they suggest the importance of assessment for suicidal ideation and behavior in individuals with ASD.

Risk Factors for Depression

There is currently a limited body of research on factors that increase the risk of individuals with ASD having comorbid depressive symptoms. However, based on findings drawn from preliminary studies in this area and research from the general population, a few generalizations can cautiously be made.

Age, Gender, and Other Demographics

Age has been found to be positively correlated with depression amongst individuals with ASD (Brereton et al., 2006; Ghaziuddin & Greden, 1998; Mayes, Calhoun, Murray, & Zahid, 2011; Vickerstaff, Heriot, Wong, Lopes, & Dossetor, 2006). This is in line with a large body of research done with the general population indicating that depression is more common among adults and adolescents than young children (Cicchetti & Toth, 1998; Ghaziuddin et al., 2002).

Symptoms of depression were found to have significant positive relationships with age, IQ, and ASD severity amongst a large sample ($n=627$) of children with ASD (Mayes et al., 2011). Results indicated that race and parent occupation were not related to levels of depression. Additionally, gender was not a significant predictor of symptom levels of depression among children with ASD (Mayes et al., 2011). The finding is notable, as females in the general population have been found to have higher levels of depressive symptoms than males (Brereton et al., 2006; Chaplin, Gillham, & Seligman, 2009; Twenge & Nolen-Hoeksema, 2002). Several other studies have also failed to find gender differences in depressive symptoms amongst this population (Brereton et al., 2006; De-la-Iglesia & Olivar, 2015).

Cognitive Ability and IQ

Depressive symptoms have been observed to positively correlate with IQ (Brereton et al., 2006; Chandler et al., 2015; De-la-Iglesia & Olivar, 2015; Mayes et al., 2011; Vickerstaff et al., 2006). This suggests that individuals with ASD who have higher cognitive abilities may be at an increased risk for depression.

Chandler and colleagues (2015) found that children with ASD who had IQs over 70 were significantly more likely to have depressive symptoms compared to those with IQs below 70. Although there were no significant differences found in total emotional and behavioral problem scores between children with IQ above or below 70, children with an IQ above 70 were found to score significantly higher on the subscales for depression compared to those with IQs under 70.

The relationship between IQ and risk for depressive symptoms does not appear to be a linear relationship. In a study with a sample of 95 children and adolescents with ASD who had no intellectual disability (IQs $\geq$ 70), 44 % of whom fell within the borderline or clinical levels of depressive symptoms, increased IQ was not found to be associated with increased depressive symptoms (Strang et al., 2012).

Negative thoughts and self-perception greatly predispose an individual to depression (Kovacs & Beck, 1978; Watkins & Teasdale, 2004). Several researchers have proposed that increased awareness of social impairments, which accompanies greater intellectual ability, is central to the relationship between IQ and depressive symptoms among individuals with ASD (Bauminger, Solomon, & Rogers, 2010; De-la-Iglesia & Olivar, 2015; Gotham, Bishop, Brunwasser, & Lord, 2014; Hedley & Young, 2006; Vickerstaff et al., 2006). Vickerstaff and colleagues (2006) directly examined the influence of self-perception of social competence on depressive symptoms amongst children with high-functioning ASD. Their findings indicated that higher IQ and higher age were both predictors of lower ratings of self-perceived social competence, which in turn predicted higher levels of depressive symptoms.

Gotham and colleagues (2014) observed that higher ratings of self-perceived autism-related impairments were significantly related to elevated depressive symptoms in adults and adolescents with verbal IQs greater than or equal to 70. A similar study found a significant correlation between depressive symptoms and self-perceived group membership among children and adolescents with high-functioning ASD (Hedley & Young, 2006).

It is reasonable that individuals with greater cognitive faculties may be more perceptive of their own social deficits and more sensitive to social expectations. As individuals with ASD transition from childhood to adolescence and adulthood, social challenges change and social expectations increase. Those who are conscious of their differences and skill deficits may be more likely to experience feelings of loneliness and symptoms of depression, and these effects may increase with age.

Symptom Severity

Findings regarding the relationship of autistic symptom severity and depression are mixed. Several studies have found symptom to be

positively related to depression amongst individuals with ASD, with those with more severe autistic symptoms being more likely to have higher levels of depressive symptoms (Gotham et al., 2014; Kanne, Abbacchi, & Constantino, 2009; Mayes et al., 2011). Other studies have found the reverse relationship, with a decrease in depressive symptoms associated with increased autistic symptoms (Lecavalier, 2006; Mattila et al., 2010; Mazurek & Kanne, 2010; Sukhodolsky et al., 2007). Additionally, among a sample of children and adolescents with ASD without intellectual disability, symptoms severity was not found to be related to levels of depressive symptoms (Strang et al., 2012).

Family History

There is a great deal of evidence from the general population indicating that genetic factors are major contributors towards depressive symptomatology (Heim & Binder, 2012; Ionescu, Niciu, Mathews, Richards, & Zarate, 2013; Levinson, 2006; Sullivan, Neale, & Kendler, 2000). Although research on family history of depression amongst individuals with ASD is limited, there is evidence to suggest that the ASD population does not differ from the general population in this respect (De-la-Iglesia & Olivar, 2015; Lainhart & Folstein, 1994). For example, one study has found that individuals with Asperger's syndrome who had a family history of depression were more likely to have elevated levels of depressive symptoms than those without such a family history (Ghaziuddin et al., 1998).

Neurochemical factors have also been implicated in the relationship between ASD and depression (Cook et al., 1994; Cross-Disorder Group of the Psychiatric Genomics Consortium, 2013; De-la-Iglesia & Olivar, 2015). Parents of children with ASD who have elevated serotonin levels have been found to have significantly higher levels of depressive symptomatology compared to parents of children with Down's syndrome with elevated serotonin levels (Cook et al., 1994). Additionally, parents of children with ASD were found to have higher levels of depression compared to parents of neurotypical children as well as parents of children with other developmental disorders (Micali, Chakrabarti, & Fombonne, 2004; Piven & Palmer, 1999). Findings indicating that in most cases the onset of the mood disorder preceded the birth of a child with ASD suggest that these higher incidences of depression among parents of children with ASD are not related to the stress of having a child on the autism spectrum (Micali et al., 2004).

Social Support

Social support is a protective factor against the development of psychopathology in the general population (Grav, Hellzèn, Romild, & Stordal, 2012; Heim & Binder, 2012; Lin, Dean, & Ensel, 2013). Individuals with low-quality social relationships are at greater risk for anxiety, loneliness, stress, and depression (Heim & Binder, 2012; Lin et al., 2013). Although children and adults with ASD are often perceived as being uninterested in friendships and other social relationships, there is a growing body of literature that suggests that individuals with ASD, particularly those who are high-functioning, are interested in social interaction but simply lack the skills and abilities necessary to initiate and sustain positive relationships (Bauminger, Shulman, & Agam, 2003; Bauminger et al., 2003, 2010; De-la-Iglesia & Olivar, 2015). Difficulty interpreting and emitting appropriate facial expressions, gestures, and a range of emotions may result in decreased quality of reciprocal social interactions with others (Boraston, Blakemore, Chilvers & Skuse, 2007; Capps, Kasari, Yirmiya, & Sigman, 1993).

Children with high-functioning ASD report higher levels of loneliness and to perceive their friendships to be of lower quality than their neurotypical peers (Bauminger & Kasari, 2000; Bauminger et al., 2003; Whitehouse, Durkin, Jaquet, & Ziatas, 2009). These feelings of loneliness and social inadequacy may increase the risk of depression amongst individuals with high-functioning ASD. Whitehouse et al. (2009) found that adolescents with Asperger's syndrome

were more likely to report poorer quality friendships and higher levels of depressive symptoms than their neurotypical peers, and that there was a negative relationship between the quality of their best-friendship and the level of their depressive symptoms. Similarly, Gotham et al. (2014) found that lower ratings of self-perceived social support were associated with higher levels of depressive symptoms amongst adolescents and adults with ASD.

Mattila et al. (2010) found that quality of friendship was a significant predictor for depressive symptoms amongst children and adolescents with ASD even when controlling for IQ and symptom severity. Interestingly, their findings indicated that this was not a linear relationship. Children and adolescents with ASD who reported having some friendships of mediocre quality were found to have higher levels of depressive symptoms when compared to both those with no friendships or very poor friendships and those with very good friendships. Similarly, Mazurek and Kanne (2010) found that children and adolescents with ASD who had fewer friendships of poorer quality experienced fewer symptoms of anxiety and depression. It is possible that children with a few friendships of mediocre quality are more interested in social relationships than those without friendships, making it more likely for them to be at risk for loneliness and depression. Taken as a whole, these findings suggest that loneliness and low levels of social support are likely risk factors for depression amongst individuals with ASD.

Life Events

Individuals who experience negative life events have been shown to be at greater risk of depression than both children and adults in the general population (Lin et al., 2013). Studies investigating the influence of negative life experiences among individuals with ASD find similar results (De-la-Iglesia & Olivar, 2015; Ghaziuddin, Alessi, & Greden, 1995; Hatton & Emerson, 2004; Martorell & Tsakanikos, 2008; Shtayermman, 2007; Storch et al., 2012). As children with ASD have an increased risk of experiencing traumatic events, such as peer victimization, abuse, and increased interactions with the legal system and law enforcement, they may also be at increased risk for developing depression and other emotional disorders (Kerns, Newschaffer, & Berkowitz, 2015).

Assessment of Depression in Individuals with ASD

Depression can be diagnosed in a manner of ways. Psychologists often diagnose depression through the use of structured and semi-structured diagnostic interviews, behavior checklists, and unstructured interviews (Goldman et al., 1999; Nezu et al., 2014). Assessment of depression in children and adults with ASD has not been well established in the literature. However, the standard method of assessing individuals for psychiatric disorder continues to be appropriate for both adults and children on the spectrum. Best practice for evaluating major depressive disorder in individuals with ASD should include a thorough history and clinical interview.

Diagnostic Considerations

Clinicians typically rely on an individual's self-report of symptoms and behavior for a diagnosis of depression. For individuals with ASD, who have difficulties with communication skills and verbal language, this presents many difficulties. Individuals who are lower-functioning and have limited verbal language skills may not be able to effectively communicate their feelings and symptoms. Individuals with high-functioning ASD and more sophisticated verbal language skills may also have difficulties in identifying and expressing their emotions to others. For this population, reports from parents and caregivers thus become especially important. While secondary reporters may not be able to provide accurate information about an individual's emotional state, they can provide valuable information regarding changes in behavior. Depressed mood

and/or anhedonia in individuals with ASD may be observable by caregivers, and may also include symptoms of irritability or apparent loss in adaptive functioning.

When assessing for depression among individuals with ASD, attention should be given to recent changes in behavior, as an increase or decrease in certain behaviors may indicate the onset of a depressive episode (Ghaziuddin et al., 2002). Special attention should be given to changes in restricted interests and stereotypies (Ghaziuddin et al., 1998). For example, there may be an increase of interest in morose topics, or a marked decrease in interest in a previously preferred activity or topic. Ritualistic behaviors may also increase, such as counting or repeatedly washing hands, as these obsessive-compulsive behaviors are often done to relieve anxiety and stress. Sleep disturbances, changes in appetite, increased social withdrawal, and increased crying spells may also be indicators of mood disturbance. It is important to consider changes in behaviors related to ASD in the context of an individual's general temperament and behavioral history. For example, if an individual demonstrates social withdrawal, it is important to establish whether this behavior is beyond what is considered "normal" for this particular individual.

Assessing Symptoms of Depression

Symptoms of MDD include symptoms that must persist over at least a 2-week period and also represent a change in previous functioning. Therefore, the diagnostician should carefully consider whether the symptom as presented may be best accounted for by individual differences. A diagnosis of a major depressive episode or major depressive disorder must include, at minimum, the presence of a depressed mood, or loss of interest or pleasure in that which the individual previously enjoyed. These symptoms may be self-reported in individuals who communicate verbally and are able to self-identify their emotions or supported by behavioral observations from those closest to the individual. In typically developing children, depressed mood may be expressed as irritability. This symptom should also be considered an indication for the disorder in ASD, especially when other symptoms are present.

Major depressive symptoms also include a variety of behaviorally observable symptoms, including significant weight loss or gain, defined as a 5 % change of body weight within 1 month, or a significant change in appetite. Difficulties with sleep or excessive sleep, as well as objective and observed psychomotor agitation or retardation, and fatigue or loss of energy should also be readily observed by family members, as would be expected in typically developing individuals.

Individuals with Low-Functioning ASD

Among individuals with low-functioning ASD and ID, depressive symptoms often manifest similarly to the general population (Ghaziuddin et al., 2002; Matson et al., 1999). However, due to deficits with verbal communications, cognitive symptoms may be harder to assess. Individuals with intellectual disability or lower verbal abilities are less likely to meet DSM criteria for depression as a result of failure to measure cognitive symptoms, despite significant impairments resulting from low mood (Hurley, 2008). Symptoms as measured in the DSM, including recurrent thoughts of death, diminished ability to think or concentrate, and feelings of worthlessness or guilt, may be more difficult to assess than changes in behavior.

Research on depressive symptoms exhibited by individuals with ID indicates that depression amongst this population is frequently characterized by increased psychomotor difficulties, irritability, and difficulties with sleep and eating (Matson et al., 1999). In these instances, overall levels of impairment resulting from the depressive symptoms should be considered during assessment. Increases in already existing behaviors, such as aggression or self-injurious behavior, may be related to depression but should be regarded cautiously if not accompanied by other behavioral changes, as these behaviors are easily shaped and influenced by environmental events and conditions (Ghaziuddin et al., 2002; Matson et al., 1999).

Individuals with High-Functioning ASD

Ghaziuddin et al. (2002) suggested that individuals with high-functioning ASD may experience greater difficulty with expressing feeling of sadness and/or other symptoms of depression. They suggest that the content of restricted interests may indicate depression. For example, a child with a restricted interest in space who fears they may be consumed by a black hole may represent negative or depressed affect in a higher-functioning individual with ASD (Ghaziuddin et al., 1998, 2002). Symptoms more commonly associated with depression, including crying spells, depressed mood, sleep problems, and loss of appetite, may also be present. Researchers have suggested that individuals with a high IQ and ASD may be at risk for depression because they may perceive themselves as having lower self-worth or may be better able to assess others' views of them (Capps et al., 1993; Sigman, Dissanayake, Arbelle, & Ruskin, 2005).

Measures for Assessing Depression

The clinician may wish to supplement a clinical interview with a broadband or single-syndrome measure. Whether to utilize a measure specific to depression or a broadband measure of psychopathology should be decided based on the individual's developmental and intellectual variables, and the suitability of the individual's behavior to the target items in the measure. For lower-functioning individuals, the use of a measure of psychopathology for individuals with intellectual disability may provide more useful information. For assessment of MDD in higher-functioning individuals, or those with greater verbal abilities, a standard measure of depressive symptoms such as the Beck Depression Inventory (BDI) or Children's Depression Inventory (CDI) may provide the most appropriate information.

Diagnostic Manual-Intellectual Disability

The Diagnostic Manual-Intellectual Disability: A Textbook of Diagnoses of Mental Disorders in Persons with Intellectual Disability (*DM-ID*; Fletcher, Loschen, Stavrakaki, & First, 2007) is a textbook reviewing research, pathogenesis, and etiology of each category, and most psychiatric disorders in the DSM-IV-TR as they relate to individuals with intellectual disability, particularly those with deficits in communication. The *DM-ID* was designed as a supplement to the DSM-IV-TR, providing adapted criteria and considerations for diagnosing psychiatric disorders in individuals with intellectual disability, with an emphasis on distinguishing challenging behaviors from psychiatric disorders (Fletcher et al., 2007).

Children's Depression Inventory (CDI-2; Kovacs, 1992) and Beck Depression Inventory, Second Edition (BDI-II; A. T. Beck, Steer, & Brown, 1996)

The Children's Depression Inventory-Short Version (CDI-S) is a ten-item self-report measure developed from the Children's Depression Inventory (CDI) for use in children from 7 to 17 years of age. Alpha for the CDI-S was found to be 0.80 and kappas ranged from 0.38 to 0.82 (Kovacs, 1992). Elevated scores on the CDI have been observed in adolescents/children with ASD to be similar to a clinical sample of children with major depressive disorder, and significantly higher than a typically developing nonclinical sample (Mazzone et al., 2013). As of 2011, the CDI-2 and CDI-2 Short are available (Kovacs, 2011). However, little research has been published on this measure as of the present.

The BDI-2 is a 21-item self-report rating scale which measures symptoms and attitudes of depression in adults and adolescents age 13–80 and corresponds to the CDI for children. The BDI measures symptoms of depression over a 2-week period and is useful as a screener for depressive symptoms. The BDI-II is highly correlated with other commonly used scales for depression, including the Hamilton Psychiatric Rating Scale for Depression ($r = 0.71$) as well as high reliability (=0.92) in the outpatient sample as well as in a sample of college students ($\alpha = 0.93$) (A. T. Beck et al., 1996). Unfortunately, no research has been conducted to determine the utility of these measures in individuals with ASD or other intellectual or developmental disabilities.

Child Behavior Checklist (CBCL; Achenbach & Rescorla, 2000, 2001)

The CBCL is a 113-item norm-referenced parent-report questionnaire which provides scores along internalizing symptoms, externalizing symptoms, and total behavioral problems in children and adolescents (Achenbach & Rescorla, 2000, 2001). The CBCL includes two broadband scales and eight syndrome scales. The CBCL has been studied in individuals with ASD and co-occurring emotional and behavioral disorders and found to be useful in the assessment of depression (Pandolfi, Magyar, & Dill, 2012).

Autism Comorbidity Interview: Present and Lifetime Version (ACI-PL; Leyfer et al., 2006)

The ACI-PL is a modified version of the Kiddie Schedule for Affective Disorders and Schizophrenia (KSADS). The sample consisted of a heavily male sample of 5–17-year-old children with autism from two specific research sites, one of which consisted of males with IQs above 65. This measure purports to differentiate impairment resulting from the ASD from impairment resulting from the comorbid disorder or symptoms. Inter-rater reliability for major depressive disorder was 90 % (kappa = 0.8), with sensitivity for this disorder being 100 %, and a specificity of 93.7 % in one sample, and 100 % sensitivity and 83 % specificity in a second sample. The authors did not provide information on the number of items in this measure or the major depressive disorder subscale, nor did they provide additional information on this measure.

Psychopathology Instrument for Mentally Retarded Adults (*PIMRA*; Matson, Kazdin, & Senatore, 1984)

The PIMRA is a measure based on DSM-III criteria developed for treatment planning, evaluation, and diagnosis of psychiatric disorders in individuals with intellectual disabilities. It exists in self-report and informant versions and consists of eight scales (schizophrenia, depression, psychosexual disorders, adjustment disorder, anxiety, somatoform disorders, and personality disorders) consisting of seven items for each subscale. The measure uses dichotomous items, with four of each subscale items necessary for a diagnosis. With respect to the depression scale, inter-rater reliability was found to be 81 %.

Psychopathology Checklists for Adults with Intellectual Disability (P-AID; Hove & Havik, 2008)

The Psychopathology Checklists for Adults with Intellectual Disability (P-AID) is a checklist developed from the DC-LD. It contains 18 checklists, 10 related to psychiatric diagnoses and 8 types of challenging behavior. The depression checklist includes 37 items which are psychometrically divided into two clusters of 14 and 23 items, respectively. The P-AID depression checklist was found to have an inter-rater reliability kappa-squared = 0.54, and a total Cronbach's alpha = 0.92 for internal consistency (Hove & Havik, 2008; Sturmey & Ley, 1990).

Treatment for Depression in Individuals with ASD

Treatment of depression in ASD with traditional therapeutic modalities has not been well established. However, previous researchers have observed that Cognitive Behavioral Therapy (CBT) and mindfulness-based therapies are effective in improving mood-related symptoms for individuals with higher-functioning forms of ASD such as Asperger's syndrome (Hare, 1997; Sizoo, Glas, & Kuiper, 2014). Results of studies of various cognitive and behavioral interventions in individuals with a range of autism spectrum disorders have shown mixed results. These interventions included social skills training, manualized CBT, cognitive restructuring, and mindfulness-based techniques. Although many of these studies targeted "low mood" and other symptoms (most commonly obsessive/compulsive disorders and anxiety), MDD was not diagnosed in a majority of these studies (Spain, Sin, Chalder, Murphy, & Happé, 2015).

Cognitive Behavior Therapy

Cognitive behavior therapy is a popular, evidence-based first-line treatment for MDD in typically developing children and adults with a variety of psychiatric disorders. CBT involves teaching individuals to notice and understand the relationship between their thoughts, emotions, and behaviors, and to teach new ways to think, cope, and respond to distressing situations and thoughts (J. S. Beck, 2011). CBT generally includes three components: behavioral activation, work on automatic thoughts, and cognitive therapeutic techniques. Behavioral activation includes monitoring one's daily activities with respect to the enjoyment and self-efficacy one experiences when engaging in the target activity, and helping an individual to problem solve and overcome obstacles to engaging in these activities, as well as broadening the behavioral repertoire. Work on automatic thoughts includes identifying maladaptive and/or negative thoughts as they arise, monitoring them in between sessions, and examining the evidence for and against these thoughts. Cognitive techniques often involve the "downward arrow" technique in order to identify intermediate and core beliefs, and examining their veracity and helpfulness, and identifying potential alternatives to holding these beliefs (Longmore & Worrell, 2007).

CBT has been studied in individuals with ASD and has been found to present some challenges and limitations. For example, previous researchers have observed that a core component skill of CBT, cognitive restructuring, is often particularly difficult for individuals on the spectrum (Cardaciotto & Herbert, 2004; Spek, van Ham, & Nyklíček, 2013). It has also been observed that gains achieved for individuals on the spectrum while in treatment for CBT may not persist, which is hypothesized to result from difficulty generalizing skills to other situations (Spek et al., 2013).

Weiss and Lunsky (2010) studied group CBT in adults with Asperger's syndrome. These individuals were diagnosed with MDD and/or anxiety disorders. Participants cited predictability, use of a book, repetition, skill-building, and group discussion with therapist facilitation, and the focus on the present as positives of this treatment modality. They also appreciated the use of concrete evidence and case vignettes, social support from other group members. In this study, participants had near perfect attendance and homework completion. Researchers found that the participants required more time to learn cognitive restructuring and working with difficult thoughts, which resulted in less time allotted for behavioral experimentation and scheduling activities. Similarly to previous studies, gains maintained were not maintained after completion of the group.

CBT in adolescents with ASD has also been studied and found effective for the amelioration of symptoms of anxiety in high-functioning adolescents (Wood et al., 2015). Interestingly, CBT-based therapies have also been found to be effective in ameliorating psychiatric disorders, including symptoms of MDD, in individuals with mild and mild to moderate intellectual disability (McGillivray, McCabe, & Kershaw, 2008).

Mindfulness-Based Therapy

Mindfulness-based therapy is a third-wave treatment that has recently become popular for use in treating mood disorders among typically developing populations. Mindfulness-based therapy teaches individuals to focus on experiences as they arrive in the present moment, with acceptance and non-judgment (Kabat-Zinn, 2003). Similarly to CBT, thoughts and feelings are a subject of identification and awareness, but unlike in CBT this treatment modality does not involve their analysis and/or modification. Mindfulness-based therapy may be easier for individuals with ASD to learn, as it focuses mainly on the skills of observation and identification. Spek, van Ham, and Nyklíček (2013) suggest that this treatment modality may be a preferable choice for use in individuals with ASD as it does not require the need to analyze one's own behavior.

Mindfulness-based therapy was studied by Spek and colleagues (2013) and found to result

in reductions in anxiety, depression, and ruminative thoughts, and an increase in positive affect amongst adults with high-functioning ASD. They observed that participants were able to generalize their meditation skills to their home, and that this likely corresponded with increased well-being.

Applied Behavior Analysis

Applied behavior analysis (ABA) is the most widely used and empirically supported treatment for the core deficits of autism spectrum disorders. This approach to treatment of ASD stemmed from the science of behavior (Lovaas, 1981). ABA is widely used to teach individuals with ASD improved communication skills and increased social skills as well as to decrease and extinguish challenging behavior. ABA refers to the use of operant conditioning to affect behavior of an individual with respect to social or socially related situations. ABA may be utilized to increase and broaden an individual's participation in pleasurable and/or mastered activities, in a manner similar to behavioral activation.

As a major component of behavior analysis is identifying the functions of an individual's challenging behavior and reinforcing adaptive behavior within a social context, an increase in reinforcers and/or reinforcing activities, or increasing an individual's involvement in leisure activities, may encourage and foster improvements in mood in these individuals. This approach may be preferable to more cognitively based interventions among those with lower IQs or who communicate nonverbally.

At present, ABA has been little studied as a treatment for mood disorders, both in individuals with ASD and in other populations. However, other forms of therapies with roots in the science of behavior have been developed and may be useful in this population. One such approach is Functional Analytic Psychotherapy (FAP; Kanter, Tsai, & Kohlenberg, 2010). This approach is based on the behavioral assumptions that behavior is more easily changed along with changes in context, and that shaping is most likely to be effective when provided with immediate consequences. Similarly to ABA, in FAP, clinically relevant behaviors are identified based on problematic behaviors which occur in-session, absence of behavior that alleviates the problem, the individual's description of the problem, and its cause. The therapeutic environment is modified such that the problem behaviors are likely to occur in session and that beneficial behaviors will be reinforced within session and within the individual's environment. This approach has been used with some success in the treatment of depression (McClafferty, 2012).

However, FAP may present difficulties similar to those posed by CBT or other treatments in which verbal abilities and/or intellectual abilities may affect treatment success. In individuals with lower IQs or lower verbal abilities, ABA may be useful in training participation in pleasurable leisure activities and/or engaging individuals in physical activities, which may help alleviate some of symptoms of depression (Nieman, 2002).

Pharmacological Interventions

Pharmacotherapy is also a first-line treatment for individuals with major depressive disorder, and similarly has been less-studied in individuals with ASD. First-line pharmacotherapy in MDD usually involves a selective serotonin reuptake inhibitor (SSRI), such as citalopram, escitalopram, fluoxetine, fluvoxamine, paroxetine, and sertraline. Other more commonly prescribed options include second-generation antidepressants such as bupropion and duloxetine, mood stabilizers, and atypical and first-generation antipsychotics (Mojtabai & Olfson, 2010).

In a review of the treatment literature, pharmacotherapy was found to be the most common treatment provided for individuals with comorbid ASD and a depressive disorder (Stewart, Barnard, Pearson, Hasan, & O'Brien, 2006). Consistent with first-line treatment of typically developing individuals, SSRI was found to be the most common medication prescribed and that the majority of individuals treated experienced a decrease in

symptoms. However, pharmacotherapy has not always been found to be effective (Stewart et al., 2006). In a study by Perry, Marston, Hinder, Munden, and Roy (2001) it was found that depression-related symptoms of self-injurious behavior (SIB), low mood, and disturbed sleep responded most favorably to treatment with SSRIs and/or mood stabilizers. Additional studies have also observed decreases in depression-related SIB in response to pharmacotherapy (Tsiouris, Cohen, Patti, & Korosh, 2003).

Atypical antipsychotics are also prescribed for irritability in individuals with ASD. Two atypical antipsychotics have been approved for use for this specific purpose: risperidone and aripiprazole (Owen et al., 2009). However, these medications are not without risks and are recommended to be used in conjunction with psychological treatments and psychoeducation (Owen et al., 2009). These medications are also associated with side effects, including somnolence, weight gain, and pulse and blood pressure changes (Shea et al., 2004).

Conclusions

Symptoms of depression result in considerable disability and decreased quality of life in individuals both with and without autism spectrum disorder. Major depressive disorder occurs at a high rate in individuals without ASD, and research on diagnostic and treatment options for these individuals is plentiful. Diagnosing depressive symptoms in individuals with autism spectrum disorders is complicated by the core symptoms of the disorder and is often impacted by intellectual disability that co-occurs with ASD at high rates.

Depressive symptomatology in autism remains an area in which additional research is needed, particularly with respect to the presentation of these symptoms in ASD, and how intellectual, communication, and social functioning may affect the prevalence, severity, and presentation of depressive symptoms. Moreover, diagnosis and treatment of depressive symptoms poses unique challenges in this population. The core deficits in communication and socialization create additional difficulties for the clinician who wishes to assess individuals with autism for these symptoms. Due to wide variation in core symptoms of autism, it is particularly important to consider changes in baseline functioning when considering questions related to differential diagnosis of MDD in individuals with ASD.

Diagnosis of depression in individuals with ASD should be conducted in a manner similar to typically developing individuals, by a clinician experienced in the assessment of individuals with ASD. A clinical interview of the patient as well as a parent, caretaker, or other informant should be conducted and additional data can be obtained through supplementing measures appropriate to the individual's developmental level, language, and social abilities of the patient.

Likewise, a clinician should consider these characteristics when determining a course of treatment for individuals with ASD. Individuals who communicate verbally and have higher IQs may benefit from psychotherapy, while behaviorally based techniques which focus on behavioral activation may be more appropriate for lower-functioning individuals. Pharmacotherapy may also be considered, but should not serve as a substitute for environmental enrichment, emphasis on increased functioning within an individual's environment, and the acquisition of long-term skills to help an individual cope with his or her challenges.

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Severe Psychopathology

16

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Introduction

Autism spectrum disorders (ASDs) are a set of conceptually related neurodevelopmental disorders that are estimated to affect as many as 1 in 68 children (Baio, 2014). While definitions of ASDs have varied over time, they are typically conceptualized in terms of social functioning deficits and restricted/repetitive patterns of behavior/interests that are pervasive and manifest early in childhood. ASDs are considered a public health crisis and exact considerable expense to society. Despite vast financial and scientific resources being devoted to understanding the genetics, neurobiology, and phenotypic expression of ASDs, they largely remain a mystery in terms of pathophysiological mechanism. Relatedly, it has become increasing clear that ASDs are highly comorbid with other brain disorders. In the present paper, we explore the epidemiological, genetic, environmental, endophenotypic, and phenotypic overlap between ASDs and "Serious Mental Illnesses" (SMIs)—defined in terms of persistent and serious functional impairments due to psychosis (e.g., schizophrenia) or affective (e.g., bipolar disorders) disorders. It is hoped that clarifying the continuities and discontinuities between ASDs and these other serious disorders will help better define the boundaries of each of these disorders and help clarify potential genetic, neurobiological and other risk factors that potentiate and maintain their expression. Implications for assessment and treatment will also be considered.

Statement of Purpose: Severe psychopathology, particularly schizophrenia and other severe forms of psychosis, has been linked to autism. This chapter explores these relationships and discusses test and other methods that can be used to establish the co-occurrence of these conditions.

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History and Clinical Definitions

The links between autism and SMI have deep historical roots. The neo-Latin term "autismus" was coined by Eugen Bleuler during a 1908 case presentation on the condition then called dementia praecox. Bleuler, who also coined the term "schizophrenia" in that same lecture, described in these patients an "autistic withdrawal … to his fantasies, against which any influence from outside becomes an intolerable disturbance" (as cited in Kuhn, 2004). This autism was one of four core symptoms (i.e., "The Four A's": association, affectivity, ambivalence, and autism) of Bleuler's schizophrenia, and was used to describe a "narcissistic withdrawal" into the patients' internal fantasy at the expense of the external world

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(McGlashan, 2011). The term was borrowed by both Hans Asperger (1944), and Leo Kanner (1943) to describe children that would likely meet criteria for contemporary definitions of ASD (Lyons & Fitzgerald, 2007). Kanner (1949) commented that early infantile autism was indistinguishable from schizophrenia, and considered the former to be an early manifestation of the latter condition.

Throughout the first half of the twentieth century, children who now are identified as having ASDs were considered to have a particularly precocious onset of schizophrenia (Kanner, 1949). The Diagnostic and Statistical Manual of Mental Disorders (DSM)—I included the diagnosis, "schizophrenic reaction, childhood type" (American Psychiatric Association [APA], 1952) and DSM-II identified "Schizophrenia, childhood type" to describe individuals who presented with "autistic, atypical, and withdrawn behavior; failure to develop an identity separate from the mother's; and general unevenness, gross immaturity and inadequacy in development (APA, 1968; p. 35)." Psychodynamic theories prevailed at the time, and many clinicians and researchers who attributed mental illness exclusively to environmental factors saw the parents, particularly the mothers, as responsible for creating and maintaining the stress necessary to cause a psychotic reaction in a helpless infant (Bettelheim, 1956). However, researchers noted that few cases of childhood schizophrenia were identified between ages 5 and 10 and that those with an onset before age 5 years displayed a distinctive course and presentation compared to those with onset in adolescence. Thus, it was argued that infantile autism should be classified as a separate condition from adult schizophrenia (e.g., Makita, 1966). Other early research programs (Ornitz & Ritvo, 1968; Ritvo et al., 1970) pointed to the psychophysiological similarities between the many identified disorders of childhood (e.g., early infantile autism, atypical ego development, symbiotic psychosis, and certain cases of childhood schizophrenia), foreshadowing the current classification of autism as a singular condition observed across a continuum of severity. With DSM-III (APA, 1980), autism finally achieved independence from the Schizophrenia spectrum, with "Infantile Autism" and "Childhood Onset Pervasive Developmental Disorder (PDD)" in DSM-III, and "Autistic Disorder" in DSM-III-R (APA, 1987). Due to concerns that DSM-III-R criteria resulted in the overdiagnosis of autism (Van Bourgondien, Marcus, & Schopler, 1992), the DSM-IV (APA, 2000) narrowed the criteria for "Autistic Disorder of Childhood," while adding "Asperger's Disorder," "Child Disintegration Disorder," and "Rett's Disorder" as distinct but related pervasive developmental disorders (PDDs).

The DSM-5 committee, arguing that differential diagnosis of "Asperger's Disorder" and "High Functioning Autism" was difficult and unnecessary (since both conditions represented a unitary spectrum), removed Asperger's Disorder, Child Disintegration Disorder, and Rett's Disorder as distinct diagnoses, reclassifying them as part of a newly defined Autism Spectrum. The effects of this change are, as yet, unknown—though projections suggest that the diagnoses will decrease in number (Matson, Hattier, & Williams, 2012; Mcpartland, Reichow, & Volkmar, 2012). Schizophrenia in childhood as a condition separate from autism can still be diagnosed using DSM 5.0. Importantly, ASDs and schizophrenia show common diagnostic criteria, notably: (a) persistent deficits in social communication and social interaction (e.g., diminished emotional expression and avolition in schizophrenia), (b) abnormalities in behavior, interests, or activities (e.g., restricted, repetitive behavioral patterns in ASD and disorganized speech and behavior in schizophrenia), and (c) catatonia is a specifier for both diagnoses. It warrants mention that illness course, notably in terms of symptom stability and age of onset are major determining factors of whether someone receives a schizophrenia or ASD diagnosis. Moreover, some symptoms, notably involving psychosis (e.g., delusions and hallucinations) are not diagnostic of ASD. The overlap in diagnostic criteria between ASDs and chronic mood disorders, notably major depression and bipolar disorder, is less overt, with the latter reflecting clearly defined episodes (i.e., weeks) whereas the former are defined in terms of much longer epochs.

Epidemiology and Overlap

Prevalence estimates for ASDs are somewhat arbitrary, at least from a historical perspective, because of dramatic changes in the diagnostic criteria and conceptualization of the disorder over time. Interestingly, rates of ASDs saw a dramatic increase from before it was operationalized in DSM-III (e.g., 4.9 cases per 10,000 persons; Wing & Gould, 1979) until after (e.g., from 4.7 per 10,000 to 11.2 per 10,000; Gillberg & Wing, 1999), while schizophrenia rates showed a notable decline (e.g., from 1 % to 0.5–0.6 %; Torrey, 1987; Kendler, 1988). These changes are not surprising given the diagnostic and conceptual overlap of these disorders. However, since 1980, prevalence of ASDs has continued to increase, with 2014 prevalence estimated at 147 per 10,000, or 1–2 % of the population (Baio, 2014), while schizophrenia rates have remained fairly steady (McGrath, Saha, Chant, & Welham, 2008; Saha, Chant, Welham, & McGrath, 2005). The reasons for the increasing prevalence of ASDs are currently unknown, but can largely be divided into two main theories, those reflecting: a) changing diagnostic sensitivity and specificity such that more cases are being identified, and b) changes in social, environmental, and genetic conditions "causing" more cases (Hertz-Picciotto et al., 2006; Matson & Kozlowski, 2011).

Despite the reality that identification of early childhood schizophrenia is difficult, available evidence suggests that it, by DSM III (APA, 1980) and IV (APA, 1994) standards, is rare. For example, Burd and Kerbeshian (1987), using a rural North Dakota sample, estimated a period prevalence rate of 0.19 per 10,000 children aged 2–12, while Remschmidt, Schulz, Martin, Warnke, and Trott (1994) estimated that 1 in 10,000 children will develop schizophrenia by adolescence. On the other hand, there is evidence that symptoms of schizophrenia, namely psychosis, are quite common in childhood. Kelleher and colleagues (2012) conducted a meta-analysis examining psychotic symptoms in childhood and adolescence, independent of diagnosis, and reported prevalence rates ranging between 4.7 and 35.3 %, depending on age and the nature of the question asked. Prevalence estimates appeared higher when the respondents were younger (median prevalence: 17 % for 9–12 years of age; 7.5 % for 13–18 years of age), and when the question was less explicitly related to psychosis. Concerning the latter point, "Do you ever hear voices or sounds that other people could not hear?" was endorsed by 35.3 % of respondents aged 9–12 years while "I hear voices or sounds that other people think are not there" was endorsed by only 4.7 % of 11–18-year-olds. Thus, while the diagnosis of schizophrenia may be rare in childhood, its symptoms may not be.

Differences in diagnostic definitions aside, epidemiological research continues to find links between the two conditions. Kohane and colleagues (2012) examined 14,000 individuals with ASD diagnoses under age 35 years and found that 8.76 % of patients over 18 years of age with an ASD also had a comorbid schizophrenia diagnosis. Other studies have reported similar levels of comorbidity in schizophrenia and also bipolar disorder (Stahlberg, Soderstrom, Rastam, & Gillberg, 2004). On the other hand, a large percentage of individuals with schizophrenia-spectrum disorders experience comorbid symptoms of autism at one time or another. These estimates are as high as 60 %, according to Hallerback, Lugnegard, and Gillberg (2012). Moreover, symptoms of psychosis, notably thought disorder, bizarre beliefs/fears, and hallucinations are common in people with ASDs (e.g., Kyriakopoulos et al., 2014; Weisbrot, Gadow, DeVincent, & Pomeroy, 2005).

Contemporary Conceptualizations of Psychiatric Disorders

There is growing awareness that psychopathological processes transcend psychiatric diagnoses, at least, as defined using DSM, International Classification of Diseases (ICD) and related diagnostic taxonomies. Genetic, molecular, anatomical, behavioral, and subjective pathological phenomena are rarely constrained to a single psychiatric disorder. Relatedly, individuals meeting criteria for the same psychiatric disorders can

show dramatic heterogeneity. Not surprisingly, there are no genetic, molecular, anatomical, behavioral, and subjective or other pathological phenomena markers uniquely typifying any ASD or SMIs, or other psychiatric disorders for that matter. The Research Domain Criteria (RDoC) initiative, advanced by the National Institute of Mental Health (NIMH), is a novel approach to understanding psychopathology that focuses on the discovery of identifiable subtypes across, rather than within, mental disorders (Insel et al., 2010). Initial efforts have focused on five broad clinical phenotypes categories (e.g., negative valence systems, cognitive systems). These categories are stratified across varying levels of complexity, from the genetic and molecular to behavioral, phenomenological, and paradigmatic. The resulting matrix provides a framework for understanding and investigating psychopathology from a mechanistic perspective, rather than focusing on phenotypic expression. Applied to the apparent overlap between ASDs and at least some SMIs, RDoC allows for delineation of convergent and divergent mechanisms both across and within disorders—without being constrained by the arbitrary diagnostic boundaries between them. With this in mind, let us discuss phenotypic expression, as well as environmental, genetic, and neurobiological concomitants that converge in ASDs and SMIs.

Converging Endophenotypes/ Phenotypes in ASDs and SMIs

Both ASD and Schizophrenia Spectrum Disorders (SSDs) are characterized by relatively broad disruption in central nervous system activity—as an impressively wide array of CNS functions is affected in each. In terms of RDoC domains (e.g., negative valence systems, cognitive systems), virtually every system is affected. A thorough analysis of the endophenotypes and phenotypes associated with these disorders is beyond the present review—but notable areas of overlap are worth discussion. Perhaps most notable involves social functioning and motivation, as impairments are considered central to both disorders. Deficits in social motivational processes are closely linked to social anhedonia—defined as diminished pleasure from social activities, in ASD and SSD (Chevallier, Kohls, Troiani, Brodkin, & Schultz, 2012; Gard, Kring, Gard, Horan, & Green, 2007). According to motivation theories, dysfunctions in neurobiological pathways associated with reward ("liking/enjoying" social interactions) and motivational ("wanting/seeking" social interactions) systems give rise to anhedonic symptoms that serve to influence future social behaviors (MacAulay, McGovern, & Cohen, 2014). In this respect, social dysfunctions in ASD or SSD appear to largely reflect deficits in social motivational processes (i.e., decreased seeking behaviors). Furthermore, as we discuss, these underlying impairments (e.g., social cognitive deficits, diminished social orienting, or limited social interactions due to low social reward) appear to facilitate a cycle that impairs future social cognitive development in ASD (Chevallier et al., 2012).

ASD and SSD are also both characterized by impairments in social cognition—involving perceiving, processing and responding to social stimuli. Interestingly, these deficits are less prominent in other SMIs, notably bipolar disorders (Martino, Strejilevich, Fassi, Marengo, & Igoa, 2011). Social cognition deficits, particularly in Theory of Mind (ToM)—defined as the implicit assumption that others have beliefs, desires, and intentions that are different from one's own (Frith & Frith, 2003), have been repeatedly implicated in ASD and SSD (Bölte & Poustka, 2003). Importantly, ToM and its posited underlying circuitry are related to the ability to detect irrational assumptions (the discrepancy between "false beliefs" and "actual states of the world") and are also involved in social learning processes (Frith & Frith, 2003). In this respect, ToM deficits can contribute to both disordered thought processes (e.g., the failure to separate reality from fantasy) and difficulties in social interactions (e.g., failure to engage in socially appropriate behavior or detect relevant information within the social environment). Emotion recognition—involving decoding emotional states from others based on body movement, nonverbal

prosodic cues, and facial expressions, is also commonly found impaired in individuals with ASDs and SSDs (Bölte & Poustka, 2003). Eye-tracking technologies, used to evaluate the strategy people use to decode emotion in other people's faces, have revealed that both ASD and SSDs tend to avoid focusing on eyes—an area particularly important for discerning other's emotions—notably in genuine versus posed emotions (Harms, Martin, & Wallace, 2010; Loughland, Williams, & Gordon, 2002).

ASDs and SMIs tend to share a number of more basic cognitive phenotypes as well. At a global level, impairments in intellectual functioning are commonly found within these disorders, despite the fact that intellectual functioning or basic cognitive deficits are not part of the diagnostic criteria for ASD or SSD (Cochran, Dvir, & Frazier, 2013; Matson & Shoemaker, 2009). While not ubiquitous across all patients with these disorders, cognitive deficits with presumed common genetic and biological bases (chromosomal changes) across a range of perception, attention, memory, language, executive functions, and other abilities tend to be the rule rather than the exception for these disorders (Crespi, Stead, & Elliot, 2010; Rosenfeld et al., 2010). Cognitive deficits are also prominent in bipolar disorders, particularly those with psychosis (Simonsen et al., 2011). Cognitive deficits are important predictors of occupational and social functioning in ASDs and SMIs (Green, 1996; Matson & Shoemaker, 2009). Furthermore, deficits in higher level cognitive abilities, such as metacognition (i.e., "thinking about thinking") or insight, substantially impacts the ability to acquire/learn knowledge and has been related to both ASD and SSD (Brüne, Dimaggio, & Lysaker, 2011; Grainger, Williams, & Lind, 2014).

There also appears to be common and distinct abnormalities of brain structure and function that may explain similarities and differences in ASD and SSD symptomatology. Although outside the scope of this chapter to discuss in detail, overall lower gray matter volumes in limbic-striato-thalamic circuitry appear to be a common feature of ASD and SSD (as well as pathology in general; see Cheung et al., 2010). Relevantly, these circuits are critical to attentional processes, the ability to filter information (sensorimotor gating) and systems involved in emotion regulation and social cognition. Distinct structural signatures are also noted, such that, lower gray matter volume in the amygdala, caudate, frontal and medial gyrus are found in SMIs, notably schizophrenia, and lower gray matter volume in the putamen are found in ASD (Cheung et al., 2010). Even impairments in olfaction sensitivity and identification, important because they are evolutionarily tied to social behavior and cognition (e.g., social recognition), have been linked to both ASD and SMI (Tabares-Seisdedos & Rubenstein, 2009). Furthermore, differences in neuro-hormonal factors such as vasopressin, oxytocin, secretin, may moderate the degree of deficits of social deficits found within both ASD and SSD (Cochran et al., 2013). Oxytocin in particular is thought to play a moderating role in the saliency of social information through its ability to influence systems involved in social motivation (Chevallier et al., 2012). As we will discuss pharmacologically, it holds promise as a treatment intervention. In sum, there is considerable phenotypic overlap between ASD and SMIs.

Shared and Distinct Shared Genetics

Both ASD and SMI disorders show a pronounced, and somewhat overlapping heritable component. Decades of behavioral genetics (e.g., adoption, twin and family studies) studies place the heritability of ASDs (64 %; Smalley, Asarnow, & Spence, 1988), schizophrenia (50 %; Tsuang, Stone, & Farone, 2001) and bipolar (85 %; McGuffin & Rijsdijk, 2003) disorders to be quite high. Moreover, these diagnoses are each interrelated in biological members of affected probands, suggesting that they share at least some common genetic pathways. For example, the odds of having a parent who is diagnosed with schizophrenia are approximately 2.9 times greater for individuals who are diagnosed with an ASD than controls, and the odds of the child having a parent who is diagnosed with bipolar

disorder is 1.9 times greater than controls (Sullivan et al., 2012). These results suggest that one or more common genetic variants predispose individuals to all three disorders.

Fueled by advances in assessment and understanding of molecular genetics more generally, more targeted inquiries in the genetic mechanisms underlying their respective neurobiologies and neural developments have been undertaken. The resulting literatures are, at the present time, still developing. However, there are several clear trends thus far. First, the amount of variance explained by individual or collections of Single Nucleotide Polymorphisms (SNPs) is remarkably modest. SNPs account for, at most, 23 % of the variance in SMIs like schizophrenia and 40 % of the variance in ASDs (Klei, Sanders, Murtha, & Hus, 2012; Lee et al., 2012), and much lower reports are more common in the literature. Second, despite ASDs and SMIs showing complex polygenic etiologies, there is evidence of overlap between them. Results of behavioral genetic studies suggest that families of individuals with schizophrenia spectrum disorders exhibit increased risk of ASDs. Between 20 and 60 % of the polymorphisms associated with ASDs are also associated with schizophrenia and between 20 and 75 % are also associated with bipolar disorder (Klei et al., 2012). Results from Genome-wide Association Studies (GWAS) provide further support for shared genetic liability. Of note, the Cross-disorder Group of the Psychiatric Genomics Consortium examined individuals with schizophrenia and autism and found that individuals with these disorders share a greater amount of genetic similarity than expected in controls. The results of this study suggest that 15–16 % of the SNPs that are associated with one disorder are implicated in the other. The discrepancies between behavioral and molecular genetic studies are of considerable interest to researchers as of late, and a number of large-scale genetic studies focusing on De novo mutations and copy number variations in both ASDs and SMIs are being conducted. These are important in that they offer greater sensitivity and potential conceptual resolution in findings from genetic methodologies, and because they offer insight into the neurobiological mechanisms underlying the disorders (and their potential commonalities).

Shared and Distinct Environmental Factors

There are a host of prenatal and perinatal factors that are associated with significantly increased, albeit statistically nominal, risk for ASD and SMI. Generally speaking, this relationship is driven by links between ASD and SSD, as opposed to other SMIs. For example, both ASD and schizophrenia have been associated with prenatal complications and potential insults, whereas prenatal and perinatal risk factors are generally not associated with an increased risk for unipolar or bipolar disorders (Larsson et al., 2005; Patterson, 2009; Scott, McNeill, Cavanagh, Cannon, & Murray, 2006; van Kooten et al., 2005). Furthermore, those who develop schizophrenia have had an abnormally high history of obstetric complications (e.g., hypoxia, breech birth, fetal distress) than those who develop bipolar (Scott et al., 2006). Prenatal nutritional deficiency, teratogen exposure, and maternal stress and viral infections (e.g., influenza) during gestation have also been linked to both SMIs and ASDs (Patterson, 2009; van Kooten et al., 2005). The higher prevalence of schizophrenia in urban than in rural areas has been used to argue that increased environmental stressors and/or greater exposure to infections during pregnancy or childhood may increase the risk for SSD (Mortensen et al., 1999; Patterson, 2009). Additionally, a seasonality effect has also been found such that a greater risk for these disorders is conferred to children conceived in winter months (Patterson, 2009). The presumed mechanism by which prenatal and perinatal factors may increase risk for ASD and SSD is through altering neural circuitry. For example, animal models of ASD and SSD suggest that fetal brain development is negatively impacted by increases in maternal antiviral immune responses (e.g., cytokines); in turn, as we will later discuss, this early perinatal insult may give rise to postnatal dysregulation of stress response systems and brain structure abnormalities (Patterson, 2009).

Early developmental experiences also appear to affect ASD and SMIs in potentially similar ways. Social learning processes have environmental and biological (e.g., epigenetic) components to them that facilitates the individuals' ability to acquire new information and abilities; and, for better or worse, these processes are highly sensitive to environmental inputs that interact with other cognitive processes (e.g., attention systems) that are substantially impacted within ASD and SMIs. Historically, ASDs and SSDs have both been attributed to lack of parental warmth—a notion arising from observations that caretakers of children with ASD and schizophrenia (Kanner, 1943), demonstrate abnormally low levels of affection towards their children. Importantly, while parental interactions are fundamental to children's emotional and neural development, it is largely agreed upon that "refrigerator mothers" do not cause either of these disorders. Rather, behavioral phenotypes (e.g., lack of warmth/reciprocity) with a presumed hereditary component (reflected in certain personality traits) are believed to underlie the relationship between parental warmth and ASD. Specifically, a trait-like lack of intrinsic interest in social contact, often referred to as social anhedonia or social apathy, has been found in parents of both children with ASDs and SSDs (Cochran et al., 2013). The mechanism is largely considered both genetic and environmental, such that these traits influence parental behaviors (e.g., reciprocal interactions and making eye contact). In this manner, familial environment via social learning processes is thought to moderate the degree of communication, interpersonal and affective deficits observed in children with ASD. As we will later discuss, these environmental factors are primary targets of empirically supported interventions (e.g., social skills training) for ASD and SSD.

Several factors appear to influence the trajectory of functional outcomes and symptomatology within ASD and SSD. First, comorbidity substantially influences ASD outcomes, such that children who show comorbidity with mood and anxiety disorders have a higher risk of developing a psychotic disorder (Cochran et al., 2013). Second, X-linked genetic factors appear to account for higher prevalence rates and worse outcome trajectories in males as compared to females with these disorders (Crespi et al., 2010; Szatmari et al., 2007). Third, the social environment appears to play an important role in resiliency to symptom exacerbations, in that both ASD and SSD are associated with increased disturbances in language and thought processes during periods of distress (e.g., Cochran et al., 2013). Furthermore, as noted within the literature, social and family support appears to increase resiliency to stress by providing a buffer as well as tangible support (e.g., financial or help problem solving). Moreover, in light of research suggesting that the beneficial effects (defined as lower cortisol, a measure of stress response) of social support during stress can be enhanced by intranasal administration of oxytocin (Heinrichs, Baumgartner, Kirschbaum, & Ehlert, 2003), it is likely that individual differences in these hormonal factors (which have been implicated in ASD and SSD) play a moderating role in responses to stress and thereby influence symptom severity.

Assessments of ASD and SMI

Despite there being a number of validated measures for evaluating ASD and SMIs, there exist very few measures for concurrent diagnostic purposes. To be fair, assessment of convergence between ASD and SMI diagnoses using DSM 5.0 (APA, 2013) criteria is an antiquated endeavor, at least, by RDoC standards. Nonetheless, there are potential clinical, public policy and other service-related reasons why one might wish to diagnose them concurrently. This again is challenged by fundamental differences in their diagnostic definitions, perhaps most importantly, age. Patients with ASDs, by definition, exhibit symptoms during early developmental period whereas SMIs tend to manifest in early adulthood. From a services perspective, ASDs are generally of primary concern during childhood whereas SMIs tend to be evaluated, at least for disability services, in adulthood. Accordingly, measures meant to diagnose ASDs tend to rely on collateral caregiver

and observational information (Matson, 2011) whereas measures evaluating SMI diagnoses tend to rely on self-report, behavioral observation, and psychiatric history (Kupfer et al., 2008). Moreover, ASD diagnostic measures tend to be developed in isolation (Lord et al., 2000; Matson, Terlonge, & González, 2006), whereas SMI measures tend to be part of a larger diagnostic battery assessing a wide range of psychiatric conditions. Finally, in part due to the importance of early intervention in childhood psychopathology, a number of screening measures for evaluating ASDs have been developed (e.g., Berument, Rutter, Lord, Pickles, & Bailey, 1999; Matson et al., 2009). In contrast, screening measures of SMI, at least for diagnostic purposes, are much less common.

Beyond clinical diagnosis, a host of measures that broadly tap psychopathological symptoms have been established—though the majority of these were developed for adult SMI populations. Of note, symptom ratings scales assessing a wide range of social, behavioral cognitive and affective psychiatric symptoms are commonly used in adults—though they neglect some symptoms associated with ASDs (e.g., repetitive interests). A number of symptom rating scales have been developed for use in SMI adult populations (e.g., PANSS; Kay, Fiszbein, & Opler, 1987; BPRS; Overall & Gorham, 1988), and a few have been modified for use in children as well (BPRS-C; Overall & Pfefferbaum, 1982). These measures tap a number of symptoms common to both ASDs and SMIs. More recently, measures have been developed to evaluate SMI symptoms in individuals with ASDs (Myrbakk & Von Tetzchner, 2008), and in many cases, an even broader range of psychiatric concern (e.g., Anxiety, Depression, Mania, Schizophrenia, PDD/Autism, Stereotypies, Self-Injury, Elimination, Eating, Sleeping, Sexual, Organic, and Impulse Control; DASH-II; Matson, 1995). As yet, these measures show promise as screening measures and indicators of domains of concern—but they tend to show modest convergence with each other (Myrbakk & Von Tetzchner, 2008). Of course, complicating this process is the lack of gold-standard for comorbid SMI diagnosis or symptoms in ASD populations, particularly those with intellectual disability.

Despite advances in the measurement of ASD and SMI symptoms using self-report scales, collateral information, structured interviews and behavioral observations, there are inherent limitations with these approaches that compromise their psychometric properties (i.e., reliability and validity), clinical application and ultimately limit their potential use. Symptom rating scales, for example, have reliability that is far from optimal, involve procedures that require considerable training and resources, and are attempting to tap constructs that are poorly understood and show considerable phenotypic variability both across people and over time (see Cohen & Elvevåg, 2014 for an elaboration). To address these sorts of concerns, considerable resources have been marshaled towards developing objective biobehavioral measures for evaluating ASD and SMIs. Generally speaking, these approaches take advantage of genetic, metabolic, brain imaging or biobehavioral data that tap, at least presumably, aspects of the underlying mechanisms associated with these disorders. This approach is advantageous in that it can often be automated, is objective—thus enjoying near perfect reliability, and in cases of biobehavioral analysis (e.g., vocal analysis, Cohen & Elvevåg, 2014), is more financially and temporally economical than traditional measures. Moreover, these approaches can take advantage of artificial intelligence and machine learning approaches to defining normative behavior (both within an individual and across individuals), and can ultimately provide much more sophisticated and accurate predictions over time. For example, biobehavioral data from an individual can continuously be updated so that its predicted relationship to outcome variables (e.g., social functioning) improves over time. It is important to keep in mind that it is extremely unlikely that these emerging technologies will be of use in "diagnosing" ASD or SMIs using DSM 5.0 criteria. Thus, they should not be seen as an alternative to clinical diagnosis, but rather, as a potential compliment for tapping homogenous and relatively distinct pathological processes.

Shared Treatments of ASD and SMI

There is a rich store of psychological treatments available for use in both ASDs and SMIs (e.g., Matson, 2011; Pfammatter, Junghan, & Brenner, 2006). While no treatments to date are by any means curative, they generally provide symptom amelioration and improvements in functioning. As yet, randomly controlled trials of psychological treatments targeting ASDs and SMIs tend to be diagnostic specific, such that individuals with ASDs are excluded from trials focusing on SMIs and vice versa. Nonetheless, there are many overlaps in treatment content and approaches. There are two particularly salient examples of this. First involves Social Skills Training (SST), which focuses on teaching the skills needed for successful interpersonal situations and relationships (Elis, Caponigro, & Kring, 2013). SST is designed to improve interpersonal skills and behaviors (e.g., expressive, receptive, conversational, nonverbal assertiveness skills) through modeling, rehearsal, and contingency management. Since individuals with SMIs and ASD share similar deficits in social skills, SST has been targeted as a treatment for individuals with ASD. A second treatment of note involves social cognitive remediation, which focuses on improving basic social cognitive skills and strategies (e.g., facial emotion recognition). In a review of psychosocial interventions for adults with ASDs, Bishop-Fitzpatrick, Minshew, and Eack (2013) examined six studies that utilized social cognition training. There was considerable variability in methods across these studies. Nonetheless, overall, improvements in social cognition, communication, and social skills were reported. Social cognitive training shows similarly promising effects in patients with SMI (Kurtz & Richardson, 2012). While many such programs exist, the Social Cognition and Interaction Training (SCIT) was developed for both individuals with Schizophrenia and ASD (Turner-Brown, Perry, Dichter, Bodfish, & Penn, 2008) and is showing promising efficacy.

There is also overlap in pharmacotherapies used for symptoms of both ASD and SMIs. Antipsychotic medications—which reflect the front-line treatment for psychotic disorders, has been approved by the US Food and Drug Administration (FDA) for use in individuals with ASDs. It is important to note that its approval for ASD involves management of behavioral problems (e.g., irritability), as opposed to symptoms of psychosis (Matson, Sipes, Fodstad, & Fitzgerald, 2011). The mechanism of action of antipsychotics, particularly as it pertains to ASDs, is not entirely clear. It is thought that blockage of D_2 and 5-HT_{2A} receptors may help to decrease severe irritability, hyperactivity, labile affect, withdrawal, and stereotypic behavior that is often a symptom of ASD (Politte & McDougle, 2014). Side effects are not benign, with weight gain, increased appetite, sedation, and an increase in serum prolactin being commonly reported. Moreover, antipsychotic medication use is generally not indicated for children (Matson, 2011). Antidepressant pharmacotherapy is also commonly used for the treatment of both ASD and Schizophrenia related symptoms. Because many behavioral features of ASD are linked to similar disorders with serotonin dysfunction, like emotion regulation and cognitive control, selective serotonin reuptake inhibitors (SSRIs) are often prescribed for symptoms such as dysphoria, repetitive behaviors, irritability, anxiety, and mood lability (West, Brunssen, & Waldrop, 2009). Of note, Fluoxetine, Fluvoxamine, and Escitalopram are found "somewhat efficacious" in the treatment of overall autism severity and disruptive and repetitive behaviors (West et al., 2009). As yet though, the empirical backing of pharmacotherapy for symptoms of ASD are far below that of SMIs.

Technological and methodological advances are providing hope for new types of therapy—ones that will target mechanisms underlying symptoms of both ASD and SMIs. While even a cursory review of these therapies is beyond the present paper, neuro-hormonal therapies and neural stimulation therapies warrant mention. Regarding the former, there is evidence that oxytocin plays an important role in systems related to social cognition and emotion regulation. Thus, normalizing oxytocin activity, for example through the use of intranasal administration, may

help reduce problematic social behaviors and improve social cognition. As yet, empirical support for exogenous oxytocin's use for treating symptoms of ASD and SMI is limited and somewhat inconsistent (e.g., Anagnostou et al., 2014). Nonetheless, given oxytocin's relative ease of administration, modest side effect profile and inexpensive nature, it is a promising treatment. Transcranial Magnetic Stimulation (TMS), another promising treatment, focuses electromagnetic fields to relatively focused cortical regions with relative specificity and, as yet, modest side effect profile (Bersani et al., 2013). Currently, deep TMS is used as a treatment for drug-resistant Major Depressive Disorder (MDD) but ongoing research is examining its potential for other psychiatric disorders. In Schizophrenia, deep TMS has contributed to improvements in cognitive and negative symptoms (e.g., Freitas, Fregni, & Pascual-Leone, 2009; Levkowitz, Rabany, Harel, & Zangen, 2011) and reductions in auditory hallucinations (Freitas et al., 2009; Tranulis, Sepehry, Galinowski, & Stip, 2008). In ASDs a preliminary case report has provided some evidence that deep TMS may help with aspects of social functioning and interpersonal understanding or theory of mind (Enticott, Kennedy, Zangen, & Fitzgerald, 2011). More research is needed to understand the types of cases and individuals deep TMS is best suited for, but these promising results suggest that deep TMS may be a viable treatment in conjunction with other therapies.

Conclusions

It is clear from the present review that ASDs and SMIs, particularly SSDs, show convergence across diagnostic, epidemiological, behavioral, cognitive, social, neurobiological, and genetic domains. At the same time, there are important differences between them, and the last four decades has seen improved diagnostic specificity in evaluating them. Despite this, treatments, particularly of a curative nature, have lagged far behind. With increased focus on trans-diagnostic mechanisms spanning psychiatric diagnoses (e.g., RDoC), our understanding of the commonalities and differences between them should improve dramatically—and may soon obviate the need for their clinical diagnosis in empirical or clinical arenas. At the same time, technological and clinical methodologies are emerging that will, at least eventually, revolutionize how ASD and SMI symptoms are assessed and treated. It is the hope of many large-scale research enterprises that cures for these disorders will be seen within the next few decades (e.g., Insel et al., 2010). In the meantime, a number of methods and technologies exist that can be used to improve the lives of individuals with ASDs and SMIs. Awareness of the potential comorbidity of ASDs and SMIs is growing, and this is important given the devastating effects that they exact.

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Assessment of Feeding Disorders in ASD: A Multidisciplinary Approach

17

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Introduction

Feeding problems and autism spectrum disorders (ASD) are historically linked. This association was first recognized by Leo Kanner, who highlighted atypical feeding patterns as a prominent feature in his initial description of the condition (Kanner, 1943). Feeding concerns were also included as a core feature of ASD by previous diagnostic systems (Ritvo & Freeman, 1978) and history is replete with anecdotal and case reports describing children with ASD as presenting with unusual eating patterns, rituals regarding the presentation or preparation of food, and/or strong emotional responses to new foods (Ahearn, Castine, Nault, & Green, 2001; Cornish, 1998). Despite this historical connection, researchers only recently focused empirical attention on identifying eating and nutrient intake patterns in this population. The first summary of the literature on this topic identified a mere seven descriptive studies (totaling 381 children) published between 1994 and 2004 (Ledford & Gast, 2006). All seven studies reported significant feeding problems in children with ASD, most often in the form of food selectivity by type, texture, brand, presentation, and/or appearance. While providing an initial foundation for understanding feeding concerns in this population, this review also presented a striking range of prevalence estimates, with between 46 and 89 % of children with ASD described as having co-occurring feeding problems. Such high variability reflected a lack of methodological rigor among the identified studies; four of the seven studies lacked a comparison group and most data was collected through retrospective chart reviews or study-specific questionnaires.

More recently, a meta-analysis by Sharp and colleagues (2013) sought to address these limitations by focusing exclusively on prospective research involving a comparison group to investigate the magnitude of feeding and nutrition concerns in children (birth to 18 years) with ASD. Inclusion criteria required use of a standardized instrument (e.g., questionnaire; food diary) to assess feeding concerns and presentation of outcome data either descriptively (e.g., percentages, means) or statistically (e.g., *p* values, *t* scores). Spanning a 31-year time period (1980–2011), the search yielded 17 studies totaling 881 children with ASD. Fifteen studies (involving 832 participants) contributed data on feeding problems and eight (involving 263 participants) contributed information on macronutrient and/or micronutrient intake (i.e., vitamins A, C, D, and E; zinc, calcium, iron,

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and protein). Findings indicated that children with ASD are approximately five times more likely to develop chronic feeding problems than their typically developing peers. Food selectivity (defined as narrow dietary variety) was the most frequently documented feeding concern, often involving strong preferences for starches and snack foods coinciding with a bias against fruits and vegetables. High rates of disruptive behavior (e.g., tantrums, crying) and rigid feeding patterns (e.g., only eating in a specific location; requiring certain utensils) were also prominent concerns. In terms of nutritional status, the analysis revealed significantly lower intakes of calcium and protein among children with ASD compared to typically developing peers. In addition, two studies (Bandini et al., 2010; Zimmer et al., 2012) provided provisional evidence of greater overall risk for dietary inadequacies in this population (Barr, Murphy, & Poos, 2002).

While yielding more definitive data regarding the strong association between feeding problems and ASD, Sharp et al. also highlighted remaining gaps in the research literature. Most notably, research in this area continues to be hampered by the lack of standardized and validated pediatric assessment tools to support clinical and research efforts. Outcomes primarily involved study-specific questionnaires or single-item measures, limiting conclusions regarding the prevalence and topography of feeding problems in ASD. Case in point, prevalence rates varied among identified studies depending on the content of the item/assessment method, with estimates reaching as high as 95 % of children with ASD described as resistant to trying new foods (Lockner, Crowe, & Skipper, 2008). This pressing problem of measurement prohibits critical questions regarding the etiology of atypical patterns of intake in ASD and makes it difficult to unravel the possible association between food selectivity, nutritional status, parent-initiated dietary restrictions (e.g., gluten-free, casein-free diet (GFCF)), and possible gastrointestinal (GI) concerns frequently observed in this population. It also limits development and evaluation of behavioral, habilitative, and/or medical interventions targeting food selectivity and related nutritional concerns.

The goal of this chapter is to review the current state of the science regarding assessment of feeding concerns in ASD. The chapter begins with a general overview of feeding disorders in pediatric populations. This review highlights the need for more definitive diagnostic models to guide and support clinical and research activities in this area. This is followed by a multidisciplinary framework for distinguishing feeding problems in ASD versus other pediatric populations, with consideration to the cause, topography, and medical/nutritional impact of atypical intake. Next, methods for assessing each of the major focal areas in the framework (i.e., behavioral, nutritional, oral-motor, and medical) are presented in detail. The chapter concludes with a discussion regarding important next steps to enhance routine screening, support greater research scrutiny, and promote development of the best standards of care.

The Problem of Classification

Lack of adequate measurement reflects a broader need to establish greater diagnostic clarity regarding feeding problems in pediatric populations. Persistent/severe feeding problems are often subsumed under the catchall term "feeding disorders"—which, broadly defined, involve disruptions in eating that (1) exceed ordinary developmental variations in hunger and/or food preference and (2) increase the risk of negative developmental, social, and medical outcomes (Sharp, Jaquess, Morton, & Herzinger, 2010). Feeding disorders, however, are not a unified construct, but rather a heterogeneous set of conditions encompassing a diverse range of mealtime concerns and outcomes. Possible concerns include poor caloric intake, nutritional inadequacies, growth failure, oral-motor deficits, lack of self-feeding, underlying medical problems, and/or severe refusal behaviors (e.g., crying, tantrums). Given such high heterogeneity, it is not surprising that the term has been used to describe various feeding issues spanning numerous etiological pathways and possible sequelae. It also helps explain why no adequate classification

system exists to capture the possible breadth of diagnostic inclusion needed to fully capture feeding disorders (Piazza, 2008). Review of available models, however, helps highlight key areas for consideration during the assessment process.

Types of Feeding Problems

One approach to categorization involves grouping children according to the specific feeding behaviors or possible function/topography of mealtime difficulties. Field, Garland, and Williams (2003) differentiated between five possible feeding problems related to deficits in motivation and/or skill (Table 17.1). These categories were developed based on review of 349 children evaluated by an interdisciplinary feeding team over a 30-month period. Oral motor deficits (44 % of the sample) were the most frequent feeding problem, followed by food refusal (34 %), selectivity by texture (26 %), dysphagia (23 %), and selectivity by type (21 %). Developmental disabilities were present in 225 of 346 children (64 %), including 22 children with ASD, 21 children with Down syndrome, and 44 children with cerebral palsy. Medical issues were prominent in the sample; they were present in all but 9 of 349 participants. Among those diagnosed with food refusal, all cases, with the exception of one child with ASD, involved a comorbid medical diagnosis. Among children with ASD, Field and colleagues reported (1) high prevalence of food selectivity by type (present in 62 % of children with ASD); (2) lower incidence of food refusal (12 %), oral-motor problems (15 %), and dysphagia (23 %); and (3) decreased likelihood of medical conditions other than constipation or diarrhea in cases involving food selectivity. In addition, all cases of food refusal in ASD involved a history of gastroesophageal reflux disease (GERD).

Table 17.1 Types of feeding problems as outlined by Field et al. (2003)

Category	Definition
Food refusal	Refusal to eat all or most foods presented resulting in failure to meet caloric or nutritional needs, excluding children who are not safe oral feeders due to medical concerns (e.g., aspiration)
Food selectivity by type	Consuming a narrow range of food (often involving rejection of one or more food groups) resulting in a nutritionally inadequate diet
Food selectivity by texture	Rejection of food textures that are developmentally appropriate, excluding children with significant oral motor problems or dysphagia that would necessitate consumption of lower texture foods (e.g., pureed or smooth)
Oral-motor problems	Problems with chewing, tongue movement, lip closure, or other oral motor areas as determined by a speech pathologist and/or occupational therapist
Dysphagia	Problems with swallowing as documented by a history of aspiration pneumonia and/or barium swallow study performed by a speech pathologist

A parallel approach to categorizing feeding disorders differentiates cases based on the target of intervention. Sharp and colleagues (2010) outlined four categories of feeding concerns in a meta-analysis of treatment outcomes: (1) feeding tube dependence, (2) food selectivity, (3) bottle/liquid dependence, and (4) poor oral intake. The review focused on the more severe end of the feeding disorder continuum, with most children (60 %) receiving treatment in an inpatient or day treatment setting. The most prevalent feeding concern was feeding tube dependence (45 % of participants), followed by food selectivity (31 %), bottle/liquid dependence (16 %), and poor oral intake (8 %). Similar to Field et al. (2003), medical concerns were prominent in the sample, with 68 % of participants having at least one medical concern; however, few children with ASD (22 %) presented with medical issues. In addition, most children with ASD received intervention for food selectivity (90 %) versus food refusal (10 %).

A closer examination of Sharp et al.'s (2010) categories suggests two primary feeding issues associated with intensive intervention—concerns with either the variety or the volume of food consumed during meals. Both categories involve significant disruptions in a child's relationship with food; however, food selectivity

describes cases in which poor dietary *variety* is the primary target of intervention (as is often the case with ASD); food refusal refers to cases in which the overall goal of intervention is to increase the *volume* of food consumed during meals. This latter category encompasses children receiving all or most of their needs through formula supplementation via tube or bottle, as well as children with faltering growth due to poor oral intake. In both cases, intense problem behaviors (e.g., tearful protests; severe disruptions) limit consumption during meals; however, refusal behaviors in ASD tend to be isolated to avoidance of new or non-preferred foods, but not coincide with restriction in the volume of preferred foods consumed during meals.

Etiology of Feeding Problems

An alternative approach to categorization focuses on the etiology of feeding disorders, most often involving a broad dichotomization between organic and nonorganic (a.k.a., functional) precipitants (Babbitt et al., 1994; Piazza, 2008). Organic factors refer to medical concerns that precipitate or coincide with the emergence of food rejection and/or growth failure; nonorganic (a.k.a., functional) factors involve environmental events (e.g., antecedents and consequences for feeding behaviors) that shape or strengthen refusal behaviors during meals. A summary of the most frequently cited organic and nonorganic factors is presented in Table 17.2.

A dichotomy of this nature is helpful in recognizing the frequent contribution of medical concerns in the emergence of feeding concerns. Estimates suggest that 40–70 % of children with chronic medical concerns experience feeding difficulties (Lukens & Silverman, 2014). For example, a chart review involving 72 children treated for feeding tube dependence at a hospital-based feeding program reported that 83 % of the children presented with oropharyngeal or GI abnormalities and 64 % had cardiac, pulmonary, neurological, or genetic conditions (Greer, Gulotta, Masler, & Laud, 2009). Of 103 children referred to an interdisciplinary feeding team,

Table 17.2 Frequently reported organic and nonorganic factors associated with feeding disorders in children

Organic factors
1. Gastrointestinal
• Gastrointestinal dysfunction
• Gastroesophageal reflux disease
• Eosinophilic esophagitis
• Food allergies
• Poor esophageal and/or gastric motility
2. Cardiopulmonary
• Bronchopulmonary dysplasia
• Congenital cardiac disease
3. Neuromuscular
• Brain injury (e.g., cerebral palsy)
• Nerve damage (e.g., paralysis of muscles used for swallowing)
4. Metabolic abnormalities requiring increased caloric needs and/or special nutrition
• Cystic fibrosis
• Renal failure
• Short bowel syndrome
5. Anatomical abnormalities involved with feeding
• Mouth (e.g., cleft palate, microstomia)
• Jaw (e.g., micrognathia)
• Airway (e.g., laryngeal cleft)
• Esophagus (e.g., narrowing after esophageal atresia repair)
• Extrinsic compression of the esophagus from congenital cardiac anomalies (e.g., vascular sling)
• Vocal cord dysfunction (e.g., prolonged intubation or laryngeal nerve damage)
Nonorganic factors
1. Behavioral mismanagement
• Negative reinforcement—Removal of feeding demand in response to problem behaviors
• Positive reinforcement—Caregiver attention for whining/crying/severe tantrums
2. Unrealistic caregiver demands based on age/developmental level
• Exposure to developmentally inappropriate food texture(s)
• Expectations regarding independence during meals (e.g., self-feeding)
3. Skill-based deficits
• Underdeveloped chewing skills due to lack of experience
• Persistence of tongue thrust due to lack of exposure to food
4. Problematic feeding practices
• Unrestricted access to food

(continued)

Table 17.2 (continued)

• Irregular mealtimes
• Lack of caregiver knowledge regarding food preparation/presentation
• Neglect
5. Socioeconomic hardships
• Poverty
• Famine

74 % experienced both behavioral and structural, neurological, cardiorespiratory, or neurological issues (Burklow, Phelps, Schultz, McConnell, & Rudolph, 1998). A similar pattern was reported by Sharp et al. (2010) in a summary of treatment literature, with GERD representing one of the most frequent medical concerns associated with feeding problems. Medical issues such as GERD, food allergy, gastroenteritis, and/or structural abnormalities are posited to create an association between food and aversive/unpleasant consequences (e.g., pain, nausea, and/or fatigue)—making eating something to avoid versus a pleasurable activity connected with the alleviation of hunger cues (Hyman, 1994).

The organic versus nonorganic dichotomy also recognizes that feeding disturbances may occur among children with no clear physiological precursor. This includes a significant number of children with ASD and food selectivity. Most past reports of severe feeding problems in ASD do not coincide with obvious organic factors or GI etiology (Ledford & Gast, 2006). However, children with ASD do have more GI-associated complaints than typical children, representing one of the most frequently cited comorbidities in this population. A recent meta-analysis indicated that children with ASD were four times more likely to experience at least one GI symptom. Children with ASD were also three times as likely to experience constipation and diarrhea and more than twice as likely to complain about abdominal pain compared to peers (McElhanon, McCracken, Karpen, & Sharp, 2014). These GI problems, however, may have a behavioral etiology, such as poor dietary diversity involving high intake of processed foods and low intake of fiber-rich fruits and vegetables. High prevalence of behaviorally based toileting concerns in ASD may also contribute to GI symptoms, including absent or delayed acquisition of bowel training. In addition, data on other GI symptoms (e.g., GERD, food allergies) typically associated with organic pathology remain insufficient and there is no evidence suggesting a unique GI pathology in ASD to account for the emergence, prevalence, and topography of food selectivity observed in ASD. This has led to the hypothesis that aberrant feeding habits among those with ASD may be a manifestation of restricted interests, behavioral rigidity, sensory sensitivity, and/or perseveration (Ahearn et al., 2001).

In general, the distinction between organic and nonorganic factors holds limited utility as a diagnostic nosology, as it is now generally accepted that (1) organic issues (when present) often operate concurrently with functional factors to maintain feeding problems; (2) most feeding disorders involve multiple causal pathways; and (3) disrupted family functioning and maladaptive patterns of reinforcement often play a central role in long-standing feeding concerns (Babbitt et al., 1994; Sharp et al., 2010). This latter point emphasizes the role of learned behaviors in promoting escape from unpleasant feeding experiences and/or gaining attention from caregivers (Piazza et al., 2003). Among children with ASD, however, the exact aversive qualities of non-preferred foods (e.g., texture, taste, temperature, color, or smell) that contribute to the emergence of food selectivity in this population remain unclear.

Impact on Family Functioning

Davies and colleagues (2006) proposed a multiaxial diagnostic framework, entitled "Feeding Disorder between Parent and Child," to capture the broader context in which feeding problems occur. This framework was built on the argument that existing diagnostic approaches (1) fail to capture relational and multisystemic processes involved in conducting meals with children; (2) focus exclusively on child factors that contribute to disrup-

tions in feeding; and (3) are overly concerned with exclusionary criteria (e.g., other medical, structural, or psychiatric disorders). Davies et al. sought to address these limitations by emphasizing the parent–child feeding relationship and broader characteristics in which disordered eating occurs. This includes (1) assessing both child and parent factors that contribute to mealtime difficulties (i.e., medical, developmental, and behavioral); (2) identifying key aspects of the parent–child relationship impacted by feeding difficulties (e.g., level of caregiver stress/concern, severity of interactional difficulties); and (3) determining contributing psychosocial and environmental problems/stressors (e.g., problems in caregiving, domestic violence, socioeconomic concerns).

This type of multifaceted approach recognizes that, as a relational process, disruptions in feeding may have detrimental outcomes beyond child factors (e.g., growth concerns) that are often the focus of clinical attention. This is particularly salient for children with ASD given existing concerns regarding high caregiver burden in this population (Fletcher, Markoulakis, & Bryden, 2012). Chronic feeding difficulties and related dietary concerns represent an additional source of strain on quality of life (Khanna et al., 2012), increasing child-rearing needs, parental stress, and social isolation. Children with ASD often exhibit a strong emotional response when presented with non-preferred food, including crying, disruption, and aggression (Sharp, Jaquess, & Lukens, 2013). As a result, severe food selectivity and related behavioral concerns often necessitate caregivers preparing multiple menus for each meal—one plate for the child with ASD and a separate menu that reflects the family's diet. For children whose behavioral disruptions occur in response to the sight or smell of non-preferred foods, they often cannot sit at the table with the family and peers and thus miss out on opportunities to learn and enjoy social engagement (Nadon, Feldman, Dunn, & Gisel, 2011). Families are also more likely to miss organized activities (e.g., birthdays; family gatherings) that involve eating and experience reduced opportunities to eat at restaurants or social occasions, resulting in further isolation (Sharp, Berry et al., 2013).

Current Diagnostic Criteria: The DSM-5

The new psychiatric diagnosis Avoidant/Restrictive Food Intake Disorder, as outlined by the *Diagnostic and Statistical Manual of Mental Disorders*, *5th Edition* (DSM-5) (APA, 2013), provides a more comprehensive framework for capturing the heterogeneity of pediatric feeding disorders compared with previous formal diagnostic systems. The main diagnostic feature of the disorder involves avoidance or restriction of food intake as reflected by failure to meet nutrition and/or energy needs. The criteria specify that this may manifest as one (or more) of the following clinical indicators: (1) significant weight loss, (2) significant nutritional deficiencies, (3) dependence on enteral feeding or oral nutritional supplementations, and/or (4) marked interference with psychosocial functioning. A notable strength of this new definition is movement beyond a singular focus on growth failure to capture significant feeding disturbances, astutely recognizing that not all children with disordered eating will present with weight concerns. This is particularly salient for children reliant on artificial supports (e.g., a feeding tube) to meet their energy requirements, as well as cases where dietary variety (vs. volume) is the primary feeding concern—as is often the case in ASD. Other strengths include consideration of the broader impact on psychosocial functioning as argued by Davies et al. (2006) and recognition of the potential role of traumatic or painful events in conditioning food aversion, with a specific reference to medical conditions involving the GI tract.

With these strengths in mind, the diagnosis remains broad and nonspecific in regard to feeding topographies, which is a frequent criticism of formal diagnostic systems (Piazza, 2008; Sharp et al., 2010). It also provides minimal guidance regarding how to navigate the diagnostic process for certain at-risk populations. For example, determination of what constitutes significant weight loss or nutritional deficiency is left up to clinical judgment. Further, while recognizing rigid eating patterns and heightened sensory sensitivity as prominent in ASD, it also notes that the

level of impairment may not meet the diagnostic threshold, although the only criteria specified is whether the eating disturbance requires specific treatment. Unfortunately, no guideline exists for determining when feeding intervention is warranted in pediatric populations. As such, avoidant/restrictive food intake disorder is best viewed as casting a more comprehensive diagnostic net with limited clinical utility for guiding the assessment process.

Beyond Anthropometrics

Compromised gross anthropometric parameters (i.e., height, weight, and body mass index [BMI]) is the most salient symptom of a feeding disorder likely to trigger attention in pediatric settings (Sharp, Berry et al., 2013). The use of anthropometrics as a primary clinical indicator makes pragmatic sense because height and weight are typically obtained as part of routine clinical care and assuring adequate energy intake is a critical consideration in supporting appropriate growth and development. The use of faltering growth as a proxy for a possible feeding disorder, however, biases detection towards children with food refusal vs. food selectivity and may help explain why feeding concerns in ASD are often overlooked in relation to other areas of clinical concern (McElhanon et al., 2014). Among children without ASD, feeding disorders most often involve severe restrictions in the volume of food consumed, leading to artificial supports (e.g., a feeding tube; oral formula supplementation) to support growth. In contrast, severe food selectivity in ASD most often involves deficits in dietary variety, not volume, and children with ASD typically consume enough food to meet gross energy needs. For example, Sharp, Berry et al. (2013) identified a pool of seven studies (involving 426 children with ASD) presenting information on growth status compared with typically developing peers. All seven studies reported significantly higher rates of feeding problems in children with ASD, but no statistically significant difference in growth status between groups. This pattern also holds true for children with ASD receiving intervention for food selectivity. Sharp, Jaquess, Morton, and Miles (2011) reported that only 2 out of 13 (15 %) children with ASD enrolled in an intensive day treatment program fell below the 5th percentile (weight for height). Similarly, Laud, Girolami, Boscoe, and Gulotta (2009) reported that only 7 out of 46 children (15 %) admitted for intensive feeding intervention met criteria for failure to thrive.

In general, it appears that most children with ASD and food selectivity are able to maintain at least minimally adequate anthropometric parameters despite restricted dietary variety. In fact, food selectivity in ASD may actually involve excessive intake of calories in some cases. This highlights the need to look beyond faltering growth as a means to quantify the impact of atypical patterns of intake in ASD. Evidence suggests that food selectivity in ASD places this population at risk for long-term nutritional or medical complications not captured by broad anthropometrics or analysis of overall energy intake. This includes vitamin and mineral deficiencies (Sharp, Berry et al., 2013) and compromised poor bone growth (Hediger et al., 2008). Selective eating patterns (e.g., complex carbohydrates and fats) may also increase the risk for diet-related diseases (e.g., obesity, cardiovascular disease). In a sample of 273 children with ASD, Egan et al. reported that 21.9 % had a body mass index (BMI) in the obese range, a rate that is higher than a nationally representative sample. Curtin et al. reported that the prevalence of obesity in children with ASD was 30.4 % compared with 23.6 % of children without ASD—corresponding to a 1.42 increased odds of obesity in this population. A recent large-scale chart review suggests that this trend extends into adulthood (Croen, Zerbo, Qian, & Massolo, 2014). When compared to non-ASD peers, adults with ASD experienced a 69 % higher incidence of obesity, 42 % greater risk of hypertension, and 50 % increase in diabetes. With the prevalence of ASD estimated at 1 in 68 children (CDC, 2014), high prevalence of feeding concerns and associated health concerns in ASD intensifies the need to develop and refine methods for detecting and remediating food selectivity in this population.

Comprehensive Framework for Assessment

A summary of key research findings regarding feeding problems among children with and without ASD is presented in Table 17.3. Among children with ASD, the comparison highlights (1) high prevalence of food selectivity; (2) low probability of faltering growth; (3) enhanced risk of nutritional deficiencies and/or excesses; and (4) lack of evidence for medical concerns to account for the pattern and prevalence of feeding difficulties in this population. It also emphasizes the presence of significant mealtime behavior problems (e.g., crying; severe tantrums) in both groups and related caregiver stress; however, problem behaviors tend to be isolated to the presentation of non-preferred foods in ASD. Finally, there is decreased likelihood of significant experienced-based oral-motor deficits in this population. Children with ASD likely consume chewable foods, often in the form of table texture snacks and processed foods (e.g., crackers, chips, chicken nuggets). As a result, they are more likely to possess foundational oral-motor skills (e.g., adequate variety of tongue movement concomitant with mastication to safely move the food bolus to swallow) necessary for processing higher texture foods, but may experience difficulty with generalizing these skills to non-preferred foods, such as fruits and vegetables, that represent a significant texture change from preferred foods.

A breakdown of this nature is intended to provide a general roadmap to guide the assessment process, with each of these major areas—behavior, nutrition, oral-motor, and medical—representing key considerations when assessing a feeding disorder in ASD. It is not, however, meant to imply that all children with ASD will fit this nomothetic pattern, nor should it be viewed as discounting the importance of a detailed medical or oral-motor examination among children with ASD and food selectivity. On the contrary, medical screening and assessment of oral-motor function should be viewed as central to the assessment process given the high association between organic issues and feeding disorders in other pediatric populations. Case in point, food refusal and feeding tube dependence, particularly among cases involving a history of GERD, have been described in past reports of children with ASD. With this in mind, this probabilistic description affords scaffolding for a more detailed evaluation to determine the topography, etiology, and potential impact of atypical intake in ASD.

Table 17.3 A comparison of feeding problems and outcomes between children with and without ASD

	ASD	Non-ASD
Primary feeding concern	Variety—food selectivity	Volume—food refusal
Mealtime behavior problems	Isolated to the presentation of non-preferred foods	Occurs with the presentation of most/all foods
Gross anthropometrics	Typically meets at least minimal gross energy needs	Faltering growth likely unless formula supplementation
Medical history	No population-level pathology to account for dietary patterns	Increased incidence of medical issues, particularly those involving the GI tract
Oral-motor skills	Intact for preferred foods; generalization to non-preferred foods a concern	Increased experience-based deficits due to lack of exposure to food
Dietary concerns	Nutritional deficiency and/or excesses; possibility of obesity and other diet-related diseases	Formula dependence (tube or oral)
Impact on family functioning	Reduced opportunity to participate in meals (child) and increased stress (caregiver); often preparing multiple menus for every meal	Reduced opportunity to participate in meals (child) and increased stress (caregiver)

A common theme throughout the assessment process is the unique challenges associated with ASD, most notably communication barriers and intense emotional responses. This necessitates increased reliance on caregiver report and adaptation to existing methodologies. The importance of a multidisciplinary continuum of care is also emphasized by this model, with distinctive contributions from behavioral psychology, nutrition, speech language pathologist (SLP) or occupational therapist (OT), and medicine to fully capture the diagnostic complexity of a feeding disorder in ASD.

Mealtime Behaviors

Existing methods for evaluating mealtime behaviors include behavioral observation and parent-report instruments. Both seek to capture the frequency, intensity, and/or impact of problem behaviors during meals. Behavioral observation is traditionally viewed as the "gold standard" for assessment, providing objective data regarding actual performance. Only two descriptions, however, are available regarding the use of behavioral observation to assess feeding issues in ASD. Ahearn et al. (2001) conducted the first direct observation of mealtime behavior in this population. The study involved 30 children with ASD aged 3–14 years. Children were exposed to 12 food items (three from each group—fruit, vegetable, starch, and protein) across six sessions using a self-feeder format (i.e., food was placed on a spoon positioned on a plate and the child was asked to fed himself or herself). One food from each group was presented during each session (four total foods): three foods at table texture and one in pureed form. Sessions were conducted in the school setting by a therapist with assistance from a teacher. A trial began with placement of the plate in front of the child along with a verbal instruction to "take a bite." Each presentation lasted for 5 s before removal (if not consumed) and the next bite was presented. There were no programed consequences for disruptive behavior with the exception of leaving the table, which resulted in neutral redirection back to the chair (i.e., without eye contact or verbalization from adults). Data on bite acceptance, food expulsion, and disruptive behavior were recorded on a trial-by-trial basis across a total of 120 bite presentations. The authors reported that more than half of the sample (57 %) exhibited food selectivity by type or texture, while more than three-quarters (87 %) exhibited low-to-moderate food acceptance.

Sharp and Jaquess et al. (2013) conducted a meal observation with 30 children aged 3–8 years. The study occurred at a feeding clinic with rooms equipped with a one-way mirror and adjacent observation room. The meal observation involved one food from each of the four food groups: peaches (fruit), potato (starch), hot dog (protein), and green beans (vegetable). Each food was presented three times at both puree and table texture, for a total of 24 bite presentations. A caregiver served as the feeder during the meal with support from a therapist provided by a wireless communication system. The structure of the meal involved a self-feeding protocol involving a four-step prompting sequence. The sequence involved the feeder systematically increasing the level of support provided to the child, with graduated movement through a series of increasingly supportive prompts (independent; verbal; model; physical). At each step, a specified amount of time (e.g., 5 s) was allotted before the next prompt and the child was provided with access to praise for accepting a bite regardless of the step in the prompting sequence. Escape (i.e., removal of the bite of food) was provided in response to disruptive behavior (e.g., head turning; pushing away the plate/spoon). Data on bite acceptance, crying, and disruptions were recorded for each bite trial. Sharp and colleagues reported that 73 % of participants exhibited low-to-moderate food acceptance. Eight participants rejected ($n=8$) all bites and 16 participants demonstrated selective patterns of acceptance by type and/or texture, with vegetables representing the most frequently rejected food.

Available descriptions of structured mealtime observations highlight important considerations for determining when and how to use this methodology to assess feeding behaviors in ASD. As noted by Sharp and Jaquess et al. (2013), the pro-

cess of conducting a behavioral observation is complicated by a number of interrelated factors, including investment of time/resources and the possibility of eliciting strong emotional responses (e.g., tantrums, aggression) during the presentation of novel or non-preferred feeding demands. Designing a meal observation must also consider key questions regarding meal formatting (Table 17.4), such as the level of structure during the assessment process, environment in which meal is conducted, and who is responsible for presenting the feeding demand. Antecedent aspects of the meal also need to be programmed into the observation (i.e., the types, texture, and variety of target foods; bite volume/portion size). With this in mind, there is also insufficient data to assure that clinic-based observations capture mealtime behaviors that children exhibit in their home environments. Further, provisional evidence suggests that parent-report measures of food selectivity correspond to behavior during a structured meal (Sharp, Jaquess et al., 2013). As such, Sharp and colleagues emphasized that, while behavioral observation will continue to play an important role in the assessment of feeding concerns in ASD, questionnaires represent a more feasibly and time-efficient front-line screening method in pediatric settings.

Table 17.4 Considerations for behavioral observation during meals

Key questions	Possible options
Level of structure	• Naturalistic
	• Semi-structured
	• Scripted prompting
Environment	• Clinic
	• School
	• Home
Feeder	• Parent
	• Therapist
	• Teacher
Foods	• Food textures
	• Variety/food groups
	• Preferred/non-preferred items
	• Bite volume
Presentation	• Self-feeder
	• Non-self-feeder

Standardized Questionaires

Questionnaires provide information on caregiver's perspective about mealtime behavior problems, degree of food selectivity, and/or the impact of atypical patterns of intake on the patient and family. Available instruments include the Brief Autism Mealtime Behavior Inventory (BAMBI; Lukens & Linscheid, 2008), Screening Tool of Feeding Problems (STEP; Matson & Kuhn, 2001), Children's Eating Behavior Inventory-Revised (CEBI-R; Archer, Rosenbaum, & Streiner, 1991), Behavioral Pediatrics Feeding Assessment Scale (BPFAS; Crist & Napier-Phillips, 2001), and the Pediatric Assessment Scale for Severe Feeding Problems (PASSFP; Crist, Dobbelsteyn, Brousseau, & Napier-Phillips, 2004). Table 17.5 provides a detailed summary of item content and psychometric properties of each measure. In terms of content, the BAMBI is the only instrument specifically designed with ASD-specific items with consideration to the unique combination of mealtime behavior problems (e.g., self-injury, aggression), rituals, and food selectivity observed in this population; however, it does not include a full range of food refusal behaviors and has no functional impairment items. Furthermore, the BAMBI was developed using a sample of children without a confirmed ASD diagnosis (only parent report). Other instruments include some items within food refusal, food selectivity, and functional impairment domains, but neglect behaviors related to ASD, such as aggressive, self-injurious, and repetitive behaviors. In terms of psychometric properties, only one of the instruments published normative data and all instruments lacked clinical cutoff scores. As a result, it is difficult to interpret scores on available measures, limiting the clinical utility. All of these instruments were developed based on literature review and expert opinion with little to no documented involvement of children or caregivers in item generation and/or measure refinement.

In sum, there is a clear lack of reliable and valid instruments of feeding problems in children with ASD, making it difficult to compare these behaviors and their impact on families across

Table 17.5 Content and psychometric properties of feeding measures

	BAMBI	STEP	CEBI-R	BPFAS	PASSFP
Item topics covered					
ASD specific	**X**				
Disruptive behaviors	**X**	**X**	**X**	**X**	**X**
Self-injury	x				
Turns head	x				
Closes mouth	x				
Pushes food away	x	x			
Throws food	x				
Turns body away	x				
Expels	x	x		x	x
Packs			x	x	x
Gags			x	x	x
Chokes		x	x	x	x
Coughs					x
Vomits		x	x	x	x
Cries	x			x	x
Whines				x	x
Elopes	x			x	
Aggresses	x				
Food selectivity/variety	**X**	**X**	**X**	**X**	**X**
Tries new foods	x			x	
Prefers certain foods	x		x		
Texture	x	x	x	x	x
Temperature		x			x
Functional impairment			**X**	**X**	**X**
Meal duration			x	x	x
Parent frustration			x		x
Child enjoys eating			x	x	x
Psychometric properties					
Internal consistency	0.63–0.88	0.27–0.70	Acceptable[a]	0.76–0.78	0.89–0.92
Test-retest reliability	0.87	0.26–0.79	0.84–0.87	0.85	0.98
Construct validity	x		x	x	0.75–0.79
Recall period	6 months	1 month	Undefined	Undefined	Undefined
Normative data				x	

[a]CEBI-R internal consistency was in the acceptable range (above 0.7) for the majority of subgroups, with the exception of 0.58 for single parents of multiple children

patients and treatments. Ideally, future efforts would adhere to the methods described in the Food and Drug Administration (FDA) Guidance on instrument development to increase clinical and research utility (US Department of Health and Human Services, 2009). Until such time, available questionnaires—particularly the BAMBI—should be viewed as screening tools for collecting information on key concerns regarding dietary variety and mealtime behavioral concerns. However, this should not take the place of a detailed behavioral interview that covers the antecedents (e.g., food presented, meal structure), behaviors (e.g., bite acceptance, swallowing, crying, tantrums, elopement), and consequences of mealtime behavior problems (e.g., food removal; meal termination). Assessment should also entail a more broad assessment of

overall behavior management strategies, occurrence of problem behaviors outside the meal setting, and generalization of mealtime difficulties across settings (e.g., home, school, restaurants). This data should also be considered within the context of information derived from nutrition, oral-motor, and medical evaluations to develop a comprehensive picture of factors influencing dietary preference and possible sequelae associated with atypical patterns of intake.

Nutrition Assessment

The primary nutrition concern in ASD is the underlying dietary insufficiencies related to food selectivity. Children with ASD typically prefer highly processed foods, snacks, and sweets (Schmitt, Heiss, & Campbell, 2008) while refusing to eat fruits and vegetables (Bandini et al., 2010; Lukens & Linscheid, 2008; Martins, Young, & Robson, 2008). This can lead to macronutrient and micronutrient deficiencies, as well as concerns regarding dietary excesses due to high intake of a single food item. With this in mind, nutrition assessment focuses on identifying (1) foods within a child's dietary repertoire and their corresponding nutrients and (2) frequently rejected food types and/or groups that may represent gaps or concerns for growth and development. Throughout this process, the overarching goal of nutrition assessment in ASD is the same as the general population—i.e., obtain anthropometrics, conduct a detailed feeding history, and measure diet adequacy. High prevalence of food selectivity combined with frequent use of caregiver initiated dietary restrictions (e.g., GFCF diet), however, necessitates increased attention to possible barriers to achieving a well-balanced diet in this population.

Anthropometrics

Careful analysis of the child's anthropometric involves plotting height, weight, and BMI on growth charts to determine growth status (de Onis et al., 2004; Kuczmarski et al., 2002). Use of the growth charts will help determine if the child is underweight (BMI-for-age < 5th percentile), normal weight (BMI-for-age, 5th–84th percentile), overweight (BMI-for-age, 85th–94th percentile), or obese (BMI-for-age >95th percentile). Determining where a child falls within these categories will help identify whether the primary feeding concern involves restriction in the volume versus variety of food consumed during meals. As noted above, assessment of anthropometrics (height/length, weight, BMI) does not usually coincide with compromised growth in children with ASD (Sharp, Berry et al., 2013). Emerging evidence, however, suggests that children with ASD are at a heightened risk for overweight and obesity (Curtin, Anderson, Must, & Bandini, 2010; Egan, Dreyer, Odar, Beckwith, & Garrison, 2013). This suggests that analysis of the child's anthropometric trends should look beyond faltering growth in cases involving food selectivity in ASD to include factors possibly contributing to excessive weight gain (e.g., increased energy intake related to calorie-dense foods).

Detailed Feeding History

Information collected during a detailed feeding history involves assessing items consumed across food groups (i.e., fruit, vegetable, meat/beans, dairy, and grains) to determine how a child's dietary intake compares with established recommendations. The most recent Dietary Guidelines for Americans focused on two primary concepts for healthy eating: (1) maintaining calorie balance over time to achieve and sustain a healthy weight and (2) focusing on consuming nutrient-dense foods and beverages (Dietary Guidelines for Americans, 2010). A diet involving a wide variety of foods across all food groups is emphasized because food group corresponds with a unique set of nutrients required for the body to function optimally (Table 17.6). One method for evaluating a child's diet is to determine how many foods in each food group category he/she regularly consumes, using a general query such as "Which foods will your child willingly accept on a consistent basis?" and then systematically prompting caregivers to list any fruits, vegetables, grains, meats/beans, and dairy foods. It is also necessary to determine if entire food groups are not being consumed by a child with ASD due to food refusal and/or food selectivity. For example, if the child

refuses to eat or drink anything in the dairy food group, the child is at risk for inadequate intake of vitamin D and calcium.

A food frequency questionnaire (FFQ) is a tool that precisely quantifies the number of foods that a child refuses and foods the child consumes in high volumes (Willet, 1998). This questionnaire contains a list of possible food items across food groups than can be summarized to reflect intake patterns. For example, Bandini et al. (2010) used a FFQ to determine the severity of food selectivity in a sample of 53 children with ASD compared with 58 typically developing children (age 3–11 years). Data from the FFQ were summarized to reflect (1) food refusal—percentage of foods offered that the child will not eat and (2) high-frequency single food intake (HFSFI)—any single food that the child ate more than 4–5 times per day. Bandini and colleagues reported that children with ASD demonstrated significantly greater levels of food refusal than peers (41.7 % of foods offered vs. 18.9 % of foods offered, respectively). Overall prevalence of HFSFI was low, presenting in only four children with ASD and typically developing peers. With this in mind, assessing for HFSFI during routine nutrition assessment can help to determine if a child is at risk of excessive intake of specific nutrients; food refusal, as captured by the FFQ, also permits detailed comparison of the percentage of foods that the child willingly consumes versus foods that the child refuses to eat and, thus, identify potential targets for intervention.

Table 17.6 Food groups and their corresponding nutrients

Food group	Primary nutrients
Fruit	Vitamin A, vitamin C, potassium, fiber
Vegetable	Vitamin A, vitamin C, vitamin E, fiber
Grains (enriched)	B vitamins (thiamin, riboflavin, niacin, and folic acid)
Meat/beans	Protein, iron, zinc, vitamin B_{12}
Dairy	Vitamin D, calcium, phosphorus

Dietary Analysis

There are a number of different ways to quantify dietary intake in children. The gold standard of dietary measurement is direct observation (Simons-Morton & Baranowski, 1991); however, this is rarely practical or feasible in a clinical setting. Other methods of dietary intake measurement include 24-h food intake recall and food intake records. The 3-day food intake record has been found to be the most accurate method for dietary measurement in school-age children and should be a standard part of a nutrition assessment for a child with a feeding disorder (Crawford, Obarzanek, Morrison, & Sabry, 1994). This procedure is best completed by providing the child's caregivers with a form to complete in real time over a 3-day period that includes the following columns: (1) date/time, (2) type of food presented (with recipes, if applicable), (3) amount of food offered, and (4) amount of food consumed. Once the 3-day food intake record is complete, daily average intake of energy, macronutrients, and micronutrients is determined through use of a dietary analysis program and results are compared to the Dietary Reference Intakes (established for gender and age groups) to determine if the child's diet is adequate in energy, macronutrients, and micronutrients. Assessment should also focus on possible excess in any nutrients, which is a particular concern in cases of ASD and food selectivity when one or a handful of foods are eaten in large quantities.

Assessment of Oral-Motor Skill

Oral-motor skills involve the systematic, intricately timed, and rhythmic coordination of the tongue, jaw, cheeks, and lips to allow for safe and proficient eating. When a feeding concern is present, it is critical to determine if a child possesses these foundational skills and whether there are any issues with managing food that may jeopardize safety. Possible factors that may impact effective mastication and swallowing of food are presented in Table 17.7. In general, dysfunction in any of these areas may contribute to the emergence of a feeding concern and/or place limitations on

oral feedings (e.g., textures and types of foods presented). In certain cases, initiation or continuation of oral feedings may be contraindicated due to serious or life-threatening consequences (e.g., aspiration) (Morris & Klein, 2001; Piazza, 2008). With this in mind, assessment of oral-motor skills and related safety concerns should precede any feeding intervention when underlying dysfunction is suspected. When medically indicated (e.g., evidence of signs/symptoms of aspiration, recurrent respiratory concerns, history of aspiration pneumonia), this should include formal evaluation of oral transit and swallow through the pharyngeal phase of the swallow via fluoroscopic study in conjunction with radiology (Oral Pharyngeal Motility Study) or through a Flexible Endoscopic Evaluation of Swallow (FEES). These evaluations assess the three phases of swallowing (i.e., oral, oropharyngeal, and pharyngeal) and are conducted to rule out risk of aspiration. Among children with ASD, available data does not support increased risk of swallow dysfunction in this population; however, consistent with consensus regarding other medical concerns (Buie et al., 2010), rates of significant oral-motor dysfunction should be viewed, at a minimum, as occurring at similar levels to those observed in the general population.

While many children with ASD possess foundational oral-motor skills necessary to swallow liquids and masticate some foods (Field et al., 2003), safety with non-preferred, non-dissolvable chewable foods should not be assumed and may pose a choking hazard in some cases. Possible oral-motor dysfunction in ASD, however, may be more subtle when compared to children presenting with food refusal and significant experience-based oral-motor deficits (e.g., little/no tongue lateralization or mastication) due to lack of opportunities with food (Piazza, 2008). In contrast, children with ASD and food selectivity have experience with preferred foods (Field et al., 2003), but experience concerns with generalization of established oral-motor skills (i.e., coordinated jaw and tongue movement to control, masticate, and swallow the bolus) to non-preferred foods—which often involve different sensory characteristics and endurance requirements. For example, highly preferred foods often consumed by children with ASD involve crispy/dissolvable snacks and processed foods with constant taste (ingredients), color, and packaging. Many of these foods require minimal effort for mastication and dissolve quickly in the mouth into a smooth starch that is ready to swallow. Processed foods are typically uniform in shape and consistency leading to little variation during oral processing. In contrast, fresh fruits, vegetables, and meats remain a chewable consistency throughout mastication and, as a result, require increased effort and coordination of the jaw and tongue to appropriately manage the food throughout mastication and transition of the bolus to the back of the mouth for swallowing. Determination of current skill level by the clinician helps establish realistic expectations for food texture during meals and provides guidance on areas to be addressed through therapy.

Table 17.7 Possible factors associated with oral-motor dysfunction

Oral-motor concern	Associated conditions
Impaired muscle function	• Down syndrome
	• Mitochondrial disease
	• Congenital hypotonia
Structural abnormalities	• Cleft palate
	• Pierre-Robin sequence
Neurological conditions	• Cerebral palsy
	• Hydrocephalus
	• Intracranial bleed
Experienced-based deficits	• Enteral feeds due to medical concerns
	• Chronic food refusal
	• Severe food selectivity

Detailed assessment of oral-motor skill involves a combination of clinical interview, direct observation, and formal evaluation of strength and coordination. This process is typically undertaken by a qualified SLP or OT as part of the continuum of multidisciplinary care (Field et al., 2003). A detailed clinical interview focuses on collecting background information on early feeding experiences (e.g., response to the introduction of solid foods; difficulty with major transitions in food types or textures), as well as determining current feeding practices (e.g., seating arrangements; utensils; support provided by

caregivers) and repertoire of food textures consumed. A clinical observation of a typical meal provides information regarding functional mastication, lingual bolus control, effort of deglutition, timeliness of the swallow, and coordination of each of these components during consumption of preferred foods. Figure 17.1 presents a checklist system for collecting key information regarding performance during meals, as well as observable signs of possible oral-motor dysfunction—including gagging, coughing, lack of chewing, and bolus management. In addition, the Beckman Oral Motor Evaluation (Beckman, 2010) is a formal tool used to establish baseline non-nutritive

Mealtime Support, Texture, & Skill Checklist
(Check all that apply)

SEATING

☐ Regular chair @ table ☐ Booster seat ☐ High chair ☐ Adaptive chair Other (please specify):

INDEPEDANCE

☐ Child self-feeds ☐ Interested but needs assistance ☐ Resistant ☐ Dependent on caregivers Other (please specify):

FEEDING UTENSILS

☐ Spoon ☐ Fork ☐ Knife ☐ Finger-feeds Other (please specify):

DRINKING FORMAT

☐ Bottle w/ nipple ☐ Sippy cup (hard spout) ☐ Sippy cup (soft spout) ☐ Straw ☐ Open cup Other (Sport bottle, Water bottle):

FOOD TEXTURE

	Frequency			
	Never	Monthly	Weekly	Daily
Liquids/soups	☐	☐	☐	☐
Strained baby food	☐	☐	☐	☐
Stage 3 baby food	☐	☐	☐	☐
Creamy foods (pudding, yogurt)	☐	☐	☐	☐
Pureed table foods	☐	☐	☐	☐
Mashed table food	☐	☐	☐	☐
Chopped table food	☐	☐	☐	☐
Regular table food	☐	☐	☐	☐
Crisp foods (crackers, chips, toast)	☐	☐	☐	☐
Chewy foods (meat)	☐	☐	☐	☐
Crunchy foods (carrots, celery)	☐	☐	☐	☐

ORAL-MOTOR CONCERNS DURING MEALTIMES

☐ Drooling ☐ Coughing ☐ Gagging ☐ Overstuffing ☐ Vomiting or Rumination ☐ Packing/holding food in mouth

☐ Limited or no biting off pieces of food ☐ Poor lip control (lip closure on spoon/open mouth posture) ☐ Lack of tongue control (tongue thrust, poor tongue mobility) ☐ Limited or no chewing (for children over 12 months) ☐ Teeth Grinding ☐ Aspiration concerns (wet-sounding or "gurgly" voice)

☐ Poor Suck/Suckle Other (please specify):

Fig. 17.1 Mealtime support, texture, and skill checklist

motor skill of the tongue, lips, cheeks, jaw, and hard and soft palate; however, specialized training is required to conduct and interpret this criterion referenced tool.

An important consideration when conducting any type of oral-motor evaluation with a child with ASD (outside of parent interview) is the inherent difficulty with the assessment process given increased sensory defensiveness—including avoiding touch in and around the mouth. That is, regardless of the oral-motor tool chosen, high rates of problem behaviors (e.g., head turning, crying, aggression) may impede the therapist's ability to complete the evaluation, particularly aspects that require the clinician to work inside the child's mouth. With this in mind, high levels of structure and routine in assessment methods, combined with systematically fading up from an initial task falling within the child's tolerance limits (e.g., beginning with light touch to the cheek or lips and systematically working up to being inside the mouth), is recommended to mitigate possible reactivity. This may lengthen the time required to complete the assessment process, but is likely to reduce the averseness of the process, yield more accurate data, and increase the likelihood of participation in future therapeutic activities.

Medical Evaluation

Research has yet to identify GI pathology unique to children with ASD (McElhanon et al., 2014); however, high prevalence of food selectivity combined with increased risk of GI symptoms warrants medical involvement to rule out and/or address possible underlying organic pathology. In general, the medical evaluation of feeding disorders in ASD should follow the thorough, logical diagnostic process appropriate for any child with a feeding disorder. This involves first screening for common organic issues that may cause or exacerbate discomfort or dysfunction along the gastrointestinal tract (e.g., aspiration, GERD, food allergy, constipation). This process, however, may require greater attention to nonverbal signs that fall outside routine screening procedures. As emphasized by expert consensus (Buie et al., 2010), children with ASD often present with limited communication and, as a result, gastrointestinal conditions may present atypically with non-gastrointestinal manifestations, such as behavioral change and/or problem behaviors. Examples include gritting teeth, facial grimacing, pica, application of pressure to the abdomen, unusual posturing, self-injurious behaviors, and aggression. Correspondingly, as emphasized by the most recent diagnostic criteria (American Psychiatric Association, 2013), sensory processing abnormalities are common among individuals with ASD, including (1) sensory over-responsivity, (2) sensory under-responsivity, and (3) sensory seeking (Mazurek et al., 2013), in which these atypical symptoms may be rooted. With this in mind, presence of a feeding disorder should trigger consideration of full or partial medical etiology regardless of the child's growth and risk of nutritional deficiencies, as presence of a feeding disorder may be the only sign of possible GI discomfort in ASD.

Given the diagnostic complexity inherent in ASD, medical work-up may necessitate greater diagnostic scrutiny, adopting a lower threshold for obtaining subspecialty consultation, and increased reliance on objective testing in order to recognize pathology, facilitate a diagnosis, and provide a treatment to improve overall quality of life (Buie et al., 2010). Consistent with general standards of care, assessment of possible medical etiology should entail obtaining a history of the feeding disturbance, past medical history, family history, and physical exam to guide diagnostic tests. A useful framework to guide this process involves a "head-to-toe" anatomical assessment—beginning with the mouth and moving through the esophagus, stomach, and intestines including associated systems along the way as outlined in Table 17.8. In addition to reviewing past swallow studies (if applicable), a physician should perform a thorough examination of the mouth, including looking at the palate, tongue, and oral mucosa for any indication of pain, neurologic, or anatomical abnormality. Patients with a history of prematurity, prolonged intubation, and/or chronic respiratory problems who fail to progress with feeding therapy should be

Table 17.8 "Head-to-toe" guide for symptoms, history, and examination in children with ASD and feeding problems

Anatomy	Key medical considerations in children with feeding problems
Mouth	• Palate—small cleft palate
	• Tongue—ankyloglossia or "tongue-tie"
	• Painful oral lesions (e.g., ulcers)
Esophagus	• Eosinophilic esophagitis
	• Inflammation from GERD
	• External compression of esophagus (e.g., vascular sling, tumor)
Airway structure	• Laryngeal cleft
	• Laryngomalacia
	• Aspiration from any cause
	• Vocal cord paralysis from prolonged intubation or cardiac surgery
	• Enlarged tonsils/adenoids
Lungs/heart	• Asthma
	• Heart failure (listening for murmurs)
	• Chronic lung disease
Stomach	• Gastritis/gastric ulcers secondary to infection (e.g., *Helicobacter pylori*)
	• Delayed gastric emptying
Intestines	• Lactose intolerance
	• Abdominal pain from any cause including constipation
	• Inflammatory bowel disease (Crohn's, ulcerative colitis)
	• Celiac disease
Systemic issues	• Food allergies
	• Increased caloric needs (e.g., cystic fibrosis, renal failure, HIV, biliary atresia, past nutritional neglect now needing catch-up growth)
	• Special diet required (e.g., ketogenic diet for seizure)

referred to an otolaryngologist for evaluation of the airway structure and vocal cord function. Assessment of the pulmonary and cardiac histories and corresponding physical exam is warranted among patients with reports of fast breathing, choking, coughing, and tiring during feeds. A history of spitting up, gagging, vomiting, and concern for discomfort while eating, and texture limited to liquids and purees, should trigger concern about esophageal pathology (Dellon & Liacouras, 2014). A pediatric gastroenterologist can make the definitive diagnosis of EoE by an esophagogastroduodenoscopy (EGD) with biopsies. This is especially important in children with food refusal and a personal history of and/or family history of atopic disease (e.g., asthma, environmental allergies, eczema, EoE). The National Health and Nutrition Examination Survey, which spans over 20,000 adults and children, reported that 6.53 % of children have self-reported food allergies (Savage & Johns, 2015). Because food allergies are inherently difficult to diagnose and highly prevalent in pediatric populations, children with ASD and feeding difficulties should be referred to an expert to determine if blood and skin testing is warranted.

One of the most common pediatric diagnoses associated with feeding disorders is GERD. When considering this, a trial of an acid suppression drug like a proton pump inhibiter will be diagnostic and therapeutic if it improves the abovementioned symptoms, including increased acceptance of food. If necessary, an EGD with biopsies will show signs of inflammation from GERD. General gastritis (inflammation of the stomach) is also common and would warrant a similar approach with an acid suppression trial and monitoring symptoms before evaluation with an EGD with biopsies. Lactose intolerance is also very common in adults and is therefore increasingly considered as children age (Montgomery, Grand, & Buller, 2015). A simple lactose-free diet trial is the first test in typical children, but given feeding difficulties in children with ASD, use of an EGD may be necessary to obtain a disaccharidase test for lactase deficiency. Constipation is highly common in all school-age children—estimated at about 9 % in a systematic review (Van Den Berg et al., 2006)—and children with ASD are more than three times more likely to complain of constipation (McElhanon et al., 2014). Thus, the medical evaluation should assess history on bowel movements and treatment for constipation if suspected. At a minimum, in unclear cases, a trial of laxatives may elucidate if constipation is related to problem behaviors during meals.

Through this process, medical evaluation can provide diagnostic clarity regarding the relative contribution of organic factors when feeding difficulties are present in a child with ASD. Moreover, a continuum of medical oversight will be needed as some medical problems only manifest as failure to progress with a behavioral intervention. In children with ASD and a feeding disorder, the process requires a higher level of suspicion of underlying medical problems combined with greater flexibility in diagnostic testing given the complexity of communication impairment, sensory abnormalities, and high reported prevalence of gastrointestinal symptoms in this population. Many common diagnostic procedures—e.g., diet trials, medication trials, and even some forms of testing (e.g., obtaining a blood sample)—although medically indicated, are not ideal for many cases given possible response to procedure or prescription. For example, a common recommendation to diagnose lactose intolerance is a trial lactose-free diet; however, food selectivity may place limits on introducing and/or removing foods from the diet (Sharp et al., 2011). In addition, in medical settings, children with ASD may become anxious or aggressive, leading to heightened resistance to medical procedures. Case in point, routine recommended blood work is often not completed as often as indicated and children with ASD require more frequent use of physical restraint and sedation to complete routine procedures (Davignon, Friedlaender, Cronholm, Paciotti, & Levy, 2014). In practice, the sum of all of these issues could manifest as moving towards more definitive and objective testing (e.g., swallow study, EGD, allergy skin testing) faster than one would in a typical child with feeding problems and if appropriate coupling blood draws with sedated procedures.

From Assessment to Triage: Levels of Intervention

When a feeding disorder is present in a child with ASD, the primary focus of intervention is to expand the variety and/or volume of foods consumed during meals. Unfortunately, there is a general paucity of research focusing on the treatment of feeding disorders in ASD. Therapeutic behavioral intervention is the only treatment for feeding disorders in pediatric populations with well-documented empirical support (Lukens & Silverman, 2014; Sharp et al., 2010) and provisional evidence suggests that ASD-specific adaptations of these techniques can improve feeding behaviors in young children with ASD and selective eating patterns (Ledford & Gast, 2006; Sharp et al., 2011). While promising, there are also notable barriers to access care given high prevalence of food selectivity in ASD combined with limited treatment options in community settings. To date, behavioral intervention targeting food selectivity in ASD has primarily occurred in highly structured settings (e.g., inpatient hospital unit; day treatment program), raising concerns about access and affordability (Lukens & Silverman, 2014). Indeed, there are few specialized programs available for children with ASD, and they are time and cost intensive—often requiring daily intensive services at a cost that can exceed $50,000 per child to eliminate disruptive behaviors that preclude food acceptance (Williams, Riegel, Gibbons, & Field, 2007). This expense combined with limited access to care highlights the need to expand the evidence base to promote greater breadth of treatment options, including (1) developing and evaluating treatments that are exportable and cost effective and (2) establishing an evidence base for other disciplines providing therapy (e.g., medical, occupational therapy, speech therapy, nutrition). This latter point emphasizes that effective treatment must also consider factors influencing eating, such as GI discomfort, food allergies, sensory processing, and oral-motor skills, during assessment and intervention, in order to maximize effectiveness (Lukens & Silverman, 2014). In addition, it is also the case that many children with ASD may respond to less intensive interventions, such as caregiver education on food presentation, training in behavior management during meals, and medical management of underlying organic concerns, such as GERD.

With this in mind, efforts to expand available treatment options should seek to provide a range of

services of various intensity levels—ranging from parent training and education (e.g., the Autism MEAL plan described by Sharp, Burrell, & Jaquess, 2013) to admission to an intensive day or hospital program (Lukens & Silverman, 2014). Key to this process is the recognition of the importance of multidisciplinary collaboration and communication when a feeding disorder is suspected. This will require increased attention to measurement, including development of standardized instruments to increase screening and promote detection. It will also be aided by the development of models or algorithms for applying data obtained in the assessment process to appropriately triage based on symptom severity. Available medical guidelines and algorithms (e.g., Furuta et al., 2012) represent potential templates to guide development of an ASD-specific algorithm for assessment and treatment of feeding disorders in this population.

Conclusions

Given the significant level of feeding concerns in ASD combined with the biological and social importance of healthy eating, greater clinical and research scrutiny is imperative to improve assessment methods, promote dissemination of evidence-based treatment, and develop more definitive conclusions regarding the impact of aberrant feeding patterns on health and development in the ASD population. Unfortunately, no comprehensive, standardized instruments exist to guide the assessment and treatment process for children with ASD. Methods identified in this chapter are based on a review of the extant literature combined with information derived from standards of care with consideration to ASD-specific adaptations. At present, available instruments fail to involve a multi-method, multidisciplinary process suggested for children with chronic feeding difficulties as a standard of care. This pressing problem of clinical measurement reflects the broader need to include assessment of feeding problems as part of routine clinical evaluations in this population, as this topic has been generally neglected with respect to other areas of clinical attention despite the possibility of serious consequences associated with food selectivity. A coordinated thrust in this area will necessitate development of a gold-standard instrument to support research which can also be efficiently applied during healthcare appointments to increase detection. Ideally, this process should capture key elements of the proposed framework—i.e., behavioral, nutrition, oral-motor, and medical concerns—while also covering aspects of family life often impacted by long-standing feeding concerns (e.g., engagement in home and community events involving food). Once available, improved measurement will help elucidate associations between food selectivity, nutrition problems, and GI symptoms often reported in this population, as well as promote development of best treatment practices.

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Assessing Sleep Problems in Children with Autism Spectrum Disorder

18

Terry Katz, Beth A. Malow, and Ann M. Reynolds

Prevalence of Sleep Problems in Individuals with ASD

Children with autism spectrum disorder (ASD) are much more likely than their typically developing peers to develop sleep problems. Research indicates that approximately 50–80 % of children with ASD have co-occurring sleep disturbance compared with a prevalence rate of 9–50 % for children with typical development (Couturier et al., 2005; Krakowiak, Goodlin-Jones, Hertz-Picciotto, Croen, & Hansen, 2008;Richdale & Schreck, 2009; Souders et al., 2009). While the frequency of sleep difficulties in all children with developmental disorders is high, children with ASD are more likely to have sleep problems than children with other developmental disabilities (Schreck & Mulick, 2000; Wiggs & Stores, 1996). The association between age and level of cognition and the presence of sleep difficulties is also different for individuals with ASD than for individuals with other developmental disabilities. While younger age and lower cognitive level are associated with higher rates of sleep problems in individuals with other developmental disabilities, these associations are not necessarily present in individuals with ASD (Krakowiak et al., 2008; Malow et al., 2006; Richdale, 1999). This may be related, in part, to the significant heterogeneity that is seen in individuals with ASD. While some research finds no age-related differences in sleep problems of children with ASD, other research has documented that parents of children who are younger than 8 years of age report more severe sleep concerns than parents of children who are older (Richdale & Prior, 1995). Studies have documented that sleep difficulties are present in high-functioning adolescents and adults with ASD (Limoges, Mottron, Bolduc, Berthiaume, & Godbout, 2005; Williams, Sears, & Allard, 2004). While there is strong evidence that individuals with ASD across all age groups have significant difficulties with sleep, the types of sleep problems that are evident may vary. Older children and adolescents have been found to have more problems falling asleep and staying asleep during the night, while younger children demonstrate greater bedtime resistance, sleep anxiety, parasomnias, and night waking (Oyane & Bjorvatn, 2005).

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Effects of Sleep Problems

Sleep problems may have profound and far-reaching implications for the individual who is experiencing difficulties as well as family members (American Academy of Sleep Medicine, 2005). Poor sleep in typically developing children has been associated with difficulties in cognition, mood, attention, and behavior (Armstrong, Quinn, & Dadds, 1994; Kataria, Swanson, & Trevathan, 1987; Pollock, 1994; Zuckerman, Stevenson, & Bailey, 1987). Studies have also linked negative mood, irritability, self-injury, and aggression to poor sleep in children with developmental disabilities (Clements, Wing, & Dunn, 1986; Quine, 1991). Additionally, sleep problems in children with developmental disabilities has been linked to disruptions in parental sleep as well as higher levels of maternal stress (Quine, 1991). The importance of good sleep has also been linked to the overall quality of life for children with developmental disabilities and their families (Didden, Korzilius, Aperloo, Overloon, & Vries, 2002; Didden & Sigafoos, 2001; Robinson & Richdale, 2004). The relationship between sleep and daytime functioning has also been documented in children with ASD. Mayes and Calhoun (2009) reported that children with ASD and sleep problems demonstrated more severe autistic symptoms, hyperactivity, and difficulties with mood and aggressive behavior than did children without sleep disturbance. Poor sleep in children with ASD has also been linked to inattention, activity level, repetitive behavior, self-injury, and affective difficulties (Goldman et al., 2009, 2011; Malow, Marzec et al., 2006). Short sleep duration in children with ASD has been linked with higher rates of stereotypic behavior, overall severity of autism, and deficits in social skills (Schreck, Mulick, & Smith, 2004). The need for sameness and an increase in repetitive behaviors has also been associated with sleep problems (Gabriels, Cuccaro, Hill, Ivers, & Goldson, 2005). Sikora, Johnson, Clemons, and Katz (2012) found that children with ASD who had reported sleep problems were also reported to have greater internalizing and externalizing behavior problems and poorer adaptive skill development that did children with ASD who had no reported sleep difficulties.

Types of Sleep Disorders

Identification of sleep disorders in children with ASD is a critical step in providing appropriate treatment.

Insomnia

Insomnia is characterized by difficulty initiating and/or maintaining sleep, and symptoms of insomnia are the main sleep concern reported by parents of children with ASD. According to data compiled through parent completed questionnaires and sleep diaries, common symptoms of insomnia in children with ASD include prolonged sleep latency (the amount of time it takes to fall asleep), increased bedtime resistance, decreased sleep efficiency (time actually asleep in relation to time in bed), decreased sleep duration, poor continuity, and increased nighttime awakenings (Couturier et al., 2005; Krakowiak et al., 2008; Richdale, 1999; Williams et al., 2004). Children with ASD often experience both sleep onset insomnia (difficulty falling asleep) and sleep maintenance insomnia (difficulty staying asleep), although sleep onset insomnia is more common (Krakowiak et al., 2008; Williams et al., 2004).

It is important to consider the variety of factors that may contribute to insomnia. While sleep habits and behavior may be a primary factor, there may also be a host of other causes that may be simultaneously contributing to this difficulty. Neurobiological factors including aberrations in neurotransmitter systems that promote sleep and establish a regular sleep–wake cycle may play a role in sleep difficulties in children with ASD. Several neurotransmitters that play a role in sleep regulation have also been associated with ASD. Melatonin is a sleep-promoting substance that is regulated by exposure to light and is released by the pineal gland (Gooley & Saper, 2011). It is synthesized from serotonin (Lin-Dyken & Dyken, 2002), and there are reports of abnormal platelet

serotonin levels in children with ASD (Rapin & Katzman, 1998). The relation between hyperserotonemia and sleep warrants additional investigation (Portas, Bjorvatn, & Ursin, 2000). Melatonin secretion has been noted to be low in individuals with ASD (Kulman et al., 2000; Melke et al., 2008; Nir et al., 1995; Tordjman, Anderson, Pichard, Charbuy, & Touitou, 2005), although one study performing overnight sampling documented normal blood levels in children responding to supplemental melatonin for sleep onset delay (Goldman et al., 2014). In another study, the level of the major metabolite of melatonin was directly related to the level of deep sleep in children with ASD (Leu et al., 2011). There is some evidence to suggest that a decrease in melatonin may be related to low activity of the last enzyme in the melatonin synthesis pathway: acetylserotonin-*O*-methyltransferase (ASMT). While the research is far from conclusive, some findings suggest that ASMT variability may contribute to abnormalities in the synthesis of serotonin to melatonin. In a study involving children with ASD, Jonsson and colleagues studied all the genes involved in the melatonin pathway and found mutations in regulatory regions in three genes: ASMT, melatonin receptor 1A, and melatonin receptor 1B (Jonsson et al., 2010). Other researchers have also found a higher rate of abnormalities in ASMT in children with ASD compared with controls as well as ASMT polymorphisms and lower levels of ASMT activity in children with ASD (Cai et al., 2008). There is also evidence, however, to suggest that there is no difference in ASMT variants (Toma et al., 2007). Melatonin is primarily metabolized by the liver enzyme, cytochrome P450 1A2 (*CYP1A2*) (Arendt, 1998; Arendt, Bojkowski, Franey, Wright, & Marks, 1985). Slow-metabolizing alleles in *CYP1A2* has been postulated to contribute to sleep problems in ASD (Braam et al., 2010; Braam et al., 2013; Veatch et al., 2015). One mechanism that reconciles the presence of normal melatonin levels with low ASMT transcript production is that these same children have reduced CYP1A2 metabolic activity. Veatch and colleagues observed an association between lower levels of ASMT transcript production and reduced CYP1A2 metabolic activity in children with ASD and comorbid sleep onset delay responding to supplemental melatonin (Veatch et al., 2015). Of note, treatment of insomnia with melatonin in children with ASD has been found to be beneficial in a number of well-controlled studies (Cortesi, Giannotti, Sebastiani, Panunzi, & Valente, 2012; Garstang & Wallis, 2006; Giannotti, Cortesi, Cerquiglini, & Bernabei, 2006; Malow, Adkins et al., 2012; Paavonen, Wendt, Vanhala, Aronen, & Wendt, 2003; Wright et al., 2011).

There are a number of medical factors that may also contribute to difficulties with sleep initiation and maintenance. Medical conditions that may cause discomfort or pain may contribute to disrupted sleep. It may be especially important to consider medical conditions that may interfere with sleep when working with individuals with ASD who are minimally verbal and who may not be able to describe physical symptoms that may be causing interruptions to their sleep. Some of the medical conditions that should be considered and may need to be addressed include reflux esophagitis, constipation, dental problems, allergies, reactive airway disease, and eczema. Primary sleep conditions such as sleep disordered breathing and restless leg syndrome may also result in poor sleep. Thus, a thorough assessment of medical conditions is an essential component of a sleep evaluation. Reynolds and Malow worked with the Autism Speaks Autism Treatment Network to develop a comprehensive screening checklist for medical comorbidities associated with sleep problems (Reynolds & Malow, 2011). The checklist is intended to be used by clinicians when interviewing families and includes questions related to reflux, constipation, abdominal pain, seizures, sleep disordered breathing, asthma, sinusitis, dental issues, eczema, nutrition, sensitivity to sensory input, restless sleep, and current medications. A physical examination is also part of this screening and includes consideration of tonsil size, hypotonia, nasal congestion or signs of allergic rhinitis, dental issues, wheezing, and eczema or dry, itchy skin.

Individuals with ASD may have co-occurring psychiatric conditions that may impact sleep. Symptoms of anxiety, depression, attention-deficit/hyperactivity disorder (ADHD), and obsessive-compulsive disorder may contribute to insomnia. The impact of sleep and psychiatric

conditions may be bidirectional as poor sleep may also intensify psychiatric symptomatology. Anxiety is a common difficulty in children with ASD and symptoms of anxiety may impact sleep in a number of ways. A child who is anxious may have difficulty falling asleep because of generalized anxiety, specific fears or concerns, or separation issues that make it difficult to fall asleep at night. Individuals with obsessive-compulsive disorder may need to engage in a number of long and complex rituals that prolong bedtime and result in shortened sleep. Depression may result in an individual waking up very early in the morning and not being able to return to sleep. An individual with bipolar disorder may experience an overall decrease in the need for sleep.

When considering the ways a psychiatric condition may impact sleep, it may also be necessary to address the role of psychotropic medications in sleep. A child with ADHD may have difficulty settling for the night, but may also have difficulty falling asleep because of the impact of taking a stimulant medication to address symptoms of ADHD during the day. In addition to the ADHD medication interfering with sleep, it can also suppress appetite. A child taking a stimulant may wake up at night due to being hungry. In addition, medications used to treat other conditions such as asthma or seizures may disrupt sleep.

There are defining characteristics of ASD which may also contribute to insomnia. Difficulties with understanding social cues may make it difficult to understand parental and societal expectations for getting ready for bed and falling asleep. Struggles with both verbal and nonverbal communication may also make it hard to help children learn a bedtime routine. An insistence on sameness and struggles with transition and change may also make it hard to prepare for bedtime. Moving from wakefulness and engagement in daytime (and potentially stimulating) activities to relaxing and sleep-promoting activities requires flexibility and the ability to adjust to a number of changes. This may be particularly difficult for individuals with ASD who often have difficulty with transitions and flexibility. Individuals who have a strong need to engage in specific activities or focus on certain topics may also have difficulty ending these activities at bedtime and may thus have trouble winding down for the night and relaxing for bed. They may also obsess about their restricted interests or worries about the school day. Hyper-reactivity to sensory input may also contribute to difficulties falling asleep. Sensitivity to noises, textures, or other sensations in the environment, for example, may interfere with falling asleep at night. Careful consideration of a child's sleep environment including bedding and pajamas can often be beneficial. Additionally, children with ASD may have difficulty with self-regulation and may easily become hyperaroused. High states of arousal will then lead to struggles with settling and establishing a relaxed state in order to initiate and maintain sleep.

Sleep Disordered Breathing

Sleep-related breathing disorders include several chronic conditions in which difficulties in breathing occur many times during the night. Symptoms may include snoring, gasping and pauses in breathing. Research using laboratory or portable home testing indicates that approximately 2 % of children ages 8–11, 4 % of adult men, and 2 % of adult women have sleep disordered breathing Rosen et al., 2003; Young et al., 1993). While sleep disordered breathing may not be more common in individuals with ASD, co-occurring genetic disorders such as Down syndrome may increase the risk. Additionally, some individuals with ASD have hypotonia which would put them at greater risk for sleep disordered breathing. Studies have documented improvement in daytime behavior and ADHD symptoms after adenotonsillectomy. A single case study reported improvement in daytime behavior in a child with ASD following treatment of obstructive sleep apnea (Malow, McGrew, Harvey, Henderson, & Stone, 2006).

Parasomnias

Parasomnias are common in childhood with over 80 % of preschool-age children experiencing parasomnia events (Kotagal, 2008). These are non-rapid eye movement (NREM) arousal disor-

ders and include night terrors, sleep walking, and confusional arousals. These events are often quite concerning to parents. Parasomnias may be related to sleep deprivation and may be a sign that medical conditions are impacting the quality of sleep. They tend to occur during the first half of the night during deep, slow-wave sleep. Many parents have difficulty distinguishing parasomnias from nightmares which tend to occur during the second half of the night. Key points that help parents make this distinction is when the event occurs (early in the night vs. late) and how responsive a child is during an episode (children are not responsive during a parasomnia but alert very quickly if they are awakened from a bad dream.) It is also important to try to distinguish parasomnias from seizures. There is some evidence to indicate that parasomnias are more common in children with ASD than in other groups, but the findings are not consistent (Honomichl, Goodlin-Jones, Burnham, Hansen, & Anders, 2002; Patzold, Richdale, & Tonge, 1998; Richdale & Prior, 1995; Schreck & Mulick, 2000).

Rapid Eye Movement Associated Sleep Abnormalities

Rapid eye movement (REM) sleep primarily occurs during the second half of the night and is the sleep phase in which most dreams occur. Normal physiologic generalized muscle paralysis occurs during REM sleep. REM sleep behavior disorder (RBD) is characterized by individuals acting out their dreams. This is a rare disorder, and it has been documented in one case series of children who were studied using polysomnography (Thirumalai, Shubin, & Robinson, 2002). A larger polysomnography study that excluded children who were taking psychotropic medications did not document REM sleep without atonia or RBD (Malow, Marzec et al., 2006). Selective serotonin reuptake inhibitors (SSRIs) are often prescribed for individuals with ASD, and these psychotropic medications can affect REM sleep and their use can be associated with REM sleep behavior disorder (Mahowald, 2011).

Rhythmic Movement Disorder

Rhythmic movement disorders typically involve repetitive whole body movements, limb rocking, rolling, or head banging. These behaviors usually occur during the transition from wakefulness to sleep (Hoban, 2003), but may often be seen at the start of bedtime or during sustained sleep. It is most common in infants and toddlers, but may persist in older children and adolescents with ASD and other developmental disorders.

Restless Legs Syndrome/Periodic Limb Movements in Sleep/Periodic Limb Movement Disorder

Restless legs syndrome (RLS) [now known as Willis–Ekbom Disease (WED)] is a sensory motor disorder that involves the urge to move the legs during times of rest or inactivity. The symptoms follow a circadian pattern and are usually either worse in the evening or at night than during the day or only occur in the evening or at night. Movement helps relieve uncomfortable symptoms. The prevalence of WED/RLS varies in the general adult population from 5 to 15 % (Phillips et al., 2000). A pediatric population-based study found a prevalence of definite restless legs syndrome in 2 % of 8- to 17-year-olds (Picchietti et al., 2007). There is a significant association of pediatric WED/RLS with ADHD seen in approximately 13–25 % of pediatric RLS cases (Kotagal & Silber, 2004; Muhle et al., 2008; Picchietti et al., 2007; Yilmaz, Kilincaslan, Aydin, & Kor, 2011) and RLS found in 25 % of ADHD cases (Oner, Dirik, Taner, Caykoylu, & Anlar, 2007; Silvestri et al., 2007; Wiggs, Montgomery, & Stores, 2005). Studies indicate that decreased iron stores are associated with RLS symptoms (Aul, Davis, & Rodnitzky, 1998; Sun, Chen, Ho, Earley, & Allen, 1998), and iron deficiency is common in children with ASD (Dosman et al., 2007; Hergüner, Keleşoğlu, Tanıdır, & Çöpür, 2012; Latif, Heinz, & Cook, 2002). This may be due, in part, to the limited and restricted diets of children with ASD; as many as 70–90 % of children with ASD have atypical feeding behaviors (Ahearn, Castine,

Nault, & Green, 2001; Nieminen-von Wendt et al., 2005; Schreck & Williams, 2006; Schreck, Williams, & Smith, 2004).

Periodic limb movement disorder (PLMD) includes repetitive limb movements in sleep that are disruptive and are not accounted for by another primary sleep disorder (including WED/RLS.) Symptoms of both RLS/WED and PLMD may contribute to a number of sleep problems including difficulty falling asleep and staying asleep as well as restless sleep throughout the night (American Academy of Sleep Medicine, 2005; Armstrong et al., 1994). It is important to evaluate the presence of RLS/WED and PLMD as treatment of both of these disorders may result in better sleep. In order to make a diagnosis of RLS, a child must be able to describe their symptoms in their own words. Many children with ASD have difficulties with communication and localizing discomfort. Thus, a diagnosis of RLS/WED in children with ASD may be quite difficult. By contrast, a diagnosis of PLMD is dependent on data obtained during a polysomnography (PSG) and does not require any self-report. Criteria for a diagnosis of PLMD include an excess of periodic limb movement sequences during an overnight PSG and associated impairment in daytime functioning or symptoms of sleep disturbance. Periodic limb movements of sleep (PLMS) is defined as an elevated frequency of periodic limb movements during an overnight PSG. Studies indicate that 63–74 % of children with RLS have an elevated frequency of periodic limb movements (Simakajornboon, Kheirandish-Gozal, & Gozal, 2009). There are a number of challenges associated with having individuals with ASD complete a PSG study, and this may lead to difficulties detecting PLMS and PLMD in this population.

Assessment of Sleep Difficulties

An obvious, but often overlooked, first step in determining whether an individual with an ASD has any sleep difficulties is to ask if this is a concern. Many individuals with ASD and their families are overwhelmed by a large number of difficulties. These may include difficult daytime behaviors as well as struggles in negotiating a number of complex medical, funding, and educational systems. Families are often dealing with so many difficulties, that it is easy to push sleep concerns to the side. Additionally, many individuals with ASD have long-standing difficulties with sleep; their families may have grown accustomed to their sleep patterns and may not realize that improvements can occur. Thus, it is important to directly ask parents specific questions about their children's sleep as they may not volunteer these concerns.

Sleep Surveys

There are a number of surveys and questionnaires that are designed to evaluate a child's sleep habits, sleep difficulties, and medical concerns that may be related to sleep. With the exception of the Family Inventory of Sleep Habits (FISH) (Malow et al., 2009) described below, these questionnaires have not been specifically designed for use with children with ASD. Nonetheless, they may serve as a useful screening device that can guide treatment and intervention.

While it was designed for use for typically developing children, the Children's Sleep habits Questionnaire (CSHQ) (Owens, Spirito, & McGuinn, 2000) has been used extensively with children with ASD. The CSHQ was originally validated on a sample of children ages 4–10. It has been used in a number of studies assessing sleep difficulties in children with ASD including toddlers and preschoolers (Goodlin-Jones, Sitnick, Tang, Liu, & Anders, 2008) as well as adolescents (Goldman et al., 2011;Goldman, Richdale, Clemons, & Malow, 2012). The CSHQ consists of 45 items that ask parents to report on their children's sleep behaviors over the past month. The majority of the questions are answered on a 3-point scale (1 = rarely, 2 = sometimes, 3 = usually). A total score is calculated as well as a number of subscale scores including sleep anxiety, sleep duration, sleep onset delay, night wakings, bedtime resistance, sleep disordered breathing, parasomnias, and daytime sleepiness.

Parents are also asked to rate whether each behavior being queried is a problem or whether it is not a problem. The CSHQ was originally validated on a community sample of 469 children, and results from this sample are often used as normative data in research studies.

The Sleep Committee of the Autism Speaks Autism Treatment Network used expert consensus to develop a practice pathway that captures best practices for the identification, evaluation, and management of insomnia in children and adolescents who have ASD (Malow, Byars et al., 2012). The guidelines are geared toward general pediatricians, primary care providers, and autism medical specialists. Practitioners are advised to screen all children who have ASD for insomnia. Screening may be accomplished by asking a series of questions that target insomnia from the CSHQ and determining if the parent considers these to be a problem. The questions are as follows: (1) child falls asleep within 20 min after going to bed; (2) child falls asleep in parent's or sibling's bed. (3) child sleeps too little; and (4) child awakens once during the night. The practice pathway also stressed the importance of addressing any medical issues that may be impacting sleep, and a questionnaire to help identify underlying medical conditions is provided.

The CSHQ and other questionnaires that examine behavioral and medical aspects of sleep are summarized in Table 18.1. While there are many other questionnaires that examine sleep, these are some of the measures that are most commonly used.

Some sleep questionnaires focus specifically on sleep initiation, maintenance, and quality. The Children's Sleep Wake Scale (LeBourgeois & Harsch, 2001) is a 40-item, 1 month retrospective parent report measure that has five subscales: going to bed, falling asleep, awakening, reinitiating sleep, and wakefulness. It is designed for children ages 2–8 years of age. LeBourgeois has also developed an adolescent self-report measure of sleep initiation and maintenance (LeBourgeois, Giannotti, Cortesi, Wolfson, & Harsh, 2005). The Adolescent Sleep Wake Scale is a 28-item questionnaire designed for adolescents ages 12–18; it is a 1-month retrospective report that includes 28 items. There are five subscales: going to bed, falling asleep, awakening, reinitiating sleep, and wakefulness.

Table 18.1 Sleep questionnaires

Name	Description	Respondent
BEARS (Owens & Dalzell, 2005)	Assesses 5 sleep domains: B = Bedtime problems (difficulty going to bed and falling asleep); E = Excessive daytime sleepiness; A = Awakenings during the night; R = Regularity and duration of sleep; S = Snoring. For ages 5–18 years	Parent and adolescent self-repot
Children's Sleep Habits Questionnaire (Owens, Spirito & McGuinn, 2000)	45 items; 4 subscales including bedtime resistance, sleep onset delay, sleep duration, sleep anxiety, night wakings, parasomnias, sleep-disordered breathing, and daytime sleepiness. Has been used with children with ASD ages 2–17 years.	Parent repot
Pediatric Sleep Questionnaire (Chervin, Hedger, Dillon, & Pituch, 2000)	69 items; 8 subscales including sleep-related breathing disorders, daytime sleepiness, snoring, and inattention. Ages 2–18 years.	Parent report
Sleep Disturbance Scale for Children (Bruni et al., 1996)	26 items; 6 subscales including sleep initiation and maintenance, daytime sleepiness, sleep disordered breathing, sleep arousal. Ages 5–15 years.	Parent report
Sleep Habits Survey (Wolfson et al., 2003)	63 items; 3 subscales including school performance, daytime sleepiness, sleep–wake behavior problems. Ages 10–19 years.	Adolescent self-report
Sleep Self Report (Owens, Maxim, Nobile, McGuinn, & Msall, 2000)	18 items assessing sleep habits, problems falling asleep, sleep duration, night waking, daytime sleepiness. Ages 7–12 years.	Child self-report

The Family Inventory of Sleep Habits (FISH) (Malow et al., 2009) is specifically designed for parents of children with ASD ages 4–10. It is the only sleep measure geared toward children with ASD. The items on the FISH assess daytime behaviors that may influence sleep and are amenable to change. Thus, the measure may yield information that can guide behavioral intervention. The items address daytime habits (such as exercise, or caffeine intake later in the day), prebedtime habits (including engagement in stimulating activities), sleep setting (amount of light and noise in the bedroom), presence (or lack) of a bedtime routine, and parental behaviors (such as remaining with a child until he or she is asleep.) Some of the items focus on sleep behaviors that are particularly relevant for children with ASD such as needing to wear pajamas made from certain fabrics. For each item the parent is asked to indicate how often the behavior was true during the last month on a five-point scale (1 = never, 2 = occasionally, 3 = sometimes, 4 = usually, 5 = always.) The FISH has been validated as a 12-item scale, although a full version contains 22 items.

Other sleep habits questionnaires are not specifically geared toward children with ASD, but can still provide important information. The Children's Sleep Hygiene Scale (Harsh, Easley, & LeBourgeois, 2002; LeBourgeois & Harsch, 2001) and the Bedtime Routines Questionnaire (Henderson & Jordan, 2010) are also brief surveys that provide information about bedtime routines and activities and the sleep environment. Both of these questionnaires are parent-report measures for parents of children ages 2–8. The Adolescent Sleep Hygiene Scale (Storfer-Isser, LeBourgeois, Harsh, Tompsett, & Redline, 2013) is an adolescent-report measure for individuals ages 12–18; it was modified from the Children's Sleep Hygiene Scale and examines behaviors that may interfere with good sleep. These include consumption of caffeine close to bedtime and level of activity before bed.

At times it may be important to specifically assess daytime sleepiness. This may be especially important when examining behaviors that may be indicative of sleep-disordered breathing. Behaviors that may be indicative of sleepiness (versus just being tired) during the day may include falling sleep during daytime activities and overall level of alertness. The Pediatric Daytime Sleepiness Scale (Drake et al., 2003; Nixon, Wawruszak, Verginis, & Davey, 2006) has been validated in children ages 5–15 years of age. It is an 8-item self-report measure that includes questions related to drowsiness, alertness, feeling the need for more sleep, and daytime hyperactivity. The Epworth Sleepiness Scale (Johns, 1991) was first designed as a measure for adults. A modified version for adolescents, The Epworth Sleepiness Scale-Revised for Children, (Melendres, Lutz, Rubin, & Marcus, 2004; Moore et al., 2009) assesses behaviors that are more applicable to teens than to adults. For example, there are items that look at sleepiness while taking a test. This questionnaire may be completed by parents or by adolescents and is designed for children and adolescents from age 2 to 18 years. The Cleveland Adolescent Sleep Questionnaire (Spilsbury, Drotar, Rose, & Redline, 2007) is a self-report measure for teens ages 11–17 years of age. Owens and her colleagues have also developed a teacher-survey, The Teacher's Daytime Sleepiness Questionnaire, (Owens, Spirito, McGuinn, & Nobile, 2000) to assess classroom behaviors of children ages 4–10 years that may be indicative of poor sleep.

Lewandowski, Toliver-Sokol, and Palermo (2011) and Spruyt and Gozal (2011) provide excellent reviews of parent and child-report sleep measures. They describe a number of limitations of these measures and note that most of these measures need additional information regarding reliability and validity. As noted above, most of these measures have not been validated for use with individuals who have ASD. Additionally, they have not been validated across diverse cultures or ethnic groups. When used clinically, it is important to review responses to survey questions in person to better understand and confirm any sleep difficulties that may be present.

In addition to using surveys that focus exclusively on sleep and sleep-related behavior, clinicians and researchers may use questionnaires that look at a variety of daytime behaviors and also

provide some information about sleep. Clinicians may find these questionnaires helpful as an initial screening tool although they will not cover all aspects of sleep that should be examined.

The Child Behavior Checklist (Achenbach & Rescoria, 2000) is a parent-report measure of childhood behavioral difficulties including symptoms that are consistent with an ASD diagnosis. It is the most common screening measure for psychopathology that is used by pediatric psychologists (Holmbeck et al., 2008). Children are rated in terms of internalizing and externalizing behavior; similar questions are grouped into a number of subscales or syndrome scales. There is a version for preschoolers (ages 18 months to 5 years) and a version for children ages 6–18 years of age. The preschool version includes a scale for sleep problems that includes 7 items (does not want to sleep alone, has trouble getting to sleep, nightmares, resists going to sleep, sleeps less than most children during day and/or night, talks or cries out in sleep, wakes often at night.) The CBCL for ages 6–18 includes multiple items that assess various aspects of sleep, but these items do not form a validated sleep scale on the CBCL. The 7 items include nightmares, overtired without good reason, sleeps less than most kids, sleeps more than most kids during the day/or night, talks or walks in sleep, trouble sleeping, and wets the bed. Parents rate their children for how true each item is currently or within the past 6 months using a 3 point scale (0 = not true, 1 = somewhat or sometimes true, 2 = very true or often true.) Research has supported the use of the CBCL as a tool in epidemiological or archival studies that do not include a more comprehensive sleep measure. It may also be useful for clinicians who do not use other validated sleep measures in their practice (Becker, Ramsey, & Byars, 2015). Becker et al. found that individual CBCL items were generally associated with sleep scales on validated sleep measures and with sleep disorder diagnoses. The CBCL sleep composite was associated with total scores on other sleep-specific measures. Some (but not all) CBCL items are also associated with other measures of sleep. For example, the item "trouble sleeping" has been found to be correlated with sleep information obtained from diaries as well as actigraphy data (Gregory et al., 2011). While the CBCL does not cover important aspects of sleep difficulties (including medical comorbidities) and will not provide a thorough evaluation of sleep problems, it does provide the opportunity to have standardized sleep scores for younger children and to directly compare sleep problems to daytime behavior.

Other measures of daytime behavior also include some sleep items. Some of these measures are: the Behavior Assessment System for Children, Second Edition (Reynolds & Kamphaus, 2004), which includes 2–4 items depending on the age of the child being assessed; the Child Depression Inventory (Kovacs, MHS, & Systems, 2003) which includes 2 items; the Pediatric Quality of Life (Varni, Burwinkle, Seid, & Skarr, 2003) which includes 1 item; and the Parental Concerns Questionnaire (McGrew et al., 2007) which includes 1 item. These questionnaires should not, of course, be relied upon for a screening of sleep difficulties, but they may provide a means to begin to identify whether there are concerns about a child's sleep and to compare sleep problems to other aspects of a child's functioning. Screening for daytime behavioral difficulties may also help determine whether a more comprehensive psychiatric evaluation is indicated. Psychiatric conditions such as anxiety, bipolar disorder, and depression can affect sleep and may be exacerbated by sleep difficulties. Thus, consideration of these psychiatric comorbidities should also be part of a comprehensive sleep evaluation.

Sleep Diaries

Information about sleep may also be obtained through the use of logs, sleep diaries, and homework sheets (Spruyt & Gozal, 2011). These parent or self-report measures are ideally completed just before bed and first thing in the morning. Parents, children, and adolescents with age-appropriate reading and writing skills may complete this information. Diaries or sleep logs include a variety of information. Respondents may be asked to record when a child goes to bed, total time asleep,

and when a child wakes up in the morning. The number of night time wakings, the time at which they occur, and the length of time a child is awake is often recorded. Sleep logs may also include times that a child gets out of his or her bed. Children may complete sleep logs that require them to record when they went to bed and how many minutes it took them to fall asleep. Information about daytime functioning including fatigue during the day and naps may also be gathered. This information can be used for an initial assessment as well as an evaluation of the effectiveness of an intervention. Observing and recording information about daytime and nighttime routines and behaviors may often help parents become aware of effective strategies and be invested in implementing beneficial techniques. At times information from sleep diaries or logs is paired with information that is acquired through the use of actigraphy (discussed below). Table 18.2 lists the type of information that can be gathered through sleep diaries, homework, or logs.

Table 18.2 Sleep diaries, sleep logs, and homework

Daytime habits: Timing of caffeine intake, exposure to morning light, exercise, naps
Evening habits: Timing of dinner, television, computers, electronics, video games, homework, exercise, other stimulating activities, relaxing activities, lowering of lights
Sleep setting: Description and evaluation of location, sensory components (e.g., noise level, temperature, light), potential distractions (e.g., electronic devices, toys, materials related to focused interests)
Bedtime routine: Time from start to finish, evaluation of consistency, inclusion of calm and relaxing activities
Use of visual supports: Are visual schedules or other visual aids used to help a child fall asleep?
Bedtime: What time is bedtime and is it consistent each night including weekends?
Sleep resistance: How long does it take to fall asleep? What happens once a child is in bed? What are parental responses?
Night wakings: How many? How long do they last? Does child leave the bed? What are parental responses?
Wake time: What time is wake time and is it consistent each night including weekends?

There are a variety of sleep diaries and logs available, but none have been evaluated for their psychometric properties. The Academy of Sleep Medicine has a sleep log that is available for download at http://yoursleep.aasmnet.org/pdf/sleepdiary.pdf and the National Sleep Foundation has a sleep diary that includes information about daytime behavior http://sleepfoundation.org/sleep-diary/SleepDiaryv6.pdf. Katz and Malow (2014a, 2014b) include a sleep record in their guide for families, and a copy is available online at www.woodbinehouse.com/SolvingSleepProblems.asp As Spruyt and Gozal (2011) note, there is no standardized format for sleep diaries. The wording, order of questions, format, number of questions, information requested, and time frame for completing diaries varies from study to study. Spruyt and Gozal (2011) make a number of key points about using diaries or logs. They correctly note that daily recording and/or rating of nighttime behavior will be more time intensive yet more valid than recording weekly or monthly information. They also note that specific questions may raise an awareness of nighttime behavior or patterns. It is important to confirm that families understand how to complete a sleep log and to take into account whether a family can reasonably gather and complete the required information. Spruyt and Gozal (2011) also state that it is advisable to have respondents demonstrate their understanding of what is expected, the importance of the information gathered, and the need for precision. They note that it is easy to create logs or diaries that may make it appealing and simple to complete and raise the possibility of creating programs that will allow the use of electronic (computer or mobile) logs with reminders for completion. They give an example of using text-messages or signals to a server as reminders. Children and adolescents may respond well to the use of computers with interactive touch screens. Spruyt and Gozal were not addressing the needs of children with ASD, but using such tools might be highly appealing to technology-minded individuals on the autism spectrum.

Actigraphy

Sleep diaries may be used in combination with actigraphy. This involves recording movement using a miniaturized watch-like device that is worn on the wrist or ankle during sleep. The actigraph records body movement, and this data is interpreted by computer algorithms as periods of sleep and wake. Information about sleep onset, sleep offset, sleep latency, total sleep duration, and wake after sleep onset may also be gathered. The actigraph can collect data continuously over an extended period of time (often 3 days to 2 weeks and in some cases even longer.) Data that is collected is then downloaded to a computer for analysis. New actigraphy devices, algorithms for interpreting data, and operating procedures are frequently being developed, and there is no consensus about which of these are best. There are also differences in the sensitivity settings that are used during data analysis. Sadeh and Acebo (2002) detail the ways in which actigraphy has become an essential tool in sleep research and sleep medicine. They advise new users to carefully review the scientific literature on each instrument that is being considered in order to determine which device, mode of operation and scoring algorithm will be most suitable for a researcher or clinician's needs. There are now many devices that are designed to measure physical activity that may also be used to obtain information about sleep, and there are also computer apps on tablets and cell phones that may do the same.

There have been multiple studies that have documented the adequacy of using actigraphy to differentiate clinical groups and to identify some sleep–wake disorders; Morgenthaler et al. (2007) detail practice parameters for the use of actigraphy in clinical practice. Meltzer, Montgomery-Downs, Insana, and Walsh (2012) provide a thorough review on the validity of actigraphy in children. Actigraphy is a useful measure of change in sleep patterns and can thus help document the effectiveness of sleep interventions for research and clinical purposes. Since it allows for data collection at home, it may provide sleep data that is obtained in a more naturalistic setting than a laboratory (Beebe et al., 2008; Blackwell, Ancoli-Israel, Redline, & Stone, 2011; Goldman et al., 2009; Goldman, Bichell, Surdyka, & Malow, 2012; Peterson et al., 2012). The most common alternative to actigraphy is polysomnography (see below for more information about this.) Polysomnography is expensive and thus usually only includes data from a single night's stay in a sleep laboratory. Actigraphy can provide many days or weeks of data and may provide a more representative sample of sleep than what may be obtained during a night of sleep in an unfamiliar setting while wearing multiple monitors and recording devices.

As with any sleep measure, there are some limitations associated with actigraphy. Most validation studies have been conducted in sleep laboratories while research and clinical studies are conducted in the home where there is less control over factors that are not directly related to sleep (Sadeh & Acebo, 2002). For example, someone who is watching television very quietly may be scored as being asleep. Detailed information from daily logs is thus very important when interpreting actigraph data. Information about bedtime, wake time, when the actigraph is worn and not worn, and external motion (such as riding in a car) or unusual events will be critical when interpreting results (Sadeh & Acebo, 2002). Increased wakefulness during the night also decreases the accuracy of information obtained from actigraphy, and decreased accuracy has been well-documented in individuals with insomnia (Chambers, 1994; Hauri & Wisbey, 1992). Quiet wakefulness while in bed can be miscoded as sleep, and actigraphy has also been documented as less accurate in people with movement disorders (Hauri & Wisbey, 1992). Overall, actigraphy results will vary as a function of age, sex, physical health, and mental health (Sadeh & Acebo, 2002). Thus, the usefulness of actigraphy to compare sleep between different groups may be limited. By contrast, actigraphy data may be very useful for within-subjects designs that assess various factors including treatment efficacy (Sadeh & Acebo, 2002).

Actigraphy with children poses specific challenges. Children may be curious about how a device works, and this curiosity may result in

damaged devices or inaccurate data. Children with ASD may have difficulty wearing an actigraph device on their wrist due to sensory sensitivity or because wearing a watch may be a new and thus stressful experience. Malow and her colleagues in the Sleep Disorders Division of the Department of Neurology at Vanderbilt University have developed a number of techniques to help children with ASD and their families successfully use actigraphy (Adkins et al., 2012). They have piloted the use of an actigraph device that is placed in a pocket on a child's shoulder. This alternative placement may be used with children who cannot tolerate wearing an actigraph device on their wrist. Pilot results indicate that shoulder placement is promising and worthy of further study. Malow and her colleagues have also developed a number of strategies to increase caregiver knowledge and skills in obtaining actigraphy data (Fawkes et al., 2014). They found that a 1-h structured parent training session resulted in an increase in scorable actigraphy data. Training included information on how to accurately complete sleep and actigraphy diary forms and the importance of having a child wear the actigraph watch each night. They were careful to review with parents when to mark bedtime and specifically discussed the difference between activities that are part of a bedtime routine (before a parent says goodnight to a child) and activities that occur after a child should be trying to fall asleep (after saying goodnight.) The training included examples that emphasized when to press the event marker, the importance of placing the device on their children for at least an hour before bedtime, and the need to leave the device on after waking. Training also included a short quiz to verify caregiver understanding of the material that was presented. Quiz scores that were lower than 80 % resulted in a review of any necessary information.

While it may be challenging for children with ASD to wear an actigraph device, there are a number of strategies that may help. As noted above, some children respond well to the opportunity to wear an actigraph watch in a shoulder pocket. At times, a slow and gradual approach may be beneficial. Children can be desensitized to wearing something on their wrist. A hierarchy of materials to be placed on the wrist can be devised (e.g., start with a thin piece of string followed by a piece of cloth, then gradually move to items that more closely approximate a watch) and a child can practice and be rewarded for wearing objects on their wrist. Some children respond well to learning about actigraphy and become interested and motivated to learn about their sleep patterns. Using a visual schedule at bedtime and including activities related to the actigraph watch can also help children comply with the procedure.

Validity of actigraph data may differ depending on the scoring algorithm and actigraph that is being used. There are some potential artifacts of measurement that can lead to inaccurate results, and actigraphy is not adequate for diagnosis in individuals with motor disorders or high motility during sleep.

Polysomnography

A critical component of an adequate sleep assessment must include a review of any potential medical contributions to poor sleep. Reynolds' and Malow's (2011) medical conditions questionnaire is an important first step in determining whether there are any medical factors that are impacting sleep. These questions can be incorporated into a review of systems that can lead to medical treatment. Please see Table 18.3 for a checklist of medical comorbidities that should be assessed.

A sleep study or polysomnography (PSG) is indicated if a child is noted to have snoring more than 2 nights per week in addition to one of the following: physical signs on exam, daytime symptoms such as difficulty with attention and learning, gasping or labored breathing, pauses in breathing, or abnormal posture during sleep. Epilepsy may also disrupt sleep and if there is a concern about possible sleep-related seizures, a sleep study with electroencephalogram (EEG) may be warranted. Sleep studies may also be used to determine if an individual has Periodic Limb Movement Disorder or if the child has excessive daytime somnolence (Kotagal et al., 2012).

Table 18.3 Screening checklist for medical conditions associated with sleep problems[a]

Gastrointestinal: Current or past symptoms of reflux, constipation, abdominal pain during the day or at night
Seizures and other nighttime events: Frequency of nighttime seizures, unusual events (behaviors or movements during the night)
Sleep disordered breathing: Snoring, loud breathing, gasping for breath, stops breathing, allergies, nasal congestion
Asthma/sinusitis: Coughing at night
Pain/itching/discomfort: Regular dental visits, tooth or gum pain, eczema/dry itchy skin, hunger at night, sensory sensitivity (light, sounds, textures, smells)
Nutrition: Iron intake: Eat an average of at least 1–2 ounces of meat per day or take vitamins with iron
Restless sleep: Signs of restless sleep, leg pains or "growing pains," frequent leg movements during sleep, or unusual feelings involving the legs when in bed
Medication: Note all medications currently being used and potential side effects
Physical exam: Large tonsils, hypotonia, nasal congestion or signs of allergic rhinitis, dental issues, wheezing, eczema, and dry or itchy skin

[a]Modified from Reynolds and Malow (2011)

PSG has been called the "gold standard" for assessing sleep. Individuals spend the night in a sleep laboratory where a number of physiological measures are gathered. These include measures of brain activity (electroencephalography), eye movements (electrooculography), muscle activity (electromyography), and heart rhythm (electrocardiography.) Oxygen levels, airflow, and carbon dioxide levels are monitored throughout the night.

In order to gather this data, sensors are placed on an individual's head, chin, legs, chest, and area near the eyes. The sensors are usually held in place with gels secured with tape or mesh netting. A person's head also needs to be wrapped with gauze to hold the sensors in place. Belts are wrapped around a child's chest and stomach. Pulse oximeter sensors to monitor oxygen are placed on fingers or toes and a flow sensor and nasal cannula will be used. It can take between 30 and 90 min to fully prepare an individual for a sleep study. While the procedure is not painful, it can be stressful and difficult for individuals with ASD who also have sensory sensitivities and who need to adjust to sleeping in a new environment. It is important to note, however, that with careful preparation, children with ASD can successfully complete a sleep study.

One of the first steps to take in preparing a child with ASD for a sleep study is to become familiar with the process. Reviewing a social story that includes photographs or other visual images of the sleep study may be helpful. The Vanderbilt Kennedy Center Leadership Education in Neurodevelopmental Disabilities (LEND) program (2014) has developed a very helpful toolkit that includes a social story, visual supports and concrete suggestions to help prepare a child for a sleep study (http://vkc.mc.vanderbilt.edu/assets/files/resources/sleepstudy.pdf) Some children enjoy learning about the technical aspects of the study. If possible, use pictures and/or videos from the sleep laboratory where the study will take place. A visit to the sleep lab sometime before the sleep study occurs can also be helpful. Some children may require several visits to get used to the idea of being in the lab. If possible, a child might be able to practice some of the procedures during a brief visit. Ending on a positive note and providing some rewards is often a useful strategy. Some individuals will also require systematic desensitization to specific aspects of the sleep study. They may need help to tolerate some of the sensory sensations involved in a sleep study such as having electrodes placed on their head.

During the actual preparation for the sleep study, it may help to provide distractions and comfort objects. Saving a special toy or materials related to a focused interest may also help a child sit through the preparation process. Sensory toys including squeeze balls or oil and water timers may be calming. Allowing a child to watch a special video or play a cherished electronic game may also be useful strategies. A visual schedule that depicts each step may help a child track and tolerate the procedure. Rewards may be paired with successfully completing each step. Whenever possible, try to offer a child some choices during the preparation. This may involve choosing which small prize or sticker he or she can earn. If possible, it might involve choosing which electrode will go on next. It helps tremendously if all the adults involved (parents and

providers) remain calm and matter-of-fact throughout the preparation. Zaremba and her colleagues have detailed a number of strategies geared toward helping children successfully complete a sleep study (Zaremba, Barkey, Mesa, Sanniti, & Rosen, 2005). They advocate a flexible approach, the use of child-friendly terms instead of medical terminology, the use of distractors, implementation of coping strategies, appropriate modeling of parental behavior, and ongoing praise and reassurance.

Some sleep labs will complete what is called a "split-night PSG with CPAP titration." They will evaluate a child for sleep apnea during the first part of the night. If it is determined that a child has moderate to severe sleep apnea and requires continuous positive airway pressure (CPAP), technicians in the lab may use the second half of the night to obtain information about the level of CPAP pressure that will be required to treat the apnea. While this may be an efficient use of sleep lab resources, it is not a good strategy for most children with ASD. As noted above, children with ASD often need a great deal of preparation to successfully complete a sleep study. They may also need time to learn to use a CPAP device. These devices use air pressure to open up airways to allow for uninterrupted use air pressure to open up airways to allow for uninterrupted breathing and require an individual to wear a face mask. Many individuals (including adults without developmental disorders) find it difficult to adjust to using CPAP. The same techniques that help children complete a sleep study are also used to teach children to comply with CPAP treatment. Thus, a slow and gradual strategy that includes social stories, systematic desensitization, distraction, and rewards should be used. Once a child is able to use a CPAP device without difficulty, a second sleep study can be scheduled to determine the proper titration levels.

Treatment

There are a number of educational and behavioral interventions that may help address insomnia in children with ASD. Thus, once medical and psychiatric disorders are addressed, it is advisable to provide families with information that can help improve sleep habits. The practice pathway developed by Malow and her colleagues notes that medical contributors to poor sleep may be assessed and treated concomitantly with a sleep education program (Malow, Byars et al., 2012) Clinical judgment along with consultation with a family will help determine whether it is best to sequentially assess medical and behavioral contributors to poor sleep or whether a simultaneous approach is best.

Johnson and her colleagues (Johnson et al., 2013) used a manualized parent training program to address sleep problems in young children with ASD and found that it resulted in better sleep based on parental report. Malow et al. (2014) demonstrated that providing parents with sleep education results in improvements as measured by actigraphy in sleep onset delay in children with ASD. Parents were taught about the importance of daytime habits, evening habits, sleep environment, and bedtime routines. Some of the basic concepts covered in each of these areas are described in Table 18.4. Many children with ASD respond very well to the use of visual information to help them with routines, manage transitions, and understand parental expectations. The sleep education provided in the Malow et al. study emphasized the use of visual schedules and other visual supports. The importance of helping children learn to fall asleep independently was also stressed. An important aspect to consider when working with families of children with ASD is that techniques often have to be modified and individualized for the child and the family. It

Table 18.4 Fundamentals of healthy sleep practices for children with ASD

Daytime behaviors: Consideration of exercise, caffeine consumption, presence and timing of naps, bedroom use
Evening habits: Reduce stimulation, light, stress, exposure to electronics
Bedtime routine: Implementation of a calm and consistent set of bedtime activities
Sleep environment: Appraisal of light, temperature, noise, and other sensory input

is important to partner with the family to develop strategies that will work best.

There are a number of resources that have been written to help families of children with ASD who are experiencing sleep difficulties. The Autism Speaks Autism Treatment Network has online toolkits related to sleep and the use of visual supports. Materials that may be used to construct pictures schedules for bedtime routines and other visual supports are also provided and may be found at http://www.autismspeaks.org/family-services/tool-kits. The books *Sleep Better! A guide to improving sleep in children with special needs* by V. Mark Durand (2013), *Solving Sleep Problems in Children with Autism Spectrum Disorders: A Guide for Frazzled Families* by Katz and Malow (2014b) and *Sleep Well on the Autism Spectrum* by Kenneth Aitken (2014) all provide useful information for families.

Research indicates that the use of melatonin may be helpful in treating sleep difficulties in children with ASD (Braam et al., 2009; Malow et al., 2012). Melatonin may be particularly helpful in addressing difficulties with sleep-onset latency, especially when it is paired with behavioral intervention. Other pharmacologic treatments may be warranted when behavioral therapy and melatonin do not result in improved sleep. There are a number of different medications that have been used clinically, but there is a paucity of research that can be used to inform the use of these medications in children with ASD. Owens and Moturi (2009) have reviewed the pharmacologic treatment of insomnia in children.

Summary

Evaluation of sleep difficulties in children with ASD is a critical and often overlooked component of ensuring an effective treatment plan. Poor sleep can have a profound effect on daytime functioning and may have medical implications as well. It also can have a significant impact on the quality of life of the entire family. The first step in assessing a child's sleep involves determining if a parent has any concerns about their child's sleep. Getting detailed information or a sleep history can be accomplished by interviewing parents, reviewing their responses to a standardized questionnaire, or both. When talking with parents of children with ASD about their sleep difficulties, it is important to ask specific questions and give clear indication that this is a critical aspect of their child's development. Key information includes knowing how long it takes a child to fall asleep, whether a child is able to fall asleep independently, the amount of sleep a child gets in a 24 h period, and how often a child awakens during the night. Knowing about daytime functioning and sleepiness during the day is also important, although, it is important to understand that unlike adults, it is unusual to see daytime sleepiness in young children who have sleep disorders. Interview data and information about daytime functioning obtained from questionnaires such as the Child Behavior Checklist may be useful. The Family Inventory of Sleep Habits may provide data that will be needed to help families develop behavioral strategies that will promote good sleep. Sleep questionnaires such as the Child Sleep Habits Questionnaire may also provide critical information about sleep behaviors and medical issues. It may often be necessary to address both behavioral and medical concerns. Strategies to address behavioral difficulties contributing to poor sleep may be implemented at the same time that medical comorbidities are being considered. In addition to a medical screening, the use of actigraphy or polysomnography may be indicated to asses some primary sleep disorders. A thorough understanding of a child's sleep difficulties may lead to interventions that have the potential to improve physical health and daytime functioning.

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Cerebral Palsy and Autism Spectrum Disorder

19

Sharon Smile and Anne Kawamura

Cerebral Palsy and Autism Spectrum Disorder

Cerebral palsy (CP) is a condition that primarily affects movement and posture and therefore impacts on motor functioning. It is caused by a group of permanent yet nonprogressive disorders that affect the developing fetal or infant brain. In the most recent definition (Rosenbaum et al. (2007) have highlighted the many other areas of functioning that can be affected in CP. These include the areas of communication and behavior, which are also core features in autism spectrum disorder (ASD).

Studies have shown that ASD is more common in CP than in the general population. Estimates place the prevalence between 8 and 15 % (Christensen et al., 2014; Kilincaslan & Mukaddes, 2009; Kirby et al., 2011). Despite the increased prevalence of ASD in CP, the diagnosis of ASD is often delayed with the median age of diagnosis being 66 months (Smile, Dupuis, MacArthur, Roberts, & Fehlings, 2013) which is above the median age of diagnosis for ASD alone (61 months) (Wiggins, Baio, & Rice, 2006). This delay is attributed to multiple factors but may in large part be due to the fact that the core symptoms of ASD are often misinterpreted as clinical features of CP (Smile et al., 2013).

In this chapter, we discuss the clinical features of CP and the impact of this condition on communication and social functioning. As features of CP are usually present in the first 2–3 years of life, we discuss the clinical features of ASD in this age range to identify distinguishing features that will aid in early diagnosis. We then outline screening and diagnostic tools for ASD in a child with CP highlighting the limitations of the application of these tools in this population. Finally, we describe an approach to diagnosing ASD in a child with CP using history, physical examination, and structured observation.

In order to enhance our discussion in this chapter, we use the following clinical case to highlight key aspects of making a diagnosis of ASD in a child with CP.

Cerebral Palsy and Autism Spectrum Disorder: Reflection on a Case Study

Brian is one of twins born at 26 weeks gestation. He had a complicated neonatal course with respiratory distress syndrome and chronic lung disease requiring prolonged ventilation and

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oxygen requirements. His cranial ultrasound showed intraventricular hemorrhage (grade IV bilaterally) and a ventriculoperitoneal shunt was inserted due to hydrocephalus. He developed retinopathy of prematurity and a visual impairment. Discussions regarding long term outcomes with Brian's parents during his neonatal intensive care unit stay centered on cerebral palsy and developmental delay.

Brian's development was followed closely in the local neonatal follow-up clinic. He began walking late at 24 months of age and was noted to have hypertonia in both legs and his right upper extremity. Brian was given a diagnosis of spastic CP, bilateral involvement. His gross motor function classification system (GMFCS) level was II. His language was also delayed; however, he began to use words around the age of 2 years. He wore glasses for his vision impairment but could independently maneuver at home and in school. He wore braces on both feet for walking and required special education support at school. Frequent and severe tantrums were noted by the parents early on and the family received parenting and behavioral management supports in the community.

At 6 years of age, Brian was seen by his developmental pediatrician for a regular follow-up for his CP. Brian spoke at length with his doctor about the city's transit system. He knew every bus route, their number, and where they stopped. His parents were thrilled that his language had improved and that he had such an impressive memory for facts. Brian continued to struggle socially at school, having a few friends but mainly playing with his twin brother. Subsequent assessment confirmed that Brian met criteria for a diagnosis of ASD.

Cerebral Palsy: A Pathway to Diagnosis

In this section, we begin by discussing how CP is diagnosed, outlining the key clinical features of this condition and reviewing the evidence regarding communication and social functioning in children with CP. CP is often diagnosed within the first 2–3 years of life (Rosenbaum & Rosenbloom, 2012). CP is a clinical diagnosis based on history and physical examination findings and is supported by radiographic evidence.

There are three main subtypes of CP using the Surveillance for Cerebral Palsy in Europe (SCPE) classification (Surveillance of Cerebral Palsy in Europe, 2000): spastic CP, dyskinetic CP and ataxic CP. In all three subtypes, motor function is impacted by changes in muscle tone and/or difficulty in motor planning and coordination. Characteristics of each of these subtypes are described below.

Children with spastic CP present with stiffness in the muscles or hypertonia (increased tone). Spasticity may be present in the upper or lower extremities and can involve one (i.e., unilateral/hemiplegia) or both sides (i.e., bilateral/diplegia or quadriplegia) of the body. Dyskinetic CP is defined by the presence of a movement disorder consisting of involuntary, recurring and occasionally stereotyped movements. If the movements are hypokinetic (slow) and there is increased tone, the child is classified as having dyskinetic, dystonic CP. If the movements are hyperkinetic (frequent rapid and jerky or constant writhing) and there is decreased tone, the child is classified as having dyskinetic, hyperkinetic CP. Ataxia involves a loss of motor coordination resulting in movements that are performed with abnormal force, rhythm, and accuracy. Children with ataxic CP often present with difficulties in balance, coordination, and motor planning. Determining the subtype of CP is important as it allows clinicians to determine outcome and management options (Sanger et al., 2003; Sanger et al., 2006). Additionally, the subtype of CP may confer different levels of risk for ASD which are discussed below (Smile et al., 2013).

Motor Function in Cerebral Palsy

A central feature of CP is its impact on motor functioning. A landmark study published in 1997 (R. Palisano et al., 1997) classified children's (0–12 years of age) motor functioning in cerebral palsy. The Gross Motor Function Classification System (GMFCS) describes five "levels" of

cerebral palsy ranging from Level I (most able) to Level V (most limited). Between the ages of 6 and 12 years, children functioning at Level I are able to walk, run, and jump independently; however, they may perform these with less speed, balance, and coordination. In contrast, children functioning at Level V have significant restrictions to voluntary movement and have difficulty maintaining head and trunk control against gravity. They need support to sit and stand. They use wheelchairs for mobility.

This classification system has been validated (Palisano et al., 2000; Rosenbaum et al., 2002) and is currently used worldwide, in both clinical and research contexts. One of the most clinically relevant features of the GMFCS is that the levels offer predictive value, enabling children, parents, and clinicians the ability to determine the long term outcome of the individual with respect to their gross motor function. Additionally, the GMFCS is used in research to provide accurate descriptions of the subjects' motor functioning and subsequently allows for translation of the results of these studies to clinical practice.

Communication in Cerebral Palsy

As highlighted in the definition of CP, communication disorders are common in CP with prevalence estimates ranging from 31 % (Wolfe, 1950) to 88 % (Achilles, 1955). A recent study showed that in a population based sample of children with CP in Norway, 51 % of children were identified as having speech problems and 19 % had no speech (Andersen, Mjoen, & Vik, 2010). The variability in prevalence rates between studies, may relate to the fact that there is no consensus definition to describe communication disorders in CP. In addition, communication difficulties in CP are often multifactorial. For example, children with CP are known to have coexisting visual and hearing deficits, motor speech difficulties (e.g., dysarthria, articulation disorders), epilepsy, and cognitive impairments which are all known to influence communication abilities.

Due to the fact that communication disorders may have multiple contributing etiologies in CP, researchers have focused on communication function to identify cohorts of individuals with similar profiles and needs. A classification scale similar to the GMFCS has been developed to describe communication function in individuals with CP. The Communication Function Classification System (CFCS) describes five levels of communication function based on the individual's ability to communicate effectively with a partner during everyday activities (Hidecker et al., 2011). Children at CFCS level I can send and receive information with familiar and unfamiliar partners effectively and efficiently. Children at CFCS level V can seldom effectively send and receive information, even with familiar partners. The CFCS levels have been shown to have good test-retest reliability, good professional interrater reliability and moderate parent-professional interrater reliability (Hidecker et al., 2011).

There is mounting evidence that CFCS level is correlated to CP subtype, GMFCS level and cognitive ability. Population-based registry data provides valuable information about the language abilities of children with CP and therefore the link between communication and other areas of functioning. An Icelandic population-based study examined the communication abilities in 5-year-olds with CP. The majority of children with CP (72 %) were able to communicate in sentences or phrases containing at least three words (Sigurdardottir & Vik, 2011). However, 16 % of their sample was nonverbal. Children were more likely to be nonverbal if they presented with spastic quadriplegia or dyskinetic CP, were functioning at GMFCS levels IV or V or had impaired cognitive function.

In another study looking at a subset of children from a population based Swedish CP registry, 51 % used speech to communicate. The majority of children (71 %) with unilateral spastic CP (hemiplegia) presented with a CFCS level of I, while children with dyskinetic CP were more likely to have lower levels of communication function as rated by the CFCS (CFCS levels II-IV) (Fisher's test, $p = 0.03$) (Himmelmann, Lindh, & Hidecker, 2013). Children who were more effective communicators were associated

with higher cognitive function and all children functioning at CFCS level V had severe cognitive impairment. These studies indicate that in children with CP, those with greater motor and cognitive impairments are more likely to present with communication difficulties. In contrast, ASD which presents with impairments in communication, is more commonly diagnosed in children with CP who are ambulatory and have higher motor functioning. This discrepancy is discussed in the sections below.

Impact of Social Functioning and Communication

The International Classification of Functioning, Disability and Health [ICF] (World Health Organization, 2001) highlights the importance of participation as a key outcome to consider in children and youth with CP. Participation is defined as "engagement in life" (Rosenbaum & Rosenbloom, 2012) or the ability to be involved in life situations through a variety of means. Both social functioning and communication hold major influences on the ability of a child to participate fully in their home, school and community and therefore been a focus of research in CP.

Research has shown that social functioning and communication in CP may deteriorate over time. In a longitudinal study examining adolescents with CP, all individuals with CP regardless of GMFCS level experience restrictions in social functioning (Voorman, Dallmeijer, Van Eck, Schuengel, & Becher, 2010). In addition, adolescents with externalizing behavior problems were found to have lower levels of social functioning over a 3 year interval. Another longitudinal study of school aged children between the ages of 5 and 9 years (van Schie et al., 2013) demonstrated that children with CP who were non-ambulatory had increasing restrictions in their social functioning as they grew older and that children with CP with lower intellectual functioning had increasing restrictions in communication over time. These long term studies have begun to uncover the complex relationships between motor, communication, and social functioning in children with CP and the changes that occur over a lifetime. While further research is still needed to understand why this relationship exists and why there is deterioration in function as the children grow older, we use this backdrop to discuss the challenge of diagnosing of ASD in children with CP.

Case Study Review

When Brian received the diagnosis of CP at the age of 2 years, his parents were not surprised. They had received counselling in the neonatal intensive care unit that Brian may have CP due to his intraventricular bleed and complicated neonatal course. In their eyes, Brian continued to "beat the odds" having survived in the NICU and proven his doctors wrong by being able to walk. His parents were diligent in bringing him to therapy sessions with the physiotherapist, occupational therapist and speech therapist. With this support, his function in these areas improved dramatically between 2 and 4 years of age. Despite this, his social development and behavior were concerning. These concerns however could be explained by his CP. Brian had difficulty keeping up with his same age peers due to his motor difficulties which limited his opportunities to play with other children. His language delay led to frustration in communicating his needs resulting in frequent tantrums.

The features of ASD that often trigger parents to seek help from professionals in a child presenting without CP such as language delay or behavioral difficulties, may be misinterpreted when the child has an existing diagnosis of CP. Moreover, delays in language, social functioning and behavior secondary to CP may be difficult to distinguish from difficulties in these same areas due to a diagnosis of ASD. We turn now to a discussion regarding the core features of ASD to help draw similarities and differences between the presenting features of CP and ASD.

Autism Spectrum Disorder

For the purpose of this chapter we focus on the presentation of ASD in early childhood. This approach is taken because the presentation of CP

occurs during the first 3 years of life. Thus understanding how these two disorders overlap and intertwine in their presentation is imperative, to be able to differentiate between the two disorders.

Clinical Presentation of Autism Spectrum Disorder

There is evidence of atypical development across multiple developmental domains in the first 2 years of life in children who subsequently meet diagnostic criteria for ASD. Qualitative evidence of these differences is mostly gathered from analysis of home video recordings, as well as retrospective and prospective studies of "at risk" infants. To review the manifestation of ASD symptoms in the first 3 years of life we approach it from the two developmental domains that define this disorder, namely, (1) social communication domain (SCD) and (2) behavior domain (BD). We also review research evidence of motor and cognitive atypicalities that occur during this critical period.

Social Communication Domain

Within the first year of life social communication atypicalities are frequently reported and observed in retrospective data, in children who subsequently meet criteria for ASD. This includes impaired social interest or orientation, poor eye contact, reduced orientation to name, and reduced spontaneous expression of positive affect (e.g., social smiling) (De Giacomo & Fombonne, 1998; Gillberg et al., 1990; Ornitz, Guthrie, & Farley, 1977; Rogers & DiLalla, 1990; Stone, Hoffman, Lewis, & Ousley, 1994). These differences were confirmed in prospective studies, with additional findings of impairment in imitation skills (Stone, Ousley, Yoder, Hogan, & Hepburn, 1997; Young et al., 2011). These features can be subtle; however, they may be evident as a child approaches their first birthday. Impairment in these social skills: social imitation, social attention and social interactions, negatively affects social learning and ultimately to the acquisition of social communication skills.

Much research has been done to elucidate emerging symptomatology of ASD in the first 6 months of life with limited success. Recent studies have identified impaired social responses, social orientation and evoked responses to dynamic gaze shift, as predictive of ASD (Elsabbagh et al., 2012; Elsabbagh et al., 2013). From a communication perspective, speech delay, limited use of gestures and slowing of language acquisition from as early as 14 months of age has been associated with a subsequent diagnosis of ASD (Landa, 2007). Impairment in acquisition of first words and reduced receptive language skills is seen in the first year of life in children subsequently diagnosed with ASD (Mitchell et al., 2006; Short & Schopler, 1988). Additional atypical forms of communication; echolalia, atypical intonation and use of another's hand as a tool are symptoms seen in the second year of life (Landa, Holman, & Garrett-Mayer, 2007; Stone et al., 1997).

In school aged children social communication skills become more sophisticated and complex, and differences and impairments in skills becomes more apparent over time in ASD. This presentation becomes complicated in the presence of cognitive impairment. Difficulties with eye contact and social attention; preference to nonsocial objects such as toys rather than social facial expressions persists (Elison, Sasson, Turner-Brown, Dichter, & Bodfish, 2012; Riby & Hancock, 2009). There is emergence of difficulty with understanding another's perspective, understanding emotions and reciprocity of social interaction.

Studies evaluating the types of social interactions executed by persons with ASD revealed that there are 5 types. These include (1) negative behaviors (e.g., aggression), (2) positive behaviors (e.g., give affections), (3) low level behaviors (e.g., imitate, echolalia), (4) attention seeking behaviors, and (5) avoidance. Children with ASD had fewer attempts of initiating play and imitating other children as compared to children with intellectual impairment or typically functioning peers (Hauck, Fein, Waterhouse, & Feinstein,

1995). Children with ASD had a third less attempts at initiating social interactions with peers as compared to intellectual impaired peers. Most behaviors displayed were positive or low level behaviors in a social context. The combination of challenges in the following areas; social attention, Theory of Mind, quality and frequency of social initiation opportunities, leads to short lived and impaired play skills between children with ASD and their peers.

Within the first year of life there is emergence of subtle differences in the quality of social communication skills. These differences become more pronounced by 2 years of life. Strong predictors for an ASD diagnosis includes; reduced babbling, decreased use of symbolic and communicative gestures, decreased directed communication, decreased orientation to name and joint attention.

Behavior Domain

The presence of repetitive patterns of behaviors is commonly seen in the first year of life in children. There are no specific repetitive behaviors that discriminate ASD from typically functioning children or children who present with developmental delay from a variety of causes in the first year of life. However, researchers have identified repetitive behaviors that have a higher frequency in young children who subsequently are diagnosed with ASD. (Loh et al., 2007), identified the presence of arm waving as a discriminator in children who later received a diagnosis of ASD. As early as 18 months of age children who later are diagnosed with ASD show evidence of frequent nonfunctional repetitive play (Christensen et al., 2010). At 2 years of age unusual visual inspection, rocking, spinning of toys is observed (Ozonoff et al., 2008). Other studies identified the presence of repetitive behaviors with objects; rocking, and swiping as well as body tensing as being more frequent in children with ASD than their typically functioning peers. The presence of rocking, body tensing, rolling and slapping behaviors, intense visual inspection or unusual visual regard is observed in the second year of life; but its presence lacks specificity.

Compared to typically developing children, repetitive behaviors demonstrated in ASD tend to be more intense, frequent and impacts the child's daily function. One of the criteria for ASD is the presence of restricted, repetitive patterns of behavior, interests or activities. This is defined by the presence of highly restricted, fixated interests that are abnormal in intensity or focus. This presentation is not typically reported as being present in the first 2 years of life. One exception is the presence of intense interests in specific toys. There are two factors that define restricted and repetitive behaviors (RRB); namely repetitive sensorimotor behaviors (RSM) and insistence on sameness (IS). RSM encapsulates behaviors such as repetitive use of objects, unusual sensory interests, body mannerisms, lining up objects, spinning and peering at objects from the side. IS encapsulates behaviors such as resistance to changes, compulsions and difficulties with changes in routines.

Children diagnosed with ASD at 2 years of age were found to have severe RSM behaviors as compared to children diagnosed with Pervasive Developmental Disorder Not Otherwise Specified (PDD-NOS). This effect is dampened at 9 years of age if the child had higher cognitive abilities (Richler, Huerta, Bishop, & Lord, 2010). IS was most frequent in children with lower Autism Diagnostic Observation Schedule (ADOS) scores.

Motor Skills

Abnormalities in motor skills ranges from; postural instability/control, delayed sitting, gait abnormality, delayed gross motor and fine motor skills acquisition, and head lag in children with ASD (Flanagan, Landa, Bhat, & Bauman, 2012; Landa & Garrett-Mayer, 2006; Ozonoff et al., 2010). Strong prospective data supports the presence of fine motor and gross motor delays within 12–18 months. The current hypothesis regarding

differences in motor control and function is thought to involve the integration of visual and proprioceptive feedback (Izawa et al., 2012). This mechanism is thought to be dysregulated and this may impact motor imitation and the execution of gestures. Interestingly, the presence of head lag has been used as a predictor for CP. The presence of motor abnormalities especially in the context of ASD is nonspecific; however, it may be indicative of an insult to the development of a normal neurocognitive pathway.

Cognitive Skills

The presence of intellectual impairment may impact the clinical presentation of ASD, particularly in the SCD. There are similar impairments in SCD noted in both groups. Interestingly, the impairments in the SCD may not decrease over time especially in the child who has an ASD diagnosis (Table 19.1). Additionally, in the BD; restricted interest, motor mannerism, preoccupation with objects are common in ASD, but these behaviors are less frequent in the child with intellectual disability. However, the frequency, quality, and severity of these behaviors appear to be more intense in ASD (Table 19.2).

Developmental Trajectories in Autism Spectrum Disorder

It is important to understand the developmental trajectories in children with ASD specifically in the following two domains; social communication domain and restricted and repetitive patterns of behaviors and interest domain may vary over time. This will help in understanding the clinical presentation of CP + ASD profile in early childhood as compared to the ASD only profile.

In children at risk for ASD, four developmental trajectories have been described. Firstly the "**non-spectrum profile**" which consists of children with an identifiable delay in development at 18 months of age who do not meet criteria for ASD by 36 months of age. Secondly, the "**severe persistent profile**" which consists of children with clear deficits in social affect and repetitive behaviors, which persists over time. Thirdly, **"the worsening profile**" which consists of children with increasing repetitive behaviors and

Table 19.1 The manifestation of ASD symptoms in early childhood

Domain	First year	Second year	Predictors of ASD
Social communication	Impaired social orientation/ attention Atypical eye contact ↓Orientation to name ↓Social smile ↓Imitation skills	↑Atypical expression of emotions Impaired social referencing/ social attention Impaired imitation skills speech delay ↓Acquisition of language ↓Use of gestures ↓Joint attention skills unusual forms of communication: hand as a tool ↓Interests in peers play—rigid and repetitive	↓Directed vocalization (12–14 m) ↓Babbling ↓Symbolic gestures (12–14 m) ↓Communicative gestures (12–14 m) ↓Orientation to name (12–18 m) ↓Joint attention skills (15–18 m)
Behaviors	Presence of nonspecific repetitive behaviors: spinning, arm waving	Persistence of motor symptomatology Nonfunctional repetitive play behavior	Atypical sensory orientation
Motor skills	Some evidence of delayed sitting and walking skills. Postural instability		

Table 19.2 Possible differentiating factors for ASD and intellectual disability

Domains	Autism spectrum disorder (0–2 years)	Intellectual disability (0–2 years)	Autism spectrum disorder (3–5 years)
Social communication	Impaired social orientation ↓Eye contact ↓Orientation to name ↓Social smile ↓Gestures ↓Joint attention skills speech delay with slowing of skills acquisition Skills decline Receptive language impairment > expressive language impairment	↓Orientation to name ↓ Eye contact but improving by age 2 years ↓Joint attention skills but improves Speech delay but improvements noted	↓Initiation of social interactions ↓Eye contact to regulate social interactions ↓Verbal responses to peers Fewer friendships created ↓Attention to voice ↓Pointing Use of hand as a tool
Behaviors	Repetitive behaviors and insistence on sameness present in both but is more intense in frequency in ASD		Hand or motor mannerisms persist

social affect deficits over time. The fourth group are children who show clear improvement in social affect and significant improvement in verbal skills; "**the improving profile**" (Lord, Luyster, Guthrie, & Pickles, 2012). Evaluating the developmental trajectories of RRB and interests has also been explored. Using the Autism Diagnostic Interview-Revised (ADI-R), in children diagnosed with ASD their RSM scores remained high over time (2 years through to 9 years of age) indicating consistent severity. Whereas the IS scores started low and increased over time, indicating gradual worsening of these behaviors. A higher nonverbal IQ at age 2 years is associated with milder RSM (Richler et al., 2010). The variability in presentation of ASD in early childhood justifies and mandates close monitoring and repeated assessment to determine the stability of the diagnosis when given in the first 2 years of life.

CP is usually diagnosed within the first 2–3 years of life. Motor challenges are usually the initial presenting challenge; however, challenges in language and social skills may coexist. Consequently the presentation of CP has the ability to mask the initial presenting symptomatology of ASD. The clinician assessing the child often relies on clinical judgement and expertise in addition to assessment instruments to differentiate between the two disorders.

Screening and Diagnostic Instruments to Identify Autism Spectrum Disorder

The aim of screening instruments are to facilitate early diagnosis and initiation of appropriate interventions to target the core features of the particular disorder. Screening instruments have limitations; they may indicate when a child has not met an expected developmental milestone but cannot be definitive in its interpretation as there is much variability in "time to achieve" a skill. Results of a screening instrument are also dependent on the observer or caregiver completing the questionnaire which may vary in reliability over time. The results from a screening instrument represent a snapshot in a child's development and symptoms may be inconsistent over time. If there are abnormalities found on a screening instrument this should prompt the clinician to complete a detailed developmental assessment. The American Academy of Paediatrics recommends screening for ASD at the 18 to 24 months age well baby visit (C. P. Johnson & Myers, 2007). In this section we briefly review screening instruments that are specific for identifying symptoms of ASD, focusing on early childhood. The psychometric properties of these screening tools has been documented extensively in other chapters of this book.

Checklist for Autism in Toddlers (CHAT)

The CHAT is the first screening instrument developed to identify ASD in toddlers (Baron-Cohen, Allen, & Gillberg, 1992). There are five items that are key indicators of ASD, inclusive of; gaze monitoring, pointing to request and pretend play. Low sensitivity, limits the CHAT as a primary instrument for identifying ASD in toddlerhood. This instrument was also tested on children with developmental delays but not with motor impairments. In the presence of a CP presentation especially with upper extremity involvement, critical items identified on the CHAT will be affected. This will negatively impact the specificity, sensitivity, and utility of this instrument.

Modified Checklist for Autism in Toddlers (M-CHAT)

The M-CHAT is a 23-item questionnaire which is a modified version of CHAT (Robins, Fein, Barton, & Green, 2001). There are six critical items which are key indicators of ASD, inclusive of; interest in other children, pointing to direct interests, showing objects, imitating, response to name and the ability to follow a point. This questionnaire has been used to identify children at risk of ASD in a population of very low birth weight infants who were born preterm (Limperopoulos et al., 2008). Of the 91 children in this study, 23 (25 %) had positive M-CHAT scores. However, only one of these children (who was 18 months of age at testing) was not climbing on objects or stairs, indicating motor delays. This finding suggests that children with social communication deficits as screened by the M-CHAT are unlikely to have coexisting motor impairments.

This is surprising as theoretically a child with CP especially with bilateral upper extremity involvement could score positive on this instrument regardless if ASD is present. This is because three of the five critical items requires coordinated motor function. Regardless of the cause, a positive result on this screening instrument should be followed by a detailed developmental assessment.

Screening Tool for Autism in Toddlers (STAT)

The STAT is a 20-min play based interaction between with a child who displays symptoms suggestive of ASD and another person (Stone, Coonrod, & Ousley, 2000). Attention is focused on the child's ability to play, directs another persons' attention and motor imitation. This instrument is aimed at screening toddlers between the ages of 14–36 months. These results are important, if validated in larger samples this tool can be used as early as 14 months as a screener for ASD. In the context of a child with CP, play and motor imitation function domains will be mostly impacted. However, evaluating the child's ability to direct another person's attention using vocalizations or eye contact might reveal information that may be useful in differentiating between the two disorders.

Social Communication Questionnaire (SCQ)

The SCQ is a 40-item questionnaire which uses questions from the more intensive Autism Diagnostic Interview-Revised (ADI-R) instrument (Rutter, Bailey, & Lord 2003). These questions evaluate the ASD symptomatology in the social, communication domain and the presence of restricted and repetitive behaviors. Psychometric properties of SCQ was only evaluated in psychiatric disorders, intellectual disability, and language delay. A recent study used the SCQ to screen for ASD in an extremely preterm population which included children with neuromotor impairments (Johnson et al., 2011). Using the established cut-off (scores $\geq$15), the SCQ had an 82 % sensitivity and 88 % specificity for identifying ASD in this population. However, it should be noted that the positive predictive value was relatively low with only 31 % of children with positive screens having received a diagnosis

of ASD. Children with functional disabilities, including those with motor impairments, were more likely to screen positive on the SCQ. This may in part be due to parents rating SCQ items positive based on behaviors associated with other neurodevelopmental sequelae. In addition, parents of children with physical and neurosensory impairments were less likely to complete all of the items on the SCQ. This may be due to the fact that some SCQ items are not applicable or are difficult to answer when isolating autistic features from other neurodevelopmental sequelae.

Social Responsiveness Scale-2 (SRS-2)

The SRS-2 is a 65 item questionnaire which evaluates ASD symptomatology in the social, communication domain and the presence of restricted and repetitive behaviors (Constantino & Gruber, 2012). There are five treatment subscales: Social Awareness; Social Cognition; Social Communication; Social Motivation; and Restricted Interests and Repetitive Behavior. The Social Communication and Behavioral subscales map unto the DSM 5 diagnostic symptom criteria for ASD. This instrument is sensitive to identify behavioral difficulties among children. There is limited specificity in discriminating oppositional type behaviors and ASD. Higher total scores indicate greater severity of social impairment. This is a good instrument to monitor change in severity of ASD symptomatology over time.

Interestingly both the CHAT and M-CHAT identifies the absence of pointing as a significant indicator for ASD. In the face of CP these instruments may be limited in their utility as a discriminator of ASD. The STAT instrument has a strong motoric component (pointing, motoric imitation) thus the clinician must be cautious in interpretation of the results in the face of CP. We have to recognize that a child with upper extremity involvement may not be able to point or show an object to another or may do so in an atypical manner. These instruments do not rely on the presence of language comprehension or speech. The CHAT, M-CHAT, and STAT instrument have not been validated in toddlers with a motor impairment, thus extrapolating its psychometric properties to the CP population should be done with caution.

Baby and Infant Screen for Children with aUtIsm Traits-Part 1

When reviewing the CP ASD literature there is one screening instrument that has been mentioned frequently, the Baby and Infant Screen for Children with aUtIsm Traits-Part 1 (BISCUIT-Part 1) (Matson, Wilkins, Sevin, Knight, Boisjoli, & Sharp 2009). This instrument was developed using a sample of 276 children including children who were neurotypical or had a diagnosis of a neurodevelopmental disorder including neuromotor disorders such as CP. This instrument is the only instrument to date that has been tested on children with neuromotor disorders. However, given the new DSM 5 diagnostic classification of ASD and the removal of the PDD-NOS profile, when using this tool one has to take this into consideration, in interpreting scores.

Diagnostic Interview and Observation Instruments

There are two instruments which are considered 'gold standard' in the assessment of a child with social communication deficits and atypical behaviors. This includes; Autism Diagnostic Interview-Revised (ADI-R) and Autism Diagnostic Observation Schedule-2 (ADOS-2). One limitation of the ADI-R tool is that its discriminatory ability decreases in children with mental ages below 20 months. This instrument is not recommended in children with a mental age less than 18 months (Cox et al., 1999). The algorithm scores generated is able to discriminate ASD from language impairment (Mildenberger, Sitter, Noterdaeme, & Amorosa, 2001) and developmental delays (Cox et al., 1999; Lord, Rutter, & Le Couteur, 1994).

Mullen Scales of Early Learning-AGS Edition

Understanding the child's level of cognitive function is important in interpreting results of diagnostic tests. The use of standardized assessment of cognitive skills and adaptive skills should be considered as part of the battery of tests administered. The Mullen Scales of Early Learning is an instrument that characterizes the cognitive and developmental profile of a child from birth to 68 months. This instrument is commonly used in the evaluation of children with neurodevelopmental challenges. A preliminary study identified that this tool lacks the ability to differentiate between a CP and ASD profile (Burns, King, & Spencer, 2013). In a child with a dual diagnosis of CP + ASD, the use of a single diagnostic instrument to differentiate between the two diagnostic profiles is nonexistent.

Overlapping Features of ASD in the Presence of CP

There has been limited studies which evaluate the co-occurrence of ASD in the presence of CP. Studies focus on the prevalence of the dual diagnosis, presentation of symptomatology, age of diagnosis of the CP + ASD subtype.

Prevalence Data

Early collective prevalence data from registry studies and clinical studies of CP and co-occurring ASD ranges from 8 to 15 % (Kilincaslan & Mukaddes, 2009; Kirby et al., 2011). Higher frequency of ASD was seen in spastic CP. This trend was also noted in Smile et al. (2013) study. In Kilincaslan and Mukaddes (2009) study a CP + ASD profile was more pronounced in children with impaired motor function. However, the CP + ASD profile was mostly seen in children functioning at a GMFCs level of 1 in another study (Smile et al., 2013). This difference could be accounted for by the exclusion of children functioning at a GMFCS level IV or V in the latter study.

In the clinical realm it is quite challenging to be definitive in identifying ASD in a child diagnosed with CP functioning at a GMFCS level of IV and V. As discussed earlier in this chapter, children functioning at GMFCS Levels IV and V have greater challenges with communication and social function. There is a higher prevalence of intellectual disability in this group as well. For these reasons, it is often difficult to identify the key presenting features of ASD in this group of children. Moreover, assessing children presenting with ASD features in this group of individuals with CP is complex; as the high prevalence of intellectual disability, severe language impairment, visual impairment, and significant motor impairment precludes participating in diagnostic instruments such as the ADOS-2. Classic ASD motor behaviors observed such as spinning, persistent toe walking in the absence of a neurological or motor etiology may not be physically possible in children with severe motor impairment (GMFCS level IV or V).

Clinical Presentation

Most recently data from a population based surveillance system which monitors CP, identified that 6.9 % (95 % CI 4.9–9.6 %) of children with CP had co-occurring ASD (Christensen et al., 2014). In this study, children with CP + ASD had a higher frequency of non-spastic CP (22.6 % vs. 7.4 %) as compared to CP only children, with a predominance of hypotonic CP subtype. The majority of CP + ASD children were independent walkers but this did not meet clinical significance. Collectively these studies highlight that ASD in the presence of CP manifests across a range of motor functioning and CP subtype. Clinicians should have a heightened level of suspicion in all children with CP who presents with an impairment in social communication skills, regardless of motor function or CP subtype.

The clinical presentation of ASD in the face of CP has been evaluated in three studies, with noted

heterogeneity in the inclusion criteria for CP subtype and outcome measures used to identify ASD symptomatology in CP. Two of these studies used data from the same data sets (Louisiana's EarlyStep program) and evaluated communication skills and the presence of restricted/repetitive behaviors using the BISCUIT-Part 1 as the primary outcome measure (Hattier, Matson, May, & Whiting, 2012; Hattier, Matson, Sipes, & Turygin, 2011). The third study used retrospective data to describe the frequency of ASD symptomatology in the CP + ASD sample (Smile et al., 2013).

Using the BISCUIT-Part 1 instrument focusing on the communication domain scores, subjects with a CP + ASD profile; either CP + Autism group ($M = 10.36$, SD = 2.80) and CP+ PDD-NOS group ($M = 9.60$, SD = 2.84) showed higher scores in the BISCUIT-Part 1 communication scores, indicating greater impairment than the CP only group ($M = 4.42$, SD = 3.33) $p > 0.05$. Using the same instrument, subjects with CP + ASD had higher restricted/repetitive behaviors scores ($M = 19.79$, DS = 11.81) than the CP + PDD-NOS group ($M = 5.70$, SD = 7.07) and the CP only group ($M = 3.82$, SD = 0.99) $p < 0.001$. No significant differences were found between the CP + PDD-NOS group and the CP alone group on the restricted/repetitive behavior domain scores ($p > 0.05$).

The commonly endorsed behaviors in the CP + ASD group in descending frequency were: expect others to know their thoughts, experiences and opinions without expressing them, limited number of interests, reaction to sound and light, curiosity with surroundings, interest in a highly restricted set of activities, abnormal, repetitive motor movements, preoccupations with parts of objects, restricted interests, prefers food of a certain texture, isolates self and maintains eye contact (Hattier et al., 2012). Collectively these two studies indicate that the CP + ASD profile presents with greater impairment in communication skills and restricted repetitive interest or behaviors as compared to a CP only profile. Other studies using retrospective data have also confirmed this finding of atypical behaviors and impairment in communication skills being the two most common presenting ASD symptom domains reported (Smile et al., 2013).

Age of Diagnosis and Comorbidity

There are few studies that examine the age of ASD diagnosis in CP. Using data from a retrospective study, CP + ASD diagnosis was made at a median age of 66.5 months (31–210 months). Interestingly 25 % of subjects with a CP + ASD profile received a diagnosis by 46 months of age and 75 % were diagnosed by 107 months of age. To put this into perspective the mean age diagnosis of ASD is 61 months (Wiggins et al., 2006).

Thus children with a CP + ASD profile are being diagnosed with ASD later than children with a ASD only profile, although parents are reporting concerning symptomatology in early childhood (Smile et al., 2013). Kilincaslan and Mukaddes (2009) identified epilepsy, learning disability and language delay to be highly associated with a CP + ASD profile. Smile et al. (2013) did not confirm this trend but identified constipation, asthma and aggression as the most common associations with a CP + ASD profile.

There are significant methodological limitations to all three studies and a larger prospective study is needed to better classify medical and behavioral comorbidities associated with the CP + ASD profile. The gulf between current research information regarding clinical trajectories of a child diagnosed with CP and ASD and our "in lived experience as clinicians in the office" is vast.

Clinical Assessment of Autism Spectrum Disorder symptomatology in a Child with Cerebral Palsy

The current best practice for diagnosing ASD in a child with CP is completing a thorough clinical assessment and combining this with the clinician's judgement. The assessment of ASD in the face of CP should entail a detailed history,

examination and structured observation of the child's social and communication skills, complemented with standardized diagnostic instruments which are validated for children with motor difficulties. Diagnostic instruments used to identify a diagnosis of ASD in the presence of significant motor impairments must be interpreted with caution. Given current limitations of ASD diagnostic instruments as outlined in the previous section, it is important that the clinician utilize a multidisciplinary approach in evaluating social communication skills in a child diagnosed with CP. This approach is preferred given the significant overlap of presenting symptomatology in the SCD in both disorders. The presence of intellectual disability can further complicate the identification of ASD in a child with CP. A clinician who is familiar with the developmental presentation and variability of both disorders should take the lead in the assessment. This team may comprise a pediatrician/developmental pediatrician, psychologist, speech and language pathologist, occupational therapist, and physiotherapist as indicated.

The clinical manifestation of CP usually occurs in early childhood and a diagnosis is usually apparent by 2–3 years of age. There is much heterogeneity in the clinical presentation of ASD. The core features of ASD manifests in early childhood; however, cases where the severity of symptomatology is milder may not demonstrate impairments until later; during the school age years. We have proposed a stepwise approach in evaluating a child who presents with CP and impairments in social and communication domain suggestive of ASD.

A holistic approach is required when evaluating a child who demonstrates impairments in social communication skills in the presence of motor impairment. We propose a five-step approach in the assessment of such a child. Establishing continuity of care with the patient to be able to appreciate subtle changes in the social affect development and behavior domains over time is strongly recommended.

Step 1: History and Examination

The first step of assessment includes a detailed developmental and behavioral history. We outline key points for each section of the history that should raise the clinician's index of suspicion regarding an possible diagnosis of ASD. Risk factors, associations, and distinguishing factors for ASD in each section are noted below:

Maternal History

The clinician should establish factors in the prenatal and postnatal period that might be risk factors for ASD. This includes; short interpregnancy interval (<18 months) (Dodds et al., 2011), birth weight, gestational age, and the presence of maternal fever. Additionally research evidence supports the association of mother exposed to rubella, cytomegalovirus, valproate and thalidomide to an increased risk of ASD (Chess, 1971; Rasalam et al., 2005). Other associated factors with ASD may include; history of encephalopathy, neonatal seizures, advanced maternal and paternal age.

Family History

Identifying if an older sibling has a diagnosis of ASD has some utility in differentiating between ASD and a non-ASD profile. Research has shown that the risk that a child with an older sibling with ASD will also develop the disorder is 18.7 % (Ozonoff et al., 2011). For families where two or more siblings have a diagnosis of ASD, the recurrence rate increases to 32.2 %. It is important to ensure that the clinician ascertains a detailed family history. A family history of genetic disorders may add perspective to the child's developmental profile. These disorders include the presence of Fragile X syndrome (up to 50 % may present with ASD symptoms) and Tuberous Sclerosis (Bolton, Park, Higgins, Griffiths, &

Pickles, 2002; Muhle, Trentacoste, & Rapin, 2004; Persico & Napolioni, 2013).

Developmental History

The developmental history should encompass the child's early acquisition of expected developmental milestones. One approach is to evaluate in detail the child's social communication skills in the first two years of life. The clinician can identify if the child met early developmental milestones in a timely manner or if there was evidence of developmental decelerating/slowing or regression. The next step is to evaluate how the child's development evolved over time. Special attention should be to the presence of regression in communication or social skills which are most common between 12 and 24 months age (up to 30 %).

Early Developmental History

It is important to elicit the presence, or absence and quality of eye contact, response to name and the pointing skills (in the absence of motor restrictions). Elicit if there is a history of regression in communication skills: loss of words, loss of previously acquired gestures or no emergences of gestures such as; pointing, or waving. Elicit if there is a history of regression in social skills; eye contact, social smiling or social engagement with others. Regression in social communication skills is noted in up to 20–47 % of children with ASD. It is important that when developmental regression is seen in the face of CP the clinician should rule out other etiologies such as seizures, blocked shunts, worsening sensory impairments, and hearing impairment. The next step is to evaluate each area of development in detail, isolating ASD specific symptomatology.

Communication Skills

It is imperative that a hearing assessment is completed to ensure that impairments in speech is not attributable to hearing impairment. Additionally, in the face of an upper extremity motor impairment (e.g., spastic CP), the use of gestures may be impaired and acquisition of motor skills should be evaluated with caution. In evaluating the child's communication skills, it is important to establish the child's level of functioning in the following domains; (1) expressive language, (2) receptive language, and (3) nonverbal communication skills.

Predictive factors for ASD will include: (1) delay in speech with limited use of nonverbal communication skills to compensate for speech deficit (especially absent pointing skills), (2) echolalia (repetition of another person's speech without a communicative intent), (3) scripted language, (4) restricted topics, (5) odd intonation, (6) limited use of gestures, (7) limited response to name, and (8) unusual prosody. It is important that the clinician not only evaluate for the presence of skills but the **QUALITY** of these skills. For example when interpreting eye contact, in a child with ASD their eye contact has an avoidant quality to it, whereas a child without ASD may tend to focus on other objects but is not avoidant in their interaction with you.

Social Skills

Lack of or impaired social reciprocity that is not explained by the child's motor, language, and/or cognitive difficulties is suggestive of an ASD diagnosis. The clinician must interpret social reciprocity in the context of the child's motor and language function. For example, a child functioning at GMFCS III, CFCS I who constantly directs the play of others with little regard to the suggestions being made by their peers is demonstrating impaired social reciprocity despite their adequate motor and communication abilities. Additionally, a child functioning at GMFCS V, CFCS V who repetitively shakes a favorite toy back and forth with no attempt to involve his parent in his enjoyment of this activity, demonstrates a lack of social engagement and shared enjoyment. Poor eye contact in a child who does not have visual impairment is also concerning. Poor eye contact cannot be reliably used as a feature of ASD in the presence of a visual impairment. Factors suggestive of ASD include: decreased

shared positive affect and decreased response to joint attention.

Play Skills

When assessing a child's play skills and interaction with peers in a social context, there are many features suggestive of a diagnosis of ASD. The presence of repetitive play such as, opening and closing doors, repetitively placing objects into containers and dumping them out again, flipping pages of book, spinning the wheels of a car, lining up objects or sorting objects rather than playing with them in a functional manner are concerning for ASD. Lack of imitation skills or pretend play skills, despite having the motor and cognitive ability to engage in this activity, and prolonged visual inspection of toys, in the absence of visual impairment, are also suggestive of ASD. When interacting with peers it is often observed that children with a dual diagnosis of ASD and CP prefer sensory motor aspect of play instead of the essence of social interaction with peers.

Behavioral History

Stereotypies are often seen across many developmental presentations. This ranges from children with typical developmental profile, intellectual disability, and sensory challenges. The presence of stereotypies is not an absolute discriminatory finding for ASD in a child presenting with CP and impairment in social communication skills. Most importantly is the presence and persistence of stereotypies in the context of communication and social impairment as an indicator for ASD. These stereotypies can manifest as the following; (1) highly focused and restrictive interest that dominates play, conversation, and/or activities, (2) insistence on sameness (e.g., a child functioning at GMFCS I, CFCS I who constantly asks about schedules and time and has frequent meltdowns when not able to follow the schedule/routine), (3) inflexible adherence to a routine which if disturbed leads to significant distress.

Motor stereotypies

Dystonic postures or hyperkinetic movements are involuntary as compared to motor stereotypies (hand flapping, finger posturing) which are voluntary movements. Toe walking may be seen in CP; however, it is associated with hypertonia on physical examination. In a child with ASD only there is usually alternating between toe walking and heel–toe foot progression on gait evaluation.

Sensory Presentation

The presence of atypical sensory profile is one of the defining symptomatology of ASD. However, these features are seen in CP, ASD profiles and neurotypical children. In the absence of visual impairment, visual fascination with objects or lights is a concerning presentation.

Medical History

The medical history should evaluate for others factors that may have contributed to the child's developmental profile. These features are not necessarily directly associated with the etiological pathway of ASD or CP; however, its mere presence is associated with medical comorbidities that are common to both disorders.

1. History of seizures: This is common in both ASD and CP, and may be associated with regression in development.
2. Hearing impairment: This presentation is more common in a CP presentation.
3. Vision impairments: Visual impairments are commoner in a CP than an ASD presentation. Consider its impact on the quality of eye contact, visual inspection of objects, visual regard of stimuli (e.g., lights).
4. Feeding: Limited food repertoire, food intolerance, textural difficulties, and high frequency single food intake are commonly seen in ASD (Sharp et al., 2013). In CP the presence of a restricted diet or resistant eater is

less common. In CP difficulty with swallowing and the presence of choking may coexist with motor impairment. Oro-motor difficulties has been documented in both disorders. However, in ASD feeding challenges are thought to be secondary to multiple factors; oro-motor dysfunction, sensory dysfunction, behavioral rigidity, and feeding practices. The presence of reduction in the number of foods eaten is typically seen developmentally in the transition phase to solid foods. In the context of ASD, food restriction persists and it becomes more challenging over time to introduce new foods. Introduction of new food may lead to severe tantrums or cessation of eating. This tends to lead to changes in family dynamics and mealtime behaviors and practices.

5. Sleep: Frequent sleep awakenings in CP may be due to motor difficulties such as muscle spasms or comorbidities such as gastroesophageal reflux. In ASD sleep initiation difficulties and nighttime awakening are the predominant disrupted sleep patterns seen.

Step 2: Observation/Informal Assessment

Important information can be derived from observing a child in a relaxed environment such as a playroom or a waiting room setting that has access to toys and/or other children. This places "no demands" on the child and the clinician will be able to observe the child's spontaneous play and communication skills. If possible it is important to have bright colored pictures on the wall of current cartoons or story book characters that may be of interest to a child; for example a picture of a car, truck, or frog. This is in order to see if the child will spontaneously draw the parent or clinician's attention towards these pictures to share their interests (shared enjoyment and joint attention skills).

During History Taking

Observing the child's use of nonverbal and/or verbal communication skills to interact with his/her parent and the clinician will be useful. One should evaluate the quality of communication skills; the way the child protest (e.g., use of words or behaviors), request (e.g., pointing or use of words), or comment during their social interactions. Take note of the child's response to his name being called and do so on multiple occasions. The child's exploration of toys and functional play skills should be documented. These findings will help to frame your overall impression of the child's social communication skills. One should observe for the presence of motor stereotypies such as hand flapping or hand regard or inspection. These mannerisms are usually precipitated when a child is excited but can also be evident in the face of distress.

Informal Interaction

The clinician should make every effort to interact with the child. One of the easiest way to do this is through interacting with the child whilst using a toy such as a cause and effect toy or bubbles. This may precipitate motor mannerisms such as hand flapping or atypical body posturing. The clinician will also have the opportunity to evaluate the child's ability to request or to initiate social interaction, using eye contact, vocalizations, and/or gestures. The frequency of attempts to get another's attention (parent or clinician's) is important to note. Children with ASD may make fewer attempts to get another's attention, especially when they are ignored.

Examination

There is no discriminatory finding to suggest an ASD diagnosis on physical examination. In CP,

there will be evidence of motor compromise. The presence of head lag in a child less than 1 year of age may be present in both disorders and is developmentally normal in a child less than 3 months of age.

Step 3: Screening

Screening

If the clinician suspects ASD, using screening instruments to complement the clinician's history and observation would be the next step of evaluation. Using the M-CHAT, STAT or the BISCUIT-Part 1, in that order is may add additional information to decipher between the two disorders. The STAT instrument is useful as this is a play based instrument. This will give the clinician "real time" information regarding the child's social communication skills. The BISCUIT-Part 1 is the only instrument that has been tested in children with CP + ASD, with some utility.

It is important to review the individual items that the child scored positively on to identify if their motor impairment could have impacted on the results. If a child scores positively on the screening tests paired with ASD specific symptomatology reported or observed, progressing to the fourth step of evaluation is recommended. This will require referral to clinician who is familiar with developmental trajectories of children with developmental challenges.

Step 4: Diagnostic Testing

The fourth tier of evaluation is administration of diagnostic instruments. This should be executed by a trained clinician, to discriminate between typical behaviors and ASD specific behaviors. This can be a difficult task and relies on the clinician's judgement. The use of the ADOS-2 diagnostic test is the recommended instrument to differentiate between and ASD and non-ASD profile. It is imperative that the clinician is aware of its limitations in children with motor involvement and who are functioning at a GMFCS level of III to V. Additionally the ADOS-2 diagnostic test, discriminatory properties are altered in children with a cognitive level functioning less than 18 month age. The ADOS-2 instrument should not be used in isolation, but should be used as supportive evidence to complement the clinicians history and observations. Using the MSEL would be useful to define the child's level of cognitive functioning in order to interpret symptoms noted on the ADOS-2 assessment. For example, a 4-year-old child with spastic diplegic CP, GMFCS level II, with communication and social skills functioning at less than a 1 year age equivalent presents with no words but vocalizations, good eye contact, mouthing toys, and body posturing may indeed not have an ASD profile. Instead the clinician should be highly suspicious of the possibility of an emerging intellectual disability profile. Close monitoring and reassessment is indicated.

In children with significant motor limitations for example functioning at GMFCS level IV and V, administration of the ADOS-2 instrument is not reliable. In these circumstances a detailed history which identifies impairments which are not explained by the child's level of cognitive function or level of motor impairment should heighten the clinician's suspicion. Using a standardized interview instrument such as the ADI-R may be indicated and useful in capturing a detailed picture of the child's social communication profile.

Step 5: Putting the Pieces Together

Combining information from the history, observation, and diagnostic assessments the clinician will now form an overall clinical impression. The clinician will identify core areas of impairment and its impact on the child's overall level of functioning. The presence of significant impairment in social communication domain and atypical behaviors which impact on the child's level of functioning is suggestive of an ASD profile. Discussion regarding appropriate intervention targeting the core areas of deficit should be initiated.

Conclusion

There is clinical evidence which acknowledges the coexistence of CP and ASD. Early intervention is key in changing developmental trajectories in children diagnosed with both disorders. The ultimate goal of identification is to minimize impairment through introduction of appropriate interventions. Due to the overlapping symptomatology of the two disorders, identification may be delayed. The use of ASD specific screening instruments should be used if an ASD profile is suspected through history and observation, even though the utility of this instrument may have significant limitations. Use of the gold standard diagnostic observation instrument ADOS-2 can be administered with some success in children with minimal functional motor impairment (GMFCS level I or II). Nevertheless, the overall approach in evaluating a child with social communication impairments should be weighted on the **"best clinical estimate**" which is defined by history, observation, and examination. There are no discriminatory features between the two disorders within the first 2 years of life. The presence of regression in social communication skills during this period should heighten the clinicians' suspicion for ASD. At 2 year of age the lack of progression in communication and reciprocal social interaction skills should warrant further detail assessment of these two developmental domains. This supports the need for developmental surveillance in CP.

Much work is needed to better define the developmental trajectories of children with a dual diagnosis of CP + ASD throughout the life span. Mapping the social, communication, and behavioral characteristics over time will allow us to be more precise in identifying ASD earlier in the presence of CP. This will be achieved through prospective research studies.

Inevitably a multidisciplinary approach is required in evaluating social communication challenges in a child with CP. It is through a detail assessment of a child's social skills, communication skills, behaviors, and cognition that clarity to his/her developmental profile will be attained. It is important to recognize that the clinical presentation of CP + ASD evolves over time in some children who may have less severe presentation of ASD. We recommend that the child with CP, social and communication developmental trajectory be monitored closely over time. This leads to earlier identification of disorders such as ASD which are responsive to early intervention.

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Intelligence

20

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Intelligence

This chapter focuses on the relationship between Intelligence Quotient (IQ) and Autism Spectrum Disorders (ASD). The chapter reviews methods based on assessments used for IQ and the research on these topics.

Assessment for Intelligence Quotient

Assessment for intellectual functioning is important in the ASD field for the following reasons: (1) To clarify the difference between ASD and non-ASD, (2) To evaluate a child's strengths and weaknesses in educational programmes, (3) To evaluate a person's characteristics and suitability in job performance.

Intellectual Disability and High-Functioning

ASD is characterised by markedly abnormal or impaired development in social interaction, a restricted and stereotyped repertoire of activities and interests, and a history of cognitive or language delay. ASD is subdivided into "high-functioning" and "intellectual disability (ID)" or "low-functioning". The classification is based on cognitive and intelligence levels. The dividing line between these two categories is a full-scale IQ score of 70 (two standard deviations below the mean); those scoring below 69 are classed as ID and those scoring above 70 as high-functioning. In some cases of high-functioning ASD, a full-scale IQ score of 70–85 is classified as borderline level.

Diagnostic Assessment for Intelligence Quotient

Assessment for IQ for a precise diagnosis of ASD is important in clinical settings. An IQ test is helpful in clarifying the strengths and weaknesses in ASD. ASD often shows scatter among skills, with areas of significant strength and

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weakness. For example, in some children with high-functioning ASD, nonverbal skills are more developed than verbal skills. In addition, diagnosing ASD is difficult, especially in adults (Kanai et al., 2012). Because some primary caregivers often only remember a portion of the patient's developmental history during early childhood, it is difficult to collect accurate information for a differential diagnosis of ASD in adults. Therefore, efficient indicators for a precise diagnosis of ASD are important in the clinical setting.

Assessment of Intellectual/Developmental Functioning

Assessment is necessary to plan medical and educational treatments of ASD children and diagnose ASD accurately in adults. There are many methods to assess intellectual/developmental functioning. This chapter provides an overview of assessment methods that are widely used in Japan (see Table 20.1).

Preschool Age

[Bayley-III; Bayley Scales of Infant and Toddler Development, Third Edition]

The Bayley Scales of Infant and Toddler Development, Third Edition (Bayley-III; Bayley, 2006), developed by Nancy Bayley, assesses developmental functioning of children between 1 and 42 months of age. The Japanese version of the Bayley-III is still being developed. The Bayley-III is also designed to measure the strengths and weaknesses of a child in the five developmental areas of cognition, language, social-emotional, motor and adaptive behaviour. A tester gives tasks of three parts (cognitive, language [receptive communication and expressive communication] directly to a child, and motor [gross motor and fine motor]). The tester also asks caregivers about two child developmental areas (social-emotional and adaptive behaviour). The Bayley-III can be administered in approximately 50–90 min.

Scoring is showed as a score profile based on the five developmental areas of cognition, language, social-emotion, motor and adaptive behaviours. A total score is not provided, because a goal of the Bayley-III is to promote understanding of a child's strengths and weaknesses in the five developmental areas.

[K-Test; The Kyoto Scale of Psychological Development]

The Kyoto Scale of Psychological Development (K-Test), developed by The New Version of the Kyoto Scale of Psychological Development Society, is one of the most widely used developmental assessments for the toddler and preschool stages in Japan (Kyoto Scale of Psychological Development Society, 2008) (see Fig. 20.1). The K-Test is standardised for 2677 Japanese infants and adults. The tool mainly assesses children's developmental progress, delay, and balance. The K-Test is based on Gesell's developmental diagnosis and refers to the Binet test. The K-Test assesses developmental and intelligence levels from infants to adults, and usually targets infants with developmental disorders and adults having no language in Japan. The utility of the K-Test is examined by the cognitive assessment of 74 children with ASD (Koyama, Osada, Tsujii, & Kurita, 2009). The K-Test developmental quotient (DQ) and the three subscales showed high correlation with the Tanaka-Binet Intelligence Scale IQ.

The K-Test consists of a series of individually administered tasks. A psychologist gives the tasks directly to children for the assessment of their development. The K-Test uses a developmental age (DA) for psychological development. A DA over a chronological age yields a DQ ratio. Also, both DA and DQ are calculated in a full scale and three subscales (postural-motor (P-M), cognitive-motor (C-M), and language-social (L-S)) (see Fig. 20.2). The K-Test can be administered in approximately 30 min.

[TB Scale-V (Tanaka-Binet Intelligence Scale, Fifth Edition)]

The Tanaka-Binet Intelligence Scale, a modified Binet test by Tanaka, assesses the intelligence and cognitive abilities in individuals from children to adults. The Tanaka-Binet Intelligence Scale is also called the Japanese version of the Stanford-Binet Intelligence Scale (Tanaka Institute for

Table 20.1 Features of intelligent and developmental tests

Instrument	Developer	Date of publication	Age range	Amount of time required	Format	Area assessed
[Intelligent tests]						
Preschool age						
TB scale-V (Tanaka-Binet intelligence scale, fifth Edition)	Tanaka Institute for Education	2005	2:0-adults	30 min	Individually administered tasks. A tester gives tasks directly to a child.	2–13 years: IQ calculated based on the chronological age
						Over 14 years: Deviation IQ for each 4 subscales
K-ABC-II (Kaufman assessment battery for children, second edition)	Kaufman, A.S & Kaufman, N.L	2004	3:0–18:0	35–70 min	Individually administered tasks. A tester gives tasks directly to a child	A nonverbal composite and a mental processing/ fluid-crystallised index, plus individual scale scores
DAP test (Good enough Draw-a-Man test)	Good enough F	1926	3:0–10:0	10 min	Individually/collectively administered screening tasks. A tester makes a child draw a picture of a person and evaluates it based on scoring	Age-based emotional or behavioural problems IQ
WPPSI-IV (Wechsler preschool and primary scale of intelligence, fourth edition)	Wechsler, D	2012	2:6–7:7	30–60 min	Individually administered tasks. A tester gives tasks directly to a child	Ages 2:6–3:11 (a full scale IQ, 3 primary index scales, and 3 complementary index scales)
						Ages 4:0–7:7 (a full scale IQ, 5 primary index scales, and 4 complementary index scales)
School age						
WISC-V (Wechsler intelligence scale for children-fifth edition)	Wechsler, D	2014	6:0–16:11	45–60 min	Individually administered tasks. A tester gives tasks directly to a child. Also, a digital format has been designed	A full scale IQ, 5 primary index scales, 5 ancillary index scales, and 3 complementary index scales

(continued)

Table 20.1 (continued)

Instrument	Developer	Date of publication	Age range	Amount of time required	Format	Area assessed
CAS (Das-Naglieri cognitive assessment system)	Das, J. P & Naglieri, J. A	1997	5:0–17:11	40–60 min	Individually administered tasks. A tester gives tasks directly to a child.	Having two forms (an 8-subtest standard battery and 12-subtest standard battery), composing of 4-subtest cognitive processing area (1. planning, 2. attention, 3. simultaneous, 4. successive)
Adult						
WAIS-IV (Wechsler adult intelligence scale-fourth edition)	Wechsler, D	2008	16:0–90:0	65–95 min	Individually administered tasks. A tester gives a adult tasks directly	A full scale IQ, 4 index scales, and 15 subtests
[Developmental tests]						
K-test (Kyoto scale of psychological development)	New version of Kyoto scale of psychological development society	2001	0:0-adults	30 min	Individually administered tasks. A tester gives tasks directly to a child.	A full scale DQ (a developmental age), and 3 subscales (1. postural-motor, 2. cognitive-motor, 3. language-social)
Bayley-III (Bayley scales of infant and toddler development-Third edition)	Bayley, N	2005	0:1–4:2	50–90 min	Individually administered tasks. A tester gives tasks of 3 parts (cognitive, language, and motor), and asks caregivers 2 parts (social-emotional and adaptive behaviour) directly to a child	5 subscales (1. cognitive, 2. motor, 3. language, 4. social-emotional, 5. adaptive behaviour)
Denverll (Denver developmental screening test)	Frankenburg, W.K	1992	0:2–7:1	20 min	Individually administered tasks. A tester gives tasks directly to a child, and asks caregivers some questions	4 subscales (1. personal/social, 2. fine motor/adaptive, 3. language, 4. gross motor)

Fig. 20.1 The Kyoto Scale of Psychological Development

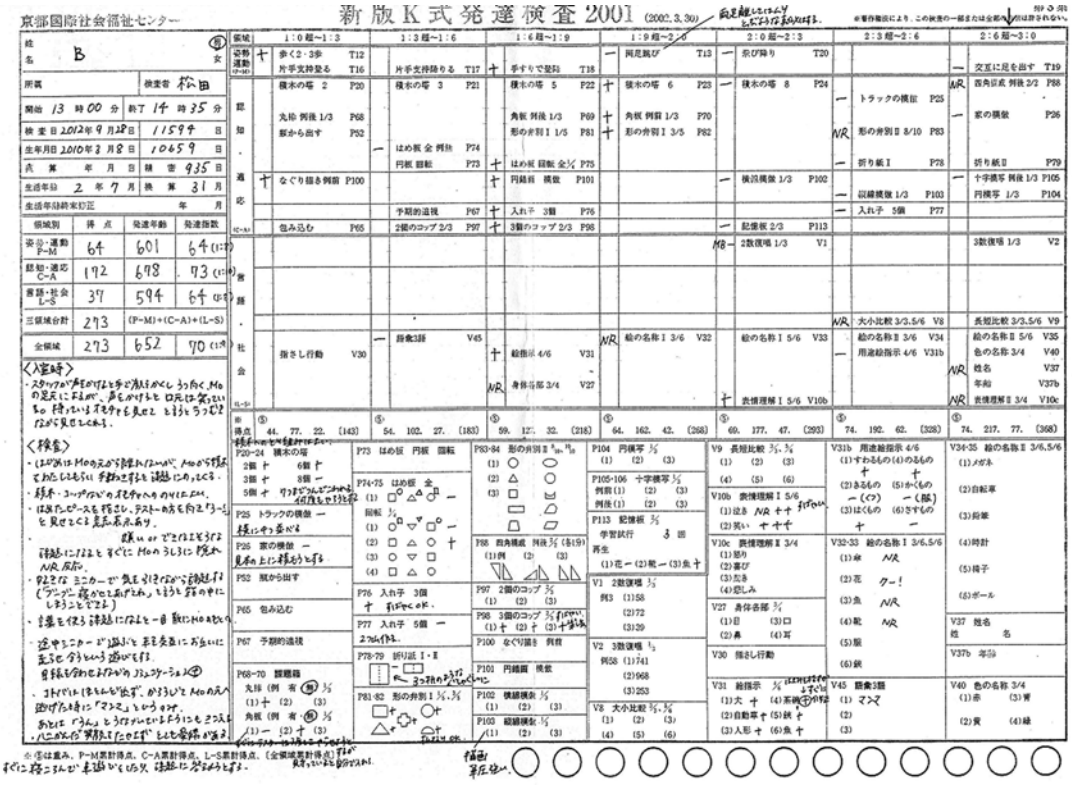

Fig. 20.2 The test format of the Kyoto Scale of Psychological Development. *Note:* The test format of the K-test is arranged age-appropriate items *horizontally*. A tester is needed to fill out pass [+] or fail [−] in each of tasks. When a child can pass a task, a tester fills out + in the format

Educational Research, 2003). The Tanaka-Binet Intelligence Scale, Fifth Edition (TB Scale-V) is the current version used in Japan. The TB Scale-V, as well as the Wechsler Intelligence Scale, the most popular standardised intelligence test in Japan, is useful for testing individuals who have limited language abilities. A full IQ is obtained by a mental age over a chronological age ratio. For people under 13 years of age, IQ is calculated based on the chronological age. For people over 14 years of age, TB Scale-V measures deviation IQ for four factors of cognitive abilities [(1) crystallised IQ, (2) fluid IQ, (3) memory, (4) logic and rational faculty]. The TB Scale-V can be administered in approximately 30 min.

The items of TB Scale-V are shown in Table 20.2. In TB Scale-V, subjects start with items of an age-equivalent level. When a subject fails a task of the age-equivalent level, he or she is asked to answer tasks of a lower age-equivalent level until he or she passes all tasks of a specific age-equivalent level. Then, he or she is asked to answer tasks of higher age-equivalent levels until he or she fails all tasks of another specific age-equivalent level.

Table 20.2 Examples of items of the Tanaka-Binet intelligence scale, fifth edition

Age	Items
1	Discrimination: animal pictures (a dog)
	Body images
	Stereo composition: building blocks
2	Picture vocabulary
	Difference between small and large
	Repeating two words
3	Comprehension: a lifestyle habit
	Similarities and differences
	Memory of designs
4	Number concepts: counting (1–3)
	Memory of orders
	Opposite analogies
5	Drawing a triangle
	Number concepts: counting (1–10)
	Concepts of right and left
6	Mutilated pictures
	Naming the days of the weeks
	Problem situations
7	Similarities: two things
	Comparison numbers
	Mutilated stories (A)
8	Repeating short sentences
	Forming sentences
9	Memory of figures (A)
	Enumeration of words
10	Numerical thinking
	Completing sentences
11	Meaning of words
	Mutilated stories (B)
12	Classification
	Memory of figures (A)
13	Way: south, north, east, west
	Code languages
Over 14 ages	Abstract words
	Meaning of proverbs
	Matrix

School Age

[WISC-V; Wechsler Intelligence Scale for Children-Fifth Edition]

The Wechsler Intelligence Scale for Children-Fifth Edition (WISC-V), developed by Wechsler, is an individually administered instrument for assessing cognitive ability in children (Wechsler, 2003) from age 6 to 16. The Japanese version of the WISC-V is still under development. The result based on profile of the WISC-V could serve as a tool in appropriate treatments and educational guidance. The WISC-V has two formats (traditional paper and pencil and digital version on Q-interactive). Also, the WISC-V is faster and easier to administer than the WISC-IV due to such factors as reduced testing time to obtain a full-scale IQ.

The WISC-V yields a full-scale IQ and five primary index scales [(1) verbal comprehension, (2) visual spatial, (3) fluid reasoning, (4) working memory, (5) processing speed], five ancillary index scales, and three complementary index scales (see Fig. 20.3). The WISC-V can be completed in approximately 45–60 min.

Adult

[WAIS-IV; Wechsler Adult Intelligence Scale-Fourth Edition]

The Wechsler Adult Intelligence Scale is one of the most widely used behavioural tests to examine cognitive profiles of adults in the world; it has been translated into many languages. Wechsler Adult Intelligence Scale-Fourth Edition (WAIS-IV) is a new version of the Wechsler

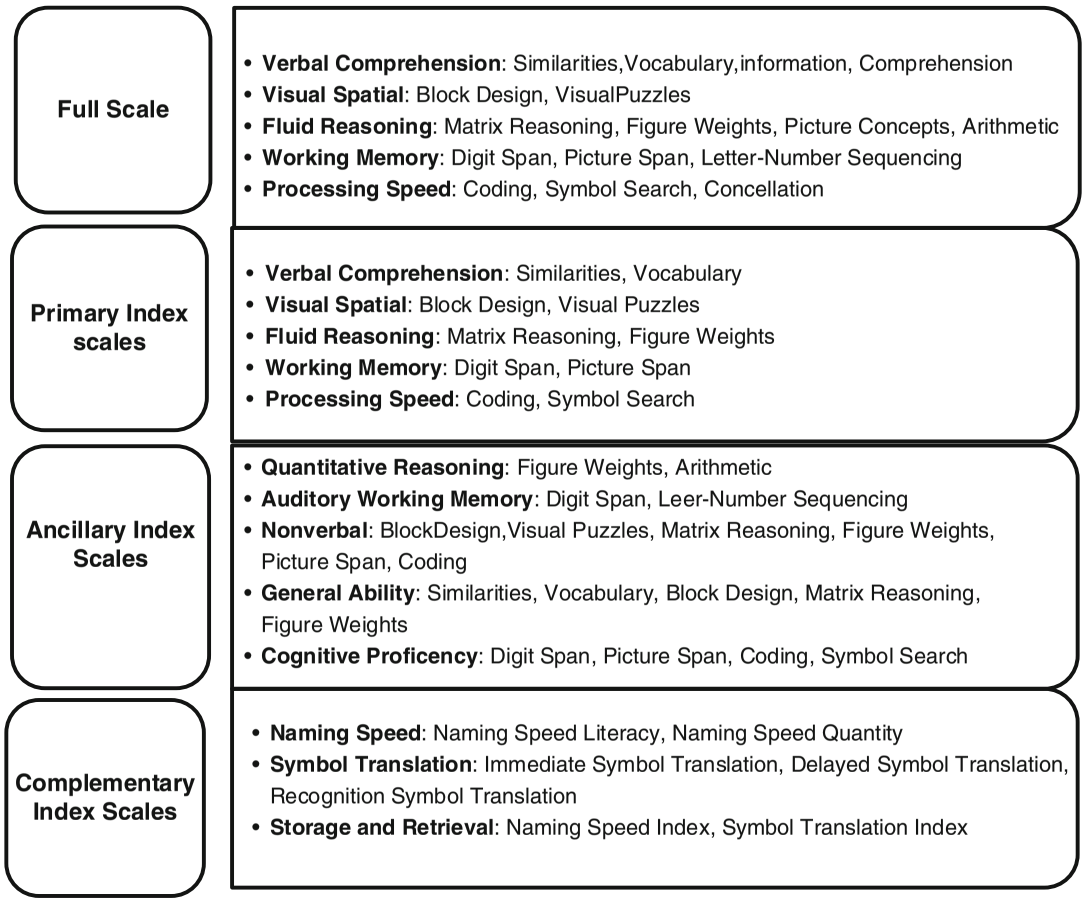

Fig. 20.3 The Wechsler Intelligence Scale for Children-Fifth Edition structure

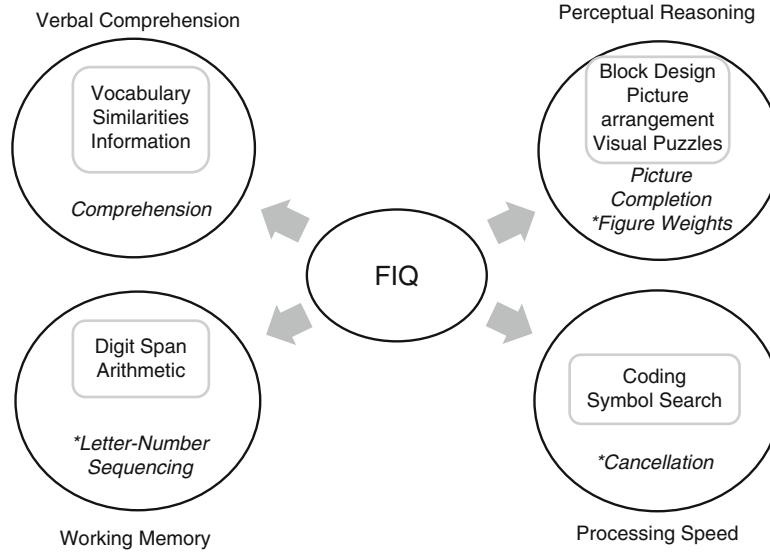

Fig. 20.4 The Wechsler Adult Intelligence Scale-Fourth Edition structure. *Note*: Subtests for only aged 16–69. *Letters in a square round* mean "core subtests". *Oblique types* mean "supplemental subscales"

intelligence test for adults. The Japanese version of WAIS-IV is under development. The purpose of WAIS-IV is for educational planning and the support of job skills. WAIS-IV has two formats (traditional paper and pencil and web-based on Q-interactive).

WAIS-IV has Full IQ [FIQ], 4 index scales [(1) verbal comprehension, (2) perceptual reasoning, (3) working memory, (4) processing speed] and 15 subtests (10 subtests and 5 supplemental subtests) (see Fig. 20.4).

Relationship Between Intellectual Development and Cognitive Functioning in Persons with Autism Spectrum Disorders and Intellectual Disability

Essential Questions and Research Directions

Research on ASD is one of the most widely funded areas in many parts of the world. Advances in fundamental research in neurological science (e.g. brain circuits and dynamic processes in individual brain development, functional connectivity), genetics, epigenetics, gene–environment interactions and environmental risk factors all aim to interpret the causes of autistic symptoms and find connections to other causes that occur with non-autistic symptoms. Social information processing, lack of a theory of the mind, neurocognitive function and intellectual attribution bias, underconnectivity in neural systems, unconventional sensory information processing, level changes in motivation and social attention are the most researched diagnostic domains of ASD (Happe, 1994; Scheuffgen, Happe, Anderson, & Frith, 2000; Williamson & Jakobson, 2014; Yirmiya, Solomonica-Levi, Shulman, & Pilowsky, 1996).

Presently, ASD and ID are the most common (approximately 3–5 %) developmental disorders in the human population. Many of the new research methods on ASD and ID seek to isolate specific brain circuits that could cause disrupted brain functions related to social and cognitive impairment in neurodevelopment. The presence or absence of ID is considered to be one of the most critical factors affecting developmentally related outcomes in individuals with ASD (Henninger & Taylor, 2013; Howlin, Goode, Hutton, & Rutter, 2004). It is a widely accepted view that ID co-occurs in approximately two-thirds of persons with ASD (Thomas et al., 2014). ASD and ID are both complex and multifactorial neurodevelopmental disorders with high

heritability, and they share overlapping risk factors (Betancur et al. 2009). The development and recent advances in aetiology, functional brain scanning (fMRI) and developmental neuroscience all show the importance of early social experiences for cognitive development and intellectual/developmental functioning (Amaral et al. 2008).

ID is characterised by significant limitations in intellectual functioning and adaptive behaviour. ID might occur as an isolated developmental disability problem or be accompanied by impairment in sensory processing development, epileptic seizures and behavioural disturbances. During childhood (before the age of 18 years), adaptive behaviour and intellectual functioning strongly contribute to the development of conceptual, social and practical adaptive skills (Schalock, 2011). Recent research results show that ID in ASD might emerge as a consequence of severe social-communication deficits on the experience-dependent mechanism underlying various neurocognitive developments. The study results of Vivanti, Barbaro, Hudry, Dissanayake, and Prior (2013) suggest that ASD symptom severity contributes to the extent to which environmental input is required to support typical brain development. This study states that the risk of developing ID increases as the number and severity of ASD social-communicative impairments increase (Vivanti et al., 2013).

There are two main conceptual frameworks related to the nature of ASD-ID/ID-ASD association. One is the so-called "co-morbid condition theory", which states that ID is a co-morbid condition that occurs over and above the ASD symptoms (Matson et al., 2011; Matson & Williams, 2014). The explanation behind the "co-morbid condition" emphasises the unrelated causality and unrelated aetiology. Thus, the co-morbid condition and/or symptoms are conceptually distinct from the principal diagnosis.

The second concept is the so-called "distinct additional theory" that suggests the aetiological relationship between ASD and ID. Some researchers think that there are common aetiological factors that could cause ASD and also cause ID (Waterhouse, 2013). Waterhouse (2013) states that the aetiological background of ASD is too broad to be sure of anything, and she uses a metaphoric "illusive butterfly" to explain that 30 years of tremendous research could not give any "certain" answer to the aetiological concept of ASD, and every "new door" that science opens up provides us with the access to another that needs to be opened.

Developmental theory-dominated clinical neuropsychology research emphasises that the early neurocognitive development of the human brain is experience-dependent by nature (Karmiloff-Smith et al. 2002). Therefore, unbalanced and insufficient early social experiences could cause an inadequate cognition of self- and peer awareness by proxy, and result in an adverse impact on cognitive brain functioning (Makinodan, Rosen, Ito, & Corfas, 2012). Many of the recent ASD- and ID-related studies focus on the best possible early detection and early intervention in order to be able to provide (e.g. design, develop, arrange, modify) the necessary social and physical environment for psychosocial and cognitive development for children at high risk of developmental delay or disability (Toth, 2010). Structured early intervention programmes and development therapies could make a difference in sensory processing, sensorimotor development and speech-language abilities (Gernsbacher, Sauer, Geye, Schweigert, & Hill Goldsmith, 2008). Developmental delay and impairment in the communication and speech domain could be the secondary results of the ID and/or ASD symptoms (Dziuk et al., 2007). If a child during the early "sensitive developmental period" does not have or cannot respond well to early sensory and social inputs from the closed physical and social environment, then he or she will not be able to demonstrate adequate adaptive responses and will show signs of either ID, ASD or both (Klin et al. 2014; Travers, Kana, Klinger, Klein, & Klinger, 2014; Ventola, Saulnier, Steinberg, Chawarska, & Klin, 2014). Researchers of experience-dependent neurocognitive development emphasise that, in the case mentioned above, ID is not a co-morbid condition, but rather is the ultimate result of an inefficient functional brain development. In this case, the severe ASD

symptoms could be found responsible for the developmental delay of intellectual development and cognitive functions. This does not mean that ASD could necessarily cause ID, but emphasises the fact that severe ASD symptoms cause an at-risk situation for intellectual developmental delay (Gotham et al. 2012; Grossmann & Johnson, 2007).

Interrelation Between Intellectual Functioning and Autism Spectrum Disorders

ASD core symptoms appear in the social communication and interaction domain of development and atypical patterns of behaviour (restricted and repetitive) and interest (Wilkins & Matson, 2009). Symptoms of ID usually group into two main diagnostic categories. The first is called intellectual functioning. It includes delayed cognitive information processing and altered development of basic intellectual skills, abilities, and virtues. The second is called adaptive functioning. It includes conceptual skills for learning (e.g. language, literacy, mathematics), social skills (interpersonal relationships) and practical skills related to self-care, health and safety. Many researchers have questioned the presence of ID in the case of children with ASD, for several reasons (Kraijer, 2000; Matson et al., 2013). One of these reasons is the reliability or unreliability of intelligence scales used to assess the IQ of children with ASD. Certain limitations make testing difficult for a child with ASD. Scheuffgen et al. (2000) state that a child with ASD might not be able to complete intellectual measurement tests. For instance, if a child with ASD has moderate or severe speech and/or language difficulty, the child may not be able to respond to interview questions (Scheuffgen et al., 2000). Another difficulty is that in most cases, the diagnosis of ASD symptoms in children with ID is based on clinical criteria validated for populations with average intelligence, thus compromising the diagnostic accuracy of ASD criteria (Javaloyes, 2006). Certain verbal subtests show low performance, while others like block design show superior performance results (Shah & Frith, 1993). A person with ASD could have one or a set of special abilities called savant skills. These are areas of surprising talent in otherwise low-functioning individuals. The estimated prevalence of savant abilities in autism is 10 %, whereas the prevalence in the non-autistic population is less than one percentile. The most common forms of savant abilities involve mathematical calculations, an extraordinary memory, musical abilities (with perfect pitch and excellent musical memory), and other types of artistic abilities (e.g. drawing, painting, singing, playing an instrument). A mathematical ability that many autistic individuals display is calendar memory, while others can multiply and divide large numbers without writing them down and can also calculate prime numbers in their heads in only seconds (Frith, 1993).

Research on ASD and ID co-morbid features concludes that the severity of ASD symptoms should be independent and separately measured from the severity of cognitive functioning and intellectual abilities. A longitudinal study with 345 participants documented that ID is a distinguishable part of the whole disability feature in children with severe ASD symptoms, but less in cases with mild ASD symptom representation; thus, cognitive functioning and ASD symptom severity are not entirely independent features (Gotham et al., 2012). Another study by Vivanti et al. (2013) targeted this latest hypothesis by developing an intervention programme that aimed to improve ASD symptoms. Vivanti and colleagues predicted that children with severe ASD symptoms are likely to have lower intellectual ability. Therefore, if these children receive a targeted therapy programme for their ASD symptoms, they should have improved results in intellectual skill development as well. They based their intervention on recent results in developmental neuroscience that support the "experience-dependent" nature of early brain development (Kuhl, 2007). Positive changes in intellectual functioning could be gained from early behavioural interventions, even if the original aim was to weaken core ASD symptoms. Early appearance of social-communication difficulties in children

with ASD could result in sensory processing disorder and cause an unintentional neuropsychological "block" against receiving essential inputs from the closed environment, thus negatively affecting cognitive skill development (Schoen, Miller, Brett-Green, & Nielsen, 2009). These results suggest the possible interdependent relation between ASD and ID (Vivanti et al., 2013).

Genetic and Epigenetic Causality Research on Autism Spectrum Disorders and Intellectual Disability

Neurodevelopmental disorders like ASD, ID and Attention Deficit Hyperactivity Disorder (ADHD) are complex traits that are influenced by more than one factor (genetic or environmental); multiple genetic determinants interact in the context of poorly understood environmental factors to give rise to clinically diverse phenotypes. Research results from genetic, epigenetic and environmental studies seek to identify candidate genes that could cause ASD, ID and ADHD and contribute to the understanding of these conditions from the comparative pathobiological viewpoint (Ben-David & Shifman, 2012; Betancur et al., 2009; Kou, Betancur, Xu, Buxbaum, & Ma'ayan, 2012). These molecular- and cellular-based results could contribute to possible therapeutic approaches in the future. From the genetic standpoint, ASD and ID are likely to be related on the molecular and biochemical level. The genetic approach sees the causal factors of ASD and ID as both similar and in many ways very different in nature. On the one hand, an estimated 70 % of diagnosed ASD individuals have some level of ID as well, while the others have dysfunctions in speech-language and communication, as well as difficulties in cognitive and social behavioural areas. On the other hand, at least 10–15 % of persons with ID diagnosis have autistic tendencies or clearly identified ASD symptoms (Mefford, Batshaw, & Hoffman, 2012). A number of genetic syndromes manifest ASD at higher than expected frequencies compared to the general population. Recent results from various genetic studies reported that no single gene could be significantly associated with ASD, and there is a high possibility that gene mutation and hundreds of gene variants might be responsible for causing the ASD condition (Anney et al., 2012; Liu et al., 2013). A large number of these gene variants and mutations could be associated with either ASD or ID, while some (e.g. SHANK1, SHANK2, NRXN1) are found to be associated with both conditions (Berkel et al., 2010; Sato et al., 2012). Kou et al. (2012) used systems biology and a combined network approach to predict candidate genes for ASD and ID. Their results showed that ASD and ID share common pathways that could perturb (i.e. alter the regular state or path of) an overlapping synaptic regulatory sub-network (Kou et al., 2012).

During the last 10 years, significant progress has been made in identifying rare variants of major effect in both ASD and ID; however, it is still difficult to find the best possible explanation for the underlying molecular mechanism of high-risk family traits and rare inherited mutations (Srivastava & Schwartz, 2014). As a result of extensive worldwide genetic research related to specific genetic causes, science now has identified many individually rare genes that could be associated with a high risk for ASD, and some of them extensively overlap with genes for ID. A particular genetic aetiology can currently be identified in about 15 % of patients with ASD (van Bokhoven, 2011). Presently on-going studies estimate that in the future 60–80 % of ASD-ID genes and "loci" (position of a gene or mutation on a chromosome) remain to be discovered, and hundreds of genes would be identified to be causally associated with these conditions (Topper, Ober, & Das, 2011). The California Autism Twins Study (CATS) reported research results on 192 identical and fraternal twin pairs. The research study reported a concordance rate of 77 % for male monozygotic twins and 50 % for female identical twins. The rates among fraternal twins were 31 % (male) and 36 % (female) (Hallmayer et al., 2011).

Although the high correlation between autism and genetic factors has been long established, the exact genetic background of ASD remains unclear. Some of the new findings turned out to

be mere chance associations, and were reported by studies because they looked significant at the time. There is a regular line of new studies reporting on possible associations between recently identified genetic conditions and ASD. Zafeiriou, Ververi, Dafoulis, Kalyva, and Vargiami (2013) reported ASD as a heterogeneous group of neurodevelopmental disabilities with various aetiologies, but with a heritability estimate of more than 90 % (Zafeiriou et al., 2013; Zafeiriou et al. 2007). Their study concludes that it is essential to identify ASD in patients with genetic syndromes, in order to ensure correct management, future therapeutic approaches and appropriate educational placement.

Findings from the study of genetic syndromes are incorporated into the ongoing research on autism aetiology and pathogenesis. Different syndromes converge upon common biological backgrounds (such as disrupted molecular pathways and brain circuitries), which probably account for their co-morbidity with ASD (Zafeiriou et al., 2013).

There are well-known syndromes and conditions that could cause ID and/or ASD as well. It is estimated that these syndromes account for more than 10 % of ASD cases. These syndromes include fragile X syndrome, Down syndrome, Prader–Willi syndrome, Williams syndrome, Angelman syndrome, Duchenne syndrome, etc. This chapter gives a short research summary on the first three in connection with ID and ASD.

Fragile X syndrome is an inherited genetic disease that causes ID and could cause developmental disabilities as well. Fragile X syndrome is found in about 1 in every 4000 males and about 1 in every 8000 females. Fragile X syndrome is the most common hereditary source of ID in men. People with fragile X syndrome may show a combination of the following signs as children and throughout life: anxiety (general or social), ASD like symptoms (e.g. social problems, such as not making eye contact, disliking being touched, trouble understanding body language), ADHD-like symptoms (e.g. impulsiveness, attention problems, hyperactivity), epileptic seizures and sleeping disorders. Nowadays, fragile X syndrome is recognised as the most common identifiable genetic cause of ID and ASD, with many overlapping phenotypic features (Yu & Berry-Kravis, 2014).

Another well-known syndrome that could cause ID and sometimes ASD co-morbidity is Down syndrome. There has been an increase in the number of children with Down syndrome who are being diagnosed as having ASD as well (Gray, Ansell, Baird, & Parr, 2011; Starr, Berument, Tomlins, Papanikolaou, & Rutter, 2005). These children with Down syndrome and identified autistic tendencies or ASD are referred as having a so-called "dual diagnosis", which means that these two are coexisting conditions. There have also been some survey studies in Europe (UK and Sweden) and in the USA suggesting that about 5–10 % of children with Down syndrome could have been diagnosed with co-morbid ASD (Kent, Evans, Paul, & Sharp, 1999; Rasmussen, Borjesson, Wentz, & Gillberg, 2001). Some of the researchers in the field are worried about a tendency to over-diagnose ASD in children with Down syndrome, so it is important to say that a vast majority of individuals with Down syndrome show no evidence of ASD (Howlin et al. 1995; Starr et al., 2005).

Prader–Willi syndrome is a rare genetic condition caused by an error in one or more genes. The responsible genes are not yet identified, but research shows that most likely the problem lies in a particular region of chromosome 15 (e.g. missing, doubled from maternal and none from paternal side, or defective paternal chromosome) (Dimitropoulos et al 2013). It presents as a number of physical, intellectual and behavioural problems. A key symptom of Prader–Willi syndrome is the constant sense of hunger (hyperphagia) that usually begins at the age of two and is caused by the dysfunction of the hypothalamus, which controls hunger and thirst. Children with Prader–Willi syndrome often show mild to moderate impairment in intellectual functioning (e.g. thinking, reasoning, problem-solving). Even those without significant ID have some learning disabilities. Infants with Prader–Willi syndrome have poor muscle tone (e.g. hypotonic muscles, poor sucking reflex), lack of eye coordination (strabismus) and poor responsiveness or reaction

to various stimuli. During early childhood, the person with Prader–Willi syndrome feels constant hyperphagia and usually has trouble with weight control (Bohm et al. 2015). Children with Prader–Willi syndrome have underdeveloped sex organs (hypogonadism), delayed motor development, speech-language disorder (e.g. delayed language development: dysarthria), sleep disorder, abnormal curvature of spine (scoliosis), endocrine problems (e.g. hypothyroidism, growth hormone deficiency, central adrenal insufficiency) and high pain tolerance that makes it very difficult to identify injury or illness. They also have various social and behavioural problems (e.g. sharp temper, rigidity, repetitive and obsessive-compulsive behaviour, aggressiveness towards themselves and others) (Lo, Siemensma, Collin, & Hokken-Koelega, 2013).

Several studies investigated the co-morbidity of Prader–Willi syndrome with ASD. The study of Descheemaeker, Govers, Vermeulen, and Fryns (2006) investigated 59 individuals with Prader–Willi syndrome and 59 controls with non-specific ID. They were matched for levels of intelligence (IQ), age, and gender. Results of this study showed prominent autistic-like behavioural phenotypes in the majority of individuals with Prader–Willi syndrome (Descheemaeker et al., 2006). Results revealed that even if a person with Prader–Willi syndrome had a higher level of intelligence, s/he still developed autistic behavioural tendencies. Descheemaeker et al. suggest reconsidering the classic symptomatology of persons with Prader–Willi syndrome to a broader ASD symptomatology.

Recently, Dimitropoulos et al. (2013) compared social functioning using the Social Responsiveness Scale (SRS) and the Social Competence Inventory (SCI) in Prader–Willi syndrome to individuals with ASD. The aim of this study is to measure if there is an increased risk of social behavioural deficits in people with the maternally derived uniparental disomy (mUPD) subtype of Prader–Willi syndrome in comparison to those with 15q11-13 paternal deletion (DEL) type, by comparing them to a group of individuals with ASD. The study results showed similar scores across most of the SRS domains in the ASD and mUPD subtype group. All groups showed great difficulty with the SCI scores, even though the DEL subtype group had the highest score on prosocial behaviour that promotes positive social interaction (e.g. helpfulness, generosity, empathy, social understanding, cooperating, handling of conflict). These findings suggest the necessity of further characterisation of social behaviour in Prader–Willi syndrome to understand better the contributions of genes in the DEL subtype to ASD susceptibility (Dimitropoulos et al., 2013).

There are other X-linked disorders that cause ID and in many cases epilepsies as well. These are less common than the fragile X syndrome, but scientifically proved to cause ID. There are fewer known examples of X-linked mutations that cause ID, for instance, the Coffin–Lowry syndrome (mutations in ribosomal protein S6 kinase: RSK2) and the Borjeson–Forssman–Lehmann syndrome. These are still under study to find out whether they could cause ASD. Introduced a preliminary result on a small subset of patients with Coffin–Lowry syndrome who have also presented with autism or transient autistic behaviour.

In summary, there are some single specific genes that can be associated with ASD, but it seems that the current genetic research and study groups support the idea of a polygenic inheritance, meaning that multiple genes are likely to be involved and predispose an individual to develop ASD symptoms (The Simons VIP Consortium, 2012). However, contemporary results and conclusions of these genetic studies are still incomplete and have limited explanations, and thus cannot be applied in clinical diagnosis yet.

Synaptic Plasticity and Cognitive Disorders

The human central nervous system processes and transmits information in the form of nerve impulses (electrical signals) through its specialised brain cells (neurons). The human brain has a trillion (10^{12}) neurons, and these vast numbers of nerve cells connect to each other with adhesive junctions called synapses. The human synaptic

system comprises a quadrillion (10^{15}) synapses. Synapses are highly specialised for mediating communication between neurons in the nervous system (Ho, Lee, & Martin, 2011). Cell-based communication through synapses involves the release of chemical information substances (neurotransmitters) from the presynaptic terminals at the end of the nerve fibre by the arrival of an electrical nerve impulse (i.e. action potential). The information carried by the neurotransmitter diffuses across the synapse (transsynaptic interaction) to another nerve fibre. Synapses are morphologically highly dynamic and can be subjected to rapid structural changes in response to stimuli (Missler, Sudhof, & Biederer, 2012). This ability to change structurally as a functional reaction to a particular impulse is called synaptic plasticity. This activity-dependent adaptability (dendritic morphogenesis and synaptogenesis) provides the human brain the strength to learn; in other words, the synaptic plasticity represents the cellular basis of memory and learning. Regulated synaptic connectivity and elimination of synapses are found to be critical for learning, memory, and behavioural function in the developing brain. Changes in the synaptic structure can lead to immense changes in information processing. Recent evidence from various studies suggests that this adaptable function of neural plasticity is disrupted in many neurodevelopmental disorders (i.e. ASD, ID, ADHD). As result of this, intellectual and behavioural functions are strongly affected (Durand et al., 2012; Tsai et al., 2012; Valnegri, Sala, & Passafaro, 2012). The dysfunction of synapse plasticity and dendrite formation is a significant developmental factor of intellectual and behavioural functions in persons with ASD and ID (Hutsler & Zhang, 2010). Tsai et al. (2012) concluded in their study that multiple ASD- and ID-associated genes are involved in the previously mentioned activity-dependent adaptability and synapse elimination process, which elaborates the accuracy of neuronal circuit formation. The dendritic morphogenesis and synaptogenesis are said to be essential neural activities to affect the neural development of a person with ASD (Ebert & Greenberg, 2013; Gilman et al., 2011).

Environmental Aetiology Research on Autism Spectrum Disorders and Intellectual Disability

Other than genetic causes, there is an active interest in various primary environmental causative factors that could also be strongly related (directly or indirectly) to ASD and ID as well.

In a full sense, human evolution, and in a narrow sense child development have been the subjects of genetic and environmental research since the early 1960s. In 1960, Zazzo (Les Jumeaux, le Couple et la Personne) suggested that genetic effects tend to be erased by environmental influences, especially in twins. In addition to a genetic heritability, common factors such as the shared prenatal environment might play a role in the formation of ASD. Therefore, to understand and interpret early childhood development, it is necessary to take into account information not just on genetic or hereditary research, but on environmental changes as well. Environmental chemicals with hormone-like activity can disrupt programming of endocrine signalling pathways during development. These so-called "environmental hormones" could result in adverse effects. Recent reports link exposure to environmental endocrine-disrupting chemicals during development with adverse health consequences. Recent research attempts to connect environmental changes with the rapid increase in ASD prevalence, and especially to the potential involvement of toxins in our environment (Grabrucker, 2012). Specific environmental factors might act as risk factors triggering the development of autistic tendencies with limited cognitive functions. Some studies link changes in early brain development of children to their mothers' exposure to hormone-disrupting environmental chemicals, but a few of these studies have looked specifically at whether they contribute to ASD or ID. Scientists suspect that hormones play a role in ASD and ID, because boys are four times more likely than girls to be diagnosed, and several hormones are known to control brain development and psychosocial behaviour. Thus, the role of environmental factors in ASD-ID aetiology is an important area of research (Grandgeorge et al., 2009).

One of the most important environmental risk factors is the exposure to toxins. Other important factors include maternal nutrition, tobacco, alcohol and other drugs, infection during pregnancy and prematurity as well as parental age at conception. These factors are under continuous study to find concrete relation to ASD-ID symptomatology.

Frequent and Varied Co-morbid Conditions with Autism Spectrum Disorders and Intellectual Disability

ASD and ID as neurodevelopmental disorders are associated with various co-morbidities, such as attention problems, externalising behaviours such as aggression, affective disorders and sensory processing difficulties. Neurological co-morbidities are motor disorder or developmental motor impairment, epilepsy and sleeping dysfunction. These co-morbidities also have significant impact on cognitive functioning and social behaviour (Dowell, Mahone, & Mostofsky, 2009; Dziuk et al., 2007; Goldman et al., 2009; Mandelbaum et al., 2006; Van Waelvelde, Oostra, Dewitte, Van Den Broeck, & Jongmans, 2010).

Motor function is essential for broader aspects of development like language, social interaction and learning. Motor disorder includes delayed movement development and deficits of different motor functions. Motor deficits include dyspraxia (difficulty in activities requiring coordinated and skilled movement like writing), motor coordination disorder or developmental coordination disorder (DCD), stereotypic movement disorder (SMD) and gait problems (walking-related abnormalities) (Fournier, Hass, Naik, Lodha, & Cauraugh, 2010). SMD is a repetitive, non-functional involuntary motor behaviour (e.g. unintentional hand waving or self-injurious behaviour like head banging, hand biting) that significantly interferes with normal daily life activities and/or could result in bodily injuries. Individuals with ASD and/or ID are at higher risk for SMD. Altogether, movement and motor dysfunction are developmental issues that facilitate earlier diagnosis of ASD and/or ID during early childhood, particularly in infants and young children (Dziuk et al., 2007).

The risk of epilepsy in persons with ASD is linked to lower IQ, with peaks of incidence occurring at pre-school age and adolescence. Between 18 % and 29 % of children with ASD are affected and any seizure type can occur (Cass, Sekara, & Baird, 2006). Relationships between autistic traits, epilepsy and cognitive functioning still remain poorly understood. Although in recent studies the relationship between ASD and epilepsy has been extensively recognised, the underlying mechanism is still unclear. Research data shows that ASD and epilepsy co-occur in about 30 % of all cases in either group. However, there is no classic epilepsy syndrome associated with ASD, though it is well documented that ID itself presents a higher specific risk factor for epilepsy (Tuchman, Alessandri, & Cuccaro, 2010; Turk et al., 2009; van Eeghen et al., 2013). The study of Tuchman et al. (2010) summarises that investigators suggest that the most common reason for the co-occurrence of ASD and epilepsy is that the same brain pathology causes both disorders. The second reason could be an epileptic process during early development that interferes with the developing function of distinct brain networks leading to the ASD phenotype. The third reason could come from the idea that the coexistence of both ASD and epilepsy aetiologically is a focal or multifocal process affecting structures common to both ASD and epilepsy such as the limbic system.

Results from various research studies show that it is very likely that there are multiple biologic and genetic substrates that could lead to ASD-epilepsy phenotypes. Most study results conclude that there is no single unifying ASD-epilepsy phenotype. On the other hand, it is crucial to understand potential commonalities in subgroups of children with an ASD-epilepsy phenotype. In the near future, the research-based understanding of such phenomena should help us to understand the pathophysiology of both ASD and epilepsy. Now, the research question that needs to be addressed is whether there are specific causes or genes that differ in individuals

with both ASD and epilepsy versus those with either disorder alone (Tuchman et al., 2010).

Finally, sleeping disorder is one of the high-risk co-morbidities in persons with developmental disorders (e.g. ASD, ID, ADHD). The development and maintenance of sleep are controlled by melatonin. Melatonin is a hormone secreted by the pineal (or endocrine) gland in the brain (epiphysis cerebri: located behind the third ventricle). It works as a "body clock", turned on during hours of darkness and switched off at dawn by the light of day. Melatonin helps the person to sleep and regulates the sleep cycle (called circadian rhythm). Typical symptoms of sleeping dysfunction are prolonged awakening time, sleep fatigue, lack of energy and lapses in memory and concentration (Grabrucker, 2012; Maski, Jeste, & Spence, 2011). Some of the studies suggest that anxiety and sensory processing disorder, two well-known co-morbid conditions for ASD, might be related to the high-risk co-morbidity for sleeping problems. The most common sleeping problems include prolonged sleep latency, bedtime resistance, sleep onset delay, reduced sleep duration, decreased sleep efficacy, sleep anxiety and night awakening (Hollway & Aman, 2011). Bruni et al. (2015) reported a study on melatonin use for children with sleep disturbances. The study states that melatonin decreases sleep onset latency and increases total sleep time, but does not decrease night awakenings.

Recent studies collected data on sleeping dysfunction of children with ASD from parents, related to their daily rhythm and everyday life difficulties. The data show that typically developing children experience an average of 25–40 % disrupted sleep cycle, while 40–80 % of children with ASD experience a sleep problem (Reynolds & Malow, 2011). Sleeping is a critical factor for early development in children. Sleeping has multiple related functions, and it significantly contributes to brain growth, enhanced memory functions, cognition and conservation of energy. Therefore, insufficient sleep could cause deficits in all of these areas for every child, but especially for those with a developmental disability. Studies on sleep problems in children with ASD show that insufficient sleep accelerates the severity of ASD symptoms (e.g. repetitive behaviour, emotional dysregulation, self-injurious behaviour, social and communication difficulties).

There is evidence that shows a significant relation between sleeping dysfunction and problematic daytime behaviour. The study of Cohen, Conduit, Lockley, Rajaratnam, and Cornish (2014) proposed that profiling sleep problems of children with ASD on the nature of their sleep disruption could provide significant data for further research. This profiling system on sleep disturbances could reveal important details and a new insight to better understand behavioural profiles of persons with ASD. On the other hand, analysis of behaviour profiles of children with ASD might help to understand sleep problems and contribute to the design of better intervention strategies to manage these symptoms.

Relationship Between "Intellectual Functioning" and "Neuroimaging/ Neuropsychological Research"

The relationship between intellectual ability and the brain has been extensively investigated since the 1880s (Galton, 1889; Rushton & Ankney, 1996; Spitzka, 1907; Wickett, Vernon, & Lee, 1994). Several lines of evidence suggest that inter-individual differences in IQ are associated with variations in brain size approximated by head size. Recent advance in neuroimaging techniques, such as magnetic resonance imaging (MRI), allows us to examine the relationship between intelligence and regional brain morphology in vivo. In this section, we review the relationships between IQ and brain morphology.

Relationship Between Intelligence Quotient and Brain Volume

With MRI, it is possible to separate volumes of gray matter (GM) from those of white matter (WM); thus, MRI allows us to examine the associations between IQ and brain volume, including the total brain volume, total GM volume and total WM volume (e.g. Andreasen

et al., 1993; Ivanovic et al., 2004). The total brain volume is moderately correlated with intelligence ($r > 0.3$) (McDaniel, 2005; Rushton & Ankney, 2009), suggesting that individuals with higher IQ tend to have a larger brain. A recent study has also demonstrated that, while correlation between IQ and the total volume of cerebrospinal fluid (CSF) is not significant ($r = 0.12$), the total GM and WM volumes are positively correlated with IQ ($r = 0.37$ for the GM volume and $r = 0.26$ for the WM volume) (Narr et al., 2007), and that inter-individual variations in IQ could be explained by variations in the total GM volume. Because the GM consists of neurons, axons and dendrites that act as the units of brain function and sites of information transfer, variability of intellectual ability might be primarily attributed to variations in the total GM volume.

Relationship Between Intelligence Quotient and Gray Matter

A number of studies have examined the relationships between IQ and the regional GM regions quantified by several measures, such as the GM density, cortical thickness and surface area (Amat et al., 2008; Haier, Jung, Yeo, Head, & Alkire, 2004; Jung & Haier, 2007; Narr et al., 2007; Schnack et al., 2014). Voxel-based morphometry (VBM) may be one of the most widely used methods to examine the GM and WM volumes segmented from structural MRI (Good et al., 2001). This method has been used to characterise the GM and WM volume changes in ageing (Good et al., 2001) and psychiatric diseases (e.g. Kosaka et al., 2010; Lai et al., 2013). Several VBM studies have consistently reported significant positive correlations of IQ with distributed brain regions, including the dorsolateral prefrontal cortex, anterior cingulate cortex and temporal and occipital regions (Frangou, Chitins, & Williams, 2004; Haier et al., 2004; Wilke, Sohn, Byars, & Holland, 2003).

The thickness of the cerebral cortex varies from 1 mm to 4.5 mm, with an overall average of approximately 2.5 mm (Fischl & Dale, 2000). The measure of cortical thickness is known to reflect the underlying cytoarchitecture, including the structure of the laminar cortical layers as well as the size, number and density of the neuronal cell bodies. Therefore, investigation of the relationship between IQ and this measure may be more informative from a neurobiological point of view. To date, a few studies have examined the relationships between IQ and cortical thickness (Narr et al., 2007; Schnack et al., 2014; Shaw et al., 2006). Consistent with previous findings from VBM studies (Frangou et al., 2004; Haier et al., 2004; Wilke et al., 2003), these studies have reported significant associations of IQ with thickness of several brain regions, including the prefrontal cortex and temporal regions. These consistent findings, therefore, have proposed a parieto-frontal integration theory (P-FIT) such that variations in a parieto-frontal network could explain the intellectual ability (Jung & Haier, 2007).

Relationship Between Intelligence Quotient and Cortical Development

Changes in intellectual ability have been associated with cortical development. The relationship between IQ and cortical development has been examined using cortical thickness (Schnack et al., 2014; Shaw et al., 2006). For instance, Shaw and colleagues have found that, in early childhood (age range: 3.8–8.4 years), the measure of cortical thickness is negatively correlated with IQ, whereas in young adulthood (age range: 17–29 years), cortical thickness tends to positively correlate with IQ in the frontal and temporal regions (Shaw et al., 2006), which is consistent with the P-FIT model.

Recently, Schnack and colleagues have also examined the relationship between IQ and cortical development using cortical thickness (Schnack et al., 2014). Consistent with previous findings (Shaw et al., 2006), they have found that, in childhood, cortical thinning is significantly associated with higher IQ (>120), particularly in the left hemisphere. Furthermore, they found that the relationship between IQ and cortical thinning weakened during adolescence, whereas cortical

thickening is significantly associated with higher IQ in adulthood (age > 21 year) (Schnack et al., 2014). Interestingly, they have observed that, depending on the level of IQ, individuals show different cortical development during adulthood (age > 28 years). For example, in adulthood, the mean cortical thickness in the left hemisphere continued to decrease for individuals whose IQ was less than 110; however, the mean cortical thickness in the left hemisphere increased for individuals whose IQ was higher than 110. Furthermore, individuals with higher IQ (>110) tend to show a slowdown in the speed of cortical thinning in the frontal regions. These findings indicate that individuals with higher IQ might keep their brains developing.

Brain development and changes in IQ might be attributed to the genetic factors. Baare and colleagues have demonstrated that genetic factors account for most inter-individual variations in brain volume (82 % for GM volume and 88 % for WM volume), and the shared gene factors have impact on brain volume (Baare et al., 2001). Posthuma and colleagues have also revealed significant heritability on brain volumes and IQ (0.82 for GM, 0.87 for WM, and 0.86 for IQ), and that the relationships between IQ and brain volumes are due to genetic factors, but not due to environmental factors (Posthuma et al., 2002). Furthermore, in adults the genetic influences are prominent in the dorsal prefrontal cortex and temporal regions (Hulshoff Pol et al., 2006; Lenroot et al., 2009), those areas that are involved in the P-FIT model. Taken together, the P-FIT might be the best available answer to the question of where in the brain intelligence resides, and cortical morphology in the parieto-frontal network could be endophenotype for the human intelligence in behavioural genetic research.

Wechsler Intelligence Scale Profile of Adult Autism Spectrum Disorders

The intelligence profile of autism is of great clinical significance for the diagnosis of developmental disorders, particularly in adulthood. Among many other means of measuring intelligence, the Wechsler Intelligence Scales (WAIS) are the most widely used tools for the assessment of autistic intelligence. Previously, several studies have attempted to identify cognitive characteristics of adult high-functioning ASD by examining the WAIS score profile at multiple levels. At the level of the Verbal versus Performance IQ, the significant VIQ advantage in high-functioning ASD has been reported by multiple studies (Ghaziuddin & Mountain-Kimchi, 2004; Kanai et al., 2012), although there exists some notable exceptions that failed to replicate the result (Spek, Scholte, & van Berckelaer-Onnes, 2008). At the subtest level, early studies were consistent in reporting that the Block Design subtest is the highest scored Performance test, whereas Comprehension is the lowest Verbal test (Siegel, Minshew, & Goldstein, 1996). However, recent studies using the WAIS-III have shown partly different results. For instance, Kanai and colleagues have examined WAIS-III profiles from a large cohort of 122 adult high-functioning ASD including 47 Asperger's syndrome (AS), 24 high-functioning autism (HFA) and 51 pervasive developmental disorder-not otherwise specified (PDD-NOS), and found that adults with ASD, particularly those with AS, performed well in Comprehension (Kanai et al., 2012). Other autistic strengths included Vocabulary and Information in the Verbal Domain. Relative strengths in these Verbal subtests were also reported in a previous study (Spek et al., 2008). In the Performance Domain, the Block Design was either in the near normal range or in the below normal range (Kanai et al., 2012), raising a possibility that this subtest may not be a particular strength for adult ASD. At the Index level, the majority of studies are consistent in showing that ASD is impaired in the Processing Speed that consists of the two Performance subtests of Digit-Symbol Coding and Symbol Search (Kanai et al., 2012; Siegel et al., 1996; Spek et al., 2008). To summarise, although some inconsistencies among the studies may still exist, the WAIS score profile provides an important source of information for the diagnosis of autism by identifying its characteristic cognitive profiles.

Functional Imaging Studies for Intellectual Profiles of Autism Spectrum Disorders

Recent advances in non-invasive neuroimaging technology have allowed us to address the neural correlates of atypical intellectual profiles of ASD. Among others, Alexander and colleagues specifically focused on the abnormal anatomy of the corpus callosum of child and adult ASD and examined its association with altered intellectual profiles of ASD as assessed either by WISC-III for children or by WAIS-III for adults (Alexander et al., 2007). The corpus callosum is a commissural white matter pathway that connects the two hemispheres and therefore is thought to be a key component for communication between homologous and heterotopic cortical regions. In the analysis of volumetric and microstructural measures provided by structural MRI and diffusion tensor imaging (DTI), they observed that the corpus callosum of ASD was significantly reduced in size and fractional anisotropy (FA) compared with matched typical controls. Furthermore, these group differences were largely driven by a subgroup of ASD that showed significantly lower performance IQ. Among multiple DTI measures, radial diffusivity in particular showed significant negative correlation with the Processing Speed Index score. Because radial diffusivity is a measure for diffusivity perpendicular to the axonal bundles that is thought to be associated with the degree of myelination, the results indicate that the microstructural alterations in the corpus callosum may partly underlie impaired processing speed characteristically observed in adults with ASD.

Functional imaging studies have also contributed to elucidating the neural correlates of autistic intelligence. Other than the Wechsler intelligence scales, the Raven's Progressive Matrices (RPM) test has recently gained attention from autism researchers because a portion of high-functioning ASD, AS in particular, has been shown to outperform typically developing individuals in this test, indicating another domain of intellectual strength of autism (Dawson, Soulieres, Gernsbacher, & Mottron, 2007; Soulieres, Dawson, Gernsbacher, & Mottron, 2011). Soulieres and colleagues used fMRI and measured cortical activity while adults with ASD were engaged in the RPM, with the aim of identifying functional brain systems that may support this intellectual advantage (Soulieres et al., 2009). Compared with matched typical controls, relatively increased task-related activity for ASD was identified in the extrastriate visual cortex and decreased activity in the lateral prefrontal cortex and the medial posterior parietal cortex. From the results, it was suggested that visual processing mechanisms might play a relatively more prominent role in solving the RPM in adults with ASD. However, the study employed a relatively small number of participants (15 adults with ASD) and the total length of the scan varied considerably among participants depending on the individual speed of solving the items. Because the detection of the fMRI signal change is greatly dependent on the number of acquired volumes, the significant variations in the length of the scan may pose serious problems in the interpretation of the data.

Yamada and colleagues performed an fMRI study for 25 adult ASD and 26 matched controls using a modified version of the RPM test in an effort to mitigate those problems (Yamada et al., 2012). In their study, they selected relatively simple RPM items based on a preliminary test such that variability in reaction time was greatly reduced. The RPM items were divided into either "figural" or "analytic" items based on the classification by previous behavioural studies (Lynn, Allik, & Irwing, 2004). "Figural" items are often characterised as "Gestalt reasoning", which requires mostly visuospatial analysis with minimal analytic/analogical reasoning, whereas "analytic" problems require abstract "analogical reasoning" in addition to figural processing. "Analytic" items were further divided into either "easy" or "difficult" based on their pilot survey. By using "figural" items as a baseline, they aimed to identify brain activation for analogical reasoning by controlling for activation for lower visual processing.

They observed significant cortical activation in a set of brain regions including the prefrontal and parietal cortex consistent with previous fMRI

studies for analogical reasoning in the typical population. Of note, direct comparison between the two groups revealed that ASD showed significantly larger activation in the left lateral occipitotemporal cortex (LOTC) during an "easy" analytic condition than typical controls. Subsequent regions of interest analyses revealed that activation in the left LOTC and ventrolateral prefrontal cortex (VLPFC) increased with task difficulty in typical controls, whereas such modulation of activity was absent in ASD. Furthermore, functional connectivity analysis revealed a significant reduction of activation coupling between the left inferior parietal cortex and the right anterior prefrontal cortex during both figural and analytic conditions in ASD. These results indicate altered patterns of functional specialisation and integration in the neural system for geometric reasoning in ASD, which may explain its atypical cognitive pattern, including performance on the Raven's Matrices test.

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Executive Functions in Autism Spectrum Disorder

21

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Introduction

Many theories have been put forth to explain the primary deficits seen in individuals diagnosed with Autism Spectrum Disorder (ASD). Specific efforts have been directed towards the description and characterization of core clinical symptoms demonstrated by these individuals in addition to related behavioural and/or cognitive features that may be unique to this population. The Executive Function (EF; Ozonoff, Pennington, & Rogers, 1991) theory has been researched extensively to aid in these efforts. The primary focus of these efforts has been to understand and describe EF abilities in individuals with ASD and to link those abilities to the primary impairments demonstrated by individuals within this population. The purpose of this chapter is to review information pertaining to EF in individuals with ASD. We begin with an overview of the construct of EF and its relation to neuropsychological functioning. Common approaches to measurement/evaluation of EF will be described. Subsequently, typical development of EF will be reviewed and compared to EF development in ASD. Specific literature pertaining to EF impairment in ASD and its relation to the social and behavioural atypicalities often seen in ASD will also be presented. Additional research regarding EF and neural structures and brain imaging in individuals with ASD will be reviewed. The chapter will end with a discussion of intervention strategies for EF in ASD, implications of the findings of EF in ASD, and future research opportunities.

Executive Function

The term 'Executive Functions' was introduced in relation to the work of Luria (1966), who proposed a cognitive system in charge of intentionality and formulation of thoughts and actions, the identification of goal-appropriate cognitive routines, and evaluation of outcomes. Some researchers gravitate towards the use of the term 'executive control' in place of EF. This is largely due to the term capturing the self-regulatory nature of the processes involved, highlighting the need of the individual to purposefully modulate and control in some fashion (Wiebe et al., 2011). Nevertheless, 'EF' continues to be the most popular term put forth in the literature. This area of mental functioning (i.e. EF) has been shown to be primarily regulated by the prefrontal cortex through imaging and neuropsychological studies, though it is not solely responsible for these cognitive processes (Elliott, 2003; Godefroy, 2003; Goldman-Rakic, 1987; Rubia

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et al., 2001; Rubia, Smith, Brammer, & Taylor, 2003). As such, this area of the brain is now thought to act primarily as a 'control centre' to mediate these cognitive functions with connections extending to other brain regions (Miller & Cohen, 2001).

Baddeley and Hitch (1974) were the first to describe EF as a 'central executive', further defined by Lezak (1983) to include a central process that controls how human behaviour is expressed. While concrete definitions have varied over time (see Jurado & Rosselli, 2007), EF is a broad term currently used to refer to higher cognitive processes that allow one to mediate their behaviour in response to an ever-changing environment (Sokol, Muller, Carpendale, Young, & Iarocci, 2010). It has also been defined as 'the ability to maintain an appropriate problem-solving set for attainment of a future goal' (Ozonoff, Pennington, et al., 1991). EF is an umbrella term that encompasses three core interacting, yet theoretically distinct processes including inhibition of prepotent (or automatic) responses, working memory, and cognitive flexibility (Best & Miller, 2010; Joseph & Tager-Flusberg, 2004; Miyake & Friedman, 2012; Toplak, West, & Stanovich, 2013). The arrival of some consensus surrounding the foundational nature of inhibition, working memory, and cognitive flexibility has been gleaned through statistical modelling and meta-analysis with data from neuropsychological test batteries at many ages of human development (Friedman, Miyake, Robinson, & Hewitt, 2011; Miyake, Friedman, Emerson, Witzki, & Howerter, 2000; Rose, Feldman, & Jankowski, 2011; Zelazo & Muller, 2002).

It is important to note that despite some inconsistent results, strong evidence exists for the validity of EF being composed of separate control processes as opposed to a single EF ability. Support for this theory includes studies that have shown low intercorrelations between different executive tasks, around $r=0.40$ or less (Lehto, 1996; Miyake et al., 2000; Salthouse, Atkinson, & Berish, 2003). The low correlations suggest minimal underlying commonality between EF tasks, or more likely, the possibility of a mechanism that ties their functions together.

Inhibition

Inhibition (IN) is the ability to control a response that will not support goal attainment and instead activate an appropriate alternative (Calhoun, 2006). In essence, it is self-control (Best & Miller, 2010). IN can be conceptualized as either simple, where a prepotent response must simply be held back, or complex, where an arbitrary rule must be held in mind to hold back a response in favour of an alternate one. An example of simple inhibition may include holding back the prepotent response to scratch an itch, or to cross the street as one last car speeds through the intersection even if the 'walk' sign has already turned on. A more complex example may be inhibiting the desire to make a merchandise purchase to instead review one's finances and consult with a significant other before doing so. Inhibitory ability has been postulated as being foundational to both the development and function of EF. This component of EF underlies the regulation of emotion, cognition, and behaviour (Miyake et al., 2000; Nigg, 2000). Barkley (1997) defines accurate performance across all areas of EF as relying upon a basis of behavioural IN ability. Thus, due to the importance of inhibitory development (and ability), and its underlying importance to EF development in general, it remains an important focus for study in childhood.

Working Memory

Working memory (WM) is the ability to hold information in a system of short-term memory while manipulating it and comparing it with information held in long-term memory without the use of external cues or aids (Alloway, Gathercole, & Pickering, 2006; Calhoun, 2006). For example, WM would be utilized when performing mental calculations or rehearsing a phone number in a specific way in order to remember it. More recent research has provided information on a sub-process of WM termed 'updating', which refers to the important cognitive process of not just maintaining information in WM, but choosing what information enters

and leaves WM due to the limited capacity it has. In one of the original models of WM by Baddeley and Hitch (1974), it was hypothesized that short-term visual and auditory information is stored and manipulated in WM, specifically, in the visuo-spatial sketchpad and phonological loop respectively (Baddeley, 2002).

Cognitive Flexibility

Cognitive flexibility (CF), or set shifting, is the ability to perceive events in a different manner, respond in unique ways, and/or to make necessary cognitive adjustments to assist goal attainment (Calhoun, 2006; Miyake et al., 2000). For example, there are different social expectations for how an individual should act in a shopping mall versus during a church service, and switching appropriately between these sets is optimal to participating in each situation. Cognitive flexibility is also important during conversational exchanges, or any situation in which topics or ideas may switch rapidly and one must show adaptability. For example, during an argument with a peer, an individual must shift his/her mindset to account for the other person's perspective in order to find a solution to the issue at hand.

Development of EF

Neuroimaging studies have shown that the frontal lobes begin activation at approximately 6 months of age, despite previous beliefs that they were relatively inactive during childhood (Chugani, Phelps, & Mazziotta, 1987; Jurado & Rosselli, 2007). Through myelination, synaptic pruning, and synaptic growth, the frontal lobes and prefrontal cortex (PFC) continue to mature into late adolescence and even into early adulthood (Casey, Amso, & Davidson, 2006; Fuster, 1993; O'Hare & Sowell, 2008). It follows then that the trajectory of development of EF coincides with the development of the PFC. In fact, researchers theorize that during typical development, many of the stages associated with childhood growth (e.g. preschoolers' ability to think of the past, plan for the future, and begin making more complex decisions) are related to the maturity of EF (Denckla, 1996). In general, EF ability appears to develop sequentially as the PFC continues to mature, with growth periods identified between birth to 2 years, 7–9 years, and 16–19 years, with variations expected for every child (Anderson, Anderson, Northam, Jacobs, & Catroppa, 2001; Anderson, Levin, & Jacobs, 2002; Anderson, Northam, Hendy, & Wrenall, 2001).

Regarding the development and differentiation of early EF abilities, some researchers argue that control processes (i.e. IN, WM, and CF) are not fully separable early in development. Specifically, the assessment of EF in young children requires language, visual-spatial abilities, memory, and motor skills among others that are still in the early stages of development and are thus likely to influence assessment (Wiebe et al., 2011). When statistical procedures such as confirmatory factor analysis are used to identify separate non-EF from EF abilities in very young children, some results indicate that a single-factor EF model best fits the data. This trend appears to exist specifically for children between 3 and 6 years old, where no improvement in statistical models is seen when separate IN, WM, or CF components are added (Hughes, Ensor, Wilson, & Graham, 2010; Wiebe, Espy, & Charek, 2008). Thus, although some researchers believe that IN, WM, and CF can be measured separately in early development, many studies point to a single EF factor that does not clearly diversify until later preschool years (Garon, Bryson, & Smith, 2008).

In summary, EF develops through infancy and childhood, with maturation continuing into adolescence and young adulthood. IN is the first EF observed in children's behaviour, with CF significantly improving later in childhood, and WM continuing to strengthen into adolescence. Best and Miller (2010) suggest that these similar, yet differing trajectories of development are in support of the differentiation of these EF components despite appearing inseparable in infancy/early development. Importantly, different EF abilities appear to have different developmental patterns, with some acting as the basis for others,

and certain components not reaching full maturity until late adolescence (Best & Miller, 2010; Passler, Isaac, & Hynd, 1985). The following description outlines the typical developmental course of IN, WM, and CF.

Inhibition

Infants can display some simple IN ability, such as delaying the urge to eat a treat, with rapid gains observed through early childhood (Garon et al., 2008). By 1 year of age, babies can inhibit an overlearned response, with the largest gains in inhibitory ability observed in children between 6 and 9 years of age (Brocki & Bohlin, 2004; Klenberg, Korkman, & Lahti-Nuutila, 2001; Passler et al., 1985). Most research seems to indicate adult-level mastery of IN between 10 and 12 years of age (Passler et al., 1985; Welsh, Pennington, & Grossier, 1991). However, inhibitory ability continues to be refined through adolescence and adulthood as its application relies on relevant cognitive skills and life experiences (Best & Miller, 2010).

Working Memory

Working memory (WM) involves more complex use of EF through the maintenance and manipulation of information, and thus its development relies on more PFC activity (D'Esposito & Postle, 1999). Simple WM, such as keeping information in the phonological loop (e.g. remembering a phone number), is present during the preschool years, with more complex WM ability, such as being able to recite given digits in reverse order, beginning to develop around 6 years of age (Garon et al., 2008; Gathercole, Pickering, Ambridge, & Wearing, 2004). Luciana, Conklin, Hooper, and Yarger (2005) observed that both simple and complex WM abilities improved linearly between the ages of 4 and 14–15. In general, WM ability improves into adolescence and adulthood, likely due to cognitive and neural maturation.

Cognitive Flexibility

Miyake and colleagues (2000) point out that IN is essential for shifting between mental sets (i.e. cognitive flexibility; CF), as a new set must be the focus of attention and the previous one inhibited. Additionally, WM abilities are required to some degree to switch between sets of mental rules (Best & Miller, 2010). As with other EF abilities, CF improves with age, starting with the ability to shift between two simple response sets around 3–4 years of age (Anderson et al., 2002; Hughes, 1998). As children reach 7–9 years-old, they begin to show the ability to maintain and shift between multiple mental sets, with the ability levelling off at approximately 15 years of age (Huizinga, Dolan, & Van der Molen, 2006), and continuing to mature throughout adolescence (Anderson et al., 2002; Davidson, Amso, Anderson, & Diamond, 2006; Zelazo & Frye, 1998).

Relation to Cognition

Cognitive intelligence (IQ) is difficult to define as it is utilized in numerous contexts. In general, it refers to 'the aggregate or global capacity of the individual to act purposefully, to think rationally, and to deal effectively with his/her environment' (Wechsler, 1944). This construct is most often used in reference to standardized testing where an individual is compared to age-related peers to determine if specific areas of cognitive strength or weakness are apparent.

As has been noted frequently in the research literature, although EF and IQ may be related, they are different cognitive constructs (Kolb & Winshaw, 1990; Pennington & Ozonoff, 1996). Indeed, a common misperception is apparent in clinical practice and the research literature regarding the relationship between EF and IQ. A high degree of overlap is often cited in the research literature, stemming primarily from the work of Sternberg (Sternberg, 1985; Sternberg & Gardner, 1982). This line of research has proposed that *g* or general intelligence represents a

person's overall cognitive intellectual functioning, and that individual differences in EF can be explained by differences in *g*.

Corollaries of this hypothesis have been explored and challenged (Crinella & Yu, 2000). Three lines of evidence have been put forward to challenge this notion of EF/IQ interdependence. First, if such a direct relationship exists, then tasks with a higher *g* loading will necessarily draw more upon EF than tasks with low *g* loadings. Researchers investigating this relationship between IQ and EF have shown that, although a positive correlation may exist between EF and IQ measures, the correlations are quite low (Ardila, Pineda, & Rosselli, 2000; Arffa, 2007; Welsh et al., 1991). Moreover, this relation appears to be most related to one aspect of cognitive ability, fluid intelligence, rather than crystallized intelligence. Several researchers have reported that individuals affected by some childhood disorders, such as learning disorders, autism spectrum disorder, phenylketonuria, and attention-deficit/hyperactivity disorder (AD/HD), demonstrate poor performance on measures of fluid intelligence and EF but relatively intact overall crystallized intelligence (Barkley, 1997; Berlin, 2003; Diamond, Prevor, Callendar, & Druin, 1997; McLean & Hitch, 1999; Pennington & Ozonoff, 1996; Stanovich, Siegel, & Gottardo, 1997; Swanson, 1999).

Second, if such a direct relationship between EF and IQ exists, then individuals with impairment in one area should necessarily demonstrate impairment in the other. There is ample research evidence that many individuals, such as those with AD/HD, demonstrate consistent EF deficits (Barkley, 1995, 1997; Pennington, Grossier, & Welsh, 1993). However, the mean Full Scale IQ scores of individuals with AD/HD do not reflect this impairment. Although individuals with AD/HD often display unique areas of deficit on common measures of intelligence such as the Wechsler Intelligence Scale for Children—Fourth Edition (WISC-IV; Wechsler, 2003), the effect size of this difference is not large, nor is it commensurate with their demonstrated EF deficits (Mayes & Calhoun, 2006; Schwean & McCrimmon, 2008; Schwean & Saklofske, 2005). Thus, although individuals may demonstrate an EF deficit, they do not necessarily demonstrate an equivalent IQ deficit (Schwean, Saklofske, Yackulic, & Quinn, 1993; Swanson et al., 1997).

Third, there is research evidence to show that the frontal lobes of the brain are clearly responsible for EF (Luria, 1966). However, minor insults to sections of the frontal lobes of the brain frequently result in deficits in EF but not IQ (Hebb, 1945, 1949; Stuss & Benson, 1984; Teuber, 1959). Thus, individuals with intact IQ are capable of demonstrating deficits in EF, providing evidence for their differentiation.

In general, a positive relationship exists between EF and IQ in that tasks of EF typically require a base level of cognitive ability in order to succeed and vice versa. Indeed, common sense dictates that problems cannot be solved without EF. However, the relationship between these two constructs is far from direct. EF is just one information processing component necessary for problem solving. Correlations between IQ and EF measures tend to be small to moderate, suggesting that many factors other than EF influence an individual's IQ. Many individuals who demonstrate an EF deficit do not demonstrate a comparable IQ deficit. Similarly, insult to the regions of the brain associated with EF does not always impair *g*. Indeed, as succinctly pointed out by Duncan, Burgess, and Emslie (1995) 'frontal patients have impaired "planning", "problem solving", etc. but preserved "intelligence"' (p. 262).

Measurement of EF

The relevance of EF to children and adolescents has been a topic of debate for many years (Toplak et al., 2013). This discussion has centred primarily around questions of the theoretical factor structure of the construct (i.e. is EF appropriately conceptualized as inhibition, working memory, and cognitive flexibility?; Miyake et al., 2000), the development of EF from infancy through to adolescence (i.e. is the theoretical factor structure stable throughout development?; Willoughby, Blair, Wirth, & Greenberg, 2010), and effective measurement processes (i.e. how can we

appropriately measure EF abilities in children of various ages?; Willoughby, Wirth, & Blair, 2011). Regarding the latter, clinical practice and empirical literature indicate that EFs are generally measured via two approaches: Task or performance-based measures and/or rating scales (Toplak et al., 2013).

Task-based approaches typically employ the use of standardized tasks designed to isolate and measure a specific EF ability. Some common measures used in childhood and adolescence are the Delis-Kaplan Executive Function System (DKEFS; Delis, Kaplan, & Kramer, 2001), the NEPSY-II (Korkman, Kirk, & Kemp, 2007), and the Wisconsin Card Sorting Task (WCST; Heaton, Chelune, Talley, Kay, & Curtis, 1993). Tasks are typically selected based upon the EF domain that they are purported to evaluate and performance is judged based on accuracy and/or speed of response in comparison to a norm-referenced group. This evaluative context is seen as supporting optimal EF performance as the examinee completes tasks designed to utilize a singular EF in a controlled environment.

In contrast, rating scales require an informant (often a parent and/or a teacher) to judge the child's challenges with common behaviours that require or utilize EF. The most common measures in this domain are the Behavior Rating Inventory of Executive Function (BRIEF; Gioia, Isquith, Guy, & Kenworthy, 2000) and the Comprehensive Executive Function Inventory (CEFI; Naglieri & Goldstein, 2013). Raters are asked to indicate the frequency with which a child demonstrates a number of important behaviours that are related to or mediated by EF abilities. Scores are then compared to a norm-referenced comparison group. These scales thus attempt to provide an ecologically valid representation of a child's competence with EF abilities. This evaluative context is seen as evaluating day-to-day EF performance as the individual is not directed or instructed to engage in specific behaviours.

Despite the use of these two forms of EF measurement, research has indicated that they likely do not assess EF in a cohesive manner (Toplak et al., 2013). Indeed, these two evaluative formats correlate poorly ($rs \approx 0.2$). As such, it has been proposed that these two forms of assessment likely measure different aspects of EF, with task-based measures evaluating cognitive aspects of the construct, and rating scales measuring behavioural implementation of EF abilities. This position is supported by research that indicates that individuals who demonstrate EF impairment on rating scales (i.e. behavioural impairment) are often capable of adequate performance on task-based measures (Gioia, Isquith, & Kenealy, 2008). In general, clinicians and researchers are advised that task-based and ratings scales are not interchangeable and can provide important and unique information about an individual's EF abilities (Biederman et al., 2008).

Executive Function in ASD

EF has received widespread attention within ASD literature for several years, largely due to the proposition that the invariance of ASD behaviours and rigidity could be explained as a primary impairment in executive control (Hughes & Russell, 1993; Ozonoff, Pennington, et al., 1991; Pellicano, 2012). Regardless of the heterogeneity of ASD, EF difficulties have been consistently demonstrated in many children, adolescents, and adults with ASD (Hughes, Leboyer, & Bouvard, 1997; Hughes, Plumet, & Leboyer, 1999). For example, several studies have reported that individuals with ASD perform significantly below typically developing matched controls on common EF measures of CF such as the Wisconsin Card Sorting Task (Ozonoff, 1997; Ozonoff, Pennington, et al., 1991; Ozonoff, Rogers, & Pennington, 1991; Verte, Guerts, Roeyers, Oosterlaan, & Sergeant, 2006), the Tower of Hanoi (Ozonoff, Rogers, et al., 1991), the Tower of London (Manjiviona & Prior, 1999; Verte et al., 2006), the Intradimensional-Extradimensional Set-Shift (ID/ED shift) task of the CANTAB (Hughes, Russell, & Robbins, 1994), and a local–global shifting task (Rinehart, Bradshaw, Moss, Brereton, & Tonge, 2001). It has been suggested that this pattern of reduced CF could be more commonly displayed as perseverative response patterns and as an inability to disengage from an

object and shift from an external to an internal point of reference, resulting in difficulties relating to people in a social manner and engaging in conversation where the topic of discussion often changes over time (Hughes & Russell, 1993; Pellicano, 2012; Russell, Mauthner, Sharpe, & Tidswell, 1991).

Additional research has indicated impaired spatial working memory in individuals with ASD (Ozonoff & Jensen, 1999; Williams, Goldstein, Carpenter, & Minshew, 2005; Williams, Goldstein, & Minshew, 2006). However, these findings are not consistent, as other studies have failed to find evidence for impairment (Griffith, Pennington, Wehner, & Rogers, 1999; Ozonoff & Strayer, 2001; Russel, Jarrold, & Henry, 1996).

Regarding IN, research has indicated that children and adolescents with ASD appear to demonstrate intact abilities in this domain when evaluated by common IN tasks (Hill, 2004a). Researchers using the Stroop task, a classic measure of IN where participants are asked to say the colour of ink a word is printed in rather than reading the word (e.g. saying 'blue' when the word 'green' is written in blue ink), have reported no differences in performance between individuals with ASD and typically developing controls (Schmitz et al., 2006). This lack of difference in the realm of IN has also been demonstrated on a task of negative priming (Ozonoff & Strayer, 2001), a Go/No-Go task, and the Color-Word Interference Task (Ozonoff, Strayer, McMahon, & Filloux, 1994), a modification of the classic Stroop task with an added inhibition/switching task that increases task difficulty. However, research findings indicate that children with ASD present with impaired IN ability when required to inhibit a prepotent (or automatic) response (Hughes & Russell, 1993; Russell et al., 1991; Russell, Hala, & Hill, 2003).

Research has also demonstrated that certain EF components have been shown to distinguish ASD from other developmental conditions, such as AD/HD (Geurts, Verte, Oosterlann, Roeyers, & Sergeant, 2004; Ozonoff & Jensen, 1999). There have, however, been inconsistent research findings that have cast doubt on the executive dysfunction hypothesis as a primary problem in ASD, as it cannot explain all autistic symptomatology (Griffith et al., 1999; Yerys, Hepburn, Pennington, & Rogers, 2007). As such, researchers have suggested that we must shift away from the idea that there is a single framework that explains the causality of ASD, and instead focus on the underlying causes that encompass multiple atypicalities (Happé, Ronald, & Plomin, 2006).

While there is evidence to suggest that executive dysfunction only acts as a primary cause for a subset of autistic symptomatology, it remains possible that the degree of difficulties in EF could possibly play a considerable role in the developmental outcomes of individuals with ASD including adaptive behaviour, social competence (e.g. theory of mind), joint attention, and academic successes (Hill, 2004b; Pellicano, 2012). Therefore, regardless of whether EF is considered a primary cause or not, deficits are likely to put an individual with ASD at risk for a poor developmental outcome (Pellicano, 2012).

The challenge within the literature is to move from research that focuses on attributing symptomatology to executive dysfunction, and instead incorporating a developmental perspective (Geurts, de Vries, & Sanne, 2014) to better understand causality. It has been described that during both childhood and adulthood, individuals with ASD display a broad range of EF deficits, but yet the developmental pattern of EF in ASD appears to be atypical (Happé, Booth, Charlton, & Hughes, 2006; Luna, Doll, Hegedus, Minshew, & Sweeney, 2007; Pellicano, 2010a). For instance, in a recent longitudinal study the planning capacity of children with ASD improved at a faster rate than that of the typically developing children (Pellicano, 2010a). These findings would suggest that at least certain EF deficits initially seen in ASD might improve over time (Geurts et al., 2014). However, there are many studies that indicate executive dysfunction that is still present in adulthood (Geurts & Vissers, 2012; Goldstein, Johnson, & Minshew, 2001; Hill & Bird, 2006), thus providing an atypical course of EF development in ASD over time. Moreover, there have been several studies that have explored executive dysfunction over time, and their combined findings suggest that there

are different developmental patterns for different aspects of EF within the ASD population (Griffith et al., 1999; Luna et al., 2007; Ozonoff & McEvoy, 1994). Therefore it is essential that future research focus on how and when EF develops in individuals with ASD, with a specific focus on EF deficits and how they develop with such a heterogeneous population.

Relation to Restricted and/or Repetitive Behaviours

Challenges with CF are the most commonly and consistently reported in ASD, thought to underlie characteristic symptoms such as perseveration, stereotyped motor behaviour, intense and circumscribed interests, and an inability to be flexible with routine or change (Geurts et al., 2004; Hill, 2004a; Ozonoff & Jensen, 1999). This deficit has been widely documented on the Wisconsin Card Sorting Task (WCST; Milner, 1963), which requires an individual to generate novel ways in which to sort cards based on simple feedback, using CF to switch between unspoken rules. Individuals who persist on the WCST and are inflexible in their responses tend to have speech that may be difficult to interrupt, and rigid behaviours and routines that are commonly seen in ASD (Liss et al., 2001). Furthermore, studies have found links between repetitive behaviours as measured on the Autism Diagnostic Observation Schedule (ADOS; Lord et al., 1999) and the Autism Diagnostic Interview (ADI; Le Couter et al., 1989) and CF in both children and adults with ASD (Lopez, Linoln, Ozonoff, & Lai, 2005; South, Ozonoff, & McMahon, 2007).

In addition to CF, other core EFs have been investigated in relation to restricted and repetitive behaviours and interests (RRBIs). Turner's (1997) early work was influential in exploring and describing RRBIs in ASD. Her research found significant correlations between both IN and CF performance and repetitive behaviour as measured by a structured Repetitive Behaviour Interview. In an adult sample of individuals with ASD, Lopez and colleagues (2005) found all three core EF (IN, WM, and CF) abilities to be negatively correlated with repetitive behaviour (as measured by interview, behaviour rating scale, and behavioural observation measures). Using an established behavioural rating scale of EF that included IN, CF, and emotional control subscales, Kenworthy and colleagues (2009) found a strong link between EF abilities (IN, CF, emotional control) and repetitive behaviours in their sample of children.

The vast majority of the previous research used established neuropsychological task-based measures or behavioural ratings of EF-related behaviours. In an attempt to isolate EF subcomponents, Mosconi and colleagues (2009) utilized an antisaccade task to measure IN in relation to ASD RRBIs. An antisaccade task involves having an individual make a planned eye movement in the opposite direction of a moving stimulus, counter to natural tendency. Mosconi and colleagues theorized that because previous research demonstrated deficits in IN when antisaccade tasks are used in an ASD population (Goldberg et al., 2002; Luna et al., 2007), the task may be sensitive to basic IN performance in the population. In comparison to controls, their sample of individuals with ASD ranging from 8 to 54 years of age made more IN errors on the task, and these errors were related to higher-order RRBIs. To clarify, the IN errors on the eye movement task were not related to repetitive motor movements, communication, or social symptoms. Instead, the authors suggest that higher-order RRBIs (e.g. insistence on sameness, preference for routine, intense interests) are a partial result of a fundamental brain-based inability to use both IN and CF normally via fronto-striatal brain systems.

Overall, the behavioural deficits encapsulated by RRBIs in ASD appear to be strongly linked to IN, WM, and CF. Particularly robust are the relationships to CF and IN performance both on neuropsychological and behavioural measures.

Relation to Social Communication Deficits

The role of EF in general is to help with flexible problem solving, shifting between rules and

behaviours, inhibiting behaviour, and coming up with alternate ways to find solutions to problems (Szatmari, Tuff, Finlayson, & Bartolucci, 1990). In regard to social communication, EF deficits theoretically underlie moment by moment planning in social contexts, shifting social behaviour or conversational topics, and holding social information in mind while processing the ever-changing features of social interactions to form appropriate responses (Landa & Goldberg, 2005). For example, children with ASD have been reported to demonstrate significant EF impairments in the form of poor CF (inflexible and perseverative response styles) which have been found to be related to problems with joint attention. Joint attention is the natural tendency to follow the gaze of a social partner, and is significantly important in social interaction, communication, and social development (McEvoy, Rogers, & Pennington, 1993).

In regard to specific EF abilities, some research has found significant correlations between IN (in combination with WM) and social abilities; however, these relationships become insignificant when the level of verbal ability of ASD children is partialled out (Joseph & Tager-Flusberg, 2004). These results have been replicated in studies finding no relationships between IN deficits and social communication symptom severity using both task-based neuropsychological measures and behaviour rating measures of IN (Bishop & Norbury, 2005a, 2005b; Kenworthy, Black, Harrison, Della Rosa, & Wallace, 2009). In a sample of children with ASD ranging from 7 to 17 years of age, Landa and Goldberg (2005) found no differences in performance on a CF task when compared to typically developing children; however, children with ASD performed worse on a spatial WM task that was related to social domain scores on the Autism Diagnostic Observation Schedule (ADOS; Lord, Rutter, DiLavore, & Risi, 1999).

EF and Theory of Mind

Likely the greatest support for a link between EF and social communication deficits in ASD involves Theory of Mind (ToM; Kenworthy et al., 2009). ToM refers to the ability to infer others' mental states, such as intentions, feelings, and beliefs (Baron-Cohen, 1988; Bauminger-Zviely & Kimhi, 2013; Levy, 2007; Shamay-Tsoory, Tomer, & Aharon-Peretz, 2005). Studies have shown that individuals with ASD have deficits in ToM (Kimbi, 2014) and perform lower on ToM tasks than typically developing individuals (Mathersul, McDonald, & Rushby, 2013; Peterson, Wellman, & Slaughter, 2012).

In the ASD population, EF has indeed been shown to be related to ToM ability. Pellicano (2007) found correlations between general EF and ToM ability in children with ASD regardless of their age and verbal ability level. More specifically, support has been found for the importance of IN and WM for ToM, independent of language abilities (Joseph & Tager-Flusberg, 2004). Some results suggest that training EF could lead to ToM improvements and thus enhance social communication for those with ASD (Fisher & Happe, 2005).

ToM falls on a continuum of increasing complexity. For example, first-order ToM involves the ability to consider another person's mental state (Miller & Marcovitch, 2012). First-order ToM understanding has often been tested using a false belief task where children must correctly predict a story character's behaviour based on the character's mistaken understanding (e.g. Wimmer & Perner, 1983). Second-order ToM tasks require children to predict a main character's behaviour based on his/her understanding of a secondary character's mistaken understanding (Baron-Cohen, Jolliffe, Mortimore, & Robertson, 1997). More advanced levels of ToM include examining more naturalistic conversations where the speaker's intentions are ambiguous or inconsistent with his/her true intentions, and then asking participants about the speaker's true beliefs and intentions (e.g. *Faux Pas*, Baron-Cohen, O'Riordan, Stone, Jones, & Plaisted, 1999; *Strange Stories*, Channon & Crawford, 2000; Stone, Baron-Cohen, & Knight, 1998).

Among individuals with ASD, ToM is not believed to be absent; instead, it appears as though ToM abilities diverge from the normal trajectory and show variability among individuals

(Kimbi, 2014). According to Frith's (2012) meta-analysis, there is an approximate 5 year delay for children with ASD with respect to passing the Sally Anne false belief task (a first-order ToM task) in comparison to typically developing children. Specifically, typically developing children exhibit this ability between 3 and 5 years of age (Broomfield, Robinson, & Robinson, 2002; Miller, 2009), whereas children with ASD pass this task at approximately age 9 (Frith, 2012). As described above, second-order ToM involves the ability to consider a person's beliefs about another person's mental state, and children who are typically developing exhibit this ability between 5 or 6 years of age (Miller, 2009). Regarding more advanced ToM tasks (e.g. sarcasm and deception), individuals with High Functioning Autism Spectrum Disorder (HFASD) have been found to struggle on such tasks into adulthood (Mathersul et al., 2013).

In contrast, Scheeren, de Rosnay, Koot, and Begeer (2013) discovered that among a range of advanced ToM tasks (e.g. faux pas; double bluff, sarcasm) children and adolescents with HFASD demonstrate intact advanced ToM abilities. According to these researchers, both verbal and reasoning abilities contributed to better ToM understanding among their sample; however, it is important to note that others have indicated that such skills do not necessarily transfer to everyday situations (Bauminger-Zviely & Kimhi, 2013).

Interestingly, EF abilities are believed to play a key role in the emergence of ToM (Pellicano, 2013). Studies have shown predictive relations between EF and ToM in both typically developing individuals (Carlson, Moses, & Claxton, 2004; Hughes & Ensor, 2007; Moses & Tahiroglu, 2010) and individuals with ASD/HFASD (Kimhi, Kugelmas, Agam Ben Artzi, Ben Moshe, & Bauminger-Zviely, 2014; Pellicano, 2010b). For example, Kimhi and colleagues (2014) discovered that CF and verbal abilities significantly predicted student's performance on ToM tasks.

Specifically, there are two ways in which EF is thought to impact ToM (Moses, 2001): EF may contribute to the 'expression' of ToM, or it may contribute to the 'emergence' of ToM. According to the expression account, children possess ToM abilities, but have trouble demonstrating these abilities because of the EF demands that are imbedded within ToM tasks (Carlson, Claxton, & Moses, 2013). Support for the expression account comes from studies demonstrating that 3-year olds' performance increases when the EF components (e.g. IN) of the task are lessened (Carlson, Moses, & Hix, 1998; Leslie & Polizzi, 1998). On the other hand, an emergence account suggests that EF is essential in order for children to develop ToM (e.g. recognizing different people's perspectives; Carlson et al., 2013). For example, if children have difficulty inhibiting their own wants and needs in a situation, they will not be able to appreciate others' perspectives (Carlson et al., 2013). The emergence explanation has been supported by multiple longitudinal studies, which have reliably demonstrated that individual differences in EF predict later ToM abilities (rather than the reverse; e.g. Hughes & Ensor, 2007; Müller, Liebermann-Finestone, Carpendale, Hammond, & Bibok, 2012; Pellicano, 2010b; Razza & Blair, 2009). Overall, individuals with ASD have difficulties with both EF and ToM, and EF is believed to play a key role in the emergence of ToM. As such, interventions that target EF abilities among children with ASD may subsequently facilitate the development of ToM.

To summarize, some evidence exists for the importance of spatial WM to social communication abilities in ASD; however, other direct results of specific EF abilities are mixed. The strongest link found thus far includes characteristic deficits in ToM that appear to be heavily reliant on the development of EF, specifically IN and WM.

Imaging/Brain Studies

Another viewpoint suggests that there is a direct link between frontal lobe abnormality and executive dysfunction in children with ASD (Hill, 2004b). It is suspected that autistic symptomatology could be associated with dysfunctional integration of the frontal lobe with the remainder of the brain, abnormal myelination, and/or abnormal development in neuronal maturation (Chugani, 1998; Hill, 2004b; Luna et al., 2002).

Other findings that support this viewpoint include findings of transient delayed postnatal maturation of the frontal lobes in ASD, and reduced functional connectivity of the frontal cortex with other cortical and subcortical brain regions (Luna et al., 2002; Ohnishi et al., 2000; Zilbovicius et al., 1995). This viewpoint would posit that the failure of the frontal lobe to follow a normal maturation pattern leads to long-term consequences in development, differentially reflected in the abnormal development of other connected systems (Hill, 2004b).

Results from studies of typically developing (TD) individuals indicate that many brain regions are required for the coordination of EF such as the orbitofrontal cortex and its connection to the amygdala, hypothalamus, subgenual cingulate gyrus, and others (Alvarez & Emory, 2006; Takeuchi et al., 2013). In general however, continued evidence supports the importance of the frontal lobes as the primary location for EF-related activity and coordination in the brain with connections projecting to many other areas (Olsen & Luciana, 2008; Roca et al., 2010; Stuss, 2011). Brain imaging has found general structural and functional deficits in frontal lobe performance in those with ASD (Girgis et al., 2007; Schmitz et al., 2006). A recent review of neuroimaging in ASD by Philip and colleagues (2012) concluded that during the majority of EF tasks used, different brain functioning is observed when individuals with ASD are compared to a TD comparison group.

In regard to IN, Schmitz and colleagues (2006) observed no performance differences between adults with ASD and a TD comparison group using go/no-go and Stroop-based tasks. However, the ASD participants showed more prefrontal cortex activity, potentially indicating greater effort required, or inefficient brain function when inhibiting prepotent responses. Kana, Keller, Minshew, and Just (2007) observed similar results in their sample of ASD participants. Despite similar performance to TD controls on a go/no-go task, the ASD group had poor functional connectivity in fronto-striatal brain regions. Using an antisaccade task to assess IN, O'Hearn and others (2008) did see performance differences with the ASD group making more errors of IN. Moreover, the ASD group demonstrated decreased activity in fronto-parietal regions. The inconsistency of specific brain areas, and increased versus decreased activation, may be the result of study composition (e.g., age, diagnoses, tasks used, sample size). Nevertheless, studies support altered brain function during IN tasks and the likelihood of increased effort required for typical cognitive and behavioural IN for individuals with ASD.

As WM is postulated to be important for social processing such as facial and emotional expressions (LoPresti et al., 2008; Phillips, Channon, Tunstall, Hedenstrom, & Lyons, 2008), there has been some attention given to brain functioning during WM tasks among individuals with ASD. In general, neuroimaging has revealed that a fronto-parietal network is the primary location for WM function in TD individuals (Barendse et al., 2013). During a visual-spatial WM task, no difference in task performance or brain function in the associated posterior parietal cortex was noted between ASD and TD controls (Palmer, 2002). However, less brain activity was noted for those with ASD in areas important to general WM in TD adolescents and adults, including the anterior cingulate, dorsolateral prefrontal cortex, and the caudate nucleus. The authors posit that a disruption in WM networks may be involved in WM performance for those with ASD (Silk et al., 2006). Other studies have produced similar results, showing that despite apparently similar WM task performance, underlying brain function is different than in TD samples, including reduced frontal-parietal functional connectivity and reduced activity in the superior and middle gyri and right posterior temporal lobes, areas particularly important in WM processing of social information (Koshino et al., 2008).

Few studies have focused on isolating CF in relation to brain function. Using a novel CF task in which participants had to switch between classifying letters based on their shape depending on the colour they were presented in, ASD participants showed similar behavioural performance to TD controls. However, similar to other neuroimaging research during EF tasks, under-

lying brain function was different. Individuals with ASD showed increased medial prefrontal cortex, parietal, temporal, and cerebellar region activation (Gilbert, Bird, Brindley, Frith, & Burgess, 2008). With a modified and simplified version of the WCST (measuring CF), Shafritz, Dichter, Baranek, and Belger (2008) found that ASD participants performed worse than TD controls. Moreover, brain regions observed in Gilbert and colleagues' (2008) study were also atypically engaged. The authors suggest that reduced activation in areas underlying CF ability may reflect a global neural processing deficit that is unique to ASD, involving ineffective strategies for switching ongoing behavioural responses. As the majority of research on EF and brain correlates focuses on adolescents and adults with ASD, Yerys and colleagues (2015) targeted their study of CF towards a sample of 7–14 year-olds. Using a novel task designed to tap CF while minimizing other EF requirements (e.g. attention, WM, IN), they found comparable results to older sample sizes. Specifically, behavioural performance was minimal between groups; however, the ASD children recruited more activation in frontal brain regions.

Studies using diffusion tensor imaging suggest that in addition to localized differences, more globalized deficits are present in ASD, such as inadequate connectivity within the frontal lobe and between the frontal cortex and other brain regions important to EF (Cheng et al., 2010; Groen, Buitelaar, van der Gaag, & Zwiers, 2011; Shukla, Keehn, & Muller, 2011; Shukla, Keehn, Smylie, & Muller, 2011). The corpus callosum, responsible for interhemispheric communication and higher cognitive functions such as EF, has received increasing attention in ASD. Studies have found reduced size of the corpus callosum as well as low white matter density required for normal connectivity (Chung, Dalton, Alexander, & Davidson, 2004; Harden, Minshew, & Keshavan, 2000; Vidal et al., 2003). Using the Tower of London task to assess planning, IN, WM, and CF simultaneously, Just and colleagues (2007) indeed found reduced connectivity between frontal and parietal regions, as well as between associated areas, in opposing hemispheres mediated by the corpus callosum.

In summary, research findings support both structural and functional differences in how individuals with ASD employ EF during traditional tasks. Primary activity differences are observed in the prefrontal cortex, sections of the corpus callosum, fronto-striatal, and fronto-parietal regions. Though more research is needed to understand the significance of these findings, most researchers believe that the observed differences reflect inefficient brain function and increased effort required for ASD individuals to carry out typical EF reliant tasks and behaviours.

Intervention for EF in ASD

To date, there are limited EF interventions specifically designed for individuals with ASD. However, there are a number of interventions that target anxiety and social skills within this population using a cognitive behavioural therapy (CBT) approach (Dawson & Burner, 2011), which also appear to target EF skills (e.g. problem solving; Bauminger, 2002; Stichter, O'Connor, Herzog, Lierheimer, & McGhee, 2012). However, these are not considered EF interventions per se. Promisingly, a recently developed EF intervention designed for children with ASD, *Unstuck and On Target* (UOT), has shown positive results (Kenworthy et al., 2014). UOT is an intervention that can be implemented in both school and home environments, and it targets EF skills such as flexibility, goal setting, and planning. UOT is a cognitive-behavioural program consisting of self-regulation scripts, scaffolding, and visual/verbal cueing. Using a randomized controlled effectiveness trial, Kenworthy and colleagues (2014) found support for the effectiveness of the UOT intervention among children with ASD. Specifically, students with ASD showed significantly more improvements in problem solving, flexibility, planning/organization, rule following, and transitions, than a comparison group who received a social skills intervention. Nevertheless, these researchers indicated that more studies are

required to address questions regarding the ability to streamline this lengthy intervention, and to examine other components of the intervention (e.g. features of interventionists that affect outcomes). Overall, there are a variety of books and resources available that target EF development among children and adolescents; however, more research is needed that focuses specifically on EF interventions for individuals with ASD.

The following section describes a variety of strategies that exist to improve EF abilities among children and adolescents in both home and school settings, which are not specific to ASD. Specifically, at home, parenting practices such as scaffolding and structured discipline have been found to support EF development. Scaffolding consists of parents providing support, while also instilling independence in their children to help them reach their goals. Structured discipline, on the other hand, refers to the practice of maintaining consistency with respect to reward and punishment, in order to ensure that children are reinforced for good behaviour and receive consequences for negative behaviour (Hughes & Ensor, 2009; Rhoades, Greenberg, Lanza, & Blair, 2011). Although no known formal interventions have been developed, early EF difficulties among preschoolers may be improved by identifying maladaptive parenting practices, and by implementing consistent discipline, scaffolding, and modelling to support the development of EF abilities (Anderson & Reidy, 2012).

Moreover, regular aerobic activity has been found to improve EF and prefrontal cortex activity among children and adults (Chaddock, Pontifex, Hillman, & Kramer, 2011; Hillman, Erickson, & Kramer, 2008). Among children in particular, intervention outcomes have been small but significant, suggesting that children between the ages of 7 and 12 years may show improvements in WM and CF after taking part in fitness training for a few days per week for 60–120 min per day (Davis et al., 2011; Kamijo et al., 2011; Tuckman & Hinkle, 1986). Furthermore, studies have found that martial arts training improves WM capacities and CF, likely because of the behavioural monitoring components of this sport. Importantly, these improvements have been shown to transfer to classroom conduct, and remain significant even when controlling for the aerobic aspects of martial arts (Lakes & Hoyt, 2004; Trulson, 1986). Also, the effects of mindfulness training have shown promise with respect to improving EF abilities. In a study of 7–9 year-olds practicing mindfulness techniques (e.g., meditation, body awareness, attention regulation), parents and teachers rated significant improvements among child participants' EF as a result of the mindfulness practices (Flook et al., 2010).

Within the classroom setting, teachers may target EF development via specific curriculum add-ons, or the use of individualized strategies. Three examples of curricula shown to improve EF include *Tools of the Mind* (TOOLS; Bodrova & Leong, 2007), *Promoting Alternative Thinking Strategies* (PATHS; Kusche & Greenberg, 1994), and the *EF Curriculum Series* (Boseday, Gidaspow, Minton, & Smith, 2010). Moreover, there are a vast number of individual strategies that can be used in the classroom in order to accommodate student differences in EF abilities (Winters, Altomare, Colp, & Matchullis, 2015). For example, to target IN, teachers can place visual cues on desks (e.g., 'stop and think!'), use nonverbal cues (e.g., raised hand; finger to nose), or establish sounds with individual students that serve as a cue. Additionally, students who struggle with IN (e.g., blurting out answers) may benefit from universal classroom strategies, such as having all students use small white boards to write down their answers to show the teacher. Moreover, students who struggle with CF may have trouble transitioning to different activities (e.g., from gym to math). Teachers can assist these students by making classroom routines and activities clear and accessible in advance (e.g., visual schedules), with reminders or warnings throughout the day (e.g., 'In 10 minutes, when this timer goes off, it is time to put our books away'). If students struggle to switch between rule sets (e.g., in math), the use of visual reminders and charts can be useful to accommodate such challenges. Additionally, teachers can help students with WM deficits by breaking down complex tasks into smaller steps, and reminding

students to write down steps (e.g., display math work, plan out writing in advance using graphic organizers, take notes while reading to ensure comprehension). The general strategy for WM is to have teachers reduce the amount of information that a student must hold in their mind, which can be done without reducing the overall complexity of the task (Winters et al., 2015).

Finally, computerized training has been explored in both school and home settings as a possible method for improving a variety of EF abilities. The appeal of computerized training is not surprising given the increasing role of technology in today's society (Otero, Barker, & Naglieri, 2014). The primary focus of computerized training programs, such as *CogMed*, has been to improve working memory and general attention. Using repeated practice and reinforcement, these programs aim to produce structural brain changes to improve WM capacity (Klingberg et al., 2005). This modality is an attractive approach to improve EF, especially due to the possibility of delivering interventions in a group setting, as well as the reduction of human error in implementation (Otero et al., 2014). Despite the fact that WM has been shown to improve as a result of computerized training (Bergman-Nutley et al., 2011; Wong, He, & Chan, 2014), a relatively recent meta-analysis by Melby-Lervag and Hulme (2013) indicated that there appears to be little generalization to other areas of cognitive or academic performance using computerized training (despite improving IN and WM on the tasks used to teach the skills). Nevertheless, due to the appeal of computerized training and its ease of use and availability (e.g., tablets, phones, computers), research in this area continues to develop.

Implications of Research Findings and Future Directions

In summary, research has demonstrated that there are both structural and functional differences in how individuals with ASD employ EF during traditional tasks, with primary activity differences observed in the prefrontal cortex, corpus callosum, fronto-striatal, and fronto-parietal brain regions. Although more research is necessary to better understand the importance of current imaging and brain research in this area, researchers currently believe that the observed EF differences among individuals with ASD reflect inefficient brain function and increased effort required for typical EF reliant tasks. However, it is important to highlight that ASD cannot be described as a primary disorder of EF (Geurts et al., 2014), as: (1) not all individuals with ASD display EF deficits, or the same deficits, and (2) executive dysfunction can also occur in individuals without ASD. Regardless, EF has been shown to play a significant role in social communication abilities, ToM, and the behavioural deficits encapsulated by RRBIs in ASD, and thus should not be ignored.

Moving forward, it will be essential for researchers to continue to identify individuals with ASD who struggle with EF, as well as those individuals who show strengths in EF. This distinction will be essential in determining the best ways to intervene, and which interventions are most suitable for each specific individual (Geurts et al., 2014). While there are limited EF interventions specifically designed for individuals with ASD, there are a number of interventions that indirectly target EF development. There are also a variety of books, resources, and strategies available that address EF development among children; however, more research is needed that focuses specifically on EF interventions for individuals with ASD. It will be important that intervention tools such as *Unstuck and On Target* (UOT) continue in their development to better and more effectively intervene with these individuals and determine any other components of the intervention that may affect positive outcomes.

Overall, our understanding of EF in ASD has evolved over the past 15 years, but more research is needed to better understand EF in ASD across the lifespan. It has been shown that there is significant variability in the developmental outcomes of individuals with ASD, yet empirical knowledge on the underlying causes of this disorder and its variability is beginning to emerge

(Pellicano, 2012). Although the executive dysfunction hypothesis has been initially presented as a primary deficit in ASD, it cannot explain the heterogeneity of ASD symptomatology (Yerys et al., 2007). Thus, researchers have moved away from a framework that suggests EF as the sole underlying cause, and instead strive to develop a richer understanding of the development and growth of EF in ASD. Tackling this challenge will not be easy and will require careful study to determine effects on functional outcomes for children with ASD, which may have importance for children with other developmental disabilities and typically developing children.

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Neuropsychology

22

Rupa Gupta Gordon and Matthew Calamia

Introduction

Neuropsychological assessment and neuroimaging are two methods of understanding brain–behavior relationships in ASD. Although these methods are not used frequently in individual assessment, the results of studies using these techniques have yielded numerous insights into ASD. By identifying a large number of neuropsychological functions impaired in ASD, as well as a large number of brain regions associated with ASD, both techniques have highlighted the complexity of ASD in its relationship to many different neural systems (Dawson, 1996; Via, Radua, Cardoner, Happé, & Mataix-Cols, 2011). It is hoped that a better understanding of neural functioning in autism and the ability to measure neural functioning on an individual basis will lead to future improvements in diagnosis and treatment (Ecker, Bookheimer, & Murphy, 2015).

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Neuropsychological Assessment

Neuropsychological assessment includes the assessment of a number of different cognitive functions including verbal and visuospatial reasoning, attention, memory, processing speed, learning, memory, and motor functioning (Larrabee, 2014). In assessing ASD, intellectual and language functioning are often assessed as these impairments are listed as two specifiers of ASD in the DSM-5 (American Psychiatric Association, 2013). The assessment of these domains is important as they commonly occur in ASD and are associated with functional outcomes (e.g., Ozonoff, Goodlin-Jones, & Solomon, 2005). In addition, many other neuropsychological functions have been studied in ASD and results have shown that pattern of neuropsychological impairment can vary significant across individuals (Tonn & Obrzut, 2005). At the group level, performance of individuals with ASD is clearly distinguishable from other developmental conditions (Minshew, Muenz, Goldstein, & Payton, 1992).

Given the time and cost of neuropsychological assessment, it is often recommended only when understanding an individual's cognitive strengths and weaknesses would be useful to answer a specific referral question and guide treatment or educational planning (Klin, Saulnier, Tsatsanis, & Volkmar, 2005). Ozonoff et al. (2005) give the

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example of problems with executive functioning leading to behavioral problems that affect school performance. Neuropsychological functioning is also related to symptoms of ASD and may suggest underlying neuropsychological impairments related to symptom expression. For example, performance on neuropsychological tasks of reward learning is associated with joint attention (Dawson et al., 2002).

It is important to note that although neuropsychological deficits in many domains have been linked to ASD, many areas of functioning commonly show little or no deficits when studied at a group level. Within a domain of functioning, certain abilities are often shown to be intact. For example, within the domain of memory functioning, in addition to areas of deficit, normal performance has been found on tasks of recognition memory and memory for frequently repeated information (Bennetto, Pennington, & Rogers, 1996; Sanders, Johnson, Garavan, Gill, & Gallagher, 2008). Within the domain of attention, normal performance has been found on measures of sustained attention despite deficits in the ability to orient attention to new stimuli (Sanders et al., 2008). In individuals with ASD without language impairment, aspects of phonological processing and syntax are found to be intact despite deficits in social communication (Dawson, 1996; Happé & Frith, 1996).

Within the domain of intellectual performance, visuospatial reasoning may be intact with concurrent impairments in verbal ability (e.g., Ozonoff, Pennington, & Rogers, 1991). Given normal performance in ASD on a frequently used nonverbal measure of fluid intelligence, the appropriateness of commonly used measures of intellectual functioning which find impairments in ASD has been questioned (Nader, Courchesne, Dawson, & Soulières, 2014). However, it has been noted that deficits found in more comprehensive measures of intellectual functioning that include verbal abilities are likely capturing actual communication deficits in ASD (Schneider, 2014). Furthermore, the size of the discrepancy between verbal and nonverbal abilities can be clinically useful; for example, it is related to social functioning (Joseph, Tager-Flusberg, & Lord, 2002). Intellectual functioning in ASD is reviewed more comprehensively in Chap. 21 of this volume.

ASD is associated with impairments in different aspects of executive functioning, including set shifting and inhibition (Sanders et al., 2008). These deficits can be found in both children and adults with ASD and are not attributable to low intellectual functioning (e.g., Ozonoff et al., 2004). Clinical assessment of these functions may be useful as they are associated with adaptive functioning (e.g., Ozonoff et al., 2004). Rating scales of real-world executive functioning deficits have some utility in distinguishing between individuals with and without ASD (Leung & Zakzanis, 2014). Executive functioning in ASD is also associated with symptoms of repetitive behavior and restricted interests (Lopez, Lincoln, Ozonoff, & Lai, 2005). Executive functioning is reviewed more comprehensively in Chap. 23 of this volume.

Memory deficits in ASD have been found on tasks of working memory, short term memory, and long term memory (Bennetto et al., 1996; Dawson, 1996) although not all studies consistently find impairments in all of these domains (Tonn & Obrzut, 2005). Memory for social information, such as faces, is associated with ASD (Barron-Linnankoski et al., 2015; Korkman, Kirk, & Kemp, 1998). In one study, poor spatial working memory was found to discriminate between individuals with and without ASD (Williams, Goldstein, & Minshew, 2006).

Among the various theories to describe the neuropsychological deficit in ASD is one that identifies the core neuropsychological deficit in ASD as a generalized deficit in processing and integrating complex information (Minshew & Goldstein, 1998). As evidence for this theory, Minshew, Goldstein, and colleagues have shown in multiple studies that within and across domains of cognitive functioning, individuals with ASD are impaired on complex tasks, but can show intact performance on simple tasks (e.g., Minshew et al., 1992; Minshew & Goldstein, 2001; Williams et al., 2006). This deficit in processing complex information has been hypothesized to contribute to real-world functional impairment (Williams, Goldstein, & Minshew, 2006).

Brain Structure Abnormalities in ASD

Studies of brain structure in ASD have yielded numerous, often conflicting results (Via et al., 2011). In aggregate, the findings seem to highlight a complex and multidimensional set of differences in grey and white matter in a number of different regions throughout the brain (Ecker et al., 2010). Differences across studies in factors such as the ages of participants, gender of participants, level of functioning, and comparison group used (e.g., typically developing or other developmental disorder) may account for some of the heterogeneity found within the literature (Brieber et al., 2007; Freitag et al., 2009; Schumann et al., 2010). Differences may also arise from factors which differ across research sites in scanning technology (e.g., magnetic field strength) and implementation (e.g., length of scan, instructions given to participants) (Nielsen et al., 2013).

Total Brain Volume

One of the most widely replicated neuroimaging findings in ASD is larger brain volumes occur in those with ASD compared to those with typical development. Meta-analyses of these studies show this increase to be widespread, with increased volume found in both cerebral hemispheres, the cerebellum, and the caudate (Redcay & Courchesne, 2005; Stanfield et al., 2008). Not all regions show increased volume; for example, the corpus callosum has been found to be reduced in volume in persons with ASD (Frazier & Hardan, 2009; Stanfield et al., 2008).

Gender differences in volume have been found with females showing greater increases in volume (Schumann et al., 2010; Stanfield et al., 2008). Larger increases are also associated with lower intellectual functioning (Freitag et al., 2009). Age appears to be an especially important factor in understanding brain volume in ASD. Abnormal, accelerated growth appears to peak by age two with continuing growth patterns in childhood matching those of typically developing children (Hazlett et al., 2011; Schumann et al., 2010).

Whole-Brain Voxel-Based Morphometry Studies

In addition to examining whole brain volume or predefined regions of interest, neuroimaging research in ASD has also used voxel-based morphometry (VBM), a technique in which differences in brain volume across the entire brain can be compared between two groups (Mechelli, Price, Friston, & Ashburner, 2005). At least two recent meta-analyses of VBM studies have been conducted which included partially overlapping, but not identical sets of studies (Cauda et al., 2011; Nickl-Jockschat et al., 2012). Both meta-analyses found a number of areas of increased or decreased volume in ASD throughout the brain, highlighting the complexity of the neural correlates of ASD. For example, both found increased volume in voxels within the cerebellum, a region involved in motor functioning, and precuneus, a region involved in visuospatial processing and the default mode network, a network of brain regions that have been shown to be active and functionally coupled at rest in healthy participants,

As with total brain volume, age again appears to be an important factor in understanding differences in volume of specific brain regions and is likely one source of heterogeneity in VBM findings (Nickl-Jockschat et al., 2012). Longitudinal studies of ASD have found evidence for a period of overgrowth prior to age two, accelerated decline in cortical thickness in later childhood, and reduced decline in adulthood (Zielinski et al., 2014). However, this general pattern varies both within and across brain regions. Notably, changes in volume over time are associated with changes in ASD symptoms (Hardan, Libove, Keshavan, Melhem, & Minshew, 2009). Volume differences in specific regions are also associated with specific symptoms; for example, amygdala volume is associated with social and communication symptoms (Schumann, Barnes, Lord, & Courchesne, 2009).

Given the heterogeneity in neuroimaging findings in ASD, some have investigated whether or not these differences may be related to differences in the individuals with ASD included in each study. Results have been mixed, with some finding minimal differences between individuals

with and without a history of delayed language (e.g., Kwon, Ow, Pedatella, Lotspeich, & Reiss, 2004) and others finding a larger pattern of differences (e.g., McAlonan et al., 2008). A meta-analysis of ASD categorizing studies by the proportion of individuals in the study with a history of delay in language acquisition found that fewer differences in volume in the ASD studies with higher proportion of individuals with a normal language history (Yu, Cheung, Chua, & McAlonan, 2011). However, when differences were found, they did not always overlap with regional differences between those with a history of language delay and typically developing children. One study comparing groups with ASD symptoms, but varying in impairment in intellectual functioning and history of language acquisition, found evidence for a continuum of differences in brain volume consistent with including individuals with these different impairments under the umbrella of ASD (Lotspeich et al., 2004).

Classification Studies

Given the findings of differences in brain volume in ASD, several researchers have attempted to use differences in volume and other structure differences as a method of diagnostic classification. These studies most often apply machine learning techniques to a sample of individuals with ASD and without ASD in an effort to see how well the groups can be distinguished based on a generated algorithms specific to the study. Using a support vector machine approach, areas of increased and decreased volume were able to correctly classify 85 % of adults diagnosed with high-functioning ASD or no psychiatric condition. Two out of 20 individuals with ASD were misclassified in the no diagnosis group and 4 out of 20 individuals without ASD were misclassified as having ASD. Applying this same classification algorithm to a comparison of the same ASD sample with a sample of individuals with ADHD, high accuracy was maintained, with 4/19 individuals with ADHD being misclassified as having ASD (Ecker et al., 2010). The same technique was also able to successfully classify individuals with ASD or no psychiatric diagnosis in a sample of female children (Calderoni et al., 2012).

Additional studies using other machine learning techniques have also demonstrated high classification accuracy: 90 % in a sample of children and adolescents with ASD compared to other without a psychiatric diagnosis (Uddin et al., 2011) and 87 % in a sample of children with ASD compared to those without a psychiatric diagnosis (Jiao et al., 2010). In general, these studies find higher sensitivity (i.e., accuracy in classifying those with ASD as having ASD) than specificity (i.e., accuracy in classifying those without ASD as not having ASD). The regions used as part of the classification algorithms have included parts of the frontal, temporal, parietal, and occipital lobes as well as subcortical structures such as the thalamus and cingulate (Calderoni et al., 2012; Ecker et al., 2010; Jiao et al., 2010). Given structural differences found across studies, it is unclear to what extent results from classification studies will replicate in new samples; studies have often developed an algorithm based on the data in their sample rather than testing previously developed algorithms. Most studies have used a comparison group of individuals without any psychiatric diagnosis and at least one study has found lower rates of successful classification of ASD vs. other developmental disorders (Neeley et al., 2007).

Structural and Functional Connectivity

While many functional imaging studies have focused on the disruption of individual brain regions such as the amygdala and prefrontal cortex, a substantial amount of research has supported the notion that large-scale structural and functional connectivity between networks of neural systems is altered in ASD. In fact, some have called ASD a "developmental disconnection disorder" (Geschwind & Levitt, 2007). Here, we review findings related to altered structural and functional connectivity in ASD, and how these disruptions might relate to behavioral outcomes.

Structural Connectivity

Structural connectivity, or the analysis of the anatomical connections between brain regions, is typically measured using diffusion tensor imaging (DTI). DTI measures the diffusion of water within tissues. DTI provides a measurement of the integrity of white matter pathways by measuring the diffusion of water molecules along axons, as axonal tracts restrict the diffusion of water, while diffusion in grey matter is less restricted (Mori & Zhang, 2006). The most commonly used DTI measurement is fractional anisotropy (FA), which measures the directional dependency of water diffusion in the brain, with higher values representing more diffusion directionality. Conversely, lower FA values are believed to reflect decreased organization and integrity of white matter fiber tracts.

Consistently across studies, whole-brain analyses have found lower FA values for adults with ASD (Shukla, Keehn, & Müller, 2011). However, there have also been regional and age dependent differences reported. In adults, the most consistent reports of under-connectivity have been in the corpus callosum and frontal and temporal regions; both believed to contribute to social processing deficits (Alexander et al., 2007; Jou et al., 2011). Disruptions in the corpus callosum may impact overall processing and connectivity between the hemispheres, but may also play a role in social skills. Individuals born with agenesis of the corpus callosum, where the corpus callosum does not develop properly, often have similar impairments in social skills as individuals with ASD (Paul et al., 2007). Furthermore, lower FA values in frontal and temporal regions have been reported in multiple studies (Barnea-Goraly et al., 2004; Cheung et al., 2009). Overall, lower FA in these regions correlated with more severe diagnostic symptoms on the Autism Diagnostic Interview—Revised (ADI-R) (Cheung et al., 2009). There is also evidence for disruptions in white matter tracts related to language processing, including the arcuate fasciculus (Fletcher et al., 2010; Knaus et al., 2010).

DTI based structural differences in temporal regions, including superior temporal gyrus and temporal stem, have been successfully used to classify individuals with ASD with 92 % accuracy, and are strongly correlated with measures of language and IQ (Lange et al., 2010). Another study found that DTI data, specifically connectivity pathways from fusiform face area, middle temporal gyrus, and other regions of the social brain were also able to classify participants with 95.9 % accuracy (Deshpande, Libero, Sreenivasan, Deshpande, & Kana, 2013).

Developmental Considerations

Researchers suggests that structural connectivity in ASD changes across development. In fact, unlike adults who have reduced FA values globally, very young children with ASD (under 4 years of age) are reported to have higher FA values compared to healthy comparison groups (Ben Bashat et al., 2007; Weinstein et al., 2011). Further evidence for developmental changes in white matter comes from a longitudinal study with high-risk infants who have siblings diagnosed with ASD (Wolff et al., 2012). DTI data were assessed at 6 months and again at 24 months. Children who met diagnostic criteria for ASD at 24 months displayed higher FA values across multiple fiber tracts at 6 months relative to those who did not meet criteria. Furthermore, the children who met criteria for ASD had blunted developmental trajectories in white matter development, resulting in lower FA values at 24 months compared to those who did not meet criteria. Researchers have speculated that increased FA early in life may reflect an excess of axonal fibers and lack of pruning of neuronal connections (Wolff & Piven, 2013).

Functional Connectivity

Functional MRI (fMRI) can be used to measure brain activation in different areas of the brain either during a task (task-related) or while at rest (resting state). Functional connectivity represents the synchronization, or temporal correlation, of fMRI activity in different regions in the brain. Overall, studies seem to support the idea that ASD is characterized by long-range functional

under-connectivity of different brain regions while local over-connectivity is reported within certain brain regions, especially the frontal lobe (Courchesne & Pierce, 2005; Vissers, Cohen, & Geurts, 2012). Functional connectivity, similar to structural connectivity, also seems to interact with development, such that young children with ASD exhibit functional over-connectivity, while adolescents and adults exhibit under-connectivity (Uddin, Supekar, & Menon, 2013).

Task Related Functional Connectivity

Across tasks, including language, theory of mind, executive function, and memory tasks, one of the most consistent findings in ASD is reduced frontal-posterior large-scale connectivity (Schipul, Keller, & Just, 2011). Most commonly reported are decreases in functional connectivity between frontal and parietal regions (Just, Cherkassky, Keller, Kana, & Minshew, 2007; Kana, Keller, Minshew, & Just, 2007). Many of these findings are reviewed in the language and social communication sections later in this chapter. In general, these results suggest that large-scale coordination of multiple brain regions that subserve complex behaviors does not occur at the same level of temporal coordination as in healthy individuals.

Resting State Functional Connectivity

Many studies of resting state functional connectivity have focused on the default mode network (DMN), a network which includes the medial prefrontal cortex, parietal cortex, posterior cingulate cortex, and the precuneus (Buckner, Andrews-Hanna, & Schacter, 2008). Decreased functional connectivity of the DMN in ASD has been reported in multiple studies (Anderson et al., 2011; Assaf et al., 2010; Cherkassky, Kana, Keller, & Just, 2006; Weng et al., 2010). Moreover, reductions in functional connectivity of the DMN correlated with impaired social communication abilities (Assaf et al., 2010; Weng et al., 2010).

Whole-brain resting state functional connectivity has been used to attempt to classify participants, in order to assess the utility of this measure as a diagnostic or predictive tool (Anderson et al., 2011; Plitt, Barnes, & Martin, 2015). Anderson et al. (2011) report that resting state functional connectivity was able to successfully classify individuals with ASD with 79 % accuracy, and was able to do so even more accurately (89 %) for individuals under the age of 20. Furthermore, classifier scores significantly correlated with social and communication symptoms on the Autism Diagnostic Observation Schedule (ADOS) (Anderson et al., 2011). Another study found that overall connectivity was able to classify participants with 78 % accuracy, with the highest classification accuracy (83 % accuracy) being in the connectivity of salience network (anterior cingulate cortex and anterior insula) (Uddin et al., 2013). Similarly, Plitt et al. (2015) report that resting state functional connectivity was able to classify individuals evincing ASD with significant accuracy (peak = 76.67 %). However, they argue that it does not yet have the specificity or sensitivity to be used as a biomarker, as behavioral measures of social impairments were more specific and sensitive to diagnosis, and outperformed the connectivity measures (95 % accuracy). Whole-brain analyses have also suggested that the most pronounced areas of reduced functional connectivity are in social brain regions, including limbic areas like the ventromedial prefrontal cortex, amygdala, hippocampus and middle temporal gyrus (Gotts et al., 2012). Reduced connectivity in these regions significantly predicted the severity of social skills symptoms on the Social Responsiveness Scale.

Developmental Considerations

Similar to the developmental changes in structural connectivity that have been described in ASD, developmental changes in functional connectivity have also been reported. The majority of studies utilizing any form of neuroimaging with individuals with ASD typically use older individuals due to the limited success rate of scanning children due to practical limitations (Yerys et al., 2009). Research suggests that functionally, compared to adolescents and adults, young children with ASD may have increased connectivity across multiple brain regions. For

example, Di Martino et al. (2011) found increased connectivity between the striatal networks and limbic regions in 7–14 year old children. Furthermore, large-scale brain connectivity was increased across multiple networks, including the default mode network, salience network (anterior cingulate and anterior insula), frontotemporal, motor and visual regions in children (Uddin, Supekar, Lynch et al., 2013). In particular, the hyper-connectivity in the salience network could discriminate between ASD and typically developing children with 78 % accuracy, 75 % sensitivity and 80 % specificity and could significantly predict severity scores on measures of repetitive and restrictive behaviors (Uddin, Supekar, & Menon, 2013). However, there are also reports of weaker functional connectivity between areas such as inferior frontal gyrus and superior temporal gyrus, and the strength of the synchronization between these areas was significantly correlated with language abilities in toddlers with ASD (Dinstein et al., 2011).

Language and Communication

Language deficits in ASD vary greatly in severity; ranging from individuals with ASD who never develop language, to those who only have difficulties with higher order aspects of pragmatics. The variability of language deficits combined with the challenges of the imaging environment, have resulted in the majority of functional imaging studies involving higher functioning adults with ASD.

Attention to Speech

Overall, individuals with ASD are less attentive to human voices and speech in general (Kuhl, Coffey-Corina, Padden, & Dawson, 2005). Relatedly, individuals with ASD do not show enhanced activation of the superior temporal sulcus in response to voice-related sounds (both speech and non-speech sounds), but show normal processing of nonvocal sounds (Gervais et al., 2004). This abnormal pattern of neural activity was also associated with impaired ability to recall the voice sounds. Resting state functional connectivity suggests that this may be related to under-connectivity between voice selective areas of the right superior temporal sulcus and emotion and reward related regions, including the nucleus accumbens, orbitofrontal cortex, and amygdala (Abrams et al., 2013). This suggests that individuals with ASD might not find human voices inherently rewarding, and therefore individuals with ASD may pay less attention to them. Furthermore, this reduced connectivity significantly predicted the severity of communication impairments on the ADI-R and ADOS (Abrams et al., 2013).

Semantic Processing

Basic semantic processing, or the ability to understand the content of a sentence based on the meaning of words, is spared in many high functioning adults with ASD (Noens & Berckelaer-Onnes, 2005). However, certain deficits in semantic processing related to memory have been shown to occur in both behavioral and functional imaging studies of ASD. For example, individuals with ASD do not display a memory benefit when learning semantically related words (Tager-Flusberg, 1991) or using semantic knowledge (Toichi & Kamio, 2002). In a simple semantic processing task, where participants had to rate words as positive or negative, participants with ASD displayed reduced activation in Broca's area, but increased activation in Wernicke's area (Harris et al., 2006). A similar finding of reduced activation of Broca's area was found when categorizing words based on their semantic characteristics (Gaffrey et al., 2007). However, some have argued that modulation of Broca's area activity may depend on task performance, as increased activation of Broca's area which was less lateralized to the left hemisphere was found in a semantic response-naming task where participants with ASD performed with high task accuracy (Knaus, Silver, Lindgren, Hadjikhani, & Tager-Flusberg, 2008).

Comprehension

During sentence comprehension, individuals with ASD show reliably less activation in left inferior frontal gyrus (Broca's area), and decreased connectivity between language related areas (Just, Cherkassky, Keller, & Minshew, 2004). The reduction in Broca's area activity has been interpreted as a deficit in the ability to integrate and interpret individual words into the context of the entire sentence. In line with this interpretation, similar reduced activations in left inferior frontal gyrus were also found in a task where contextual information was required to properly comprehend a sentence (Tesink et al., 2011). Other research has suggested that individuals with ASD use mental imagery more, as reflected by increased activation in occipital regions, when attempting to comprehend sentences that do not typically require mental imagery (Kana, Keller, Cherkassky, Minshew, & Just, 2006). Despite this, the comprehension of sentences that are high in mental imagery was associated with reduced functional connectivity of frontal and parietal regions involved in language and spatial processing (Kana et al., 2006). In sum, the results across both semantic processing and comprehension studies suggest that typical language related regions (e.g., Broca's area) might not be as specialized for language processing in ASD as they are in healthy individuals.

Pragmatics

Pragmatic language is the ability to use extralingual cues (e.g., tone of voice) to understand and use language in context, beyond simply understanding the literal meaning of words. Listeners often have to understand the underlying meaning of language using context cues, knowledge of the environment, and past experiences with the speaker. Pragmatic language includes the use of irony, sarcasm, metaphor, and puns. Increased activation in right inferior frontal gyrus in participants with ASD relative to healthy participants has been found both when making inferences about a speaker based on context (Tesink et al., 2009) and when interpreting ironic statements (Wang, Lee, Sigman, & Dapretto, 2006). Similarly, researchers have found increased distributed right hemisphere activity when trying to understand puns (Kana & Wadsworth, 2012) and making inferences about emotional states and intentions (Mason, Williams, Kana, Minshew, & Just, 2008). The increase in right hemisphere processing in ASD has been hypothesized to reflect more effortful processing of pragmatic language (Mason et al., 2008; Tesink et al., 2009).

One specific aspect of pragmatic language is prosody, or the rhythm and intonation of language. Prosody can carry meaning above and beyond the content of speech, allowing the listener to derive meaning about the emotional state of the speaker, the grammatical nature of the utterance (i.e., a question), and the intentions and underlying meaning of the speaker, including irony and sarcasm. Research has supported the idea that understanding prosodic cues is impaired in ASD, and this is associated with more nonspecific activation in ASD to both grammatical and emotional forms prosody (Eigsti, Schuh, Mencl, Schultz, & Paul, 2012). Others have suggested that reduced inhibition of the default mode network may contribute to disruptions in prosody tasks (Hesling et al., 2010).

Laterality

Consistent with the literature already reviewed, perhaps the most notable and replicated neuroimaging finding in ASD related to language processing is reduced laterality of neural processing in ASD relative to healthy participants. For example, Kleinhans et al. (2008) found reduced left laterality in a verbal fluency task, and increased right hemisphere activation in participants with ASD. A combined fMRI and DTI study also reported reduced left hemisphere laterality for individuals with ASD, and those with atypical language laterality also had reduced FA values in the arcuate fasciculus, the white matter tract connecting Broca's and Wernicke's areas (Knaus et al., 2010). Another combined functional and structural connectivity study found

reduced activation of frontal regions in a language task, and reduced structural connectivity between inferior frontal regions and temporal regions (Sahyoun, Belliveau, Soulières, Schwartz, & Mody, 2010).

Furthermore, there is evidence that this alteration in language laterality occurs early in development. Children between the ages of 12–48 months who were either at-risk or diagnosed with ASD participated in an fMRI study while asleep with a simple story spoken (Eyler, Pierce, & Courchesne, 2012). Those children with ASD had reduced left temporal laterality and increased right hemisphere activity to speech and these disruptions were more pronounced in older children. Moreover, toddlers with ASD also show reduced functional connectivity between language related areas such as inferior frontal gyrus and superior temporal gyrus, and the strength of the synchronization significantly correlated with language abilities (Dinstein et al., 2011). These results suggest that early connectivity disruptions may lead to reduced functional specialization of language related brain regions, including those results seen earlier related to comprehension and semantic processing.

Nonverbal Communication

Behavioral research has shown a strong relationship between early nonverbal communication, specifically gestures, and verbal expressive and receptive language in typically developing children (Iverson & Goldin-Meadow, 2005; Rowe & Goldin-Meadow, 2009). Likewise, gestures are also predictive of later language outcomes in young children at-risk for ASD (e.g., Gordon & Watson, 2015; Watson, Crais, Baranek, Dykstra, & Wilson, 2013). While it is known that the production of gestures in ASD is disrupted (e.g., Carpenter, Pennington, & Rogers, 2002; Loveland, Landry, Hughes, Hall, & McEvoy, 1988), there is recent neuroimaging evidence that the recognition and understanding of gestures may also be disrupted because of altered neural processing. Hubbard et al. (2012) found that when viewing a person speaking while using beat gestures (rhythmic co-speech gestures), typically developing children display increased activity in secondary auditory regions, including right superior temporal regions. Participant with ASD did not display activity in superior temporal regions, but rather had increased activity in visual cortex, and this activity positively correlated with social communication symptom severity on the ADOS and Social Responsiveness Scale. This suggests that individuals with ASD may not be effectively integrating multimodal communicative information in complex social situations.

Social Cognition and Emotion

Disruptions in social and emotional processing are hallmark characteristics of ASD. It is clear that specific regions of the human brain are finely tuned towards recognizing and processing social stimuli. The term "social brain" has been used to refer to this set of structures, including the superior temporal sulcus, amygdala, orbitofrontal cortex and fusiform gyrus (Brothers, 1990). Evidence suggests that a combination of disrupted developmental of neural structures involved in social processing may impair behavior, and likewise, lack of early experience with social interactions may impair proper functional specialization and development of neural structures (Harms, Martin, & Wallace, 2010; Pelphrey, Shultz, Hudac, & Vander Wyk, 2011). Here, we review the evidence for disruptions in neural structures involved in social cognition and emotion processing in ASD.

Face Processing

Similar to voice processing, individuals with ASD show reduced attention to human faces, and this disruption occurs early in life and is a strong predictor of later diagnosis (Osterling & Dawson, 1994). In healthy participants, face processing involves activity of the fusiform face area (FFA) (Kanwisher, McDermott, & Chun, 1997). In contrast, one of the most consistent fMRI findings has been that participants with ASD display

reduced or lack of activation of the FFA when viewing faces (Corbett et al., 2009; Kleinhans et al., 2008; Pierce, Müller, Ambrose, Allen, & Courchesne, 2001). Rather, activation is found in distributed neural regions (e.g., frontal cortex, cerebellum) and may be different in different individuals (Pierce et al., 2001). Kleinhans et al. (2008) found reduced functional connectivity between FFA and other regions involved in social processing, including the amygdala, superior temporal sulcus, and posterior cingulate in ASD. Furthermore, greater social impairment on the ADI-R was associated with reduced FFA and amygdala connectivity and increased connectivity between FFA and inferior frontal gyrus (Kleinhans et al., 2008). In fact, multi-voxel pattern analysis associated with hypoactivation of the FFA has been used to predict clinical symptom severity on the ADOS and ADI (Coutanche, Thompson-Schill, & Schultz, 2011).

There is evidence, however, that the reduction in FFA activity may be dependent on familiarity, such that participants with ASD have been reported to have normal levels of FFA activity when viewing familiar faces (e.g., their mother) (Pierce & Redcay, 2008). In fact, familiar faces also elicit typical activation of other brain regions involved in face processing, including the amygdala, but did not elicit activity in the medial frontal cortex as seen in healthy participants (Pierce, Haist, Sedaghat, & Courchesne, 2004). This suggests that in individuals with ASD, the FFA has the capability to respond to faces, but this activation does not occur unless the person is familiar, suggesting that social drive and motivation factors may be modulating the activity of the FFA.

Emotion Processing

The ability of individuals with ASD to recognize and understand emotions has been most often studied using facial expressions of emotions or emotional body positions. Neuroimaging findings related to emotional prosody and tone of voice were reviewed earlier in the pragmatic language section of this chapter.

The ability to recognize emotions from facial expressions is critical for successful social interactions. The majority of reports suggest that facial emotion recognition is impaired in ASD; however, there is evidence that this ability may be dependent on intellectual ability (Harms et al., 2010). While some studies have found intact basic emotion recognition in high functioning individuals with ASD, there is also a possibility that compensatory mechanisms and task cues may benefit these individuals that are not found in real world social situations (e.g., matching tasks where emotional labels are provided) (Harms et al., 2010). Similar to studies of basic face processing, neuroimaging evidence suggests that individuals with ASD use compensatory or alternative mechanisms for facial emotion recognition, as seen by reduced activation in the FFA and amygdala (Ashwin, Baron-Cohen, Wheelwright, O'Riordan, & Bullmore, 2007; Wang, Dapretto, Hariri, Sigman, & Bookheimer, 2004), but increased activation in the anterior cingulate cortex (Ashwin et al., 2007) and precuneus (Wang et al., 2004) relative to healthy individuals. The anterior cingulate and precuneus are involved in cognitive processing such as monitoring performance and attention, supporting the idea that emotion recognition is a more effortful and cognitively based process for individuals with ASD (Ashwin et al., 2007; Wang et al., 2004). Reduced functional connectivity between the amygdala and visual cortex areas was also found during facial emotion recognition in ASD (Rudie et al., 2011). Furthermore, reduced FFA and amygdala activity when viewing faces, including emotional expressions, may be related to gaze fixation on faces, such that time spent fixating positively correlated with amygdala and FFA activity in individuals with ASD (Dalton et al., 2005) As participants with ASD tend to spend less time looking at faces, this may negatively impact the ability of these neural systems involved in face recognition to properly develop and process faces. Moreover, recognition of facial expressions depicting complex social emotions (e.g., guilt, envy) pose a greater difficulty to individuals with ASD, including high functioning individuals, and this is associated with

reduced activity in the amygdala (Baron-Cohen et al., 1999; Baron-Cohen, Jolliffe, Mortimore, & Robertson, 1997).

Other forms of nonverbal behavior including body posture and eye gaze can also convey important communicative and emotional information. Researchers suggest that participants with ASD have difficulty recognizing emotional body postures, and this is associated with reduced activity in the amygdala and inferior frontal gyrus (Grèzes, Wicker, Berthoz, & de Gelder, 2009). Other studies of emotional body position have supported the finding of reduced activity in the inferior frontal gyrus, but have also found reduced activity of the insula (Hadjikhani et al., 2009). Individuals with ASD have difficulty understanding intention conveyed by eye gaze, and this is associated with reduced modulation of activity in the superior temporal sulcus (Pelphrey, Morris, & McCarthy, 2005).

Biological Motion

The ability to understand and interpret the actions of others is critical for normal social processing. In fact, humans can very easily understand the actions of others simply through kinematic patterns from lights attached to the major joints of the body, termed point-light walkers (Johansson, 1973). Based off of very little perceptual information, we can attribute intention, emotion, personality and gender to point-light walkers (Allison, Puce, & McCarthy, 2000). In healthy participants, perception of biological motion cues involves greater activation of superior temporal sulcus relative to nonbiological motion (Grossman & Blake, 2002). Individuals with ASD have difficulty automatically recognizing biological motion (Blake, Turner, Smoski, Pozdol, & Stone, 2003), and this is associated with a lack of enhanced activity in superior temporal sulcus for biological motion relative to nonbiological motion (Carter & Pelphrey, 2006). Furthermore, functional under-connectivity of the superior temporal sulcus with fronto-parietal regions can successfully predict the ability to recognize emotion from point-light walkers (Alaerts et al., 2013).

Theory of Mind

Researchers have long theorized that a core deficit in ASD is an impairment in theory of mind, or the ability to understand the thoughts and beliefs of others and to attribute mental states to others (e.g., Baron-Cohen, Leslie, & Frith, 1985). Multiple tasks have been used to study the neural processes involved in theory of mind in ASD. Some have argued that many of these tasks rely too heavily on language; therefore other nonverbal tasks have been developed (e.g., Castelli, Frith, Happé, & Frith, 2002; Gallagher et al., 2000). Verbal theory of mind tasks typically involve stories about the thoughts and beliefs of others. One common type of task is a false belief task, which requires the participant to understand that two people can have different knowledge of a situation, and that knowledge can be incorrect and can differ from the knowledge of the participant (Baron-Cohen, 2000). Other tasks involve short stories or vignettes that involve understanding others mental states (Happé, 1994). Many nonverbal tasks of theory of mind rely on either cartoons or animations that require participants to attribute mental states to nonhuman entities, like geometrical shapes (e.g., Castelli et al., 2002; Heider & Simmel, 1944).

Across all of these different types of tasks, participants with ASD show reduced ability to attribute mental states to others (for review see Baron-Cohen, 2000). Furthermore, this is associated with reduced activation in areas such as the medial prefrontal cortex, superior temporal sulcus, and temporoparietal junction (Castelli et al., 2002). A combined structural and functional connectivity study found reduced temporoparietal junction and inferior frontal gryrus activity in participants with ASD when making intentional attributions, as well as reduced white matter integrity of the superior temporal cortex using DTI (Kana, Libero, Hu, Deshpande, & Colburn, 2014). Reduced functional connectivity between superior temporal sulcus and extrastriate cortex was also found in individuals with ASD during a visual theory of mind task (Castelli et al., 2002). Further research also suggests reduced connectivity between frontal regions involved in theory

of mind and posterior regions such as the temporoparietal junction (Kana, Keller, Cherkassky, Minshew, & Just, 2009). In sum, multiple theory of mind studies support the idea of reduced activity and functional connectivity between areas of the frontal lobe, superior temporal sulcus, and temporoparietal junction in ASD.

Mirror Neuron Hypothesis

In trying to develop a comprehensive theory for the social and neural disruptions in ASD, some have hypothesized that dysfunction of mirror neurons may be at the heart of the disorder (Oberman & Ramachandran, 2007; Rizzolatti & Fabbri-Destro, 2010). Mirror neurons were first discovered in monkeys and were found to fire both when the monkey performed an action, as well as when the monkey observed another person or monkey performing the same action (Gallese, Fadiga, Fogassi, & Rizzolatti, 1996). Research in humans has supported the general idea of a "mirror neuron system," where the same brain involves areas in both the observation and execution of actions. The most commonly found brain regions with these properties include the inferior frontal gyrus and inferior parietal lobule (Rizzolatti & Craighero, 2004). There is some evidence of an extended mirror neuron system that is involved in emotion processing (Wicker et al., 2003), somatosensory stimuli (Keysers et al., 2004), and language processing (Hauk, Johnsrude, & Pulvermüller, 2004). As human studies of the mirror neuron system rely on functional imaging, which does not have the resolution to see activity of individual neurons, it is impossible to know if the same individual neurons are active in both the observation and execution conditions, rather they may be independent populations of neurons that are located in similar regions (Dinstein, 2008; Hickok, 2009). Therefore, there has been considerable skepticism of the nature and function of the mirror neuron system in humans (Dinstein, 2008; Hickok, 2009).

Due to the implication that brain regions with mirror properties respond to the behaviors of others in a similar way they respond to self-executed actions, many have hypothesized that this may be the mechanism used to recognized, understand, and empathize with the behaviors of others (Rizzolatti & Craighero, 2004). As ASD is characterized by difficulty with social impairments included impaired imitation, emotion recognition, and empathy, it has been hypothesized that dysfunction of the mirror neuron system may contribute to ASD (Oberman & Ramachandran, 2007; Rizzolatti & Fabbri-Destro, 2010). This idea has some support from fMRI studies, for example, imitation and observation of emotional facial expressions resulted in reduced inferior frontal gyrus activation in participants with ASD, and this reduction in activity was significantly correlated with symptom severity on the social subscales of the ADOS and ADI-R (Dapretto et al., 2006). However, other studies do not support the notion of a primary deficit in the mirror neuron system, and rather suggest that social processing and imitation deficits are associated with differences in areas such as the amygdala, which is not believed to be part of the mirror neuron system (Grèzes et al., 2009; Williams, Waiter et al., 2006). Rather, the clear distinctions in amygdala, fusiform gyrus, superior temporal sulcus and global connectivity differences in ASD, as reviewed throughout this chapter, suggest a more widespread cortical deficit (Dinstein, 2008). Overall, there is little clear fMRI evidence of a mirror neuron dysfunction in ASD (Hamilton, 2013). The general idea of a "broken" mirror neuron system has been met with resistance (Dinstein, 2008; Fan, Decety, Yang, Liu, & Cheng, 2010; Southgate & Hamilton, 2008), and until more is understood about the nature and existence of the human mirror neuron system, many argue it is premature to use it as an explanatory mechanism of ASD (Dinstein, 2008; Hamilton, 2013).

Repetitive Behaviors and Restricted Interests

Despite being a core symptom domain in the diagnosis of ASD, neuroimaging research on repetitive behaviors and restricted interests (RRBs) has not been researched to nearly the

same degree as deficits in social communication and language (Pina-Camacho et al., 2012). Research in this area is challenging given the likelihood that different symptoms within this domain may have different functional and structural neural correlates (Langen, Durston, Kas, van Engeland, & Staal, 2011). Differences in neural correlates across specific symptoms are in line with other evidence that these symptoms cluster together less strongly than social and communication deficits and vary in their developmental trajectories and relationships with individual difference variables such as IQ (Lord & Bishop, 2015; Lord & Jones, 2012).

Neural Correlates

Despite differences in specific findings across studies, one set of regions regularly found to be associated with RRBs is the basal ganglia (Calderoni, Bellani, Hardan, Muratori, & Brambilla, 2014). Increased volume of the caudate, a region involved in goal-directed behavior, has been found in multiple studies of children and adults with ASD and linked to RRBs (e.g., Hollander et al., 2005; Langen et al., 2009, Rojas et al., 2006). While the majority of these studies used cross-sectional designs, based on the results of a longitudinal study, the authors (Langen et al., 2009) suggested it was likely ASD symptoms were driving the increased caudate volume, an example of behavior shaping brain development.

Another region often found to be associated with these symptoms in multiple studies is the anterior cingulate, a region also involved in goal-directed behavior. For example, greater activation was found in this region for children with ASD compared to typically developing children when viewing pictures of personally relevant vs. non-personally relevant interests (Cascio et al., 2014). Using a saccade task paradigm in which individuals have to shift their eye gaze towards or away from a target depending on the trial, adults with ASD were more likely to direct gaze towards the stimulus regardless of the trial, leading to faster correct responses, but more antisaccade errors, or errors in shifting gaze away from the target (Thakkar et al., 2008). This pattern of response was structurally and functionally associated with the anterior cingulate. In the same study, diagnostic ratings of RRBs made on the Autism Diagnostic Interview-Revised were also associated with the anterior cingulate.

Relationship to Executive Functioning

The saccade task used in the Thakkar et al., 2008 study is often used as a measure of executive functioning (e.g., Kramer et al., 2014). Multiple studies have demonstrated a relationship between RRBs and executive functioning as measured by neuropsychological measures. For example, in a study of adults with ASD, scores on multiple executive functioning measures, including measures of set-shifting or cognitive flexibility, monitoring or working memory, and response inhibition were associated with ratings of RRBs made on multiple, widely used diagnostic instruments (Lopez et al., 2005). Using a different measure of set-shifting, individuals with ASD were found to be able to make initial shifts in learning new rules, but had difficulty continuing to follow those new rules (Miller, Ragozzino, Cook, Sweeney, & Mosconi, 2014). This pattern of response was associated with ratings of RRBs.

Based on the results of functional imaging studies, a large set of neural networks have been identified as being related to both executive dysfunction and RRBs (Pina-Camacho et al., 2012). These networks include the fronto-striatal system, a system which connects the basal ganglia to multiple frontal areas, including the anterior cingulate. Given the overlap in neural correlates, many have speculated as to how executive dysfunction and repetitive behavior and restricted interests are related. The extent to which executive dysfunction is a cause, consequence, or correlate of RRBs is unclear; however, some have argued that given the repetitive behaviors shows up early in the developmental course of ASD, they are more likely a cause rather than a consequence of executive dysfunction (Leekam, Prior, & Uljarevic, 2011).

Chapter Summary

Neuropsychological assessment and neuroimaging are two useful tools in understanding ASD with current or future clinical applications. Neuropsychological assessment has identified a set of cognitive deficits found in some, but not all, individuals with ASD, including deficits in aspects of intellectual functioning, executive functioning, memory, attention and language (Dawson, 1996; Klin et al., 2005). Identifying these deficits can be clinically useful given their relationship to adaptive functioning (Klin et al., 2005). Although there is significant variability at the individual level, the overall pattern of neuropsychological deficits in ASD is distinct from that of other neurodevelopmental disorders (Minshew et al., 1992). The pattern of deficits found in ASD may reflect a more generalized deficit in the processing of complex information (Minshew & Goldstein, 1998).

Although not currently used as part of clinical practice, in the future it is hoped that neuroimaging will improve ASD diagnosis and facilitate the development of biologically grounded, individualized ASD treatment (Ecker, Bookheimer, & Murphy, 2015). There is much work to be done, but several studies using differences in brain structure across individual regions (Anderson et al., 2011; Calderoni et al., 2012; Ecker et al., 2010; Uddin et al., 2011) or differences in structural or functional connectivity (Anderson et al., 2011; Deshpande et al., 2013) to distinguish between individuals with or without ASD have yielded high classification accuracy rates. In contrast, neuroimaging has not yet yielded any direct benefits in terms of ASD treatment (Lord & Jones, 2012).

Differences in total brain volume and the volume of specific regions in those with ASD compared to typically developing individuals have been identified (Frazier & Hardan, 2009; Redcay & Courchesne, 2005; Stanfield et al., 2008). These differences have been linked to specific symptoms (Schumann et al., 2009). It is clear that developmental stage is a critical factor in understanding neuroimaging results. Depending on the age at assessment, the same brain region may be found to be larger, smaller, or no different in individuals with ASD compared to typically developing individuals (Nickl-Jockschat et al., 2012, Zielinski et al., 2014). Structural and functional connectivity may also be higher or lower in individuals with ASD compared to typically developing individuals depending on age at assessment (Ben Bashat et al., 2007; Shukla et al., 2011; Uddin, Supekar, & Menon, 2013). In general, early development is associated with larger total brain volume and greater connectivity with subsequent varying trajectories for brain volume across neural regions and decreased structural and functional connectivity (Ben Bashat et al., 2007; Hazlett et al., 2011; Shukla et al., 2011; Uddin, Supekar, & Menon, 2013). Differences in connectivity occur across large-scale networks and ASD has been referred to as a "developmental disconnection disorder" (Geschwind & Levitt, 2007).

Functional neuroimaging studies have identified differences in activation and recruitment of brain regions to perform specific tasks in those with ASD compared to typically developing individuals. In terms of language processing, ASD is associated with abnormal processing of voice-related sounds (Gervais et al., 2004), less activation in traditional language processing regions for tasks such as sentence comprehension (Just et al., 2004) and reduced laterality of language processing (Kleinhans et al., 2008). Individuals with ASD also show altered processing of extra-lingual cues such as prosody (Eigsti et al., 2012) and gestures (Hubbard et al., 2012).

Abnormal neural processing of social and emotional stimuli has been identified in individuals with ASD, showing reduced fusiform face area (FFA) activation when viewing faces (Corbett et al., 2009; Kleinhans et al., 2008; Pierce et al., 2001). This reduction in FFA activation is related to ASD symptom severity (Coutanche et al., 2011). Reduced activation in the FFA and amygdala has been shown for facial emotion recognition (Ashwin et al., 2007; Wang et al., 2004). Theory of mind is impaired in ASD (Baron-Cohen, 2000) and at the neural level, individuals with ASD show reduced neural activity and functional connectivity in social processing

regions when completing theory of mind tasks (Castelli et al., 2002; Kana et al., 2009).

Although less well studied and understood than language and social communication and interaction, neuroimaging studies of repetitive behaviors and restricted interests (RRBs) have shown that those symptoms are related to regions involved in goal-directed behavior and planning such as the basal ganglia and anterior cingulate (Calderoni et al., 2014, Cascio et al., 2014). Greater severity of RRB symptoms is associated with poorer executive functioning (Lopez et al., 2005). Neuroimaging studies also show a relationship between RRBs and executive functioning (Pina-Camacho et al., 2012).

Limitations and Future Directions

Although there are many replicated findings, the large body of ASD neuroimaging research is notable for variability in findings across studies. These differences in findings likely reflect differences in the individuals studied (e.g., differences in age and level of functioning; Brieber et al., 2007; Freitag et al., 2009; Schumann et al., 2010) as well as differences in scanning methodology (e.g., magnetic field strength and instructions given to participants; Nielsen et al., 2013). Given the cost and amount of time required to conduct and analyze the results of neuroimaging studies, sample sizes are often relatively small; in a review of 16 voxel-based morphometry studies, sample sizes of ASD participants ranged from 11 to 33 (Nickl-Jockschat et al., 2012). Small sample sizes in neuroimaging research may contribute to overestimates of real differences and failures to replicate findings (Button et al., 2013). In evaluating the results of classification studies based on neuroimaging, it is important to note that simulation studies have shown that with small sample sizes, high accuracy of 70 % or greater can result from chance rather than true differences across groups (Combrisson & Jerbi, 2015).

Recent developments in neuroimaging research in ASD have attempted to solve the problem of small sample sizes by developing data sharing agreements across individual research sites. One such collaboration is the Autism Brain Imaging Data Exchange (Di Martino et al., 2014). This collaboration and others have and will continue to produce studies which involve the analysis of data from several hundred individuals with ASD across the lifespan. In one recent study of over 500 individuals with ASD and 500 typically developing individuals, although some relationships were found at the whole brain level between neuroanatomy and ASD, on the whole the authors concluded that the individuals with ASD had "anatomical profiles that are mostly indistinguishable from those of control individuals" (Haar, Berman, Behrmann, & Dinstein, 2014, p. 9). The null results from this well-powered study differ from the results of many smaller studies which found more robust differences; however, it is important to note that this study was limited to higher functioning individuals with ASD and there is some evidence of greater differences in lower functioning individuals (Freitag et al., 2009).

It has been recommended that to understand the variability in findings, future research divide ASD individuals based on genetic factors or clinical presentation to look for differences that may be specific to certain subgroups with ASD (Haar et al., 2014). Studies which examine continuous dimensions such as symptom severity rather than binary diagnosis may also prove useful given the variability across individuals with ASD in symptom expression (Ecker et al., 2015). In terms of clinical practice, regardless of the continuous nature of ASD symptoms, there will always be a need for diagnostic classification. If classification algorithms based on brain structure and function are to be used in the future, there is a need to replicate past findings in new, larger samples and to use diverse samples that better reflect the types of individuals encountered in clinical settings. It will be important to establish that classifiers not only successful distinguish those with ASD from those with typical development, but also that they can distinguish between those with ASD and those with other neurodevelopmental or psychiatric disorders (Ecker et al., 2015).

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Current Status and Future Directions

23

Lindsey Williams and Johnny L. Matson

Introduction

Study of autism spectrum disorders has grown exponentially in the decades since it was first described by Kanner (1943), and the 1960s, when Uta Frith and others began challenging the predominant view that autism was a very rare disorder caused by socio-environmental factors (e.g., poor parenting). Due in no small part to the dedicated efforts of researchers over the years, autism spectrum disorder (ASD) is now widely recognized as having significant genetic and biologic bases. In keeping with the increased diagnostic rate in the past decade, the pace of research in autism spectrum disorders (ASD) seems to be picking up speed each year. Damiano and colleagues (2014) recently estimated that the number of published, peer-reviewed journal articles on the topic increased from 800 in 2003 to more than 3400 in 2013. With the significant social, economic, and emotional toll ASD can exact on individuals, families, and society, continued interest in research and clinical implications comes as no surprise. Indeed, the gains made in research over the ensuing decades have served to greatly improve assessment and treatment practices from the creation of validated, standardized assessments to informing practitioners and social policy advocates on which types of treatments have proven efficacious in treating ASD and comorbid symptoms. As is common in scientific research, the process of answering one research question often leads to several new questions.

Diagnosis of ASD is based on observed core deficits in social communication, restricted interests/repetitive behaviors, and atypical sensory responses, typically exhibited from very early on in development. However, symptoms are heterogeneous in the context of widely varying adaptive and intellectual capacity across affected individuals. Heterogeneity also exists within the same individual across time. Core symptoms affect emotion regulation and practically all areas of behavior; sleep, feeding, and behavioral disorders are common but may present differently across individuals. As discussed within previous chapters, comorbidity is high in individuals with ASD, with an estimated 50 % or more exhibiting comorbid psychiatric disorders such as ADHD, obsessive compulsive disorder, mood disorders, or anxiety disorders (Mazefsky et al., 2012). Accordingly, assessment of ASD and comorbid concerns can be difficult, with heterogeneity presenting challenges to both research and practice. Nonetheless, the ability of professionals to comprehensively assess and treat individuals with ASD continues to advance. Improvements particularly in the understanding of comorbid disorders and transdiagnostic issues affecting

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individuals with ASD have enabled us to provide better care for this population. However, there is still much work to be done towards understanding assessment and treatment of both ASD and concurrent disorders.

At present, ASD is often not diagnosed until around age 4 years in the USA (Baio, 2012) although parents often express concern months or even years earlier (Goin-Kochel, Mackintosh, & Meyers, 2006). Obstacles such as distance, insurance, and wait lists likely contribute to delay between first concern and assessment. Future improvements in accurately identifying at-risk children and in diagnosing ASD are likely to improve assessment in the future. Methods for more economical and time-efficient objective data collection would reduce wait-list times. Furthering our understanding of atypicalities and risk factors will improve our ability to diagnose accurately and target "at risk" children to provide appropriate intervention at younger ages, thus improving outcomes. The burgeoning use of increasingly sophisticated technology will contribute to such efforts. This chapter summarizes the most recent developments discussed in this book, with a particular focus on emerging research and future directions.

Etiology

The advent of neuroimaging has led to rapid developments in the area of etiology (Anagnostou & Taylor, 2011; Ecker & Murphy, 2014), even though the heterogeneity of ASD complicates identification of neurobiological markers such as brain abnormalities or endophenotypes (Volkmar et al., 2019). Recent research results offer promising avenues towards identifying underlying biological markers via assessment of underlying developmental constructs (e.g., attentional control, executive functioning, visual fixation, face processing) in young children (Klin & Jones, 2008; Klin, Lin, Gorrindo, Ramsay, & Jones, 2009; Ozonoff, Heung, Byrd, Hansen, & Hertz-Picciotto, 2008; Rogers, 2009; Zwaigenbaum et al., 2007). Animal models will likely remain important avenues to advance understanding of epigenetic contributants to development of ASD, hypothesized shared pathways with other disorders (e.g., ADHD; Matson, Rieske, & Williams, 2013), and potential mediators. For example, recent studies indicate a correlation between atypical enteric bacteria colonies and brain functioning in both animals and humans. Altered gut micro biota have been correlated with repetitive behaviors and social impairment in mice (Desbonnet, Clarke, Shanahan, Dinan, & Cryan, 2014); in humans, atypical gut micro biota have been associated with ASD and potential brain changes in humans (Adams, Johansen, Powell, Quig, & Rubin, 2011; Dinan & Cryan, 2013; Mulle, Sharp, & Cubells, 2013; Stilling, Dinan, & Cryan, 2014). Current research results are mixed and largely correlational, but our nascent understanding of the interaction between the brain and neurotransmitters and bioflora elsewhere in the body suggest a need to continue research that looks beyond the brain alone.

Even given the challenges of studying heterogeneous samples, overlaps in findings contribute to important etiological clues including structural differences in the brain (e.g., synaptic overgrowth early in life, reduced white matter, differences in frontal lobe, limbic, and cerebellar structure, and anomalous cortical organization; Dinstein et al., 2011; Hazlett et al., 2011; Wolff et al., 2014). Research has furthered our understanding of genetic correlates of increased ASD risk (see State & Levitt, 2011, for review), which has also increased our understanding of syndromes commonly concurrent with ASD (e.g., Fragile X syndrome, tuberous sclerosis). With regard to assessment of existing cases of ASD, research continues to inform conceptualization of the disorder as indicated by changes in diagnostic criteria from *DSM-IV-TR* to *DSM-5* and removal from Rett Syndrome from the ASD spectrum (Volkmar & McPartland, 2014).

Evidence thus far suggests ASD is affected by the interaction of numerous factors, both biological and environmental. It is likely that the continuing development towards preclinical models of ASD will continue to advance our understanding of etiology, with potential to inform further research on assessment and treatment.

Screening and Assessment in Early Childhood

Future advances in understanding etiology will likely improve our ability to screen for ASD. Stoner and colleagues (2014) examined postmortem tissues from children with and without autism, finding disruption of cortical laminar architecture in 10/11 children with ASD, but only 1/10 without. The authors suggest differences in layer formation and neuronal differentiation may be observable quite early in development, perhaps even prenatally. As neuroimaging and other biomedical techniques improve over the next few decades, the possibility of accurately detecting high-risk infants is an exciting prospect. Even if it were to become possible to identify cases of ASD via neuroimaging or some sort of definitive physiological test, such diagnostic tools would not obviate the need for behavioral and psychological assessment due to the heterogeneous nature of symptom expression and comorbidities, and the importance of such assessment to determining treatment and prognosis.

Other promising techniques are also emerging. At present, clear, defining symptoms of ASD may not be readily apparent until at least a year (Ozonoff et al., 2010), but it may be possible to detect endophenotypic differences at an earlier age (Elsabbagh et al., 2012; Wolff et al., 2014). Reviewing advancements in identifying risk factors at earlier ages, Damiano and colleagues (2014) suggest consideration of a "prodromal ASD" diagnosis similar to commonly used labels in other areas (e.g., pre-hypertension, pre-diabetes). The authors propose that as our ability to identify risk factors improves, use of such a label may enable more targeted intervention or closer scrutiny of possible symptoms in "at risk" individuals at follow up appointments. Alternatively, in a move fitting with increased attention to the high comorbidity of ASD with other neurodevelopmental disorders, Damiano, Mazefsky, White, and Dichter (2014) and colleagues propose categorizations highlighting heightened risk for a variety of disorders known to have overlapping risk factors. For example, a number of disorders (e.g., ASD, some cases of intellectual disability, attention deficit/hyperactivity disorder) are considered likely to have common etiological features, an area of continuing research (Gillberg, 2010; Matson et al., 2013). In this vein, Gillberg (2010) coined the term ESSENCE: Early Symptomatic Syndromes Eliciting Neurodevelopmental Clinical Examinations in recognition that "the co-existence of disorders and sharing of symptoms… is the rule rather than the exception." Gillberg uses the term ESSENCE to refer to a pattern of symptoms commonly presenting within the first 3 years of age, which are considered indicators of potential neurodevelopmental disorder (Gillberg, 2010).

Damiano and colleagues (2014) offer a thoughtful analysis of important areas for future research into early risk markers. Among these are potential differences in risk factors in high-risk versus low-risk populations. Thus far, samples in studies of ASD risk factors have included those already assumed to be at higher risk for ASD development (e.g., siblings of those with ASD, premature infants; Limperopoulos et al., 2008; Wetherby et al., 2004). Studies sampling different populations may reveal new information about risk factors. For example, the significance of certain behaviors or markers may change depending on group. Young and colleagues (2009) noted that fixation on eyes over mouth in early infancy may adversely affect language development in a high-risk group, but not be correlated with adverse outcome in low-risk, typically developing infants. Protective factors are another area for continuing research in childhood; for example, what differences exist between siblings of children with ASD who go on to also receive an ASD diagnosis, versus those who do not? This line of research may help us identify and promote protective factors in the future.

Although in some cases ASD symptoms may not become readily apparent until a child's environment becomes more cognitively and socially demanding (e.g., upon entering school), it is generally agreed that developmental deficits in social and communication skills are evident around the second year of life, if not sooner (McConnell, 2002; Webster, Feiler, & Webster, 2003; Woods

& Wetherby, 2003). However, significant differences exist between research showing reliable and stable diagnoses by 2 years of age (Lord et al., 2006, Webb & Jones, 2009), and the average age of diagnosis in a community setting. Wiggins, Baio, and Rice (2006) estimated the time delay between initial evaluation and ASD diagnosis is approximately 13 months. The estimated average age for ASD diagnosis in the USA is around 4–5 years of age (Centers for Disease Control and Prevention [CDC], 2012). Efforts at improving screening in the general population and continuing assessment for those identified as "at risk" have been elemental in reducing the average age of ASD diagnosis, though age at diagnosis varies significantly depending on symptom expression. Maenner et al. (2013) found that children exhibiting all 12 of the behavioral features listed in the *DSM-IV-TR* ASD criteria were diagnosed at an average age of 3.8 years, while those evincing only 7 features were diagnosed at an average age of 8.2 years. In one large study, children with impairments in nonverbal communication, pretend play, inflexible routines, and motor stereotypies were diagnosed earlier than those with impairments in conversation skills, peer relations, and with idiosyncratic speech (Maenner et al., 2013). Using information available from the Autism and Developmental Disabilities Monitoring (ADDM) Network, Maenner et al. (2013) found the average age of ASD diagnosis by community professionals was as late as 5.7 years among the 8-year-old sample. Identification of which features of ASD are likely to emerge at different ages would assist in assessment in community settings. The researchers identified impairments in nonverbal communication, repetitive motor behaviors, inflexibility with routines, and pretend play were indicative of earlier diagnosis, but contrary to expectations, reduced sharing of interests was not (Maenner et al., 2013).

The percentage of pediatricians routinely screening for ASD has increased over the years to a current rate of approximately 50 % (Arunyanart et al., 2012; dosReis, Weiner, Johnson, & Newschaffer, 2006; Gillis, 2009); however, this means approximately half of pediatricians do not routinely screen for ASD despite published recommendations. Necessary steps for increasing screening include increasing primary care provider (PCP) knowledge about ASD symptoms and screeners, and structuring the practice setup to allow adequate time and resources for screening. In a study of early intervention professionals and ASD screening, Tomlin and colleagues (2013) found providers felt unprepared to talk with families about ASD-related concerns and ill-equipped to utilize various ASD measures. These same providers were, however, eager for training in these areas. Per Zuckerman et al. (2013), PCPs feel especially unprepared to identify ASD symptoms in Spanish-speaking Latino families and in African American children.

The CDC launched the "Learn the Signs. Act Early" campaign to target PCPs and allied professionals, with efforts to address some of the needs identified by these professionals. Continuing efforts to improve early screening and assessment in community health care should address the following needs: provision of socioculturally sensitive measures, access to systems that could adequately handle an increase in referrals, availability of effective early intervention programs to which to refer clients, and continuing education (Crais et al., 2014).

An additional impediment to timely, accurate diagnosis in early childhood is the lack of established developmental milestones and trajectories related to the skills underlying core ASD deficits. If such data existed, PCPs might make use of skill acquisition charts similar to the widely recognized growth charts to identify troubling changes in trajectory, and as a means of conveying concerns to caregivers. Because of the lack of established developmental milestones, it remains imperative that healthcare providers are knowledgeable about early ASD symptoms (Ibanez, Stone, & Coonrod, 2014) such as language regression, which often (but not always) occurs between the ages of 20 and 24 months (Barger, Campbell, & McDonough, 2013). Early identification is a target of the national Healthy People 2020 initiative in the USA (Honda, Shimizu, Imai, & Nitto, 2005) and will remain an important area

of research for the foreseeable future. Trends in developmental trajectories are emerging, including regression and stasis in cognitive, social, and language development (Anderson, Liang, & Lord, 2014; Baird et al., 2008; Fein et al., 2013; Landa, Gross, Stuart, & Bauman, 2012); a greater understanding of such trajectories and ages at which behavioral features of ASD are likely to be observed would improve detection of ASD in community settings (Maenner et al., 2013). Additionally, as recommended by the American Academy of Pediatrics, multilevel screening should occur repeatedly through 3 years of age because of variability in topography and timing of emerging ASD symptoms (Ozonoff et al., 2008; Rogers, 2009; Zwaigenbaum et al., 2007). Research and clinical practice should continue to target reduction of time lapses between initial parent concerns, initial screening, and ASD diagnosis.

The diagnostic process varies widely across cultural and national divides; for example, families in India may travel for days in order to access qualified professionals (Daley, 2004). Future efforts should continue to explore the varied experiences and needs of individuals across global and cultural settings, using quantitative and qualitative research to discern the nuances of these environments and identify effective means of improving care. Efforts should also be made to bridge the gap between research and clinical practice, including practical concerns related to systemic health care policies, insurance, improving efficiency, and insuring resource availability (see Dingfelder & Mandell, 2011; Jensen & Foster, 2010; Stahmer & Aarons, 2009).

Assessment in Adolescence and Adulthood

In the scope of ASD research, adolescents and adults are notably underrepresented. In a recent review of intervention studies for adults with ASD, Bishop-Fitzpatrick, Minshew, and Eack (2013) found only 13 randomized control trial studies for adults with ASD, coinciding perhaps unsurprisingly with the distinct drop-off in federal funding for intervention programs at age 21 (Damiano et al., 2014). Overall there are few professionals with the requisite expertise and skill in assessing adults and who are able to implement resulting recommendations.

Research and assessment measures are particularly sparse for transition-aged individuals, adolescents, and young adults making the transition from child to adult services. Well-researched assessments and interventions to prepare for and facilitate the transition into adulthood are sorely lacking. Individuals with ASD often have disparate skill levels across domains, and high skills in one area may obscure skill deficits in another. For example, just because an individual seems quite knowledgeable about weather patterns and meteorology does not mean he or she is adept at picking out appropriate clothing to prepare for expected rain or cold; skill at tidying one's desk and assignments at school (perhaps a skill that has been explicitly taught) does not necessarily generalize to ability to organize and clean one's home. One risk adolescents with ASD and their families face is an oversight of some important skill area that will be necessary to maintain a level of independence once the child ages out of the school system. Without purposeful assessment, families may be surprised and somewhat at a loss when assumed skills do not generalize to a new setting (e.g., from school to work, or from parent's home to supported independent living or group home). An important role of continuing assessment throughout childhood and adolescence is to systematically assess skills in various domains to ascertain skills and deficits and different points in development. These assessments should extend beyond academic skills and the school/home settings, with an eye towards developing and generalizing skills to increase independence in various settings and situations likely to be en countered in adulthood. In the past few decades we have seen an increase in community and employer awareness of the desire and ability for many individuals with ASD to maintain gainful employment. Underemployment is a pervasive problem for individuals with ASD, both with and without intellectual disability. Estimates of employment for young adults with ASD range

from just under one third to significantly less, depending on intellectual level, environmental barriers, etc. (Taylor & Seltzer, 2011). Assessments geared towards informing service providers and potential employers about employment-related skills of an individual with ASD are few. Many employers are not aware of the ease with which they may accommodate an employee with ASD-related needs; for example, one of the most important architectural factors in workplace fit for individuals with ASD is acoustics (Mostafa, 2007). Simple accommodations such as use of earphones or rearrangement of workspaces can significantly reduce acoustic noise. One measure that has been employed with notable success is the TEACCH Transition Assessment Profile (TTAP; Mesibov & Shea, 2010). This assessment investigates an individual's skill at various tasks across a number of domains, including initiating and sustaining performance when faced with a number of issues often encountered in a real work environment: visual and auditory distractions, correction, being left to work alone in a room or continuing after interruption, when required to ask for help, and changes in instructions/schedule. The need for services related to transition to adult medical and community services, independent adult living, and employment are only expected to grow as the children diagnosed in the past two decades age out of the public school system and child-oriented treatments. Future directions in this field of great importance include identification of domains important for safe, healthy, fulfilling independent living while there is still time to teach these skills before the individual ages out of school and other support providers. Examples of such skills include how to use public transportation and what to do if unexpected things happen; making healthy food, exercise, and financial decisions; identifying, communicating, preventing and treating common health issues; issues related to sexuality and romantic interests. Future research should also address attitudes of potential employers, best practices to begin and maintain suitable employment, and factors that affect both individual and employer satisfaction. As the number of adults with ASD continues to grow, it is imperative that service availability increases as well. There are a few measures to screen for or diagnose ASD in young to middle-aged adults, but greater research is also needed in this area. As is mentioned in the chapter in assessment in adulthood, assessment of this population should include assessment not only of the individuals needs and skills but also the quality, amount, and role of family, peer, employer, and community support (Henninger & Taylor, 2012). Assessment should also be done with an eye towards how recommendations derived from the assessment might be practically implemented for individuals in this developmental stage.

Research on assessment and intervention for the geriatric ASD population is even more lacking. Following a multidisciplinary meeting to identify research needs for this population, Piven and Rabins (2011) identified several research priorities targeting older adults with ASD. First listed is the need to develop tools to diagnose and assess the needs of older adults with ASD; assessment in adults can be difficult as assessment often relies in part on childhood history. Additionally, it is possible that symptom expression may differ across the life span, particularly in the context of any mental and physical disorders arising later in life. As the authors point out, recent research suggests stability of ASD rates across the life span, yet prevalence in older adults is less than would be statistically suspected (Piven & Rabins, 2011). This raises the likelihood of a large number of undiagnosed older adults with ASD, but there are no validated instruments designed specifically to screen or diagnose this population.

Comorbidities

Undoubtedly, significant progress has been made over the past few decades in understanding ASD and comorbidities. Only a few decades ago, it was widely thought that an ASD or intellectual disability diagnosis precluded a comorbid psychological disorder (Matson & Williams, 2013). Now, we know not only that comorbid diagnoses are possible, but that individuals with ASD are at

a higher risk of comorbid psychiatric and neurodevelopmental disorders than the typically developing population; in fact, the majority of individuals with ASD have at least one comorbid psychiatric diagnosis (Mazefsky et al., 2012). A great deal of research is still needed to improve assessment for comorbid disorders in the context of ASD, where symptoms may be differentially expressed and for which few well-established measures currently exist. Assessments should also take into consideration the possibility that scores on some domains (e.g., anxiety) may be inflated due to the nature of ASD, and adjust for phenotypic overlap (e.g., social avoidance, decreased eye contact) accordingly. Additionally, an increased understanding of the reasons for high rates of comorbidity may prove critical to understanding etiological contributions of ASD. Are ASD-related deviations in core developmental processes (e.g., joint attention, social understanding) causing a greater risk for disorders such as depression and anxiety? Are prenatal architectural differences in the brain a common denominator in ASD and common comorbidities? As Mansell and colleagues (2008) ponder, how might transdiagnostic features such as a propensity towards rumination, poor emotional regulation, or avoidance underlie a range of disorders over the life span? Future clarification of these questions may help identify new assessment and treatment targets.

Tools and Technology

It seems unlikely that a singular biomarker for ASD will be found, given that the current state of etiologic research points to a number of environmental and biologic factors which overlap with other neurodevelopmental disorders. Therefore it is likely that the use of psychometrically sound assessment measures will continue to play a key role in ASD diagnosis and in tracking treatment efficacy. We have seen that changes to classification systems over the years have affected sensitivity and specificity of clinical diagnoses. The accurate diagnosis of ASD across settings necessitates the use of standardized clinical tools designed to elicit sufficient information in line with the diagnostic criteria being used. As diagnostic criteria change over time, diagnostic tools in use should be examined and revised accordingly to ensure their fidelity to current understanding of the disorder. As discussed in the chapter on implications of *ICD* and *DSM* criteria, some of the most widely used ASD assessments were based on *DSM-IV-TR* criteria, and thus may not sufficiently measure all of the behaviors designated in the *DSM-5* (e.g., sensory sensitivities). Of course, diagnostic measures are not designed for use in isolation and should not overrule clinical judgment. As our understanding of ASD evolves, so must diagnostic criteria and our means of assessment. Research into the impact of diagnostic changes from *DSM-IV-TR* and *DSM-5* is underway and will likely continue for the next several years.

As technological advances continue, new tools will further improve diagnosis and intervention assessment. Damiano and colleagues (2014) posit that technological advances such as eye tracking may allow for tracking social reciprocity in infancy and early childhood, using predicted and plotted developmental trajectories to notice changes in a manner similar to which physical growth charts are commonly used at pediatric visits. While recognizing variability in child development, tracking individual trajectories using objective data may help increase accuracy of children referred for more comprehensive ASD evaluation. Further research is needed to use eye tracking in this way, but as technology becomes less expensive and more accessible it is plausible that eye tracking could become an important tool at the primary care level.

Additional promising technologies include those capable of automatic vocal analysis to help discern differences in language acquisition and use in early childhood (Yoder, Oller, Richards, Gray, & Gilkerson, 2013). Yoder and colleagues (2013) utilized single, all-day recordings for their sample and found that this methodology can provide a stable estimate for vocal use, offering the ability to compare ASD and typically developing samples. Larger sample sizes are needed, but similar technology may allow us to use

objective data and efficient analysis to understand language development trajectories. This may lay the groundwork for using such technology to detect expressive language differences that may indicate a heightened risk of later autism diagnosis.

The ability to gain more objective data both in and out of the clinic is improving with the use of Ecological Momentary Assessment (EMA). Understanding socio-affective states is key to a greater understanding of ASD impairments; however, recall of emotional states is biased even in typically developing individuals with only a moderate correlation between self/caregiver report and objective measures (Coyne & Gottlieb, 1996). EMA helps remove that bias by eliminating the need for recall over hours, days, or weeks typical for self-reports, thus showing less bias in reporting cognitive and emotional events (Coyne & Gottlieb, 1996; Schwartz, Neale, Marco, Shiffman, & Stone, 1999; Whalen, Jamner, Henker, & Delfino, 2001). EMA has been successfully used in populations including pediatrics and individuals with severe mental illness, and shows promise for use with adults and adolescents with ASD (for overview see Damiano et al., 2014). Use of EMA may hold particular advantages for use in ASD assessment. First is the scope in which it may be employed. Clinicians and researchers frequently contend with claims that a child's behavior in the clinic setting is not representative of their functioning in daily life. This is particularly true in the case of ASD or social anxiety. EMA may be used across the usual daily activities and locations rather than the unusual laboratory or clinic environment, thus providing more representative data if appropriately utilized. Second, adolescents and adults with ASD tend to be skilled at and enjoy using EMA-compatible technology such as smartphones, which may increase likelihood of completing EMA measures according to instructions (Hurlburt, Happe, & Frith, 1994; Klin, McPartland, & Volkmar, 2005; Shane & Albert, 2008). Interestingly, Khor, Gray, Reid, and Melvin (2014) found EMA adherence was not correlated with age, gender, or ASD severity in a group of high-functioning adolescents with ASD. Finally, a freely available or low-cost way of collecting objective data (e.g., via smartphone app) can save valuable money (and time) in the clinic. Examples of factors that may be explored using EMA in ASD assessment include differences in mood depending on social context (e.g., when alone, with peers, or others; when engaged in preferred vs. non-preferred activities in these contexts). An added bonus is that data is captured over time, thus allowing the possibility to more accurately track changes in mood or behavior based on time of day, day of the week, month, etc.

For clients who live in rural settings, have difficulty accessing transportation or time off of work, or have other barriers to attending a clinic, telemedicine offers a useful model worthy of further exploration. Reese and colleagues (2013) used interactive video-conferencing to simulate ASD assessment, using clients who already had an ASD or other developmental disability diagnosis. These researchers used the ADOS and ADI-R, common ASD assessment tools, via teleconferencing. In a sample of ten children (3–5 years), the researchers found no significant difference in diagnostic accuracy, ADOS observations, ADI-R parent report ratings, or parent satisfaction. Future research should determine whether these results are maintained in larger samples, but use of telemedicine offers a possibility to greatly reduce the burden of obtaining an assessment in many families. In addition to using such technology to assess those in rural areas or with transportation difficulties, teleconference assessment would allow greater ecological insight as it takes place in the child's home; additionally, this technology would facilitate the provision of qualified interpreters when necessary. Parmanto and colleagues (2013) reported success in using a telehealth system to assess adults with ASD; it is conceivable that brief but more frequent assessments of overall wellbeing could be provided to adults with ASD between scheduled appointments. Telehealth could also be used to assess treatment fidelity and provide real-time feedback to in-home therapists or family members.

Collaboration

The National Institute of Mental Health's Research Domain Criteria (RDoC) initiative to emphasize dimensional constructs and objective, observable symptoms in research will undoubtedly influence future ASD research. As is evident by the changes in ASD criteria in the DSM over the years and debates surrounding the changes in diagnostic criteria between *DSM-IV-TR* and *DSM-5*, widespread consensus has not been reached on how to best diagnose and label ASD and related features. The heterogeneous nature of ASD and related symptoms leads to widely varying presentations; in light of such heterogeneity, it is no surprise that research to date has implicated a plethora of etiological suspects, and continued research into possible endophenotypes within ASD will remain an important area of research (Vivanti et al., 2013). The Research Domain Criteria (RDoC; Insel et al., 2010) propositioned that a dimensional rather than categorical approach may advance our understanding of the relationship between biology and behavior, and clinical presentation. Shifting focus on defining research populations from *DSM*-based to RDoC-based criteria may lead to new advances in understanding ASD-related impairments such as social communication, positive and negative valance systems (Damiano et al., 2014), and executive functioning deficits. Such a focus may also provide a deeper understanding of common constructs underlying comorbid disorders, including anxiety or attention deficit/hyperactivity disorder. Additionally, this dimensional approach may help us better understand the heterogeneity of presentation within ASD.

Collaborative efforts wherein resources and data are collectively gathered and shared among researchers offer opportunities for research using sample characteristics and sizes that have been impossible until relatively recently. Such resources include the National Institute of Health's National Database for Autism Research, which has incorporated a number of previously existing databases from other sites and which released its first round of data released in 2010 (Hall, Huerta, McAuliffe, & Farber, 2012). Allowing for aggregation and secondary analysis of data from over 20,500 participants, this large database promises to accelerate progress in ASD research.

Addressing Barriers

Finally, all the work we do towards advancing ASD assessment and intervention is no good if those needing our services do not walk through our doors. Barriers to assessment and treatment include an array of geographic, socioeconomic, educational, and language/cultural factors. Screening for ASD has undoubtedly improved in the past decade, with increased efforts towards educating primary care providers and the public, streamlining screening methods, and large-scale efforts to reach a wider array of individuals in the community. These efforts mean more individuals now get screened for ASD in early childhood. However, much remains to be done both in researching ways to improve assessment and the practicalities of providing it. Furthermore, the clinicians involved in the process of interviewing family members are often the ones to deliver the final diagnosis. It is incumbent on clinicians to keep the big picture in mind throughout the assessment process, recognizing the importance of building and maintaining rapport not only to elicit accurate information for diagnostic purposes, but so that clients feel engaged in order to ensure greater likelihood of following through with referrals and recommendations, and returning with follow-up questions (Kasari, 2014).

Conclusion

Considerable progress has been made in assessment for individuals with ASD, both for diagnostic purposes and to assess the efficacy of and improve interventions. Areas of continuing research include efforts to define and improve diagnosis of ASD, assess comorbid conditions and intervention efficacy, and evaluate skills and deficits in this population. Efforts by researchers to better understand these areas are likely to

continue at a rapid rate as innovations in research methodologies and technologies emerge. Addressing barriers to assessment and applying research findings to clinical practice will continue to aid professionals in effectively treating individuals with ASD across the life span.

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ERRATUM

Chapter 6
Monitoring Progress in Autism Spectrum Disorder

Valsamma Eapen, Katrina Williams, Jacqueline Roberts, Nicole Rinehart, and Jane McGillivray

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In Chapter 6 titled "Monitoring Progress in Autism Spectrum Disorder", the affiliation of the author J. McGillivray was incorrect.

The correct affiliation should read as follows:

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The correct author affiliation for J. McGillivray is also updated in the List of Contributors.

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Erratum to: Report Writing for Autism Spectrum Disorder Evaluations

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Index

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