Autism spectrum disorders (ASDs) consist of five heterogeneous disorders with several core features in common (Matson et al., 1996). Deficits in communication, social behavior such as recognition of facial affect, rituals, and stereotypies are the key features of ASD (Lewis, Woodyatt, &
caused by neurodevelopmental deficits (Matson & Boisjoli, 2007; Matson, Nebel-Schwalm, & Matson, 2007). Clear genetic markers have been established for Rett Syndrome, and the remaining disorders are also believed to be caused by neurodevelopmental deficits (Matson & Boisjoli, 2007; Matson, Nebel-Schwalm, & Matson, 2007). Rett Syndrome and Childhood Disintegrative Disorder are very rare. However, autism, PDD NOS, and Asperger's Syndrome are considered to be high incidence disorders (Fombonne, 1999). Furthermore, these disorders all appear to have a life long course (Heiman & Berger, 2008; Hengeveld, van Londen, & van der Gaag, 2008; Matson et al., 1996).

The focus on differential diagnosis has traditionally been on early childhood (Matson, Wilkins, & González, 2008). Furthermore, advances in early childhood intervention has pushed researchers and clinicians to find effective means of diagnosis in children 2 years of age and younger (Ben Itzchak, Lahat, Burgin, & Zacher, 2008). However, in practice it is often difficult to obtain an accurate diagnosis (Oslejskova, Kontrova, Foralova, Dusek, & Nemethova, 2007; Siklos & Kerns, 2007). And, in the most recent edition of the DSM (APA, 2000), criteria for ASD has expanded. Thus, even assuming accurate diagnosis prior to that time, some adults with the disorder would have been missed. Finally, ASD while chronic in nature are not static in symptom presentation, particularly with intensive treatments at early ages. ASD also are frequently accompanied by co-occurring challenging behaviors which often require intensive interventions (Dawson, Matson, & Cherry, 1998; Matson, Dixon, & Matson, 2005; Matson & Minshawi, 2007; Matson & Neal, 2008). These co-occurring problems tend to develop at an early age and persist and intensify over time without treatment.

Seltzer, Krauss, Orsamond, and Vestal (2001) suggest that a conceptual framework they describe as a life course perspective is important when assessing ASD. These authors note that changes in family function, and other substantial life events and changes can markedly effect symptom presentation. Furthermore, these authors note that symptoms may not just get better as the researchers cite above hypothesize. Rather, symptom patterns may wax and wane. For example, symptoms may be less pronounced in middle childhood compared to young children (Ando & Yoshimura, 1979; Bebko, Konstantareas, & Springer, 1987) but become more pronounced again in adolescence and early adulthood (Bristol & Schopler, 1983). We would add a pragmatic concern to these points. Bishop, Whitehouse, Watt, and Line (2008) describe diagnostic substitution in 38 adults with autism. They found that some cases which would clearly be identified as autistic now, had in the past been clearly defined as developmental language disorder. For all these reasons, periodic assessment is highly advisable (Moore & Goodson, 2003; Myers & Johnson, 2007). Thus, yearly or biennial evaluations during childhood, adolescence, and early adulthood to assess strengths and weaknesses would seem to be appropriate. However, once symptom profiles have stabilized in adulthood, assessment could be less frequent. Some factors that might serve as “behavioral triggers” for further evaluation would be health issues, onset of challenging behaviors or psychopathology, new living or work placements, or marked deterioration in cognitive functioning (e.g., stroke or dementia).

Our review then will focus on a number of critical issues in the context of available assessment methods and procedures. As previously noted, two well established and accepted principles are that ASD are chronic life long conditions, and that diagnosis should be made as early as possible (Scahill, 2005). Acceptance of these hypotheses has important implications for assessment. First, evaluation needs to be life long since, as previously noted, symptoms can wax and wane. Treatment may have a profound effect on symptoms patterns, short and long-term health status, maturation, comorbid conditions, and other factors can complicate and change ASD symptom profiles. Seltzer et al. (2003) underscore this point based on their assessment of 405 persons with ASD between 10 and 53 years of age. They found that while almost all met criteria for autism in childhood, fewer than half met criteria based on data collected during the study. Adolescents were more likely to improve in reciprocal social interactions than adults, while adults evinced fewer symptoms associated with restrictive and repetitive behaviors.

Many important questions regarding the assessment process for persons with ASD, across the lifespan are still unknown. This is the case despite the fact that diagnosis of adults with ASD has been a
topic of discussion for at least 20 years (Matson, 1989). Howlin, Mawhood, and Rutter (2000), for example, tested autistic children at 7–8 years, and again at 23–24 years of age. They found that autistic persons continued to show marked impairments in stereotypies, social relationships, independence and job skills. Using a comparison group of language disordered individuals they noted particularly large disparities in social competence. Bolstering these findings, Billstedt, Gillberg, and Gillberg (2005) conducted a prospective study over a period of 13–22 years, re-evaluating the 120 autistic individuals studied at 17–40 years. Very poor psychosocial outcomes were noted at follow-up. Similar findings have been reported by Rydén and Bejerot (2008) who reported greater social deficits for adults with ASD compared to patients with other psychiatric conditions. Persons with ASD were much more incapacitated on social behaviors than the comparison group. And, while a host of behaviors in the social context are problematic, eye gaze and eye tracking have been singled out as particularly problematic (Nation & Penny, 2008). These data as a whole then support the idea that continued, periodic assessment of ASD is of value (Moore & Goodson, 2003; Myers & Johnson, 2007). But, what to assess for and how often are still open questions.

While significant social and communication deficits are evident relative to other groups, some improvements may be noted over time. Piven, Harper, Palmer, and Arndt (1996) note that of 38 participants diagnosed as autistic in childhood, five no longer met criteria for the disorder as adults. Having said this, the authors note that even these five still evinced significant impairments. A more pessimistic scenario is described by Wolf and Goldberg (1986). They followed up 80 adults diagnosed with autism in childhood. These authors found that 50% required long-term institutional care, almost a third had seizures, and few could work or live independently.

Researchers and clinicians should not see these ASD as binary; just determining if the person meets criteria for the disorder or not. We know that a considerable amount of heterogeneity in symptom presentation occurs. This variability could be looked at as occurring on a spectrum for some individuals. Others, may exhibit a pattern of mixed severity in symptom presentation. For example, while client A may have mild and severe symptoms, client B symptom patterns of mild and more severe items may be reversed. Thus, looking at the specifics of individual symptoms, and symptom clusters requires careful consideration. This must be done in the context of specific behavioral domains, and with the addition of specialized assessment tools. And, as we have discussed, periodic monitoring and the knowledge of how autistic behavior looks for a given individual over time may differ.

1. Testing

A great deal of variability exists in the literature with respect to differential diagnosis methods and procedures. Matson (2007a) and Scahill (2005) are among those who have divided testing into roughly three domains: (1) IQ and adaptive behavior; (2) measures of ASD; and, (3) measures of psychopathology and challenging behaviors. There is no reason at this time to suspect that these three broad content areas are not applicable across the lifespan. Thus, it would seem advisable to cover these three areas except where average to above average IQ has been established. In those cases only, categories two and three would need to be assessed (e.g., Asperger’s Syndrome and High Functioning Autism). However, for autism and Pervasive Developmental Disorder, Not Otherwise Specified (PDD NOS) where borderline IQ, or intellectual disability are likely, the evaluation of the IQ/adaptive behavior domain is critical (Goin-Kochel, Peters, & Treadwell-Deering, 2008; Matson, Nebel-Schwalm, et al., 2007). A brief discussion of these major areas of diagnosis follows.

2. IQ and adaptive behavior

Most studies report the use of the Stanford Binet or Wechsler Scales as the method of evaluating intelligence (Matson, 2007b). We would note, however, that for persons with sensory impairments, very low IQ, or major language and other communication deficits, these test are likely to be inappropriate. The Peabody Picture Vocabulary Test and Leiter International Performance Scale may be more viable options in these cases. However, lack of motivation to do well on these individually administered tests enhances the importance of adaptive behavior scales in the diagnostic process. And, for the ASD population, many persons simply have little or no interest in how they “perform.”

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Easily the best recognized and most widely used of the adaptive behavior measures is the Vineland Adaptive Behavior Scale (Sparrow, Balla, & Cicchetti, 1984). For the majority of adults with autism or PDD NOS, this measure is sufficient. However, for persons with severe ID, measures geared to individuals with greater cognitive deficits are advisable such as the Matson Evaluation of Social Skills for Individuals with Severe Retardation (Matson, Carlisle, & Bamburg, 1998; Matson, Dixon, Matson, & Logan, 2005; Matson, Leblanc, & Weinheimer, 1999).

3. Measures of ASD

Intellectual functioning is a primary diagnostic indicator for what additional assessment methods are likely to be the most useful. Thus IQ/adaptive behavior should be assessed first. This initial evaluation will produce an Asperger’s Syndrome/High Functioning Autism or PDD NOS group or it will identify a second larger autism PDD NOS group. The latter cohort will have borderline intellectual functioning or below. A review of the literature shows that groups are broken out in this way. We will therefore discuss assessment in the context of two distinct groups.

The bulk of the assessment instruments from the 26 we identified measure autism (21), while five tests have been developed to evaluate Asperger’s Syndrome only (Matson & Boisjoli, 2008b). For the tests of autism, PDD NOS is identified as someone with autistic features who does not meet criteria for autism. Thus, an upper limit for PDD NOS is established in the literature for many of the autism instruments. However, rarely is a lower limit specified. Testing takes from 15 min to 4 h based on the test used. Various combinations of parent report, client observation, teacher report, or a “trained examiner” are employed to obtain data. No research suggests that a particular time is needed for accurate diagnosis or that a particular examination method is superior to another. These questions certainly warrant further investigation. Claims of particular tests or methods (e.g., clinical consensus) as a “gold standard” in diagnosis are based on extrapolation of psychometric properties or number of studies where given methods are used. No direct test of these claims has been made. Thus, from a scientific perspective they should be viewed with some skepticism. Further, it is increasingly less likely that any one test will be the gold standard. As instruments are tailored to more and more specific needs, it is likely that different measures will be best for particular subsets of persons with ASD based on type of ASD, intellectual disability, and age.

Since a review of the Asperger’s scales has been provided elsewhere (Campbell, 2005; Matson & Boisjoli, 2008b), we will limit our discussion to measures of PDD NOS and autism for adults and those designed to differentiate autism from Asperger’s Syndrome. A number of scales are appropriate for 2–22 years of age, or some subset of this range. Since these measures are aimed almost exclusively at children and adolescents, however, we will use 23 years old and older as our definition of “adult” scales. Using this criterion, the Autism Behavior Checklist (Krug, Arick, & Almond, 1980), and the Autism Diagnostic Interview-Revised (Lord, Rutter, & Couteur, 1994) would qualify as adult measures. Neither scale was designed specifically to look at symptom profiles in adults; however, both have had studies published, after initial development, which extend their use to adult populations (Hus, Pickles, Cook, Risi, & Lord, 2007; Matson, Nebel-Schwalm, et al., 2007). A second limitation is that PDD NOS is determined largely by having some symptoms of an ASD, but where autism criteria are not met. Thus, as previously stated, a lower subthreshold is not available, only an upper threshold.

More recently, researchers have stressed the need for the assessment of adults who may have ASD, since autistic symptoms may mimic or be overshadowed by various types of psychopathology (Kan, Buitelaar, & van der Gaag, 2008). The Diagnostic Interview for Social and Communication Disorders (DISCO) is one test that can be used for this purpose (Wing, Leekam, Libby, Gould, & Larcombe, 2002). The interview is designed for the diagnosis of ASD and related disorder, and the evaluation of individual needs. The authors assert that the DISCO is suitable for all ages and ability levels, and can serve to help differentiate ASD from catatonia like symptoms which are characteristic of some forms of psychosis (Wing & Shah, 2006). In one interesting study, Billstedt et al. (2005) followed 105 children with autism into adulthood, evaluating them with the DISCO. Perceptual, social, communication, and sensory problems were still evident in adulthood. Thus, the DISCO proved to be well suited for studying these characteristics of autism.

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Another scale recently proposed for adults is the Ritvo Autism and Asperger’s Diagnostic Scale (RAADS) (Ritvo et al., 2008). Unlike the 5 Asperger’s scales previously alluded to, which only assess this one condition, the RAADS is used to evaluate autism as well. The idea is to distinguish between Asperger’s Syndrome and High Functioning Autism, which as previously noted, has been a frequent subject of discussion in the literature. However, much is yet to be done to establish the utility of this scale. At present, this is the only study conducted on the measure and the sample size was very small. There were 17 persons with autism, 20 with Asperger’s Syndrome, and 57 controls in the study. Nonetheless, the idea is a good one and scales such as this one, which is based on DSM-IV and ICD-10 criteria, warrant further development.

A second measure, developed to distinguish between high functioning autism in adults from Asperger’s Syndrome has received more empirical support. The Autism Spectrum (AS) was first described in 2001 (Baron-Cohen, Wheelwright, Skinner, Martin, & Clubley, 2001). The Autism Spectrum Quotient (AQ) is derived from the AS which is a 50 item Likert 4 point self-report scale aimed at giving a score on “autistic” traits. However, it is pointed out by the authors that scores do not render a diagnosis. Wakabayashi, Tojo, Baron-Cohen, and Wheelwright (2004) report reliability and validity of the AS using a sample of 57 adults with Asperger’s Syndrome or high functioning autism, 194 normal adults and 1050 college students. They note that scores for the two autism spectrum disordered people were much higher than for the other two groups studied. Similarly, good psychometrics have been reported in a Dutch version of the scale by Hoekstra, Bartels, Cath, and Boomsma (2008). Wheelwright et al. (2006) have also found that the AS has a weak negative correlation to empathizing along with intact or superior abilities in systemizing. Thus, it may also prove to be a useful research tool for looking at various parameters of adult ASD.

The Autism Spectrum Disorders adult battery is a test method developed to assess ASD symptoms in adults with intellectual disabilities. The scale is limited to persons with severe and profound intellectual disability which also makes it different from and complementary to the other scales we have reviewed above. There are three specific tests in the battery: one measure is used as an aid for diagnosing autism and PDD NOS, one test is for the evaluation of comorbid psychopathology, and one scale was designed to evaluate challenging behaviors (Matson & Boisjoli, 2008a; Matson, Boisjoli, González, Smith, & Wilkins, 2007; Matson, Wilkins, Boisjoli, & Smith, 2008). The battery is administered to a third party informant and can be completed in about 30 min. The measures have well-established reliability and validity, and have proven useful in not only distinguishing persons with and without autism spectrum disorders, but in differentiating autism from PDD NOS (Matson, Wilkins, & Ancona, 2008; Matson, Wilkins, Smith, & Ancona, 2008). Additionally, it allows for the evaluation of psychopathology and challenging behaviors which occur at high rates in the ASD with ID population.

4. Measures of psychopathology and challenging behaviors

Persons with ASD and the frequently co-occurring ID are at particular risk for comorbid psychopathology and challenging behaviors (Cherry, Matson, & Paclawskyj, 1997; Duncan, Matson, Bamburg, Cherry, & Buckley, 1999; Holden & Gitlesen, 2007; Matson, Smiroldo, Hamilton, & Baglio, 1997c). Additionally, these two comorbid problem areas are also known to covary at high rates (Myrbakk & von Tetzchner, 2008). We have briefly mentioned the ASD scales and efforts to develop measures of psychopathology and challenging behaviors. In addition to these efforts, other researchers have developed or adapted scaling methods for this purpose. La Malfa et al. (2007) for example, studied 90 severely intellectually disabled adults with autism and pervasive developmental disorders (PDDs). To assess psychopathology they used the Diagnostic Assessment for the Severely Handicapped-Revised (DASH-II) (Matson et al., 1996; Matson, Hamilton et al., 1997; Matson, Kiely et al., 1997; Matson & Smiroldo, 1997). PDD was associated with a high rate of comorbid psychopathology, particularly with respect to anxiety, depression, and organic syndromes. These data are confirmed by Ghaziuddin and Zafar (2008) who found 28 adults with ASD to be particularly vulnerable to symptoms of anxiety and depression. Tsakanikos, Sturmey, Costello, Holt, and Bouras (2007) also report high rates of psychopathology in ASD adults (58.4% of 137 cases). Types of disorders they observed to be most frequent were schizophrenia, followed by depression, adjustment reaction, and anxiety.
Helverschou, Bakken, and Martinsen (2008), noting the vulnerability of adults with autism and ID to comorbid psychopathology, have also developed a scale to assess these conditions. The Psychopathology in Autism Checklist (PAC) is a 30 item measure of psychosis, depression, anxiety, and obsessive compulsive behavior, along with 12 additional items on “general adjustment.” Items were based on ICD-10 and DSM-IV criteria. They tested 35 adults with autism and ID, and established acceptable psychometric properties. This scale and the data collected in studies above all support a growing body of evidence that adults with ASD are particularly vulnerable to comorbid psychopathology (Hansman-Wijnands & Hummelen, 2006).

Researchers then, are beginning to recognize the importance of comorbid conditions and the need to develop scales to assess them. Additionally, some forms of psychopathology and challenging behaviors are more common in high incidence ASD, with ID being a particularly important moderating variable. These data, as noted, speak to the need to develop specialized assessment tools and other assessment methods that address these issues. Researchers in the field now seem to be more interested in the topic, and it may prove to be an active area for research in the near future, particularly as ASD is viewed more in terms of a life long condition versus a problem specific to young children.

5. Future priorities

Given the general, although not unanimous, view that Asperger’s Syndrome and High Functioning Autism are separate disorder, scaling methods designed to parse out these distinct subtypes of ASD would seem to be advisable. Matson and Wilkins (2008) and Spek, Scholte, and van Berckelaer-Onnes (2008) review studies differentiating symptoms across the two conditions and present a template based on these data. Differences appear to exist on onset and achievement of developmental milestones, social interactions, communication, verbal behavior, restrictive and repetitive behaviors, sensory-motor skills, performance on subscale scores of traditional I.Q. tests, frequency and type of comorbid psychopathology and course, and number of autistic symptoms. Given all these potential differences, adult measures to diagnose these disorders would seem to be a priority. However, as pointed out by others, these populations, particularly in the adult years have largely gone underserved (Huang & Wheeler, 2006). Some promising initial developments in scaling have been reported. However, much is yet to be learned in this regard.

A second issue is the need to develop and norm better methods for differentially diagnosing comorbid psychopathology in these groups. Various studies have been published suggesting that a number of different emotional disorders are present. Among these are thought disorders (Dykens, Volkmar, & Glick, 1991), bipolar disorder, schizophrenia (Antonacci & Attiah, 2008; Stahlberg, Soderstrom, Rastam, & Gillberg, 2004), catatonia (Kakooza-Mwesige, Wachtel, & Dhossche, 2008; Wing & Shah, 2006), anxiety, suicidal ideation, and depression (Shtayermman, 2007). However, these efforts have been largely anecdotal. Thus, well developed comprehensive diagnostic methods that can be routinely used with adults evincing high incidence ASD are urgently needed. This issue is becoming more important given increasing information which appears to support high rates of comorbid psychopathology, and the general lack of specific information about type, symptom profiles, course, sensitivity, and effect on prognosis of adults with high incidence ASD.

Challenging behaviors and adaptive behavior and IQ methods are much better developed, largely due to decades of effort with persons evincing intellectual disability (Matson & Bamberg, 1998; Paclawskyj, Matson, Bamberg, & Baglio, 1997; Rojahn, Aman, Matson, & Mayville, 2003). Given the large overlap between ASD and ID, it has been relatively easy to apply these techniques where the two conditions do overlap. An omission at this point with respect to challenging behaviors is the need for functional assessment procedures to help identify maintaining variables for these behaviors (Paclawskyj, Matson, Rush, Smalls, & Vollmer, 2000). This line of research is particularly important for establishing better behavioral methods to treat these problems behaviors. At this point, pharmacology is used too frequently, and this research would help establish better parameters pertaining to drug therapy (Singh, Matson, Cooper, Dixon, & Sturmey, 2005). This issue and many others are in need of investigation. Researchers are beginning to attend to many of these variables. More efforts of this sort are needed.
References


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