Strategies for assessing Asperger’s syndrome:
A critical review of data based methods

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Abstract

Asperger’s syndrome has gained tremendous recognition and popularity in the last 20 years. However, controversy around the nature of the disorder, whether it is distinct from high functioning autism, and whether it can be reliably and validly diagnosed has continued throughout this period unabated. Fortunately, there has been a strong tradition of developing systematic data based methods of differential diagnosis in the autism spectrum disorders. The bulk of the effort has been in autism, but there has been moderate, yet consistent efforts to develop data based methods to diagnose Asperger’s syndrome as well. The present paper provides an up to date critical review of the existing literature on the topic. Strengths, weaknesses of the research, and avenues for future efforts are discussed.

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Asperger’s syndrome (AS), first described in 1944 (Asperger, 1944), was little known in the English speaking countries until the paper of Wing in 1981. Her use of the term Asperger’s syndrome was used to heighten awareness about this particular type of autism spectrum disorder (ASD; Frith, 2004). Since that time, the disorder has become one of the most written about disorders in mental health, with over 1000 papers published on the topic (Matson, Rojahn, & Wilkins, 2007). Despite that, controversy still centers around whether this disorder exists as a distinct entity or might be better subsumed under autism, using the term high functioning autism (HFA; Howlin, 2003; Howlin & Asgharian, 1999; Schopler, Mesibov, & Kunce, 1998; Willemsen-Swinekels & Buitelaar, 2002). Leekam, Libby, Wing, Gould, and Gillberg (2000), for example, question the value of an AS diagnosis and posit the notion that a dimensional versus a categorical approach to classification might be more appropriate. Thus, the primary issue is not whether AS individuals meet criteria for ASD, but rather whether there should be a separate category in ASD for AS. The primary argument

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for a categorical approach, and it is a very powerful one, is the historical movement of dichotomous groupings that has dominated the field of differential diagnosis. However, a major shift to spectrums in DSM-V may add considerable momentum to the spectrum model. Efforts appear to be underway to sort this out, but this goal can only be achieved through rigorous empirical study of these diagnostic issues (Matson & Minshawi, 2006).

Fortunately, the field of ASD has had a tradition of developing diagnostic measures to assist in differential diagnosis and for measuring treatment outcome (Matson, 2007a,b; Matson, Nebel-Schwalm, & Matson, 2007). Thus, while clinical judgements are still emphasized as the gold standard for differential diagnosis of ASD, quantitative tests are typically employed along with clinical assessment to provide objective evidence methods of differential diagnosis (McConachie, LeConteur, & Honey, 2005). Developing quantitative methods to establish a diagnosis among the five ASD of autism, Asperger’s Syndrome, PDD-NOS, Rett’s Syndrome, and Childhood Disintegrative Disorder would seem to be needed most for AS at this time. We say this given the controversies surrounding the nosology and diagnosis of the condition, the differences in prognosis, types of interventions, and tremendous life long cost of providing adequate care that is evident with the AS group (Jarbrink, McCrone, Fombonne, Zanden, & Knapp, 2007). The development of qualitative methods would seem to be particularly salient for not only diagnosing but for better defining AS in the context of other ASD. These concerns are further underscored by recent research on the significant difficulties parents encounter in obtaining a relevant diagnosis. Siklos and Kerns (2007), for example report that the average parent needed 3 years and saw an average of 4.5 professionals before a relevant diagnosis could be obtained. Thus, adequate scale development might further aid in the diagnostic process by serving as a needed aid to educate clinicians about what symptoms do and do not constitute AS. Finally, better delineated scaling methods and diagnostic precision should prove valuable as a shorthand concerning what symptoms and challenging behaviors to expect, as well as to assist in the linkage of assessment to specific treatment methods (Crocket, Fleming, Doepke, & Stevens, 2007; Dominick, Davis, Lainhart, Tager-Flusberg, & Folstein, 2007; Hill & Furniss, 2006).

1. Scales

1.1. Tests for Asperger’s syndrome

The number of scales which have been used to evaluate AS is remarkable when put into the context of the size of the assessment literature as a whole. By this, we mean that there are a substantial number of scales, but none have been well developed empirically at this point. Typically 1–3 studies have been published on a given measure. Many of these tests are designed specifically to look at the core symptoms of the disorder, but other measures are employed to look at ancillary but related issues such as I.Q. For conveniences and ease of review, we have grouped these measures into four general categories (see Table 1). These groups of tests are designated core symptoms, measures of intelligence, tests of social and neuropsychological problems, and tests for comorbid psychopathology and challenging behaviors. We have selected these categories based on the fact that they are representative of the current published literature on the topic.

1.2. Measures of core symptoms

What would appear to be a straightforward issue, the development of Asperger’s scales to measure the disorder in fact becomes considerably more complicated when the literature is
Table 1
Measures used in Asperger assessment research

<table>
<thead>
<tr>
<th>Measures of core symptoms</th>
<th>Measures of intelligence</th>
<th>Social and neuropsychological problems</th>
<th>Measures of comorbid psychopathology and challenging behaviors</th>
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<tr>
<td><strong>Measures of autism</strong></td>
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<td>Autism Spectrum Screening Questionnaire (ASSQ; Ehlers, Gillberg, &amp; Wing, 1999)</td>
<td>Test of Nonverbal Intelligence (Brown et al., 1990)</td>
<td>Empathic Accuracy Task (Ickes, 1997; Ponnet et al., 2004)</td>
<td>Isle of Wight Semistructured Informant and Child Interview (IOWI; Green et al., 2000)</td>
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<tr>
<td>CARS-TV (Kurita, Miyake, &amp; Katsuno, 1989)</td>
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<td>Isle of Wight Subject Interview (IOWS; Green et al., 2000)</td>
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**Measures of Asperger syndrome**
- Adult Asperger Assessment (AAA; Baron-Cohen, Wheelwright, Robinson, & Woodbury-Smith, 2005)
- Asperger Syndrome Diagnostic Interview (ASDI; Gillberg, Gillberg, Rastam, & Wenz, 2001)
- FMRI (Herrinton et al., 2007)
- Matson Evaluation of Social Skills with Youngsters (MESSY; Matson, Rotatori, & Helsel, 1983)
- Social Skills Rating Scale (SSRS; Gresham & Elliott, 1990)
consulted. The sheer number of measures used to diagnose core symptoms is daunting and requires a bit of organizing. A list of the scales found in the published literature to diagnose core symptoms of AS are presented in Table 1. Furthermore, nowhere is the problem underscored more than by the absence of direct comparisons of various Asperger’s scales to determine their accuracy and overall utility in differential diagnosis relative to each other.

The reader will note that 5 tests used in studies to diagnose AS are measures of autism only, 5 scales have been published that are specifically designed for the diagnosis of AS, only 3 instruments measure more than one disorder under the spectrum, and two major diagnostic systems are used, in

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<tr>
<td>Asperger Syndrome Diagnostic Scale (ASDS; Boggs, Gross, &amp; Gohm, 2006; Myles, Bock, &amp; Simpson, 2001)</td>
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<td>Australian Scale for Asperger Syndrome (Garnett &amp; Attwood, 1995; Melfesen, Walitza, Attwood, &amp; Warneke, 2005)</td>
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<td>Childhood Asperger Syndrome Test (Scott, Baron-Cohen, Bolton, &amp; Brayne, 2002)</td>
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<td>Die Marburger Beurteilungsskala zum Asperger Syndrome (MBAS; Kamp-Becker, Mattejat, Wolf-Ostermann, &amp; Remschmidt, 2005)</td>
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<td>Gilliam Asperger’s Disorder Scale (GADS; Gilliam, 2001)</td>
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<td>Screening Questionnaire for Asperger Syndrome and other high Functioning Autism Spectrum Disorders in school age children (ASSQ; Ehlers et al., 1999)</td>
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<td>Measures of multiple conditions on the autism spectrum</td>
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<td>Autism Spectrum Disorders-DC (Matson &amp; González, 2007)</td>
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<td>Behavior Flexibility Rating Scale (BFRS; Green et al., 2006)</td>
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<td>Pervasive Developmental Disorders Questionnaire (PDD-Q; Baron-Cohen et al., 1996)</td>
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<td>Diagnostic Systems</td>
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<td>DSM-IV (APA, 1994)</td>
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<td>ICD-10 (WHO, 1992)</td>
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effect, as scaling methods, DSM-IV and ICD-10. Thus, scales to date appear to be designed largely on the dichotomy model; they measure one ASD versus the spectrum model where multiple ASD could be evaluated along a continuum. The reasons for these general approaches to the diagnosis of AS appear to have strong historical roots which have produced a considerable, and apparently, a difficult to change momentum in the current use patterns of scales for differential diagnosis.

1.2.1. General comments on scaling methods

A number of the major autism diagnostic methods have been applied to diagnosing AS. This model parallels the approach taken to diagnose PDD-NOS. Thus, the AS diagnosis is made based on the fact that the child does not meet criteria for autism. After this first step, “clinical judgement” and additional modified symptoms which are deemed characteristic of AS are added to arrive at the relevant diagnosis. This approach not only reflects limits in scale development but also dissatisfaction with DSM-IV and ICD-10 criteria as written. Scales used in this manner have included the Autism Diagnostic Interview, Autism Diagnostic Interview- Revised, the Autism Diagnostic Observation Schedule-Generic, and the CARS-TV. The premise of working from the most reliable, valid, and most heavily researched scales in the ASD spectrum, measures of autism, helps establish that the identified AS cases are not in fact autistic and is a diagnostic model previously used with PDD-NOS as well (Matson & Boisjoli, 2007). However, not specifically measuring AS also presents its own set of challenges.

A second set of measures has been designed to specifically measure AS. However, they were not designed to allow for the differentiation of AS from other ASD which is particularly interesting since there is so much debate in the literature about differentiating between AS and HFA. These scales are of considerable value because they allow for opportunities to more precisely measure AS symptoms, how they vary between cases, and what symptoms appear to be most salient for diagnosis. Scales that fit this description include the Adult Asperger Assessment, Asperger Syndrome Diagnostic Interview, Australian Scale for Asperger Syndrome, and Childhood Asperger Syndrome Test. The biggest issue at this point with respect to all of these measures is that initial development has not been followed by continued research to expand and refine the various scales applicability. Furthermore, no direct comparisons between the various scales has been made to determine if they are measuring the same construct, nor have they been used in conjunction with other tests of ASD. For example, one interesting approach would be to use established autism and AS scales in the same study with persons diagnosed with both conditions included as participants to determine if these scales could accurately differentiate a person in the AS and autism cohorts. Studies of this type are urgently needed.

A third approach to the diagnostic questions surrounding AS has been approached with three scales that are designed specifically to measure multiple ASD, and to allow for the differentiation of these various subcategories or disorders. This approach may prove to be particularly useful for differentiating between the various ASD, since symptom presentation is developed on a continuum, allowing the researcher to identify demarcating points between groups based on symptom presentation. The Autism Spectrum Disorders-Diagnosis for Children (ASD-DC) is one such instrument. A second measure which has considerable promise is the Behavior Flexibility Rating Scale (BFRS) which was tested on 968 persons with autism, AS, or Down Syndrome (Pituch et al., 2007). This scale fills a large gap in the literature with respect to core features of resistance to change and insistence on sameness. They found distinct differences between the autism and AS groups with the latter scoring particularly high relative to autism on interpersonal mishaps.

To date, several avenues for objectively diagnosing AS have been developed. This trend is encouraging, and at present reasonably reliable parameters for ASD versus no ASD have been
established. However, considerably more research is needed to establish the parameters of the various disorders within ASD. Particularly, emphasis on distinguishing between PDD-NOS, AS, and autism would seem to be a potential priority topic, given that these are the “high frequency” ASD, and are the particular categories with the greatest potential for existing on a continuum.

1.3. Measures of intelligence and academic performance

Several researchers have reported on the use of individually administered I.Q. tests in the diagnosis of AS. Thus, it has been reported in a few papers that AS can occur in persons with borderline or mild intellectual disability (Strum, Fernell, & Gillberg, 2004), but the unspoken rule for most researchers appears to be that below normal I.Q. is a rule out (e.g. Klin, Pauls, Schultz, & Volkmar, 2005; Ozonoff, South, & Miller, 2000). In fact, the primary use of I.Q. measures has been as a method of including or excluding people from Asperger’s groups in nosological and treatment studies. However, intelligence tests have been used in some few instances to help further describe symptom patterns of those who evince the disorder. For example, looking at subdomains of intellectual functioning appears to be useful in sorting out people who have an ASD versus those who do not. However, these data do not seem to show differential patterns of responding between AS and other ASD. The flip side of the coin is that these common features help build an argument for the notion of a spectrum of differing disorders, which nonetheless have many overlapping features.

1.4. Social and neuropsychological problems

In the research literature, alternating terms are used to describe a group of tests that address language, social interaction, and perspective taking which are common core deficits in ASD (Lee, David, Rusyniak, Landa, & Newschaffer, 2007; Matson & Wilkins, 2007). Social and neuropsychological tend to be among the most common labels, thus the reason for the current heading. Sanders, Johnson, Garavan, Gill, and Gallager (2007) provide a critical review of neuropsychological and neuroimaging research as it applies to attention, inhibition, and cognitive flexibility in the ASD population. Their review notes that ASD does have some striking differences from the regularly developing population.

One example of these tests is described by Ponnet, Roeyers, Buryse, De Clercq, and Van der Heyden (2004). They discuss a task labelled emphatic accuracy as a method of differentiating between an AS group and typically developing individuals. This test was designed as a form of perspective taking, where the individual tested attempted to discern thoughts and feelings of another in a particular context. Another interesting study designed to differentiate AS and HFA was by Lewis, Murdoch, and Woodyatt (2007). They looked at linguistic performance on the Clinical Evaluation of Language Fundamentals-Fourth Edition (CELF-4; Semel, Wiig, & Second, 2003) and the Test of Nonverbal Intelligence-Second Edition (Toni-2; Brown, Sherbenou, & Johnson, 1990). They found that the children with ASD could be distinguished from their normally developing peers, but not between AS and HFA. However, grouping was done using DSM-IV criteria, which as we have noted, has been problematic and could have effected accurate grouping. The 2 measures used in their study covered core linguistic issues, but certainly not all potential language problems. Having stated this, it would seem only natural that some skills will differentiate AS and HFA from each other, while other behaviors will not, even assuming a true diagnostic distinction exists between AS and HFA. An alternate interpretation is
that the data support a dimensional versus dichotomous view of ASD; a point made by a number of researchers (e.g., Howlin, 2003; Howlin & Asgharian, 1999).

1.5. Measures of comorbid psychopathology and challenging behaviors

While a bit sparse at this point, some research has been conducted on the potential for comorbid psychopathology and challenging behaviors in persons with ASD in general and Asperger’s syndrome in particular (LaMalfa et al., 2007; MacDonald et al., 2007; Matson & Minshawi, 2007; Matson & Nebel-Schwalm, 2007). Green, Gilchrist, Burton, and Cox (2000), for example studied 20 boys with Asperger syndrome ages 11–19 and compared them to 20 children and adolescents with conduct disorder. High levels of anxiety and obsessive compulsive behavior relative to the conduct disorder group were reported, and they noted that both groups had high rates of depression and suicidal ideation. These data appear to support the notion that AS is a risk factor for mental heath conditions. However, this area has received almost no empirical study to this point and no scales of comorbid psychopathology for AS, or AS norms on existing childhood psychopathology scales have been published to date. The recent recognition of AS for research attention and the observation that comorbid psychopathologies can be present in ASD versus being part of the ASD core symptoms are likely major reasons for this state of affairs. Nonetheless, it would appear that the time has come for the introduction of comorbid psychopathology research with AS. Most likely, researchers will show that particular forms of psychopathology are likely to be present in this group. Such knowledge would be of considerable value in better pairing assessment and treatment and may prove valuable in giving insights as to the causes of ASD.

1.5.1. Autism scales and diagnostic systems

Table 2 presents some eye opening diagnostic practices for AS, from our perspective at least. We say this because there is an almost total disconnect between scale development for AS and the

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<th>Assessment methods used in selected studies of Asperger’s syndrome</th>
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<td>Gilchrist et al. (2001)</td>
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<td>Green et al. (2000)</td>
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<td>Herrinton et al. (2007)</td>
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<td>Klin, Volkmar, Sparrow, Cicchetti, and Rourke (1995)</td>
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<td>Lewis et al. (2007)</td>
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<td>Ozonoff, Rogers, &amp; Pennington (1991)</td>
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<td>Rondan and Deruelle (2007)</td>
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<td>Strum et al. (2004)</td>
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measures researchers use to diagnose Asperger’s for treatment and nosology studies. Ironically, autism scales and the ICD-10 and DSM-IV have been and continue to be the preferred method of differential diagnosis of AS in the research literature. This finding is particularly interesting in light of the frequent comments that the symptoms presented in these manuals are inadequate to reliably differentiate AS and HFA in particular while at the same time multiple additional symptoms that distinguish the groups are being reported in the literature (Matson et al., 2007b). The reader will note that most of these papers we have cited were published after the AS scales were introduced and the bulk of the nosology papers presenting differences on AS and HFA were published. Thus, the introduction of scales specific to AS and related nosological studies have had little impact to date on the diagnosis of AS; in studies on the topic. It would be interesting to know if these AS scales have had an impact on the actual diagnosis of AS in clinical practice. At present the answer to this question is unknown. However, if clinical practice mirrors the research literature, then scale development in AS has a long way to go to win over what apparently is a sceptical audience.

2. General discussion

While debate continues, a summary statement for AS might be that most researchers consider the disorder distinct from HFA despite the fact that the general core areas of dysfunction such as perception, stereotypies, affect, and social skills are present in both (Balconi & Carrera, 2007; Chung et al., 2007; Hilton, Graver, & La Vesser, 2007; Ingersoll & Gergans, 2007). Additionally, however, the majority view also seems to be that DSM-IV and ICD-10 do not provide sufficient detail and clarity to make reliable and valid distinctions between these two ASD on a consistent basis, although researchers continue to use these symptoms as the primary method for differentially diagnosing AS. This problem is compounded by the fact that measures used to distinguish HFA from AS typically measure only autism or AS thus clinicians and researchers must “wing it” to a certain extent when diagnosing AS from HFA. Scales would seem to be needed that measure both ASD as a means of adding standardization and objectivity in diagnosis. This approach would allow for the distinction to be better made between symptoms that represent AS and those which characterize HFA. It appears at present that the literature has outpaced thinking about scaling methods. Tests are generally designed to distinguish autism or AS from the general population of individuals. However, a primary need relative to HFA and AS is scales that differentiate between these two ASD. Thus, the literature appears to support the notion that ASD can be reliably identified from the general population with existing measures but HFA and AS are still hard to differentiate from each other.

The development of scaling methods that make the HFA and AS distinction requires more fine-grained symptom descriptions, since as noted the same general “core” deficit areas are present in both groups. A number of nosology papers appear to be providing some of this detail with a substantial number of papers providing a large number of discrete symptoms where the two groups do differ (Matson et al., 2007b). The refrain that more research is needed is common in the ASD field in general, but nowhere is this point more relevant than for scale development as a means of differential diagnosis of AS from HFA. However, we are very positive regarding developing trends in differential diagnosis of ASD. Scales are proliferating which signifies the important point that researchers in the field accept the notion that objective scaling methods versus clinical interviews alone, projective tests or other less than reliable methods should be paramount. In areas of mental health diagnosis, those latter views still hold sway to a large degree. Thus, the ASD diagnostic literature is cutting edge relative to most other areas of
differential diagnosis. Having a large number of measures is welcome since this demonstrates that a considerable number of research teams are “in the hunt” to develop reliable and valid diagnostic instruments which can also be used to help define types of ASD along the way. Time and persistence will result in a shaking out of those testing methods which will have staying power versus scales or symptoms which fall by the wayside. Traditionally, this factor is decided by which research teams continue to publish and in the process further refine diagnostic methods as the field of knowledge advances.

References


