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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.

Keywords: Asperger's syndrome; Assessment; Children; Data based

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-Swimkels & 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