Review

What is the future of assessment for autism spectrum disorders: Short and long term

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**Abstract**
The autism spectrum disorders (ASD) are common, debilitating and life long. Thus, early identification of the disorder is considered to be critically important. Furthermore, periodic and life long assessment is necessary to calibrate the level and type of supports each person requires. The heterogeneity of ASD further highlights the need for reliable and valid methods which can establish overall severity of ASD, as well as specific skills for intervention. The methods and procedures used to achieve these goals have evolved considerably in the last 60 years with the rate of change accelerating. This paper highlights past practices, current methods and future directions in assessment.

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Autism spectrum disorders (ASD) are considered to be neurodevelopmental in origin. The course is life long, symptoms emerge early and are increasing (Matson & Kozlowski, 2011). ASD can be diagnosed by two years of age (Matson, Boisjoli, Hess, & Wilkins, 2010; Matson, Wilkins, et al., 2009; Rojahn et al., 2009).

There is considerable variability in symptom presentation across individuals. For example, people can vary from profound intellectual disability to persons with superior IQs (Matson, Dempsey, LoVullo, &Wilkins, 2008; Matson & Neal, 2009; Matson, Smiroldo, & Bamberg, 1998; Matson & Wilkins, 2008). Factors such as IQ effect how symptoms are expressed. However, common core characteristics including social skills, communication deficits and rituals and stereotypes are present in some form for all persons with an ASD (Ganz, Davis, Lund, Goodwyn, & Simpson, 2012).

In addition to the core symptoms of ASD, a number of comorbid conditions present at high rates with the disorder. Cerebral palsy, behavior problems and psychopathology are some of these problems (LoVullo & Matson, 2009; Matson & LoVullo, 2008; Matson & Rivet, 2008; Smith & Matson, 2010a, 2010b, 2010c). Obviously, when ASD is suspected, these and other comorbid disorders that are likely to be present should be assessed. As more information becomes available, the methods used to assess for ASD are evolving. And, the pace at which these changes are occurring is accelerating.

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1. Early assessment efforts

Kanner (1943) and Asperger (1944) independently, came up with descriptions of disorders that formed the core of the autism spectrum. Their assessment was done based on observation of the children and parent interview, and arriving at a common set of behaviors displayed by the group. While the method of identifying these core deficits has been refined, social deficits, communication problems, rituals and stereotypies were identified then as now (Fodstad, Matson, Hess, & Neal, 2009; Hattier & Matson, 2012; Horovitz & Matson, 2010; Matson, Kozlowski, & Matson, 2012).

WWII slowed the spread of knowledge on the topic and the resources aimed at developing new clinical knowledge and expanding clinical services. This phenomenon extended well into the post war period. By 1958 however, a paper had been published describing one of the first structured assessments of ASD (Kramer, Rabkin, & Spitzer, 1958). This test, although phrased differently at the time, was a measure of stereotyping behavior. Their whirling test study involved observing and inducing children up to 11 years of age to hold their arms out, close their eyes and turn in a circle. They noted that this activity decreased with age but was far more common in psychotic schizophrenic children (what would now qualify as autistic spectrum disorder) compared to typically developing children. Having said that, the authors concluded that the whirling test was not precise enough, and therefore could not be successfully employed in child psychiatry.

A year later, Mosse (1958) published a paper on childhood differential diagnosis that in many ways was ahead of its time. The paper in our view is a seminal and very important paper, and was based on a presentation the author made at the 1957 Second International Congress for Psychiatry in Zürich, Switzerland. He noted at the time the paper was written, that diagnosis of childhood disorders was in its infancy and that no valid diagnoses had been worked out. He decried the trend to popularize a particular diagnosis, at that time childhood schizophrenia, and stressed the need to develop and use tests of childhood mental health. He concluded his paper by noting that psychiatry needed to be advanced as a science.

Kramer, Rabkin, and Spitzer (1958) describe the whirling test. Eveloff (1960) also put particular emphasis on rituals and stereotypies. He described the child with ASD as having a passion for sameness. Eveloff (1960) also noted the “poorly understood,” at that time, symptoms such as rhythmical movements (e.g. jumping, rolling, rocking, preferred toys and of course whirling). As the reader knows, these were later described as core features of ASD.

Because of the early popularity of the childhood schizophrasias we have documented, much of the early diagnostic efforts centered around differentiating ASD from the former disorders. DeMyer, Churchill, Pontius, and Gilkey (1971) describe one of the earliest studies emphasizing the establishment of psychometric properties of four early checklists that had been developed, but had not been scientifically evaluated. These were checklists of Polan and Spencer (1959), Rimland (1964), Lotter (1966) Rende-Short and Clancy (1968), and the British Working Party (Creak, 1964). Forty-four children were referred to a center for childhood schizophrenia. They were diagnosed independently from the aforementioned ASD measures. Children were diagnosed based on intelligence, a psychiatric disorder and on neurological functioning. Diagnostic methods included EEG, skull X-ray, bone age, urinalysis, blood count, neurological soft signs, adaptive skills, language skills, and psychological testing. Two psychiatrists, or a psychiatrist and a psychologist independently made the diagnosis. The authors found a very anemic overlap of only 35% between the four diagnostic methods noted above to a diagnosis of ASD. DeMyer et al. (1971), also had a set of ASD criteria they applied to the sample. Their criteria were most closely related to Rimland’s. What these authors demonstrated was that in 1971 no agreed upon diagnostic criteria for ASD had been developed. However, some initial efforts had occurred. Polan and Spencer (1959) for example in the scale noted above used 30 items divided into five categories; social detachment, language difficulties, disintegrative nervousness, and family nervousness. Rimland’s scale, developed in 1964 had 80 items and included questions about birth history, social responsiveness, and speech.

The first scale that had established psychometrics was published by Ruttenberg, Dramton, Fraknoi, and Wenar (1966). He called it the Behavior Rating Instrument for Autism and Atypical Children (BRIAC). This test consists of eight subscales, but tended to be used primarily to set and monitor goals for treatment. None of the measures addressed so far however would survive scientific scrutiny. Moving forward, the first diagnostic test for ASD to demonstrate long term staying power would be the Childhood Autism Rating Scale (CARS).

Schopler, Reichler, Devellis, and Daly (1980) were responsible for the development of the CARS. They explain that their intervention program which would be called TEACCH and would be used throughout the state of North Carolina (USA), obviously require methods to identify persons in need. They initially used Rimland’s (1971) scale, and Creak (1964) classification system. However, they concluded that these methods were not useful for young children, and we would add that they were not psychometrically sound. They noted that the CARS presented a broader set of criteria than Kanner originally described, and that the scale was more in line with Rutter’s (1978) symptom formulation. This test has over the years become one of the standards in the field. The CARS has good psychometrics, has been translated into a number of languages, and has recently been revised. This scale continues to be widely used and has demonstrated admirable longevity.

Rutter and associates developed two measures that are more in depth than the CARS, but also follow Rutter’s (1978) symptom formulation. Developed as semi-structured diagnostic tools, the Autism Diagnostic Interview (ADI), now revised (ADI-R) and the Autism Diagnostic Observation Schedule (ADOS), have been widely used over the past three decades.

What these three scales in particular, and many other scales as well, have established are high test standards. The use of the standardized test with established reliability, validity and norms is an essential part of the diagnostic process. Thus, best practice no longer involves using DSM or WHO criteria with parent interview, and child observation only. The debate has evolved into selecting which measure or measures of core symptoms of ASD should be involved in making the diagnosis.
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