Title
Myths and Realities of Evaluation and Diagnosis of Autism Spectrum Disorder

Presenters

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Abstract

Schools and communities are seeing an increase in requests for assessment of autism spectrum disorders (ASD). There are many benefits of evaluation that can only be realized through quality work. Accurate evaluation and diagnosis of ASD are critical to obtaining appropriate services and supports. Conversely, the potential for harm is ever-present. High quality work results from evaluation by a team of experts. Expertise in characteristics of ASD, evaluation tools, and diagnostic and eligibility criteria are necessary but not sufficient characteristics of an effective evaluation team. Unfortunately, the field is far from where it needs to be.

One of the greatest obstacles in improving assessment is the proliferation of myths. These myths may become part of a "culture of misunderstanding" that is perpetuated in school boards and communities and can have a direct negative impact on the services and supports that individuals with ASD receive. Myths are present in all aspects of assessment from understanding the diagnostic guide itself to appropriate use of instruments and misperception of the characteristics of ASD.

Evaluation of ASD requires knowledge and experience. Professionals who are not skilled in the art of evaluation can misdiagnose and cause unnecessary and costly delays. While it is unethical for professionals who are not competent to conduct evaluations, it is a common occurrence. Research is showing that long-term outcomes for individuals on the spectrum are often poor (Seltzer & Krauss, 2002). Many individuals with ASD are not achieving their potential. Myths play a role in these outcomes. Studies have shown that early intervention is critical to improving long-term outcomes (Dawson, Rogers, Munson, Smith, Winter, et al., 2010; Harris & Handleman, 2000). This emphasizes the importance of early identification of ASD. While accurate diagnosis is possible by age two, delays of two years or more are commonly seen (CDC, 2009; Chakrabati & Fombonne, 2001; Charman & Baird, 2002; Lord, 2005; Lord, & Spence, 2006). Delays often result from myths. For example, when first confronted with parent concerns, some professionals simply dismiss them—assuming that parents' perceptions are inaccurate. In fact, research has shown that parents are accurate reporters of their child's symptoms (see Filipek, et al., 2000). Other professionals delay assigning a diagnosis because they believe that the most conservative approach is to "Wait and see." Given the benefits of early intervention, the contrary is true. This is supported in the guidelines adopted by the American Academy of Pediatrics (Johnson, Myers, & Council on Children with Disabilities, 2007).

Some delays in identification result from a poor understanding of ASD. For example, there is a common misbelief belief that individuals with ASD cannot have friends. In fact, there is no single behavior that could rule in or rule out an ASD. Autism spectrum disorders are defined by a pattern of behaviors. This myth causes harm by resulting in failure to identify individuals who need support and services.

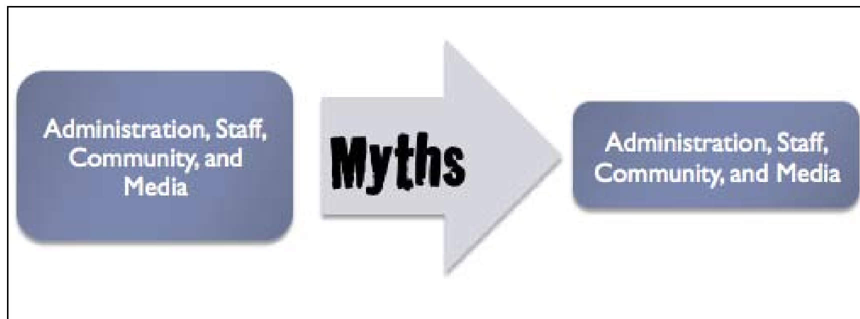
Some professionals believe that the current Diagnostic and Statistical Manual (DSM-IV-TR) provides concrete rules for diagnosis of ASD. In fact, according to the DSM, the criteria are meant to serve as guidelines for diagnosis (APA, 2000). Further, the APA stresses the importance of clinical judgment. While the use of a categorical diagnostic system has been shown to aid in accurate identification (Klin, Lang, Cicchetti, & Volkmar, 2000), the characteristics of ASD outlined in the DSM are not as sensitive when applied to children under the age of three (Volkmar, Chawarska, & Klin, 2005) and some of the criteria are not even applicable for this young population (Stone, Lee, Ashford, Brissie, Hepburn, et al., 1999). For example, DSM criteria, such as unusual stereotyped movements and behaviors, do not emerge until later (Volkmar, et al., 2005). In sum, strict interpretation of the guide and dismissal of sound clinical judgment have lead many to make incorrect diagnostic decisions and ultimately impacts the patient/client.

There is a fundamental misperception of the nature of clinical diagnosis and how it differs from "medical diagnosis." A clinical diagnosis of ASD is based on observations of behaviors while a medical diagnosis is based on medical tests. To date, there are no reliable medical tests to evaluate ASD; therefore, there a "medical diagnosis" is itself a myth. The mistaken use of this term falsely conveys to others that accurate evaluation can be made only by medical professionals. In fact, there is no presumption of expertise that can be made based on field or degree.

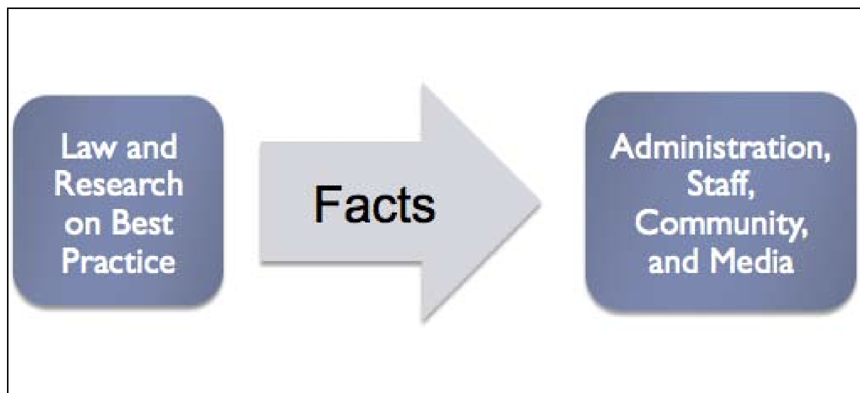
There are some who know how to administer standardized measures used to diagnose ASD but lack the knowledge to properly interpret them. Many assessment tools provide cut-off scores to assist in accurate diagnosis and identification of ASD. The nature of these scores in autism evaluation is highly misunderstood and frequently misused. Without the prerequisite knowledge, individuals who lack clinical judgment rely heavily on these cut-off scores to "tell them" if their client has ASD. In contrast, good clinicians know that tests are tools. They use their knowledge of ASD to *interpret* test results in the context of other data in order to make an informed decision. Clinical judgment develops from specialized training and experience.

There are myths concerning special education law that impact proper identification of students. Many staff members hold these myths to be true because they have been told, "This is how it is done." It is important to refer to the law and to provide ongoing training to staff on updates to the law. Myths result in the failure to provide appropriate services and supports in the schools.

Myths are spread easily and can be difficult to overcome. It is essential that accurate information be disseminated and maintained. We need to move from a culture of misunderstanding to a culture of understanding.



Culture of Misunderstanding



Culture of Understanding

This session will explore common myths associated will all aspects of evaluation and diagnosis of individuals with ASD. Topics including intellectual, speech and language, sensory motor, adaptive, achievement, and psychological assessment of individuals with ASD will also be discussed.

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