

Assessing Autism Spectrum Disorders

Guidelines for Parents and Educators

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THE DIAGNOSIS OF AUTISM SPECTRUM DISORDERS (ASDS) PRESENTS A MAZE OF QUESTIONS THAT CAN BE PERPLEXING FOR PARENTS AND EDUCATORS. WHEN IS THE RIGHT TIME TO SEEK AN ASSESSMENT? WHO SHOULD CONDUCT THE ASSESSMENT? WHAT SHOULD BE INCLUDED IN THE ASSESSMENT? THIS ARTICLE WILL PROVIDE GUIDELINES TO HELP PARENTS AND EDUCATORS TO NAVIGATE THIS MAZE.



When is the Right Time to Seek an Assessment?

The importance of early identification and treatment of ASDs has been well established. Parents and educators should seek assessment as soon as signs become evident. Early symptoms of ASDs may be apparent by the age of 12 months to 18 months or sooner. While diagnosis often is possible by the age of two (Lord & Spence, 2006), most children are not identified until years later. Indeed, there typically is a delay of two to three years after symptoms first become apparent (Filipek, et al., 2000). Because early intervention

makes a critical difference in the progress of people with ASDs, delay in identification is a matter of great concern.

Many factors, including symptom severity, race, gender and attitudes toward diagnosis, contribute to the delay in identification. Children with more severe communication deficits tend to be diagnosed at younger ages than those with primarily pragmatic language (social language) challenges. As a result, the average age of diagnosis of autism is four to five years earlier than Asperger’s disorder. Special awareness of the relationships between race and gender also is needed with early identification. Research has found that African-American children are identified later and receive alternative diagnoses prior to being identified with an ASD (Mandell, Ittenbach, Levy, & Pinto-Martin, 2006). Further, it is well established that girls are diagnosed at a later age than boys. Finally, evaluators sometimes hesitate to assign a diagnosis for fear of the impact of the label or misdiagnosis. Likewise, parents may hesitate to accept the diagnosis for the same reasons. Given the benefits of early intervention, the risks associated with delayed identification carry serious consequences.

Who Should Conduct the Assessment?

There is extensive literature regarding the best instruments and techniques for identifying ASD; however, even the best instruments are meaningless when those interpreting them do not have the training and experience to make accurate judgments. Assessment of ASDs may be completed by a number of professionals, including psychologists, neurologists, pediatricians or psychiatrists. Parents and educators should be careful not to make assumptions about the knowledge base of professionals. In each of these fields, there are those who are knowledgeable in ASD assessment and those for whom this is not a strength. It is most important to find specialists who are knowledgeable and experienced in assessing ASDs. The *field* of the professional is less important than *expertise*.

Seeking an assessment from an experienced and knowledgeable professional prevents delay in accurate identification and frustration of unanswered questions. Parents often describe experiences of being told that their child is “going through a phase” and that they need to be patient while their child “grows out of it.” Others report that they have been advised that a single behavior, such as showing affection or using sentences, indicates that their child does not have ASD. These same

parents later may learn that their child has the diagnosis. Early encounters with professionals who provided false reassurance may sabotage parents’ receptiveness to the input of others who recognize the symptoms of ASD exhibited by their child. Alternatively, the error of incorrectly assigning the diagnosis of an ASD carries risks. Working with professionals with expertise in ASD helps to avoid these pitfalls.

Parents and educators should know that the terminology surrounding assessment can be confusing. In particular, the terms “medical diagnosis” “diagnosis” and “eligibility” are often misunderstood. While the term “medical diagnosis” is often used, it is a misnomer. “There are no medical tests for diagnosing autism. An accurate diagnosis must be based on observation of the individual’s communication, behavior and developmental levels.” (Autism Society of America, n.d.) Wide use of the term also has resulted in the false belief that the diagnosis must be made by a medical professional. In fact, in the absence of specific medical concerns, many specialized teams do not require staff with medical training.

The contrast between “diagnosis” and “eligibility” is subtle (see Table 1). The term diagnosis is used most often in assessments conducted in the private sector. Diagnosis in the United States most often is based on the current *Diagnostic and Statistical Manual (DSM-IV-TR)*. In this system, the umbrella category of pervasive developmental disorders encompasses autistic disorder, pervasive developmental disorders - not otherwise specified, Asperger’s disorder and others.

TABLE 1.

DIAGNOSIS VERSUS ELIGIBILITY	
DIAGNOSIS	ELIGIBILITY
Based on a set of criteria (e.g., DSM-IV-TR).	Based on federal law (IDEA).
Refers to a specific disorder (e.g., autistic disorder, Asperger’s disorder).	Refers to a broad disability category.
Used in private settings.	Used only in public school system.
May be determined by an individual or team.	Must be determined by a team.

Assessment in the public school system is conducted for the purposes of establishing *eligibility* for special education services and gathering information to assist in planning an individualized

education program. The Individuals with Disabilities Education Act (IDEA) defines the eligibility category of “autism” as a disability that affects communication and social interaction. When there is a need for an assessment to determine eligibility for autism (or any eligibility category), it is the responsibility of the public schools to provide it, at no expense, to the family. According to IDEA, autism may have associated features, such as repetitive activities, stereotyped movements, resistance to change and unusual sensory responses. Students with characteristics of DSM diagnoses, including autistic disorder, Asperger’s disorder, pervasive developmental disorders - not otherwise specified or other ASDs may qualify under the eligibility category of “autism.” A disability must have an adverse effect on a student’s education for the student to be considered eligible for special education services. Therefore, a previous diagnosis in the private sector does not necessarily result in eligibility in the public

integrated, and decisions are made with little collaboration.

Participants in interdisciplinary assessment teams should have expertise in their field as well as in ASDs. Assessment teams typically include a speech pathologist and a psychologist.

Based on the needs of the individual, additional team members may include a specialist in cognitive assessment, an occupational therapist, a physical therapist or a medical professional. Federal law mandates that autism spectrum assessments in the schools be conducted by professionals from multiple disciplines. In contrast, there is no such requirement in the private sector. In both the public schools and the private sector, assessments can range in quality (from a diagnosis jotted down on a prescription pad to a thorough interdisciplinary team assessment report). Parents and educators should ask questions about the approach being used. Another area to consider is the scope of the ASD assessment.

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schools. Unfortunately, school teams sometimes fail to consider educational factors beyond academics. As a result, academically capable students with ASDs who display deficits in socialization that impact educational progress often are not served.

What Should Be Included in the Assessment?

Autism spectrum disorders are classified as pervasive developmental disorders. This means that multiple areas of functioning are impacted. Due to the complex nature of ASDs, a comprehensive assessment that addresses a range of areas must be conducted by professionals with expertise across a number of fields. This is best accomplished through an interdisciplinary approach.

An interdisciplinary approach to assessment results in the strongest diagnostic and programming decisions. The word “interdisciplinary” is not interchangeable with the word “multidisciplinary.” While both approaches involve professionals from various fields, only in interdisciplinary assessment do professionals work in a truly collaborative manner to integrate information for diagnostic and programming decisions. In contrast, in a multidisciplinary approach, results are compiled, rather than

A comprehensive autism spectrum evaluation should include a developmental history, observations, direct interaction, a parent interview and an evaluation of functioning in the following areas: social, communication, sensory, emotional, cognitive and adaptive behavior. At times, additional assessments are indicated. For example, significant motor difficulties or suspicion of seizures require further evaluation. By gathering information across multiple areas, a complete diagnostic picture can be obtained. A thorough assessment helps parents and educators to make more comprehensive treatment decisions. The results of the ASD evaluation should be summarized in a written report and include specific and meaningful recommendations. The evaluation should be followed by a face-to-face feedback session with the opportunity for questions.

Summary

There are real benefits of early identification and treatment based on accurate and comprehensive assessment. In contrast, incomplete assessment results in a limited understanding of strengths and needs and, in turn, decreases the quality of care. Because of the importance of early identification, parents and

educators should learn the signs of ASDs and refer for screening and assessment if symptoms are observed. Parents and educators may further advocate for children by seeking a comprehensive, interdisciplinary assessment completed by evaluators who are knowledgeable and experienced in assessing ASDs.

ABOUT THE AUTHORS

Ruth Aspy, Ph.D., and Barry G. Grossman, Ph.D., are licensed psychologists with the Ziggurat Group who specialize in assessment and intervention for individuals with ASDs. Together, they wrote *The Ziggurat Model, a book on designing interventions for students with Asperger's disorder and high-functioning autism.*

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Correction from the Editor:

The following poem by a young man on the autism spectrum was printed in the last edition of the *Autism Advocate* (2nd ed. 2007, vol. 47) with two typographical errors. I have made the corrections and am re-printing it with sincere apologies to the author.

Robin Gurley, ASA Managing Editor

I Am

BY DYLAN GONZALEZ

I am restless and intelligent
 I wonder where we will all be in ten years
 I hear the rustling chatter of a thousand students
 I see endless avenues of growth
 I want a world with no war and
 global brotherhood

I am restless and intelligent
 I pretend I have been talking all along
 I feel happy about being more capable
 I touch the lives and hearts of all who know me
 I worry I won't ever overcome my speech disabilities
 I cry from frustration and pain

I am restless and intelligent
 I understand why I need teachers and role models
 I say most everything through writing
 I dream of attaining impossible total independence
 I try harder each day than the day before
 I hope everybody will always be safe and happy

I am restless and intelligent

*Dylan Gonzalez is a 13-year-old
 on the autism spectrum.*