

# Evaluation for Identification and Programming and Issues Related to Eligibility vs. Diagnosis

Autism spectrum disorders (ASD) are not rare. In 2009, the Centers for Disease Control and Prevention (CDC) reported the average prevalence rate to be 1 in 110 for 8-year-old children (CDC, 2009). Research has shown that early treatment leads to better outcomes (Dawson & Osterling, 1997; Eikeseth, Smith, Jahr, & Eldevik, 2007). Therefore, early identification can make a critical difference in the lives of individuals with autism. Conversely, delay in identification and intervention is a matter of great concern (Siklos & Kerns, 2007).

## Early Recognition of Autism

Typically, parents are the first to suspect developmental differences in children with autism spectrum disorders. Parents' first concern, usually when the child is 17 to 19 months old, is most often related to a delay in the development of language (De Giacomo & Fombonne, 1998). Unfortunately, when these concerns are initially reported to professionals, they are met with reassurance that there is nothing to worry about; reflecting either a reluctance to label young children or a lack of knowledge about autism spectrum disorders (Coonrod & Stone, 2004). Thus, a two-year delay between the first contact with professionals regarding concerns related to autism spectrum disorders and the official diagnosis is not uncommon (Filipek et al., 2000).

In response to this critical and often unwarranted delay, the American Academy of Pediatrics released a clinical report with guidelines for identifying children with autism spectrum disorders (Johnson, Myers, & Council on Children with Disabilities, 2007). The guidelines emphasize the importance of early intervention and recommend surveillance for autism spectrum disorders at every well-child visit. In addition, formal screening at 18 and 24 months (or at any point when a parent raises concern) is advised. When multiple risk factors are present, it is recommended that the physician avoid adopting a "wait-and-see" approach (p. 1206). Further, the report emphasizes the importance of a team evaluation conducted by specialists in autism spectrum disorders.

Because of the importance of early intervention, if a student has not been identified by school age, it is essential for school professionals to recognize the signs of autism, to respect the validity of parents' concerns, and to use effective tools for screening and identification.

## Diagnosis and Eligibility

Assessment in the public schools is conducted for purposes of identification or establishing eligibility for special education services and to assist in planning an individualized education program (IEP). In Texas, assessment for identification requires that a licensed or certified specialist, such as a licensed specialist in school psychology or a speech pathologist, be involved in the assessment. Evaluation for programming, on the other hand, can be conducted by educational professionals. It is the responsibility of the public schools to provide for assessment (and eligibility determination) of autism at no expense to the family.

The contrast between diagnosis and eligibility is subtle. The term "diagnosis" is used most often in assessments conducted in the private sector. In the United States, diagnosis is based on the current edition of the *Diagnostic and Statistical Manual of Mental Disorders* (DSM), currently the 4<sup>th</sup> Edition, Text Revision (DSM-IV-TR, American Psychiatric Association, 2000). In other countries, the International Classification of Diseases-10<sup>th</sup> Revision (ICD-10; World Health Organization, 1993) serves as the diagnostic guide.

...the terminology surrounding assessment can be confusing. In particular, the terms "medical diagnosis," "diagnosis," and "eligibility" are frequently 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 has also 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. (Aspy & Grossman, 2007, p. 12)

The Individuals with Disabilities Education Act (IDEA; 2004) defines autism as a disability that affects communication and social interaction. In addition, associated features, such as repetitive activities, stereotyped movements, resistance to change, and unusual sensory responses, may be present. In Texas, students with DSM diagnoses, including Autistic Disorder, Asperger Syndrome, Rett Syndrome, Childhood Disintegrative Disorder, Pervasive Developmental Disorders-Not Otherwise Specified or other pervasive developmental disorders, may qualify under the eligibility category of autism.

A diagnosis of autism spectrum disorders in the private sector does not necessarily result in eligibility in the public schools. In order for a child to be eligible for special education supports and services, his or her disability must have an adverse effect on the student's education. Unfortunately, school evaluation teams sometimes fail to consider educational factors beyond traditional academics. As a result, academically capable students with autism spectrum disorders who display deficits in socialization and communication that impact educational progress often are not served.

This practice conflicts with the very purpose of special education. According to federal law (IDEA), the purpose of special education is "to ensure that all children with disabilities have available to them a free appropriate public education that emphasizes special education and related services designed to meet their *unique* needs and *prepare* them for *further education, employment, and independent living*" (Individuals with Disabilities Education Act, 2004, §300.1; emphasis added). In light of this purpose, it is evident that the social and communication deficits displayed by students with autism must be included in the evaluation of educational need. In order to properly prepare students in these areas, the curriculum must include intervention beyond traditional academics.

## Diagnosis versus Eligibility

Diagnosis	Eligibility
Based on a set of criteria (e.g., DSM-IV-TR, ICD-10)	Based on federal law (IDEA)
Refers to a specific disorder (e.g., Autistic Disorder, Asperger 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

## Educational Need

Education need may include:

- Academic performance
- Social functioning
- Organizational skills
- Problem-solving skills
- Hygiene
- Attention
- Vocational assessment
- Communication functioning
- Pragmatic language
- Group work skills
- Emotional regulation
- Behavior
- Daily living skills/adaptive behavior

## Differential Diagnosis

Many of the characteristics of autism are also seen in other diagnostic conditions. What makes autism unique from other disorders is a pattern or “triad” of characteristics, including impairments in social interaction and communication, and the presence of restricted, repetitive behaviors. Trained and experienced evaluation professionals are able to use a range of information to distinguish autism spectrum disorders from other disorders by close examination of the student’s developmental history and presentation of symptoms.

Often individuals with autism spectrum disorders meet the criteria for one or more additional diagnoses. According to one study, co-occurring diagnoses or comorbidity “is to be expected” (Gillberg & Billstedt, 2000, p. 327). Indeed, in one study 65% of individuals with Asperger Syndrome were diagnosed with at least one other psychiatric disorder (Ghaziuddin, Weidmer-Mikhail, & Ghaziuddin, 1998). Disorders that often coexist with autism spectrum disorders include anxiety, depression, attention-deficit/hyperactivity disorder (ADHD), bipolar disorder, fetal alcohol syndrome, nonverbal learning disabilities, and obsessive-compulsive disorder.

If a student who is eligible for special education under the category of Autism or Other Pervasive Developmental Disorder has an additional eligibility, the student should be served under both categories. IDEA stipulates “Autism does not apply if a child’s educational performance is adversely affected primarily because the child has an emotional disturbance” (IDEA, 2004, §300.8, (c)(1)(ii)). In the vast majority of cases, Autism or Other Pervasive Developmental Disorder is appropriately considered the primary eligibility area. For example, when disorders such as depression or anxiety are observed, autism is most likely the underlying or “primary” disorder. Given that, by definition, symptoms of autism must emerge by age 3, it is difficult to imagine a scenario where symptoms of anxiety or depression precede the autism.

#### **Other Conditions That May Share Some Characteristics with Autism Spectrum Disorders**

• Attention-deficit/hyperactivity disorder (ADHD)	• Early speech delays
• Obsessive-compulsive disorder	• Cognitive disabilities
• Bipolar disorder	• Nonverbal learning disabilities
• Reactive attachment disorder	• Fetal alcohol syndrome
• Schizophrenia	• Visual impairment

## **Texas Eligibility Criteria for Autism or Other Pervasive Developmental Disorders**

Autism is a developmental disability significantly affecting verbal and nonverbal communication and social interaction, generally evident before age 3 that adversely affects a child's educational performance. Other characteristics often associated with autism include engagement in repetitive activities and stereotyped movements, resistance to environmental change or change in daily routines, and unusual responses to sensory experiences.

(ii) Autism does not apply if a child's educational performance is adversely affected primarily because the child has an emotional disturbance, as defined in paragraph (c)(4) of this section.

(iii) A child who manifests the characteristics of autism after age three could be identified as having autism if the criteria in paragraph (c)(1)(i) of this section are satisfied.

## **DSM-IV-TR Characteristics of Autistic Disorder, Asperger's Disorder, Rett's Disorder, and Childhood Disintegrative Disorder, and Pervasive Developmental Disorder-Not Otherwise Specified**

### **Autistic Disorder (American Psychiatric Association, 2000)**

A. A total of six (or more) items from (1), (2), and (3), with at least two from (1), and one each from (2) and (3):

1. Qualitative impairment in social interaction, as manifested by at least two of the following:
  - a. Marked impairment in the use of multiple nonverbal behaviors such as eye-to-eye gaze, facial expression, body postures, and gestures to regulate social interaction
  - b. Failure to develop peer relationships appropriate to developmental level

- c. A lack of spontaneous seeking to share enjoyment, interests, or achievements with other people (e.g., by a lack of showing, bringing, or pointing out objects of interest)
  - d. Lack of social or emotional reciprocity
1. Qualitative impairment in communication as manifested by at least one of the following:
    - a. Delay in, or total lack of, the development of spoken language (not accompanied by an attempt to compensate through alternative modes of communication such as gesture or mime)
    - b. In individuals with adequate speech, marked impairment in the ability to initiate or sustain a conversation with others
    - c. Stereotyped and repetitive use of language or idiosyncratic language
    - d. Lack of varied, spontaneous make-believe play or social imitative play appropriate to developmental level
  2. Restricted repetitive and stereotyped patterns of behavior, interests, and activities, as manifested by at least one of the following:
    - a. Encompassing preoccupation with one or more stereotyped and restricted patterns of interest that is abnormal either in intensity or focus
    - b. Apparently inflexible adherence to specific, nonfunctional routines or rituals
    - c. Stereotyped and repetitive motor mannerisms (e.g., hand or finger flapping or twisting, or complex whole-body movements)
    - d. Persistent preoccupation with parts of objects
- B. Delays or abnormal functioning in at least one of the following areas, with onset prior to age 3 years: (1) social interaction, (2) language as used in social communication, or (3) symbolic or imaginative play.
- C. The disturbance is not better accounted for by Rett's Disorder or Childhood Disintegrative Disorder.

**Asperger's Disorder (American Psychiatric Association, 2000)**

- A. Qualitative impairment in social interaction, as manifested by at least two of the following:
  - 1. Marked impairment in the use of multiple nonverbal behaviors such as eye-to-eye gaze, facial expression, body postures, and gestures to regulate social interaction
  - 2. Failure to develop peer relationships appropriate to developmental level
  - 3. A lack of spontaneous seeking to share enjoyment, interests, or achievements with other people (e.g., by a lack of showing, bringing, or pointing out objects of interest to other people)
  - 4. Lack of social or emotional reciprocity
- B. Restricted repetitive and stereotyped patterns of behavior, interests, and activities, as manifested by at least one of the following:
  - 1. Encompassing preoccupation with one or more stereotyped and restricted patterns of interest that is abnormal either in intensity or focus
  - 2. Apparently inflexible adherence to specific, nonfunctional routines or rituals
  - 3. Stereotyped and repetitive motor mannerisms (e.g., hand or finger flapping or twisting, or complex whole-body movements)
  - 4. Persistent preoccupation with parts of objects
- C. The disturbance causes clinically significant impairment in social, occupational, or other important areas of functioning.
- D. There is no clinically significant general delay in language (single word used by age 2 years, communicative phrases used by age 3 years).
- E. There is no clinically significant delay in cognitive development or in the development of age appropriate self help skills, adaptive behavior (other than in social interaction), and curiosity about the environment in childhood.
- F. Criteria not met for another Pervasive Developmental Disorder or Schizophrenia.

**Rett's Disorder (American Psychiatric Association, 2000)**

- A. All of the following:
  - 1. Apparently normal prenatal and perinatal development
  - 2. Apparently normal psychomotor development through the first 5 months after birth
  - 3. Normal head circumference at birth
- B. Onset of all of the following after the period of normal development:
  - 1. Deceleration of head growth between ages 5 and 48 months
  - 2. Loss of previously acquired purposeful hand skills between ages 5 and 30 months with the subsequent development of stereotyped hand movements (e.g., hand-wringing or hand washing)
  - 3. Loss of social engagement early in the course (although often social interaction develops later)
  - 4. Appearance of poorly coordinated gait or trunk movements
  - 5. Severely impaired expressive and receptive language development with severe psychomotor retardation

**Childhood Disintegrative Disorders (American Psychiatric Association, 2000)**

- A. Apparently normal development for at least the first 2 years after birth as manifested by the presence of age-appropriate verbal and nonverbal communication, social relationships, play, and adaptive behavior.
- B. Clinically significant loss of previously acquired skills (before age 10 years) in at least two of the following areas:
  - 1. Expressive or receptive language
  - 2. Social skills or adaptive behavior
  - 3. Bowel or bladder control
  - 4. Play
  - 5. Motor skills

- C. Abnormalities of functioning in at least two of the following areas:
1. Qualitative impairment in social interaction (e.g., impairment in nonverbal behaviors, failure to develop peer relationships, lack of social or emotional reciprocity)
  2. Qualitative impairments in communication (e.g., delay or lack of spoken language, inability to initiate or sustain a conversation, stereotyped and repetitive use of language, lack of varied make-believe play)
  3. Restricted, repetitive, and stereotyped patterns of behavior, interests, and activities, including motor stereotypes and mannerisms
- D. The disturbance is not better accounted for by another specific Pervasive Developmental Disorder or by Schizophrenia.

**Pervasive Developmental Disorder – Not Otherwise Specified (American Psychiatric Association, 2000)**

Severe and pervasive impairment in the development of reciprocal social interaction associated with impairment in either verbal or nonverbal communication skills or with the presence of stereotyped behavior, interests, and activities, but the criteria are not met for a specific Pervasive Developmental Disorder, Schizophrenia, Schizotypal Personality Disorder, or Avoidant Personality Disorder. For example, this category includes “atypical autism” – presentations that do not meet the criteria for Autistic Disorder because of late age at onset, atypical symptomatology, or subthreshold symptomatology, or all of these.

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## Resources and Materials

Autism Internet Modules: <http://www.autisminternetmodules.org/>. The Autism Internet Modules provide information on the characteristics of autism spectrum disorders, assessment, and intervention.

First Signs: <http://www.firstsigns.org/>. This website identifies the characteristics or signs of autism spectrum disorders that facilitate early identification.

Legal Framework for the Child-Centered Special Education Process - <http://framework.esc18.net/>. The Legal Framework for the Child-Centered Process is a template in an electronic format that summarizes state and federal requirements for special education by topic.

National Institute of Mental Health: <http://www.nimh.nih.gov/health/topics/autism-spectrum-disorders-pervasive-developmental-disorders/index.shtml>. This website provides information on autism spectrum disorders.

Texas Project First: <http://www.texasprojectfirst.org/>. This website was created by parents for parents. It is a project of the Texas Education Agency and is committed to providing accurate and consistent information to parents and families of students with disabilities.