Myths and Realities of Evaluation, Identification, and Diagnosis of ASD

Ruth Aspy, Ph.D., Barry Grossman, Ph.D., Penny Woods, M.S. Ed., & Susan Jamieson, M.Ed.

The Ziggurat Group

www.texasautism.com

Autism Spectrum Disorder

Research on Outcomes

Outcome

- Of adults 22 and older, 73% lived with their parents
- 90% could not gain or keep employment
- 95% had difficulty making and keeping friends

Outcome

Findings from a 2008 study (Cederlund, Hagberg, Billstedt, Gillberg, & Gillberg, 2008)
- Outcome for males with Asperger’s were worse than expected (given their high IQs), but better than males with autism.

A Study in Contradictions

- 22% have IQs in the superior to very superior range
- 12% are employed full-time**
  - 1% of this 12% are employed in an area in which they were trained/educated

**most did not have interventions at a young age

Brenda Smith Myles

Myths and the Culture of Misunderstanding

Belief in Myths Causes Harm
**Myths Harm**

- Myths result in delayed identification
- Myths result in delayed intervention
- Myths prevent students from being identified
- Myths prevent students from receiving services

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**Culture of Misunderstanding**

![Diagram showing the flow from Myths to Administration, Staff, Community, and Media]

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**Culture of Understanding**

![Diagram showing the flow from Law and Research on Best Practice to Facts to Administration, Staff, Community, and Media]

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**Myth: Individuals with autism do not make good eye contact**

Reality: There is no SINGLE behavior that rules in or rules out ASD. Diagnosis is based on a pattern of symptoms

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**Myth: Individuals with autism do not play with others**

Reality: There is no SINGLE behavior that rules in or rules out ASD. Diagnosis is based on a pattern of symptoms

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**Myth: Individuals with autism do not show affection**

Reality: There is no SINGLE behavior that rules in or rules out ASD. Diagnosis is based on a pattern of symptoms
Autism Spectrum Disorders

- Pattern of behaviors
- Impairments in social interaction
- Communication
- Restricted, repetitive patterns of behaviors, interests, or activities

Myth: The Purpose of the DSM is to provide concrete rules for diagnosis
Reality: The DSM criteria are guidelines

Not a “Cookbook”

“The specific diagnostic criteria included in the DSM are meant to serve as guidelines to be informed by clinical judgment and are not meant to be used in a cookbook fashion” (APA, p. xxxii)

Proposed Revisions for DSM-V (2013)

- New name: Autism Spectrum Disorder
  - Autistic Disorder
  - Asperger’s Disorder
  - Childhood Disintegrative Disorder
  - Pervasive Developmental Disorder NOS
- Characteristics in two domains
  - Social/communication deficits
  - Fixated interests and repetitive behaviors

Myth: A private diagnosis is required to be eligible for special education supports and services
Reality: Eligibility is the responsibility of the school district
Question

“Am I correct in assuming that the diagnosis of an ASD is made by a healthcare professional such as a neurologist or psychiatrist? And, then schools use that information to provide appropriate educational services, correct?”

Incorrect Answer

“It depends on the state in which you live. Some states allow for the educational diagnosis of autism under the Individuals with Disabilities Education Act. For example, Nebraska’s Rule 51 defines the educational diagnosis of autism…”

Child Find – 20 USC §1412

All children with disabilities residing in the State, including children with disabilities … regardless of the severity of their disabilities, and who are in need of special education and related services, are identified, located, and evaluated and a practical method is developed and implemented to determine which children with disabilities are currently receiving needed special education and related services.

All Areas of Suspected Disability

A child must be tested in all areas of suspected disability. 20 U.S.C. § 1414(b).

How Does Your District Identify…?

- Learning Disabilities
- Speech Impairment
- Emotional Disturbance
- Autism Spectrum Disorders

Diagnosis Versus Eligibility

<table>
<thead>
<tr>
<th>Diagnosis</th>
<th>Eligibility</th>
</tr>
</thead>
<tbody>
<tr>
<td>Based on a set of criteria (e.g., DSM-IV-TR, ICD-10)</td>
<td>Based on federal law (IDEA)</td>
</tr>
<tr>
<td>Refers to a specific disorder (e.g., Autistic Disorder, Asperger Disorder)</td>
<td>Refers to a broad disability category</td>
</tr>
<tr>
<td>Used in private settings</td>
<td>Used only in public school system</td>
</tr>
<tr>
<td>May be determined by an individual or team</td>
<td>Must be determined by a team</td>
</tr>
</tbody>
</table>
IDEA Definition of Autism

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

34 CFR 300.8(c)(1)(i)

Comparison of DSM and IDEA

<table>
<thead>
<tr>
<th>DSM-IV-TR</th>
<th>Federal Definition of Autism</th>
</tr>
</thead>
<tbody>
<tr>
<td>Qualitative Impairments in social interaction</td>
<td></td>
</tr>
<tr>
<td>a) marked impairment in the use of multiple nonverbal behaviors such as eye-to-eye gaze, facial expression, body posture, and gestures to regulate social interaction</td>
<td>Disability affecting nonverbal communication</td>
</tr>
<tr>
<td>b) failure to develop peer relationships appropriate to developmental level</td>
<td>Disability affecting social interactions</td>
</tr>
<tr>
<td>c) a lack of spontaneous seeking to share enjoyment, interests, or achievements with others (e.g., by a lack of showing, bringing, or pointing out objects of interest)</td>
<td>Disability affecting social interactions</td>
</tr>
<tr>
<td>d) Lack of social or emotional reciprocity</td>
<td>Disability affecting social interactions</td>
</tr>
</tbody>
</table>

Parent Educational Level Does Not Cause Autism

“[Higher education] gets you the diagnosis more frequently.” says Irva Hertz-Picciotto, one of the study’s authors and a researcher at the UC Davis MIND Institute.

Wall Street Journal online February 1, 2010

Parent Educational Levels and the Autism Cluster in California

“Families often have to fight with state bureaucracies to be deemed eligible for services, and some spend thousands of dollars for private evaluations. ‘You can see the possibility for inequity according to social advantage or cultural background.’

- James McCracken, Child Psychiatrist

Identification Imbalance

- It is not appropriate to have a system where those “in the know” and those with means have access to evaluation services and those with less education and less resources do not.
IDEA – There Should Be No Imbalance

IDEA requires that “…all children with disabilities…who are in need of special education and related services…are identified, located, and evaluated…” - Child Find 20 USC § 1412

This includes any and ALL areas of suspected disability - 20 U.S.C. § 1414(b)

Moral of the Story

Eligibility is the responsibility of the school district.

- This means that school districts MUST provide for evaluation in ALL areas of suspected disability, AND...
- If a district does not conduct the required evaluation, they must pay for the evaluation and ensure that the law (IDEA) is followed.

Myth: The statewide average identification rate is a good guide for school districts in determining the accuracy of their own rate of identification

Reality: Most states under-identify in comparison to National/International prevalence rates

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Best Guide

- The National prevalence rate is the best estimate that is available.
- Underidentification = Underserved

Myth: Autism is a medical diagnosis

Reality: There are NO medical tests for diagnosing autism. Autism is a clinical diagnosis.
Myth of “Medical Diagnosis”

“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.)

Clinical Judgment

“It is important to remember that ASD is first of all a clinical diagnosis. Therefore, it is mandatory to have a trained and experienced provider coordinate the results of the complex diagnostic process”

(Freeman & Cronin, 2002, p. 4)

Expertise is Key

- The field of the professional is less important than the expertise of the professional.

IDEA Definition of Autism

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(Myth: A student who can pass the state exam does not have an educational need for special education
Reality: Educational need does not equate to “academic need”

300.8(c)(1)(i)
Eligibility and the Myth of Educational Need

- Educational need extends beyond academics and includes social, emotional, and adaptive skills.
- This concept applies to both initial and reevaluations. Evaluation teams must always consider the functional performance of a student.
- Consider changing needs/demands (e.g., social demands in 7th grade differ from 3rd grade).

Eligibility and Educational Need

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

Myth: Students with Asperger’s are not eligible for special education

Reality: Asperger Syndrome is covered by Federal Law

Adverse Effect on Educational Performance

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

Eligibility and Educational Need

- “A child with Asperger’s Disorder may be more verbal than other children with autism and may have average or above average intelligence, yet still be in need of services.”


IDEA Definition of Autism

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

- 300.8(c)(1)(i)
Myth of Asperger Syndrome and Eligibility

- Individuals with Asperger Syndrome have a pervasive developmental disorder. It is impossible to have a “pervasive” disorder and not be significantly impacted.
- While many of these individuals are highly intelligent and articulate, they have significant impairments and often require supports and services in order to make educational progress.

Myth: If a student has an emotional disturbance they cannot be eligible under the category of autism

Reality: Regardless of the presence of an behavioral disturbance, a student can be served under the category of autism

“Primary”

- Autism does not apply if a child’s educational performance is adversely affected primarily because the child has an emotional disturbance… 300.8(c)(1)(ii)
- Primary
  1. Of chief importance; principal
  2. Earliest in time or order of development

Macintosh Dictionary

Comorbid Psychiatric Disorders

“Comorbidity is to be expected” (Gillberg & Schulsink, 200, p.277)
- ~65% comorbid psychiatric disorder (Ghaziuddin et al., 1998)
- 44% Specific Phobia (Leyfer, et al., 2006)
- 37% Obsessive Compulsive Disorder (Leyfer, et al., 2006)
- 31% ADHD (Leyfer, et al., 2006)
- ~10% Major Depression (Leyfer, et al., 2006)

Consequences of Late Diagnosis – Consider Which is Primary

- Autism
- Asperger's
- PDD-NOS
- Social Isolation
- Peer Rejection
- Lower Grades
- Anxiety
- Depression

(Wilkinson, 2008, p.3)
Myth: If a score falls below the cut-off he cannot have autism

Reality: Test are tools. Autism is a clinical diagnosis based on observation of behaviors.

Myth: If a score falls on or ABOVE the cut-off he has autism

Reality: Test are tools. Autism is a clinical diagnosis based on observation of behaviors.

Test Error

“There are no objective measures that can be used for accurate diagnosis” (Freeman & Cronin, 2002 p.1).

Tests are tools.

Need for Quality Clinical Training

“...cut-off scores should not be viewed as similar to a standard score, such as an IQ score. Rather, these scores should be used as a clinical guide and taken in the context of other information about the child...This issue alone emphasizes the critical importance of the need for school districts to invest in providing quality clinical training...” (p.270)

Myth: If a student chats with friends, he must have good communication skills

Reality: Communication skills appear more typical when the individual is discussing areas of strong interest.

Myth: The best measure of an individual’s conversation skills is when she is discussing her special interests

Reality: Communication skills appear more typical when the individual is discussing areas of strong interest.


Façade of Normality

“...a short encounter or routine interaction will not reveal anything unusual. However, over time and in unexpected situations, it appears that the façade of normality cannot be kept up” (Frith, 2004, p.675)

Change it Up

• Communication skills appear to be more typical when discussing topics of intense interest.
• Communication skills often look more impaired during spontaneous social interactions.
• Be sure to “change it up” when evaluating individuals with ASD.

Good Evaluators Gather Data from Multiple Sources

• Parent Interview
• Teacher Interviews
• Observations in multiple settings

Myth: The individual cannot have Asperger’s because he had a language delay

Reality: Experts recommend using current language functioning

DSM Diagnosis of Aspergers

“...It can be argued that Asperger Syndrome is logically impossible to diagnose according to the DSM IV.” -Frith, 2004

Possible solution- consider verbal ability in later childhood or adulthood as a discriminating criterion. (Frith, 2004)

Language Delay and Aspergers

“...Early speech delay may be irrelevant to later functioning in children who have normal intelligence and clinical diagnoses of autism or Asperger syndrome and that speech delay as a DSM-IV distinction between Asperger’s disorder and autism may not be justified.” (Mayes & Calhoun 2000, p.81)
Myth: Full-scale IQ is a good description of a student’s cognitive ability

Reality: Individuals with ASD often demonstrate a scattered profile on comprehensive cognitive measures

Scattered Profile

Individuals with ASD often demonstrate a profile of scatter on comprehensive cognitive measures, performing better on tasks involving rote skills than on tasks involving problem solving, conceptual thinking, and social knowledge (Mayes & Calhoun, 2008; Meyer, 2001-2002)

Well-Below Average IQ

Formal cognitive assessments may not yield valuable information for assessing current level of functioning and needs for programming. For example, a flat profile of skills may indicate difficulty assessing what the student knows.

Myth: Formal IQ is more valid than informal data from the classroom

Reality: Analyzing formal and informal data to determine patterns of skills and learning is a key component of assessment.

IDEA (2004) on Evaluation Procedures 300.304 (b)(1)

The public agency must use a variety of tools and strategies to gather relevant functional, developmental, and academic information about the child …

The Importance of Informal Data

Informal classroom data…

Daily functioning

“Informal classroom data may be more valuable than information gathered in a contrived one-on-one setting when assessing skill levels and determining appropriate programming for a student with ASD.”

(Hagiwara, 2001-2002)
Differences in Adaptive Behavior Across Settings

- Lee & Park (2007) suggest that differences in measured adaptive skills may reflect differences in demands across settings and a lack of skill generalization.
- Some settings are more supportive and facilitate success.

Transition Assessment

- Transition skills can be assessed at any age. The earlier assessment occurs, the earlier the school team can begin teaching skills that lead to adult success.
- ALL students with ASD can benefit from transition assessment – even those who are college bound. Transition assessment identifies skills that lead to success in multiple environments.

Transition IEP Requirements

- Beginning not later than the first IEP to be in effect when the child turns 16, or younger if determined appropriate by the IEP Team, and updated annually, thereafter, the IEP must include:
  - (1) Appropriate measurable postsecondary goals based upon age appropriate transition assessments related to training, education, employment, and where appropriate, independent living skills; and
  - (2) The transition services (including courses of study) needed to assist the child in reaching those goals.

The Purpose of Special Education (IDEA)

... prepare them for

- Further Education
- Employment
- Independent Living
FYI: Transition Assessment

- Assessment of any skills related to personal autonomy and self-determination can broadly be considered as related to transition assessment although not specific to secondary or post-secondary levels.
- Examples:
  - Ability to communicate effectively
  - Independent work habits
  - Associating with peers

Myth: Because AU criteria do not include motor and sensory characteristics OTs are not needed on evaluation teams

Reality: Motor and sensory issues are frequently seen in ASD and impact functioning.

Occupational Therapists and ASD Evaluation

- Motor and sensory issues are associated features of ASD and impact functioning at a very basic level.
- Occupational therapists have unique training and experience and are vital for ASD evaluation and treatment planning for motor and sensory issues.

Myth: If an individual does not display an immediate reaction to a sensory stimulus during the evaluation, or at school, he or she does not have sensory processing issues that need to be addressed.

Reality: Reactions to sensory events can be cumulative.

Need for Sensory Intervention

- Reactions can be cumulative. A student may be able to tolerate a certain level of sensory discomfort from individual events; however, once a threshold is met, he may have a reaction at a later time. This may indicate a need for sensory intervention throughout the day to prevent problems later in the day (Dunn, 1999; Glennon, Miller-Kuhaneck, Henry, Parhan & Ecker, 2007).

Novice Errors

Myth: If you don’t see it .... it doesn’t count

Reality: Skilled examiners value observations of others.
Value Observations of Others

- Research has shown that parents are accurate reporters (Glascoe & Sandler, 1995)

Novice Errors

- Myth: If a noteworthy symptom occurs infrequently, it doesn’t count
  - Reality: There are low-threshold behaviors. Their presence, no matter how frequent, is significant

Low-Threshold Behaviors

- Echolalia
- Flapping
- Head banging

Novice Errors

- Myth: If a skill is present one time, the student does not have a deficit
  - Reality: You need to look at quality in addition to frequency

Comments

- He is my most sensitive child. He is the one that comforts me when I cry.
- She has good communication skills. She spoke to me about the Titanic for 30 minutes.
- He looked at me when I gave him the top. Eye contact is not a problem.

Contact Information

- Ruth Aspy, Ph.D.
  aspy@texasautism.com
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  grossman@texasautism.com
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  woods@texasautism.com
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