

Best Practice for Autism Team Evaluation and Intervention Planning – Part 1

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Autism Spectrum Disorder

Research on Outcomes

Outcome

Findings of a 2002 U.S. study of 405 children and adults on the spectrum (Seltzer and Krauss, 2002)

- ▶ 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

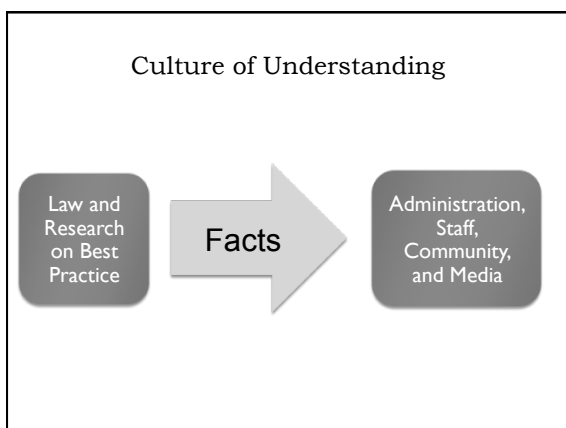
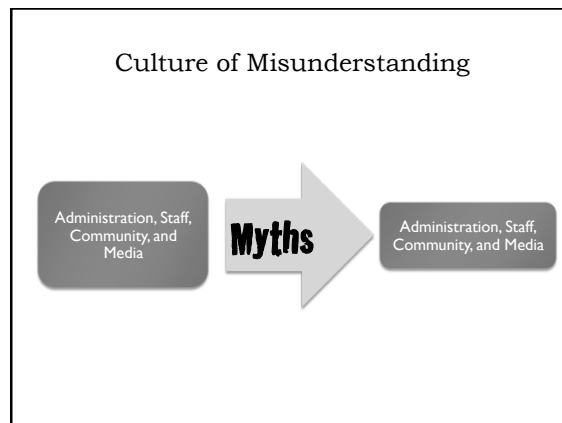
▶ Brenda Smith Myles

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



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

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

Autism Spectrum Disorders

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


Myth: A private diagnosis is required to be eligible for special education supports and services

Reality: Eligibility is the responsibility of the school district



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

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

▶ Wall Street Journal online February 1, 2010

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: Delaying identification of ASD, especially in young children, is conservative

Reality: Best Practice is to identify as soon as signs are evident

Early Intervention

Harris & Handleman (2000)

- ▶ Children who received services prior to 48 months of age had better outcomes four to six years later (e.g., inclusion in general education classroom and increase in cognitive functioning measured with the Stanford-Binet-4) than those who began services after this age.

Early Intervention

- ▶ Preschool children with ASD displayed significant improvement in speech and development when provided with **at least two years** of intensive early intervention services (see Filipek, et al., 1999 for a review)

Early Intervention

“Very early intervention may be viewed as a mechanism to prevent the full unfolding of symptoms of ASD by minimizing the associated secondary abnormalities in brain development.”

- Wetherby & Woods, 2008, p. 173

When is the right time to seek an evaluation?

- ▶ As soon as signs become evident
- ▶ Early symptoms may appear by 12-18 months or sooner
- ▶ Diagnosis is often possible by two (Lord & Spence, 2006)
- ▶ Delays of two to three years after symptoms are first apparent are typical (Filipek, et al., 2000)

Typical Age of Identification

- ▶ Autistic Disorder
 - ▶ 5.5 years
- ▶ Asperger's Disorder
 - ▶ 11 years

What Factors Contribute to Delayed Identification?

- ▶ Race and gender, SES
- ▶ Attitudes towards diagnosis
- ▶ Fear of the impact of identification
- ▶ Symptom severity

Race and Ethnicity

- ▶ African Americans are identified later and have more previous diagnoses (Mandell, Ittenbach, Levy, & Pinto-Martin, 2006).
- ▶ Hispanics are less likely to be identified with Asperger's Disorder (Rosenberg, Daniels, Law, Law, & Kaufmann, 2009).

Dismissive Statements Made by Professionals

- ▶ "Don't worry; all children do that sometimes."
- ▶ "We had a delightful conversation in my office. He cannot be on the spectrum."
- ▶ "She will grow out of that."
- ▶ "Everyone thinks that their child has autism. Trust me; your child does not have autism."

American Academy of Pediatrics Guidelines

- ▶ Recommends surveillance of ASDs at every well-child visit
 - ▶ Formal screening at 18 & 24 months or any point in which a parent raises concern
 - ▶ Recommends avoidance of "wait-and-see" approach
 - ▶ Emphasizes the importance of team assessment conducted by specialists in ASDs
- Johnson, Myers, & Council on Children with Disabilities, 2007

Early Identification

- ▶ ... with due consideration to the burden of uncertainty and concerns regarding over-diagnosis, it bears emphasizing that providing 'false hope' and postponing a diagnosis also incurs costs to children and families. ... the most critical issue in mitigating the negative impact of uncertainty is timely access to appropriate intervention services for the child and supports for the parents.

Zwaigenbaum, Bryson, Lord, Rogers, Carter, Carver, et al., 2009, p. 1387

Additional Benefits of Early Identification

- ▶ Allows parents to begin the process towards accepting/adjusting to the diagnosis
- ▶ Early diagnosis leads to early provision for family support and education



Myth: Eligibility is fundamentally different from diagnosis using the DSM

Reality: The same characteristics that result in a DSM diagnosis result in eligibility for special education

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

Autistic Disorder (DSM IV-TR)

Impairment in social interaction

- ▶ Difficulty using nonverbal behaviors to regulate social interaction (e.g., eye-contact, physical proximity, etc.)
- ▶ Failure to develop age-appropriate peer relationships
- ▶ Little sharing of pleasure, achievements, or interests with others
- ▶ Lack of social or emotional reciprocity

Communication

- ▶ Delay in or total lack of development of spoken language
- ▶ Difficulty holding conversations
- ▶ Unusual or repetitive language
- ▶ Play that is not appropriate for developmental level

Restricted, repetitive behaviors, interests, or activities

- Interests that are narrow in focus, overly intense, and/or unusual
- Unreasonable insistence on sameness and following familiar routines
- Repetitive motor mannerisms
- Preoccupation with parts of objects

Asperger's Disorder (DSM IV-TR)

Impairment in social interaction

- Difficulty using nonverbal behaviors to regulate social interaction (e.g., eye-contact, physical proximity, etc.)
- Failure to develop age-appropriate peer relationships
- Little sharing of pleasure, achievements, or interests with others
- Lack of social or emotional reciprocity

Restricted, repetitive behaviors, interests, or activities

- Interests that are narrow in focus, overly intense, and/or unusual
- Unreasonable insistence on sameness and following familiar routines
- Repetitive motor mannerisms
- Preoccupation with parts of objects

■ **No clinically significant general delay in language and no significant delay in cognitive development or adaptive behavior**

Autism Spectrum Disorder DSM-5 (Draft)

Impairment in social communication

- ▶ Basic deficits in nonverbal and vocal communication, particularly in integrating behaviors with communicative intent
- ▶ Lack of social reciprocity
- ▶ Lack of interest in and/or difficulty in establishing relationships with peers and others beyond caregivers

Fixated interests and repetitive behaviors

- ▶ Repetitive behaviors, including stereotyped language unusual sensory behaviors, hand and finger mannerisms; complex mannerisms
- ▶ Insistence on sameness; compulsions and rituals
- ▶ Fixated interests



IDEA/Texas 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)

Texas Commissioner's Rules/SBOE

- ▶ A student with autism is one who has been determined to meet the criteria for autism as stated in 34 CFR, §300.8(c)(1). Students with pervasive developmental disorders are included under this category. The team's written report of evaluation shall include specific recommendations for behavioral interventions and strategies.



IDEA Definition of ASD (cont)

- ▶ Autism does not apply if a child's educational performance is adversely affected primarily because the child has an emotional disturbance
- ▶ (d). Children with autism spectrum disorder vary widely in their abilities and behavior. [34 C.F.R. § 300.8(c)(1)(i)]

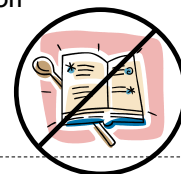


Myth: The Purpose of the DSM is to provide concrete rules for diagnosis

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)



Not a "Cookbook"

▶ DSM is not perfect

For example:

- ▶ Criteria begin around age 3
- ▶ Criteria under-identify infants and young children

▶ Volkmar, F., Chawarska, K., & Klin, A. (2005). Autism in infancy and early childhood. *Annual Review of Psychology*, 56, 315-336.



American Psychiatric Association
DSM-5 Development

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: 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

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 that are readily available 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)

Freeman & Cronin (2002). Diagnosing autism spectrum disorder in young children: An Update. *Infants and Young Children*, 14(3), 1-10.

Expertise is Key

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



Myth: A student who earns passing grades does not have an educational need for special education

Reality: Educational need does not equate to "academic need"



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"

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)

The Purpose of Special Education (IDEA)

▶ Ensure that all eligible children with disabilities have available to them a free appropriate public education (FAPE) that emphasizes special education and related services designed to meet their unique needs and prepare them for **further education, employment and independent living** ; [34 C.F.R. § 300 .1 (a) emphasis added]

Evaluation Procedures

- ▶ In conducting the evaluation, the public agency must —
 - (I) Use a variety of assessment tools and strategies to gather relevant **functional, developmental, and academic** information about the child, including information provided by the parent, that may assist in determining —
 - (i) Whether the child is a child with a disability under § 300.8;

▶ 34 Code of Federal Regulations § 300.304. Evaluation procedures (emphasis added)

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.

Eligibility and the Myth of Educational Need

- ▶ Educational need extends beyond academics and includes functional and developmental skills (e.g., 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)

Two Tiers to Eligibility



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

Reality: Asperger Syndrome is covered by Federal Law

IDEA Definition of Autism

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▶ 300.8(c)(1)(i)

Texas Commissioner's Rules/SBOE

- ▶ A student with autism is one who has been determined to meet the criteria for autism as stated in 34 CFR, §300.8(c)(1). **Students with pervasive developmental disorders** are included under this category. The team's written report of evaluation shall include specific recommendations for behavioral interventions and strategies.

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

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."
- U.S. GAO. *Special Education: Children with Autism*, 23. Washington, D.C., January 2005.

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

Reality: Regardless of the presence of an emotional 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

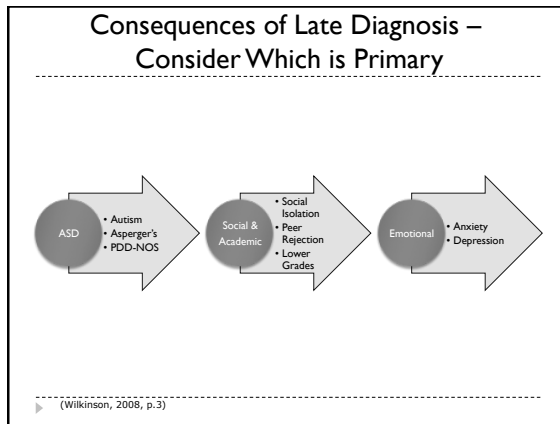
Comorbid Psychiatric Disorders

"Comorbidity is to be expected"
(Gillberg & Billstedt, 200, p.237)

- ▶ ~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)

"The consequences of a missed or late diagnosis include social isolation, peer rejection, lowered grades, and a greater risk for mental health and behavioral distress such as anxiety and depression during adolescence and adulthood."

(Wilkinson, 2008, p.3)



Myth: If a score falls below the cut-off he cannot have autism

Reality: Test 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 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**.

Freeman & Cronin (2002). Diagnosing autism spectrum disorder in young children: An Update. *Infants and Young Children*, 14(3), 1-10.

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)

Noland & Gabriels (2004). Screening and identifying children with autism spectrum disorders in the public school system: The development of a model process. *Journal of Autism and Developmental Disorders*, 34, 265-277.

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.

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.

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: 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)

Myth: If adaptive behavior measures demonstrate a discrepancy between home and school, the results are invalid.

Reality: Demands of settings differ and skills may not generalize across settings.

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.

▶ Lee, H.J., & Park, H. (2007). An integrated literature review on the adaptive behavior of individuals with Asperger Syndrome. Remedial and Special Education, 28, 132-139.

Myth: Assessment of transition skills should not occur until age 16

Reality: Transition skills can be assessed at any age

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.

▶ IDEA 300.320(b)

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.

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