

Screening and Evaluation of ASD in  
Early Childhood

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

**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

**Very Early Signs**

---

**As young as eight to twelve months, children show:**

- Poor visual orientation, excessive mouthing of objects, aversion to social touch (Baranek, 1999)
- Lack of orienting to name (Osterling, Dawson, & Munson, 2002)
- Repetitive object use (e.g., spinning; Ozonoff, Macari, Young, et al, 2008)

---

▶

**Very Early Signs**

---

- ▶ Atypical orientation to objects (e.g., prolonged visual inspection of objects, use of peripheral vision; Ozonoff, Macari, Young, et al, 2008; Zwaigenbaum, Bryson, Rogers, Roberts, et al., 2005)
- ▶ Less orienting to voices (De Giacomo & Fombonne, 1998; Zwaigenbaum, Bryson, Rogers, Roberts, et al., 2005 ).

---

▶

**Parent Concerns that are Red Flags**

Social	Communication	Repetitive Behaviors
<ul style="list-style-type: none"> <li>■ No social smile</li> <li>■ Prefers solitary play</li> <li>■ Poor eye contact</li> <li>■ In own world</li> <li>■ Not interested in peers</li> </ul>	<ul style="list-style-type: none"> <li>■ No response to name</li> <li>■ Cannot express wants</li> <li>■ Does not follow directions</li> <li>■ Appears deaf</li> <li>■ Not pointing</li> </ul>	<ul style="list-style-type: none"> <li>■ Tantrums</li> <li>■ Does not know how to play with toys</li> <li>■ Repetitive behaviors</li> <li>■ Unusual attachment to toys</li> <li>■ Lines up objects</li> </ul>

---

Filipek, et al (1999). The screening and diagnosis of autistic spectrum disorders. JADD, 29, 439-484.

**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).

---

▶

### Gender Differences

“One reason why the prevalence in girls and women is so low in comparison to boys and men may be the fundamental lack of awareness of what Asperger’s Syndrome looks like in females”

-Fattig 2007

► Kaede ©2008 Kristi Sakai

### Regional Differences- Rural/Small Town/Urban

- Small towns - under-diagnosis of higher functioning and atypical varieties of ASD
- Rural and Urban have same rate of diagnosis across ASD categories. Individuals residing in rural communities are referred to urban specialty centers

► Rosenberg, Daniels, Law, Law, & Kaufmann, 2009

### 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

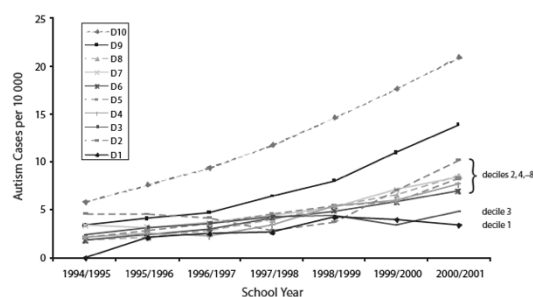


FIGURE 1—Rates of child autism in Texas school districts from 1994 to 2001, by unadjusted decile of district resources. p. 127

► Palmer, Blanchard, Jean, & Mandell (2006). School district resources and identification of autistic disorder. American Journal of Public Health, 96(1), 125-130.

### Survey of 1,300 Parents: The Diagnostic Process

#### Symptoms Evident by 18 months

#### At 2 years:

- Fewer than 10% diagnosed at initial consultation
- 10% told to return if concerns persisted or that their child would, “Grow out of it”
- Remaining were referred to another professional (at mean age of 40 months)

#### Of those referred:

- 40% diagnosed
- 25% told, “Not to worry”
- 25% referred to a third or fourth professional

Holwin P, Moore A. (1997). Diagnosis of autism. A survey of over 1200 patients in the UK. Autism 1, 135-162.

### 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.”

### Parents are Accurate Reporters of Early Signs

- ▶ Signs are seen within the first two years of life (Short & Schopler, 1988; Wimpory, Hobson, Williams, & Nash, 2000).
- ▶ Speech and language delays are the first concerns reported (Chawarska, Paul, et al., 2007)
- ▶ Concerns are initially expressed to the pediatrician by the time the child is 18 months (Howlin & Moore, 1997; Siegel, Pliner, Eschler, & Elliot, 1988)



### 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

"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)



### 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




### Legal Foundations



### Child Find

- ▶ Each school district shall adopt and implement written policies and procedures... that ensure all children with disabilities residing within the district... and who are in need of special education and related services are identified, located, and evaluated as required by the Individuals with Disabilities Education Act...

▶ 20 U.S.C. § 1412


 **All Areas of Suspected Disability**

---

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

---

▶

 **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) [emphasis added]

**Working Assumption**

---

We must take into account:

- ▶ Child's chronological age
- ▶ Child's developmental skills
- ▶ The child's temperament
- ▶ The culture of the family and parenting style for program planning

---

▶

**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

---

▶

**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.)

---

▶

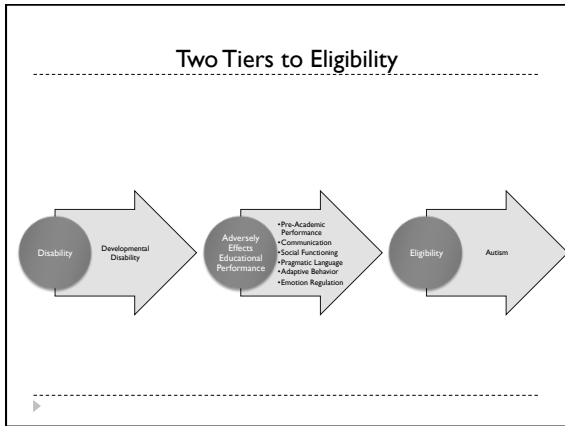
**Myth of "Medical Diagnosis"**

---

- ▶ This myth has resulted in a widespread egregious practice in the United States—inaction of the public schools until receipt of an outside "medical" diagnosis, or even worse, the response to an evaluation request with a counter request for a private diagnosis. This is illegal and may deny a student FAPE.

---

▶



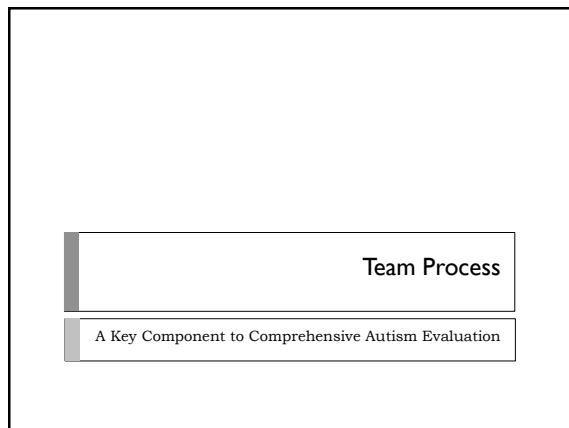
### The Purpose of Special Education (IDEA)

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**

§300.1 (emphasis added)

### 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.



### Comprehensive Evaluation

- ▶ “Ideally, the definitive diagnosis of an ASD should be made by a team of child specialists with expertise in ASDs.” (p.1202)

▶ Johnson, Myers, & Council on Children with Disabilities, 2007

### Comprehensive Evaluation

- ▶ “To thoroughly evaluate all relevant domains, different areas of expertise...are required. Hence the clinical assessment of individuals with this disorder is most effectively conducted by an experienced interdisciplinary team (Klin & Volkmar, 2003, p. 4).”

▶ Klin, A., & Volkmar, F. (2003) Asperger syndrome: diagnosis and external validity. *Child and Adolescent Psychiatric Clinics of North America*, 12, 1-13.

Comprehensive IEP Planning

- ▶ “Educational objectives for children with autism should include the development of:
  - ▶ social skills;
  - ▶ expressive verbal language, receptive language,
  - ▶ nonverbal communications skills;
  - ▶ a functional symbolic communication system;
  - ▶ engagement and flexibility in developmentally appropriate tasks and play;
  - ▶ fine and gross motor skills;
  - ▶ cognitive skills (symbolic play and academic skills);
  - ▶ conventional/appropriate behaviors; and
  - ▶ independent organizational skills and skills for success in a regular classroom.” U.S. GAO, *Special*

▶ Education: Children with Autism, 36. Washington, D.C., January 2005.

Areas of a Comprehensive Evaluation

- ▶ Developmental history
- ▶ Health history
- ▶ Adaptive skills
- ▶ Psychological evaluation
- ▶ Communication evaluation
- ▶ Cognitive and achievement evaluation
- ▶ Motor
- ▶ Sensory

Team Members

“A job title or position is not a strong indicator of who is appropriately qualified. . . Evaluation professionals must have prior education, training, and supervised experience that includes **extensive** exposure to autism-spectrum disorders.”

(Monteiro, 2006, p.4)  
emphasis added

Team Members

“**Expertise** in the area of autism spectrum disorders is much more important to a thorough, accurate diagnosis than particular credentials.”

(Ozonoff, Dawson, & McPartland, 2002, p.46)  
[emphasis added]

Expert Defined

▶ Having, involving, or displaying special skills or knowledge derived from training or experience.

▶ Merriam-Webster

Expert Defined

- ▶ Practical knowledge of ASD – what does it look like ACROSS the spectrum.
- ▶ Experience with differential diagnosis.
- ▶ Know typical development
- ▶ Evaluation skills
  - ▶ Observation
  - ▶ Interview (parent, child, teacher)
  - ▶ Formal/Informal evaluation procedures
- ▶ Knowledge of Federal and State law regarding evaluation and eligibility
- ▶ Know how to work as a team

-----  
**Considerations: Qualified Team Member**  
 -----

- ▶ How do you get expertise?
- ▶ What does “extensive” exposure to ASD mean?
- ▶ How are you going to know when you are there?

-----  
▶

-----  
**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.

-----  
▶

-----  
**Possible Team Members**  
 -----

- ▶ Psychologist
- ▶ Speech Pathologist
- ▶ Educational Diagnostician
- ▶ Occupational Therapist
- ▶ Teacher
- ▶ Autism Specialist

-----  
▶

-----  
**Types of Teams**  
 -----

	Multidisciplinary	Interdisciplinary	Transdisciplinary
Testing	Disciplines conduct evaluation in consecutive sessions and in isolation from one another	Disciplines conduct evaluation in consecutive sessions and in isolation from one another	Evaluation is collaborative with multiple team members present during evaluation sessions

-----  
▶

-----  
**Types of Teams**  
 -----

	Multidisciplinary	Interdisciplinary	Transdisciplinary
Decision Making	Conclusions made by case manager or team leader based on compiled information	Conclusions made through consensus with all team members	Conclusions and recommendations made through collaboration and consensus

-----  
▶

-----  
**Types of Teams**  
 -----

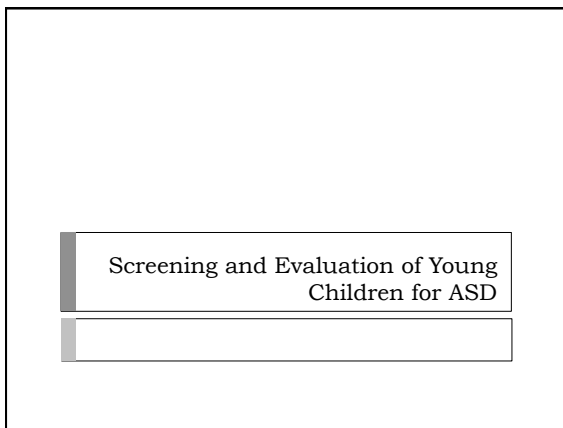
	Multidisciplinary	Interdisciplinary	Transdisciplinary
Recommendations	Recommendations made by individual members and then compiled	Recommendations are made through consensus	Recommendations are made through collaboration and consensus

-----  
▶

**Types of Teams**

	Multidisciplinary	Interdisciplinary	Transdisciplinary
Report	Reports are compilation of individual "write ups"	Reports are combination of compilation of individually written sections based on team consensus and collaborative writing	Reports are combination of compilation of individually written sections based on team consensus and collaborative writing

- Team Member Responsibilities**
- ▶ Participate in all aspects of team evaluation
    - ▶ Parent interview
    - ▶ Record review
    - ▶ Observations
    - ▶ Evaluation
    - ▶ Report writing
    - ▶ Parent feedback
    - ▶ Staffing and IFSP/IEP preparation (goals and programming decisions)



- Screening for ASD: Legal Requirements**
- ▶ By law, schools are required to ensure that all children with disabilities are identified, located and evaluated  
Child Find [34 C.F.R. § 300.111]
    - ▶ Any age
    - ▶ Any grade
    - ▶ Regardless of whether there is an existing eligibility
    - ▶ Regardless of whether the student is passing or failing

- Screening for ASD**
- ▶ Follow written district procedures
  - ▶ Best practice: Ensure that a member of the team be familiar with characteristics of ASD
  - ▶ The goal is to avoid unnecessary delays in identification
- Delay in identification = Delay in intervention**

**Interview: Screening vs. Evaluation**

	Screening Interview	Evaluation Interview
<b>Purpose:</b>	To determine whether further assessment is needed	To determine whether the individual is eligible for special education
<b>Timing:</b>	Child Find Parent concern School Concern	Immediately following a positive screen
<b>Interviewer:</b>	Individual professional	Best Practice: Qualified transdisciplinary team
<b>Respondent:</b>	Parent	Parent Professionals (e.g., teacher)
<b>Length:</b>	Brief (as short as 5 minutes)	In-depth (1-3 hours)
<b>Format:</b>	Unstructured: Q&A Structured (with instrument)	In-depth Q&A based on deep knowledge of ASD
<b>Instruments:</b>	Informed clinician questions Red Flags Screening instruments	Informed clinician questions Evaluation instruments such as the CAR52 and ADI-R

Grossman, Aspy, & Myles (in Press). *Transdisciplinary evaluation of autism spectrum disorders: From diagnosis through program planning.*

### Screening Instruments

- ▶ “Screening instruments are intended to help clinicians identify children who present with developmental delays and/or atypical behavior for whom a diagnosis in the autistic spectrum may be considered . . . [those] who should be referred for a more intensive diagnostic evaluation” (p. 6). Charak and Stella (2001-2002)
- ▶ In practice, there is no distinct line where screening ends and diagnostic assessment begins.

### Examples of Screening Instruments for EC

- ▶ Autism Behavior Checklist (ABC)
- ▶ Autism Screening Instrument for Educational Planning (ASIEP-3)
- ▶ Autism Spectrum Quotient [Version]
- ▶ Childhood Asperger Syndrome Test (CAST)
- ▶ Gilliam Asperger’s Disorder Scale (GADS)
- ▶ Social Responsiveness Scale (SRS)



### Examples of Diagnostic Instruments

- ▶ Autism Diagnostic Interview-Revised (ADI-R)
- ▶ Autism Diagnostic Observation Schedule (ADOS)
- ▶ Childhood Autism Rating Scale – 2 (CARS2)
- ▶ Gilliam Autism Rating Scale – 2 (GARS-2)
- ▶ Psychoeducational Profile – 3 (PEP-3)

### Need for Experienced Clinicians

- ▶ “To date the most robust method to diagnose autism in infants and very young children remains the use of experienced clinicians (Adrien et al. 1992, Cox et al. 1999, Lord 1995, Stone et al. 1999) . . . [who] draw upon a much richer range of knowledge than that embodied in diagnostic guidelines or criteria (Klin et al. 2000).”

### Not a “Cookbook”

- ▶ DSM is not perfect
- For example:
- ▶ Criteria begin around age 3
  - ▶ Criteria under-identify infants and young children

### Contact Information

Ruth Aspy, Ph.D.  
 aspy@texasautism.com

Barry G. Grossman, Ph.D.  
 grossman@texasautism.com

Nicole Brin, M.A., CCC-SLP  
 brin@texasautism.com



[www.texasautism.com](http://www.texasautism.com)

▶ Volkmar, F., Chawarska, K., & Klin, A. (2005). Autism in infancy and early childhood. *Annual Review of Psychology*, 56, 315-338.