Autism Spectrum Disorders in Very Young Children: From Screening to Diagnosis to Intervention

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Our Triple Mission
Increasing capacity in the community
Serving families
Making discoveries

Clinical Services
- Diagnostic evaluations
- Psychotherapy
- Speech-language evaluations & therapy
- Medical evaluations
- Behavioral and educational consultation
- ABA therapy
- Executive functioning & Social skills interventions
- Summer camp

Serving individuals with ASD and their families from infancy through young adulthood

Training Activities
- School Consultations
- Community Workshops
- Summer Training Series
- In-House Trainees:

School District Contracts
- Central Kitsap
- Evergreen
- Lake Washington
- Monroe
- Montesano
- Morton
- North Mason
- North Thurston
- Olympia
- Orting
- Renton
- Shelton
- Shoreline
- Yelm
Research Activities

Eight core research faculty studying...

- The relation between brain functioning and behavior
- Genetic mechanisms in the etiology of autism
- Early behavioral and biological markers of autism
- The effectiveness of early interventions
- Risk/protective factors in the development of associated conditions in adolescence

Autism Spectrum Disorders in Very Young Children

- Why is early detection important?
- How do we identify young children with autism?
- What do we know about early intervention for young children with autism?
- Can we improve the process from detection to intervention?

Autism Basics

- Complex brain-based disorder
- Diagnosis is based on a pattern of impairment in 3 domains of behavior:
  - Social interaction & understanding
  - Language/communication use & understanding
  - Restricted activities and interests
- Characterized by extreme variability in symptom expression

Prevalence of Autism

- Autism is common
  - Occurs in about 1 in 110 children (CDC, 2009)
  - 1 in 70 boys
  - formerly 3-4 per 10,000; 20-fold increase
- Numbers have increased steadily over the past 15 years
  - Increased recognition/awareness
  - Changing diagnostic criteria (more inclusive)
  - Younger age of diagnosis
- Recurrence risk to siblings is 18.7% (Ozonoff et al., in press, Pediatrics)

Causes of Autism

- No single identified cause
  - More likely different etiologies for the different “autisms”
- Strong genetic component
  - Twin studies
  - Sibling recurrence risk
  - “Broader autism phenotype” in families
- Multifactorial: combination of genetic vulnerability and environmental influences
Onset and Diagnosis

- Behavioral symptoms must be present before 36 months for DSM-IV autism diagnosis
- Symptoms develop gradually over the first 18 months, with different onset patterns (Ozonoff et al., 2008)
- Parents report first concerns at an average age of 17-18 months
- Average age of diagnosis is 3-4 years

Why does it matter if this toddler has autism?

Importance of Early Detection

Early Detection

Early & Specialized Intervention

Improved Child Outcomes

Results from neurobiological, behavioral, & social science research:

- Brain development is influenced by both genetics and experience
- Environmental influences can moderate the development of inherited tendencies
  - “Genes provide the hardware, but early experience is the software that drives the system”
- The early years of life are an important time for active brain development and organization


Models of Development & Outcome

Professional Practice Guidelines

Professional Practice Guidelines recommending early identification and intervention for autism

- National Academy of Sciences (2001)
- American Academy of Pediatrics (2001)


2007: Recommended autism-specific screening starting at 18 months
Benefits of Early Detection

- Early Detection
  - Understand core deficits
- Identify underlying causes
- Develop targeted treatments
- Enhance parenting efficacy

Improve screening & diagnostic tools
- Early & Specialized Intervention
- Increase community awareness
- Build capacity for community-based services

Improved Child Outcomes

How can we tell whether this toddler has autism?

Early Symptoms of Autism

Behavioral symptoms in the social and communication domains are the most reliable clinical indicators of autism in young children.

Early Symptoms of Autism

Behavioral symptoms only in the domain of restricted and repetitive interests are not reliable clinical indicators of autism in young children.

Diagnostic Challenge!

Social and communicative behaviors are NEGATIVE SYMPTOMS

- It’s not what we see, it’s what we don’t see
- Negative symptoms are difficult to interpret
- How do we interpret the non-occurrence of an expected behavior?
- Can it be explained by situational factors?

Characteristics of Typical Social Development

- Rich, dynamic interactions
- Back-and-forth exchange involving both initiation & responding
- Spontaneous & synchronous
- Mutual engagement
- Shared enjoyment

In autism, we see these behaviors less often
Diagnostic Challenge!
Social behavior is not all-or-nothing

- Social behaviors are not completely absent
- Children with autism do show social behaviors (e.g., eye contact, imitation, attachment)
- Social behaviors occur less consistently across people and settings
- It takes more effort to elicit social behaviors

Characteristics of Typical Communication Development

Children communicate for a variety of reasons:

- To request (get something they want)
- To protest
- To share enjoyment in an interaction
- To direct attention to objects or events (share interest or enjoyment in aspects of the environment)

Characteristics of Typical Communication Development

Children have many different ways to communicate:

- Gestures
- Eye contact
- Facial expressions
- Body language
- Vocalizations/Words
- Combining verbal and nonverbal behaviors

In autism we see:

- less expression of social awareness/intent
- less eye contact and more physical behaviors
- less directing attention

Typical Play Development

- Play with a variety of toys
- Use toys functionally and flexibly
- Create a variety of different play schemes
- Act out real-life scenarios with toys

In autism we see:

- less functional play
- more rigid and sensory-based play

Unique Contributions of Infant Sibling Research

- Learn about the earliest behavioral and biomedical markers of ASD
- Study early developmental course (including regression)
- Understand factors influencing diverse outcomes
- Assist families through monitoring & referral

Infant Sibling Research at the UW Autism Center

- Early brain growth and its relation to behavior
- How the brain processes social and nonsocial events
- The early development of joint attention skills
- Validity of early screening methods
How will this toddler be identified as having autism?

How are young children identified?

<table>
<thead>
<tr>
<th>Early Detection</th>
<th>Early &amp; Specialized Intervention</th>
<th>Improved Child Outcomes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Fail a routine screening</td>
<td>Diagnostic assessment</td>
<td>Someone expresses concerns</td>
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</table>

Characteristics of Screening

- Measures are relatively easy to administer and score
- Require minimal training
- Indicate risk, not diagnosis
- Not 100% accurate – Will yield false positives & false negatives

Dimensions of Screening Tools

| Where used | Primary care setting | Referral setting |
| Purpose/Use | Level 1: Identify autism among general population | Level 2: Identify autism from other disorders |
| Format | Parent report | Interactive |

Screening in Primary Care

| Where used | Primary care setting | Referral setting |
| Purpose/Use | Level 1: Identify autism among general population | Level 2: Identify autism from other disorders |
| Format | Parent report | Interactive |

Screening in Referral Settings

| Where used | Primary care setting | Referral setting |
| Purpose/Use | Level 1: Identify autism among general population | Level 2: Identify autism from other disorders |
| Format | Parent report | Interactive |
Autism-Specific Screening Tools For Young Children

<table>
<thead>
<tr>
<th>Parent Report</th>
<th>Interactive</th>
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</thead>
<tbody>
<tr>
<td>Level 1</td>
<td></td>
</tr>
<tr>
<td>M-CHAT</td>
<td>CHAT-23</td>
</tr>
<tr>
<td>PDDST-II</td>
<td></td>
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<tr>
<td>ESAT</td>
<td></td>
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<tr>
<td>Level 2</td>
<td></td>
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<tr>
<td>PDDST-II</td>
<td>STAT</td>
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</tbody>
</table>

Unique Functions of Interactive Screening Tools

- To communicate with parents (about areas of concern)
- As teaching tools (to increase awareness about early red flags)
- To plan intervention goals & activities (social & communication)

Characteristics of Diagnostic Assessment

- Requires advanced clinical training and specialized experience
- Involves comprehensive procedures
  - Synthesizing information from multiple sources
  - Integrating input from multiple disciplines
  - Evaluating behavioral symptoms within the context of developmental history, family factors, and cognitive skills

Components of a Comprehensive Diagnostic Assessment

- Developmental assessment
  - Cognitive/IQ
  - Language
  - Adaptive behavior
- Diagnostic assessment
  - Autism Diagnostic Observation Schedule (ADOS)
  - Autism Diagnostic Interview – Revised (ADI-R)
- Medical assessment

What type of intervention should this toddler get?

How should we approach intervention?

Early Detection

- What do we teach?
- Early & Specialized Intervention
- How do we know if it’s working?

Improved Child Outcomes
The unique characteristics of autism have important implications for teaching & learning

Social impairments: Implications for teaching

Children with autism may be:
- Less motivated by social attention or praise → Find other motivators
- Less able to learn by imitating others → Use other teaching strategies/ Teach imitation
- Less attuned to emotional cues of others → Teach understanding of facial expressions

Communication impairments: Implications for teaching

Children with autism may:
- Have difficulty following verbal directions/Understanding what is expected of them → Provide positive routines & visual supports
- Be less able to express their needs or desires verbally OR nonverbally → Teach a system of communication

Restricted activities: Implications for teaching

Children with autism may:
- Become upset when established routines are changed → Provide predictability; teach to deal with change
- Have limited or repetitive play interests/ Fewer opportunities for social and language learning → Teach functional play!

(Selected) Characteristics of Effective Intervention Programs for ASD

Educating Children with Autism, National Research Council, 2001

- Start at young ages
- Encourage active involvement of parents
- Provide specialized instruction in core deficit areas (e.g., social interaction, communication, imitation, play)
- Encourage active, sustained engagement of child
- Involve staff with training & experience in autism

Treatment Approaches

- Incidental Teaching
- More Than Words
- Auxiliary Communication
- ABA
- Sensory
- Social Skills Training
- Vision Therapy
- Social Skills
- Pivotal Response Therapy
- Speech
- Augmentative Communication
- Physical
- Visual
- Music Therapy
- PECS
- Occupational
- Autism
- Denver Model
- Denver
- Behavioral
- TEACCH
- Discrete Trial Training
- RDI
- cylinder
- Discrete Trial Teaching
Differences Between Autism Treatments

- **Scope** (skill-focused vs. comprehensive)
- **Targeted outcomes** (language, behavior)
- **Setting** (clinic, home, school)
- **Intensity** (hours per week)
- **Duration** (weeks, months, years)
- **Recipient** (child, caregivers)
- **Methodology** (behavioral vs. developmental)

Differences in Scope and Intensity

**Comprehensive Interventions**
- Early Start Denver Model (ESDM)
- Early Intensive Behavioral Intervention (EIBI)

**Focused Interventions**
- Hanen’s More Than Words (MTW)
- Reciprocal Imitation Training (RIT)
- Picture Exchange Communication System (PECS)

Why We Need Treatment Research

<table>
<thead>
<tr>
<th>Improved</th>
<th>Didn’t Improve</th>
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</thead>
<tbody>
<tr>
<td>Tried Treatment</td>
<td>![Images]</td>
</tr>
<tr>
<td>Didn’t Try Treatment</td>
<td>![Images]</td>
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Stages of Intervention Research

1. **Develop new intervention**
   - Manualize intervention and replicate
   - Conduct randomized clinical trial
   - Test in community

Current Status of Early Intervention Research in Autism

- Most intervention research has been conducted with preschoolers (not children under 3)
- Few randomized clinical trials (RCTs) have been conducted
- Even fewer interventions have been assessed in community settings
- There is support for both behavioral and developmental approaches
- Most interventions are associated with improvements for some children; No interventions show improvement for all children

Understanding Individual Differences in Treatment Response

**KEY RESEARCH QUESTIONS:**

- Which interventions are more effective for which children (and for which skills)?
- What are the characteristics of treatment responders (e.g., joint attention, object play, social initiations)?
- How can we match children to the most appropriate interventions for them?
Can we improve upon the current model?

Diagnosis-Intervention Model

Detection/Screening
If screening indicates “AT RISK”

Comprehensive diagnostic evaluation
If evaluation indicates “ASD”

Specialized Intervention

The reality...

• Less than 50% of primary care physicians use a validated developmental screening measure
• 8% screen for autism
• Barriers to MD screening:
  – Lack of time
  – Inadequate compensation
  – Lack of training
  – Lack of assessment and treatment resources in the community

Sources: Dosreis et al., 2006; Sand et al., 2005; Sices et al., 2003

The reality...

• Long waits for diagnostic evaluations are the norm
• The number of clinicians with experience in early diagnosis cannot meet increased demands
• Children may age out of birth-to-three services before receiving the diagnosis
Diagnosis-Intervention Model

**Detection/Screening**
If screening indicates "AT RISK"

<table>
<thead>
<tr>
<th>Comprehensive diagnostic evaluation</th>
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<tbody>
<tr>
<td>If evaluation indicates &quot;ASD&quot;</td>
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Specialized Intervention

The reality...

- Most state birth-to-three programs do not provide autism-specific services
- Compared to preschool programs, providers for toddlers have less autism experience
- We are just beginning to learn about:
  - The efficacy and effectiveness of treatments for toddlers
  - How to match interventions to individual children (and families)

(Sices, 2007; Stahmer, 2007; Stahmer & Mandell, 2007)

Policy Recommendations

- Consider adopting a "Risk-Prevention" model of service delivery
- Increase community capacity for screening and assessment
  - Provide office-based training in screening for MDs
  - Conduct interactive screening in referral settings
  - Establish regional primary care providers with assessment expertise
- Consider caregiver needs in planning intervention services
  - Elevated levels of stress and depression are common

Risk-Prevention Model

- Identify children at risk for autism
  - Children who fail autism screening
  - Younger siblings of children with autism
  - Children with social & communication delays
- Provide low-intensity intervention
  - Information & training for families
  - Combination of group activities & individual coaching
  - Provide strategies to foster social & communication development during daily routines
- Re-assess & adjust intensity as needed

Advantages of a Risk-Prevention Model

- Enables earlier initiation of services (i.e., before formal diagnostic evaluation)
- Decreases emphasis on autism diagnosis for very young children
- Provides caregivers with information and strategies for fostering development and managing behavior (before negative attributions or patterns develop)
**Educational Risk-Prevention Model**  
*Fuchs & Fuchs*

- Responsiveness to Intervention (RtI)
- Dynamic assessment
  - Identify children at risk
  - Provide less intensive, preventive strategies
  - Monitor progress
  - Transition to more intensive strategies if needed

**Early Childhood Risk-Prevention Model**  
*Hemmeter & Fox, 2009*

- Tertiary intervention
- Secondary prevention
- Universal promotion
- Intensive intervention
- Targeted supports
- High quality supportive environments
- Responsive caregiving

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**Medical Risk-Prevention Model:**  
*Cardiovascular disease*

<table>
<thead>
<tr>
<th>Undesired outcome</th>
<th>Cardiovasc. Disease</th>
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<tbody>
<tr>
<td>heart attack, stroke</td>
<td>functional impairment</td>
</tr>
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<table>
<thead>
<tr>
<th>Screening for risk factors</th>
<th>Cardiovasc. Disease</th>
</tr>
</thead>
<tbody>
<tr>
<td>family hx, hi chol, smoking, diabetes, hypertension</td>
<td>older sibling, positive M-CHAT</td>
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<table>
<thead>
<tr>
<th>Prevention/Monitoring</th>
<th>Cardiovasc. Disease</th>
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<tbody>
<tr>
<td>lifestyle changes (e.g., exercise, diet)</td>
<td>parent training</td>
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<table>
<thead>
<tr>
<th>More intensive intervention as needed</th>
<th>Cardiovasc. Disease</th>
</tr>
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<tbody>
<tr>
<td>medication, stent, bypass surgery</td>
<td>additional tx - in home, center-based</td>
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