Identifying and Treating Toddlers with ASD: Is it time for a paradigm shift?

Wendy L. Stone, Ph.D.
Professor of Psychology
University of Washington

Overview

- Importance of early detection
- Challenges associated with early detection and intervention
- Early behavioral features of ASD
- A new health care delivery model for expediting early detection and intervention

Basics of ASD

- Complex neurodevelopmental disorder
- Present from early in development
- Diagnosis is based on a pattern of impairment in 2 broad domains of behavior:
  - Impaired social interaction & social communication
  - Restricted & repetitive behaviors or interests
- Characterized by extreme heterogeneity in symptom expression

Why is early detection important?

Importance of Early Intervention: Concepts from neuroscience, social science, & economics research
Shonkoff & Phillips, 2000; Knudsen, Heckman, Cameron, & Shonkoff, 2006

- Brain development and skill acquisition are influenced by both genetics and experience
- Environmental factors (positive or negative) can influence the development & expression of inherited traits in children
- The early years of life are an important time for active brain development and organization
- Provision of positive experiences early in life is more effective and less costly than corrective intervention at later ages

Models of Development & Outcome
Underlying neurobiology can inform treatment

Core Social Impairment

- Attentional/Sensory Processes
  - attention allocation
  - cross-modal integration

- Social Motivation
  - social orienting
  - positive affect sharing
  - social reward systems

Develop strategies to improve visual & auditory attention and their coordination

Develop strategies to enhance reward properties of social interaction

Practice Guidelines & Initiatives recommending early identification and intervention for autism

- National Academy of Sciences (2001)
- American Academy of Pediatrics (2001)
  2007: Recommends autism-specific screening at 18 months
  2012: Autism Tool Kit (2nd edition)
  2012: Autism Case Training (ACT)

Early Detection: How are we doing?

Diagnosis Timeline

Early intervention services

Child receives a definitive ASD diagnosis

Child from minority background receives ASD diagnosis

Gap between concerns and dx

Parents express concerns about child’s development

Child’s age (yrs)

Child’s age (yrs)

Obstacles to early detection and intervention for children with ASD

- The challenges of early diagnosis of ASD
  - The delays in translation of scientific knowledge into community practice
  - The nature of our current service delivery system

Diagnosis of Autism

- Behaviorally-based diagnosis
- There are no medical tests or biological markers that indicate the presence of autism
- Diagnostic criteria are specified in the Diagnostic and Statistical Manual of Mental Disorders (DSM-5)
  American Psychiatric Association, 2013

Challenges of Early Diagnosis

- Increased behavioral variability at young ages
- Lack of clear cultural expectations for social milestones or “social reciprocity”
- Parental scaffolding to elicit optimal child behavior
- Different patterns of symptom onset in first 18 months
- Difficulty interpreting “negative symptoms”
**DSM-5 Criteria for ASD**

- Impairments in social communication and social interaction
  - Deficits in social-emotional reciprocity
  - Deficits in nonverbal communication
  - Deficits in developing and maintaining relationships

- Restricted, repetitive patterns of behavior, interests, or activities
  - Stereotyped or repetitive speech, movements, or use of objects
  - Inflexible adherence to routines
  - Highly restricted, fixedated interests
  - Unusual sensory interests or reactivity

**Research strategies for identifying the early signs of autism**

- Ask parents of children diagnosed with ASD what their children were like as infants and toddlers (retrospective studies)
  - Mid '90s: review of early home videos
- Early 2000s: Track the development of younger siblings of children with ASD (prospective studies)

**Unique Advantages of Studying Younger Siblings**

- Learn about the earliest behavioral markers of ASD (from birth)
- Understand risk for ASD and the components of the “broader phenotype”
- Study developmental course (including regression)
- Investigate potential genetic/biological influences & mechanisms
- Assist families through monitoring & referral

**DSM-5 Criteria for ASD**

- Impairments in social communication and social interaction *(must show all 3)*
  - Deficits in social-emotional reciprocity
  - Deficits in nonverbal communication
  - Deficits in developing and maintaining relationships

- Restricted, repetitive patterns of behavior, interests, or activities
  - Stereotyped or repetitive speech, movements, or use of objects
  - Inflexible adherence to routines
  - Highly restricted, fixedated interests
  - Unusual sensory interests or reactivity

**Impairments in social communication and social interaction**

- Deficits in social-emotional reciprocity
  - Social approach, back-and-forth conversation (or chatter)
  - Sharing of interests, emotions, or affect
  - Initiating or responding to social interactions

- Deficits in nonverbal communication
- Deficits in developing and maintaining relationships

**Social-Emotional Reciprocity**

- Rich, dynamic interactions
- Reciprocal, back-and-forth rhythm
- Mutual engagement & enjoyment
Impairments in social communication and social interaction

- Deficits in social-emotional reciprocity
- **Deficits in nonverbal communication**
  - Integration of verbal and nonverbal communication
  - Use of eye contact & body language
  - Understanding and use of gestures & facial expressions
- Deficits in developing and maintaining relationships

Using Nonverbal Forms of Communication

- Gestures
- Eye contact
- Facial expressions
- Vocalizations/Sounds

Integration of communicative behaviors is key

Impairments in social communication and social interaction

- Deficits in social-emotional reciprocity
- Deficits in nonverbal communication
- Deficits in developing and maintaining relationships
  - Adjusting behavior to different social contexts
  - Sharing imaginative play
  - Showing interest in peers
  - Making friends

Social-communicative behavior is not all-or-nothing

- Social behaviors are not completely absent in autism
- Children with autism do show social behaviors (e.g., eye contact, imitation, attachment)

BUT...

- These behaviors occur less consistently across people and settings
- Parents may have to work harder to elicit them
- Subtle qualitative differences may exist (e.g., timing, integration, coordination of behaviors within interactions)

**DSM-5 Criteria for ASD**

**A. Impairments in social communication and social interaction**
1. Deficits in social-emotional reciprocity
2. Deficits in nonverbal communication
3. Deficits in developing and maintaining relationships

**B. Restricted, repetitive patterns of behavior, interests, or activities** (must show at least 2)
1. Stereotyped or repetitive speech, movements, or use of objects
2. Inflexible adherence to routines
3. Highly restricted, fixated interests
4. Unusual sensory interests or reactivity

**Characteristics of 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
**Restricted/Repetitive Behaviors & Interests**

- Repetitive object or body use
- Fixated interests
- Atypical sensory responses
- Rigid adherence to routines

---

**Current state of the science: Early markers of ASD**

Zwaigenbaum et al., 2015, *Pediatrics* (online)

- Reduced levels of social attention and social communication, and repetitive object use, apparent between 12 & 24 months
- No reliable behavioral markers < 12 months
- Potential markers: abnormal body movements and temperament dysregulation
- Atypical developmental trajectories – declines in language, motor, and social communication skills

---

**Obstacles to early detection and intervention for children with ASD**

- The challenges of early diagnosis of ASD
- The delays in translation of scientific knowledge into community practice
- The nature of our current service delivery system

---

**Current State of the Science**

**Early detection**

- Increased knowledge about early behavioral signs of ASD
- ASD diagnosis can be made by 24 months
- Increased availability of validated ASD screening tools
- Increased awareness of sibling recurrence risk

**Early intervention**

- Strong evidence for effectiveness of ASD-specialized early intervention
- Both ABA approaches and developmental approaches are effective interventions (and share many features in common)

---

**Translating research knowledge into community practice**

“It takes an estimated average of 17 years for only 14% of new scientific discoveries to enter day-to-day clinical practice”

*Westfall, Mold, & Fagnan, 2007*

---

**Obstacles to early detection and intervention for children with ASD**

- The challenges of early diagnosis of ASD
- The delays in translation of scientific knowledge into community practice
- The nature of our current service delivery system
Concerns about ASD Diagnosis–Evaluation
- Long waits for diagnostic evaluations
- Limited availability of ASD-specialized services and providers

Current Healthcare Delivery Model
Diagnosis–Treatment model

Roadblocks
- Limited knowledge of early signs
- Limited and selective use of validated ASD screening tools
- Long waits for diagnostic evaluations
- Limited availability of ASD-specialized services and providers

Concerns about Strep Throat
Provide indicated treatment
- Strep test

Provide indicated treatment

Proposed Healthcare Delivery Model
Preventative Intervention model

Concerns about ASD
- Routine ASD screening at 18 months
- Expedited ASD assessment & ASD-specialized intervention
- ASO-specialized early intervention

SCREEN
REFER
TREAT

Proposed Healthcare Delivery Model
Preventative Intervention model

BENEFITS:
- Provide children with ASD-specialized intervention at younger ages (while waiting for formal dx)
- Capitalize on early brain plasticity to optimize outcomes
- Help parents understand and promote their child’s development
- Increase awareness of early signs of ASD among community providers

A Screen-Refer-Treat (SRT) Model to Promote Earlier Access to ASD Intervention

PI-Stone NIMH 1 R01 MH104302-01 2014-2019

UW Collaborators:
- Lisa Ibanez, PhD – Psychology
- Ann Vander Stoep, PhD – Psychiatry/Epidemiology
- Kathleen Myers, MD, PhD – Psychiatry
- Kyle Steinman, MD, MAS – Neurology
- Shannon Dorsey, PhD – Psychology
- Chuan Zhou, PhD – Pediatrics

CHDD LEND Grant Faculty
State Collaborators: DOH, DEL, WCAAP
Community Collaborators: Skagit, Lewis, Spokane, & Yakima

Study Aims
- To increase screening and referral for ASD at 18 months by primary care providers (PCPs)
- To increase the number of toddlers with ASD (or suspected ASD) who receive specialized behavioral intervention before 24 months
- To improve parent well-being & health care satisfaction
- To improve child social-communication skills
- To reduce disparities in screening and diagnosis for underserved populations (especially Hispanic)

SRT Training & Supports Provided
- Training PCPs in correct use of the M-CHAT-R/F to screen
- Giving parents an online version of the M-CHAT-R/F that incorporates follow-up interview Qs to reduce PCP time burden
- Training EI providers on using the STAT to screen
- Providing telemedicine coaching for the expedited assessment
- Training providers in using RIT intervention & coaching parents
- Training providers in using a standard form for referral & communication
Components of SRT Training

PCPs
• Two-hour workshop
  – Early characteristics of ASD
  – Importance of early detection
  – Local resources
  – Use of the M-CHAT-R/F, Screening checklist, & EI Referral form
  – How to talk to parents
• Technical assistance

El Providers
• One-day STAT workshop
  – Early characteristics of ASD
  – Use of the parent interview, telemedicine consultation, & PCP Feedback form
• One-day RIT workshop
  – Use of RIT & parent coaching
• Technical assistance

Modified Checklist for Autism in Toddlers – Revised, with Follow-up (M-CHAT-R/F)
Robins et al., 2001, 2014

• Level 1 screening tool (for primary care settings)
• Consists of 20 Yes/No items rated by parents
• Developed for children 16-30 months
• Well-researched using large samples
• Has strong psychometric properties when used correctly

M-CHAT-R/F Administration
Robins et al., 2014

Two Stages:

STAGE 1: Parent-report questionnaire
– Consists of 20 Yes/No items, such as:
  • Does your child play pretend or make-believe?
  • Does your child point with one finger to show you something interesting?
  • Does your child make unusual finger movements near his or her eyes?

STAGE 2: Follow-up interview (for scores from 3 to 7)
– Provider or medical staff asks prescribed questions about items that were endorsed on initial report

M-CHAT-R/F Scoring Algorithm

<table>
<thead>
<tr>
<th>Initial Results</th>
<th>Next Step</th>
</tr>
</thead>
<tbody>
<tr>
<td>Total score ≤ 2</td>
<td>No follow-up interview or referral required</td>
</tr>
<tr>
<td>Total score = 3-7</td>
<td>Follow-up interview required</td>
</tr>
<tr>
<td></td>
<td>If score ≥ 2, refer for diagnostic evaluation and early intervention</td>
</tr>
<tr>
<td>Total score ≥ 8</td>
<td>Bypass follow-up interview, refer for diagnostic evaluation and early intervention</td>
</tr>
</tbody>
</table>

M-CHAT-R/F Psychometric Properties
(Robins et al., 2014)

<table>
<thead>
<tr>
<th></th>
<th>Sensitivity</th>
<th>Specificity</th>
<th>PPV</th>
<th>NPV</th>
</tr>
</thead>
<tbody>
<tr>
<td>M-CHAT-R Initial Scoring</td>
<td>.91</td>
<td>.96</td>
<td>14</td>
<td>.99</td>
</tr>
<tr>
<td>M-CHAT-R w/ Follow-up</td>
<td>.85</td>
<td>.99</td>
<td>48</td>
<td>.99</td>
</tr>
</tbody>
</table>

• Use of the follow-up interview is critical for reducing false positives!
• The PPV for any type of developmental delay is 0.96

Screening Tool for Autism in Toddlers (STAT)
Stone et al., 2000; 2004; 2008

• Level 2 screening tool (for referral settings)
• Consists of 12 interactive items assessing core social-communicative behaviors
• Developed for children 24-35 months; provisional cutoff score for 14-23 months
• Takes 20 minutes to administer
• Strong psychometric properties
Four Domains Assessed by STAT

- Requesting (2 items)
- Directing Attention (4 items)
- Motor Imitation (4 items)
- Play (2 items)

STAT Psychometric Properties
(Stone et al., 2004)

<p>| | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Sensitivity</td>
<td>.92</td>
</tr>
<tr>
<td>Specificity</td>
<td>.85</td>
</tr>
<tr>
<td>Positive Predictive Value</td>
<td>.86</td>
</tr>
<tr>
<td>Negative Predictive Value</td>
<td>.92</td>
</tr>
</tbody>
</table>

Test-retest reliability $K = .90$
Interrater agreement $K = 1.0$
Concurrent validity with ADOS $K = .95$

Unique Functions of Interactive Screening Tools

- To communicate with parents about observed behaviors
- As teaching tools (to increase awareness about early red flags)
- To identify intervention goals & activities (in social & communication domains)

Reciprocal Imitation Training (RIT)

- A play-based, naturalistic intervention with a strong evidence base
- Targets the spontaneous use of imitation within a social context
- Based on ABA principles
- Short-term, low intensity, easy to implement
- Associated with improvements in imitation, joint attention, play, and social interaction
- Can be used by therapists, parents, teachers, paraprofessionals, and siblings

RIT Flow (for object play)

- Imitate the child’s object play (1-2 min)
- Praise the child, even if a prompt was needed
- Model a new action with the same object (up to 3 times)
- Use a physical prompt if the child doesn’t imitate
- Physically prompt if the child doesn’t respond after 3 models
- Use lots of praise!
Study Recruitment

Recruiting from 4 counties in WA State: Lewis, Skagit, Spokane, & Yakima

<table>
<thead>
<tr>
<th></th>
<th>Sample</th>
<th># of County</th>
<th>Total #</th>
</tr>
</thead>
<tbody>
<tr>
<td>PCPs</td>
<td>10</td>
<td>40</td>
<td></td>
</tr>
<tr>
<td>EI Providers</td>
<td>20</td>
<td>80</td>
<td></td>
</tr>
<tr>
<td>Families</td>
<td>70 pre 70 post</td>
<td>280 pre 280 post</td>
<td></td>
</tr>
</tbody>
</table>

PROPOSED #s:
2 PCP practices & 2 EI agencies per county

ACTUAL #s:
2-3 PCP practices & 1-3 EI agencies per county

Data collected before and after SRT Intervention
(all measures available in English and Spanish)

From PCPs
- Knowledge/Practices Survey
- Screening checklist for all 18-month old visits

From EI Providers
- Knowledge/Practices Survey
- Child intervention checklist

From Parents*
- Child diagnosis and services received
- Parenting stress (PSI-SF)
- Parenting efficacy (MERS)
- Quality of life (WHOQOL-BRF)
- Service satisfaction (MPOC-20)
- Child social-communication behavior (PIA-CV)

* Parents complete questionnaires every 3 months until child is 36 months or until child receives diagnostic evaluation

Acknowledgements

My terrific lab

Funding sources:
National Institute for Mental Health (NIMH)
WA State Attorney General’s Office