Overcoming Challenges of Early Screening for Autism in Primary Care

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January 12, 2016
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Early Intervention for Children With Autism Spectrum Disorder Under 3 Years of Age: Recommendations for Practice and Research

Zwaigenbaum et al. Pediatrics 2015; 136:S60-S81

• Review of 24 interventions for children with ASD < 3 years published from 2000-2013 identified comprehensive and targeted treatment models with evidence of clear benefits.

• Emphasized the central role of the parent and interventions designed to incorporate learning opportunities into everyday activities, capitalize on “teachable moments” and facilitate the generalization of skills.
Treatment Studies of Toddlers with ASD Do Not Separate Cases Recruited from Primary Care

<table>
<thead>
<tr>
<th>Ascertainment Methods to Recruit Families</th>
</tr>
</thead>
<tbody>
<tr>
<td>➢ Referral for Suspected ASD</td>
</tr>
<tr>
<td>➢ Screening for ASD in Early Intervention</td>
</tr>
<tr>
<td>➢ Younger Siblings of Children with ASD</td>
</tr>
<tr>
<td>➢ Screening for ASD in Primary Care Settings</td>
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</tbody>
</table>
Wetherby et al. (2014) – RCT of 82 toddlers diagnosed with ASD at 18 months demonstrated significant differential treatment effects of a parent-implemented intervention

- 43 toddlers were referred for suspected ASD at UM site; 39 were recruited from screening in primary care at FSU site
- Site differences in cognitive level (=72 vs. 77 ELC on Mullen) but no site differences in treatment effects
# How many children were missed?

<table>
<thead>
<tr>
<th>Screener</th>
<th>Sample Size</th>
<th>Age in months</th>
<th>Hits</th>
<th># per 1,000</th>
</tr>
</thead>
<tbody>
<tr>
<td>CHAT</td>
<td>16,235</td>
<td>m=18.7</td>
<td>33</td>
<td>2.03</td>
</tr>
<tr>
<td>Baird et al., 2000</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>M-CHAT</td>
<td>18,122</td>
<td>m=20.4</td>
<td>95</td>
<td>5.24</td>
</tr>
<tr>
<td>Chlebowski et al., 2013</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>M-CHAT</td>
<td>52,026</td>
<td>at 18</td>
<td>60</td>
<td>1.15</td>
</tr>
<tr>
<td>Stenberg et al., 2014</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>ESAT</td>
<td>31,724</td>
<td>m=14.9</td>
<td>18</td>
<td>0.57</td>
</tr>
<tr>
<td>Dietz et al., 2006</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>ITC</td>
<td>5,385</td>
<td>m=16.4</td>
<td>60</td>
<td>11.14</td>
</tr>
<tr>
<td>Wetherby et al., 2008</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Selection Bias of Screening Samples for Estimates of Sensitivity and Specificity

- Intellectual ability or developmental level is an indication of how representative the sample is.
- Percentage of children with average or above average IQ has increased to at least half.
- Selection bias if the average developmental level is far below 75.
  - Ozonoff et al. (2015): Mullen ELC=79 ($n=38$)
  - Robins et al. (2014): Mullen ELC = 68 ($n=105$)
  - Wetherby et al. (2008): Mullen ELC = 73 ($n=60$)
Need to Improve Early Identification of Developmental Disabilities

Percentage of Population Receiving Special Education or Early Intervention Services in 2007:

- School-Age Children
  6 to 17 years 11.4%
- Preschool Children
  3 to 5 years 5.7%
- Infants and Toddlers
  Birth to 2 years 2.5%

✔ This means, 80% of children are missed.

Where do we draw the line?

<table>
<thead>
<tr>
<th>SD</th>
<th>SS</th>
<th>%ile</th>
</tr>
</thead>
<tbody>
<tr>
<td>0.00</td>
<td>100</td>
<td>50th</td>
</tr>
<tr>
<td>-1.00</td>
<td>85</td>
<td>16th</td>
</tr>
<tr>
<td>-1.25</td>
<td>81</td>
<td>10th</td>
</tr>
<tr>
<td>-1.50</td>
<td>77</td>
<td>7th</td>
</tr>
<tr>
<td>-2.00</td>
<td>70</td>
<td>2nd</td>
</tr>
</tbody>
</table>

2nd percentile is too low to detect the 11.4% who will be eligible for special education at school age in time for early intervention.
Parent Concern & Positive Screen on the Infant-Toddler Checklist for Children with ASD (n=60)

Wetherby, Brosnan-Maddox, Peace, & Newton, 2008
Parent Concern is Less Accurate for Children at Younger Ages

- Retrospective and prospective studies of parents of children with ASD show:
  - About 75% have concerns by 24 months
  - About 50% have concerns by 18 months
  - About 30% have concerns by 12 months

- Reported concerns not usually specific to autism

- Parents are fairly accurate reporting what their child can and cannot do but not as accurate at knowing when to be concerned.
Focus Groups with Families (n=105): Overcoming Barriers to Improving Early Detection of ASD in Community Systems

- Information on developmental milestones and spectrum of autism symptoms
- Stigma related to diagnosis of autism
- Access to services for diagnosis and intervention

Wetherby et al. (Oct. 2015) Mobilizing community systems to tackle challenges of early detection of ASD, Oral Presentation at the DEC Conference, Atlanta, GA
Birth to 5: Watch Me Thrive!
Office of the Administration for Children and Families

Coordinated federal effort to help families and providers:

- Celebrate milestones.
- Promote universal screening.
- Identify possible delays & concerns early.
- Enhance developmental supports.
Learn the Signs. Act Early.
Are these milestones contributing to the solution or the problem?

<table>
<thead>
<tr>
<th>9 Months</th>
<th>12 Months</th>
<th>18 Months</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Social &amp; Emotional</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>May be afraid of strangers</td>
<td>Is shy or nervous with strangers</td>
<td>Likes to hand things to others as play</td>
</tr>
<tr>
<td>May be clingy with familiar adults</td>
<td>Cries when mom or dad leaves</td>
<td>May have temper tantrums</td>
</tr>
<tr>
<td>Has favorite toys</td>
<td>Has favorite things &amp; people</td>
<td>May be afraid of strangers</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th><strong>Language</strong></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Understands “no”</td>
<td>Responds to simple spoken requests</td>
<td>Says several single words</td>
</tr>
<tr>
<td>Makes a lot of different sounds</td>
<td>Uses simple gestures, like shaking head “no” or waving</td>
<td>Says and shakes head “no”</td>
</tr>
<tr>
<td>Copies sounds and gestures</td>
<td>Makes sounds with changes in tone</td>
<td>Points to show someone what he wants</td>
</tr>
</tbody>
</table>
Development of gestures at 9 to 16 months predicts language 2 years later

(Caselli, Rinaldi, Stefanini, & Volterra, 2012; Rowe & Goldin-Meadow, 2009; Watt, Wetherby, & Shumway, 2006)

Children should use at least 16 gestures by 16 months.
Focus Groups with Professionals (n=41): Overcoming Barriers to Improving Early Detection of ASD in Community Systems

- Training on the early signs of ASD
- Available validated screening tools feasible for primary care
- Available intervention services if screening is implemented

Wetherby et al. (Oct. 2015) Mobilizing community systems to tackle challenges of early detection of ASD, Oral Presentation at the DEC Conference, Atlanta, GA
Autism Navigator is a unique collection of web-based tools and courses that uses extensive video footage to bridge the gap between science and community practice.
About Autism in Toddlers

- Our first online course – FREE to the public
- For families, professionals, or anyone interested in learning about autism spectrum disorder (ASD)
- Video clips of over a dozen toddlers with ASD at 18-24 months of age

Courses for professionals, parents, and anyone interested in learning about autism.

About Autism in Toddlers

Our first online course free to the public is for families, professionals, or anyone interested in learning about autism spectrum disorder (ASD). You will learn about the core diagnostic features and early signs of autism in toddlers, the critical importance of early detection and early intervention, and current information on prevalence and causes of autism. This self-paced course has video clips of over a dozen toddlers with ASD at 18-24 months of age. It takes about 2 hours to go through all the slides and videos or spend a few minutes and visit again later.
Course Introduction

1. Core Diagnostic Features

2. Prevalence and Cause

3. Early Detection

4. Collaborating with Families

5. Screening & Referral

6. Early Intervention Basics

This 7-hour course launched in Summer, 2015.

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A Seamless Path for Families

The Autism Navigator® is linked with a tiered system of online courses, tools, and resources to support families. Families are first invited for universal screening with the Smart Early Screening for Autism and Communication Disorders (ESAC) beginning at 9 months of age and to join a parent portal. This portal posts the screening report and sends invitations to the tiered system of supports for families based on the child’s screening outcome. Families are invited to be re-screened every 3 to 6 months until 30 months of age. Following are the tiered supports for families:

1. **16 Gestures by 16 Months & more**
   - For all families—the 16 by 16™ series of Lookbooks to help families and others learn critical social communication skills that children should reach by 16 months to help their child learn to talk.

2. **Social Communication Growth Charts**
   - For all families—explore video clips to learn key social communication milestones that develop from 9 to 24 months and chart their child’s social communication development.

3. **About Autism in Toddlers**
   - For families of children with a positive screen for autism—to learn about the early signs of autism with video clips of over a dozen toddlers with ASD at 18-24 months of age and see early intervention in action.

4. **ASD Video Glossary**
   - For families of children with a positive screen for autism who want more information—to see a library of hundreds of video clips illustrating diagnostic features and different interventions.

5. **How-To Guide for Families**
   - For families who suspect their child has ASD—to get started right away and learn intervention strategies to use in their everyday activities and support their child's learning and development.
Seamless Path for Families

For all families

1. 16 Gestures by 16 Months & more
2. Social Communication Growth Charts
What does it take to learn to talk?
It takes gestures, sounds, play... and much more.

Watch, Learn, and Spread the Word
Because the development of infants and toddlers is important to everybody.

www.FirstWordsProject.com
16 Gestures by 16 Months
Lookbook now Available
Language Learning
16 Gestures by 16 Months

Imagination
16 Actions with Objects by 16 Months

Social Connectedness
16 Ideas to Communicate by 16 Months

Cooperation
16 Ways to Manage Emotions by 16 Months

Critical Thinking
16 Messages to Understand by 16 Months

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At 10 months, children learn through exploration and experiences with others as they reach to take an object...
10 MONTHS: REACH, RAISE ARMS

then, with an open hand facing up, ...

16 GESTURES BY 16 MONTHS
...and finally, with their arms raised asking to be picked up.
Social Communication Growth Charts
Learn the milestones. Launch language early.

GUIDED TOUR

GET STARTED
Seamless Path for Families

For all families

1. 16 Gestures by 16 Months & more
2. Social Communication Growth Charts

For families of children with a positive screen for autism

3. About Autism in Toddlers
4. ASD Video Glossary
5. How-To Guide for Families
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www.AutismNavigator.com
Carter, Alice S; Sheldrick, Radley
Addressing Systemic Health Disparities in Early ASD Identification & Treatment
University Of Massachusetts Boston

Feinberg, Emily
Early Identification & Service Linkage for Urban Children with Autism
Boston University Medical Campus

Pierce, Karen
Detection of ASD at the 1st Birthday as Standard Of Care: The Get SET Early Model
University of California San Diego

Stone, Wendy
A Screen-Refer-Treat (SRT) Model to Promote Earlier Access to ASD Intervention
University of Washington

Wetherby, Amy; Klin, Ami; Lord, Catherine; Newschaffer, Craig
Mobilizing Community Systems to Engage Families in Early ASD Detection and Services
Florida State University, Emory University, Weill Cornell Medical College, Drexel University