Implementing Developmental Screening Tools in the Patient Centered Medical Home

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Children’s Specialized Hospital
Outline

• Definitions and guidelines
• Why follow the guidelines?
• What happens after children are identified with developmental concerns?
Developmental Surveillance

“A flexible, longitudinal, continuous, and cumulative process whereby knowledgeable health care professionals identify children who may have developmental problems”

- Eliciting and attending to parent concerns
- Maintaining developmental history
- Making accurate and informed observations
- Identifying risk and protective factors
- Documenting process and findings

Developmental Screening

• Using a validated, structured tool at designated intervals to help identify children with developmental delay
  – General developmental screening
  – Disorder specific
AAP Recommendations for Birth to 3

• Developmental surveillance at all well visits

• General Developmental Screening
  – 9, 18 and 24 or 30 month visit
  – Any visit where a concern is identified

• Autism Specific Screen
  – 18 and 24 month visit
  – Any visit where a concern is identified

## Scheduled Well Visits

<table>
<thead>
<tr>
<th>2 mos.</th>
<th>4 mos.</th>
<th>6 mos.</th>
<th>9 mos.</th>
<th>12 mos.</th>
<th>15 mos.</th>
<th>18 mos.</th>
<th>24 mos.</th>
<th>30 mos.</th>
<th>36 mos.</th>
</tr>
</thead>
</table>

- Surveillance
- Surveillance and General Screening
- Surveillance and Autism Screening
- Surveillance, General and Autism Screening

* Screen whenever a developmental risk is identified or elicited
<table>
<thead>
<tr>
<th></th>
<th>ASQ-3</th>
<th>PEDS</th>
<th>SWYC</th>
</tr>
</thead>
<tbody>
<tr>
<td>Ages</td>
<td>2 months- 5.5 years</td>
<td>Birth – 8 years</td>
<td>2 months – 5 years</td>
</tr>
<tr>
<td>Sensitivity</td>
<td>0.7- 0.91</td>
<td>0.75- 0.79</td>
<td>0.78-0.81</td>
</tr>
<tr>
<td>Specificity</td>
<td>0.79- 0.86</td>
<td>0.8</td>
<td>0.73-0.76</td>
</tr>
<tr>
<td>Reading level</td>
<td>4&lt;sup&gt;th&lt;/sup&gt;-6&lt;sup&gt;th&lt;/sup&gt; grade</td>
<td>4&lt;sup&gt;th&lt;/sup&gt; – 5&lt;sup&gt;th&lt;/sup&gt; grade</td>
<td>2.7 grade</td>
</tr>
</tbody>
</table>
### DEVELOPMENTAL MILESTONES

These questions are about your child's development. Please tell us how much your child is doing each of these things. If your child doesn't do something any more, choose the answer that describes how much he or she used to do it. Please be sure to answer ALL the questions.

<table>
<thead>
<tr>
<th>Activity</th>
<th>Not Yet</th>
<th>Somewhat</th>
<th>Very Much</th>
</tr>
</thead>
<tbody>
<tr>
<td>Runs</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Walks up stairs with help</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Kicks a ball</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Names at least 5 familiar objects - like ball or milk</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Names at least 5 body parts - like nose, hand, or tummy</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Climbs up a ladder at a playground</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Uses words like &quot;me&quot; or &quot;mine&quot;</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Jumps off the ground with two feet</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Puts two or more words together - like &quot;more water&quot; or &quot;go outside&quot;</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Uses words to ask for help</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Available at: https://sites.google.com/site/swycscreen/home
Autism Specific Screeners

• Modified Checklist for Autism in Toddlers
  – Parent report
  – Assesses for symptoms of autism spectrum disorder
M-CHAT

Please fill out the following about your child’s usual behavior, and try to answer every question. If the behavior is rare (you’ve only seen it once or twice), please answer as if your child does not do it.

1. Does your child enjoy being swung, bounced on your knee, etc.? Yes No
2. Does your child take an interest in other children? Yes No
3. Does your child like climbing on things, such as up stairs? Yes No
4. Does your child enjoy playing peek-a-boo/hide-and-seek? Yes No
5. Does your child ever pretend, for example, to talk on the phone or take care of a doll or pretend other things? Yes No
6. Does your child ever use his/her index finger to point, to ask for something? Yes No
7. Does your child ever use his/her index finger to point, to indicate interest in something? Yes No
8. Can your child play properly with small toys (e.g. cars or blocks) without just mouthing, fiddling, or dropping them? Yes No
9. Does your child ever bring objects over to you (parent) to show you something? Yes No
# Sensitivity and Specificity

<table>
<thead>
<tr>
<th>Condition</th>
<th>True Positive</th>
<th>False Positive</th>
</tr>
</thead>
<tbody>
<tr>
<td>Positive Test</td>
<td>True Positive</td>
<td>False Positive</td>
</tr>
<tr>
<td>Negative Test</td>
<td>False Negative</td>
<td>True Negative</td>
</tr>
</tbody>
</table>

**Sensitivity** = \( \frac{\text{True Positive}}{\text{True Positive} + \text{False Negative}} \)

**Specificity** = \( \frac{\text{True Negative}}{\text{True Negative} + \text{False Positive}} \)
### Too Many False Positives?

<table>
<thead>
<tr>
<th></th>
<th>Dev. Delay</th>
<th>No Dev. Delay</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Positive Test</td>
<td>91</td>
<td><strong>183</strong></td>
<td>274</td>
</tr>
<tr>
<td>Negative Test</td>
<td>39</td>
<td>687</td>
<td>726</td>
</tr>
<tr>
<td>Total</td>
<td>130</td>
<td>870</td>
<td>1000</td>
</tr>
</tbody>
</table>

- You decide to screen 1000 infants and toddlers in your practice
- Assume sensitivity of 0.7, specificity 0.79, and prevalence of developmental delays- 13%
- Expect 183 false positives! ?
Even “False Positives” Can Benefit from Early Detection

Table 4. Comparison of Children’s Performance on Diagnostic Measures Across Screening Outcomes

<table>
<thead>
<tr>
<th>Characteristics of Children</th>
<th>True Negative</th>
<th>False Positive</th>
<th>False Negative</th>
<th>True Positive</th>
<th>F†</th>
</tr>
</thead>
<tbody>
<tr>
<td>Adaptive behavior quotient</td>
<td>103 (18.3)</td>
<td>93 (15.0)</td>
<td>90 (10.1)</td>
<td>83 (12.6)</td>
<td>30.78</td>
</tr>
<tr>
<td>Language quotient</td>
<td>105 (19.0)</td>
<td>96 (15.2)</td>
<td>74 (15.4)</td>
<td>72 (14.0)</td>
<td>85.23</td>
</tr>
<tr>
<td>Intelligence quotient</td>
<td>113 (15.8)</td>
<td>99 (15.2)</td>
<td>95 (17.8)</td>
<td>92 (15.2)</td>
<td>50.08</td>
</tr>
<tr>
<td>Achievement quotient</td>
<td>103 (11.0)</td>
<td>94 (10.9)</td>
<td>95 (10.9)</td>
<td>89 (9.8)</td>
<td>32.46</td>
</tr>
</tbody>
</table>

*Data are given as median (SD). Outcomes are defined in the first footnote of Table 3.
†P<.001 for all.

From Neurons to Neighborhoods: The Science of Early Childhood Development

NATIONAL RESEARCH COUNCIL
INSTITUTE OF MEDICINE
Part C of the Individuals with Disabilities Education Act

• Federal program administered at the state level
• Participating states are required to identify and provide early intervention services to infants and toddlers with developmental delay
• Goals
  – Enhance the development of infants and toddlers with disabilities
  – Enhance the capacity of families to meet their infants needs
Early Intervention Helps Families

• 82% of parents felt their families were better off because of early intervention

• 96% of parents felt they were able to work with professionals and advocate for services

• 96% of parents felt they knew how to help their child develop and learn

Source: Bailey, Pediatrics 2005;116;1346
Early Intervention Helps Children

• Programs like Part C Early Intervention
  – Improve developmental outcomes
  – Improve behavioral outcomes

Sources: Nordhov *Pediatrics* 2012;129;e9; Nordhov Pediatrics DOI: 10.1542/peds.2010-0778; Shonkoff *Pediatrics* 1987;80;650-658
Potential Barriers to Developmental Screening

• Time
• Cost
• Literacy burden
• Parental confusion
• False positives
• Lack training
• Disrupts work flow
• EMR compatibility
Why not just do surveillance?
Translating Evidence Based Developmental Screening into Primary Care

• Randomized controlled trial evaluating 3 arms:
  1. Developmental screening with office staff support
  2. Developmental screening without office staff support
  3. Surveillance alone

• Conducted at 4 urban pediatric practices which served as continuity clinic training sites

• Eligibility: <30 months old, born ≥ 36 weeks EGA, without congenital malformations or genetic syndromes, not currently enrolled in EI

Time to Identification of Developmental Delay

Number at risk
- Office Staff Support: 704
- No Staff Support: 693
- Surveillance only: 695

<table>
<thead>
<tr>
<th>Time to Identification in Days</th>
<th>0</th>
<th>100</th>
<th>200</th>
<th>300</th>
<th>400</th>
<th>500</th>
</tr>
</thead>
<tbody>
<tr>
<td>Office Staff Support</td>
<td>655</td>
<td>609</td>
<td>562</td>
<td>297</td>
<td>72</td>
<td></td>
</tr>
<tr>
<td>No Staff Support</td>
<td>635</td>
<td>589</td>
<td>531</td>
<td>275</td>
<td>66</td>
<td></td>
</tr>
<tr>
<td>Surveillance only</td>
<td>668</td>
<td>654</td>
<td>612</td>
<td>330</td>
<td>90</td>
<td></td>
</tr>
</tbody>
</table>

Time to Early Intervention Referral

<table>
<thead>
<tr>
<th>Number at risk</th>
<th>0</th>
<th>100</th>
<th>200</th>
<th>300</th>
<th>400</th>
<th>500</th>
</tr>
</thead>
<tbody>
<tr>
<td>Office Staff Support</td>
<td>704</td>
<td>660</td>
<td>629</td>
<td>590</td>
<td>318</td>
<td>74</td>
</tr>
<tr>
<td>No Staff Support</td>
<td>693</td>
<td>656</td>
<td>633</td>
<td>583</td>
<td>316</td>
<td>77</td>
</tr>
<tr>
<td>Surveillance only</td>
<td>695</td>
<td>677</td>
<td>666</td>
<td>628</td>
<td>339</td>
<td>93</td>
</tr>
</tbody>
</table>

What Happens After Children are Identified with a Developmental Concern

434 Developmental concern → 253 Referred to EI → 129 Evaluated by EI

Factors Associated with Referral

• Increased odds of EI referral
  – Special health care needs odds of referral
  – Concerns involving 2 or more developmental domains

Families Influence Decision to Refer

“‘Ok, we won’t refer today, but let’s come back in a month’, so I shorten the time to next visit and I make a plan... if he’s doing ‘x’ by then, great, if he’s still not doing ‘y’ then let’s refer, and they usually are on board with that. So that’s when I tend not to refer....”

Pediatrician

Problems with Screening Tools

• “I think [the questions] are written well for the most part, but I definitely absolutely have families who are at a low enough cognitive level that they don’t understand.”

Pediatrician

Factors Associated with Completed Evaluation

- Two or more developmental domains
- Faxed referral form versus just handing parents a phone number

Just the Fax

• 58% of children referred by fax completed an evaluation
• 33% of children whose parents were only given the EI phone number completed an evaluation

“I think before we relied on the parents to make the first contact, that wasn’t working because the parents would either forget or [EI] was so busy they would tell them to call back... but now that we fax our forms, it’s much better.”

Pediatrician

Family Perspectives on the EI Referral Process
Themes

• Miscommunication
• Parents Want to be Heard
• Wait and See
• Practical barriers
• Skepticism

Miscommunication

“I was voicing my concerns...she agreed with them but didn’t seem overly concerned, so that kind of brought me down a few notches and so my urgency was already dropping at that point. So I didn’t realize that maybe that [EI referral] was something I should definitely do.”

Not evaluated

Parents Want to be Heard

“I spend all my time with her, so I know her habits and I know her speech.”

“... to contact [EI] if I felt that he needed services or not.”

Wait and See

“We were like, no, we’ll just work with him, at first. So we tried to work with him. Then at the next appointment he didn’t make too much progress and they were like, yeah we recommend [EI]. So we called the number.”

Evaluated

Practical Barriers: Time constraints

“I did put it in my pile of to-dos, which is a mountain. And it got lost in the mountain.”

Not Evaluated

Practical Barriers: Not Understanding the Referral Process

"I didn’t have a number to call. I wasn’t really sure why the process was going on and I was also in school. So I just focused on school and didn’t really pay it any mind"

- Not evaluated

Skepticism

"Some people they already have other issues going on. They might feel insecure about their home environment. It might not look the way other people think it should look. That’s their standard of living. Because it’s in the home, it’s not like you’re coming to a location, they might feel insecure, like okay I know I’m not the best parent or they might judge me when they come in here, or they might take my kids“

EI Employee

## Parental Health Literacy

<table>
<thead>
<tr>
<th></th>
<th>Evaluated (n=20)</th>
<th>Not evaluated (n=20)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Possibly Limited</td>
<td>3 (13.6%)</td>
<td>9 (40.9%)</td>
</tr>
<tr>
<td>Unlikely Limited</td>
<td>17 (77.3%)</td>
<td>11 (50%)</td>
</tr>
</tbody>
</table>

## Differences by Health Literacy

<table>
<thead>
<tr>
<th>Issue</th>
<th>Possible Limited literacy (n=12)</th>
<th>Unlikely limited literacy (n=28)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Confusion about EI process</td>
<td>6 (50%)</td>
<td>9 (32%)</td>
</tr>
<tr>
<td>Issues contacting EI</td>
<td>4 (33.3%)</td>
<td>3 (10.7%)</td>
</tr>
<tr>
<td>Physician does not explain EI</td>
<td>4 (33.3%)</td>
<td>5 (17.8%)</td>
</tr>
<tr>
<td>No established pediatrician</td>
<td>7 (58.3%)</td>
<td>8 (28.6%)</td>
</tr>
</tbody>
</table>

Effective communication strategies

• Attend to parent concerns
• Clear communication
• Communicate concerns in the context of specific strengths
• Delineate clear action steps
• Provide ongoing support
SERIES

• Screening
• Early identification
• Referral
• Intake
• Evaluation
• Services

Take Away Messages

• Developmental screening is effective

• Children at risk for developmental problems benefit from services

• Identification does not guarantee intervention
Take Away Messages

• Educate and partner with families to help link them to services

• Simplify the referral process for families when you can

• Be aware of families with low health literacy
NJ 0 to 3 EI

• Regional Intake Line 1-888-653-4463

• Service coordinator helps arrange evaluation

• Assessment and Evaluation occur at no cost for family (sliding scale for services)
Additional resources

• American Academy of Pediatrics National Center for Medical Home Implementation- Developmental Screening
  http://www.medicalhomeinfo.org/how/clinical_care/developmental_screening/implementing/

• Early Childhood Developmental Screening: A Compendium of Measures for Children Ages Birth to Five. Available at:
Questions?
Contact Information

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