Parent Experiences with Infant Hearing Testing

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Early Diagnosis of Hearing Loss

- The objective of Early Hearing Detection and Intervention (EHDI) programs is to provide an opportunity for early identification and intervention for babies born with hearing loss.
  - Screening: complete before 1 month of age
  - Diagnostic hearing test: complete before 3 months of age
  - Hearing aid fitting: within one month of diagnosis for parents that choose amplification
  - Intervention: begin before 6 months of age

Intervention cannot begin until a diagnosis has been confirmed with appropriate detail to guide intervention decisions

JCIH Year 2007 Position Statement: Principles and Guidelines for Early Hearing Detection and Intervention Programs
Purpose of the Survey

The survey was designed to ask parents:

• about their experiences with the diagnostic process,

• the information they received after the diagnosis, and

• if they knew what they needed to do next following the diagnosis.
Participants

- The survey was distributed to parents through Parent Organizations:
  - The Hands & Voices December 2009 newsletter
  - American Society for Deaf Children

- Data collection period
  - December 2009 – February 2010

- 339 surveys received to date
Preliminary Results
Age at Diagnosis

- Median age: 3 months
- Range: <1 month to 8 years
- Responses from parents included children born in the following years:
  - 1979 – 1996 (44)
    - 2 states mandated NHS
  - 1997 – 2001 (59)
    - 34 additional states mandated NHS
  - 2002 – 2005 (95)
    - 3 additional states mandated NHS
  - 2006 – 2009 (138)
    - 5 additional states mandated NHS
Scheduling Support

- Doctor advised parent: 22%
- Nurse scheduled appointment: 18%
- List of audiologists provided: 13%
- No information provided: 10%
- Other: 34%
  - Hospital had audiologist; Found information on own; tested in NICU; baby passed NHS; referral from friend or other professional; baby missed screening
Wait Time for Appointment

- Median: 2 weeks
  - Same day: 10%
  - Within 2 weeks: 39%
  - 15 days to 4 weeks: 23%
  - 5 weeks to 8 weeks: 10%
  - > 2 months: 6%
**ABR Test Condition:**

Natural sleep, Sedation, Operating Room

<table>
<thead>
<tr>
<th>Option Offered</th>
<th>Preferred Option</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>No:</strong> 51%</td>
<td><strong>Natural Sleep:</strong> 73%</td>
</tr>
<tr>
<td><strong>Yes:</strong> 48%</td>
<td><strong>Sedation:</strong> 17%</td>
</tr>
<tr>
<td>- Natural Sleep: 41%</td>
<td><strong>Operating Room:</strong> 2%</td>
</tr>
<tr>
<td>- Sedation: 30%</td>
<td></td>
</tr>
<tr>
<td>- Operating Room: 5%</td>
<td></td>
</tr>
</tbody>
</table>
ABR Test Condition:
Natural sleep, Sedation, Operating Room

- Support for parent’s Preferred option
  - Supportive: 67%
  - Somewhat supportive: 14%
  - Not supportive: 13%

- Test Condition Used:
  - Natural Sleep: 59%
  - Sedation: 33%
  - Operating Room: 5%
Number of Tests to Diagnose

- 1 appointment: 41%
- 2 appointments: 26%
- 3 appointments: 18%
- Other: 14%
  - 4 to 5 appointments, many more than 5 appointments
# Challenges to Obtaining Test Prior to 3 Months of Age

<table>
<thead>
<tr>
<th>Challenge</th>
<th>Frequency</th>
</tr>
</thead>
<tbody>
<tr>
<td>Delay in appointment availability</td>
<td>86</td>
</tr>
<tr>
<td>ABR noisy repeat testing needed</td>
<td>52</td>
</tr>
<tr>
<td>Live far from testing facility</td>
<td>52</td>
</tr>
<tr>
<td>Sedation only option</td>
<td>50</td>
</tr>
<tr>
<td>Baby had middle ear fluid</td>
<td>48</td>
</tr>
<tr>
<td>Baby had other health problems</td>
<td>47</td>
</tr>
<tr>
<td>Unsure where to get test done</td>
<td>36</td>
</tr>
<tr>
<td>Missed newborn hearing screening</td>
<td>32</td>
</tr>
<tr>
<td>Testing problems: equipment; obtaining accurate results</td>
<td>27</td>
</tr>
</tbody>
</table>
# Challenges to Obtaining Test Prior to 3 Months of Age

<table>
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<tr>
<th>Challenge</th>
<th>Frequency</th>
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<tbody>
<tr>
<td>Screening results not provided</td>
<td>19</td>
</tr>
<tr>
<td>Doctor not helpful, poor communication</td>
<td>12</td>
</tr>
<tr>
<td>Passed NHS</td>
<td>10</td>
</tr>
<tr>
<td>Transportation problems</td>
<td>8</td>
</tr>
<tr>
<td>Unable to afford</td>
<td>4</td>
</tr>
<tr>
<td>Missed appointment</td>
<td>4</td>
</tr>
<tr>
<td>Other reasons</td>
<td>70</td>
</tr>
</tbody>
</table>
Other Challenges

- Other Challenges:
  - Screening was not available
  - Differing opinions among professionals
  - No support
  - Family situations (e.g. moving)
  - Lack of available providers
  - Given wrong information
  - Feared results of testing

- Parent reported experiencing NO Challenges (47)
## Information Provided Following Diagnosis

<table>
<thead>
<tr>
<th>Information Provided</th>
<th>Frequency</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hearing Aids</td>
<td>195</td>
<td>58%</td>
</tr>
<tr>
<td>Early Intervention System</td>
<td>190</td>
<td>56%</td>
</tr>
<tr>
<td>Resources on Childhood hearing loss</td>
<td>164</td>
<td>48%</td>
</tr>
<tr>
<td>Medical referrals</td>
<td>151</td>
<td>45%</td>
</tr>
<tr>
<td>Parent Support Organizations</td>
<td>113</td>
<td>33%</td>
</tr>
</tbody>
</table>
Knowing Next Steps Following Diagnosis

- After talking with the audiologist at the time the hearing loss was diagnosed I was comfortable with what I needed to do next for my child:

<table>
<thead>
<tr>
<th>Response</th>
<th>Frequency</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Strongly Agree</td>
<td>77</td>
<td>23%</td>
</tr>
<tr>
<td>Agree</td>
<td>143</td>
<td>42%</td>
</tr>
<tr>
<td>Disagree</td>
<td>58</td>
<td>17%</td>
</tr>
<tr>
<td>Strongly Disagree</td>
<td>61</td>
<td>18%</td>
</tr>
</tbody>
</table>
Parent Comments: Challenges

- Provide accurate and unbiased resource information

“There should be some sort of guide for babies who failed the screening, outlining the steps from fitting hearing aids to and regular testing afterwards. More resources should be provided in explaining the steps in the whole process so that parents know what to expect instead of not knowing until the next appointment.”
Parent Comments: Challenges

- Need well trained pediatric professionals in testing as well as counseling parents

“Our newborn hearing screening... was correct but no one could tell us what failing this test meant, and that made me more worried, but once we met the audiologist all of my concerns were removed and I got all of the answers I needed.”
Parent Comments: Successes

- Positive relationships with caring professionals

“It was a very smooth experience for our son... our audiologist was wonderful.”

“Testing and diagnosis went as smoothly as possible, our son had aids at two months of age and immediately started speech therapy. Our audiologist specializes in pediatrics and she has been outstanding.”
Parent Comments: Successes

• Coordinated and supportive process

“Everyone did their jobs exceedingly well, and as a result our family received the critical support needed to provide the best care for our child. Within just one month we had a complete medical diagnosis and were fully supported by the [Center].”
Questions?