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In the Trenches: EI Provider Perceptions
Diane Behl, Sara Doutre, Heather Mariger, Juliana Plucinik, Karl White

PRELIMINARY REPORT: DO NOT DISSEMINATE WITHOUT AUTHOR PERMISSION
Research questions

1. What are characteristics of typical EI providers serving families of infants and toddlers birth-3 who are DHH?
   - What are characteristics of EI services delivered?
   - What are strengths?
   - What are challenges?

2. How do audiologists engage with EI & EHDI?
   - Referrals
   - Teaming, training, consultation
   - Family support
Survey Methods

› 10 states invited to participate
› States ID’d EI providers and audiologists serving DHH, including Part C, Schools for Deaf and private providers
› Providers received email from their state administrator with hyperlink to online survey
› Completed survey using Qualtrics online data system
› Presenting aggregate data for:
  – 402 EI providers
  – 187 Audiologists
EI Provider Characteristics:
Part C & private providers  n=402 (12% return rate)

Education level:
• 53% Master’s degree
• 25% Bachelor’s degree
• 8% Doctoral level
• 14% Certificate/other

Degree areas:
• 15% Deaf Ed.
• 17% SLP
• 20% ECSE
• 37% “Other” (OT, social work, etc.)

General Characteristics:
• 98% female
• 96% Caucasian
• 5% are D/HH
• 25% over age 55
• 8% fluent in ASL

Years experience:
• 32% ≤5 years
• 33% 6-15 years
• 35% 16 years or more
What types of services do you provide?

- Service Coordination: 50%
- Speech/Language therapy: 26%
- EI Developmental Services: 34%
- D/HH Specific Early Intervention: 27%
- Listening and Spoken Language Therapy: 18%
- Sign Language Instruction: 17%
- Other: 10%
Communication modalities used by families >75% of the time

- Listening and Spoken Language: 60%
- Total Communication: 32%
- Sign Language: 17%
- Cued Speech: 9%
EI Providers: How adequate was your educational program in preparing you to provide early intervention services to families of children who are DHH?

- Very Adequate: 8%
- Adequate: 42%
- Inadequate: 37%
- Very Inadequate: 12%
<table>
<thead>
<tr>
<th>Early intervention</th>
<th>Excellent</th>
<th>Good</th>
<th>Fair</th>
<th>Poor</th>
</tr>
</thead>
<tbody>
<tr>
<td>19% 36% 29% 17%</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Audiology</td>
<td>16% 32% 25% 26%</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Assessment of children who are D/HH</td>
<td>18% 36% 24% 22%</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Teaching children who are D/HH using Sign Language</td>
<td>32% 37% 19% 12%</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Hearing technology</td>
<td>42% 41% 13% 3%</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Telehealth or teleintervention</td>
<td>40% 32% 20% 9%</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Family support</td>
<td>43% 40% 14% 3%</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Service coordination</td>
<td>2% 9% 24% 66%</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>IDEA Part C regulations</td>
<td>14% 33% 33% 20%</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Pre-literacy instruction</td>
<td>13% 31% 35% 21%</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Teaching children who are D/HH using Listening and Spoken Language</td>
<td>22% 36% 27% 15%</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Teaching children who are D/HH using Total Communication</td>
<td>19% 36% 33% 12%</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>State EHDI</td>
<td>44% 44% 11% 1%</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
In what areas would you have liked more training? (open-ended)

Common themes:
• Family support
• Multidisciplinary assessment and treatment
• Sign language, total communication
• Pre-literacy Instruction
<table>
<thead>
<tr>
<th><strong>How often do you.....</strong></th>
<th>Never</th>
<th>Sometimes</th>
<th>Often</th>
<th>Always</th>
</tr>
</thead>
<tbody>
<tr>
<td>Provide families with choices concerning services and supports</td>
<td>2%</td>
<td>27%</td>
<td>29%</td>
<td>42%</td>
</tr>
<tr>
<td>Help families learn about all communication modalities</td>
<td>8%</td>
<td>31%</td>
<td>30%</td>
<td>32%</td>
</tr>
<tr>
<td>Coach families to take the lead in setting goals</td>
<td>2%</td>
<td>15%</td>
<td>33%</td>
<td>50%</td>
</tr>
<tr>
<td>Help parents understand their legal rights</td>
<td>3%</td>
<td>19%</td>
<td>22%</td>
<td>56%</td>
</tr>
<tr>
<td>Help families get services like child care, transportation, respite care, or food stamps</td>
<td>15%</td>
<td>29%</td>
<td>31%</td>
<td>25%</td>
</tr>
<tr>
<td>Help families get in touch with other families for support</td>
<td>6%</td>
<td>36%</td>
<td>33%</td>
<td>25%</td>
</tr>
<tr>
<td>Serve families from different cultures than yourself</td>
<td>6%</td>
<td>28%</td>
<td>33%</td>
<td>34%</td>
</tr>
</tbody>
</table>
EI providers: Do you coordinate with the following partners?

<table>
<thead>
<tr>
<th>Provider</th>
<th>Yes (we coordinate well with them)</th>
<th>Yes (but our coordination needs some work)</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td>Child care providers</td>
<td>63%</td>
<td>29%</td>
<td>8%</td>
</tr>
<tr>
<td>Other therapists outside of your program</td>
<td>51%</td>
<td>40%</td>
<td>8%</td>
</tr>
<tr>
<td>Primary care providers (e.g., pediatricians)</td>
<td>42%</td>
<td>44%</td>
<td>14%</td>
</tr>
<tr>
<td>Audiologists</td>
<td>72%</td>
<td>22%</td>
<td>6%</td>
</tr>
<tr>
<td>Family support organizations</td>
<td>39%</td>
<td>48%</td>
<td>13%</td>
</tr>
<tr>
<td>Language interpreters for family if needed</td>
<td>66%</td>
<td>27%</td>
<td>7%</td>
</tr>
</tbody>
</table>
How much do you know about these organizations?

- Disability Law or Advocacy Centers: 44% Poor, 43% Fair, 51% Excellent
- Hands & Voices: 13% Poor, 20% Fair, 28% Excellent
- AG Bell: 11% Poor, 28% Fair, 61% Excellent
- Associations of the Deaf (National or State): 10% Poor, 41% Fair, 49% Excellent
- American Society for Deaf Children: 4% Poor, 25% Fair, 71% Excellent
- Your State PTIs: 4% Poor, 27% Fair, 31% Excellent
- Your State F2Fs: 31% Poor, 35% Fair, 34% Excellent
Rate the barriers faced by families of infants and toddlers who are DHH:

- Lack of qualified providers in the area: 43% (Large), 40% (Small), 32% (Not A Barrier)
- Need for more intensive services: 45% (Large), 40% (Small), 15% (Not A Barrier)
- Lack of financial resources: 51% (Large), 41% (Small), 8% (Not A Barrier)
- Ability to communicate with providers in languages other than English: 48% (Large), 30% (Small), 22% (Not A Barrier)
- Lack of services available in all communication modalities for their child: 55% (Large), 27% (Small), 18% (Not A Barrier)
- Finding out about other D/HH providers (e.g., private programs, specialists): 61% (Large), 22% (Small), 17% (Not A Barrier)
Audiology Survey: (n=187)

› Experienced respondents: Over half > 15 yrs experience.
› Majority had at least half of caseload comprised of children birth to three
› Most worked in a hospital setting
<table>
<thead>
<tr>
<th>Question</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>See a child with hearing loss and refer the family to early intervention because they were not already receiving services?</td>
<td>81%</td>
</tr>
<tr>
<td>See a child referred to you from the early intervention program?</td>
<td>83%</td>
</tr>
<tr>
<td>Provide requested audiological information about a child to the early intervention program?</td>
<td>90%</td>
</tr>
<tr>
<td>Receive an invitation to participate in an IFSP meeting?</td>
<td>16%</td>
</tr>
<tr>
<td>Participate in an IFSP meeting?</td>
<td>13%</td>
</tr>
<tr>
<td>Receive a copy of an IFSP for a client?</td>
<td>32%</td>
</tr>
<tr>
<td>Consult with early intervention staff about a client’s needs to inform your or their services?</td>
<td>68%</td>
</tr>
<tr>
<td>Consult with early intervention staff about a client's progress to inform your or their services?</td>
<td>59%</td>
</tr>
<tr>
<td>Provide requested training to early intervention providers on hearing-related issues?</td>
<td>21%</td>
</tr>
<tr>
<td>Receive information or training from the early intervention program?</td>
<td>32%</td>
</tr>
</tbody>
</table>
Audiology Challenges and Successes

- Experience difficulty contacting the early intervention program? 17%
- Suspect that an infant or toddler who is D/HH may not be receiving appropriate early intervention services? 49%
- Hear from parents that the early intervention system is not working for them? 41%
- Hear positive feedback from parents on the state’s early intervention system? 78%
- Receive requests from parents seeking private services to supplement early intervention services? 62%
Audiologist relationship with EHDI

- Share requested audiological information with a child’s primary care provider or physician?
  - Yes: 90%
  - No: 10%

- Receive training or information from EHDI
  - Yes: 80%
  - No: 20%

- Respond to a request for information about a child/family from EHDI
  - Yes: 80%
  - No: 20%

- Experience difficulty contacting EHDI
  - Yes: 10%
  - No: 90%
What challenges do families of infants & toddlers who are DHH face?

• Transportation
• Language barriers, and communicating the importance of early invention to cultures who believe the child is too little to have hearing aids/early intervention
• Limited access to services outside of metropolitan areas, esp. pediatric audiologists & DHH trained EI providers
• Accessing places that will accept Medicaid/EHDI funding for hearing aids. Very few places can fit pediatric patients with hearing aids because they can not afford to see Medicaid patients.
• Lack of unbiased options regarding communication options provided at point of diagnosis and enrollment
• Family support programs; grief after diagnosis
• *Families like to make contact with another family in our area, however this has been easier with facebook. Parents that I encounter typically do not want this information right away which is different that what our state likes to do. I find that they are more ready and open for it 1-2 years after diagnosis.*
Our Conclusions

1. Many EI providers are not specifically trained in serving infants and toddlers who are DHH

2. Many are insecure about their knowledge of EI components and feel their training was inadequate

3. Knowledge in regard to family support resources needs to be strengthened

4. Service coordination is an area for improvement, particularly with audiologists, medical homes, outside providers and family support org’s.

What are your conclusions?
Comments?

Questions?

For more EI SNAPSHOT findings:

Supporting Frontline Responders: Tuesday, 11:00 – 11:30

- How Many clicks does it take: Tuesday, 11:30 – noon

- EHDI and Part Collaboration: Tuesday, 3:00 – 3:30

Thank you!