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EI Snapshot: Family Perceptions on Early Intervention for Children Who Are DHH

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PRELIMINARY REPORT: DO NOT DISSEMINATE WITHOUT AUTHOR PERMISSION
Early Intervention Systematic Nationwide Analysis of Programs’ Strengths, Hurdles, Opportunities, and Trends (EI SNAPSHOT)

› Funded by the Maternal and Child Health Bureau & Oberkotter Foundation
› One year study
› Family perceptions
› EI Provider & Audiologist Perceptions
› EHDI and Part C Infrastructure
› Deaf Ed. Personnel Prep. Programs
› Family access to Public Info.
EI SNAPSHOT Parent Survey

Method:
- Families Identified by EHDI/Part C
- 10 diverse states, 318 respondents (10%)
- Paper and online options

Child Characteristics:
- Children ages 2-6 years
- Range of HL from unilateral to bilateral profound loss;
- Primarily speech/language delays &/or other diverse developmental delays/disabilities

Family Characteristics:
- 10% high school or less, 63% some college/bachelors, 27% masters or doctorate
- 48% with public insurance, 70% private (not exclusive)
- 9% Latino ethnicity; 83% Caucasian, 12% African American, 11% other race
Please help us learn about your family’s experience with early Intervention (EI) services—those therapies and supports received for children who are between birth and 3 years of age. Although your child may be much older, we want to get your input about these early years.

- A parent or primary caregiver who knows about the services you received should complete this survey.
- Your responses will give us a better idea about how to improve programs, so they can better serve children and families.
- Please provide honest feedback. The survey does not collect sensitive information, and no identifiable information about your family or child will be shared.
- This survey takes about 15 minutes to complete. Simply mail the survey back in the enclosed envelope, or complete the survey online by going to elsnapshot.org.

### About Your Child

1. When was your child born? 
   - Month: [ ]  
   - Year: [ ]

2. When was your child first diagnosed as D/H? 
   - Month: [ ]  
   - Year: [ ]

3. What is their current, unaided degree of hearing loss? (check all that apply)

<table>
<thead>
<tr>
<th>None</th>
<th>Mild</th>
<th>Moderate</th>
<th>Moderate/Severe</th>
<th>Severe</th>
<th>Profound</th>
</tr>
</thead>
<tbody>
<tr>
<td>Right ear</td>
<td>[ ]</td>
<td>[ ]</td>
<td>[ ]</td>
<td>[ ]</td>
<td>[ ]</td>
</tr>
<tr>
<td>Left ear</td>
<td>[ ]</td>
<td>[ ]</td>
<td>[ ]</td>
<td>[ ]</td>
<td>[ ]</td>
</tr>
</tbody>
</table>

4. Does your child currently have any of the following? (check all that apply)

<table>
<thead>
<tr>
<th>None</th>
<th>Mild</th>
<th>Moderate</th>
<th>Severe</th>
</tr>
</thead>
<tbody>
<tr>
<td>Speech/language development delay</td>
<td>[ ]</td>
<td>[ ]</td>
<td>[ ]</td>
</tr>
<tr>
<td>Motor delays</td>
<td>[ ]</td>
<td>[ ]</td>
<td>[ ]</td>
</tr>
<tr>
<td>Social/emotional delays</td>
<td>[ ]</td>
<td>[ ]</td>
<td>[ ]</td>
</tr>
<tr>
<td>Autism diagnosis</td>
<td>[ ]</td>
<td>[ ]</td>
<td>[ ]</td>
</tr>
<tr>
<td>Cognitive delays</td>
<td>[ ]</td>
<td>[ ]</td>
<td>[ ]</td>
</tr>
<tr>
<td>Vision problems</td>
<td>[ ]</td>
<td>[ ]</td>
<td>[ ]</td>
</tr>
<tr>
<td>Other (please specify)</td>
<td>[ ]</td>
<td>[ ]</td>
<td>[ ]</td>
</tr>
</tbody>
</table>
How many families were connected by 6 months?

Of the 216 diagnosed by age 3 months:

- 71% received EI between 0-5 months
- 18% received EI by 6-12 months
- 11% received EI after 13 months of age
EI Impact on Family

EI improved my family's quality of life

I feel more confident in my skills as a parent because we received EI Services

EI services taught me how to stand up for my child's needs

- Strongly Agree
- Agree
- Disagree
- Strongly Disagree
EI Service Experiences

- I was often frustrated in my efforts to get EI services
- I was given choices concerning my family's services and supports
- I felt pressured to choose one communication option over the others
- I felt our service plans supported my goals for my child
- I felt like I was part of the team when meeting to discuss my child

Response Options:
- Strongly Agree
- Agree
- Disagree
- Strongly Disagree
- Don't Know
Family open-ended comments

› (It was) A lot all at once. Confusing/overwhelming. Then and now still feel my child isn't getting everything he needs to improve in every area, like pulling teeth. Great all the way up until he reached school age and it’s like he lost everything because of technicalities or state guidelines.

› Early intervention was the best thing that could have happened for our son. He would never be where he is now without them. They gave us hope and pushed through goals that we wanted our son to accomplish! Things that we never thought he could do...they got him to do them!
## Services Needed and Problems Accessing

<table>
<thead>
<tr>
<th>Service</th>
<th>We needed this and received it with no problems</th>
<th>We needed this but had problems getting it</th>
</tr>
</thead>
<tbody>
<tr>
<td>Genetic counseling</td>
<td>35%</td>
<td>15%</td>
</tr>
<tr>
<td>Sign language instruction</td>
<td>33%</td>
<td>15%</td>
</tr>
<tr>
<td>Speech/language therapy</td>
<td>71%</td>
<td>15%</td>
</tr>
<tr>
<td>Assistive hearing devices (hearing aids, cochlear implants, etc.)</td>
<td>74%</td>
<td>11%</td>
</tr>
<tr>
<td>Family training</td>
<td>40%</td>
<td>11%</td>
</tr>
<tr>
<td>Auditory/verbal or listening and spoken language therapy</td>
<td>54%</td>
<td>14%</td>
</tr>
<tr>
<td>Opportunities to interact with adults who are deaf or hard of hearing</td>
<td>21%</td>
<td>23%</td>
</tr>
<tr>
<td>Meeting with other families with children who are D/HH</td>
<td>33%</td>
<td>26%</td>
</tr>
</tbody>
</table>
FAMILY OPEN-ENDED COMMENTS:

Advice:
1. Don’t wait (for services, hearing aids, being involved)
2. Ask for what you need
3. Use all resources (e.g. Other parents & services)
4. Advocate

Barriers:
1. Insurance troubles (don't cover services, high deductibles, trouble accessing)
2. Travel to Appointments (distance)
3. Struggling with cost
4. Unaware of Services
5. Wish I had known... (e.g. I should learn ASL now, get second opinions, services in general)

“(This therapy) was never offered, I wish that I would have educated myself more. I was just going off what I was told through the program he was in.”

“I had very difficult time trying to get speech pathologist to come to my house, once my child's cochlear implant was placed. Months went by and I needed to do a lot of work on my own. EI had trouble with the process. His situation changed so I needed a specialist, had to enroll in other programs.”
EI Service Coordination Experiences

My service coordinator helped me get services like child care, transportation, respite care, or food stamps

My service coordinator helped me get in touch with other parents for help and support

My service coordinator asked whether the services my family was receiving met our needs

My child's doctor got information about our services

- Strongly Agree
- Agree
- Disagree
- Strongly Disagree
- Don't Know
Rate the quality of information provided to you about:

PTI

- Excellent: 19%
- Good: 19%
- Fair: 20%
- Poor: 41%

Hands & Voices

- Excellent: 33%
- Good: 23%
- Fair: 15%
- Poor: 29%

F2F HIC

- Excellent: 16%
- Good: 16%
- Fair: 23%
- Poor: 45%
Our insurance does not cover hearing devices and the copayment for his audiologist is pretty high. I'm glad we could afford it, but at the time we struggled to pay it.
Conclusions: Primary Challenges

• Understanding role of Service Coordinator to receive comprehensive, coordinated services

• Family support: Getting connected with:
  - Family support organizations
  - Connecting with other families of children who are DHH
  - Connecting with DHH adult role models/mentors

• Financial burdens
Potential Impacts from the state systems level

› Part C Service coordination models vary
› Part C and EHDI often in different departments
› State data bases don’t contain needed info & difficult to share
› State level Family Organizations on limited budgets
› DHH Adult Role Models, Guide By Your Side programs too limited
Study Limitations & Next Steps

Return rate (10%) relatively low

Having family email addresses may work better

Greater SES, cultural diversity needed

Difficult to determine services provided via Part C and broader EI

Plan to “drill down” to learn more

Analyze very rich information from open-ended comments
Questions?
Comments?

Thank you!

Please stay for Provider Survey Report