ei snapshot

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NCHAM:
National Center for Hearing Assessment and Management

EI SNAPSHOT

Early Intervention for Children who are Deaf or Hard of Hearing: Systematic Nationwide Analysis of Program Strengths, Hurdles, Opportunities, and Trends

Contents

Executive Summary

Early Intervention Systematic Nationwide Analysis of Program Strengths, Hurdles, Opportunities and Trends (EI SNAPSHOT)

The National Center for Hearing Assessment and Management (NCHAM) received funding from the Maternal and Child Health Bureau and the Oberkotter Foundation to assess the early intervention system in the United States for families of children who are deaf or hard of hearing (DHH). The goals of the **E**arly **I**ntervention: **S**ystematic **N**ationwide **A**nalysis of **P**rograms' **S**trengths, **H**urdles, **O**pportunities, and **T**rends (EI SNAPSHOT) project were to assess:

I. **Family Perceptions, Needs, and Choices** via surveys with families of children ages 2-6 years who are deaf or hard of hearing (DHH).

II. **EI and Audiology Sirect Service Provider Perceptions** via surveys with EI providers and audiologists about their training, experience, and practices in regard to service provision and coordination.

III. **Systems-level Coordination Among Part C, EHDI and Other Relevant Programs** via telephone interviews with state-level EHDI and Part C coordinators.

IV. **Family Access to Information Via Family-to-Family Support Organizations and Part C Websites** through phone surveys with federally-funded Parent Training and Information Centers and Family-to-Family Health Information Centers along with critiques of all Part C websites.

V. **Characteristics of Current Personnel Preparation Programs for Teachers of the Deaf** via interviews with university program directors and surveys with recent graduates.

Findings: Cross-cutting Trends

Trends - consistent themes identified across methodologies and participants – reveal insights about the state of early intervention for families of children who are DHH, both in terms of what appears to be working well (strengths) and areas that warrant attention (hurdles):

Strengths

Part C EI programs are accessible and are viewed as positively supporting families.

- Almost 90% of families reported that it was easy to get connected to early intervention services and that it improved their child's quality of life.
- About two thirds of babies identified as DHH before 3 months of age were connected to EI before 6 months of age.
- EI providers generally have a positive attitude about their work and the role of EI in serving families of children who are DHH.
- Good working relationships and formal referral processes between EHDI and Part C EI to support families are in place in most states.
- Family-to-family support organizations funded to educate and support families of children with disabilities (not specific to hearing loss) report that they consistently refer families to EI when they call with concerns about their child's hearing and thus are an important conduit to the EI system.

Hurdles

A significant number of families believe that publicly funded EI programs are not providing enough services.

- Almost one third of families reported arranging for supplemental private EI services.
- Some families experience frustration in finding providers to address the family's desired communication option.
- Almost two thirds of audiologists received requests from parents seeking supplemental EI services.
- Very few programs for teachers of the deaf provide coursework or practical experience focused on EI/early childhood education in spite of the fact that children who are DHH are increasingly being identified during their first six months of life as a result of newborn hearing screening programs.
- The number of students graduating from deaf education programs is small, thus few are entering the workforce at any one time.

Families have difficulty connecting with family-to-family support systems.

- The majority of families reported that they received little or no opportunities to meet with other parents of children who are DHH.
- About two-thirds of families reported little to no information provided about general disability-focused family-to-family support organizations, and 44% received little to no information about DHH-specific groups like Hands & Voices.
- One-third to one-half of EI providers reported inadequate knowledge about family-to-family organizations.
- Fewer than half of Part C websites – an initial source of information for families – have information about family-to-family support organizations.

Family-level service coordination needs strengthening, particularly to address financial and social supports.

- Almost half of families reported that their child's hearing-related needs posed a moderate to unbearable financial burden, reflecting the need for the EI system to help families access financial resources.
- The minority - about 35% of families - reported that their service coordinator had helped them get non-therapeutic services such as child care or food stamps.
- Inclusion of the medical home to support coordination of EI services is a need, given that 40% of families reported that their medical home did not receive information about their EI services.
- Although the majority of EI service coordinators reported that they coordinate with other providers, about one quarter of respondents reported that coordination with relevant partners "needs more work."
- Although the large majority of audiologists refer families to EI, only about 32% received copies of their clients' IFSP's and only 13% reported that they participated in an IFSP meeting within the past year.

Opportunities for Systems Improvement

Opportunities – potential policies and practices for improving the EI service system – reveal ways that EHDI, Part C, family organizations, and other stakeholders can work together to address hurdles:

- State EHDI and Part C programs should consider building formal partnerships with family-to-family support organizations, both DHH-specific and non-disability-specific. The expansion of such efforts would be a great enhancement of family support opportunities.
- Although referrals from EHDI to EI seem to happen easily, no babies should "fall through the cracks." Developing more efficient shared data systems would allow for more timely tracking of families who are not receiving appropriate services. States with "live" integrated data systems that adhere to privacy and security regulations allow for more effective monitoring, and they can serve as models for other states.
- Further investigation into EI service coordination models would provide insights into how to ensure the broad needs of families are being met, such as connections to financial resources and social supports. Some states have identified service coordinators who specialize in serving families of children who are DHH, ensuring these service coordinators know about DHH-specific resources. Methods to increase inclusion of audiologists in the IFSP process is also important along with greater inclusion of family organizations.
- Expanding personnel preparation options would provide an opportunity to create a workforce of more providers with expertise to serve infants and toddlers who are DHH. Also, EHDI programs can support EI providers via training and technical assistance, e.g., increasing their knowledge about the importance of ensuring families are connected to EI and the contribution of audiologists in promoting optimal learning environments.
- Part C, EHDI, and family organizations' websites need to be improved to ensure families can find information more easily. Improvements would include ensuring diverse families are represented in website material, using simpler language, providing videos to help families with low literacy levels, offering linkages to family organizations, and inclusion of hearing-related resources.
- Inter-agency collaboration and family engagement should be emphasized. EHDI HRSA grant requirements to partner with family organizations and to form learning communities with key stakeholders are two relevant activities that can address the challenges found in this study.

Introduction

Over the past 25 years, significant gains have been made in appropriately and efficiently identifying children with hearing loss through universal newborn hearing screening programs. While 98% of infants are screened for hearing loss (White, 2014), the Centers for Disease Control and Prevention (CDC) reports that a large number of children who are deaf or hard of hearing (DHH) either do not receive early intervention (EI) services or do not receive appropriate services (CDC, 2014).

Evidence continues to accumulate showing that the combination of earlier identification, effective use of state-of-the-art hearing technology, and appropriate early intervention services that focus on teaching language (spoken or signed) can have dramatic benefits for children who are DHH and their families (Bond, et. al., 2009; Sparreboom et. al., 2010; Turchetti et. al., 2011). Although more and more children who are DHH are receiving the benefits of early identification and early intervention, there is anecdotal evidence and widespread professional opinion that there are still many children who do not receive appropriate services.

Without better data about (a) parents' perceptions, needs, and choices regarding services for their children who are DHH, (b) the accessibility of early intervention services, (c) the gap between personnel preparation programs and current needs, and (d) the quality, accuracy, and comprehensiveness of information and support services provided by various agencies and programs to parents of DHH children, it will be difficult to ensure that children who are DHH and their families are receiving the types of services they need for their children to achieve their full potential. Early Hearing Detection and Intervention (EHDI) programs need evidence-based information to help them fulfill their program's role in ensuring families of infants and toddlers who are DHH are receiving comprehensive, family-centered EI services.

The National Center for Hearing Assessment and Management (NCHAM) received funding from the Maternal and Child Health Bureau and the Oberkotter Foundation to evaluate the broader early intervention system for families of children who are deaf or hard of hearing in the United States. NCHAM conducted this multi-method study from 2016 - 2017.

The goals of the **E**arly **I**ntervention: **S**ystematic **N**ationwide **A**nalysis of **P**rograms' **S**trengths, **H**urdles, **O**pportunities, and **T**rends (**EI** SNAPSHOT) project were to measure:

I. **Family Perceptions, Needs, and Choices** from a nationwide sample of caregivers about the degree to which they are being given appropriate information and support to make choices, what barriers and obstacles they encounter, and how the existing systems can better meet their needs.

II. **EI and Audiology Direct Service Provider Perceptions** about the services they provide to families of children who are DHH; the training, experience and expertise of existing early intervention program staff; and the availability and use of related services such as speech therapy, audiology, consistent use of the hearing technology chosen by the family (if any), and linkages to other health care and support services.

III. **Coordination Among Part C, EHDI and Other Relevant Programs** with state-level EHDI and Part C coordinators about policies that support or hinder collaboration and monitoring of families receiving EI services.

IV. **Family Access to Information and Connections to General Disability-Focused Family-to-Family Support Organizations and Part C websites** via Part C and information and services from federally-funded state-based organizations that aim to serve families of children with special needs, including children who are DHH.

V. **Characteristics of Current Personnel Preparation Programs for Teachers of the Deaf** including information about recruitment and placement practices, curricula and internship experiences of students, and perceptions of graduating students about the quality of their graduate training program.

This report presents findings from the EI SNAPSHOT study in relation to strengths and hurdles that were revealed in each of the preceding areas, followed by conclusions about trends and opportunities for improving the EI system for families of children who are DHH. Quotes from research participants are provided as supplementary information along with study materials and related presentations. Appendices featuring the analyses of open-ended responses, study protocols, a research bibliography, and presentations can be found at http://www.infanthearing.org/ei-snapshot/.

I. Family Perceptions, Needs, and Choices

EHDI and Part C coordinators from 10 geo-politically diverse states (Nevada, Montana, Colorado, Minnesota, Iowa, Vermont, Massachusetts, Georgia, South Carolina and Louisiana) partnered with NCHAM to survey families of 2 through 6-year-old children who are DHH. These families described their experiences as participants in the EI system through a survey administered on paper and online. Survey questions assessed when and how families accessed EI services, the types of services received, families' satisfaction with services, and any hurdles they experienced in receiving services and supports. The list of families of children who were identified as DHH to whom surveys were distributed was created through the state EHDI program data bases, since most EI programs identify children by their eligibility category only and do not track whether children found eligible for early intervention services have a hearing loss if that is not the basis for their eligibility. NCHAM created the surveys. The invitation to complete the survey came from the state EHDI and/or Part C program. State EHDI coordinators mailed paper surveys and provided the option of an online response link. A total of 321 families completed the survey (10.0% response rate); 303 surveys included sufficient information for analysis and were from families with a child within the study's specified age range of two to six years.

Chart 1. Characteristics of Family Survey Respondents

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
- Median income level range: $50,000 to $74,999

Child Characteristics:

- Children ages 2-6 years (mean of 3.4 years)
- Range of degrees of hearing loss:
  47% Bilateral Severe/Profound
  28% Bilateral Mild/Moderate
  15% Unilateral Severe or Profound
  6% Unilateral Mild/Moderate
- Primarily speech/language delays (69%), with 22% having additional delays not related to hearing

As seen in Chart 1, the families who responded to the survey reported relatively high education levels, with 90% having at least some college. About 70% of the families reported having private health insurance coverage, while half of the families reported that they had some public health insurance either exclusively or in addition to their private coverage.

Accessing EI by 6 months as part of 1-3-6 goal. The survey sheds light on the extent to which children are accessing EI services before 6 months of age in accordance with EHDI's goal to ensure hearing screening completed before 1 month, diagnosis before 3 months, and initiation of EI services before 6 months of age. Families reported early diagnosis of hearing loss overall with 44% reporting that their child was diagnosed less than 1 month after birth and 80% reporting that their child was diagnosed by 6 months of age.

Chart 2 shows the percentage of children that began early intervention by the age of DHH diagnosis. For those children who were diagnosed by 3 months, almost three quarters of the families were connected to EI prior to 6 months. Interestingly, some families reported that their child began receiving EI services began before the child was diagnosed with a hearing loss. This may have been because the diagnosis was secondary to another developmental delay such as speech and language delays, for which a child may have started to receive EI services.

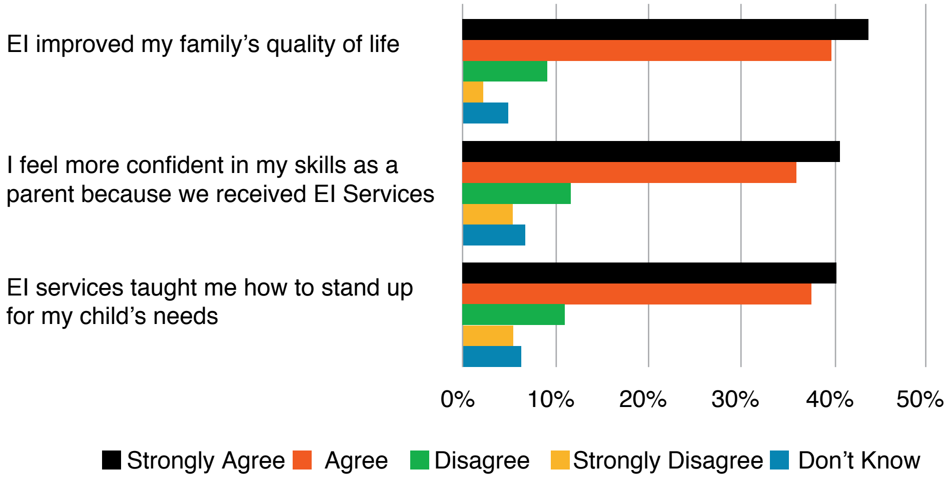
Chart 2. Age of Diagnosis in Relation to Age Beginning of EI

	Percent that began early intervention			
Age at Diagnosis	by 6 months	between 6 and 12 months	between 13 and 24 months	between 25 and 36 months
0-3 months (n=192)	72%	18%	8%	2%
4-6 months (n=21)	57%	33%	10%	0%
7-12 months (n=9)	22%	67%	11%	0%
13-24 months (n=24)	21%	25%	37%	17%

Strength: EI is perceived as important for child and family well-being.

Families provided their perceptions about their EI experience via the anonymous survey. As shown in Chart 3, roughly 85% of families strongly agreed or agreed that EI had a positive impact on their quality of life and improved their confidence as a parent and advocate. In general, families reported positive experiences in getting EI services, and the reported that they felt part of the team in creating service plans that supported the goals they had for their child.

Chart 3. Family Report of EI impact on their Family



Strength: Families receive choices about communication opportunities.

Communication modality is an important and sometimes debated decision for families of infants and toddlers who are DHH. When asked if they felt pressure to choose one communication option over another, 80% of families reported that they did not feel pressure. As shown in Chart 4, the majority of families also reported that they received excellent or good quality information about communication options except for cued speech, which is a less commonly used communication modality. As noted below, while parents reported receiving excellent or good information about total communication, their reporting on their child's communication choices reflects various understandings of the communication modalities as named in the survey, especially listening and spoken language and total communication.

Chart 4. Family Report of Quality of Information Provided About Communication Choices Upon Diagnosis

	Percentage of Families Reporting Quality of Information			
Communication Modality	Excellent	Good	Fair	Poor
Listening and Spoken Language	46%	30%	10%	14%
Sign Language	38%	29%	17%	17%
Total Communication	36%	28%	15%	21%
Cued Speech	22%	21%	25%	32%

In addition to the quality of information provided about communication modalities, each family that responded to the EI SNAPSHOT survey was asked to identify the communication modality their child currently uses. The results reflect a diversity of choices. Families were asked to report the percentage of time each day that their child spends using the following modalities: total communication, sign language, listening and spoken language, and other. Response options were not mutually exclusive, allowing families to indicate that they use multiple communication modalities.

Chart 5 shows the wide variety of communication modalities reported by families. Only 52% of families use one communication modality exclusively (49% listening and spoken language and 3% sign language). Nearly half of families supplement their primary choice with at least one other communication modality. Analysis of survey data revealed that families' definitions of communication modalities differ. Chart 5 reflects categorization based on the percentages reported by the family as well as clarification gained from parent comments and the types of early intervention services the child received. For purposes of this report, listening and spoken language means that the child uses spoken language to communicate even if the child does not need listening and spoken language therapy. Some comments indicated that families did not understand the definition of listening and spoken language as a communication modality. One parent indicated that their child communicated 0-5% in listening and spoken language and then wrote that their child uses "normal communication as a hearing child would use." Families also seemed to use different definitions of total communication. For example, some appeared to define total communication as communication with no accommodations, others as using sign language for part of the day and listening and spoken language for part of the day, and others as the simultaneous use of both voice and sign language. A re-coding of these responses was made when sufficient information was provided to accurately categorize responses into another category, i.e., mostly LSL or mostly ASL.

Chart 5. Family Report of Child's Primary Communication Modality

Communication Modality	Percentage of Families
Listening and Spoken Language only	49%
Sign Language only	3%
Mostly Listening and Spoken Language (supplemented by sign language, cued speech, or other)	17%
Mostly Sign Language (supplemented by listening and spoken language, cued speech, or other)	3%
Mostly Cued Speech (supplemented by listening and spoken language, or other)	12%
Equal Parts Sign Language and Listening and Spoken Language (including total communication)	14%
Other	1%

Hurdle: Families report challenges accessing DHH-specific services and supports.

In spite of the overall positive evaluation of their EI services, families reported numerous hurdles in obtaining DHH-specific services. As shown in Chart 6, a quarter of families reported having problems connecting with other families of children who are DHH, and almost as many reported problems connecting with adults who are DHH (sometimes referred to as "deaf mentors"). A smaller portion of families reported problems accessing genetic counseling, communication services and therapies, and family training. These are all services that are important for many families of children who are DHH.

Chart 6. Family Report of Services Needed and Problems Accessing Services

Service	**We needed this and received it with no problems**	**We needed this but had problems getting it**
Opportunities to interact with adults who are deaf or hard of hearing	22%	23%
Meeting with other families with children who are DHH	34%	25%
Genetic counseling	35%	15%
Sign language instruction	34%	15%
Speech/language therapy	71%	15%
Assistive hearing devices (hearing aids, cochlear implants, etc.)	75%	11%
Family Training	40%	11%
Auditory/verbal or listening and spoken language therapy	55%	14%

"I had a very difficult time trying to get a 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.

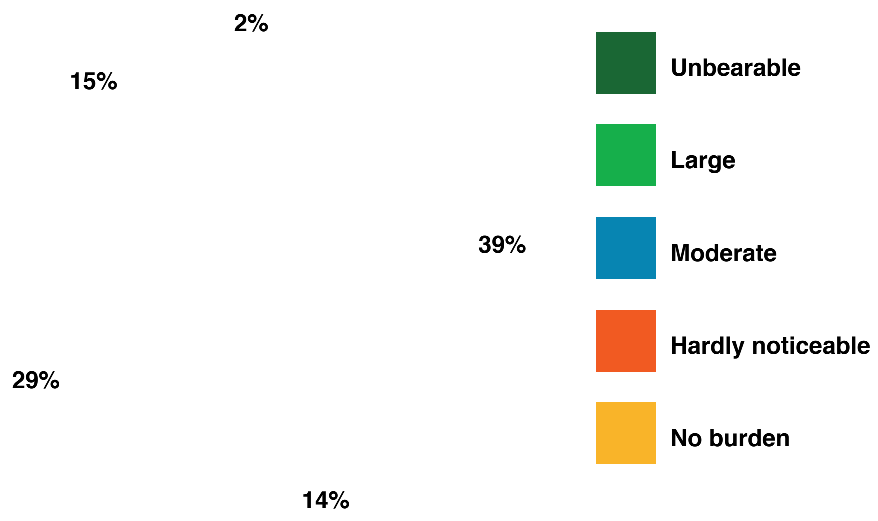
~Parent~

[It was] a lot all at once. Confusing/overwhelming. Then and now I still feel my child isn't getting everything he needs to improve in every area. [It was] 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.

~Parent~

Nearly half of families reported that their child’s out-of-pocket hearing-related needs were a financial burden for the family. About 44% of families expressed this was a moderate to large burden, with 2% describing the burden as unbearable (see Chart 7). As reported earlier, 48% of families had public insurance, and 70% had private insurance. Thus, it appears that insurance did not alleviate financial burdens for many of the families.

Chart 7. Family Report of Perceived Financial Burdens Associated with Hearing Related Needs



Hurdle: Comprehensive service coordination and access to family support systems are lacking.

Service coordination, a primary component of an effective EI system, was reported by many families to be missing the mark (see Chart 8). Only about 35% of families reported that their service coordinator helped them get non-therapeutic services such as child care or food stamps (strongly agree and agree combined), and a significant portion of families reported “don’t know” in response to these questions. It is unclear if perhaps this is because they potentially didn’t need such outside supports or if they didn’t know if their service coordinator or someone else assisted them. About 60% reported that their medical home received information about their EI services, and about 20% reported that they “didn’t know.” Roughly a third reported that their service coordinator did not help them get in touch with other parents for support. It appears that greater inclusion of the medical home as well as ensuring connections with support services is needed within the current EI system for families of children who are DHH.

Families were asked about the extent to which they received information about family-to-family support organizations that help connect families with EI and other needed services and offer advocacy and parent-to-parent support. As shown in Chart 9, roughly two thirds of families reported that they received fair to poor information from EI about their state Parent’s Training and Information (PTI) Center and the Family-to-Family (F2F) Health Information Center, federally funded family-to-family support organizations in each state that serve families of children with all disabilities and are not DHH-specific. Over half of families reported receiving excellent to good information about Hands & Voices (H&V), a DHH-specific family-to-family support organization. It is important to note that state H&V chapters are present in most but not all states surveyed.

Chart 8. Family Report of Service Coordination Help in Accessing Services

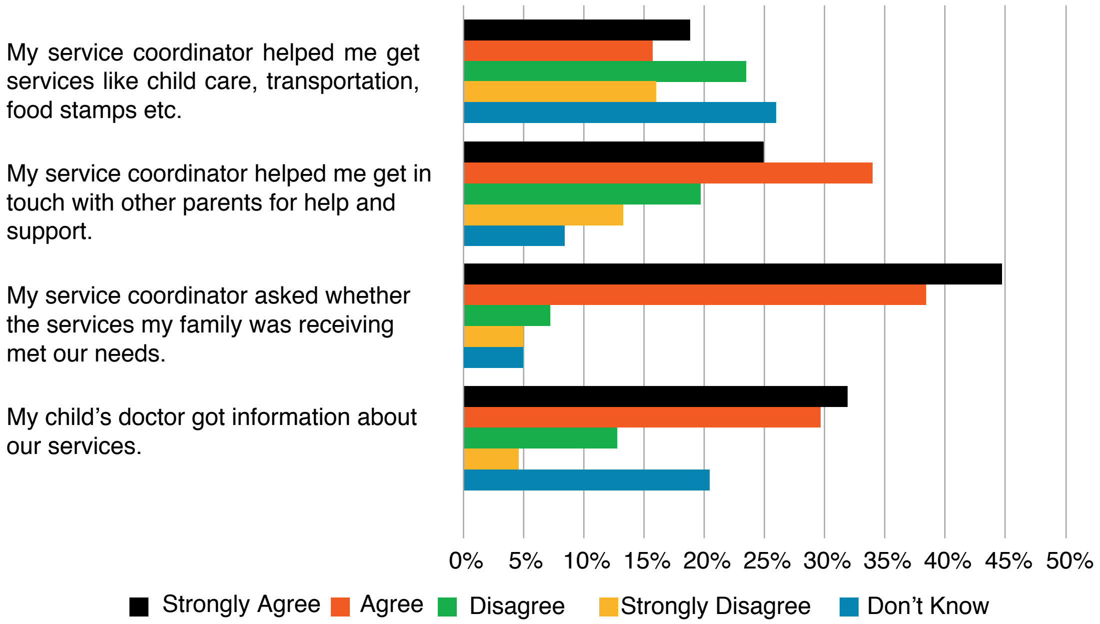
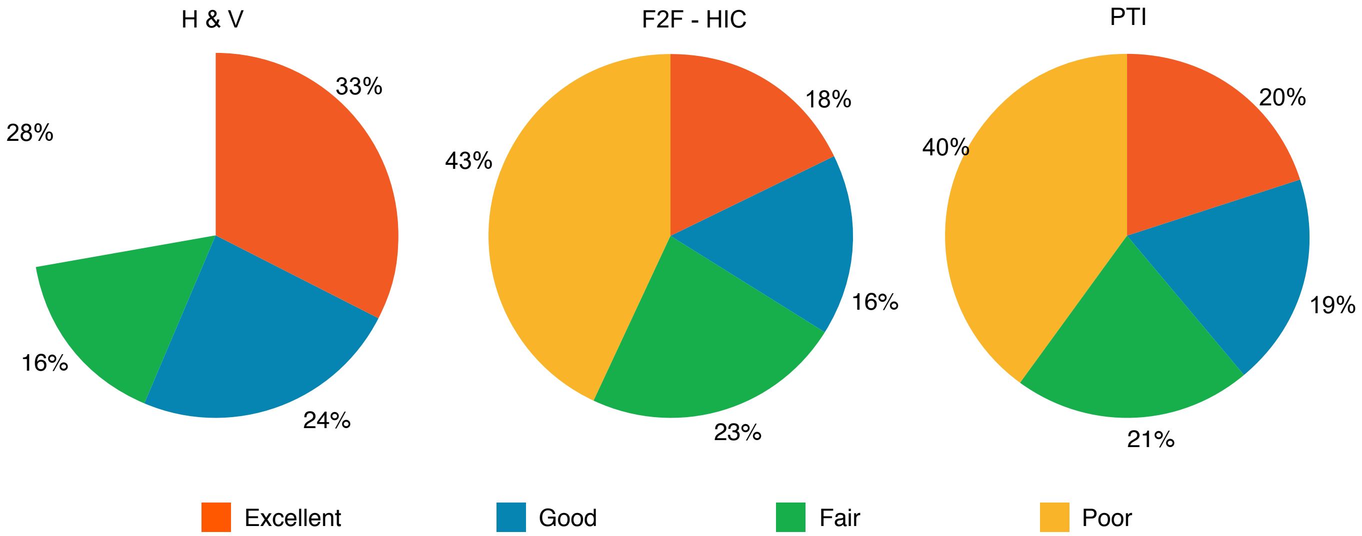


Chart 9. Family Report of the Quality of Information Received about Family Organizations



Note: H&V - Hands & Voices; F2F-HIC - Family-to-Family Health Information Center; PTI - Parent Training Information Center;

Summary

The results from the family survey show that although families reported overall satisfaction with EI services, there are gaps in the extent to which families received comprehensive services that addressed their social support and financial needs. Connections with family-to-family supports is an apparent need based on results from this survey, and one that is reinforced through other data collected in the SNAPSHOT study as noted elsewhere in this report. Appendix A (see http://www.infanthearing.org/ei-snapshot/) provides additional insights into the family perspective, offering categorized responses to open-ended questions, such as “What advice would you offer to other families?”

II. EI Provider and Audiology Perceptions

Early intervention providers and audiologists serving infants and toddlers who are DHH were identified with the help of EHDI and Part C leaders in each of the ten states. Separate surveys, with an invitation from the state EHDI and Part C Coordinators, were sent via email to the people identified in each group with a hyperlink provided to complete an online survey. The response rates were 15% and 23% from EI providers and audiologists respectively.

EI Provider Survey Findings

Chart 10 describes the characteristics of the 424 EI providers who responded that they currently provide early intervention services to birth to 3 year old children who are DHH. Over half of responding providers had a Master's degree, almost all were female, and about two thirds had at least 6 years of experience providing early intervention. About half of the service providers reported providing service coordination, either exclusively or in addition to providing direct service. Early childhood special educators, deaf educators, and speech/language pathologists constituted most of the sample; 9% of respondents reported a variety of unique degrees or certifications too few to categorize.

Chart 10. Characteristics of the 424 EI Providers Who Responded that they Currently Provide Early Intervention Services to Birth to 3 Year Old Children Who are DHH

EI Provider Characteristics

Education level:

1% Associates degree
24% Bachelor's degree
59% Master's degree
9% Doctoral level
8% Certificate/other

General Characteristics

98% Female
96% Caucasian
5% are DHH
25% over age 55
8% fluent in ASL

Years Experience

32% <5 years
33% 6-15 years
35% 16 years or more

Degree Areas:

19% Early Childhood Special Education
19% Speech Language Pathology
19% Deaf Education
9% Audiology
6% Early Childhood
6% OT/PT
5% Special Education
5% Psychology / Mental Health
2% Elementary Education
1% Social Work / Counseling
1% Nursing

Types of early intervention services provided (not mutally exclusive):

50% Service Coordinator
26% Speech Language therapy
34% EI Developmental Services
27% DHH Specific Early Intervention
18% Listening and Spoken Language Therapy
17% Sign Language Instruction

Strength: Providers encourage families to take the lead.

As shown in Chart 11, EI providers reported that they often or always provided families with choices about services and supports, coached families to take the lead in setting goals, and helped families understand their rights. About 64% of providers reported that they often or almost always help families learn about all communication modalities. Consistent with the results of the family surveys, almost half of the providers reported that they never or only sometimes helped families get non-early intervention services like child care or food stamps, and about 42% never or only sometimes helped families get in touch with other families for support.

Chart 11. Frequency of Key Activities Reported by EI Providers

How often do you...	**Never**	**Sometimes**	**Often**	**Always**
Provide families with choices concerning services and supports	2%	26%	29%	43%
Help families learn about all communication modalities	7%	29%	29%	35%
Coach families to take the lead in setting goals	2%	14%	32%	52%
Help parents understand their legal rights	3%	18%	23%	56%
Help families get services like child care, transportation, respite care, or food stamps	18%	30%	30%	22%
Help families get in touch with other families for support	6%	36%	32%	26%

Strength: EI providers report being knowledgeable about EI, DHH-specific services.

The majority of EI providers rated their knowledge of DHH-specific topics as excellent or good in areas of early intervention, family support, IDEA Part C regulations, and pre-literacy instruction. Given the role of service coordinators, a closer look at the reported knowledge levels of service coordinators (SCs) versus other direct EI service providers was conducted. Results revealed that SCs reported they were more knowledgeable than non-SCs about service coordination and IDEA regulations, while non-SCs reported greater knowledge related to DHH-specific aspects, such as assessing children who are DHH and instruction using various communication options (see Charts 12 and 13). It appears that a substantial portion of both SC's and non-SC's are not confident about their knowledge of the state EHDI program which points to the need to strengthen relationships among EHDI and local providers. As discussed in the later section of this report, state program directors reported that one of their biggest concerns is with families "falling through the cracks" at the local level.

Chart 12. Service Coordinator Self-Report Ratings of Knowledge of EI and DHH-Specific Services (n=180)

What do you know about:	Excellent	Good	Fair	Poor
Early Intervention	47%	43%	9%	1%
Audiology	10%	37%	39%	14%
Assessment of children who are DHH	14%	38%	29%	19%
Teaching children who are DHH using Sign Language	7%	31%	40%	22%
Hearing technology	6%	27%	42%	25%
Telehealth or teleintervention	2%	6%	22%	70%
Family support	44%	38%	15%	3%
Service coordination	58%	35%	6%	2%
IDEA Part C regulations	56%	35%	8%	1%
Pre-literacy instruction	36%	36%	18%	10%
Teaching children who are DHH using Listening and Spoken Language	11%	33%	29%	27%
Teaching children who are DHH using Total Communication	11%	28%	31%	31%
State EHDI	15%	36%	31%	18%

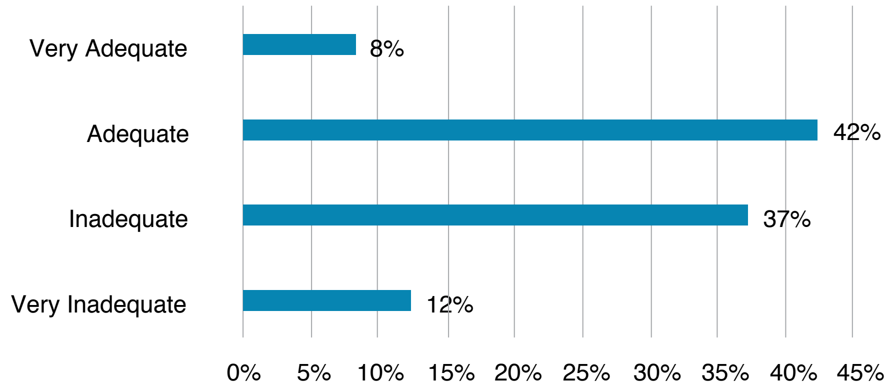
Chart 13. Non-Service Coordinator Self-Report Ratings of Knowledge of EI and DHH-Specific Services (n=185)

What do you know about:	Excellent	Good	Fair	Poor
Early Intervention	45%	41%	12%	2%
Audiology	31%	36%	24%	10%
Assessment of children who are DHH	34%	35%	22%	9%
Teaching children who are DHH using Sign Language	24%	30%	29%	17%
Hearing technology	24%	39%	23%	14%
Telehealth or teleintervention	1%	15%	31%	54%
Family support	45%	39%	12%	4%
Service coordination	19%	29%	35%	17%
IDEA Part C regulations	27%	47%	18%	8%
Pre-literacy instruction	30%	38%	18%	14%
Teaching children who are DHH using Listening and Spoken Language	30%	38%	17%	15%
Teaching children who are DHH using Total Communication	25%	36%	19%	20%
State EHDI	24%	38%	26%	12%

Hurdle: There is a need for increased preservice education related to serving children who are DHH.

EI providers also were asked about the adequacy of their educational training pertaining to EI. Chart 14 shows that roughly half of respondents reported that their training was inadequate or very inadequate in preparing them for their positions. It is likely that providers received most of their knowledge while "on the job" versus via formal personnel preparation training. This is reinforced in the later section of this report that shows the relatively small amount of focus on EI in personnel preparation programs for teachers of DHH.

Chart 14. Perceived Adequacy of Personnel Preparation Programs in Preparing EI Providers to Provide EI Services to Families of Children who are DHH



"I strive very much to bring a wealth of information to the families I work with and respect the choices that they make for their children…It's completely up to the family to decide and I'll be that support person who will put them in touch with the necessary people to help them feel confident in their decision."

~EI Provider~

Hurdle: Coordination with other providers and family-to-family support organizations is lacking.

Providers were asked the extent to which they coordinated with other providers (see Charts 15 and 16). Service coordinators (SC's) were analyzed as a subgroup and compared to other non-SC providers. As shown in Chart 15, almost three quarters of SC's reported that they coordinate well with child care providers, and two thirds reported coordinating well with audiologists and language interpreters. Fewer SC's (about half) reported coordinating with other therapists outside of the program and primary care providers, and a significant portion rated their coordination with these partners as "needing some work." Less than half of SC's reported that they coordinate well with family support organizations, and the greatest percent of SC's characterized their coordination with family organizations as "needing some work." In general, a greater percentage of non-service coordinators rated their coordination with partners as either needing some work or nonexistent. Slightly more non-SC's reported "coordinating well" with audiologists.

Chart 15. Service Coordinator Report of Coordination with Other Partners (n=180)

With whom do you work?	**Yes - we coordinate well with them**	**Yes - but our coordination needs some work**	**No**
Child care providers	73%	22%	5%
Other therapists outside of your program	55%	41%	4%
Primary care providers (e.g., pediatricians)	48%	43%	10%
Audiologists	69%	25%	6%
Family support organizations	44%	48%	7%
Language Interpreters for family if needed	69%	26%	5%

Chart 16. Non-Service Coordinator Report of Coordination with other Partners (n=185)

With whom do you work?	**Yes - we coordinate well with them**	**Yes - but our coordination needs some work**	**No**
Child care providers	48%	36%	17%
Other therapists outside of your program	47%	40%	13%
Primary care providers (e.g., pediatricians)	33%	43%	24%
Audiologists	70%	21%	8%
Family support organizations	35%	45%	19%
Language Interpreters for family if needed	65%	24%	11%

Additionally, providers were asked to rate their knowledge of organizations that serve families with children who are DHH in their state using the state-specific names. As shown in Chart 17, many EI providers rated their knowledge of Disability Law and Advocacy centers, their state's Parent Training and Information Center (PTI), and DHH-specific organizations such as Hands & Voices and American Society of Deaf Children as "poor." Slightly more providers reported knowing about their state's Family to Family Health Information Center (F2F-HIC), yet still almost one third rated their knowledge of this organization as "poor." It is important to note that even though some of the organizations often are not present at the state level, it is surprising that more providers are not aware of them, particularly the organizations that support a DHH-specific population. As with the family survey, it appears that increased knowledge of providers about and partnership with these family support and advocacy groups is needed to support access to these important resources.

Appendix B (see http://www.infanthearing.org/ei-snapshot/) of this report provides open-ended comments from the EI providers, highlighting their specific recommendations for improving the EI system for families and areas in which they'd like further training. The largest number of comments pertained to the need for a) EI training to meet specialized needs of children who are DHH; b) the importance of attracting and retaining more providers; c) ensuring families are provided with information, funding and services, and d) increased collaboration with team members.

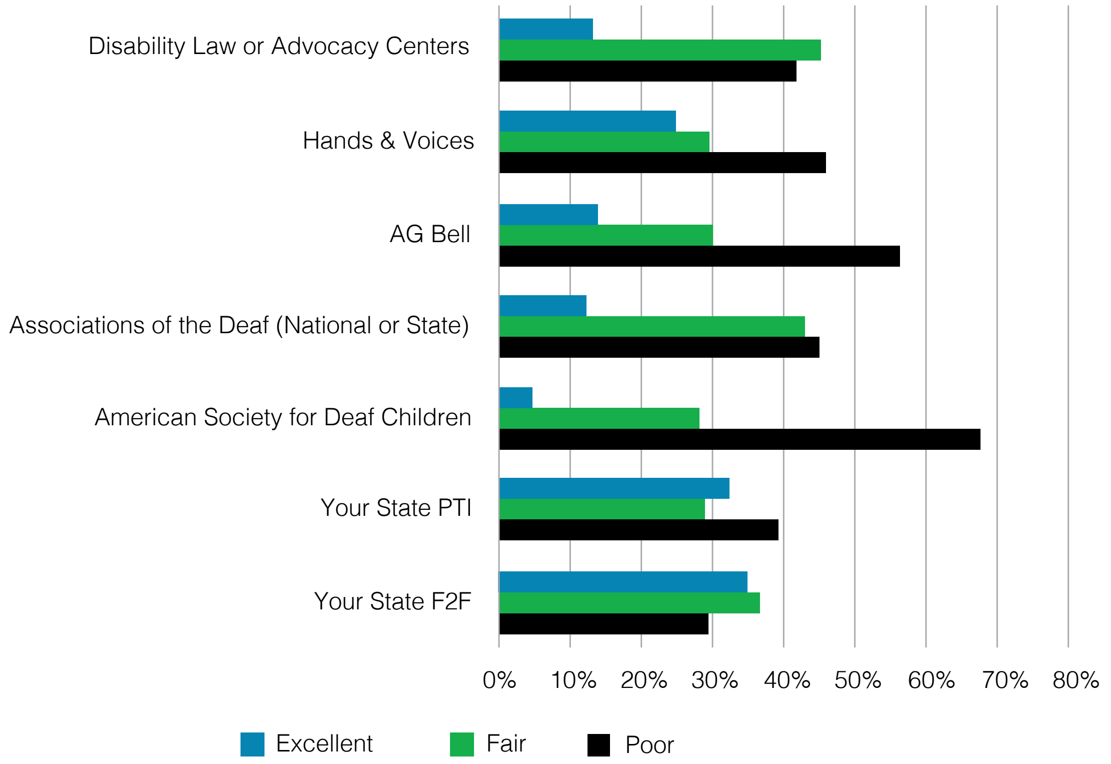


Chart 17. EI Provider Rating of their Knowledge of Family Organizations

Audiologist Survey Findings

A total of 187 audiologists from 10 states responded to an online survey request from their state EHDI and Part C administrators. Chart 18 shows that 53% of the surveyed audiologists had over 15 years of experience and the majority had at least half of their caseload comprised of children ages birth to three. Respondents worked in a variety of public and private settings; most worked in a hospital setting or clinic, with only 16% working for a school district or EI program.

Chart 18. Audiologist Respondent Characteristics

Median years of experience: 12.6

- 0-2 Years: 13%
- 3-5 Years: 10%
- 6-10 Years: 11%
- 11-15 Years: 13%
- 16+ Years: 53%

Caseload birth to three:

- 5-10% of caseload: 10%
- 6-25% of caseload: 35%
- 26-50% of caseload: 29%
- 51-75% of caseload: 14%
- 76-100% of caseload: 12%

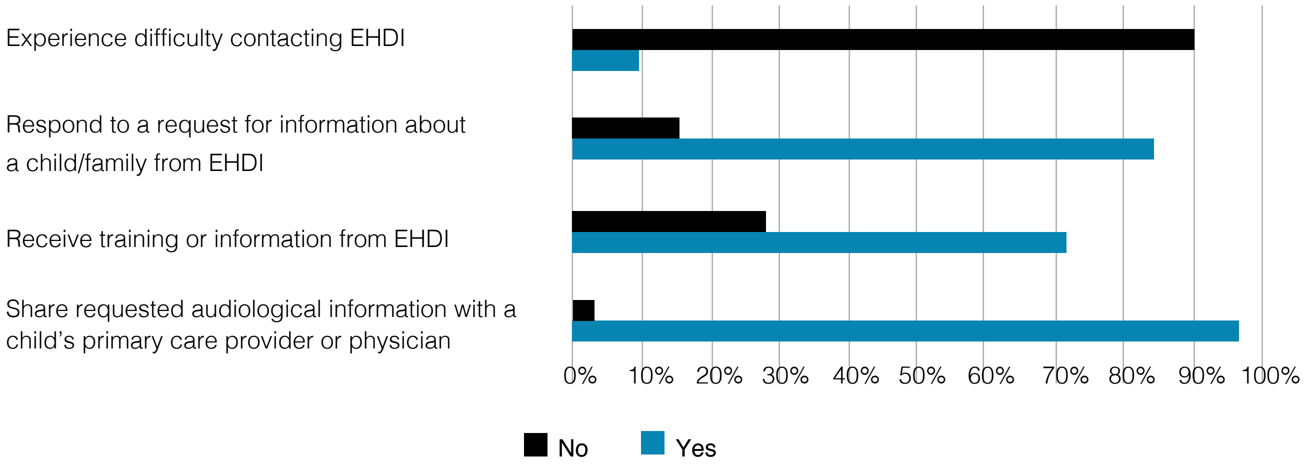
Work Setting:

- Private, for profit clinic: 22%
- Public health agency: 11%
- School district/early intervention program: 16%
- Hospital: 29%
- Non-hospital clinic: 18%
- Other: 3%

Strength: Audiologists report positive communication with EHDI & EI system partners.

Audiologists were asked whether they share child-specific information with EHDI, EI staff, and a child's primary health care provider. As reflected in Chart 19, almost all of the audiologists reported that they provide reports to the child's medical home, and about 85% reported that they provide information to the state EHDI program. Additionally, very few audiologists reported difficulty contacting the EHDI program. About 90% reported providing requested audiological information to the EI program. The majority also reported that they consulted with EI staff about a child's needs.

Chart 19. Audiologist Report of Communication with EHDI and EI Partners



> *"I think we do great at tracking these infants and making sure they have received proper follow-up. We also have many great EI programs."*
>
> *~Audiologist~*

Hurdle: Child-specific teaming with EI program staff is needed.

Beyond providing requested child-specific audiological information, only about one third of audiologists received a copy of their client's IFSP, and even fewer participated or had ever been invited to an IFSP meeting. About one third of audiologists reported that they do not consult with EI staff about a child's needs or progress (see Chart 20). Thus, although the majority of audiologists refer families to EI and offer some consulting about a child's needs, this communication appears to be one directional with little information being provided from EI to the audiologists.

Chart 20. Audiologist Report of EI Related Activities They Performed in the Past Year

In the past year, did you:	% Yes
Provide requested audiological information about a child to the early intervention program?	90%
See a child referred to you from the early intervention program?	83%
See a child with hearing loss and refer the family to early intervention because they were not already receiving services?	81%
Hear positive feedback from parents on the state's early intervention system?	78%
Consult with early intervention staff about a client's needs to inform your or their services	68%
Receive requests from parents seeking private services to supplement early intervention services?	62%
Consult with early intervention staff about a client's progress to inform one another about their services	59%
Suspect that an infant or toddler who is DHH may not be receiving appropriate early intervention services?	49%
Hear from parents that the early intervention system is not working for them?	41%
Receive information or training from the early intervention program?	32%
Receive a copy of an IFSP for a client?	32%
Provide requested training to early intervention providers on hearing-related issues?	21%
Experience difficulty contacting the early intervention program?	17%
Receive an invitation to participate in an IFSP meeting?	16%
Participate in an IFSP meeting?	13%

Hurdle: Audiologists report families are challenged in getting affordable, comprehensive services.

As shown in Chart 20, almost half of audiologists reported that in the past year they suspected an infant or toddler they served may not have received appropriate EI services. Audiologists were not asked about the proportion of families for whom this was true, so it could have been just one family or many. On this same note, 62% of audiologists had a parent request help in seeking private services to supplement their EI services. Thus, although over three-quarters of audiologists heard positive feedback from parents about EI, it appears that there are also families for whom EI is not meeting their needs.

These needs are reflected in the responses to an open-ended question posed to audiologists, "What challenges do families of infants and toddlers who are DHH face?" Based on the analysis of common themes, the most frequent concern reported by audiologists were limited access to specialized services and supports, particularly for families living outside of metropolitan areas, and lack of funding for hearing aids. Appendix C (see http://www.infanthearing.org/ei-snapshot/) contains the verbatim comments from all of the early interventionists and audiologists.

Summary

These findings demonstrate that EI providers recognize the importance of delivering services via a coaching model, supporting families as decision makers. These results also point to ways that the EI system can be improved via provider collaboration. For example, inclusion of audiologists in the IFSP process is one important way to enhance coordination. Providers also can ensure families are knowledgable about family-to-family support organizations. As evidenced in the open-ended comments, both EI providers and audiologists also referred to the challenges of high caseloads and limited access to specialists, which are especially problematic for families living in rural areas. There are also opportunities for coordination between local EI providers and the medical home as well as the EHDI program. Such efforts would reinforce timely referral to services as well as emphasize to families the importance of EI services.

> ***"I think it's difficult for families to find appropriate audiological services to meet the needs in their local communities. "***
>
> ***~Audiologist~***

III. Coordination among Part C, EHDI and Other Relevant Programs

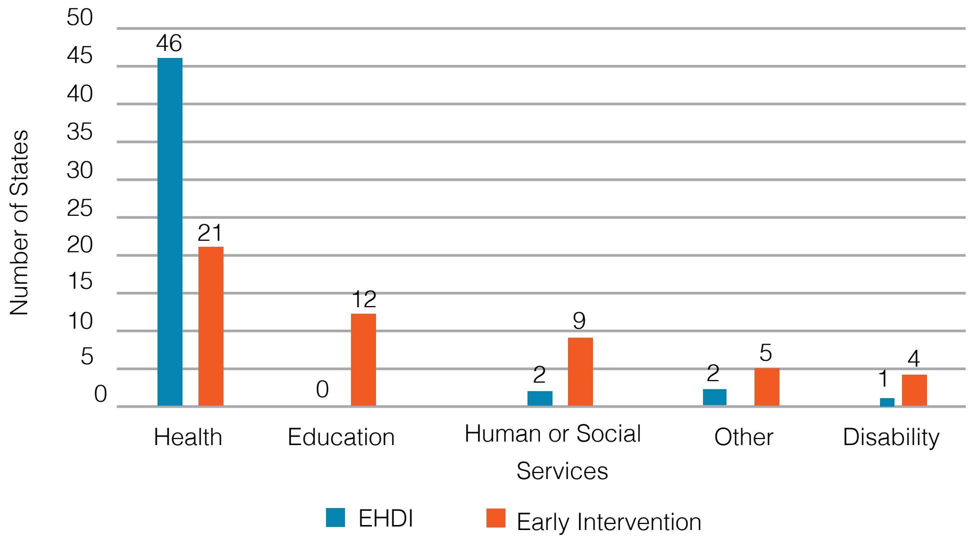
As described in the Joint Committee on Infant Hearing Guidelines (JCIH, 2007 and 2013), comprehensive early intervention systems for families of children who are DHH require collaboration at a systems level among key administrators. Particularly critical is the need for collaboration between EHDI, Part C early intervention, Schools or Commissions for the Deaf and Hard of Hearing, and other key organizations.

Telephone interviews were conducted with state EHDI and Part C coordinators to learn more about the levels and types of collaboration occurring among the programs and the referral and transition of children who are DHH from newborn hearing screening to early intervention programs. Part C and EHDI coordinators in each state were invited to participate. EI SNAPSHOT staff conducted interviews with coordinators from 33 states. In 15 of these states, both the EHDI and Part C coordinator participated in an interview, in 13 states only the EHDI coordinator participated, and in 5 states only the Part C coordinator participated.

Interview questions focused on understanding state governance structures for both the EHDI and Part C systems, eligibility criteria for infants and toddlers with hearing loss for Part C early intervention services, the referral processes between programs, and data sharing between programs. Additional data on state governance of EHDI and Part C programs and eligibility criteria for early intervention services were obtained from the websites of the 17 states and the District of Columbia that did not participate in an interview.

Structure, formality, and mechanisms of collaboration differ across states. Part C early intervention and EHDI programs are in the same state agency or department in only 43% of states. Although nearly all EHDI programs are located within state departments of health, only half of Part C early intervention programs are in departments of health. Other Part C programs are distributed across a broad variety of agencies connected to education and other disability services. Chart 21 shows the distribution of lead agencies responsible for EHDI and Part C early intervention.

Chart 21. State EHDI and Part C Program Department Locations



Strength: EHDI and Part C coordinators recognize the value of collaboration.

In every state interviewed, EHDI and Part C coordinators conveyed dedication to ensuring that infants and toddlers who are DHH receive timely, appropriate early intervention services. Respondents emphasized their efforts to ensure collaboration across programs. While some agencies collaborate because of shared agencies or even supervisors, there are many other reasons for collaboration. Interviews confirmed findings from the 2008 Infant Toddler Coordination Association EHDI Survey (ITCA, 2008) that reported approximately half of the programs have a formal interagency agreement that describes how the organizations coordinate. Many state coordinators attributed the strength of their collaboration to frequent, informal "open door" communication. Two examples of formal collaboration defined in an interagency agreement are shown below.

MOU Excerpt Regarding Participation in Child Find

- [Part C program] assures that a system is in place to identify and locate eligible children. Child Find activities include outreach, public awareness, developmental monitoring and community screenings.
- [State School] agrees to contribute to public awareness and to participate in vision and hearing screening activities determined by regional/community needs and regional agreement.

MOU Excerpt to Support Early Childhood Identification

"THEREFORE, it is hereby mutually agreed by and between the parties that:

- [EHDI program] will provide Otoacoustic Emission Screening Equipment to Point of Entry offices purchased through (grant name).
- [EHDI program] will provide training on use of equipment, reporting format, and provide technical assistance as warranted.
- [Part C program] will be responsible for annual calibration and any needed maintenance or repair of equipment either directly or via contract with Point of Entry offices.
- [Part C program] will be responsible for consumables (disposable eartips) that are necessary for testing and infection control either directly or via contract with Point of Entry offices.
- [Part C program] will obtain written parental consent and provide child specific data to (EHDI program) regarding screening test results for documentation in the statewide database and for possible referrals for further diagnostic evaluations.

Strength: Most EHDI advisory boards include the Part C Coordinator or a representative.

Because one of the main goals of the EHDI program is to ensure a child receives timely early intervention services, the participation of the Part C coordinator or his/her designee is crucial for an EHDI advisory board. Of the 33 interviewed states and an additional 7 states that responded to a survey regarding interagency collaboration, eighty-seven percent reported that the Part C coordinator is a permanent member of an EHDI advisory board. Six states (15%) reported that while there is not an official EHDI advisory board, committees and workgroups have included the Part C coordinator.

Strength: Procedures are in place to ensure infants and toddlers who are DHH are referred to Part C early intervention.

All interviewed states have processes in place for the referral of children identified as DHH to early intervention services. In most states (87%), referral is made upon diagnosis of a confirmed hearing loss. In four states, all children who fail the newborn hearing screening are referred to Part C early intervention for follow up. Some states' processes include multiple referral points to serve as a check to ensure referrals are made. Interviewers assigned a ranking of the state's referral processes, from weak (meaning little in the way of systematic procedures) to fair (standard procedures but no way of efficiently monitoring) to strong (systematic procedures with safeguards such as data monitoring). When asked to rank states referral processes, interviewers ranked only one state as weak, 48% as fair, and 48% as strong. Many states reported effective referral procedures via the use of "parent guides", i.e., an individual, often a parent of a child who is DHH, who calls to assist the family in navigating early intervention and other services. In some states, parent guides are employees of the state and in others, they are contracted by the state or employed by another organization such as the Guide By Your Side program within Hands & Voices.

Hurdle: Most Part C Interagency Coordinating Councils (ICCs) do not include EHDI coordinators.

Most children identified and diagnosed as DHH through the EHDI system go on to receive Part C services. Even though infants and toddlers who are DHH and their families represent only a small proportion of the population served by Part C early intervention, it is concerning that so few EHDI coordinators participate on the required Part C ICC in each state. Only 23% of coordinators reported that the EHDI coordinator serves on the program's ICC. Including EHDI coordinators on ICCs helps to raise awareness about the referral of children who are DHH and would benefit Part C programs and the broader early intervention community that participates in state ICCs.

Hurdle: Early intervention eligibility criteria for infants and toddlers who are DHH vary by state and can be confusing to professionals and families.

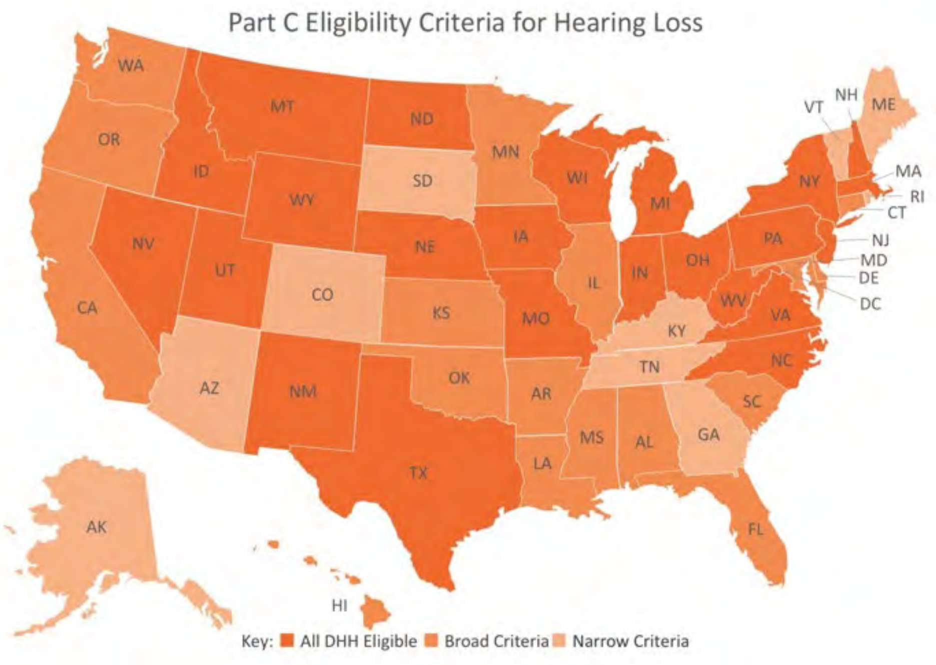
Federal regulations require each state to develop eligibility criteria for Part C early intervention services. Those criteria must include diagnosed conditions that are likely to result in a developmental delay including hearing loss. Each state is authorized to define the level of hearing loss that results in eligibility for Part C early intervention services. EI SNAPSHOT divided the criteria used by states into the three levels of eligibility shown in Chart 22. Chart 23 applies these categories to each state's Part C eligibility.

Chart 22. Catergories of Part C Eligibility Criteria Based on Hearing Loss

Category	Example Criteria
All DHH	Hearing loss: Any degree of hearing loss (unilateral, bilateral, mild, moderate, severe) makes the child eligible. Hearing loss must be diagnosed by a licensed audiologist.
Broad Criteria	Hearing loss in any degrees listed below (in one or both ears at one or more of the following frequencies - 500 Hz, 1000 Hz and 4000 Hz) Mild hearing loss - 20-40 dB HL Moderate hearing loss - 41-44dB HL Moderately severe hearing loss - 56-70 dB HL Severe hearing loss - 70-90 dB HL Profound hearing loss - 91 or greater dB HL
Narrow Criteria	Limited eligibility (diagnosis with bilateral hearing loss to children with some combination of bilateral loss or severe unilateral loss (>45dB).

In addition to variation in DHH eligibility for early intervention across states, eligibility for Part C programs within a state can be confused with different eligibility criteria for services provided to children who are DHH under other programs, such as by a School for the Deaf and Blind or a DHH agency which typically serve all children regardless of the degree of hearing loss. Of the interviewed states, 58% reported that there is a separate agency or program that provides these specific services. In some states, that agency coordinates with early intervention and in some states it does not. Not only is this variation confusing for the providers and coordinators referring infants and toddlers and their families for services, it also introduces additional hurdles to state collaboration by adding additional partners. This is especially true for families and providers of children who have additional conditions that necessitate services across multiple agencies, e.g. a DHH agency and another early intervention program to provide services such as physical or occupational therapy. Examples of interagency agreements including a third party are provided in this section. The role of the additional DHH agency varies significantly across states.

Chart 23.



Hurdle: Most state EHDI systems rely on audiologists or primary care providers to make referrals to early intervention.

While procedures are in place to ensure timely referrals of children identified as DHH to early intervention, that referral is often dependent on a party outside of the state system. Of 30 states that reported who makes the referral to early intervention, 20 (67%) reported that an audiologist must make the referral directly to the early intervention program or through the state EHDI system. It was often reported that there are more opportunities for individual providers – be it audiologists or Part C providers – to either not make a referral or to not ensure prompt contact with the family. Some states employ a “double-barreled” system whereby referrals are made by the local audiologist to the local Part C program, and the state EHDI program also refers the family to Part C. While 90% of interviewed EHDI programs reported following up with the Part C program, only 70% reported following up directly with the family to ensure they have gotten connected with Part C.

Several state EHDI coordinators reported inconsistent referrals from audiologists as a point of weakness in the referral system, and that continuous training is needed to ensure that all audiologists in the state understand the importance of referring children who are suspected or confirmed of being DHH to early intervention -- including children with a mild or unilateral hearing loss. One state reported that some audioligists had waited up to one year to refer families to early intervention in order to allow the time to process the child’s hearing loss. Because audiologists are an important referral source for early intervention, additional training may be needed to ensure they understand the importance of referring children upon diagnosis and not waiting for the child or family to meet other criteria.

Hurdle: Many states face obstacles to sharing meaningful data between programs.

An effective EHDI system relies on sharing data between programs. CDC reporting requirements for EHDI grants stipulate that each EHDI program report annually on the number of children identified as DHH who receive EI services by six months of age. Every EHDI program reported that it is able to share data from EHDI to Part C through a referral process, but at least three EHDI programs reported that they do not share information via a referral to Part C without consent from the family.

A much greater challenge exists for states when data from Part C programs is in turn shared with the EHDI program. Such sharing of information from Part C to EHDI is important for evaluating whether a child is receiving EI services, which services they are receiving, and the outcomes of those services. Twenty-one percent of interviewed states reported that Part C is not able to share any child-specific information and can only provide an aggregate number of the children who were identified through the EHDI program and later received Part C early intervention services. Many states have found solutions to data sharing challenges, and 79% of states reported that they can share some level of child-specific information, ranging from a yes or no response to the question of whether an individual child has been found eligible for and received Part C early intervention services to actually sharing service records. Factors that contribute to successful data sharing include being located in the same office or agency, decision makers and advisors who are knowledgeable about the privacy regulations in the Health Insurance Portability and Accountability Act (HIPAA), the Family Educational Rights and Privacy Act (FERPA), and IDEA Part C, and commitment to gathering additional data points beyond the required data for reporting to the CDC. Some states have included data sharing in their formal memorandums of understanding, examples of which are included below.

MOU Excerpt for Child-Specific Data Sharing Exchange

- The purpose of this agreement is to allow the [State EHDI program] to exchange case information with the [Part C program]. The EHDI program's secure web-based tracking system ensures infants receive needed hearing screens, diagnostic evaluations, and referrals to EI, genetics, and other services. Audiologists use this secure EHDI system to report diagnostic results and EI referrals to the Department of Health. [State School] agrees to contribute to public awareness and to participate in vision and hearing screening activities determined by regional/community needs and regional agreement.

- Under this agreement, the EHDI program will use the Part C secure data exchange web service to provide Part C with demographic and contact information for infants with hearing loss. EHDI will provide referral information to the identified Local Lead Agency in the Country/Service Area. The contact receiving the referral is normally identified as the Lead.

MOU excerpt supporting collaboration among Part C, EHDI, and State School for the Part C program

State Part C:

- Receives referrals on all infants and toddlers including referral from [State School] who may be eligible for early intervention services. Regardless of the referral source, [Part C] provides service coordination to assure timely evaluations for eligibility determination and to assure that evaluations are at no cost to the family.

- Includes [State School] Specialist during intake meetings, evaluations and planning meetings for parent education and functional assessment of any child where there is a concern identified regarding vison/hearing.

- Invites, in a timely way, and assures participation of the [State School] Specialist in the IFSP development for all children with vision and/or hearing loss.

State School for the Deaf:

- Refers to [Part C program] all children, birth to three, for whom they initially receive referral.

- Receives referrals for evaluations and completes functional assessments of visual, auditory, or communication skills.

- Participates in IFSP development for all children with vision and/or hearing loss.

- On a quarterly basis, supply [State EHDI] with a current list of all children either receiving services or being monitored for future services.

Summary

Collaboration between EHDI and Part C systems within a state is essential to meeting the goals of both programs and ensuring the best possible outcomes for infants and toddlers who are DHH and their families. While all states have procedures in place for collaboration, there are opportunities for improving that collaboration by streamlining referral processes and overcoming barriers to sharing data between systems; these states should be used as examples for other states seeking to improve collaboration. Eligibility criteria for early intervention for infants and toddlers who are DHH varies across states, meaning that a child may be eligible in one state but not a neighboring state. Policy changes allowing for all children with a diagnosed hearing loss to be eligible for Part C early intervention services would help to clarify referral systems and ensure that children receive timely, appropriate services.

IV. Family Access to Information Via Family-to-Family Support Organizations and Part C Websites

Families who have concerns about their child's hearing or who are seeking help for their child who is DHH often search the internet for information. Additionally, family-led support organizations can play a key role in ensuring families have access to information. To evaluate the extent to which appropriate, family-friendly information is easily available on the internet, EI SNAPSHOT conducted interviews with family-led organizations and conducted searches on websites that are designed to connect families to state Part C early intervention program websites.

Access to Information Via Family-to-Family Support Organizations

The U.S. Department of Education Office of Special Education Programs funds Parent Training and Information centers (PTIs) and Community Parent Resource Centers (CPRCs). These are family-led organizations whose purpose is to provide resources on IDEA early intervention and special education for families of children with disabilities, including children who are DHH. Every state has at least one PTI and there are fewer CPRCs that focus on reaching targeted underserved populations such as Latino communities.

Each state also has a Family-To-Family Health Information Center (F2F-HICs), funded by the Health Resources & Services Administration (HRSA). These are also family-staffed organizations that provide support, information, resources and training to assist families of children and youth with special health care needs – including families of children who are DHH - and the professionals who serve them.

While each of these family-to-family support organizations serve children with all disabilities and can provide valuable resources for families, too few families and service providers know about them. As discussed earlier in the Family Survey results, 41% of families reported that they did not receive any information on PTIs and 45% reported that information on F2F-HICs was not provided. Even service providers reported poor knowledge about these general disability-focused family-to-family support organizations (42% knew about PTIs, 31% knew about F2F-HICs).

To learn more about the relevance and usefulness of the information provided by PTIs and F2F-HICs to families of children who are DHH, EI SNAPSHOT conducted telephone interviews with staff members from these organizations. PTIs, CPRCs, and F2F-HICs in fifty states and DC were invited to participate. Trained parent interviewers contacted 107 organizations. Seventy-nine programs (39 PTI or CPRCs, 23 F2F-HICs, and 17 organizations that house both PTIs and F2F-HICs programs) in 44 states and DC completed the interview.

Parents of children who are DHH were trained to call these organizations and conduct an interview consisting of 7 scenarios with potential questions a parent would ask when calling the organization. Chart 24 provides the script for each of the 7 scenarios.

Chart 24. Scenarios Posed to Family Organization via Telephone Interview

Scenario #1 I just found out that my two-week old infant has a hearing loss. We found out through the newborn hearing screening. How can you help me?
Scenario #2 My baby failed his newborn hearing screening and is now two months old, but my pediatrician said not to worry about it. What would you recommend I do? Can I really wait until he's one to do something?
Scenario #3 I am worried that my 6-month old baby girl cannot hear me, I'm wondering if she has a hearing loss. Do you know how I can find out?
Scenario #4 My son is two years old I am hearing a lot about sign language versus Listening and Spoken Language and people are very passionate about both. Can you explain a bit about the different options and tell me more about potential benefits and disadvantages of each?
Scenario #5 I think my child needs hearing aids or cochlear implants. Who should I contact to get them? Do you know about any money available to help to pay for hearing aids or implants? (assume I have insurance) What if I don't have insurance? What if my insurance said no?
Scenario #6 I am frustrated that my two-year-old daughter who is deaf is not getting the amount of early intervention services she needs. She only gets two visits a month and I want her to get therapy every week because she isn't making progress. I'm also worried that her provider is just an aide. What if I can't remember all of these questions to ask at her meeting? What if I ask and they say no? They said no last time I asked.
Scenario #7 I would like the chance to talk to other families of children who are deaf or hard of hearing. Who could help connect me with other families?

Strength: General disability focused family-to-family support organizations provide valuable connections to DHH-specific family supports.

In response to Scenario 7, asking for connections to other families, each of the 79 interviewed organizations provided a resource for families to connect to other families, either directly or through another organization. About 52% provided direct connections to other families of children who are DHH, and 69% referred families to other organizations including Schools for the Deaf, Hands & Voices, Guide By Your Side, local Parent to Parent programs, or specific Facebook groups and other social media forums.

Part C early intervention and EHDI programs were suggested as resources for making connections to other families much less frequently. Only 9 interviewed organizations (11%) referred parents to early intervention to connect to other families and only 1 organization (1%) referred parents to EHDI. As EHDI programs increase family engagement efforts, they need to promote their efforts among these organizations to ensure that these family organizations understand what is available and how to facilitate families connecting with what EHDI programs have to offer.

Strength: Good resources are available through the PTIs, CPRCs, and F2F-HICs.

Family-to-family support organizations provide information to families about resources relevant to all children with special needs, including children who are DHH. These include resources for navigating the IFSP process, advocating for their child, and obtaining healthcare and insurance. These resources were available primarily in the form of links that were provided to parent interviewers, and hard copy materials that the organizations mailed to NCHAM.

The types of resources provided and referrals made depended on the type of organization that was interviewed. Chart 25 shows the differences between PTIs and F2F-HICs when responding to Scenarios 1, 2, and 3, which all request assistance for a young child who is DHH. It is notable that PTIs are more likely to refer to early intervention programs while F2F-HICs are more likely to refer to audiologists and pediatricians. This is consistent with the purpose of and funding sources for each type of organization. It also is important to note that all the family organizations supported the engagement of the medical home in regard to addressing Scenario 3 which deals with providing direction to a parent concerned about their child's hearing. For issues related to resolving disputes about EI, as presented in Scenario 6, PTI's made offers to assist families in accessing informal and formal dispute resolution with their service providers, consistent with their funding.

Chart 25. Percentage of Referrals and Resources Provided in Response to Scenarios, by Type of Organization

	Scenario 1			Scenario 2			Scenario 3		
	All	PTI	F2F HIC	All	PTI	F2F HIC	All	PTI	F2F HIC
Referral to Early Intervention	73%	87%	56%	49%	54%	43%	39%	46%	30%
Referral to EHDI	6%	7%	0%	6%	10%	0%	2%	5%	0%
Referral to Audiologist	10%	3%	17%	24%	13%	43%	29%	18%	26%
Referral to Pediatrician	26%	21%	35%	35%	33%	43%	72%	67%	78%

Strength: Family-to-Family support organizations provided unbiased information about communication modality options or referred families to experts.

Scenario 4 asked family-to-family support organizations to provide advice about communication modalities and the benefits of choosing either a manual or a spoken language for a child who is DHH. Thirty-nine percent of the organizations told the families that they did not have the expertise to provide information about communication modalities and referred families to another organization or to a specific family. Thirty of the 79 organizations very clearly articulated to the parent interviewers that modality is a family choice. Of the remaining 61% of organizations (n=48) that provided the family with information about one or more communication modalities, trained parent interviewers found 81% (n= 39) responses to be unbiased, with only 9 biased responses. The biased responses tended to favor the use of American Sign Language. Examples of advice considered to be unbiased and biased by trained parent interviewers are provided in Chart 26.

Chart 26. Examples of Statements Made by Family-to-Family Organizations

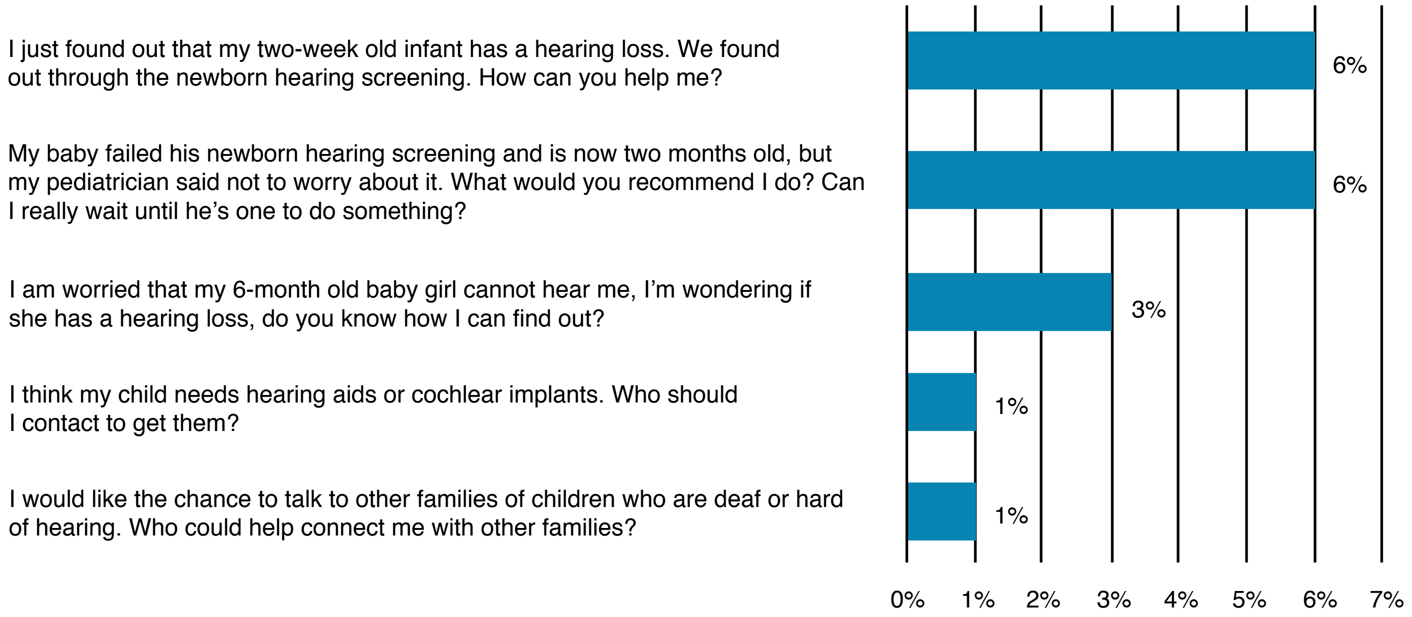
Examples of Unbiased Statements
Make sure that the person teaching your child is properly trained and knows that modality very well.
Communication is good! We don't recommend one over the other.
Consider how supportive your community is and the resources that are available.
There are unbiased organizations like Hands & Voices that have resources available.
(The point) at which a child acquires language is most important. Spoken or manual, doesn't matter.
Acquiring language is what matters.

Examples of Biased Statements
Using spoken language can provide auditory access to family events because extended families never learn ASL.
If child is not already amplified, they need access to any language and [I] would strongly push them towards ASL, and parents need to learn ASL as well.
[I] believe in total communication.
Total communication is popular and maximizes all possible learning modalities.
Children without hearing impairment are using sign language. You don't need to be afraid of ASL.
Many professionals say CI's are right for everyone. It's not a cure and there are many infections and risks involved.
Spoken language is most successful for wealthy families who can afford private schools.

Hurdle: Family-to-family support organizations made very few referrals to state EHDI programs.

Many EHDI programs have helpful resources for families of children who are DHH, yet very few staff from the family-to-family support organizations referred parent interviewers to the state's EHDI program (ranging from 1% in scenarios 5 and 7, to 6% in response to scenarios 1 and 2 (see Chart 27). Because scenarios 1 and 2 reference the newborn hearing screening directly, it would be desirable if there had been a greater number of references to the state's EHDI program. There appears to be a strong need for providing professional development to family organizations about EHDI systems, and in turn more outreach from EHDI programs to family organizations to promote the resources and services that are available in each state.

Chart 27. Percentage of Family Organizations that Refer Families to the EHDI System in Response to Specific Questions



Hurdle: Family-to-family support organizations identified few resources available to help families of children who are DHH.

While family-to-family support organizations provided a high number of resources about disabilities in general and navigating the early intervention and education (PTI and CPRCs) and medical (F2F-HICs) systems, they offered very few resources specific to hearing loss. Several respondents recommended the interviewers search Google for resources and stated that they would likely search Google to provide resources to families who contacted them. The family-to-family organization respondents identified gaps in resources available, especially related to services available in rural areas and resources for non-English speakers.

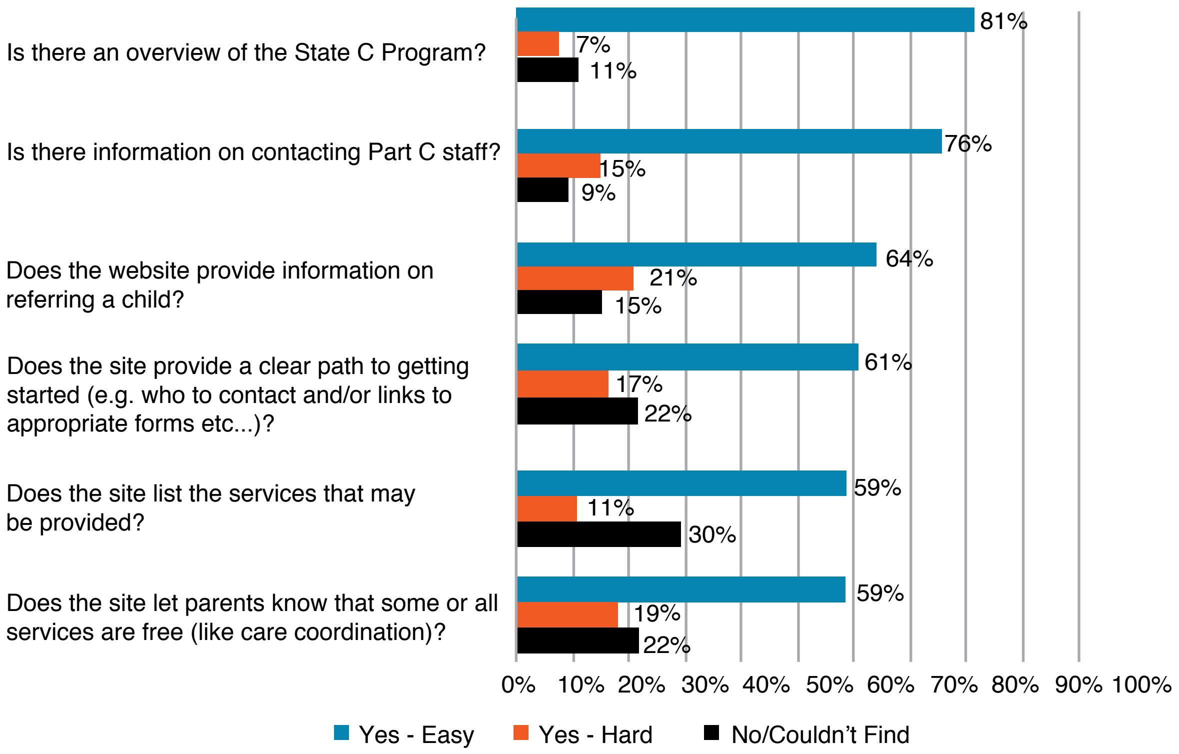
Access to Information via Part C Websites

The internet is often used by families as well as professionals who are seeking information about health-related issues and services. The PEW Research Center (2013) estimates that 72% of internet users have gone online for health information in the past year. Therefore, it is essential that parents of children who are DHH find accurate and useful information online including how to access Part C early intervention for their child to maximize outcomes. Parents of children who are DHH were recruited and trained to review all Part C websites, search for commonly needed information, evaluate their usability and friendliness, and assess their reflection of cultural diversity. Two reviewers were assigned to 10% of the states to check for inter-rater reliability, with satisfactory reliability results. To evaluate general information online, parents were trained to google search with specific search terms.

Strength: Information about Part C services and program contact information is generally easy to find on a state's early intervention website.

Parents were provided with a link to the state's Part C website and asked to search the site for specific information about Part C. As shown in Figure 18 parents were generally able to find information about Part C and how to contact Part C staff. At least three-quarters of the websites provided an overview of the program and contact information.

Chart 28. Percentage of State Part C Early Intervention Websites Where Specific Information was Found



Strength: Most Part C websites were welcoming and easy to use.

In addition to reporting on their ability to find specific information, parents were asked to share their overall impression about the usability and look and feel of the Part C websites. On a 5-point scale, the average rating for both ease of use and friendliness of the look and feel was 3.3; about one quarter were rated as not easy/unfriendly. However, as noted in upcoming sections, the specific details pertaining to services often were difficult to find. In addition, it is important that Part C websites reflect the cultural diversity of the intended audiences, representing the broad spectrum of the population and providing accessibility for non-English speakers. The majority of websites - 57% - provided information in a language other than English.

Hurdle: Search engines do not direct families to state websites.

When looking for information on the internet, parents are likely to use a common search engine to find information. It is important that commonly-used search engines point families to valid and useful sites and lead parents to early intervention services if their child may be eligible. Parents trained by EI SNAPSHOT were instructed to employ various search engines (i.e., Firefox, Google Chrome, Internet Explorer, and Safari) by entering the name of each state followed by a specific phrase. The phrases used were:

1. [state] I'm concerned about my child's hearing;
2. [state] can my baby hear me?
3. [state] help for my deaf baby;

As shown in Chart 29, search engines rarely connected the parent to the state Part C program or EHDI. Instead, search engines more often first offered a less direct resource, such as some other general state website or non-specific early intervention site.

Chart 29. Percent of Websites Found in the First Page of Web Search Results for Each Phrase

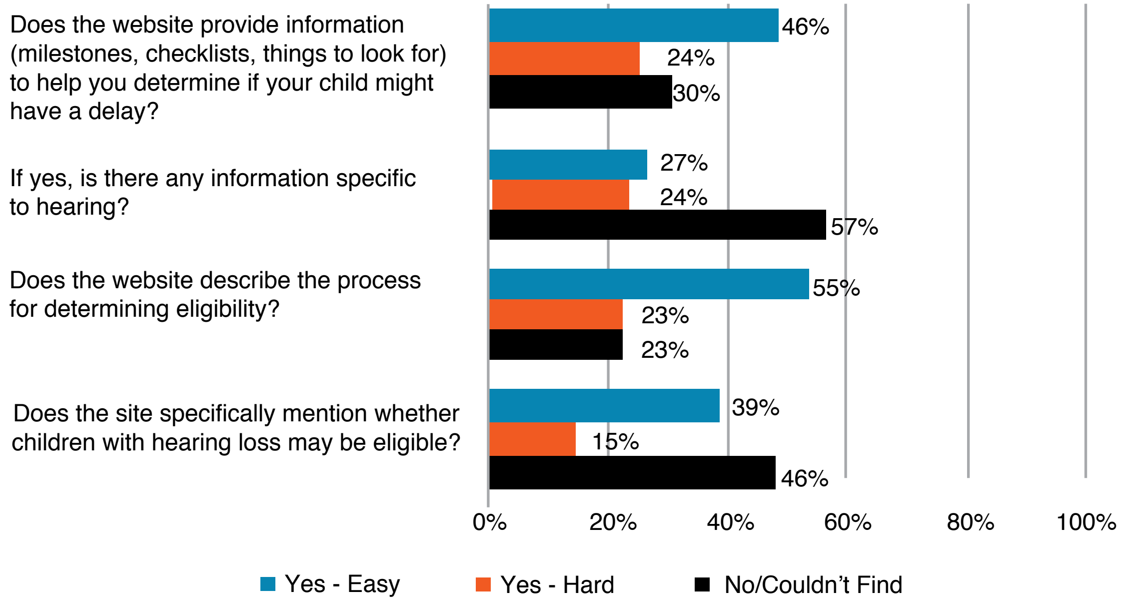
Website	**(state) I'm concerned about my child's hearing**	**(state) Can my baby hear me?**	**(state) Help for my deaf baby**
The State Part C website	2%	11%	24%
The State EHDI site	7%	19%	33%
Any State Website	50%	50%	69%
Any State-Based Parent Support Agencies or Family Support Groups	26%	17%	85%
Anything about Early Intervention	19%	37%	67%

These results suggest that Part C programs and EHDI programs need to improve their search engine optimization. State resources including those provided by both Part C and EHDI programs for parents of children who are DHH were not found easily by typical types of web searches. Search results were better when terms "baby" and "deaf" were used, especially for state-based family support organizations (85%). A tool such as Google's Search Optimization Guide provides useful, easy-to-follow strategies that can be used by both Part C and EHDI improve search efficiency for families.

Hurdle: While information on delays and eligibility can be found on most websites, information specific to hearing loss was generally not available.

Parent reviewers were instructed to search for information that would help a parent determine if their child may have a delay and potentially need early intervention. While two thirds of sites did provide information on broader developmental delays, information specific to hearing was found on fewer Part C early intervention websites. When looking for eligibility criteria, parents were able to easily find broad information on 55% of the websites, but eligibility criteria specific to hearing loss was only easily found on 39% of the websites (see Chart 30).

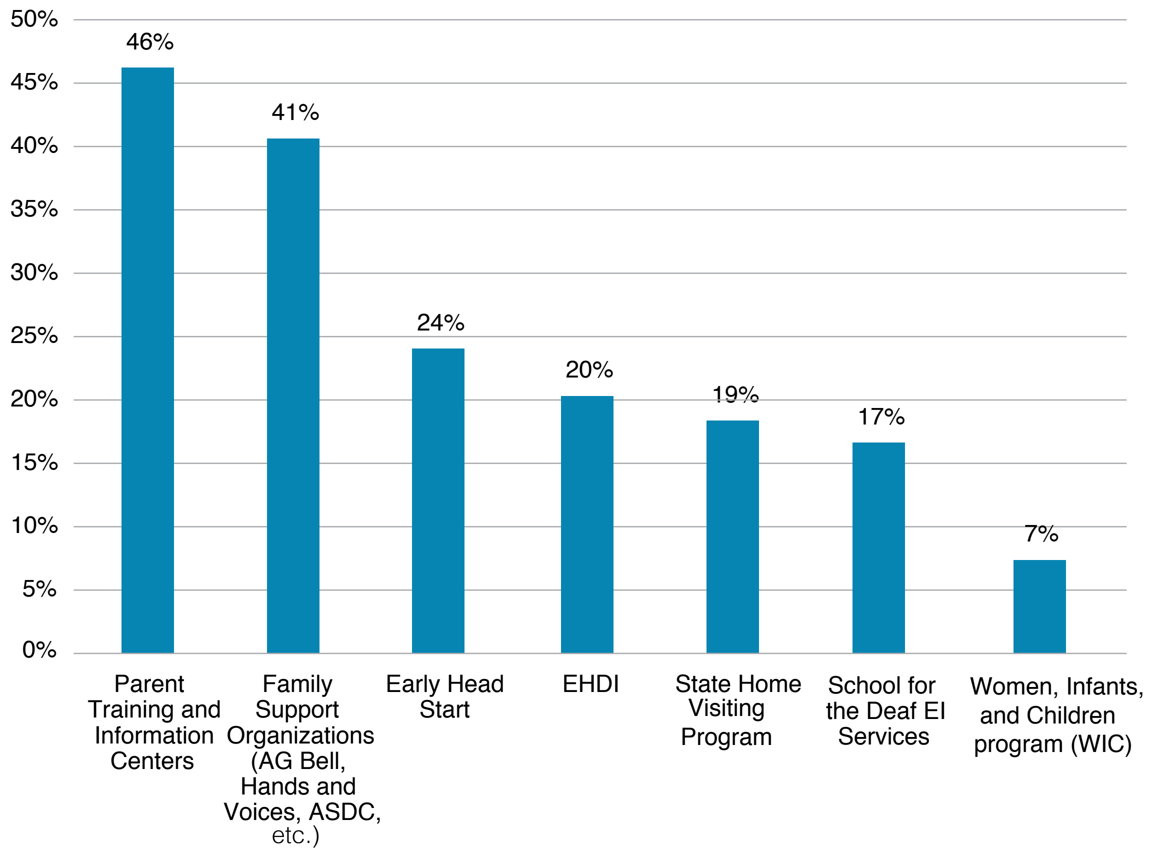
Chart 30 Percentage of State Part C Early Intervention Websites Where Eligibility Information Was Found



Hurdle: Most Part C websites do not direct families to other resources available in the state.

Parents were instructed to search Part C websites for information that could be used to link families to other important services and resources. As shown in Chart 31, fewer than half of the sites provided information about family support organizations, such as the state Parent Training and Information centers and Family to Family Health Information centers (state-specific names of programs were provided to reviewers). Fewer than a quarter of the state websites provided links to other relevant services or agencies, such as EHDI, Schools for the Deaf, WIC, or Early Head Start.

Chart 31. Percentage of State Part C Early Intervention Websites that Refer Users to Relevant Resources



Summary

There are resources that would be helpful for families of children who are DHH – provided that families can find them. The results of this activity suggest that families will have a difficult time finding comprehensive information about how to meet their DHH-related needs when they search online for information and connecting to non-disability specific family-to-family organizations. EDHI and Part C programs should better educate their staff and providers as well as families about family-to-family support organizations, embedding information about these organizations into their protocols. Online searches do not currently lead families of children who are DHH to family-to-family support organizations or to state EHDI and Part C programs. Family organizations are also not referring families to EHDI programs. Overall, communication, training, and collaboration among these stakeholders is needed to "close the loop" for families seeking information be it via direct service, phone, or the internet. Family organizations can provide needed supports to families through the EHDI and Part C programs and State EHDI and DHH-specific organizations can provide expertise on issues specific to DHH to these broad-based family organizations so that families have access to high quality accurate information from both sources.

The methodology employed by EI SNAPSHOT also serves as an example of how state EHDI and Part C stakeholders can incorporate families in their own quality improvement efforts pertaining to building family-centered information systems. Families are the "first responders" in regard to being able to judge whether information is easily accessible and if it is meeting the needs of families. Therefore, partnering with families is a valuable strategy to promote family engagement.

V. Characteristics of Current Personnel Preparation Programs for Teachers of the Deaf

Improved technology and early hearing screenings facilitate the identification of infants and toddlers who are DHH sooner than ever before (CDC 2017). However, a diminishing number of post-secondary programs to train teachers of the deaf has resulted in a worrying shortage of deaf education teachers trained to meet the needs of these children who are DHH (NCPSSERS, 2017). This shortage is especially noticeable in the area of early intervention (Houston & Stredler-Brown, 2012).

To understand the current state of Deaf Education programs, EI SNAPSHOT conducted a review of the Deaf Education personnel preparation programs across the country to examine how new teachers are being prepared to serve children who are DHH. Deaf education programs were identified using lists published by the American Annals of the Deaf, and deafed.net. There were 72 programs identified at 51 universities that lead to a license to teach children who are DHH. Several universities had multiple programs either at different levels (i.e., Bachelors and Masters) or programs with a different focus (i.e., listening and spoken language and American Sign Language).

First, websites for these 72 higher education programs for Deaf Education were reviewed and customized reports of the website reviews were developed for each program. Second, follow-up telephone interviews were conducted with the directors of 36 programs to verify and expand on the website information. Through these interviews, researchers were able to correct the often inaccurate or incomplete website information and better understand the focus and activities of these teacher training programs. Third, graduates from 9 of the 36 personnel preparation programs completed an online survey about their perceptions about how well the program prepared them for their current professional positions.

Personnel Preparation Programs

Deaf education programs were identified using lists published by the American Annals of the Deaf, and deafed.net.

- 72 Universities listed
- 3 no longer accepting students
- 12 defunct / misidentified
- 6 that did not result in licensure
- 51 Universities with 72 Deaf Education Programs resulted
- Websites for each of the 72 programs were reviewed
- 36 Program Directors participated in telephone interviews

> *"Our program offers a comprehensive approach to teaching deaf and hard of hearing students. We prepare our students for "real" classrooms and "real" students. We discuss theory in relation to practice only. We emphasize the importance of understanding the diverse needs of students who are deaf and hard of hearing and advocate for individualized instruction. We offer a wide range of field experiences."*
>
> *~Program Director~*

Strength: The majority of institutions offer Masters Programs in Deaf Education.

As shown in Chart 32 there are more Master's level programs than Bachelor's level options for teachers of the deaf. By requiring a Master's level program for deaf education licensure, more overall college credits can be devoted to Deaf Education and related subjects. Graduates of the programs will have more exposure and experience than they would have obtained through a bachelor's degree program.

Program directors reported a variety of program accreditations, and some programs have accreditation from multiple sources. Apparently there is not a generally accepted accreditation source across programs as there is in other areas. The most frequent accreditation body for these program was the National Council for the Accreditation of Teacher Education (NCATE), followed by the Council on Education of the Deaf (CED), but these organizations only accredited 50% and 47% of the programs respectively (see Chart 33).

Chart 32. Degrees Offered by the 72 Programs at 51 Institutions

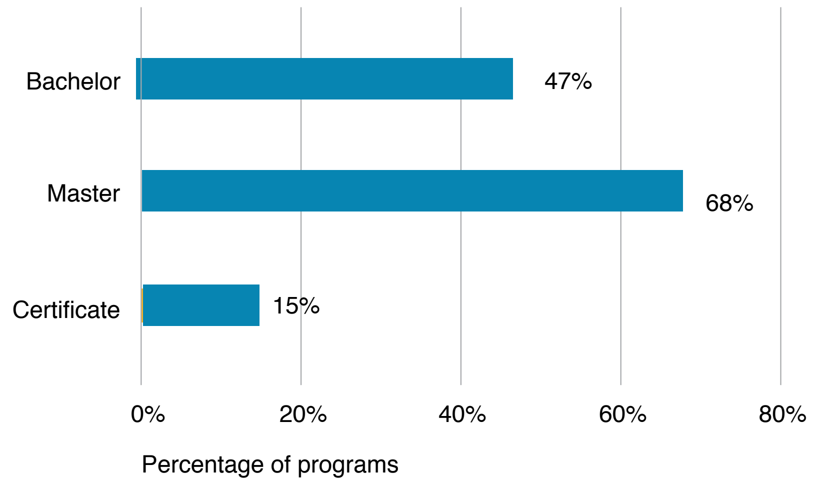
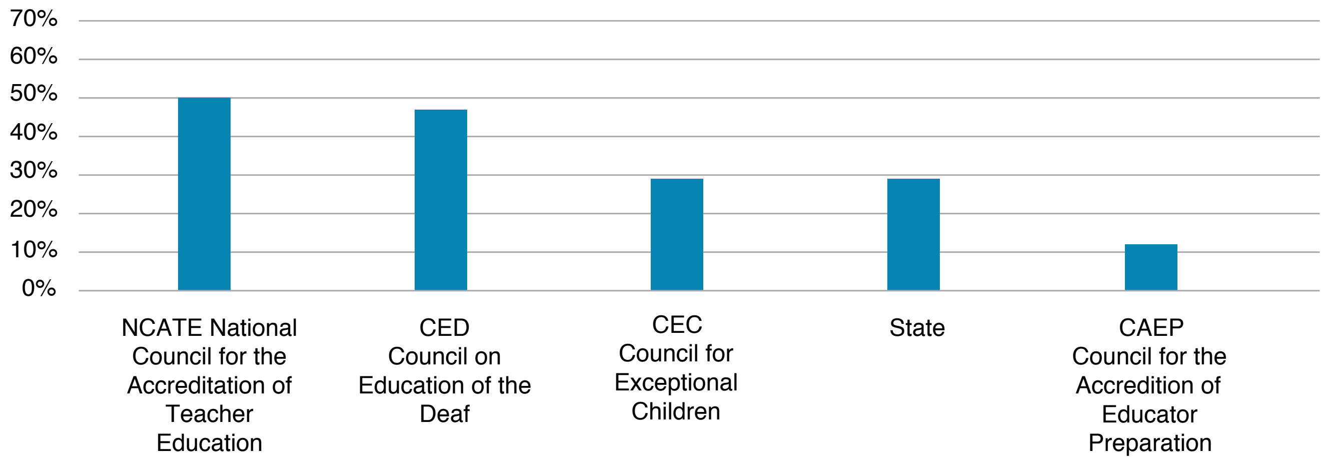


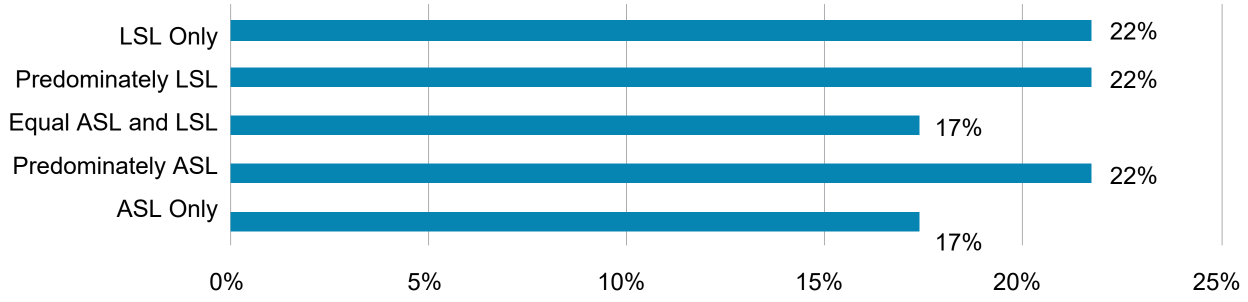
Chart 33. Percentage of Programs Accredited by Specific Accrediting Organizations



Strength: Communication modality focus is evenly distributed across manual and spoken language.

During interviews with the 36 program directors, each director responded to a question about whether their program focused on a particular communication modality or modalities. The results show that there appears to be a relatively even distribution of communication focus across programs (see Chart 34). The responses provided during the interviews about any focus on a communication modality were not always consistent with the information obtained from reviewing program's websites. Further research is needed to explore evidence needed and establish criteria to evaluate the focus of a program that is not based solely on the opinion of the program director.

Chart 34. Communication Modality Focus of the 36 Interviewed Deaf Education Programs



Strength: Program Directors reported that their programs cover most topics well.

Program directors rated the amount of information regarding a number of topics related to teaching children who are DHH (see Chart 35). Interestingly, given the even split of the focus of programs reported above, the highest average rating of information was for teaching using LSL or auditory verbal therapy. This might mean that programs who cover both ASL and LSL have a stronger focus on LSL than ASL. The topics covered least by programs were medical home and telehealth; this is consistent with lack of knowledge reflected in the aforementioned EI provider survey .

Chart 35. Deaf Education Program Director Ratings of How Well Topics are Covered in Programs - Overall Average on a Scale of 1 (not at all) to 4 (very well)

Topics Covered	**Mean Rating**
Teaching using LSL or Auditory	3.3
Itinerant teaching models	3.3
Working with children who are DHH and have additional disabilities	3.2
Audiology	3.0
Advocacy/Promoting system change	3.0
Learning a manual language	3.0
Providing family-centered services/family support	2.9
Teaching using a manual language	2.9
Medical Home	1.6
Telehealth	1.5

Hurdle: Very few programs devote targeted credit hours to Early Intervention.

The website review included an analysis of the most current plans of study for each program posted on a program's website. The review of 72 programs at 51 universities found that a large majority of programs dedicated no credits in the plan of study specifically to coursework on early intervention. Chart 36 shows the number of credits offered according to website reviews and as corrected by program coordinators by email or during telephone interviews.

Chart 36. Number of Credits Offered on the Topic of Early Intervention by Deaf Education Programs

Number of Credits	Number of Schools
0 credits	49
1-4 credits	14
5-10 credits	6
11 or more	3

During the follow-up interviews, many directors added that information on early intervention was embedded in other courses although not specifically mentioned in course descriptions. When asked to rate the coverage of different age groups across the program on a scale of 1 (not at all) to 4 (very well), the average rating for early intervention was 2.97. Thirteen of 34 programs (38%) reported that they provide a lot of information about early intervention and three of 34 programs (9%) reported that their program does not cover early intervention at all.

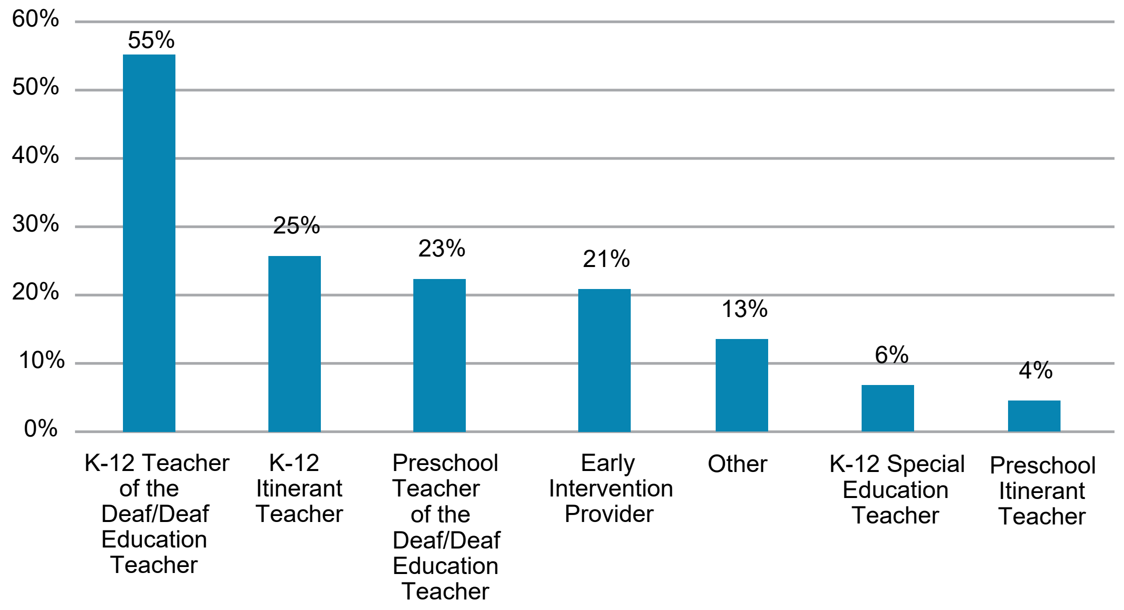
Hurdle: Deaf Education programs are small and graduate only a few students each year.

Program Directors were asked about recruitment, acceptance and graduation rates for their students. Their responses indicate the programs and the number of students graduating per year are small, with an average of 6.5 graduates annually. This may contribute to the shortage of qualified staff identified as a hurdle by state Part C coordinators.

Recent Graduate Study

Following interviews with program directors, EI SNAPSHOT staff asked each director to send a short survey to graduates of the program from 2011 through 2016 in order to ascertain their perceptions of how their programs prepared them for their employment. Fifty four students from 9 Institutions responded to the survey. Most respondents were Caucasian (94%) females (92%). This is consistent with the demographics of the respondents to the provider and audiologist EI SNAPSHOT surveys. As shown in Chart 37, 81% of graduates reported serving children ages K-12, 27% reported serving preschoolers, and 21% reported serving children birth to three (note that the total sums to more than 100% because some respondents reported serving children in more than one category).

Chart 37. Populations Served by Recent Graduates in the Job they have held the Longest Since Graduating



Strength: Recent graduates reported that their program prepared them well on most topics.

Graduates were asked to rate how prepared they felt at graduation about a number of topics using a scale from 1 (not taught) to 4 (excellent). The ratings were above average to good in most areas, including early intervention. The recent graduates reported that they felt well prepared to work with teachers and administrators, that they had the skills for teaching children, and that they were well prepared to use the communication modality emphasized by the program. Additionally, graduates had the opportunity to respond to an open-ended question about the strengths of their program. As shown in Appendix D (see http://www.infanthearing.org/ei-snapshot/), respondents described the passion of their instructors, faculty support, and an emphasis on family centered principles and practices.

Hurdle: Recent graduates may need more information in areas such as IEP/IFSPs, LSL, assessment and serving children who are DHH and have additional disabilities.

When asked about areas where they would have liked more training, recent graduates identified several areas where personnel preparation programs could be strengthened. Responses to an open-ended question about perceived weaknesses of their program included a lack of training in teaching children with additional disabilites, the need for more focus on speech and hearing technology, and a need to focus on current research. Some respondents voiced frustration about the length of the program, with opinions varying on whether it was too intense within a short period of time or too long to complete. A more detailed report of open-ended responses from graduates about program weaknesses and ways to improve training are provided in Appendix D (see http://www.infanthearing.org/ei-snapshot/).

"The program is family and child centered. The program helped me to be open and empathetic to all families. To truly listen to their stories and to work at the families' pace in areas and on goals that would help the child and families' emotional needs and the listening and language needs of the child."

~Recent Graduate~

Summary

The EI SNAPSHOT review of deaf education personnel preparation programs found programs to be lacking in training on early intervention. However, based on the provider surveys reported in Section II, it appears that most people who are providing early intervention to children who are DHH do not have a degree in deaf education but are trained in early childhood special education or speech language pathology. Because so many children are identified as DHH in infancy, deaf education programs may want to consider increasing their emphasis on early intervention.

The modality focus of the 36 interviewed programs appears to be split evenly across ASL and LSL. Interestingly, comments from graduates from these programs reflected that they would have liked more exposure to multiple modalities. As demonstrated by the family perceptions survey, individual families reported using a variety of communication methods. Thus, graduates working in the field are likely faced with being expected to have greater breadth of expertise regarding communication options. From the EI provider survey, we know that fewer than 20% of early intervention providers serving children who are DHH in early intervention are teachers of the deaf. Thus, a study of speech language pathology and early childhood special education programs and the extent to which they also received EI training to support families of children who are DHH would provide a more comprehensive picture.

"I don't think I knew how political and challenging public school deaf ed programs could be. I wasn't prepared to work with kids equipment (they expect us to do listening checks, clean out aids, connect FM systems, etc.) I wasn't prepared to deal with the amount of behavior issues there are in mainstream programs."

~Recent Graduate~

"[My program] gave me exposure to every modality and created a platform for students to discuss the need for all modalities according to the student's needs."

~Recent Graduate~

Conclusion: Trends and Opportunities

EI SNAPSHOT: Early Intervention Systematic Nationwide Analysis of Programs' Strengths, Hurdles, Opportunities and Trends was a project that investigated the state of early intervention for children who are DHH from the perspectives of families, direct service providers, state leaders, and personnel preparation programs. The findings present a valuable picture of the strengths, hurdles, and trends based on the experiences and perspectives of a diverse sample of participants. This information also provides opportunities to guide EHDI and EI system improvements. The most important findings of the project are summarized below.

Trends

Trends - consistent themes identified across methodologies and stakeholders – reveal insights about the state of early intervention for families of children who are DHH, both in terms of what appears to be working well and areas that warrant attention. Trends included:

Strengths

Part C EI programs are accessible and are viewed as positively supporting families.

- Almost 90% of families reported that it was easy to get connected to early intervention services and that it improved their child's quality of life.
- About 71% of babies identified as DHH before 3 months of age were connected to EI before 6 months of age.
- EI providers generally have a positive attitude about their work and the role of EI in serving families of children who are DHH.
- Good working relationships and formal referral processes to support families exist in most states between EHDI and Part C EI.
- Family organizations report that they consistently refer families to EI when they call with concerns and thus are an important conduit to the EI system.

Hurdles

Many families seek more intensive services from specialized providers than are available through Part C EI programs.

- Almost one third of families reported arranging for supplemental private EI services.
- Many families are frustrated by their inability to find providers to address the family's desired communication option.
- Almost two thirds of audiologists received requests from parents seeking supplemental EI services.
- Very few personnel preparation programs for teachers of the deaf provide coursework or practical experience focused on EI/early childhood education in spite of the fact that children who are DHH are increasingly being identified during their first six months of life as a result of newborn hearing screening programs.
- The number of students graduating from teachers of the deaf programs is small, thus few are entering the workforce to meet the demand for DHH-trained EI providers.

Families have difficulty connecting with family-to-family support systems.

- The majority of families reported little or no opportunities to meet with other parents of children who are DHH.
- About two-thirds of families reported little to no information provided about federally funded general disability focused family-to-family support organizations, and 44% received little to no information about DHH-specific groups like Hands & Voices.
- A third to half of EI providers reported inadequate knowledge of family-to-family support organizations.
- Less than half of Part C websites – an initial source of information for families – have information about family-to-family support organizations.

Family-level service coordination needs strengthening, particularly to help address financial and social supports.

- Almost half of families reported that their child's hearing-related needs posed a moderate to unbearable financial burden, reflecting the need for the EI system to help families access financial resources.
- About two thirds of families reported that their service coordinator had not helped them get non-therapeutic services such as child care or food stamps.
- Roughly 40% of families reported that their medical home did not receive information about their EI services.
- Although the majority of service coordinators reported that they do coordinate with other providers, about one quarter of respondents reported that coordination with relevant partners, particularly medical home providers and family support organizations, "needs more work."
- Although the large majority of audiologists refer families to EI, only about 32% receive copies of their clients IFSP's and only 13% reported that they participated in an IFSP meeting.

Opportunities

There are many resources available for families of children who are DHH. EHDI programs have developed resources related to hearing loss and the process of identifying a hearing loss and moving to early intervention. Part C Early Intervention programs have resources and services available to infants and toddlers and their families. Family-to-Family support organizations have specialized resources, including family organizations that are specific to DHH such as Hands & Voices, American Society for Deaf Children, and the Alexander Graham Bell Association.

However, it appears that the coordination of these resources and sharing the breadth of available information with families is not occurring as needed. As reported in the parent and provider sections of this report, there is room for improvement in providing information on family-to-family support to both families and providers. State EHDI and Part C programs can also provide additional information and training to family-to-family support organizations to better serve families of children who are DHH.

Given the trends that are evident from this study, it is important to consider opportunities for addressing these issues and improving the EI system for families of children who are DHH. Based on examples of promising practices that resulted from the state EHDI and Part C coordinator interviews, the following opportunities should be pursued:

- State EHDI and Part C programs should consider building formal partnerships with family-led organizations, both broad-based and DHH-specific. Several State EHDI programs reported that they contract with Hands & Voices to help with follow up and to inform families of family support opportunities. Additionally, several states have programs to help families have opportunities to interact with adults who are DHH.
- Although referrals from EHDI to EI seem to happen easily, information flow from EI to EHDI is more problematic and is frequently not happening. Developing more efficient shared data systems would allow for more timely tracking of families who are not being served. States with “live” integrated data systems that adhere to HIPAA, FERPA, and Part C privacy and security regulations allow for more effective monitoring, and they can serve as models for other states.
- Expanding personnel preparation options would provide an opportunity to create a workforce with more providers with expertise to serve infants and toddlers who are DHH. Also, EHDI programs can support EI providers via training and technical assistance, e.g., increasing their knowledge about the importance of ensuring families are connected to EI and the contribution of audiologists in promoting optimal learning environments.
- Development of tools to help Part C, EHDI, and family organizations improve their websites is needed to ensure families can find information more easily. It would be helpful to engage family representatives to guide specific improvements, such as ensuring diverse families are reflected, using simpler language, providing videos to help families with low literacy levels, offering linkages to family organizations, and inclusion of hearing-related resources in materials disseminated by the family-to-family support organizations.
- Inter-agency collaboration and family engagement should be emphasized to continue to improve the system of services for families of children who are DHH. Requirements for EHDI and Part C programs, as well as PTIs and F2F-HICs to partner with family organizations and to form learning communities with key stakeholders would help address the challenges found in this study while building on the strengths.
- Further investigation into EI service coordination models would provide insights into how to ensure the broad needs of families are being met, such as connections to financial resources and social supports. Some states have identified specific service coordinators to serve families of children who are DHH, ensuring these service coordinators know about DHH-specific resources. As a part of such efforts attention should be given to increasing inclusion of audiologists in the IFSP and engaging family organizations such as the PTIs, H&V, and the F2F-HICs.

Acknowledgments

This EI SNAPSHOT study has made a significant contribution to our understanding of the strengths, hurdles, trends and opportunities pertaining to our shared goal to ensure a family-centered, comprehensive, coordinated, culturally-competent early intervention system for children who are DHH and their families. This would not have been possible without support from key stakeholders. Families were an essential voice, both in their role of collecting data as well as sharing their experiences via surveys, providing the focus of this study. We are grateful for the state EHDI and Part C coordinators, family-to-family organization leaders, EI providers, audiologists and personnel preparation program directors who dedicated time and expertise to make this study a success. We also wish to thank our funders, HRSA’s MCHB Integrated Services Branch and the Oberkotter Foundation, who made this study possible. The findings and resulting conclusions are those of the researchers and not those of the funding entities.

The EI SNAPSHOT study was funded in part by a cooperative agreement (U52MC04391) from the Maternal and Child Health Bureau (MCHB) of the Health Resources and Services Administration (HRSA) at the United States Department of Health and Human Services.

Photos in the report are courtesy of Utah State University, the Centers for Disease Control and Prevention, and Oticon A/S.

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