



## Needs Assessment Report Family Leadership in Language and Learning (FL3)

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### **About Hands & Voices**

Hands & Voices (H&V) is dedicated to supporting families with children who are deaf or hard of hearing (D/HH) without a bias around communication modes or methodology. H&V is a parent-driven, professionally-collaborative, non-profit organization focused on enabling children who are D/HH to reach their highest potential. H&V strives to provide families with the resources, networks, and information they need to improve communication access and educational outcomes for their children. This is accomplished through outreach activities, parent/professional collaboration, and advocacy efforts. We believe that we have more that unites us than divides us. Learn more about H&V at [www.handsandvoices.org](http://www.handsandvoices.org).

### **About the National Center for Hearing Assessment and Management (NCHAM)**

NCHAM serves as the National Technical Resource Center for the implementation and improvement of comprehensive and effective Early Hearing Detection and Intervention (EHDI) systems. As a multidisciplinary Center, our goal is to ensure that all infants and toddlers with hearing loss are identified as early as possible and provided with timely and appropriate audiological, educational, and medical intervention. Learn more about NCHAM at [www.infant-hearing.org](http://www.infant-hearing.org).

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## Needs Assessment Acronyms

<b>AAP</b> American Academy of Pediatrics	<b>HHS</b> U.S. Department of Health and Human Services
<b>AMCHP</b> Association of Maternal & Child Health Programs	<b>HIPPA</b> Health Insurance Portability and Accountability Act
<b>ASDC</b> American Society for Deaf Children	<b>HRSA</b> Health Resources and Services Administration
<b>ASL</b> American Sign Language	<b>IEP</b> Individualized Education Program
<b>CDC</b> Centers for Disease Control and Prevention	<b>IRB</b> Institutional Review Board
<b>CYSHCN</b> Children & Youth with Special Health Care Needs	<b>MCH</b> Maternal and Child Health
<b>D/HH</b> Deaf and/or Hard of Hearing	<b>MCHB</b> Maternal and Child Health Bureau
<b>EHDI</b> Early Hearing Detection and Intervention	<b>MOU</b> Memorandum of Understanding
<b>EI</b> Early Intervention	<b>NCHAM</b> National Center for Hearing Assessment and Management
<b>EI SNAPSHOT</b> Early Intervention, Systematic Nationwide Analysis of Program Strengths, Hurdles, Opportunities and Trends	<b>P2P</b> Parent-to-Parent USA
<b>ENT</b> Ear, Nose, and Throat	<b>PCP</b> Primary Care Provider
<b>F2F HIC</b> Family-to-Family Health Information Center	<b>PTI</b> Parent Training and Information Centers
<b>FBO</b> Family-based Organization	<b>QI</b> Quality Improvement
<b>FL3</b> Family Leadership in Language and Learning	<b>RFP</b> Request for Proposal
<b>FV</b> Family Voices	<b>UNH</b> Universal Newborn Hearing Screening
<b>H&amp;V</b> Hands & Voices	<b>USU</b> Utah State University
	<b>VL2</b> Visual Language and Visual Learning Science of Learning Center



# I. EXECUTIVE SUMMARY

To strengthen the important professional-parent partnerships, the federal Maternal and Child Health Bureau (MCHB) established a cooperative agreement entitled the **Family Leadership in Language and Learning Program (FL3)** for the Universal Newborn Hearing Screening and Intervention Program. The inaugural cooperative agreement was awarded to Hands & Voices (H&V) in 2017. An important initial activity of H&V's FL3 was to conduct a comprehensive national needs assessment to inform their scope of work. The assessment was designed to take an in-depth look at the needs of families, family-based support organizations (FBOs), and U.S. state and jurisdiction Early Hearing Detection and Intervention (EHDI) programs with the purpose of ensuring that the FL3 is helping to meet the needs of all families of children who are or are at risk for being deaf or hard of hearing (D/HH).

A combination of online and paper surveys were used with families of children who are D/HH, with 458 responses by families of children who are 0-6 years old. Online surveys were completed by 56 of 59 EHDI Coordinators and 40 of 59 FBOs. Additionally, 5 focus groups were held with parents (3 of which were with underserved families), 2 with EHDI Coordinators, and 4 with FBOs.

Results showed that families need to be offered comprehensive information about services and support at different points in their child's life; coordinated, trusted resources; contact with and support from other parents who share their lived experience; increased support for underserved families; and access to D/HH role models. The EHDI Coordinator results revealed that they need a clear delineation of responsibilities for their contracted FBO; strategies to establish a collaborative partnership with their FBO; ways to work with FBOs and parents to address barriers to involvement and leadership; and tools to provide consistent, accurate information and resources to offer families. FBOs report they need training in working with families with diverse communication choices; familiarity with D/HH resources; tools to train parents to be involved in all levels of the EHDI system; earlier access to newly identified families; better ability to offer families a variety of activities in a variety of formats; strategies for engaging families from diverse or underserved populations; a better understanding of the EHDI system; and clear expectations and deliverables from their EHDI Program.



## II. INTRODUCTION

The purpose of this report is to present the findings of the FL3 Needs Assessment and includes background information, methodology, results, discussion, and limitations.

The federal Maternal and Child Health Bureau (MCHB) has long promoted the role of families as partners in decision making. In the recently revised Title V Maternal and Child Health Services Block Grant Guidance to states, MCHB defines family/consumer partnership as *“The intentional practice of working with families for the ultimate goal of positive outcomes in all areas through the life course. Family engagement reflects a belief in the value of the family leadership at all levels from an individual, community and policy level”* (Association of Maternal & Child Health Programs [AMCHP], 2016). Additionally, MCHB has articulated this as the first of its six key outcomes for children and youth with special health care needs (CYSHCN), which includes children and youth who are deaf or hard of hearing (D/HH).



Early Hearing Detection and Intervention (EHDI) programs, supported by MCHB, support the philosophy that EHDI systems must ensure families have the information they need to make the best decisions for their child as they navigate their journey of raising a child who is D/HH. Since the inception of the Universal Newborn Hearing Screening (UNHS) grants in 2000, EHDI Programs, the recipients of the UNHS grants, have consistently focused

on families as the foundation for their work. A recent example of this focus is the inclusion of family-based organizations (FBO), defined as an organization that provides support services to families with children with CYSHCN, as a sub-contract of the MCHB-funded UNHS grants (HRSA-17-059). FBOs vary from EHDI Program to EHDI Program, but at their core are intended to ensure that families are integrally involved in the development, implementation, and evaluation of the EHDI system and provide the needed support and resources to families with a child who is D/HH.

To further strengthen the importance of professional-parent partnerships, MCHB established the **Family Leadership in Language and Learning (FL3)** Funding Opportunity. This cooperative agreement was awarded to Hands & Voices



(H&V) in 2017 with the purpose, described in HRSA 17-061, “to ... *promote the inclusion of families, parents and caregivers of deaf or hard of hearing infants/children... as leaders in the statewide EHDI system and thereby to support children’s language, literacy and social-emotional development.*” More specifically, the goals of the FL3 are:

1. All (100%), state/territory EHDI systems will **develop partnerships** with identified statewide, family-based organizations or programs that provide family-to-family support to families of children who are D/HH identified through newborn screening by the end of the three-year project period (2020).
2. To increase by 30% from baseline, the number of families who report **increased knowledge, skill, ability, and self-efficacy to serve as leaders** in national and state/territory EHDI systems by the end of the three-year project period (2020).
3. To increase by 50% from baseline, the number of families that **receive family-to-family support** by the end of the three-year project period (2020).
4. To increase by 50 percent from baseline, the number of families with **knowledge of opportunities for language, literacy, and social development** for their children by the end of the three-year project period (2020).
5. To increase by 30 percent from baseline, the number of families that are **offered support from Deaf Mentors** by the end of the three-year project period (2020).

H&V has brought together organizations and diverse groups to work collectively on issues and topics that pertain to these goals. An important initial activity of the FL3 was to conduct a comprehensive national needs assessment to inform their scope of work. H&V contracted with the National Center for Hearing Assessment and Management (NCHAM) at Utah State University to conduct the needs assessment. Specifically, NCHAM established a needs assessment core team that included Alyson Ward, M.S. IA, CHES, Director of Quality Improvement (NCHAM); Vicki Hunting, B.S., Director of Data and Evaluation (H&V and FL3); and Diane Behl, M.Ed., Senior Research Scientist (NCHAM) to develop, administer, and analyze the content of the needs assessment. The needs assessment was designed as an in-





depth examination of the needs of families, EHDI Programs, and FBOs in their ability to work in partnership to improve family engagement in the EHDI system. The overarching questions of the needs assessment were:

1. What types of support did families receive or wish they had received when their child was diagnosed as D/HH?
2. What are the supports EHDI Programs need for effective family engagement in ensuring the EHDI Programs meet the needs of all families of children who are or are at risk for being D/HH?
3. What do family support organizations need from the FL3 program to better serve families who have a child who is D/HH?

### III. BACKGROUND

The needs assessment began with consideration of what is already known about the support and resources provided to families and the continued needs of families, EHDI Programs, and FBO. This background information, primarily obtained via a literature search, is provided below.

#### **What do we already know about meeting family needs?**

The following information provides background information from relevant studies and publications pertaining to family needs for resources, support, and knowledge.



*Family Support.* Various studies involving families of children who are D/HH have been conducted, providing some direction in understanding family needs. Family support, defined here as assistance given to parents to help their child who is D/HH, has been a particular focus. A study by Jackson (2011), examined supports perceived as important by families of newly-identified children who were D/HH. On a questionnaire, 456 respondents rated the importance



of different aspects of family support, the quality of supports they experienced, and their preferences about informational resources. They verified the importance of informational resources, social, and emotional support, and educational advocacy. Families expressed a preference for discussion with other parents of children with hearing loss (4.5 versus 2.7 on a 5-point Likert scale) over discussion with parents of children without hearing loss. Additionally, Internet resources were rated 4.4 as a preferred source of information. The quality of 19 sources of support that families actually received was also measured; the top-ranked sources included professionals and service providers, other parents of children with hearing loss, family support organizations, and grandparents and extended-family members. Open-ended written responses reinforced these findings; the most prevalent comments reflected a desire to connect with parents of children who are D/HH, family support organizations, other children who were D/HH, and adults who were D/HH.

A study conducted by NCHAM (2017) also provides valuable needs assessment information. The Early Intervention for Children who are D/HH: Systematic Nationwide Analysis of Program Strengths, Hurdles, Opportunities and Trends (EI SNAPSHOT) surveyed families of children who are D/HH ages 2 to 6 years of age. Questions focused on family perceptions of their early intervention (EI) experiences, particularly needed resources and supports. Roughly



60% of the family respondents reported that they needed opportunities to connect with other families of children who are D/HH. About one third (34%) of the total respondents had no trouble having this need met while 25% of the total respondents reported that they had trouble getting this connection. In turn, 45% of all the family respondents stated that they desired opportunities to interact with adults who are D/HH, with 23% of the total sample reporting that they needed this connection but had problems getting the opportunity. When asked about the extent to which they received information about family-to-family support organizations, 61-66% of families reported that they received fair to poor information from EI about their state's family organizations, such as the state Parent Training and Information Center and the Family-to-Family Health Information Center. Additionally, over 40% of the families reported receiving fair to poor information about H&V. The EI SNAPSHOT study also revealed the extent to which families face financial burdens tied to their



child's hearing-related needs. Nearly half of families reported that their child's out-of-pocket hearing-related needs were a financial burden, with 44% reporting a moderate to large burden and 2% reporting that the burden was unbearable. This information points to an important need of families to access financial support.

These studies identified that connection to other families with D/HH children are important to families who have children who are D/HH. However, these studies were limited by breadth of the families surveyed (e.g., the age of their child, small number of states and their socioeconomic status [SES] characteristics) and by depth of information solicited (e.g., assistance from providers, information about specific supports received). Therefore, the FL3 needs assessment collected new information to obtain a more comprehensive picture of family support needs.

Access to D/HH Role Models. For this needs assessment, D/HH role models were defined as adults who are D/HH who meet with families to provide support and are sometimes referred to as mentors or guides. The value of D/HH role models was investigated by a 2016 report by Wilder Research entitled "Lifetrack's Deaf Mentor Family Program: An Evaluation of the Experiences and Outcomes for Participating Families (Peterson, et al., 2016)." This study considered a deaf role model to be "...an adult who is Deaf (called a "Deaf Mentor"), who meets with the family approximately weekly over the course



of two years to teach the family American Sign Language (ASL) and to help them learn about Deaf culture and other resources..." This Minnesota-based program matched families with young children who are D/HH with a D/HH role model. Evaluation results showed that 85% of families reported that their child's quality of life had improved as a result of their participation, and 2/3 of respondents said that communication with their child had "gotten much

better." Nearly all (96%) received information on Deaf culture or the Deaf community during their sessions with their deaf role model and 76% found the information "very helpful." It is important to note that this study evaluated a program using a much narrower definition "deaf mentors", and thus it does not inform us about the effectiveness of D/HH roles models that represent individuals using a variety of communication modes.



In a recent NCHAM study (2018), Shuler-Krause reported that 24 states offer D/HH role model programs to families with children who are D/HH, typically using the term “deaf mentor.” Of the 22 states that responded to a survey about their programs, the majority of the programs (56%) served less than 25 families per year and only 6% served 150 or more families per year. It is unclear if families of children with varying degrees of hearing are served by



D/HH role model programs. Of the ten programs that answered the question about whether they emphasize a particular communication modality, nine answered that they focus on ASL or sign language, and one focused on both sign language and spoken English. Thus, it appears that few D/HH role model programs are designed to provide opportunities for families who do not choose ASL. The availability of opportunities to meet with adults who are D/HH that use diverse communication modalities requires further assessment.

These gaps in current research and practices regarding D/HH role models provided the FL3 needs assessment team an opportunity to gather more in-depth information about what was the best support they received from their D/HH role model and if they were offered a role model and didn’t meet with him/her, what was the main reason why. Such information can help guide the FL3 efforts to enhance D/HH role model opportunities for families.

*Family Knowledge of Supporting Early Language, Literacy, Social, and Emotional Development.* The role of caregivers in supporting early language and literacy in children has received a great deal of attention. As a result, there are numerous studies demonstrating effective practices that can be implemented by parents of young children (Mol, Bus, De Jong, & Smeets, 2008; National Academies of Sciences, Engineering, and Medicine, 2016; Sénéchal & LeFevre, 2014; Wasik & Van Horn, 2012). Studies pertaining to children who are D/HH also demonstrate successful interventions for families in supporting their child’s language and literacy (Desjardin & Eisenberg 2007; Desjardin, Ambrose & Eisenberg, 2009; Wauters and Dirks, 2017). A recent study reported that family involvement explained the most variance in child performance on language test scores after controlling for the influence of the other factors ( $r = .615$ ;  $F$  change = 58.70), with age of enrollment in early intervention being the second most significant factor (Moeller, 2000). Additionally, there are



resources available that provide instruction for families of young children who are D/HH on ways that they can promote their child's language and literacy (Global Family Research Project, 2018).

Social and emotional development is a crucial part of a deaf or hard of hearing child's overall development. It impacts the child's language development, academic and social success, and psychological well-being throughout the school years and beyond. Consequently, it is vital to build the foundations for healthy social and emotional development starting at birth (Freeman, 2016). Healthy social and emotional development involves the ability to form satisfying, trusting relationships



with others, play, communicate, learn, face challenges, and experience and handle a full range of emotions (Zero to Three, 2018). It is through the creation of positive social and emotional relationships that literacy and language development are fostered. Positive caregiving relationships provide young children a sense of comfort, safety, and confidence. They teach young children how to form friendships, communicate emotions, and to deal with challenges. Strong,

positive relationships also help children develop trust, empathy, compassion, and a sense of right and wrong. Guiding children's emotions and helping them find ways to express themselves in a healthy manner helps them regulate their responses to challenges and even aids their academic and social competence (Siegler, DeLoache, & Eisenberg, 2011).

Although families are intrinsically involved in the social and emotional development of their children, they are often unaware of how important social and emotional skills are and how to support development in these areas (Visual Language and Visual Learning Science of Learning Center; [VL2], 2016). There are numerous parenting resources for supporting early attachment, language development, and positive discipline approaches for the general population of young children (Darling-Churchill & Lippman, 2016), yet resources designed for families of children who are D/HH such as the those developed by the VL2 Center are just recently getting disseminated.

What is less known is the extent to which families of children who are D/HH know about and access resources as well as the extent to which families feel confident in supporting their child's development. The FL3 needs assessment explored to



what extent families have in fact received resources to help with their child's development in the areas of language, literacy, social and emotional development and if they felt they were adequately supported and educated in these areas.

### **What do we Already Know About the Needs of EHDI Programs to Support Family Engagement?**

In 2016, AMCHP conducted a survey about family engagement in policies and practices within state Title V MCH and CYSHCN programs, which frequently house state EHDI Programs. State MCH and CYSHCN programs reported a need for strategies to recruit and engage culturally diverse, under-represented and under-served families, and a desire to learn more about how changes related to family engagement in the Title V Block Grant Transformation may impact their programs. More than one-third of MCH programs reported having no mechanism for teaching staff members about family engagement. In turn, these state Title V MCH and CYSHCN programs reported a high need for training and technical assistance around methods to evaluate the extent, impact and effectiveness of family engagement. This study informs the FL3 in regard to potential barriers and areas of need to be addressed at a systems level (e.g., training and technical assistance to EHDI Program staff and their family partners). Additionally, respondents were asked about noticeable or tangible benefits their programs had experienced as a result of family engagement. The top three benefits identified by both MCH and CYSHCN respondents are heightened awareness and understanding of family issues and needs; increased family-professional partnerships and communication; and improved planning and policies resulting in services more directly responsive to family needs.

In preparation for writing the FL3 proposal, NCHAM surveyed EHDI Coordinators about the extent to which family members were contributing to the leadership within their EHDI Program. The average of family engagement at the systems level was 2.95 on a 5-point scale (1 being non-existent and 5 being excellent), with 18 of the 42 programs (43%) rating themselves at 2.5 or under. It is also important to note that 20% of states reported that they do not have an



active advisory committee and thus this was not an option as a way for EHDI Programs to engage families. Of those that did report having an advisory committee, two did not have any parents of children who are D/HH and five did not have



any individuals who are D/HH. When asked about the EHDI Program's role in providing information to families of newly-identified children, 62% of programs reported that they did not offer information to families about D/HH role model services. The data from AMCHP and the EHDI Coordinator surveys provided a springboard for the needs assessment to further assess what types of support, resources EHDI Programs are providing families and further explore types of leadership opportunities families have in EHDI Programs.

### **What do we Already Know About the Needs of EHDI-contracted FBOs?**

As described earlier, the HRSA funding to support EHDI-contracted FBOs represent a new initiative, and as such, little information was available pertaining to their specific needs prior to conducting the FL3 needs assessment. However, investigation of the needs of existing family support organizations in regard to their capacity to support families of children who are D/HH provides useful background information. A survey was conducted with state level chapters from Family



Voices, Parent Training and Information Centers, and Parent-to-Parent USA to understand their current activities to support families of children with hearing-related concerns and to identify gaps in their ability to support families of children who are D/HH (Behl, DesGeorges & White, 2016). Ninety percent (90%) of the respondents reported that they provide information about family support (90%), early intervention (90%), referral sources for hearing concerns (92%), financial help (90%), and information about

education-related legal rights (80%). They also conveyed that they receive few requests from parents with hearing-related concerns, with 58% reporting that they get contacted by fewer than 50 parents per year with hearing-related concerns. Additional results showed that the greatest challenges for these organizations in their efforts to help families of children who are D/HH were 1) identifying financial resources pertaining to hearing-related needs (62%), 2) knowing how to engage families of children who are D/HH in their organization's activities (44%), 3) having resources available in other languages (47%), and 4) identifying pediatric providers that serve children who are D/HH (41%).



The recent EI SNAPSHOT (2017) study also informs the FL3 in regard to areas of need for the FBOs. Only about 10% of the family-to-family support organizations surveyed (i.e., Parent Training and Information Centers, Family-to-Family Health Information Centers) reported that they refer families to the state’s EHDI Program if the parent was concerned about their child’s hearing, if they had questions about where to get a hearing test, or what to



do following a diagnosis. Thus, there appears to be a strong need for providing professional development to family support 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. While family-to-family support organizations provided a high number of resources about disabilities in general and navigating the early intervention and education and medical systems, they offered very few resources specific to hearing loss (e.g., connecting families to Hands & Voices, AG Bell, ASDC). This could be due to a lack of knowledge about these organizations, or it could be due to a lack of chapter presence within their state.

The new EHDI-contracted FBOs will likely receive similar requests for information as those investigated in these two studies. The need to foster relationship building with the EHDI Programs and the FBOs will be an important focus for the FL3. Additionally, the broad-based family support organizations such as state chapters of Family Voices, Parent Training and Information Centers, and Parent-to-Parent USA will be important partners of the FBOs in their efforts to create a strong system of supports for families.



## IV. METHODS

This section describes the collection of new needs assessment information to inform the FL3. The three primary target populations are described, followed by the data collection methodologies applied.

### Target Populations

As stated in the H&V FL3 proposal (HRSA 17-061), the national needs assessment identified three target populations: parents of children who are D/HH, EHDI Coordinators, and FBOs that are contracted with EHDI Programs.

Parents. A sample of parents of 0-6-year-old children who are D/HH was surveyed. The parent pool included 214 parents who had previously consented to further research through NCHAM's EI SNAPSHOT study. This sample was used because respondents had provided background demographic information as well as some relevant information about their access to family supports and resources. This provided a good opportunity to gather the FL3-specific information from a known cohort. An additional group of parents was solicited using social media.



EHDI Coordinators. There are 59 states or U.S. jurisdictions that receive funding from MCHB to operate EHDI Programs. NCHAM maintains information about the coordinator contact for each of these programs and reached out to all coordinators to collect needs assessment data.

FBOs. As part of their latest funding from MCHB, EHDI Programs must contract with and provide 25% of their funding to an FBO who provides support to families who

have children with special needs. At the time of the needs assessment, there were 48 contracted FBOs, some states are contracted with more than one organization. EHDI-contracted FBOs and their contact information are listed here: [www.handsandvoices.org/fl3/topics/fam-fam-support/need-support.html](http://www.handsandvoices.org/fl3/topics/fam-fam-support/need-support.html)



## **Survey Development and Collection Procedures**

*Institutional Review Board.* The needs assessment protocol was approved by Utah State University's Institutional Review Board (#8646).

*Survey Development.* The needs assessment team developed target population-specific surveys based on the goals outlined by the FL3 and the background information. The team followed Dillman's (2014) guidelines for choosing words and formatting questions (e.g., asking one question at a time, technically accurate, simple language). Additionally, the team sought to achieve a 7th-grade reading level as recommended by the United States Department of Health and Human Services for health-related information and reinforced by Walsh and Volsko (2008). Prior to full implementation, all surveys were pilot tested and revised as needed. The team then moved the survey from a paper format into RedCap, a HIPAA-compliant data management system and survey tool.



*Survey Collection Procedures.* Following Dillman's (2014) guidelines, the team administered the surveys using a mixed-mode framework and tailored design. Each target population had a set contact timeline with multiple survey reminders. Parents in the EI SNAPSHOT cohort received the survey and reminders via email and text. Parents in the Social Media cohort received multiple reminders via Facebook and Twitter that linked to the survey. The team spread the survey posts on social media through the Facebook pages and Twitter accounts of FBOs, NCHAM, H&V, and other stakeholder groups. Furthermore, as requested by the their EHDI Coordinators, parents in the islands who receive MCHB EHDI funding (Virgin Islands, Puerto Rico, American Samoa, Republic of Marshall Islands, Federated States of Micronesia, Commonwealth of Northern Mariana Islands, Guam, and Palau) received printed surveys in English, printed Spanish surveys were requested by Virgin Islands and Puerto Rico. Printed surveys came with explicit instructions on how to complete and return the survey in a self-addressed, stamped envelope. All parents that completed the survey and chose to provide their contact information, were entered to win one of five \$50 Amazon gift cards.



In July 2017, the team sent a needs assessment introduction to all EHDI Coordinators that outlined what information would be gathered, from whom, and how. This introductory letter was intended to increase cooperation and responses from the EHDI Coordinators. Reminder emails only went to those who had not completed the survey. Coordinators had an option to include their name and state. Since nearly all EHDI Coordinators are public employees, they could not accept payments or gifts for participation; hence no incentives were provided for coordinators to participate.

Garnering information from the FBOs began with the FL3 directly reaching out to EHDI Coordinators asking for the contact information for their contracted FBO. EHDI-contracted FBOs consisted of several types of organizations including H&V Chapters, Family Voices, Family-to-family Health Information Centers, etc. Once the FL3 received contact information, they emailed the FBOs to alert them to the upcoming needs assessment, then an introductory



email with a link to the survey. Reminder emails only went to those who had not completed the survey. After the FBOs had received 5 reminder emails, the team called the FBOs to remind them to take the survey online or complete the survey over the phone. The FBOs had the option to include their organization, name, and phone number. All FBOs who completed the survey were entered to win one free registration to the 2018 H&V Leadership Conference.

Focus Groups. The needs assessment team held focus groups for each of the target populations. All focus groups were audio and/or video recorded, the recordings were then transcribed and coded for themes. Each focus group was comprised of 8-15 individuals.

At the end of the parent survey, the survey stated *“Parents needed! We are looking for parents to participate in a small focus group.”* The team offered to pay \$50 for the hour-long parent focus group. After a parent indicated they would participate, they were directed to enter their name, email, and phone number. The team then sent a focus group invitation email and two reminder emails for each focus group. All parent focus groups were held virtually on ZOOM, a secure videoconference service. Two general parent focus groups were held, and 15 randomly- selected parents invited to participate in each



group. The team held 3 additional parent focus groups that sought to gain information from underrepresented groups (i.e., fathers, Deaf Plus, and Latino families). Questions for the parent focus groups were developed to not only verify the survey findings but also to gain more insight and to expand on the issues in question.

Both EHDI Coordinators and FBOs were selected for focus groups by the needs assessment team based on geographic region, birth population, and type of FBO (H&V Chapter, Family Voices etc.). Invitations and two reminders were emailed to those selected for participation for each focus group. There were two focus groups for EHDI Coordinators, both were held virtually on ZOOM. Focus group prompts for the coordinators were based on survey responses. There were four FBO focus groups; two were held in-person at the 2017 H&V Leadership Conference, and two were held virtually through ZOOM. The focus group findings served to guide the content for the survey. There was no payment offered for these focus groups.

## V. RESULTS AND DISCUSSION

This section presents the results for all target populations, followed by a discussion of points of interest by each area being assessed.

### Families

The total number of parent surveys was 1,067; the total number of surveys fully completed was 979. Out of those 979, 458 were parents of children ages 0-6 and 521 were ages 6-18. The results below are reflective of the 458 surveys of parents of children ages 0-6, the total number of parents in individual questions may vary depending on whether the respondent(s) skipped that question. From the EI SNAP-SHOT parent cohort, there were 66/214 surveys completed, equating to a 31% response rate. Completed surveys from parents of children 0-6, through social media, totaled 392 equating to 86% of responses from the total number of surveys submitted. The team was not able to calculate a response rate from the social media cohort because the number in the population is unknown. Demographics and





data between the EI SNAPSHOT parents and parents from the social media cohort were similar and have been combined into one data set. Respondents were dispersed unevenly with parent participants from 48 of the 59 EHDI Programs. Data from children over 6 years old were excluded in the data analysis as the needs assessment team determined that the experience of families over age 6 would not be as reflective of the current EHDI system. The needs assessment team plans on examining the responses of the older children after the FL3 report is complete. See the full family survey in Appendix A.

Table 1 highlights the demographics of the parents with children who are D/HH and between 0-6 years old. It is interesting to note that 21% of the families who participated met or were near Medicaid eligibility of \$33,948 (138% of federal poverty level) for a family of 4, and just over half (55%) of the of the parents responded that their child met the mile marker of being diagnosed by 3 months of age. Moreover, nearly a quarter (21%) of parents responded that their child was diagnosed after 1 year of age. It is unclear if the delayed diagnosis is due to late onset loss, missed screening, or lost to follow up.

**Table 1  
Parent Demographics**

<b>Race</b>	White	86%
	Hispanic	9%
	Black	3%
<b>Parent</b>	Mother	94%
	Father	5%
	Gaurdian	1%
<b>Age of child represented</b>	0-2	35%
	3-4	33%
	5-6	32%
<b>Primary Language</b>	English	92%
	ASL	4%
	Other	4%
<b>Yearly Income</b>	> \$150,000	12%
	\$75,000-\$149,999	36%
	\$35,000-\$74,999	31%
	< \$25,000-34,999	21%

### Question #1: Involvement with EHDI programs and FBOs.

EHDI Programs and FBOs collectively strive to meet the needs of parents, yet parent awareness of these groups was unknown. Definitions of both groups were provided in the introduction to the survey. As shown in Table 2, 19% of parents reported that they did not know about EHDI, and a slightly larger portion stated that they were not involved with EHDI but would like to be. This reflects an opportunity for the FL3 to reach out to all families of children who are D/HH to help increase awareness of and services provided by the EHDI Program. About the same percentage of families have participated in EHDI activities, again reflecting an opportunity to engage more families in EHDI-related family activities. Additionally, EHDI Programs spend a lot of time and energy around building their EHDI website, yet only 14%

**Table 2  
Parents Involvement with EHDI and FBOs**

	<b>EHDI</b>	<b>FBO</b>
I don't know about this program	19%	12%
Not involved, but would like to be	21%	15%
Not involved and would NOT like to be	9%	1%
I have visited their website	14%	24%
I follow them on social media	9%	28%
I have participated in their activities or programs	21%	42%
I am an EHDI family leader	4%	N/A



of parents responded that they visit the EHDI website. This may indicate that EHDI Programs should spend more time increasing awareness of their website among families, the FL3 could help facilitate this effort. In comparison to EHDI Programs, more parents reported that they reviewed the websites and social media of the FBOs (14% versus 24%).

With such a drastic difference, future research could include reviewing both EHDI and FBO websites to determine if they reference one another. Despite the existence of many FBOs having long-term experience, there are still 12-15% of parents who don't know or are not involved with their state's FBO. Furthermore, since many more parents reported that they had participated in FBO- sponsored activities, this may be a great way for EHDI and FBO to combine efforts and conduct joint activities for parents. Some parents responded via the "Other" option, stating that they know the EHDI Program exists because their child had a hearing screen or that they are involved in their FBO and they [the FBO] had introduced them to the EHDI Program. During the father focus group, the team asked how these programs can get more fathers involved. Several fathers said that the information they received from both the EHDI Program and the FBOs was directed towards their wives, and they would find it meaningful to be included from the beginning.

**"Maybe during hospital intake, when initially signing up, I would say capture both the dad's and mom's information, not just the mom's information. Let them decide if they both want to participate."**

**-Parent (father)**

In additional data analysis, the needs assessment team collapsed the response categories (I don't know about this program, not involved but would like to be, not involved but would not like to be, somewhat involved [website, social media, activities], and very involved). The purpose of this was to determine if family involvement by EHDI or FBO were correlated with what support or resources the family received. This additional analysis is exhibited in the following questions where relationships were identified.

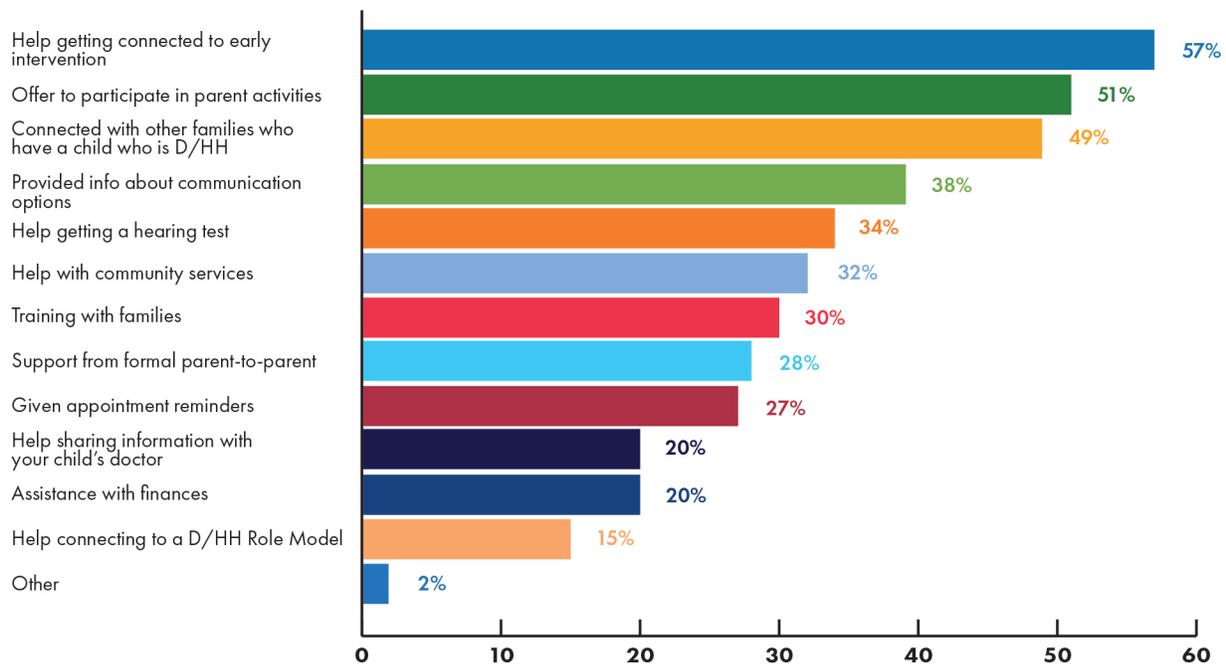
### **Question #2: Types of support families received.**

Parents were asked what types of support they received for their child who was D/HH. Support in this survey referred to assistance given to parents to help their child who is D/HH. Figure 1 describes the results for a question about supports families received. Examples were given for each option and can be seen in the full survey. As shown in Figure 1, the most frequently cited supports that families reported were appointment reminders, connections to EI, and invitations to participate in parent activities. A follow-up question was "Who provided these supports?" Parents were able to select the top 5



providers from a list of 12 options (see Appendix A). The top five providers cited for providing supports were audiologists (58%), early intervention staff (58%), family support organization (28%), physicians (28%), and website or social media (27%). In cross referencing support received with responses on involvement with EHDI and FBO, there were some notable differences between the groups, signifying that the more involved the parent is with both their EHDI Program and their FBO, the more likely they were to report that they received certain supports. However, it is unclear if the supports were received because they were more involved, or if they were more involved because they received the supports. The most significant connections were parents reporting they had help connecting with families who have a child who is D/HH, getting support from other parents, and attending activities and trainings for families were more commonly received by those parents when they were somewhat to very involved with their EHDI Program or FBO. The needs assessment team could not determine whether the percentage that received a particular type of support is indicative of the percentage who needed that support.

**Figure 1**  
**Types of support families received in their community**



During the focus groups, the team asked parents what supports they would recommend that other parents obtain. The most cited support was Guide By Your Side, a H&V branded parent support program. Parents were also asked what would make accessing support easier. There were several themes identified from the focus group responses. The most common was to have one contact, such as a family support coordinator. Others cited the value of having access to an easily navigated



website that contains reliable information on the entire process from screening to diagnosis, types of hearing loss, what to expect from early intervention etc. The Latino focus group parents cited their unique challenges in finding and accessing culturally appropriate supports. Specifically, parents in the Latino focus group highlighted the complex immigration status and education level issues that make the access more challenging. Another question asked during the focus groups was what would make it easier for families to participate in family-to-family support activities. Suggestions frequently mentioned were location of the event, offering of child care, offering events during the weekend, offering virtual meetings, and sending invitations in various formats (e.g., emails, social media, text). During the Deaf Plus focus group, these parents of children who have additional disabilities or health needs beyond being D/HH, discussed their unique needs. One parent expressed that she wished the Deaf community had a better understanding of the additional complexities of a Deaf Plus child, such as exponential increase in providers and more emphasis on self-care for these parents. Moreover, parents in the Deaf Plus focus group stressed the importance of connecting with other parents of children who are Deaf Plus. In the fathers focus group, participants suggested having “dad-focused” activities that are designed to be a father-son or father-daughter events.

In general receipt of support is rather low, with only 3 supports received by more than 50% of the parents—leaving the remaining 9 supports received by less than half of the surveyed parents. Additionally, the top support received and who provided these resources are correlated. For example, 58% responded that they had support connecting to early intervention, and early intervention providers and audiologists were in the top five providers connecting families to support. Moreover, focus group parents gave great insight, described above, about what support they would recommend and what would make it easier for families to participate in activities. This information not only informs the FL3 but acts as a gauge to EHDI Programs and FBOs to what families are reporting they receive and where support and connection to support could be bolstered.

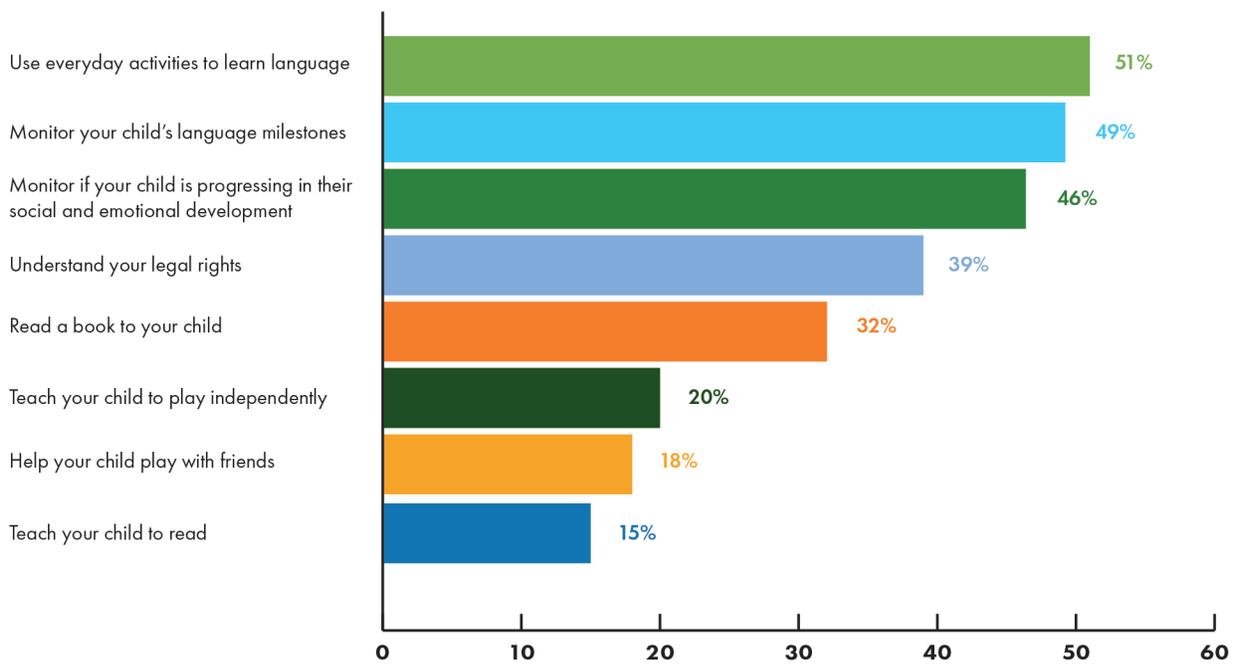




### Question #3: Types of resources families received to support language, literacy and social-emotional development.

When presented with a list of options pertaining to their child’s development, parents were able to select all the resources they had received. Examples were given for each option and can be seen in the full survey. Results to this question are presented in Figure 2. When asked who provided these resources, parents cited early intervention staff (54%), audiologists (37%), website or social media (26%), their child’s school (26%), and physicians (23%) as the top five for providing these resources. Again, the needs assessment team examined resources received by the categories described in Table 2 regarding involvement with EHDI and FBOs. Those who reported that they were very involved with their EHDI Program (72%) reported that they received resources helping them understand their legal rights.

**Figure 2**  
**Types of resources families received**



During the focus groups, the team asked parents where they go for trusted resources and asked for suggestions of how to increase awareness of these resources. Overwhelmingly, the parents stated that the Internet was their primary resource—specifically the H&V website, blogs, and social media. Parents suggested the best way to increase awareness of resources was to increase outreach to parents and to highlight trusted resources on social media—particularly Facebook and Instagram.



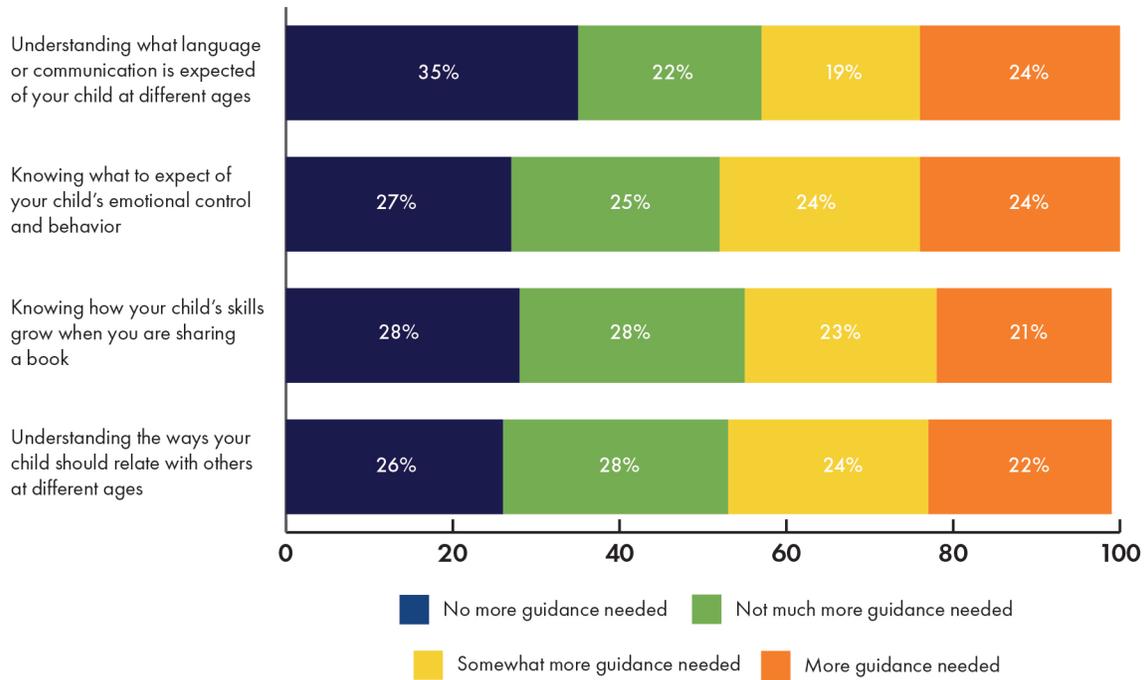
In general, families are not consistently receiving a full array of resources. Only 2 of these resources were received by more than 50% of families. Survey results showed that websites and social media as the third top provider for these resources. Focus group participants also commented that the accuracy of information varies among sites. This emphasizes the importance of websites and social media to families as well as ensuring those resources are trusted and accurate. Revisiting the responses regarding their involvement in EHDI and FBOs, parents are going to websites and social media as a primary resource for information, but they are not using the EHDI Program's website or social media as one of these resources. Again, this highlights the need for EHDI Programs to increase awareness of their website. It is not surprising EHDI Programs do not make the top 5 providers of these resources; EHDI Programs are often behind the scenes providing their resources to audiologists, early intervention, and other stakeholders to provide support to families. Furthermore, with audiologists being listed as a top provider of support and resources, the FL3, EHDI Programs, and FBOs need to recognize the power of partnering with audiologists and supplying them with accurate, current resources to provide to all families.

#### **Question #4: Developmental areas where families wanted more guidance.**

The survey also asked families about developmental areas for which they would have liked more guidance using a 4-point Likert scale; responses are outlined in Figure 3. The needs assessment team found it interesting that there was not much variation between responses to each area. In general, 1/2 to 2/3 of the parents reported that they would have liked more guidance in each of areas. With language, literacy, social, and emotional development as foci of the FL3 program, these results are particularly insightful and highlight how much more assistance parents would like in these areas. This may be a ripe area of collaboration for MCHB, the Centers for Disease Control and Prevention (CDC), NCHAM, and the FL3.



**Figure 3**  
**Where families would like more guidance**

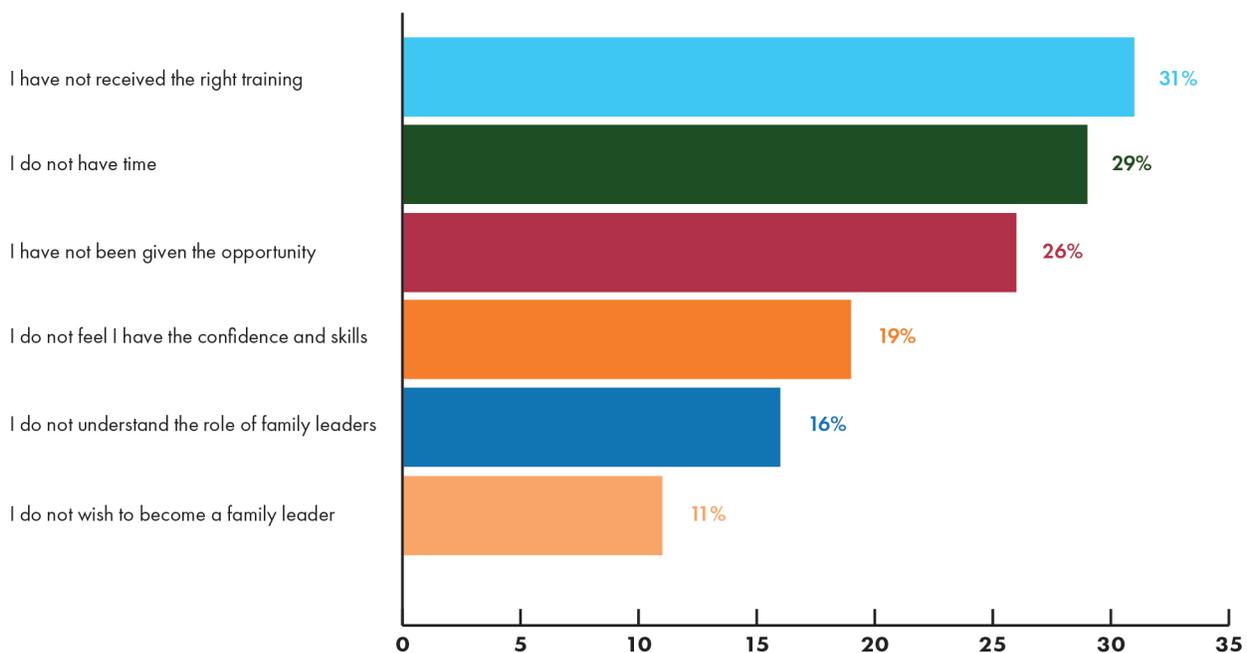


**Question #5: Challenges families face in becoming leaders.**

The survey investigated the barriers for families in becoming leaders. A definition of family leader was provided along with examples of what family leaders may do (e.g., building partnerships, advocating for D/HH children in the larger community, participating on EHDI advisory committees). Parents were able to mark all that apply. Results to this question are detailed in Figure 4. Many responses highlight lack of communication surrounding opportunities (lack of understanding, 16% and not given opportunities, 26%). Focus group information added additional information about what would help parents build their confidence in becoming a family leader. Ideas generated during this discussion were educational webinars, open forum discussions, opportunities to learn from deaf educators and deaf adults, being offered opportunities from early intervention and parent support organizations and having a clear map of how families can get involved locally and nationally.



**Figure 4**  
**Challenges families face in becoming leaders**



Interestingly, only 29% of families indicated that having time to participate was a challenge. Described later in the report, EHDI Coordinators had a different perspective, with 79% of them reporting challenges in finding families with the time to assist the EHDI Program. The team speculates that the contradiction might be due to the same parents being asked by multiple groups, making those parents' time limited to any one program or that time of day may be a factor as many of the EHDI Program activities are held during business hours and may interfere with the schedule of working families or make finding childcare a challenge. The FL3 could provide coaching to EHDI Programs and FBOs to help alleviate the challenges cited by parents as well as strategies to recruit additional family leaders.

**Question #6: Additional support or resources families wished they would have received.**

An open-ended question “What resources or support do you wish you had...” was included in the survey, allowing parents to identify what they wished they would have received to help support their family and their child who is D/HH. The team grouped themes identified in the open-ended responses; they are listed below in order from the most common to least. Only 70% of the parents entered text to this question and of those 43% responded they received all the resources they needed, entered in none, or n/a.



Theme #1: Increased Connection to Resources. This was the most often cited theme, with 14% (n=45) of responses falling into this category. This highlights that parents want as many resources as possible to help them understand their baby's hearing status, what communication options are available, and what early intervention means for their child and their family. One parent wrote "I've been trying for 4 years to find good resources for reading with a deaf child, but none exist in my area." Another parent stated that he/she would have liked any resource offered since they had to find all the resources themselves.

**"I wish someone would have reached out to me first instead of having to do research to find the right service on my own for my child. "**

**-Parent**

Theme #2: Social and Emotional Support for Families. As cited in the earlier background section "Need for Family Access to Support," 10% (n=31) of families report that they want access to support from other families with children who are D/HH. In this question, social and emotional support from other families was specifically identified by 10% of the relevant open-ended responses. The responses in this area demonstrated that parents are open to receiving this support in a variety of formats from in-person activities, to phone calls and virtual meetings. A parent stated, "[My child] was the first deaf person I'd known; I would have liked someone to tell us that his deafness wouldn't keep us from doing things." Several parents stated that connection to other parents with children who are D/HH helped them understand what to expect, what is normal, and what is concerning.

**"Early on, I wish I had some grief support as well as another trained parent guide."**

**-Parent**

Theme #3: Access to ASL Instruction. Eight percent (8%, n=27) of parents who responded to this question, stated that they would have liked increased access to ASL classes as a stand-alone communication or to use in combination with hearing aids or cochlear implants. Half of the parents that cited ASL instruction, commented that their child had access to ASL, but that the family wanted instruction as well. One parent wrote "The school for the Deaf was wonderful in teaching signs, but I would have liked to find a class we could have taken as a family." Another comment was "I wish someone would have stressed how important learning sign language was even if you made the choice to get your child a cochlear implant."



*Theme #4: Access to D/HH Role Models.* As noted earlier, very few families have access to D/HH role models. Access to a Deaf role model was requested by 6% (n=18) of the parents who answered this question. One parent cited “I wish we could have a deaf mentor or at least access to a program. I really would like to have a deaf person weekly in our home teaching us.”

*Theme #5: Improved Early Intervention Services.* Six percent (6%, n=18) of parents reported that they would have liked faster referral and entry into early intervention and more comprehensive intervention services. One parent stated, “ I wish early intervention therapy would have been automatic after my son was diagnosed with hearing loss. Our audiologist referred him, but then we were never contacted by early intervention.” Another parent responded “More information relative to milestones for kiddos who are D/HH. For example, almost every ‘test’ or ‘timeline’ has been set for typical hearing kiddos; no tests are designed for D/HH kiddos (that we have had her assessed with anyway).”

**“I would love the opportunity to speak one on one with an adult who has the same condition as my son. Get their perspective on how they think I could advocate for my son as he gets older and navigates the world. ”**

**-Parent**

*Other Themes Identified.* There were a few comments that did not fit into a specific category or were not mentioned frequently enough to qualify as an additional theme. For example, navigating hearing technology was cited as a challenge, a parent wrote “I’d like hearing aid or equipment to help with my child’s hearing and training on how to better communicate with my child.” A few parents wrote about the financial burdens that accompany services and technologies to serve those who are D/HH. A parent responded “We’d like insurance coverage for ear molds. We have always had to pay out of pocket.”

This open-ended question provided a great opportunity for parents to add additional context to their responses and further demonstrate that there is opportunity for improvement in regard to the resources and support offered to families with children who are D/HH. These responses provide EHDI Programs and the FL3 direction additional information on where to focus their efforts



### Question #7: Barriers to participating in family-to-family activities.

As described previously, families rank receiving support from other families as number one in importance of what resources they wished they would have received. Attending family-to-family activities is one such forum where this support is received. Responses to this question were grouped by themes and ranked from most to least cited. Only 326 parents wrote text to this question, and of those, 11% of these parents stated that they did not experience any barriers, wrote none, or n/a.

Barrier #1: Time or Schedule. Twenty-nine percent (29%, n=106) of the families who responded to this question, reported that time was the primary barrier for attending events. This is similar to the 33% of parents who responded time as barrier to the question about challenges in becoming a family leader. One parent stated, “I have a big family with 6 children and with my husband’s work schedule we have a lot going on and it’s hard making it to everything we would like to.” Another parent wrote, “Time and proximity to home. I’m a single, full time working mother. ‘Extra’ time needs for medical appointments, early intervention, ASL classes, etc., it’s so hard on me to fit it in.” Other parents stated that the day of the week and time of day make it a challenge to attend activities, one parent wrote “Scheduling, the activities are during the day, conflict with my workday.””

Barrier #2: Distance or Location. Time and distance are often linked as it takes more time to attend an activity that is farther away. Twenty-six percent (26%, n=84) cited location of the activities as a barrier. State geography vary greatly. The EHDI Program is often located at the state health department, in the state’s capitol and may be hours away from a family. This distance is a burden for those with their own transportation but may be impossible financially or otherwise for those without their own transportation. Highlighting this challenge, one parent reported “Everything is so far away from where we are located. We try to attend things that are within an hour drive.”

**“Living in a more remote part of the state, often these events require a 3-hour drive 1 way.”**

**-Parent**



Barrier #3: Unaware of the Opportunity. Twelve percent (12%, n=38) of parents reported that they were unaware the activities were even being offered.

Several parents speculated they were not included in the activities because their child had a unilateral loss. Some mentioned they moved recently and haven't gotten involved yet.

**"I am not yet aware if such activities exist, but I would like to attend."**

**-Parent**

Barrier #4: Discomfort Based on Communication Mode. Though parents cite having support from other parents with children who are D/HH is helpful, there were 7% (n=22) of parents reported that they didn't feel comfortable attending family-to-family support activities. Comments in this theme included that parents were concerned about being accepted or treated respectfully because of the communication mode(s) they have chosen for their child. One parent stated, "I have bad experiences with anti-cochlear people, I don't want my children to witness this." Another parent reported "Being threatened by other hearing parents for being a deaf parent or avid ASL speaker. Constantly seen as a deaf militant for favoring ASL." Parents with children with unilateral loss reported feeling unwelcome, one parent wrote "Because our son had a unilateral hearing loss and not many families with a similar situation attend, so we often felt like outsiders." This is an interesting comment, since children with unilateral loss comprise the largest group of children who are D/HH. The remainder of parents did not feel comfortable because it was a large setting with new people. Such comments reflect the importance of having a variety of settings and formats for parent-to-parent activities.

Other Barriers. There were a few comments that did not fit into a specific theme or were not mentioned frequently enough to make them a theme. For example, lack of child care and lack of activities for children of all ages were cited as barriers.

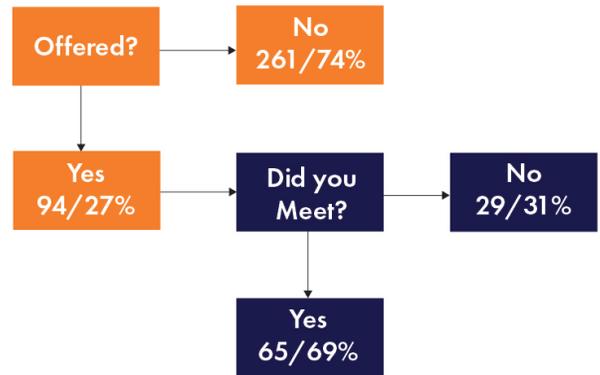
### **Question #8: Access to and meeting with a D/HH role model.**

D/HH role models were defined in this survey as adults who are D/HH who meet with families and are sometimes referred to as mentors or guides. As seen in Figure 5, of the parents who have a child who is D/HH between the ages of 0-6, 27% of parents stated they were offered a D/HH role model; out of those who were offered, 69% responded that they met with the D/HH role model.



Parents in the focus groups also were asked if they were offered a D/HH role model, if they met with them, and whether the D/HH role model was valuable to their family’s experience. Many of the focus group parents responded that if they had been offered, they would have met a D/HH role model. One mother stated, “I would have jumped right on it!” During the Latino parent focus group, the team asked if they would be more likely to meet with a D/HH role model if they were Spanish speaking, to which many of the parents responded that it would help because they could identify with each other’s cultures and traditions and would help narrow the gap between ASL users and Spanish speakers.

**Figure 5**  
**Access to a D/HH Role Model**



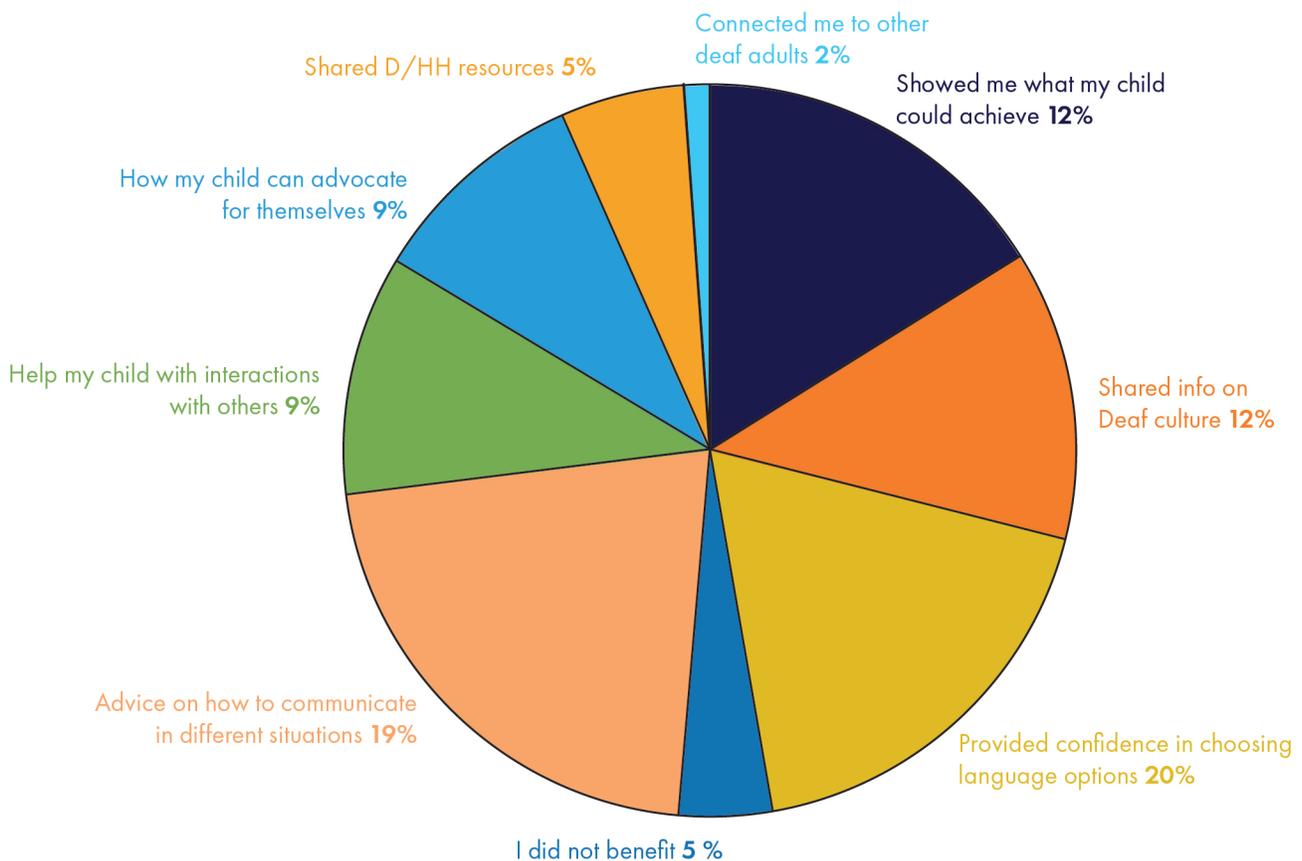
The findings for this question are consistent with what the team found during their literature review, that few parents are offered a D/HH role model. Through the focus group responses and the open-ended question “Are there any resources or supports that you did not get but wish you would have received,” parents expressed interest in meeting with a D/HH role model or at least would have liked to be offered the option.

### **Question #9: Benefits of meeting with a D/HH role model.**

This question about the perceived benefits of a D/HH role model was only asked to those who responded that they had in fact met with a D/HH role model. Each respondent was asked to choose one item that they thought was most helpful. Responses to this question are depicted in Figure 6. The most frequently cited benefits were that the D/HH role model provided information about communication in different situations and helped increase the family’s confidence in choosing a communication language. Of those that selected “Other” (only 9 people commented on this question) the most common comments had to do with the D/HH role model helping the family learn ASL, connecting them to Deaf culture events, and how to work with the school during an Individualized Education Program (IEP) for ASL supports and services.



**Figure 6**  
**Benefits of meeting with a D/HH role model**



Focus group participants were asked “How would a D/HH role model be valuable to your family’s experience?” Several examples were cited, such as “They could help you ask the questions you don’t know you have yet,” and “They could answer questions about the future, things she can do, things she can’t, and the best way to teach her about hearing loss.” Other parents said that a D/HH role model could be a good networking tool such as “How to access interpreters,” and “Learn how to connect more with kids my son’s age who have cochlear implants.”

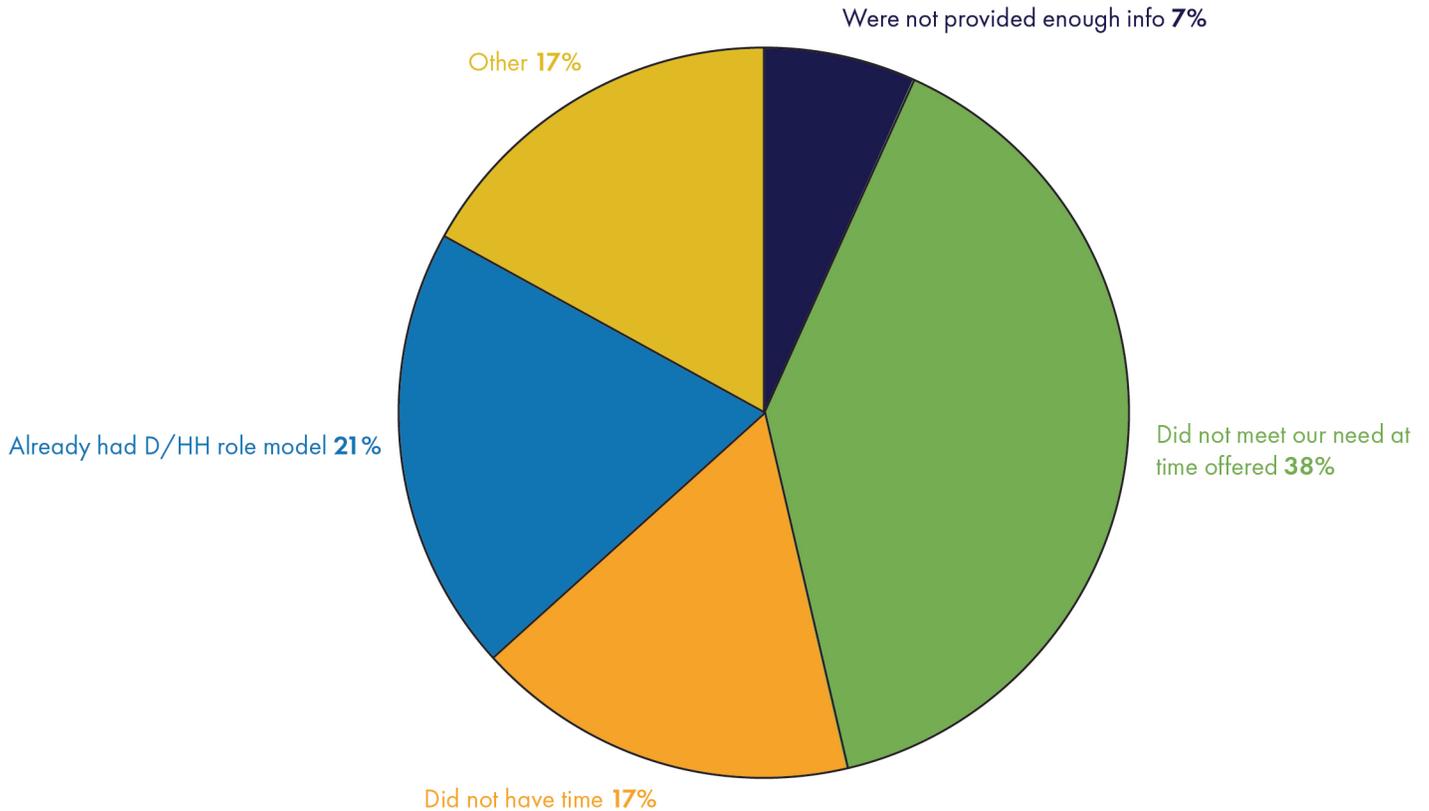
Ninety-five percent (95%) of the parents who responded to this question reported that they benefited in some way by meeting with the D/HH role model. Again, through open survey responses and focus group, parents who were not offered a D/HH role model, cited they believe a D/HH role model would have been beneficial to their family. Future research regarding D/HH is warranted to determine their value to families with a child who is D/HH. Also, it would be valuable to investigate the diversity in D/HH role models, such as meeting with a role model with unilateral loss and use different communication modes.



### Question # 10: Why families did not meet with a D/HH role model.

This question was only given to the 31% who had responded that they were offered a D/HH role model but did not meet with him/her. Respondents were asked to select only one primary reason, which are described in Figure 7. Under the options of why families did not meet with a D/HH role model, parents were able to enter in an alternative reason why they did not meet. A significant number of parents (38%) indicated that it did not meet their needs at the time offered. More than half of those that selected “Other” as their answer indicated it was because no one was available in the family’s local community.

**Figure 7**  
**Reasons families did not meet with a D/HH role model**



There is more to learn in this area, such as how and when the role model was offered and how good was the fit between the role model and the family. Additional research would help contribute insight as to why families choose not to meet with a D/HH role model when offered.



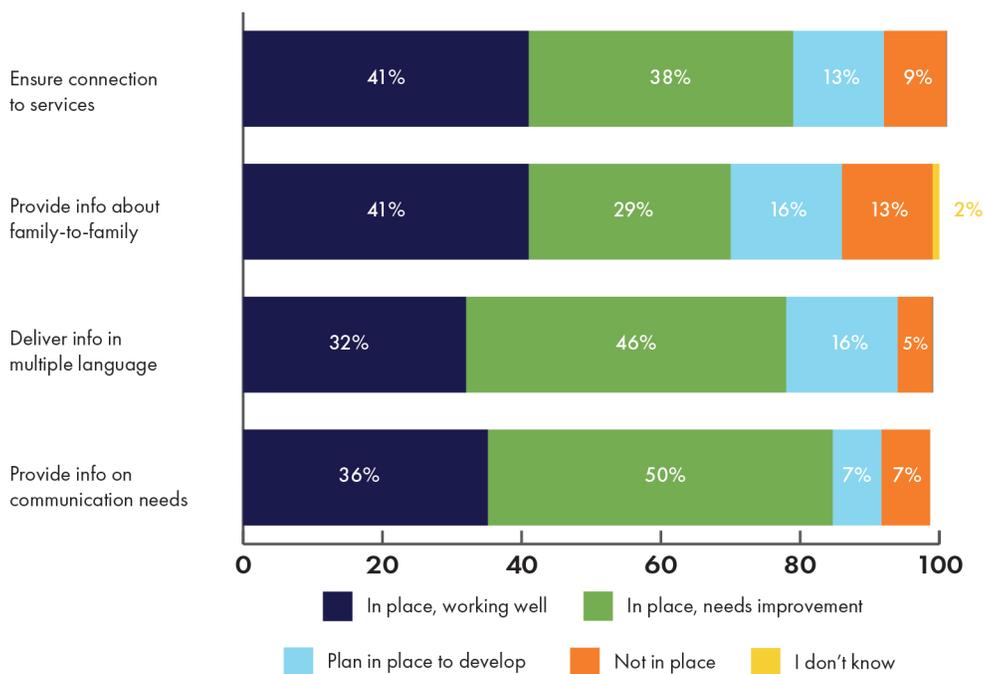
## EHDI Coordinators

All 59 states and U.S. jurisdictions are funded by MCHB to operate EHDI Programs. There were 56/59 EHDI Coordinators who responded to the survey for a 95% response rate; this included 6 EHDI Coordinators from U.S. jurisdictions. The full EHDI Coordinator survey is located in Appendix B.

### **Question #1: EHDI activities to support families who have children who are D/HH.**

EHDI Coordinators were asked to identify the extent to which they have plans in place to support families who have children who are D/HH. Responses are shown in Figure 8. Between 30-40% of the EHDI Coordinators reported that these activities were in place and working well. Nearly half (41%) of programs relayed they have an effective plan to connect families to services and family-to-family support.

**Figure 8**  
***EHDI activities to support families***



Although the answer options were general in nature, the team found it interesting that 59% of EHDI Programs do not report that they have effective plans in place for connecting families to services. While this survey did not address the types of information EHDI Programs are providing to families, it presents a great opportunity for the FL3 to help ensure EHDI Programs are providing consistent, up-to-date information to families. Coordinators were also given the option to enter in an “Other” activity that EHDI Programs use to support families. Other activities cited were hosting social events for families, contacting primary care provider (PCP) to ensure they are aware of D/HH resources, paying for families to attend

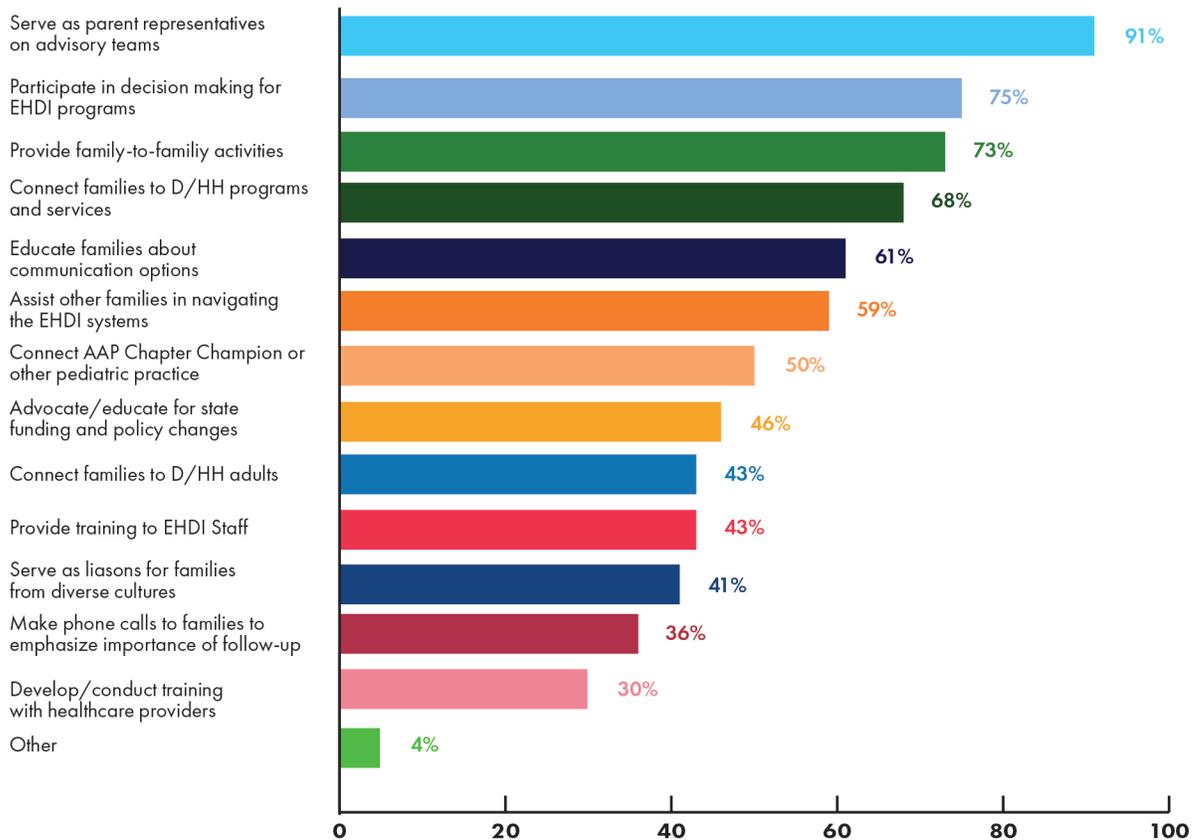


conferences and participate in workshops, and utilizing hearing coordination centers. Coordinators were also asked to enter the languages that they offer their materials. Spanish (73%) was the most frequently cited. Information yielded from this question provides guidance to the FL3 where the EHDI Programs may benefit from assistance. The FL3 may consider holding area specific focus groups to garner information from coordinators on how to bolster some of these key activities of EHDI Programs.

### Question #2: Activities family leaders perform in EHDI.

As defined in the survey, family leader is a term used to describe families whom partner with professionals in decision making. Coordinators were given the option to mark all that apply. Responses to this question are highlighted in Figure 9. The most frequently reported activities were serving on advisory committees, providing family-to-family activities, and connecting families to D/HH programs and services. These results offer guidance to the FL3 in regard to how they help EHDI Coordinators expand the roles and responsibilities of family leaders.

**Figure 9**  
**Activities family leaders perform in EHDI**





During the focus group discussions, the team posed several questions as to investigate this area further. Coordinators responded that time and travel were primary barriers when asked “What do you think the biggest barriers are for parents becoming advocates?” Similar to parent comments stated earlier in the report, one coordinator said, “I think they might not be aware that it is even an option for them,” and “A parent expressed that she was inhibited to become a leader because she perceived a disagreement between groups that use different communication modalities.” The team followed up with the question “What it would take to increase by 10% the number of states responding that parents are leaders or advocates?” Coordinators stated they believed they would have to do a lot of advertising to parents that they are encouraging parents to become leaders and offer “Regionalized trainings, stipends for trainings, and having trainings led by other parents.” Another coordinator stated that she believed that becoming a leader had to be realistic for parents, since she has noticed that “There is a tendency for parents to get overwhelmed.” The team then asked, “What are the barriers in partnering with parents in providing provider education or trainings?” Coordinators offered the insight that it has been challenging to get families involved in providing trainings, in part, because doing onsite visits involves time, travel, and availability. One coordinator reported she has tried to bring the family perspective to the trainings without the family there through videos and storytelling. Another coordinator stated that “The impression that medical and educational providers have superior knowledge about having children with a hearing loss and the perception that hearing loss is not a priority disability” can inhibit a parent’s willingness to help deliver presentations.

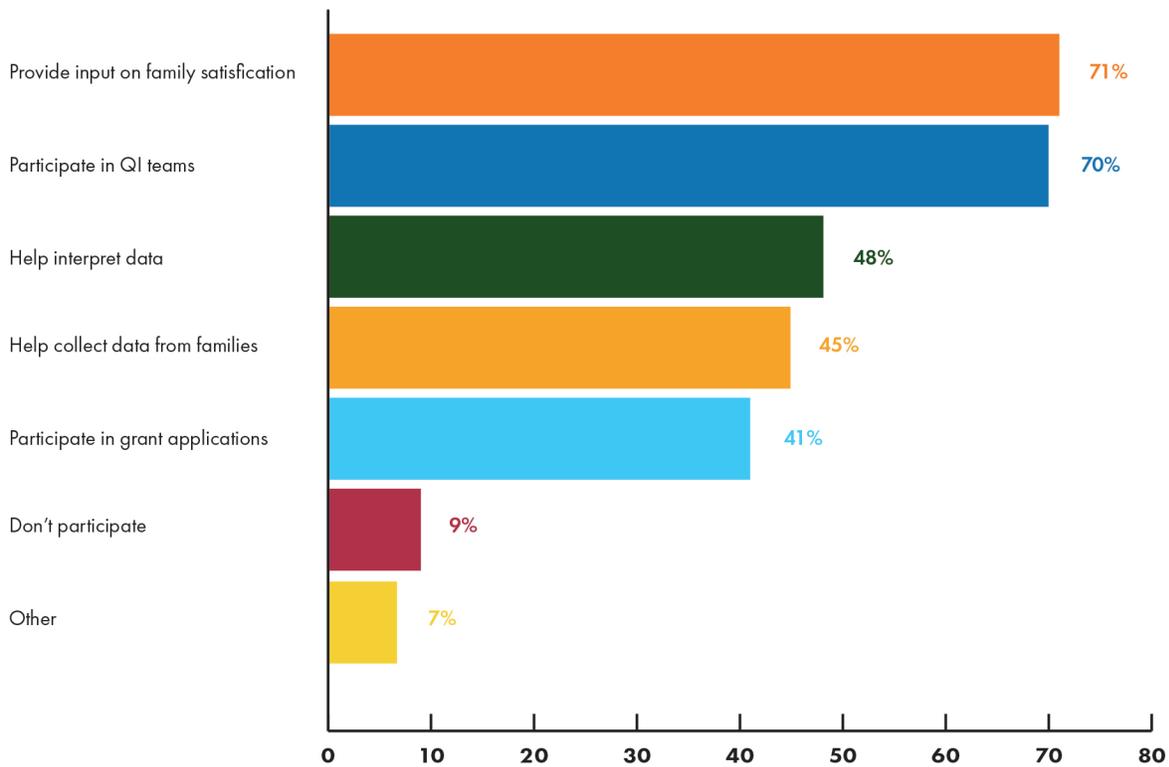
The team found it interesting that there are so few EHDI Programs reporting that family leaders are helping to reduce lost to follow up (36%) and connecting with the healthcare providers (30%), especially since these have been primary foci for MCHB for over 10 years. There were some discrepancies between what parents report they received and what EHDI Programs report they are providing. As noted earlier in regard to the parent survey, EHDI Programs were not listed on the top 5 providers of support and resources for parents. In the future, it would be interesting to compare what family leaders report they do compared to what coordinators report family leaders do. Additionally, the FL3 should consider how these answer options fit into the H&V Partnership Continuum, a continuum that outlines level of engagement for family-professional partnerships. When family leaders are actively involved in activities such as those explored here, it can build their confidence as a leader, offers opportunities to build relationships with providers, and brings their parent voice directly to the providers.



### Question #3: Family leaders' involvement in EHDI Program quality improvement (QI) and evaluation.

Involving families in the various components of the EHDI Program can help provide a fresh perspective. Coordinators could mark multiple options and their answers are shown in Figure 10. Seventy percent (70%) of coordinators stated that family leaders in their state are participating in their QI teams and provide input on family satisfaction. To a lesser extent, 40-48% of family leaders were reported to help in data collection, interpretation of data, or developing grant applications. Seven percent (7%) of EHDI Programs selected “Other” for this question, with comments indicating that family leaders for QI had not yet been identified or were newly identified to participate in QI.

**Figure 10**  
**Family leader involvement in EHDI Program QI and evaluation**



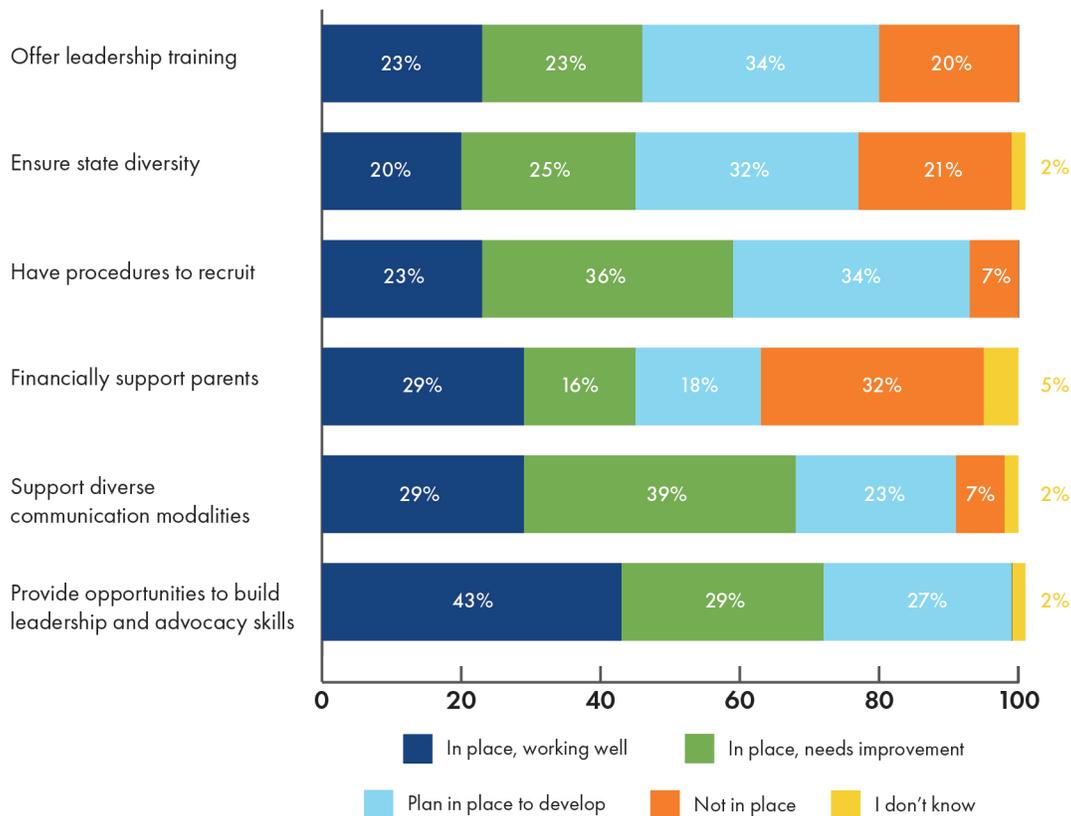
The team was surprised to learn that family leaders from 30% of the states are not participating in QI projects and evaluation of EHDI Programs. If family leaders are not participating in QI initiatives and also not providing input to programs on family satisfaction and concerns it would be challenging for EHDI Programs to know what improvements are necessary to better meet families' needs. Further investigation into specific projects family leaders are involved in and sharing those successes would give other programs additional ideas of how they could better utilize family leaders.



**Question #4: Strategies used to enhance and maintain EHDI family leadership.**

Coordinators were asked to respond to what extent they are implementing strategies to enhance and maintain family leaders in multiple areas. Responses are outlined in Figure 11. Nearly half (43%) of EHDI Coordinators report that they are effectively providing families opportunities to increase their leadership and advocacy (e.g., attend the annual EHDI Meeting, H&V Leadership Conference). Approximately, 2/3 of coordinators state the remaining strategies addressed in this question need improvement or there is not a current plan in place to implement these strategies.

**Figure 11**  
**Strategies used to enhance or maintain family leaders**



Through the focus groups, coordinators were able to share barriers to providing leadership training and some possible solutions. Several coordinators stated that the 25% of funding allocated to their contracted FBO has limited their ability to directly work with parents and provide parent training. A coordinator asked that the FL3 consider partnering with FBOs to offer these trainings. Another coordinator suggested that “Partnering with another agency that has parent leadership training may be a good idea.” Some coordinators were unclear what is considered a family leader and family leadership training and believed that clear definitions would help. The needs assessment team also inquired about the low percentage of programs that responded they have a good plan in place for paying parents for their time. Coordinators responded that



budget restrictions make it challenging to pay families. One stated “We can’t even pay for food to entice them to come.” Another coordinator proclaimed that “our statute actually says that our advisory committee has to be volunteer” but they are able to pay parents a small travel stipend.

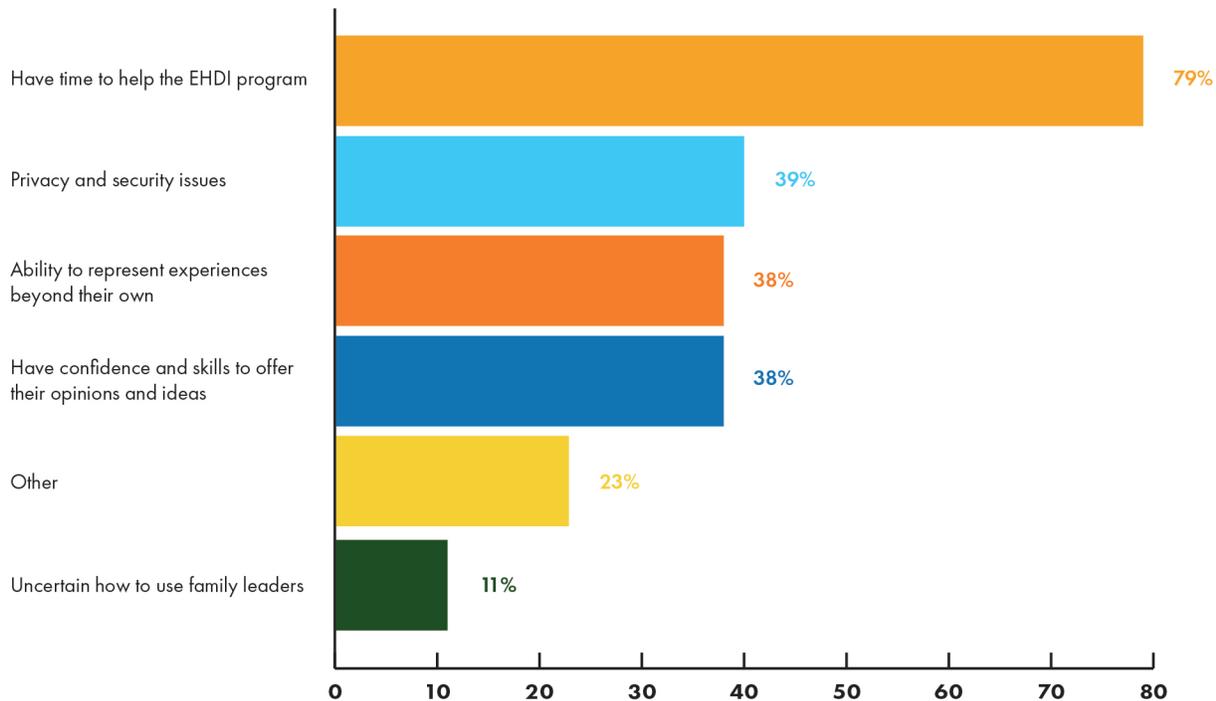
There is an opportunity for system-wide discussions about who should be responsible for ensuring training is in place to help parents become successful EHDI leaders and partners—EHDI Programs, FBOs or the FL3. Overcoming administrative rules to pay parents for their time has been an issue in EHDI for many years, despite advocacy from national organizations such as Family Voices, Hands & Voices, and NCHAM. Some states have been creative in the ways they make payment work. Future investigation into the activities for which parents are paid (time in meetings, travel, child care reimbursement) and how parents are paid (e.g., cash, check, gift card) would be useful information to share with other coordinators. It would also be informative to learn how states obtain administrative approval for providing such compensation.

#### **Question #5: Challenges in getting active family leadership in EHDI.**

Coordinators provided information about what they consider are the greatest challenges in getting families to become leaders; results from this question are highlighted in Figure 12. Overwhelmingly (79%), of coordinators responded that they believe families do not have time to get involved and almost 40% identified privacy and security issues prohibited their ability to involve families. Twenty-three percent (23%) of coordinators responded in the “Other” category and cited additional challenges, such as getting families from under-represented groups to want to be leaders, finding families with the financial means to participate, and inability to pay families to participate.



**Figure 12**  
**Challenges in getting active family leaders**



During the focus groups, coordinators were asked if they had ideas of how to alleviate the challenge of recruiting family leaders. One coordinator stated, “I think the key is getting a group that is really motivated to stay in touch with families... as a parent I know I get really busy...so the family support organizations are going to have to be strong in staying in touch with families and engaging them.”

There is a discrepancy between what coordinators’ respond as time as a barrier to getting involved in EHDI (79%) to parent responses to time as a barrier (29%). It is challenging to speculate to what the different responses could be attributed. Coordinators may be making the assumption that families do not have time, when in reality it could reflect the previous parent responses that lack of awareness of opportunities to lead and issues with childcare and time of day as barriers to getting involved. Moreover, the barrier of privacy and security revolve around EHDI Programs being able to share names and contact information of newly identified children with their contracted FBOs. Therefore, FBO family leaders are not able to contact newly identified families and are less likely to be able to get those families involved. Another area to contrast is around confidence to lead; only 19% of parent survey respondents indicated only they don’t feel like they have the confidence and 38% of EHDI Coordinators report they believe that their families do not have the confidence. The FL3 could work to alleviate this misperception among coordinators and help build the confidence of families.

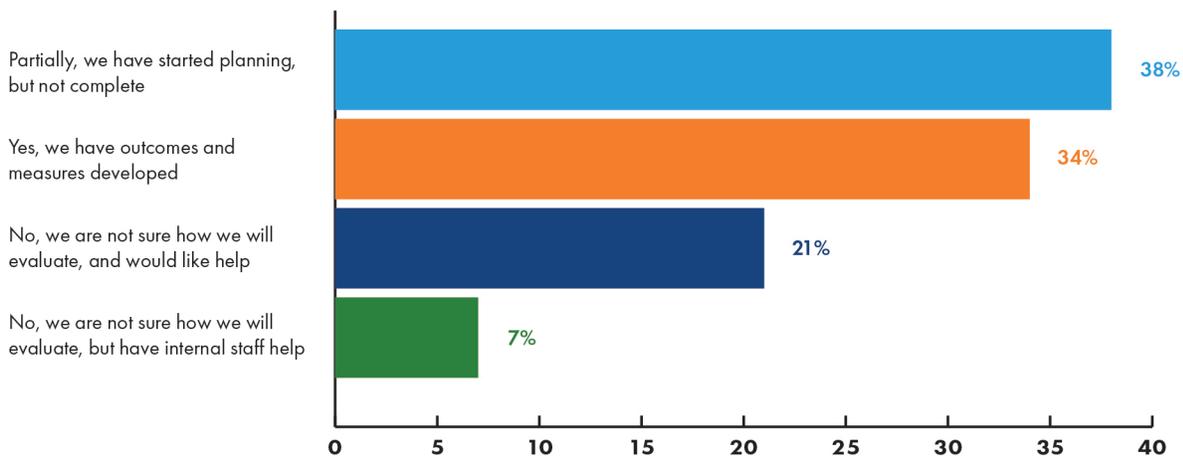


**Question #6: Plan to evaluate the effectiveness or impact of your partnership with your contracted FBO.**

Coordinators completed this survey Fall 2017, nearly 8 months after the beginning of their grant cycle. These results suggest that about 2/3 of the contracts with FBOs began without any evaluation or quality improvement plan in place and 21% of EHDI Coordinators asked for assistance in developing a plan. Additional results are shown in Figure 13.

Nationally, there have been no standards developed in this area to assist EHDI Programs and FBOs in evaluation, representing an area of need that the FL3 could address. It would be worthwhile to use the results from this question to follow up with the 19 EHDI Programs who indicated that “yes, we have outcomes and measures developed” to find out what is working and share these resources with others to assist in developing their own plans to evaluate the effectiveness or impact of the partnership of their FBO.

**Figure 13**  
**Plan developed to evaluate EHDI-contracted FBO**



**Question #7: Challenges regarding the partnership with the contracted FBO.**

This was an open-ended question that allowed coordinators to expand challenges they may be experiencing with their contracted FBOs. A substantial number of coordinators (23%) responded that their partnership with their FBO was going well or had no challenges to report. The challenges cited, have been organized into themes with the most often cited first.

Challenge #1: Contract Issues. Thirty-nine percent (39%, n=22) of EHDI Coordinators cited contract complications as an issue with their FBO. Any new requirement from a funder can cause challenges for the recipient organization. Many states have encountered obstacles within their own departments of health (i.e., inability to identify an FBO in their state, inadequate funding from HRSA, encountered issues with delivering funds to FBO, and experienced hurdles with data sharing).



One coordinator responded, “We have issues around privacy and security regulations that inhibit utilizing family leaders effectively.” Another wrote “State procurement procedures delay the process; the contract is not in place and we do not have an anticipated timeline that it will be completed, and we cannot initiate any activity until that happens.” Moreover, EHDI Programs that had a parent on staff may not be able to maintain that parent staff member due to the 25% release of funding to FBOs.

**“We may lose the ability to maintain a staff parent due to the requirement to ‘give’ 25% of our funds to a family organization. If we lose the ability to maintain a parent on staff, this would be detrimental to our program and state-wide EHDI system of care. ”**

**-EHDI Coordinator**

Through focus groups, the team sought additional information from coordinators about their FBO contracts and many of the themes identified through this open-ended question were reinforced during the focus groups. One coordinator expressed that “their relationship with their FBO is being compromised by the contract stating that “We’ve had a great relationship for years, but now trying to formalize the relationship through a contract takes away from the richness and may end up ruining our relationship.” There are a lot of challenges around the FBO contracting requirement, however nearly 2/3 of the challenges cited had to do more with logistics and building capacity and not around whether it was a worthwhile endeavor.

**“I hope the FL3 will provide training to the family-based organization on how to bolster their infrastructure... build their capacity... and help them show data around effectiveness. ”**

**-EHDI Coordinator**

Challenge #2: Infrastructure and Skills. Many EHDI Coordinators (32%, n=18) expressed concern about the infrastructure and skills of their contracted FBO, citing that many of the contracted FBOs have been small, informal, volunteer, parent-led groups that have not formally been structured to provide state-wide, systematic, organized family support with a budget and accountability. One coordinator responded that “Our family support organization has limited staff and expertise,” another stated that “We don’t have one organization that has the infrastructure to be able to use the entire amount, so we had to split the funding between organizations, which requires a great deal of time and effort for the EHDI Program to manage.”

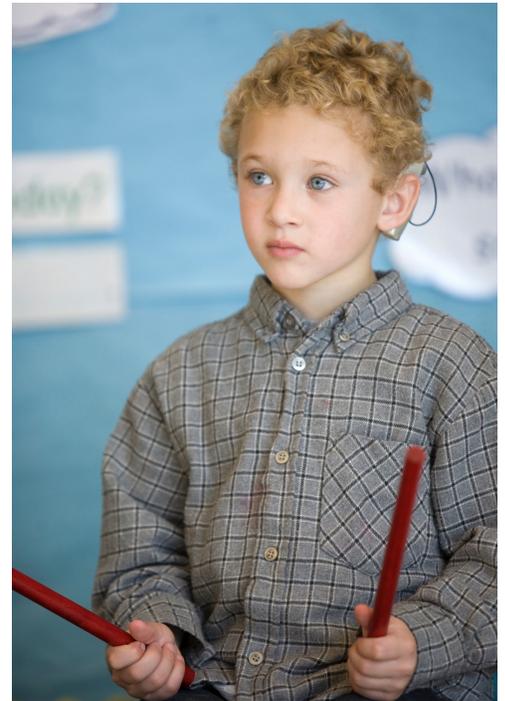
Challenge #3: Evaluation and Accountability. A few EHDI Programs (7%, n=4) reported that they are still trying to develop an evaluation and quality improvement plan with their FBO. The free-form responses reinforced this, with 12% of coordinators describing evaluation as a challenge. One coordinator stated, “Our evaluation plan [with our FBO] is still a plan in



progress” and another wrote “We are still unclear about who is responsible for deliverables and what to do if expectations are not being met.”

*Challenge #4: Lack of Content Expertise.* A small number (7%, n=4) FBOs focus on the broader population of children with special needs versus being D/HH specific. Such FBOs typically have the infrastructure to provide services and support to families who have children who are D/HH. That said, several coordinators (12%) cited that their FBOs needed D/HH specific training to be able to provide more effective support. One coordinator stated, “We have some concerns about their abilities to adequately include input from the Deaf community, specifically with respect to implementation of the Deaf/ Hard of Hearing mentoring project.”

*Challenge #5: Lack of Partnership.* Three coordinators (5%) expressed that their FBO has primarily focused on family-to-family support and do not have the partnerships in place or the skills to work with a broader group of EHDI stakeholders. One coordinator stated that “Our FBO lacks professional skills and understanding of state partnerships,” another wrote “We need to work to expand our family support organization leadership experiences to include the span of the EHDI system.” The FL3 has a great opportunity to bridge the gap between EHDI Programs and their FBOs as well as highlight those relationships that are running effectively.



### **Question #8: Support and resources requested by EHDI Coordinators of the FL3.**

This was an open-ended question that allowed coordinators to explore what they would like to receive from the FL3. Because the FL3 is a new resource for EHDI Coordinators, this is a fundamental area to explore and the coordinators had some great ideas. Responses are listed by most prevalent to least.

*Request #1: Engaging Families and Providers.* Thirty percent (30%, n=17) of EHDI Coordinators expressed concerns around getting families meaningfully engaged so the relationship is mutually beneficial between the EHDI Program and the family. Moreover, EHDI Coordinators would like help getting providers (e.g., pediatricians, family practice physicians, audiol-



ogists) involved. A coordinator stated, “I’d like [the FL3] to help states share what they are doing to engage parents, and another wrote that “[The FL3 to] provide workshops for providers on how to work with families with children who are D/HH.”

Request #2: Advocacy and Leadership Training. This reinforces the earlier reporting by 77% of coordinators stating that they need support in providing leadership training to families. To this question, 27% (n=15) stated that they would like more leadership training. A coordinator wrote “[I would like the FL3] to provide quality leadership/advocacy training through family support organizations...” and another coordinator suggested that the FL3 could help by, “Bringing in parents that can help address cultural issues and effective ways to address working with families from multiethnic backgrounds.”

**“Check lists or script for parents to help a parent move from their own story to helping others with different needs. ”**

**-EHDI Coordinator**

Request #3: Skill and Infrastructure Building. Twenty-one percent (21%, n=12)) of coordinators asked the FL3 to develop trainings to help the FBOs with non-profit management (e.g., grant writing, money management, logic models). One coordinator requested that the FL3 “Provide a roadmap or checklist for getting an FBO started in being able to contract with FBOs, and another asked that the FL3 “Provide training for QI, logic models, and help with improving structure to be more businesslike.”

Request #4: Evaluation of Family Engagement. This theme reinforces an area that was addressed in an earlier survey question which emphasized that help with evaluation of family engagement is an area of need for coordinators. Eleven percent (11%, n=6) of coordinators wrote specifically that this is an area they would like assistance from the

**“We need help evaluating our state’s family support program”**

**-EHDI Coordinator**

FL3. One coordinator stated, “I need ideas of how to best have the FBO report to the EHDI Program” and another asked “We need some data supported strategies for improvement activities”

Request #5: Deaf Role Model Resources. As a new area for both EHDI Programs and FBOs, a few coordinators (8%, n=5) would like help in the area of connecting families to existing D/HH role model programs in their state or assistance in the development of a D/HH role model program. One coordinator requested that the FL3 “provide a list of activities other



states have done with Deaf mentor training.” another stated, “I would like to hear from other states what they are doing with D/HH role models.” There is a current project from NCHAM that may help answer some of these D/HH role model requests from EHDI Coordinators. Therefore, this is a great area for the FL3 and NCHAM to partner to help meet the requests of EHDI Coordinators around D/HH role models.

*Request #6: Materials Development.* Five percent (5%, n=3) of EHDI Coordinators would like the FL3 to develop materials for families and providers that cover a variety of topic areas including communication options, social and emotional development, and importance of peer support. One coordinator wrote “[I would like] resources that focus on creative and effective ways to optimize language, literacy, and social and emotional development of infants and young children... and to spread the message of the sense of urgency to families” and another asked for resources that “Cover the unique needs of children with mild or unilateral hearing loss.”

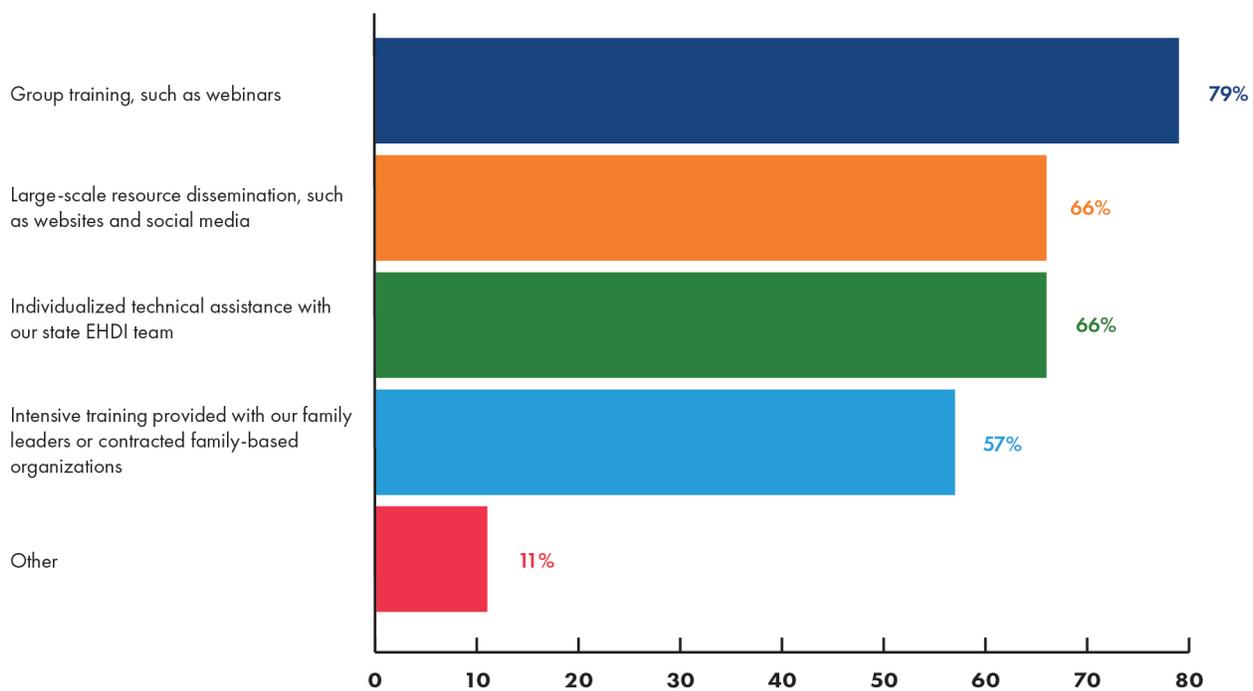
Focus group discussions added additional information to the requests from coordinators of the FL3. EHDI Coordinators requested that all FBOs have access to resources developed by H&V such as their Guide by Your Side and ASTra programs. Other EHDI Coordinators asked that the strategies used by some H&V chapters to get fathers involved be shared with all FBOs and that the FL3 help FBOs reach out to ethnically diverse families since they suspect that cultural and geographical barriers play a role in decreasing their involvement or delaying services. Some coordinators also suspect that the FL3 or FBOs may be better received by families because of potential distrust of government agencies.

### **Question #9: Requested ways to receive support from the FL3.**

Coordinators were asked to identify how they would like to receive support from the FL3, selecting all that apply. Their requests are highlighted in Figure 14. Group training, such as webinars were preferred by nearly 80% of coordinators. The other options were popular with the majority of coordinators as well. Comments by the 11% of coordinators who responded “Other” included that they would like the development of clear pathways for improving family engagement, training, and technical assistance to FBOs to help them meet the deliverables of their state-specific contract and they would like an opportunity for a national meeting for EHDI Coordinators and their FBOs.



**Figure 14**  
**Requested ways to receive support from the FL3**



The needs assessment was a great way for EHDI Coordinators to honestly convey where they need assistance from the FL3. Based on survey responses, EHDI Coordinators are open to receiving support from the FL3 in a variety of formats directly to the EHDI Program and to their contracted FBO. Anticipating some of these needs, the FL3 has already begun delivering technical assistance through some of the requested avenues.

## Family-based Organizations (FBOs)

There were 48 EHDI-contracted FBOs who responded to the survey from 40 different states. Some states have more than one designated FBO (6 states have 2 FBOs, 1 state has 3 FBOs). No FBOs from U.S. jurisdictions responded to this survey. Most organizations included their organization's name and contact information with their survey. More than half of the responding FBOs (56%) are H&V chapters. There are 21 non-H&V FBOs, with 3 of them being considered non-traditional FBOs meaning that providing direct family support is outside their typical scope of services. FBOs proved to be the hardest target population to complete the survey. The team alternated email reminders or phone calls with FBOs until they accomplished a 68% response rate. The FBO survey is located in Appendix C.



### Question #1: Experience in working with families who have a child who is D/HH.

Respondents were asked to rate their experience in supporting families of children who are D/HH; results are shown in Table 3. Additional analysis of the 21 organizations who are not associated with H&V, indicated that 62% were “very experienced, regularly serving these families”. Thirty-eight percent (38%) indicated they were “not at all, not very, or only somewhat experienced” working with families who have a child who is D/HH.

**Table 3**  
**Experience in supporting families with children who are D/HH**

Very experienced	75%
Somewhat experienced	17%
Not very experienced	6%
Not at all	2%

During FBO focus groups, participants indicated that training is essential in helping them become more comfortable in working with families with a child who is D/HH, especially in supporting families whose communication choices were different than their own, adding that the training helped them to understand other relevant perspectives, gain experience, and broaden their resource list. Participants also shared that attending the annual H&V Leadership conference, gave them experience and confidence they were unable to get elsewhere as well as an opportunity to form individual relationships with a nation-wide networking group.

Many of the FBOs that participated in the survey are H&V Chapters or are being led by parents with children who are D/HH, which may explain the perceived high level of experience. In line with EHDI Coordinator requests, the FBOs also indicated that the FL3 should consider providing additional training opportunities on best practices in working with families with children who are D/HH.

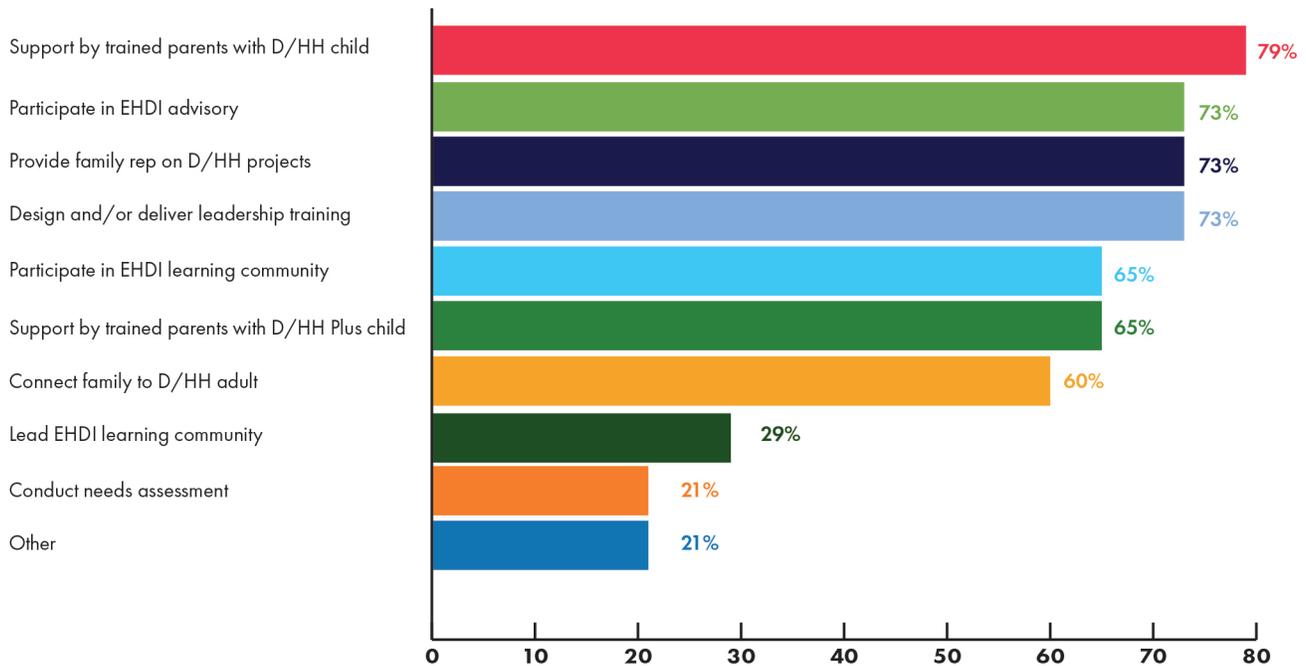
### Question #2: FBO current responsibilities in EHDI.

FBOs were provided with a list of responsibilities and asked to identify all that applied. Their responsibilities are outlined in Figure 15. Almost three quarters of the respondents reported that they support other families, develop leadership training, and participate on EHDI advisory boards. A minority conduct needs assessments or lead the EHDI learning community. Twenty-one percent (21%) selected “Other” as a response to this question and indicated their organization is working to develop EHDI related materials and training for families and professionals; provide trained parents to share stories with professionals and staff; provide resources to families who can’t afford hearing devices; and maintain relationships with hospitals and midwives. Of the non-traditional FBOs who do not provide family support by trained parents with a D/HH



child, two organizations indicated that they provide support for in-home early intervention and services families cannot afford (e.g., hearing aids, earmolds, dispensing fees).

**Figure 15**  
**FBO responsibilities in EHDI**



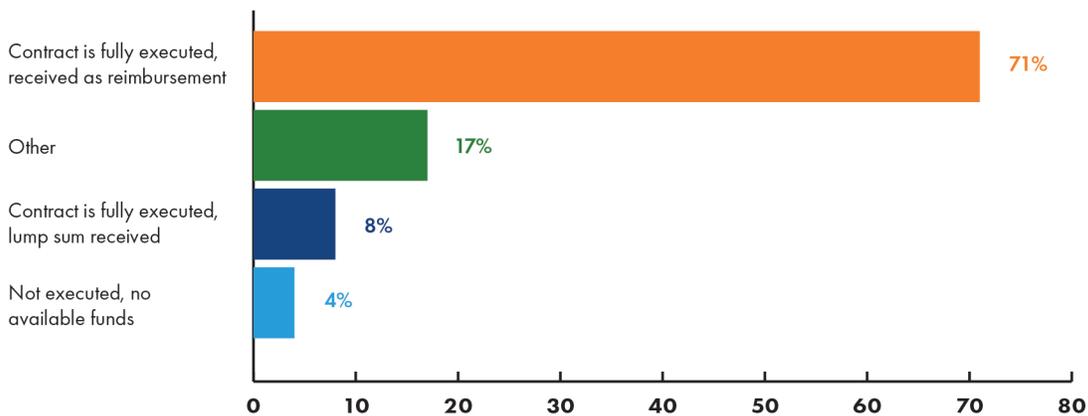
Although HRSA-16-061 requirements mainly target developing and maintaining family engagement, the requirements do not specify that FBOs should provide support for families from families who have children who are D/HH. The FL3 should consider working with MCHB to more clearly define what is meant by providing family support and who should be providing that support. An additional consideration for the FL3 is to investigate why the 27% of FBOs are not participating on EHDI advisory committees. It is also interesting that 60% of FBOs report connecting families to a D/HH role model; however, with just 22 programs existing nationwide, it would be worth exploring to what D/HH role model programs FBOs are referring. Moreover, 74% of parents respond that they were not offered access to a D/HH role model. There is a discrepancy in reporting of the connection to D/HH role models that warrants further exploration.



### Question #3: Status of the contract with the EHDI Program.

At the time of this survey (February 2018), 71% of the FBOs had secured a contract with their EHDI Program. In addition, many EHDI Programs will be reissuing or reworking contracts for year 2 of their grant funding that began April 1, 2018. Results of this question are outlined in Figure 16. The 17% of organizations who marked “Other” commented that they receive quarterly advance payments, funds are not yet available because of delays in processing, and contract signed but state finance department process is slow.

**Figure 16**  
**Status of contract with EHDI Program**



During the focus group sessions, many FBOs indicated good relationships with their EHDI Programs and said they felt supported by their EHDI Coordinators. Some FBOs reported challenges associated with doing business with state agencies or universities and specifically cited issues with not receiving timely funds and complicated payment that make it challenging to provide support and meet contract deliverables.

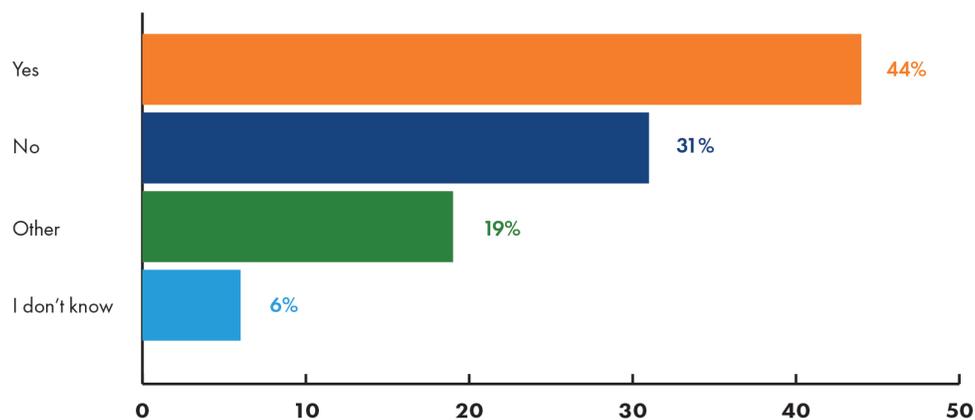
While most contracts were fully executed at the time of the survey, there are some states and jurisdictions that are still working to determine a designated FBO even though year 2 is underway. The FL3 can work with these remaining EHDI Programs to help identify organizations that would fit the FBO requirements for family support and engagement. The FL3 can also share strategies used by programs that were able to successfully identify and contract with FBOs to support families with children who are D/HH. More discussion will follow on concerns of FBOs who have to wait for reimbursement for activities completed under their EHDI contract.



#### Question #4: Direct referrals from the EHDI Program for all children newly identified as D/HH.

FBOs were asked whether they are able to receive direct referrals and family contact information from the EHDI Program; these answers are shown in Figure 17. Forty-four percent (44%) responded “yes,” 31% responded “no”, with at least three organizations reporting that they do not typically provide direct parent-to-parent support. Of the FBOs that chose “Other,” 44% stated that they are in the process of being able to receive direct referrals and 22% reported that the parents have to opt in to have their information shared directly with the FBO.

**Figure 17**  
**Direct referrals from EHDI Program**



During the focus group sessions, several FBOs indicated that their FBO was granted access to the EHDI database so that they can directly access family contact information. Some FBOs are required to enter the contacts they have made with the family back into the EHDI database. This helps both the EHDI Program and FBO track the family and not duplicate services. A few focus group members relayed that despite the access they have to the EHDI database, sometimes the contact information is not accurate and their resources for tracking down contact information is limited. One FBO stated “Our biggest hurdle is that we have to find the family and get the correct telephone number, but then number won’t work three days later. Also, getting everybody on the same page as to the urgency of timely follow up. “We still have audiologists or families that are saying they want to wait till the next audiological is done and that could be six months down the road. Then we’ve already missed our 1-3-6...” Additionally, one FBO indicated that they only receive referrals from families who know about their organization and have signed a consent form that gives EHDI permission to share their contact with the FBO. As a contrast, five FBOs that do not receive direct referrals from EHDI indicated that they must do all the research on their own to find families or get referrals from other providers (e.g., audiologists, pediatricians, EI). These same FBOs report that coordinators provide the FBO information to families, and then it is the family’s responsibility to contact the FBO.

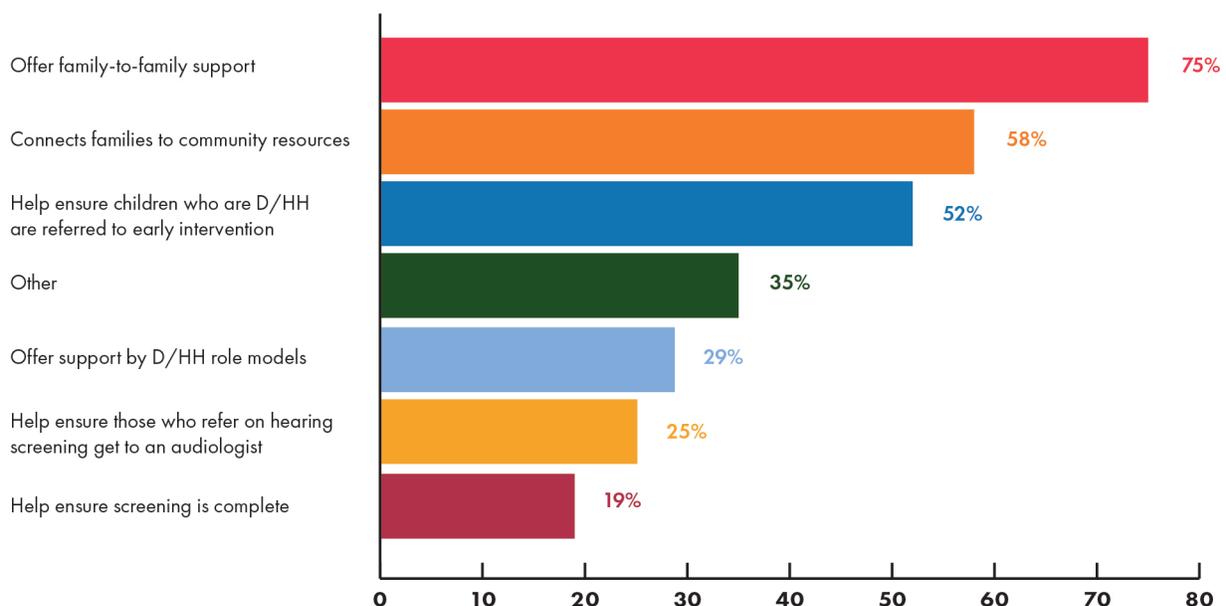


This question provides insight to the challenges families have in accessing family support. FBOs that do not receive referrals from EHDI may not have the same success at finding and supporting families as FBOs who do receive direct referrals. One of the program requirements for the FL3 is “To increase by 50 percent from baseline, the number of families that receive family-to-family support by the end of the three-year project period.” It may be concerning to the FL3 is that if EHDI Programs are not referring families to FBOs for direct family-to-family support, it makes it difficult for FBOs to find and connect with families who have children at risk for or identified with a permanent hearing loss and therefore families are not receiving the support they’d like to receive. This may impact the FL3’s ability to reach this program requirement.

### Question #5: Kinds of contacts or outreach FBOs make on behalf of EHDI.

FBOs were asked to select the types of information they provide, checking all that apply. Examples for each of these types of outreach were provided in the survey and can be viewed in Appendix C. While a high number of FBOs indicated that they provide family-to-family support (75%), the rest of the responses are less than 60%. Reasons cited in previous questions likely explain why these numbers are lower. Results to this question are shown in Figure 18. Thirty-five percent (35%) of the FBOs indicated “Other.” Comments included that the EHDI Program does not provide direct referrals, so they cannot contact families; they have plans in place to do outreach; they only provide these supports to families who request them; or once a contract is executed they will provide some of outreach activities.

**Figure 18**  
**Outreach FBOs make to help EHDI Programs**



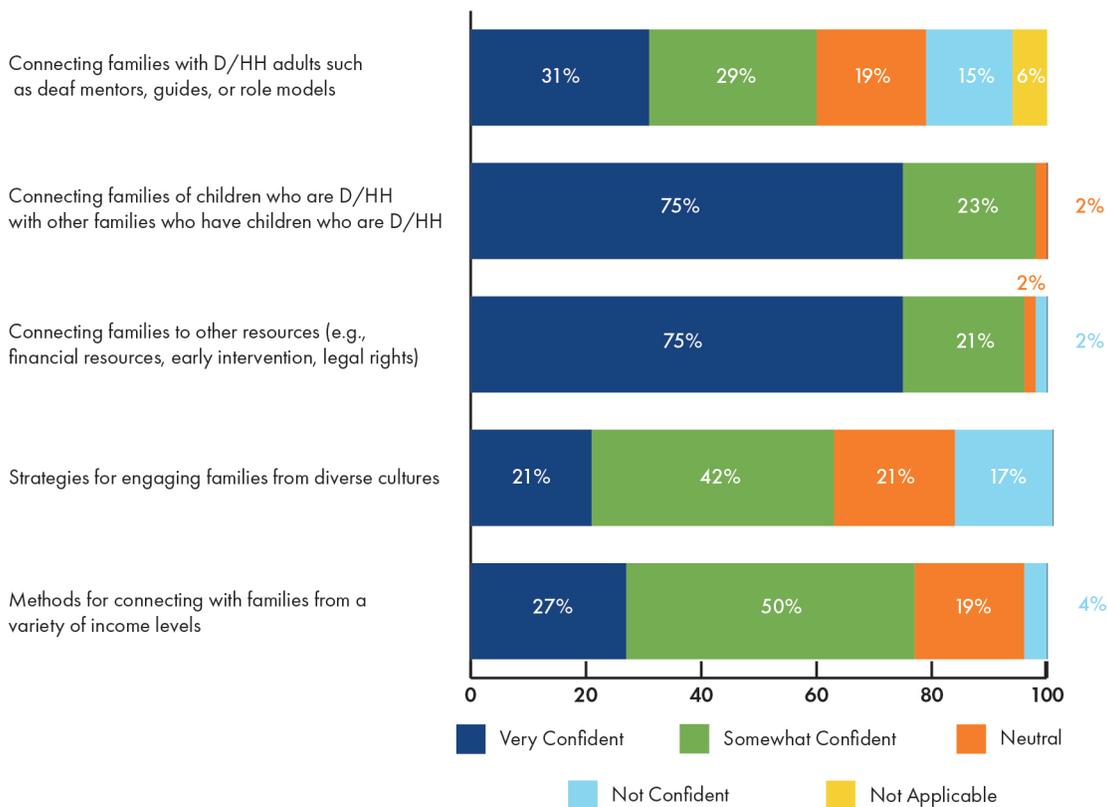


While most organizations are offering family-to-family support, it is unknown if this support is provided by families who have children who are D/HH or by families who have other special needs. FBO responses are similar to those of parents and EHDI Coordinators, stating that very few FBOs offer support by D/HH role models. Also, the number of FBOs that are assisting EHDI Programs with follow up by contacting families to ensure newborn hearing screening is complete (8 states) and ensuring children who did not pass or refer on their screening get in to an audiologist for diagnosis was much lower than expected (11 states).

**Question #6: Confidence in supporting families who have children who are D/HH.**

FBOs were asked to describe their confidence in supporting families by selecting one response to each category. The answers followed a 5-point Likert scale and responses can be viewed in Figure 19. Less than half of respondents said that they were very confident in connecting families with D/HH adults or engaging with families from diverse cultures. Additional analysis of the fifteen FBOs that indicated they were “very confident” in making connections to D/HH adults, almost all of them had known D/HH role model program already in operation.

**Figure 19**  
**Confidence in supporting families with a child who is D/HH**



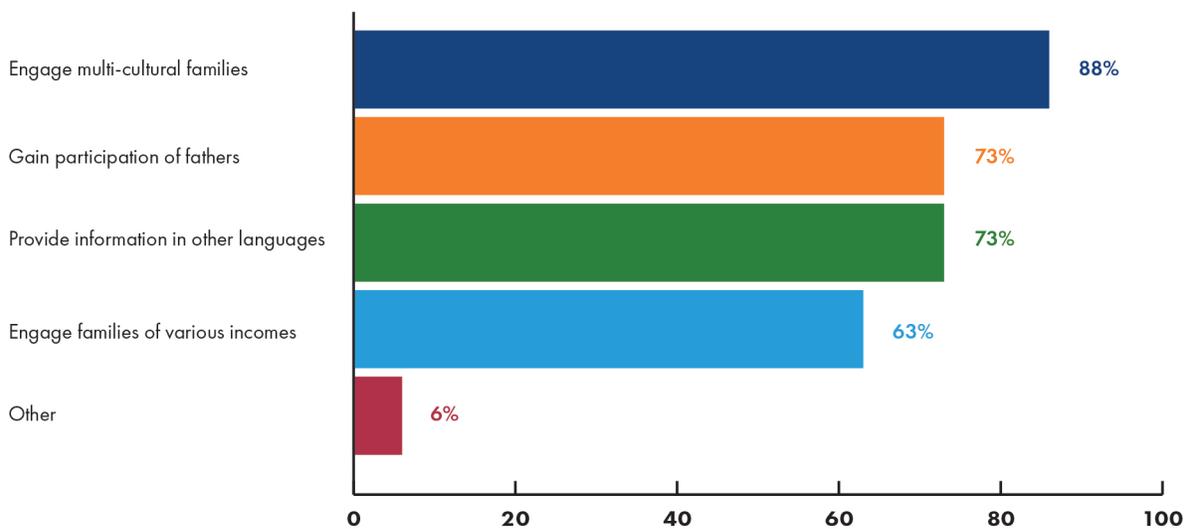


As we have seen from extant data and results from this needs assessment, there is still work to be done to ensure FBOs can achieve their goal of supporting families. While confidence is high in several areas, there are still opportunities for the FL3 to provide additional support in areas with lower confidence and highlight strategies used by those who report they are very confident.

### Question #7: Ways FBOs would like to increase inclusivity.

Inclusion of a broad spectrum of families is an important aspect of family engagement. Responses to the question about how FBOs would like to increase their inclusivity are shown in Figure 20. Almost all respondents (88%) stated that they would like greater engagement of multi-cultural families, followed by greater engagement of fathers, and families with diverse incomes. The availability of materials in other languages also was viewed as important by the majority of FBOs. Of the organizations who selected “Other,” comments included that they have a strong Spanish speaking outreach, several use translators to bridge language barriers, and a few reported that they have a specific father support group.

**Figure 20**  
**Ways FBOs would like to be more inclusive**



Given that most respondents are open to ensuring their organizations are inclusive of all families of children who are D/HH, the FL3 could provide training in ways to be more inclusive of all families, such as identifying and communicating resources already in place (e.g., trusted websites, social media, research articles, blogs) and holding webinars or group trainings to share best practices in this area. The team speculated that the FBOs who did not indicate their desire to engage more families from different cultures may already have programs in place to engage these families or are the type of FBO who typically does not provide direct family-to-family support.



**Question #8: Alignment of FBO and EHDI goals and activities.**

FBOs rated the extent to which their own goals are aligned with their state EHDI Program; responses are shown in Table 4. Of the FBOs that selected “Other,” their responses indicated that the contract still was not in place or that the contract is not directly through the EHDI Program but rather through another entity such as a university or a non-profit organization.

Several of those who responded that they were somewhat aligned were those organizations who do not traditionally provide family-to-family support or organizations that serve families but are not D/HH specific. Given that the FL3 has already begun to serve FBOs, FL3 staff suspect that the 75% of FBOs who report that they are fully aligned is high. This may warrant further investigation about what FBOs are considering as alignment.

**Question #9: Data being reported to EHDI.**

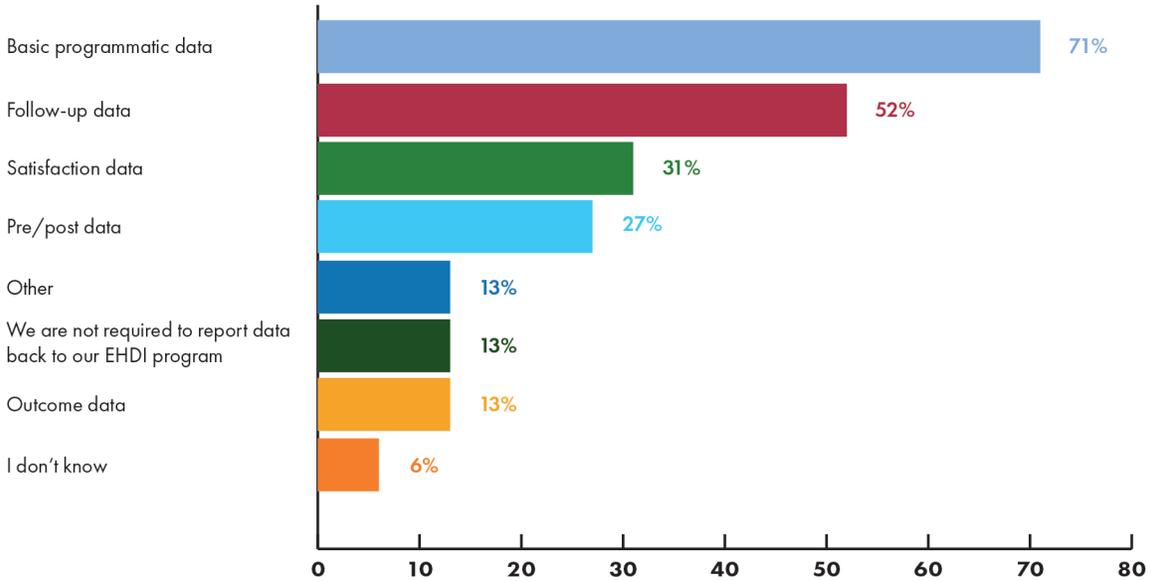
FBOs were presented with a menu of data that they are reporting, checking all that apply. Each type of data was accompanied with examples. Basic programmatic data was defined as how many parents they are serving, how many events they hold, and how many attend those events. Follow-up data included examples of how many parents they assist with getting to diagnosis and early intervention. Satisfaction data examples were how satisfied parents feel about the support and resources they receive, and pre/post data highlighted parental knowledge level before and after a training. Finally, outcome data was defined as a change in parent and/or child skills or development as a result of receiving services. Basic data was the most cited data reported at 71% and slightly over half of the FBOs report follow-up data. Of those that selected “Other,” their responses indicated that the data they gather is directly entered into the EHDI database, so they do not duplicate reporting. Others stated that they will start collecting data once the contract is finalized.

**Table 4  
Contract Alignment  
with EHDI Programs**

Fully aligned	75%
Somewhat aligned	17%
Not aligned	0%
I don't know	0%
Other	8%



**Figure 21**  
**Data reported to EHDI**



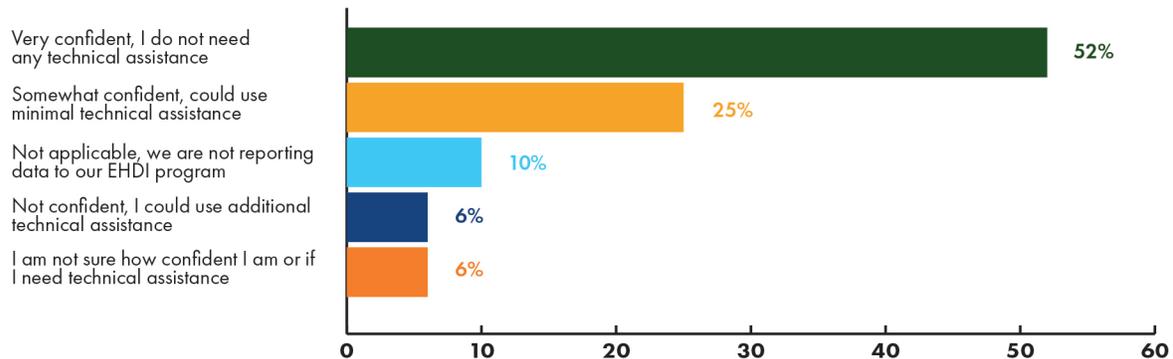
FBOs are likely required to report what is outlined in their contract with their EHDl Program. Data collected can provide a picture on the processes of FBOs and how families are supported. The low responses to outcome data is not surprising because it can be intensive to collect and can be time consuming. It may be worth investigating the organizations that state that they report outcome data to consider what they are gathering and how it helps them to improve support to families who have children who are D/HH. Moreover, it is unclear whether EHDl Programs are reporting this type of data back to MCHB. Currently, the primary data collection methods for EHDl data is through a survey from the CDC and CDC data does not include any type of family engagement data. Tying this back to the coordinators response that 66% are not sure how they will evaluate the effectiveness or impact of their FBO suggests that there may be a benefit in standardizing data gathered from FBOs. In addition, standardized data would give the FL3 additional information on where they need to focus their efforts and assist in their reporting.

**Question #10: Confidence in reporting data to EHDl Program.**

FBOs were asked to rate their confidence in reporting data, their responses are reflected in Figure 22. Slightly more than half rated themselves as “very confident”, followed by 25% that were somewhat confident yet still wanting technical assistance.



**Figure 22**  
**Confidence of reporting data to EHDI**



During the focus group sessions, there were comments that “The EHDI Program does the management, the data processing and our group works with parents and making sure the follow up to families takes place.” Another FBO reported that “They provide their EHDI Program with information about early intervention status and services, we feed the EHDI Program that data, so they can report it for their 1-3-6 surveillance data.” When focus group participants were asked how they measure their success and how do they know they are making a difference, one FBOs replied, “We keep a lot of operational kind of data, timeline is very important.” Another FBO reported that “We also collect the anecdotal/qualitative data, ... we need to understand how families are perceiving the benefit that they’re getting from the family-to-family contact and this qualitative or anecdotal information isn’t necessarily reflected in the numbers...” Nearly half the FBOs report they were somewhat or not confident in reporting data. Information garnered from this needs assessment, highlight the need for the FL3 to assist both EHDI Coordinators and FBOs at the national level in the area of data development and management around family engagement and support.

**“There is more power in what parents say.”**

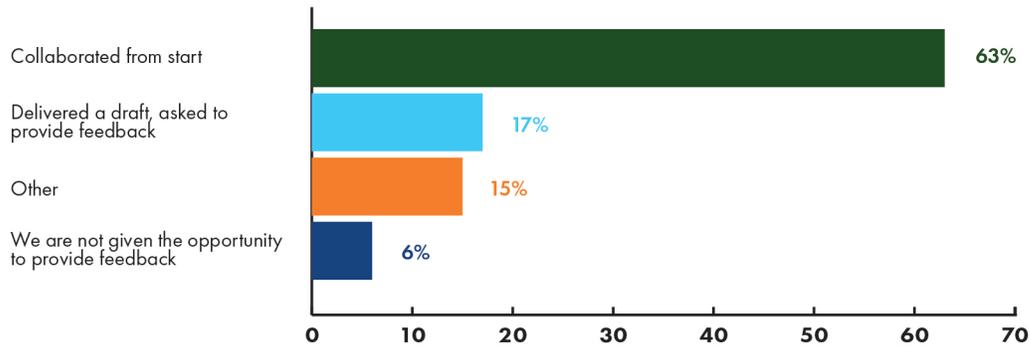
**-FBO**

**Question #11: FBO participation in the development of EHDI contract.**

FBOs were asked to describe their participation in the development of the EHDI contract. Responses to this question are highlighted in Figure 23. The majority (63%) had collaborated with EHDI from the start, and 17% provided feedback after reviewing a draft contract. Only 6% had no opportunity to provide feedback. Of those that selected “Other,” some indicated they were still in the process of developing the contract. Others responded that they were asked for feedback but had no say in the language of the contract.



**Figure 23**  
**FBO participation in EHDI contract**



While most indicated they collaborated from the start on contract development, there are still eleven organizations who did not collaborate from the beginning. There may also be some correlation of these responses to a previous question about how well their contract activities were aligned with the FBOs goals and objectives, with 75% indicating their goals were fully aligned and 63% indicating that they collaborated from the start. Focus group conversations and free-form answers also highlight more specific challenges in this area which are discussed in following questions. The FL3 has an opportunity to help both FBOs and EHDI Programs work to collaborate on developing a contract that fits the needs of both organizations and ultimately benefit families.

### **Question #12: Challenges regarding the EHDI partnership.**

FBOs answered an open-ended question about the perceived challenges regarding their partnership with the EHDI Program. The information below reflects coded themes of concerns, with 23% of FBOs responding that they did not have any concerns or challenges to report or left the question blank.

Challenge #1: Complicated State Processes. Process challenges were mentioned in both in the survey and focus groups (38%, n=18). EHDI Programs have policies and procedures dictated to them from their administration, when changes occur they are required to go through the many levels of local government or university for approval. One FBO responded that “they had little or no input to, or control of, the work they are tasked with.” This type of comment was echoed by other FBOs. Another stated “We are not directly

**“We would like more input and a more formal process for discussing and modifying the content of our contract with the EHDI Program.”**

**-FBO**

involved in the process of developing the scope of work.” Such hierarchies often require a lot of time and management by the EHDI Programs that could delay the start of work. In addition, processes required by the EHDI Program are new



to many FBOs, as most are small non-profits and do not have the infrastructure in place to manage large projects (e.g., management of private health information). One FBO cited, "... managing data of private health information requires a different level of tracking and storage than small nonprofits across a big state typically have." Pay structure is also complicated, many FBOs cited that reimbursement is a challenging pay structure and many of them do not have a large enough reserve to front costs for staff and family support activities.

Challenge #2: Collaboration and Communication. Several FBOs (15%, n=7) report a good working relationship including communication and collaboration with their EHDI Programs. One FBO stated "... We work in close collaboration with this program and know that if we have any questions/comments/ concerns the EHDI Program is also available to provide support and answers." Though some FBOs report positive experiences, there are still a number of FBOs who expressed concerns in this area. Some FBOs reported no challenges currently and others indicated that EHDI Programs are not being transparent and that communication from their EHDI Program has been vague and often no communication at all. One FBO stated "...months passed with no word [from EHDI], until one day when we got a message saying they had just learned that they would have to do a competitive RFP to find a family organization to work with...as of January 2018, it still has not happened." A few FBOs stated that their scope of work, despite the contract, has been hard to understand. One FBO stated that after almost a year "we are still working out how best to report back to the EHDI Program, what they need and want in regard to reporting." Other FBOs voiced that EHDI Programs have unrealistic expectations of them or some disconnect of how to work with parents. One FBO wrote "...there is some disconnect around formality/consistency of services versus our principle of meeting parents where they are at and following their lead as we support them."

**"Our EHDI Program has been very supportive to our organization. They have gone out of their way to find ways to help our program when we have funding issues. It is a wonderful relationship."**

**-FBO**

Challenge #3: Logistical Issues (e.g., referrals, contract, funding). Many FBOs (29%, n=14) reported complicated state processes and commented about contract delays. One reported, "It was a tough start this year because EHDI's HRSA funding was delayed, therefore our contract was not finalized until halfway through the contract year. Thus, our hiring, finalizing budget, beginning new projects were delayed and many contract deliverables will not be met..." Another FBO reported, "The primary challenge we have is the lengthy time it has taken for the contract to go through the state's financial approv-



al process.” The challenge of EHDI Programs providing direct referrals to their FBOs was explored earlier in the report and reiterated through the free-form comments and focus groups. Another commented about experiencing funding issues including inconsistent or delayed payments for work completed.

### **Question #13: Supports and resources requested by FBOs of the FL3.**

FBOs also responded to an open-ended question about the supports and resources they’d like to receive from the FL3. The information below reflect themes of areas that FBOs would like the FL3 to develop and/or provide. Several FBOs (27%, n=13) responded that they were unsure of what to suggest because they were new at this work or just getting started.

Request #1: Materials Created in Other Languages and are Culturally Competent. Seventeen-percent (17%, n=8) of FBOs would like to have materials in languages other than English. One FBO requested that they would like publications that “...don’t position ASL and spoken language as ‘opposite’ (or mutually exclusive) choices, rather as ways to augment and enhance a child’s linguistic development.” Other FBOs suggested looking into ways to, “Join with other family service groups to bring down costs for development of Spanish and Arabic language materials.” Another FBO suggested including training on “Working cross-culturally with competence”, as well as “Information and training to support underserved and multicultural families, including the Native American population.”

Request #2: Measurement of Family Support and Engagement. One FBO stated “[We’d like] tools to evaluate program/service outcomes and parent satisfaction and guidance on serving on or leading learning communities.” Another FBO asked for “Templates for family satisfaction surveys or other forms that aid in reporting and tracking outcomes.” Such templates would help them to know if families are getting what they need and want, when they need and want it.

Request #3: Training for FBOs and D/HH Adults. Seventeen percent (17%, n=8) of FBOs indicated that they needed training in the best ways to support the families with children who are D/HH and developing parent leaders. FBOs would like new ideas or ways to utilize parents within their programs, for example, “...participating on advisory boards, feedback/focus groups, QI initiatives, lost to follow up, etc.”

**“[We need help with] identifying what is meaningful data; warm and fuzzy stories, qualitative and quantitative measures.”**

**-FBO**

Another FBO stated that they would like ideas for “Promoting the parent partnership and organization overall instead of



it being just the parent organization promoting the EHDI Program.” An

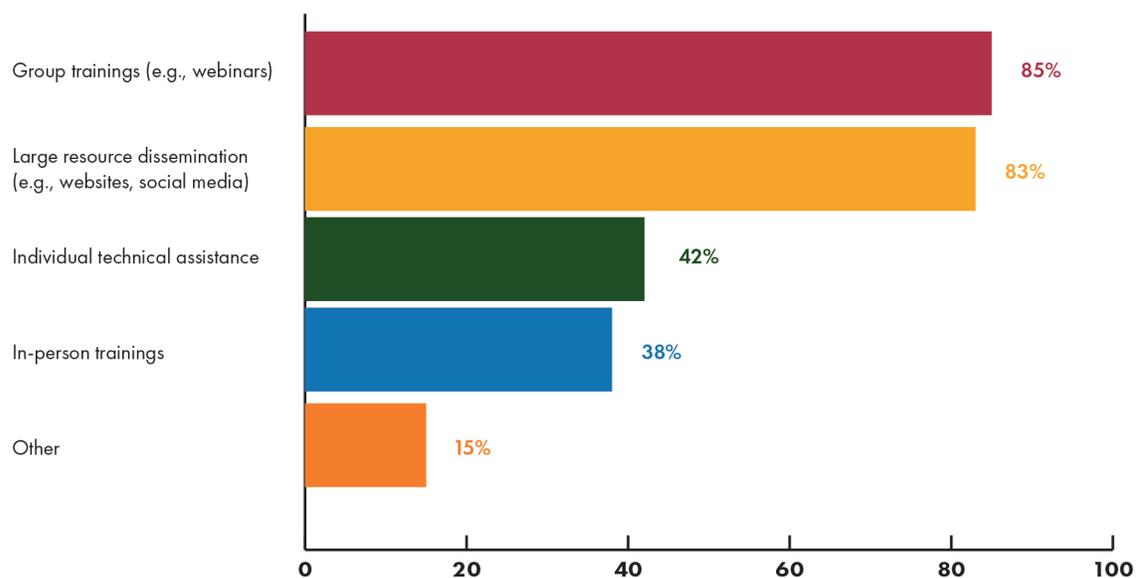
FBO also asked for training to help them support families who are low income, underserved, and who have low literacy levels. In addition to providing training to FBOs, the FBOs would like assistance in training the professionals they interact with, specifically D/HH role models.

*Request #4: Other.* There were notable other requests that did not fit under the above themes. One FBO suggested assistance with coordinating services across several FBOs (e.g., negotiating discounts for all FBOs on website services, web meeting services, captioning, mass email, foreign language translation). It was also suggested that the FL3 help them develop a D/HH role model program.

#### Question #14: Requested ways to receive support from the FL3.

FBOs responded to a menu of ways to receive this support from the FL3, marking all that apply; results are shown in Figure 24. Group trainings via webinars and broad-based resource dissemination were identified as desirable by over 80% of FBOs. A significant minority (38%) identified in-person trainings. Of those that chose “Other”, their comments included “wanting to bring back the Family Leadership Conferences...” Several requested that they would like “Peer-to-peer support opportunities to learn from and share with other family organizations doing this work and help understanding how to implement deaf mentor program in our state.”

**Figure 24**  
**Requested ways to receive support from the FL3**





This information helps inform the FL3 program about the preferred ways that FBOs want to receive support. Results from this needs assessment will provide specific content areas to deliver via webinars, resource identification and housing on the H&V FL3 website ([www.handsandvoices.org/fl3/index.html](http://www.handsandvoices.org/fl3/index.html)). All webinars will be housed in this location: [www.handsandvoices.org/fl3/resources/trainings-webinars.html](http://www.handsandvoices.org/fl3/resources/trainings-webinars.html).

## VI. LIMITATIONS

Not surprisingly, there are some limitations to the FL3 needs assessment findings described in this report. The primary limitations are discussed below.

### **The degree to which family respondents are representative of the larger population is unclear.**

In an effort to obtain as many responses as possible, many of the family respondents were identified via invitations posted on the Facebook and Twitter accounts from NCHAM and H&V. This strategy was useful in terms of obtaining a large number of responses. However, this distribution method limits the sample to families who use these social media sites and are connected to the organizations who posted the survey. Second, there was no way to verify that the respondents actually met the desired criteria, i.e., caregivers of children who are D/HH, and it is not possible to know if someone completed a survey more than once. Third, there were few Spanish speaking respondents; this, combined with the constraints of not being able to reach families speaking other languages, resulted in little diversity in the family survey responses. Although focus groups were conducted to gain insights into the needs of families from minority cultures, it would be valuable for the FL3 to continuously collect data from under-represented families to guide their efforts. Additionally, family survey responses from many U.S. jurisdictions were missing.



### **There is possible inflation of EHDI Coordinator knowledge and practices.**

There is the likelihood of EHDI Coordinators wanting to present themselves in the most knowledgeable, competent light. As a result, rating scores of their knowledge or practices may be inflated and therefore not be an accurate reflection of



their needs. This is a potential limitation of the data collected from self-report surveys, particularly for the state/jurisdiction EHDI Coordinators. As state administrators who are continually being judged based on their accomplishments and EHDI data, these respondents may be less inclined to reveal vulnerabilities or challenges via their responses in spite of the researcher's promise of protecting their anonymity. Additional methods to triangulate the findings, such as observations, reviews of proposals and reports, would be one way to confirm the results of the EHDI Coordinator survey.

**Family-based Organization respondents are new to their roles in the EHDI system.**

The concept of EHDI-contracted FBOs to serve as partners with the EHDI Programs was initiated in 2017, and thus most of the FBOs were newly identified, with a few programs still waiting for contracts to be completed before beginning their efforts. As a result, some of the FBO respondents may not have had the requisite knowledge base nor time to interact with other partners to adequately judge their capabilities and practices.

**Protecting confidentiality hinders providing program-specific technical assistance.**

To obtain as honest, open responses, respondents were guaranteed that their names and state identification would not be made known unless they voluntarily chose to allow this information to be shared. The researchers believed that ensuring their anonymity was important to obtain forthright responses and to obtain as many responses as possible. This means that the FL3 staff members will not have the opportunity to identify state-specific needs and tailor training and technical assistance accordingly. However, these overall needs assessment findings will still be useful to the FL3 staff persons as they reach out to state-level partners and begin conversations regarding how they can best support their individualized needs.



## VII. CONCLUSION AND RECOMMENDATIONS

This section identifies commonalities among the three target populations and identifies macro-level conclusions based on the three questions posed in the purpose of the needs assessment. Additionally, the team identified some areas of future study for the FL3 in examining the data for the needs assessment and comparisons to some extant data.

### **What types of support did families receive or wish they had when their child was diagnosed as D/HH?**

1. Families need to be offered comprehensive information at different points in their child's life, not just at diagnosis.
2. Families need coordinated, trusted resources.
3. Families need support from other parents who share their lived experience.
4. Underserved families (e.g., minorities, low income) need additional support.
5. Families need more awareness of and access to D/HH role models.

### **What do EHDI programs need to support effective family engagement?**

1. EHDI Programs need a clear delineation of responsibilities for parent engagement for their program and for their contracted FBO.
2. EHDI Programs need to establish a trusted partnership with their FBO to ensure improvement of the overall EHDI system as well as to provide seamless services to parents.
3. EHDI Programs need to increase awareness of their websites and social media and ensure those sites are ability friendly, easily accessed, and current.
4. EHDI Programs need to provide consistent, accurate information and resources to all parents at different stages of the 1-3-6.

### **What do family support organizations need from the FL3 program to better serve families who have a child who is deaf or hard of hearing?**

1. FBOs need help creating D/HH specific networking and support for families who have a child who is D/HH (e.g., itunesattending the H&V Leadership Conference, the Family Voices Leadership Conference FBO track at the EHDI Meeting).



2. FBOs need support that allows them to provide direct family support by trained parents who themselves have D/HH children.
3. FBOs need ideas of how to encourage parents who have children who are D/HH to participate at all levels of EHDI system (e.g., advisory committees, quality improvement).
4. FBOs need assistance problem solving issues regarding direct referrals or easy access to family contact information.
5. FBOs need training that helps learn how to identify and create relationships with all stakeholders in the EHDI system (e.g., audiologists, ENTs, Title V programs).
6. FBOs need strategies for family activities that encourage involvement from fathers and under-represented groups.
7. FBOs need assistance to ensure that their websites and social media are ability friendly, easily accessed, and current.
8. FBOs need support connecting families with D/HH role models.
9. FBOs need materials and other resources that are culturally competent and available in languages other than English.
10. FBOs need training to increase their confidence in working with families with children who are D/HH and have chosen various communication modalities.
11. FBOs need a clear delineation of roles, responsibilities, deliverables, and evaluation outlined in their contract with their EHDI Program.
12. FBOs need a better understanding of their EHDI Program's administrative processes.

This needs assessment has yielded valuable insights to guide the activities of the FL3. Additionally, the methods used in this assessment may be useful in guiding the FL3s evaluation of their own accomplishments as they strive to assist FBOs and EHDI programs in supporting families with children who are D/HH. The FL3 and NCHAM wish to thank all of the participants, especially the families of children who are D/HH, for their contributions to this important study. Also, thank you to Oticon for the use of select pictures.



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# Appendix A: Family Survey

The Family Leadership in Language and Learning Program is reaching out to families of children who are deaf or hard of hearing (D/HH) to learn about the resources and support you have received to support your child. Your input will help our program develop resources to improve support to families who have children who are D/HH.

We will not share any of your personal information. This survey should only take about 15 minutes, and you can enter to win a \$50 Amazon gift card for your participation. Please complete the survey by **January 22, 2018**.

This survey has been approved by Utah State University's Internal Review Board. To read about how they will protect your privacy and how this information will be used here. Please read the Letter of Information at the end of the survey.

For questions, email [alyson.ward@usu.edu](mailto:alyson.ward@usu.edu)

## About your family

1. Person completing this survey:

- Child's mother
- Child's father
- Other guardian/caregiver, please specify: \_\_\_\_\_

2. When was your child born?

Month \_\_\_\_\_

Year \_\_\_\_\_

3. At what age was your child diagnosed as deaf or hard of hearing? \_\_\_\_\_

4. What state/island do you live in? \_\_\_\_\_

## Newborn Hearing Screening Programs and Family Support Organizations

### What is a Newborn Hearing Screening Program?

Each state/island has a newborn hearing screening program called the Early Hearing Detection and Intervention (EHDI) program, typically located at your department of health. This program directs the newborn hearing screening in the state and makes sure babies are diagnosed and get to early intervention.



### **What is a Family Support Organization?**

Family support organizations are organizations in each state/island that help families whose children have special needs, such as finding information about services and learning about your legal rights. This includes organizations such as Hands & Voices, Family Voices, Family to Family Health Information Centers, and Parent Training and Information Centers.

5. How involved are you with your state's newborn hearing screening or EHDI program? (mark all that apply)

- I am not involved with this program, but would like to be.
- I am not involved with this program and would not like to be.
- I have visited their website.
- I follow them on social media.
- I have participated in their activities or programs.
- I am an EHDI family leader (for example, builds partnerships, advocates for DHH children in the larger community, participates on EHDI advisory committees).
- Other: \_\_\_\_\_

6. How involved are you with your state's family support organizations? (mark all that apply)

- I don't know about this program.
- I am not involved with this program but would like to be.
- I am not involved with this program and would not like to be.
- I have visited their website
- I follow them on social media.
- I have participated in activities or programs
- Other: \_\_\_\_\_

### **Family Support and Resources**

The next question ask about help provided to you and who provided that help.

7. What types of support have you received? (mark all that apply)

- Help getting a hearing test
- Appointment reminders for hearing test
- Help getting connected to early intervention process (for example, how to get from diagnosis into early intervention)



- Help connecting with other families of children who are DHH
- Support from other parents in formal parent-to-parent programs (for example, Guide By Your Side)
- Chances to participate in activities with other families with children who are D/HH (for example, community events, picnics, meet and greet)
- Information about all languages and communication options
- Help sharing information with your child’s doctor (for example, how to talk to your doctor about your child’s hearing)
- Help finding out about community services (for example, sign language classes, child care)
- Training for families (for example, what to expect in planning your child’s Individual Education Plan [IEP], transition from early intervention to preschool)
- Assistance with finances (for example, insurance, assistive technology)
- Help connecting to a Deaf role model or adult who are D/HH in my community
- Other: \_\_\_\_\_

8. Choose the top five people who provided these resources:

Newborn hearing screening program/EHDI staff

Audiologist

Physician

My child’s school

Early intervention staff

Family support organization

Birth center or hospital

Friends or families

Deaf adult role model, mentor, or guide

Another parent with a child who is D/HH

Website parent with a child who is D/HH

Website or social media

I don’t remember

Other (Specify): \_\_\_\_\_

1 <sup>st</sup>	
2 <sup>nd</sup>	
3 <sup>rd</sup>	
4 <sup>th</sup>	
5 <sup>th</sup>	



9. Have you received resources that taught you how to: (mark all that apply)?

- Read a book to your child?
- Teach your child to read?
- Teach your child to play on their own?
- Help your child play with friends?
- Tell if your child is progressing in his or her language(s)?
- Tell if your child is progressing in his or her social and/or emotional development?
- Use every day activities (bath time, meal time, etc.) to help your child learn language(s)?
- Understand your legal rights if you don't think your child's needs are being met?
- Other: \_\_\_\_\_

10. Choose the top five people who provided these resources:

Newborn hearing screening program/EHDI staff

Audiologist

Physician

My child's school

Early Intervention staff

Family support organization

Birth center or hospital

Friends or families

Deaf adult role model, mentor, or guide

Another parent with a child who is D/HH

Website parent with a child who is D/HH

Website or social media

I don't remember

Other (Specify): \_\_\_\_\_

1 <sup>st</sup>	
2 <sup>nd</sup>	
3 <sup>rd</sup>	
4 <sup>th</sup>	
5 <sup>th</sup>	



11. How much more guidance would you have liked in:

	1 (no more guidance needed)	2	3	4 (I would have liked more guid- ance)
Understanding what language or communication is expected of your child at different ages (for example, coos, babbles, cries in different ways to show when hungry or tired)?				
Knowing what to expect of your child's emotional control and behaviors (for example, briefly calms him or herself, likes to play with people, watches things move, responds to other people's emotions)?				
Knowing how your child's skills grow when you are sharing a book (for example, uses finger to point at things, looks at the right picture or thing when it's named, scribbles on their own, names items in a picture book)?				
Understanding the ways your child should relate with others at different ages (for example, makes eye contact, waves bye-bye, plays with other children)?				

12. What challenges do you face in becoming a family leader (for example, building partnerships, advocating for D/HH children in the larger community, participating on EHDI advisory committees)? (mark all that apply)

- I do not feel I have the confidence and skills to lead
- I do not understand the role of family leaders
- I do not have the time to become a family leader
- I have not received the right training to become a family leader
- I have not been given the opportunity to become a family leader
- I do not wish to become a family leader
- Other \_\_\_\_\_

13. Are there any resources or supports that you did not get but wish you would have received?



14. What was your biggest barrier in participating in family-to-family support activities, such as workshops or group picnics?

## Deaf or Hard of Hearing (D/HH) Role Models

### What is a D/HH role model?

D/HH role models are typically adults who are deaf or hard of hearing who meet with families. Such people are sometimes called deaf mentors or guides.

15. Was your family offered access to a D/HH role model?

- Yes
- No

16. Did you meet with D/HH role model?

- Yes
- No

17. If yes, what did you find most helpful? (select one)

- Showed me what my child could achieve as an adult
- Provided me with confidence in choosing our language option(s)
- Provided advice on how to communicate with my child in different situations
- Provided information on how to make my house safer for my child (for example, signaling devices, phone devices)
- Provided guidance on how to help with my child's interactions with others in the family, such as dinner table tips, supporting sibling engagement)
- Shared information on Deaf Culture
- Shared information about local, state and national D/HH resources and services
- Told me about or connected me to other D/HH adults
- I did not benefit from D/HH role models
- Other: \_\_\_\_\_



18. If no, what was the main reason? (select one)

- We did not have time
- We were not offered enough information to understand why it was important
- At the time it was offered, this service did not meet our family's needs
- We already had other D/HH role models in our community
- The deaf adult used a different type of communication than we chose for our child
- We were not provided enough information
- Other: \_\_\_\_\_

## Deaf or Hard of Hearing (D/HH) Role Models

19. What is your highest education level? \_\_\_\_\_

20. In the last year, what was your total household income before taxes?

- Less than \$25,000
- \$25,000 to \$34,000
- \$35,000 to \$49,000
- \$50,000 to \$74,999
- \$75,000 to \$99,999
- \$100,000 to \$149,999
- \$150,000 or more

21. What race is your child that is D/HH? (mark all that apply)

- White/Caucasian
- Black/African American
- American Indian/Native American
- Alaska Native
- Asian
- Native hawaiian
- Pacific Islander
- Other: \_\_\_\_\_



22. Is your child who is D/HH of Hispanic, Latino, or Spanish origin?

- Yes
- No

23. What language does your family use at home most of the time? \_\_\_\_\_

24. Are there other languages that your family use at home? \_\_\_\_\_

**This project is supported by the Health Resources and Services Administration of the U.S. Department of Health and Human Services under grant number UJ1MC30748-01-00 for Family Leadership in Language and Learning.**

### Interested in being entered to win a \$50 Amazon gift card?

If yes, please provide your name and email address.

Name: \_\_\_\_\_

Email: \_\_\_\_\_

### Are you willing to participate in a focus group?

Parents needed! We are looking for parents to participate in a small focus group. The group will meet virtually for one hour in January to talk in more detail with researchers and other families about their experiences and will be **paid \$50 for their time**. At a minimum, you will need a phone that can dial a U.S. number. Also, it is best, but not necessary, to have a computer with a camera and speakers to participate.

Would you like to participate in this focus group?

- Yes
- No

Thank you for your time and sharing your experiences. Please contact [alyson.ward@usu.edu](mailto:alyson.ward@usu.edu) if you have any questions or comments.



# Appendix B: EHDI Coordinator Needs Assessment Survey to Support Family Engagement

Thank you for taking time to provide us with information about your family engagement efforts for the purpose of guiding the Family Leadership in Language and Learning (FL3) Program. Please answer the following questions about family engagement within your state/territory EHDI system. This survey should only take about 15 minutes. Please complete the survey by September 29th, 2017. Please contact Alyson Ward at [alyson.ward@usu.edu](mailto:alyson.ward@usu.edu) if you have questions.

This survey has been approved by USU’s Internal Review Board. To read about how we will protect your privacy and how this information will be used, please read the letter of information located at the end of this survey.

## Deaf or Hard of Hearing (D/HH) Role Models

- To what extent are you implementing any of the following activities to support families who have children who are deaf or hard of hearing (D/HH) served in your state? Respond to each item. Our EHDI program routinely:

	In place, needs improvement	In place and working well	Plan in place to develop	Not in place	I don't know
Provides information to all families of children identified as D/HH through EHDI about the communication needs of their child					
Has someone that contacts families as a follow up to ensure families gain access to needed services and supports					
Provides information to families about family-to-family support services					
Provides information to families in multiple languages					
Other strategies you use:					

In what languages is your information available? \_\_\_\_\_



**Family Leaders-** This section is asking about family leader engagement in EHDI programs. Family leader is the term used to describe all families whom you partner in decision making. This may include the family organization with whom you may be contracting for your HRSA grant as well as other family representatives, such as members on advisory teams.

2. Thinking about family leaders, what activities do they currently perform in your state's EHDI system?

(Check all that apply)

- Assist other families in navigating the EHDI system (serve as follow-up coordinators to support receipt of diagnostic evaluation)
- Connecting families to local D/HH adults
- Connecting families to statewide D/HH programs or services
- Advocate/educate for state funding and policy changes
- Serve as parent representatives/leaders on advisory team or committee
- Provide family-to-family connections, such as picnics, social events, etc.
- Placing phone calls to families between screening and diagnosis to ensure families understand the importance of follow through, where to go for follow-up, and assist with identifying barriers to these services
- Educate families about communication options
- Participate in decision-making about goals for the EHDI program
- Providing pre-service and in-service training to EHDI staff, screeners in hospitals and others; presenting at conferences, on topics related to family support, parent involvement in systems, parent leadership, etc.
- Help develop and/or conduct training with health providers
- Serve as representatives or liaisons for families from diverse cultures
- Connecting with the AAP Chapter Champion and/or local pediatric practices providing the parent perspective
- Other (Describe): \_\_\_\_\_



3. In what ways do your family leaders partner with your EHDI program in quality improvement and evaluations?

(Check all that apply)

- Our family leaders don't participate in quality improvement.
- Participate in quality improvement teams with EHDI staff.
- Provide input to the EHDI program on family satisfaction and concerns.
- Help collect data from families to evaluate the EHDI program.
- Help interpret findings from the family perspective.
- Participate in committees that work on grant applications (HRSA, private foundations, etc.)
- Other (Describe):

4. To what extent are you implementing the following strategies to enhance and maintain strong family leaders?

(Respond to each item)

	In place, needs improvement	In place and working well	Plan in place to develop	Not in place	I don't know
Family leadership training is in place for families to help them be successful leaders and partners					
We ensure that family leaders represent the diversity of the state, especially under-represented racial/cultural groups					
Procedures to recruit new family leaders					
All families are supported financially for their time and expenses to participate in EHDI program efforts					
We give families the opportunity to increase their leadership and advocacy skills by attending webinars, workshops, conferences (Annual EHDI Meeting, AMCHP, FV, H&V Leadership).					
We recruit families that reflect diversity in support of various communication modalities					



5. What challenges do you face in getting active family leadership in your EHDI system? (Check all that apply)
- Finding families with the ability to represent family experiences beyond their own
  - Finding families who have the confidence and skills to effectively offer their opinions and ideas
  - Uncertain how to use family leaders in our EHDI program
  - Finding families with the time to help the EHDI program
  - Issues around privacy and security regulations that inhibit utilizing family leaders effectively (for example, unable to share family contact information with family leaders).
  - Other (Describe): \_\_\_\_\_

**Family Support Organizations- Most EHDI programs, as part of their HRSA grant, have contracted with one or more family support organizations. The following questions ask about collaborative work between EHDI and these contracted organizations.**

6. Do you have a plan developed to evaluate the effectiveness or impact of your partnership with your contracted family organization(s)? (Check one)
- Yes, we have outcomes and measures developed.
  - Partially; we have started planning but it is not completed
  - No, we are not sure how we will evaluate this, but have internal staff helping do the evaluation.
  - No, we are not sure how we will evaluate this, and would like help developing an evaluation
7. Please tell us about your challenges or concerns about your partnership with this family support organization(s).



**FL3 Supports- This section is asking for your input to the technical assistance provided by Hands & Voices, the Family Leadership in Language and Learning (FL3) Program, to state/territory EHDI programs.**

8. What supports or resources would you like the FL3 to develop or provide in an effort to support EHDI coordinators and their partners with the intent of strengthening family engagement?

9. How would you like to receive this support from the FL3? (Check all that apply)

- Group training, such as webinars
- Large-scale resource dissemination, such as websites and social media
- Individualized technical assistance with our state EHDI team
- Intensive training provided with our family leaders or contracted family-based organization
- Other (describe): \_\_\_\_\_

Please consider offering your contact information to help us better tailor our FL3 support to meet your state’s specific needs. However, providing it is optional:

Name: \_\_\_\_\_

State: \_\_\_\_\_

Email: \_\_\_\_\_

Phone: \_\_\_\_\_

Thank you for taking the time to answer this survey. We look forward to future communications.



# Appendix C: Family-based Organizations that Serve Families with Children who are Deaf or Hard of Hearing

Help us learn more about your family-based organization's (FBO) and your efforts and resources to support families who have children who are deaf or hard of hearing (D/HH) and how you are partnering with your state's Early Hearing Detection and Intervention (EHDI) program. Your answers are confidential, and your personal information will not be shared. This survey should only take about 10-15 minutes. Please complete the survey by January 23rd 2018.

This survey has been approved by Utah State University (USU) Internal Review Board. To read about how we will protect your privacy and how this information will be used, please refer to last page.

1. Where do you live? \_\_\_\_\_
2. Family-based Organization name: \_\_\_\_\_
3. How experienced is your organization in working with families who have a child who is D/HH?
  - Very experienced, we regularly serve these families
  - Somewhat experienced, we have served several per year
  - Not very experienced, we have served only a few D/HH families
  - Not at all, directly supporting D/HH families is new
4. What are your organizations current responsibilities? (select all that apply)
  - Lead D/HH children-focused learning communities
  - Participate in D/HH children-focused learning communities
  - Develop and administer EHDI state level needs assessment or gap analysis
  - Participate on state EHDI mandated advisory boards
  - Provide a family representative on deafness-related projects
  - Provide family support by trained parents who have children that are D/HH
  - Provide family support by trained parents who have children with other special needs
  - Design and/or deliver leadership training (for example, advocacy training, IEP training)
  - Connect families to deaf adults such as deaf mentors, guides, or role models
  - Other \_\_\_\_\_



5. What is the status of your contract with the EHDI program?
- Contract is fully executed; funds are received in a lump sum (all funding received at the same time)
  - Contract is fully executed; funds are reimbursed after work is completed (your organization must submit invoice)
  - Not executed, funds not available to our organization at this time
  - Other \_\_\_\_\_
6. Do you receive direct referrals (for example, names and contact information) from the EHDI program for all children newly identified as D/HH?
- Yes
  - No
  - I don't know
  - Other \_\_\_\_\_
7. What kind of contacts or outreach does your organization make to help your Early Hearing Detection and Intervention (EHDI) programs? (select all that apply)
- Contacts families to ensure newborn hearing screening is complete
  - Contacts families to ensure children who did not pass (aka refer) on their screening test get in to an audiologist for a diagnosis
  - Contacts families to ensure children who are identified with a permanent hearing loss are referred to Early Intervention (EI)
  - Contacts families to refer them to other community resources (for example, sign language classes, parenting classes)
  - Contacts families to offer family- to- family support from your organization
  - Contacts families to offer support from D/HH adults such as deaf mentors, guides, or role models
  - Other \_\_\_\_\_



8. How confident are you in the following areas supporting families who have children who are D/HH?

	Not applicable	Not confident	Neutral	Somewhat confident	Very confident
Connecting families with D/HH such as deaf mentors, guides, or role models					
Connecting families of children who are D/HH with other families who have children who are D/HH					
Connecting families of other resources (for example, financial resources, early intervention, legal rights)					
Strategies for engaging families from diverse cultures					
Methods for connecting with families from a variety of income levels					

9. What are some ways your organization would like to be more inclusive in serving all families? (select all that apply)

- Engage more families from different cultures
- Have activities to gain participation from fathers
- Provide information to families who speak a language other than English
- Engage families of various socio-economic levels
- Other \_\_\_\_\_

10. The activities in our contract with the EHDI program are aligned with our organization's goals and objectives:

- Yes, fully aligned
- Somewhat aligned
- Not aligned
- I do not know
- Other \_\_\_\_\_



11. What kinds of data are you reporting to your EHDI program? (select all that apply)
- Basic programmatic data (for example, how many parents you are serving, how many events you hold, how many attend those events)
  - Follow-up data (for example, how many parents you assist with getting to diagnosis and early intervention)
  - Satisfaction data (for example, how satisfied parents feel about the support and resources they received)
  - Pre/post data (for example, parental knowledge level before and after a training)
  - Outcome data (for example, as a result of receiving services, parents and/or child skills or development are improved)
  - We are not required to report data back to our EHDI program
  - I don't know
  - Other: \_\_\_\_\_
12. How confident do you feel in reporting data back to your EHDI program?
- Very confident, I do not need any technical assistance
  - Somewhat confident, could use minimal technical assistance
  - I am not sure how confident I am or if I need technical assistance
  - Not confident, I could use additional technical assistance
  - Not applicable, we are not reporting to our EHDI program
13. How much did your organization participate in the development of your contract with your EHDI program?
- We collaborated from the start to determine activities and evaluation
  - We were delivered a drafted contract and then asked to provide feedback
  - We were not given the opportunity to provide input on the contract content
  - Other \_\_\_\_\_
14. Please tell us about any challenges or concerns you may have with the contract with your state/island EHDI program.



15. What supports or resources would you like the FL3 program to develop or provide in an effort to support the families you serve or assist in the partnership between FBOs and their EHDI programs?

16. How would you like to receive support, resources or technical assistance from Hands & Voices/FL3 program? (select all that apply)

- Group training, such as webinars
- Resource dissemination, such as websites and social media
- Individualized technical assistance with our organization and stakeholders
- In-person trainings
- Other \_\_\_\_\_

Thank you for taking time to provide this important information. If you're willing, please provide your name and contact information if you'd like us to follow up with you about your FBO's specific needs. However, you may also remain anonymous.

Your name: \_\_\_\_\_

Email: \_\_\_\_\_

