

## Supporting Families of a Deaf or Hard of Hearing Child: Key Findings from a National Needs Assessment

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### Abstract

This article reports findings from a national needs assessment to ascertain the needs of families of young children who are deaf or hard of hearing (DHH), and what supports, resources, and opportunities Early Hearing Detection and Intervention (EHDI) programs and EHDI-contracted Family-based Organizations (FBOs) were providing to families. Results are intended to guide the activities of a federally funded technical assistance center charged with promoting Family Leadership in Language & Learning for families of children who are DHH. There were 458 completed surveys by parents of children who were DHH between the ages of 0–6. Surveys were completed by 56 of the 59 EHDI coordinators and by FBO staff representing 40 of the 59 EHDI programs. Focus groups were conducted with parents, EHDI coordinators, and FBO staff members. This article focuses on answering the question, *What types of support did families receive or wish they had received when their child was diagnosed as DHH and what are EHDI programs and FBOs doing to support parents?* Key findings were that: 1) Families should be offered comprehensive information at different points in their child's life; 2) Families need coordinated, trusted support and resources; 3) Families need support from other parents who share their lived experience; and 4) Underserved families need additional support.

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**Key Words:** Deaf or Hard of Hearing, Family Support, Early Hearing Detection and Intervention (EHDI), Family-Based Organizations (FBO)

**Acronyms:** ASL = American Sign Language; DHH = deaf or hard of hearing, EHDI = Early Hearing Detection and Intervention; EI SNAPSHOT = Early Intervention, Systematic Nationwide Analysis of Program Strengths, Hurdles, Opportunities and Trends; FBO = Family-based Organization; FL3 = Family Leadership in Language and Learning; HIPAA = Health Insurance Portability and Accountability Act; H&V = Hands & Voices; HRSA = Health Resources and Services Administration; MCHB = Maternal and Child Health Bureau; NCHAM = National Center for Hearing Assessment and Management

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The federal Maternal and Child Health Bureau (MCHB) has long promoted the role of families as partners in decision making and has articulated this as the first of its six key outcomes for children and youth with special health care needs, which includes children and youth who are deaf or hard of hearing (Children with Special Health Needs, n.d.).

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 deaf or hard of hearing (DHH). Since MCHB began the competitive award of funds to support Universal Newborn Hearing Screening programs in the year 2000, they have

consistently focused on families as the foundation. A recent example of this focus is MCHB's requirement, as part of HRSA-17-059, that 25% of the total award to each EHDl program had to be subcontracted to a family-based organization (Universal Newborn Hearing Screening and Intervention Program, n.d.). The activities of family-based organizations (FBO) vary across EHDl programs, but all are working to ensure that families are integrally involved in the development, implementation, and evaluation of their local EHDl system and provide the needed support and resources to families with a child who is DHH.

In an effort to strengthen the effectiveness of professional-parent partnerships, MCHB established the Family Leadership in Language and Learning (FL3) funding opportunity in 2017. Funds were competitively 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 EHDl system and thereby to support children's language, literacy and social-emotional development"* (Family Leadership in Language and Learning [FL3], n.d.).

An important initial activity of the FL3 was to conduct a comprehensive national needs assessment to inform their scope of work (see full report at [https://www.handsandvoices.org/fl3/resources/docs/HV-FL3\\_NeedsAssessment\\_19Jul2018\\_Final-opt.pdf](https://www.handsandvoices.org/fl3/resources/docs/HV-FL3_NeedsAssessment_19Jul2018_Final-opt.pdf)). H&V collaborated with the National Center for Hearing Assessment and Management (NCHAM) to conduct the needs assessment, which was designed as an in-depth examination of the needs of families; and what supports, resources, and opportunities EHDl coordinators and EHDl-contracted FBOs were providing to families with a child who was DHH. This article summarizes the data from the needs assessment that addresses the question, *"What types of support did families receive or wish they had received when their child was diagnosed as DHH and what are EHDl programs and FBOs doing to support parents?"*

## Method

### Participants and Procedures

The national needs assessment described in this article collected information from three populations: parents of young children who are DHH, EHDl coordinators, and FBO staff that are contracted with EHDl programs. Each population participated in a survey and focus groups. Institutional Review Board approval was obtained through Utah State University.

**Parents.** A sample of parents of 0–6-year-old children who are DHH was surveyed. The parent pool included 214 parents who had previously consented to further research through NCHAM's Early Intervention for Children who are Deaf or Hard of Hearing: Systematic Nationwide Analysis of Program Strengths, Hurdles, Opportunities, and Trends (EI-SNAPSHOT, n.d.) 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. Both groups of parents participated in the parent-

specific survey and were entered to win one of five \$50 Amazon gift cards.

**EHDl coordinators.** Programs in 59 states or U.S. jurisdictions have successfully competed for funding from MCHB to operate EHDl programs. Coordinators of all 59 programs were contacted via email and asked to complete a coordinator-specific survey. No incentives to participate were given to EHDl coordinators as the majority are unable to accept gifts.

**FBOs.** As part of the funding from MCHB awarded to EHDl programs in 2017, each program was required to contract with and provide 25% of their funding to an FBO who provided support to families who have children who are DHH. At the time of the needs assessment, there were 48 contracted FBOs with some states having contracted with more than one organization. Current EHDl-contracted FBOs and their contact information are listed at <https://www.handsandvoices.org/fl3/topics/fam-fam-support/need-support.html>. All contracted-FBOs were asked to complete an FBO-specific survey. Respondents were entered to win one free registration to the 2018 Hands & Voices Leadership Conference.

### Survey Instruments

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, EHDl programs, and FBOs. This background information, primarily obtained via a literature search, helped shape the instruments developed for the needs assessment. The search used a rubric beginning with the overarching questions of the FL3 needs assessment, then reviewed existing research that addressed those questions and identified gaps about what is known about support and resources offered to parents of children who are DHH. The gaps in existing literature led to the specific questions asked in the survey and focus groups.

The study used a cross-sectional survey design and responses were anonymous. The authors developed a different survey for each group based on the goals outlined by the FL3 and using Dillman's (2014) guidelines for survey development. Following the recommendations of Walsh and Volsko (2008) and the United States Department of Health and Human Services for health-related information, surveys were constructed with a 7th grade reading level. Surveys were administered using a mixed-mode framework—using electronic surveys delivered through email and social media, mailed paper surveys, texted survey reminders, and reminder-phone calls.

In all three surveys, when terms needed clarification, definitions were provided within the survey. For example, the term *support* referred to assistance given to parents to help their child who is DHH as well as support to become family leaders. *Resources* in the surveys were defined as materials given to parents to help them understand their child's development. All surveys were administered in 2017.

### Focus Groups

At the end of their survey, parents could indicate if they were willing to participate in an hour-long focus group.

Five parent focus groups were held, two focus groups from randomly selected parents, one comprised of parents of children that have additional disabilities (also known as Deaf Plus), one for Latino parents, and one comprised of fathers of children who are DHH. Twenty EHDl coordinators were randomly selected and emailed an invitation to participate in one of two EHDl coordinator focus groups. FBO directors were randomly selected and invited by email to participate in one of four focus groups. Two FBO focus groups were held in-person during the 2017 Hands & Voices Leadership Conference and two were held virtually. Each focus group was comprised of 8–15 participants.

### Data Analysis

Survey data were collected in RedCap, a Health Insurance Portability and Accountability Act (HIPAA)-compliant data management system and survey tool. Analyses were done using the statistical software R, which computed descriptive statistics for the survey data collected (R Project for Statistical Computing, n.d.). Discussions in all focus groups were audio and/or video recorded, the recordings were then transcribed and coded for themes.

## Results

### Demographics

A total of 979 parents completed surveys of which 458 were parents of children ages 0–6 and 521 were ages 6–18. The results below are responses from the 458 surveys of parents of children ages 0–6. The total number of parents who responded to each question varied slightly because some parents skipped some questions. Data from children more than 6 years old are not included in this article because the experience of families with children older than age 6 would not be as reflective of the current EHDl system as it has evolved. See Table 1 for demographic information about the parents included in the analyses for this article.

Fifty-six of the 59 EHDl coordinators responded to the survey for a 95% response rate; this included 6 EHDl coordinators from U.S. jurisdictions. At the time of the survey, 40 states had contracted with an FBO and 48 FBO staff responded to the survey (some EHDl programs had contracted with more than one FBO).

### Support and Resources Received by Parents

Both EHDl programs and FBO staff strive to meet the needs of parents, yet some parents may not be aware that these groups exist or that they have services to meet the needs of families with children who are DHH. Therefore, the initial question posed was about family involvement with EHDl programs and the FBO that had contracted with the EHDl program in that state or U.S. jurisdiction. 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 EHDl programs, and a slightly larger portion stated that they were not involved with EHDl but would like to be. Despite the fact that many of the FBOs had been operational in that state or decades, there were still 12–15% of parents who did not know or were not involved with their state's FBO. Additionally, most EHDl programs spend a lot of time and energy building their EHDl website, yet only 14% of parents responded that they had visited their EHDl website and only 24% had visited their FBO's website. Focus group participants

**Table 1**  
**Parent Demographic Characteristics**

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

commented that they believed the accuracy of information varied among websites and were unclear which websites had the most accurate information. During the focus group with fathers, the team asked how these programs can get more fathers involved. Several fathers said that the information they received from both the EHDl program and the FBO was directed toward the mother of the child and they would be more likely to be involved and use the information if more information was directed to fathers.

Parents were asked about the support they received after their child did not pass the newborn hearing screening test. EHDl coordinators and FBO staff were asked about the support they provided to parents. Figure 1 describes the results for the question about the types of supports families received. The most frequently cited supports that families reported were connections to EI, invitations to participate in parent activities, and connections to other families with DHH children.

During the focus groups, the authors asked parents, "What supports would you recommend to other parents?" The most frequently cited support was the *Guide By Your Side* program, a H&V parent-to-parent support program. Parents were also asked, "What would make accessing support easier?" The most common theme was to have one contact, such as a family support coordinator to help connect families with supports and resources. Other frequently cited themes included the value of having access to an easily navigated website that contains reliable information on the entire process from screening to early intervention, information about types of hearing loss, and guidance about what to expect from early intervention. The parents in the Latino focus group cited their unique challenges in finding and accessing culturally appropriate supports. The Latino parents also highlighted the complex immigration status and parent education issues that make support access more challenging for Latino families. 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, availability of child care, offering events during the weekend, having virtual



**Table 2**  
**Parent Involvement with Early Hearing Detection and Intervention (EHDI) Programs and Family-Based Organizations (FBO)**

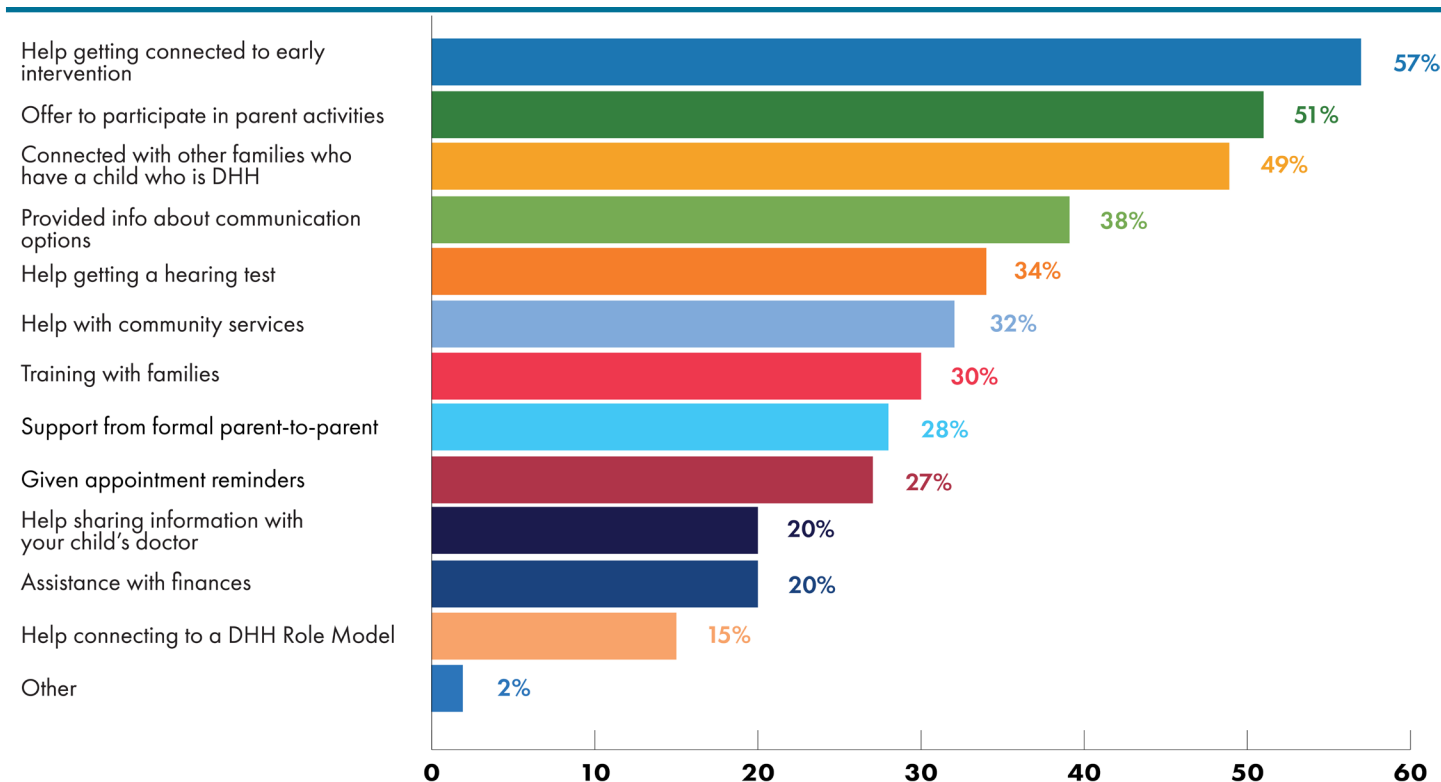
How involved are you?	EHDI	FBO
I don't know about this program	19%	12%
Not involved, but would like to be	21%	15%
Not involved and would NOT like to be	9%	1%
I have visited their website	14%	24%
I follow them on social media	9%	28%
I have participated in their activities or programs	21%	42%
I am an EHDI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

meetings, and sending invitations in various formats (e.g., emails, social media, text). During the Deaf Plus focus group, parents of children who had additional disabilities or health needs beyond being DHH discussed their unique needs. One parent expressed that she wished that more people had a better understanding of the additional complexities of a child who is Deaf Plus, such as the increased number of providers and an increased emotional toll on the parents. Additionally, 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 event.

In the survey, parents were asked to indicate the various resources they had received to support their child's developmental growth. When unclear, options were accompanied by an example, for instance, "use everyday activities to help your child learn language" included the examples of bath and meal times. Results to this question are presented in Figure 2. Families were also asked about developmental areas for which they would have liked more guidance using a 4-point Likert scale. Responses are summarized in Figure 3.

Recognizing that some important resources may not have been listed on the questionnaire, parents were asked to respond to an open-ended question on the survey, "Are there any resources or supports that you did not get but wish you would have received?" Nearly 70% ( $n = 321$ ) of the parents responded to this question and 43% ( $n = 183$ ) of those said they received all the resources they needed or entered *none* or *not applicable*. The remaining 138 responses were sorted into several categories; the top three are listed as themes below (the total  $n$  will not equal 138).

**Theme #1: Increased connection to resources.** This was the most often cited theme, with 14% ( $n = 20$ ) of responses in this category. This highlights that many parents want to know (a) about additional resources to help them understand their baby's hearing status, (b) what communication options are available, and (c) 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.



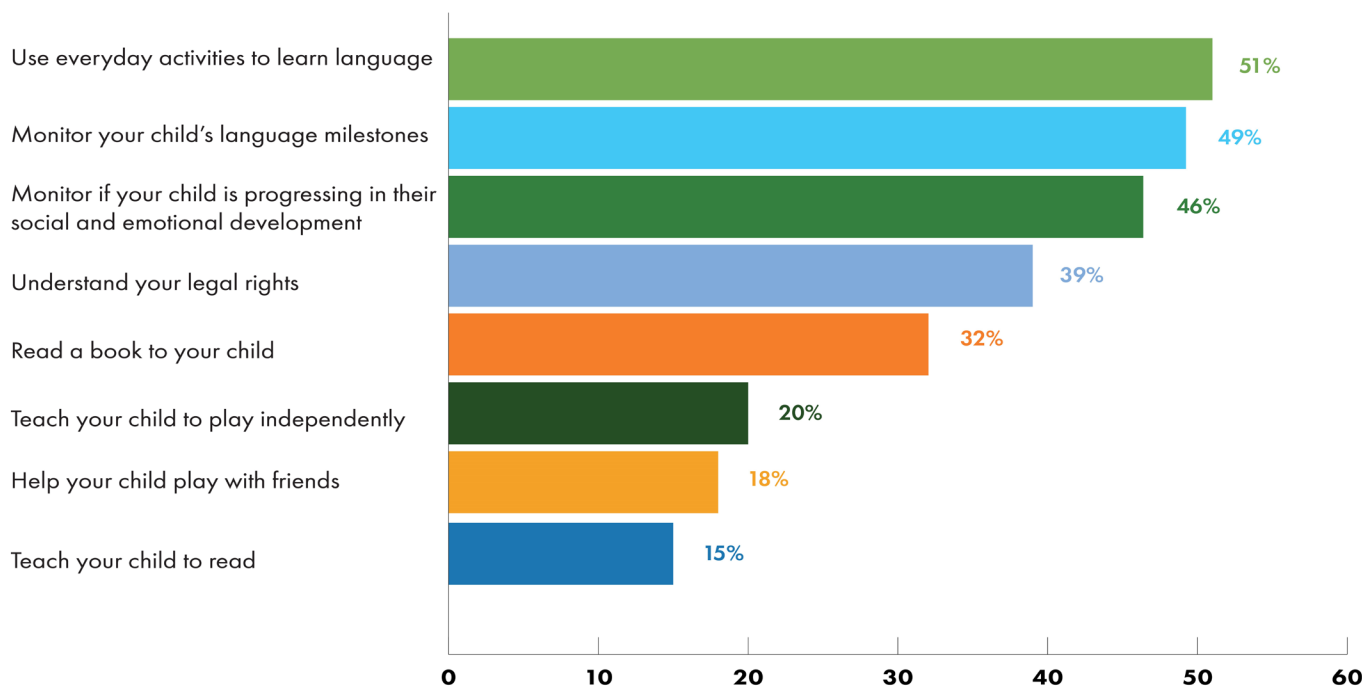
**Figure 1.** Types of support families of children who are deaf or hard of hearing (DHH) reported having received in their community.

## Theme #2: Social and emotional support for families.

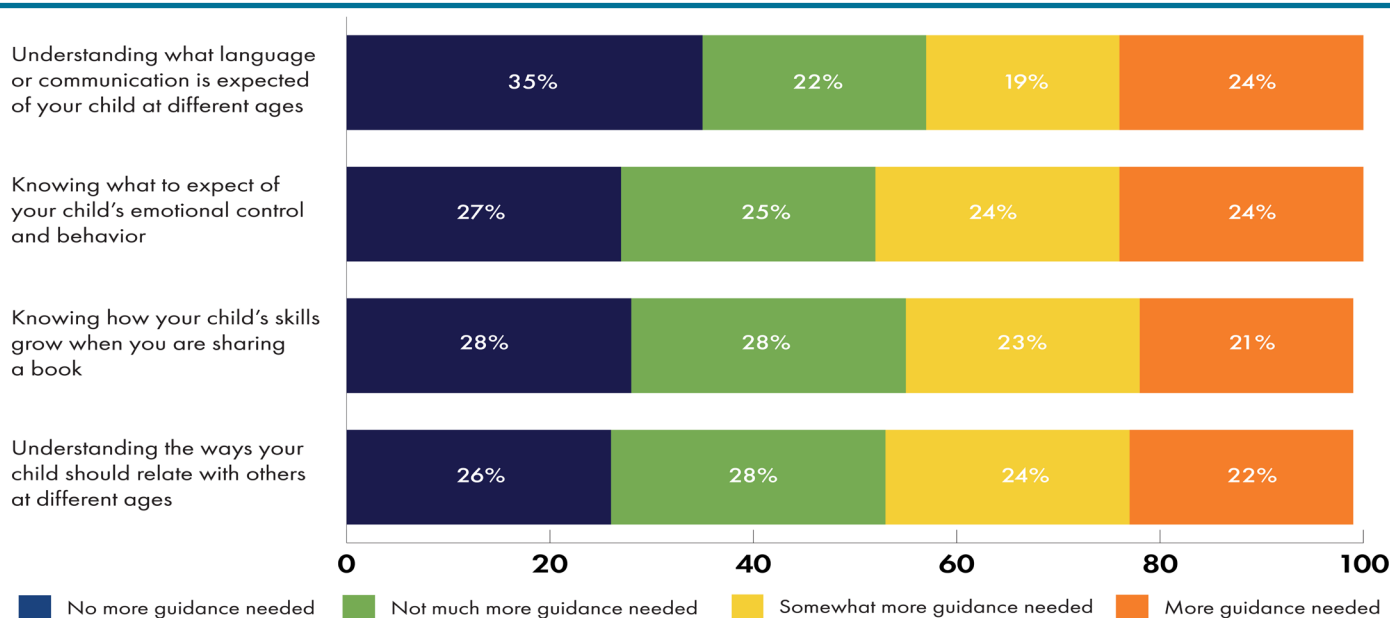
As noted above, 10% ( $n = 14$ ) of those who made comments reported that they want access to support from other families with children who are DHH. The responses in this area demonstrated that parents are open to receiving this support in a variety of formats from in-person activities, phone calls, or 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 DHH helped them understand what to expect, what is normal, and what is concerning.

## Theme #3: Access to American Sign Language

**(ASL) instruction.** Eight percent ( $n = 11$ ) 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 mentioned ASL instruction commented that their child had access to ASL, but that other family members also wanted instruction. 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.”



**Figure 2.** Types of resources that families of children who are deaf or hard of hearing received to assist with their child's developmental growth.



**Figure 3.** Areas where parents would have liked more guidance.

Parent Leadership in EHDI Systems

In the parent survey, family leader was defined along with examples of what family leaders may do (e.g., build partnerships, advocate for children who are DHH in the larger community, participate on EHDI advisory committees). The survey also investigated the challenges in becoming family leaders. Results to this question are detailed in Figure 4. Many respondents stated they had not received enough communication (lack of understanding the role of family leaders, 16%, and not been given opportunities, 26%). In addition, 29% of families reported that time to participate was a challenge.

Focus groups with families provided additional information about what would help parents be more confident about becoming a family leader. Ideas suggested during these discussions 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 better guidance and information about how families can get involved in local, state, and national EHDI programs.

Support Offered to Parents by EHDI Programs and FBOs

EHDI coordinators were asked about the extent to which they had plans to support families who have children who are DHH. Responses are shown in Figure 5. Between 30-40% of the EHDI coordinators reported that these activities were in place and working well. Nearly half (41%) of programs stated that they had an effective plan to connect families to services and family-to-family support. Coordinators were also given the option to enter *Other* activities that EHDI programs use to support families. Other activities cited were hosting social events for families, contacting primary care providers to ensure they are aware of DHH resources, and paying for families to attend conferences and participate in workshops. EHDI coordinators were also asked to indicate the languages in which they offered their materials. This is important because offering materials in a parent’s first language can help facilitate understanding of their child’s hearing and what follow up is needed. Spanish (73%) was the most frequently cited and only 32% of the coordinators stated that their process of offering materials in multiple languages was working well.

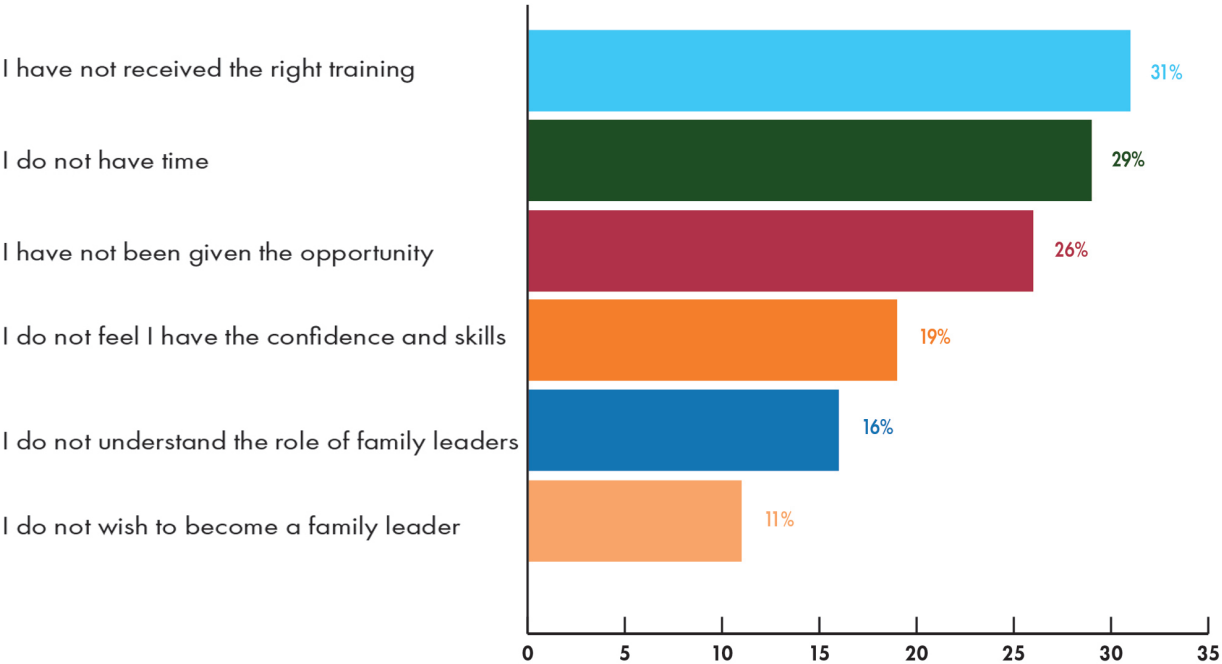


Figure 4. Challenges families face in becoming leaders.

Many EHDI programs face challenges that impede their ability to meet the needs of all the families they serve. In response to an open-ended question, EHDI coordinators were able to request support and resources from the FL3 to help them better meet the needs of their families. The top three types of support are listed below.

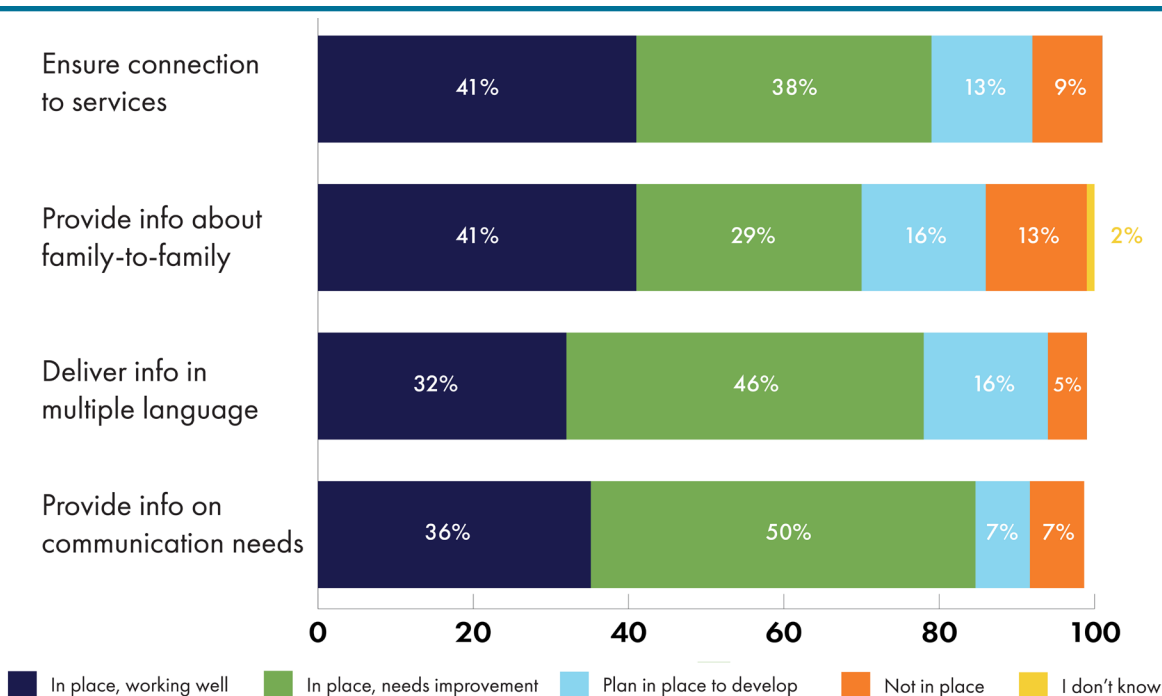
Support #1: Engaging families and providers.

Thirty percent (n = 17) of EHDI coordinators expressed concerns of getting families meaningfully engaged so the relationship between the EHDI program and the parent is mutually beneficial. EHDI coordinators would also like help getting service providers (e.g., pediatricians, family practice physicians, audiologists) more 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 should] provide workshops for providers on how to work with families of children who are DHH.”

Support #2: Advocacy and leadership training.

Coordinators wanted more support in providing leadership training to families, which is consistent with related questions in the coordinator survey. For example, 27% (n = 15) of the coordinators stated that they would like more leadership training. One 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 who could help address cultural issues and effective ways to address working with families from multi-ethnic backgrounds.”



**Figure 5.** Support offered by Early Hearing Detection and Intervention programs. Participants were asked, “To what extent are you implementing the following activities to support families who have children who are deaf or hard of hearing (DHH)?”

**Support #3: Skill and infrastructure building.** Twenty-one percent ( $n = 12$ ) 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 EHDI programs started in being able to contract with FBOs,” and another asked that the FL3 “provide training for quality improvement, logic models, and help with improving structure to be more businesslike.”

Focus group discussions included information about what EHDI coordinators wanted the FL3 to do. EHDI coordinators requested that all FBOs have access to resources developed by H&V such as their Guide by Your Side and Advocacy, Support, and Training Program. 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 suggested that the FL3 or FBOs may be more effective than EHDI programs in reaching families because of potential distrust of government agencies.

FBOs were asked to select the types of family outreach they provided on behalf of the EHDI program they were contracted to assist. Results to this question are shown in Figure 6.

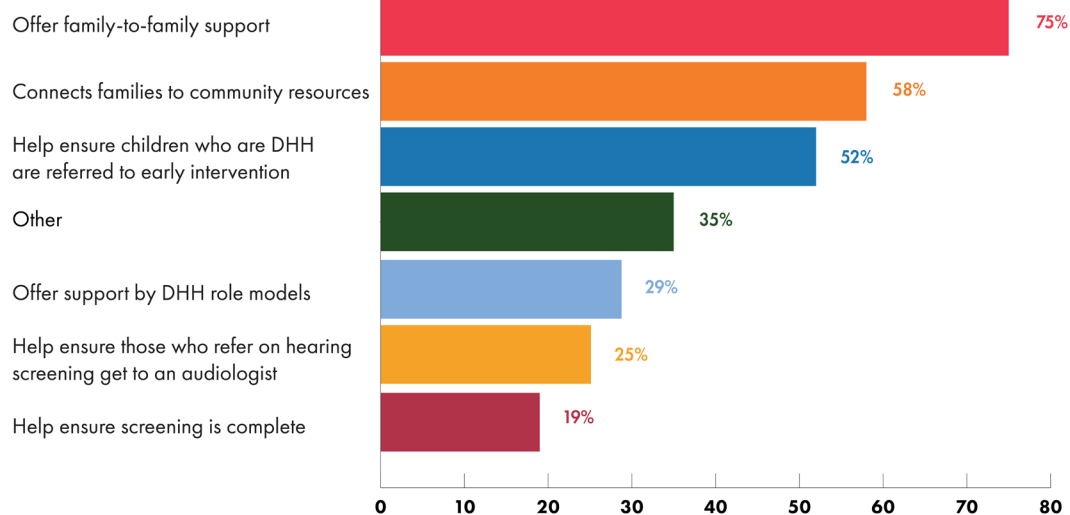
In addition to being asked about what outreach they do on behalf of EHDI, FBOs were asked to describe their confidence in their ability to support families in various ways, as shown in Figure 7. Less than half of respondents said that they were very confident in connecting families with adults who are DHH or engaging with families from diverse cultures. Additional analysis of the FBOs indicated

they were *very confident* ( $n = 15$ ) in making connections to adults who are DHH, almost all of them had DHH role model programs already in operation.

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

**Resources #1: Materials created in other languages that are culturally competent.** Seventeen percent ( $n = 8$ ) of FBOs wanted 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.”

**Resources #2: Measurement of family support and engagement.** One FBO director stated “[We would 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 know and understand if families are getting what they need and want and when they need and want it.

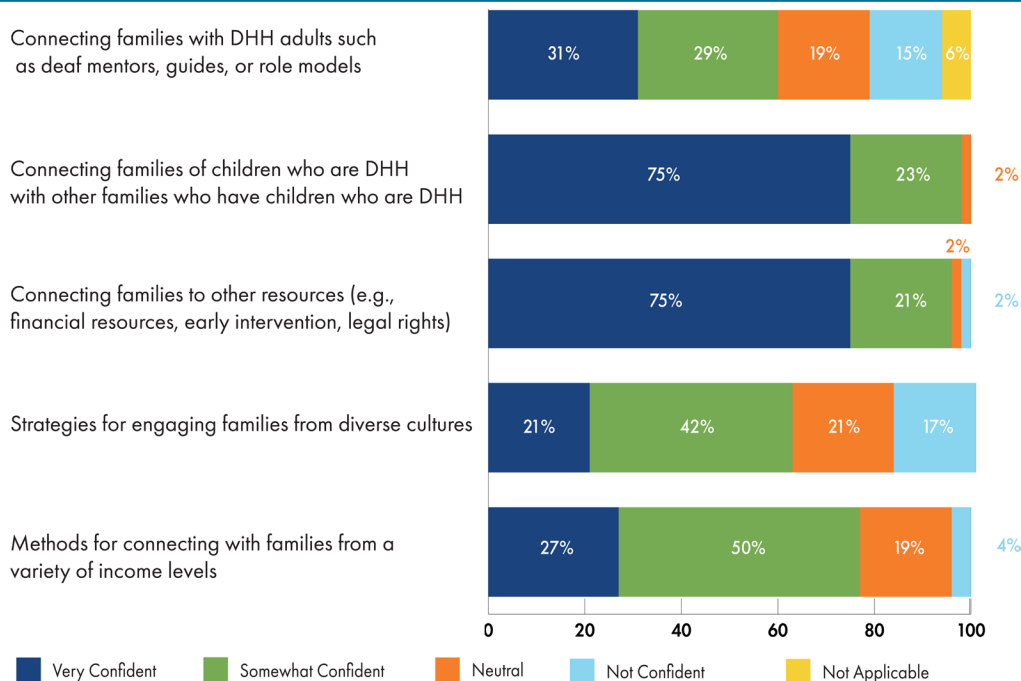


**Figure 6.** Outreach that Family Based Organizations (FBOs) make to help Early Hearing Detection and Intervention (EHHI) programs. DHH = deaf or hard of hearing.

**Resources #3: Training for FBOs and adults who are DHH.** Seventeen percent ( $n = 8$ ) of FBOs indicated that they needed training in the best ways to support families with children who are DHH and developing parent leaders. FBOs would like new ideas or ways to engage parents within their programs, for example, "... participating on advisory boards, feedback/focus groups, quality improvement initiatives, reducing lost to follow up, etc." 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 EHHI 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, DHH role models.

EHHI coordinators were given the definition of a family leader as "a family member who partners with professionals in decision making." Coordinators were then asked what activities family leaders perform in their EHHI system. Responses to this question are shown in Figure 8. The most frequently reported activities were serving on advisory committees, providing family-to-family activities, and connecting families to DHH programs and services.

The activities of family leaders were discussed further during the focus groups. Coordinators responded that time and travel were primary barriers when asked "What do you think the biggest barriers are for parents becoming advocates?" One coordinator said, "I think they might not be aware that [being a family leader] 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



**Figure 7.** Family Based Organization (FBO) confidence in supporting families with a child who is deaf or hard of hearing (DHH).



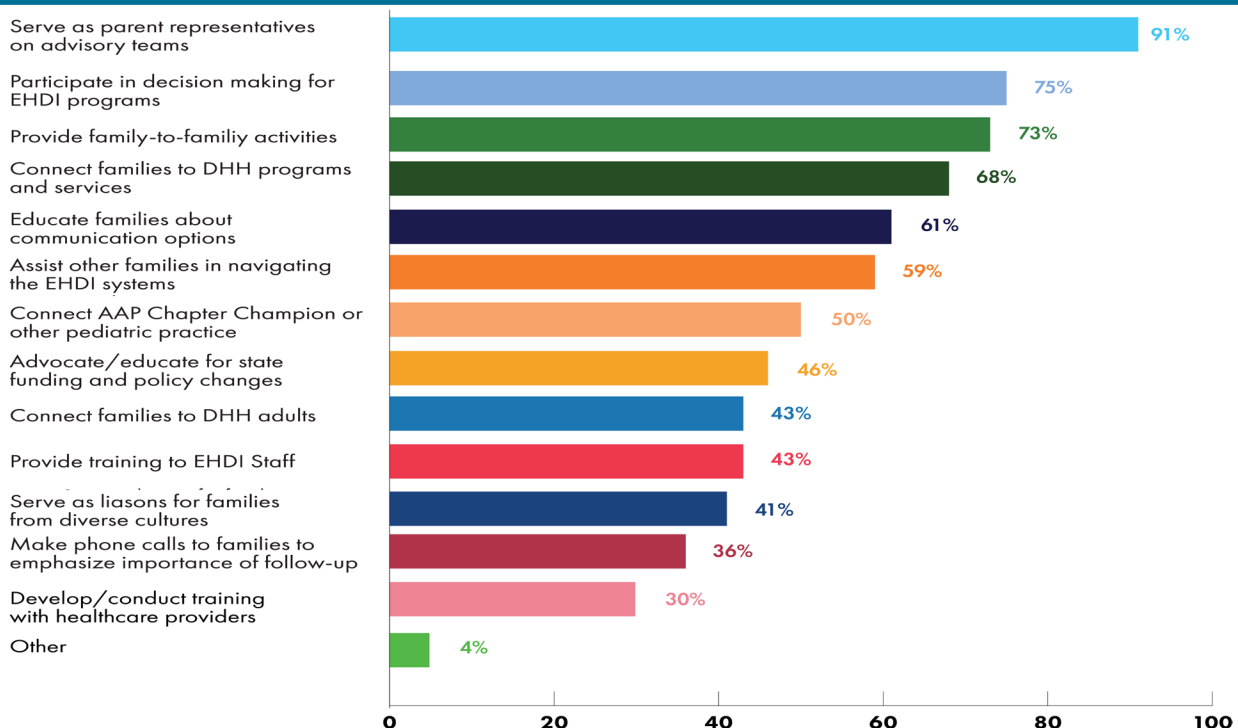
modalities.” Participants in the focus group were asked, “What would it take to increase by 10% the number of states responding that parents are leaders or advocates?” Coordinators stated that increasing the number of family leaders would require better recruitment and the availability of “regionalized trainings, stipends for trainings, and training activities led by other parents.” Another coordinator stated that she believed that becoming a leader had to be realistic for parents because “there is a tendency for parents to get overwhelmed.” Focus group participants were also asked, “What are the barriers in partnering with parents in doing 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 children who are DHH and the perception that hearing loss is not a priority disability” can inhibit a parent’s willingness to help deliver presentations.

In addition to asking what EHDI activities family leaders are involved in, coordinators were asked to respond to what extent they are implementing strategies to enhance and maintain family leaders in multiple areas. Responses are shown in Figure 9. Nearly half (43%) of EHDI coordinators reported that they are providing families opportunities to increase their leadership and advocacy by attending meetings such as the EHDI Annual Meeting or the H&V Leadership Conference. Approximately two-thirds of coordinators stated the remaining strategies addressed in this question need improvement or there is not a current plan in place to implement these strategies.

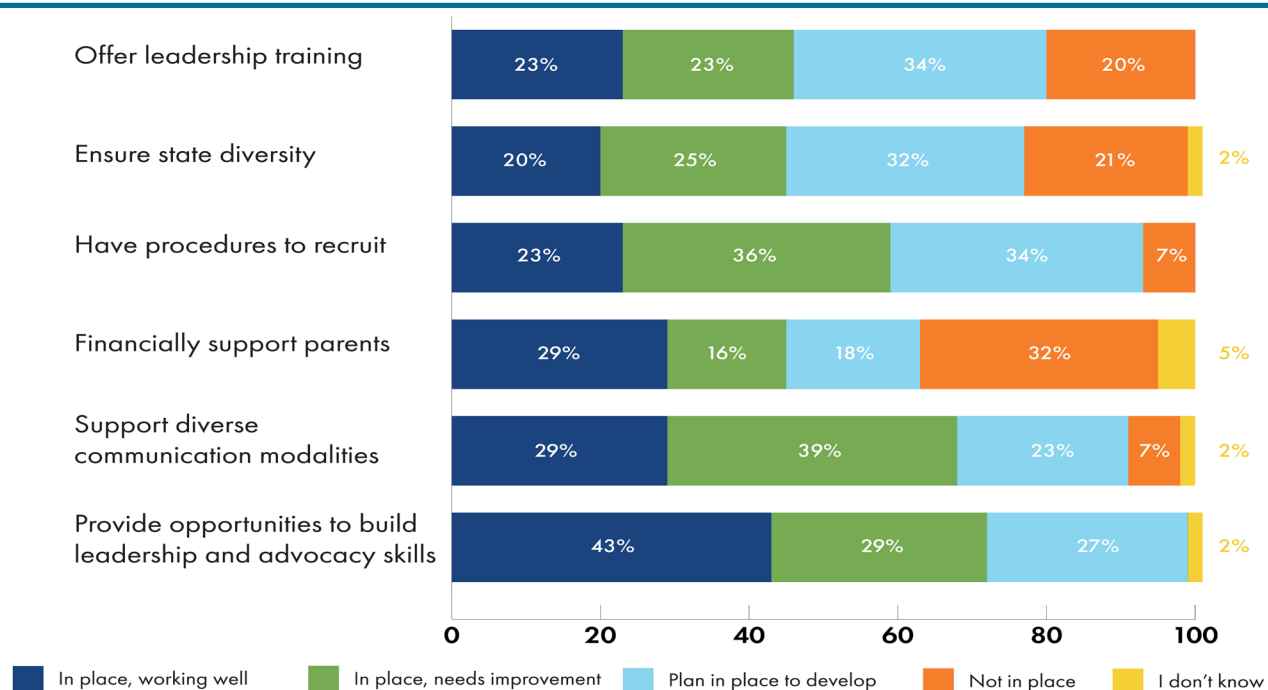
During the focus groups, coordinators were able to share barriers to providing leadership training and some possible

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. In discussing why so few programs are 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.

EHDI coordinators were also asked what the greatest challenges were in getting families to become leaders. Results from this question are shown in Figure 10. Overwhelmingly, 79% of coordinators responded that families do not have time to get involved and almost 40% said that privacy and security issues interfered with their ability to involve families. Twenty-three percent 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. 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 [an FBO] that is really motivated to stay in touch with families...as a parent I know I get really busy...so [the FBO is] going to have to be strong in staying in touch with families and engaging them.”



**Figure 8.** Activities performed by Early Hearing Detection and Intervention (EHDI) family leaders. AAP = American Academy of Pediatrics; DHH = deaf or hard of hearing.

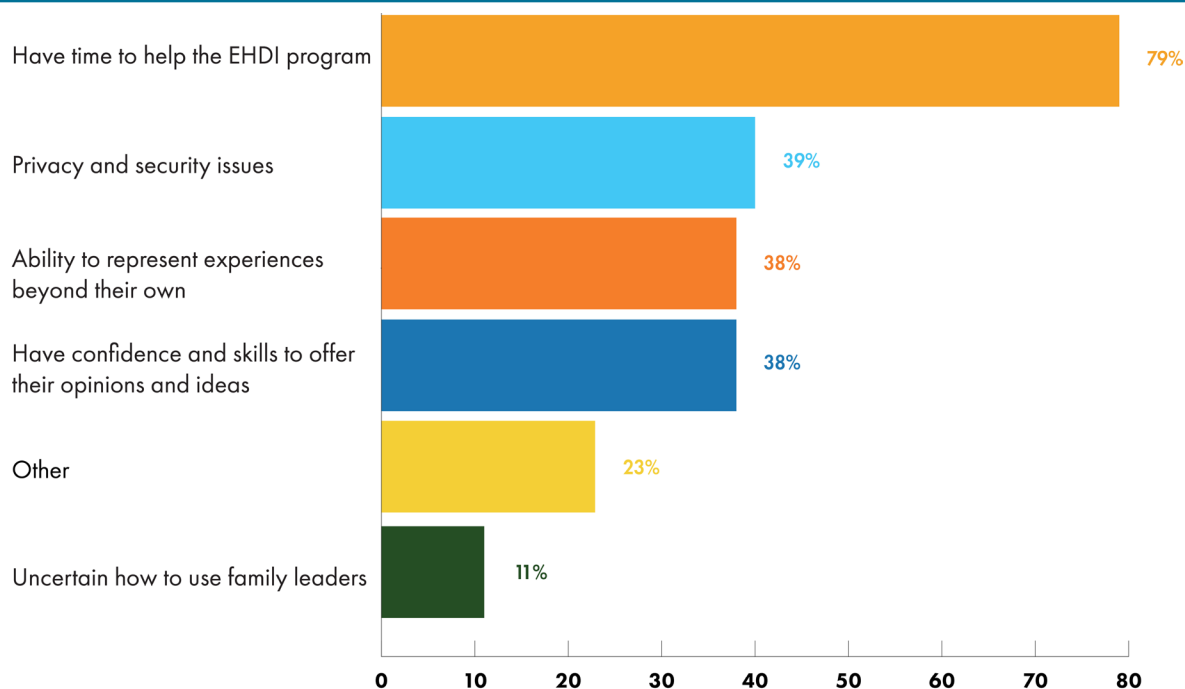


**Figure 9.** Strategies used to enhance or maintain family leaders.

### Discussion

The purpose of this study was to help the Family Leadership in Language and Literacy (FL3) project better understand the needs of families of children who are DHH, family-based organizations (FBOs), and state EHDI programs who are serving these families. The needs assessment results provided valuable information about the supports and resources needed by families who have a child who is DHH. Some needs were consistent for all three groups. For example, all three groups indicated the importance of family-to-family support, families as leaders

in the EHDI system, and providing guidance to families from screening to early intervention. In other cases, responses were not consistent. The support and resources families report receiving differed compared to the support and resources EHDI programs and FBOs report providing. Another discrepancy was that many parents reported a desire to become family leaders, but EHDI programs reported difficulty in recruiting family leaders. Specific key findings regarding support and resources provided to families, including leadership opportunities are outlined below.



**Figure 10.** Challenges in getting active family leaders. EHDI = Early Hearing Detection and Intervention.

### **Key Finding #1: Families Need to be Offered Comprehensive Information at Different Points in Their Child's Life**

In general, families would like to be offered more information. Early in the survey parents were asked about involvement with EHDI and FBOs as well as some of their dissemination strategies (i.e., website, social media, activities). Overall, parents reported they were unaware or uninvolved with these programs and infrequently or never accessed the agencies' websites and social media platforms (see Table 2). As stated earlier, websites are an important source of information for all parents, and this is no different in the population of parents who have a child that is DHH. However, more than three-quarters of parents reported that they had not accessed the websites of the EHDI programs or the FBO in their area. By identifying and highlighting or sharing trusted resources via websites and social media sites, families can better access information they need, when they need it. This reflects an opportunity for the FL3 to reach out to all families of children who are DHH to help increase awareness of services provided by their EHDI program and FBO.

When families were asked about the areas of child development for which they would have liked more guidance, one half to two-thirds of parents indicated they would have liked more guidance in understanding what language or communication is expected of their child at different ages, what to expect of their child's emotional status and behavior, how their child's skills grow when sharing a book, and ways their child should relate with others at different ages (see Figure 3). Language, literacy, social, and emotional development are a primary focus for early intervention providers. The earlier these resources are provided to families, the better the outcome for infants and children who are DHH. The FL3 project can assist the FBOs and EHDI programs with strategies and resources to strengthen these important areas of development, which will help provide some consistency across programs. For example, if families are given the same information from audiologists and early intervention providers, it would reinforce that they are getting accurate information and hopefully make their journey smoother. These resources and strategies can also be shared with other providers, which may strengthen relationships among professionals serving infants and children who are DHH.

### **Key Finding #2: Families Need Coordinated, Trusted Support and Resources**

In general, receipt of support is rather low, with only three types of support received by more than 50% of the parents—leaving the remaining nine types of support received by less than half of the surveyed parents (see Figure 1). Not each family needs all the different types of support listed. However, many of the supports are likely to be beneficial to families and their child who is DHH (e.g., assistance with finances, connection to other families with a child who is DHH). This is particularly disconcerting as families ranked receiving support from other families as the most important of all the resources they wished they would have received. Additionally, these results were surprising because many supports have been the foci of funding for

MCHB newborn hearing screening for over a decade and should be reported as received by nearly 100% of parents. For example, 40% of parents reported that they did not get help connecting to early intervention, 62% did not receive information about communication options, and 66% reported not receiving support getting a hearing test.

Though families desire more support and resources and EHDI coordinators expressed that providing family support is a goal of their program, 59% of EHDI coordinators reported that their programs do not have effective plans in place or their plans need significant improvement in a variety of areas of supporting families (see Figure 5). With major funding changes in EHDI programs (e.g., 25% of program funding going toward an FBO), funds that would typically be used to make EHDI program improvements may have been diverted to FBOs. This highlights the importance of building a trusted partnership with their FBO in an effort to provide seamless support and resources to families. For example, the FBOs can play a critical role in assisting EHDI programs with follow up by contacting families to ensure newborn hearing screening is completed and ensuring that children who do not pass their screening receive a diagnostic evaluation. The results of this needs assessment, as shown in Figure 6, revealed that very few FBOs are assisting in this important follow up and thus training and technical assistance in preparing FBOs in this role is needed. Moreover, although the study did not assess the types of information EHDI programs and FBO staff are providing to families, it seems there is an opportunity for the FL3 to help bolster their ability to provide support and resources to families.

A priority of MCHB is that “families partner at all levels of decision making,” which emphasizes the importance of family leadership. The EHDI coordinator survey and focus groups shed light on the extent to which family leadership is present. As shown in Figure 8, the fact that so few EHDI programs reported that family leaders are helping to reduce loss to follow up (36%) and connect with the healthcare providers (30%) is concerning given that these have been some of the primary foci for MCHB for almost 20 years.

This needs assessment attempted to understand the barriers to family involvement and leadership (see Figure 4). The results revealed differences in the perceived barriers to family involvement based on the family survey and the EHDI coordinator survey. For example, over three quarters of EHDI coordinators perceived time availability to be a barrier for family involvement in leadership activities, while less than a third of families reported time as a barrier. Coordinators may be making the assumption that families do not have time. Additionally, a greater percentage of EHDI coordinators reported that they believe families lack the confidence to serve in leadership roles (38%) compared to the percentage of families that reported they were not confident in serving as leaders (19%). These varying perspectives should guide the FL3 in how they can help both EHDI coordinators and families in understanding each other's challenges and needs in regard to family involvement and leadership. The FL3 could provide resources to help EHDI coordinators approach families, recruit diverse family voices, and provide training in how families and EHDI coordinators can work together to ensure meaningful family-professional partnerships.

### **Key Finding #3: Families Need Support from Other Parents Who Share Their Lived Experience**

Parents reported that the most significant connections they had were associations with families who had a child who was DHH, getting support from other parents, and attending activities and trainings for families. Open-ended written responses reinforced these findings; the most prevalent comments reflected a desire to connect with parents of children who are DHH, family support organizations, other children who were DHH, and adults who were DHH. During the father focus group, participants indicated that father-focused support is often overlooked and that fathers would find it meaningful if they were included from the time their child was first identified as DHH. These findings are also supported by Jackson (2011) who examined supports perceived as important by families of newly-identified children who were DHH. Jackson found that families expressed a preference for discussion with other parents of children with hearing loss over discussions with parents of children without hearing loss. Moreover, the NCHAM EI SNAPSHOT study found that over half of the family respondents reported that they needed opportunities to connect with other families of children who are DHH. These studies identified that connection to other families with DHH children is important to families who have children who are DHH. Though most FBO staff reported that they offered family-to-family support, it is unknown if this support is provided by families who have children who are DHH or by families with children who have other special needs.

### **Key Finding #4: Underserved Families Need Additional Support**

There are many families with children who are DHH who experience additional challenges such as having to travel long distances to obtain services, language and cultural barriers experienced by minorities, and those with additional disabilities. For example, travel time for rural families to attend family support events was identified as a significant barrier. These parents said it would be better if there were more virtual events, events spread throughout the state, events held in the evenings and on weekends, and additional activities for their hearing children. During the Latino focus group, parents cited their unique challenges in finding and accessing culturally appropriate supports. Additionally, they highlighted the complex immigration status and parent education issues that make access more challenging for people in their culture. In the Deaf Plus focus group, parents of children who have additional disabilities or health needs beyond being DHH discussed their unique needs. One parent expressed that she wished others had a better understanding of the additional complexities of a child who is Deaf Plus, such as an exponential increase in providers and the additional care of their children. These parents stressed the importance of connecting with other parents of children who are Deaf Plus and highlighted an increased importance of self-care and respite.

### **Limitations**

Although there are important and valuable findings from this study, there are also limitations. First, 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 Facebook and Twitter accounts from NCHAM and H&V. This strategy was useful in terms of obtaining responses, but it is impossible to know how representative these responses are of the population of families with children who are DHH. As with any self-report survey, there may also be a tendency for some respondents to be overly positive in some of their responses. For example, EHDI coordinators may have the desire to present themselves in the most knowledgeable, competent light. As a result, rating scores of their knowledge or practices may not be an accurate reflection of what supports they are offering parents nor what they need from the FL3 to better support parents. Additionally, FBO staff were new to their roles in the EHDI system and as such may not have had the requisite knowledge base nor time to interact with other partners or parents. Lastly, protecting confidentiality hinders providing program-specific technical assistance. To obtain responses that were as honest and open as possible, respondents were guaranteed that their names and state identification would not be made known unless they voluntarily chose to share this information.

### **Conclusion**

Results of this needs assessment revealed that despite current efforts of EHDI programs and FBOs, parents of children who are DHH continue to report that they would like more support and resources in a variety of areas and would like to receive these at different points in their child's life. Additionally, parents in this study expressed the desire to become family leaders and would like to be given the opportunity to be aware of opportunities, develop leadership skills, and serve in the EHDI system in meaningful ways.

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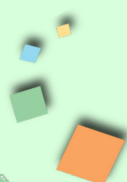
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