

## The Role of Family-led Disability Organizations in Supporting Families with Hearing-Related Concerns

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### Abstract

A survey was conducted with state level chapters from Family Voices, Parent Training and Information Centers, and Parent-to-Parent USA to understand how their current activities support families of children with hearing-related concerns and to identify gaps in their ability to support families of children who are deaf or hard of hearing (DHH). These organizations reported that they are contacted with parent requests for information in regard to family support opportunities, early intervention, referral sources pertaining to hearing concerns, financial help, and providing information about legal rights. Results showed that the greatest challenges for these organizations were related to needing to connect families to financial resources pertaining to hearing-related needs, engaging families of children who are DHH in their organization's activities, having resources available in other languages, and identifying pediatric providers that serve DHH children. Potential ways to strengthen the capacity of these organizations to meet the needs of families with hearing-related concerns as well as increasing their awareness of partnerships with the EHDI system are discussed.

**Acronyms:** AG Bell = Alexander Graham Bell Association for the Deaf and Hard of Hearing; ASDC = American Society for Deaf Children; CPIR = Center for Parent Information and Resources; CYSHCN = children and youth with special health care needs; DHH = deaf or hard of hearing; EHDI = Early Hearing Detection and Intervention; F2F HICs = Family-to-Family Health Information Centers; FV = Family Voices; H&V = Hands & Voices; MCHB = Maternal and Child Health Bureau; P2P USA = Parent-to-Parent USA; PTI = Parent Training and Information

### Introduction

Over the past three decades, family-led organizations have played an important role in supporting families of children with special needs (Adinbinder et al., 1998; Henderson, Johnson, & Moodie, 2014). Based on the core principle of “parents helping parents” these early organizations have served to not only connect families with one another as sources of support but also have been effective advocates in driving the direction of family-centered services and legislation.

With the recognition of family leadership as a cornerstone in driving the development of family-centered services for children and youth with special health care needs (CYSHCN; McPherson, Arango, & Fox, 1998) the number of such organizations has grown throughout the United States. (National Consensus Framework for Systems of Care for Children and Youth with Special Health Care Needs Project, 2014; National Committee for Quality Assurance, 2011). Organizations such as the Parent Training and Information Centers, Family Voices, Family-to-Family Health Information Centers, and Parent-to-Parent USA all have state chapters as well as national headquarters. As shown in Table 1, these organizations vary in their funding and emphasis, but they all serve as an important “door” for families to enter when they need help to address concerns related to their child. The Parent Training and Information Centers (Center for Parent Information and Resources, 2015), funded under the Individuals with Disabilities Education Act (2004), have expertise in education-related issues faced by families

of children ages birth to 22 years with disabilities. Family Voices (2015) is a family-led organization established to address access to family-centered care for families of CYSHCN. Family-to-Family Health Information Centers (F2F HICs), typically awarded to Family Voices state chapters, were established to help families of CYSHCN navigate the often-confusing maze of services, especially those related to obtaining health care. Parent-to-Parent USA (P2P USA) programs focus on providing emotional and informational support to families of children who have special needs primarily by matching parents seeking support with an experienced, trained “support parent.”

Given their focus on serving families of children with diverse special needs, all of these organizations claim to address questions related to where to find services or resources pertaining to hearing. Thus, these broad-based organizations can potentially play a central role in connecting families who are concerned about their child's hearing but may not yet have a diagnosis to essential resources, such as state Early Hearing Detection and Intervention (EHDI) programs.

Additionally, these organizations could be an important partner in helping families connect to resources to meet the unique service needs of children who are DHH. A family's quality of life—defined as the degree to which the family's needs are met—is often impacted by having a child who is DHH (Jackson & Turnbull, 2004). The literature demonstrates that these families often have difficulty accessing needed care (Arehart & Yoshinago-Itano, 1999; Data Resource Center for Child and Adolescent Health,

**Table 1. Descriptions of Family Organizations Surveyed**

Organization	Coverage, Focus, and Website
Family Voices (FV)	Established over 30 years ago by families who strove to care for their children and youth with special health care needs (CYSHCN) in their home and community in a time when institutionalization was the norm. FV operates state affiliate chapters in most states, offering families of CYSHCN—which includes children who are DHH—resources and support to make informed decisions regarding health care, advocating for improved public and private policies, and building partnerships among families and professionals. FV operates the National Center for Family-Professional Partnerships funded by the federal Maternal and Child Health Bureau (MCHB). <a href="http://www.familyvoices.org">http://www.familyvoices.org</a>
Family to Family Health Information Centers (F2F HICs)	These non-profit, family-staffed organizations provide information, education, training, support and referral services, outreach to underserved/underrepresented population, and guidance on health programs and policies. MCHB provides the primary funding for F2F HICs, as authorized by the Family Opportunity/Deficit Reduction Act of 2005. Through this funding, MCHB currently supports F2F HICs in all states and the District of Columbia. Family Voices provides technical assistance, training, and connections to F2F HICs. <a href="http://www.familyvoices.org">http://www.familyvoices.org</a>
Parent Training and Information Centers (PTIs)	Each state has at least one PTI, which focuses on supporting parents of children with disabilities, including children who are DHH; some states also have Community PTIs that focus on underserved populations (e.g., low English proficiency). Their purpose is to provide parents with information and training about disabilities, rights under the Individuals with Disabilities Education Act (IDEA, 2004) and other relevant laws, and resources pertaining to education issues in particular. They conduct workshops and conferences for parents. PTIs are funded through the Office of Special Education and Rehabilitative Services as authorized by the IDEA. The Center for Parent Information and Resources (CPIR) serves as a central resource of information to the PTIs. <a href="http://www.parentcenterhub.org/find-your-center/">http://www.parentcenterhub.org/find-your-center/</a>
Parent to Parent USA (P2P)	P2P programs have offered parent-to-parent support as a core resource for families with children (including those who are DHH) who have a special health care need, disability, or mental health issue. Their main approach is to match parents seeking support with a one-to-one “match” with an experienced, trained “Support Parent” who provides emotional support and assistance in finding information and resources. To date, 32 states have P2P affiliate programs, and 2 have a P2P nonmember—or emerging—program. P2P USA was created in 2003 with funding from the Robert Wood Johnson Foundation and obtains funding through other donations. <a href="http://www.p2pusa.org">http://www.p2pusa.org</a>

2015). Additionally, parent-to-parent support is particularly important for hearing parents of DHH children (Hintermair, 2000). Families of children newly-diagnosed as DHH expressed a preference for discussion with other parents of children with hearing loss over discussion with parents of children without hearing loss (Jackson, 2011). Therefore, organizations such as Parent-To-Parent USA—with the mission of connecting parents with other parents who have gone through similar experiences—can connect families with groups such as Hands & Voices, the American Society for Deaf Children (ASDC), or the Alexander Graham Bell Association for the Deaf and Hard of Hearing (AG Bell).

Finally, these organizations can play a valuable role in meeting needs that are universal to all families of children with special needs, such as insurance coverage or education rights. Family Voices and the Family-to-Family Health Information Centers can help families in need of financial support to obtain needed audiological evaluations or hearing assistive technology. Parent Training and Information (PTI) Centers, for example, ensure that the educational and early intervention service needs for children who are DHH are provided in accordance with federal and state laws and regulations.

In spite of the potential for these organizations to support the needs of families who have questions or concerns about their child who is DHH, little is known about the extent to which these family organizations are currently contacted by families with hearing-related concerns. Understanding the extent to which they link families with DHH resources as well as being aware of the challenges experienced by these groups would help ensure that families of children who are DHH receive the assistance and support they need.

## Methods

An online survey was conducted with four organizations to determine the number of families that contact them with hearing-related concerns, the types of information and referrals they provide, and the challenges they face in supporting these families.

## Subjects and Recruitment

Subjects consisted of state-level directors from the following organizations:

1. Family Voices (FV)
2. Family-to-Family Health Information Centers (F2F HICs)
3. Parent Training and Information Centers (PTIs)
4. Parent-to-Parent USA (P2P USA)

National leaders of these organizations were contacted prior to survey administration to ensure their support in dissemination of the survey. The national offices provided a list of state affiliates, and they each sent a formal request to their members to respond to the survey that was integrated into a standardized recruitment letter developed by the researchers.

During the initial recruitment process, it became apparent that many of the state affiliates of these organizations were actually housed within the same organization. For example, New Jersey's Statewide Parent Advocacy Network houses the state's FV, F2F, PTI, and P2P USA. This is because some organizations received grants to operate multiple programs and it was financially practical to house these grants under one roof with a shared staff. However, varying individuals may staff each of these different organizations. To ensure that the survey reached all potential state leaders, the online survey was sent to whomever was listed as the state-level contact according to the national level office.

A total of 164 surveys were sent and 127 responses were received representing 77% of the targeted respondents. Responses were obtained from 96% of the F2F HIC programs, 85% of the Family Voices state chapters, 84% of the PTIs, and 58% of Alliance Members of the P2P USAs. When asked to identify all of the organizations the respondent represented, 58% reported that they represented more than one organization (e.g., FV and F2F). When multiple responses were received for the same

organization, information was consolidated, resulting in a total of 104 responses that were analyzed.

## Survey Development

An online survey that consisted of eight multiple choice questions with options for adding open-ended responses was developed by the researchers, with initial content created based on input from the National Center for Hearing Assessment and Management's family advisory members. A paper version of the survey was then piloted with three state level administrators representing the aforementioned organizations. Revisions were made based on recommendations, and the resulting survey was sent using SurveyGizmo. The survey contained questions to ascertain (a) the number of families that contact them with hearing-related issues; (b) the types and content of information they provide to families; (c) the challenges they face in trying to meet the needs of families who have children with hearing-related issues; and (d) the extent to which they partner with other DHH organizations including their EHDI program.

## Data Entry and Analysis

Data entry and analyses were conducted using Microsoft Excel. Descriptive univariate analyses (primarily frequency distributions) were conducted. Given the uniformity in responses across the three organizational groups, the responses were collapsed to present an overall picture of the role of these organizations in supporting families with hearing-related concerns.

## Results

The results from the online survey, primarily in the form of frequency distribution, are presented below. Findings are reported in relation to the main topics of the survey:

1. The number of families with hearing-related concerns who contact the organizations,
2. The types of information provided,
3. The self-reported challenges of the organizations,
4. The relationship of the organization with the state EHDI program.

## Number of Contacts Regarding Hearing Issues

Respondents from each organization were asked to identify how many families, on average, contact them for information or support pertaining to hearing-related needs within a one-year time period. Their responses, based on the categories offered them, are provided in Table 2. The largest number of respondents (28%) reported 1-10 families, while 18% of respondents reported 11-25 families, another 18% reported 25-50 families, 15% reported 50-100 families, and close to 23% reported being contacted by more than 100 families each year. Roughly 11% reported that they did not know how many contacted them with this specific need.

**Table 2. How Many Families with Hearing-Related Concerns Contact You on an Annual Basis?**

Number of Families	<i>n</i>	Percent of Responses
1-10	29	22%
11-25	19	18%
25-49	19	18%
50-100	15	15%
100-199	7	7%
200 or more	2	2%
Don't Know/Can't Estimate	12	12%

**Table 3. What Types of Information Do You Provide to Families With Hearing Related Needs (Check All That Apply)**

Type of Information	<i>N</i>	%
Parent support opportunities	92	94%
Addressing EI issues/finding EI services	90	90%
Where to go if concerned about hearing loss	87	92%
Addressing school issues/finding educational services	86	80%
Paying for services/insurance issues	74	90%
Legal rights on behalf of child	68	67%
Other health issues	65	82%
Where to find pediatric providers for hearing evaluation	64	76%
Information regarding hearing aids	38	55%
Information regarding cochlear implants	38	49%

Note. EI= Early Intervention

### Types of Information Provided

Respondents were provided with a list of options pertaining to the types of information they could provide to families of children with hearing-related needs. Table 3 reflects the percent of programs reporting specific types of information provided to families. Nearly 90% of the programs reported that family support opportunities were requested, along with requests for information addressing early intervention issues. Information in response to “where to go if family is concerned about the child’s hearing loss” was identified as information provided by nearly 85% of the programs. Roughly 72% of the programs reported providing information pertaining to questions about how to pay for services or insurance-related issues. Two-thirds of the programs reported providing information about legal rights, and slightly more than 60% reported providing information on where to find pediatric providers as well as providers for other health-related issues. Approximately 37% of the programs provided information pertaining to cochlear implants or hearing aids.

Slightly less than half of the programs reported providing information about communication options. When reviewing the types of communication options discussed by this subgroup, 88% reported that they present information about sign language, total communication, and listening and spoken language approaches. Over 20% of the programs reported providing information about an array of other communication options, such as assistive technology or cued speech.

### Challenges of Family Organizations

To identify the issues facing these family organizations, respondents were asked, “What are the challenges or frustrations your organization faces in trying to help families with children with hearing-related needs?” As shown in Table 4, knowing about financial resources to cover hearing-related services (such as hearing aids) was identified as a challenge by 61% of respondents, followed by having materials available in languages other than English (47%), and engaging families of children who are

DHH in the organization’s activities, such as training and newsletters (44%). Identifying health care and education providers with experience in serving infants and young children with/at risk for hearing loss was identified by 41% of respondents, and providing objective information to families about communication options was checked by 37% of the programs. “Explaining to families the importance of hearing screening or diagnostic follow-up” was identified as a challenge by 29% of respondents.

Respondents also were given the opportunity to write in other types of challenges or frustrations they face. Many of the comments dealt with access to care issues. For example, one respondent wrote, “It is sometimes hard for families to find the services that are being provided... (especially) in rural areas.” Others voiced frustration with schools and other services for children who are DHH, such as the comment that “Sometimes the school districts are biased as to communication options, they tend to promote the mode for which they have proficient employees and not according to what families may want.” Getting timely referrals as well as connections to early intervention also were identified as frustrations experienced. Supporting parents who are DHH themselves was identified as a challenge, along with identifying adequate supports for children with multiple diagnoses. Five programs said that they would like to be able to connect families of children who are DHH with other families but that they lack the contacts or hearing-loss specific groups in their state.

## Referrals to EHDI System Partners

The extent to which these family-led organizations connect families with the state EHDI program and other hearing-related organizations was investigated. As shown in Table 5, programs were asked to identify from a list to which organizations they refer families of children with hearing-related needs. Almost 70% of the respondents reported that they refer families to the state EHDI program, with roughly half of the respondents identifying the state association of the deaf as well as the state school for the deaf. About 44% of programs reported referring families to a disability rights organization. The most frequently mentioned hearing-specific family support groups were Hands & Voices (41%) and AG Bell (26%).

Respondents were asked specifically about the ways that they are working with their state’s EHDI program. As shown in Figure 1 the majority of respondents reported making referrals to one another (60%). Other responses included working together on training activities (20%), being on their state EHDI advisory board or task force (17%), developing materials together (14%), and working on grants together (11%).

## Discussion

The purpose of this study was to understand the role of broad-based family organizations that support families of children with special needs in helping families with hearing-related concerns. Additionally, the researchers sought to understand the needs of these organizations to better support their capacity as a partner in the broader

**Table 4. What Are Challenges You Face in Helping Families (Check All That Apply)**

Type of Challenges	<i>n</i>	% of Programs
Importance of screening and follow-up	30	29%
Information regarding communication options	38	37%
Identifying pediatric DHH providers	42	41%
Engaging DHH families	45	44%
Materials available in other languages	48	47%
Knowing DHH financial resources	63	62%

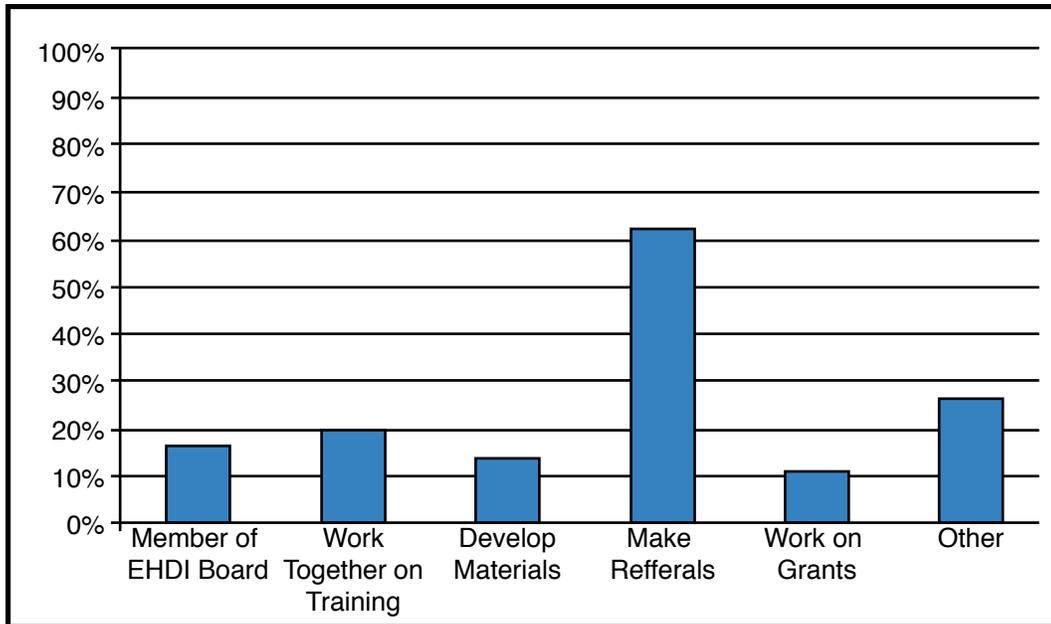
Note. DHH = deaf or hard of hearing.

**Table 5. To Which Organizations Do You Refer? (Check All That Apply)**

Type of Challenges	<i>n</i>	% of Programs
Hands & Voices	42	41%
Disability Rights Organizations	45	44%
AG Bell	27	26%
State Association of the Deaf	55	53%
State School for the Deaf	53	51%

Note. AG Bell = Alexander Graham Bell Association for the Deaf and Hard of Hearing.

**Figure 1. In Which Ways Do You Work With Your State EHDI Programs?  
(Check All That Apply)**



Note. EHDI = Early Hearing Detection and Intervention.

service system for families of children who are DHH. Family Voices, Family-to-Family Health Information Centers, Parent Training and Information Centers, and Parent-to-Parent USA state chapters were invited to participate.

Although survey findings show that these organizations are being contacted by families with hearing-related issues, the number of families reaching out to them is relatively small in relation to the number of children who are DHH. Based on the numbers reported by all of the respondents and assuming that the non-respondents were contacted about the same number of times, there were approximately 6,000 contacts with these organizations during a 12-month period. Even if all of these contacts were by different people (which is unlikely), this number is a tiny percentage of the estimated 100,000 to 350,000 school-aged children in the U.S. with permanent bilateral hearing loss greater than 25 dB (Lin, Niparko, & Ferrucci, 2011; Lundeen, 1981). The fact that such a small number of families of children who are DHH are contacting these organizations is consistent with reports in the literature about the difficulty families report about accessing information, obtaining resources, and finding social support (Jackson, 2011; Jackson & Turnbull, 2004). The results of this study reinforce the need for increased awareness about these family organizations. EHDI system stakeholders—EHDI program coordinators, physicians, audiologists, and early interventionists—can all help connect families to these resources.

When asked about the types of information they provide to families, slightly less than half of the organizations reported that they provided information about communication options. Although they appear to be providing information about the main types of communication modalities used with children who are DHH, the level of expertise and their ability to clearly explain the various options and

considerations is unknown. Delivering information in an unbiased manner and understanding the complexity of the decision making process for families in selecting communication modalities is critical. Because this is an important issue that has been cited in the literature as a frustration for families (Jackson, Becker, & Schmitendorf, 2002), methods to support these broad family organizations warrants further exploration. It also is important to note that about a third of respondents identified “providing information about communication options” as a challenge. These results speak to the importance of linking families to hearing-specific resources that have the expertise to address this complex decision.

The survey sheds light on additional challenges these organizations face in supporting families with hearing-related concerns. Knowledge about financing hearing assistive technologies and care, having materials available in multiple languages, and explaining the importance of hearing screening and follow up were reported as issues these organizations face in their efforts to help families.

Since it’s unlikely that these broad-based organizations can be experts on every disability, it is important that they refer families to hearing loss–specific services and organizations that have the needed expertise. The extent to which these organizations make referrals to other DHH-related state resources such as Hands & Voices or AG Bell, as well as state Schools for the Deaf and EHDI programs showed that roughly half of these organizations referred families to their state’s School for the Deaf or state Association of the Deaf, and even fewer organizations referred families to Hands & Voices and/or AG Bell. Ideally, higher referral rates are desirable. It is important to note, though, that these latter two organizations are not currently present in all states, which likely influences the lower percentage

of referrals. Regardless, tools such as the “*Just in Time Hearing Related Resources for Families*” (National Center for Hearing Assessment and Management, 2014) can be distributed to all family organizations, providing them with concrete information about essential resources that they in turn can share with families.

Both disability specific and non-disability specific organizations have contributions to make in the support of families who have children who are DHH, particularly for DHH children with additional special needs. For example, Family Voices has considerable experience in regard to financing strategies and communicating with insurance companies, and they could be a valuable partner in working toward more hearing assistive technology coverage in states. Parents to Parents can help connect families with other parents who have children with similar multiple needs, such as autism and hearing loss. Parent Training and Information Centers can lend expertise to families facing legal disputes about educational placements.

Opportunities for these organizations to contribute to the EHDI system in particular are worthy of expansion. In addition to the frequent referrals they are already making, these organizations can contribute by having their voice heard on state EHDI advisory boards, assisting in training, assisting in raising public awareness of the importance of early screening and timely diagnosis, and connections to early intervention services.

There are limitations to this study. First, the data were obtained primarily via respondent recollection of their activities over the past year and dependent on the knowledge base of the respondent about their organization. Additionally, since many of the organizations were integrated under the same infrastructure “umbrella” in their state, it is difficult to isolate the activities of one particular organization, such as analyzing all the responses of Family-to-Family Health Information Centers alone. Therefore, there is a need for more in-depth analyses to guide the direction of how to provide targeted support to specific family organizations. Finally, this study focused primarily on the provision of information to help families connect with needed resources and to navigate the service system. Further research on how organizations can address other important aspects for families of children who are DHH (i.e., emotional support, building confidence, and competence) is warranted (Henderson et al., 2014). This is likely an appropriate activity for stakeholders within specific states who desire to ensure comprehensive family support systems.

All of these organizations, both broad-based organizations as well as DHH-specific family organizations, play an essential role in supporting EHDI systems by bringing the family perspective to the table—an essential component for creating family-centered service systems. They can emphasize important needs of families that the service system should address and they can, in turn, ensure families get accurate information about DHH services. In

a recent analysis of family participation in serving children with special health care needs, “a key finding is that while some state and local government entities incorporate and support robust family participation, overall involvement of families is very inconsistent and often fairly anemic in policy making and implementation of decisions” (O’Sullivan & Tompkins, 2014). State EHDI programs can work on strengthening their support for families as well as family-professional partnerships by outreach to all family organizations in their state.

There is much work to be done, and it will take collaboration and shared leadership to ensure all families who have children who are DHH obtain the knowledge, support, and decision-making skills in accordance with their needs. Successful outcomes for children who are DHH are tied to well-supported families. When family-led organizations collaborate and work together for this shared purpose, families and children are the beneficiaries.

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