Involvement of Adults Who Are Deaf or Hard of Hearing in EHDI Programs

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Abstract: Consistent with a position statement of the Joint Committee on Infant Hearing (JCIH, 2007), several key organizations and groups have supported involving adults who are deaf or hard of hearing (DHH) in Early Hearing Detection and Intervention (EHDI) systems, including providing families of children who are DHH opportunities to interact with adults who are DHH. This article reviews the available data on the involvement of adults who are DHH in EHDI systems to determine the availability of opportunities for families who have children who are DHH to interact with adults who are DHH, how families feel about these experiences, and describe the programs that exist to provide these experiences. The article is based on results from three separate national surveys which included responses from parents and from EHDI related programs and organizations. Results showed that about half of parents with children who are DHH wanted opportunities to interact with adults who are DHH, but often experienced difficulty accessing these connections. Also, the variety of these services were too limited, and programs that promote involvement of adults who are DHH need more funding to provide these services to families.

Key Words: Deaf, Children, Adults Who Are Deaf or Hard of Hearing, Deaf Mentor

Acronyms: ASL = American Sign Language; DHH = deaf or hard of hearing; EHDI = early hearing detection and intervention; FL3 = Family Leadership in Language and Learning; GBYS = Guide By Your Side; HRSA = Health Resources and Services Administration; JCIH = Joint Committee on Infant Health; LSL = Listening and Spoken Language; MCHB = Maternal Child Health Bureau; NCHAM = The National Center for Hearing Assessment and Management

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are DHH is a good first step and added that adults who are DHH should be included in all aspects of EHDI programs, including serving on state EHDI advisory boards.

Other groups have also advocated for the inclusion of adults who are DHH in providing support to families of children who are DHH. For example, Moeller, Carr, Seaver, Stredler-Brown, and Holzinger (2012), described the conclusions of an international consensus panel about Best Practices in Family-Centered Early Intervention for Children Who are Deaf or Hard of Hearing. The panel noted that “Families [should be] connected to support systems so they can accrue the necessary knowledge and experiences that can enable them to function effectively on behalf of their DHH children ... [including supporting] connections between families and adult role models who are DHH” (p.435). Moeller et al. encouraged early intervention programs to provide families with opportunities for “meaningful interactions” (p. 441) with adults who are DHH including involving them on early intervention teams as role models, mentors, and/or consultants, who can offer information and resources, and “demonstrate enriching language experiences” (p. 441).

Providing families of children who are DHH with opportunities to interact with adults who are DHH is also encouraged in federal legislation that provides funding for all of the state-based EHDI programs. As noted in the Early Hearing Detection and Intervention Act at 42 USC 280g-1(a)(1)(c), “Programs and systems under this paragraph shall offer mechanisms that foster family-to-family and deaf and hard-of-hearing consumer-to-family supports.”

Additionally, the U.S. Department of Health and Human Services, Maternal Child Health Bureau/Health Resources and Services Administration (MCHB/HRSA) issued guidance for funding the “Family Leadership in Language and Learning (FL3)” program in 2017. HRSA noted one goal of the program was “[t]o 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” (p.1). The term Deaf Mentors was later clarified to include “[m]entoring by a variety of DHH adults including those who use ASL [American Sign Language], Cued Speech, Listening and Spoken Language (LSL), and combinations of modalities” (Hands & Voices, 2017b).

Given the widespread support for programs to provide opportunities for families of children who are DHH to interact with adults who are DHH, this article summarizes the available data to paint a picture of what is known about the programs that offer these opportunities to families of children who are DHH.

Data Collection Methods

Data were collected from the following sources to draw conclusions about how many families of young children who are DHH have opportunities to interact with adults who are DHH. Data also indicated how they felt about those interactions if they had them.

- The National Center for Hearing Assessment and Management (NCHAM) at Utah State University surveyed the coordinators and state-based EHDI programs in all states and territories in 2010 and updated that information via a similar survey and telephone interviews in 2017. State EHDI coordinators were asked to provide information about programs in their state or to recommend other people in the state who might have better information. Data were collected from people in 49 states and territories (Shuler-Krause, 2018). Details about the data collection methods and a report on the findings are available at https://tinyurl.com/dhhadultinvolvement

- In 2018, NCHAM published the results of a national study entitled EI SNAPSHOTS (Early Intervention for Children who are Deaf or Hard of Hearing: Systematic Nationwide Analysis of Program Strengths, Hurdles, Opportunities, and Trends). A part of the EI SNAPSHOTS study included data collected from a national sample of 303 families with 2–6 year-old children who were DHH. Details about the data collection methods as well as results, conclusions, and recommendations of the larger study are available at https://infanthearing.org/ei-snapshot/

- During 2017–2018, the newly funded FL3 program conducted a national needs assessment to take an “in-depth look at the needs of families, family-based support organizations (FBOs), and U.S. state and jurisdiction 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 DHH” (p.5). One part of this Needs Assessment collected information from a national sample of 458 families of 0–6 year-old children who were DHH. Information from these families included their responses to questions about the extent to which they had had interactions with adults who were DHH and, for those who had had such interactions, their perceptions about benefits, challenges, and opportunities for improvement. Details about the data collection methods as well as results, conclusions, and recommendations of the complete Needs Assessment study are available at https://handsandvoices.org/fl3/resources/needs-assessment.html

Summary of Available Data

To provide context for the results about the availability of programs that provide opportunities for families of young children who are DHH to interact with adults who are DHH,
it is important to briefly describe the purpose of these programs and to define some key terms. The document, *Guidelines for Deaf and Hard of Hearing Mentor/Guides/Role Model Programs* (Hands & Voices, 2017b) produced by the FL3 project stated:

The inclusion of DHH adults in the lives of families with children who are DHH can have a profound impact for everyone involved; child, parent, professionals and DHH adults. Trained DHH adults who act as mentors, guides or role models are uniquely qualified to provide families with a positive and hopeful perspective from their day-to-day, real life experiences as a DHH person living in a hearing world. In sharing these experiences and insights, DHH mentors/guides/role models may be able to articulate what a young child cannot, which brings an important perspective and credibilty to the team discussion of the child’s needs, extending beyond academics.

When the parent of a child newly identified as deaf or hard of hearing looks ahead, they may tend to focus on what is missing. The DHH mentor/guide/role model has an opportunity to present to the family a perspective of optimism. By sharing stories, experiences, and asking questions, the DHH mentor/guide/role model may help the family take a step beyond that first awkward moment of how to “talk to a Deaf or Hard of Hearing person.” The DHH mentor/guide/role model can build a relationship with the family and support the bond between the parent and child. What is desired for all families, hearing or not, is the ability for their children to form and maintain lifelong relationships. Initiating a connection with an adult who is DHH starts the family on the path of building new social networks, ones they may not have ever pursued without knowing their child was deaf or hard of hearing. (p.3)

As is clear from the preceding statement, a number of different terms are used to refer to DHH adults who work with families of children who are DHH. Some of the most common terms are Deaf Mentors, DHH guides, and DHH Role Models. Different people use these terms to mean different things. The FL3 guidelines note that the term Deaf Mentor is used by many people to refer to adults who are DHH and who use the Deaf Mentor Curriculum developed by the SKI-HI Institute (Hands & Voices, 2017b). In most cases, these Deaf Mentors focus primarily on teaching American Sign Language and helping families understand deaf culture (Watkins, Pittman, & Walden, 1998). Other people use the term Deaf Mentor in a more generic way such as was the case in the 2017 HRSA guidelines for the FL3 project referenced in the beginning of this article. Another term, DHH Guides, is used by Hands & Voices to refer to a diverse group of adults who are DHH, who work with others in the Guide By Your Side (GBYS; Hands & Voices, 2017c) program. The FL3 guidelines (Hands & Voices, 2017b) state that the role of DHH Guides, is to “share with children and families their unique life experiences, use of technology, how they navigate social situations, how they developed their personal identity, etc.” (p.4). The term, DHH Role Models, refers to adults who are DHH, but according to the FL3 guidelines (Hands & Voices, 2017b),

may communicate via Listening and Spoken Language (LSL), Cued Speech/Cued English, and/or American Sign Language. They provide children who are deaf or hard of hearing and their families with insight into life experiences as an adult who is deaf or hard of hearing. In their position as an Adult Role Model, they do not teach ASL. (p. 4)

In seeking to establish how many programs are focused on providing families of children who are DHH with opportunities to interact with adults who are DHH, a deliberately broad net was cast to include all of the different types of programs described above. The current availability of programs that provide opportunities for families of young children who are DHH to interact with adults who are DHH, the focus of those programs, and how they are funded and administered is summarized below.

### Availability and Benefits of Deaf Mentor/DHH Guide/DHH Role Model Services

Based on the national survey done by Shuler-Krause (2018), 24 states reported that they had established and functioning programs that systematically offer families of young children who are DHH opportunities to interact with adults who are DHH (see Figure 1). More states may have informal opportunities to interact with adults who are DHH. Information about who administers the program, the program goals, curriculum used (if any), and how to contact the program is available at [http://infanthearing.org/dhhadultinvolvement/states/](http://infanthearing.org/dhhadultinvolvement/states/). This information is updated at least annually.

![States that report having an active program for involving adults who are DHH with families of children who are DHH.](Figure 1. States offering families of children who are deaf or hard of hearing (DHH) opportunities to interact with adults who are deaf or hard of hearing.)
The approximate number of families served in each of the programs is shown in Figure 2. Most of the programs serve less than 25 families at any point in time. Combining the results across programs, we can estimate that less than 1,000 families were receiving services from DHH Mentors/Guides/Role Models at the time these data were collected. Table 1 shows that 45% of families reported that they wanted opportunities to interact with adults who are DHH and 22% had no problems accessing such services. Slightly more families (59%) reported that they wanted to meet with other families who had children who were DHH and 34% were able to access these experiences.

Table 1
Data from EI SNAPSHOT Study (2018): Percentage of Families of Children who are Deaf or Hard of Hearing (DHH) who Wanted and were Able to Access Opportunities to Interact with Adults who are DHH and Families who had Children who are DHH

<table>
<thead>
<tr>
<th>Type of service</th>
<th>We Needed and received it with no problems</th>
<th>We Needed, but had trouble getting it</th>
</tr>
</thead>
<tbody>
<tr>
<td>Opportunities to interact with adults who are DHH</td>
<td>22%</td>
<td>23%</td>
</tr>
<tr>
<td>Meeting with other families with children who are DHH</td>
<td>34%</td>
<td>25%</td>
</tr>
</tbody>
</table>

As shown in Figure 3, the FL3 Needs Assessment had similar findings with 27% of families reporting that they had access to a DHH Role Model. Interestingly, of those families offered the opportunity to interact with an adult who is DHH, only 69% actually met with an adult who is DHH. Families in the FL3 Needs Assessment who had an opportunity to meet with an adult who was DHH but opted not to do so reported being too busy, feeling that it did not meet their needs, or they already had contact with adults who are DHH (see Figure 4).
that adults who are DHH helped them with issues like “How to access interpreters,” (p. 33) and “How to connect more with kids my son’s age who have cochlear implants” (p. 33).

Program Administration and Funding
Shuler-Krause (2018) also gathered information about the programs’ structures including administrative affiliations, annual budgets, and funding sources. As shown in Figure 6, most programs that involve adults who are DHH are administered by non-profit organizations, family-based organizations, and state schools for the deaf.

Programs that systematically involve adults who are DHH use a variety of funding sources including private grants, early intervention/Part C funding, state EHDI/HRSA federal funding, Medicaid billing, and state or federal grants (see Figure 7).

Many programs (41%) used other sources of funding which included State Department of Education, State Schools for the Deaf, Deaf and Hard of Hearing Resource Centers, School Districts, State Association of the Deaf, and State Department of Health and Human Services. Almost all programs (21 of 22) reported using multiple sources to fund their programs.

Annual budgets for programs involving adults who were DHH ranged from under $10,000 to over $150,000 each year as shown in Figure 8. The amount of budget for the program was positively correlated with the number of families receiving services.

Figure 5. Benefits of meeting with a Role Model who is deaf or hard of hearing reported in the Family Leadership Language and Learning (FL3) Needs Assessment.

Figure 6. Affiliation of programs that provide opportunities for families of children who are deaf or hard of hearing (DHH) to interact with adults who are DHH.

Figure 7. Funding sources of programs that offer opportunities for families of children who are deaf or hard of hearing (DHH) to interact with Adults who are DHH. EHDI = Early Hearing Detection and Intervention; HRSA = Health Resources and Services Administration.

Figure 8. Annual budgets of programs that offer opportunities for families of children who are deaf or hard of hearing (DHH) to interact with adults who are DHH.
Focus and Frequency of Visits
Most programs reported that a majority of the families served by their programs had children who were DHH in the 13 to 24-month age range, and 70% of programs responded that families were provided opportunities to interact with adults who are DHH on a weekly basis, as shown in Figure 9.

![Figure 9. Frequency of Deaf Mentor services.](image)

Programs were asked about the emphasis placed on teaching children and families a specific language or modality. As shown in Figure 10, 16 of the 24 programs (67%) reported that their programs had a moderate-major emphasis on teaching children and families a specific language or communication modality, with all of these focusing on ASL or sign language.

![Figure 10. Emphasis placed on teaching families a specific language or communication method.](image)

When asked if their program used an established curriculum or training, 13 programs responded that they used the SKI-HI curriculum (SKI-HI), two programs used the Hand & Voices (2017c) Guide By Your Side training, and one program used the Shared Reading Project curriculum (Clerc Center, 2015).

Challenges
As shown in Figure 11, programs cited securing and maintaining funding as the number one challenge they faced. Other commonly reported challenges were in the areas of recruitment of skilled/qualified staff and lack of training opportunities. Some programs mentioned difficulty finding racially, linguistically, culturally, and hearing level diverse DHH individuals in their state, as well as challenges in receiving timely referrals to their programs.

Discussion and Conclusions
Support for including adults who are deaf or hard of hearing in EHDI systems and ensuring that parents of children who are DHH have the opportunity to connect and interact with adults who are DHH is not new, but has gained momentum following the 2007 JCIH position statement, the signing of the EHDI Reauthorization Act, and the initiation of the FL3 project. Widespread support for including adults who are DHH in EHDI systems is undeniable, yet less than half of states report having a systematic program for ensuring these connections and 45% of families who have children who are DHH report that they would like to have such interactions. Of the families who wanted these opportunities, 22% reported that they had difficulty accessing them. However, of the parents who were offered the opportunity to meet with adults who are DHH, only 69% actually met. The parents that did not take advantage of these offerings said they were too busy or felt that the program did not meet their needs at the time. It is also important to note that in answering this question in the SNAPSHOT study, a slightly higher percentage (59%) of families reported being interested in meeting with other parents of children who are DHH, and 25% of these families had difficulty accessing these experiences. Although many families are interested in opportunities to interact with adults and have difficulty accessing these experiences, an even higher percentage are interested in meeting other parents of children who are DHH and these families have even more challenges finding these opportunities.

Although there is a strong desire for opportunities to interact with adults who are DHH, the availability of these programs is only one factor to consider in providing support from adults who are DHH to parents. EHDI systems should also consider other factors that influence parent engagement in these systems and ensure that their programs provide these services in a way that meets the needs of each family. These factors include consideration of what stage in the journey families most benefit from these services, scheduling opportunities at a time that works for families, and ensuring diversity of the adults who are both DHH and available to meet with families. Over 67% of programs reported a moderate to major emphasis on instruction of a specific language or modality, and of those, 100% of the programs reported a focus on sign language or ASL instruction. This is significant because...
children who are DHH and their families use a variety of different methods and languages to communicate with each other. Regardless of the way the child or family communicates, all families can potentially benefit from interacting with adults who are DHH. This finding suggests that EHDI systems should also consider how to provide a wider range of opportunities to interact with adults who are DHH. EHDI systems should work to reflect the diverse communication preferences of children who are DHH and their families including ASL and sign language instruction as well as a focus on English language acquisition, listening and spoken language skills, cued speech, and other communication modalities.

When families did meet with adults who are DHH, they touted many benefits which echoed some of the findings of the Deaf Mentor Experimental Project conducted more than 20 years ago (Watkins et al., 1998). These benefits included increased parental confidence in deciding how to communicate with their child and increased parental understanding of different ways to communicate with their child in different situations. Additionally, parents reported benefiting from information the adult who is DHH shared with them about Deaf culture and from seeing a model of what their child is capable of achieving in the future.

Data available about programs that offer opportunities for adults who are DHH to interact with families do not address whether parents see any disadvantages of such interactions. This would be important information in definitively determining the overall effect these experiences have on parents. However, it appears that parents receive significant benefits from these experiences.

Surprisingly, programs designed to offer opportunities for families of children who are DHH to interact with adults who are DHH varied significantly in how they are administered. Programs are run by state schools for the deaf, Part C services, parent support groups, and non-profit organizations among other types of groups. Many programs are quite small, serving less than 25 families, although some of the larger ones serve at least 50 families each year. Annual program budgets also reflect this with a range from less than $10,000 to over $150,000 per year with funding coming from a variety of sources including private grants, early intervention/Part C funding, state EHDI/HRSA federal funding, Medicaid billing, and state or federal grants. Almost all programs reported that they get funding from more than one of these sources. The fact that these programs are administered by so many different groups and in so many different ways, may contribute to the low availability of these opportunities for families depending on which part of the country they live in, what programs they are aware of, and how eligibility criteria differ.

Results also pointed to other barriers in providing these services to families. Not surprisingly, funding was the biggest challenge faced by programs. Programs also reported challenges with recruitment of diverse, skilled, and qualified individuals who are DHH. Finally, programs struggled with finding affordable training and appropriate curricula. Funding, staff, training, and curriculum are all vital components of programs that offer families support from adults who are DHH. These challenges are yet another reason for a low availability of these opportunities for families of children who are DHH.
Results indicate that many families would like opportunities to interact with adults who are DHH, and that families who forge these connections benefit from them, but these opportunities are too limited in availability and scope within EHDI systems. Additionally, increased funding is needed to administer these programs alongside other EHDI services.

As these programs continue to expand, it is important that research and evaluation data be collected to determine the costs, benefits, and challenges associated with programs that provide opportunities for families to interact with adults who are DHH. Future research should focus on the following questions:

- What kinds of interactions with adults who are DHH most benefit families?
- At what stage in the family’s journey do they most benefit from these interactions?
- What kinds of outcomes do these interactions produce for the child’s social/emotional development and/or educational attainment?
- Do these opportunities have an impact on family engagement in the EHDI system?

This article drew data from surveys completed by parents, state EHDI coordinators, service providers, and family based organizations. More research outside of surveys is also needed to determine the answers to the questions asked above, as well as to provide evidence to encourage public health agendas in regards to funding these kinds of programs.

Although there is widespread agreement about the positive benefits of families of children who are DHH interacting with adults who are DHH, there is little data available on this topic. As these programs become more widely available, it is important this data is collected and carefully considered to ensure that resources are expended in ways that will be most beneficial to families.

References


