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Deaf adults in early intervention programs*

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ABSTRACT

Family-Centred Early Intervention (FCEI), an international congress that meets biannually, concurred that programmes serving young deaf and hard of hearing (D/HH) children and their families should include D/HH adults when offering family social and emotional support (Principle 4) and engaging in collaborative teamwork with D/HH adults (Principle 8) (Moeller, Carr, Seaver, Stredler-Brown, & Holzinger, 2013). However, to date, there is no known published research investigating roles of D/HH adults in such programmes. This article discusses results from an online exploratory survey distributed internationally with the focus on the support and roles of deaf adults working in programmes serving young deaf children and their families. Forty-eight respondents completed the survey. Findings indicate that the support provided by deaf adults includes educational information and communication support, and that the major roles provided by deaf adults are as role models and language providers. Additionally, respondents reported that families do not have a diverse range of deaf professionals to connect with in early intervention programmes. This article concludes with a call to action for infusing deaf adults in programmes that include Formalisation, Collaboration, Education, and Infusion. For the purpose of this manuscript, the term “deaf” is an inclusive term representing all individuals with various hearing levels and cultural experiences.

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Family-Centred Early Intervention (FCEI), a global partnership between parents and professionals who are both deaf and hearing, developed an international consensus of best practices for programmes serving young deaf children and their families. The consensus panel, which had participants from ten different

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*This paper is dedicated to the memory of Amy Hile, a leader and role model who made a positive impact in Deaf education.

This article has been republished with minor changes. These changes do not impact the academic content of the article.

nations, agreed on foundational principles, and it included deaf and hard of hearing (D/HH) adults connecting with families and being collaborators in the system (Moeller, Carr, Seaver, Stredler-Brown, & Holzinger, 2013). Because there is no known published research investigating roles of D/HH adults in early intervention programmes on an international scale, this research project explored the role(s) of deaf adults in early intervention programmes within the context of diverse cultures in a global society such as roles deaf adults may have in early intervention systems, how they are able to connect with families to provide support, and if they are infused throughout the system in diverse roles. For the purposes of this paper, the term “infuse” will be used to describe deaf adults as part of the entire early intervention system steeped into the fabric at all levels that may include collaboration, connecting, leadership, partnering, or engaging in all levels of decision-making and service provision. The term “deaf” is being used in this paper as an inclusive term representing all D/HH individuals with various hearing levels, different primary language usages, ways of communicating, and cultural experiences. This paper focuses on why it is important to infuse deaf adults in early intervention systems using anecdotal and scientific evidence and concludes with a call to action.

Why it is important to have deaf adults in early intervention

There are 34 million children with “disabling hearing loss,” which is defined as greater than 30 dB hearing loss in children (World Health Organization, 2018). If hearing loss is not addressed early, consequences include the possibility of delayed language development, academic underachievement, social isolation, higher risk of injuries, and increased poverty (WHO, 2018). Furthermore, with 90% of deaf babies residing in low-resourced countries where quality health care and educational opportunities can be challenging, it is important to identify effective ways to address and improve the quality of life for deaf children (Storbeck & Young, 2015). Having deaf adults connect with families and collaborate with professionals is important since more than 90% of deaf children are born to hearing parents (Mitchell & Karchmer, 2004). While experiences with deaf adults can be different depending upon geographic and cultural situation, the literature shows that hearing parents often do not know what to expect, having little or no experience with deaf people. For example, when a mother from the United States first found out that her son was deaf, she said she was surrounded by hearing people and had no idea what to expect until a deaf adult walked in the door:

When we first received our son’s diagnosis, I looked at the doctor, he was hearing. I looked at the audiologist, she was hearing. I looked at the nurse, she was hearing; and as we walked out, I looked back at the receptionist and she was hearing. I had

no idea what this (raising a deaf or hard of hearing child) was going to look like until you (the deaf adult) walked in the door. (Olson & Rogers, 2012)

In retrospect, another mother commented on the value of having deaf adults provide support to her family:

Deaf and hard of hearing encounters really were positive and taught us a lot. For my daughter, it was the best thing we could have done because she was able to see from a very young age, Deaf and hard of hearing adults who were out in the community, who were working and doing amazing jobs, who had social skills that were wonderful and welcoming and so that is something I could have not taught her because I am not Deaf and hard of hearing so for her that was something I would not have been able to give her if we hadn't had those visits with Deaf and hard of hearing adults. (Gale, Berke, Olson, & Benedict, 2018)

Deaf adults can provide a unique perspective from their own experiences as well as providing culturally-created solutions for effective living (Holcomb, 2013). Fred Schreiber, the first Executive Director of the National Association of the Deaf (NAD), described the value of deaf adults:

The basic reason for becoming involved with deaf adults (is this); we are your children grown. We can, in many instances tell you the things your child would like to tell you, if he had the vocabulary and the experiences to put his feelings and needs into words. (Schreiber, 1980, as cited in Leigh, Andrews, & Harris, 2016)

Studies show deaf children with deaf parents have similar cognitive development patterns as their hearing peers while deaf children with hearing parents show significant delays in theory of mind (Schick, De Villiers, De Villiers, & Hoffmeister, 2007) and executive function development (Hall, Eigsti, Bortfeld, & Lillo-Martin, 2016). Regarding vocabulary development, children who had at least one deaf parent had better vocabulary outcomes (Yoshinaga-Itano, Sedey, Wiggan, & Chung, 2017). Deaf children with cochlear implants raised by deaf parents exceeded speech and language development when compared with deaf children with cochlear implants raised by hearing parents (Davidson, Lillo-Martin, & Chen Pichler, 2014; Hassanzadeh, 2012). Furthermore, deaf children with cochlear implants raised by deaf parents who sign had higher intelligence quotients when compared with deaf children with hearing parents (Amraei, Amirjalali, & Ajalloueyan, 2017). These findings suggest that when deaf adults connect with young deaf children regularly, cognitive development is positively impacted in addition to language and social-emotional development. By extension, the strategies that deaf adults are using with their children can be shared with and taught to all parents in order to support their own child's development.

There is evidence that deaf children of families who received services from deaf mentors in a Deaf Mentor Experimental Project focusing on bilingual-bicultural programming made more language gains than the deaf peers without deaf mentors (Watkins, Pittman, & Walden, 1998). Additionally, parents who had

encounters with deaf adults felt a “strong sense of competence in regard to their child’s upbringing” (Hintermair, 2000, p. 41), felt their sign language skills, as well as the communication interactions with their deaf or hard-of-hearing children, improved (Delk & Weidekamp, 2001), felt it was important to connect with deaf adults (Jackson, 2011), and felt their child had an improved quality of life by participating in the Deaf Mentor Family Program (Petersen, Kinoglu, Gozali-Lee, & MartinRogers, 2016). Furthermore, the deaf adults, who were role models for young deaf children and their families, felt the families they worked with had “more positive perspectives on deafness and positive outlooks for their children” (Rogers & Young, 2011, p. 15).

In addition to connecting families with deaf adults, it is also important that deaf and hearing professionals collaborate throughout the system for practical and ethical reasons. From a practical perspective, deaf adults are experts in issues important to deaf people and can adequately describe what it means to be deaf. From an ethical perspective, infusing deaf adults in the system or with a family reduces misrepresentations or irrelevant information (Benedict & Sass-Lehrer, 2007). Furthermore, having a diverse representation of highly qualified professionals who happen to be deaf infused throughout the early intervention system in leadership roles is important for parents to see that deaf professionals have diverse expertise and professions (Yoshinaga-Itano, 2015).

Recommendations for deaf adults in early intervention

Recommendations to have deaf adults connect with families to provide support and to collaborate with professionals throughout the system have been published as best practice principles in the International Consensus Statement (Moeller et al., 2013). Briefly, committee members from FCEI gathered a diverse panel of experts in Bad Ischl, Austria in 2012 with the mission to establish best-practice principles. The goal was to provide valid, evidence-based principles for programmes serving families with deaf children. The panel agreed on ten foundational principles that guide FCEI. Two of the ten principles explicitly recommend including deaf adults.

Family-Centred Early Intervention Principle 4

The first explicit best practice (found in Principle 4) focuses on social and emotional support systems for families and recommends that service providers “support connections between families and adult role models who are D/HH” (Moeller et al., 2013, p. 435). The intention of Principle 4 is to connect families to “support systems so they can accrue the necessary knowledge and experiences that can enable them to function effectively on behalf of their D/HH

children” (Moeller et al., 2013, p. 435). Supporting evidence includes “parents who have many contacts with hearing-impaired adults show evidence of a strong sense of competence in regard to their child’s upbringing” (Hintermair, 2000, p. 41). Also, in a study examining supports and resources for families with deaf children, parents rated connecting with mentors and role models as important (Jackson, 2011).

Family-Centred Early Intervention Principle 8

The second explicit recommendation (found in Principle 8) focuses on collaborative teamwork and recommends that early intervention teams include “individuals who are D/HH (role models/mentors)” (Moeller et al., 2013, p. 440). The intention of Principle 8 is to establish an optimal team through transdisciplinary teamwork focusing on the family that “includes professionals with experience in promoting early development of children who are D/HH” (Moeller et al., 2013, p. 440). Supporting evidence includes the parents’ needs to have deaf role models to better understand the capabilities of their deaf children (Rogers & Young, 2011), and includes promoting language development (Watkins et al., 1998).

Furthermore, it was recommended that early intervention teams offer families opportunities for meaningful interactions with adults who are D/HH:

- (a) D/HH adults can serve as role models, consultants, and/or mentors to families, offering information and resources and demonstrate enriching language experiences.
- (b) Involve D/HH community members on the team in culturally and linguistically sensitive ways. (Moeller et al., 2013, p. 441).

The consensus published by FCEI was influenced by recommendations published by the Joint Committee on Infant Hearing (JCIH), which was established in 1969 to make recommendations regarding early identification for children with, or at risk for hearing loss and newborn hearing screening in the United States. The JCIH has explicitly recommended including deaf adults in their position statements since 1995 (JCIH, 1995; JCIH, 2000; JCIH, 2007; Muse et al., 2013). The JCIH provides recommended best practices to Early Hearing Detection and Intervention (EHDI) programmes throughout the United States and was approved by the American Academy of Pediatrics, the Council of Educators of the Deaf, the National Association of the Deaf, the American Academy of Otolaryngology: Head and Neck Surgery, American Academy of Audiology, American Speech, Language and Hearing Association, Directors of Speech and Hearing Programs in State Health and Welfare Agencies, the Alexander Graham Bell Association. EHDI is the practice to screen all newborns’ hearing level before

they leave the hospital. For infants who are identified as deaf should receive diagnostic evaluation before three months and early intervention by 6 months. This consensus document was approved by all professional organisations working with young deaf children and their families. The first position statement published in 1995 recommended that deaf and hard of hearing adults provide information regarding hearing levels and the range of available communication and educational options (JCIH, 1995). In 2000, the JCIH updated their position statement by adding a recommendation to allow for opportunities for families to interact with adults and children who are deaf and hard of hearing (JCIH, 2000). Seven years later, in another JCIH position statement update, it was recommended that “adults who are deaf or hard of hearing should play an integral part in the EHDI program” (JCIH, 2007, p. 903). While this goal specifically identifies EHDI systems (a term widely used for programmes in the United States) it can also be expanded to early involvement programmes globally. Additionally, while the JCIH position statement is focused on evidence-based practice in high resourced countries, not all countries have a fully developed system for early hearing detection and identification. There are countries that may have newborn screening in place, but not early support framework to contact families. Other countries cannot afford newborn screening, but they may have other ways of early identification using risk factors, and they may have very effective early follow-up. Regardless of how countries utilise early hearing detection and identification, deaf leadership in early intervention programmes would apply to any programme globally and is not restricted to countries that have a fully developed EHDI system. In the 2013 supplement to the 2007 JCIH position statement, four of the twelve goals recommended the involvement of deaf adults.

Joint Committee on Infant Hearing Goal 3

Goal 3 by JCIH emphasises ensuring deaf adults as stakeholders with the goal for families and their young deaf children to “have EI providers who have the professional qualifications and core knowledge and skills to optimize the child’s development and child/family well-being” (Muse et al., 2013, p. e1328). While more evidence is needed, “research suggests that outcomes for young children and their families are better when providers have specialized training specific to working with infants and toddlers who are D/HH and their families” (Muse et al., 2013, p. e1329). Goal 3a by JCIH specifically recommends deaf adults as collaborative partners in assisting with the development of providing competent sign language instruction. The intention was that “intervention services to teach ASL will be provided by professionals who have native or fluent skills and are trained to teach parents/families and young children” (Muse et al., 2013, p. e1329). In addition to focusing on families learning ASL from a professional native or fluent signer, there is the need for families to have access

to “a language development programme that incorporates classroom-based teaching, incidental learning opportunities for hearing parents and their children in natural sign language immersion contexts with deaf adults and children, and additional support in the form of learning resources.” (Napier, Leigh, & Nann, 2007, p. 84). Additionally, another resource supporting Goal 3a includes results from a Deaf Mentor Experimental project in which children who received Deaf Mentor services in a bilingual-bicultural home environment made greater language gains than children who did not receive Deaf Mentor services (Watkins et al., 1998). Lastly, resources supporting Goal 3a showed the significant correlation between parents who had good signing skills and contacts with deaf adults to the lessening of parental stress since parents displayed more positive attitudes and could relate to their child more easily (Hintermair, 2000).

Joint Committee on Infant Hearing Goal 10

Another JCIH goal that explicitly calls for the involvement of deaf adults is Goal 10, which recommends that deaf adults be active participants in the development and implementation of EHDI systems at the national, state/territory, and local levels. The goal is that “their participation will be an expected and integral component of the EHDI systems” (Muse et al., 2013, p. e1337). The rationale is that language and communication are the heart of the support services and that it is critical to include “individuals who are D/HH (because they) know what works to meet their language and communication needs in a way that people who are hearing cannot.” (Muse et al., 2013, p. e1337).

Joint Committee on Infant Hearing Goal 11

Goal 11 by JCIH is also an explicit goal which recommend deaf adults supporting, mentoring and guiding young deaf children and their families for the purpose of ensuring that “all children who are D/HH and their families have access to support, mentorship, and guidance from individuals who are D/HH” (Muse et al., 2013, p. e1338). Support for Goal 11 in the 2007 JCIH supplement included parents having a strong sense of competence for raising their deaf child (Hintermair, 2000), parents identifying deaf adults as an important support source (Meadow-Orlans, Sass-Lehrer, & Mertens, 2003), and deaf community members providing perspectives that hearing community members cannot provide (Chute & Nevins, 2002). When hearing families with young deaf children have support opportunities from deaf adults, family support of the child is promoted and family stress is reduced (Calderon & Greenberg, 2003; Hill, 1993).

There have been recommendations for best practices and goals to infuse deaf adults in programmes serving young deaf children and their families. However, to date, there is no known research examining the role of deaf adults in programmes serving families with young deaf children nationally or internationally.

This paper explores deaf adults in programmes serving young deaf children and their families, specifically connecting with families and collaborating with professionals.

Materials and methods

Survey development and distribution

The FCEI Deaf Leadership committee, which was a group of deaf and hearing professionals with early intervention experience based in the United States, developed a 26-question online survey using Qualtrics, a survey software. An online survey was selected for the advantages it offers, which includes being an effective way to reach a large population and offering respondents flexibility to complete the survey at their own pace (Callegaro, Manfreda, & Vehovar, 2015). The survey was developed to prepare for a pre-conference workshop focusing on Deaf Leadership with the purpose of learning and sharing information about the role of and best practices for infusing deaf adults in early involvement programmes around the world. Survey questions and options were developed by the Deaf Leadership committee as a first attempt to explore the involvement of deaf adults in early intervention programmes globally. The survey included questions about newborn screening and services, questions about deaf adults in early intervention systems, and questions about respondents' backgrounds (See Appendix A). All work was conducted with formal approval from the first author's Institutional Review Board (IRB), which ensures protection of the rights and welfare of humans participating in research. After data collection, all respondents' names and emails were removed to protect respondents' identities.

Of all the data collected, this article focuses on results related to questions derived from the International Consensus statement's (Moeller et al., 2013) Principle 4 (social and emotional support for families from adult role models who are D/HH) and Principle 8 (early intervention transdisciplinary teams). Specifically, are deaf adults connecting with families to provide support and are deaf adults working collaboratively and in diverse roles in early intervention systems?

An email invitation to participate in the survey (with a link to the survey included) was sent via different avenues. One invitation was sent to professionals serving families with children who are deaf via the FCEI listserv with around 350 participants. Another invitation was sent to the Association of College Educators – Deaf and Hard of Hearing (ACE-DHH), an American organisation with around 250 participants. Professionals included teachers of the deaf, speech-language pathologists, and audiologists. A third invitation was sent to approximately 50 organisations listed under the International Deaf and Disability Organization link via Gallaudet University's Office of Research Support and International Affairs (Gallaudet University, n.d.) also received the email invitation. Additionally,

a snowballing effect was utilised whereby professionals were encouraged to share the invitation with others in the field.

Survey respondents

Out of a total of 133 recorded responses, 48 respondents successfully completed the survey by answering all the questions. The 48 respondents who completed the survey represented six continents including North America (United States, Canada, & Haiti), Europe (Austria, England, Germany, & the Netherlands), South America (Ecuador), Asia (Bangladesh, Cambodia, India, Iran, Israel, & Palestine), Africa (Ethiopia, Kenya, Nigeria, & South Africa), and Australia (Australia & New Zealand) (see Figure 1). Additionally, 52% of the respondents listed their profession as an educator (such as early interventionist, teacher, and faculty), 16% of the respondents listed their profession as either an audiologist or Speech Language Pathologist (SLP). The remaining 31% of the respondents listed a variety of roles that included administrator, clinical psychologist, therapy

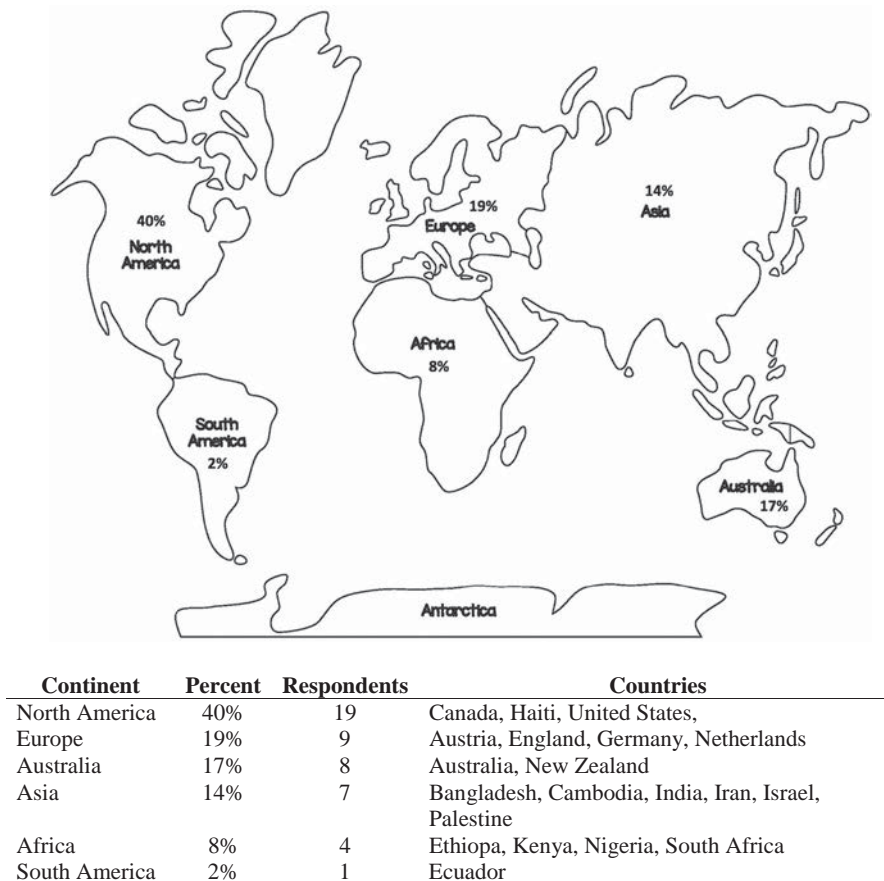


Figure 1. Respondents residence grouped by continent ($n = 48$).

assistant, consultant, project manager, volunteer, parent, and computer scientist. The survey questions analysed and reported in this article focused on deaf adults working in programmes serving young deaf children and their families related to the following: the hearing status of the first point of contact; whether there is a diverse range of deaf adults; possible reasons that programmes do not have deaf adults; roles of deaf adults in programmes; and support provided to families by deaf adults.

Results

Out of 48 respondents, 40 answered the question regarding the hearing level of the professional who is the first point of contact for the family once an infant is identified as deaf. The meaning of “first point of contact” is the person who follows up with the family after the infant is identified as deaf. Answers to the hearing level of the first point of contact resulted in 80% hearing, 15% hearing and deaf, and 5% deaf. More specifically, two respondents (Austria and Cambodia) indicated that the first point of contact is deaf, and seven respondents (two from USA, two from Australia, two from Austria, and one from Israel) indicated that the first point of contact is both, deaf and hearing. The remaining 31 respondents indicated that the first point of contact is hearing (See [Figure 2](#)).

Furthermore, when asked if there is a diverse range of professionals who are deaf for families to connect with at some point in the child’s life, 73% of the 48 respondents reported no and 27% reported yes (See [Figure 3](#)).

Respondents were asked “If there are no professionals who are D/deaf and hard of hearing, why do you think that is?” and to answer the question why

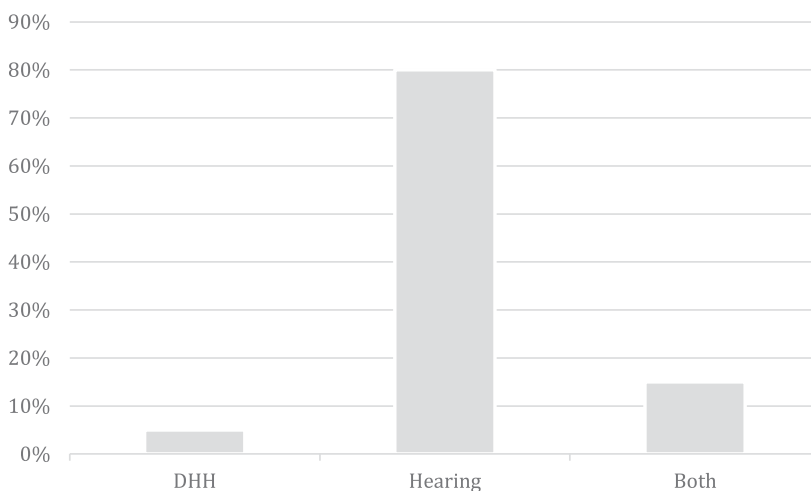


Figure 2. The hearing status of EI professionals who are the first point of contact for families family ($n = 40$).

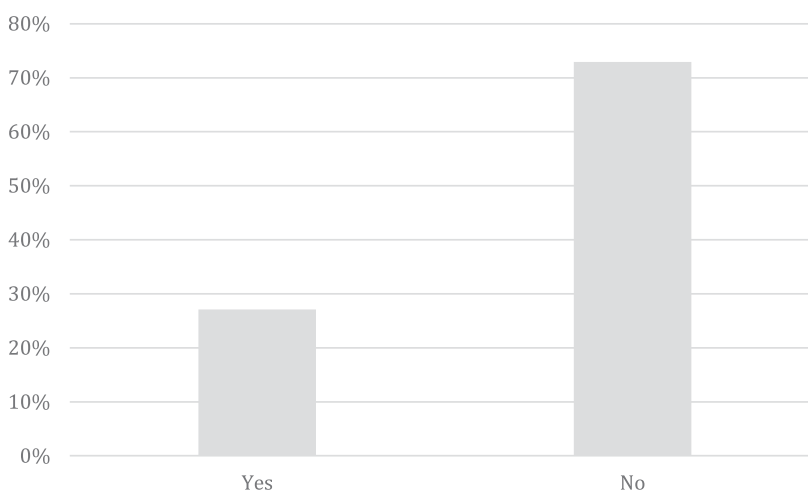


Figure 3. Diverse range of deaf professionals for families to connect with at some point in the child's life ($n = 48$).

there are no professionals who are deaf, respondents were given three choices and asked to check all that apply. The three choices were “lack of funding,” “lack of available professionals who are deaf and hard of hearing,” and “other,” which included a text box. There were 45 response counts. “Lack of funding” accounted for 20%, “lack of available professionals who are deaf and hard of hearing” accounted for 42% and “other” accounted for 38%. Overall there were 17 comments provided in the “other” textbox and 12 comments related to perceptions. Comments included, “People who are dhh are not encouraged to work in the EI field”, “not recognizing the skill sets of Deaf/HH”, “attitudes of hiring personnel”, and “our institute is too small”.

For the question that asked “what support do the professionals who are D/deaf and hard of hearing provide to families?” respondents were instructed to check all listed supports that apply. The types of supports listed included counselling support, intervention strategies, educational information, and communication support. The respondents also had the option to check “other” and leave a comment. With the option to check more than one support, there was a total of 105 response count. Out of the 105 response count, the two most common responses were educational information (25%) and communication support (25%) (See [Figure 4](#)).

For the question “what role(s) do the professionals who are D/deaf and hard of hearing have in your program?” respondents were instructed to check all listed roles that apply. The roles listed included the first contact, mentor/role model, sign language instructor, early intervention provider, counsellor, health professional (physician, audiologist, speech/language, etc.), director, and supervisor. The respondents also had the option to check “other” and leave a comment. Out of the 103-response count, the two most common roles selected were mentor/

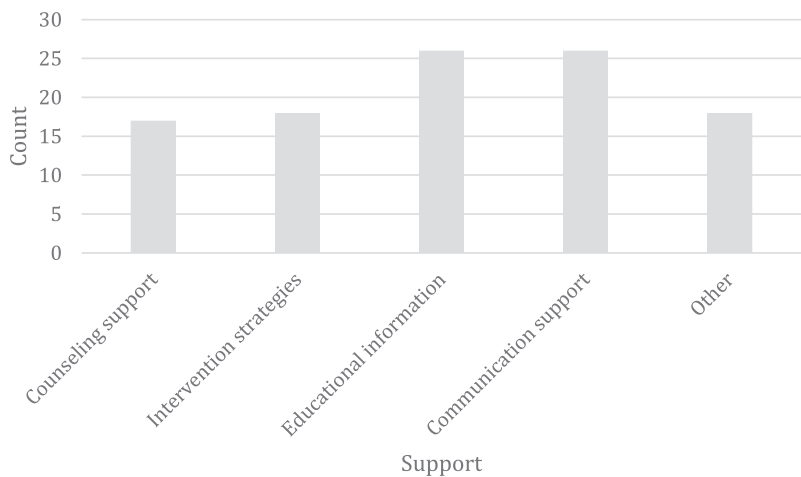


Figure 4. The support role of deaf professionals in the family ($n = 48$).

role models (24%) and sign language instructors (20%). The two least common roles were director (3%) and first contact (3%) (See [Figure 5](#)).

Discussion

FCEI best practice principles state that deaf adults should connect with families (Principle 4) and engage in collaborative teamwork on a transdisciplinary team (Principle 8) (Moeller et al., 2013). Results of this study show that when deaf adults are involved in early intervention programmes, they serve as role models and language providers, and typically provide educational and information support. The finding is supported by programmes such as the Deaf Mentor Experimental Project (Watkins et al., 1998), Deaf Mentor Family Program (Petersen et al., 2016), and HI-HOPES (Storbeck & Pittman, 2008). However, other roles, such as deaf adults being a first point of contact once a child is identified, being a health professional, and/or being a director, are not as common. The finding that there is a lack of a diverse range of deaf professionals who are deaf with whom families can connect does not reflect the deaf population in general as there is no shortage of deaf adults from diverse backgrounds, from a range of ethnic backgrounds, hearing levels, occupations, and family backgrounds (Benedict et al., 2015).

A reason why deaf adults do not have diverse roles in early intervention systems could be that professionals are not aware of the positive impact deaf adults can have throughout the system. For example, survey respondents commented that reasons for the lack of deaf adults is due to personnel attitudes, a perceived lack of deaf professionals, not encouraging deaf individuals to work in the field, and not recognising skill sets of deaf individuals. Regarding personnel attitudes, because deafness is commonly framed in a pathological way

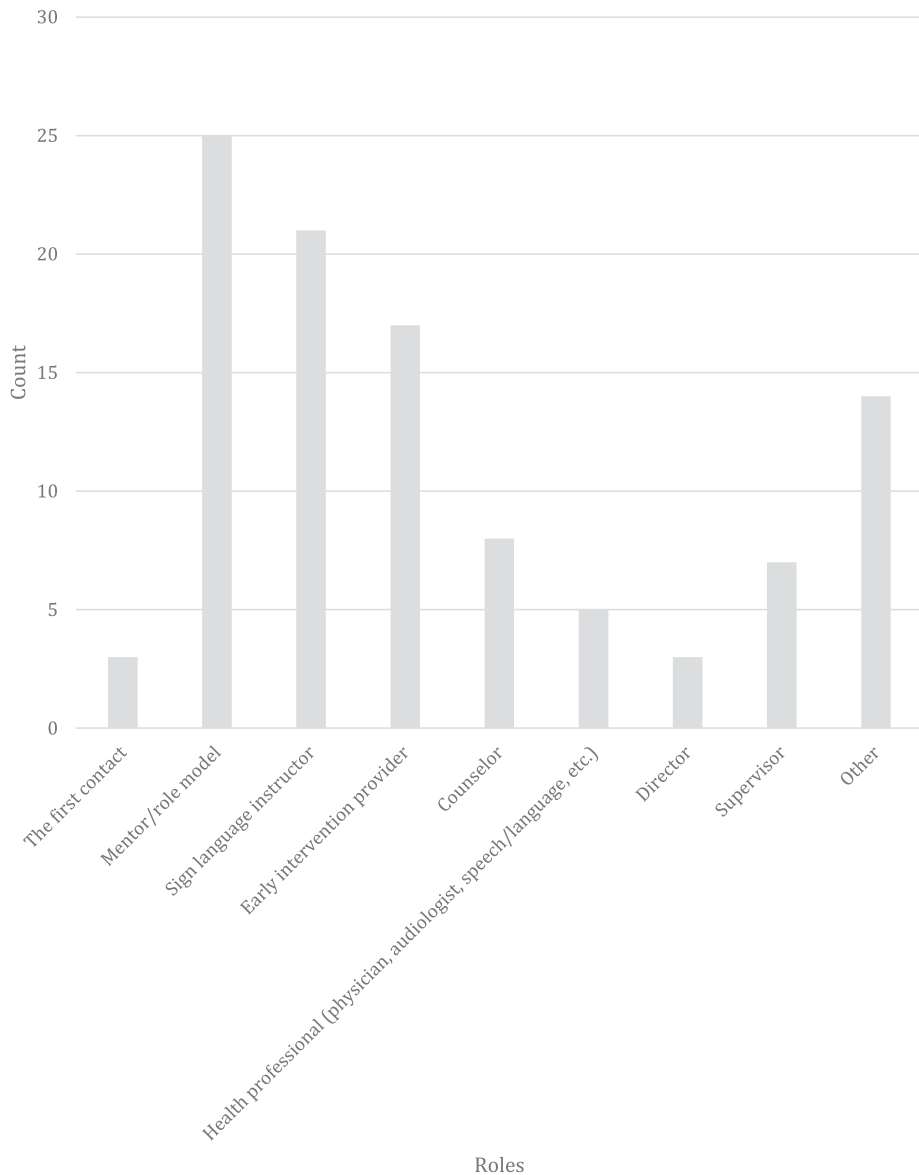


Figure 5. Roles deaf professionals have in EI programmes ($n = 43$).

focusing on the lack of hearing as a problem to be fixed with assistive devices such as hearing aids and cochlear implants, a solution can be education about deaf people and deaf culture, which can increase understanding and respect for deaf culture and promote more positive attitudes about deaf people (Lee & Pott, 2018). This solution includes framing deafness using the social model (Bauman & Murray, 2014) focusing on linguistic and cultural identity that values using sign language as primary means of communication. It can be eye opening for people to learn that deaf parents who are expecting a child often wish for a deaf newborn because they want to share their language and

culture (Holcomb, 2013). Furthermore, deaf parents with deaf children who are proud of their language and deaf culture indicate high expectations for their deaf child to be fluent in ASL and English (Mitchiner, 2014).

Another strategy to infuse deaf adults throughout the early intervention systems is to explicitly include deaf adults in other foundational principles. Currently there are ten foundational principles in the FCEI consensus statement (Moeller et al., 2013) but only two of the ten principles explicitly include deaf adults. Perhaps explicitly including deaf adults in other principles could help increase and diversify deaf adult roles throughout the early intervention system. For example, the first principle focusing on early, timely, and equitable access to services is crucial; however, deaf adults are not explicitly identified as being part of the early support team. Intentionally having deaf adults as initial service providers could be a valuable resource for families when their child is first identified as deaf. Increasing awareness of the positive impact deaf adults provide and including deaf adults in other principles can be a step forward for infusing a diverse range of deaf professionals in early intervention.

Limitations and next steps

There were several limitations to the study, including reliability of the instrument, self-reported data, sample size, demographic skew of the sample, and, quite possibly, limited access to the online survey format. Limitations related to the reliability of instrument includes the order of questions and accessibility of the survey. While the number of survey questions provided helpful insights when analysed, there were a few questions that were difficult to analyse because of the order in which they were presented. For example, a survey was not considered complete unless the background questions were answered, and out of 133 who started the survey, 85 did not complete it. It is possible that the 85 respondents who did not complete the survey were unable to answer the questions related to the early identification and intervention system. It could be that some respondents were not able to complete the survey because they did not have early identification and intervention in place. Many participants stopped at the third question, which asked about the first point of contact for the family, and did not continue on with the survey. This could be due to not knowing the information or not having an early intervention system in place. With the unanswered background questions at the end of the survey, the authors were unable to follow up with those respondents. Perhaps the demographic background/information questions should have been at the beginning of the survey.

Another limitation was that the survey was only made available in English and online. This resulted in a sampling bias because only those who were comfortable with written English and had access to the internet could reply. This also resulted in the majority of respondents being from North America. A survey in

multiple languages (both spoken and sign) would attract a larger pool of respondents and result in a more balanced representation of continents. Additionally, interpretation of meaning and questions such as “FCEI,” “D/deaf,” and “first point of contact” may mean different things to different respondents and should be interpreted with caution.

Despite the limitations, this preliminary survey provided information and validated earlier anecdotal information about the role of deaf adults involved in early intervention systems around the globe. This information will enable the authors to continue the discussion and to promote the need to infuse deaf adults wherever such programmes exist.

Call to action

Similar to the call to action from FCEI’s best practices international consensus statement (Moeller et al., 2013), recommendations for moving forward include a call to action for infusing deaf adults worldwide in programmes serving young deaf children and their families by implementing the following actions:

- **Formalise and Fund:**
 Formalise plans to infuse deaf adults in programmes (e.g. legislation, measurable goals)
 Funds to support deaf adults in leadership roles (e.g. grants, scholarships, positions)
 For example, write a letter of endorsement from your agency, organisation, or personal point of view for the Principles Statement and send it to appropriate policy makers in the respective countries.
- **Collaborate and Communicate:**
 Collaboration between deaf and hearing professionals (e.g. research, training)
 Communicate resources (e.g. success stories, research findings)
 For example, share the Principles document with colleagues and leaders.
 Support research agendas through collaboration or examination of practices.
- **Educate and Evaluate:**
 Educate deaf and hearing individuals (e.g. training programmes, workshops)
 Evaluate FCEI programmes to ensure deaf adults are infused in early intervention programmes (e.g. goals, principles)
 For example, embed these Principles in legislation, guidelines, consensus papers, and position papers regarding early intervention services and models.
- **Infuse and Include:**
 Infuse deaf adults in programmes at all levels (e.g. advisory board, director)
 Include diverse deaf adults (e.g. communication choices, professions)
 For example, recruit deaf adults to take part in the leadership related to FCEI.

Conclusion

FCEI best practice principles recommend deaf adults connect with families (Principle 4) and engage in collaborative teamwork on a transdisciplinary team (Principle 8) (Moeller et al., 2013). Results of this study showed deaf adults serve as role models and language providers, and typically provide educational and information support. However, results also showed it is not common for deaf adults to be in roles as a first point of contact once a child is identified, a health professional, and/or a director.

Infusing deaf adults in the early intervention system is a way for deaf adults to be ingrained in the system at all levels providing parents support regarding the health and education systems assuming diverse roles throughout the system, including educational, leadership, and medical positions. It is important to infuse deaf adults in early intervention because more than 90% of deaf children are born to hearing parents (Mitchell & Karchmer, 2004) and the parents may have little or no experience with deaf people or even expectations regarding their deaf child. Programmes that have diverse representation of highly qualified deaf professionals in first-contact roles after identification simply provide parents with the most qualified professionals who may happen to also be deaf. When parents interact with deaf adults, it is “not because they are deaf or hard of hearing, but because they have a significant service and expertise to provide the family” (Yoshinaga-Itano, 2015). Recognising the positive impact that deaf adults provide to their own children as well as deaf children with hearing parents and including deaf adults in other FCEI principles are strategies to encourage the infusion of deaf adults throughout the early intervention system. A call to action to infuse deaf adults in the early intervention system includes Formalisation, Collaboration, Education, and Infusion.

Disclosure statement

No potential conflict of interest was reported by the authors.

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Appendix A

Survey questions

Newborn screening and services questions

- (1). **Does your country/region mandate Universal Newborn Hearing Screening?**
Answer selection: Yes, No, Not Sure
- (2). **Does your country have a referral programme?**
Answer selection: Yes No, Not Sure (if No is selected, Qualtrics skips to #6.)
- (3). **Once an infant is identified as D/deaf and hard of hearing, who is the first point of contact for the family?**
Answer selection: Audiologist, Parent, Early Intervention Specialist, Social Worker, Other (text box), There is no referral programme
- (4). **Is this first point of contact either:**
Answer selection: Deaf and Hard of Hearing, Hearing, Both, Neither
- (5). **At what point in the child's life does the referral process happen?**
Answer selection: text box (If 5. At what point in the chi ... Is Not Empty, Then Skip To 7.)
- (6). **If there is not a referral process in place, are there plans to implement one?**
Answer selection: text box
- (7). **What types of services are available to families in Early Involvement programmes? (Select all that apply)**
Answer selection: Early language support, Counselling services, Information on cognitive development, Information on social-emotional development, Education information, Centred-based language instruction/services, Other (text box)
- (8). **If language instruction in the home is an available service, please choose the language being taught: (Select all that apply)**
Answer selection: Sign language, spoken language, Language in the home is not an available service
- (9). **How many times will a family with a child who is D/deaf and hard of hearing have contact with a professional who is also D/deaf and hard of hearing? (up until the child is 5 years old)**
Answer selection: (Drag slider to express numeric amount from 0 to 100 to indicate number of times)
- (10). **Is there a diverse range of professionals who are D/deaf and hard of hearing for families to connect with at some point in the child's life?**
Answer selection: Yes, No

Professionals who are D/deaf and hard of hearing questions

- (11). **About how many professionals does your programme have in total (D/deaf, hard of hearing, and hearing)?**

Answer selection: (Drag slider to express numeric amount from 0 to 100 to indicate number of total professionals)

- (12). **Of the professionals in your program, about how many are D/deaf and hard of hearing?**

Answer selection: (Drag slider to express numeric amount from 0 to 100 to indicate number of total professionals who are DHH)

- (13). **If there are no professionals who are D/deaf and hard of hearing, why do you think that is? (Check all that apply)**

Answer selection: Lack of funding, Lack of available professionals who are Deaf and Hard of Hearing, Other (text box)

- (14). **Which professionals/expertise professionals in your system are D/deaf and hard of hearing: (Check all that apply)**

Answer selection: Early Interventionist, Audiologist, Physicians, Social Workers, Counselors, Psychologists, Teachers, Professors, Engineers, Writers, Actors, Other (text box)

- (15). **What role(s) do the professionals who are D/deaf and hard of hearing have in your programme? (Check all that apply)**

Answer selection: The first contact, Mentor/role model, Sign language instructor, Early intervention provider, Counselor, Health professional (physician, audiologist, speech/language, etc.), Director, Supervisor, Other (text box)

- (16). **What support do the professionals who are D/deaf and hard of hearing provide to families? (Check all that apply)**

Answer selection: Counselling support, Intervention strategies, Educational information, Communication support, Other (text box)

- (17). **Do professionals who are D/deaf and hard of hearing receive formalised training in the support they provide to the families?**

Answer selection: Yes, No

- (18). **In your opinion, what are best practices related to including professionals who are D/deaf and hard of hearing in Early Intervention programmes?**

Answer selection: text box

- (19). **In your opinion, what are the barriers/challenges for including D/deaf and hard of hearing professionals in Early Intervention programmes?**

Answer selection: text box

- (20). **Please identify any suggestions on how to overcome barriers/challenges for including D/deaf and hard of hearing professionals in Early Intervention programmes.**

Answer selection: text box

- (21). **Do you plan to attend the 3rd annual Family Centred Early Intervention (FCEI) conference?**

Answer selection: Yes, No, Not Sure

- (22). **Do you plan to attend the D/deaf and Hard of Hearing Leadership pre-conference at the 3rd annual FCEI conference?**

Answer selection: Yes, No, Not Sure

- (23). **If you do not plan to attend the 3rd annual FCEI conference, would you be interested in future information and/or results of this survey?**

Answer selection: Yes, No, Not Sure

- (24). **Any feedback you may have regarding this survey:**

Answer selection: text box

Background questions

- (25). **Name:**
Answer selection: text box
- (26). **Email:**
Answer selection: text box
- (27). **Country in which you reside:**
Answer selection: text box
- (28). **State or region in which you reside:**
Answer selection: text box
- (29). **Your profession:**
Answer selection: text box