

Empirical Article

The Nature of Parent Support Provided by Parent Mentors for Families With Deaf/Hard-of-Hearing Children: Voices From the Start

Rachel Friedman Narr^{*,1}, Megan Kemmery²

¹California State University

²Franciscan University of Steubenville

Received April 16, 2014; revisions received July 28, 2014; accepted August 11, 2014

This study used a qualitative design to explore parent mentors' summaries of conversations with over 1,000 individual families of deaf and hard-of-hearing (DHH) children receiving parent-to-parent support as part of an existing family support project. Approximately 35% of the families were Spanish speaking. Five parent mentors who have DHH children provided varied support primarily via the telephone to families with DHH children, frequently birth to age 3. The nature and types of support provided were examined and resulted in an in-depth analysis of the summary notes prepared by the parent mentors. The notes were coded using a mixed-methods software application. Three topics were the most prevalent within the conversations between parent mentors and family members: hearing-related topics, early intervention, and multiple disabilities. Several differences emerged between English-speaking and Spanish-speaking families receiving support. Implications and the significance of this study are discussed.

Understanding what it means to have and to raise a deaf and hard-of-hearing child (DHH) is a perspective only another parent of a DHH child can understand (Lederberg & Golbach, 2002). Regardless of a professional's expertise, insights into parenting, and knowledge about deafness, that professional cannot know what it is like to parent a DHH child (unless of course they have one). Expertise, experience, and content knowledge cannot substitute for the joys, needs,

worries, feelings, and experiences parents possess (Quittner et al., 2010). The moment a child comes into the world, the parent is counting 10 toes and 10 fingers, noticing the tuft of hair on a child's head, embracing their tiny infant, seeking assurance of the health and well-being of the new baby. Soon after birth, the child is screened for a variety of conditions. The parent may or may not even realize that, but what they may learn quickly is whether or not their child "passed" the hearing screening or if there is a need for the child to undergo further testing.

Since the advent of newborn hearing screenings almost 20 years ago, infants have been identified as DHH earlier and earlier (White, 2006). Conversations about the benefits of early identification and early intervention versus parent acceptance and opportunities for bonding emerged early on in the professional discourse. Most conclusions acknowledge the overwhelming benefits of early intervention for children who are DHH while simultaneously recognizing the role and value of parent-to-parent support, in particular with families who have very young children (Yoshinaga-Itano, 2003).

Parent-to-parent support found its roots in the early 1970s within a wider disability orientation, largely through the work of Rud and Ann Turnbull and the Beach Center on Disability (Parent-to-Parent USA, 2010). Today, few people doubt the value and necessity of family-oriented support. Affiliations with national

*Correspondence should be sent to Rachel Friedman Narr, California State University, Northridge, 18111 Nordhoff Street, Northridge, CA 91330-8265 (e-mail: rachel.narr@csun.edu).

and local parent-to-parent support networks were rated by Early Hearing Detection and Intervention (EHDI) program coordinators as the two top strengths of current EHDI practices (Bradham, Houston, Hutsell Guignard, & Hoffman, 2011). Parent-to-parent support networks and parent mentors have the opportunity not only to provide support to families but also to build understanding among educators and other professionals (Meadow-Orlans, Mertens, & Sass-Lehrer, 2003). Cohen and Canan (2006) suggest that mentors in parent-to-parent support networks are able to train parents on the skills of empowerment and how to identify strengths, work effectively with professionals, and fully participate in treatment planning. Empowerment, from the start, certainly impacts the adults in the family but also has the potential to create an environment that is positive and productive for the child and their future (Hintermair, 2006).

Parent-to-Parent Support for Families With DHH Children

Although families with DHH children may have been included in some of the early research related to families with disabilities in general, it is widely acknowledged that these families require unique support and an orientation that differs from the wider disability community (Siegel, 2008). In most cases, for many parents, their DHH child is the first DHH person the parents have encountered. With early identification, parents very quickly enter a whole new world involving many professionals, potentially complex decisions pertaining to medical interventions, and conversations and controversy about language and communication (DesGeorges, 2003; Young & Tattersall, 2007).

Insider knowledge and understanding occurs when mentors possess similar experiences as the families they are supporting and when they share a particular narrative (Klein & McCabe, 2007). When asked about parent mentoring support opportunities, families and parents of DHH children expressed a preference and a value for discussion with other parents of DHH children over discussion with parents of children who were not DHH (Jackson, 2011). Parent mentors are able to better meet the parents' needs, both personally and emotionally, when engaging in dialogue through the mentoring relationship.

Several researchers have examined factors related to parent-to-parent support for families, specifically with DHH children. Jackson, Wegner, and Turnbull (2010) examined parents' perceptions of their quality of life after their child was identified as DHH. Only one third of their participants ($N = 73$) reported participating in *any* kind of parent support group, whereas the *desire* for additional support was identified as a common theme among the parents. Jackson (2011) examined family support after a child was identified as DHH. She surveyed 456 parents on different aspects of family support including the quality of support received and families' preferences for informational resources. Results from the parent surveys indicated families expressed a preference for discussion with other parents of DHH children over discussion with parents of children who were not DHH.

Zaidman-Zait (2007) used a questionnaire to specifically examine coping factors of parents whose children had cochlear implants. The 28 parents surveyed overwhelmingly indicated that interacting with "similar others," or other parents of DHH children, reduced anxiety and increased a sense of belonging. The support parents received from these other parents was different from the support they received from professionals not only because it was "trustworthy" and "firsthand" but also because the support was free from tacit organizational agendas that could influence the information received (Zaidman-Zait, 2007).

Jamieson, Zaidman-Zait, and Poon (2011) surveyed 38 parents of preadolescent and adolescent DHH children and conducted focus groups with a subset composed of 15 parent participants. The surveys pertained to family support needs, whereas the focus groups examined those needs in greater depth. Perhaps characteristic of other parents' experiences during the school-age years, the parents in the focus groups remarked they had few opportunities to interact with other parents of DHH children since transitioning from their early intervention programs. Jamieson et al. (2011) underscore the need for parent-to-parent support to be provided consistently throughout a child's school years, not just during the early intervention stage that is so customary to current practice.

Mentorship and support occurs both formally and informally. Social opportunities for networking

and experiences meeting other families with DHH children lead to positive outcomes for DHH children and their parents. Research highlights and identifies the direct value and need for parent-to-parent support for families with DHH children; however, there has not been a description of the nature of support for families with DHH children provided by parent mentors themselves within the literature.

In a national survey of issues pertaining to family support services, national and local parent-to-parent support organizations were the top two strength items cited by EHDI coordinators (Bradham et al., 2011). The current study uses parent mentor notes from within a local, though large geographic area, parent-to-parent support project to describe the nature of conversations with families with DHH children and provide group demographics. Although there are ubiquitous agreements and mandates for family involvement, parent education, and provision of enhanced family support in deaf education, there is still much to be learned and documented pertaining to the dimensions of support provided by parent mentors for families with DHH children, particularly with families from culturally and linguistically diverse backgrounds.

The present study has scholarly significance because of the large number of families included within the database ($N = 1,056$) with 35% of the families identified as Spanish speaking. As a low-incidence disability, deaf education experiences a paucity of research including large data sets. Although there are only five parent mentors identified as participants in the present study, their experiences and resultant data are gathered from over 1,000 conversations with families with DHH children. The study is also unique in that the design is set up to provide insight into the parent mentors' views of support networks and relationships established with parents raising DHH children. The essential role of the parent mentor in this process is valued throughout the study. Although other researchers have directly examined types of support the families receiving the mentor support value, the perspectives and voices of the parent mentors have not been well documented in either the larger disability field or within the discipline of deaf education.

Method

Context of the Study

This study utilized a qualitative design to analyze the nature of support provided to 1,056 families with DHH children. Data were part of an existing database used for an ongoing parent-to-parent support project implemented since early 2009. The data analyzed for study were limited to March 2009–August 2011. The institutional review board at the university where the project was implemented approved the present study. Parent-to-parent support for the purposes of this paper and research broadly entails meeting the parents where they are to offer acknowledgement that they are not alone in this process of raising a DHH child. The parent-to-parent mentoring encompasses assistance in the form of education and training on topics like audiograms, hearing aids, and language; navigating the school system; establishing connections with other parents; and general advice pertaining to the everyday considerations of raising a DHH child.

Data Source

An existing database, established and maintained as part of a parent-to-parent support project, served as the data set for this research. Data included demographic information obtained by the parent mentors directly from the families and parent mentor notes pertaining to 1,056 families contacted between March 2009 and August 2011 through the parent-to-parent support project. Families of children who are DHH contacted by parent mentors in the project were referred by permission through any of several sources including from the statewide newborn hearing screening program, from school districts, through local Family Resource Centers, and/or self-referral. Established and ongoing relationships between the researcher, parent mentors, and local school programs were also fostered to gather additional referrals.

The primary mode of contact between parent mentors and family members was via telephone. After, or during, each phone conversation, the parent mentors created summaries by hand, in word documents, or directly into the database of the individual conversations with the parents. If not entered directly into the

database, they were put in shortly afterward and all were delineated by the date of the conversation. There was no formal process specified for the parent mentors to capture the content of the conversations. In most cases, the parent mentor would provide the gist of the conversation through the notes, including general ideas discussed during the conversation. In some cases, the parent mentor would provide her own perception of a parent's feelings or state of being. Summary notes taken by the parent mentors were also entered into the database after face-to-face contact with a family during a project event or training. Aside from basic demographic information when available, the parent mentors were not given any guidelines or time requirements for entering information into the database. They were generally requested to enter conversational notes into the database following phone calls or other interactions with families. Information from the project database was imported into Dedoose (2013) for data analysis. Dedoose, an online software application, was selected because of its affordability, ease of use, cross platform function, and anytime anywhere access.

Procedure

Quantitative variables pertaining to the demographic characteristics of families and children as well as anecdotal summaries written by five parent mentors were analyzed. The anecdotal summaries written by the parent mentors contained notes of the communication between themselves and the families with DHH children whom they were supporting.

Quantitative analysis. Group characteristics including families' home language(s), age group of the children (0–3 or 3+ years old), and characteristics of the child's hearing (type, degree, configuration of hearing loss) were identified. Not all of the demographic information was available for every family, so total *Ns* for respective variables differ.

Qualitative analysis. A constant comparative method of qualitative inquiry was used to complete an in-depth analysis of the parent mentors' anecdotal summaries (Bogdan & Biklen, 2003). Analysis was conducted through an iterative process of identifying

themes and subthemes that were coded within the summary notes. Each note was read thoroughly, excerpts were selected and then coded. Throughout the process, 63 individual codes were applied to 5,150 excerpts. Codes were both high- and low-inference descriptors (Seale, 1999). In other words, some excerpts were straightforward and concrete, requiring little interpretation, whereas other excerpts required more inferential deduction using the context of the conversation and knowledge of the people, places, and support being provided. Among the 63 codes, some were applied frequently and some were seldom applied to the excerpts. The Dedoose software was used to attribute codes to the excerpts that were then used to identify themes and subthemes. Because the codes were applied at the level of the excerpt and not at the level of the individual family, it was inappropriate to examine the findings in relationship to one another.

After the primary researcher coded all the excerpts, a research assistant, a doctoral student who was trained in understanding the project and the codes, re-coded multiple sets of excerpts. A subset of descriptor codes, those that required a high level of inference and were used frequently, were tested for inter-rater reliability using a blind test-like format within Dedoose. As suggested by the Dedoose developers, we used a pooled kappa to report an overall result that included more than one code to summarize rater agreement across many codes as reported in De Vries, Elliott, Kanouse, and Teleki (2008). The initial pooled kappa was .76 indicating good agreement as suggested by the Dedoose visual indicators. The two researchers discussed differences in the attribution of codes until $>.80$ agreement was achieved.

Throughout this article, parent mentors' notes are used to provide examples of the themes identified and create a narrative of the kinds of conversations parent mentors engaged in with family members. In many places, spelling within the notes was corrected and proper names of places and people have been removed to ensure confidentiality and anonymity. The abbreviation *PL* is used numerous times within the notes in reference to the parent mentor herself. The following note is characteristic of the kinds of complex conversations parent mentors had with families

Said she [mom] is going through a very difficult time. Her husband got deported, she works all day, and has very little time to spend with her son. Per mom, child will be a year old soon. Has hearing in left ear and has profound hearing loss in right ear. Also has facial paralysis. Is [receiving early intervention], has several specialists who come to the home and work with son. Was improving a lot, unfortunately, husband got deported and now mom has to work. Says she has had to cancel several home visits from teachers. Communicates using voice and signs. Will send her a packet.

Participants

Participants in the present study included five parent mentors who were employed in the parent-to-parent support project. These five mentors were the only employees of the project and as such were participants by convenience. Each of the parent mentors was employed initially because they have a DHH child or children and were adept at providing organic parent-to-parent support through their own initiative and personal networks. The grant project allowed them to essentially be paid for what they were already doing. Eventually it also systematized and coordinated their work more as the project was funded. Over the course of the project, the parent mentors participated in multiple and varied training opportunities related to mentoring/coaching, listening techniques, and issues pertaining to raising a DHH child. Training opportunities included participation in formal workshops, attendance at EHDI national conferences, National Center for Hearing Assessment and Management Family Support conferences, and national Hands & Voices conferences. Less formal opportunities included reading books and informational resources pertaining to parent support and participation in an “in-house” parent support group where the mentors provided support to each other. The parent mentors received informal supervision and guidance by the project coordinator. Their responsibility as parent mentors in this project was quite generically to connect with families and provide support. The conceptual “guidelines” were to be respectful and accepting of where parents were in learning about raising a

DHH child and guide parents to a place of acceptance and understanding pertaining to their DHH child. There was no script parent mentors followed and support was provided differently among the parent mentors.

All of the parent mentors were hearing mothers. Three parent mentors were bilingual (English, American Sign Language: ASL) and two mentors were trilingual (English, ASL, and Spanish). Four of the parent mentors worked for the project for 4+ years, whereas one of the trilingual mentors worked for the project for several months.

Results

Demographics of Families Served

Home language used by the family, age of the child, and the child’s hearing characteristics were obtained through parent self-report. This data was not available for each of the 1,056 families within the database. Spanish was the home language for 35% of the families ($N = 987$) who we attempted to contact from the database. A total of 2.3% of the families used ASL. English was the primary language used by most of the remaining families. Less than 1% of families used languages other than English or Spanish. Families with children 0–3 years old comprised 66.5% of the families ($N = 686$). Because most interactions were with families who had young infants, data pertaining to hearing characteristics of the children were more limited because in many cases, the child had not yet been fully diagnosed. And again, not all of the demographic information was available for every family, so total N s for respective variables differ.

Approximately 66% of the children had bilateral hearing loss ($N = 572$). The type of hearing losses ($N = 738$) were (a) sensorineural hearing loss: 56%, (b) mixed: 8%, (c) auditory neuropathy (when known these cases were identified separately from sensorineural): 8%, and (d) conductive: 26.4% including microtia (1.4%) and atresia (22%). Finally, hearing levels were available for 583 children and were rounded up (i.e., if a child was reported with a severe-to-profound hearing loss, the data were entered as profound): (a) profound: 37.5%, (b) severe: 15.5%, (c) moderate: 27.8%, and (d) mild: 16.8%.

Key Themes

Dimensions of support that emerged from the parent mentors' summary notes resulted in three primary themes across both families who spoke English and families who spoke Spanish. Perhaps predictable because of the purpose and nature of the parent-to-parent support, conversations that pertained to hearing and early intervention were the two most common. The third most prevalent theme was content from conversations pertaining to children with multiple disabilities.

Hearing-related conversations. Hearing-related conversations were those in which hearing screenings, hearing levels, hearing tests and diagnostics, and hearing aids and/or cochlear implants were discussed. In these conversations, parent mentors noted that they explained the importance of follow-up visits for further diagnostic assessment, the purpose of hearing aids, how to encourage the baby to wear hearing aids, and other topics related to these issues including steps in the process of identification. Aside from explanations of "what happens next" and describing benefits of early intervention, parent mentors also just listened to what the parents shared through the conversations.

Summary notes coded within the category of "hearing" consisted of what the parents told them or how the parent explained where they currently were in the process of parenting a child was recently identified as being DHH. The following is an example of a note with this theme,

At the moment the family is waiting for hearing aids. Mom doesn't understand what his hearing level is. She has never received copies of any audiograms. Each time he has a hearing test he ends up having an ear infection so the doctors told her to wait for an accurate test. He received ear tubes in August. Mom has seen a slight difference in his response. She says there are times when he responds to sound and times when he doesn't. We had a long conversation about audiograms, the different hearing levels, and sign language.

Early intervention. Early intervention conversations included discussions about the initiation of early intervention and the type and frequency of early

intervention services the family was receiving at the time. Early Start is the early intervention system in the state where the present study occurred. Whenever possible, parent mentors empowered families by helping the families to articulate questions for their audiologists and early interventionists. For example, the following note was coded with "hearing" and "early intervention" as themes,

Spoke to mom and she told PL that baby did get New Born Screening Test @ [XXX] and did not pass it. Was then referred to [XXX]. Had ABR, and was diagnosed with severe hearing loss. Baby is now 13 months and has hearing aids. Is enrolled in the [XXX] Program. PL and [our program] were explained to mom. When asked if child is enrolled in Early Start Program, mom stated she has never heard of it. PL provided mom with 800 # to Early Start and also to [the resource center] in her area. Mom was very happy to get help. She also agreed to join Impact and ASDC verbally. PL will fill out appropriate paper work for mom. PL explained the process and she agreed to all. Mom was very excited to have gotten PL call and she agreed to have f/u calls. I gave mom PL contact # for future concerns and questions. She was very grateful. Also, the importance of communication was explained to mom. Although mom says she uses speech to communicate with child, PL explained to mom that the use of signing would be a great help for her daughter to acquire language as well. Mom agreed and PL will mail her packet of info.

Multiple disabilities. The theme of multiple disabilities was the third most frequently occurring theme during conversations with the parents. It was similarly prevalent as a topic of conversation for families who spoke both English and Spanish. During these conversations, families mentioned and discussed many topics pertaining to additional services their children were receiving through Regional Centers (local agencies providing direct services to families of children with developmental disabilities), the complexities of care pertaining to the child, health care needs, and hospital visits among other topics. Frequently, within these conversations, the child's hearing status and follow-up related to hearing did not have the same priority as other

pressing health concerns the family also experienced. This notion is exemplified by this parent mentor note, “Baby is currently receiving services from Regional Center due to him having Down Syndrome. PL asked mom how she felt and she replied she was overwhelmed with everything.” In another note, a different parent mentor wrote,

Overall the mom has a team but she is not comfortable with asking for explanations from them. She does what they tell her to do, yet leaves every appointment lost. Mom would love to connect with other parents that have children with CHARGE.

Other themes. Other themes occurred less frequently but were no less interesting. Parent mentors identified that parents seemed overwhelmed or emotionally stressed. This theme was coded 167 times within the data, with prevalence emerging similarly for English- and Spanish-speaking families. Parent mentors noted stress stemming from many sources including lengthy and complex identification of the baby being DHH, the presence of other disabilities or medical complications, guilt on the part of the parents, communication with spouses, acceptance of the baby being DHH by other family members, and coordination of and understanding early intervention services. Examples of these sentiments were seen in parent mentor notes such as,

Mom said that baby referred and AuD said normal hearing so come back in 6 months and [then] they said oops hearing loss. They were shocked and mom really got depressed. She thinks parent group would be helpful she feels guilty. Husband was really sad too.

And,

Dad is not supportive and mom said they probably will not last. Mom feels dependent on dad financially, only gets unemployment right now. Mom said her situation is stressful but she is going to do whatever she has to do to provide her daughter everything she needs.

Although the sources of stress were in many ways similar across English- and Spanish-speaking families,

Spanish-speaking families faced unique challenges such as the deportation of spouse or family immigration issues. As noted by [Hintermair \(2006\)](#), the prevalence of stress for parents with DHH children experience is not unexpected. Hopefully, conversations with parent mentors, providing social support, and providing resources and information to these families of children who are DHH will play a role in reducing or mitigating the effects of stress felt by the parents in relation to the identification.

On the other hand, a different theme that emerged was characterized by descriptions of proactive or advocating families. This theme was five times more prevalent in the notes written by parent mentors talking with English-speaking families than in the mentors’ notes with Spanish-speaking families. Two examples of this theme coded in the notes are as follows,

I suggested discussing this with her Early Start teacher. Mom talked about her initial denial and final acceptance. She has the attitude that she needs to move forward and do what needs to be done to help her son. She has a very positive attitude about things. S is very interested in meeting other families, she has a great energy.

And, Great talking to Dad! This family is a very active family that is jumping in to learn everything they can! Family going to [XXX] at night and Friday Family class.

Biases against the use of ASL. Information contrary to best practices or misinformation given to parents surfaced as a theme within the parent mentors’ notes. In particular, many of the notes contained remarks that families were specifically told not to use sign language with their children, not only by professionals but by other parents as well. Although not an extremely prevalent theme among all excerpts, the examples were concrete. In one excerpt, the parent mentor wrote,

The regional center asked mom if she wanted to continue signing now that A has his hearing back in one ear. They told mom most parents drop the signing. [Mom] was upset by this. She wants to continue signing as it’s been a part of her family through her grandmother, and she considers it to be a second language for A.

And from another excerpt, Mom has started to use sign language. Mom said the first question she asked the audiologist was should they start using sign language. The audiologist told them ‘No, it will impair him.’ [The program] teacher disagreed and told parents ‘It’s a way for him to communicate now until he can talk’.

This theme was approximately four times more common in the notes pertaining to English-speaking families than in Spanish-speaking families.

Differences between notes for English- and Spanish-speaking families. Several apparent differences emerged between the summary notes written by the parent mentors speaking with English-speaking families and the mentor speaking with Spanish-speaking families. Recall approximately 35% of the families contacted through the database designated Spanish as their home language. This statistic corresponds with the general Hispanic or Latino ethnic population of the state where the present study took place (U.S. Census Bureau, 2010).

The parent mentor who connected with most of these Spanish-speaking families spoke with approximately twice as many fathers than did the English-speaking parent mentors. The Spanish-speaking mentor noted she spoke with fathers 39 times compared to speaking with fathers 20 times as noted by English-speaking mentors. Although not applied to many excerpts overall, this finding is considered notable because of the difference between English- and Spanish-speaking families. This observation and other findings will be addressed further in Discussion section of the present study.

Also within the notes written by this parent mentor of the Spanish-speaking families, a prominent theme arose characterized by parental resistance of the child’s identification as DHH. In these conversations, parents expressed disagreement with the diagnosis and gave multiple examples of how the child would respond to sound. For example, in one note, the parent mentor summarized: “Finally father picked up the phone and we spoke briefly. [Child] is a 3 month baby. Dad says that he does not believe his baby girl has a [hearing loss]. He says they are still waiting for more results.” This theme is also exemplified in a conversation with another family,

Spoke with mom for the first time. She claims that her daughter does hear because when she turns on the radio or tv, the baby turns toward the sound. She also said she has another 4 yr. old daughter with special needs. Mom did not want to talk about her. The baby with HL is 6 months and had a [hearing test] done [in September] and has another one [in October]. I suggested she let the audiologist know what she observes of her baby at home. I also told her I would call her after the appointment.

Again, although not coded frequently overall, this theme was noted seven times more frequently with Spanish-speaking families than English-speaking families.

Several other interesting themes only emerged within the notes written by the parent mentor connecting with Spanish-speaking families. For example, she provided numerous explanations of hearing loss and listening devices as exemplified in these excerpts,

Mom asked PL about the HA. She wanted to know that if baby wore HA everyday if he would be able to hear and talk. PL explained to mom, that every child is different and that with her help and support, maybe her child will benefit from them

and

... baby is 4 months and is being seeing at [XXX]. Is in process of getting tiara-like hearing aid (mom’s words). Home teacher is [XXX] and mom stated baby can hear because the family calls her name and she turns around. PL explained to mom what atresia means. PL will also download info from the internet in Spanish and mail it to mom, per mom’s request.

In the following excerpt, the parent mentor addressed concerns and confusion pertaining to access of information and knowledge of language development,

Father admitted to being confused and lost. We talked about the different [hearing losses] and I explained to him what comes next...He had a few questions regarding language and if his son was going to have a normal life, I assured him that it was not the end of the world having a child with HL. ... he was very excited to hear from another parent about kids with HL.

Discussion

By describing the content and nature of conversations parent mentors conducted with families raising DHH children, this study uses the perspective of the parent mentor to validate what has been reported in previous studies and publications regarding parent mentor support programs. The present study also adds to the literature base by contributing a unique perspective suggesting differences in conversations between English- and Spanish-speaking families.

In a discussion of topics families may question, DesGeorges (2003) listed many of the themes that emerged within the conversations parent mentors engaged in with family members in the present study including the implications of different hearing levels, questions about audiograms, early intervention, and the future of the children. In addition to providing explanations and elucidating the hearing identification process and early intervention system to the parents, the parent mentors in this project provided support to parents by just listening and being there for them. Consistent with findings from Jackson (2011) and Jackson, Traub, and Turnbull (2008), parents frequently needed someone to talk to, someone with whom they could identify with regarding their experiences and questions. Jackson (2011) also found the two most common themes among parents surveyed were the desire to connect with others and receive informational resources. In the present study, the researchers noted many of the conversations parent mentors had with parents consisted of providing resources and listening to shared information.

There was a high frequency of conversations that addressed issues pertaining to infants and young children who were DHH and had disabilities. This finding was the third most common theme coded within the conversations according to the parent mentor notes. Chapman et al. (2011) examined comorbid birth defects in 485 DHH children and found that one third of their sample had at least one other reported birth defect. Although this finding was reportedly higher than they expected because it included minor disabilities, this statistic is roughly consistent with other reports indicating approximately 40% of DHH children are also diagnosed with multiple disabilities (Gallaudet Research Institute, 2011). In the National

Parent Project, Meadow-Orlans et al. (2003) reported 32% of their respondents described disabilities or behavioral problems. From parent mentors' notes in the present study, it seemed clear that for many families with children with additional needs, issues pertaining to the child's hearing status were the least of their concerns. In these cases, it is not uncommon for identification and intervention of hearing to take a back seat to other more pressing concerns (Chapman et al., 2011; Meadow-Orlans et al., 2003).

The disciplines of deaf education, and certainly early intervention, are replete with stories of parents who are given biased advice from professionals and other parents. Much of this advice could be considered misconceptions; however, many times, the advice comes from professionals who are in the disciplines of deaf education and early intervention. Although the researchers of the present study acknowledge the parent mentors' notes are subjective, numerous instances emerged of parents recounting stories of advice that were considered against best practices and plainly incorrect. This reflects proliferation of continued biases that exist in the deaf education and early intervention (Meadow-Orlans et al., 2003). There is clearly still a great need for education and information dissemination to the medical field, and not only the medical field, about what it can mean to be DHH. Some teachers of DHH students continue to proliferate myths and promote biases that continue to promulgate 20th century practices with DHH children.

The finding that the Spanish-speaking parent mentor engaged in speaking with fathers more frequently than did the English-speaking parent mentors was surprising. Perhaps the Spanish-speaking fathers were more receptive to speaking with the parent mentor because they felt comfortable with communicating directly with a fellow parent, more so than they would have with medical staff and/or educational professionals through an interpreter. In contrast to the experience of the Spanish-speaking parent mentor, McWayne, Campos, and Owsianik (2008) reported Spanish-speaking fathers were less involved with school-based activities than English-speaking fathers. It makes sense that the inability to communicate with school or medical personnel could be a barrier to parental involvement

in schools for parents who speak languages other than English.

Communication gaps and cultural differences in expectations, including how a child is labeled, may have contributed to the finding that Spanish-speaking parents seemed to disagree with the identification of their child. Harry (2008) discusses how mismatches in understanding arise when there are differing views of disability across cultures. In the present study, Spanish-speaking families who “denied” there was something “wrong” with their child also gave examples of how much the child could actually hear. The idea that the child was being labeled, in some cases at a very young age, despite what the family perceived as evidence to the contrary, could explain this mismatch in understanding. The label itself and need for early intervention could be counterintuitive in some cultures, as well as a plain overreaction to a perceived minimal impairment.

Two primary limitations may be found within the present study. First, the findings are based upon subjective notes written by only five parent mentors after speaking with families. Parent mentors were not given a uniform guide for writing notes, nor were they asked to include any specific information in their notes. Demographic information was collected when it was available, and each parent mentor had their own style of note taking including their own filters through which the notes were created. This allows for the possibility that parent mentors only noted what was important for them and that subsequently influenced the themes that emerged in the data. Second, there was a large volume of data that was coded *by excerpt* rather than being coded *by family*. If the data were initially coded by family, some of the findings could have been correlated with other findings. Currently, analysis among the themes could only be accomplished with a few definitive codes.

There are several implications for practice that arise from this study. Despite ubiquitous agreement and mandates for family involvement, parent education, and provision of enhanced family support in deaf education, there is still much to be learned and documented pertaining to the dimensions of support provided by parent mentors for families with DHH children, particularly with families from culturally

diverse backgrounds. This study provides a starting point for characterizing the nature of parent-to-parent support provided to families raising DHH children and the kinds of support they are requesting. There is also an opportunity to continue to examine how families from diverse cultures process their journey raising a DHH child. Based upon this information, parent mentor programs can tailor their support and better pair parent mentors with specific family support.

Further, this study holds scholarly significance because of the large number of families included within the sample. The study is also unique in that researchers, those within the larger disability field or within deaf education, have directly examined types of mentor support families value but have not analyzed the parent mentors’ perspectives and voices as was done in the present study. These findings may stimulate additional examination of parent mentors as well as add to the suggestions for training and documenting support provided to families.

There is also potential for this study to impact policy issues pertaining to the crucial need for parent-to-parent support within deaf education and early intervention programs. Programs can use the findings identified within this study to support parent-to-parent support programs as integral parts of the early intervention system. The dimensions of support parents receive when raising a DHH child can only come from parents like themselves who have walked or are walking the same journey. Parent mentors are *the voices from the start* families of children who are DHH identify with and turn to in order to help normalize their visions for their DHH children and their families.

Conflicts of Interest

The parent mentors and the primary author were compensated for their roles in the parent-to-parent support grant (but not the research). The data collected were part of the responsibility of the parent mentors.

References

- Bogdan, R. C., & Biklen, S. K. (2003). *Qualitative research for education: An introduction to theories and methods* (4th ed.). New York, NY: Allyn & Bacon.

- Bradham, T. S., Houston, K. T., Hutsell Guignard, G., & Hoffman, J. (2011). Strategic analysis of family support in EHDI systems. *The Volta Review*, *111*, 181–194.
- Chapman, D. A., Stampfel, C. C., Bodurtha, J. N., Dodson, K. M., Pandya, A., Lynch, K. B., & Kirby, R. S. (2011). Impact of co-occurring birth defects on the timing of newborn hearing screening and diagnosis. *American Journal of Audiology*, *20*, 132–139. doi:10.1044/1059-0889(2011/10-0049)
- Cohen, E., & Canan, L. (2006). Closer to home: Parent mentors in child welfare. *Child Welfare*, *LXXXV*, 867–884.
- Dedoose Version 4.5, web application for managing, analyzing, and presenting qualitative and mixed method research data. (2013). Los Angeles, CA: SocioCultural Research Consultants, LLC. Retrieved from www.dedoose.com
- DesGeorges, J. (2003). Family perceptions of early hearing, detection, and intervention systems: Listening to and learning from families. *Mental Retardation and Developmental Disabilities Research Reviews*, *9*, 89–93. doi:10.1002/mrdd.10064
- De Vries, H., Elliott, M. N., Kanouse, D. E., & Teleki, S. S. (2008). Using pooled kappa to summarize interrater agreement across many items. *Field Methods*, *20*, 272–282. doi:10.1177/1525822X08317166
- Gallaudet Research Institute. (2011). *Regional and national summary report of data from the 2009–2010 annual survey of deaf and hard of hearing children and youth*. Washington, DC: GRI, Gallaudet University.
- Harry, B. (2008). Collaboration with culturally and linguistically diverse families: Ideal versus reality. *Exceptional Children*, *74*, 372–388.
- Hintermair, M. (2006). Parental resources, parental stress, and socioemotional development of deaf and hard of hearing children. *Journal of Deaf Studies and Deaf Education*, *11*, 493–513. doi:10.1093/deafed/enl005
- Jackson, C. W. (2011). Family supports and resources for parents of children who are deaf or hard of hearing. *American Annals of the Deaf*, *156*, 343–362. doi:10.1353/aad.2011.0038
- Jackson, C. W., Traub, R. J., & Turnbull, A. P. (2008). Parents' experiences with childhood deafness. Implications for family-centered services. *Communication Disorders Quarterly*, *29*, 82–98.
- Jackson, C. W., Wegner, J. R., & Turnbull, A. P. (2010). Family quality of life following early identification of deafness. *Language Speech and Hearing Services in the Schools*, *41*, 194–205. doi:10.1044/0161-1461(2009/07-0093)
- Jamieson, J. R., Zaidman-Zait, A., & Poon, B. (2011). Family support needs as perceived by parents of preadolescents and adolescents who are deaf or hard of hearing. *Deafness & Education International*, *13*, 110–130. doi:10.1179/1557069X11Y.0000000005
- Klein, S. M., & McCabe, H. (2007). From mother to disability professional: Role change, resilience, and rewards. *Journal of Early Intervention*, *29*, 306–319. doi:10.1177/105381510702900403
- Lederberg, A. R., & Golbach, T. (2002). Parenting stress and social support in hearing mothers of deaf and hearing children: A longitudinal study. *Journal of Deaf Studies and Deaf Education*, *7*, 330–345. doi:10.1093/deafed/7.4.330
- McWayne, C., Campos, R., & Owsianik, M. (2008). A multidimensional, multi-level examination of mother and father involvement among culturally diverse Head Start families. *Journal of School Psychology*, *46*, 551–573. doi:10.1016/j.jsp.2008.06.001
- Meadow-Orlans, K. P., Mertens, D. M., & Sass-Lehrer, M. A. (2003). *Parents and their deaf children: The early years*. Washington, DC: Gallaudet University Press.
- Parent-to-Parent USA. (2010). Retrieved from <http://www.p2pusa.org/p2pusa/SitePages/p2p-about.aspx>
- Quittner, A. L., Barker, D. H., Cruz, I., Snell, C., Grimley, M. E., & Botteri, M. (2010). Parenting stress among parents of deaf and hearing children: Associations with language delays and behavior problems. *Parenting: Science & Practice*, *10*, 136–155. doi:10.1080/15295190903212851
- Seale, C. (1999). *The quality of qualitative research*, Introducing Qualitative Methods Series. London, UK: Sage.
- Siegel, L. (2008). *The right to human language: Communication access for deaf children*. Washington, DC: Gallaudet University Press.
- U.S. Census Bureau. (2010). 2010 census demographic profile summary file. Retrieved from <http://www.census.gov/prod/cen2010/doc/dpsf.pdf>
- White, K. (2006). Early intervention for children with permanent hearing loss: Finishing the EHDI revolution. *The Volta Review*, *106*, 237–258.
- Yoshinaga-Itano, C. (2003). From screening to early identification and intervention: Discovering predictors to successful outcomes for children with significant hearing loss. *Journal of Deaf Studies and Deaf Education*, *8*, 11–30. doi:10.1093/deafed/8.1.11
- Young, A., & Tattersall, H. (2007). Universal newborn hearing screening and early identification of deafness: Parents' responses to knowing early and their expectations of child communication development. *Journal of Deaf Studies and Deaf Education*, *12*, 210–220. doi:10.1093/deafed/enl033
- Zaidman-Zait, A. (2007). Parenting a child with a cochlear implant: A critical-incident study. *Journal of Deaf Studies and Deaf Education*, *12*, 221–241. doi:10.1093/deafed/enl032