

Early Experiences of Parents of Children who are Deaf or Hard of Hearing: Navigating through Identification, Intervention, and Beyond

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Abstract

Guidelines created by the Joint Committee on Infant Hearing ([JCIH], 2019) were designed to aid in the early identification of infant hearing loss. Despite these guidelines, a quarter of children who do not pass their initial screening are lost to the follow-up process and many more do not receive care in line with the 1-3-6 guidelines (Centers for Disease Control and Prevention [CDC], 2018; JCIH, 2019). To acquire more information about the experiences of families and identify specific barriers to timely diagnosis and intervention, interviews were conducted with 13 parents of children who are deaf or hard of hearing whose children were enrolled in a larger longitudinal study. These interviews revealed common themes regarding delayed identification, frustrations about timely intervention, and confusion when choosing communication modalities. Common themes amongst families who felt well-supported were also identified.

Keywords: Parent perspectives, hearing loss, qualitative design, hearing screening

Acronyms: ASL = American Sign Language; CI = cochlear implant; EHDI = Early Hearing Detection and Intervention; HA = hearing aid; JCIH = Joint Committee on Infant Hearing

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Early identification is key to minimizing potential language delays in children who are deaf or hard of hearing. Children who are deaf or hard of hearing exhibit deficits in oral language compared to their typical hearing peers (Tomblin et al., 2015), especially in the preschool years (Lund, 2016; Werfel et al., 2022). Delays in early oral language skills (i.e., vocabulary) can improve with amplification and therapy (Moeller et al., 2010; Yoshinaga-Itano et al., 2017). Even as children with hearing loss eventually develop age-appropriate language skills (Ching & Leigh, 2020), deficits in literacy skills remain (Camarata et al., 2018; Nittrouer et al., 2018). Early identification of hearing loss has been associated with improved language (Ching et al., 2017; Fulcher et al., 2012; Grey et al., 2021) and literacy skills (Pimperton et al., 2016). Despite this support for early hearing loss identification and intervention, many children are still not receiving amplification or being enrolled in intervention by the recommended six months of age (Grey et al., 2021; Muñoz et al., 2011).

Establishment of Guidelines

To obtain optimal language and literacy outcomes for children who are deaf or hard of hearing, the Joint Committee on Infant Hearing (JCIH, 2019) created a series of guidelines for universal newborn hearing screenings and follow-up through Early Hearing Detection and Intervention (EHDI). The guidelines recommend that hearing screenings be completed by one month of age, hearing loss diagnosis obtained by three months of age, and enrollment in early intervention by six months of age. Hearing technology should be introduced within one month of diagnosis for those pursuing spoken language outcomes. New guidelines by the JCIH (2019) suggest moving the timelines of diagnosis and early intervention even earlier—diagnosis by two months of age and enrollment in early intervention by three months of age. Universal hearing screenings before hospital discharge were first recommended by the JCIH in 2000 and programs were subsequently established in all 50 states

(JCIH, 2000). The implementation of newborn hearing screenings has resulted in earlier diagnosis of congenital hearing loss (Gaffney et al., 2010; Muñoz et al., 2013; Yoshinaga-Itano et al., 2017) and proves to be critical for improved language outcomes and vocabulary scores (Grey et al., 2021; Yoshinaga-Itano, 2003; Yoshinaga-Itano et al., 2017).

Barriers to Attainment of Guidelines

Despite these guidelines, many infants who do not pass newborn hearing screenings do not meet this recommended timeline and even become *lost* in the follow-up process. The most recent EHDI data reports that 25.9% of infants in the United States who did not pass a hearing screening are lost to the follow-up process (CDC, 2018). This number varies greatly by state; nearly 90% of the infants who failed a hearing screening in Washington DC were lost to follow-up. In South Carolina, 50% of infants were lost to follow-up. Conversely, Vermont and Wyoming reportedly have no infants who were lost to follow-up post hearing screening. Factors responsible for a delay in obtaining timely services include improper documentation or lack of transportation, funding, or resources (Russ et al., 2010; Sass-Lehrer, 2004). Difficulty obtaining funding and long wait times for appointments were also cited as contributing delays for parents whose children were born as late as 2010 (Muñoz et al., 2013).

It is critical to have an objective measure of the progress toward meeting the 1-3-6 guidelines for all children across the United States. However, these numbers cannot provide a description of the lived experiences of the families who had a confirmed hearing loss or were lost to follow up. Qualitative inquiries into the experiences of parents and families can provide us with information about the diagnostic process that may help us improve outcomes and experiences for future families and children who are deaf or hard of hearing. Additionally, qualitative inquiries may aid in the identification of specific barriers to completing additional audiological assessments and eventually decrease the number of families who do not receive timely and adequate services.

Parent Experiences with Hearing Diagnosis and Follow Up

Previous qualitative investigations have examined parent experiences with pediatric hearing loss identification across Canada, the United Kingdom, Australia, South Africa, and rural areas of the United States (Davids & de Jager, 2018; Elpers et al. 2016; Fitzpatrick et al., 2008; Minchom et al., 2003; Nickbakht et al., 2019; Porter & Edirippulige, 2007). Several studies have closely examined the hearing screening and diagnostic process from the family perspective (DesGeorges et al., 2003; Fitzpatrick et al., 2008; Gilbey, 2010; Scarinci et al., 2018). Among these studies, parents have reported confusion about next steps after a hearing loss diagnosis (Fitzpatrick et al., 2008; Fitzpatrick et al., 2016; Gilbey, 2010). Parents have also wondered about their child's prognosis in developing spoken communication (Fitzpatrick et al., 2008), as well as the impact on academic performance and overall concerns

for their child's development (Fitzpatrick et al., 2016). Regarding hearing healthcare professionals, parents reported that overuse of medical terminology negatively impacted the communication of hearing loss results (Gilbey, 2010) and delayed communication of results to families prolonged the follow-up process (Elpers et al., 2016). Furthermore, professionals may neglect to share follow-up information such as early intervention services or medical referrals (Larsen et al., 2012). Previous qualitative investigations have reported that parents desire connections with other families and peers with hearing loss to develop an understanding of the long-term impact of a hearing loss diagnosis (Nickbakht et al., 2019).

The reported needs and desires of families receiving a hearing loss diagnosis for their child have largely remained unchanged in the past few decades. The two primary needs of parents after a hearing loss identification identified by Luterman and Kurtzer-White (1999) were (a) connections to families and children who are deaf or hard of hearing and (b) unbiased information from professionals regarding communication modality or educational method. For many years, we have known about the needs of parents in the process of a hearing loss diagnosis and have been working to meet the guidelines established by the JCIH. However, some of the same barriers to expedient care present twenty years ago continue to prevent timely acquisition of diagnosis and care today.

Current Study

There has not been a qualitative study exploring parent's experiences with the diagnostic process for children who are deaf or hard of hearing since the implementation of the updated EHDI guidelines in 2019. Furthermore, previous studies that have explored parent's experiences with the early diagnostic and intervention system have been limited primarily to other countries (i.e., Canada, Fitzpatrick et al., 2008; Fitzpatrick et al., 2016, Israel, Gilbey 2010; and the United Kingdom, Minchom et al., 2003) or subsets of the United States (i.e., an Appalachian region of Kentucky, Elpers et al., 2016). The purpose of this study was to obtain information from families of children who are deaf or hard of hearing about their identification, amplification, and therapeutic journey. Parent experiences were also evaluated in relation to child scores on language measures collected as part of a longitudinal study. This study is one essential step to gaining information of the lived experiences of families of children who are deaf or hard of hearing following the implementation of more rigorous newborn hearing screening guidelines. Interviews were conducted with parents of children who are deaf or hard of hearing to answer the following questions:

1. How do parents describe their experience of the journey of hearing loss identification, amplification, and intervention for their child?
2. How do parents of children who are deaf or hard of hearing describe the services they obtained related to their child's hearing loss and communication between the providers of these services?

Method

All study procedures were approved by the University of South Carolina Institutional Review Board. Consent for participation in recorded interviews was obtained prior to each interview.

Participants

Participants included 13 caregivers of children who are deaf or hard of hearing who use amplification and spoken English. The caregivers consisted of nine mothers, three fathers, and one grandmother who participated in 12 interviews. Between the caregivers, there were 14 children who are deaf or hard of hearing who were participating in a longitudinal study. One father and one grandmother each had two children in the study, and one interview involved both the mother and

father of one child with hearing loss. One mother had two children who are deaf or hard of hearing, but only one was a participant in the longitudinal study. The caregivers were recruited from the ongoing longitudinal Early Language and Literacy Acquisition in Children with Hearing Loss Study (ELLA; Werfel, 2017; Werfel et al., 2022; Werfel et al., 2023). The established qualitative inquiry convention of recruiting participants until saturation is reached was used; saturation occurs when no new themes emerge, evidenced by an absence of new codes (Higginbottom, 2004; Saunders et al., 2018). Table 1 presents demographic information of the caregivers and children. Demographic information was gathered from a survey distributed to all guardians of children in the longitudinal study.

Table 1
Caregiver and Child Demographics at Time of Interview

Caregiver	Caregiver Hearing Status	Caregiver Education	Child Age (years; months)	Child Gender	Child Amplification	Language and Communication Mode*	Urban Status
Mother	Hearing	Bachelor's Degree	8;1	Female	CI	100% English	Not Urban
Father	Hearing	Associate's Degree	4;7	Female	HA	75% English; 25% ASL	Urban
Mother	Hearing	Some College	7;4	Male	HA	75% English 25% Spanish	Urban
Mother	Hearing	Graduate/ Professional Degree	7;0	Female	CI	100% English	Not Urban
Mother	Hearing	Bachelor's Degree	7;4	Female	CI	100% English	Urban
Mother	Hearing	Graduate/ Professional Degree	5;2	Female	HA	90% English; 90% Signed Exact English**; 5% Chinese; 5% Spanish	Not Urban
Grandmother	Hearing		8;9	Female	HA	95% English; 5% ASL	Urban Urban
			4;8	Male	HA	95% English; 5% ASL	
Mother	Hearing loss	Bachelor's Degree	7;8	Male	CI	50% ASL; 50% English	Urban
Father	Hearing	Associate's Degree	10;4	Female	CI	100% English	Urban Urban
			6;0	Female	CI	100% English	
Mother	Hearing	Bachelor's Degree	4;9	Female	CI	93% English; 7% ASL	Not Urban
Mother	Hearing	Graduate/ Professional Degree	7;6	Female	HA	85% English 15% Russian	Urban
Father	Hearing loss	Bachelor's Degree					
Mother	Hearing	Graduate/ Professional Degree	4;10	Female	HA	99% English; 1% ASL	Urban

Note. ASL = American Sign Language; CI = cochlear implant; HA = hearing aid

*Parent reported language and communication mode use at home

** Signed Exact English used in conjunction with ASL

Procedures

Child Testing

In the national longitudinal ELLA study, from which participants were recruited, children who are deaf or hard of hearing completed a comprehensive battery of early language and literacy measures at set intervals. Study personnel conducted the testing in the child's home or a local library. Study personnel conducted the testing for preschool-aged children at the child's home or local library every six months. School-age children completed a comprehensive battery of language and literacy measures annually after each school year, beginning after first grade at a two-day summer camp.

For the purpose of this study, we used the children's scores on language measures, described below, from the testing session at which their caregiver participated in the semi-structured interview or the following testing session if the interview was via Zoom. Preschool-aged children completed the Peabody Picture Vocabulary Test—Fifth Edition (PPVT; Dunn, 2019), a measure of receptive single-word vocabulary skills. School-aged children completed either the Comprehensive Assessment of Spoken Language—Second Edition (CASL; Carrow-Woolfolk, 2017) or the Clinical Evaluation of Language Fundamentals—Fifth Edition (CELF; Wiig et al., 2013) depending on their age. The CASL and CELF are both omnibus measures of language, assessing language across multiple domains.

Semi-structured Interviews

Caregivers participated in semi-structured interviews in person while their child was participating in the longitudinal study testing or via an online Zoom video call. Twelve interviews in total were completed (one interview involved both the father and the mother so there were 13 participants in total). The majority of interviews took place with caregivers who accompanied their child to the summer camp affiliated with the larger study. Two interviews took place via Zoom, and two took place in person during study visits when study personnel had traveled to the families' location. The interview questions focused on the time around diagnosis of their child's hearing loss, as well as questions they had, support they received, professionals they worked with during this period, what information they were given about childhood hearing loss, subsequent services (e.g., early intervention, speech-language, academic) their child received, and their satisfaction with those services. All interviews were conducted by the first and second author or a trained lab member who had previously observed at least one interview. The interviews lasted an average of 38 minutes.

Coding Process

The interviews were video recorded and transcribed verbatim using NVivo Transcription. The first author reviewed and approved the final transcripts before coding began. Interview data were analyzed using two types of coding: process coding and in vivo coding. We chose

to use these two coding approaches to triangulate the themes identified in the interviews.

Process coding. The procedure for process coding was as follows: first, the second author read a printed copy of each interview and made handwritten notes that consisted of initial ideas. Next, she read each interview again and constructed process codes that emerged from the initial ideas. A data analytic memo for each interview and a codebook consisting of all codes used across interviews were created during this phase. The second author then created a process model that was reviewed by and discussed with the research team. Finally, she made a final pass through each interview that involved streamlining the codes within the codebook and incorporating feedback from the research team, resulting in a final codebook and process model. The entire research team reviewed and agreed upon these final products from the process coding analysis.

In vivo coding. The procedure for in vivo coding was as follows: first, the first author read a copy of each interview. Next, she read each interview again and coded the text following in vivo coding methods, in which the codes use the exact wording of the participants. The first author wrote analytic memos to document her thought process during the coding process. After a first pass was completed for each interview, the first author read through the interviews, codes, and analytic memos. She then completed a second pass of in vivo coding focusing on codes that emerged across interviews. Finally, she compiled all of the codes in a codebook that contained the codes, the corresponding quote from the interview, the participant code, and additional notes for context as needed. The entire research team reviewed and agreed on the final codebook from the in vivo codebook analysis.

Results

In this investigation, we were interested in parents' experiences from the time of suspicion that their child might not be hearing as expected to attainment of a diagnosis and enrollment in intervention services. Two different experience paths emerged based on the reported information from the parents. Children were classified on paths according to parent report. Qualitative coding revealed themes across and between paths.

Path Classification

First, we identified the beginning of the process of interest as either a newborn hearing screening that was not passed or the time at which a parent described first becoming concerned about their child's hearing. For most families, this time was at the point of the newborn hearing screening; however, some families reported passing or not receiving a newborn hearing screening and later becoming concerned about their child's hearing. We then considered the time at which the parents received a definitive diagnosis of hearing loss. Children whose parents felt the diagnosis went quickly were classified in the Fast to Diagnosis group and had a time until diagnosis of 4 months or less ($n = 9$ children). Children whose parents felt the diagnosis did not go smoothly were classified in the Slow to Diagnosis group and had an average time

to diagnosis of 5 months or more ($n = 5$ children). Of note, those whose time was four months or less felt like this process went smoothly even though it is one month beyond the recommended guidelines from EHDI. We used parent experience, and not time to diagnosis, to determine this grouping. Importantly, because this metric is based on the time from suspicion of a hearing problem, it does not necessarily correspond to chronological age. Average age at identification was 5.39 months for the Fast to Diagnosis group ($SD = 11.54$) and 13.25 months ($SD = 13.33$) for the Slow to Diagnosis group.

In addition to this classification, we also considered each child's language skills. All children in the Fast to Diagnosis group had spoken language skills within the average or above average range. For children who were in the Slow to Diagnosis group, there was a mix of performance, such that one child had average to above average language scores, one child had low average scores, one had a mix of average and below average scores, and two children had below average language scores. Figure 1 shows the boxplots of language scores for children in the two groups. The groups were corroborated via mixed methods of parent-reported time between suspecting hearing loss and receiving a diagnosis (as detailed above), process coding, and current language scores. We refer to the Fast to

Figure 1
Boxplots Showing Scores on Most Recent Language Assessment

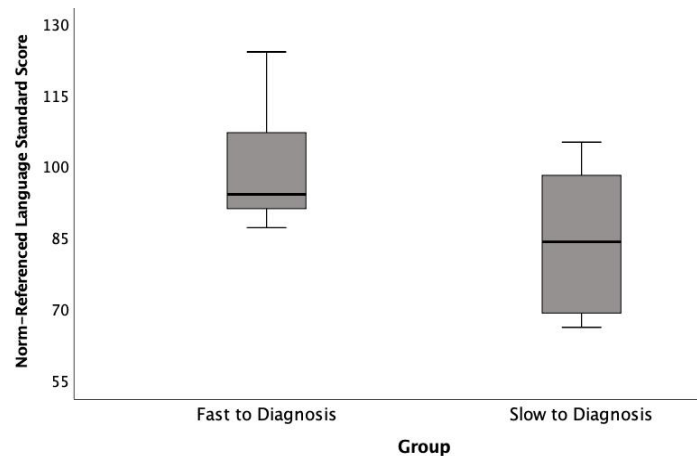
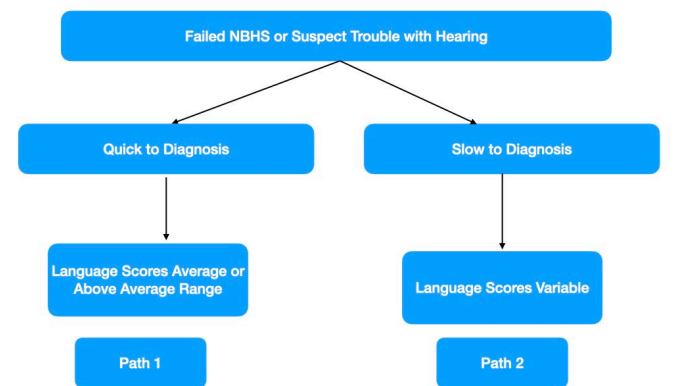


Figure 2
Classification of Families Depending on Perceived Time to Diagnosis and Language Scores



Diagnosis group as Path 1 and the Slow to Diagnosis group as Path 2. See Figure 2 for path classification details.

Process Coding

Path 1

Using process coding, we identified characteristics and experiences of parents on two paths. For families on Path 1, five prominent themes repeatedly were observed in the interviews. First, these parents were connected with hearing healthcare professionals who had specific knowledge of pediatric hearing loss and who the parents trusted. The combination of knowledge and trust was an important defining characteristic for Path 1. On Path 2, parents often reported *either* trusting their professionals or that they were knowledgeable, but no parents on Path 2 reported both. Second, parents on Path 1 often conveyed a *just do it* attitude. These parents expressed that they listened to their providers and did what they were told. This attitude also reflects the importance of having trusted and knowledgeable professionals; some parents on Path 2 also reported following the providers' recommendations, but those recommendations did not follow best practice for pediatric hearing loss. Some examples of this include: not following up on a newborn hearing screening that was not passed on the recommendation of the child's pediatrician; returning to the audiologist every six months for three years to try to obtain a valid conditioned play audiometry result; selecting a communication approach recommended for a child by their speech-language pathologist without fully considering the implications for their child and family. Third, parents on Path 1 often had previous experience navigating the hearing healthcare system, either as a result of having hearing loss themselves or having an older child with hearing loss. Those with prior experience reported encountering fewer obstacles, even in cases where the families were navigating different healthcare systems (i.e., they had moved to a new city). Fourth, families on Path 1 often reported that all of their child's services, including ENT, audiology, speech-language pathology, and in some cases, preschool, were located in the same building. Parents reported that this was beneficial not only for convenience of appointment scheduling but also because of the high occurrence of intercommunication among the members of their child's hearing healthcare team. Finally, parents on Path 1 reported that when their child reached elementary school, the schools were either willing to provide the services their child needed *or* the parents were well-prepared to advocate for them.

Path 2

The shared experiences of parents on Path 2 included four primary themes. First, parents reported that someone downplayed the need for follow-up; this downplaying occurred for some families after their child did not pass a newborn hearing screening and for others after they reported to their pediatrician a concern about their child's hearing. Many families reported that after their child did not pass their newborn hearing screening, they were told to not worry. Often the families heard things like, "Failing

the screening doesn't mean your child has hearing loss," or "It's probably just fluid." Parents reported pediatricians often downplayed the need for follow-up to a hearing screening when a child, for example, flinched in response to a loud sound while in their office for a visit. Newborn hearing screeners' counseling was often interpreted by families to mean that the child's hearing was okay, even in the presence of a refer test result. Second, multiple parents on Path 2 reported being told that their child passed their newborn hearing screening. These children often received multiple screenings that they did not pass before the one they passed, even in the case of a family history of pediatric hearing loss. Third, parents on Path 2 often reported getting the run-around from professionals prior to their child's diagnosis. Importantly, this occurred across all types of professionals that a child with hearing loss might encounter before their diagnosis, including pediatricians, audiologists, speech-language pathologists, and early interventionists. Additionally, some parents reported that community audiologists had them come in for many testing visits before they received a diagnosis; in one case, these visits spanned up to three years. Other parents reported that early interventionists and early intervention speech-language pathologists were slow to refer the child for a hearing screening, even in the presence of a family history of hearing loss and speech sound production errors characteristic of children who are deaf or hard of hearing.

Most parents on Path 2 reported that sometime after their child's hearing loss diagnosis, they connected with hearing healthcare professionals who were knowledgeable about pediatric hearing loss and who the parents trusted. Importantly, families generally were not connected to these professionals via the healthcare system. Instead, an intervening figure, such as a family member or a family friend, connected families with these professionals. In fewer, but multiple, cases, the intervening figure came in the form of other families of children who are deaf or hard of hearing that the parent met through a local or online support group. One parent on Path 2, however, reported a continued lack of access to professionals with pediatric hearing loss knowledge as a result of their geographic location, a lack of available services in their area, and a lack of resources to seek services elsewhere.

In Vivo Coding

Triangulating with the results of the process coding analysis, four themes, seven subthemes, and four categories emerged from the in vivo coding of the transcribed interviews (see Table 2 for an overview). First, themes were identified. Within those themes, subthemes were identified. Finally, categories within the subthemes were identified when applicable. Some themes were reported by parents on both paths and some were only experienced by parents on one path.

Table 2
Themes, Subthemes and Categories from In Vivo Coding

Theme	Subtheme	Category
Limited access to hearing loss services	Parents reported issues with professionals during hearing loss diagnosis	Parents reported pediatricians lacked hearing loss knowledge
		Parents reported receiving insufficient information from professionals regarding next steps in process
	Parents reported lack of local hearing loss services	
Parents received insufficient information from hearing loss professionals	Parents reported concerns over communication modality	
	Parents desired connections	Parents desired a connection with a family who had a child diagnosed with hearing loss
Parents desired a connection with a member of the Deaf community		
Parents reported concerns about their child's development	Parents felt something was not right with their child's hearing	
	Parents reported guilt about not obtaining diagnosis sooner	
Parents reported good experiences	Parents reported ease of having multiple services in one location	

Theme 1: Limited Access to Hearing Healthcare Services

One of the overarching themes identified that was present across parents on both paths was *limited access to hearing healthcare services*. This limited access was due to struggles in their interactions with professionals in the process of obtaining a hearing loss diagnosis for their child, represented in the subtheme *parents reported issues with professionals during hearing loss diagnosis*. One category that emerged from this subtheme was *parents reported pediatricians lacked hearing loss knowledge*. Several parents brought their concerns to their pediatrician but were assured it was likely “just fluid” in their child’s ear canal. Based on this feedback from their healthcare provider, many families in our study on Path 2 were satisfied in the short term which resulted in a delayed diagnosis of their child’s hearing loss. One father said of his experience seeking a diagnosis of his daughter’s hearing loss, “Every time we contacted a pediatrician’s office, they all kind of had the same one liner, ‘Oh it’s fine. Don’t worry about it. It’s just fluid.’” Notably, parents on Path 1 reported hearing this information from a healthcare provider but were not satisfied and sought second opinions or continued to request an audiological evaluation. Another category we identified from this subtheme was *parents reported receiving insufficient information from professionals regarding next steps in process*. Several parents also reported that at the time of the hearing loss diagnosis, they felt they received insufficient information from the audiologist. One mother recounted from her daughter’s initial diagnosis:

A very young audiologist that did the test and she came into the recovery room and said “She’s deaf but it’s more than that. She actually has something called auditory neuropathy and we don’t treat that here so you’ll have to go somewhere else” and she walked out and left us with nothing.

Another mother said of the audiologist who made her son’s initial diagnosis,

When he has hearing loss and everything was...we were crying like [shrugs]... she barely had time to talk to us because she was getting ready to leave for Thanksgiving break.

Parents reported feeling overwhelmed emotionally with the information of the diagnosis. Parents also reported feeling unsupported by not being given information on what the next step was for their child. One mom said, “We should have had just more information up front. Someone to give us a clear path, or a clearer path of at least what our next step was.” Another father shared this about his experience, “Nobody ever gave me that big arc like this is how it works.”

In some cases, the limited access to hearing healthcare services was caused by a physical restriction, such as lack of local hearing healthcare services or a limited number of hearing loss professionals sufficiently familiar with pediatric

hearing loss. These physical limitations are reflected in the subtheme *parents reported lack of local hearing healthcare services*. Parents, especially those in rural or less populous areas, reported traveling far distances to find professionals who were sufficiently familiar with pediatric hearing loss. For many of these parents, the professionals in the towns in which they lived were not sufficiently familiar with pediatric hearing loss. One mother said, “I really wish we were in an area where there was more than one pediatric audiologist so I could have gotten a second opinion instead of going to [nearest large city].” Another mother responded, in answer to a question about what she disliked about the services she received, “The fact that we had to go so far to get quality access, access to quality professionals.”

Even for parents on Path 1 who had overall positive experiences, the distance they traveled for their child’s audiology appointments and therapy sessions was notable. One mother said, “It’s about 45 minutes...you know there’s nothing really offered in our town.” Another mother recounted how she and her daughter did not move with her husband when he was stationed across the country in order to remain close to her daughter’s preschool for children who are deaf or hard of hearing. She said, “We were like, we’re not moving [child’s name] from her services at [hearing loss preschool]... It was definitely a deciding factor as to where our family would stay.” The distance families traveled for their children’s services was mentioned in eight of the 12 interviews.

Theme 2: Parents Received Insufficient Information from Hearing Loss Professionals

Several parents on both paths reported limited information received from hearing healthcare professionals and desiring additional information from other routes. This was supported by the subtheme *parents reported concerns about their child’s communication modality*. Specifically, these concerns were often related to the process of selecting a communication modality for their child, spoken English or American Sign Language (ASL). Only one mother was a fluent native signer of ASL. For several parents, they identified this process as a negative experience even if the chosen communication modality has been working for their family. Many parents reported that the decision to use spoken language or ASL was theirs to make; however, they felt ill-equipped to make this decision and wish they were given more information about either ASL or long-term spoken language outcomes. One mother said of her speech-language pathologists’ recommendation to use ASL instead of spoken English, “We would have liked to understand the rationale for the things he was recommending.” Another mother whose daughter attends a school for the Deaf said, “It’s just kind of like here’s your choice, like well how do I choose if I don’t have some additional information, you know.” A mother whose daughter uses spoken English told us of the recommendation to use only spoken language, “I would have liked to have gotten a more balanced opinion and seen quality research on both sides of that opinion.” This mother recounted an instance when she regretted

heeding the advice of professionals who encouraged her to exclusively use spoken language with her daughter:

[Child's] processor failed and she was without hearing for three weeks and we don't know enough sign language to carry on quality conversations. So, it would have been nice to have had... access to more quality balanced research to know where to go.

Parents also reported that at the time of their child's diagnosis they would have benefitted from being connected with an individual with hearing loss, identified in the subtheme *parents desired connections*. Two categories emerged; the first being *parents desired a connection with a family who had a child diagnosed with hearing loss*. Parents reported wanting to know what the future looked like for their child. Several of them either had no or limited familiarity with individuals with hearing loss. During the interview, one dad recounted this question he had at the time of his daughter's diagnosis, "I didn't know if that meant you're going to speak like me, you're going to speak like that kid I remember from school." Parents reported that being put in contact with a family with a child with hearing loss who was a few years older than their child would have helped them see what their choices would look like in the future. One mother told us:

One of the other things I wish had been done was I wish I had been given the opportunity to meet families who are a few years down the path from me because that was really like I remember the first time I met a high schooler who was implanted and was like he can talk. He has been through you know a normal public-school education. He plays football. He kind of seems like a normal kid and that he really was like for the first time for me like a sigh of relief like OK it's going to be fine. [child's name] is going to have a normal life.

Another category that emerged is *parents desired a connection with a member of the Deaf community*. Some parents reported that they desired the opportunity to learn sign language or Deaf culture from a member of the Deaf community. Two parents that we interviewed sought these services to learn sign language on their own as well as to better communicate with their children. One mother desired that opportunity, but did not know how to make that initial connection with a member of the Deaf community. She reported

Anybody that's taught sign language to us is a hearing person....That's been difficult. We've got videos and stuff like that. But there's still that incidental stuff in sign culture that we don't get. There's good access to the base language but conversational language and colloquial stuff, I don't know where it is.

Theme 3: Parents Reported Concerns about Their Child's Development

A subset of parents across both paths reported multiple instances throughout the diagnosis process where they were concerned about their child's development. One subtheme that emerged was *parents felt something was not right with their child's hearing*. Many parents described knowing their child's development was not proceeding normally even before they knew their child's diagnosis. One mother said, "I had this mama gut feeling that there's probably something more going on." Another mother said of their experience, "We saw something like seven audiologists and five ENTs between when she was born and when she was 13 months old because they kept saying, 'she's fine, she can hear.' But we knew that she couldn't."

Another subtheme we identified for parents on Path 2 was *parents reported feeling guilt about not obtaining diagnosis sooner*. One father said "I blew it. I was an idiot," in regard to not seeking hearing aids for his child earlier. One mother said, "I didn't push as hard as I could have because I was upset I was even having to do this" and "I felt like I didn't push hard enough." This mother repeatedly mentioned her suspicions of her daughter's hearing loss to her pediatrician and attempted to have her tested by a friend who was an audiologist before obtaining an appointment for a sedated ABR that would provide the diagnosis. Another mother said, "I wish I had done something sooner" and "I felt cheated that we had not had this diagnosis earlier." This mother's child did not pass the newborn hearing screening and was seen by three different audiologists before being diagnosed at age three.

Theme 4: Parents Reported Good Experiences

Although most parents reported difficulties or frustrations with aspects of the diagnosis and amplification process, parents on Path 1 and some parents from Path 2 also reported positive experiences. One mother shared,

They immediately fitted her with hearing aids and put hearing aids on her even though they didn't work really. And they immediately started, I think by the time she was two months old, they were doing a speech service.

When asked if she had questions at the time of her daughter's initial diagnosis, another mother said, "We didn't have to ask a lot of questions because our audiologist was awesome. Just love her to death. She's just the best."

By seeking out a medical center in a major city, some families were able to get many of the necessary services, such as audiology appointments, speech-language therapy, and parent education, under one roof, reflected in the subtheme *parents reported ease of having multiple services in one location*. One father said, "I liked having all the services in one place...For us living so far away, it was great to have everything under one roof, even the audiologist, because we already spent so much time in the car."

One father said of the preschool his daughter attended for children who were deaf or hard of hearing, “I felt like this was the place to be.” Another mom describes the close relationship she and her daughter have with her daughter’s first teacher of the deaf; she describes texting her after meeting with new professionals and that she continues to check in about her child even though she is no longer in her class.

Discussion

The purpose of this study was to obtain information from families of children who are deaf or hard of hearing about their identification, amplification, and therapeutic journey. The children of the participants in this study were born after the implementation of the EHDI 1-3-6 standards. However, for many families in this study, those guidelines were not met. The results of the coding and analysis revealed common elements that contributed to overall positive or overall negative outcomes for the families in our study.

Two paths emerged for families on their child’s hearing journey in this study. On Path 1, parents felt the period of time between suspected hearing loss and diagnosis was short and that they were quickly connected with knowledgeable and trusted professionals. On Path 2, parents felt there was a long period of time between suspected hearing loss and diagnosis, but upon diagnosis families were *typically* connected with knowledgeable and trusted professionals.

Connections of Themes to Previous Work

An overarching theme that emerged was limited access to hearing healthcare. Some families were not able to access services in a timely manner, preventing them from meeting recommended EHDI guidelines, whereas other families were inconvenienced by the difficulty in obtaining these services but were able to access them. This difficulty in limited access to hearing healthcare services was also reported in investigations exploring barriers to timely healthcare for families in rural America (Elpers et al., 2016) and Canada (Fitzpatrick et al., 2008).

The importance of frequenting hearing healthcare providers knowledgeable about pediatric hearing loss was evident from our participants. Many parents in our study related their experiences with pediatricians lacking hearing loss knowledge who played primary roles in preventing them from obtaining a timely diagnosis. Similar difficulties were encountered by some parents who were seeing audiologists not familiar with *pediatric* hearing loss. These professionals prevented the parents from obtaining a confirmation of the diagnosis of hearing loss. In a survey study in the United States, Larsen et al. (2012) found that more than 50% of participating parents were lacking information regarding medical referrals. Parents in previous studies also reported professionals minimizing hearing loss, resulting in delay of diagnosis and even speech and language delays (Elpers et al., 2016; Fitzpatrick et al., 2016).

Several parents reported some misgivings regarding the process of selection of communication modality, either because they themselves desired more information or they did not feel they were working with a professional knowledgeable about hearing loss. In fact, unbiased information from professionals surrounding communication modality has been identified as one of two primary needs of parents surrounding a hearing loss diagnosis (Luterman & Kurtzer-White, 1999). A nationwide study by the National Center for Hearing Assessment and Management (NCHAM; 2021) reported some families’ frustration regarding locating professionals who used their desired communication modality.

Parents expressed a desire to connect with others throughout their hearing loss journey, in particular families with other children who are deaf or hard of hearing who were a few years older than their children to see what their future might look like. This theme supports previous findings. Following a hearing loss diagnosis, parents desire connections with other members of the hearing loss community, particularly children (Luterman & Kurtzer-White, 1999; Nickbakht et al., 2019). Nickbakht and colleagues (2019) reported that parents of children who are deaf or hard of hearing in Australia wanted to connect with other families “in the same boat” (p. 677) and desired professionals to “walk the journey” (p. 677) with them. The difficulty families encounter connecting with family-to-family support systems has been identified as a major hurdle (NCHAM; 2021); NCHAM suggests these organizations formalize partnerships with state-level EHDI programs.

Future Directions and Limitations

Many parents, in our study and in the existing literature, refer to the “steps in the process” of navigating a hearing loss diagnosis. Some of our parents desired a “blueprint” or a “roadmap.” In many ways, EHDI guidelines provide a blueprint for hearing loss providers. Hearing healthcare professionals should inform families of next and future steps to decrease families’ feelings of frustration and increase adherence to recommended guidelines. Future work should investigate the impact of increased parent education and support on adherence to recommended EHDI guidelines.

It should be noted, all participants in this study had a child who was enrolled in a longitudinal study for children who are deaf or hard of hearing, many of whom found this study through connections with professionals well-versed in hearing loss or through preschools and centers for children with hearing loss. Every child in this study eventually obtained a diagnosis of hearing loss. Even so, one parent on Path 2 never was connected with a knowledgeable professional. This suggests that there may be additional paths or subsets of paths for families who have struggled or are still struggling to obtain a diagnosis and connect with hearing healthcare professionals that were underrepresented in these interviews. These families may have experiences that differ from the caregivers in our study. Additionally, parents in this study were generally

highly educated, their experiences may not be reflective of parents from all socioeconomic and educational backgrounds.

Conclusion

This study investigated the experiences of parents whose child had been diagnosed with hearing loss. Important themes that emerged highlight areas of hearing loss service delivery that can be improved, including limited access to hearing healthcare services and receiving insufficient information from professionals. The results from this study shed light on the navigation of hearing healthcare services from the parents' point of view and may aid in the identification of barriers to timely diagnosis and intervention and children lost to follow-up. Furthermore, collaboration between professionals and a trusted network of referrals may significantly decrease family frustration and increase adherence to EHDI 1-3-6 guidelines.

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EHDInfo

CONGRATULATIONS to Wyoming for being the 2023 EHDl Website of the Year!

The screenshot shows the homepage of the Wyoming Early Hearing Detection & Intervention (EHDl) website. At the top, the logo reads 'eHDI WYOMING Wyoming Early Hearing Detection & Intervention'. A navigation bar includes links for Training, Pediatric Audiology, Resources, Wyoming EHDl-IS, and Directory. A search bar is located in the top right. The main content area features a large banner with a baby's face and the text 'Better Outcomes with Early Detection' and a 'Learn More' button. Below this are two columns: 'Knowledge Center' with a gear icon and a 'Check It Out' button, and 'WEll Resources for Families and Professionals' with a mountain icon and a 'WEll Resources' button.

GUAM EHDl Program recognized as the best website among the website of the year awards for the past 13 years.



Guam Early Hearing Detection & Intervention
University of Guam Center for Excellence in Developmental Disabilities Education, Research, & Service (Guam CEDDERS)



2023



NENI DIRECTORY

Håfa Adai & Welcome!

Newborn hearing screening is extremely important as it helps to determine whether infants have hearing loss. Guam EHDl works to assure that all babies born on Guam get screened for hearing loss by 1 month. If a baby does not pass their hearing screen, a Diagnostic Audiological Evaluation (DAE) will be conducted by 3 months of age. A baby with hearing loss will be enrolled in early intervention services by 6 months of age.

Universal newborn hearing screening is mandated by [Guam Public Law 27-150](#).



Early identification of hearing loss is key to providing appropriate intervention services to promote language development.

Available in 4 languages: [Chamorro](#), [Chuukese](#), [Korean](#), and [Tagalog](#).



[Hearing Screening Data](#)



[Guam EHDl Project Na' Mas Fitme](#)



[Early Intervention](#)