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HOW HEARING PARENTS WITH DEAF OR HARD OF HEARING CHILDREN CONSTRUCT DEAFNESS THROUGH THEIR EARLY INTERVENTION EXPERIENCE

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by

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DISSERTATION

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Dedication

To my husband, for unending support and encouragement in accomplishing my lofty dreams and believing I can change the world.

To my children, who taught me more about my social constructions than any class and have always been the inspiration for my dreams.

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B.A. LIBERAL ARTS AND SCIENCES, M.ED. DEAF EDUCATION EARLY

INTERVENTION

PH.D. EDUCATIONAL LINGUISTICS

Abstract

This dissertation explores how hearing parents with deaf/hard of hearing children come to understand deafness. This mixed methods study used an online survey and multiple case studies (volunteers from survey). Participants were asked about early intervention experiences and beliefs about deafness. The survey had 74 respondents and five families participated in the interviews. Survey participants' beliefs about deafness were primarily medical, focusing on the perceived barriers caused by deafness and the remediation of those barriers through spoken language options. A small number of respondents adopted a cultural perspective of deafness and focused on remediation of barriers through involvement in the Deaf community. Case study family stories show the impact of the social environment on the family's construction of deafness. Results suggest that early intervention can combat those barriers by providing options, including deaf/hard of hearing adults, and being mindful of how provider beliefs about deafness further limit families.

Keywords: mixed methods, social construction, deafness, early intervention

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CHAPTER 1: INTRODUCTION -- How Hearing Parents with Deaf or Hard of Hearing

Children Construct Deafness Through Their Early Intervention Experience

When I was in high school, I wanted to learn American Sign Language (ASL) because I saw a woman on TV who signed and because my sister was taking an ASL class in college. When I went to college, I registered for an ASL class as soon as I could. My ASL teacher was the first Deaf person that I met. He, like me, was from a small western town. When he lost his hearing due to illness at a young age, his parents lost their means of communicating with him. He detailed their struggles with trying to find resources and learning what to do next. I could easily imagine his small town, like mine, being devoid of services. He talked about growing up and learning to identify himself as Deaf, a person in a cultural and linguistic minority. Prior to this class, my ideas of deafness were about what I would miss about hearing and that ASL was a beautiful language. After meeting a Deaf person and learning some ASL, I understood that Deaf people have a language and culture and are less concerned with hearing ability.

After taking ASL and becoming pregnant with my first child, I thought back to my teacher's parents. How could they have known what their son needed when they were not provided with resources or support? How would I, as a parent, know what to do if I had not taken this class? How would I know how to communicate all that I wanted my child to know if I did not know ASL? I began to learn about early intervention (EI) for deaf and hard of hearing children and their families and changed my major.

All along my educational journey, I learned more about parenting, child development, education, deafness, ASL, and who I am. After completing a masters in Deaf Education Early Intervention, I began working as an early intervention provider for a state school for the deaf. After nearly a decade of experience, I decided to return to school to further my education. I could see that not all early intervention providers or

programs are the same and I wanted to see what I could do to ensure more quality support

for families. My experience working with families teaches me the most about what I can

do to better support individual families. However, working with Deaf adults has taught

me about checking my biases and assumptions and helping me construct my

understanding of what it means to be deaf or hard of hearing (d/hh[1]). These experiences

shape my beliefs and, in turn, the way I interact with families shapes their beliefs about

their child.

       In reading the description of my journey in the field of deaf education, depending

on your experiences and understanding of deafness, you have formed or constructed some

idea about what deafness means to me. We all have some understanding of what it means

to be deaf or hard of hearing based on how we have been socialized. I was influenced by

media, my desire to be like my sister, my Deaf ASL teacher, the philosophy of my chosen

major, my experiences with Deaf professionals and families with deaf or hard of hearing

children, as well as the federal policies that mandate early intervention (to name a few). I

continue to be socialized to understand more about what it means to be d/Deaf.

       What people believe about deafness varies from a debilitating disability and basis

for discrimination (audism[2]) to a dynamic distinction (Deaf Gain[3]) with a wide range in

between. The medical perspective focuses on the biological condition and finding a

"cure." The social perspective celebrates diversity and the possible contributions a variety

of people have to society. (These viewpoints will be discussed more in the Rationale and

Theoretical Framework section.)

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[1] In this paper, I will use d/hh to signify someone who has the hearing condition of being deaf or hard of hearing regardless of their affiliation with the Deaf culture or use of American Sign Language. A capital "D" for Deaf will indicate a cultural and linguistic affiliation if one is known.

[2] Defined by Humphries (1977, p.12) as "the notion that one is superior based on one's ability to hear or behave in the manner of one who hears."

[3] Deaf Gain is defined by Bauman and Murray (2014) related to the shift from a focus on hearing being the norm and deafness being a "loss" of the norm. It focuses on deafness as a positive and diverse way of being. To be discussed more in the Signing and Stigma section.

Background of the Problem

The vast majority of deaf or hard of hearing (d/hh) children are born to hearing parents (Mitchell & Karchmer, 2004) who often have very little knowledge of hearing differences. Since 1999, every child born in the United States is required, by law, to have their hearing screened (42 U.S.C. § 280g-1). Thus, the first professionals that parents[4] encounter shortly after the birth of their child are the more knowledgeable doctors, the experts, who tell them that their child has hearing "loss" or "failed" the hearing screening. The family's understanding of who their child is – or can be – is shaped by the focus on the perceived deficit. Although these interactions are brief, the impact can be lasting. According to Beazley and Moore (1995), the images conjured by these statements "are likely to be firmly and forever etched upon parents' minds" (p. 13). What providers believe impacts what and how they present information to families (Eleweke & Rodda, 2000) and the recommendations they make highly impact parental decisions about communication (Li et al., 2003). The words they use and the way they present information will continue to shape the view a family has of their child (Watkins, 1997).

Historically, the average d/hh child was identified with a hearing difference at 2 years of age. These children would then often enter preschool (at 4 years old) with language skills far below the 10th percentile (Yoshinaga-Itano, 2003). After several studies by Yoshinaga-Itano and her colleagues (1998), the evidence in favor of early identification of hearing differences led a push for universal newborn hearing screening (UNHS, the practice of screening all children's hearing at birth) and Early Hearing Detection and Intervention (EHDI[5]) programs. Research by Yoshinaga-Itano and colleagues (1998, 2000, 2001) shows that the earlier a child is identified with a hearing

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[4] The term 'parents' is inclusive of biological parents as well as any primary caregivers.
[5] EHDI programs vary by state and include any professionals involved in the hearing screening and diagnostic process and early intervention. For example: audiologists, speech language pathologists, service coordinators, etc.

difference, the better possible language outcomes are for that child. Because of this need for identification, each state has an EHDI system in place. EHDI focuses on the 1-3-6 timeline for early intervention: hearing screened by 1 month, hearing diagnosed by 3 months, and early intervention started by 6 months.

Early intervention services are federally mandated, however the kinds of services provided vary by agency and are dependent on beliefs about deafness. Since the early identification process is primarily medical, deafness is often seen as "an illness or disease" (Young & Tattersall, 2007, p. 218) with a focus on medical interventions. If deafness is seen as a disability, the early intervention services follow a special education paradigm (typically functional/behavioral). By contrast, when deafness is seen as a difference, an early childhood education paradigm which is typically developmental in approach motivates early intervention services (Sass-Lehrer & Bodner-Johnson, 2003).

Statement of the Problem

Since the vast majority of d/hh children are born to hearing parents with little to no experience with the communication needs of d/hh people, these children are at risk for language deprivation (Hall, 2017; Hall et al., 2017; Humphries et al., 2012; Humphries et al., 2016). In other words, without proper support (quality early intervention) and language access, these children will grow up without a fully functional language. Language development is linked to future language and cognitive skills and is therefore crucial to every child (Humphries et al., 2016).

Bailes et al. (2009) suggest that "without unbridled access to natural language, the quantity and quality of language input for most deaf children is severely impoverished" (pp. 449-450). Cummins argued that growing up without a strong first language not only negatively impacts the child as an individual, but also impacts what contributions they could have made to society (as cited in Bailes et al., 2009). Difficulties with working

memory (Marshall et al., 2015), delay in executive function (which is needed for behavior regulation and metacognition) (Hall et al., 2017; Hauser et al., 2008; Humphries et al., 2016), structural brain changes (Humphries et al., 2016; Mayberry et al., 2011; Penicaud et al., 2013), higher risk for abuse and neglect (Humphries et al., 2016), issues with phonological development (Lu et al., 2016; Morford & Mayberry, 2000), and general cognitive and mental health problems (Embree et al., 2017; Hall, 2017) are some of the results of language deprivation.

Language deprivation researchers argue that the only way to avoid this devastating situation is to teach all children a signed language (Hall, 2017; Hall et al., 2017; Humphries et al., 2012; Humphries et al., 2016). They argue that there is no harm for any child in learning a signed language but not signing with certain children will lead to language deprivation. Redmond (1992) seems to argue in favor of this approach when they said it is "better practice to err on the conservative side when grave things are at stake, one could argue that nothing is lost if we act as if the critical period does exist" (p. 25).

Statistically in the United States, according to Gallaudet Research Institute (2013), only about 5-10% of d/hh students have Deaf parents and acquire a signed language naturally. However, 50% of d/hh children are enrolled in educational programs that use listening and spoken language only. This approach is characteristic of a medical or remedial perception of deafness. Medical professionals generally do not direct parents to sign language resources and some even discourage using a signed language (Mauldin, 2016). Hall (2017), Hall et al. (2017), Humphries et al. (2012), and Humphries et al. (2016) warn that these children are at the greatest risk for language deprivation because they are not exposed to a signed language until they "fail" at spoken language and begin to learn signs as a last resort. They are past the critical period for language acquisition,

that is, the period in early life when children exhibit a heightened sensitivity to linguistic structure in the environment and are at risk for long term cognitive and social-emotional effects (Mayberry & Kluender, 2018). This situation constructs the disabling barrier many believe is caused by deafness alone but is rather a result of not having access to language at an early age.

One of many reasons for the frequent selection of listening and spoken language programs is because parents' choices are limited to the philosophies of their local early intervention program. Early intervention is federally mandated, but the programming is determined by the beliefs (and funding sources) of the local program directors. Garate and Lenihan (2016) explain that program philosophies guide the communication options offered. For example, if a program director, or backing donor, believes that a listening and spoken language approach to educating d/hh children is the best method, then they focus their efforts on assimilating the child into the wider, hearing world. Mauldin (2016) further explains that families are already socialized to a medicalization of deafness before their child is screened and are carried along with the system into getting hearing aids and cochlear implants without much consideration of a signed language or Deaf culture.

The attitudes and beliefs that early intervention providers bring into families' homes impact how families socialize their child. Bogdan and Knoll (1995) agree that children are socialized to fit the expectations of those who "serve" them. "Whether they are ashamed or proud of their condition, or feel neutral about it, is mediated by significant others – parents, teachers, peers, attendants – who enter their lives in social interaction" (Bogdan & Knoll, 1995, p. 694). For example, Young and Tattersall (2007) mention one mother in their study who noted how learning from her deaf provider helped her find enjoyment in language activities with her child. The stories shared by the families in

Young and Tattersall's study, teach us "to be mindful, as professionals, of the constructs of deaf children that may be transmitted to parents in the earliest stages" (2007, p. 218).

Medical professionals and early intervention providers have a potentially powerful role in the lives and socialization of children and families with d/hh children. When a family has just learned that their child "failed" a hearing test and they are envisioning their child's future, they may see a path strewn with barriers and impossibilities. These views become a self-fulfilling prophecy for the child (Bogdan & Knoll, 1995). Alternatively, if exposed to a deafness as difference framework, they can learn to see the "possible contributions, benefits, or pleasures the infant born with a disability might bring to its family and society" (Fine & Asch, 1988, p. 15). This can be difficult because most information parents get about deafness comes from a remedial perspective and they may not have information "about the social, cultural, and linguistic life of the Deaf community" (Hyde et al., 2010, p. 163).

Purpose of the Study

Hyde et al. (2010) recognize that hearing parents with d/hh children are influenced by their own "beliefs, values, and attitudes" and their "emotional reactions" (p. 163). Parents' beliefs are also shaped by the professionals that interact with their family (see also Mauldin, 2016; Li et al., 2003; Young & Tattersall, 2007; Young, 2010). In their study, Hyde et al. (2010) found that the most important source of information to parents were medical professionals (cochlear implant program, ENT, Audiologist, Pediatrician = 54%), with considerably less importance placed on other parents (14%), and early intervention providers (13%). Perhaps if early intervention providers introduced parents to a different way of thinking about deafness, instead of just accepting the medical model perspective, they could have more impact in the lives of the families they serve.

Beliefs guide not only professional practice but how people act in their own homes. If parents' beliefs about their child are centered on their difference and trying to "fix" the "problem," then their child will see themselves as such. However, if parents learn to see people who are deaf or hard of hearing as people who overcome societal barriers, then the child will learn to do so as well (Bogdan & Knoll, 1995). Based on their beliefs, families help construct their child's identity through the communities in which they are involved, the language(s) they use, and the ways they talk to and about their child(ren) (Danforth, 2001).

Questions to be Addressed

The questions I hope to explore with this dissertation are: (1) What are some of the meanings of deafness that hearing families with deaf or hard of hearing children currently hold? (2) How are hearing families with deaf or hard of hearing children constructing (or coming to understand) what it means to be deaf or hard of hearing? (a) What sources of information seem to inform these constructions? (b) How does early intervention programming impact these constructions?

Conceptual Assumptions and/or Operational Definitions

Early intervention, as a federally mandated part of the special education law, is considered a social institution. EHDI programming, though important for identifying a need for early intervention and for listening devices when applicable, is primarily run by healthcare professionals who traditionally operate from a medical model framework (Mauldin, 2016). The medical model framework assumes a deficit that needs remediation. Early intervention programs are able to determine their own philosophy and approach to supporting d/hh children and their families under the general guidelines. Often the listening and spoken language approach operates under the medical model – focusing on hearing devices to remediate hearing difficulties and speech to help the child interact with

mainstream society. Programs that primarily use American Sign Language tend to lean toward a cultural model of deafness and focus on visual communication and learning. Bicultural bilingual or bimodal bilingual programs support both ASL and some form of English (written, spoken, or signed). The cultural or social perspective of deafness follows the shift mentioned by Bauman and Murray (2014) from "an overarching framework of normalcy to one of diversity" (p. xv). Some programs offer the range of communication approaches and listening supports to the family and adjust as needed. There is a wide range of options[6] across the United States but not always a range of options within a local community.

Social construction of disability or deafness (introduced below) does not assume that any one view of deafness is inherently bad or good. It acknowledges that conceptions of disability or deafness are not objective, and instead focuses on identifying the factors that contribute to an individual's understanding of what it means to be a person with a disability or a person who is d/hh within a social context. It recognizes that social interactions, media images, and other experiences impact how each person constructs their understanding of disability or deafness. Parents learn to understand what it means to be d/hh through their own life experiences and while interacting with their d/hh child over time.

Rationale and Theoretical Framework

The social construction model is a useful theoretical framework because it can "include both those with disabilities and those without" (Jones, 1996, p. 350). In this framework, persons with disabilities, their families, and professionals work together to

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[6] Communication options vary from strictly auditory-oral approach with no visual support to primarily visual communication. Within this continuum, the majority of communication approaches still favor a medical perspective of deafness, with spoken language being the ultimate goal, while still allowing for some use of signs or visual supports. A bilingual bicultural approach includes some form of English (written and/or spoken) and Deaf culture and ASL.

construct meaning. Bogdan and Knoll (1995) further explain that meaning is derived from a person's interpretation of something and develops through interaction with others. Therefore, disability, from the social construction standpoint, has different meanings based on the perspectives and experiences of different people. Valente et al. (2011) argue that the "biological notion of normative sensory experience is not so natural and normal after all but is, rather, a phenomenon formed through the complex interplay of biological function and cultural and political mediation" (p. 246).

In order to better understand the social construction model, it is important to first understand the medical model as it is the prevalent perception of deafness. Rao (2006) explains three assumptions of the medical model: the individual has an organic deficit, the deficit is objective and can be quantified, and exists regardless of cultural norms. With the 1-3-6 timeline, EHDI looks at identifying the deficit (hearing screening), quantifying it (getting a diagnosis with hearing levels), and remediating the impact to the child and family (early intervention). Branson and Miller's (2002) explain that one way people with a disability are defined, is based on how they are assessed in order to qualify and access support services. They are described as "a collection of people who are defined as disabled by others for administrative purposes such as housing, education, income tax, and social services." (Branson & Miller, 2002, p. xiii). In order to access early intervention, a child must access special education services by qualifying for support under a defined need. These qualifying categories are assessed by professionals to define the need and access funding from the federal government.

Research supporting this medical model shows that identification of a hearing difference before six months of age results in higher language and cognition scores (Yoshinaga-Itano, 2003) and thus benefits the child and family. Unfortunately, in the rush to identify a hearing difference and maximize access to sound as early as possible, puts

parents on the medical model path at birth (Mauldin, 2016; Young, 2007). Mauldin (2106) mentions how the system basically primes the parents for getting listening devices and becoming speech/listening therapists for their d/hh child. Young (2007) further explains that this rush through the system places families in the position of making medical decisions for their child before they have a chance to speak with other families, an early intervention provider, or deaf adults (thus ignoring a possible cultural context of deafness). Hearing parents often have "no experience or understanding of what it means to be deaf" (Sass-Lehrer & Young, 2016, p. 27). These parents often begin their journey towards understanding deafness based on a "failed" hearing screening. According to Beazley and Moore (1995), this initial "failure" sets up the parents to hope that their child will eventually "pass."

One assumption of special education, according to Bogdan and Kugelmass (1984), is that progress is evidenced by the improvement of diagnosis, intervention, and technology. This continues to hold true today as evidenced by support for EHDI programs. In 2020, the U.S. Department of Health had a grant available, for which state EHDI systems could apply, totaling $28,000,000 which was to be used to improve the documentation of EHDI "diagnostic and intervention data" (funding opportunity number CDC-RFA-DD20-2006 was found on the grants.gov website). The grant further explains that it was to be used to document and track children identified through newborn hearing screening to make sure they are being diagnosed and enrolled in early intervention. There are currently 3 grants posted that are for screening support. By contrast, no grants are found that promote the improvement of intervention program *quality*.

Bogdan and Kugelmass (1984) also mention that the use of technology is seen as evidence of success in special education. In early intervention for d/hh children, this is evidenced in advances in hearing support devices like cochlear implants (or CIs). The

FDA began approving cochlear implants in 1985 (Sorkin, 2013) but children under 3 were not approved until 1990 (Eshraghi et al., 2012). According to Raine (2013), about 250 children were implanted in 1992 and over 2000 children were implanted in the year 2002. Zeng et al. (2008) tracked the exponential growth in both medical articles about cochlear implants (from 100 articles in 1990 to over 200 articles published in 1995) and the number of implants (from 4000 total implants in 1999 to 16,000 in 2007). Cochlear implants were ranked a $1.5 billion industry as of 2018 and are estimated to increase 10.8% by 2026 (grandviewresearch.com). These numbers show how the importance of the cochlear implant in the medical field has impacted the number of d/hh people receiving implants, thereby confirming the idea that technological advances in special education are viewed as evidence of success. In this rush to accept and improve technology, Humphries et al. (2012) suggest that medical professionals may be overlooking the risks involved with the surgery and assumptions about their effectiveness. Hintermair and Albertini (2005) argue that CIs have increased in popularity because of "the public's preoccupation with deafness as a disability and promises that technological breakthroughs such as the cochlear implant will 'cure' deafness" (p. 184).

On the other hand, Jones (1996) notes that the social construction model does not deny the biological difference but distinguishes between the "condition" and "the handicapping social environment in which the person with disabilities exists" (p. 351). A condition that an individual has does not automatically equate to disability. "Rather, a disability is formed on the basis of a complex interplay of a variety of factors internal and external to the person. These factors *mediate* the extent to which a condition results in a disability" (J. Scherba de Valenzuela, personal communication, January 23, 2020). In this study, I am looking at the interplay of these factors in mediating the disability of a d/hh child with hearing parents.

Danforth (2001) defines the social construction of disability as "a product of social interaction, thought, belief, and language use" (p. 344). According to Bogdan and Knoll (1995), disability is socialized through interactions with people and the environment. Disability is socially constructed through media, education, work, and other social institutions as well as the language used in modern culture. One way to change the social environment is to start with the language used regarding persons with disabilities. The language used when talking about persons with disabilities as well as in everyday colloquial expressions reflects societal beliefs about disability. Everyday conversations perpetuate ableism and stereotypes or stigmas about disability (Bogdan & Knoll, 1995).

Valente et al. (2011) define the social construction of deafness as "a phenomenon formed through the complex interplay of biological function and cultural and political mediation" (p. 246). They argue that beliefs about deafness have so much more to do with our cultural perception of vision and hearing and which is the preferred sense. However, this preference "tells us more about the culture than the sense itself" (Valente et al., 2011, p. 248).

Importance of the Study

Young and Tattersall state "that it is fundamentally wrong to believe that deaf children by dint of deafness are not capable of development and achievement within the normal range and diversity of those that hear" (2007, p. 218). Under the social construction theory, no longer is the condition alone to blame for stigmatization, but also the values of society that are reinforced by social systems and institutions. This means, according to Danforth (2001), that the definition of disability is fluid and changeable. Therefore, a person with a disability, as defined by the medical model or by our current socialization, does not have to accept the current limitations placed on them. Each person can change their perception of disability and persons with a disability.

How can individuals who work with d/hh children change the social environment? Effecting true change in policy cannot happen until the beliefs of policymakers change. Jones (1996) believes that this social construction framework can have a huge impact on practice. However, one barrier to this model is getting the theory out of the mainly academic realm and into more mainstream dialogue (Danforth, 2001).

Unfortunately, Spencer and Marschark (2010) lament that the practice in deaf education relies more heavily of beliefs and attitudes than on what works. However, there is little done to evaluate where these beliefs and attitudes come from. This study will be looking at the process of change regarding beliefs of deafness that hearing parents experience in early intervention. This could potentially show the impact of programs and policies on this experience and lead to changes in early intervention. Also, these examples could lead to change in research around language acquisition – instead of just documenting developmental trajectories, research is needed to evaluate the impact of programs and the beliefs of early intervention specialists and families on those developmental trajectories. Also, in sharing family stories, I hope to reach families as well, not just researchers or policy makers.

Scope and Delimitations of the Study

This study includes a survey of families in the United States with d/hh children and specifically looks at a few families' experiences. Therefore, it will not provide an answer to which is the best approach for early intervention for all d/hh children. Guardino et al. (2018) explained that there is no one right answer for educating d/hh children. Each story and experience is unique to that child and family. This study does not cover the varied experiences of each family in early intervention but shares a few that provide insight into early intervention practice and can help other families not feel alone in their experience.

The scope of this study does not include an in-depth look at all of the early intervention programs serving d/hh children in the world or even the United States. International early intervention services are too vast and varied and are not necessarily mandated. Early intervention in the United States is mandated under IDEA, but the programs providing early intervention vary from state to state and city to city. IDEA, EHDI, and JCIH provide some basic guide as to what best practices in early intervention should look like. It would likely take another study to focus completely on early intervention programs in the United States to characterize their variety.

The families who participated in the case study interviews shared some of their early intervention experiences. The programs the families were enrolled in were briefly analyzed specifically for the program beliefs and the quality of the program in terms of whether or not they met the Joint Committee on Infant Hearing (JCIH) guidelines. Brief information about other sources of information regarding the social construction of deafness was noted also including websites, media sources, and personal contacts. This study does not cover all dimensions of social construction of deafness. For more information regarding social construction of deafness, see Branson and Miller (2002), Lane (2006), and Valente et al. (2011).

Further, this study does not include any direct assessment of language acquisition by the children of the families who participated in the interviews. Incidental information about the children's language ability was gathered. Although language acquisition and access are the primary goal for all d/hh children and their families, this study is looking at beliefs about deafness that shape early intervention experiences and programming and therefore communication approaches. I believe, as Spencer and Marschark (2010) propose, that these beliefs guide practice more often than research does.

Because the survey and case studies were voluntary, convenience samples, the responders are not representative of the whole range of hearing parents with d/hh children. They are parents who volunteered to share their experience. They are involved in online parent support groups. Recruitment materials were in written English, and this may have influenced whether families chose to participate. These factors may have limited the diversity of the sample.

CHAPTER 2: REVIEW OF LITERATURE

This literature review looks at several *factors* that contribute to parents' construction of deafness and their complex interplay. These factors impact language choices and beliefs about deafness and the overall wellbeing of the child and family. Other studies are included to provide insight into the complexity of the study and the complex environment in which the parents of this study exist.

Six factors were identified in the review of the literature that may be particularly relevant to the current study. Each will be discussed below and the relevant literature will support my claims regarding these factors. First, the brain is ready to learn language if it has *access to language*. Early identification and intervention are meant to take advantage of the early flexibility of the brain. Second, parents are asked to choose which type of intervention they want for their child. *Informed choice* should include more perspectives of deafness. Third, the brain does not discriminate between languages or modalities. There are *benefits to using a signed language* with all children. Parents often choose not to sign with d/hh children because it is stigmatized. Fourth, there is a *stigma around deafness and using a signed language* that equates to disability. However, if there is access, there is no disability. Fifth, *meeting with d/hh adults changes parents' perceptions about deafness*. Finally, we *learn from d/hh parents* how to best facilitate language acquisition in d/hh children – including child directed sign and visual attention – and the process is equivalent to hearing parents with hearing children acquiring speech.

Access to Language

Beams (2004) explains that an infant's brain has about 100 billion cells at birth that are waiting to make connections. By the time they are 3 years old, they have made over 1,000 billion connections. When enacting the Individuals with Disabilities Education Act (IDEA), Congress found that if children with disabilities can get early access to

developmental support, they can increase their early success and decrease their later needs (20 U.S.C. § 1431). Because a hearing difference is considered an invisible disability (Shohet & Bent, 1998), a child born with a hearing difference and no other obvious differences can be easily overlooked and therefore may not have immediate access to spoken language at birth.

Historically, significant hearing differences were, on average, identified at age 2 (Yoshinaga-Itano, 2003). Based on research findings regarding the benefits of an earlier age of identification and intervention (Yoshinaga-Itano et al., 1998), the Early Detection, Diagnosis, and Treatment Regarding Deaf and Hard-of-Hearing Newborns, Infants, and Young Children Act (42 U.S.C. § 280g-1), commonly referred to as EHDI, was passed in 1999 and reauthorized in 2017. This system, which is governed by public health services under both the Centers for Disease Control and Prevention and National Institutes of Health, primarily focuses on identifying hearing differences, determining the level, getting listening devices (hearing aids or cochlear implants) as soon as possible, and beginning early intervention services. Therefore, addressing the immediate concern regarding access to language.

Informed Choice

Deaf education, which includes early intervention, is not a "one size fits all" field because no two children are alike (Garate & Lenihan, 2016; Guardino et al., 2018; Marschark & Spencer, 2003). Yoshinaga-Itano (2003) points out that newborn hearing screening is a minor medical practice where the follow-up is mostly educational and "does not typically specify treatment components" (p. 252). Rather than prescribe a signed language to all families with d/hh children, early intervention providers are responsible for providing information about communication choices and education options (Eleweke & Rodda, 2000; JCIH, 2013; Moeller et al., 2013; Young et al., 2006).

Between medical professionals, early intervention providers, friends, family, social media, and the internet (to name a few), families get mixed messages about what to do for their child (Crowe et al., 2014; DesGeorges, 2016). The biggest decision facing families seems to be deciding between using spoken language or signed language (Eleweke & Rodda, 2000). DesGeorges (2016) views this decision as a debate between seeing deafness as a disability to be habilitated by learning to listen and speak versus seeing deafness as a culture and embracing the use of a signed language. This division is perpetuated when people say, "don't sign with your deaf/hard of hearing child or they will never learn to speak" or some variation (DesGeorges, 2016). However, this division is not necessary. Mitchiner et al. (2012) cite six sources that actually support the use of sign in teaching speech. Garate and Lenihan (2016) argue that "early competence in a visual language can be effectively used to support and facilitate a child's spoken language development" (p. 250). Early first language (i.e.: ASL) exposure supports second language (i.e.: English – spoken or written) learning and bilingualism (Morford & Mayberry, 2000).

Informed choice is a key principle in best practices for early intervention (Moeller et al., 2013, principle 3). The key barriers related to informed choice presented by Young et al. (2006) are not having access to important information, some choices not being available ("denied, unacknowledged, or not resourced"), and not empowering parents to choose due to professional bias (p. 323). The value of these findings depends on the extent to which these ideas impact professional practice (Young et al., 2006). The attitude of professionals towards deafness impacts whether professionals present deafness as a deficit or as an identity and culture (Young, 2002). They further explain that risks and benefits of medical interventions (hearing aids, cochlear implants) can be easily explained

but not the psychosocial impact of whether or not a person can identify with a community

or culture (Young et al., 2006).

Benefits of a Signed Language

A child's brain is hardwired to detect patterns of natural language regardless of

the modality (Petitto, 2000). Several studies have been done that look at the signed

language acquisition of hearing children with d/hh parents (Marentette & Mayberry,

2000; Orlansky & Bonvillian, 1985). At least as far back as the 1800s, hearing children

have been acquiring a signed language. Whitney (1867) noted that parents who worked at

schools for the deaf would use both signed language and spoken language with their

hearing children and those children would develop signs first. Orlansky and Bonvillian

(1985) list several reasons why a signed language may be easier to acquire than a spoken

language. First, the area of the brain responsible for motor and visual processing develops

faster than the areas for listening and voice. Second, features of signs are more visible.

Third, motor control of the hands develops sooner than motor control of the speech

articulators. Fourth, it is possible to move the child's hand to produce the correct sign

which can give them immediate visual feedback of what they signed (Orlansky &

Bonvillian, 1985). These and other reasons are why Orlansky and Bonvillian (1985)

recommend using a signed language with a greater variety of children.

Signing Time, a popular program for children, teaches children ASL through

video and song. They boast that teaching children ASL will help the child communicate

much earlier, decrease frustration and tantrums, increase bonding, self-esteem, IQ,

vocabulary, and memory (signingtime.com). The goal of Signing Time is to enhance the

communication between all children and their parents regardless of their hearing level.

This is great news with regards to the recommendation for avoiding language

deprivation. However, Marschark and Spencer (2003) point out that although society

seems to be more accepting of signed languages and people who are d/hh, the emphasis is still placed on hearing and speech. King (2017) points out the hypocrisy of the fact that the general public is encouraged to use a signed language with their *hearing* babies but are encouraged not to sign or are not interested in signing with their *d/hh* children.

Signing and Stigma

Eleweke and Rodda (2000) conducted a case study to see what factors influenced parents' choice whether or not to use a signed language with their d/hh child. They found four main themes: "(a) the influence of information provided to the parents, (b) the parents' perceptions of assistive technology, (c) attitudes of service professionals and educational authorities, and (d) quality and availability of support services" (p. 377). These boil down to what and how parents are presented information from professionals and what parents already think about technology. Young et al. (2006) agree that information provided by professionals has an impact on families and offer some key points for professionals to understand about informed choice.

Berke (2018) lists several reasons why hearing parents might choose to not learn sign to communicate with their d/hh child: deafness becomes real, wanting a cure, too busy, not confident, difficult to learn, child might not speak, do fine without signs. Each of these reasons seems to support the negative stereotypes associated with using a signed language to communicate and deafness as a disability. Berke (2018) refutes each of these reasons by explaining why it is more important to sign than let these barriers come between the parent and their ability to connect with their child. Pointing out that, "a communication gap between hearing parents and deaf children has been known to harm both familial relations and academic progress" (Berke, 2018, para. 2).

Bianca Birdsey (2016), a mother of three deaf daughters, talks about why she believes parents choose not to learn sign language. She explains how experiencing grief –

especially denial – keeps a parent from learning to sign. She also notes that feeling pressured, lacking confidence, feeling insecure, thinking of deafness as a bad thing and signing making a child seem "more deaf" can all be contributing factors. However, she turns it around to explain why she chose to learn to sign. The listening and spoken language approach was not working for her child – although it had worked for others. She recognized within months that her daughter needed more visual support to be able to communicate. Once she started learning to sign, she discovered that "there is nothing sweeter, than the ability to communicate with your child" (Birdsey, 2016).

Berke (2018) mentions how learning to sign might make deafness more "real" because parents are focused on trying to help their child hear. However, the reality of the condition of having a hearing difference is already there. It seems to me that the reality that is avoided is the stigma surrounding deafness. I find it sad to see a child get farther and farther behind in their ability to communicate with their family because the family is too worried about what the world will think.

Bailes et al. (2009) did a case study of a d/hh child with Deaf parents. They observed their interactions and focused on the ways the Deaf parents naturally facilitated language acquisition and literacy development in their child. They credit "culturally situated social interactions during everyday activities" as the fundamental reason for the child's age-level language and cognitive skills (Bailes et al., 2009, p. 417). They cite one of the reasons for this success is the parents' construction of deafness focusing on the child's abilities instead of a perceived disability.

This can be very difficult for hearing parents when the only understanding of deafness they have is regarding the lack of one of their senses. Historically, Locke and Hobbes both emphasized the critical development of humanness through the experiences of five senses (Branson & Miller, 2002). Valente et al. (2011) explain that the social

construction of deafness as a disability revolves around the current importance of hearing in our society. In the United States, if someone speaks loudly they are seen as obnoxious but if they are soft-spoken they are insecure. Valente et al. (2011) further explain that a person's status - biological, psychological, and social - is determined by the way a person speaks. If a person speaks clearly and uses formal vocabulary they are deemed to be well-educated and from a higher socio-economic class and race. If a person speaks using certain expressions and informal manner, they are considered to be of a lower education and class. These allow people to form opinions about who someone is and make judgments about them. When this information is lacking, because a person does not speak, "that person is not seen as an intelligent and capable person but rather as a caricature of all that society preconceives about those who do not speak" (Valente et al., 2011, p. 253). If a d/hh person does speak, certain judgments are made depending on the quality of the person's voice. All these examples lead to the construction of seeing deafness as a deficit and leads to the push to improve hearing and speech to better conform to society.

Parents may believe these ideas and want to protect their child from these types of judgements. However, it is suggested that professionals should take time to understand the language ideologies of the families before making assumptions about what would be the best language approach (Kite, 2019; Mitchiner & Batamula, 2021). Mitchiner and Batamula (2021) explain that several factors impact language choice including family education, knowledge of bilingualism, and perceptions about languages. However, hearing families with d/hh children often report being influenced by professionals to adopt a spoken language only approach (Mitchiner & Batamula, 2021) which follows the professionals' beliefs about deafness as a disability.

Bauman (2005) addresses the question of deafness and disability. They argue that in some conditions, like the child in Bailes et al. (2009), being deaf is not a disability. Nothing about the child's hearing ability was a barrier to their ability to communicate and learn. They further argue that the main reason deafness is seen as a disability is because the majority of d/hh children are born to hearing parents who struggle to overcome the communication barrier. Following the social construction definition, Bauman (2005) explains that disability exists where "disabling conditions are most prevalent" (p. 313).

Bauman and Murray (2014) take the idea one step further as they introduce the idea of Deaf Gain. Instead of seeing deafness from the normative view of hearing, they offer the idea of deafness as diversity. Deafness contributes to the many ways of being human and enhances our society. They further argue that "falling outside the boundaries of the normal can serve as a stimulus to creating new technologies and new ways of thinking" (Bauman & Murray, 2014, p. xxiii).

Changing Perceptions

Kara and Harvey (2017) conducted a case study with six mothers of d/hh children (between 3 and 8 years old) in South Africa who did not get early intervention services. They "investigated the construction of deafness through the experiences of mothers" and looked at the impact of these constructions on the family (Kara & Harvey, 2017, p. 72). They found that the mothers in their study knew little about what it means to be d/hh and what, if any, options there were for their child. They found that after meeting deaf adults or seeing deaf people working, they begin to understand what might be possible for their child. Both the JCIH best practices and International Consensus Statement encourage the involvement of d/hh adults in early intervention programming (JCIH, 2013; Moeller et al., 2013). These are not limited to introducing signing Deaf adults to all families. There are many ways of being d/Deaf. In Kara and Harvey (2017), we see how the construction

of deafness changes over time and with experiences. However, there are few studies that show how the construction of deafness changes over time. This is one reason why the current study, this study, is important. We need more insight in to how these constructions are made and how it relates to early intervention programming.

Watkins et al. (1998), published a study about the Deaf Mentor[7] project. They introduced Deaf Mentors as early intervention providers who teach parents ASL, about Deaf culture, and introduce families to the Deaf community. Among the linguistic benefits of a bilingual bicultural approach, this experiment provided families with a cultural perspective of deafness. Those who did not have a Deaf Mentor, talked about their child's future as measured by our cultural perceptions of success: education, career, contribution. However, those with a Deaf Mentor wanted their children to be "self-confident, happy, loved, and proud of who they were and what they wanted for themselves" (Watkins et al., 1998, p. 33). This changed perception of deafness positively influenced how these parents felt about their d/hh child, which, in turn, helps the child feel better about themselves. According to Wilkinson and Morford (2020), "a family's openness to bilingualism conveys their acceptance of deafness, the ways of the deaf community, and the language of the deaf community. This communicates to deaf children that their families accept and embrace them" (p. 1335).

Learning from D/HH Parents

Another benefit to involving deaf adults in early intervention is learning from deaf parents how to use "effective, natural strategies, involving visual and physical means to promote communication with a deaf child" (Traci & Koester, 2003, p. 194). Both Moeller et al. (2013) and the JCIH supplement (2013) supplement encourage the involvement of d/hh adults in early intervention. The difficulty for hearing parents with a d/hh child is

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[7] For a more recent look at the benefits of Deaf Mentors, see Hamilton and Clark (2020).

that child-directed speech and sign is a natural, intuitive part of communicating with babies and parents struggle to modify these behaviors when instructed to do so (Meadow-Orlans et al., 2004). Although the signing may not be as rich as what Deaf parents provide, studies show that hearing parents are using signs appropriately (Lu et al., 2016) and d/hh children can acquire language within the age-appropriate range if hearing parents begin signing with their d/hh children from an early age (Caselli et al., 2021; Yoshinaga-Itano et al., 1998). The hearing difference alone does not cause a language delay, but the lack of linguistic experience. This is the goal of early intervention – to provide access to linguistic experiences.

As mentioned previously, children with Deaf, signing parents can acquire a signed language naturally and at the same rate that hearing children acquire spoken language (Bailes et al., 2009; Marentette & Mayberry, 2000; Petitto, 2000). Deaf parents begin signing with their children from birth, using their own natural language. In these studies, children acquired sign language with the same milestones as spoken language: babbling, 1-word, 2-word sentences, and so forth. Bailes et al. (2009) looked closely at how the parents modified their communication to help facilitate their child's language development.

In general, parents often will modify the way they communicate with their child in order to support their child's acquisition (Gros-Louis et al., 2014; Koester & Lahti-Harper, 2010; Schwab & Lew-Williams, 2016; Vigil et al., 2005). This was originally called motherese/parentese then later child-directed speech/sign (see sources in previous sentence). This is characterized by "structural modifications that make the language attractive and interesting" (Bailes et al., 2009, p. 427). Koester and Lahti-Harper (2010) point out several ways that Deaf mothers modify their signs to their babies: larger movement, hold signs longer, repetition, sign slower, orient themselves to be in the

child's visual field, tap on the child to get attention, and sign on the child's body (p. 7).

Morford and Mayberry (2000) noted that the adults around d/hh infants need to sign

where the child can see them and thus "infant-directed sign may play a greater role in

early signed language development than infant-directed speech plays in early spoken

language development" (p. 121).

Piaget (1962) argued that before a child can acquire language, they need the

cognitive foundational skills for learning language. These include things like joint

attention and object permanence (Kaplan, 2000). Joint attention is defined by Akhtar and

Gernsbacher (2007) as "parents' and children's coordinated attention to each other and to

a third object or event" that specifically supports language acquisition and it "relies only

on overt indicators of attention, is studied predominantly in the visual modality, and

varies by culture" (p.195). Erting et al. (1994) point out that Deaf parents generally have

the skills and "cultural knowledge about how to interact with their infants … to get and

maintain their attention, to focus their attention on signing as an activity, and to begin to

relate the interaction to the environment in a meaningful way" (p. 106). "By extension,

the strategies that deaf adults are using with their children can be shared with and taught

to all parents in order to support their own child's development" (Gale et al., 2019, p.3).

This is another reason why best practices in EI suggest involving d/hh adults.

From this literature, we see why it is so important to understand what parents

believe about deafness because of the long-term impact it can have on the child and

family. However, there are no studies that provide documentation of parents' own

reflections on their experiences with early intervention and their changing conceptions of

what is possible for their d/hh child. This study provides insight into how early

intervention programs can be improved to better support the expressed needs of the

family regarding their d/hh child.

CHAPTER 3: METHODS

Overview

The goals of this study are to investigate: (1) What are some of the meanings of deafness that hearing families with deaf or hard of hearing children currently hold? (2) How are hearing families with deaf or hard of hearing children constructing (or coming to understand) what it means to be deaf or hard of hearing? (a) What sources of information seem to inform these constructions? (b) How does early intervention programming impact these constructions? And then conclude with a discussion about the implications for early identification and intervention programming.

This study gathered data from hearing parents of d/hh children about how they came to understand what deafness means. An initial survey was used to gather a wide variety of responses. Subsequently, five families who indicated a willingness to participate in a case study about their early intervention experiences and how it impacted their construction of deafness were recruited for in-depth interviews. Interview data was analyzed for themes.

Research Design/Description of Methodology

Mixed methods research could generally be described as a form of research that "brings together both quantitative and qualitative data to tell the story" (Creswell & Plano Clark, 2011, p. 1). A mixed methods design was used in this study because my focus is on the practical application of the information. According to Creswell & Plano Clark (2011),

> Pragmatism is typically associated with mixed methods research. The focus is on the consequences of research, on the primary importance of the question asked rather than the methods, and on the use of multiple methods of data collection to inform the problems under study. Thus, it is pluralistic and oriented toward "what works" and practice. (p. 41)

According to Miles et al. (2013, p. 42), "numbers and words are ***both*** needed if we are to understand the world." As this paper aims to understand how hearing parents with d/hh children construct deafness, it was important to get a wide range of responses as well as specific examples. The survey provided a broad scope in order to help identify general trends and the case studies helped provide detailed experiences. As an early intervention provider who works with families with d/hh children, I wanted to know about the trends in how deafness is constructed as well as details to how it is done. This information has the potential to impact both professionals in early intervention and families with d/hh children. Often professionals want to see quantitative data to show the impact and trends, yet families want to see individual stories they can relate to. In my practice and training over the years, I found that both types of data are important in understanding best practices in early intervention. Numbers can add weight to an argument but are not enough alone. Individual stories can be inspiring but it's difficult to hear everyone's story.

An explanatory design using the participant selection model (Creswell & Plano Clark, 2006) was used for this study. An explanatory design was chosen because it uses qualitative data to expand on or explain quantitative findings (Creswell & Plano Clark, 2006). The participant selection model means that the quantitative method was used to help select participants for the qualitative method. In this study, this design's two phases are: a quantitative survey and qualitative case studies. The survey was used to collect information about a large sample of hearing parents with d/hh children. The anonymous online survey reached a large pool of participants and provided an overview of how early intervention and society as a whole impact hearing parents' construction of deafness. A quantitative analysis provides measures of general trends. Questions regarding early intervention, language choices, and beliefs about deafness helped to guide selection of

participants for the qualitative case studies. Participants were selected who showed a

unique perspective, explained a change in belief, or who were from an underrepresented

group in research.

This study also includes a multiple case study because the research question asks

how something happens without control over the behavioral events (Yin & Campbell,

2018). A case study also looks at the complexity and uniqueness of a situation that links

to the social context (Glesne, 2015). A multiple case study was used to get an in-depth

understanding of what hearing parents experience in the early intervention process. The

telling of their complete stories can provide more details as to the nuances in the

construction of deafness and provide qualitative data. Therefore, this study looks at a few

unique situations. Since the social construction theory is being employed, each case study

will explore the relationship between parents' developing understanding of deafness and

the social context in which they live.

Selection of Participants

This study includes two sets of overlapping participants – those who participated

in the survey and those who participated in the case study. The survey was distributed

using snowball[8] sampling and was shared electronically with anyone interested. I posted

the flier (written in English[9]) and survey link on my Facebook page and made the post

public. The flier, then, recruited hearing parents/caregivers of d/hh children born in 2002

or later. (Since 1999, every child born in the United States is required, by law, to have

their hearing screened [42 U.S.C. § 280g-1] and setting the birth year to 2002 would

hopefully mean that all children in the study were screened at birth.) I tagged people I

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[8] Naderifar et al. (2017) explain that snowball sampling is a convenience sampling method that begins with people the researcher knows and is then shared to other people that are members of that population – i.e.: hearing parents with d/hh children.

[9] The survey was in English because I am not literate in another language and did not have the means to hire translators. Since I would also be doing the interviewing myself, I needed participants fluent enough to be interviewed in English. This will be discussed in the limitations section.

know (families with d/hh children, colleagues, etc.) in a comment on the post and asked
them to share the survey with people they know (through email, online parent support
groups, social media, etc.). This allowed the gathering of a variety of responses and a
larger picture of the families' experiences.

The survey was open for just over two months, at which time it was closed
because the number of responses was sufficient for analysis. By comparison, Guiberson
(2013) carried out a survey-based study that had 71 participants. At the time my survey
was closed, there were 79 responses. Incomplete surveys were not included in the
analysis. The survey included an option for families to volunteer for more in-depth
interviews by including their email address.

Of those survey participants who shared their email address, I recruited five
families for the in-depth interviews/case studies. Selection criteria is described below. 42
survey respondents volunteered. Priority was given to families whose children were
currently in early intervention or who were under 4 years old in the hope that they
remembered details about their early intervention experience. I felt this would more likely
provide information about the impact of early intervention than those who had early
intervention years ago and had continued to construct their understanding of deafness.

Of the 42 volunteers, 13 had children under the age of 4. Other demographic
information was collected in the survey to help in selecting participants with varied
experiences. For example, the vast majority of participants in early intervention research
are mothers – including in this survey. However, six of the survey respondents were
fathers. All three of the fathers with children under 4 years old who had early intervention
participated in the case study. (Two of the three fathers had the mother join us for the
interviews.)

Five mothers were also contacted about participating in the case studies. These were chosen based on their responses to questions about their understanding of deafness, their child's age, and their various demographic information. Unfortunately, the three mothers who did not identify as White/not Hispanic did not want to participate in the interviews (two did not respond and one declined). That left a total of five case study participants. The maximum was set at six because Kara & Harvey (2017) had six participants in their case study and that was a successful study that looked at social construction of deafness. I also knew that six would be a manageable number to handle myself. I did not reach out to others while I waited for responses because I didn't want to include more than six families and have to turn someone away. Compensation for the interview participants was in the form of a $25 Amazon electronic gift card sent after the second interview.

Procedures

Development of survey questions

The goals of this study are aimed at investigating (1) What are some of the meanings of deafness that hearing families with deaf or hard of hearing children currently hold? (2) How are hearing families with deaf or hard of hearing children constructing (or coming to understand) what it means to be deaf or hard of hearing? (a) What sources of information seem to inform these constructions? (b) How does early intervention programming impact these constructions? The survey was developed to try to elicit some information about the child and their early intervention experience. Ideally, the goal of early intervention in the United States is to have all children's hearing screened by 1 month, hearing diagnosed by 3 months (if referred on the screening), and into early intervention by 6 months. The survey asked about when the parents' child was screened and diagnosed and at what age early intervention began. This also provides information

about how long the child was enrolled in early intervention, which has to end at age 3, to

investigate whether the length of early intervention had an impact on parents'

construction of deafness. Other questions about hearing level and listening devices also

contributed to providing a picture of the medical aspect of intervention as well as the

impact that the hearing level has on what deafness could mean. The survey also included

questions about EI program philosophies, amplification, and language use in order to give

more insight into the social context that the family was in as well as how their beliefs may

have shaped or been shaped by their EI experience. The most direct answers came from

questions 14, 15, and 16 that asked the parents to describe what deafness meant to them

before their d/hh child was identified, what they believed about deafness at the time of the

survey, and what sources of input shaped their beliefs. This comparison is meant to show

how their construction evolved over time and how specific sources shaped that

construction (sources that were impactful).

The survey consisted of 21 questions, an opening statement requesting consent to

participate, and the last statement providing an opportunity to volunteer to be interviewed.

Six questions were related to the child's age and early intervention experience. Four

questions were about the child's hearing (age of identification, amplification, description

of hearing). Two questions were about language use and then three questions probed

beliefs about deafness. Six questions were related to the demographics of the

parents/caregivers. (See appendix A for survey questions.)

Distribution of the survey

Starting on 3/22/2021, the survey was open for participation and was publicly

posted on my Facebook page[10]. Once posted, the flier and link could be shared by others

amongst their friends and/or interest groups. (Based on some responses, it seems to have

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[10] This will be addressed in the limitations section as well.

been posted on some parent groups.) The flier recruited hearing parents or primary

caregivers of d/hh children born in 2002 or later. The survey was only provided in

English and was open until 6/1/2021. However, all 79 surveys were completed by

3/31/2021.

Attempts were made with the University of New Mexico's Institutional Review

Board (IRB; they protect the rights of potential research subjects) to get permission to

post the survey on other websites (like Hands and Voices, an organization that provides

parent-to-parent support of parents with d/hh children), but there were external issues that

delayed the process. By 6/1/2021, the survey already had 79 respondents and 42

volunteers. The minimum number hoped for was 71 (which was the number of survey

respondents in Guiberson, 2013), so I decided to close the survey.

The survey was administered through an online survey program, Opinio, that is

provided by the University of New Mexico to faculty and students for the purpose of

research and academic needs and is a secure survey tool. I designed the survey to have

varying options for responses including fill in the blank, multiple choice, to yes/no. The

surveys addressed the two research questions – understandings of deafness and how these

understandings were constructed (including sources – people, media, agencies, etc. – that

impacted the construction and early intervention programming). General information

about their child's hearing and communication were gathered. The survey did not ask for

any identifying information beyond general demographics, with one exception. Email

addresses were collected from participants who volunteered to participate in the case

studies. All identifying information from survey participants was destroyed after the

participating families in the case studies had been confirmed.

After the survey was closed, a response spreadsheet and a variety of collated

responses were generated in Opinio to assist in analysis. All survey reports were

downloaded and saved to a secure external hard drive and Microsoft OneDrive a secure cloud storage service provided by the university.

Data Collection and Recording of Interviews

Interviews were conducted over an online video platform (Zoom) to adhere to COVID-safe practices in place during the spring and summer of 2021. The interviews were recorded and saved to OneDrive. At the beginning of each interview, I reminded the family that I would be recording the interview (video and audio) and wait for them to verbally confirm their consent. When the recording began, an automated message in Zoom would say "recording in progress" which provided families a second reminder. Parents were also notified that a separate audio recording was also made as a back-up using the voice memos applications on an iPhone.

Interviews were typed into a Microsoft Word document using the automatic voice recording transcription feature in Office365. The audio recordings from the iPhone were uploaded into a Microsoft Word document and then automatically transcribed by the program. I then edited all of the transcriptions by listening to the voice recording and/or video recording to verify the accuracy of the transcriptions. Some notes were taken by hand during the interviews to help me to remember questions to ask or key sources of information. Electronic notes were saved to a secure external hard drive and on OneDrive. The paper notes were kept in my home office until the end of the study and then shredded. No names were recorded on the paper notes, only participant numbers.

To protect their confidentiality, families who were interviewed created their own pseudonyms or allowed me to create them on their behalf. After recordings were transcribed, all actual names were replaced with pseudonyms in the transcriptions. Documents/sources shared by the families were collected and analyzed for possible impact on construction of deafness. Early intervention programs were unnamed. Any

other possibly identifiable information was edited out before and redacted before analysis

of the transcripts. For example, if a parent named a city such as Santa Fe, it would be

changed to [name of town] on the transcript. All data was saved on a password protected

external hard drive and OneDrive.

As mentioned above, because of COVID, there were no in-person visits. While

this may seem to pose a threat to ecological validity, carrying out the interviews via Zoom

had some benefits for the research process. First, it removed barriers to participation

created by distance and travel. Second, families participated in a chosen and familiar

setting, which seemed to put them at ease. Prior to completing the interviews, I met with

potential participant families to explain the scope of the interviews, and to get to know

them. They then were able to consent or decline to continue with the study. If they chose

to continue, I set up two additional visits that were recorded and lasted about one hour

each. However, if the family wished to meet longer because they had more they wanted to

share, I extended the length of the interview depending on family choice and rationale for

extension.

The first interview focused on the family's journey with their d/hh child and

allowed for observation of the family's construction of deafness. At the end of the first

interview, the family was asked to think about their early intervention programming and

be prepared to share any documents or electronic resources they received that they felt

impacted their understanding of deafness. The second interview focused on early

intervention experiences as a source of information for constructing deafness and any

other impacting sources of information the family wished to share. Many of the questions

were developed based on the Joint Committee for Infant Hearing (JCIH) guidelines for

best practice in early intervention. This was an attempt to evaluate the quality of

programming the family received. I asked for their EI program website, if they had one,

so that I could review what the program says about themselves.

Data Processing and Analysis

Surveys

Averages and measures of distribution were calculated for the child's age, age of

identification, languages used, early intervention methodology, and other demographic

information.

The analysis of specific questions was handled differently, based on question type.

Question 14 asked what deafness meant to parents before their d/hh child was identified,

and question 15 asked what they believed about deafness at the time of the survey. Survey

responses to questions 14 and 15 were therefore analyzed using Values Coding because

the codes "reflect a participant's values, attitudes, and beliefs, representing his or her

perspectives or worldview" (Saldana, 2013, p. 110). I started with some Provisional

Codes that I thought I would be applying, i.e.: medical perspective vs. cultural

perspective. However, almost all responses reflected a predominantly medical perspective

(only three responses mentioned a cultural perspective on question 14). In order to try to

capture a more specific and complete idea about how parents' perspectives are changing,

I compared questions 14 and 15 to see if the comparison would clarify what their initial

understanding of deafness meant. An initial pass through the survey responses to

questions 14 and 15 brought up some common themes in the data. On the second pass, I

underlined key words: disability, can't hear, different, limit, must sign, normal, spectrum,

technology, deaf culture. Four main Value Codes emerged from the responses. Since the

responses seemed to be the initial belief in 14 and the expanded belief in 15, the number

codes matched these. The responses often went from limited to options, different/other to

same as hearing, etc. The four Value Codes that came out of the data were: cultural

understanding (with or without), limited vs. choices, different vs. normal, and no opinion vs. medical/disability understanding. (These codes will be discussed in detail in the results section.) After coding all survey responses to questions 14 and 15 with the four Value Codes, I wrote up a data coding manual. This coding manual and the responses to 14 and 15 were shared with a research assistant. The research assistant reviewed the manual and asked any clarification questions before coding all of the data using the four Value Codes. The author's and the research assistant's coding were then evaluated for agreement. There was substantial agreement (84%) on question 14, but only moderate agreement (58%) on question 15.

Because question 14 asked parents for their initial beliefs about deafness, their responses were briefer and somewhat limited in comparison to question 15. After experiencing life with their d/hh child, parents' understanding of deafness became more nuanced. Therefore, coding for question 15 was more difficult. The parents did not present one single value response like they did with question 14. They had many different levels of understanding, and it was more difficult to choose which understanding had the best match or was more prevalent in their response. I met with the research assistant, and we discussed the coding. I explained in greater detail what each code meant. We went through some responses and gave examples of why one might pick one code over another. Through discussion, we made minor adaptations to the coding instructions to distinguish ambivalent cases. Both of us then recoded the data and we recalculated our agreement. On question 14, agreement improved to 89% (*Cohen's k* = 0.78) and on question 15 to 84% (*Cohen's k* = 0.76), achieving substantial agreement for both questions.

An analysis of question 16 (sources that impacted understanding) lead me to create codes based on 5 common sources (social media, EHDI professionals, d/hh adults,

own research, and books/movies) which were then color coded, marked, and counted.

Each source mentioned by a respondent was only counted once even if they mentioned

several different social media platforms or EHDI professionals. The resulting distribution

of sources is reported in the results section.

Case Studies

Before analysis began, I read through and edited the transcripts for accuracy. I

became very familiar with each family's story. I also found myself highlighting key

quotes or phrases while reading through the interviews. Once the transcripts were clean, I

began my formal analysis with a Provisional Coding list. I created this list based on my

previous knowledge and experience (see Saldana, 2013, p. 144) in working with families

in early intervention and my understanding of social construction theory. My Provisional

Coding list included these themes (with their assigned color): sources of information

(pink), terms for deafness (red), catalysts of change in understanding (orange), previous

understandings (green), early intervention program philosophy (blue), meeting d/hh

adults (purple). I was surprised to find that there was very little information coded in the

interviews about early intervention philosophy but upon analyzing sources of information

and catalysts of change, I was able to discern the extent that EI programs impacted the

family's construction of deafness.

I then analyzed the interview transcripts for answers to the research questions: (1)

What are some of the meanings of deafness that hearing families with deaf or hard of

hearing children currently hold? (2) How are hearing families with deaf or hard of hearing

children constructing (or coming to understand) what it means to be deaf or hard of

hearing? (a) What sources of information seem to inform these constructions? (b) How

does early intervention programming impact these constructions? After a complete

rereading of each interview, I wrote a memo note to summarize how the families'

responses answered each of these questions. Finally, I wrote up a narrative summary of each family's journey so far.

I employed both theoretical propositions (Yin, 2018, p. 168) and explanation building (Yin, 2018, p. 179) in my analysis. Theoretical propositions were selected because I developed my Provisional Coding list based on what I know about the social construction theory and what types of things impact constructions (language use, institutions, cultural values). Explanation building was selected because I am attempting to explain how or why these constructions were formed.

Validity

According to Maxwell (2013), validity in qualitative research concerns "the correctness or credibility of a description, conclusion, explanation, interpretation, or other sort of account." (p. 122). He further explains that qualitative research has a couple of inherent threats to validity: bias and reactivity. Bias has to do with the positionality of the researcher and what they bring to the research. The researcher has an idea of what they hope to gain in doing their research and their prior experiences play into their bias. Reactivity is related to how the participants react to the researcher. Do the participants behave differently when being observed and interviewed? Of course, these two threats do not automatically invalidate a study. The researcher must take care to address these threats to validity and acknowledge their influence and biases in order to decrease these threats. The following are my attempts to help reduce the threats to validity in my study.

Regarding bias, I let the families know my positionality – that I work in early intervention and have been coming to understand deafness for at least 20 years. Although I am a parent, I do not have a d/hh child and cannot personally relate to the experiences of the parents being interviewed. I also honestly answered the few questions that families asked about my biases. As far as parent biases are concerned, I cannot change any bias

they may have toward me or schools for the deaf or people who are d/hh. I am actually looking for these biases. Being aware of my biases has helped me to analyze their impact on the study.

Regarding reactivity, I try to be open and honest and trustworthy. I am often developing relationships with parents in Early Intervention and hope my skills were an asset in this situation. Parents have reacted to many things about me personally. They may have reacted to the way I worded questions or my status as an early intervention provider. I made every effort to ease any concerns by listening and being encouraging. My experiences working with families for over 15 years allowed me to handle a variety of responses from parents. I believe I was encouraging and understanding as I listened to their stories.

There are things that Maxwell (2013) suggests that I can do to try to control some of the external threats to validity. First, I can use long-term involvement. Although I was not interacting with each family for a long time and my study was relatively short in duration, I have worked with families with d/hh children for a long time. I believe this comes across in how I interacted with each family and understand the early intervention process. I met with each family a few times to hear their story and that helped to establish rapport. Their experience with welcoming EI providers made them seem to accept me sooner than they might have otherwise. This helped build their trust in me and reduced some of the reactivity threat. Second, I also used quantitative results. For example, the survey provides some numerical results that support the ideas the families shared. Checking sources that the families shared corroborated what the families said they experienced. Third, I used observation. I observed the families at home during our video visits. Observation helps to take away some of the reactivity and bias (especially if video-taped). I saw a little bit how the parents interacted with their child. Some families would

model a sign they use with their child. I observed their expressions as they talked about

what it means to be deaf, and it added a layer of understanding that the transcript alone

could not provide. Fourth, I looked at exceptions for comparison. I was able to compare

the case studies to each other to better tell if the responses or experiences were very

unique or more common. Fifth, and most important, I checked my understanding with the

participants during the interviews by asking clarifying questions and was given

permission to check back with them if I had any questions. I chose to reach out to a

couple of families via email to make sure I understood a certain passage or idea.

CHAPTER 4: SURVEY RESULTS

Survey Participants: Parents

All respondents who completed the entire survey were included in the analysis, for a total of 74 responses. Five incomplete surveys were not included. The vast majority of respondents self-identified as White[11] (85%), 10% self-identified as Hispanic/Latino/Mexican, and the other 5% were composed of individual respondents self-identifying as Chinese American, Muslim, Indian Asian, and other. Hearing mothers filled out most of the surveys (90%), however six surveys (8%) were filled out by fathers, and one survey was filled out by a relative with legal custody.

The average age of the caregivers was 38.5; with the youngest being 24 and the oldest being 57. The majority of respondents were college educated and hold a degree (80%) and 46% of those hold a graduate degree (see Table 1). The annual income of respondents was also higher than the national average (see Table 2).

Table 1

Education of Caregivers

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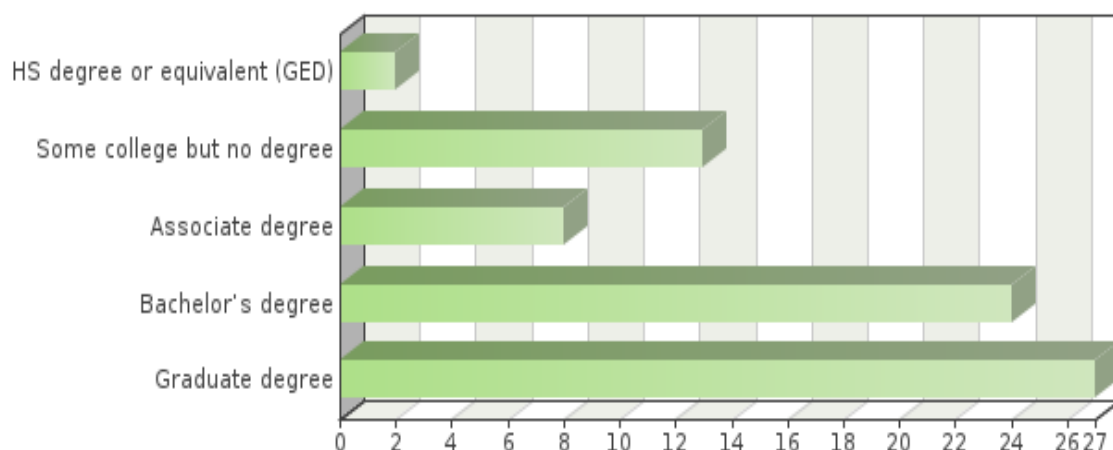
[11] This will be discussed in the limitations section.

Table 2

Income comparison of U.S. census and survey respondents

Annual Income	U.S. Census	Survey Respondents
Less than $34,000	26.2%	16.7%
$35,000 to $49,000	11.6%	2.7%
$50,000 to $74,000	16.5%	25.68%
$75,000 to $99,000	12.2%	16.22%
$100,000 to $150,000	15.3%	17.57%
Over $150,000	18.3%	20.27%

(U.S. Census Bureau, 2020, p.28)

Survey Participants: D/HH children

The average age of the respondents' d/hh child was 7 years 8 months; with the youngest being 10 months and the oldest being 17 years. Only four of the 74 respondents did not have early intervention (5%). Of the 14 children under 3 years old, only one was not enrolled in early intervention (7%). 51 respondents had "assistive listening technology" (or listening devices) for their child by 12 months (69%), with 39 of those having devices by 6 months of age (53%). 23 respondents explicitly mentioned their child having cochlear implants (CIs), while another 15 mentioned being part of a parent group for children with CIs or their CI team, and another three mention CIs in their interviews. In sum, at least 55% of respondents got cochlear implants for their d/hh child.

Language Use

Reports of language use were somewhat inconsistent and unclear. Three different questions were asked, listing several response options, of which more than one could be checked): "(1) What was the educational or language philosophy of your Early Intervention (EI) program? (2) What language(s) do you use with your child at home and in conversation? (3) What communication methodology (methodologies) do you use now,

and have you used in the past with your child? (This is typically the language philosophy of the program your child attends for school after they left early intervention.)"

As part of the survey, parents were asked several questions about language use, and the language philosophy of their EI programs. Again, choices were provided, and families were asked to select any that applied. The philosophies were not described because I wanted to also see how much the families understood about program philosophies based on their responses. (See a full copy of the survey questions in Appendix A.) In response to the question regarding the language philosophy of their EI program, 47% (35) marked LSL, 32% (24) marked Bi-Bi, 14% (10) marked Signed English, 11% (8) marked "other", and 2% (2) marked ASL only (see Figure 1). This shows that most programs that survey respondents were enrolled in offered a medial/remedial listening and spoken language approach. However, there was some concern regarding the reliability of the answers to this question (see Limitations section). The general program beliefs could not be accurately assessed with this question.

Figure 1

EI Program Language Philosophy
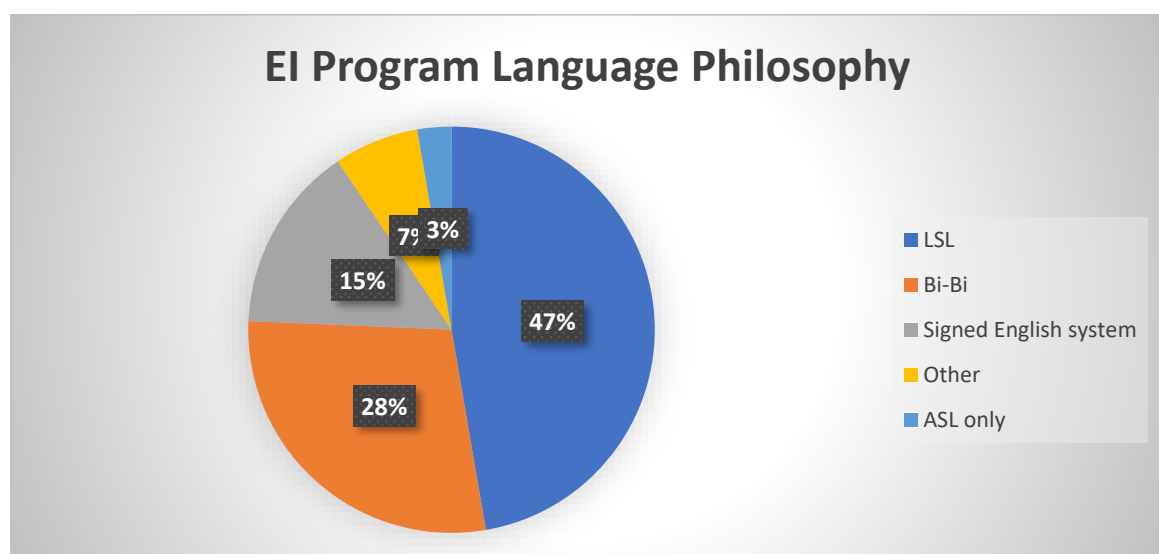
The survey also asked parents about language(s) used in the home. When responding, 90% of parents selected English (63), 27% marked ASL (20), 23% marked a combination of signs and spoken language (17), about 9% (7) selected some other spoken language, and about 4% (3) some other signed language. This question seems a good representation of how families perceive their own language use because there were not questions about philosophy. They could just self-report how they perceive their language use.

The final language question was about the language methodology used by the school the child is currently attending or schools they attended in the past. 80% (59) said spoken language, 30% (19) said some signs and speech, 24% (18) said sign supported speech, 20% (15) said a signed language, 8% (6) visual/gestural language, 5% (4) other, and 4% (3) picture exchange. This question seems a better estimate of program beliefs. Families could have changed programs over time, but most families (80%) have participated in a spoken language program at some point during their child's life, which means that the vast majority of programs available to families in this study employ spoken language.

Since the responses to language use did not seem particularly accurate overall, I did not use these results to determine their impact on understanding of deafness. Rather, this is a brief description of the parents' perception of their language use. It is important to note that language use changes over time. A couple families mentioned in their survey responses that they used to use ASL or learned ASL later.

Meaning of Deafness BEFORE and NOW

On question 14, the parent's understanding of deafness before their d/hh child was put into four Value codes. Any mention of a cultural understanding of deafness or "d/Deaf" (n=3, 4%), deafness was viewed as "limited" or a "major disability" or "can't

hear" or "must sign" (n=51, 69%), deafness meant being "different" or "bullied" or not "normal" (n=6, 8%), and some had no solid opinion about deafness (n=14, 19%).

On question 15, the same four Value Codes were used with a slight adjustment. They shifted to include a cultural perspective (n=16, 22%), to "no limitation" and being able to "choose" what language the child could use (n=34, 46%), to "typical life" and a "mainstream school" and "totally verbal" (n=8, 11%), to a "medical condition" and a "range of abilities" that can "affect learning" (n=16, 22%). The largest Value Code changes were the decrease of the limitation/choices category (from 51 to 34) and the increase of including a cultural perspective (from 3 to 16).

Figure 2

Understanding of Deafness Before and Now
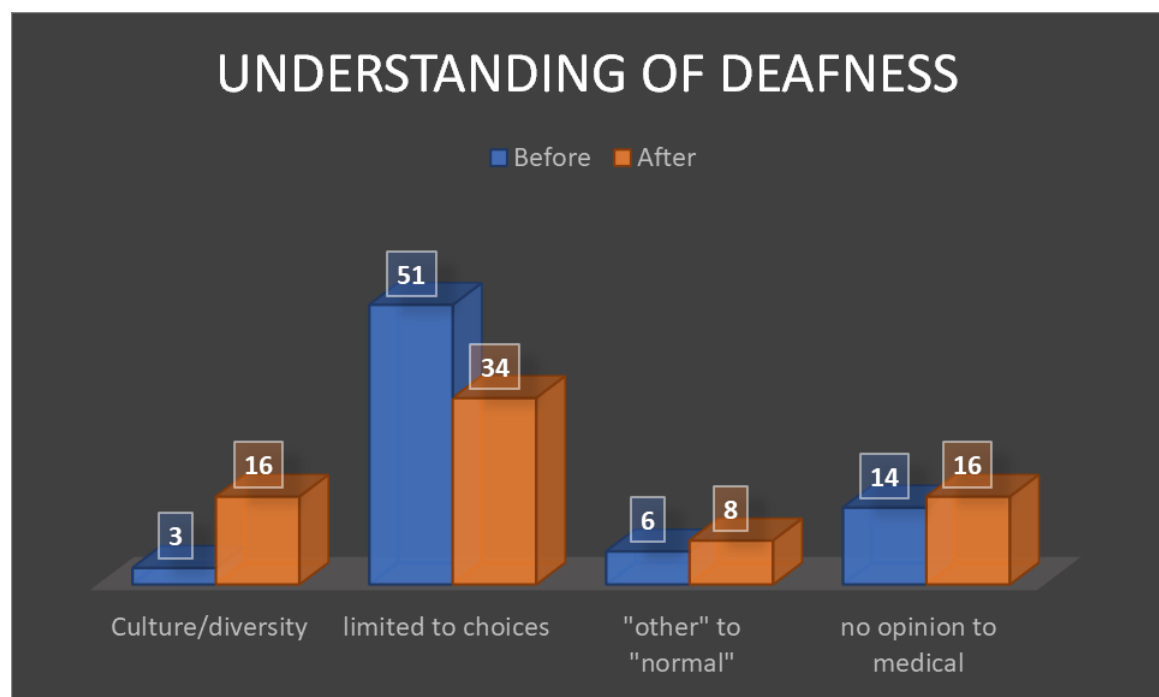
Prior to having a d/hh child, the majority of respondents believed that deafness was limiting and that the central characteristics of deaf people are that they can't hear or must sign and have a disability. The most common change in their construction of deafness was not to shift from this perspective to a more cultural or diversity perspective

but to one that allowed for choices and being "able" to do things with support. After experiencing life with their d/hh child for several years or more, more people included a cultural perspective. Even if they did not ascribe to it themselves, they knew about it. Almost the same number of people who worried that their child would not fit in or be "normal" shifted to say that their child was "like hearing" people. Those who did not seem to have an opinion, often shifted to understanding more about the condition of different hearing levels like "understanding an audiogram" and that there is a "range of hearing abilities"

The meaning of deafness that parents expressed did not completely transform from a medical only perspective to a purely cultural perspective. What responses indicate is that their beliefs moved from general assumptions about a group to specific ways their own d/hh child might develop. That is not to say that some people do not shift from a primarily medical understanding to including a cultural understanding. Rather, it seems the primary focus for parents is about the day-to-day approach and whether it includes a celebration of diversity or not.

In summary, the survey results suggest that families have already constructed beliefs about deafness before they have a d/hh child. The predominant social construction of deafness is a medical perspective that focuses on remediation. Most of the respondents keep similar beliefs after having a d/hh child but have added hope to their fears in the form of technology/devices/accommodations. They were afraid their child would be bullied or not fit in, and now their child can fit in because they "pass" as hearing. They were afraid they would not have a "normal" life and now they see their child goes to a mainstream school with other hearing kids. They were afraid they would have to learn a signed language and now they see they can choose to speak. They did not think about deafness and now they can "understand an audiogram." These results are consistent with

a generally medical perspective and what Young and Tattersall (2007) found that "the

expectation of normalization into hearing speaking children is underpinned by

assumptions of deafness as something to be fixed and the gold standard of achievement

being to match hearing peers" (p. 218). However, these parents have come to understand

some of the nuances of having a d/hh child and their perspective has expanded to include

some achievements they thought impossible before. The once limiting, isolating diagnosis

is now comprised of options regarding treatment and inclusion.

Sources

On the survey, 71 people (of the 74) responded to the question regarding sources

of information. Here I was looking to see what sources of information parents would

report as valuable or important in how their understanding of deafness has developed.

Question 16 asked, "What specific sources (people, programs, media, etc.) have had the

most impact on your current understanding of what it means to be d/hh? (Be as specific as

you can. Ex: movie title, Facebook group name, type of therapist or doctor, other parent

of d/hh child, website, etc.)" Respondents often mentioned several sources impacting

their understanding of deafness. I separated these responses into five main categories. The

most frequently mentioned source was social media/other parents (38/71 or 54%). I put

these categories together because parents often mentioned "Facebook groups for parents."

The second most frequently mentioned source was EHDI professionals (SLP, audiologist,

EI consultant, Deaf school, etc.) at 32 mentions (45%). Deaf adults (and ASL classes)

were the next highest at 17 mentions and 24%. The other two categories were research at

8% and general media/books/movies at 7%.

Based on parent responses to question 16, the two most common sources of

understanding of deafness come from the medical professionals/EHDI providers who

support families and other parents who themselves were likewise supported and

influenced by EHDI professionals. By contrast, the fact that d/hh adults were only

mentioned by 24% of the respondents indicates that families are continuing to construct

the meaning of deafness but without direct involvement of d/hh people. Finally, a

minority of parents (6) reported doing their own research, actively looking for

information online – from websites and online groups (8%).

CHAPTER 5: CASE STUDY RESULTS

Case Study Participants

All five participants identified as White. Two live in eastern states, two in western states, and one in a central state. Three have graduate degrees, one a bachelor's, and one an associate degree. One earns less than $20,000 per year, two earn $50-74K per year, one earns $100-150K, and one earns over $150K per year. The income level of the case study participants reflects the four highest percentages of survey respondents' income. The average age is 35 with the youngest being 24 (the youngest of the entire study) and the oldest 43.

Children of Case Studies

One of the families who participated has two children who are d/hh and the mother reported the older child's age, identification, etc. on the survey. The average age of children in the case studies was 2 years 3 months with the oldest being 3 years 1 month and the youngest being 1 year 7 months (not including the second child in one family – age is unknown).

Four children were identified as d/hh at 1 month, one at 2 months, and one at 1 year 2 months, with the average age of identification being 4 months. Of the six children, four had profound hearing levels and received cochlear implants (CIs). Two used hearing aids: one of whom has mild to severe hearing levels, and one with mixed mild to moderate hearing levels.

Family Stories

As an early intervention provider, I learn the most about how to support families by hearing their stories. The stories families share and the experiences they have, lead me to be reflective in my own approach to early intervention. Likewise in the current study, the richest information comes from the summarized stories of the individual journeys of

the case study participants. It is through these lived experiences that we see and feel the

impact that early intervention programming has on families. The details of these stories

are essential for understanding the steps and the processes that families go through as they

construct deafness through their experiences (explanation building, Yin, 2018). The

families' stories have been arranged based on the amount of support they received from

EHDI programing, from perceived limited to perceived significant support from EHDI

programming and perceived least to most understanding of deafness.

Jason & Laura (Emily)

At birth, Emily the hospital conducted a BAER (Brainstem Auditory Evoked

Response) test. About that test, Jason noted, "all they do at that stage is give you an up or

down kind of information." Emily had several inconclusive tests as the months followed

because she did not stay asleep during the test (which is necessary). Ultimately a sedated

BAER was scheduled but "they like, blew a bunch of veins" trying to do the IV. They

finally completed the sedated test when Emily was 11 months old, in part due to a

COVID delay of 5 months. The medical provider recommended ear tubes[12] as a result of

the test. At 15 months, they sedated Emily again to put in the tubes and then did another

BAER test. At 16 months, Emily got hearing aids. Emily was 21 months at the time of the

interviews, and they were set to start speech therapy with someone trained to work with

d/hh children. After the tubes were placed, the family had no contact or support from that

ENT. The family then found a pediatric ENT, who is a 2-hour drive away, that they had

just met at the time of the interview. He was the first person to tell them that Emily has a

"moderate mixed hearing loss." They "finally" got a description of Emily's hearing at 21

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[12]Ear tubes are tiny cylinders implanted in the ear drum to allow for fluid or air to more easily move in and out of the middle ear. For a full description, see the Mayo Clinic website: https://www.mayoclinic.org/tests-procedures/ear-tubes/about/pac-20384667

months. Jason believes that the doctors knew back when Emily was 11 months old but "nobody else ever gave us that information."

Jason noted, "this has been a very arduous and like very frustrating process with a lot of people that I felt like could have done us a better service. … There aren't pediatric specialists in our area." The parents felt like they were not referred to the specialists because Emily doesn't have a more severe hearing level. However, at 21 months, Jason said, "she's not talking at all." An additional challenge to this family's ability to access services, besides distance and referrals, is that their insurance is not accepted many local providers.

At about 17 months, the audiologist made a referral to early intervention after hearing aids were purchased. The family met with early intervention when Emily was 18 months. Laura said, "we haven't said no to anything people have suggested." They are interested and willing to get support, but they feel the system has not been providing them with much.

Regarding the placement of the ear tubes, Jason stated, "I was furious that we did this whole ear tube thing, and we didn't just go to hearing aids 'cause we had the information. It could have improved things slightly, and that would have been great. But we were losing months and months and months of time." Laura explained that "they didn't want to proceed with any type of interventions for hearing loss until they had a complete BAER." The ENT who placed the ear tubes lives in another state and travels to their area only every couple of months. That distance and limited schedule was what caused the delay in getting the ear tubes following the first successful BAER. Then there was no follow up from the ENT at all.

Laura's mother "has a hearing loss" and they assumed that was the cause of Emily's hearing. However, now that they just learned that it is mostly conductive[13], they are hoping genetic testing will show the cause. Laura's mom uses hearing aids and was diagnosed as a child. Jason says, "she can hear without the hearing aids" but it is obvious that she's not hearing everything. Laura explains that "even with her hearing aids, you can tell … she has no idea what you really said. She missed some of it." For example, Jason said, "we had a cat for the last five years. His name is Mack, and she still calls him Max." Jason assumes that "it's probably a frequency she's not hearing as well."

The early intervention provider they have recently begun seeing has been giving them general ideas to support Emily's communication. Laura was told "any way she communicates, go with it. Because if you frustrate her too much then she won't communicate at all." Jason said he:

> started doing research on my own and I found out about developing Theory of Mind and the kind of rates in which children developed with just hearing aids alone. I became really convinced that we needed to supplement with sign language at that time. So, we started doing it a little bit.

They have not yet seen much progress with signing, but it hasn't been very long. She does sign "all done" when she's eating. Laura is sure it is because they don't sign enough with Emily for her to be picking it up very much. Laura said that she believes that part of the reason for not signing as much was because she was "naïve and thinking – when [Emily] gets her hearing aids, she's just gonna skyrocket and it's all going to change. And it didn't." Jason said he assumed it wouldn't work that way because "it has to be an all-week thing and all-day everyday thing" and he is at work all day. "So, I think that really

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[13] Conductive, when referring to hearing, is related to whether the sound waves can get through the ear canal and move the ear drum (or through the outer ear and middle ear). Mixed hearing refers to hearing that is impacted by both conductive and sensorineural (in the inner ear or neural pathway). See https://www.asha.org/public/hearing/conductive-hearing-loss/ for more details.

took wind out of both our sails." Laura shared that they are learning signs by themselves on the internet based on what they need to communicate with Emily.

According to this family, none of their providers have ever mentioned using a signed language. Jason was the one to mention it to providers. The audiologist with the early intervention program directed them to resources online once Jason mentioned his interest. Jason expressed a wish that the providers would have mentioned it to them early on so they would not have wasted time wading through the diagnostic process and instead communicating with their child.

None of the providers they have worked with are d/hh. Jason says that he frequents an online Deaf community on Reddit. "That's where I first heard about sign language and getting information." When talking to these groups online, Jason was shocked that someone said to him, "don't be surprised if you get pushback from her wearing hearing aids and people who think that you were robbing her of her deaf or hard of hearing identity." As they thought more about it, they could see why people might be upset at them going against what is someone's natural identity. The family did express that they have not gotten any "pushback" from providers or anyone else about wanting to sign with Emily – only encouragement.

When asked what their hopes are for Emily's future, Laura said, "normalcy." Jason said, "the ability to communicate ourselves and develop her own identity. … Communication is just everything. You don't have the language and the vocabulary; you can't develop an identity." Jason explains that it's related to developing Theory of Mind[14]. "How we relate to other people and all these things. I mean, it's part and parcel to humanity." This has been their struggle with Emily. At 21 months, she can't

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[14] Jason explains that he was most impacted by an article by Kordus (n.d.) that he found on Reddit. Kordus explains Theory of Mind as an understanding that other peoples' thoughts are different from your own. The link to the article can be found in the references.

communicate her frustrations. There is a lot of crying and tantrums. Jason explains,

"when you can't communicate, all you can do is get upset."

After driving over two hours to the pediatric ENT recently, the doctor "ordered a

behavioral referral" but Jason and Laura feel like Emily was "unhappy" and her

uncooperative behavior had to do with the fact that she'd been in the car for over two

hours, and she doesn't have the communication skills to express her needs. The parents

stated that they will go ahead with the behavior evaluation, but they believe it is not the

cause of her lack of compliance with the ENT. They say she behaves much better most of

the time and in various situations.

Jason described his first understanding of deafness as "simply a barrier between

hearing everything" and then said now he knows "there's different kind of manifestations

for each individual. … I just have a better picture of what it is." Laura said she didn't

realize "how much harder it is when your child has a disability. How much harder it is to

do basic things other kids just do – things people take for granted."

Jason said that if he could go back and give his previous self advise, he would

have told himself to "push even harder" and trust that his intuition was right. "Instead of

getting frustrated, I should have just been stern and steadfast". Laura's advice to others

would be to accept any help offered and "do your own research."

The early intervention program provided the family with a list of apps to learn

ASL as well as a list of websites where they might find support. Jason said this was "a

little bit overwhelming because we just got these lists of links and there's really not much

direction." He said the websites were "clunky and outdated" and "hard to navigate."

Many of the mobile ASL apps were subscriptions but he had no idea which ones were

good enough to subscribe to, adding yet another barrier to information. He joined the

Facebook groups and was interested in the local face to face resources but due to COVID,

there wasn't much going on. In the end, Jason has used free apps and YouTube to learn signs. He liked the apps or websites that were personally recommended to him via Reddit because:

> those came from people that I was meeting and talking to online. They would describe more of what it is and why you should visit this, what value you can get from this, and it was more of a discussion. … Instead of like, here you go. Here's this link.

> With respect to other communication approaches, Jason said he had heard of Cued Speech and other approaches through his group on Reddit. He said he appreciates knowing what options there are because he'd hate to miss out on something that would work for Emily just because he didn't know about it. He had previously assumed that every deaf child learns ASL because "how else can you communicate?" He says there are limits to medical interventions and they sometimes don't work. He just assumed everyone who was deaf used ASL. He was grateful that someone mentioned to him the importance of ASL and the impact it has on learning and developing identity. Jason "never got [information about the importance of ASL] by the professionals. That we're paying to help our daughter."

> As noted above Jason and Laura reported beginning to use signs with Emily at about 11 months old. They said they didn't see much growth or her picking up many signs. They still want to sign but, Jason said:

> you kind of get wrapped up in developing verbal language and devoting your time to that. And getting to know speech therapy and the early intervention. They're all giving you these concrete things to do and you're not getting any concrete things to do with ASL. You're getting all this energy from everybody around focused on verbal language.

Jason would like for Emily to be bilingual.

> It's pretty clear that doing multiple languages at the same time does not hurt in any way. It doesn't stunt the verbal language, so I wish that the people that are helping us gave us more of an idea what to do with sign language. How to use it more and what to use and how to get her to respond to it.

Regarding the providers that they are interacted with, Laura said that "they all think it's great that we try" but they don't give any direct support.

Jason reported that he would like to take an ASL class, but the pandemic made that difficult. He says he needs a coach to help him instead of trying to learn on his own. He is not sure about a class at a local college or something because it would not focus on signing with toddlers. He knows what he wants and needs but not how to get it. "I have the information; I know how important [signing] is. I don't have the way to use that information." I asked if they reached out to the local school for the Deaf or Hands and Voices for information about finding a child friendly ASL class. They said they hadn't, but the local Hands and Voices is over 2 hours away.

Phil and Janet (Milo)

Janet works in the medical field and Phil works in the technology field. Their older child "failed" their 1st, 2nd, and 3rd hearing tests soon after birth, but was ultimately not diagnosed with a hearing difference. Their 2nd child, Milo, "failed" his hearing screenings and was then told their son has a severe to profound hearing level. Both parents expressed a lot of early concern about whether or not the hearing level was related to a syndrome. With a hint of sarcasm, Phil explained that Milo had a "kidney ultrasound, heart EKG, his eyes – that was a super fun test. And…genetic testing." Because of Janet's background, she knew that many diseases are "fixed" with medicine. There was even a time when she "thought that 'Oh, this could be fixed with hearing aids,' and so that's

what I was holding onto. Although it became pretty apparent that was not going to work at all." Milo received hearing aids at 5 months followed by an MRI/CT scan to see if he qualified for cochlear implants (CIs). For Janet:

it was like torture …waiting to get the implants done and then waiting another four weeks to activate and then another four to six weeks to map them correctly.

So, it was just like, oh my God, we're losing time and I want to just go.

Milo got CIs at 11 months old, and they were activated[15] at 12 months. Phil, who describes himself as a "techie," was "very excited about the technology." He sent information to his family to let them know about the devices and how they work and that they can connect directly with other electronic devices. When using his CIs, the family reports that Milo tests at "mild to no hearing loss."

The family reported that Milo started early intervention at 3 months. He had a language therapist weekly, physical therapy (PT) twice a month, and then added weekly speech therapy after he was 12 months old. COVID meant all services were virtual – and the family noted that Milo didn't participate well. At the time of our interview, they were starting to see therapists in person at home. When asked how supportive he felt the therapist are, Phil said, "I feel like they're there for their session, and then that's it." The daycare Milo goes to showed their support by getting artwork that showed a kid with a hearing aid and a kid with a CI and a poster of the ASL alphabet.

At the time of the interview, the family reported that all of the therapists came from separate agencies – the family chose who they wanted based on a brief description (none had experience with d/hh kids). They chose their language therapist because their description mentioned the therapist knew signs but then after cochlear implantation, the

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[15]Cochlear implant surgery is when the internal device is implanted into the person's head. After the surgery site heals, typically for at least a month, then the external device is placed on the outside of the head and the internal components are "activated" or turned on to receive signals from the external processor.

therapist changed more to a speech/listening focus. The parents were cautioned that they were "signing too much" and "you need to try to force him to say the word" but never told "you can't do sign language." Janet is more active in sessions with therapists than Phil. She is actively trying to learn ASL and has hired a hard of hearing tutor and participates in online classes. She knew they would probably do the CIs but also "wanted him to learn sign as well because we were making a decision for him that he wasn't able to make, and I struggled with that personally." So, she's been trying to sign with him as much as she can. They did "baby sign" with their older son, but he stopped signing when he started speaking more. The family has identified a d/hh preschool that they believe uses both ASL and spoken English and state that they will try to try to get Milo into that school.

When the discussion was focused on sources of information, the family described a Facebook group where they found strong opinions on both sides – with some individuals expressing that the right way was not to sign at all, while others felt strongly that families should only use ASL. This family disagreed with the idea that they had to choose only one language because "it's not a problem for … millions and millions of bilingual kids." The family is more concerned about Milo developing good ASL because he is surrounded by spoken English and so that will come. Mom noted that she is trying to learn and teach ASL at the same time and she said, "I wish I had more support in how to do that." She believes getting more involved in the Deaf community will help, but they have not had any opportunity to gather since COVID.

The family stated that they feel that EI providers give them too much to work on and not enough time to complete it before the next visit a week later. They also felt they get a little "criticism – what you worked on was good but not enough". However, they added, the EI services are free (or covered by insurance) and have been easy to access.

There was also no out-of-pocket cost for the CI surgery. They felt the audiologist has been a really great support and directed them to Hands and Voices. It was also the audiologist who made the referral to EI. They are close, too, so they don't have to drive far for services. Phil said he felt like in general, they "took it in stride" but that "there were moments of just grief and sadness" about the diagnosis. He would put on a "brave face… when talking to other family members…or even Janet." However, he feels like once it was accepted and they were moving forward, it was easier to be optimistic about the surgery, technology, and lots of support. "You know, there's nothing wrong with being deaf, like, you can still have a very fulfilling, wonderful life."

After this change of heart, Phil said his uncle, who he loves and admires, called, and said:

> 'I'm just so sorry to hear about your son, Phil, and it's so terrible' blah blah blah blah and I got angry. I was like, it's not terrible. …He's gonna be great and he's just gonna be awesome. …It's not a death sentence. It's an adjustment."

Phil grew up in Maryland and saw the Maryland School for the Deaf and had admired the athletes. He felt like deafness, and participation in the Deaf community, was very binary – "you were either in the Deaf community or you were out of [the] Deaf community." He thought, "if you're deaf, you interact with other deaf people. You live in communities with deaf people. You work with deaf people and that's it. …you just kind of join a new part of society and that's how it is." After their son was born, Phil said he didn't want there to be a division and that:

> there was no reason for that. … You can be both. … I'd rather him be bilingual. … We want to put him into the position where he has the background and the know how to …have that kind of flexibility in life. … It's just another language.

Janet went to middle and high school with a deaf person who was part of her circle of friends. She said she did not think along the same binary lines as Phil did. Her friend used ASL. Janet learned the alphabet but didn't pick up a lot of signs at that time. Her friend "did everything that we did. …He just kind of fit in. He was just deaf." Dances, sports, calculus class, college, career – "he lived the same life that I lived." Except that he was the only deaf person in the school. Janet never saw him with other deaf people and had no idea if he associated with the Deaf community at all.

When I asked the parents to tell me what sources of information "really informed your understanding of what it means to be deaf." Janet said, "I really don't think anything we have talks about the deaf experience." She explained that she is not sure how to answer the question because she is not deaf. However, she said that her "way to understand about the Deaf culture is to surround Milo with other hard of hearing/Deaf people who are in that culture and understand it." Phil said that there was one thing that was "the closest thing I've had to maybe learning more about the deaf experience." Through the Described and Captioned Media Program (DCMP.org), he found resources about Deaf Life and Cochlear Implants. One video is a TEDx talk by Heather Artinian (young star of *Sound and Fury*), who talks about growing up in a Deaf family and then getting CIs and learning to listen and speak as well. In the video, Artinian explains that people ask her what world she is in, and she says, "the Heather World" – not the hearing or Deaf world, but both worlds and a bridge between the two (TEDx Talks, 2013).

Phil said that he felt like there is still a controversy between the Deaf Community and cochlear implants, but that it has evolved over the past 20 years. Janet said that she felt like CIs are still very divisive because although some people are more accepting, they also see extreme comments against it like "you're mutilating children." Phil said he felt like those comments were so ridiculously extreme that "I'd roll my eyes and say, 'that's

stupid.'" Phil said, "to me, that kind of response should not be attacking the parents that just learned their newborn is deaf." Janet said that "it upsets me a little bit" because "I'm not a deaf person. I don't know what it's like to see a kid get cochlear implants and feel like, well, you're telling that kid I'm imperfect or there's something wrong …you have to fix it with surgery." Janet agrees that there is a concern for the Deaf Community because "some hearing parents jump into cochlears too quickly." Phil is shocked when families say they stopped signing after getting the CIs because he and Janet feel strongly that signing will give Milo options and access.

　　　　Both Phil and Janet have really wanted to meet other parents but as of the time of our interview there were no events because of COVID. They said they sometimes saw a family from their state post in their Facebook group but that the other family would be several hours away, making meeting a challenge. Phil is hopeful that "one day we'll find somebody else who has a similar kid in a similar situation." They do try to be a support to other, new parents in their Facebook group by sharing their experiences. They remember what it was like at first, googling everything they could think that they might need to know and "watching video after video" from the CI surgery to teenagers with CIs.

　　　　Phil tried to share some videos with friends and family to help them understand what the CI is and how it works for Milo, but they mostly went un-watched. Phil said that understanding the technology "just made me feel better about how it works and that it does work." Phil and Janet were given "a whole two books of items" to read and understand but they both felt like they were too much to go through. It was easier to look things up and take bite-sized chunks of information at a time. The parents felt that they were given lots of information about CIs but nothing about how to "learn more about deaf people." Janet has wanted to ask the ASL tutor about what book she could read that might help her understand the deaf experience, but she feels like it might be offensive. Janet

said that the most helpful thing has been "my interactions with the two hard of hearing people I've talked to. … I like interacting with them…I feel like that's been the best thing for me."

Media has impacted Janet because she now notices deaf characters in the shows she watches. She doesn't know if it's because having her son has made her more aware or if there is a greater presence of deaf people. She said that it is comforting that the media is making being deaf more accepted and represented. Phil said it was like a "flip got switched and all of a sudden you see every little article that's posted, and you click on every little link. You just dive a little deeper so you're much more aware of it." Phil is active in Facebook groups and is encouraged when he sees other people's older kids being successful. It's been a good resource since COVID has impacted their ability to interact with people in person.

Phil said that if he could go back and tell himself something at the beginning of this process, he would say, "well, he's just deaf. You don't have to worry about all those other things that you were really freaked out about. I think we can handle deafness." Janet added that Milo being deaf is "just different."

Danielle (Len)

Danielle is a special education teacher. Her first child was screened[16] in the hospital, and it took "like 20 seconds" and then they were done. When Len was screened, it was taking a long time, Len got fussy, so the screener said they'd come back the next day to screen. The next screen took a long time too, and Danielle was told "he came really close to passing." They came back two weeks later and had the same result. Danielle was told "'he was just born. It's probably fluid.' …I was kind of latching onto

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[16] Danielle used the words "screen" or "screened" and so I followed her wording preference for describing her experience.

fluids" being the explanation for Len not passing the screening. "Then my husband would say to me, 'he doesn't react to sound or anything.'" They had an ABR (Auditory Brainstem Response) test at 2 months old and it was at that time that they were told that Len was "profoundly deaf". Danielle often blamed herself and wondered what she may have done during her pregnancy to cause Len's deafness. Later, genetic testing showed Len has Connexin 26[17] and that eased some of her guilt. No one on either side of their families is deaf, but Danielle and her husband were both carriers.

"As soon as we found out" about Len's hearing levels, Danielle and her husband went home and "just sat in bed with the baby" and processed their new situation. "You have to grieve … you thought your child's life was going to be one way – now, it's not. I need to have a moment to kind of let go of that." After that, she says they were ready to figure out the next steps: early intervention, doctors, whether to get CIs – where to go, etc. The hospital made a referral to an audiologist who then emphasized the need for further testing (eyes, heart) to make sure it was not a syndrome. Someone told Danielle that she needed to go to the health department to sign up for early intervention – which she did. Early intervention started at 3 months (the same month Len got his hearing aids). The health department had other parents who had been in Danielle's situation who were trained to walk her through the early stages of the process.

Because Danielle has connections through her profession, she was able to find a speech language pathologist (SLP) who works for a Deaf school. The SLP talked to them as a friend and then was able to take their family on as an SLP client through the early intervention program. Len "loved her because she signed with him right away." Danielle said, "As soon as we found out that he was deaf, immediately, [we were] trying to learn

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[17] Berke (2021) explains that connexin 26 is a technically a protein found in the human body – specifically inside the inner ear. A mutation in the GJB2 gene can cause a lack of this protein which causes the inner ear to not transmit sound to the brain. As a recessive gene, parents can be carriers of the gene with no family history of deafness. One in 30 White people are carriers of the gene.

as much sign language as we could." Their goal was to sign with Len early so that if they did get CIs, they could use the signs as a "bridge to helping him understand the sounds and to hopefully start speaking." Danielle recognized how fortunate they were to have an SLP who is fluent in ASL and aware of the needs of deaf children, because she knows that most are not. After a time, the SLP had to stop seeing the family because her job at the school demanded more of her time.

In their area, Danielle said that parents of d/hh children (and their siblings) have access to free ASL classes – which their family participated in – until COVID hit. Their family watched a lot of Signing Time. "I have nonverbal students that I work with who also prefer to sign. So, I'm able to also practice my signing at work and use it more often." Danielle does not consider herself fluent in ASL because she does a lot of talking while she signs. They are trying to learn as much as they can, but COVID has made it difficult to take classes. Danielle said that they want Len to be bilingual.

Len got bilateral CIs that were activated when he was 8 ½ months old. He had a few months of speech therapy before COVID hit and then had to have speech therapy online for over a year. According to Danielle, at 26 months, Len's language skills were 18-20 months and 24 months (using the SKI-HI Language Development Scale which is normed on d/hh children and gives children credit for both spoken and signed languages). Danielle reports that Len is at age level in all areas except language. They had SLP services twice a month until Len got his CIs and then the services increased to weekly. They started getting weekly auditory verbal[18] therapy as well but were paying about $1000/month out of pocket and stopped when COVID hit. As an educator, Danielle felt that she was perfectly positioned to support Len's development.

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[18] Briefly mentioned earlier regarding the range of communication options. Auditory verbal therapy focuses on using listening and speech without visual cues.

Initially, Danielle felt like she and her husband were ignorant about deafness and were grieving over what it might mean for Len and his life. However, after "reading, learning more about the Deaf Community and just talking with other parents, I think the overall theme was always it's fine. It's just – that's who they are. … They're gonna have the life that you envisioned for them." As Len's personality began to develop, Danielle realized that "even if he couldn't be implanted, he was going to be happy. And that's, I mean, that's all that matters. …I want Len to be seen as Len – who happens to be deaf. … He's who he's meant to be."

Danielle tries to support other parents through participating in research and talking to other parents because she knows "how scary it was initially." Danielle has a close friend who is on the board of their local Hands and Voices chapter who also has a d/hh child. Danielle is also involved in various Facebook groups. She said she "learned very quickly" how divisive the different groups can be (parents of children with CIs and parents who sign). Danielle prefers Hands and Voices because it supports the family regardless of their communication modalities. In her own journey, other parents have been so supportive of her that she wants to "pay it forward."

One thing another parent did for Danielle was to help her accept their situation. That parent is an ASL/English interpreter and the parent of a deaf child, she was teaching their free ASL class. The parent had said, "I just want to let you all know it's fine, you're fine." Danielle said that although it was a very stressful time and she's not discounting that, it was also so comforting. She realized the truth in those few words and that Len has a "family that loves him. That's here to support him." Even Len's extended family is trying to learn signed language. Danielle's sister also told her that Len is "gonna show us all the wonderful things that he can do." Danielle's older brother said he will "walk this road with him. Whatever he needs, I'm there."

When asked what she believes about deafness now, she has not fully decided. She knows there is a rich Deaf culture. She said that at first "we kind of looked at it like it was a disability." Now, she is on the fence about what it means for her son here and now.

> Sometimes when I look at my son, I look at it like he has a sensory difference. And then sometimes it can be looked at as a disability. …My mission is making sure that my son is a part of that [culture] because his deafness is who he is and he's always going to be. And that's a big reason why we sign, too.

Danielle shared that lots of families tell her why they don't sign, and she has been told by SLPs not to sign. "I just want to make sure [that] I'm always sensitive to the culture and just kind of making sure that we expose Len to that and make sure that he feels included in that community."

Danielle learned about the Deaf community through parent groups, researching online, Signing Time, and other resources. The SLP (who worked at the Deaf school) told them that she knew a young man from their town who attends Gallaudet University (the world's only liberal arts university for deaf and hard of hearing students). The SLP contacted the young man's mother and later introduced her to Danielle. When Len was less than a year old, they got the chance to meet the son, and asked him what he would want hearing parents to know. As it happens, the student is involved in sports and so Len's dad asked lots of questions about the logistics of playing different sports. Danielle is now hoping to get a Deaf Mentor and the family has signed up to participate in the pilot of that program in their area.

Danielle is concerned that because Len has CIs, he is neither hearing nor deaf and yet both. Danielle wants him to feel like "he's a part of whichever community he feels like he wants to associate with" and that his "deafness is what makes [him] unique and interesting." Danielle said they are trying to encourage him to have a sense of humor,

confidence, and "a little bit of a thick skin." She is worried because when Len starts

school, "he will probably be the only deaf child in our town." Danielle is thankful that she

works for the school district and knows who will be involved and how to advocate for

Len.

Danielle kept a binder for medical information and another binder for early

intervention resources. They received handouts from the health department and the

audiologist. She started doing extensive reading on the Gallaudet website and watching

their videos. She got connected to Hands and Voices and parent groups on Facebook. She

and her husband started watching movies with or about Deaf characters. In their

searching, they realized that some resources were not for them. For example, Danielle

said that at first, she would "like" any online resources related to deafness. One time, her

SLP told her about a webinar on deafness and literacy and so Danielle signed up and

started the pre-assessment. "The pre-assessment said something like 'true/false – sign

language is detrimental to deaf children' and the answer to them was true. So, I realized it

was probably not the resource I would like."

Danielle feels has an interesting perspective on using a signed language because

of her work. Working with kids who are nonverbal, she has often heard that "signing is

the lazy way out." However, her older, hearing child was in a Montessori preschool, and

they were signing with all the kids. At the time, Danielle asked an SLP friend, "Is that

gonna hurt her with her speaking?" The SLP responded, "No no no. If anything, that

helps." Danielle says that she wants "more research that goes out that shows that it

[signed language] is so beneficial to deaf children. So that's kind of like my mission,

too." Danielle tries to share information with others who continue to think signing is

detrimental. She cited a research paper she had recently read (Caselli et al., 2021) that she

understood to be showing that "hearing parents that are signing to their children – the

vocabulary is coming out the same as a hearing peer with hearing parents. So, I try to direct people towards that."

Danielle has seen the benefits of signing in her professional life. She uses it with children and school. She said her school has been teaching signs to the whole school and their reading scores have improved. She said, "It's not …detrimental. Use it as a bridge or …another language …there's so much research too about bilingualism in the brain. I just try to, you know, combat anything negative with data." In her area, she feels like not many families will use a signed language or really consider it long term and it's a little disappointing to her because she knows what an asset it can be.

Danielle mentioned that she posted the Caselli et al. (2021) article on a Facebook group for parents of children with cochlear implants because that group "tends to be a little bit more friendly to parents like me that are hearing" than "the deaf and hard of hearing group want to kind of focus solely on sign language." Danielle makes it sound like, even though she is a proponent of using a signed language, she gets push back for getting CIs and also doing spoken language. In her perspective,

> [Len's] cochlear implants are a way that he can access the hearing world, but he's deaf. …I really feel like sign language is his first language and that's his innate language and we wanna respect that. … I just can't sing the praises of that enough 'cause we've just seen how positively it's impacted him and helped him to speak, too.

Matthew (Oliver)

For many years before his son, Oliver, "didn't pass the newborn screen," Matthew had been constructing deafness. As a child, he learned how to sign the alphabet from his grandmother (who he later found out was a CODA – Child of Deaf Adults). When Matthew was in high school, his dad decided to take an ASL class to better communicate

with Deaf people at work; and what his dad learned, he shared with Matthew. This included more about his Deaf grandparents, Deaf culture, and that ASL is a "full language" (as opposed to a gestural form of English). In graduate school, Matthew briefly dated an oral deaf woman who was "very bitter about not learning sign language. She was … constantly struggling in the hearing world. She was … a success by oral standards, but still very isolated and struggling in a lot of ways socially."

 As the person doing the newborn screening was trying to minimize Oliver's results by assuring them that it often does not mean anything, Matthew said he thought about his family history of deafness and his "spider sense started tingling." That screening was the first of months of medical tests and clinical observations for the family. They were referred to an audiologist – his wife called those visits "traumatic" and eventually Matthew volunteered to go to those appointments on his own. At 3 months old, Oliver had an ABR and was "identified as profoundly deaf, profound sensorineural deafness. Bilateral. So, he's got a perfect score, basically." They were then referred to early intervention provided by the local school district and an early intervention center for d/hh children. Oliver was eventually diagnosed with connexin 26.

As Matthew was carrying his "sweet, fat" baby out of the audiologist's office after his "perfect score" on the ABR,

> another child came up and was like, 'oh, hi,' and I was signing to Oliver at that
> point … and she started signing a little bit, too. It turns out that she was deaf, and
> her mother was deaf, and they were the first two members of the Deaf community
> that we were able to contact, and they remain good friends.

These friends introduced them to the Deaf world and Matthew says that it's the Deaf world that "did more for us than anything that early intervention ever, ever, ever did."

Before they started early intervention services, Matthew said,

We had decided on pursuing a bi-bi educational course, to get CIs, but also to

strongly pursue ASL and learn it as a family. …I knew that ASL was going to be

a part of what we were going to pursue, and the CIs were basically hedging our

bets because we had no clue as to what deaf education was like in our area. … So,

we did both.

They had their first Individualized Family Service Plan (IFSP)[19] when Oliver was 6

months old. None of the early intervention providers for Oliver's family were d/hh.

The early intervention center for d/hh children provided the family with weekly

home visits from a teacher of the deaf as well as twice weekly SLP services. The early

intervention center for d/hh children had a preschool that used a total communication

approach – "SEE[20] [Signing Exact English] with some ASL." Through their contact with

the Deaf community, they felt like the program at the preschool would not be offering

ASL instruction and "was not a place where he could learn strong language skills."

Matthew reports that "we experienced a lot of pressure to enroll in the program."

"As an alternative, we actually sought out and found a signing Deaf nanny who

could care for our son" and found another family with a deaf child who was interested in

sharing the nanny. Matthew and his wife started taking ASL classes that varied in

quality. The better program was several hours, twice a week and difficult to do with a

young baby. The class was not expensive, but the cost of the sitter for their older child

was very expensive. They were grateful they could afford it, but it was difficult. He

shared that their family loved going to events at the state school for the Deaf. Even

Oliver's older brother had a good time. They had fun, were welcomed, and felt validated.

Being in a Deaf environment was encouraging. During one event at the Deaf school, the

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[19] This is the federal document under part C of the Individuals with Disabilities Education Act. The family and team members decide on early intervention goals and services and document them here.
[20] According to signingexactenglish.com, SEE is a manual English system that follows the English language and is not a language in itself.

audiologists spoke briefly to the group and then said they were switching to ASL.
Matthew said that experience had a powerful impact. It was a way to show that they
"acknowledge the equivalency of languages. … Gestures like that were really
wonderful."

The early intervention program they were participating in did not offer any kind of
ASL support according to Matthew. They were told to try contacting the school for the
Deaf. Matthew reports that as they were leaving their "first IFSP meeting with the
[school] district, we were approached by the woman who was the coordinator for deaf
education for [our] school district" and the coordinator asked them (Oliver's parents) for
"any recommendations where she could take [an ASL] class." Matthew admits that
maybe it was good that the school district had no idea how to support them because at
least they were not fighting against what they wanted. They were, he said, able to find
some support on their own. They reached out to the local Deaf services agency and got a
Deaf Mentor. They attended family events at the Deaf services agency. Many of these
services they found because of the d/hh friends they made as they were leaving the
audiology office where Oliver had his ABR test.

Matthew reports that the "first major conflict" they had with early intervention
was with the SLP from the early intervention center for d/hh children. At the second
IFSP, the parents expressed their desire to focus on ASL and after getting CIs, they'd like
to add listening and speech. The parents knew they wanted ASL to be part of Oliver's life
and were shooting for a bi-bi education. After they shared their goals, this SLP told them
they were concerned that Oliver would have too much ASL exposure. The family felt like
their goals were "completely undermined" by this comment. "We heard from the research
to learn sign language. We heard from the Deaf community to learn sign language. And
then we went to the hearing educators, and they wanted to do literally anything but ASL."

Matthew said that SLP "was always, I would say, dismissive of ASL and she was always kind of discouraging about it." She "kind of played up her experience in the Deaf community" events when she was younger and then would say "derogatory things about deaf adults like, 'Oh. You know, their English skills are never good' and 'Oh, you know, they're never going to get you.'" Matthew said his wife stopped going to see the SLP because what she was saying was "too insulting. It's just too awful." When they told the SLP they planned to attend the state school for the Deaf, the SLP told them that Oliver would not get a good education there.

As a scientist, Matthew's wife knows how to read research and together they did a lot of research on their own right after Oliver was born. They learned about language acquisition, the "birth-to-three window" (aka the critical period), and bilingualism. Based on the current research they read, they decided they wanted a bilingual bimodal[21] approach for their child. "And then to go out into the community and to see none of this stuff in practice. Absolutely none of it in practice was shocking. And more than that, really dismaying." With their knowledge of best practice guidelines, they were upset by the system's complete disregard for it. Other parents were being told their children were doing fine because the child was (according to Matthew's report):

> just a year behind. The three-year-old was a year behind in language acquisition and was identified at six months. … These children were being impaired by their educational experiences. They were not born with the handicaps that they were developing.

Matthew expressed appreciation for their audiologist who supported the family by suggesting resources for ASL support as well as any listening supports, they might be

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[21] Bilingual bimodal in deaf education refers to using two languages in two modalities – in this case ASL and spoken English.

interested in. Matthew felt like he got more support and options than other parents he had talked to in his area.

Oliver had bilateral cochlear implant surgery at 8 months old and was activated at 9 months. Matthew was confident in the surgeon but also felt conflicted about performing surgery on their child. Matthew was concerned about how the Deaf community would react to their decision to implant. He said that ultimately, they "got a little bit of side eye from some people in the Deaf community, but honestly, almost nothing." Oliver used his first sign at 5 months old. By 9 months, he had 4 or 5 signs already. On the morning of the CI surgery at 8 months old, he signed 'daddy' for the first time.

After getting CIs, they decided to find a different SLP through their private insurance. Matthew said,

> I cannot tell you how nice it is to work on English with a group of people who have no ax to grind on the oralism/manualism spectrum. They didn't sign. They didn't object to us signing. They only asked that we speak English to him in the sessions.

After cochlear implantation, Oliver made about a year of progress in six months. However, they did not have a way to track Oliver's ASL skills. No one could do an ASL evaluation. Matthew ended up asking someone online if they knew of anyone in their area. They found someone an hour away who could do an ASL assessment after being added to the IFSP. Matthew felt like they needed the ASL evaluation to be able to prove ASL was Oliver's first language and to be able to get support and possibly send him to the school for the Deaf. He complained about this "disability model. If we were a Spanish speaking family, we wouldn't need to prove that our child spoke Spanish." By 18 months, Oliver was at age level in both spoken English and signed ASL.

At three, Oliver started virtually attending the school for the Deaf and plans to attend there in person in the future. His parents were able to get him into the bilingual bicultural program they wanted. "After three insane, traumatic years, we landed. … We feel like we got through. He has acquired an L1, an L2, now, you know, we can laugh and the rest of it will take care of itself."

When asked what advice Matthew would give other parents or himself back at the beginning, he said, "talk to Deaf adults," things will work out fine, and include the older sibling more. His future hopes for Oliver are "college. Career. Deaf President Now – U.S. edition" but honestly,

> My hopes for my deaf son and my hearing son are kind of lining up and I hope
> that they will both be happy in their lives, get a good education, find a good
> partner, and amaze us with what they discover.

Jasmine (Sean and Jackson)

> Jasmine has two deaf children. According to Jasmine, Sean:
> Failed his newborn hearing screening and then we went back. Failed the next test
> and then we had the ABR when he was four weeks old and showed he was
> profound on both sides. They recommended us for cochlear implants, and they
> notified our early intervention team. …We started getting things in the mail and
> phone calls. "Hey! Your kid's deaf. Here's some information." Or – "Hey! We're
> going to come and visit you."

Jasmine met her early intervention team when Sean was six to eight weeks old and had the IFSP by 2 months old. Sean got bilateral cochlear implants at 15 months.

The team included a parent advisor from the school for the Deaf, a Deaf Mentor, and an occupational therapist. At the time of the interview, Sean was 3 years old, and the Deaf Mentor has continued with the family for the full 3 years. The family has also had a

parent advisor the whole time, though the individual providing the service changed. Jasmine was told about the services that were available – the parent advisor and Deaf Mentor – and was able to choose both. As a result of selecting both a parent advisor and a Deaf mentor, their team had one Deaf member who Jasmine says, "was able to teach us ASL and about Deaf culture" and one member trained specifically to work with d/hh children who "talks about listening spoken language and different programs and transitions." Each of these two providers came 3 times a month.

After Sean's first screening, Jasmine was told that it was probably fluid. After the second screening, Jasmine and her husband began to suspect that there was "something wrong." After the ABR, it validated their fears, but they were still surprised. When their second son, Jackson, was born and didn't pass the hearing screen, they quickly scheduled the ABR. Jackson "was different cause he is mild to severe bilateral. … We were expecting either just the same thing or a hearing kid."

Jasmine felt that the process was even faster with Jackson because they already had services in place for Sean. They got his hearing aids by 6 weeks. She notes:

> I texted our parent advisor in early intervention like as soon as we found out. I was like, "Hey! We just got the test results back and my second kid is deaf, too. So, I guess we'll see you in a week or two."

She felt that they knew how the system worked and what goals they wanted to work on – and things moved quickly.

Jasmine has talked to other parents at events hosted by the school for the Deaf, in online groups, and other situations. She feels "very blessed, very lucky" to have their early intervention resources be so easily accessed. She's heard stories about families who have to drive hours to get to a provider or don't have any resources available. The EI providers come to her house; her audiologist is "less than 10 minutes away." She said

they reached out to her right after Sean was born. "They all showed up and said, 'Hey, we're all here. How can we help?"

Jasmine related interesting experiences she her husband both had with d/hh people when they themselves were growing up. They both went to church with older Deaf adults who used ASL and younger deaf individuals (close to Jasmine and her husband's age) who used CIs and spoken language. When Sean came along, both parents thought, "oh, he's deaf. We can do cochlear implants and he can talk. He can use ASL. It was still hard, but we had seen people be successful." After Sean was born, Jasmine and her husband reached out to the parents of the deaf individuals near their age and asked for advice and about their experiences.

Because of their past experiences, Jasmine described her views of deafness at first as very "dichotomous":

> … there's two different ways. Go straight ASL and that's all – just visual. Or you're cochlear implant oral. That's your life. Since then, we've been able to meet a lot of deaf people with a variety of experiences. … So, now we see a greater variety of different options and different lifestyles. We've just been able to reach out to the Deaf community and see a lot of different ways of doing it.

Jasmine had not heard of the Deaf community before her sons were born and says she has enjoyed learning about and participating in it the past couple of years. Knowing about the varied experiences, "gives us a lot more flexibility" in what's possible for the kids' futures.

> If something is not working, it gives us permission to change or if one of them wants to do it one way and the other wants to do a different way. That's totally fine. … As long as they get what they need and they're happy.

Jasmine and her family started attending a church that uses ASL when Sean was 8

months old and have met lots of families that way. She said it has been one of her greatest

supports as a parent.

> When we go to church, everyone loves our kids 'cause there's so many deaf
>
> people there. They love having our kids to, like, teach them their culture and …try
>
> to raise them better than they were raised themselves. It's really neat to have
>
> people who want our kids to have everything.

Reading research on the Gallaudet (Clerc Center) website also helped solidify their

decision because it shows how a bilingual approach provides "a good language

foundation from ASL, but also English because that's what they need in this world, and

the ability to read and write makes a huge difference in opportunities and potential."

> I asked Jasmine what other sources were helpful to her on this journey. She said:
>
> The first thing I went to was – I got this huge binder. You can tell it's really thick.
>
> …[my state] health department just sent it straight to me when Sean was three
>
> months old. Very soon after he got his diagnosis, I just got this big package in the
>
> mail. … It talks about family support, communication possibilities, cochlear
>
> implants, FM systems, hearing loss, hearing aids, advocating, … keeping track,
>
> and then it has parent resources. … It gave me a bunch of websites and
>
> organizations that I could go look at.

Jasmine reports that her sources of information include her early intervention resources

(parent advisor and Deaf mentor), the audiologist, Facebook groups, people in the Deaf

community, the local school for the Deaf, etc.

Jasmine likes to know as much as possible to be prepared, so she read through the

binder and then went to the websites recommended and read for hours. She admits that it

is a huge asset that she was able to stay home[22] and devote time to doing all this reading. She also recognizes that it might have been harder to focus so much time and energy on learning and working with providers if it had not been her first child. The first thing that really struck her in the binder was that it starts by "talking about celebrating your child." Jasmine also liked the "stories from other families" because it "was good to see other people have been in that same situation and everyone is different." She appreciated seeing the "whole range of options for your deaf kid."

Jasmine is hoping to get Sean into a bilingual bimodal preschool program. "'Cause his speech is going so well, I want him to have the option of bilingual to pick up on his ASL skills." Jasmine would like the option of a mainstream school in the future because there are sometimes more extracurricular opportunities. Jasmine emphasizes that she "would love for them to be bilingual bicultural in both ASL and English. …After that…be able to get a job. Go to college if they want or trade school if they want and find their own path."

Jasmine says that "meeting deaf people" has had the greatest impact on her hopes for her kids. In these meetings, many deaf people expressed their frustrations growing up oral and then learning a signed language later in life. These people wished that ASL had been part of their lives all along. They also were sad that their families were no longer able to communicate with them. "That really impacted us that we didn't want to lose that connection with our kids." However, since they don't anticipate that their extended families will be able/willing to learn ASL, they wanted their kids to have hearing aids and CIs to be able to communicate with the hearing world as well. "When we had all our

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[22]This family reported the lowest income in the study. It seems remarkable that Jasmine was still able to choose to stay home with the children and access so many support services. In this case, it is not income alone that determines access to services.

discussions about – should we do ASL or English? We thought, we need both for

everything that we wanted."

Jasmine does feel very strongly that providing a bilingual bimodal opportunity for

her kids is the best option for them. When I asked how she interacts with other families

who feel strongly to the contrary, she said that her reactions vary depending on the day.

Some days I'm very much – this is the way it should be. This is what every kid

needs. And then take a step back and say, "that's what works for our family.

That's what works for our kids, and it doesn't work for every family. It's not the

same in every situation."

If Jasmine could go back and tell herself one thing, she'd say that "you're gonna

do better than you think you are. It's gonna turn out great" and "there are so many people

out there who want to help and support."

Meanings of Deafness

As mentioned at the beginning of the family stories, I organized the case studies

by my perception of the parents' understanding of deafness progressing generally from

least to most. Jason is learning about Deaf culture and talking to Deaf people online.

However, their journey has been almost completely medically focused. They are

theoretically understanding deafness as a culture but dealing with the day-to-day struggles

of raising a 21-month-old who has very little language ability. Phil and Janet know there

is a Deaf community – Phil felt like it was a binary – either you're in or you're not.

However, they felt like they want Milo to have both, and they'd rather not think about

extremes. Janet felt like someone who is deaf is like anyone else. Danielle's first

impressions were all medical because of all the testing. With her special education

background, she does not see disability with such a negative stigma. Deafness is a

difference, and it is also an identity. She advocates for all kids signing because she has

seen the benefits to many children. Matthew firmly believes in the cultural perspective of deafness. He said on his survey, "the medical issues of my son's ears pale in comparison to the social/ emotional/ cultural issues." Jasmine supports all of the ways of being d/hh and interacts with d/hh adults with a variety of experiences as she participates frequently with the Deaf community at church.

The social construction of deafness is not a simple process. Each of these families shared their unique way of coming to understand deafness. For several families (Jason and Laura, Phil and Janet, Matthew, and Jasmine and her husband), the construction of deafness began years before their child came along. From their past observations of d/hh people, they began to understand what might be possible or difficult for their d/hh child. Danielle did not have previous experience with d/hh people, but she knew about the potential in people with disabilities. This belief expanded to include her d/hh son. In this case, all five families' perceptions of deafness included some limitation that was removed by their decision to use a bilingual bimodal communication approach. They all wanted to give their child all possible options.

Sources

The five sources coded for in the surveys (social media/other parents, EHDI providers, d/hh adults, general media, own research) were mentioned by all five case study participants in their interviews, with the exception that one family did not mention general media. This seems to confirm the impact of these sources on parents' perception of deafness. Large portions of the second interview were spent discussing sources that shaped the families understanding of deafness. Since the case study participants also filled out the survey, I was curious to trace the overlap of responses. Two of the case study participants (Phil and Danielle) only mentioned social media/other parents on their survey. One family (Matthew) only mentioned Deaf adults. The other two mentioned a

combination of sources (Jason mentioned social media and an audiologist; Jasmine

mentioned Deaf adults/ASL classes, social media, and research).

During the interviews, all of the families discussed the value of doing their own

research online. They would get links from EI or from other parents and then they would

find research articles or stories that encouraged using a signed language. When they

found things that told them not to sign, they disregarded those sources. The research they

read did not support the idea that signing was detrimental. The Deaf people they talked to

said the opposite as well.

For all case study participants, the top source for understanding deafness was d/hh

people. Jason talked to Deaf people online. Janet mentioned her ASL tutors as the most

helpful resource. Danielle met a Deaf young adult who helped her see possibilities for her

son. Matthew said that Deaf people (his great grandparents, his ex-girlfriend, his Deaf

friends) have done more for him than the early intervention program did. Jasmine and her

husband both knew d/Deaf people before and then attending church with them and

learning about their varied experiences gave her the confidence to be open to various

ways of being d/Deaf. One thing was very clear in these interactions – all of the d/hh

adults they met encouraged them to use a signed language so their child would have

options. The benefits they listed included cognition, second language development,

identity, access, literacy, and Theory of Mind.

Early intervention was mentioned by all participants as impacting their

understanding of deafness, which shows the respect the families have for the position.

However, what is most notable, is that these families also had a healthy amount of

determination to do what they felt was best for their child. When EI providers would say

things against what the families felt to be right for their child, they were able to continue

to push for what they wanted – even if it meant going elsewhere for support. Families do

listen to and learn from EI providers, but they will need to genuinely meet families where they are if they want to provide quality early intervention.

Quality of EI programming

The survey as designed did not allow for a very good analysis of the early intervention programming. In these interviews, I asked families about their EI experiences and specific questions I developed as a Provisional List regarding meeting the JCIH best practices (see Appendix B). Only one family (Jasmine) had d/hh EI providers. Jasmine was the only one who had providers trained to work with d/hh children during the whole EI 0-3 experience. Matthew's family had service providers who were trained to work with d/hh children at the early intervention center, but Matthew's family stopped services there after the providers (according to Matthew) expressed "audist" ideas and then got better support from providers not trained to work with d/hh children. Danielle had an SLP briefly. Jason said their EI provider would be trained but did not yet know at the time of our interview. Phil and Janet did not.

Their programs did offer regular assessments to check the progress of the child. However, Matthew had to find another provider to assess Oliver's ASL skills. Jasmine had opportunities to meet other families through the early intervention program and the other families were trying to find other programs (Hands and Voices, Facebook groups) but were hindered by COVID. They all felt fairly able to participate fully in IFSP meetings. EI providers were not all able to adapt their approach to meet the needs of the families. It seems clear that the programs are not following all the JCIH guidelines – except for Jasmine's.

Summary

It is striking how the case studies were so similar while the families' stories were so different from each other. They are similar because they are good parents trying to do

the best they can for their d/hh child within the system around them. They were all

respectful of Deaf culture although their experiences with it varied greatly. They all

wanted to provide their child with options for communication, specifically bilingual

bimodal ASL and English. They seemed to understand on some level that "bilingualism

empowers deaf individuals to choose for themselves the life that will allow them to

flourish" (Wilkinson & Morford, 2020, p. 1336). Because of these similarities, we see the

impact that EHDI systems have on families and that families desire more involvement of

d/hh professionals.

Had Jason's family been able to move quickly through the diagnostic process,

they would have been better able to take advantage of early intervention supports instead

of waiting to figure out how much Emily was hearing. Had Jason's family had access to

Deaf adults in person, he may have been able to ask how to teach a child to sign. If Janet

and Phil had providers trained to work with d/hh children or a Deaf Mentor, they could

have asked more about the "deaf experience" (as Janet called it). Janet would not have

had to carry the burden of trying to learn and teach ASL simultaneously. If Danielle had

more opportunities to talk to Deaf adults like the college student they met, she could have

a broader idea of what it means to be d/hh. If Matthew's early intervention program had a

philosophy that matched his, he would have been able to avoid some of the "deaf

emergency" that they experienced trying to get their needs met. Oliver could have had his

ASL supported and tested through an EI provider. And then there's Jasmine. As the

youngest and lowest income parent, she could have been highly limited in her support.

However, her EI program included d/hh adults as direct providers (Deaf Mentors) as well

as in administration. Her EI providers were all trained to work with d/hh children and

supported her desire to have both ASL and LSL bilingual bimodal support. These services

came to her and provided her with the foundation she needs to support both of her d/hh children as they grow.

Only Jason mentioned getting nothing but encouragement when he said he wanted to sign with his child (which may be related to the late identification and language delay – though that is a study for another day). All other case study participants had been told by someone or heard from certain providers/agencies not to sign. However, even Jason said that the providers would say they had no problem with signing but then put all the energy and emphasis on verbal language.

These stories contained several examples of social construction in action. Here are two examples from Matthew's story. First, the SLP said they support Deaf people and their language and culture, but when it came down to it, they said derogatory things about the educational outcomes of signing deaf people. Second, the school for the deaf showed how equal they believe the languages to be by hosting events in both ASL and English. How we, as professionals, view d/hh adults translates to families how we view their children.

CHAPTER 6: DISCUSSION

As we have seen from each family's story and from the predominantly medical perspective of the survey respondents, parents first understanding of deafness is that it is a medical condition. Young and Tattersall (2007) state that this is due in part to the fact that "the model of deafness that is so prevalent in these early discussions with parents is one predominated by a medical model of deafness and that appears to be parents' … most early influence" (p. 218). The first discussions that parents have are with the medical professionals in their rush to identify any difference. However, we see from several of these parents' experiences that they often have had other experiences with deafness. Matthew saw the benefits of using ASL to reduce the communication burden and Phil saw deaf students belonging to a community.

Conclusions

Guiberson (2013) cites several articles stating that parents want to know all their options, they want unbiased information, and they don't want to be limited to what resources they have access to. This appears to also be the case for the participants in this study. For many survey respondents, they want to know that spoken language is an option for their d/hh child (25 specifically mention it and more implied it). Although research shows that parents want their children to speak (Mauldin, 2016; Mitchiner & Batamula, 2021), this surprised me. I assumed that parents knew they had the option of their child being able to speak and that seeing signing Deaf adults on TV would encourage people to want to learn ASL. However, for many parents, it is still seen as a disabling barrier to "have to sign." Conversely, the parents in the case studies felt like offering ASL and spoken language was the best way to offer all of the options to their child(ren). They seemed to understand the idea of language deprivation and wanted to avoid that for their child(ren). Many of them found out about the need for including a signed language

through their own research or from d/hh adults they talked to. However, they were often

limited by the resources that were available to them.

Implications of Findings.

This study specifically wanted to know what implications these findings have for

early identification and intervention programming and practice. This is critical because

"early identification is of little importance if it is not combined with quality services that

can realize for children and families the potential advantage of significantly earlier

diagnosis" (Young & Tattersall, 2007, p. 209). There are many studies that look at early

identification, but fewer look at early intervention. Early identification is important, as we

saw from Jason's story, but it needs to be followed by quality programming. The results

of this study indicate that quality programming varies enormously from one family to the

next. Parents want early intervention programming to provide *options* for their d/hh child.

They are also interested in *d/hh adult involvement* in early intervention and learning more

about deafness from d/hh community members, mentors, advisors and professionals.

Finally, parents would appreciate early intervention providers who are aware of how their

beliefs about deafness impact the quality of service they provide. Although not

specifically mentioned in this way, parents did talk about how often early intervention

providers would discourage using signs or would just focus on spoken language. This

displays a bias, conscious or unconscious, for spoken language. This was only a problem

because the families were not able to access the kinds of support they wanted from EI.

Thus, EI was effectively reducing options for the child which was the opposite of parents'

expressed desire.

In the following section, I explain these three main principles that were the most

impacting to me as an early intervention provider. I acknowledge that their impact is a

result of my experiences with families over the past 15 years combined with this study

and the open responses from families on the survey or during our discussions. Or, in other words, my social construction of deafness is a contributing factor in what the data communicated to me.

Parents Want Options

DesGeorges (2016) explains how parents are often caught between competing professionals and what communication approach those professionals believe is "right" for all d/hh children. However, DesGeorges further explains that there may not be one way that is right for every person/family/child. It is important that professionals provide parents with information so they can make informed choices. Parents in several previously mentioned studies (DesGeorges, 2016; Eleweke & Rodda, 2000; Guiberson, 2013; Young, 2002; Young et al., 2006) mentioned their desire for more information and choices. Early intervention programs should honor these desires by not just offering one approach to language, which includes not just offering English. Young (2002) reminds professionals that decision-making is a process, and it can change over time. We need to be flexible and adapt to the child/family's needs.

As we saw from the family stories, there are many barriers that prevent families from learning ASL including COVID, untrained professionals, and expense. Liberman et al. (2022) point out that the system can be a major obstacle due to the "attitudes and advice against learning ASL" provided by professionals (p. 20). We should not be causing disabling barriers with our biases.

Include Deaf/Hard of Hearing Adults

If the first d/hh person you meet is your own child, I can imagine it would be difficult to see past the medical condition to envision your child's future. In the many years I have worked in early intervention, I have been impressed by the many times parents have told me that they feel better about their child's future after meeting a d/hh

adult. It is less important what communication methodology they use and more important to see what kinds of things are possible. When introducing a d/hh adult to a family, parents often ask about everyday things like education, work, driving, or ordering food at a restaurant. When families meet d/hh adults, they can start to rebuild the dream they had of their child. The families in these case studies shared how they asked questions of the d/hh adults they met. For example, Danielle asked the Deaf college student details about how they play sports.

All of the parents in this study reached out to d/hh adults to help them understand what they might expect for their child. Some of them had frequent interactions and some were limited. The early intervention system can and should foster these interactions. Gale et al. (2019) encourages the involvement of d/hh adults in EI because "when deaf adults connect with young deaf children regularly, cognitive development is positively impacted in addition to language and social-emotional development" (p. 3). We see the evidence of this in the cases of families who had frequent interaction with d/hh adults. The families were able to see more options for their child – more ways of being d/hh. Knowing there are options helps destroy some of the perceived barriers that being d/hh causes. In their study about Deaf Mentors, Hamilton and Clark (2020) elaborate on this idea by saying that "with a Deaf identity, family support, language access and [Deaf community cultural capital], these families gained confidence that their child could do anything" (p. 730).

What We Believe about Deafness

Social construction is a process. As mentioned before, it is communicated in a variety of ways from words to policy to media. Rachel Benedict (ASLized!, 2011) offers suggestions to EI providers regarding word choice when working with families. Words like "diagnosed" and "hearing loss" make parents feel like something is wrong. Changing our words to "identified" and "hearing level" reframe deafness as a way of being without

the negative connotation (ASLized!, 2011). We can choose to change our construction by changing our word choices and providing new ways of understanding deafness for families.

It is important that, as professionals, we should check our biases. Clark et al. (2020) recommend that "each EHDI provider needs to engage in self-reflection and awareness of their own biases" (p.1343). As mentioned previously, parents' constructions of who their child can be are influenced by the perceptions of the professionals – conscious or not – with whom they interact (Bogdan & Knoll, 1995; Danforth, 2001; Fine & Asch, 1988; Hyde et al., 2010; Li et al., 2003; Watkins, 1997; Young, 2010; Young & Tattersall, 2007). Parents need to see what is possible with a variety of life and communication opportunities. Even more important, our biases come out in the way we treat and talk about d/hh people – including children. Including d/hh adults in the early intervention process as equal professionals communicates what we believe is possible for d/hh children. Matthew's story has a couple of examples of how professionals' perceptions of deafness came through in their actions. It is not enough to just say we value d/hh people; we must show it through our actions. We must believe it. As Matthew eloquently said, "no best practices will ever be effective if you don't approach it in a spirit of joy. And they will never be effective unless deaf people are at the helm."

Limitations

There were several limitations to the study. Based on survey responses, it seemed that some of the questions were not clear to respondents. For example, one respondent who also participated in the case study marked "Bi-Bi" as the EI philosophy of their child's program. However, in the interview, they explained that they *wanted* Bi-Bi support but were not getting it. More evidence that the accuracy of these results is questionable is that one respondent marked "other" in response to the survey question

about the language philosophy of the EI program, and then typed in "Total

Communication" instead of selecting "Signed English system (SEE, Total

Communication, Cued Speech, etc.)." Another final example, one family said their EI

philosophy was ASL only, but the program listed uses a bilingual philosophy. However,

on the positive side, all but one case study participant described their program philosophy

in the interviews in a manner that was consistent with their survey response, providing

evidence that some respondents correctly interpreted the question about EI program

language philosophy.

   In some cases, it could be that the families were never explicitly told the

methodology of their EI program. In other cases, there may not have been a methodology

because the EI providers were not trained to work with d/hh children (as we see in 3 out

of the 5 case studies). Another limitation is that the language use questions allowed for

more than one option to be selected. It was difficult to tell if the family actually knew

what each meant, if they were just interested in them all, or if they actually had

experience using all approaches. It seems as though the questions and response options

should be adjusted in future studies to improve clarity. The one family from the case

studies whose survey response did not match their interview responses, marked all of the

options on the survey even though they had not yet met with their EI provider. These

kinds of inconsistencies decreased the reliability of the responses to the language

questions. For this reason, I did not rely on survey results to estimate the influence of

language use or program philosophy on respondents' understanding of deafness.

   Social media may have been overrepresented on the survey responses as a source

of construction because the survey was circulated via social media. Along those same

lines, it seems that the survey was shared on a Facebook group for parents whose children

have cochlear implants because it was mentioned multiple times. This may have skewed

the results of how many children got CIs or how many respondents used primarily spoken language.

As previously mentioned, the survey was in English which limits the access of parents who do not have strong English literacy skills. Also, the survey was posted on my Facebook page. As a white, middle-class, hearing woman, the algorithm of those who would see my page may be already skewed to a similar audience. Facebook also seems to attract a certain audience when compared to other social media platforms. Access to internet has been much more available since the pandemic but is also a barrier to some possible participants. There were no real connectivity problems with the case study participants other than an occasional and temporary drop in the connection. Another way that the study sample may have been skewed were that the participants volunteered which indicates that they had some interest in participating in research. Some mentioned in their interviews a desire to "pay it forward" after other parents had been helpful to them. There was no compensation for the survey, as one respondent kindly pointed out, "it's not like filling out the survey earns me a reward for my time or some sort of compensation." All of these factors increase the probability of this survey being more likely to attract predominantly White, middle-class mothers.

Case studies are not typically meant to be as generalizable as survey data. Just because all five families wanted a bilingual approach and interaction with d/hh adults does not mean this is true for all families with d/hh children. Comparing the case studies with the survey data suggests that spoken language support is more accessible and familiar for hearing families than signed language support, but all families are interested in having options to pursue to find the right fit for their child. They may not have all wanted their child to be bilingual, but they did want their child to have options, they want to reduce barriers to their child's success. Since these interviews were done in May of

2021, COVID was also a confounding variable. Jason mentioned COVID's impact on their medical journey and their ability to access in person ASL classes or events where they might meet other families or Deaf adults.

Future Directions

This study provides an intimate glimpse of the experiences of some hearing parents with d/hh children in the United States. However, it is not representative of all families with d/hh children. It would be beneficial to expand this kind of study to include more diverse populations and see how their cultural perceptions impact their understanding of deafness. Reworking and posting another survey that could be accessed in more ways than social media would be one way to extend the reach of this type of study.

Evolving Perceptions

Danforth (2001) talks about getting theory out of the academic arena and into practice. As previously mentioned, mixed methods research is meant to be applicable to practice. Holler et al. (2021) conducted a study to look at the medical model and social model of disability to see how they are used in occupational therapy practice. They state that the medical model has "unintended negative consequences" including focusing on a perceived deficit (p. 1). They found that practitioners who were familiar with a social model of disability preferred it to the medical model and would focus on ability. The barriers they found to implementing a more social model approach to therapy were in the system, not in the practitioners.

King (2017) asks, "is it not logical and linguistically savvy to play to a child's strength and not his/her weakness?" (p. 51). In other words, a child with a hearing difference who focuses on learning language through the sense that has the most limited

access is not logical. Instead, using a language that relies more on vision, the sense that is not impeded, would be playing to the child's strengths.

Groce (1985) did an ethnohistory about the unusually high incidence of deaf people born on Martha's Vineyard in the early 1800s. In collecting their oral histories, Groce (1985) asked Islanders about those who were "handicapped by deafness" and was told "those people weren't handicapped. They were just deaf" (p. 5). Interestingly, in defining the difference between disease, impairment, disability, and handicap, Groce (1985) found that a handicap is "not determined by one's physical capabilities but rather reflect the social consequences of that disability. In short, the individual's perception of a handicap is tempered by the society in which the person lives" (p. 127). Groce further explains that what makes deafness a handicap is when the surrounding community has no way to communicate with the individual, leading to isolation. At that time on Martha's Vineyard, for several generations a higher proportion of the population than is typical were deaf. The deaf people on Martha's Vineyard were not considered handicapped because, as one man eloquently told Groce, "everyone here spoke sign language" (1985, p. 2). This is an example of how the interaction between persons identified with a biological condition and their environment work together to create or negate "disabling" barriers. If every child, hearing or deaf, was exposed to a signed language, would deafness be a disability? This is one possible way to support families in their desire to give their child all available options and reduce disabling barriers in society.

Appendices

Appendix A: Survey

How hearing parents with deaf/hard of hearing children construct deafness

Consent

Jill Morford and Bettie Petersen, from the UNM Department of Linguistics, are conducting a research project. The purpose of the research is to learn how hearing parents with deaf/hard of hearing (d/hh) children understand deafness. You are being asked to participate because you are a hearing parent or caregiver who was primarily responsible for a d/hh child born in 2002 or later.

Your participation will involve filling out the following survey regarding your experiences with your d/hh child. The survey should take about 10-15 minutes to complete. The survey includes questions such as when your child was identified, when they began using listening devices, describe your child's hearing, and communication options. Your involvement in the research is voluntary, and you may choose not to participate. You can refuse to answer any of the questions at any time. There are no names or identifying information associated with your responses unless you choose to include your email address. There are no known risks in this research, but some individuals may experience emotional or physical discomfort or loss of privacy when answering questions. Data will be collected through the electronic survey software. All identifiable information (your email address, any names you use in your answers) will be removed from the information collected in this project. After we remove all identifiers, the information may be used for future research or shared with other researchers without your additional informed consent.

The findings from this project will provide information on how hearing parents understand deafness and what sources impact that understanding. If published, results will be presented in summary form. Any direct quotes will be attributed to your general marker (i.e., "parent of a d/hh child").

If you have any questions, concerns, or complaints about the research, please feel free to call Bettie Petersen at 505-699-0628 or Jill Morford at 505-373-0452. If you have questions regarding your rights as a research participant, or about what you should do in case of any harm to you, or if you want to obtain information or offer input, please contact the UNM Office of the IRB (OIRB) at (505) 277-2644 or irb.unm.edu.

By clicking "OK", you will be agreeing to participate in the above-described research.

Q1: I agree to participate in this survey.

◯ OK

Child's Age

Q2: What is the age of your deaf/hard of hearing (d/hh) child? (put age in years:months)

Q3: If under 3, are you and your child currently enrolled in early intervention for d/hh children? (y/n)

◯ Yes ◯ No ◯ N/A

Q4: If over 3, were you and your child enrolled in early intervention for deaf/hard of hearing children?

◯ Yes ◯ No ◯ N/A

Early Intervention
Note: if you have answered/chosen item [2] in question 4 AND answered/chosen item [2] in question 3, skip the following question Note: if you have answered/chosen item [2] in question 3 AND answered/chosen item [2] in question 4, skip the following question

Q5: At what age did early intervention services begin? (put in age years:months)

Note: if you have answered/chosen item [2] in question 4 AND answered/chosen item [2] in question 3, skip the following question Note: if you have answered/chosen item [2] in question 3 AND answered/chosen item [2] in question 4, skip the following question

Q6: How long were you enrolled in early intervention? (put in years:months)

Note: if you have answered/chosen item [2] in question 4 AND answered/chosen item [2] in question 3, skip the following question
Note: if you have answered/chosen item [2] in question 3 AND answered/chosen item [2] in question 4, skip the following question

Q7: What was the educational or language philosophy of your Early Intervention (EI) program?
◯ Bilingual/Bicultural (ASL or some other signed language and spoken/written English) American Sign Language only
◯ Listening and Spoken Language only (Aural/Oral, Auditory/Verbal, etc.)
◯ Signed English system (SEE, Total Communication, Cued Speech, etc.)
◯ Other:
If you have chosen "other", please specify:

About the Child
Q8: When did you first think that your child might be d/hh?

◯ At birth
◯ Before 3 years old
◯ After 3 years old
◯ Other:

If you have chosen "other", please specify:

Q9: At what age was your child identified as d/hh? (put in age years:months)

Q10: Describe your child's hearing.

Q11: If your child uses/used assistive listening technology, at what age did they begin using it? (includes hearing aids, cochlear implants, bone conduction aids - mark the age for each if new devices were used).

	Left Ear	Right Ear
0-6 months old		
6-12 months old		
1-2 years old		
2-3 years old		
over 3 years old		
N/A		

Q12: What language(s) do you use with your child at home and in conversation?
- ◯ English
- ◯ American Sign Language
- ◯ some other signed language
- ◯ some other spoken language
- ◯ a combination of some signed and spoken language
- ◯ other:

If you have chosen "other", please specify:

Q13: What communication methodology (methodologies) do you use now, and have you used in the past with your child? (This is typically the language philosophy of the program your child attends for school.)
- ◯ Spoken language (English or another spoken language)
- ◯ Signed language (ASL or another signed language)
- ◯ Sign supported speech (combination of signs and speech used simultaneously)
- ◯ a mix of some signs and speech
- ◯ visual/gestural
- ◯ picture exchange
- ◯ other:

If you have chosen "other", please specify:

Being D/HH

Q14: Briefly describe your understanding of what being deaf/hard of hearing MEANT TO YOU BEFORE your child was identified.

Q15: Briefly describe your understanding of what being deaf/hard of hearing MEANS TO YOU NOW.

Q16: What specific sources (people, programs, media, etc.) have had the most impact on your current understanding of what it means to be d/hh? (Be as specific as you can. Ex: movie title, Facebook group name, type of therapist or doctor, other parent of d/hh child, website, etc.)

Parent/Caregiver Demographics

Q17: Age (number in years)

Q18: Race/Ethnicity

Q19: Role/Relationship to child
◯ Mother
◯ Father
◯ Grandparent
◯ Primary Caregiver
◯ Other:
If you have chosen "other", please specify:

Q20: Home Language

Q21: Education
◯ Less than HS degree
◯ HS degree or equivalent (GED)
◯ Some college but no degree
◯ Associate degree
◯ Bachelor's degree
◯ Graduate degree

Q22: Annual income
◯ less than $20,000
◯ $20,000 to 34,000
◯ $35,000 to 49,000
◯ $50,000 to 74,000
◯ $75,000 to 99,000
◯ $100,000 to 150,000
◯ more than $150,000

Volunteer for Interviews
Q23: *If you would be interested in being interviewed by the researcher to give a more in-depth account of your experience in early intervention, please leave your email address.

Appendix B: Interview Guide

Initial meeting (~30 minutes): Explain the study, tell the family about my early intervention background, get verbal consent, schedule interviews.

Interview #1 (1-2 hours): Focus on the family's story. "Tell me about your child and your early intervention journey." End with a request for documents, websites, groups, etc. that they feel impacted their experience – to prepare for next interview.

Interview #2 (1-2 hours): Focus on the sources that impacted the family's understanding – specifically early intervention. "Tell me about these documents/websites/etc. that impacted your family and how."

Possible supplemental questions to encourage sharing:

After your child was identified as d/hh, what did you do? Who did you talk to?

What are your future hopes for your child as an adult? (education, work, family)

Who, or what, has had the biggest impact on these hopes for your child?

Who, or what, do you feel supports you the most as a parent of a d/hh child?

Or to whom or what do you turn when you need support?

What, if anything, have you heard about ASL? Deaf Culture?

How has your opinion of what it means to be d/hh changed since your child was identified?

If you could go back in time, to the beginning of this journey, and tell yourself one thing, what would it be?

If you could tell parents of newly identified d/hh children one thing, what would it be?

Experiences with D/HH adults:

Did you personally know d/hh people before your child was identified as d/hh?

If yes: how did you know them and how often did you interact?

If no: how old was your child when you first met a d/hh adult?

Quality of EI programming (based on JCIH best practice guidelines):

Were any of your EI providers d/hh?

Did the EI providers have specialized training to work with d/hh children?

Were assessments of your child's development done every 6 months or so to monitor their progress?

Have you had opportunities, through EI, to access other families with d/hh children?

Did you feel well-informed and able to participate fully in the IFSP process?

Were the EI providers able to adapt their approach to your family's cultural preferences?

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