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Assessment of Medical Experiences of Hearing Guardians With Deaf or Hard of Hearing Children in the Twin Cities

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ASSESSMENT OF MEDICAL EXPERIENCES OF HEARING GUARDIANS WITH DEAF OR HARD OF HEARING CHILDREN IN THE TWIN CITIES

A MASTER'S THESIS SUBMITTED TO THE GRADUATE FACULTY

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ABSTRACT

This paper assesses the medical experiences guardians of deaf or hard of hearing children have after their children are first diagnosed with a hearing loss within the Twin Cities region of Minnesota. Data collection used a mixed methods approach through a survey containing Likert scale questions and opportunities to elaborate on personal experiences. The non-profit organization MN Hands & Voices provided a population qualified to participate in this study who were hearing guardians with a child under ten years old diagnosed within the Twin Cities region of Minnesota. Hearing loss can cause delays in language development if not diagnosed early, and in turn can affect a child’s social skills, self-esteem, learning capabilities in school, and communication abilities (ASHA, n.d.). Results showed that 14 out of 17 respondents had children diagnosed with hearing loss between zero to six months of age. Our survey indicated that, once a child was diagnosed with hearing loss, the care option most frequently offered was hearing aids. The majority of participants felt their child's medical provider only discussed resources and information related to corrective treatment. Most participants felt their child's medical provider offered information on all options for technology related to hearing restoration and were supported by medical providers when receiving a diagnosis of hearing loss.

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Chapter One: Research Introduction

Introduction

According to the National Institute on Deafness and Other Communication Disorders (NIDCD) (2021) for every 1,000 babies born, two to three have a noticeable level of hearing loss in either one or both ears. In 2018, there were 3,788,235 documented births in the United States, the first major decrease in birth rate within 32 years (Chappell, 2019). The incidence of children born deaf or hard of hearing in Minnesota is one in every 350 (MN Hands & Voices, n.d.). Of the babies diagnosed with hearing loss, 96% are born to hearing parents with limited knowledge on congenital hearing loss (Humphries et al., 2019). Parents desire their children to one day become healthy competent adults and from birth look to healthcare providers for reassurance and guidance. Although it is assumed most providers have basic knowledge regarding congenital hearing loss, specific approaches to addressing and educating families may vary greatly.

The Hippocratic Oath states to do no harm, but these standards are not always applied with hearing loss. For some providers, sensorineural hearing loss is a pathology that needs to be fixed. However, consequences from limited hearing improvement methods can induce language and developmental delay, creating lifelong psycho-social effects (Humphries et al., 2019). The present study addresses sources, options, and perceptions offered by medical providers overseeing the care of deaf or hard of hearing children. Understanding the importance of language development, parental support, local resources, and Deaf culture training can be fundamental in shaping the lives of those with hearing loss. This chapter will introduce obstacles a majority of these individuals face from an early age, and how their lives are influenced by medical and local communities.

Background

The most common congenital defect in the United States is hearing loss (American Academy of Pediatrics, n.d.). Hearing loss is twenty times more common than detection of phenylketonuria, which is routinely screened for in infants (MN Department of Health, n.d.). Fifty percent of newborns with hearing loss have no associated risk factors; this makes it very important for medical practices to perform routine Universal Newborn Hearing Screening (UNHS) (US Preventive Task Force, 2010). Screening leads to referral to a selective team of medical professionals who dedicate their practice to diagnostic auditory screening, utilizing advanced technology to accurately determine any level of sensorineural hearing loss (Ravi, Gunjawate, Yerraguntla, & Rajashekhar, 2018). Opinions and attitudes towards auditory screening vary within the medical field, and there are difficulties with interpretation of auditory screening results. What happens after an infant is diagnosed with hearing loss depends on the provider’s knowledge of the subject and resources (Ravi et al., 2018). Medical training alone is rigorous and systematic, however as shown by researchers Hoang, LaHousse, Nakaji, & Sadler (2010) cultural training can change the medical approach entirely. Interviews with medical students trained in Deaf culture, versus students and faculty who were not, showed each group had different ideas on how to care for patients with hearing loss. Guardians often adopt perceptions of hearing loss from medical professionals without question, regardless of the amount of training the provider has in the subject. Therefore, limited or biased options given to a family may not be what best suits the child and the family. Personal perceptions and associated treatment plans for hearing loss may cause unnecessary struggles for a child starting from birth and could last a lifetime.

Guardian observation of missed developmental milestones plays an important role in helping detect hearing loss in children. The American Academy of Pediatrics developed Early Hearing Detection and Intervention (EHDI) guidelines to improve detection of hearing loss by healthcare providers (Minnesota Department of Health, n.d). Yoshinaga-Itano, Sedey, Wiggin and Chung (2017) found that when all three of the EHDI guidelines are met, children have significant vocabulary gains. Minnesota Department of Health (n.d.) states that not all infants identified with hearing loss receive follow-up care. Shulman et al. (2010) identified possible barriers preventing follow-up such as lack of provider knowledge, service-system capacity, difficulty receiving services, and information gaps. For pediatric patients who pass hearing tests, ongoing assessment of hearing related growth milestones and auditory skills should still be performed at all well-child checkups starting at 2 months of age (Joint Committee on Infant Hearing, 2007). A young child whose hearing loss is not detected at an early age can fall behind in development (ASHA, n.d.). Developmental delays can affect social skills, success in school, and communication ability. A child with untreated hearing loss is more likely to become an adult with lower education and lower paying employment opportunities (Joint Committee on Infant Hearing, 2007).

Recognizing the value of early educational intervention, in 1975 the United States Congress under President Gerald Ford created what became known as the Individuals with Disabilities Education Act (IDEA) for those diagnosed and living with a disability. The IDEA requires that public schools provide eligible students special education and intervention services, giving them the equal opportunity to enhance their learning and not be left behind (IDEA, n.d.). To be eligible for these benefits, children need to be evaluated to determine if they have a learning disability, then an Individualized Family Service Plan (IFSP) is created and carried out (PACER Center, n.d.).

To assist and support families and individuals in this process, many organizations have started in Minnesota that offer unique services. These organizations include, but are not limited to: the Minnesota Department of Health Early Hearing Detection and Intervention Program (EHDI), a program created to initiate early detection and intervention programs for deaf or hard of hearing children (Office of the Revisor of Statutes, 2007); PACER Center, a place where families can go to get assistance in the creation of their IFSP (PACER Center, n.d.); MN Hands & Voices, where guardians of deaf or hard of hearing children can come alongside other guardians of deaf or hard of hearing children (MN Hands & Voices, n.d.); Lifetrack, a non-profit organization that teaches families how to communicate with their deaf children (Lifetrack, n.d.); and The Deaf Club, a space that allows deaf individuals to come together and find community (MN Hands & Voices, n.d.).

Problem Statement

Deaf and hard of hearing individuals live in a hearing world, but how transparent or available are personalized options for language and communication? For many, the differences between hearing and deafness is simple. Having any degree of hearing loss is labeled as an impairment in need of fixing. Hearing guardians with deaf or hard of hearing children may not be provided with the resources necessary for success of their children. Guardians are often taught to focus on improving their children’s hearing and ability to assimilate into the predominant hearing culture. Medical professionals are in a position of influence and have the ability to help guide those who work alongside children with hearing loss. This study will explore how hearing guardians of children who are deaf or hard of hearing perceive the care and resources provided by medical professionals.

Purpose

The purpose of this study is to assess medical experiences of hearing guardians with medical providers who care for their deaf or hard of hearing children after a diagnosis of a hearing loss is made. Collecting the stories of hearing guardians will allow for further understanding of the approach medical professionals take in situations where a child is found to be deaf or hard of hearing and what resources are offered to these guardians. This study will focus on surveying families associated with MN Hands & Voices, located in the Twin Cities region of Minnesota. The Twin Cities is defined as Anoka, Hennepin, Washington, Ramsey, Dakota, Scott, and Carver County and the cities located within these limits.

Significance of the Study

Provider training in hearing loss accommodations, including Deaf culture, can positively affect outcomes of many patients. Guardians of deaf or hard of hearing children deserve to be informed of all the possible ways their child can achieve success in a hearing world. Deaf and hard of hearing individuals deserve to be respected, embraced, valued, and considered equal by society regardless of what they can or cannot hear. This trend needs to be implemented and demonstrated by those who provide primary care for deaf or hard of hearing individuals, especially from birth. The study will indicate whether guardians got adequate diagnosis and referrals for care and support from healthcare providers in the Twin Cities. This study may have implications for medical practice and for further study.

Research Question

The goal and purpose of this study is to answer this research question: what experiences with medical professionals are hearing guardians with deaf or hard of hearing children having after their children are initially diagnosed with hearing loss? Specifically, this study will look to assess the experiences of families living in the Twin Cities region of Minnesota and will focus on the experiences that have occurred within the past ten years.

Limitations of the Study

Assessment of hearing loss detection and resources was limited to the Twin Cities region of Minnesota. This study was not able to assess family experiences in other regions in Minnesota or areas of the United States. By limiting the location, the results of this study will only represent the specific region of assessment, therefore excluding other Minnesota locations as well as the rest of the country.

The results of this study are limited to the accuracy of responses provided by those surveyed. Guardians of deaf or hard of hearing children surveyed may withhold information, or may have preconceived opinions or biases that are not made apparent to the researchers of the study. The responses collected may not represent all guardians with deaf or hard of hearing children in the Twin Cities area. Additionally, the amount of time since diagnosis will affect the ability of guardians to accurately recall circumstances regarding initial diagnosis.

An additional limitation of this study could be feelings or preconceived opinions of research members affiliated with this study who have deaf family members associated with the Deaf community. Every effort was made to be objective in evaluating the study design and results to rule out any possible experimental bias.

Definition of Terms

The following terms are foundational for the discussion of hearing loss from both a cultural and medical perspective:

Deaf: Used "when referring to a particular group of deaf people who share a language - American Sign Language (ASL) - and a culture" (National Association of the Deaf, 2019).

Deaf culture: The values, beliefs, art, literary traditions, and history of individuals who identify as deaf or hard of hearing, who use sign languages as their main form of communication.

deaf: Individuals who have an audiological condition where they have a hearing loss of more than 81 decibels (IQWiG, 2008).

Normal hearing threshold: Humans have a hearing threshold of 0 decibels, where anything above this frequency is heard as discernible sounds (IQWiG, 2008).

Hearing loss: Mild hearing loss is considered a decrease of 20 to 40 decibels, moderate hearing loss defined as 41 to 60 decibels, and severe hearing loss is 61 to 80 decibels (IQWiG, 2008).

Guardian: A person, or parent, who is legally responsible for someone, such as a minor, and takes ownership of that person as they are unable to take care of themselves.

Conclusion

At birth, infants are screened for a number of metabolic, hormone, hematologic and other congenital defects. This list includes 21 unique and rare diseases such as phenylketonuria (PKU), sickle cell disease, beta thalassemia, cystic fibrosis, congenital heart disease, and hearing loss (Nemours, 2019). Of all the congenital defects screened for, hearing loss is the one most frequently diagnosed in newborns (American Academy of Pediatrics, n. d.), yet training and knowledge regarding the many ways to care for deaf patients varies greatly (Hoang et al., 2010).

This study will assess how hearing guardians who care for deaf or hard of hearing children perceive the healthcare and support provided by medical professionals in the Twin Cities. This literature review will further describe the training healthcare providers receive in Deaf culture, how newborn hearing screening is conducted, what language development milestones should be observed in healthy children, and what resources are available in Minnesota for those children diagnosed with hearing loss.

Chapter Two: Literature Review

Introduction

Medical care of a newborn requires multiple screenings and interventions, including screening and diagnosing hearing loss. Modern medicine utilizes innovative technology to help provide accurate and precise detection of hearing loss early in life, which dictates what follow-up medical care will be needed later. Since the year 2000, The Association of American Medical Colleges (AAMC, n.d.) has required the broad integration of cultural competence of all medical colleges, emphasizing its importance. Providers trained in cultural sensitivity tend to incorporate learned cultural practices into medical care, exemplified by providers who specifically had experience with Deaf culture (Hoang et al., 2010). Establishing a level of understanding about Deaf culture strengthens medical relationships, reduces frustration, and instills trust and understanding between providers and their patients who identify with Deaf culture.

Early detection of abnormalities in developmental milestones is important for children with hearing loss in order to receive timely interventional services. The American Academy of Pediatrics developed guidelines to help providers and non-providers recognize hearing loss in children early on (n.d). Failure to detect hearing loss can have serious negative effects on children's self-esteem, social skills, education, and employment opportunities as adults (ASHA, n.d.). If the AAP's guidelines are followed, children have significant gains in vocabulary (Yoshinaga-Itano, Sedey, Wiggin and Chung, 2017). In Minnesota, some children with hearing loss do not receive follow-up screening (MDH, n.d.). Potential barriers of early detection of hearing loss could be lack of provider knowledge, service-system capacity, difficulty receiving services, and information gaps (Shulman et al., 2010). Guardians with deaf or hard of hearing children have access to many national and local support programs. These programs equip families with a variety of tools to tackle new challenges and stresses related to caring for a deaf or hard of hearing child (Beginnings, n.d.; HelpMeGrow, n.d.; Lifetrack, n.d.; MN Hands & Voices, n.d.; PACER Center, n.d.).

Newborn Hearing Screening

From birth, a newborn child is measured by numerous standard criteria to determine the presence or absence of various physiological functions. For instance, medical staff quickly determine a newborn's ability to breathe, breastfeed, digest, see, and hear. Specifically, a designated team of healthcare professionals analyze and assess a child's hearing, although audiologists are directly responsible for screening, diagnosis, and management of hearing (Ravi et al., 2018). Initial screening is recommended for all infants before they become four weeks old, preferably before they are discharged from the hospital following birth. Tools used for newborn hearing screening (NHS) include Auditory Brainstem Response (ABR), Auditory Steady State Responses (ASSR), Otoacoustic Emissions (OAE), and tympanometry (NCHAM, 2018).

Due to its accuracy, ABR testing is typically considered first-line for auditory diagnostics regarding infant hearing loss. While sleeping, electrodes are placed on an infant's head to record activity, if any, of the auditory nerve when stimulated with different frequencies. Both air and bone conduction thresholds are tested and compared bilaterally (NCHAM, 2018). If an audiologist believes an infant requires hearing aids or possibly a cochlear implant, an ASSR test, in addition to an ABR test, is used to further differentiate frequency detection and help personalize any assistant hearing device prescribed. Another form of screening, OAE testing, includes looking at the cochlea itself by monitoring its own sound production in response to an external source. A probe is placed inside an infant's ear and emits a sound, it then documents any sound waves that may return from a functioning cochlea (NCHAM, 2018). Tympanometry has limited use on infants due to the developing anatomy of their external auditory canals, however, this test can be modified for more reliable results by increasing frequency. Tympanometry focuses on the ability of the tympanic membrane to move in conjunction with the ossicles of the middle ear when pressurized air is introduced (NCHAM, 2018). Each test provides valuable data regarding sensorineural hearing loss, however, even with a sophisticated system of screening in place, the quality of care related to hearing loss is not without complications. A recent systematic review, conducted by Ravi et al. (2018), investigated knowledge and attitudes toward NHS of pertinent medical staff and discovered a common lack of understanding related to NHS purpose, protocol, importance, and resources. When questioned about state regulations, current practices, and special needs for this patient population, many reported a knowledge deficit; this leads to a question about how often do hard of hearing and deaf infants remain undiagnosed (Ravi et al., 2018)?

In addition to lack of knowledge, some medical professionals internalize negative perceptions of NHS, thereby affecting their practice. These negative perceptions are rooted in uncertain reliability, cost, and parental anxiety (Ravi et al., 2018). In fact, some medical professionals believe that this introduced anxiety disrupts bonding between parent and child resulting in relational disconnect (Ravi et al., 2018). Even if knowledge of hearing incapability were to cause friction between parent and child, it seems that more harm would be done if the child were to fall behind developmentally due to language and cultural ignorance.

Language Development in Children

From the moment infants are born, they are continually growing and learning. To detect hearing loss early on, parents need to pay close attention to any abnormal behavior in their children. By three months of age, infants should make audible cooing sounds, recognize a parent's voice, and give different cries for different needs (Mayo Clinic, 2019). The American Speech-Language-Hearing Association (ASHA) (n.d.) suggests that a lack of smiling or playing with others indicates a language problem in children up to three months of age. By six months, infants should make gurgling and babbling sounds, notice audible toys and music, respond to different phonetic tones in parents' voices, and turn their eyes towards sound. By 12 months, infants should be mimicking their parents, verbalizing short words such as "dada" or "mama," and understanding short instruction (Mayo Clinic, 2019). Failure of these behaviors in children should raise concern. To help medical providers in detecting hearing loss in infants, the American Academy of Pediatrics (AAP) developed the Early Hearing Detection and Intervention (EHDI) 1-3-6 guidelines (AAP, n.d.). These guidelines suggest all newborns, by one month of age, should be screened using an otoacoustic emissions test and auditory brainstem response test to detect possible hearing deficiencies. By three months, infants with hearing loss should be diagnosed by an audiologist, and by six months of age, those infants should be enrolled in interventional services. Early detection helps children receive intervention sooner, so they can achieve important developmental milestones. Interventional therapy for infants with bilateral hearing loss by nine months of age is associated with better verbal ability in later years (Kennedy et al., 2006). Yoshinaga-Itano, Sedey, Wiggin and Chung (2017) found significant gains in vocabulary in children with hearing loss if all three of the EHDI guidelines are met.

The Minnesota Department of Health (n.d.) says not all infants born in Minnesota with hearing loss are identified and not all infants who are identified receive follow-up care. One goal of the AAP is to bring more awareness to providers and non-providers of the EHDI-1-3-6 guidelines (MDH, n.d.). In 2011, 49% of infants detected with hearing loss in Minnesota did not receive a follow-up screening (MDH, n.d.). In addition, only 84 infants of the 142 diagnosed with hearing loss in 2011 enrolled in an early intervention program. Detection of infants with severe hearing loss has dramatically improved in the last 20 years due to screening efforts but follow-up care remains a significant issue (Shulman et al., 2010). Shulman et al. (2010) identified potential barriers of early detection as lack of provider knowledge, service-system capacity, difficulty receiving services, and information gaps. The Joint Committee on Infant Hearing (JCIH) (2007) states that even if infants pass hearing screening tests, they should be monitored and rechecked at each well-child checkup starting at two months of age.

Effects of Late Language Acquisition

If hearing loss is not identified early on, delays in language development can affect a child's social skills, self-esteem, learning capabilities in school, and communication abilities (ASHA, n.d.). This is manifested in adulthood as lower education acquisition and minimal employment opportunities (Joint Committee of Infant Hearing, 2007). The JCIH suggests that statewide EHDI 1-3-6 guidelines can improve detection and increase access to resources to prevent children from delayed cognitive, reading, and social-emotional development.

Healthcare Provider and Deaf Culture Training

Becoming a medical provider requires an extensive amount of training, years of academic dedication, all with hopes of making a difference in the lives of others. Even with medical knowledge and best intentions, many providers are unaware of the multiple subcultures who they serve. The Deaf community is an example of a population whose culture is often neglected and misunderstood by the world of medicine. Researchers Hoang et al. (2010) conducted a study that compared and assessed Deaf culture competency of medical students and faculty who received Deaf cultural training (DCT) and those who did not. An anonymous survey, with six multiple choice and 28 true-false questions, was used to test participant's knowledge about Deaf culture.

A higher score reflected greater knowledge pertaining to Deaf culture. Some of the questions and results of the study can be found summarized in Table 1. Based on the results, it was evident that medical students who had additional Deaf culture training would, in many cases, integrate what they had learned into practice when interacting with deaf or hard of hearing patients (Hoang et al., 2010).

Although Hoang et al. conducted their study in 2010, it was in 2000 when the Liaison Committee on Medical Education integrated cultural awareness into the curriculum for all medical students (Thew, Smith, Chang, & Starr, 2012). Researchers Thew et al. (2012) challenged student understanding of culture by taking students out of the classroom and placing them into real life situations. The study focuses on new students enrolled at the University of Rochester School of Medicine and Dentistry who participated in the University's Deaf Strong Hospital (DSH) program. These students were put into situations where they needed to provide for deaf volunteers as patients. Roles were also reversed, deaf volunteers served as providers and students as patients with given scenarios. As patients, the students had to rotate among four different stations with deaf providers: office visit, psychiatrist, pharmacy, and emergency department. An ASL interpreter was available, however only for one station (Thew et al., 2012). Of all the feedback collected from the students since 2006, "more than 90% of the students 'strongly agree' or 'agree' that participating in the DSH program helped them realize the importance of the cultural, linguistic, and communication issues in delivering health care to patients from different cultures" (Thew et al., 2012, p.5). Student participants were also surveyed later in their career and shared how their hands-on experience with the DSH program helped shape their practice and approach to patient care (Thew et al., 2012). These educational opportunities permit a greater appreciation for culture and allow providers to be mindful of what is best for an individual with hearing loss rather than automatically prescribing a generic fix.

Table 1.

Group comparison on knowledge regarding Deaf culture from DCT medical students, non-DCT medical students, and faculty.

Survey Question	Correct Answer	Percentage of Deaf culture trained (DCT) students who answered correctly (n)	Percentage of non - Deaf culture trained students who answered correctly (n)	Percentage of faculty from medical school who answered correctly (n)	Differences between groups considered significant when compared (Chi-Square)
A cochlear implant ...	Destroys any residual hearing in the ear that the patient may have had	66.7% (14)	18.8% (38)	25.8% (31)	● DCT medical students and faculty ● DCT medical Students and non-DCT medical students
You have a deaf couple who refuse to have their newborn baby's hearing tested. You should:	Accept their decision	31.8% (7)	7.4% (15)	14.0% (17)	● DCT medical students and faculty are significant ● DCT medical students and non-DCT medical students are significant
True or False: The majority of hearing parents with deaf children never learn to sign	True	90.9% (20)	9.9% (19)	13.7% (16)	● DCT medical students and faculty are significant ● DCT medical students and non-DCT medical students are significant
True or False: Trying to help cure your patient's deafness should be your top priority	False	100.0% (22)	88.0% (169)	83.8% (98)	● DCT medical students and faculty are significant
True or False: Ninety percent of deaf people have hearing parents	True	77.3% (17)	36.8% (70)	44.4% (52)	● DCT medical students and faculty are significant ● DCT medical students and non-DCT medical students are significant
True or False: If you suspect hearing loss in an infant, you should make a note to recheck the	False	13.6% (3)	12.8% (24)	22.2% (26)	● Faculty and non-DCT medical students are significant

infant's hearing on the next visit					

(Hong et al., 2010)

Individuals with Disabilities Education Act (IDEA)

Children are first exposed to communication and language from their guardian. Through imitating a baby's sounds, playing, singing, and reading books, guardians demonstrate language to their children and assist with communication and cognitive skill development (HelpMeGrow, n.d.). Having a child who is deaf or hard of hearing, however, creates new challenges for hearing guardians who have no prior experience or interaction with the Deaf community. Now, hearing guardians have to decide how they want their family to communicate, which poses new challenges and stresses (Hintermair, 2006). A study conducted by Quittner, Glueckauf, and Jackson (1990) assessed the difference in stress levels between mothers with a child who is deaf or hard of hearing and mothers with hearing children. They found children who are deaf or hard of hearing are more hyperactive and distracting, temperamental, less adaptable, and more demanding. The mothers of these children also rated their parenting activities in the 90th percentile on the Parenting Stress Index (PSI) (Quittner et al., 1990). Additionally, the mothers with children who are deaf or hard of hearing indicated that they felt socially isolated, having smaller social networks and contact with family, friends, and support systems (Quittner et al., 1990). With increased stress and lack of support, many of these families feel "depressed, interpersonally sensitive, anxious, and hostile" (Quittner et al., 1990, p. 1271) and begin seeing a professional for these symptoms (Dammeyer et al., 2018).

To accommodate and assist these families during a stressful beginning in their child's life, and to make sure that the child is receiving adequate developmental support, the Individuals with Disabilities Education Act (IDEA) was created (IDEA, n.d.). This legislature was put into law by President Gerald Ford in 1975, then known as Education for All Handicapped Children Act, which governs all states in the United States, requiring them to make available free public education and early intervention services to children who are eligible, “ensuring that children with disabilities have opportunities to develop their talents, share their gifts, and contribute to their communities” (IDEA, n.d.). Within the 2017 to 2018 academic year, approximately 6.9 million children in the United States were served under IDEA with 118,800 being served in Minnesota alone (IDEA, n.d.). According to Shanahan and Lonigan (2010), establishing reading and writing skills early – from birth to five years of age – showed increased success later in life, indicating a correlation between early intervention in children and future cognitive abilities.

The Early Intervention System

Early intervention programs begin immediately at birth and are offered until the child is three years old, for those who qualify. These first few years of life are critical developmental years for a child due to the extensive number of milestones that occur, such as smiling with social interaction, turning toward noise or sound, babbling, following instructions, and imitating their parents (PACER Center, n.d.). In Minnesota, the early intervention programs are run by the Minnesota Department of Education (MDE). The MDE along with the MDH and IDEA, created HelpMeGrow, an online resource for healthcare providers, families, and other professionals to use to identify children who may be eligible to enroll in these programs (HelpMeGrow, n.d.). The free services that are provided to children who are eligible include, but are not limited to: assistive technology devices and services, audiology services, family training and counseling, health services, medical services, language services, and transportation services (PACER Center, n.d.).

To enroll the child in the early intervention system, the child's parents, physician, family members, or childcare provider must refer them to the MDE. Initially, an intake form and medical survey will be completed by the child's parents. Then, an evaluation will be done on the child to determine the child's developmental progression and capabilities for their specific age. The evaluation will then determine if the child is eligible to participate in early intervention. If considered eligible, an Individualized Family Service Plan (IFSP) will be created by the IFSP facilitator and the family, determining the outcomes, services, and support that will be provided to the child and family (PACER Center, n.d.). At any point during the eligibility and IFSP creation process, the family of the child can disagree, allowing for a more desirable and effective plan to be made, tailored for their child's individual needs (PACER Center, n.d.). Throughout the first three years of life, the child will follow this plan and their development will be routinely assessed to see if any adjustments need to be made to the plan. Once the child turns three, they are transitioned into Part B under IDEA where an Individualized Education Program (IEP) is created (PACER Center, n.d.).

Resources and Support Services for Parents in Minnesota

Although creation of an IFSP is a critical initial step in the life of a child who is deaf or hard of hearing, guardians need support as well. Minnesota is home to many tailored programs that equip families to overcome unique challenges, ultimately giving deaf or hard of hearing children the tools and resources needed to face challenges in the months and years to come.

Minnesota Department of Health Early Hearing Detection and Intervention (EHDI). The incidence of children born deaf or hard of hearing in Minnesota is one in every 350 (MN Hands & Voices, n.d.). Minnesota's legislature understands the prevalence of this population, and the importance that early detection and intervention plays in cognitive development (Office of the Revisor of Statutes, 2007). This understanding brought about the Early Hearing Detection and Intervention Act, which implemented programs in hospitals, the education system, and in the MDH (Office of the Revisor of Statutes, 2007). This act requires hospitals to implement a Universal Newborn Hearing and Infant Screening unit that would be overseen by the MDH. The UNHS unit gives the necessary information and resources to the guardians of potentially deaf or hard of hearing children, so that early intervention may begin (Office of the Revisor of Statutes, 2007).

MN Hands & Voices at Lifetrack. One of the largest non-profit organizations that positively impacts the deaf and hard of hearing community is MN Hands & Voices. According to MN Hands & Voices, they are a "community of families with children who are deaf and hard of hearing" who partner directly with the MDH to meet the needs of this community, by providing the necessary support and resources to parents of children who are deaf or hard of hearing (MN Hands & Voices, n.d.). The staff of the organization are parents themselves of children who are deaf or hard or hearing. Having this perspective, and their own personal experiences, allows the staff to effectively navigate the families through their questions and concerns (MN Hands & Voices, n.d.). To do this, MN Hands & Voices initiated a Deaf and Hard of Hearing Guide program that partners families with a staff member of a similar culture and background to assist the family without bias in making tough decisions for their child (MN Hands & Voices, n.d.).

PACER Center. The PACER Center started its mission in 1977 with the goal of parents-helping-parents (PACER Center, n.d.). Today, PACER now offers 30 unique programs for parents, students and professionals who are individuals or family members of someone who has a disability. Out of the 30 PACER programs, one program assists parents of children who are deaf or hard of hearing by helping to initiate the early intervention process, and ensuring that guardians receive access to services that are available (PACER Center, n.d.).

Lifetrack. Lifetrack is a community focused resource that believes making connections in the community is how families can be successful, thrive, and overcome challenges they may face. One of their main support programs for guardians with children who are deaf or hard of hearing is the Deaf Mentor Family Program (Lifetrack, n.d.). Many deaf children are born to hearing guardians, often limiting them to audible language as a method for comprehension and communication. This program is offered to both the guardians and children within the family to facilitate proper communication techniques and establish early language skills. Communication techniques can include American Sign Language (ASL), auditory and oral techniques, cued speech, or combined methods (Beginnings, n.d.). Being in a comfortable and non-judgmental environment allows guardians to learn, ask questions and begin to immerse themselves in the Deaf culture community (Lifetrack, n.d.).

The Deaf Club. Many individuals find comfort in being surrounded by people who are similar to themselves. The Deaf Club in Minnesota is a club for deaf or hard of hearing individuals and their families to find community. This group has been meeting for over 80 years, now located at the Charles Thompson Memorial Hall where they can interact and support each other in the hearing world (MN Hands & Voices, n.d.).

Conclusion

Language develops communication and learning while it also captures emotion and experiences. Although language fundamentally serves as a staple in our everyday lives, every individual is unique when it comes to its use. Children diagnosed with hearing loss should not be limited to a specific method of language practice, but rather be offered a personalized approach to maximize their experience in the world around them. Chapter 3 will discuss the method of data collection utilizing hearing guardians of children who are deaf or hard of hearing to answer the research questions in this study.

Chapter Three: Methodology

Introduction

The purpose of this chapter is to describe the methods used to collect data for this project's research question: What medical experiences do hearing guardians with deaf or hard of hearing children have after their child is diagnosed with hearing loss in the Twin Cities? The content of this chapter includes details evaluating population, materials, study design, procedure, statistical analysis, validity and reliability, as well as limitations and delimitations of this study.

Study Design

This study used a mixed methods approach to collect data from qualifying guardians of hearing impaired children. The reasoning for the mixed method approach was to allow for qualitative and quantitative interpretations of data. A survey containing Likert scale questions (Appendix A) was provided to participants with the option to give explanations of personal experiences, to ensure maximum response potential is met. Survey results were analyzed with a quantitative approach whereas individual comments in response to survey questions were evaluated qualitatively for common themes. Independent variables included age of screening, resources offered by providers, and guardian perception of medical care for dependents. These variables were used to reflect perceptions and experiences of hearing guardians with deaf or hard of hearing children under ten years-old within the Twin Cities, Minnesota.

Study Population

MN Hands & Voices is a nonprofit organization that comes alongside guardians of children who are deaf or hard of hearing. Services provided give a variety of resources to equip guardians with deaf or hard of hearing children. Assistance is tailored to each family's needs and is granted without bias in hopes, "to improve communication and educational outcomes," for children with hearing loss (MN Hands & Voices, n.d.). Hearing guardians connected with MN Hands & Voices, with children ten years of age or younger born in the Twin Cities, was the population evaluated in this study. Approximately 1,351 families affiliated with MN Hands & Voices have a deaf or hard of hearing child under the age of ten. Parameters of the described population were placed in an attempt to best reflect current medical practice specific to this metro area. Eligible participants were recruited through the MN Hands & Voices electronic monthly newsletter. Permission was obtained and granted by MN Hands & Voices to use their organization members as potential participants for the research study, this includes reaching out to them via MN Hands & Voices newsletter (Appendix C).

Procedures & Protocols

This study used an online survey tool (Qualtrics) to collect data from hearing guardians of deaf or hard of hearing children, age ten years and younger, who are affiliated with MN Hands & Voices. The online survey consisted of 14 questions: the first four questions were inclusion/exclusion questions, followed by two demographic questions, one question that prompted a “select all that apply,” and the last seven questions utilized a Likert scale. A text entry box for each question was provided to allow participants to rate their experiences and to explain their answers in greater detail, if desired (Appendix A). Inclusion criteria required participants to be hearing and have a deaf or hard of hearing child who is ten years old or younger diagnosed within the Twin Cities region of Minnesota. For exclusion criteria, the first four questions within the survey excluded participants from the survey if they did not qualify. For example, the first question of the survey, after the consent, was “How old is your child, who has been diagnosed with hearing loss, currently?” The options participants were offered: (1) zero to ten years of age, and (2) 11 years of age or older. If the participant clicked on option (2), they were immediately directed to the end of the survey statement that thanked them for their participation in the survey.

A consent form containing the perceived risks of participating in the survey, contact information, and a debriefing of what is being studied through the use of the survey, was presented to the participants upon opening the survey link (Appendix B). The consent was the first thing seen and at the end it stated: “Clicking the continue arrow/button to begin the survey serves as your signature for consent to participate in the survey. If you do not consent, exit the survey at this time. Please only fill out one survey per household. Remember, you may discontinue the survey at any time. Thank you.” The survey was created in a way that did not require the participant to answer each question prior to moving on to the next question, this included the text entry box located at the bottom of some of the questions, which allowed participants to further document their experiences and include explanations. If the participants did not answer the first four exclusion criteria questions, their survey results were not used for final data analysis or presentation. At any time during the survey, if the participants felt uncomfortable or did not want to continue, they could exit the survey, as indicated in the informed consent. To protect the data and ensure accuracy of results, a restriction was placed on participants from completing more than one survey. Qualtrics had a Survey Protection option that allowed the creators of the survey to choose specific protection options, such as ‘invitation only,’ ‘password protected,’ or ‘open access.’ This assessment was created so that ballot box stuffing was prevented and the survey was accessed only by someone who had the specific link. The Survey Protection option, however, cannot guarantee that no more than one survey per family was completed. For example, a mother or father, or another guardian, could decide to complete the survey individually, completing two total surveys per household. To try and eliminate this specific problem, a statement was placed within the consent form that asked participants to only complete one survey per household to avoid this issue. No names, or other personal identifiers were collected of the survey participants. The survey was included in the MN Hands & Voices monthly newsletter until a satisfactory number of participants responded.

The necessary materials used for this study included a password protected laptop that was shared and used only between researchers. All personal identifiers were omitted to ensure confidentiality. A password-protected computer owned by the researchers was used to store the electronic data during collection and analysis. After completion of the study, an external storage device containing the data was placed in the locked PA program office for a minimum of five years, per securing requirements for Bethel University's Physician Assistant Program.

Data Collection

The survey contained 14 questions total, asking age of hearing loss diagnosis in the child, location of diagnosis, current age of child, education level of guardian, and additional questions that assessed the guardian's medical experience when their child was diagnosed with hearing loss. Other questions were centered on what resources were known to be available, what resources were offered, amount of support felt, and perception of medical care. Survey questions were designed using the Likert scale, ranging from strongly disagree to strongly agree. After data collection, statistical analysis was conducted to determine the presence of significant patterns.

Since the tool was original, a method of establishing its validity or reliability was desired. The original survey was sent to an expert research panel, composed of five different individuals, with varying education levels and perceptions, who are parents with children younger than age ten with any level of hearing. For example, one individual of the research panel was an English teacher who is a mother of two children, another was a small business owner and father of three young children, another was an individual with a background in agriculture and has two children under the age of two, and another member was an accountant, with deaf parents of her own and two children under the age of three. Feedback from this expert research panel indicated no changes needed to be made to the survey for it to be readable and understood by future participants. The survey was also sent to the Community Research Chair of this study to analyze the survey for any changes deemed necessary considering her perspective and background working with the Deaf community. The Community Research Chair suggested a number of edits to the survey, as seen in Appendix E, that were considered by the research team. Changes were made by the research team that were deemed appropriate for the study.

Limitations, Delimitations, & Biases

The assessment of guardians with a child who is deaf or hard of hearing was limited to the Twin Cities region of Minnesota. The study was unable to assess providers and hearing guardians in other areas of the United States. By limiting the location, this study only represents this specific region of Minnesota and did not represent the state as a whole or the United States as a nation. By limiting the sample location, the population and number of participants involved in the study were limited. In the amount of time allotted for the project, research on a larger population size was unable to be completed at this time.

A limitation regarding reliability of the study involved the method of disbursement of the surveys to the participants of the study. Because an email format of the survey was sent out through a third party, MN Hands & Voices, it cannot be guaranteed that biases were completely eliminated. Guardians associated with MN Hands & Voices may have felt pressured to participate in the study or to create answers they felt were desired by the organization or the researchers of the study. To combat this, the informed consent indicated no favor by MN Hands

& Voices would be given to those who participated in the study (Appendix B). Additionally, recall bias could be present in the participants surveyed, depending on the length of time that had passed since their children were first diagnosed with hearing loss.

One delimitation purposefully put on the study by the researchers was the assessment of guardians with deaf or hard of hearing children who are under the age of ten. Healthcare is continually changing through new screening requirements, advancements in technology, and increased understanding of physical and mental health diseases. Putting this limitation on the study allowed for more recent and relevant data to be collected that is not skewed by older practices in healthcare.

Other limitations of the study revolved around external or implicit biases that might be held by participants of the study. Personal bias may stem from guardians having negative views against medical personnel. In addition, guardians of deaf or hard of hearing children may put clinicians on a pedestal, thinking they can do no wrong or have all the answers. Recall bias could result from trying to remember a diagnosis received years prior to filling out the survey. These biases could alter the outcomes of this study, leading to a smaller sample size not representative of the Twin Cities region.

Conclusion

The assessment of hearing guardians of deaf or hard of hearing children was limited to the Twin Cities region in Minnesota. This study was a mixed method study, utilizing a survey that was sent to members of MN Hands and Voices. Data collection and analysis was limited to participants who are hearing guardians of deaf or hard of hearing children under ten years old who were diagnosed and received treatment in the Twin Cities region of Minnesota. After data collection, descriptive analysis was conducted on quantitative results, while the qualitative results were compiled and analyzed for common themes within the given population.

Chapter 4 compiles the results that were collected from the surveys sent to hearing guardians of children who are deaf or hard of hearing. Data included answers from the questions asked in the mixed method survey, seen in Appendix A. Chapter 5 will discuss the results and answer the research questions posed in Chapter 1.

Chapter Four: Results

Introduction

This chapter reviews the quantitative and qualitative results from the survey issued through MN Hands & Voices. Before data analysis, participants had to meet established criteria in order to answer the research question about experiences that hearing guardians have after their children are diagnosed with hearing loss. The survey contained questions which utilized the Likert scale in addition to providing the opportunity for participants to further comment below each survey question they answered. This chapter describes the techniques used for data analysis, demographics found in assessment, and descriptive analysis of the collected data.

Techniques of Data Analysis

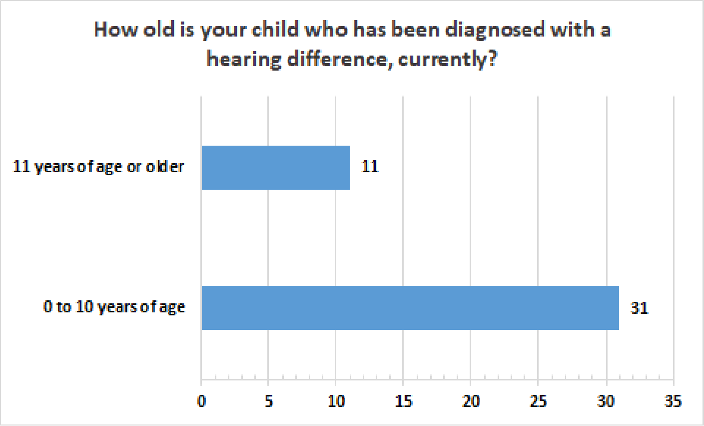
The survey entitled *Assessment of Medical Experiences of Guardians with DHH Children in the Twin Cities* (Appendix A) was sent as an invitation to members of MN Hands & Voices, a non-profit organization located in Minnesota that assists families in navigating life when a child has been diagnosed with hearing loss. The survey was linked within the organization's electronic newsletter which is sent out to families registered to receive monthly updates. There are approximately 1,351 families affiliated with MN Hands & Voices, of which it is unknown how many receive the electronic newsletter each month. For this study, 42 surveys were completed with 19 of these surveys fitting all the demographic and research criteria, making them available for analysis. Criteria required participants to be: associated with the MN Hands and Voices organization, hearing guardians of deaf or hard of hearing children who are ten years and younger, the child's hearing diagnosis occurred in the Twin Cities region of Minnesota and the child continued to receive care from a Twin Cities location.

Survey Demographics

Question one of the survey asked participants, “How old is your child who has been diagnosed with a hearing difference, currently?” Of the 42 participants total who began the survey, 31 participants identified their child was ten years old or younger when diagnosed with hearing loss; therefore, due to the research parameters, these participants were allowed to continue the survey. For the 11 participants who had a child 11 years old or older, they were directed to a page that thanked them for their participation and excused them from continuing to answer the survey questions. The purpose of the first question of the survey was to eliminate participants who did not meet the inclusion criteria of having a child with hearing loss age ten or younger (Figure 1).

Figure 1.

Results from survey question one. How old is your child who has been diagnosed with a hearing difference currently?

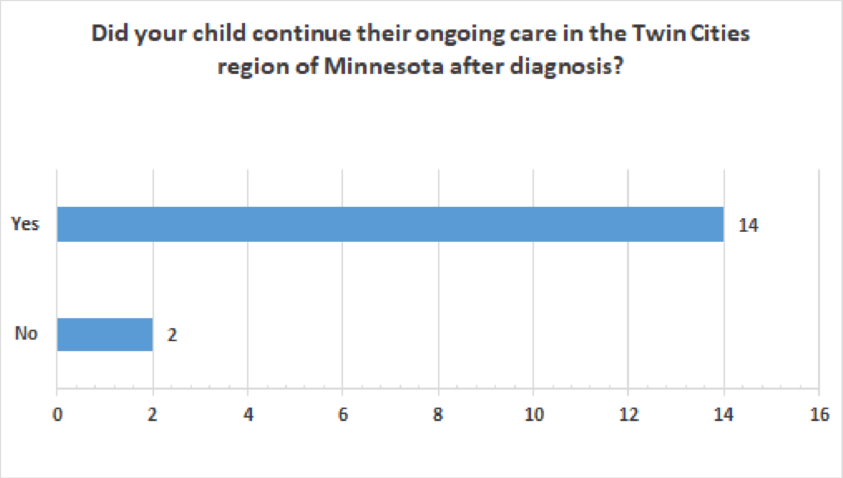


Questions two and three were also utilized to narrow the participant population to individuals who fit the specific research question criteria. Question two asked: Do you, the guardian of the deaf or hard-of-hearing child, have a hearing difference yourself? From this, two more participants were eliminated from the original 31 participants who had a child diagnosed with a hearing loss under the age of ten. The results of survey question two found that 29 participants did not have a hearing loss, while two participants did have hearing loss themselves. Question three asked: Was your child diagnosed with a hearing difference at a clinic or hospital in the Twin Cities region of Minnesota? The findings from question three of the survey indicate that 19 families, out of the 29 families that were found above, had a child diagnosed with hearing loss within the Twin Cities region of Minnesota.

Figure 2, shown below, displays the number of participants who, after being diagnosed with hearing loss, had their child continue their care in the Twin Cities. Out of the 19 participants, who were found to fit the research criteria from questions one to three, 14 children continued their hearing care in the Twin Cities region of Minnesota.

Figure 2.

Results from survey question four. Did your child continue their ongoing care in the Twin Cities region of Minnesota after diagnosis?

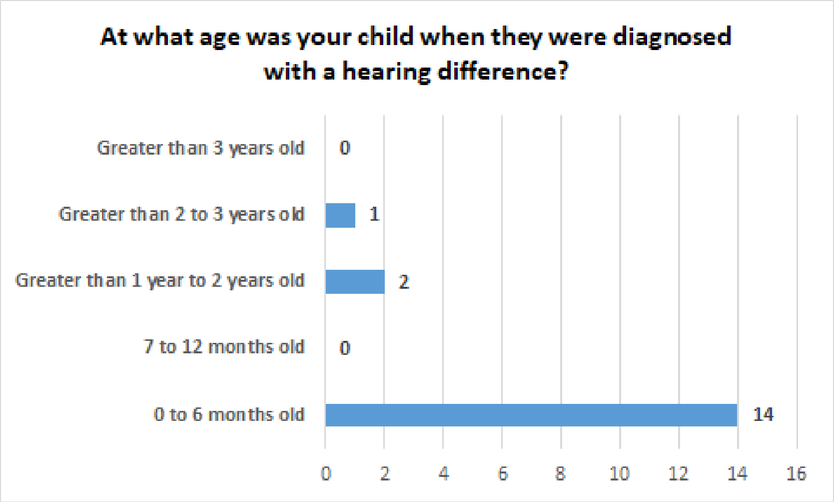


However, of the 19 participants who fit the research criteria, only 16 participants answered this question. As a requirement of research conducted through Bethel University's Physician Assistant Program, participants of research need to have the ability to withdraw from participating in a study at any time, and to have the opportunity to skip questions if they do not feel comfortable answering. Regarding this question, it is unknown why only 16 of the 19 remaining participants answered question four of the assessment.

Figure 3 demonstrates the age at which the participants' children were diagnosed with hearing loss. Results indicate that 14 children were diagnosed with a hearing loss from zero to six months of age. Zero children were diagnosed between seven to 12-months old, two children were diagnosed at greater than one-year to two-years old, one child was diagnosed between the ages of two-years and three-years old, and lastly, zero children were diagnosed older than three-years of age.

Figure 3.

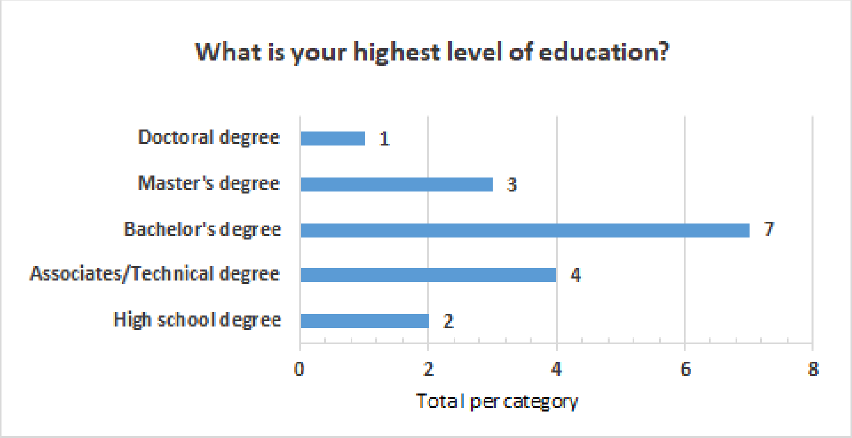
Results from survey question 5. At what age was your child when they were diagnosed with a hearing difference?



The last demographic question of the assessment asked what the highest level of education was for the hearing guardian of the child who had been diagnosed with hearing loss. Figure 4 demonstrates the findings of this question: one participant had a doctoral degree, three had master's degrees, seven had bachelor's degrees, four had associate degrees and two participants had high school diplomas.

Figure 4.

Results from survey question 6. What is your highest level of education?



Descriptive Analysis of Collected Data

The survey tool contained 14 questions that, beyond supporting demographics, highlighted time and location of a child's hearing loss diagnosis as well as resources, support, and medical perception shared. Answers from 17 surveys were taken and quantified to illustrate patterns, if any, regarding experiences with medical professionals associated with a hearing loss diagnosis. The ability to further comment on answer selection, paralleled each survey question to allow additional perspective. As illustrated in Figure 5, data showed that following the child's diagnosis of hearing loss, 76% of respondents agreed that information regarding the follow-up screening process was sufficient. Expanded answers to this question primarily expressed that a lot of information was provided (Figure 5a). Two participants (12% of the qualified survey participants) strongly disagreed or disagreed that they were provided sufficient information at their follow-up appointment.

Figure 5.

Results from survey question 7. Did the participant feel the information received regarding the follow-up screening process for his or her child, after the child was diagnosed with a hearing difference, was sufficient?

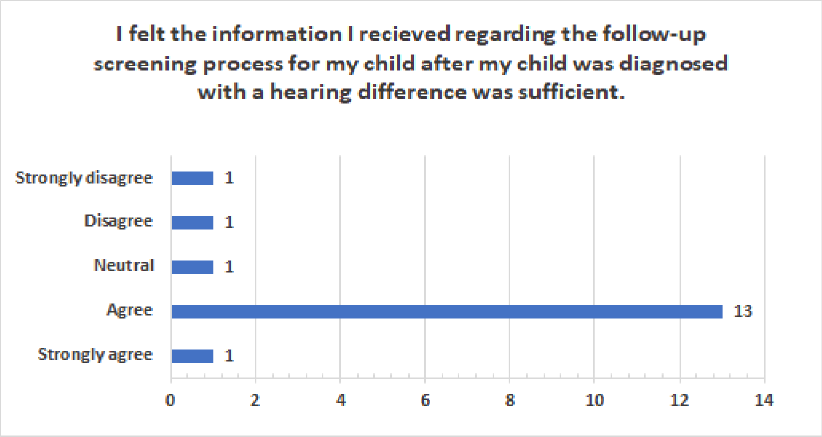


Figure 5a.

Participant comments from survey question 7.

Question 7: **I felt the information I received regarding the follow-up screening process for my child after my child was diagnosed with a hearing difference was sufficient: strongly disagree, disagree, neutral, agree, strongly agree - please explain.**
"I was given a pamphlet and told by the pediatrician that we should make an appointment with an audiologist but it is likely just fluid and not something to worry about. Although I suspected the diagnosis at the ABR a month later, I was unprepared for the news. I'm not sure if more information at the hospital would have been helpful since it was such a chaotic time (first child, such a blur!)."
"My child has auditory neuropathy - a rare and under-researched hearing disorder. I feel the medical team provided me with the best information they had. Unfortunately, there just isn't a lot of information out there."
"We reviewed an abundance of information and options."
"We were told the next few steps to take, what doctors to see etc."
"My child did not pass her newborn screening, came back again and failed but we were told it was probably a cold. Our ENT noted her speech and was concerned about hearing during an appointment for tonsils. After care from there was amazing."
"I was almost given too much info. The department of health book is overwhelming. I still haven't opened it."
"I guess I agree. I remember having the follow up and the audiologist explained everything to us and was very patient, friendly, and caring. Was very reassuring and made us feel as comfortable as possible."

“Child was diagnosed at birth. A lot of information was provided and it was difficult to take it all in combined with having a new baby to take care of.”
“We received a lot of support through our clinic and agencies available to our family and child. We have an amazing audiologist who is available with questions, concerns and makes sure we know what the next steps are for our daughter. I will say once our daughter was diagnosed at 2 months, there was so many unknowns initially but with a couple of meetings with the audiologist and getting some additional supports in place through Help Me Grow, we feel well supported."

When asked what information or services were received when the participant’s child was diagnosed with a hearing difference, 15% said they received information about hearing aids, 12% reported referral to Minnesota Department of Health and Minnesota Hands & Voices, 12% reported receiving information on the HelpMeGrow Program, and 11% reported being given information about family support services (Figure 6). Figure 6a shares three responses related to the question and suggests a theme of receiving information about hearing aids but overall a wide approach of assistance. One response to question eight given by a participant was omitted from being displayed, or considered, due to the inability of the research team to understand its nature in the context of the question.

Figure 6.

Results from survey question eight. Indicate which resources or information, if any, was provided to them when his or her child was diagnosed with a hearing difference.

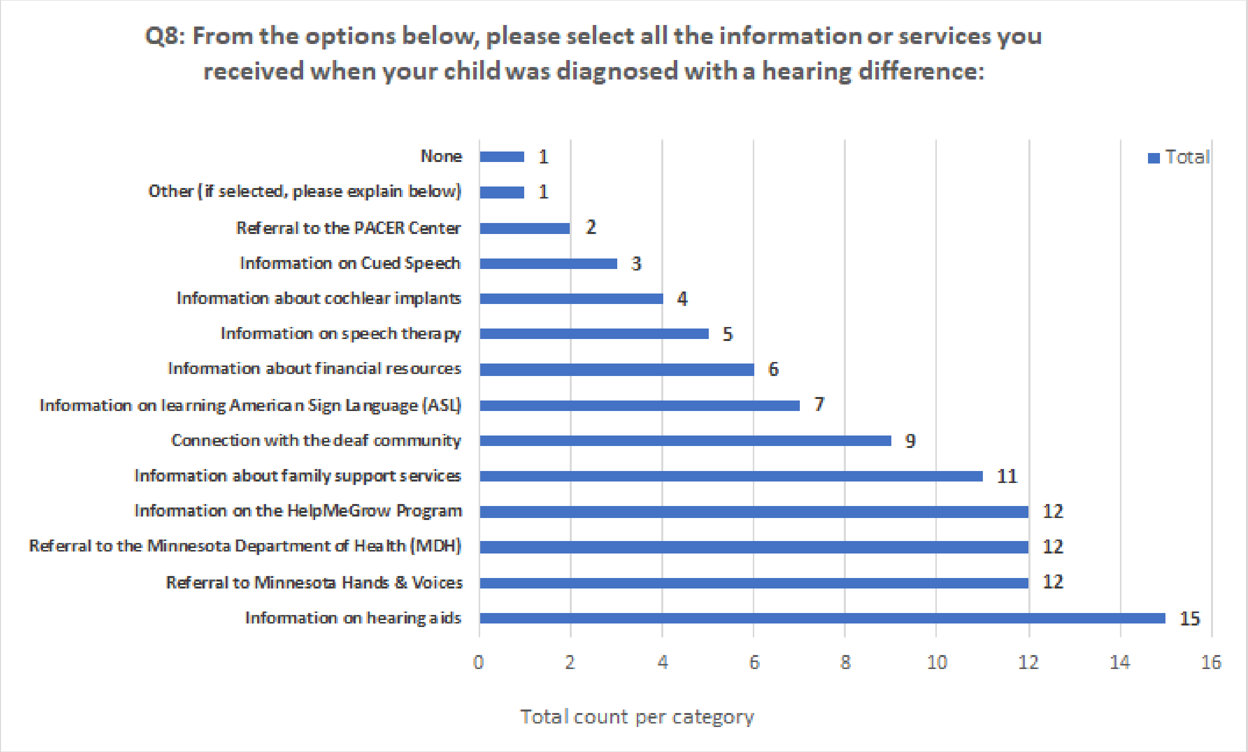


Figure 6a.

Participant comments from survey question 8.

Question 8: From the options below (listed on survey), please select all of the information or services you received when your child was diagnosed with a hearing difference - please explain your answer.
“We were able to get Help Me Grow started right away and get a team in place. MN Hands and Voices reached out too and offered support where we learned about the different types of communication we may want to consider with our child. Since our daughter was 2 months old when diagnosed, it actually was kind of overwhelming to think about all the things that was in the future. At the time, we were more concerned with the now in terms of how do we put in her hearing aids, are they working okay, is she reaching her developmental milestones generally.”
“I was told hearing aids would likely help and I shouldn't worry about cochlear implants yet. Had the ear impressions made at the follow up ABR appointment and was referred to MDH, H&V, and St. Paul Public Schools (Help me grow). Through our early intervention team, I later learned about speech therapy. My baby is only 5 months old so we are still learning!”
“The information prompt us to seek detailed information about ASL and deaf community. We discovered Metro Deaf School and Lifetrack family mentor.”

When asked about understanding of having their child follow-up with other medical providers regarding the new diagnosis of hearing difference, 35% of respondents were neutral on the matter and 29% considered it to be extremely critical (Figure 7). Figure 7a shows four responses with similar discussion of relying on audiologists, ENT specialists, geneticists, and pediatricians for further action.

Figure 7.

Results from survey question 9. What was the understanding of participants with having their child follow-up with other medical providers regarding their newly diagnosed hearing difference?

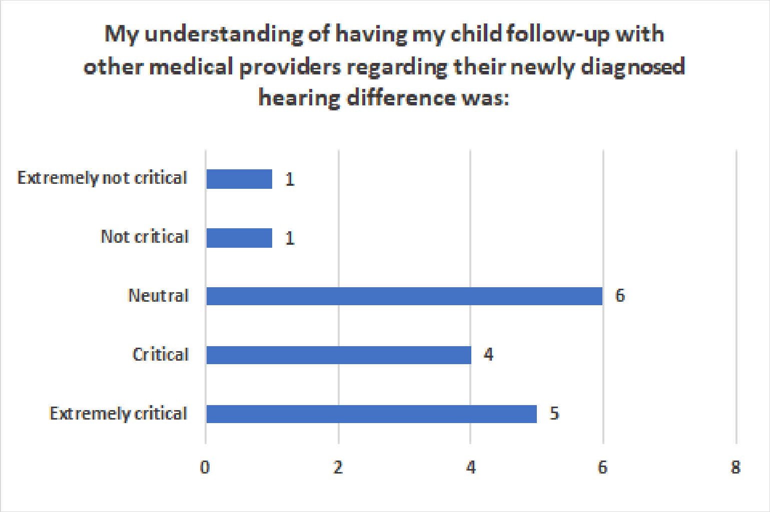


Figure 7a.

Participant comments from survey question 9.

Question 9: **My understanding of having my child follow-up with other medical providers regarding their newly diagnosed hearing difference was: extremely not critical, not critical, neutral, critical, extremely critical - please explain.**
“After discussing next steps with our clinical audiologist, we received recommendations to see an ENT doctor and genetics to try and determine a cause of the hearing loss. For us, it was important to understand if there is anything else that we should be concerned with (i.e., syndromes, additional complications, progressive loss versus non-progressive loss).”

"I relied on our audiologist to tell us next steps. She had us make an appt with the ENT doctor, which was needed for the hearing aids. Our pediatrician was notified and helped me with the referrals for genetics testing and ophthalmologist appts."
"I knew we were in good hands with the clinic that diagnosed my child. I also did research on my own and the information my clinic provided matched with what I researched as well."
"We kept treatment with our ENT, and switched pediatricians."

The ability to follow-up with an audiologist after the children did not pass the first hearing test was very easy for 47% of respondents and easy for 29% of respondents (Figure 8). Figure 8a highlights some difficulties and hesitations some participants had making these appointments.

Figure 8.

Results from survey question 10. What was the participant's ability to follow-up with an audiologist after their child did not pass their first hearing test?

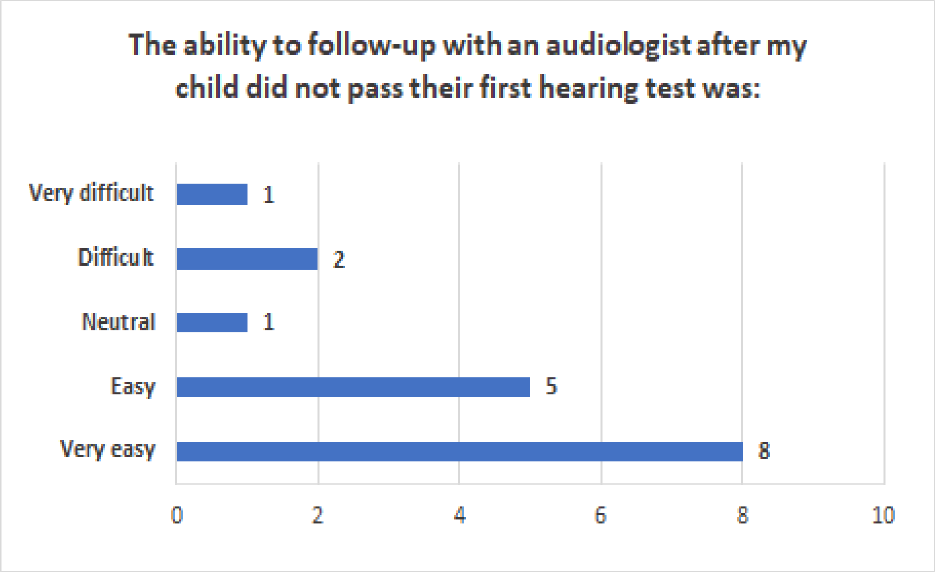


Figure 8a.

Participant comments from survey question 10.

Question 10: **The ability to follow-up with an audiologist after my child did not pass their first hearing test was: very difficult, difficult, neutral, easy, very easy - please explain.**
“Appts were booked over a month.”
“After our daughter did not pass her hearing test in the hospital, we were referred to a clinical audiologist for an OAE. This was relatively easy to schedule. When she did not pass that, we were referred to a different clinic to conduct an ABR. This one was a little more difficult to schedule as there was not a lot of availability at the time, so things were pushed out a little bit. Once we got that done and new she had a hearing loss, we were referred back to our local clinic and scheduling has been pretty easy since. We have a great relationship with our audiologist and find that especially when she needs new ear molds, she can fit her in that week.”
“They were originally not taking appointments due to Covid (my baby was born 3/15/2020) but Fairview eventually decided to allow audiologists to see newborns so they called me back and an appointment was made for when she was 3 weeks old.”
“My child passed every hearing test. In fact, it was me that insisted he have an ABR done to see if there was an underlying issue as to why he did not seem to hear as well as his peers and not the ENT. The ENT did not agree with me but authorized the test anyway. It was then when the audiologist conducted the ABR that we found out about his hearing disorder.”
“We had the ability but found the need difficult. We ended up following audiologist recommendations without seeing the hearing loss when he was an infant.”
“We have had wonderful experiences with our audiologist.”

Regarding whether a child was promptly referred to the Minnesota Department of Health (MDH) after being screened for and diagnosed with a hearing loss, 35% of participants strongly agreed and 41% agreed (Figure 9). Despite the percentage of those who agree on being contacted, one respondent commented that he or she does not remember for sure if he or she was contacted by MDH and another commented on being contacted but is still uncertain what help was offered by MDH (Figure 9a).

Figure 9.

Results from survey question 11. Was the participant's child promptly referred to the Minnesota Department of Health (MDH) after his or her child was screened for and diagnosed with a hearing difference?

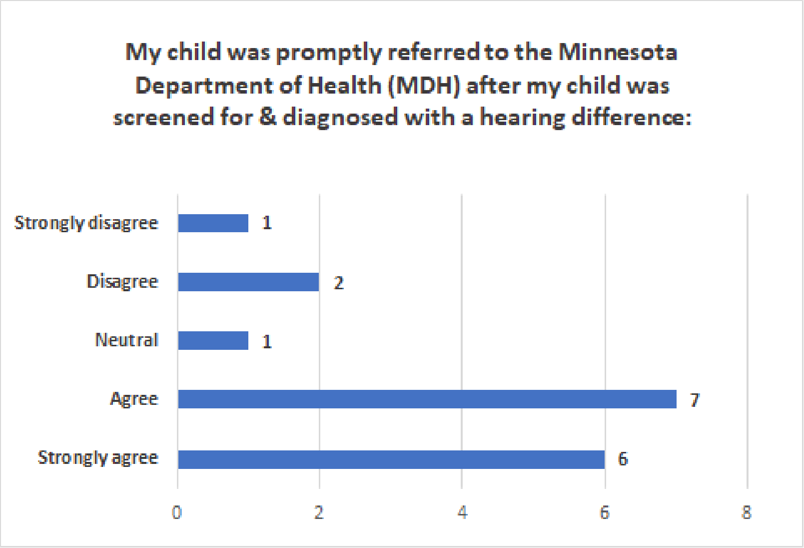


Figure 9a.

Participant comments from survey question 11.

Question 11: **My child was promptly referred to the Minnesota Department of Health (MDH) after my child was screened for and diagnosed with a hearing difference: strongly disagree, disagree, neutral, agree, strongly agree - please explain.**
"I don't remember, but I'm assuming that he was."
"They were in contact right away. I didn't know what they help with and still don't."
"I received a call from MDH about the referral."
"I don't recall MDH ever being referred to me."

When asked if respondents felt as though the child's medical provider gave information on all options for technology, 47% said they agree, 29% said they strongly agree, and about 17% were neutral (Figure 10). Each comment offered for the present question included the need or use of hearing aids, one comment briefly mentioned cochlear implants and another inquiring about amplification systems (Figure 10a).

Figure 10.

Results from survey question 12. Did the participant feel as though his or her child's medical provider gave all the information on the options for technology?

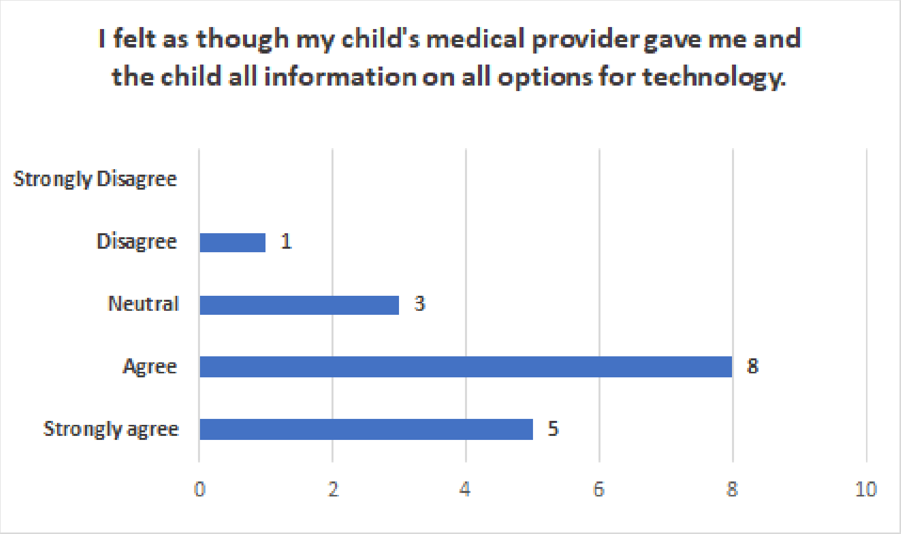


Figure 10a.

Participant comments from survey question 12.

Question 12: **I felt as though my child's medical provider gave me and my child information on all options for technology: strongly disagree, disagree, neutral, agree, strongly agree - please explain.**
"For mild-mod hearing loss, as an infant there was only 1 option for hearing aids."
"When we first received her diagnosis, the audiologist indicated she would benefit from hearing aids. We didn't receive any other options for technology and were initially in disbelief that she would need hearing aids. When we met with our clinical audiologist, she was great about showing us the types of sounds she can hear un-aided and what hearing aids would provide for her."
"I was told that she could be fitted for hearing aids and to not worry about cochlear implants yet. We have her evaluation to test hearing with amplification next month. I am planning to ask about FM systems at that appointment (or the use of mini mics at home/car)."
"It was recommended that he have a hearing aid and he began using it at 2 months old."

Survey question 13 asked respondents if they felt as though their child's medical provider only discussed resources and information related to non-corrective treatment: 17% strongly disagreed, 35% disagreed, 23% were neutral, 17% agreed and 6% strongly agreed (Figure 11). Explanations highlighted the need or push for corrective options, from both hearing guardians and medical professionals, specifically hearing aids (Figure 11a).

Figure 11.

Results from survey question 13. Did the participant feel as though his or her child's medical provider discussed resources and information related to non-corrective treatment?

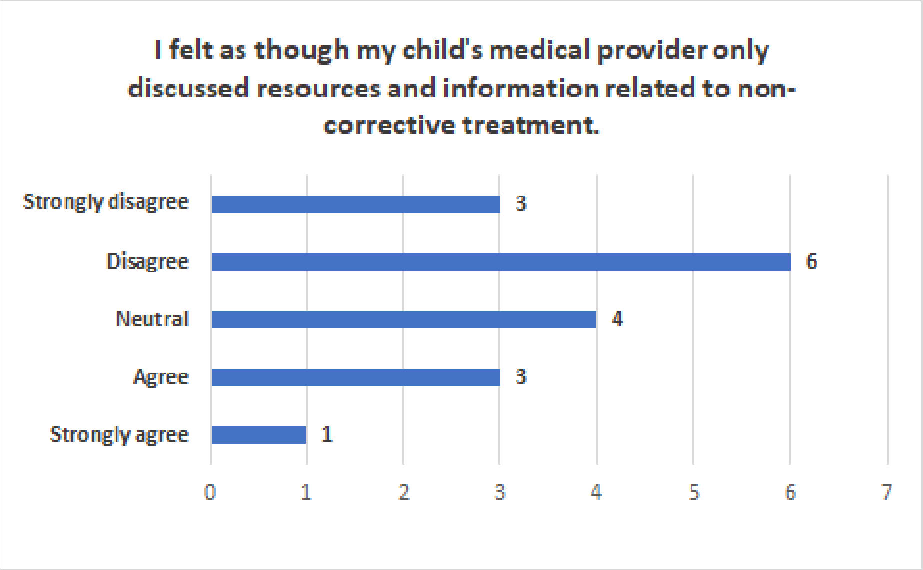


Figure 11a.

Participant comments from survey question 13.

Question 13: **I felt as though my child's medical provider only discussed resources and information related to non-corrective treatment: strongly disagree, disagree, neutral, agree, strongly agree - please explain.**
"We asked about whether there were corrective options, but given that she was so little when she was diagnosed, there are not many options that would be viable."
"I was immediately told hearing aids would likely allow my child to do well (mild-moderate loss in right ear, severe in left)."

“All of the medical professionals involved recommended hearing aids. All disagreed with us considering to wait and accommodate his development based on his natural hearing.”
“I am not clear about the question.”

Over 58% of respondents reported they strongly agree and 29% reported they agree that they felt supported by their child’s medical provider when their child was diagnosed with a hearing difference (Figure 12). Follow-up comments stated directly by respondants collectively reflected support from medical professionals (Figure 12a).

Figure 12.

Results from survey question 14. Did participants feel supported by their child’s medical provider when their child was diagnosed with a hearing difference?

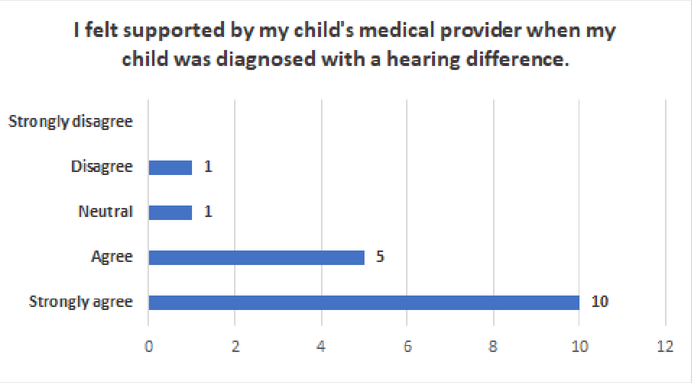


Figure 12a.

Participant comments from survey question 14.

Question 14: **I felt supported by my child's medical provider when my child was diagnosed with a hearing difference: strongly disagree, disagree, neutral, agree, strongly agree - please explain.**
“We have a great audiologist.”
“Everyone involved were very supportive.”
“Our clinical audiologist has been fantastic. However, I would say our general pediatrician felt like she may have been inappropriately diagnosed at first, and likely just given the fact that he hasn't seen a baby who needed hearing aids. Once she was diagnosed, he follows up with about how things are going and is supportive.”

Conclusion

This chapter accounts for 42 survey responses, further analyzing 17 of them due to fitting pre-established research criteria. The first six questions of the 14 question survey focused on demographics and survey criteria, while the last eight questions were answered using a Likert scale and an optional open-ended response. The children of 14 respondents were diagnosed with a hearing difference between zero to six months of age. The highest level of education for seven of the participants is a bachelor's degree; eleven of the participants had a bachelor's degree or above. Of options listed in the survey, hearing aids were the care option most frequently offered once the child of a participant was diagnosed with hearing loss. Majority of participants felt their child's medical provider only discussed resources and information related to corrective treatment. Additionally, most participants felt as though their child's medical provider offered information on all options for technology related to hearing restoration and were supported by medical providers when given a hearing difference diagnosis. Chapter 5 discusses findings and applications based on data presented in Chapter 4.

Chapter Five: Discussion and Conclusion

Introduction

Chapter 5 evaluates and interprets results collected from the survey tool described in Chapters 3 and 4. Patterns of provider preference and patient experience are considered after reviewing both written and graded responses. This includes level of provider support, follow-up after hearing loss diagnosis, proposed action, and provided information. Applications of data interpretation are limited to those diagnosed within the past ten years in the Twin Cities region of Minnesota and are associated with MN Hands & Voices. Accounted experiences were not limited to medical provider level or specialty, except audiology follow-up experiences.

Answering the Research Question

To adequately answer the research question, an assessment was created to evaluate the medical experiences of hearing guardians after their child was diagnosed with hearing loss. The assessment was sent out through MN Hands and Voices, a reputable and prominent organization in the Twin Cities region of Minnesota, which functions as a resource for families navigating their child's new diagnosis of a hearing difference. After survey data collection, results were condensed into visual graphic representations and analyzed with a descriptive lens.

The research question being addressed is: what are the medical experiences of hearing guardians of deaf or hard of hearing children after their child was diagnosed with hearing loss? The results show the majority of survey respondents had a positive encounter with their child's medical providers and felt well supported. For example, one respondent stated that "everyone involved [was] very supportive" while another stated "we have had wonderful experiences with our audiologist," which aligned with 87% of the participants in the survey response who felt they were supported by their providers. Additionally, over half, approximately 53% of participants, after meeting and discussing their child’s care with their provider, understood the importance of being connected with other medical professionals for further follow-up on their child’s hearing loss (Figure 7). These findings directly answer the above research question by indicating that the medical experiences of guardians located in the Twin Cities region of Minnesota, are mainly positive in nature. When comparing this to the information found within the literature review in Chapter 2 of this thesis, these findings contradict what Shulman et al. identified that “follow-up care remains a significant issue” due to “potential barriers [in] early detection…, difficulty receiving services, and information gaps” (2010).

This study’s results of evaluating hearing guardians of children diagnosed with hearing loss showed that 82% of participants felt the information regarding the follow-up screening process was sufficient (Figure 5). Different participants directly stated: (1) “We reviewed an abundance of information and options,” and (2) “We received a lot of support through our clinic and agencies available to our family and child. We have an amazing audiologist who is available with questions, concerns and makes sure we know what the next steps are" (Figure 5a).

The literature review also found that Minnesota has created guidelines, opportunities, and programs for families with children who are deaf or hard of hearing to make the detection process and overall experience easier. These programs include early intervention services conducted by the Minnesota Department of Education (MDE); organizations that receive direct referrals from providers on the behalf of their patients such as the Minnesota Department of Health (MDH), HelpMeGrow, MN Hands & Voices organization, and PACER Center that receive all referrals from providers; and Lifetrack organization and The Deaf Club that allow families to learn more about communication techniques and connect with others within the Deaf community (HelpMeGrow, n.d.; MN Hands & Voices, n.d.; PACER Center, n.d.;). According to the results of the assessment, only one participant did not receive any information or services that Minnesota offers, while more than 12 participants received information on the HelpMeGrow program, referral to the MDH, and referral to MN Hands & Voices (Figure 6). Additionally, multiple other participants stated that they received information or services on cued speech, cochlear implants, speech therapy, American Sign Language (ASL), other family support services, and were connected with the Deaf community (Figure 6). Out of all the information patients received from their providers, information on hearing aids was offered the most (Figure 6). When comparing these findings with the results of question 13, which asked participants if they felt their provider only discussed non-corrective treatment options, many respondents disagreed or were neutral on the topic (Figure 11). Two of the four respondents stated, “I was immediately told hearing aids would likely allow my child to do well... ” and “All of the medical professionals involved recommended hearing aids” (Figure 11a). These findings suggest that most families are being offered a variety of resources which is allowing families to tailor what is best for the needs of their children. However, many providers are still favoring or are suggesting that corrective options are the best option, such as hearing aids, when it comes to the overall well-being of deaf or hard of hearing children. This aspect of medical care is one area of improvement that not only providers need to work on, but the schools that educate them need to address as well. Making providers more knowledgeable and more comfortable to discuss all options available to families regarding their child’s hearing loss, can give guardians more confidence in these important decisions they are making on the behalf of their child.

Lastly, the early detection of hearing loss in an infant has a large impact on developmental milestones that occur in the beginning stages of a child’s life, especially those involving language development (ASHA, n.d.). According to the American Speech-Language-

Hearing Association, delays in language development from late detection of hearing loss can impact a child's self-esteem, communication skills, and overall learning capabilities in school (n.d.). This can place increased stress on families if their child is diagnosed with a hearing loss later in life, causing an overall negative medical experience. The research in this study asked participants at what age range their child was diagnosed with hearing loss, in order to better understand how effective Minnesota providers were at detecting hearing loss and following through with the guidelines put in place in Minnesota. The results found that 82% of deaf or hard of hearing children of participants were diagnosed with a hearing difference at zero to six months old (Figure 3). These results suggest that medical providers are doing a good job at early detection of hearing loss in infants, which ultimately impacts the experience MN families are having.

Implications to Medical Practices

The results of this assessment should be encouraging to physicians, advanced care practitioners, and other providers from the Twin Cities region who are involved in the care of children who are deaf or hard of hearing. These results show that the medical practices and regulations currently in place in Minnesota, from diagnosis to treatment, are making the process easier and more reliable for the guardians involved. For example, roughly 88% of families felt as though they were supported by the provider they were seeing for their child's newly diagnosed hearing loss, and a large number of families were referred to, or given information on, further assistance from the Minnesota Department of Health (MDH), the HelpMeGrow program, and other supportive entities in the Twin Cities. In addition to this, many families still felt as though they received more information and guidance regarding hearing aids for their child in comparison to other treatment options. This study indicates to providers what is effective and what needs improvement in working with families, and indicates to families that they can trust providers with caring for their children during this process.

Limitations of the Study

This study focused on members of the MN Hands & Voices organization who were willing to participate in the survey released by MN Hands & Voices. The data from this study is limited to the responses of those associated with the MN Hands and Voices organization. The data of this study may not fully represent the experiences of all Minnesota parents with children who have hearing loss or the United States as a whole. In addition, hearing guardians with more passionate viewpoints may have been more motivated than others to participate in this study than others with more neutral experiences.

The data collected was retrieved from an online survey. Access to appropriate technology and computer skills may have prevented some parents from participating in this study. Furthermore, English language literacy may have been a barrier for some who otherwise would have been interested in expressing their opinions. In person advertisement of this study at MN Hands & Voices events was not possible due to Covid-19 restrictions. This may have caused a lower volume of participants to partake in this study. In addition, having a restricted timeline for completion of this study may have contributed to a lower sample size than what otherwise could have been obtained.

Since participation of this study was volunteer based, the participants were allowed to not answer questions if they so desired. As a result, not all 17 participants answered all of the survey questions. Due to this option, the data collected may not have had the desired consistency. Furthermore, this study started with 42 responses but after completing qualifier questions to participate in this study, data from only 17 participants could be used.

Areas of Further Research

As stated previously, the study was volunteer based, and in addition to this, parameters were placed on the study to exclude any participants who did not meet the inclusion criteria. Both aspects of this study, although necessary, limited the number of participants willing to respond to the survey or be included in the survey results. In order to address this limitation, and to further validate the reliability of this study's results, we recommend this study should be replicated with a larger sample size. Repeating this study with a larger sample from the Twin Cities region could be done by reaching out to additional participants who are not affiliated with the MN Hands & Voices organization or sending out the survey for a longer duration.

Parameters of this study were placed due to new regulations and new processes put in place approximately ten-years ago that changed the way children were diagnosed and given resources around their hearing loss. To assess the medical experiences families experienced prior to these changes, research could be conducted asking these same questions to families whose children were diagnosed with a hearing loss greater than ten-years ago. The researchers could then compare the experiences they find with the results this research found, seeing if there was any improvement in the diagnosis process from the families' perspective.

Although it is important to understand how patients and families are feeling when in medical or healthcare situations, it is equally important to understand the perspective of the providers in these situations to evaluate the difference their experience and view-points may have. Two areas that could be studied in the future from the provider perspective are: (1) examining if medical providers, who diagnose and treat families with a child experiencing a hearing difference, feel adequately trained to support these families, and (2) creating an assessment or interview process to further understand providers' thoughts on barriers related to medical management of hearing differences in children with guardians who are hearing or non-hearing.

Summary and Conclusion

Of the questions asked on the survey entitled *Assessment of Medical Experiences of Guardians with DHH Children in the Twin Cities,* a majority of the responses were positive in nature. Many families felt as though they were given information on different technological treatment options in addition to non-technological options, but when looking at the comments from participants, many mentioned how hearing aids was amongst the items discussed most frequently by providers. In addition, the majority of families were easily referred to both an audiologist and the MDH after their child was diagnosed with a hearing loss. Most importantly, almost 90% of guardians involved in the study felt supported by providers who guided them through this new experience of their children's hearing loss.

With new experiences, such as having a child diagnosed with hearing loss, families can become increasingly stressed. These results suggest that the current medical processes and regulations in place for diagnosis of hearing loss in a child, are creating an overall positive impact on hearing guardians and their child in the Twin Cities region of Minnesota. This information not only is beneficial for future guardians and families, but it is encouraging for providers who find themselves helping families through these types of medical experiences.

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Appendices

Appendix A: Mixed Method Survey Questionnaire

Question 1: How old is your child, who has been diagnosed with hearing difference, currently?

- 0 to 10 years of age
- 11 years of age or older

Question 2: Do you, the guardian of the deaf or hard of hearing child, have hearing difference yourself?

- Yes
- No

Question 3: Was your child diagnosed with hearing difference at a clinic or hospital in the Twin Cities region of Minnesota?

- Yes
- No

Question 4: Did your child continue their ongoing care in the Twin Cities region of Minnesota after diagnosis?

- Yes
- No

Question 5: At what age was your child when they were diagnosed with hearing difference?

- 0 to 6 months old
- 7 months to 12 months old
- Greater than 1 year to 2 years old
- Greater than 2 years to 3 years old
- Greater than 3 years old

Question 6: What is your highest level of education?

- High school degree
- Associates/Technical degree
- Bachelor’s degree
- Master’s degree
- Doctoral degree

Question 7: I felt the information I received on the follow-up screening process for my child after my child was diagnosed with hearing difference was sufficient.

- Strongly disagree
- Disagree
- Neutral
- Agree

- o Strongly agree

Please explain your answer from above:_______________________________________

Question 8: From the options below, please select all of the information or services you received when your child was diagnosed with a hearing difference:

- o Information about cochlear implants
- o Connection with the deaf community
- o Information on hearing aids
- o Information on speech therapy
- o Information on learning American Sign Language (ASL)
- o Information on Cued Speech
- o Information about family support services
- o Information about financial resources
- o Referral to the Minnesota Department of Health (MDH)
- o Referral to Minnesota Hands & Voices
- o Referral to the PACER Center
- o Information on the HelpMeGrow Program
- o None
- o Other (if selected, please explain below)

Please explain your answer from above:_______________________________________

Question 9: My understanding of having my child follow-up with other medical providers regarding their newly diagnosed hearing a difference was:

- o Extremely not critical
- o Not critical
- o Neutral
- o Critical
- o Extremely critical

Please explain your answer from above:_______________________________________

Question 10: The ability to follow-up with an audiologist after my child did not pass their first hearing test was:

- o Very difficult
- o Difficult
- o Neutral
- o Easy
- o Very easy

Please explain your answer from above:_______________________________________

Question 11: My child was promptly referred to the Minnesota Department of Health (MDH) after my child was screened for and diagnosed with a hearing difference.

- o Strongly disagree
- o Disagree
- o Neutral
- o Agree
- o Strongly agree

Please explain your answer from above:_______________________________________

Question 12: I felt as though my child's medical provider gave me and my child information on all options for technology.

- o Strongly disagree
- o Disagree
- o Neutral
- o Agree
- o Strongly agree

Please explain your answer from above:_______________________________________

Question 13: I felt as though my child's medical provider only discussed resources and information related to non-corrective treatment.

- o Strongly disagree
- o Disagree
- o Neutral
- o Agree
- o Strongly agree

Please explain your answer from above:_______________________________________

Question 14: I felt supported by my child's medical provider when my child was diagnosed with a hearing difference.

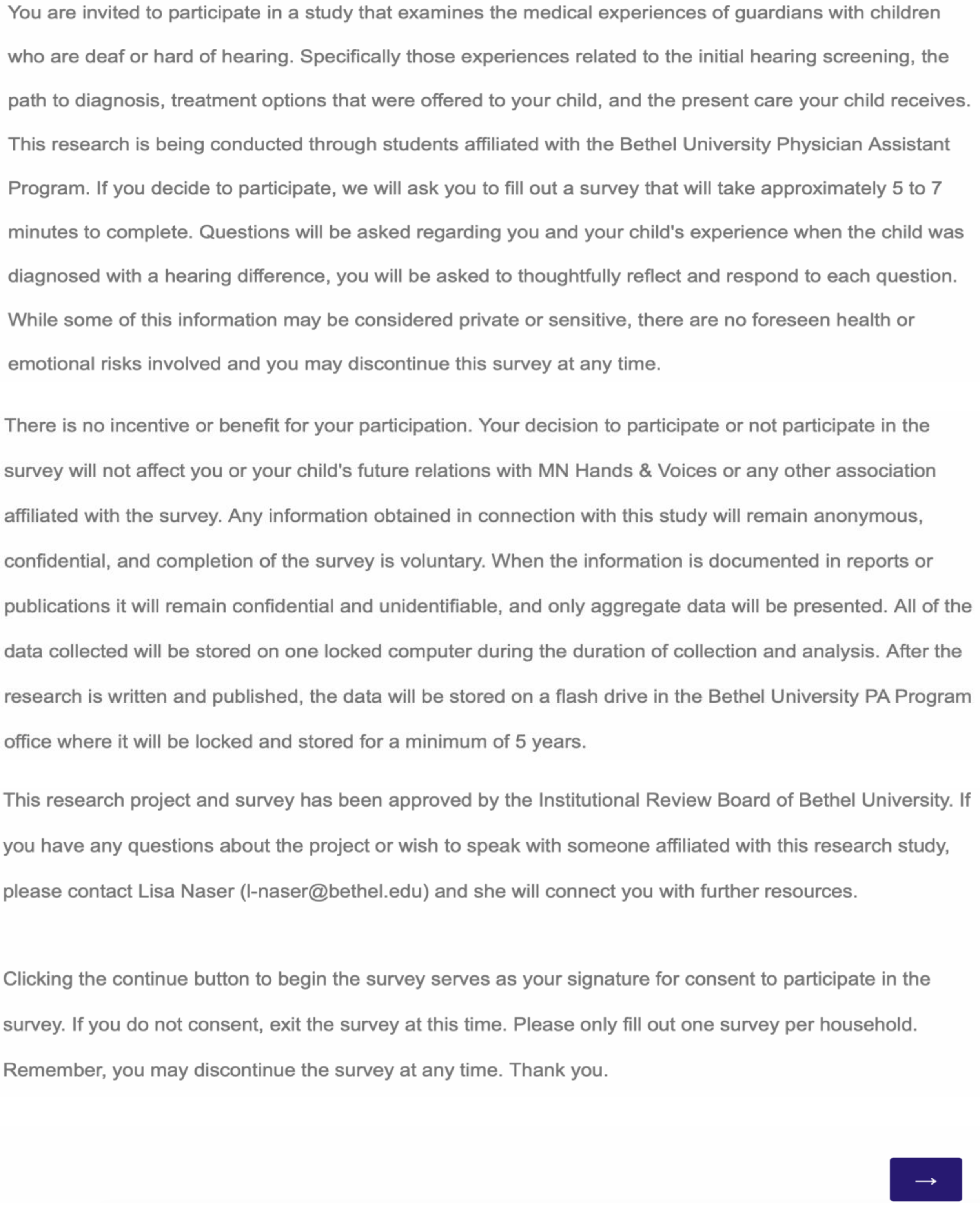
- o Strongly disagree
- o Disagree
- o Neutral
- o Agree
- o Strongly agree

Please explain your answer from above:_______________________________________

Thank You Message: This message indicates that you have completed the survey, and for that we want to thank you!

We are very appreciative of the time you have taken to assist in our research and analysis by giving honest, thoughtful answers to the questions presented. The information collected from this survey will be analyzed and put into a document stating our findings. Once again, thank you!

Appendix B: Consent Form



You are invited to participate in a study that examines the medical experiences of guardians with children who are deaf or hard of hearing. Specifically those experiences related to the initial hearing screening, the path to diagnosis, treatment options that were offered to your child, and the present care your child receives. This research is being conducted through students affiliated with the Bethel University Physician Assistant Program. If you decide to participate, we will ask you to fill out a survey that will take approximately 5 to 7 minutes to complete. Questions will be asked regarding you and your child's experience when the child was diagnosed with a hearing difference, you will be asked to thoughtfully reflect and respond to each question. While some of this information may be considered private or sensitive, there are no foreseen health or emotional risks involved and you may discontinue this survey at any time.

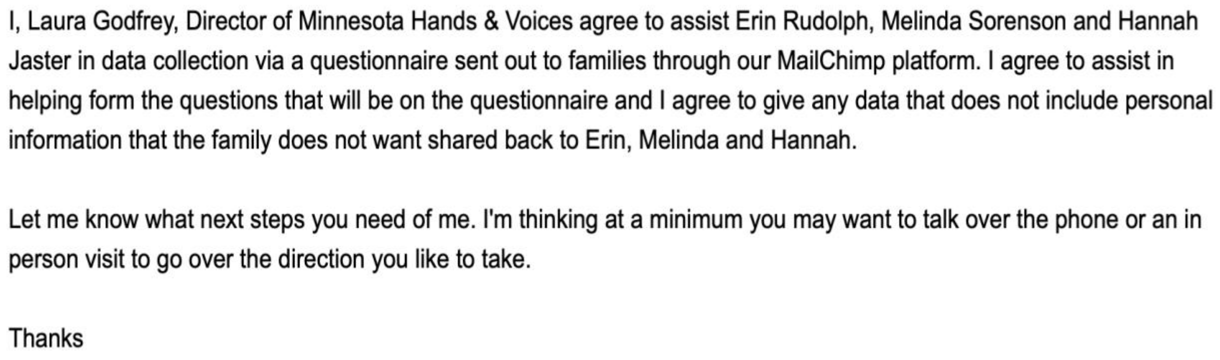
There is no incentive or benefit for your participation. Your decision to participate or not participate in the survey will not affect you or your child's future relations with MN Hands & Voices or any other association affiliated with the survey. Any information obtained in connection with this study will remain anonymous, confidential, and completion of the survey is voluntary. When the information is documented in reports or publications it will remain confidential and unidentifiable, and only aggregate data will be presented. All of the data collected will be stored on one locked computer during the duration of collection and analysis. After the research is written and published, the data will be stored on a flash drive in the Bethel University PA Program office where it will be locked and stored for a minimum of 5 years.

This research project and survey has been approved by the Institutional Review Board of Bethel University. If you have any questions about the project or wish to speak with someone affiliated with this research study, please contact Lisa Naser (l-naser@bethel.edu) and she will connect you with further resources.

Clicking the continue button to begin the survey serves as your signature for consent to participate in the survey. If you do not consent, exit the survey at this time. Please only fill out one survey per household. Remember, you may discontinue the survey at any time. Thank you.

Appendix C: Consent to Survey Guardians Associated with MN Hands & Voices

Official Consent given via Email by MN Hands & Voices at Lifetrack Director



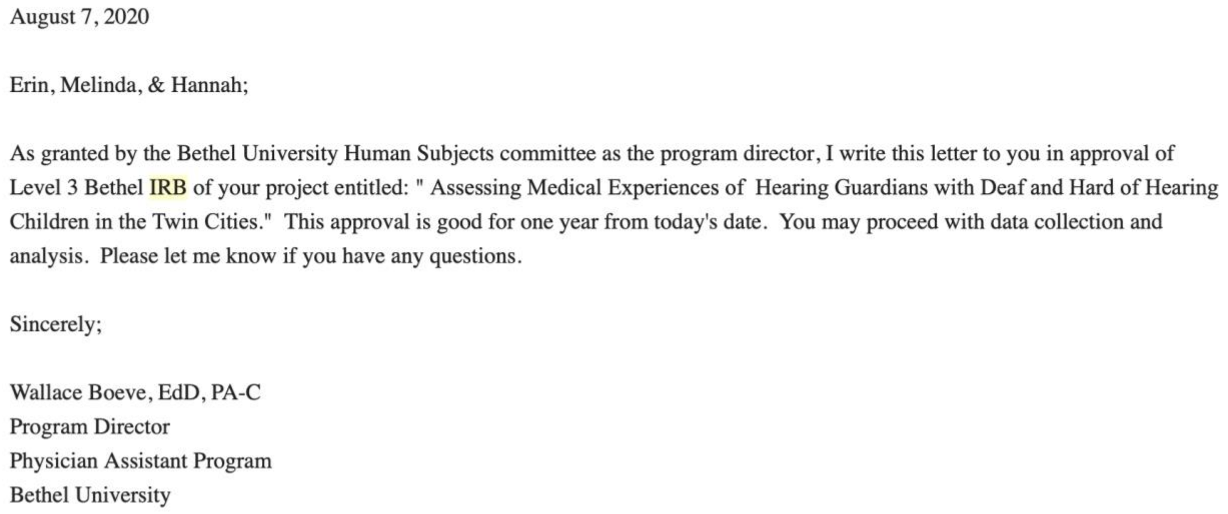
I, Laura Godfrey, Director of Minnesota Hands & Voices agree to assist Erin Rudolph, Melinda Sorenson and Hannah Jaster in data collection via a questionnaire sent out to families through our MailChimp platform. I agree to assist in helping form the questions that will be on the questionnaire and I agree to give any data that does not include personal information that the family does not want shared back to Erin, Melinda and Hannah.

Let me know what next steps you need of me. I'm thinking at a minimum you may want to talk over the phone or an in person visit to go over the direction you like to take.

Thanks

Appendix D: IRB Approval

Official Level 3 IRB Approval Letter from Wallace Boeve, Bethel University Program Director



August 7, 2020

Erin, Melinda, & Hannah;

As granted by the Bethel University Human Subjects committee as the program director, I write this letter to you in approval of Level 3 Bethel IRB of your project entitled: " Assessing Medical Experiences of Hearing Guardians with Deaf and Hard of Hearing Children in the Twin Cities." This approval is good for one year from today's date. You may proceed with data collection and analysis. Please let me know if you have any questions.

Sincerely;

Wallace Boeve, EdD, PA-C
Program Director
Physician Assistant Program
Bethel University

Appendix E: Community Research Chair Survey Suggestions

Suggested Survey Edits given via Email by MN Hands & Voices at Lifetrack Director

Here are just a couple of thoughts:
We use the term Hearing difference these day. Professionals are still going to say Hearing loss. We just sort of thought it fit better and helps the community a little bit by saying difference because technically these kiddos haven't lost anything because most of them weren't born with the hearing to start. Up to you on how you'd like to work this.

Q3 - asks about where Dx was made but not where ongoing follow up will happen; Metro or Greater MN. You'll find that many families come to the cities for the diagnosis but ongoing audiology services (and more importantly what you're looking for, the main person that will give them support and if it was sufficient) will be located outside of the cities.

A lot of the time, the diagnosing Audiologist may run the tests like a sedated ABR but then will forward that information to their clinic audiologist. And that may be someone in Mankato, Duluth, etc. It could even be an educational audiologists that a family gets their information from.

Q6 - is this question asking if information regarding the importance of follow-up was sufficient, or that the information received at the follow-up appointment was sufficient? if it is regarding, then I would suggest using the word "regarding the follow-up" in place of "on the follow-up"

Q7 - should Cued Speech be included?

Q11 - Q13 - which medical provider? ENT? Audiology? Peds?
Chiro/DO/NP/PA/MD?
The diagnosing provider or the follow-up provider?
Parents interact with any number of providers in pretty rapid succession.

Q11 - Q12 - You are wondering if their audiologist only talked to them about CI's (surgical)? and then to balance that out you are asking if they did nothing (non-corrective) in the next question. Is this correct?
What is the question you are getting at? I would guess that you've been told that audiologist only want to fix the hearing difference so they automatically bring up Cochlear implants, right? Less than 10% of our families/kids have cochlear implants. Most are hearing aid users. So you aren't going to get a straight answer from asking surgical or non corrective because Hearing aids don't fit either of these.

Maybe ask questions like this instead?
"I felt that my child's audiologist gave me all the options for technology" or "From the options below, please select all of the information that relates to your experience with your child's audiologist" Information on CI's, Information on Hearing aids, Information on BAHA's, Information on my option for no technology, etc.

I'm not sure if that's helpful but there is something about Q11 and Q12 that is telling me you're not going to get the information you are looking for. You're trying to be unbiased but those two questions tell me that you think the outcome is going to tell you that families are giving surgical information and are not given information about doing nothing. There just a little biased in my opinion.