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Communication Resources for Deaf or Hard of Hearing Children in Mississippi: Parents' Perspectives

by

Julia Rossano

A Thesis
Submitted to the Honors College of
The University of Southern Mississippi
in Partial Fulfillment
of Honors Requirements

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ABSTRACT

A parent's ability to communicate with their child through formative years may often be taken for granted, as the options for such communication seem intuitive and apparent. However, hearing parents of children with hearing loss must not only make a choice between several communication methods, but they must also navigate an environment where the methodologies are not clearly delineated. Blaiser and colleague provide succinct descriptions of the most common methods which can be chosen. These methods include listening and spoken language systems, manual-visual systems, and systems combining these two modalities (Blaiser & Bargen, 2018). This choice is often challenging because many factors impact the accessibility to and availability of each. Availability of communication resources can vary across geographic locations, and absence of access to certain services render some options moot. It has been reported that rural areas are especially lacking in such resources (Furno et al., 2020; Meadow-Orlans et al., 2003).

Consequently, the purpose of this study is twofold: Primarily, it explores variables that may affect the communication choices of hearing parents for their deaf or hard of hearing child. Secondarily, it seeks to gain a better understanding of these choices, investigating why parents chose their communication method and exploring the choices they felt they had available. A mixed methods research design was employed to address the question: What factors contribute to the communication choices made by hearing parents of deaf and hard of hearing children in the state of Mississippi? Quantitative and qualitative analyses were performed on the data to reveal correlations between variables

and themes in the decision-making processes of parents. The results indicated correlations between (a) parent age and child age, (b) parent proficiency in American Sign Language (ASL) and child proficiency in ASL, and (c) parent ratings of communicative support in recreational environments and community environments. Themes identified in the qualitative data were (a) general knowledge on hearing loss prior to the child's diagnosis, (b) support systems, and (c) methods of communication used.

Keywords: *communication resources, Deaf, Hard of Hearing, children, Mississippi, parent perspectives*

DEDICATION

This research project is dedicated to parents of deaf and hard of hearing children and the professionals who help them. I sincerely hope that more attempts are made to understand your experiences and that Mississippi becomes a greater place of advocacy and education.

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Special thank you to my advisor, Dr. Joann P. Judge, for supporting me during this learning process. Thank you to Dr. Scott G. Piland and the staff of the School of Kinesiology & Nutrition. Thank you to the faculty and staff of the Speech and Hearing Science department for the information and encouragement I received during my undergraduate career. Thank you to the Honors College and Drapeau Center for their support. Special thanks to the friends and fellow honors students for the comradery shared through the thesis process and our undergraduate education. Finally, thanks to my family for their unceasing support through my entire educational journey.

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LIST OF ABBREVIATIONS

ABR	Auditory Brainstem Response
ABI	Auditory Brainstem Implant
AEBE	ASL/English Bilingual Education
ASHA	American Speech-Language-Hearing Association
ASL	American Sign Language
BAHA®	Bone Anchored Hearing Device
dB	Decibels
CI	Cochlear Implant
CDC	Centers for Decease Control and Prevention
D/HH	deaf or hard of hearing
EI	Early Intervention
IDEA	Individuals with Disabilities Education Act
MSDH	Mississippi State Department of Health
NIDCD	National Institute on Deafness and Other Communication Disorders
OAEs	Otoacoustic Emissions
PI	Principal Investigator
UCI	Unilateral Cochlear Implant
USDA-ERS	United States Department of Agriculture Economic Research Service
USDOE	United States Department of Education
WHO	World Health Organization

CHAPTER I: INTRODUCTION

An exciting moment for the parents of a new baby is when the child utters their first word. This milestone may be shared among friends and family, documented in a memory book, and reminisced upon for years to come. For most parents, their child speaking their first word is highly anticipated; their child speaking at all is a given. For deaf and hard of hearing (D/HH) children, of which 90-95% (Weaver & Starner, 2011) will have hearing parents, speech is less certain. According to Blaiser and Bargen (2018), hearing parents of children with hearing loss can choose between several communication options (i.e., listening and spoken language systems, manual-visual systems, and systems combining these two modalities). This chapter will (a) provide an overview of information on the deaf and hard of hearing, (b) examine the challenges that hearing loss can cause, (c) review the communication methods for the deaf and hard of hearing, and (d) state the purpose of this study.

Overview of the Deaf and Hard of Hearing

According to the World Health Organization, approximately 466 million people around the world have a disabling hearing loss, of which 34 million are children (WHO, 2020). In the United States, the National Institute on Deafness and Other Communication Disorders (NIDCD) reported that 2-3 infants per one thousand births are born with a detectable hearing loss (NIDCD, 2016). Newborn hearing screenings are practiced in hospitals nationwide to identify babies who likely have a permanent hearing loss and to screen for conditions which could lead to the development of hearing loss later in the child's life (ASHA, 2021c). These screening procedures include otoacoustic emissions

(OAEs) tests and auditory brainstem response (ABR) tests (Hearing Health Foundation, 2020).

For young children, such deficits can have detrimental consequences for language development and academic performance (WHO, 2020). Thus, the Early Hearing Detection and Intervention guidelines specify that infants have a hearing screening completed by one month of age (ASHA, 2021c). By 3 months of age, any child with a hearing loss must have a diagnosis; if parents decide their child will use hearing aids, they must be properly fitted within one month of the diagnosis; children must enter early intervention (EI) services by six months of age (ASHA, 2021c).

Nevertheless, people of all ages can be negatively impacted by a hearing loss. In the adult population, data from the NIDCD reported that non-Hispanic white adults are more than twice as likely as other groups to have a hearing loss. Meanwhile, non-Hispanic black adults had the lowest rate of hearing loss of all racial/ethnic groups (NIDCD, 2016). Interestingly, Jung and Bhattacharyya (2012) found that adults with hearing loss were more likely to be unemployed than their hearing counterparts; those with hearing loss also earned significantly less wages. These findings are consistent with previous data. The 1994 National Interview Health Survey shows that, as family income increases, the prevalence of hearing impairment for all ages decreases; families earning less than $10,000 a year were twice as likely to have hearing impairments when compared to families earning $50,000 or more (Holt et al., 2012). Furthermore, the prevalence of hearing impairments was found to be greater at all ages in rural communities (Holt et al., 2012). Similarly, Kubba et al. (2004) concluded that childhood congenital hearing loss and socio-economic deprivation were clearly associated.

In more recent studies, such rural areas were found to face significant challenges in providing hearing healthcare to their residents (Bush et al., 2015). In these communities, as many as half of those newborns identified with hearing loss do not receive a diagnosis by the time they reach 3 months of age. Such delays in diagnoses could result in children from rural areas facing challenges academically and socially (Bush et al., 2014). Disparities in services result in members of some socioeconomic groups becoming "lost to follow-up" (Bush et al., 2015, p. 763). A lack of specialty care in rural areas can further complicate the provision of services (Bush et al., 2015). According to the Mississippi State Rural Health Plan, a rural area is defined as, (1) a county that has a population of less than 50,000; (2) an area with less than 500 people per square mile; or (3) a municipality of less than 15,000 people (Mississippi State Department of Health [MSDH], 2014). The United States Department of Agriculture Economic Research Service (USDA-ERS) reported in 2019 that there were 2,976,149 total residents in Mississippi, and 1,393,789 of these were living in areas defined as "rural" (USDA-ERS, 2020). The Magnolia State is infamous for its high poverty levels, low education levels, and lack of industry. Intertwined with these concerning statistics are the health disparities seen in rural residents and minority populations (Mississippi State Department of Health, 2014).

In response to an urgent need to establish avenues of support for infants and toddlers with disabilities, the federal government instituted Part C of the *Individuals with Disabilities Education Act* (IDEA) in 1986 (2004). The policy provides funds to individual states to support such services. Currently, all states participate in Part C of IDEA (2004). As a result, children age birth to 36 months with any type or degree of

hearing loss can receive services in Mississippi. In this state, hearing services are directed through the State Department of Health. A Service Coordinator is provided through the Mississippi First Steps Early Intervention Program. The role of the Service Coordinator is to connect families with service providers that will assist them in understanding their communication options (Mississippi State Department of Health [MSDH], 2019).

While the national percentage of adults living with a disability is 25.6%, Mississippi's percentage is slightly higher, with 33.5%. The percentage of residents living with deafness or a disabling hearing loss is also higher in Mississippi than on the national level, 6.3% compared to 5.6% (Centers for Disease Control and Prevention [CDC], 2020). In the Mississippi school system, 12.0% of the students have a disability, which is comparable to the national percentage of 12.9%. Of all students enrolled in Mississippi schools, 0.15% have a hearing impairment, equal to the national percentage (United States Department of Education [USDOE], 2013).

To understand their communication options, families must first learn the terminology associated with hearing loss. The definitions of the terms "deaf" and "hard of hearing" are not completely standardized across service fields and popular jargon. While other specifications exist, one commonly used chart provided by the American Speech-Language-Hearing Association (ASHA) indicates that a hearing loss range of 91 decibels (dB) or above is considered profound hearing loss, while hearing loss ranges below 91 dB through 16-25 dB are labeled severe, moderately severe, moderate, mild, and slight (ASHA, 2021a). "Hard of hearing" can refer to a limited amount of hearing loss, while "deaf" refers to extensive hearing loss in the profound range. Still, according to Schow and colleagues, "deafness can also be described functionally as the inability to

use hearing to any meaningful extent for the ordinary purposes of life, especially for verbal communication" (Schow et al., 2018, p. 6).

Understanding the terminology involved in the definition of hearing loss is crucial in knowing how drastically it will affect a child's ability to communicate. There are three types of hearing loss: conductive, sensorineural, and mixed. Conductive hearing loss, which inhibits sounds' ability to travel through the outer and middle ear, is usually temporary or treated with medicine or surgery (ASHA, 2021c). Notably, otitis media, an infection in the middle ear with an associated hearing loss, is the most diagnosed ailment among children in the United States (Roberts, 2004). The second type of hearing loss is sensorineural, which is typically the result of inner ear damage and cannot be remedied medically (ASHA, 2021d). According to the American Speech-Language-Hearing Association, this is the most common type of permanent hearing loss (ASHA, 2021d). Another facet of hearing loss is its time of onset. This could be prelingual, perilingual, or postlingual. Prelingual deafness is defined as, "hearing loss present at birth or prior to the development of speech and language" (Schow et al., 2018, p. 8). Prelingual deafness is distinct from the category of perilingual deafness, in which the person became deaf while learning his or her first language. Lastly, postlingual deafness occurs after language has been fully acquired (Schow et al., 2018). This study focuses on permanent, prelingual hearing loss.

Hearing parents will likely face many challenges when trying to communicate with their deaf and hard of hearing child. These may include trouble calming their infant (Marschark & Hauser, 2012), a lack of supportive resources in certain locations (Meadow-Orlans et al., 2003), an inability to communicate in situations where the child

cannot use their implant, and difficulty mastering their chosen form of communication because of a lack of time (Weaver & Starner, 2011).

Methods of Communication

Studies have determined that, in the case of prelingually deaf children, it is imperative that the child is provided with a method of communication. The method of communication is itself not as important for the child's development as the mere fact that the child has a communication method from an early age (Gilkerson et al., 2018). Parents may decide between manual-visual methods, listening and spoken language methods, and methods combining these two modes (Schow et al., 2018).

In the United States, the typical manual-visual approach is American Sign Language (ASL). Many deaf parents bringing up deaf children consider themselves part of the larger Deaf community, where Deafness is acknowledged as a unique culture rather than simply a medical diagnosis (Laurent Clerc National Deaf Education Center, 2015). ASL is the primary language within the Deaf community. Just as a typically hearing child will likely learn their native language from their parents, so will a Deaf child acquire ASL from their Deaf parents. This may not be so much a conscious choice as it is a natural occurrence.

Meanwhile, hearing parents may choose a listening and spoken language method. These include the Auditory-oral and Auditory-verbal approaches. Like their titles suggest, these two methods encompass similar practices, but emphasize different skills. While both train the child's auditory abilities, taking advantage of residual hearing through devices, the Auditory-oral approach incorporates visual communication, such as gestures and speech-reading; the Auditory-verbal method relies solely on audition

(Schow et al., 2018). Combination methods include Total Communication and Cued Speech. Total Communication encourages communicating through several means: signing, speech-reading, spoken language, etc., allowing the child to perceive information in many ways. Cued Speech involves the use of a system of hand placements and movements, known as "cues," to help the person with hearing loss distinguish between speech sounds that look similar on a speaker's lips. This facilitates speech-reading (Schow et al., 2018).

Using the Internet, parents can discover websites dedicated to educating them on their communicative options. Humphries and colleagues (2019) outline the advantages that the Internet offers. Namely, these include opportunities to connect with other parents having similar experiences, websites focusing on language development, resources for learning sign language, and even avenues for children of people living in remote areas to develop language (Humphries et al., 2019). Furthermore, parents may find national and state organizations and foundations, schools for the deaf, speech and hearing clinics or audiologists, the state Early Hearing Detection and Intervention (EHDI) program, etc. Parents can assess what communication option best fits their lives. They can familiarize themselves with what systems are in place in their location to support their communication decisions. There are countless factors that may affect the communication method that hearing parents of deaf and hard of hearing children may ultimately choose. The next chapter will summarize the current literature regarding parent perspectives on communication choices and the variables that play into their decision-making.

Purpose Statement

The purpose of this research is to first explore the communication choices made by hearing parents of deaf and hard of hearing children in Mississippi. The second intent is to further understand the factors that led these parents to making their choices. Thus, this research utilizes both quantitative and qualitative measures to approach the topic.

CHAPTER II: LITERATURE REVIEW

Parent-child Interactions

In the United States, 90-to-95% of deaf children are born to hearing parents (Weaver & Starner, 2011). When informed that their baby has a significant hearing loss, hearing parents must quickly decide what communication method(s) they will use with their child and what method(s) their child will subsequently use with the world. All the while, they are likely internalizing considerable emotional distress. Additionally, these parents have probably had little to no exposure to ASL or Deaf Culture (Weaver & Starner, 2011); they may fear their child will not thrive academically, with literacy stunted at the fourth-grade level (Morere, 2011). While this assessment has been validated throughout the years by various studies (Furth, 1966; Karchmer & Mitchell, 2003; Quigley & Kretschmer, 1982), it is important to remember that most deaf children have hearing parents and, therefore, do not have the same access to a natural language that both deaf children of deaf parents and hearing children of hearing parents do. One significant contributor to this slower lingual development among deaf children of hearing parents is the hearing parents provide an incomplete language model (when using ASL) to their children, along with less parent-child interaction (Weaver & Starner, 2011).

According to Marschark and Hauser (2012), parent-child interactions form a critical foundation from which the child interacts with the world. The parent-child bond eventually shapes the child's self-esteem and self-confidence. Furthermore, such behaviors are the cornerstone to language building. Owens (2016) stated that interactions between caregivers and their children include joint referencing, joint attention, joint action, turn-taking, and situational behaviors – imperative factors for the development of

a child's language skills. A new mother likely does not consider the benefit that her cooing or babbling might have on her baby; she interacts with her child in these specific ways because it is an instinctual tendency (Bryant & Barrett, 2007). Unfortunately, these natural tendencies may be interrupted when hearing loss is present in one of the participants. Consider, for example, that a crying deaf baby will not respond to a caregiver's comforting whispers like a hearing infant might (Marschark & Hauser, 2012).

Early unpleasant communication attempts can precede major frustrations. In a study conducted by Weaver and Starner (2011), several hearing parents of deaf children discussed barriers they faced when trying to communicate with their offspring. A mother shared her inability to communicate in situations where the child was unable to wear an implant; parents reported they had waited too long to learn ASL, so the child was at a linguistic disadvantage; some admitted they were embarrassed to sign in public. In a study conducted by Jackson and colleagues, parents of deaf children conveyed that caring for their deaf child was "equivalent to caring for two to three children" (Jackson et al., 2008, p. 89). Parents lacked free time to learn ASL between doctor appointments, therapy, and the usual parental tasks (Jackson et al., 2008). According to Meadow-Orlans et al. (2003), communication methods were often determined by the services and opportunities available in the location where the family lived.

It has been shown that early language exposure leads to higher kindergarten language skills, which is the best indicator for future academic success (Pace et al., 2019). However, a child's language exposure varies widely among families in both quality and quantity. Among hearing children aged 2-4 months, exposure to new words in a single day can vary by up to 6,000 words (Gilkerson et al., 2017). This information for

hearing children is easily applied to the deaf and hard-of-hearing. A child's opportunity to practice turn-taking with their guardian can expand their lingual understanding by enhancing their vocabulary (Cabell et al., 2015) and activating language centers of the brain (Romeo et al., 2018).

Many researchers have provided valuable information to the parents and teachers of deaf children (Marschark & Hauser, 2012; Morere, 2011; Weaver & Starner, 2011). Previous literature has shown that resources are available to families who live in the proper geographical areas to receive them (Meadow-Orlans et al., 2003). In some cases, parents expressed that they did not have a choice as to how they communicated with their children because of the lack of services where they lived (Meadow-Orlans et al., 2003). Rural areas are especially lacking in such resources (Furno et al., 2020).

Methods of Communication

While the choices regarding communication are difficult for modern-day parents, a probe into history reveals that the communicative decisions of the deaf and hard of hearing have always been complex. The availability of language for deaf and hard of hearing individuals has been marked with tension and oppression. Demonstrating the highs and lows of communication and education for the deaf, Harvard University's Linguistics department developed a timeline of key events in Deaf history.

Harvard's timeline shows that sign languages have been available to the deaf for centuries, with systems like Martha's Vineyard Sign Language and French Sign Language existing in the 1700's (Harvard University Linguistics Department, 2020). Eventually, Laurent Clerc and Thomas Gallaudet established the first school for the Deaf in America, which combined these two languages into a unique form ultimately

considered American Sign Language (Harvard University Linguistics Department, 2020). Recognition of the Deaf community continued with President Abraham Lincoln's inauguration of Gallaudet University in 1864 (Harvard University Linguistics Department, 2020). Yet, Alexander Graham Bell's support of the oralist method of deaf education prompted a general dismissal of sign language as the primary educational modality (Harvard University Linguistics Department, 2020). According to the *Oxford English Dictionary*, oralism is "[a] system or method of teaching profoundly deaf people to communicate by the use of speech or lip-reading; (also) advocacy of this system in preference to the use of sign language, etc." (2021). The world of Deaf education soon shifted toward oralism in 1880, with the International Congress on the Education of the Deaf Conference held in Milan, Italy. As a result of its proceedings, an oral education was enacted in all schools (Harvard University Linguistics Department, 2020). Within 40 years, the percentage of Deaf children being orally educated skyrocketed from a slim proportion to 80%, while the number of Deaf teachers in schools dropped from 45% to only 11% (Smith et al., 2008).

Today, a separation still exists between those who defend oralist methods of communication for the deaf and those who support manual methods. One needs only to view movies like *Sound and Fury* and plays like *Tribes* to understand the deeply rooted tension between these two viewpoints. Modern times have seen technological advances which allow for other options for families with deaf members. The option of Total Communication aims to ease this tension. Exposing deaf children to speech, lip-reading, auditory training, fingerspelling, and sign language, while using technological and medical advances to aid in hearing allows the child to decide which method they prefer

(Flaskerud, 2014). The inconsistent and unclear implementation of Total Communication has given rise to doubts of its effectiveness on both sides (Hands & Voices, 2014).

Communication options involving speech include Auditory-Oral or Auditory-Verbal methods and cued speech. In both the Auditory-Oral and Auditory-Verbal approaches, the goal is full participation in hearing society. As such, an emphasis is placed on listening to speech using residual hearing. Hearing is often amplified with hearing aids or implants. The Auditory-Oral approach integrates various communication features: speech, audition, and speech reading (Rady Children's Hospital, 2021). Furthermore, while the use of signed languages is discouraged, gestures and body language are acceptable. Contrarily, the Auditory-Verbal approach relies solely upon the auditory channel to gather information. Speech reading and gestures are discouraged, and the two communication features used are speech and audition (Rady Children's Hospital, 2021). Cued Speech is a system used to visually assist speech reading. Consisting of eight hand shapes representing groups of consonants and four hand placements representing vowels, Cued Speech can be successfully used with children who do not have residual hearing. The goal of cued speech is to allow children to learn the native spoken language of their area as their first language, meaning reading and writing will come more easily (Rady Children's Hospital, 2021). This system involves four communication features: Cued Speech hand shapes, speech reading, speech, and the use of existing hearing (Rady Children's Hospital, 2021).

Parent Perspectives

Researchers have investigated the factors that influence caregivers' decisions regarding communication methods with their deaf or hard of hearing child (Crowe et al.,

2014a; Crowe et al., 2014b; Scarinci et al., 2018). By revealing these characteristics, such studies allow service providers to craft interventions with family-centered orientations. Scarinci and associates contributed to this research in their article, examining parents' reasons for changing their communication methods after previously establishing a different mode. After discovering the influences involved in caregivers' initial decisions, the researchers investigated why parents' change their communication methods through in-depth, semi-structured interviews. Seven caregivers provided their perspectives. Thematic analysis indicated five key factors: family characteristics, family access to information, family strengths, family beliefs, and family-centered practice. Overall, this investigation determined that the family unit was the core of decision-making, more than the factors surrounding the child's hearing loss itself (Scarinci et al., 2018).

While qualitative studies offer meaningful insights, quantitative studies have also been conducted on this topic. Crowe and associates used a questionnaire to gain an understanding of the decisions of 177 caregivers. Respondents indicated that most deaf and hard of hearing children used speech in their communication, with a significantly lower portion using sign language. Finally, a minute portion used more than one spoken language. Several factors were found to weigh into caregivers' choices, including: "their children's audiological and intervention characteristics, communication with those around them, community participation, access to intervention and education services in English, and concerns about their children's future lives" (Crowe et al., 2014b, p. 234). Furthermore, "[t]he advice of speech-language pathologists, audiologists, and specialist teachers was more important to caregivers than advice from medical practitioners and nonprofessionals" (Crowe et al., 2014b, p. 234). Though each of these factors affected

decision-making, some bore more weight (Crowe et al., 2014b). These insights can assist professional endeavors to form intervention services to the family's specific needs.

These researchers paired this quantitative study with qualitative techniques. The accompanying study analyzed the questionnaire data to identify themes. Themes gleaned from the questionnaire responses were explored in further detail. First, the study examined the parents' sources of information regarding their communication options. Advice from professionals, especially allied health professionals, the caregivers' own research efforts, and advice from their family and friends were found to sway their decisions regarding communication. Second, the practicalities of communication were considered. Subthemes found were the accessibility of communication, the timing of acquisition, and the necessity of each family's situation (Crowe et al., 2014a).

In Mississippi, institutions have developed from these various theories regarding the best education for the deaf. The American Society for Deaf Children provides a summary of resources that support the learning of ASL in each state. Some schools for the deaf uphold the philosophy that deaf children be provided with access to both ASL and English, called ASL/English Bilingual Education (DeLana et al., 2007). A similar concept known as bilingual-bicultural education maintains the importance of a group's natural language while incorporating the language of the country where the educational institution is located. Many schools for the deaf have adopted this philosophy and its methods (Gibson et al., 1997).

Modern day facilities instruct students in speech and listening skills, but without the reportedly oppressive atmosphere of the past. Reading these schools' mission statements clarifies their positions as supporters of achievable long-term communicative skills. In

addition to education-based settings, community-based settings are also available to support parents' communication decisions. These include camps for the deaf, audiology clinics, religious centers, and other community-based venues. Parents can find these services through online web searches.

CHAPTER III: METHODOLOGY

Research Design

To address the research questions, the PI used a mixed methods research design. A mixed methods approach indicates the use of quantitative and qualitative measures. Specifically, the study employed a triangulation design. This is a one-phase approach where the quantitative and qualitative methods are implemented over the same timeframe and have equal weight for the research. The two datasets from the quantitative and qualitative methods were compared and contrasted to understand the research questions (Creswell, 2014). Thus, this research method is further designated as a convergence triangulation. This combination of research techniques allows for a greater depth of understanding of parents' decision-making processes. First, an online survey was created to gather quantitative data, such as parent gender and age, child gender and age, county of residence, hearing loss and hearing device(s) used, and other variables. Second, virtual focus groups were conducted with the parents of deaf and hard of hearing children in the state of Mississippi. This component of the research provided qualitative data, the lived experiences of these parents, which service providers may find notable. In this chapter, topics covered include participants, recruitment protocols, and data collection. Before recruitment of participants commences, this study received IRB approval. All participants gave their consent prior to data collection procedures. Refer to Appendix A for IRB approval.

Data Collection Procedures

A Qualtrics survey was created to gather quantitative data. Qualtrics is an online software provided through The University of Southern Mississippi. To create the survey,

the PI first consulted the pertinent literature on the topic and other research projects to help formulate 20 questions. These were input in the Qualtrics system one by one and assessed for readability. Approximately 30 adult participants were eventually recruited to complete the survey questionnaire. Eligibility requirements specified that the participants must (a) be over eighteen years of age, (b) have typical hearing, (c) be the parent or caregiver of a deaf or hard of hearing child, (d) be raising their child in the state of Mississippi, and (d) be English speakers. For the virtual focus group, 2 adult participants volunteered. In addition to the previously stated requirements, those participating in focus groups were also required to have adequate technology and provide a completed, signed, and returned consent form prior to the virtual focus group.

Survey participants' responses were anonymous. Consent was required to progress to the first question of the survey. After clicking the survey link, participants reviewed the description of the study and the consent information. To continue with the survey, they clicked the consent button. If participants did not wish to continue, they were informed of their option to close their browser window at any time.

To distribute the online survey, the PI contacted the program coordinators of organizations for deaf and hard of hearing children in the state of Mississippi. The PI contacted the program coordinators via phone or email conversations. The PI sought permission to recruit participants through their organization. The link for the survey was emailed to the program coordinator, who distributed it to the parents/caregivers. The email to the organizations also contained a recruitment flyer (see Appendix B), in case the directors or the parents wanted more information. This was made through the free

version of the Canva website. This flyer contained a QR (Quick Response) code to the survey, and the QR code was also attached to the email.

In contacting such programs, a systematic approach was taken. Categories of facilities were approached, such as educational facilities, speech and hearing clinics, and organizations that provide after-school or supplementary activities, such as summer camps, to those who are deaf and hard of hearing. Additionally, national organizations that serve the deaf and hard of hearing population were approached through their social media accounts. Specifically, organizations' Instagrams were found, and the PI contacted their representatives through emails found there or on their Facebook pages. Representatives were asked if they could distribute their survey to parents in the state of Mississippi.

While information gathered from those participants who completed the online survey was anonymous, parents who volunteered to participate in the virtual focus groups were asked to provide an email address on the form. To maintain confidentiality for these participants, the PI responded to each participant individually and kept all communications with the participant confidential. A note on the survey questionnaire ensured respondents that their email addresses and all communication would not be shared with anyone outside of the investigative team. Participants were then contacted to discuss availability for focus groups. Informed consent forms were emailed to each participant. These were signed and emailed back to the PI before the virtual focus group. Prior to the scheduled focus group, participants were emailed a reminder regarding the date, time, and link to the virtual meeting. Virtual focus groups were hosted on the Zoom

meeting platform. Meetings were recorded via Zoom and with a SONY UX570 Digital Voice Recorder.

Prior to the start of the focus group, the PI reminded the participants that the discussion would be recorded, data secured, and that all participant and family names would be coded and de-identified in the thesis. Information would be secured in a dedicated external hard drive, and this information would be deleted at the completion of the research. The PI also addressed any questions or concerns the participants had prior to the discussion. Finally, the participants were reminded that they could end their participation in the focus group at any time by logging off of the meeting.

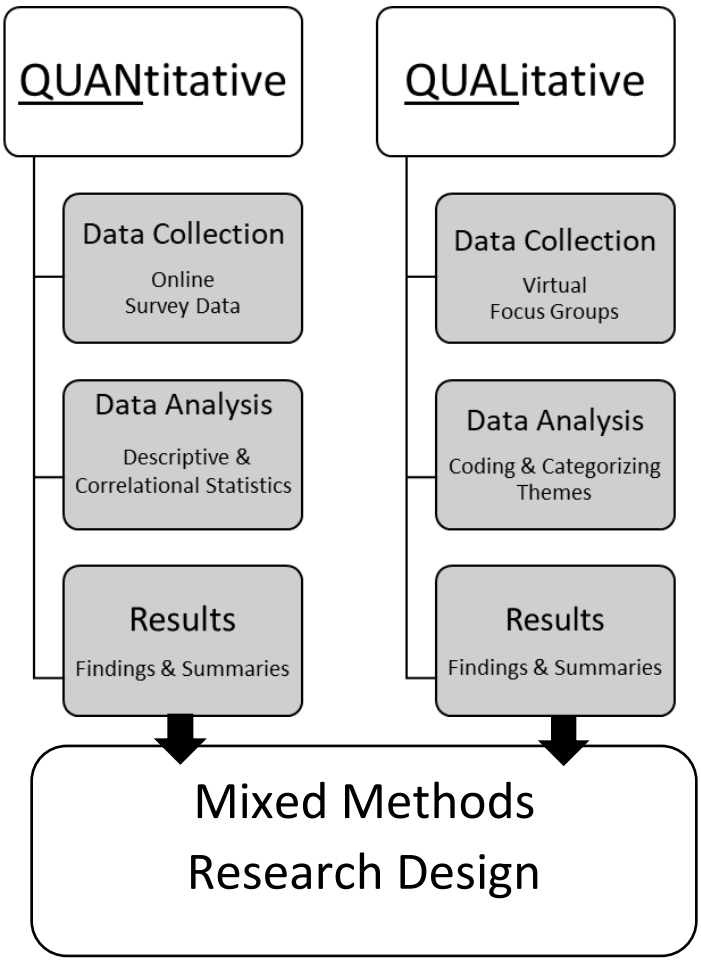
During the virtual focus group, the PI facilitated a semi-structured focus group by asking participants a series of questions, investigating their personal experiences with communication options in Mississippi. Participants were given time to answer each question. At the end of the meeting, participants were thanked for their contribution to the research study. They were reminded that they would receive a follow-up email asking for their mailing addresses, where the PI would then send them a $25 gift card incentive. The total duration of the focus groups was approximately 15-25 minutes. Transcriptions were generated in part by the Otter.ai automatic transcription technology. The resulting transcriptions were reviewed and edited to ensure accuracy.

Data Analysis Procedures

Once the online survey was removed from public access, the quantitative data were uploaded and analyzed using IBM SPSS Statistics (Version 27). Surveys deemed incomplete were omitted from the study. Once the descriptive data were organized and analyzed, written summaries and tables were created to illustrate the findings of the

online survey. To determine if there were any relationships between the variables, the Pearson's *r* statistical analysis was conducted. The values of the Pearson's *r* range from +1 to -1. Therefore, values greater than 0 would indicate a positive relationship, values less than 0 would indicate negative relationship, and values of 0 would indicate no relationship between the variables (Laerd Statistics, 2020). The assumptions for Pearson's *r* are listed accordingly: (a) variables are measured on a continuous scale, (b) variables are paired, (c) there is independence, (d) a linear relationship is evident between the variables, (e) normal distribution, (f) homoscedasticity, and (g) no outliers (Laerd Statistics, 2020). As a result of this analysis, it was found that the data did not meet the assumptions of Pearson's *r*. Therefore, the Spearman's rho, a non-parametric correlational analysis was conducted in SPSS. The qualitative data obtained from the focus groups were analyzed using a transcript-based analysis. According to Krueger (1994), transcript-base analysis is a rigorous and time-intensive approach to analyzing qualitative data. After multiple reviews of the transcripts and audio recording, themes were identified, summarized, and supported by documentation (i.e., quotations). By comparing the transcriptions of the two focus groups, themes surrounding parents' decision-making processes were identified. Once qualitative and quantitative data were analyzed separately, data were merged to provide a deeper perspective on the topic. Figure 1 below conceptualizes the mixed methods approach.

Figure 1 *Conceptualization of Mixed Methods Research Design*



CHAPTER IV: RESULTS

A mixed methods research design was utilized to explore the communication choices made by hearing parents of deaf and hard of hearing children in Mississippi. This section provides written summaries, tables, and graphic illustrations of the quantitative and qualitative data obtained from the investigation.

Quantitative Results

In total, 30 participants provided informed online consent to participate in the survey. After review of the online survey data, five studies were deemed incomplete and not included in the data analysis. Overall, the online survey had a completion rate of 83.3%. The following section summarizes the quantitative data retrieved from the online survey: (a) parent/caregiver demographics, (b) child demographics, and (c) ratings of communicative supports.

A total of 25 hearing parents of deaf and hard of hearing children in Mississippi completed the online survey. The most frequently represented counties were Harrison (*n* = 4), De Soto (*n* = 3), Rankin (*n* = 3), and Lamar (*n* = 2). See Table 1 for complete information. Ninety- six percent of the participants were female (*n* = 24), 56% of the participants ranged in age from 30-39 years (*n* = 14), and 33.3% of the participants reported an annual household income of $100,000 or greater (*n* = 8). For a complete summary of results, see Table 2. As for the deaf and hard of hearing children represented in the study, 60% were male (*n* = 15), and 40% were female (*n* = 10). Thirty-three percent of the children ranged between 4-6 years (*n* = 8), and 37.5% ranged between 1-3 years (*n* = 9). As for race/ethnicity, 84% of the children were white/Caucasian (*n* = 21);

and 16% were Black/African American (*n* = 4). For a complete summary of results, see Table 3.

The online survey further probed for data on the deaf or hard of hearing children. The results indicated the 76% of the participants (*n* = 19) did not have any disabilities that co-occurred with their hearing loss. Meanwhile, parents/caregivers who indicated their child had a comorbidity, 28.6% of the children (*n* = 2) had a learning disability, and 71.4% of the children (*n* = 5) had a comorbidity not listed as a choice on the survey. Refer to Table 3 for complete information.

The online survey also inquired about the siblings of the deaf or hard of hearing child. Sixty-eight percent of the participants (*n* = 17) reported that their deaf or hard of hearing child had one sibling. Additionally, 43.5% of the participants (*n* = 10) responded that their deaf or hard of hearing child attended a School for the Deaf in either a residential or day school capacity. Lastly, 30.4% of the participants (*n* = 7) chose the "Other" option for the type of school attended. This response was selected as parents/caregivers noted their child was too young to attend school. More information can be found in Table 3.

As the type of hearing device used may correspond with the child's communication method, the survey requested information on the children's use of hearing devices. Forty-four percent of the participants (*n* = 11) indicated that their child used hearing aid(s) and 36% of the participants indicated that their child had bilateral cochlear implants (*n* = 9). Additional choice options included: unilateral cochlear implant, bone-anchored hearing device (BAHA®), auditory brainstem implant, other, or no device. The complete data on hearing devices used is found in Table 3.

As for the methods of communication used, the participants reported the following: 54.8% chose Auditory-oral or Auditory-verbal methods (*n* = 17); 22.6% chose Total Communication (*n* = 7); 16.1% chose ASL (*n* = 5); and 6.5% chose Cued Speech (*n* = 2). Since the online survey provided opportunity to select multiple methods of communication, the results concluded that 76% of the parents/caregivers reported the use of one method of communication (*n* = 19), while 24% of the parents/caregivers reported the use of two methods of communication. Refer to Table 4 for complete data.

Similarly, parents/caregivers could choose use ASL as their method of communication, identify several means in which they learned ASL. For example, 14.8% learned ASL via online classes (*n* = 4) and 11.1% learned ASL through avenues not listed on the survey (e.g., college courses and deaf family member). Additional ASL instructional strategies included, community-based classes (*n* = 2), books/video program (*n* = 1), and phone apps (*n* =1). One participant also indicated the use of multiple strategies to learn ASL (i.e., community-based classes, online classes, book/video programs, and phone app(s).

Results of the Parent/Caregiver's ASL Proficiency Rating indicated that 16.7% rated their proficiency in ASL as basic (*n* = 4); 12.5% rated their proficiency as conversational (*n* = 3); and 12.5% rated their proficiency as fluent (*n* = 3). It was also indicated that 58.3% of the participants did not know ASL (*n* = 14). Results of the Child's ASL Proficiency Rating indicated that 16.7% of the participants rated their child's ASL proficiency as basic (*n* = 4); 12.5% rated their child's proficiency as fluent (*n* = 3); and 4.2% rated their child's proficiency as conversational (*n* =1). Results of the

online survey also indicated that 66.7% of the parent/caregivers reported that their child does not know any ASL (n = 16). For a summary of the results, see Table 5.

Lastly, parents were asked to rate the adequacy of the communicative support their child received in school, community, and recreational environments. Results of the online survey indicated that 76.2% of the participants rated the school environment as extremely adequate in providing communicative support (n = 16), and 33.3% of the participants rated the community environment as slightly adequate (n = 8). As for the adequacy of the communicative support in recreational sports and activities, the results varied. The data indicated that 28.6% of the participants (n = 6) rated the recreational sports and activities environment as extremely adequate, while 19% of the participants rated the environment at extremely inadequate (n = 4). Refer to Table 6 for complete information.

Some ordinal variables surveyed in the online questionnaire were found to have a significant relationship according to the Spearman correlation. First, results of the Spearman correlation indicated that there was a significant positive association between reported child age and reported parent age ($r_s(24) = .642$, $p < .01$). Second, results of the Spearman correlation indicated a significant positive correlation between ASL proficiency of the child and ASL proficiency of the parent ($r_s(23) = .901$, $p < .01$) Finally, the third significant, positive correlation found through the Spearman test was between parent ratings of communicative support in children's recreational activities and in their school environments ($r_s(20) = .472$, $p < .05$). Each of these relationships seems logical in nature: review Table 7 and Figure 2, Figure 3, and Figure 4 for further information.

Table 1: Participants' County of Residency in Mississippi

County of Residency (*n* = 25)	*n* (%)
Copiah	1 (4.0)
Covington	1 (4.0)
DeSoto	3 (12.0)
Harrison	4 (16.0)
Jackson	1 (4.0)
Lamar	2 (8.0)
Lauderdale	1 (4.0)
Leake	1 (4.0)
Marion	1 (4.0)
Newton	1 (4.0)
Pearl River	1 (4.0)
Pike	1 (4.0)
Rankin	3 (12.0)
Smith	1 (4.0)
Yazoo	1 (4.0)
Not reported	2 (8.0)

Note. Total number of counties in the State of Mississippi (*n* = 82). Total number of counties represented in this study (*n* = 15).

Table 2: Parent/Caregiver Demographics

Gender (n = 25)	n (%)
Male	1 (4.00)
Female	24 (96.0)
Age in Years (n = 25)	
18-19 years	0 (0.0)
20-29 years	4 (16.0)
30-39 years	14 (56.0)
40-49 years	5 (20.0)
50-59^{+} years	2 (8.0)
Annual Household Income (n = 24)	
< $20,000	3 (12.5)
$20,000 - $29,999	3 (12.5)
$30,000 - $39,999	1 (4.2)
$40,000 - $49,999	1 (4.2)
$50,000 - $59,999	4 (16.6)
$60,000 - $69,999	2 (8.3)
$70,000 - $79,999	1 (4.2)
$80,000 - $89,999	1 (4.2)
$90,000 - $99,999	0 (0.0)
$100,000 <	8 (33.3)

Table 3: Deaf or Hard of Hearing Child Demographics

Gender (n = 25)	n (%)
Male	15 (60.0)
Female	10 (40.0)
Age in Years (n = 24)	
< 1 year	0 (0.0)
1-3 years	9 (37.5)
4-6 years	8 (33.3)
7-9 years	0 (0.0)
10-12 years	1 (4.2)
13-15 years	3 (12.5)
16-18 years	2 (8.3)
19-21 years	1 (4.2)
Race/Ethnicity (n = 25)	
Asian	0 (0.0)
Black/African American	4 (16.0)
Hispanic/Latino	0 (0.0)
Native American	0 (0.0)
White/Caucasian	21 (84.0)
Other	0 (0.0)

Table 3 (continued).

Any Comorbidities (*n* = 25)	*n* (%)
Yes	6 (24.0)
No	19 (76.0)
Comorbidities (*n* = 7)	
Autism Spectrum Disorder	0 (0.0)
Intellectual Disability	0 (0.0)
Learning Disability	2 (28.6)
Other	5 (71.4)
Siblings (*n* = 25)	
NO siblings	5 (20.0)
1 sibling	17 (68.0)
2 siblings	2 (8.0)
3 or more siblings	1 (4.0)
Type of School Attending (*n* = 23)	
Public mainstream school	4 (17.4)
Private mainstream school	2 (8.7)
School for the Deaf (day school)	6 (26.1)
School for the Deaf (residential)	4 (17.4)
Other	7 (30.4)

Table 3 (continued).

Type of Hearing Device (*n* = 25)	*n* (%)
No device	2 (8.0)
Hearing aid(s)	11 (44.0)
Unilateral Cochlear Implant (CI)	1 (4.0)
Bilateral cochlear implant (CI)	9 (36.0)
Bone anchored hearing device (Baha®)	1 (4.0)
Auditory brainstem implant (ABI)	0 (0.0)
Other	1 (4.0)

Table 4: Method of Communication

Method of Communication (*n* = 31)	*n* (%)
American Sign Language (ASL)	5 (16.1)
Auditory-Oral or Auditory-Verbal	17 (54.8)
Cued speech	2 (6.5)
Total Communication	7 (22.6)

Note. The parent/caregiver could select multiple Methods of Communication (*n* = 31).

Table 5: Parent/Caregivers' ASL Training and Parent-Child ASL Proficiency

Parent/Caregiver's ASL Training (n = 27)*	n (%)
Community-based classes	2 (7.4)
Online classes	4 (14.8)
Book/video program	1 (3.7)
Phone app	1 (3.7)
Other	3 (11.1)
I do NOT use ASL.	16 (59.3)
Parent's ASL Proficiency Rating (n = 24)	
Basic	4 (16.7)
Conversational	3 (12.5)
Fluent	3 (12.5)
Does not know any ASL.	14 (58.3)
Child's Parent ASL Proficiency Rating (n = 24)	
Basic	4 (16.7)
Conversational	1 (4.2)
Fluent	3 (12.5)
Does not know any ASL.	16 (66.7)

Note. There were multiple options available for the Parent/Caregiver's ASL Training (n = 27).

Ratings of proficiency (a) *basic* - knowledge of the alphabet, numbers, greetings, simple phrases; (b) *conversational* - ability to participate in conversations about many familiar topics; can understand signs within context, but has difficulty expressing abstract ideas or unfamiliar topics; (c) *fluent* - ability to initiate conversations, express abstract ideas, relate formal and informal topics, new and familiar topics.

Table 6: Parent/Caregivers' Ratings of Communicative Support for their Child

In School (*n* = 21)	*n* (%)
Extremely adequate	16 (76.2)
Moderately adequate	3 (14.3)
Slightly adequate	2 (9.5)
Slightly inadequate	0 (0.0)
Moderately inadequate	0 (0.0)
Extremely inadequate	0 (0.0)
In the Community (i.e., church, organizations, & clubs) (*n* = 24)	
Extremely adequate	7 (29.2)
Moderately adequate	4 (16.7)
Slightly adequate	8 (33.3)
Slightly inadequate	1 (4.2)
Moderately inadequate	3 (12.5)
Extremely inadequate	1 (4.2)
In Recreational Sports/Activities (*n* = 21)	
Extremely adequate	6 (28.6)
Moderately adequate	5 (23.8)
Slightly adequate	4 (19.0)
Slightly inadequate	2 (9.5)
Moderately inadequate	0 (0.0)
Extremely inadequate	4 (19.0)

Table 7: Correlation Matrix between Ordinal Variables

	1	2	3	4	5	6	7	8
1. Parent_age	-							
2. Annual_income	.280	-						
3. Child_age	.642**	.202	-					
4. ASL proficiency _ parent	.314	-.120	.164	-				
5. ASL proficiency _ child	.375	-.226	.318	.901**	-			
6. Rating support _ community	.154	-.149	.162	-.320	-.284	-		
7. Rating support _ school	.270	.007	.363	.346	.244	.199	-	
8. Rating support _ recreation	-.029	-.139	.089	.022	.013	.328	.472*	-

** Correlation is significant at the 0.01 level (2-tailed).

* Correlation is significant at the 0.05 level (2-tailed).

Figure 2 *Correlation between Child Age and Parent Age*

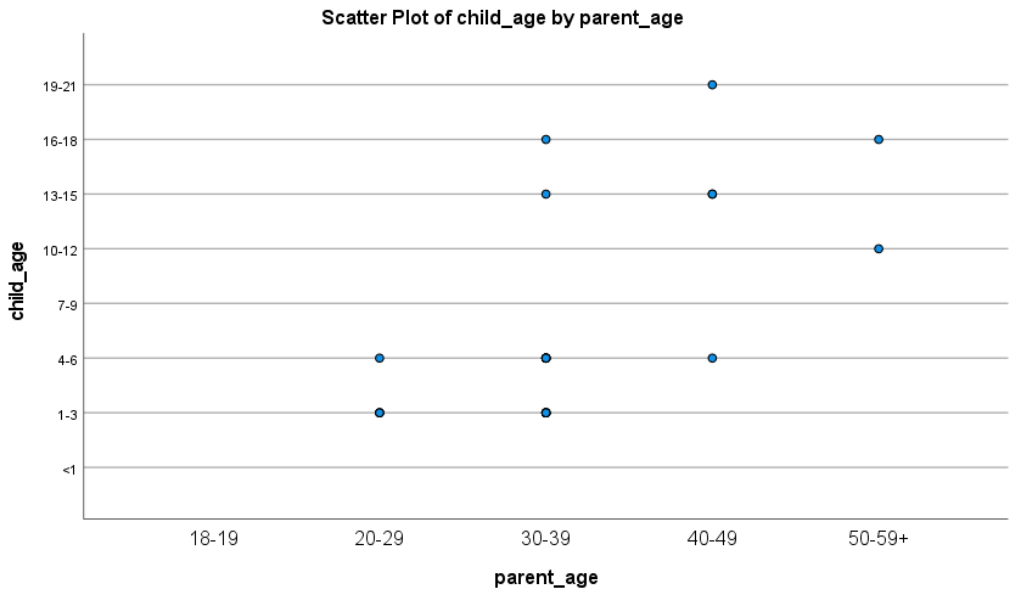


Figure 3 *Correlation between Support in Community and Recreation Settings*

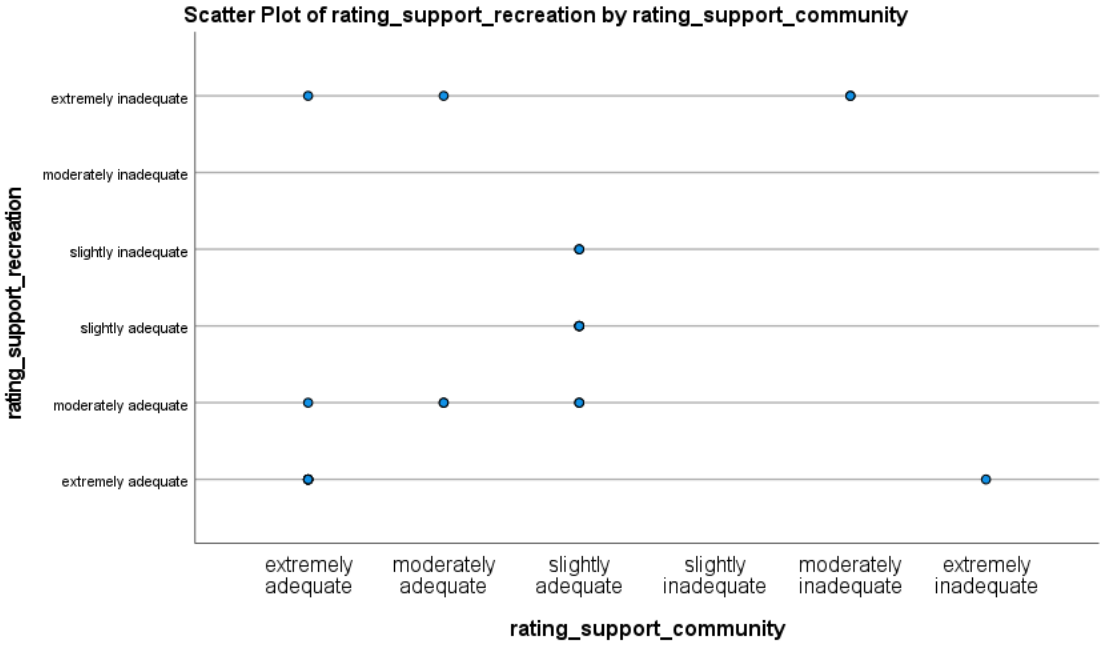
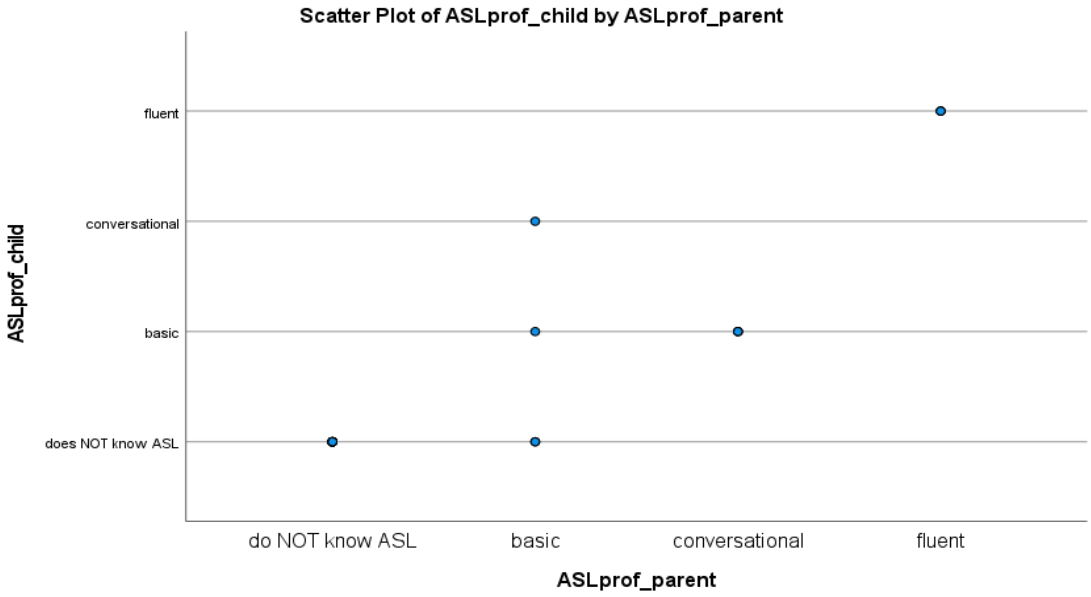


Figure 4 Correlation between ASL Proficiency of Child and Parent



Qualitative Results

In total, two hearing parents of deaf and hard of hearing children in the state of Mississippi participated in virtual focus groups. Because only one participant arrived to separate focus groups, these will be referred to as interviews. Interviews lasted 25 minutes and 15 minutes, with 14 standard questions asked to both interviewees. Using a semi-structured approach, additional inquiries were made based on the unique perspectives and experiences provided by each caregiver. From these conversations, the PI identified three themes, including (a) general knowledge on hearing loss prior to the child's diagnosis, (b) support systems, and (c) methods of communication used.

First, the commonality of a low level of general knowledge about hearing loss prior to the child's diagnosis is a notable finding. Both parents indicated that they did not have any true understanding of the lives of the deaf and hard of hearing prior to being informed that their children had hearing loss. The PI prompted the participants to consider their prior knowledge with the question, "Before your child's diagnosis, how familiar were you with the communication methods of the deaf and hard of hearing?" The parents' individual responses are presented in Table 8. As evidenced by these responses and previous literature, it is likely that parents of deaf and hard of hearing children in the state of Mississippi have little exposure to the choices available to those with hearing loss before they are in the situation of making them.

The second theme discovered was the parents' access to support systems. While discussing resources that were available to these parents and the factors that impacted their communication choices, each mentioned the importance of people and systems that could provide guidance. One parent indicated great satisfaction with her support system.

Having friends and family professionally involved in specific interventions allowed her immediate access to reliable advice. Meanwhile, the other expressed regret that she did not have access to other families facing similar challenges. Rather than turning to friends or family, she turned to internet resources to discover her options herself. Lacking the benefits of personal recommendations, this parent relied upon the information presented by state professionals. Both parents received services through the Mississippi First Steps Early Intervention Program, but they made divergent decisions regarding communication method and schooling. Examples of the importance of support systems on communication decisions are presented in Table 8. When asked what resources they wished had been available to them but were not, Parent A, who reported having a satisfactory support system, indicated that she would not change anything in her experience. On the other hand, Parent B commented that she wished she had access to a community of deaf and hard of hearing individuals in which her children could participate.

The final theme found through these interviews was the method of communication ultimately used. Both parents indicated that they desired their children to have the use of speech. Yet, Parent A stated that her child attended a school explicitly employing auditory-verbal methods, and Parent B stated that her children used mainly ASL for communication. The parents' responses to the question, "What communication method did you choose, and what led to that choice?" are found in Table 8.

Though Parent A's child uses auditory-verbal methods, Parent A explained that her child used cued speech initially, then gradually progressed to using speech without cues. Both parents indicated that their children had or were getting cochlear implants

bilaterally. Interestingly, both parents stated that their children's hearing loss was progressive in nature. Parent B indicated that this was one reason she chose to use ASL:

> Parent B: *"I want them to be bilingual, to have the ASL…just in case, for whatever, their…hearing loss goes completely profound, they'll have a back-up language."*

Contrarily, Parent A indicated that, despite the diagnosis of progressive hearing loss, her child's speech has not reduced in quality:

> Parent A: *"He went from mild to moderate to profound [hearing loss]. [I]t was a huge shock for us, but…they did the cochlear implants at 23 months and…he has completely excelled. He talks 90 miles-an-hour."*

Table 8: Qualitative Themes and Supporting Quotes

Theme	Example Quotes
General knowledge about hearing loss prior to the child's diagnosis	Parent A: *"I knew, of course, sign language, but I didn't…really know any deaf people. And I knew maybe, when I was younger, two people that were deaf, but they only signed, they did not talk. So, of course, when we got the diagnosis, I just assumed…my child will never talk…."* Parent B: *"Oh, none. To be honest, none."*
Support systems	Parent A: *My mom's best friend actually has worked at Magnolia Speech School for…40 years, so I just instantly called her and she…gave me all this information. But First Steps actually contacted me within probably two weeks of his birth….[They] gave me all my options as far as oral communication or sign language, and that's when we chose really, probably, at a month that we were going to go the oral route."* *"…I was just so overwhelmed at the beginning, but First Steps…gave me every opportunity and option that they…could give me."* Parent B: *"I honestly just…didn't know anything. I…googled about early intervention in Mississippi and called and got him in there."* *"[W]hen [the healthcare professionals] told me, "Oh, your son has hearing loss," they didn't…direct me or anything [about] what you can do….[W]e were there for…an hour, maybe an hour and a half doing an ABR, and they told us, and then we just left."* *"[First Steps Early Intervention Program] actually helped us with…telling us about how either you can go the ASL route…or you can go [with] speech."* *"[I would have liked to] have other people who have their families who…are in the same situation, who've gone through or are going through the same process…to…give you guidance."*

Table 8 (continued).

Communication method	Parent A: *"[My child] has done auditory verbal therapy since three months old [and] still continues to do that at…school. [W]e don't do any kind of sign right now."* Parent B: *"Right now, he's non-verbal. His first language will be ASL, at least for a while."* *"I want them to be bilingual, to have the ASL and speech…."*

CHAPTER V: DISCUSSION

Limitations

Research is rarely a streamlined process. Adjustments and modifications are inherent to the progress of inquiry, and this project is no exception. Though this study may provide valuable information and experience, it had several limitations. These include mainly a small sample size (*n*) and a shortened data collection period catalyzed by changes in methodology inflicted by COVID-19 restrictions.

First, a small sample size limits the ability to generalize the information gathered through this research. Initially, the survey was intended to gather the responses of approximately 50 participants. Overall, 30 responses were reported. Of these, only 25 were completed and able to be analyzed; 5 were incomplete. This was perhaps a sign of those who clicked on the link to examine the survey and then determined they did not wish to participate. This could also be the result of distraction, where they intended to complete the form but were sidetracked by other responsibilities. It is unfortunate that these individuals were unable to offer their insights, as this study and future research could benefit from all perspectives on the subject.

A small sample size also restricts the diversity of the participants. For the survey, only 4% of the respondents were male caregivers, while the remaining 96% were female. One wonders if there are more male perspectives on communication that might have been offered, or if this is a genuine reflection of the landscape of caregiving in Mississippi. Moreover, 16% of the respondents were Black or African American, and 84% were white or Caucasian. Although the opinions offered by the majority of white respondents were invaluable, notable differences in the experiences of white and Black parents of deaf or

hard of hearing children may exist but are not evident in this study. Asian, Hispanic/Latino, Native American, and other races or ethnicities were not represented in this research.

Finally, a larger sample size may have contributed to a deeper understanding of the effect of rurality on service provisions and communication choices. Represented in this study are 9 of 67 counties in Mississippi recognized as "rural" by the Office of Rural Health Policy (Health Resources & Services Administration [HRSA], 2018). These reports cannot be deemed to reflect the general experience of parents in Mississippi's rural areas. Knowing the previously stated challenges faced by rural places, it is possible that an online survey received through email may not have reached those parents in the most isolated of counties.

Admittedly, the methodology of this study would have benefitted significantly from more time to polish. As with the majority of plans made in the year 2020, however, this research underwent major upheavals before again settling into a solidified plan of action. Originally, this study had a completely different aim and methodology. Using the eye-tracking lab at The University of Southern Mississippi, the author hoped to gain insights into the differences in the way typically hearing children and children with hearing loss attended to and learned ASL. Restrictions intended to limit the spread of the COVID-19 virus meant that a face-to-face research method was no longer ideal. Thus, the study morphed into the research here presented. Shorter time in which to conduct the research affected the consideration put into some maneuvers and, most unfortunately, less ability to perfect the methodology through trial-and-error. This is most seen in initial attempts to conduct focus groups. Understanding the most effective ways to contact

volunteers required several tries. Eventually, the investigator learned that shorter emails worked better, and direct communication regarding availability was preferable, though more tedious, than using a Doodle Poll.

Organizing focus groups proved a significant challenge. In all, ten survey participants provided their emails on their questionnaires to volunteer for a focus group. Only two were ultimately interviewed. An early attempt to use a Zoom scheduling feature left 1 participant without a link to the meeting; this participant did not attempt to meet at another time. Thankfully, the investigator learned through this experience to copy and paste the meeting invitation to participants in an email, and subsequent meetings proceeded with no technical difficulties.

Implications for Practice

The results of the questionnaire show that, among respondents in this study, Auditory-oral and Auditory-verbal methods were the most chosen approaches to communication. This seems reasonable considering the prevalence of deaf and hard of hearing children born to hearing parents. Data from the interviews reveal that, though parents may live in the same general area, their understanding of their communication options may be different. Themes identified in the interviews included (1) support systems, (2) previous information, and (3) multiple methods of communication.

The parents' support systems appeared to greatly impact their satisfaction with their experiences when choosing a communication method. If parents have access to friends and family members with experience with the communication of the deaf and hard of hearing, their perceptions of organizations and programs aimed at assisting them may be seen as helpful and beneficial. They may have outside opinions which they trust

and on which they feel they could rely. Unfortunately, if parents do not have such a support system, they may only rely on the information which the program presents. In some cases, this may mean the parents feel they have only two options. These parents may not have an understanding of the communication options of the deaf and hard of hearing prior to receiving such a diagnosis for their child. A lack of previous information or limited experiences could give parents skewed outlooks on the possibilities for their child's future. When assessing their communication options, parents may choose multiple communication methods. One parent indicated using Cued Speech and Auditory-oral/Auditory verbal approaches; the other indicated using ASL and some speech. These were not necessarily used simultaneously but sometimes in succession.

Speech and hearing professionals and other service providers can use this information to improve their services to these parents. Service providers must themselves understand the various communication options available and the resources in the state of Mississippi from which families can benefit. By familiarizing themselves with the family's personal support system, their previous knowledge on hearing loss and communication options, and their desire to use multiple methods of communication, service providers can fill in any missing information so parents can make an educated decision that will best fit their priorities and lifestyles.

Future Research

Though the small sample size of this current study renders the data unable to be generalized, it may serve as a springboard for necessary future research in this area. As explained earlier, Mississippi is notorious for its poverty and health deficits. Childhood hearing loss is a concerning medical condition that requires careful monitoring and

intervention. Yet, it is possible that a portion of the children with this challenge live in areas in Mississippi that are unable to offer adequate support. Parents may consequently not realize that they have many options with which to communicate with their child.

Future research could continue to investigate the opinions of hearing parents with deaf or hard of hearing children in Mississippi. Focusing on any individual factor that the survey portion of this research touched upon, future research could determine to what degree each variable affects parents' communication decisions in this state. Further research should aim for a large sample size. To achieve this, the investigators might consider conducting the research over a longer period of time and resending survey links to organizations previously contacted. This may allow parents who did not participate initially to change their minds, or it might contact parents who recently became involved in the organization. Additionally, future researchers should consider modifying the survey by adding "no schooling" as an option to accommodate parents of young children, adding more options to the methods parents use to learn ASL and asking respondents to simply input their children's ages as a single numerical value. This will allow investigators to gather more well-rounded information.

APPENDIX A: IRB APPROVAL LETTER

Office *of*
Research Integrity

THE UNIVERSITY OF SOUTHERN MISSISSIPPI

118 COLLEGE DRIVE #5125 • HATTIESBURG, MS | 601.266.6576 | USM.EDU/ORI

NOTICE OF INSTITUTIONAL REVIEW BOARD ACTION

The project below has been reviewed by The University of Southern Mississippi Institutional Review Board in accordance with Federal Drug Administration regulations (21 CFR 26, 111), Department of Health and Human Services regulations (45 CFR Part 46), and University Policy to ensure:

- The risks to subjects are minimized and reasonable in relation to the anticipated benefits.
- The selection of subjects is equitable.
- Informed consent is adequate and appropriately documented.
- Where appropriate, the research plan makes adequate provisions for monitoring the data collected to ensure the safety of the subjects.
- Where appropriate, there are adequate provisions to protect the privacy of subjects and to maintain the confidentiality of all data.
- Appropriate additional safeguards have been included to protect vulnerable subjects.
- Any unanticipated, serious, or continuing problems encountered involving risks to subjects must be reported immediately. Problems should be reported to ORI via the Incident template on Cayuse IRB.
- The period of approval is twelve months. An application for renewal must be submitted for projects exceeding twelve months.
- Face-to-Face data collection may not commence without prior approval from the Vice President for Research's Office.

PROTOCOL NUMBER: IRB-20-468
PROJECT TITLE: Communication resources for deaf and hard of hearing children in Mississippi: Parents' perspectives
SCHOOL/PROGRAM: School of KINN, Kinesiology
RESEARCHER(S): Julia Rossano, Joann Judge

IRB COMMITTEE ACTION: Approved
CATEGORY: Expedited

6. Collection of data from voice, video, digital, or image recordings made for research purposes.
7. Research on individual or group characteristics or behavior (including, but not limited to, research on perception, cognition, motivation, identity, language, communication, cultural beliefs or practices, and social behavior) or research employing survey, interview, oral history, focus group, program evaluation, human factors evaluation, or quality assurance methodologies.

PERIOD OF APPROVAL: December 10, 2020

Donald Sacco Jr.

Donald Sacco, Ph.D.
Institutional Review Board Chairperson

APPENDIX B: SURVEY RECRUITMENT FLYER



APPENDIX C: QUALTRICS SURVEY QUESTIONNAIRE

Qualtrics Survey Questions

Q00. Thank you for agreeing to participate in this research!

INTRODUCTION: In the United States, 90-to-95% of deaf children are born to hearing parents (Weaver & Starner, 2011). When informed that their baby has a significant hearing loss, hearing parents must quickly decide what communication method(s) they will use with their child and what method(s) their child will subsequently use with the world, all while likely internalizing considerable emotional distress. These parents have probably had little to no exposure to American Sign Language (ASL) or Deaf Culture (Weaver & Starner, 2011); they may fear their child will not thrive academically, with literacy stunted at the fourth-grade level (Morere, 2011). While this assessment has been validated throughout the years by various studies (Furth, 1966; Karchmer & Mitchell, 2003; Quigley & Kretschmer, 1982), it is important to remember that most deaf children have hearing parents and, therefore, do not have the same access to a natural language that both deaf children of deaf parents and hearing children of hearing parents do. One significant contributor to this slower lingual development among deaf children of hearing parents is the hearing parents provide an incomplete language model (when using ASL) to their children, along with less parent-child interaction (Weaver & Starner, 2011).

Researchers have provided valuable information to the parents and teachers of deaf children (Marschark & Hauser, 2012; Morere, 2011; Weaver & Starner, 2011). According to Meadow-Orlans et al. (2003), the availability of communication resources varies across geographic location. In some cases, parents expressed that they did not have choices as to how they communicated with their children because of the lack of services where they lived. What's more, Furno et al. (2020) indicated that rural areas are especially lacking in such resources. Hearing parents of children with hearing impairments must choose between several communication options: listening and spoken language systems, manual-visual systems, and systems combining these two modalities (Blaiser & Bargen, 2018).

PURPOSE: The purpose of this study is twofold: first, it will explore variables that may affect the communication choices that hearing parents make for their deaf or hard

of hearing children. Second, it will seek a deeper understanding of these choices. It will further investigate why parents chose their communication method and explore the choices they felt they had available. The intent of the survey portion of this research is to gather descriptive data regarding the variables which may or may not affect the communication choices which parents have made. This is the first step in answering the question: Do communication resources available in certain geographical locations have a significant bearing on the communication methods parents use with their deaf or hard of hearing children?

DESCRIPTION OF STUDY: This study will use a survey powered by Qualtrics. It will consist of 20 questions and will require less than 10 minutes of the participants' time to complete. They will be able to access the survey through a clickable link. Participants will receive this link through an online announcement made by the program coordinators of academic and community-based organizations.

BENEFITS: Participation in this study will offer important information to those who provide services to this population, which will benefit this population in the future. Those who participate in the survey will have an opportunity to choose to participate in a focus group. If they choose to do so, they will receive a $25 gift card.
RISKS: This study is low risk. There is a possibility of the subject encountering an emotional memory through the questions asked, but participants maintain the ability to end their participation at any time.

CONFIDENTIALITY: Survey responses are anonymous. If the participant indicates a desire to take part in the virtual focus group portion of the research, they are asked to provide an email address on their survey questionnaire. Results will be saved on an external hard drive containing no other data. All names will be de-identified and coded in the written document.

PARTICIPANT'S ASSURANCE: This project and this consent form have been reviewed by the Institutional Review Board, which ensures that research projects involving human subjects follow federal regulations. Any questions or concerns about rights as a research participant should be directed to the Chair of the Institutional Review Board, The University of Southern Mississippi, 118 College Drive 35125, Hattiesburg, MS 39406-0001, 601-266-5997.
Any questions about this research project should be directed to the Principal Investigator, Julia Rossano, julia.rossano@usm.edu.

CONSENT to PARTICIPATE in this RESEARCH PROJECT (IRB #20-468)
I understand that participation in this project is completely voluntary, and I may withdraw at any time without penalty, prejudice, or loss of benefits. Unless described above, all personal information will be kept strictly confidential, including my name and other identifying information. All procedures to be followed and their purposes were explained to me. Information was given about benefits, risks, inconveniences, or discomforts that may be expected. Any new information that develops during the project will be provided me if that information may affect my willingness to continue participation in the project.

Q01. Please indicate your **COUNTY of RESIDENCY** from the dropdown menu.

Q02. Gender of the **PARENT/CAREGIVER** completing this survey.

- ☐ Male
- ☐ Female

Q03. Age of the **PARENT/CAREGIVER** completing this survey.

- ☐ 18-19 years
- ☐ 20-29 years
- ☐ 30-39 years
- ☐ 40-49 years
- ☐ 50-59^{+} years

Q04. Annual **HOUSEHOLD** Income

- ☐ < $20,000
- ☐ 20,000 - $29,999
- ☐ 30,000 - $39,999
- ☐ 40,000 - $49,999
- ☐ 50,000 - $59,999
- ☐ 60,000 - $69,999
- ☐ 70,000 - $79,999
- ☐ 80,000 - $89,999
- ☐ 90,000 - $99,999
- ☐ $100,000 <

Q05. Gender of deaf or hard of hearing **CHILD**.

- ☐ Male

- Female

Q06. Please indicate the birth date of your deaf or hard of hearing **CHILD.** (MM/DD/YYYY).

Q07. Race/Ethnicity of the deaf or hard of hearing **CHILD.**

- Asian
- Black/African American
- Hispanic/Latino
- Native American
- White/Caucasian
- Other

Q08. Does your deaf or hard of hearing child have **comorbidities** (i.e., autism spectrum disorder, intellectual disability, learning disability)?

- Yes
- No

Q09. Please list your child's comorbidities:

- Autism spectrum disorder
- Intellectual disability
- Learning disability
- Other (please specify) _____

Q10. What **hearing device(s)** does your deaf or hard of hearing child use?

- No device
- Hearing aid(s)
- Unilateral cochlear implant (CI)
- Bilateral cochlear implant (CI)
- Bone anchored hearing device (Baha®)
- Auditory brainstem implant (ABI)
- Other (please specify) _____.

Q11. Does your deaf or hard of hearing child have any **siblings**?

- NO siblings
- 1 sibling
- 2 siblings
- 3 or more siblings

Q12. Please indicate the **type of school** your deaf or hard of hearing child attends from the list below:

- Public mainstream school
- Private mainstream school
- School for the Deaf (day school)
- School for the Deaf (residential)

Q13. What communication method(s) do you use with your child?

- **Auditory-Oral or Auditory-Verbal** - emphasis on use of residual hearing, with hearing aids or implants, sometimes incorporating visual cues with speech reading (lipreading).
- **Cued speech** - use of cueing, a set of hand shapes or movements visually differentiating between phonemes that look similar on the lips; typically includes use of residual hearing with a goal of spoken language
- **American Sign Language (ASL)** - use of a distinct and natural language different from spoken English; use of amplification or implants is not critical.
- **Total Communication** - "...the use of manually coded English, fingerspelling, speechreading, natural gestures, residual hearing, and speech...the use of amplification and/or cochlear implants is usually encouraged" (Schow et al., 2018, p. 169).

Q14. If **ASL** is used, how did you as the parent/caregiver learn ASL?

- Community-based classes
- Online classes
- Book/video program
- Phone app
- Other (please specify) _____
- I do NOT use ASL.

Q15. Please rate your and your child's **proficiency** in ASL:

- Does not know any ASL.
- Basic (knowledge of the alphabet, numbers, greetings, simple phrases, etc.).
- Conversational (ability to participate in conversations about many familiar topics; can understand signs within context, but has difficulty expressing abstract ideas or unfamiliar topics).
- Fluent (ability to initiate conversations, express abstract ideas, relate formal and informal topics, new and familiar topics).

Q16. Please **rate** your agreement or disagreement with this statement: There is adequate communicative support for my deaf or hard of hearing child in his or her school.

- Extremely adequate
- Moderately adequate
- Slightly adequate
- Slightly inadequate
- Moderately inadequate
- Extremely inadequate

Q17. Please **rate** the adequacy of the communicative support your deaf or hard of hearing child receives from the community (i.e., in church, organizations, clubs).

- Extremely adequate
- Moderately adequate
- Slightly adequate
- Slightly inadequate
- Moderately inadequate
- Extremely inadequate

Q18. Please **rate** the adequacy of the communicative support your deaf or hard of hearing child receives in recreational sports/activities.

- Extremely adequate
- Moderately adequate
- Slightly adequate
- Slightly inadequate
- Moderately inadequate
- Extremely inadequate

Q19. Would you be interested in participating in a virtual focus group to further supplement this research? Participants will receive a $25 gift card.

- Yes
- No

Q20. If you would like to participate in a virtual **FOCUS GROUP** to further contribute to this research, please provide an email with which the investigator can contact you with further information. Your email will be kept confidential; it will not be shared with any third party and will only be used by the investigators. Focus groups will be comprised of 8-12 participants, last 30-40 minutes, and be recorded and de-identified for the confidentiality of the volunteers.

Participants will receive a $25 gift card for their involvement.

APPENDIX D: VIRTUAL FOCUS GROUP QUESTIONS

Virtual Focus Group Questions

1. Tell me about your child (ex. age, school, kind of hearing loss).
2. Before your child's diagnosis, how familiar were you with the communication methods of the deaf and hard of hearing?
3. What communication method did you choose and what led to that choice?
4. When were you made aware of your communication options? How were you made aware of these options (physician, clinician, friend, etc.)?
5. From what communication resources in Mississippi have you or your child benefitted?
6. Have the choices you made in regard to your child's communication been influences by the availability of these resources?
7. Has geographical location proved a barrier in receiving these services or benefitting from the resources (cost or practicality of commute, availability of service providers with expansive areas of responsibility, etc.)?
8. Have you been in contact with another family with a deaf or hard of hearing child?
9. Have you ever been involved in a mentorship with such a family?
10. Are you aware of the presence of a Deaf Community in your area> Have you sought participation in this community? Why or why not?
11. Does your deaf or hard of hearing child have siblings? Are they older or younger? Are any of these siblings also deaf or hard of hearing? How is quality in the communication between siblings?
12. Do you feel as though you had a free choice between your communication options, or do you feel as if your choices were restricted?
13. What is the main reason you feel you were restricted, if so?
14. What services or resources do you wish were available to you?

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