PERCEPTIONS OF EARLY INTERVENTION PROGRAMS FOR DEAF CHILDREN AND THEIR FAMILIES

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Abstract

Over 90 percent of deaf individuals have hearing families. When a hearing loss is detected at birth, it is often a surprise to the family. Early detection allows for entry into early intervention programs that enhance the prospects for future language acquisition and serve to educate families and prepare deaf children, who will have to adjust to living in a hearing world. In Minnesota, various programs connect families to support services. The current research involved in-depth interviews with six professionals that work with deaf children and early intervention programs in Minnesota to examine the following: (1) their backgrounds and context of existing deaf services; (2) perceived benefits of early intervention programs; and (3) perceptions of the challenges in providing early intervention for deaf children and families. The surveys documented the expanding programs and outreach to deaf children and their families, and there was consensus about the value of early intervention. Challenges that were discussed included concerns about reaching every deaf child and the potentially negative consequences when utilization of services is delayed. The results highlighted the need for more trained specialists and for resources to serve the needs of all deaf children beginning as early as possible.
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INTRODUCTION

What is life like for those without their sense of hearing? What would life be like to be without one of your senses? To a hearing individual, these may be interesting questions, but most hearing people typically associate deafness only with the elderly, who may gradually become deaf with the effects of aging. We typically do not think of deafness in younger adults or children and its impact on their lives and their families. It is only when we meet a deaf person ourselves that we begin to ponder these questions. Encountering a Deaf individual, one may ask, how do they communicate with others, is their family deaf, how did they become deaf, or how do they use American Sign Language with their families?

My research has focused on Deaf culture, with a capital D to acknowledge those individuals who use American Sign Language and participate in a Deaf friendly society. My interest in the topic began with a family member of mine. My aunt was born with tumors in her ears, which resulted in losing the majority of her hearing. She learned to lip read, and since she is not profoundly deaf she was able to develop speech. I have learned through my background reading that since she can adequately communicate with others, does not use ASL, and is not mute she would not necessarily be associated with Deaf culture. However, this exposure to deafness sparked my interest and began my path to learning about Deaf culture and ASL.

My background work in sociology allowed me to explore my interest in Deaf culture and review existing literature on deaf families. Through this reading, I repeatedly encountered the distinctions in the education that deaf children receive, including early intervention programming. My reading emphasized the importance of language acquisition in early childhood and the importance of supporting families, who are typically naïve to deafness. I realized the importance of such programming for both the parents and deaf children, but across all of my
research something stood out to me. From the parents’ feedback, as well as professional accounts of dealing with families, I noticed that they all expressed concerns about the support services available to families. Despite a vast literature on deafness and Deaf education, it was difficult to find clear information on how families receive support and what kinds of support they receive during the vulnerable process of first learning that their child is deaf. After extensive research and involvement with both ASL and Deaf culture, I chose to further explore what early intervention support services are available to deaf families and how these programs assist families. Based on my previous research, I realized that this question needed closer examination to determine if these services are, in fact, readily available to families in need and to document professionals’ perceptions of the benefits and challenges of providing such services.

**LITERATURE REVIEW**

Nearly all deaf children are born into hearing families. In fact, it is the most common birth defect, affecting roughly 3 infants for every 1,000 births (Kurtzer-White & Lutterman, 2003). Over 90 percent of deaf children enter the world with hearing family members who have little to no knowledge about their disability (Houston Bradham & Guignard, 2011). How then do these children learn how to adapt to a hearing world? The most common complaint I noticed in the literature on families was the lack of direction from health care professionals in acquiring the proper support services for deaf children. Overall, families felt a lack of support and services from doctors in particular regarding their deaf child’s care (Marschark, 2007). In regards to support and education provided to families and their deaf children, the only clear solution for all parties involved were early intervention programs. Before getting into the importance and impact of these programs, it is essential to review the steps families take leading to such programming, beginning with the diagnostic process. These steps play a vital role in the Deaf child’s potential
success in such programs and life.

Hearing screening is the first step to reaching a diagnosis. Screening newborns at birth positively contributes to the parents’ ability to begin adapting to their child’s disability immediately. Most recently, it has been estimated that 97% of newborns undergo screenings at birth (Houston Bradham & Guignard, 2011). The importance of early diagnosis comes from its successful partnership with early intervention. Together, they allow for a timely diagnosis and entry into early intervention programs, producing “age-appropriate communication outcomes by the time the child enters kindergarten or first grade” (Houston, Bradham & Guigard, 2011).

Unfortunately, even with enhancements in newborn hearing screening, “an estimated 50% of infants referred from Universal Newborn Hearing Screening do not receive a timely diagnosis and intervention” (Houston, Bradham & Guigard, 2011). Various factors involved can delay a proper diagnosis, like failure to test a newborn before leaving the hospital, tests producing false positives, or even not following up with doctors (Marschark, 2007). Studies have shown that due to shortcomings in newborn hearing screening, many deaf children born into hearing families are typically not diagnosed until they are about two or three years old (Marschark, 2007). In addition to the stresses surrounding the diagnosis of a deaf child, it can be unclear to families, especially hearing, what steps they need to take next.

Research has shown that language learning in a child’s first years of life is critical for successful future communication and language acquisition (Marschark, 2007). American Sign Language is a form of communication that can satisfy this need. Yet, the majority of Deaf children are born into hearing families, who are likely to be inexperienced and in need of support. A lack of guidance or professional support could ultimately threaten the successful language development of the Deaf child. To deter this risk, the first step towards the healthy upbringing of
a Deaf child is early hearing detection intervention (EHDI). Houston and colleagues’ (2011) review of early intervention programs identified the following areas as particularly effective: the screening process, state mandated universal newborn hearings screening (UNHS), and efficient data collection. On the other hand, weaknesses included insufficient funding, inadequate number of professionals employed in these programs, and inconsistencies in follow up procedures (Houston, Bradham & Guigard, 2011). Other studies have found significant delays between the time of diagnosis and the start of support services, including hearing aids, speech and audiology support, or sign language instruction (Proctor, Niemeyer, & Compton, 2005). Ultimately, communication gaps between health care professionals and families serve as the greatest threat to the success of such programs in helping families.

Given that the diagnosis process is a lengthy one, the support that professionals and early intervention programs can provide to families starts before the actual diagnosis, during the screening phase (Tattersall & Young, 2006). The procedures involved in newborn hearing screening can represent a trying time for parents as they are unsure of the correct courses of action they need to be take, ultimately seeking advice from trained adults on what to do next for their deaf child (Kurtzer-White & Lutterman, 2003). Kurtzer-White and Lutterman (2003) note both the vulnerability of parents and the challenges faced by professionals:

In short, they are seeking someone who can resolve their confusion and select the “right” course of action. Parental coping in this instance can involve evading taking responsibility for the complex choices facing them. This is a very delicate time in the parent/professional relationship; if the professional assumes responsibility for the parental choices the parents frequently become dependent.

Professionals need to strike a balance in providing important information and support for parents of Deaf children while empowering them to make informed decisions in seeking appropriate
services for their children. As a disability, a child’s deafness calls for a lot of additional decisions that parents must make early on in the child’s life; early intervention programs provide families with the education, resources and support to make informed decisions that are in the best interest of their child (Marachark, 2007).

To fully understand the importance of newborn hearing screening, along with early intervention programs, one must grasp the principles of language acquisition, which is extremely important in a child’s first years of life. There are varying degrees of hearing loss or deficit, but providing even profoundly deaf individuals with some form of communication, like American Sign Language, allows for the acquisition of strong communication skills for the future (Marschark, 2007). Early intervention programs for infants are known as parent infant programs, since parents attend with their newborns (Marachark, 2007). Their goal is to promote strong communication skills early in a child’s life, as well as to teach parents the fundamentals of deafness and proper communication (Marachark, 2007). Communication and language enhancement are a fundamental focus of early intervention programs, but also important are healthy practices and lifestyles that are supported for the entire family.

Other than family support, participation in early education programs enhances the overall development of a deaf child in ways that are extremely beneficial later in life. These programs allow for a deaf child to keep up with, if not exceed, the expectations and accomplishments of their hearing peers. So much of the successful development of a deaf child is dependent on the age of language acquisition, that any delay in language development can ultimately be the root of future problems, whether academic, social or in general communication abilities. If families make no use of a formal language (either speech or sign) in this prime period of a deaf child’s life, the child will learn minimal to no language fluency.
There are different paths families can take in the first years of a deaf child’s life as far as communication preferences, including working with a speech therapist to teach the child speech, using American Sign Language, or practicing both. From personal experience, I am aware that families may struggle to pick a route that will be successful for their child. By focusing too much on teaching speech to a profoundly deaf child, without employing some sign, or even not introducing sign early enough to a mute child, the result can be profound for the child later on. If a family has no knowledge of the services available to them or where to seek professional help, the result would be a serious delay or deficit in the child’s communication abilities.

The process of diagnosing a hearing impairment is unique for every family due to the time it takes the child to initially undergo hearing screening, the diagnosis process, and then the follow up procedures to receive support. In order to allow for optimal language fluency and development, deaf children should start early intervention programming at 6 months (Proctor, Niemeyer & Compton, 2005). Unfortunately, this goal is not always met whether it is the fault of the families or the responsibility of health care professionals. Lack of access may occur because families are not aware of programs, they do not live near programs, or the programs available to them are full due to a lack of staffing or too high of a demand for services. From the perspective of early intervention professionals, there is a clear need for additional training of specialists in early intervention programming to provide needed services to families (Proctor, Niemeyer & Compton, 2005). There is a dire need for more professionals in pediatric audiology, as advancements in newborn hearing screening have created new demand for audiologists for the early years of a child’s life (Roush, 2011). Until recently, the screening process was not as advanced as it is today and the majority of individuals seeking audiology care were much older. Today, the need for audiologists for deaf individuals, as young as infants, is expanding (Roush,
Trained, specialized individuals in the field of early intervention programs for deaf children also need to be considerate of each family’s situation (Sebald & Luckner, 2007). Professionals working in this field must be able to work with each unique family since ultimately, there is no one right answer that can be given to families to ensure the successful and healthy upbringing of their deaf child. By valuing the uniqueness in each deaf child, professionals can both better understand the family dynamic and educate them on the options available to them.

Given the importance of early intervention programs for deaf children and the irreplaceable support these programs provide to families, what improvements can be made to ensure that every deaf child is capable of full language acquisition and adaptation to the hearing world? The current research seeks to explore professionals’ perspectives to help address this question.

**RESEARCH QUESTION**

My senior honors thesis examined early intervention programs for deaf children, specifically from the viewpoint of those professionals working in them. The aim of this research was to document the following: (1) the characteristics of professionals and agencies that provide early intervention services in one major urban area; (2) how these professionals perceived the benefits that these programs provide to enrich the lives of deaf children; and (3) the challenges that they face in providing these services to deaf children and their families. Based on a review of the literature on Deaf culture and families, I have found that there are a variety of views among professionals with regard to how deaf children are raised and educated, which greatly depend on age of diagnosis and family preference. The degree and timing of intervention can have a significant impact on the child’s further abilities in life. The current research focused
specifically on how professionals who work with deaf children perceive these benefits and the challenges they face in providing services to children and their families. This research was inductive, and the aim was to document and examine professionals’ perspectives without a set of predetermined expectations or hypotheses.

METHODS

I conducted my research in the Minneapolis-St. Paul, Minnesota area, which contains a very large deaf-blind community. There is a large presence of schools for both deaf individuals and those studying to work with the deaf. As a large urban area and one of the largest cities in the Midwest, there is a significant population of highly educated and experienced professionals who work with Deaf children and families, many of whom are nationally recognized experts in the study of Deafness.

Procedure

Through Internet research, I developed a list of agencies with specific ties to early intervention programs for deaf children. My first step was to contact individuals at these agencies through email, briefly introducing myself and inquiring about setting up a meeting. The email consisted of the following message (see Appendix A):

Dear [Deaf School Faculty/Professional]:

My name is Emily O'Keeffe, and I recently moved to Minneapolis. I am finishing up my final semester as a Sociology major at the University of Florida, and I am working on my senior honors thesis.

My senior honors thesis focuses on Early Intervention Programs for Deaf children and their families. I am particularly interested in talking with teachers and other professionals who work with Deaf children to learn their perspectives of the benefits and challenges of early intervention programs.

The research involves a 20-30 minute meeting to complete a written questionnaire and brief interview. The meeting would be scheduled at your convenience, with regard to both the time and place of the meeting. If you prefer, I can send the questionnaire to you
to complete in advance, and then follow up with a 10-15 minutes interview in person or by telephone.

I understand that your time is valuable. Your perspectives are very important for understanding both the benefits and challenges of Early Intervention Programs. Your identity will be kept confidential and will not be disclosed in any report.

I hope to hear back from you, as I am eager to hear more about your work with Deaf children.

Further recruitment was conducted by snowball sampling, through which I asked respondents for recommendations of other professionals and agencies in the community that I should contact.

In-person interviews were set up with individuals that replied to this email. The recruitment efforts resulted in interviews with six professionals currently working in deaf education or other intervention services with deaf children or their families. One additional professional agreed to participate in the study but was unable to schedule an interview in the time available for the research study.

The interview process began by presenting respondents with the Informed Consent Form (see Appendix B). My project was approved by the University of Florida Institutional Review Board (2012-U-1031). I discussed the nature of the project and their participation and answered any questions. Once informed consent was obtained, participants filled out the questionnaire while I was present, and I followed with a brief interview. Although I only asked for 20-30 minutes of their time to conduct each interview, the meetings all lasted the full 30 minutes. Some even ran a few minutes over, since each participant had a great amount of information to provide. After the respondents completed the written questionnaire, I asked them to clarify any responses that were unclear, provide greater detail about particular areas of interest to my research, or explain any details I was unfamiliar with. For example, during these interviews if there was a word, phrase or phenomenon I was not aware of, I would ask participants to go into further
detail. As a result, I learned new terms used in Deaf culture as well as the names of other deaf service providers in Minnesota. This was extremely helpful in allowing me to construct a comprehensive review of available services and providers in the area, including many that were new to me. From there, I could develop a better understanding of what early intervention programming is available to families with deaf children, and seek interviews with other individuals or agencies I had learned of.

*Questionnaire*

The questionnaire consisted of nine general questions and covered three basic areas of focus, based on my reading of existing research: their background, their views on what early intervention is and the benefits it provides to families, and finally the challenges they felt both the families and professionals faced. In these three distinct areas, I believe the questions offered the best way to get the most detailed information in the most precise way. The questions are outlined below. First, the following questions collected information about each professional’s background:

1a. Could you briefly tell me your job title and the kinds of work you currently do?

1b. Do you currently work in early intervention programs for deaf children and their families? How much of your work is in this area?

1c. How long have you worked in early intervention programs?

2. What schooling or training led you to this field of work?

3. How did you develop an interest in working with the Deaf community?

This first set of questions allowed me to become familiar with the individuals I was interviewing and their work.
The next set of questions inquired about the perceived benefits of early intervention programs, as outlined below:

4a. In your opinion, what are some of the specific benefits of early intervention programs for deaf children? For parents? For other family members?

4b. What roles do family members play in early intervention programs?

5a. How do families generally discover or get started in early intervention programs?

5b. Is there a usual sequence that children and families go through in early intervention programs? At what point do the programs conclude for the child and family?

6. What is your preference in the use of ASL or speech in early intervention? Do you notice the use of one favorable to the development of the Deaf child? How do you encourage positive communication at home?

This line of questioning gave individuals the chance to define early intervention programs in their own way. Although I expected to hear similar answers in regards to the importance of such programming, by allowing individuals to express this in their own way I expected that the interviews would provide unique and varied perspectives on the nature and value of early intervention programs. This section also provided me with detailed information on the resources available to deaf children and their families in the Minneapolis-St. Paul area.

The final set of questions focused on professionals’ perceptions of challenges and struggles with early intervention programs. Specifically, the following questions were asked:
7a. In your opinion, what do you believe is the biggest challenge or struggle families face when starting intervention programming with a Deaf child?

7b. Any other challenges or struggles? Do these improve over the course of intervention?

8. What advice would you have for someone who is interested in entering this field? What kinds of opportunities and challenges do you think lie ahead for current and future professionals in the field?

This area was particularly important to me, since I felt these questions would produce the largest variety of results. These questions also provided the basis for further discussion in the interview. Although I expected the results to echo observations in existing published research, I was careful not to try to bias respondents towards a particular issue. This allowed me to gain some insight into what truly concerned them in their work with deaf children and their families. The ultimate concern driving my research was to identify what programming is available, whether what is available to families is enough, and if not, what improvements could be made. Therefore, I felt this section was the most informative and of greatest importance to my thesis.

*Follow-up Questions*

The follow up questions in each interview depended heavily on the content of the individual responses. In particular, by using my previous knowledge from my background reading and preceding interviews, I could better recognize what early intervention resources were available in Minnesota and learn more about them through the interviews. For example, if I was aware of a particular deaf school that provided early intervention programming and was speaking to the health department, I could ask for more specific information regarding their
relationship and communication with each other, if any. I also followed up with questions asking respondents to elaborate on their various answers. If I could sense some irritation or disappointment with a support service or dissatisfaction with early intervention programming, I would inquire further. From my own understanding of specific controversies in Deaf culture, I asked additional questions, for example, about their own preferences with regard to teaching a deaf child speech or American Sign Language. I used my knowledge of early intervention as the basis for my questions, combined with the feedback they provided.

Analyses

The completed interviews and surveys were analyzed using qualitative methods to identify the overall accessibility and quality of early intervention programs for families and their deaf children. These qualitative analyses were conducted throughout the process of conducting interviews so that I could record my observations and build on information obtained in previous interviews. The results focus on three main areas of interest: (1) the characteristics of professionals and agencies that provide early intervention services; (2) how these professionals perceived the benefits of these programs; and (3) the challenges that they face in providing these services to deaf children and their families.

RESULTS

The findings in this research can be divided into four sections: a description of variations among the respondents, the services available for Deaf children and their families, perceived benefits of early intervention programming, and the challenges and struggles with programming.

The Respondents

I used Minnesota as the area of focus and interviewed a wide array of professionals, in all stages of the early intervention support model. The first indication of strong programming
available in Minnesota was the broad range of positions occupied in this field. No two individuals I met with had the same job title. In the six interviews I conducted, each individual proved to be significant to deaf children’s success, but had unique duties. The six questionnaires that were completed for my research featured preschool teachers working with children in early intervention programming, state representatives working as liaison between audiologists and support services to families, professionals running the primary state support services to families with hearing impaired children, and even psychologists for the Deaf. Each respondent was female, ranging in age from roughly mid twenties to mid forties.

Each individual had a well-established education, many having both bachelor and master degrees. If the individual did not receive their undergraduate degree in Deaf education, it was in education, often early childhood education, with them later going on to graduate school to acquire a masters degree in Deaf education. Although this background was typical for most of the individuals interviewed, for some professionals Deaf education was only part of their educational background. A few did not have specific educational backgrounds in deaf education, but had experience with deaf children of their own. Interestingly, the older respondents in my research were hearing and had deaf children, and they indicated that their connection to services for the Deaf began later in life after discovering their child’s hearing loss. The younger participants had a hearing loss and had already been acclimated to Deaf society, allowing them to establish themselves in a career of working with the deaf soon after finishing college.

Each respondent emphasized the uniqueness of every child and that the effectiveness of a method of intervention or communication type is dependent solely on the child. Regardless of one’s personal preference with regard to American Sign Language or Speech, ultimately the child should be given a chance with each so that the most effective communication method can
be identified for each child. Furthermore, by receiving information about available services, schools, and communication types, parents can make informed decisions based on their Deaf child’s needs.

Another common point made in the interviews was the goal of full access to language for each Deaf child. In all of my interviews, there was no doubt in the full potential of a deaf child’s abilities. It was very clear that deaf children could be as successful in both school and life when given a language at the proper age. It is mutual understanding that encourages the work these professionals do and the threat of any Deaf child not reaching their potential is truly what motivates each of these individuals.

An observable trend I noticed early on in my research was the strong connection and efficient communication between all of these professionals and various Minnesota agencies. This was apparent in the comprehensive answers I received on early support services for the deaf from each professional I interviewed. With the varied professions of each participating individual, due to their distinct involvement in the development of Deaf children, the feedback I received took into account the child’s transition into support services in its entirety. Their knowledge of early intervention programs was extensive, and they were able to describe in detail the entire process that families take when first learning that their child has a hearing loss. It is apparent in my research that not every interviewee worked directly with early intervention, but this is not to be confused with a lack of knowledge about the services these programs provide. Each individual I interviewed had a fascinating story as to how they ended up in this specific career path: they either had a hearing loss themselves or a family member with some hearing loss. This contributed to the practicality of my thesis, as not only did these individuals incorporate early intervention programming into their careers, they also had a personal
experience with deafness. Essentially, I had the benefit of interviewing individuals about their own personal accounts of hearing loss and the expertise of helping other families with dealing with a hearing loss.

*Deaf Services in Minnesota*

*State of Minnesota Projected Timeline for Early Intervention.* From my interviews I learned that the state of Minnesota has an approximate timeline for the services leading to the timely participation in early intervention programming. Starting with newborn hearing screening at birth, if a hearing loss is detected then audiological follow up is expected to occur by 3 months of age. When this is carried through, the state then plans to offer services by the time the child is 6 months of age.

Early intervention specialists in state Deaf schools conduct home visits with children between birth and 2 or 3 years old. Here, they meet the family, begin providing support, inform them of resources, and assess the newborn for further support. During this time, families attend monthly playgroups, which allow the babies to socialize, and families to meet other adults in similar situations. At the age of about 2 or 3 years old, children begin attending preschool, usually four days a week. At two years old they will attend half days of school and when they are 3 they will start full days. These direct services for families end when the child is 3 years old, although family ASL services continue.

*Location of Services.* As to be expected, many of the Deaf schools and services are found in the most heavily populated areas. Minneapolis is the largest city in Minnesota, and the closer you are to the city the more resources you will find for the deaf. For those living in rural areas of the state or in Northern Minnesota it can be more difficult to gain access to all of the resources provided for Deaf children. Consequently, some families move to be closer to Deaf schools and
services, or early intervention specialists travel to meet with families in more distant or remote areas.

Order of services - Minnesota State Department of Health. The strong ties between agencies in the state of Minnesota were apparent because of the need for these organizations to communicate with each other for the benefit of the hearing impaired child. Essentially, if such agencies failed to connect, families would have a poor understanding of what support services were available to pursue help in a timely fashion. From each of my interviews, I learned of the projected order in which families receive services in the state of Minnesota. First, there is a state mandate that all newborns undergo hearing screening prior to leaving the hospital. If this shows a hearing loss in the child, families are then instructed to meet with an audiologist to undergo further testing. By law, if an audiologist determines that the child has some degree of hearing loss they are required to provide the child’s information to both the state department of health and Minnesota Hands and Voices. The state department of health is a middleman to ensure families are connected to available services. They are responsible for connecting families to early intervention programming and tracking down those who do not follow up with services. This includes a fair amount of behind the scenes work, as well as initial home visits that may be deemed necessary.

Overall, the rate of diagnosis and entry into early intervention programming for those showing a hearing loss was praised by the individuals I interviewed. Each participant felt, to some degree, that when parents were informed of services and in contact with health care professionals, their deaf child could receive all the support they needed. However, concerns were raised about those families that were disconnected from support services.

Lifetrack Resources is the agency I would call essential in the state of Minnesota for
supporting families and ensuring the successful upbringing of deaf children. This is an agency that oversees Minnesota Hands and Voices, the Deaf Mentor Program, along with various speech therapy and early intervention services for the Deaf. Another important agency is Minnesota Hands and Voices, a non-profit organization run by parents of deaf children. The objective of this program is to have parents of deaf children, who have been in this situation, guide and support parents newly experiencing deafness. By providing families with fair and complete accounts of all resources available to them, Minnesota Hands and Voices can educate families facing important choices for their deaf child, including everything from school to communication preference. This program requires that all employees be parents of a deaf child in order to provide the finest and most comprehensive support available. When providing information on resources, Minnesota Hands and Voices must provide an unbiased description of what is available to families. Not only is this done so parents can make their own decisions, but if agencies like Hands and Voices were to provide partial or subjective information regarding resources they would regard this as failing to serve the families.

Minnesota Hands and Voices was mentioned frequently and described in detail during each of my interviews. It is without a doubt an established program that is valued by those familiar with early intervention services for the deaf. The professionals I interviewed were aware that this is one of these best support programs out there and noted the need for similar agencies nationwide.

*Minnesota State Academy for the Deaf.* Minnesota has a state academy for the Deaf, located in Faribault, roughly an hour north of Minneapolis. Here, children live at the school to receive perhaps the best education and support, where they are surrounded by other hearing impaired children. Through these Deaf schools they are able to receive early intervention and
speech therapy. Prior to attending pre-k, teachers working with children between the ages of birth and 3 years old conduct home visits.

**Working with Newborns.** When you think of a newborn with hearing loss, it may be hard to imagine what early intervention specialists can work on with newborns. I learned that even at birth, early intervention specialists can work with deaf children, with practices such as introducing puppets. By engaging these newborns directly, they can build on the skills they will need to communicate and live in a hearing world. At this time, specialists are also able to teach parents sign, so they are prepared if the child begins learning sign later on. When children are a little older, they can begin playing peek-a-boo, rolling balls, and taking turns to develop their skills.

**Additional Services.** Other services I learned of in the metro area of Minnesota included the Metro Deaf School, Volunteers of America, and a variety of schools with unique communication preferences. These included schools that focused on the following communication types: bilingual/ bicultural, American Sign Language only, and cued speech, which uses spoken language and a few hand shapes, not American Sign Language. Although these are not early intervention programs, the importance of such programs is emphasized when learning of a Deaf child’s progress once they are at the school age. To start, Volunteers of American has a Mental health clinic for the Deaf and hard of hearing. This is an incredibly rare and specialized program; in fact it is the only one in the state to provide therapy to this population of individuals. Serving Deaf and Hard of Hearing kids between the ages of 0 and 18, Volunteers of American sees first-hand the stresses and behavior problems that these children experience. They will also tell you that these frustrations are often rooted in communication difficulties, often because hearing loss was not detected at an early age or because adequate
support services were not in place for that child. The school that a hearing-impaired child attends can contribute to these problems: often teachers of the Deaf will tell you a small program for the hearing impaired in a large public school will consist of students with little or no language and with serious behavior problems. The benefits of going to a specialty Deaf school are especially important earlier on. When Deaf children are allowed a less restrictive class with individual focus on each child, you can find hearing-impaired children at just 4 or 5 years old with a language complete with full access to a communication type and good behavior.

Benefits of Early Intervention Programs

It is clear from the details provided by each participant regarding the timeline of services for deaf children that these professionals can achieve so much within the first years of a deaf child’s life. The first indication of this was the recent state mandate that calls for Newborn Hearing Screening before a child can leave the hospital. This is the initial step to detecting hearing loss and connecting families with the necessary resources. Any threat to this vital step compromises a deaf child’s future language acquisition and communication abilities. With a screening rate already at approximately 98% for a mandate just put in place within the last decade, this seems promising for the state of Minnesota ("Minnesota title v," 2004)

If support programming is started at a young enough age, a deaf child has the ability to live comfortably in a hearing world. However, respondents acknowledged that not everyone in need is fully connected to the available services. Listening to all of these professionals speak of the achievements for the deaf in Minnesota, there was a recognition that without families knowing of services or having accessibility to them, their services would fall short of reaching those in need. It is for this reason, I learned, that programs like Hands and Voices are crucial to families’ access to early intervention services. Even in a state like Minnesota, with a nearly
perfect hearing screening rate at birth and well-established early intervention programs, every professional stressed that without accessibility to the services that deaf children and their families are entitled to, these children will have difficulty learning any formal language.

**Challenges in Providing Services**

Professionals working in early intervention programming noted several flaws and challenges in working in these agencies. Starting with initial consults with health care professionals, there still remains a fair number of children with a hearing loss that are lost to follow-up. This means that even with the 10,000-plus phone calls a year that the state health department makes to attempt to close such cases, they still lose contact with some families. This is often the result of children being retested and passing the hearing screening or families moving without contacting their local health department. Regardless of the reason, Minnesota is unable to answer for the whereabouts or progress of every child displaying a hearing loss at birth. This uncertainty is unsettling knowing the consequences of delayed access to support services for a Deaf child.

Expanding on problems with initial connection to early intervention, advocacy was a big concern found in my research. Given that most parents with Deaf babies have no experience with hearing loss, this is a completely new experience. Families do not yet understand the needs of their deaf child and how to access those services available to them. They truly will only know information regarding support services from their initial contacts, whether that is a doctor, nurse or early intervention specialist. How much, or little, these first contacts choose to share with them about their early intervention options can have a big influence on the next steps and choices that the family of a deaf child makes.
Specifically in Minnesota, the cluster of services within the Twin Cities or in a near suburb seems to be well equipped. Unfortunately, for the rest of the state not as many services are available for the Deaf. Having limited access to early intervention can risk the child’s proper development of a language and cause greater problems as he or she gets older. Living outside of support services often leads to early intervention specialists having to travel to visit families and perhaps not being able to meet with them as frequently. If families decide that their child needs to be closer to support services they often have to choose between commuting over the long distance, moving their family, or sending their child to the state Deaf academy, which houses students. Ultimately, the only clear solution to this problem seems to be opening more early intervention locations across the state.

Furthermore, if families choose hearing aids or cochlear implants for their child, there are further dilemmas and complications. With hearing aids, the turn around time once a hearing loss is detected and the child meets with an audiologist can be over a month. Having to wait over a month is deemed too long, and improvements need to be made in this process. To put it simply, as a deaf child’s language acquisition phase is incredibly sensitive, any further delay, like waiting for a hearing aid to use in speech therapy, can threaten their future abilities in the use of a language. For families that decide to obtain a cochlear implant for their child, it is important to note that this does not mean that the child will be fully is hearing. Even with an implant, their child is still deaf and will require support services, particularly speech therapy. As each child is unique, various factors, like the age at which the child received a cochlear implant, play a role in a deaf child’s use of speech or English. Oversimplifying the process and over-estimating the benefits of a cochlear implant can mislead people to believe that a child with an implant can attend a mainstream school or only associate with hearing friends, without need for specialized
education for the Deaf. Social misconceptions like these may oversimplify a deaf child’s use of a very exceptional device; no Deaf child, with or without implants, is actually fully hearing.

**DISCUSSION**

_Relationships Among Agencies_

Across this small group of interviews, I found that the interviews often built on each other and allowed me to learn about the broader context of services for Deaf children and the agencies that offer these services. Going into my first interview, I was unaware of many of the programs that Minnesota has to offer. Since many of these agencies interact with one another, I was able to get a broad view of how exactly the early intervention programs in Minnesota work and how the agencies involve one another. The state has contracts with agencies to provide support to families, so as soon as the child is diagnosed with some hearing impairment, there is a specific line of action that is automatically taken. With this being said, in the questionnaires regarding early intervention programming as a whole, individuals were not only able to provide me with detailed responses, but they were also able to recommend other agencies or individuals to contact for interviews. This high level of interaction among agencies and professionals reflects a remarkably organized, coordinated system in which multiple individuals and organizations play an important role in the success of early intervention programming overall.

After a thorough analysis of all the resources Minnesota has to offer to Deaf children and their families, I was able identify the support services that are available and get an overall sense of how effective they are. It is clear from my interviews that there is an amalgam of support services available to Deaf children and their families. With Minnesota Hands and Voices offering guidance to families, organizations like Volunteers of America specializing in therapy for the Deaf and Hard of Hearing, and Deaf schools focusing on unique communication types,
there seems to be a wide variety of available options. By speaking directly with the professionals providing these services, I was able to examine the strengths and weaknesses of available early intervention services in Minnesota.

Strengths and Limitations

I was fascinated to learn of the innovative nature of the existing agencies, like Minnesota Hands and Voices. I could not imagine a better group of individuals to assist parents with newborn hearing impaired children. The organized mentoring by parents of deaf children allows parents with newly diagnosed children to be informed and to feel confident in their decisions. This mentoring offers parents the comfort of knowing their child will receive prompt care and attention. Furthermore, having schools specializing in particular communication types allows families to experiment with various language preferences and ensure that they can discover the form that works best for their child. Once a formal mode of communication is established, families can practice both in the home and outside of the home. By finding a school that encourages the use of their child’s communication preference, parents can ensure that their child’s language abilities will not be compromised.

The vast number of choices that parents must make early on seems very overwhelming, and the time it takes to undergo audiological testing and the initial support service referral seems to create a time gap in which parents are especially vulnerable. That is, if the state can even get through to families and set them up with programs available to them. When families are participating in early intervention services, they weigh the decisions they will make for their deaf child heavily with the input they receive from the professionals in these agencies. As each child is unique, there is no one solution that can be given to all parents. Families face the risk of receiving partial or biased accounts of available options for their deaf child. Although most
agencies pride themselves on the exceptional information they provide to families, one respondent voiced concern in this matter. This was a controversy I was familiar with from my readings, and this individual feared that families may occasionally be presented with one-sided, biased advice that can negatively influence the decisions they make for their Deaf child. Even if done unintentionally, providing families with anything less than every available option for their Deaf child is an injustice to the child.

Overall, interviewing six people allowed me to explore the topics in depth with a small set of professionals in the field. Although this permitted a qualitative analysis of the perceptions of these professionals, it was clear to me that much more time would be needed to expand my findings to be as comprehensive and representative as possible. Fortunately, I was located exactly in the cluster in which many support service agencies were located. Seeking respondents in less populated areas of the state might have offered additional perspectives, though the centralized nature of the programs in Minnesota suggests that going further out from Minneapolis-St. Paul may not necessarily have offered more diversity in the results. I feel that the people I interviewed were able to provide me with a broad view of services across the state of Minnesota.

Final Comments

What are the perceptions of early intervention services to Deaf children and their families to those professionals working in them? In Minnesota, I believe that there is no one person that can answer this question. Given the involvement of so many professionals to determine hearing loss, connect families to support services, provide the services, and then work with a child after early intervention programming, this is a team effort. Given that early intervention, for a large part, has much to do with connecting and educating families, as well as providing direct services
to deaf children, there are many components to early intervention that need to be looked at to answer this detailed question. Overall, I was impressed to find that Minnesota had established services in each of the areas I had learned of in my background readings.

Throughout my interviews, I was most impressed by the background of each person I interviewed, as they were each highly educated and experienced with Deaf Culture. The need to expand the availability of services across the state is the largest threat to families seeking help with their hearing impaired newborn. It is vital that these individuals and agencies continue to advocate for the Deaf and teach others of the services they are entitled to. With this growth of knowledge and support, early intervention programming will enhance the lives of countless Deaf children and their families. My overall observation based on my research is that the available early intervention programs for Deaf children in Minnesota are highly developed, but the perpetual risk of families not having full access to these agencies, regardless of the exact reasons, places a shadow over their successes -- if one child misses out on the early intervention support services for both them and their families, the state has failed them.

The interviews confirmed a crucial observation from my readings. The education of those entering the field of early intervention is a vital means to enhancing programming, and ultimately will be very telling of the futures success of such support services. There needs to be a greater focus on deafness in infants, which requires a specialized training of pediatric nurses and audiologists. By promoting the availability of such specialized fields of study, higher education institutes can produce individuals trained specifically in dealing with childhood deafness. This in turn would directly address the need for more specialists in early intervention programs. By staffing a high quantity and quality program, not only are these agencies able to serve more families and children who are deaf, but this can provide an overall benefit with regard to the
experiences that families have in early intervention. Providing more professionals in the field of early intervention means that more families may benefit from their services in a positive way, which can spread the word about such services. Ultimately, if more families with deaf children are aware of such programming they have a better chance of actually getting involved. All of these steps consequently benefit the next, providing children who are deaf with more accessible care.

Reflections on the Research

Reflecting on my own role in this thesis project work, the experience of interviewing professionals actively working in the field was incredibly enriching to my understanding of the area and built on my previous coursework. I was able to combine my sociological knowledge with my interest in Deaf culture and American Sign Language. I was able to reflect on the lessons I learned in my undergraduate sociology courses and apply them to Deaf culture, and I was able to complete a thesis that would greatly benefit me in the future. By researching an area encompassing both my academic and personal interests, I was able to learn more about a profession I am interested in as a future career. Through my qualitative approach to this research, I sought to understand each individual’s training, including their educational background. This was both important to my research and helpful to me, as I could see the variety of educational backgrounds that led each individual I interviewed to their career in early intervention programming. As I am preparing to graduate, this thesis allowed me to put all my undergraduate experience into one assignment, and plan for my future, by showing me the different paths I could take to work with Deaf children in the future.
REFERENCES


APPENDIX A: RECRUITMENT EMAIL

RECRUITMENT EMAIL TEXT:

Dear [Deaf School Faculty/Professional]:

My name is Emily O'Keeffe, and I recently moved to Minneapolis. I am finishing up my final semester as a Sociology major at the University of Florida, and I am working on my senior honors thesis.

My senior honors thesis focuses on Early Intervention Programs for Deaf children and their families. I am particularly interested in talking with teachers and other professionals who work with Deaf children to learn their perspectives of the benefits and challenges of early intervention programs.

The research involves a 20-30 minute meeting to complete a written questionnaire and brief interview. The meeting would be scheduled at your convenience, with regard to both the time and place of the meeting. If you prefer, I can send the questionnaire to you to complete in advance, and then follow up with a 10-15 minutes interview in person or by telephone.

I understand that your time is valuable. Your perspectives are very important for understanding both the benefits and challenges of Early Intervention Programs. Your identity will be kept confidential and will not be disclosed in any report.

I hope to hear back from you, as I am eager to hear more about your work with Deaf children.

Sincerely,

Emily O'Keeffe
eok514@gmail.com

Approved by
University of Florida
Institutional Review Board 02
Protocol # 2012-U-1031
For Use Through 10-03-2013
APPENDIX B: INFORMED CONSENT

Informed Consent
Protocol Title: Early Intervention Programs for Deaf Children

Please read this consent document before you decide to participate in this study.

Purpose of the research study:
The purpose of this study is to examine the perspectives of trained professionals regarding early intervention programs for deaf children, particularly the benefits and challenges of early intervention programs.

What you will be asked to do in the study:
You will be asked to complete a 3-page survey. The survey includes questions about your work and educational background, how you became involved in early intervention, and the benefits and challenges of providing these programs to deaf children and their families. After you complete the survey, you will be asked to complete a 10-15 minute interview (in person or over the phone) to clarify any responses and to answer a few additional questions.

Time required: 20-30 minutes

Risks and benefits:
We do not anticipate that there would be any risks to you participating in the study. We do not anticipate that you will benefit directly by participating in this survey.

Compensation: None.

Confidentiality:
Your identity will be kept confidential to the extent provided by the law. Your information will be assigned a code number. Your signed consent form will be kept in a locked file in the Principal Investigator’s office and will not be linked to your completed survey. Upon completion of the study, the list will be destroyed. Your name will not be used in any report.

Voluntary participation:
Your participation in this study is completely voluntary. There is no penalty for not participating.

Right to withdraw from the study:
You have the right to withdraw from the study at anytime without consequence.

Whom to contact if you have any questions about the study:
Tayna Koropeckyj-Cox, Ph.D., 3353 Turlington Hall, (352) 294-7177

Whom to contact about your rights as a research participant in the study:
UFIRB Office, Box 112250, University of Florida, Gainesville, FL 32611-2250; (352) 392-0433

Agreement:
I have read the procedure described above. I voluntarily agree to participate in the procedure and I have received a copy of this description.

Participant: ___________________________ Date: __________

Principal Investigator: ___________________________
APPENDIX C: QUESTIONNAIRE

Survey: Early Intervention Programs for Deaf Children
Questions for Early Intervention Professionals

A. Background

1a. Could you briefly tell me your job title and the kinds of work you currently do?

1b. Do you currently work in early intervention programs for deaf children and their families? How much of your work is in this area?

1c. How long have you worked in early intervention programs?

2. What schooling or training led you to this field of work?

3. How did you develop an interest in working with the Deaf community?

B. Perceived Benefits of Early Intervention Programs

4a. In your opinion, what are some of the specific benefits of early intervention programs – for deaf children? For parents? For other family members?

4b. What roles do family members play in early intervention programs?

5a. How do families generally discover or get started in early intervention programs?

5b. Is there a usual sequence that children and families go through in early intervention programs? At what point do the programs conclude for the child and family?

6. What is your preference in the use of ASL or speech in early intervention? Do you notice the use of one favorable to the development of the Deaf child? How do you encourage positive communication at home?

C. Perceptions of Challenges and Struggles with Early Intervention Programs

7a. In your opinion, what do you believe is the biggest challenge or struggle families face when starting intervention programming with a Deaf child?

7b. Any other challenges or struggles? Do these improve over the course of intervention?

8. What advice would you have for someone who is interested in entering this field? What kinds of opportunities and challenges do you think lie ahead for current and future professionals in the field?

Thank you very much for your help!