

TYPES OF STRESS PLACED ON PARENTS OF DEAF CHILDREN WHEN  
DECIDING ON COCHLEAR IMPLANTATION

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ABSTRACT

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Types Of Stress Placed On Parents Of Deaf Children When Deciding On Cochlear Implantation

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Parents need to make complex, tough decisions about their children's welfare all of the time. This is especially true for parents of deaf children. One such decision for parents of deaf children is in deciding how their child should communicate in the world. These parents need to decide if they want their child to live in the Deaf community or if their child should live in the hearing world. This is a hard decision to make since it touches all aspects of the child's life.

A relatively new decision that parents need to make is in deciding if their child should receive a cochlear implant. The topic of cochlear implantation is a highly controversial topic and both sides of the debate are passionate about their beliefs. Individuals who favor cochlear implantation feel it is in the best interest of the children. Cochlear implantation gives the children a chance to hear the world around them. Many parents feel that they want their child to have as "normal" of a life as possible.

The Deaf community opposes cochlear implantation. They visually demonstrate their discord by the ASL sign for cochlear implant. The ASL sign for cochlear implant contains a two-fingered stab to the back of the neck, indicating a "vampire" in the cochlea (Tucker, 1998). Members of the Deaf community do not view their deafness as a disability. Rather, many Deaf

individuals view themselves as a minority group that has its own distinct history, language, and value system. The belief that being Deaf is a culture is mainly based on ASL. This form of communication is a distinct language with its own syntax and grammar (Crouch, 1997; Tucker, 1997).

Many individuals who are Deaf do not perceive being Deaf as a problem. Kristin Snodden received a cochlear implant in 1990, at age 15 (Swanson, 1997). She described it as “the darkest period of my life. When my parents confronted me about this implant...I was shocked, because I did not think there was anything wrong with me physically, emotionally, and mentally” (p. 931).

It is apparent from the readings that cochlear implantation is a highly debatable subject. Parents want to do what is in the best interest of their children and the researcher wondered if parents were faced with an abundant amount of pressure when deciding on cochlear implantation for their children. The researcher wanted to examine how much pressure is placed on parents from the Deaf community versus the hearing world. The research attempted to answer the following questions:

1. What types of pressure were felt by the parents when deciding on cochlear implantation?
2. What community placed the most pressure on the parents?
3. Did the pressure change the parent’s view of cochlear implants?
4. What percentage of deaf children of hearing parents received cochlear implants?
5. What percentage of deaf children of deaf parents received cochlear implants?

This study included parents in Wisconsin and Minnesota who had to decide upon cochlear implantation for their children. The decision by the parents had to have been made

before the child reached age 10 to qualify for this study. Parents who chose to allow their children to receive cochlear implants, as well as parents who decided against implantation were included in this study.

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## CHAPTER ONE

### Introduction

When a child is born deaf, undoubtedly, the child and his or her family will encounter certain obstacles to overcome. One such obstacle is deciding whether the child should live in the Deaf community, or should the child try to live in the hearing world. This is often a much harder decision for parents to make than it may initially appear.

When parents are deciding this, it is a very hard and complex decision to make. A decision needs to be made on whether or not the child will learn American Sign Language (ASL) or Signing Exact English (SEE). The parents may also need to decide if the child will learn lip-reading, with the aid of hearing devices. ASL is the most commonly used form of sign language and bears little resemblance to English, due to the fact that ASL has its own syntax and grammar. For example, an English-speaking person might ask, "Have you been to San Francisco?" and an ASL user might sign or write, "Touch San Francisco yet you?" (Tucker, 1997).

### Education

Educational choices are also an integral part in deciding whether the child should live in the Deaf or the hearing community. Parents are forced to choose if they want their child mainstreamed with hearing children in the public school system, or to enroll their child in a private school for the Deaf. In 1975, the Individuals with Disabilities Education Act (IDEA-B) mandated that deaf children be mainstreamed into regular hearing classrooms. This law was enacted so that the oral skills of deaf children would improve, as well as their emotional and social skills. Unfortunately for some deaf individuals, as access to oral education increased, there was a decrease in their quality of education (Crouch, 1997). Additionally, deaf students



often had to endure unskilled ASL interpreters. For many deaf students, being mainstreamed into the public school system can also be socially difficult. As stated in Crouch (1997), a boy in the eighth grade who spoke before the U.S. National Council on Disabilities testified that “Learning through an interpreter is very hard; it’s bad socially in the mainstream; you are always outnumbered; you don’t feel like it’s your school; you never know deaf adults; you don’t belong; you don’t feel comfortable as a deaf person” (p. 20).

### Educational Expenses

Although there are disadvantages to mainstreaming deaf children in public schools, there are also reasons to mainstream. One such reason is money. The costs of special schools for the deaf are high. One study estimated that the yearly cost of educating one child in a residential school for the deaf is \$35,780 and educating one child in a self-contained class for the deaf in a public school costs approximately \$9,689. To educate the same child in a regular classroom will cost only \$3,383 per year (Tucker, 1998). In 1997, Phoenix Day School for the Deaf, located in Phoenix, Arizona, had a budget of nearly \$5.8 million to educate approximately 230 children. In addition, the federal budget for Gallaudet University’s college programs for deaf students in 1995 was \$54.2 million (Tucker, 1998).

### Technological Advances

Cochlear implants play a tremendous part in deciding whether a child will be part of the Deaf community or the hearing community. For many individuals, cochlear implants have become a source of hearing, but for many in the Deaf community, cochlear implants are inhumane, as well as unnecessary. A study has shown that children who received a cochlear implant between the ages of 2 and 13 years, and had an average of 63.3 months of cochlear-implant experience, attained higher reading-achievement levels than children who are deaf

(Spencer, Tomblin, & Gantz, 1997). Another study showed that after five years of implant use, the mean score for correct pronunciation of vowel sounds was 70% (Crouch, 1997).

Many individuals believe that this statistic means that cochlear implants are successful. Other individuals think that this is only a modest gain when considering what the individual must go through. The children in this study had to endure five long, hard years of language training. In some individual's eyes, 70% is not a high enough number to undergo the training (Crouch, 1997). In another study, speech intelligibility of prelingually deaf children who had used their cochlear implant for 3½ years or more was measured. The results indicated that only 40% of words spoken by these children were understood by a panel of three persons (Crouch, 1997).

### Decision

Deciding whether or not your child should enter into the hearing or Deaf community is a serious decision. Parents want the best for their children and may find themselves torn between two completely opposing views. Since the decision for cochlear implants usually takes place before the child can produce language, the decision lies solely with the parents. This can be a huge burden on parents. Will the surgery work? To what degree will their child be able to hear? Will the surgery put their child in more pain than it is worth? Will the child reject the parent's decision when he or she is older? Will the child hold this against the parents? How will other people accept the child? These are some of the questions that parents will ponder when deciding their child's future.

### Social Pressure

There is more to the decision than just determining what is best for the child. Both the Deaf community and the hearing community can place pressure on the family. This research will examine the pressures that parents encounter from both communities. The researcher

believes that great stress and pressure is added to making this decision. The study would also like to examine whether parents had their views changed by the Deaf or hearing communities.

It is hoped that this research may help families of deaf children make an informed choice about cochlear implants. Parents should consider both sides of the issue before making a final decision as to whether cochlear implants are a wise choice for their child.

### Statement of the Problem

The purpose of this study is to examine the pressures felt by the parents of deaf children when deciding on cochlear implantation. A literature review will be completed, and a survey will be implemented to gather information will be conducted in the summer of 2001.

### Research Questions

There are five questions this research wishes to address. They are:

1. What types of pressure were felt by the parents when deciding on cochlear implantation?
2. What community placed the most pressure on the parents?
3. Did the pressure change the parent's view of cochlear implants?
4. What percentage of deaf children of hearing parents received cochlear implants?
5. What percentage of deaf children of deaf parents received cochlear implants?

### Definition of Terms

For clarity of understanding, the following terms need to be defined. Many definitions were obtained by using the Encyclopedia of Deafness and Hearing Disorders (1992). Definitions not found in the Encyclopedia were listed by the researcher's knowledge and are marked with an asterisk (\*).

American Sign Language (ASL) – A visual, gestural language, rather than spoken language, which has its own syntax and grammar.

Cochlear implant – A surgically implanted device implanted in the mastoid bone to stimulate the hearing nerve and enable a hard-of-hearing person to perceive some sound. The implant restores some hearing and speech understanding to individuals who are deaf.

deaf (\*)– Individuals who are deaf (with a small ‘d’), are impaired in their ability to hear, but have assimilated into the hearing society and do not view themselves as members of a separate culture.

Deaf (\*)– Individuals who are Deaf (with a capital ‘D’), consider themselves as members of a separate Deaf Culture.

Postlingual deafness – Deafness occurring after acquisition of language.

Prelingual deafness – Deafness occurring before acquisition of language.

Signing Exact English (SEE) – A visual form of language that uses the same rules as English. SEE uses only one sign to represent an English word that may be expressed by several signs in American Sign Language, depending on the meaning of the word in context.

### Assumptions and Limitations

There are a couple of assumptions and limitations that are apparent in this research.

These are:

1. All subjects will answer truthfully.
2. The sample size selected is just a small portion of the deaf population.

## CHAPTER TWO

### Literature Review

This chapter focuses on pertinent topics relating to deafness. This chapter will begin by explaining how sound is transmitted through the ear and to the brain. An understanding of how sound is transmitted is necessary in order to comprehend how cochlear implants function, which will be explained afterward. In this chapter, it will also be imperative to discuss the Deaf culture. This will include the Deaf culture's belief system, and their views on cochlear implants. The Americans with Disabilities Act (ADA) will also be discussed in brief detail, as well as a conflict that occurs between the Deaf culture and the ADA. The chapter will conclude by examining the hearing culture views on deafness.

#### Sound Transmission

Understanding how cochlear implants work is best accomplished by understanding how in normal hearing, sound is transmitted through the ear and to the brain. Our hearing mechanism can be easily divided into three parts. When working together, the outer ear, middle ear, and inner ear make up our hearing system.

#### Outer Ear

The outer ear consists of the pinna (ear), the external auditory meatus (ear canal), and the tympanic membrane (eardrum). The role of the pinna is to act as a funnel collecting sound waves. The waves need to travel through the ear canal to reach the tympanic membrane. The tympanic membrane separates the outer and middle ears. When the sound waves hit the tympanic membrane, the membrane vibrates.

### Middle Ear

The middle ear consists of three small bones, or ossicles, known as the malleus (hammer), incus (anvil), and stapes (stirrup). These bones act as a lever system, driven by the tympanic membrane. The malleus is attached to the tympanic membrane, and as the tympanic membrane vibrates, the malleus is moved. As the malleus moves, the incus gets pushed, and the incus propels the stapes. As the stapes moves, the footplate of the stapes fits into the oval window and hits a membrane covering the oval window. The oval window is at the base of the cochlea, which is part of the inner ear (Sherwood, 1997).

### Inner Ear

The inner ear is made up of a pea-sized, snail-like structure called the cochlea. This coiled, tubular system lies deep in the temporal bone (Sherwood, 1997). At the base of the cochlea is the oval window, and tip of the cochlea is called the apex. Throughout the cochlea, there are two canals and a duct. The vestibular and tympanic canals contain a fluid called perilymph. The cochlear duct contains another fluid called endolymph (Sherwood, 1997). Thin membranes separate the canals. The Reissner's membrane separates the vestibular canal and the cochlear duct, and the basilar membrane separates the tympanic canal and the cochlear duct (Sherwood, 1997).

### Organ of Corti

The Organ of Corti is a gelatinous mass that is enclosed in the cochlea and is the sense organ for hearing (Sherwood, 1997). It spirals around within the cochlea. It is filled with a fluid, surrounded by other fluid. The Organ of Corti responds to the movements in the fluids, which were induced by sound waves.

The Organ of Corti is supported by the basilar membrane. Within the Organ of Corti is a mass of cells that contain fine hairs. The ends of the hairs are embedded in a thick, overhanging sheet, known as the tectorial membrane (Sherwood, 1997). As the basilar membrane moves, so does the Organ of Corti. Pressure waves in the scala vestibuli are transferred through the thin vestibular membrane, into the cochlear duct, and then through the basilar membrane into the scala tympani, where they cause the round window to bulge in and out. Since the hairs have their tops embedded in the tectorial membrane, and their roots fixed in the hair cells, the motion of the basilar membrane bends, twists, pulls, and pushes the hairs. The movement of the hairs generates electrical signals, which then stimulates the auditory nerve, which is also known as the acoustic nerve and the eighth cranial nerve.

#### Cochlea to Brain

The fibers that make up the auditory nerve are grouped by the frequency of a sound signal. In addition, the number of fibers a sound requires gives the brain an idea of the intensity of the sound. When these electrical impulses reach the brain, the electrical stimulation is recognized as sound.

#### How Cochlear Implants Work

Cochlear implants are designed to bypass the damaged part of the hearing mechanism and directly stimulates the auditory nerve to send information to the brain. The cochlear implant consists of three parts: receiver, headpiece, and speech processor (Cochlear Implant Association, 1997).

The receiver is implanted in the individual's head. It is placed under the skin, behind one ear. A wire leads from the receiver to an electrode that is placed 25 millimeters into the cochlea

(Lane, et al, 1996). The receiver is magnetic and is approximately the size of a quarter (Cochlear Implant Association, 1997).

The headpiece is worn behind the ear and contains the microphone that picks up the sound and the transmitter sends the sound through the system. Approximately four to six weeks after the surgery, the headpiece is fitted (Cochlear Implant Association, 1997). The headpiece is held in place over the implanted receiver by small magnets.

The speech processor is needed to amplify the sounds picked up by the microphone and is worn on the body. The speech processor can be worn on a belt or in a pocket and is attached to the transmitter by a cord.

Once the cochlear implant is in place, the system begins to work by sound waves entering the microphone, which is in the headpiece. The sound is then sent through the transmitter and along a wire to the speech processor. The speech processor converts the sound into a signal that is sent to the implanted receiver. The receiver sends the signal to the brain, where it is interpreted as sound (Cochlear Implant Association, 1997).

Currently, cochlear implant surgeries are performed on one ear only. There have, however, been a few bilateral surgeries completed (Cochlear Implant Association, 1997). These bilateral surgeries have been done within recent years, and as the success rate is evaluated on these individuals, decisions will be made about operating on both ears for other individuals.

The surgery may be done as an outpatient or may require a short hospital stay. For adults, the surgery takes between two to three hours; children, however, take longer (Cochlear Implant Association, 1997). For children, the surgery may last approximately five hours and usually requires an overnight stay in the hospital.



### Cost of Cochlear Implantation

The total cost of a cochlear implant, which includes pre-surgical testing, medical personnel services, surgery and hospital fees, and the implant device itself, costs between \$30,000 and \$50,000 (Cochlear Implant Association, 1997). In almost all cases, insurance covers the costs. The costs may also be covered by Medicare, Veterans Administration, Children's Special Services, and State Vocational Rehabilitation Services (Cochlear Implant Association, 1997).

### Deaf Culture

Individuals in the Deaf community do not view themselves as being disabled. Rather, many Deaf individuals see themselves as a minority group that has its own distinct history, language, and value system. One Deaf man was quoted in ASHA (1995) as saying:

I am not hearing-impaired. The word "impaired" implies a problem, and I, as well as many other Deaf people, do not perceive being Deaf as a problem. Deaf adults...would rather be viewed as a minority group with their own language and culture (p. 59).

Janice Springford, deaf since age eight, was quoted in Swanson (1997) as saying that "deaf is not bad, deaf is not wrong, deaf does not need to be fixed. What is between the ears is a lot more important than what goes in the ears"(p. 930).

As Tucker (1997) explained, Deaf culturists claim that deaf individuals are "in no more need of a cure for their condition than are Haitians or Hispanics" (p. 30). The belief that being Deaf is a culture is mainly based on ASL. This form of sign language is a distinct language with its own syntax and grammar (Crouch, 1997; Tucker, 1997). The Deaf community feels that since they have their own language, they are a minority group, like Native Americans or Italians.

### Deaf culture's view on cochlear implants

Since the Deaf community does not consider deafness as a disability, they view cochlear implants as unnecessary and unwelcome. The implant suggests that deaf individuals need to be cured. Kristin Snodden received a cochlear implant in 1990, at age 15 (Swanson, 1997). She describes it as “the darkest period of my life. When my parents confronted me about this implant...I was shocked, because I did not think there was anything wrong with me physically, emotionally, and mentally” (p. 931). Snodden became deaf at five years of age and remembered hearing sound and voices. She was disturbed that the implant was “not like hearing at all—it was like vibrating in my skull [and] was very annoying” (p. 931).

Members of the Deaf community also feel that children with cochlear implants have their lives centered upon their disability. These children are always aware that they are outsiders who are trying to be on the inside (Crouch, 1997). Crouch continued by stating that children using cochlear implants will not be totally viewed as “normal” in the hearing world, and will feel like an outsider. The child will also be condemned from the Deaf world as well, since the Deaf community frowns upon individuals with cochlear implants. Therefore, the child will not belong to any group and will always be an outsider.

The Deaf community is also concerned about the psychological effects that can occur from implantation. Dr. Hartley Bressler is a family physician who is deaf and is quoted in Swanson (1997) as stating “Deafness is not something you should make a child feel defective or incomplete about.” He goes on as saying, “I wonder about the future self-esteem of a child who is aware that she or he has undergone major surgery for a prosthetic device, not to save life, but to please parents” (p. 932).

Additionally, prelingually deaf children using a cochlear implant must be intensively taught and trained through the speech process. They need to learn to recognize and produce each vowel and consonant sound. Every word they learn needs to be taught from the ground up. Therefore, for the implant-using prelingually deaf child, the development of their oral language skills is a long and difficult task. To make the situation worse, there is no guarantee that the goal of oral language may be reached (Crouch, 1997).

From the readings, it is obvious that the Deaf culture is opposed to cochlear implants. The ASL sign for cochlear implant visually demonstrates this. The ASL sign for cochlear implant contains a two-fingered stab to the back of the neck, indicating a “vampire” in the cochlea (Tucker, 1998). As Tucker (1997) explained, to the Deaf community, cochlear implants represent “the ultimate invasion of the ear, the ultimate denial of deafness, the ultimate refusal to let deaf children be Deaf” (p. 30). A former president of the National Association of the Deaf (NAD) was quoted in Tucker (1997) as criticizing cochlear implants as a form of “assault...by zapping the auditory nerve tissue electrically” (p. 30). He described this as being comparable to the beating of a blind man to make him see stars. Roz Rosen, another former president of the NAD, was quoted in Tucker (1998) as stating that since “[h]earing is not a life or death matter...[it is] consequently not worth the medical, moral and ethical risk of altering a child” (p. 9).

Many individuals in the Deaf community feel that hearing parents of deaf children need to better understand Deaf culture before they make a decision about cochlear implants. They suggest early contact with people in the Deaf community to expose the parents to successful and happy Deaf individuals (ASHA, 1995). The Deaf culture believes that cochlear implants deprive individuals of the linguistic, educational, and social opportunities that the Deaf community can

offer (Crouch, 1997). Other members of the Deaf community feel that parents should not make decisions about cochlear implants for their children, but that the children should make the decisions themselves when they are old enough to do so. However, it has been proven, as Tucker (1998) pointed out, that early implantation is necessary for maximum results. Therefore, waiting 10 to 15 years is like deciding that the child will not have an implant.

### Americans With Disabilities Act (ADA)

Since deafness poses limitations in communication, it is without doubt that certain communication obstacles would exist. Since the ADA was passed in 1990, many of the communication barriers have been removed. Historically, however, many forms of discrimination existed, one of those barriers being the telephone system (Tucker, 1997). Without an accessible telephone system, deaf individuals were excluded from certain jobs, social functions, and many other activities.

Television was another obstacle (Tucker, 1997). Deaf individuals were unable to watch the news and also were unable to receive emergency broadcast warnings. Movies and plays were also unavailable to the Deaf community, as well as other forms of entertainment.

A third obstacle was the communication barrier that made everyday life difficult (Tucker, 1997). Due to a lack of interpreters, many deaf individuals were unable to properly communicate with their doctors, lawyers, or other professionals. In addition, many deaf people were unable to participate in government and non-government programs. Deaf individuals also lacked equal or fair access to the courts, due to the lack of interpreters.

It is evident that deaf individuals did not have fair treatment due to both intentional and unintentional discrimination. Therefore, deaf and hard-of-hearing individuals were heavily involved in advocating for the passage of the ADA (Tucker, 1997).

Since the ADA was passed in 1990, the world has been opened up to people with hearing impairments. Title I of the ADA prohibits both public and private employers from refusing to hire or promote an individual because of his or her hearing impairment and requires employers to provide reasonable accommodations for applicants or employees who are deaf or hard-of-hearing (Tucker, 1997). Reasonable accommodations may include the provision of special equipment, such as teletypewriters (TTYs) or amplified telephones, assistive listening devices, qualified interpreters, real-time captioning, or any other necessary services to allow the particular individual with a hearing impairment to perform the job or task at hand.

Title II of the ADA requires state and local government entities to make their programs and services fully accessible to deaf and hard-of-hearing individuals (Tucker, 1997). This includes any necessary aid to allow equal participation by individuals with hearing impairments. Places and services affected by Title II include the court system, government meetings, state colleges and universities, libraries, state offices, transportation terminals, and telephone emergency services.

Title III of the ADA requires all public accommodations to ensure that deaf or hard-of-hearing people may benefit equally from the goods or services they provide (Tucker, 1997). This includes motels, restaurants and bars, movies, theaters, concert halls, stadiums, stores, banks, doctors' and lawyers' offices, museums, parks, day care centers, homeless shelters, and gyms. In addition, Title III requires that all newly constructed and altered places of public accommodation and commercial facilities, such as factories, warehouses, and office buildings, must be fully accessible to people with hearing impairments.

Title IV of the ADA amends the Communication Act of 1934 to require that all telephone companies provide 24-hour-a-day, seven-day-a-week telecommunications relay services to allow deaf and hearing-impaired persons access to the telephone (Tucker, 1997).

The ADA provides many benefits to persons who are deaf and hard-of-hearing. Making the necessary accommodations is very costly. Since deaf individuals have the same rights as the general public, the costly expense for making the necessary accommodations is placed on the private sector and on state and local governments (Tucker, 1997).

### ADA Conflict

However, a conflict becomes apparent between the Deaf culture beliefs and the ADA. As stated earlier, the Deaf culture clearly articulates that being Deaf is not a disability, but a culture. If being Deaf is not a disability, why were members of the Deaf community so heavily involved in the passage of the ADA?

Many of the accommodations listed in the ADA were very costly. For example, Title IV of the ADA mandated telephone relay services. In 1995, Arizona Relay Service employed 140 to 160 relay operators, in addition to administrative and technical personnel. The relay operators processed approximately 60,000 calls per month. The cost for this service to Arizona telephone users was approximately \$300,000 per month, or \$3.6 million per year (Tucker, 1997). This does not even include the thousands of dollars to purchase the necessary equipment for this service to operate. Interpreter fees are also costly. In most cities, the hourly charge ranged from \$20 to \$40. In addition, most of the interpreter agencies require a minimum of a two-hour fee (Tucker, 1997).

All individuals who are deaf have a right to utilize services to accommodate for their deafness. However, some individuals believe that steps should be taken in order to reduce the effects of the disability. Tucker (1997) stated the following:

While society has moral and ethical obligations to persons who are deaf, deaf people also have moral and ethical obligations to society. To fulfill those moral and ethical obligations, deaf people should support, rather than protest, research to cure deafness, and agree to accept full responsibility for the ramifications of chosen deafness. In this age of budget crises and cries for tax reform, when there is talk of, and some action with respect to, the necessity to cut funding for welfare, Medicaid, Social Security, federally supported food banks, and other social welfare programs, it is unrealistic, at best, for Deaf culturists to expect society to fund expenditures that could be eliminated (p. 31).

#### Disadvantages of being deaf

Although members of the Deaf community see their deafness as being part of a culture, many deaf people do not agree (Tucker, 1998). Tucker, who is deaf, explained how many deaf individuals feel. Most of the time, deaf individuals are unable to talk on the telephone alone. Unless the person they are calling has a TTY, the deaf person will need to use an interpreter or a relay service. Tucker described this as very awkward and did not like the fact that there is no privacy. Tucker also noted that deaf individuals would like to go see a movie or a play regardless of whether captioning or interpreters were available. Individuals who are deaf would also like to participate in group conversations.

Tucker also wished that it were possible to talk to someone without needing to always look at him or her. This makes it difficult to communicate with people when hiking or bicycling. Individuals who are deaf would also like to enjoy music, especially when riding in the car and

would like to have a car phone. Deaf individuals would also like to utilize drive-up windows at restaurants or banks as well. Tucker also wished that deaf individuals would be able to pursue any job they desired, without worrying that their deafness may interfere with their job duties. Lastly, deaf individuals would like to hear their children and grandchildren laugh and cry. Tucker asked why would any human being want to deny such pleasures to their children?

### Previous Studies

A case study of two families with deaf children was conducted in England (Eleweke & Rodda, 2000). Both sets of parents had normal hearing. One family chose to use sign language and the other family chose the oral approach. Open-ended questions were asked to the families and the following themes emerged from the data analysis: (a) the influence of information provided to the parents, (b) the parents' perceptions of assistive technology.

The parents stated they were strongly influenced by the information they received, especially in the time period immediately after the hearing loss was diagnosed. According to Eleweke & Rodda (2000), after they were informed of the hearing loss, the family that chose the sign language approach stated that:

It was a very emotional thing, really. We didn't know any better and we had no guidance. They said she had some hearing left, and we just clutched to that because when people tell you things like that you clutch to them thinking that they know best. That was what we just believed: clutching to the information they gave about the hearing left in her. Although we have got some reservations, but still believed it because we wanted to believe it. At that time we would have liked to know how deaf she was (p. 378).



The parents stated that their experts did not believe in the sign language approach and they felt that they were not given all of their options. After a period of time, the parents lost faith in the experts and felt that the oral approach was not the best option for their child. The parents developed their own form of sign language and used this communication mode until they met a social worker that was deaf. The parents stated “it opened a new and better world for us and our daughter because before then we had been reliant on the advice of those who did not believe in the sign language approach” (p. 378).

However, the parents who chose to raise their child with the oral approach felt they had received information about all the options. They said, however, that the teachers of the Deaf appeared hesitant about providing them with all of the information. The parents stated that:

[The teachers of the Deaf] told us that it was going to be slow with the oral approach and that the children will be behind their hearing mates for a long time. But we didn't realize how slow and that the gap would be so wide even as they [were] advancing in age. It is only now that she brings her hearing friends home that we see a lot of difference in her language and theirs (p. 378).

When receiving information about hearing aids and other assistive hearing devices, both families stated they were given information about hearing aids. Both families thought that the hearing aids would help their children hear normally; and both families were disappointed. The sign language family thought that the hearing aid would:

Be able to make our daughter hear normally. Because we had no knowledge of hearing aids, we thought that they would make her hear normally. We saw lots of old people with hearing aids and they can hear and can talk. So that made us think of it in that line, [that is] to that extent [of making our child hear normally]. We thought if we put the

hearing aids on her she could hear. We think this was because of lack of proper explanation. They told us that they will put these hearing aids on her and they will help her. And we were made to believe that once she starts wearing these hearing aids all the time she will start making sounds like a baby (p. 379).

The family that decided on the oral approach stated that they were surprised to find that the aids help only slightly. The parents stated that:

...You have got to show them the objects that are making the noises and to be able to discriminate the sounds. They have to be taught to listen. For example, we have to take her to the barking dog to show her while she listens to the different sounds and show her when the door is slammed to make the difference between the noises (p. 379).

As of 2000, the child who uses sign language was on the waiting list for a cochlear implant. Her parents said:

She will always be deaf, even with an implant. We feel it is appropriate that she continue with total communication, signing, lip-reading, everything appropriate to her needs in a hearing world as a deaf child, and as she grows into a deaf adult she has to understand the hearing world and the deaf world, both cultures (p. 379).

## CHAPTER THREE

### Methodology

#### Introduction

This chapter will describe the subjects under study and how they were selected for inclusion in this study. In addition, the instrument being used to collect information will be discussed as to its content. Since the instrument was developed specifically for this study, no validity or reliability studies have been done. Data collection and analysis procedures will then be presented. The chapter will conclude with some of the methodological limitations.

#### Description of Subjects

The subjects for this study were all parents of deaf children. The decision made by the parents in regards to their child's hearing had to have been made before the child reached age 10 to qualify for this study. Parents who chose to allow their children to receive cochlear implants, as well as parents who decided against implantation were included in this study. When the surveys were mailed, it was not known if any of the parents were deaf themselves, or if they knew of any deaf individuals.

#### Sample Selection

The parents were chosen by utilizing the stratified random sampling method. Since there are a limited number of organizations in Minnesota and Wisconsin that agreed to participate in the survey, the researcher sent out as many surveys as possible to two different groups. The first group consisting of parents who decided to allow their children to have cochlear implants, and the second group consisted of parents who decided against cochlear implantation.

#### Instrumentation

The survey consists of 18 questions (see Appendix A). To insure confidentiality, the surveys were mailed out to specific organizations that agreed to help the researcher. The

organizations then mailed out the surveys to the parents. A consent form explaining the purpose of the study, requesting their cooperation, and assuring them of their confidentiality was attached to the survey (see Appendix B). Completed surveys were returned to the researcher, and no identifying information was included. The survey will answer the following questions:

1. What types of pressure were felt by the parents when deciding on cochlear implantation?
2. What community placed the most pressure on the parents?
3. Did the pressure change the parent's view of cochlear implants?
4. What percentage of deaf children of hearing parents received cochlear implants?
5. What percentage of deaf children of deaf parents received cochlear implants?

While reading the available literature, it became apparent to the researcher that the Deaf community has very strong opinions when it comes to cochlear implantation. The researcher recalled hearing stories of how some students with cochlear implants in Deaf schools were constantly pressured. Due to this pressure, some students had their implants removed, or ceased wearing them. Remembering those stories made the researcher wonder if parents were faced with the same pressure when deciding on cochlear implantation for their children.

### Data Collection

To insure confidentiality, the surveys were mailed out to specific organizations in Wisconsin and Minnesota that agreed to help the researcher. Organizations that agreed to help the researcher include the Wisconsin School for the Deaf in Delevan, Wisconsin and the Metro Deaf School, located in Minneapolis, Minnesota. After the surveys have been answered, the parents will mail the surveys back to the researcher. The researcher had also enclosed self-addressed stamped envelopes with the surveys to ensure a better return rate.

### Data Analysis

As this was a descriptive study, the survey responses were analyzed to describe the frequency in which pressure was placed upon parents when deciding upon the best route in regard to their child's hearing future. For interpretation purposes, both the frequencies and corresponding percentages were reported.

### Limitations

Limitations in this study include the researcher's instrument. Since it was developed for this particular study, no reliability or validity information is available. Another limitation is the sample size. This study includes only a small portion of the deaf population and may or may not reflect the feelings of other parents.

## CHAPTER FOUR

### Results and Discussion

This chapter will report the results of the survey, as well as anecdotal responses given by the parents. The information given was analyzed and will be used to answer the following research questions:

1. What types of pressure were felt by the parents when deciding on cochlear implantation?
2. What community placed the most pressure on the parents?
3. Did the pressure change the parent's view of cochlear implants?
4. What percentage of deaf children of hearing parents received cochlear implants?
5. What percentage of deaf children of deaf parents received cochlear implants?

Out of the 117 surveys mailed out, 57 were answered and returned; however, two surveys were excluded since two children were adopted at ages six and ten. Therefore 55 were counted, which yielded a 47% return rate. Question one investigated the current age of the child in question. Thirty-five (64%) responded eleven or over, seven (13%) answered seven or eight, six (11%) responded nine or ten, four (7%) were five or six, and three (5%) were three or four.

Question two asked how old was your child when he/she was diagnosed as deaf. The response patterns did not follow the survey responses, but came back with the following numbers. Twenty-seven (49%) were one or two, sixteen (29%) were less than one year old, nine (16%) were diagnosed at birth, and three (6%) were three or four.

The third question inquired if the child was deaf before learning to verbally speak. Forty-nine (89%) answered yes. Five (9%) responded no, and one (2%) did not reply.

Question four asked the parents how many deaf people they personally knew before their child was diagnosed as deaf. Thirty-one (56%) answered none. Eleven (20%) responded many, nine (16%) replied a few, and four (7%) answered some.

The fifth question inquired when your child was initially diagnosed as deaf, what did you want to do. Thirty-one (56%) replied they accepted their child's deafness. Twenty-two (40%) responded they wanted to cure their child's deafness. One (2%) responded they wanted to do both, and one (2%) did not respond.

Question six asked the parents to rate various sources of information utilized when making the decision of how to treat their child's deafness. The respondents rated the top three influences as audiologists, other parents of deaf children, and family members. To see a complete breakdown of the ratings, refer to Table 1 on the following page.

The seventh question asked the parents if they were aware of the Deaf community before their child was diagnosed as deaf. Twenty-four (44%) replied no. Seventeen (31%) responded yes. Nine (16%) replied yes, as they were also members of the Deaf community. Five (9%) answered no and this was the first time they have heard about the Deaf community.

The eighth question asked how the parents learned of the Deaf community and culture. It should be noted that some surveys contained more than one response. Seventeen (31%) responded literature and another seventeen (31%) replied a member of the Deaf community. Thirteen (24%) replied they were already aware of the Deaf community. Eight (15%) did not respond according to the survey responses but added school as their source of learning. Two (4%) also added they learned about the culture while attending a sign language course. Two (4%) responded pediatricians and one (2%) stated they did not learn about the Deaf culture.

Table 1

Sources of Information

Sources:	1 <sup>st</sup>	2 <sup>nd</sup>	3 <sup>rd</sup>	4 <sup>th</sup>	5 <sup>th</sup>	6 <sup>th</sup>	7 <sup>th</sup>	NA	MI
Pediatricians	3	6	4	9	5	7	3	14	4
Audiologists	17	7	5	7	7	2	0	6	3
Deaf Comm.	5	11	7	6	11	5	1	5	4
Family Members	8	6	8	8	5	6	2	8	4
Other Parents of Deaf Children	12	7	10	11	1	3	2	5	4
Teachers	7	9	14	4	9	4	0	4	4
C.I. Team	1	1	1	0	2	4	8	33	4
Other	1	1	0	0	0	0	0	0	0

Other responses: (books) (person at UW-Speech and Hearing Clinic)

Question nine investigated if the parents felt that pressure was placed on them when deciding upon what was best for their child in regard to his or her hearing future. Eighteen (33%) responded no pressure was felt. Sixteen (29%) felt some pressure, twelve (22%) felt little pressure, and nine (16%) felt a lot of pressure. One parent stated that most of the pressure felt was self-imposed as the parent wanted to learn as much information as possible.

The tenth question asked who placed the most pressure of the parents when deciding what was best in regard to the child's hearing future. Eighteen (33%) responded they did not feel any pressure from anyone. Sixteen (29%) felt that the hearing world placed the most pressure. Twelve (22%) replied both communities placed pressure. Eight (15%) responded that the Deaf



community placed the most pressure. One (2%) responded that neither community placed pressure, but the parent placed pressure on him or herself. Another parent explained that pressure was placed by their extended family because, “they have very little knowledge of deafness and Deaf culture, and don’t learn sign language. They see the implant as a cure.”

Question eleven inquired what types of negative feedback, if any, came from the hearing world. Some surveys responded with more than one answer. Twenty-five (45%) answered no negative feedback was given. Twenty-three (42%) replied negative discussions. Six (11%) responded other and included message boards, media, articles, journals, workshops, and presentations. Five (9%) contained no answers. According to the surveys, no negative mail or negative phone calls were received. One parent who received negative discussions wrote “I needed to make my child hearing to fit in. I was to focus on what was wrong with them (deafness) instead of the whole person.” Another parent, who worked as an audiologist for the past 24 years stated the following:

Everyone on Earth seems to have advice and opinions about what is right for a deaf child, regardless of whether they have any connection to that child or any real knowledge of the issues involved. Total strangers in the grocery store do not hesitate to say things like “Will she ever learn to talk?” and “You know she can be healed if you pray to God for forgiveness” or “Why does she wear hearing aids if she signs?” and “Why does she sign, don’t the hearing aids work?”

Question twelve asked what types of negative feedback, if any, came from the Deaf community. Some parents responded to more than one source. Twenty-four (44%) replied negative discussions. Twenty-one (38%) answered none. Six (11%) responded other and four (7%) did not reply. Three (5%) answered negative mail. Two (4%) received negative phone

calls. One parent who received negative discussions added that, “My son stayed with two deaf adults when he was 12 to 15 months old. The deaf men always took off his hearing aid daily.”

Question thirteen asked when learning about the views from the Deaf and hearing communities, was your initial decision about your child’s deafness changed. Thirty-two (58%) responded no and fifteen (27%) replied yes. Four (7%) replied non-applicable. Three (5%) stated they did not receive any information on the Deaf culture. One (2%) did not respond.

The fourteenth question asked the parents if they learned about cochlear implants while making their decision about their child’s deafness. Forty-seven (85%) responded yes. Six (11%) replied no. One (2%) replied non-applicable and one (2%) did not answer. Three parents who responded yes added that the surgery was new and did not feel comfortable with it. One parent who also responded yes stated that they received little information, but felt it was not enough. Another parent who answered yes added, “We were told if she got a cochlear implant that she would lose any hearing she has. Because she can hear some in her right ear with a hearing aid, she was not eligible.” Another parent who answered yes said the following:

Our daughter would have been the first child implanted at the University of Minnesota. She was about two. We started the process to see if she was a candidate, but did not finish. We decided against implantation because there weren’t enough kids with them and no studies had been conducted to see if kids were successful with them. Also, we felt the surgical complication risks were too great; we could have never forgiven ourselves if something went wrong.

Question 15 asked if their child had a cochlear implant. Forty-six (84%) replied no, and eight (15%) answered yes. One (2%) responded yes, but their child no longer uses it. The parent replied, “She received so much feedback from the Deaf community. When she graduated, she

took it and her hearing aid off.” No parents indicated that their children were going to receive an implant in the future. One parent who answered yes added that, “When our daughter was 21 years old she had a cochlear implant, so the decision was made by her.” One parent who replied no reported “We decided (parents) that we could not make this choice for our child.”

Question 16 investigated the primary method of communication used by the children. Forty-four (80%) indicated sign language. Ten (18%) responded speech and sign language evenly. One (2%) replied speech.

The seventeenth question asked when making the decision about how to handle your child’s deafness, do you feel you had enough information at the time to make the right decision. Forty-four (80%) answered yes, and eleven (20%) responded no. Parents who replied no had the following responses: “There is never enough information. It’s such a small population and each child is different.” Another parent stated “We trialed and errored it. We never were aware of all options.” Another replied, “It never felt enough. It’s a very lonely feeling.” Another reported, “People were afraid to give their opinions. We were always told it was our decision, even though we desperately wanted others opinions.” Another parent, who indicated their child had a cochlear implant, explained, “It was very much pushed that my child be mainstreamed through our school district and not be put in a deaf environment. This was not a good decision for my child. He had no deaf peers and few friends.” Another replied, “Pediatricians really weren’t much help after telling us our daughter was deaf at six months...As hearing parents, we were very proactive, which I believe most parents are in educating themselves and finding the right resources and connections in the Deaf world...”

Question 18 asked if you had the decision to make over again, would you have made the same decision. Forty-five (82%) responded yes, seven (13%) replied no, and two (4%) indicated they did not know. One (2%) responded neither yes nor no, and explained that:

In 1989, cochlear implants were so new so I didn't want my child to have one. If my child were born in 2001, I might make a different decision. I feel I made the right decision for my child eleven years ago. However, I learned that things change with how cochlear implants have improved and become more accepted. If my child were born today, I possibly would be more open to a cochlear implant.

Another parent whose child has a cochlear implant stated they had enough information for the cochlear implant, but "I would have found a Deaf school for my child to attend and not mainstream him. My child feels much more accepted and has more friends in the Deaf school he now attends. He now likes school where before he hated it and had few friends." Another parent added, "We would not have chosen the cochlear implant. Our son hates it and is very involved in the Deaf community. He was one of the first kids to receive it at Froedent Hospital in 1991 and they (cochlear implant team) were learning to work with the kids and were not trained well at the time."

A parent who responded no explained that if her son was one year old now, she would consider an implant because, "...It is a hearing world and I think he would have an easier life ahead of him if he had some speech." Another parent who replied she would have made the same decision stated she "would have made a larger effort to have all family members (extended also) learn ASL by the time she was ten or so. This is when her using speech only at home became difficult. Adolescents have been a rough one."

The parent, who is also an audiologist, responded that if her child were two today instead of 15, she would probably choose cochlear implantation, but:

...I would never give up signing and raise her strictly orally. Some cochlear implant teams really pressure the families to go a strict oral approach and that saddens me. I see the Deaf community becoming more open about the implant as one more tool or option, while the hearing community of professionals becomes more close-minded...

A deaf parent also stated the following:

My strong opinion is that many deaf people reject that other deaf people get cochlear implanted due to their fear that those who are implanted will get a better life, better job, etc. They also think that the patients would leave the Deaf world, which wouldn't be true. For myself, I'd not try to improve my three kids' chances. However, I am not totally against the other's decisions.

## CHAPTER FIVE

### Summary, Conclusions, and Recommendations

This chapter will explore the responses and summarize the study. The paper will conclude with recommendations for further exploration and implications for the vocational rehabilitation profession.

According to the study, two-thirds of the parents reported feeling at least some pressure when deciding the best approach for their child. This included pressure from the hearing world, Deaf community, and self-imposed pressure. However, twice as much pressure came from the hearing community. Types of negative feedback from both communities mainly resulted from discussions, but other sources of pressure were also used, such as phone calls, mail, media, journal articles, message boards, workshops, and presentations.

Although 37 parents surveyed indicated feeling pressure, only 15 responded that their initial decision about their child's deafness was changed. This indicates that although parents receive feedback from both communities, their decision is not primarily based on others' beliefs and opinions.

Out of those surveyed, no children of deaf parents received cochlear implants. This is consistent with information provided by ASHA (1995) and Tucker (1997) stating that Deaf individuals do not view themselves as having a disability, but Deafness is a minority group with their own language and culture. Out of the 46 hearing parents who responded, nine children were implanted with a cochlear implant, which yielded a 19.5% implantation rate. However, one of those implanted no longer uses his or her implant due to feedback from the Deaf community. This is consistent with Crouch (1997) who reported that individuals who receive cochlear

implants will be condemned from the Deaf world, since the Deaf community frowns upon individuals with cochlear implants.

### Conclusions

Based on the results of the study, the researcher concludes that as time continues, more and more parents will be considering cochlear implants. Some parents who participated in this study replied that if their child were born deaf today, they would have been more open to the idea of implantation. However, at the time, cochlear implants were relatively new and not enough information was available as to the effectiveness and safety of the child during surgery.

Based on responses given by the parents, the researcher concludes that one of the better ideas is to combine the oral and sign approaches. As one parent who responded, “It is a hearing world and I think he would have an easier life ahead of him if he had some speech.” Another parent stated she “would have made a larger effort to have all family members (extended also) learn ASL by the time she was ten or so. This is when her using speech only at home became difficult...” This is consistent with a parent’s statement in Eleweke and Rodda (2000) who reported that their daughter:

...will always be deaf, even with an implant. We feel it is appropriate that she continue with total communication, signing, lip-reading, everything appropriate to her needs in a hearing world as a deaf child, and as she grows into a deaf adult she has to understand the hearing world and the deaf world, both cultures (p. 379).

The researcher also noticed that all family’s situations are different and no two families will encounter the same situation. Therefore, there is no right or wrong answer and although the family may receive feedback from others, every family has to consider what is right for them.

### Recommendations

Some parents who participated in this study responded that they might have been more open to implantation if their child was born today. It is recommended that this study be repeated in ten years. This will allow more studies to be performed on the effectiveness of the surgery.

It is also suggested that when this study is repeated, the researcher should cover a wider geographical area. Since the deaf population is relatively small, it would be beneficial to survey as many different areas as possible. This would allow for a more accurate reading on other parents' views and feelings.

### Implications for vocational rehabilitation professionals

When working with individuals who are deaf, it is important that rehabilitation professionals be respectful to all individuals who are deaf, no matter what their clients' beliefs are and if they do or do not have an implant. In a few years, vocational rehabilitation professionals will begin to work with more individuals who have implants and to properly work with them, professionals will need to be conscious that although somebody may have an implant, that does not mean that they do not experience any hearing difficulties. As stated by Crouch (1997), prelingually deaf children using a cochlear implant must be intensively taught and trained through the speech process. Therefore, for the implant-using prelingually deaf child, the development of their oral language skills is a long and difficult task, and there is no guarantee that the goal of oral language may be reached. Therefore, it is important that rehabilitation counselors and evaluators do not minimize the functional limitations associated with hearing loss just because someone has a cochlear implant.

In addition, vocational rehabilitation professionals need to be aware that the decision to be implanted is a hard decision to make and although the decision may not reflect the views of



the professional, it is the consumer's and/or the parents' choice and needs to be respected. As one parent stated:

We all want the best for our kids whether its cochlear implants, mainstreaming, cued speech, ASL, residential schools, etc. We always second-guess ourselves! In the end, I think all our kids will be successful because we are involved with their education.

## REFERENCES

- American Speech-Language-Hearing Association. (1995). *Deaf Culture*.
- Cochlear Implant Association, Incorporated. (1997). *What Is a Cochlear Implant?*
- Crouch, R.A. (1997). Letting the Deaf Be Deaf. *Hastings Center Report*, 27(4), 14-22.
- Eleweke, C.J. Rodda, M. (2000). Factors Contributing to Parents' Selection of a Communication Mode to Use With Their Deaf Children. *American Annals of the Deaf*, 145(4), 375-383.
- Lane, H., Hoffmeister, R., & Bahan, B. (1996). *A Journey into the Deaf-World*. California: DawnSignPress.
- Sherwood, L. (1997). *Human Physiology from Cells to Systems* (3<sup>rd</sup> ed.). Wadsworth Publishing Company.
- Spencer, L., Tomblin, J.B., & Gantz, B.J. (1997). Reading Skills in Children with Multichannel Cochlear-Implant Experience. *Volta Review*, 99(4), 193-203.
- Swanson, L. (1997). Cochlear Implants: The Head-On Collision Between Medical Technology and the Right To Be Deaf. *CMAJ: Canadian Medical Association Journal*, 157(7), 929-933.
- Tucker, B.P. (1997). The ADA and Deaf Culture: Contrasting Precepts, Conflicting Results. *Annals of the American Academy of Political & Social Science*, 549, 24-37.
- Tucker, B.P. (1998). Deaf Culture, Cochlear Implants, and Elective Disability. *Hastings Center Report*, 28(4), 6-15.

Turkington, Carol and Sussman, Allen E. 1992. *Encyclopedia of Deafness and Hearing Disorders*. New York: Facts on File.

## APPENDIX A

## SURVEY

1. How old is your child currently?
  - A) 3-4
  - B) 5-6
  - C) 7-8
  - D) 9-10
  - E) 11 and over
  
2. How old was your child when he/she was diagnosed as deaf?
  - A) 3-4
  - B) 5-6
  - C) 7-8
  - D) 9-10
  - E) 11 and over
  
3. Was your child deaf before learning to verbally speak?
  - A) yes
  - B) no
  
4. Before your child was diagnosed as deaf, how many other deaf individuals did you personally know?
  - A) none
  - B) a few
  - C) some
  - D) many
  
5. When your child was *initially* diagnosed as deaf, did you want to:
  - A) cure your child's deafness
  - B) accept your child's deafness
  
6. When making the decision of how to treat your child's deafness, rate these sources of information in order from most important to least important, with 1 being the most important. (if one of the following does not apply, then put NA next to the category)  
  
Pediatricians \_\_\_\_  
  
Audiologists \_\_\_\_  
  
Deaf community \_\_\_\_  
  
Family members \_\_\_\_  
  
Other parents of deaf children \_\_\_\_  
  
Teachers \_\_\_\_  
  
Cochlear implant team \_\_\_\_  
  
Other \_\_\_\_ (please name)

- 7) Before your child was diagnosed as deaf, were you aware there was a Deaf community/culture?
- A) yes, I was aware
  - B) no, I wasn't aware
  - C) yes, I am also a member of the Deaf community
  - D) no, this is the first time I heard about the Deaf culture
- 8) How did you learn about the Deaf community/culture?
- A) pediatrician
  - B) literature (books, articles, pamphlets)
  - C) a member of the Deaf community
  - D) I already was aware of the Deaf community
  - E) I did not learn about Deaf culture
- 9) Do you feel that pressure was placed on you when deciding upon what was best for your child in regard to his/her hearing future?
- A) no pressure was placed on me
  - B) little pressure was placed on me
  - C) yes, some pressure was placed on me
  - D) yes, a lot of pressure was placed on me
- 10) Who placed the most pressure on you when deciding what was best for your child in regard to his/her hearing future?
- A) the hearing world (i.e. peers, family, teachers, etc.)
  - B) the Deaf community
  - C) both communities placed pressure on me
  - D) I did not feel any pressure from anyone
- 11) What types of negative feedback, if any, came from the hearing world?
- A) negative discussions
  - B) negative mail
  - C) negative phone calls
  - D) other (please list)

- 12) What types of negative feedback, if any, came from the Deaf community?
- A) negative discussions
  - B) negative mail
  - C) negative phone calls
  - D) other (please list)
- 13) After learning about the views from both the hearing world and the Deaf community, was your initial decision about your child's deafness changed?
- A) yes
  - B) no
  - C) I did not receive information on the Deaf culture
- 14) When making the decision about your child's deafness, did you learn about cochlear implants?
- A) yes
  - B) no
- 15) Does your child have a cochlear implant?
- A) yes
  - B) no
  - C) yes, but he/she no longer uses it (If so, please explain why)
  - D) no, but he/she is going to soon
- 16) What communication method does your child *primarily* use?
- A) speech
  - B) sign
  - C) my child uses speech and sign evenly

17) When making the decision about how to handle your child's deafness, do you feel you had enough information at the time to make the right decision?

A) yes

B) no

If no, please explain (if more room is needed, write on the back of the page)

18) If you had the decision to make all over again, would you have made the same decision?

A) yes

B) no

If no, please explain (if more room is needed, write on the back of the page)

## APPENDIX B

## Consent Form

Dear Participant(s):

My name is Amber Hoffman and I am a graduate student at University of Wisconsin-Stout. I am conducting my research project, the purpose of which is to examine the pressure placed upon parents when deciding on cochlear implantation for their children. I also want to examine the sufficiency of information parents are given to make their decision. Attached to this form is an 18-question survey. Please answer the questions to the best of your ability. Please feel free to write additional responses on the back of the survey.

You are asked to participate because you have a child who attends the Metro Deaf School (ISD 4005) or the Saint Paul Public School system (ISD 625) or one of the other organizations that has agreed to participate in this study.

The school has agreed to send out the surveys so that confidentiality and anonymity are maintained. Included is a self-addressed, stamped envelope for you to return the survey, there is no way to identify who participated. There is no risk to you. If you do not feel comfortable in participating, you do not have to; however, your input is very important to my research project.

Your decision to participate is voluntary and will in no way affect your relationship or your child's relationship with the participating organization.

If you would like more information before agreeing to participate, feel free to call Amber Hoffman at (715) 235-9716 or my advisor, Dr. Robert Peters at (715) 232-1983.

Thank you,

Amber Hoffman  
Graduate Student  
Vocational Rehabilitation  
University of Wisconsin-Stout