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# The Parent's Journey into the World of Cochlear Implants

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# THE PARENT'S JOURNEY INTO THE WORLD OF COCHLEAR IMPLANTS

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# THE PARENT'S JOURNEY INTO THE WORLD OF COCHLEAR

FAATIN BRYANT

## ABSTRACT

The present study investigated the similarities and differences in the lived experiences of parents who made the decision to have their child implanted with a cochlear device. The aim of this study was also to explore the parents' views of the success of the cochlear implant (CI) device as it relates to language and academic development. Four parents shared their experiences through the process of obtaining a cochlear implant for their children and their lived experience with the cochlear implant device from the surgery to the present time. Three of the interviewed parents discussed their experiences with one child who was implanted. One parent who was interviewed reported on her experiences with two children who were implanted. The parental cochlear implant experience/journey appears to be directly related to how successful the child is with his or her device. The interaction and relationship between the parent and professionals on the cochlear implant team, early intervention, follow-up care, amount of therapy received, and the use of the cochlear implant all affect the speech and language outcomes as well as the academic outcomes of children with cochlear implants. Given the significance and limitations of this study, further research is needed to better understand how the differences in one's parental cochlear implant journey can vary the language and academic outcomes.

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# CHAPTER I

# INTRODUCTION

Deafness is considered a low incidence disability. According to the U.S Department of Health and Human Services, each year in the United States, about 2 to 3 out of every 1,000 children are born with some degree of hearing loss in one or both ears. In addition, more than 90% of deaf children are born to hearing parents.

Hearing is critical to speech and language development as well as to learning. Hearing sounds and words helps children learn to speak and understand. When a child has hearing loss, they miss out on theses sounds. Hearing loss in children can lead to delayed speech and language skills, learning difficulties in school, low self-esteem, and difficulty making friends. Getting help early is essential.

Children with hearing loss do not learn words as easily or quickly as children who have normal hearing sensitivity. They do not typically have difficulty with learning concrete words like *giraffe*, *blue*, *three*, and *run*. However, they may struggle with words that are abstract such as *nervous*, *after*, *patience*, and *equal to*. They may omit words like *the*, *a*, *an*, and *are*. Children with hearing loss may also have trouble with words that have multiple meanings. For example, the word bark has more than one meaning. *Bark* can mean the outer covering of a tree, the sounds a dog makes, or it can be used to express something said in an angry tone. They fall further behind children with normal hearing as they get older. Children with hearing loss will not catch up to their hearing peers in academic or speech and language development without assistance.

Deaf children have trouble understanding and using sentences, and they may have difficulty speaking clearly (ASAHA). Most children who are born profoundly deaf fall significantly behind their hearing peers in the development of oral language (Svirsky, Robbins, Kirk, Pisoni, & Miyamoto, 2000). They may have a hard time hearing word endings like *-s* or *-ed*. This may lead to them having a tough time understanding or using plurals like *giraffes*. Possessives like *John's* may be hard to hear or use. Children with hearing loss may omit using past tense words like *jumped* when speaking in sentences. In addition, children with hearing loss typically use shorter sentences than children with normal hearing. They struggle to use complex sentences and may not use clauses. An example of a clause is "*When I get to school, I will show my teacher*". Because their hearing is impacted, they may not be able to hear their own voices when they speak and as a result may speak loudly or quietly. There is also "deaf speech", in which it may be said that the deaf child sounds "different" due to the monotone nature. When a child grows up without hearing and learn speech without hearing feedback, their speech may take on speech patterns that set them apart. Quiet speech sounds like *s, sh, f, t, or k* may not be used due to difficulty hearing these softer sounds.

Hearing loss in children can lead to social isolation and poor self-concept. Children who have profound hearing loss often have difficulty developing friendships with peers (Calderon & Greenberg, 2011). They may have a difficult time talking with others, and as a result, may not want to talk or play with other kids. These effects can be emotionally taxing for a child. It is not uncommon for children with hearing loss to avoid situations where it is hard to hear in order to prevent feelings of stress, anxiety, and embarrassment about one's hearing loss. Isolation and social withdrawal can lead to feelings of depression or make them worse.

Hearing loss in children can cause problems with reading and school success. Academic failure has been documented in children who are deaf in every area especially reading and math (Kyle & Harris, 2011). Due to the limited access to spoken language as a result of their hearing loss, most deaf and hard of hearing children start school with notable delays in language development compared to hearing peers (Knoors & Marschark, 2012). The average person who is deaf reads at a fourth-grade level, even after graduating from high school (Marschark & Hauser, 2008). Appropriate early educational intervention can help to improve this. Deaf children do not perform as well as their hearing peers in school and the gap between them usually increases as they progress through school. Even with a cochlear implant many students with hearing loss may find the acoustics in a classroom challenging and may experience problems with literacy.

A child who is born deaf, cannot receive enough amplification from a hearing aid to have access to all the sounds of speech. A hearing aid, then provides minimal assistance for these children who had historically struggled to develop oral language. The invention of the cochlear implant device provided people who were deaf, or those with profound hearing loss, the first opportunity to have auditory access to sound including all the sounds of speech. Cochlear implants were approved for use in children in the United States in 1985. Today, a cochlear implant is the standard of care for children born with severe to profound hearing loss. It is important to note however, that not everyone who is born deaf opts for having a cochlear implant. This is due to two opposing views on deafness: a medical view vs. the cultural view of deafness.

Those who view deafness from a medical perspective, believe that deafness is a deficit condition, one that needs to be “fixed.” Most speech-language pathologists and audiologists view deafness from the medical perspective. This is likely due to the fact that deafness has a long-standing history of being viewed as a deficit condition. Aristotle said, “Those who are born deaf all become senseless and incapable of reasoning” (Bridges for the Deaf and Hard of Hearing, 2019). Professionals who view deafness through the lens of the medical perspective are quick to offer “remedies” for the hearing loss such as surgery, cochlear implants, and extensive speech and language therapy.

There are people who are deaf who do not believe that they have a deficit. Many deaf people consider themselves to be a cultural minority. Members of the Deaf culture celebrate their deafness, reject cochlear implants, and choose to remain deaf because they do not see deafness as a problem or disability; it is merely a difference. Members of Deaf culture are composed of a group of individuals, typically born deaf, who communicate with American Sign Language (ASL). The Deaf culture is both defined and bound by their deafness and their language.

Lane and Bahan (1998) argued that cochlear implants are unethical because of the possibility of the device resulting in “genocide” of Deaf culture due to the dwindling number of children who might otherwise become a part of the Deaf World and help maintain its viability.” Members of the Deaf community consider themselves, recognize themselves, and view their interpretation of the world as the standard. They are empowered by the rich history of their own Deaf community. They believe that their deafness allows them to be part of this community with its own language and value system and is not a deficit or impairment that sentences them to a world of silence.

The hearing world defines the Deaf culture by its loss of hearing ability, whereas the Deaf culture defines itself by its distinct visual language (ASL). It is the belief of the Deaf culture that making the decision for infants who are born deaf to be implanted with a cochlear device is unethical as it affects their communication mode and their inclusion in a specific culture; thus, it has serious ethical implications. The Deaf community makes the point that since the parents of most deaf-born children are hearing, they have no standpoint upon which to base their selection regarding cochlear implants. Without personal understanding of the Deaf culture, hearing parents can't make a "best interest" decision for their deaf children. Furthermore, when hearing parents decide to have their born-deaf children implanted with a cochlear device, the decision is ill-informed, ill-prepared, ill-founded, ill-advised, and ill-fated. Members of the Deaf culture view an attempt to make them into hearing individuals as discriminatory, and an attack on them as an individual. The Deaf culture views the implantation of an infant as an attempt to assimilate the infant into a culture different from its birthright.

There is now a growing body of literature that supports the notion that cochlear implants facilitate the development of speech and language skills (Baldassari, et al., 2009; Svirsky et al., 2004). If a child is born with severe to profound hearing loss and his or her parents decide to seek a cochlear implant, their hope is to maximize the chances that the child will be able to interact independently in the hearing world (Svirsky et al., 200). Cochlear implants are used for both children and adults with sensorineural hearing loss. Sensorineural hearing loss generally involves damage to tiny hair cells inside of the cochlea (inside the inner ear). These hair cells function to pick up the vibrations of sounds and send them to the brain via the auditory nerve. When there is damage to the hair cells in the cochlea, sound cannot reach the auditory nerve. The two major function of the normal cochlear are amplification and frequency-resolution (Schauwers et al., 2005). A cochlear implant is a small electronic device that is surgically implanted under the skin. It provides a sense of sound to individuals with severe to profound hearing loss. The parts of a cochlear implant consist of a microphone, which picks up sound from the environment. A speech processor, which selects and arranges sounds picked up by the microphone. A transmitter and receiver/stimulator, which receive signals from the speech processor and convert them into electric impulses. Finally, there is an electrode array, which is a group of electrodes that collects the impulses from the stimulator and sends them to different regions of the auditory nerve. In short, A cochlear implant receives sound from the outside environment, processes it, and sends small electric currents near the auditory nerve. The electric currents activate the auditory nerve which then sends a signal to the brain. The brain learns to understand this signal and the person wearing the device experiences this as “hearing”. It is important to note that a cochlear implant does not restore normal hearing to the individual with hearing loss. The implant provides a functional depiction of sounds in the individual’s surroundings, reducing the barriers to him or her understanding speech (NIDCD, 2016). As of December 2019, approximately 65,000 children in the U.S. have been implanted with a cochlear device (NIDCD, n.d).

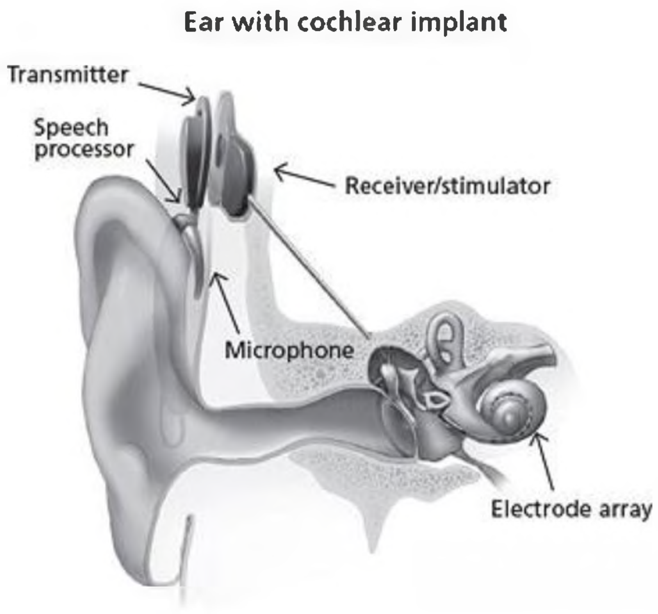

Figure 1. Diagram of a cochlear implant inside a human ear. Reprinted with permission from NCID.com

Though cochlear implant surgery is very safe, it does not come without the possibility of certain risks. As with any surgical procedure, bleeding and infection as well as problems from the anesthesia may occur. Other possible complications include nerve damage that causes weakness or paralysis in the face, nerve injury that alters one's sense of taste, dizziness or issues with balance, tinnitus (ringing in the ear), leaking of cerebrospinal fluid (the fluid around the brain), loss of residual hearing (the ability to hear some sounds even if a hearing loss exists), and Meningitis. In addition, once implanted the device may not work or may get infected and need to be removed and replaced (Center for Devices and Radiological Health).

Vast differences exist as it relates to outcomes for children with cochlear implants. There are many benefits to deaf children when implanted with a cochlear device. Children who were born deaf are able to detect the presence of sound within hearing ranges may improve to near normal or even normal hearing level following cochlear implantation. Due to the access to sound provided by the cochlear implant, it is easier for the child to understand speech. Many who are implanted are able to perceive the differences between loud, medium, and soft sounds. Individuals report that they can perceive different types of sounds, such as footsteps, slamming of doors, sounds of engines, ringing of the telephone, barking of dogs, whistling of the tea kettle, rustling of leaves, the sound of a light switch being switched on and off, and so on. Many children are able to understand conversations without lip reading. Even if this is not possible, using the implant helps with lip reading. A lot of implanted individuals are able to have conversations on the phone and understand familiar voices over the telephone. Some good performers can make normal telephone calls and even understand an unfamiliar speaker. However, not all people who have implants are able to use the phone. Some have more access to entertainment via listening to music and more enjoyment watching television (FDA, 2021).

Due to recent growth in the universal newborn hearing screening, children are being identified with hearing loss earlier in life than ever before. Advances in medical technology (i.e., digital hearing aids and cochlear implants) are better than ever. Because of this progress, today, more deaf and hard of hearing children have opportunities to acquire spoken language. Despite these advances, deaf and hard-of-hearing (DHH) children still lag behind their hearing peers. Even within the pediatric cochlear implant recipient population differences in their academic achievement varies. Not all children who have cochlear implants develop to the same extent. Communication specialists do not understand what experiences facilitate or thwart success with the device. This lack of understanding inhibits professionals from helping children to reach their fullest potential.

## Personal Reflection

As the mother of two daughters with congenital bilateral severe to profound hearing loss, I know how difficult and long the cochlear implant journey can be. I first learned about the hearing loss of both girls after their newborn hearing screenings in the hospital. My experience with my first daughter was very different from the experience I went through with my second daughter. With my first daughter, I was very shocked and surprised. It took me a while to process the diagnosis. There was no familial history of hearing loss on either side. I went from one hospital to the next expecting for the diagnosis to change. She underwent several Auditory Brainstem Response (ABR) tests for my own certainty. I didn't understand why she would turn her head if I dropped a pot or pan on the kitchen floor. I did not believe that she was deaf. I had a really difficult time accepting the diagnosis. I was never provided with any information about Deaf culture from any members on the cochlear implant team. I only learned of Deaf culture when I decided to go back to school (post-bac) and take some speech and hearing courses to better educate myself on the best options for my daughter. She received her first hearing aids at around 2 months of age. It was difficult getting her to keep them in once she reached around 4/5 months of age. She would pull the out of her ears and put them straight into her mouth. She loved to chew on the ear molds. Imagine driving while your baby is in the back seat chewing on her hearing aids and there is nothing you can do about it at that moment. My daughter received weekly early intervention services through Ohio's Help Me Grow and Regional Infant Hearing Program until she was 3 years old. I had a teacher of the deaf who would come to my home once per week to work with my daughter and I from about three months of age. The teacher of the deaf helped teach some basic sign language (American Sign Language) to use with my daughter. The ASL was very helpful, and my daughter picked up the signs quickly. Some of the signs we used included “more”, “water”, “milk”, “hot”, “mom”, “dad”, “thank you”, “eat”, “baby”, “play”, “outside”, and a few others. In addition, my daughter started receiving weekly speech language services at a local outpatient rehabilitation facility from about 13 months of age. She just turned 10-years-old and is currently still receiving weekly speech and language services through this hospital. My daughter also received weekly speech and language services at a local university. By the time I decided on the cochlear implant for my daughter, she was already 20 months. There was a number of appointments she needed to attend with various specialists before she could undergo surgery for the cochlear implant including a sedated MRI. Expectations for my daughter after implantation and activation were never discussed with me. I had no idea about the continuous weekly speech services that would be needed. The cochlear implant was presented to me as a “fix”. As if once implanted with the device she would be hearing. I was not educated on the mappings that would need to be updated throughout this cochlear journey. The most frustrating thing for me had to be the lost and broken cochlear device parts. It literally put me in a state of feeling completely helpless. I had put so much into my daughter “hearing”, but never imagined that it would be taken away the moment something went wrong with her cochlear device. After she was implanted, I was instructed by her audiologist and speech language pathologist that I should stop using signs with her so that she could maximize the benefits of the cochlear implant. I did not stop signing with her, though I did focus on her spoken language. She received her second cochlear implant for the other side at 7 years old. Currently, she is in a mainstream classroom where she gets preferential seating in the classroom to access visual information and for improved auditory information, she has a sign language interpreter, teacher of the deaf, utilizes a Frequency Modulation System (FM system) which picks up the speaker's voice and sends it directly to the cochlear implant, and speech and language services. She is at grade level with most of her subjects. She does have some difficulty with her reading comprehension.

My second daughter was implanted at 13 months and received all of the services my older daughter received. She is now 6 years old in the first grade and has recently "graduated" from speech and language services at our local hospital. She was also dismissed from speech and language services in school this school year. Currently, she is in a mainstream classroom where she received preferential seating in the classroom to access visual information and for improved auditory information, she has a sign language interpreter, teacher of the deaf, and utilizes a FM system. She is at or above grade level in all of her subject areas. Both girls have developed speech that is intelligible to familiar and unfamiliar listeners. On the other hand, there are several of their peers with cochlear implants who have not developed any amount of speech. I have to wonder why. Why is it that these other children have not developed spoken language to the same degree that my two daughters have?

## Purpose of the Study

The purpose of this study is to explore the similarities and differences in the lived experiences of parents who made the decision to have their child implanted with a cochlear device and their outcomes. The aim of this study also includes exploring the parents' views of the success of the CI device as it relates to language and academic growth and development. This study is significant because it will hopefully help to determine factors that may help to create more successful outcomes in children who are implanted with cochlear devices.

## Research Questions

The overarching research question is: What differences have occurred in the parental cochlear implant journeys that may account for the differences in their child's outcomes? More specifically, this research aims to find out: What are the similarities and differences in these told stories that may explain differences in the child's language outcomes? Additionally, what are the similarities and differences in these told stories that may explain differences in the child's academic outcomes?

# CHAPTER II

# LITERATURE REVIEW

In a 2015 article by Marschark, Shaver, Nagle, and Newman, academic achievement of deaf and hard of hearing (DHH) secondary students was researched based on specific factors that affect this. The history of efforts to educate DHH students is controversial regarding placement of instruction and language of instruction. Are DHH students best served by regular schools with a diverse student population (students with and without disabilities), or a specialized school with programs for the DHH learners? Do DHH students benefit more when they receive instruction in sign language, spoken language, or a combination of the two? Fifty years ago, 80% of deaf and hard of hearing children received their education in some sort of special setting where instruction was typically offered through some form of signed communication. However, today more than 85% receive their education in regular schools. Regardless of the setting, the most significant challenge in educating DHH learners is meeting their communication needs. Generally speaking, DHH children born from deaf parents, with access to a natural sign language from birth and those who have considerable (not complete) access to oral language exhibit better academic outcomes than DHH children without those features.

Even still, they do not achieve at the level of their hearing peers. Is this because DHH children do not have access in its entirety to the language and environment diversity of their hearing peers? The authors of this article state that the academic success of DHH students depends on the interplay of many elements, including those which are intrinsic to students themselves (family characteristics and expressive and receptive language abilities) as well as their experiences inside and outside of school. Previous studies have been limited in their ability to look at those extrinsic and intrinsic factors while restricting the population specifically to children with a cochlear implant.

Some children with cochlear implants display much better communication abilities than others. Several factors contribute to this variability that is seen between individuals with cochlear implant. These factors include duration of deafness; age of onset of deafness; age at implantation; duration of CI use; physiological or device factors such as the number of surviving spiral ganglion cells, electrode placement and insertion depth, electrical dynamic range, and signal processing strategies; and other psychological, educational, and social factors such as the recipient/parent motivation and level of intelligence (Waltman, 2000). There are also 2 family factors which appear to be critical to the speech and language outcomes in children with cochlear implants. The first is parental involvement. It has been known that parental involvement plays a significant role in children's early learning. "Parental involvement can be defined as the amount a parent is involved in his or her child's program or how a parent is involved" (DesJardin et al., 2006). It has been proven to be directly linked to improved developmental for children. The second family factor is the parents' own self-efficacy. Parental self-efficacy is "belief that a parent has knowledge and competence as a parent" (DesJardin et al., 2006). This is the parental practices one does to increase their child's ability to operate in a way which is more efficacious.

It was found that the reading skills of deaf children with a cochlear implant seemed to be much better than the reading skills of deaf children without a cochlear implant. Still, the reading comprehension skills of children implanted with a cochlear device was found to be poorer than the reading comprehension skills of children with normal hearing (Vermeulen, Bon, Schreuder, Knoors, and Snik, 2007). The process of reading depends on the spoken language which provides the basis of the writing system. Knowledge of spoken language and spoken language skills give to reading comprehension and visual word recognition. With this knowledge, it makes sense that the development of reading in deaf children will be behind that of their hearing peers without age-appropriate spoken language skills. Reading is critical to the enhancement of educational attainment and for full participation in society.

Hall et al. (2019) found that language deprivation is indicated as one of the primary reasons for why the language acquisition and proficiency of some DHH children is impaired. Language deprivation is the overall experience of lacking fully accessible language input. The majority of children are born into a world abundant with language input. For these children language acquisition starts at birth, or even prior to birth. With the exception of children born with severe neurocognitive deficits, these children will have mastered their native language(s) by around age 5. Furthermore, nearly all other domains of development will depend on their linguistic skills. Many DHH children enter into a world where access to language is much more restrictive. With over 90% of DHH children being born to hearing parents, the mismatch between the child's perceptual abilities and the family language environment often results in a deficiency of easily accessible language input for the child. This results in subsequent adverse outcomes in other developmental domains that rely on language such as social-emotional skills, school readiness, and academic outcomes.

Not all DHH children are affected by language deprivation. Some DHH children have sufficient exposure and access to language (spoken, signed, or both) to support full first-language mastery on a developmentally appropriate timetable. Language deprivation is commonly seen in DHH children; however, it is rarely seen in hearing children except in cases of extreme developmental delay or abuse. When a child with normal hearing exhibits language delays, it is almost never due to lack of accessible input; instead, it is usually a sign of an underlying language disorder. On the other hand, when a DHH child demonstrates delayed or incomplete mastery of a first language it is most likely due to lack of total accessible input. It is becoming increasingly likely that children born with severe to profound bilateral hearing loss will receive a cochlear implant by toddler age. Findings from recent studies conducted in the United States indicate that spoken language outcomes in implanted children is still highly variable and unpredictable.

Findings from a 2011 study conducted by Punch and Hyde consisting of 247 parents of children with CI explored areas of functional communication, educational, and psychosocial outcomes, as well as the pre-implant expectations of parents, their postimplant experiences, and the degree of agreeance between the expected and experienced outcomes. In addition, the study explored the experiences of parents making the decision to choose a cochlear implant for their children, along with their experiences of the rehabilitation pressures involved after their children’s implantation. The findings indicated that the relatively high expectations of most of the parents had been met, however, a tenth of the respondents stated that their expectations had not been met (Hyde, Punch, and Komesaroff, 2010). Findings from a successive study suggests that the majority of parents found the decision-making process to be demanding and strenuous. A statistically significant difference was found between parents' expectations and experiences on the rehabilitation stress subscale of the survey of a related study (Punch & Hyde, 2010). Results indicate that parents experienced more stress than they had expected before their children's CI. A major theme collected in the data concerned the amount of work and time parents dedicated to their deaf children in the areas of early intervention and speech training as well as in terms of frequent appointments for mapping and other ongoing requirements related to the use of the cochlear implant. Many parents reported feeling stressed due to the time required to travel to and attend appointments, and by the hardships this imposed on their children and on the family's financial circumstances. In addition, parents reported feelings of frustration due to frequent problems with the implant equipment breaking and parts needing replacing. When this happens and parts are unable to be replaced quickly, it becomes upsetting to both the parents and children as they are unable to use their implant and therefore without their means of hearing until the replacements arrive.

Another recurring theme throughout the data was of the strain and worry experienced by the parents living some distance from implant, rehabilitation, and early intervention services.

A few from this study reported that the decision to implant was easy as there was no alternative option for their child and they wanted for the implantation process to proceed as soon as possible (Hyde, Punch, and Komesaroff, 2010). Overall, the decision-making process was pretty short, with 60% of parents taking less than 3 months to make the decision to have their child implanted.

Punch and Komesaroff,(2010) examined the communication, academic, and social outcomes of pediatric CI individuals of teachers working with children with cochlear implants. One hundred and fifty-one teachers were surveyed and fifteen of those teachers were interviewed. Accomplishments were reported in literacy, numeracy, and social development were below grade levels. Another successive study in 2011 by Hyde and Punch investigated psychosocial factors, including socioemotional well-being, peer relationships, as well as social inclusion with hearing and deaf peers. This study consisted of interviews with 24 parents, 15 teachers, and 11 CI users (children and adolescents). The results across all three groups of participants displayed reoccurring themes suggesting positive experiences regarding the children's psychosocial development with their cochlear implants. Results also pointed out ongoing problems communicating in groups of people and difficulties related to social skills. Findings from a related survey revealed that the area of their children's social skills and participation remained a concern for most parents who were aware of their children's struggles in groups and how those struggles affected their social inclusion. In addition, the teacher data suggest less than optimal social outcomes. The results from the interviews with parents, teachers, and adolescents indicated that situation involving hearing peers were often difficult. It was also indicated that the development of some social skills, such as understanding subtleties and nuances in social interactions, were delayed in these children with cochlear implants. Children attending schools where there were other deaf children valued friendships with both deaf and hearing peers. Some children had little interaction with other deaf children although both parents and teachers believed this contact to be beneficial to the child. Adolescence was an especially hard time for some as they battled with self-conscious feelings about their deafness and external CI equipment. They also struggled with feelings of self-consciousness about friendship, dating, and their future place in the world. Even children with excellent outcomes in spoken language development and communication experience the phenomenon of "social deafness". "Social deafness" is a term used to describe the effects of hearing loss in social interactions involving groups of people or in noisy environments, compared to one-on-one interactions, which are typically easier for people who are deaf or hard of hearing to manage.

Results from Punch and Hyde (2011) found that almost 60% of parents believed that their child functioned like a child with normal hearing, while on the contrary only 30% of teachers stated this. In terms of identity, close to 30% of parents and teachers believed the child had developed an identity as a deaf individual. However, approximately 67% of parents, and slightly more than 33% of teachers, reported that the child comfortably shared both deaf and hearing identities. These findings are consistent with those of implanted adolescents' self-reported sense of identity in other studies.

Punch and Hyde surveyed 247 parents and 151 teachers investigating the modes of communication used by CI children and the role of sign language in the children's lives. Spoken language communication abilities were reported to be relatively high by parents and somewhat lower by teachers. Some children were developing, or had developed over a period of years, near normal speech and language outcomes. However, these tended to be in specific circumstances involving familiar communication partners, such as family members, and in familiar contexts and optimal listening environments. In wider contexts, such as in mainstream classrooms and in social groups and gatherings, the image was not as positive, with both teachers and parent reporting a difficult time for children with CI in these environments. Twenty percent of parents and 48% of teachers reported that the child had a hard time following a spoken conversation with a group of people. Data revealed that 15%-20% of the children in the parent surveys were using some form of sign language. Approximately 30% of the children were reported to use some form of sign language in the teacher surveys. The development of oral language was the primary goal of the majority of parents; however, sign language was believed to support their children's personal, social, and academic development. Some switched between sign language and spoken language depending on their communication partners, topics, and settings.

Out of 151 teachers, between 50%-60% did not feel that the children with CI were achieving at the expected level for their age in reading, writing, and math. In contrast, out of 247 parents, between 18% and 23% did not agree with those reports. Almost 70% of children in the teacher reports fell below the class median in academic performance. The teachers interviewed identified several problems and challenges, although they were generally positive about the outcomes and educational experiences of students with cochlear implants. A major concern was that some students were at risk of missing out on learning in certain instructional environments such as group discussion activities, and that often students would not admit their difficulties and seek out help in those situations. This is a challenge for educators, particularly in secondary schools, where children who have done well in primary school may need more specialist support to access a more challenging curriculum. Another problem is that adolescents don't want to be seen as different, therefore they resist what is seen as a stigma, being called out for help by visiting teachers or other support services. The findings also reported that some CI students in secondary schools were even hesitant to use FM systems and other support systems in school (Punch and Hyde, 2011).

Both parents and teachers referred to the children as "still deaf" and reported that many people, including mainstream class teachers and school authorities, had misunderstanding about the nature of cochlear implants. They believed that there was a lack of understanding that cochlear implants do not "fix" deafness and that the children with CIs still encounter difficulties in many auditory environments and delays in aspects of their development that necessitate ongoing support and accommodations in the school setting. This lack of understanding was especially the case for children with good spoken language.

Some of the teachers reported a lack of collaboration with CI clinics and with professional development about cochlear implants for themselves. Teachers reported on the complexity of the technology involved especially when cochlear implants are used in conjunction with FM systems. In addition to this, the challenges for parents and teachers in troubleshooting problems with the equipment.

In a 2015 research article, Academic outcomes for school-aged children with severe-profound hearing loss and early unilateral and bilateral cochlear implants, Sarant, Harris, and Bennet conducted a study to determine whether academic outcomes for children who received early CIs are age appropriate, to determine whether bilateral CI use significantly improves academic outcomes, and to identify other factors that are predictive of these factors. Although there have been great improvements in the speech perception outcomes of children with cochlear implants, it has become evident that good speech perception skills do not guarantee age-appropriate results in other areas. There have been documented advancements in speech perception, speech production, language, literacy, and social development for children with cochlear implants. It is expected that comparable improvements in academic outcomes would follow.

The proportion of children who achieve academic outcomes that ae within the average range for children with normal hearing is still uncertain, especially for older children, because not many children have had long term follow-up of academic outcomes. There is a lack of research into educational outcomes, due to most studies concentrating on literacy development in spite of delays being observed across the curriculum. Academic outcomes are assessed in four categories:  oral language, math, written language, and reading. Initially, oral language outcomes of children with cochlear implants were compared to that of their peers with severe to profound hearing loss who use hearing aids. Because children with CIs performed significantly better on average than children using hearing aids, their outcomes have been shifted to being compared with their peers who have lesser degrees of hearing loss or normal hearing. There is a general consensus that for most children CIs aid the development of oral language, there is still substantial variation in the rate of oral language development between children, and a significant proportion of children with CIs still demonstrate significant delays. Some predictive factors of oral language development include age at diagnosis, age at implantation, degree of hearing loss, cognitive ability, socioeconomic status, maternal education, and gender (girls typically achieve better results than boys).

The limited literature on the mathematical abilities of children with cochlear implants has yielded conflicting results with below average, average, and above average performance documented, and language ability identified as a key predictor of performance. The writing of children with hearing loss has historically differed from that of their peers with normal hearing in that their sentences are shorter, there are more errors of omission, phrasing is more repetitive, subject-object-verb constructions are overused, substitution, and word addition. Errors of morphology, such as plurality, tense, and verb agreement are also more common in children with hearing loss. Children with hearing loss also typically use less adjectives, adverbs, prepositions, and conjunctions. It has been documented that reading development in many children with hearing loss plateaus resulting in ongoing problems with reading to learn and a lack of ability to use top-up and bottom-up processing, which reduces comprehension and the ability to acquire new knowledge. There has been increasing evidence that some children with CIs can achieve reading scores that are within one standard deviation of the mean for their peers with normal hearing. On the other hand, there are also reports that impressive early reading development in children with cochlear implants may not necessarily be sustained as they grow older. Factors that have been found to affect reading development in children with CIs include higher nonverbal cognitive ability, younger age at implantation, female gender, later onset of hearing loss, family socioeconomic status, and use of spoken language opposed to sign language. Spoken language abilities have been found to correlate highly with reading abilities. Generally, children who are proficient oral narrators demonstrate better reading comprehension skills. Phonological development, auditory development, and visual memory have also been linked with reading attainment.

Finally, speech perception ability has been shown to be highly predictive of reading outcomes. Bilateral cochlear implants have been demonstrated to result in improved speech perception through two ears because the brain has two opportunities to process the signal, provide a slightly louder signal. It is reported that these perceptual benefits lead to significant improvements in children's abilities to perceive speech in both noisy and quiet listening conditions.

Forty-four children 8-year-old children with early cochlear implants were selected for this study. This study extends the literature showing that children with cochlear implants can achieve academic outcomes similar to their peers with normal hearing. The outcomes of this study indicate that children with binaural hearing through two CIs produces notable benefits in oral language, written language, and math over a single CI. Binaural hearing through two CIs may help children with profound hearing loss to achieve age-appropriate academic performance. The benefit was shown to be greatest when the second cochlear implant is implanted at a younger age. These benefits were statistically significant. High levels of parental involvement and in children's intervention and educational programs, including establishing a regular reading habit with the children, were shown to be highly influential on academic outcomes.

### Summary

In summary, a review of the literature found various factors that affect academic achievement of deaf and hard of hearing children. These factors include family characteristics, expressive and receptive language abilities, and experiences outside of school. Some factors which affect the language abilities of children with CIs include duration of deafness, age of onset of deafness, duration of CI use, educational, and social factors (especially parental involvement). The vast majority of DHH children are adversely affected by language deprivation that is not seen in typically developing hearing children.

Spoken language skills provides the basis for reading abilities. While cochlear implants have improved the reading skills of deaf children, the reading comprehension skills of cochlear implanted children is still below that of their typically developing hearing peers. Reading is critical to one's academic success and beyond.

When looking at the academic and language outcomes of children with cochlear implants, most parents reported that their high expectations of the CI had been met. Parents who stated that their expectations for their children with CIs had not been met were of the minority. Parents experienced more stress than what was expected before having their children implanted with a cochlear device. Parents noted the amount of work and time that was dedicated to their deaf children regarding early intervention, speech training, and frequent ongoing appointments related to the use of the CI. Feelings of stress were reported by parents due to frequent problems with the CI equipment and parts.

There is a general consensus that children with cochlear implants still demonstrate significant delays. This illustrates the significance of examining the experiences of parents who have traveled along the cochlear implant journey, to find similarities and differences that may account for variability in academic and speech and language outcomes. If we can identify those differences, perhaps we can be more effective in helping all children who are born with severe to profound hearing loss, to develop to their fullest potential.

# CHAPTER III

# METHODOLOGY

This study seeks to understand the similarities and differences in the parental cochlear implant journeys and to explore their experiences with cochlear implants. A qualitative research methodology was used. Qualitative research can be defined as a research method that examines the *nature* of phenomena and is especially appropriate for answering questions of *why* something is (not) observed (Busetto et al., 2020). The qualitative methodology was the best approach for this study since the aim of the study was to examine the nature of the phenomena of differences in language outcomes in children who receive cochlear implants. Some children who receive cochlear implants speak clearly and nearly match their hearing peers in oral language competencies. Other children who receive cochlear implants have limited oral speech, cannot be understood by unfamiliar listeners, and may even use sign language as a primary method of communication. Perhaps in exploring the individual stories of parents who lived the experience of the cochlear implant journey can provide answers that explain *why* such vast differences occur.

Narrative inquiry was used as the qualitative approach. Narrative inquiry was chosen because this approach allows the researcher to understand human experience as lived and told stories. This research study allowed me to capture the stories of four parents, and to record their individual stories about their experiences.

## Sample

Nonprobability sampling and purposive sampling was used. Non-probability sampling is a method that does not allow all members of the population to have an equal chance of participating in the study. Purposive sampling was used since participants were chosen only if they were parents of children who had cochlear implants.

Study participants were from three states in the United States of America. Four parents used for participating in this study. I paid attention to thematic saturation, and determined that by the fourth interview, there were no new ideas emerging from the data. I obtained data that was rich and used thick descriptions to present the parent stories. The criteria for participation in this study included the following:

1. Participants must be parents of children who have had cochlear implant surgery
2. Parent must be primary caregiver of child with cochlear implant
3. Child must have been implanted for at least 5 years

Completed questionnaires used in the analysis totaled 4 for parents. Of the completed parent questionnaires, 75% were mothers. Twenty-five percent represents the one father. All of the parents (100%) identified as hearing individuals. One of the children in the parent questionnaire was reported to have Cerebral Palsy and was born prematurely at 25 weeks gestation.

## Data Collection

Initially, a short questionnaire was used to capture demographic information such as How old was your child when they underwent surgery for the cochlear implant? What grade is your child in? etc. Other questions focused on the use of hearing aids before implantation, educational setting, communication approach in the educational setting, grade in school, and the name of the child's school. Examples of the Questionnaire can be found in the Appendix.

Each parent was interviewed twice using semi structured interviews that were conducted via Zoom, a videoconferencing platform. Both interviews were audio recorded. The first interview explored the child's diagnosis of deafness and the decision to pursue a cochlear implant. At the end of the interview, parents were asked to give "one way the process can be improved for future cochlear implant recipients." The second interview was used as a follow up to interview questions that may arise from the first interview. In addition, the second interview was also used to triangulate data. The interview questions consist of open-ended questions. The questions were divided into four major categories.

1. Pre-diagnosis and diagnosis of deafness
2. Exploration of cochlear implant
3. Life after cochlear implant surgery
4. Intervention and nurturing of language and academic development

The semi structured interviews utilized a preliminary list of questions functioning as a guideline only, allowing unanticipated information to emerge. The questions included in the interview guide covered the parents' decision making about a cochlear implant for their children, their expectations before their children's implantation, and their experiences and perceptions of their children's language and academic development since implantation.

A copy of the Individualized Education Plan (IEP) of each child was collected. The IEP provided information about services the children were receiving in school and provided insight into the academic achievement of each student.

The researcher also wrote memos after each interview (e.g., how did it go, was each question answered, and what needs to be asked during the next interview).

## Data Analysis

Inductive systematic analysis was used to identify themes as they emerged from the data through repeated examination and comparison such as studying documents (IEPs) and the recordings (via Zoom). All conducted interviews were transcribed verbatim. Transcriptions will be read and re-read. Data will be organized and labeled or coded using terms that reflect the meaning generated by them (Galletta, 2013). The researcher will keep a written record of thematic codes.

## Trustworthiness, Credibility and Rigor

To ensure trustworthiness, credibility, and rigor, data was triangulated, the researcher maintained an audit trail, and used rich and thick description to enhance transferability, the researcher also used reflexive memo writing, and utilized a peer auditor to review data analysis and codes.

There is some insider positionality as the researcher is a speech language pathology graduate student and also the parent of children with cochlear implants.

**Ethics**

Approval for the project was gained from the Communication Sciences & Disorders Program at Cleveland State University as well as from the Institutional Review Board. Participation in all parts of this study was agreed upon by its participants. To ensure and maintain confidentiality of the participants, each parent and child has been assigned a pseudonym. Figure 3 shows each parent participant (pseudonym), their children who have cochlear implants (also given pseudonyms), gender of the child, race of the parent, cause of child's hearing loss, age at first implantation, age at second implantation, current age of the child and grade of the child in school.

**Table I. Summary of Participants (pseudonyms), and their children who have CIs**

| Parents | Child(ren) with CI | Gender of child | Race | Cause of hrg loss | Age at 1st implant | Age at 2nd implant | Current age | Grade |
|---|---|---|---|---|---|---|---|---|
| Yolanda | Joseph | Male | Black | Oxygen deprivation at birth (premature) | A little over 1 | Almost 3 years | 13 | 7th |
| Ashley | Sebastian | Male | White | Mondini dysplasia<br>&<br>Enlarged Vestibular Aqueducts | 13 months | 19 months | 6 | 1st |
| Nancy | Bryce | Male | White | Genetic: X-linked hemizygous | 3 years | 3 years | 9 | 3rd |
| Nancy (same as above) | Shane | Male | White | Genetic: X-linked hemizygous | 2 years | 2 years | 7 | 1st |
| Jonathan | Alicia | Female | Hispanic | Connexin 26 | 23 months | 7 years | 10 | 4th |

Table 1 shows each parent participant (pseudonym), their children who have cochlear implants (also given pseudonyms), gender of the child, race of the parent, cause of child's hearing loss, age at first implantation, age at second implantation, current age of the child and grade of the child in school.

## Summary

This chapter provided the methodological approach, participants, data collection, and analysis that were used in this research study. In summary, a qualitative research methodology was used. Semi-structured interviews allowed four parents to share their stories about their lived experience of raising a child or raising children who were born with severe to profound hearing loss, and who received cochlear implants.

# CHAPTER IV

# RESULTS

The purpose of this study was to examine the lived experiences of hearing parents who are raising children with cochlear implants. The research questions that guided this study were: (1) What differences have occurred in the parental cochlear implant journeys that may account for the differences in their child's outcomes? (2) What are the similarities and differences in these told stories that may explain differences in the child's language outcomes? (3) What are the similarities and differences in these told stories that may explain differences in the child's academic outcomes?

Four hearing parents of children who have cochlear implants participated in this study. In this chapter, I present co-constructed stories or narratives of the participants. Additionally, data from semi-structured interviews are presented. The data provided thick description of the lives of the journey that these parents have taken with their children in the world of cochlear implants. This chapter will present six major themes that emerged from the codes that were developed from the interview data. The major themes include: 1) Differences in thE information provided at the diagnosis of deafness, 2) early intervention services happen early, but are implemented differently, 3) speech and language and reading outcomes vary, 4) the Individualized Education Plan – IEP-

Every parent could use a little help, 5) Satisfaction and Disappointment – Experiences and feelings about the implant, and 6) The Need for More Information - How the cochlear implant experience be improved.

## Differences in the Information Provided at the Diagnosis of Deafness

This theme explains how the medical team (physicians, audiologists, speech-language pathologists, etc.) relayed information to the parents as they learned of their child's diagnosis, and the quantity of the information that was given. There were varied experiences that were revealed from the parent stories. Some parents were abruptly informed of a failed hearing screening, with no additional information. For example, when Ashley was asked about her experience and thoughts on when she first learned of Sebastian's diagnosis she stated that she found out of her son's hearing loss while in the hospital not long after giving birth. She said,

> "They never told us anything until literally 10 minutes before discharge, as they discharged us. They told us we need a follow up because he failed his newborn hearing screening. There was no discussion. It was really traumatizing. Honestly, it was awful. We never got to speak to the pediatrician about it. Nobody ever told us until we were walking out the door."

She later went on to discuss her thoughts and experience when the cochlear implant was first brought up as an option. She explained,

> "I was completely for it. With both hearing parents and never knowing a deaf person, if giving me any hope of a chance my child could maybe hear, I was signing up for it and I was pushing for it. If anything, I pushed for it (the cochlear implant)."

It was surprising to learn that in Ashley's case, other options were offered to her in terms of using sign language and the type of educational options that were available to her. Ashley said,

> "If anything was pushed on me, it was sign language. And pushing us to go to the state school. Our state has Romney (a school for the deaf and blind), and they actually even let, once the child is three, they can live there, and they like just come home for weekend visits and stuff. And I thought it was crazy talk that they wanted me to talk about signing up my toddler to leave my home. That that sign language and Romney is what was pushed down our throat and still is. With every single IEP meeting they have to tell us about the state opportunity for Romney. My biggest question and the biggest thing that drives me nuts is why is it not required to tell me of the other option, which is listening and spoken language, and that we also have one place in our state where they can learn how to speak with hearing device. So, um, yeah", the CI team was "Very thorough and professional and that all options were given to us repeatedly."

Similar to Ashley, Nancy felt the CI team did a good job presenting all significant information. Nancy felt supported and developed trust with the audiologist. Nancy reported,

> "When they said the cochlear implant was an option I was like, give me all the handouts. Give me all the pamphlets about the three different companies and let's start the process. Like I didn't even actually wait 'cause I was like we're, family wise sign language is wonderful, and I love it I actually teach it at the university that I teach at, but at the same token, how many people actually know it. So, I was like we have to step forward, but it was never pushed. In fact, me and my sons' audiologist, I love her 'cause she's very straightforward and I like that in a practitioner. She was like Nancy; this is not just like a cure. She's like its intense speech therapy. It's intense, it is intense, and it requires you as a parent to actively be involved in this, and it's going to take a while before they develop speech. And if you don't make him wear it, then he's never going to develop speech, so you have to make sure that this is something that you're going to do as a parent too. So, it was almost like I found they did such a good job at telling you exactly what was going to happen. Like you can't just have the surgery and then expect them to develop speech, that's not how it works. So, I think they actually almost did the opposite rather than push. It was like make sure that this is what you're wanting."

While Nancy felt that she received complete information from the audiologist, listing options and expectations, Yolanda's experience was different. Yolanda felt that the professionals on Joseph's CI team did not explain her child's hearing loss and options in any detail. Yolanda said,

> "I didn't want my son to be deaf. Basically, that's what it was. I didn't want him to be deaf. I didn't think that was fair to him. I didn't think that he would be able to have the best in life If he was deaf. I felt like I didn't have any other options. They did not inform me much about deaf culture and other alternatives and how you know some children and some people choose to be deaf, and they're perfectly fine with it. They didn't tell me, you know, they didn't stress that even though he's gonna get this implant, you guys still need to learn sign language, because that would be, a lot of times, his primary language. All of those types of things were not explained to me. So, in that sense I do feel like it was pushed on me, but it was pushed on me as if it was like a cure all for everything. You know it was like this is the only way that your child can be successful in life is if he gets this and he needs to get it right now. He's gonna be able to speak perfectly fine. You know all of that, and that's not the case. Like why did y'all say that to me? They don't explain how there's still a difference in how they hear. They didn't explain that to me and I didn't learn that until you know, and I guess that's where you know, doing your own research comes in, but I'm a young mom with a 25-week-old and I'm just trying to do everything possible for him. It was just so much stuff going on, and I was just trying to get every intervention. Everything that they wanted me to do I was just trying to do it. So, I was just more of okay, okay, yes, yes. They said do this, they said do that. With me not having any experience with anybody deaf in my family or anything like that, I just was looking for a cure. And that's kind of how I felt like it was explained to me. Like it was a cure, and it's not." I believed it was fine in the beginning, but now I believe they could have explained some things better, such as the need for us to still learn ASL. Some sounds he would not be able to hear. The difference in the way he hears. They never explain to you that there's a chance that maybe your child, especially when it comes to reading, will never be at a typical level."

Jonathan stated that he and his wife were notified that Alicia had had been referred for a hearing evaluation based on the newborn hearing screening results while still in the hospital. He said he didn't give it much thought at the time because although they were told to go for a follow-up, the nurse reassured them that Alicia's failed hearing screening was likely due to a fast labor and birth resulting in fluid remaining in her ear canal. After further testing confirmed Alicia's severe to profound hearing loss, he noted,

> "The audiologist compared my daughter's hearing loss by saying sound needed to be at the volume of a plane's engine for her to hear it. I was very sad; I cried. I felt terrible at first. I felt it was my fault for some reason. I wanted to fix it, but I had no power over the situation."

When asked about his experience with the cochlear implant team, Jonathan reported that he did not believe that the cochlear implant team did a good job explaining in full detail the extent of therapy that would be needed post-surgery. His experience was similar to Yolanda's. Jonathan said,

> "I wish that I would've had more information up front as far as the cochlear team. I wish they would have informed me more as far as it being 10 years old, and she still has to go to speech therapy. In a sense they almost made it feel like, you know, like a surgery, it's done, it's over and you move on to your life. They made it seem like that. They didn't make it seem like…I didn't know that it would be a continuation of things and episodes that would prolong until you know 10 years old. They didn't provide me all the information up front. At first it seemed like it was gonna be, you know, one decision fix all if you will, but it wasn't that it was. I didn't know that the cochlear implant was not going to give her hearing like us. She hears differently and she still does not hear everything. She misses a lot, and we have to repeat things for her a lot of the time. She's doing great, but there is so much we did not know and have learned and are continuing to learn on our own along the way. I didn't know about all these extra things and devices she would need once she started school. I thought she would be a regular kid in the classroom just like I was. I wish we would've been told about a support group or some sort of meetup where we could have met other kids with cochlear implants. Also, they never explained to us that being deaf doesn't mean that you can't hear anything at all which is why it took us so long to decide on the surgery. For almost two years we put off the surgery because there were instances when she definitely heard something. All they had to do was explain what it means to be deaf. I think as doctors they just expect people to do exactly what they say, but I need you to explain things to me. Let me know all of the details so that I can make the best decision for my daughter. It would have been nice to have others to talk to who went through or were going through the same things as us. I think that is the least the team could have done. If you can't provide all the information, then at least point us in the direction of someone who can."

### Early Intervention Services Happen Early but are Implemented Differently

This theme describes the services and supports that the parents involved their child(ren) with CIs in (from birth to age 3) and how often they received those services. All the children were involved in some type of early intervention service, however, they differed in the number of services they were involved with.

> During the interview, Nancy reported that both her CI children (Shane and Bryce) "have been getting speech therapy since three months old. They were like, OK, we're gonna do speech therapy in the house and they started that. And then our Louisiana school for the Deaf also has a program called PPEP. And they send people into your house, and they can help you with any services. They can help you like learn sign language if you choose to do so. So, I had both of those services. I don't know if you've heard of hands and voices. If you're familiar with them, that's a national program. I'm actually a guide by your side representative for our area, so it's a parent driven program and they also help you. They'll go to like audiology, appointments with you, they'll go to IEP meetings with you, and they can also like help guide you through the process if you have questions. If you're just having a bad day with like breaking implants or having you know, just like having a tough time, it's a program that really can help those parents in those situations."

Ashley also received early intervention services. She stated,

> "We were immediately referred to our state, um, early intervention birth to three program, which I actually currently work with, um, as well, I didn't at the time. And, um, we started services with a speech therapist and discovered, um, listening and spoken language, which is the route we chose for our son. "His first hearing aids were at two months". He started speech "2 months after he got his first hearing aids". Through birth to three, we actually only have one place in the state. It's in Hunting, it's called the L lab. Um, and it's two and a half hours from us. And they, um, had to hire someone to come to Charleston, which would be an hour and a half away. And they were billing the early intervention services, the West Virginia birth to three, but we actually had to go in office cause that was closest she could come. So, our technical speech frequency was twice weekly. Um, but one, one speech therapist was, she was actually in her additional training for the LSL portion. And one was just a regular SLP that had been for 20 plus years. And then we also had a developmental specialist That came weekly. I really, um, I'm an occupational therapy assistant and I'm um, at the time I was considering going my masters for OT. Um, so I really knew how beneficial the early intervention was and I really pushed for as many services as possible. So, we actually had three weekly. The developmental weekly, um, and then both of the SLPs were weekly."

Jonathan also received early intervention services. He said,

> "There was someone who came to the home and in addition to that she received speech services where she went to an office. The lady who came to the house was through the state or the county, I'm not sure which one, but she would sign and talk with her. This started early, at about 6-9

> months and she would come out each week. She wasn't a speech therapist. I think she called herself a teacher of the deaf. The speech that was in an office was at the University Hospital and the speech therapist there did not sign with her at all. I don't know why because she couldn't hear at all, but she did start reading lips and actually had around 10 thru 15 words before she got her cochlear implant. She picked those up from reading lips. Still now, she is very good at reading lips. I can have a conversation with her when her processor isn't on. I asked her if she could hear me, and she said no I'm a lip reader. At around 20 months, she started seeing another speech therapist for services every week. So, all together she had three services weekly. One inside the home and two outside of the home."

Finally, Yolanda also received early intervention services for Joseph. She said, "someone came out to the home if not once a week, then every other week. That was the extent of early intervention services for Joseph

## Speech and Language and Reading Outcomes Vary

This theme elaborates on how the parent rates their child's speech and language compared to typically developing peers without hearing loss. Parents were asked whether or not they felt their child is currently at the same level as their hearing peers with regards to their speech intelligibility and reading. The parent participants in this study report varied results with speech and language and reading outcomes.

When compared to typically hearing peers, Jonathan said that he would rate Alicia's vocabulary a 4 out of 5. He explained that there are some words that she has never heard before which maybe the average "hearing" child her age is familiar with. He added that her reading is proficient and that she was recently on the honor roll. Jonathan expressed that he is very pleased with her speech intelligibility and added that her teacher referred to her as being "very successful" with her cochlear implant in regard to her speech. He said that they do not have a problem with familiar or unfamiliar listeners understanding what she says and that she sounds "normal".

> On the report of Alicia's IEP, Alicia took the NWEA in September of 2021. This test gives her scores in both reading and math and compares her abilities to students across the country in these two main subjects. She got a 193 this fall in reading which represents a growth of 14 points since the Fall of 2020. This represents above average growth, and a score that is within the average range. Her reading goal for last year focused on informational (non-fiction) text, and her highest score was in identifying key ideas and details in informational text. Her lowest score was in the language, craft and structure of informational text, so she has developed both strengths and weaknesses over the past year. Vocabulary was also considered a strength, while the identification of key ideas and details in literary (fiction) text is another weakness. These could be our new focus for the next year in reading. The test suggests that Alicia is ready to develop skills in identifying evidence that supports a statement in informational text and to determine the meanings of words and phrases (figurative language) in both literary and informational text. It also suggests she is ready to develop skills in drawing conclusions and making inferences from literary text based on characters, setting, events or the title."

When Ashley was asked about Sebastian's reading, she reported,

> "He's reading on the first-grade level, but he's reading on like early first grade. And, and, you know, we're halfway through the year, but I feel like also all of his classmates, I've talked to the teacher, and she said she would put him about in the middle of the class. So I think everybody's behind just with COVID and craziness. My kid's articulation, I mean, honestly, he speaks better than a lot of typical-age kids. I mean, his articulation's great. What he needs and struggles with is auditory memory. Just basically with that and just lack of vocabulary, and just simple things that he just doesn't know the words for. I'm really hyper focused on his, on his reading and, um, just especially with the deaf children, typically only come up to third grade level, especially if they're focus, if they're ASL. So, I definitely wanna surpass that. I also have concerns socially. I just wanna make sure he's able to hear his classmates and converse with them and have as typical of a childhood as he can."

When Ashley was asked about Sebastian's vocabulary level she said

> "That's really hard because he can do a lot, but it's, I guess it's the understanding. Um, probably honestly right now, a two or three out of five. Now last year I would've said four, but I feel like this first grade has been a big year and I think that it's starting to kind of show that things are take a little bit longer for him."

Nancy felt that her son, Bryce was reading at the appropriate grade level, but her younger son, Shane was not working at the same level as his hearing peers. She said, “Bryce is on grade level. My 7-year-old is like Pre-K”. Bryce’s vocabulary (my 9-year-old) he's on level.”

Yolanda expressed worry about her son’s vocabulary, as it is clear to her that he is not having the same level of success academically as his hearing age peers. She said, said,

> “He’s got some catching up because he went so many years without, you know, even though he's been implanted a long time. I would rate his vocabulary as maybe a 3 out of 5. My baby is in 7th grade, but he probably reads at like a third-grade level. Normally the books that my third grader is reading we just kind of all read them together and just, you know, make sure he understands the definitions or like during the summertime. I was like looking up like third grade sight words and everything like that.”

### The IEP- Every Parent could use a Little Help

IEP stands for Individualized Education Plan. It is a written legal document which lays out the program of special education instruction, supports, and services necessary for a child to be successful in school. In order for a child to receive an IEP, he or she must first be evaluated. The evaluation reveals the child’s strengths and weaknesses. These results are used to create a program of services and supports that are tailored to fit the needs of each individual student. Both family members and school faculty should work together to create each child’s IEP. The IEP team is comprised of a parent/guardian of the student, general education teacher, special education teacher, a school district representative (usually the principal or assistant principal), and an expert who can interpret the student’s evaluation results (i.e., school psychologist, SLP). Schools are required to hold an annual IEP meeting in which all members of the IEP team are required to attend to discuss, develop, and review a student’s progress (Belsky, 2014). The IEP process and meetings can prove to be overwhelming for parents.

This theme expounds on the parent's level of comfort during IEP meeting (initially and currently). Some parents were confident and assertive, others were afraid and intimidated. This theme also explores whether or not the parent had someone to help advocate for their child at these meetings. Some parents had highly trained professional therapists who accompanied them to the IEP meeting and helped to advocate for their child(ren) with hearing loss, others traveled the road alone. Differences in the accommodations that each child received as indicated in their IEP are also noted here.

Ashley recalled the support that she received from her listening and spoken language therapist (LSL) who attended the first two IEP meetings,

> "It was so helpful to have her there. She does attend IEP meetings anytime she is available. However, she keeps a very full schedule. Initially I was worried I would get negative responses from ST and deaf teachers for not implementing ASL with my child. Also, concerns they would push those views on me and my child. However, I have had a positive experience and with strong boundaries they have respected them. Now I know the teachers are on my side on how to help Liam rather than the mindset I had initially was they would be against me in a way. I'm no longer defensive. They know my feelings and respect them. We can now all come together with the same goal on what modifications will reap the best success for my son." Sebastian receives speech in school "sixty minutes a week. I sent you his IEP and then now we have upped his deaf and hard of hearing teacher and she just does pre-teach and reteach with him. And that is 90 minutes a week. And we actually do that before school. We don't have any out of class time other than speech therapy.
> With the assistance, I feel like our auditory verbal therapist does a good job in, in preparing you for the IEP. And she also gives out basic guidelines that you should maybe request preferential, simple stuff. Um, one thing that I did do that is not typical. I've asked for any therapist or whoever they see, I just have one notebook that they would sign and actually write down. It can be really simple, but just what you focused on that day. And I think that is a simple thing that helps hold them accountable. Whoever sees him that day, they sign and they do a little note basically. I mean, I'm talking one or two sentences. I just want, like, you know, he worked on reading comprehension or whatever. It's normally just quick. I don't expect them to do a lot, but I just think it's a good communication, so I can kind of see what they're doing through the day. And it lets me make sure that he's receiving his services."

Nancy explained that sometimes parents need to know and understand their rights

And when to advocate for themselves.  Nancy said,

> "I get what I want because I've had to threaten a PWN (prior written notice) one-time last year and that was like the magic word. I'm very comfortable. I will fight for any deaf child." When further asked about any accommodation/modification on her children's IEP she noted, "They get wonderful accommodations at school. They each have their own interpreter. They have a Deaf Ed teacher who sees them for 60 minutes, three times a week. They get a special ED teacher five times a week for 60 minutes, 30 minutes in math, 30 minutes in English. They get the speech therapy twice a week at school for 30 minutes. They have an FM system. They get priority seating; they have all the modified tests you can imagine." Yolanda expressed the same level of advocacy as Nancy.  She said,
> "I'm really comfortable. I'm just like I am now. If I've got something to say I'm gonna say it. I'm gonna be really involved. I'm gonna advocate for him. You know 'cause he's been there since preschool, so I feel like I know everybody, everybody knows me. Everybody know how I am. You know, anything you tell me that that can help him I'm gonna do it."

Yolanda, unlike Ashley,  stated that she never had anyone to help advocate for her son during IEP meetings.

According to Joseph's IEP, his strengths are in understanding the main idea and key details of both literary and informational text. His weakness is in vocabulary acquisition and use and in the language, craft and structure of both literary and informational text. Joseph is currently pulled out of the classroom by a teacher of the deaf to help address his difficulties with reading comprehension, writing, and math. He is also pulled out for reading comprehension services with the speech language pathologist. Joseph receives audiological services at school and has a sign language interpreter. He is to be provided with flexible seat assignment allowing for optimal visual access during instruction and when educational technology is employed. A visual alert system for fire, tornado, security breaches, and other emergencies is also in use at school. Accommodations further include, clarified or simplified directions, extended time for assignments, small group instruction that allows for repeated, guided practice on specific skills and for limited distractions during testing.

Jonathan explained that the IEP process takes some getting used to. He expressed a level of discomfort with the process that has gotten better over time. Jonathan said,

> "My wife is very comfortable at our daughter's IEP meetings. She wasn't too comfortable at the beginning, but along the way you know it took a lot of consulting and we got her to feel more comfortable along the way, but not at the beginning it."

Jonathan said that it would have been nice if they would have had someone to help them and advocate for their daughter during the IEP meetings. Jonathan and his wife both felt as though they did not really have a say in what was included in Alicia's IEP. Initially they always just went along with whatever was proposed at the meetings. As they started to understand the needs of their daughter better, they became much more comfortable with expressing their wants for Alicia.

According to Alicia's IEP, she receives weekly pull-out services by a teacher of

the deaf for assistance with reading comprehension and math word problems. She is also pulled out for speech and language services. Alicia has an interpreter and uses a FM system while in school. As stated by the IEP, "The classroom teacher reports that Alicia is making good progress and is passing all of her classes. She receives preferential seating and a small group environment for tests and quizzes. Alicia was in a remote learning environment for most of last year and she sometimes was not able to get online. When we returned to in person learning she was in a classroom for the deaf for the last few months of that school year. She has not been in a regular classroom for more than a year (due to COVID) and the class is being exposed to challenging curricula. The interpreter indicates that she does sometimes ask for instructions to be repeated or for the interpreter to slow down. The regular education teacher is pleased with her performance and is hoping that Alicia will advocate for herself and ask the teacher for help when she needs it. In English, Alicia is learning to write a summary paragraph and to use domain specific vocabulary. The first math module has included adding and subtracting with numbers to the 100,000 place. Alicia can add and subtract with appropriate regrouping but may still need help to represent a problem with a drawing and to determine the

> correct operation to use to solve the problem. She will soon be solving multi-step word problems that involve other than whole numbers, including fractions and decimals."

**Satisfaction and Disappointment - Experience/Feelings about the Implant**

This theme clarifies the parents' thoughts about the cochlear implant meeting their expectations. One of the four parents expressed that the cochlear implant has not met her expectations. The other three parents expressed that they were very pleased with the outcome of the cochlear implant. Overall the majority of the parents in this study expressed satisfaction with the cochlear implant device. One parent expressed disappointment.

Ashley reported that overall, she is happy about her choice to have Sebastian implanted with a cochlear device. Ashley noted,

> "My only downfall is I wish that there was another place for auditory verbal therapy in the state. I mean, one place in the state is very challenging and thankfully with technology it's made things easier, but it's, it was very hard in the beginning to get a three-year-old to sit down in front of a computer for therapy."

Ashley expressed that she is very pleased with her son's outcomes due to having a cochlear implant. When asked about expectations pre-implantation she said,

> "Surpassing, my child lives a typical life. He is on soccer team, baseball. I mean he does all the sports and converses with kids. He is all his friends. I mean, honestly, our life is no different. There's so many people that meet him and talk to him and if they don't happen to see, we wear a, they don't happen to, they think he's just wearing a sweatband like most, most of the time, that is not an unusual thing. They don't even realize he's deaf. I feel like it is surpassing expectations.
>
> Nancy's feelings about the cochlear implant were similar to Ashley's. She said,
>
> "I'd give you more than 100%. I do not regret my decision at all. I say I wouldn't relive those years, but if it was them not having the implant versus them having it. I would do it over again right now without a shadow of a doubt. Even as scary as it was, because their surgeries were like 5 hours because of their abnormality. It was a long surgery and there's no doubt in my mind about doing it. The cochlear implant absolutely met my expectations.

Similar to Ashley and Nancy, Jonathan explained how happy he is with his decision to have his daughter implanted with a cochlear device. Jonathan was asked about his overall thoughts and feelings on the cochlear implant, and he responded,

> "I'm happy with the outcome. I'm happy and very grateful that, you know, my oldest daughter could hear and could communicate with me. No Alicia does not hear the same way we do, but she is doing great. She can have a conversation on the phone. She has friends and can communicate with them using sign or by talking. She can place her own order when we go out to eat and the waiter will take her order with no problem. This is because of the cochlear implant. Yes, it has been extremely hard and a very long road, but it is one of the best decisions I ever made. I am ever so blessed."

Yolanda had an opposing viewpoint when compared to that of Nancy, Ashley, and Jonathan. Yolanda reported that the cochlear implant has not met her expectations. She said,

> "His implant has been in my purse and my person gotten stolen. It has been lost in the playground. He has lost it on the school bus. No one ever found it. He has lost it outside of the school and they didn't find it until the snow melted the very next season. He has flushed it down the toilet. He was in Miss Kay's class, and she like all I know is Joseph ran to the bathroom, he flushed, and we can't find it. I'm like, oh my God! So, a lot of times it has just been a headache that I just have said I'm not about to deal with. I'm just not about to deal with this right now. Like you know I'm trying to explain to the company why, yet again, my child needs another replacement. It was a mess."

### The Need for More Information - How the Cochlear Implant Experience be Improved

This theme captured the ways in which the participants feel the cochlear implant experience can be improved for future parents who go through the process. Although experiences varied among the parents, three of the four parents had a very similar response when asked about any advice they would give to the parents of future cochlear implant recipients. Most parents feel a great need for more information about the actual device, process, and follow up therapy.

Ashley felt that there was very little information provided to the parents about the technology and what to expect from the cochlear implant. She said,

> "I think a big problem with cochlear is exposure. I don't think people know that it's even available. I talk to people, and I tell them about Sebastian. He's a deaf person who can hear. It could be more well-known. Maybe actual videos would help. I think it speaks for itself, the technology, and the proof is there. It's just, no one has, I know cochlear does some little videos, but there's no content. I wish there was a lot more content available for parents."

Ashley also thought that it would be helpful if there were instructional videos about speech and language development and what milestones should be expected by parents of children who received cochlear implants. She said,

> "It would be great to know what to expect. In the beginning I was kind of questioning what should he really know because children start listening in the womb. And I know, you know this because, so they have to hear for a little bit before they're even able to speak. So when after he's had hearing access, should I actually hear these sounds or hear words? It would be great to have a database with information. If cochlear could do that … I know that's a big ask, but, that would really help.

Ashley also found support in an online parent group, and pointed to this as a

Possible lifeline for other parents who are raising children with cochlear implants, but who feel that they have little support or that they need more information. Ashely went on to say,
I try to share and post things about my, as much as I can on the parent group. So, parents now join because they realize that other people are going through the same thing. That is why most of them joined. And I didn't know about that group until my kid was four or five. So just having more information available on the Internet is a help. If cochlear gave support like that, they could add timelines so that people could see how much progress their child is making as they are learning to talk. Parents need some kind of guide to follow. Plus, if parents see deaf children with implants speaking in a video, it gives hope and inspiration.

Nancy was also asked about how the cochlear implant process can be improved, Her suggestions centered around improving the insurance approval process and providing parents with information so that they could align their expectations regarding the development of hearing their children use oral language. She said,

> If it was me, I would say not waiting the six weeks for insurance approval. Like if they could speed that up and make it quicker, that would actually be more beneficial. It puts them behind." The advice she gave for the parents of future cochlear implant recipients is, "To not expect overnight success. That it would take time. It's going to take time for them to develop speech and actually start recognizing sounds and have that identification. You can't expect them to get activated and then suddenly the next day have some normal development of speech. And I guess I would say that because that was told to me, and it was heavily emphasized. Like, this is not a cure. This is not going to be oh, you got implanted and now they're hearing. No, they're still deaf and they're still going to need this adjusted for the rest of their life. It's a lot of work. As a parent it's a lot of work.

Yolanda's advice to parents centered around the knowledge and belief that a child who was born with severe to profund sensorineural is deaf, and the cochlear implant will not change that. She said,

> I think I would stress to them that no matter what, your child is always deaf. So go about the things that you would do for yourself as far as learning, sign language and everything like that. The things that you would do and adaptive things that you would have to have if you had a deaf child. I would say just to continue to think about it like that. Don't think that you're going to have a hearing child just because they have a cochlear implant. I think that will prepare them better to knowing the fact that even though their child has this assistive device, think of it as an assistance, not as a cure. Still, take the time to learn sign language, teach your child sign language. Stress the importance of the speech therapy and everything, but also know that some kids are not going to do as well as other kids are going to do. There will be times when your child doesn't even want to wear the implant. There will be times when they're going to lose the implant. I think Joseph has lost his implant more than anybody. There has literally been years where Joseph has not had his implant, you know, and I didn't expect that. It's been hard.

## Summary

To summarize, six themes emerged from the interview data: 1) Differences in the amount of information provided at the diagnosis of deafness, 2) early intervention services happen early, but are implemented differently, 3) speech and language and reading outcomes vary, 4) the Individualized Education Plan – IEP- Every parent could use a little help, 5) Satisfaction and Disappointment – Experiences and feelings about the implant, and 6) The Need for More Information - How the cochlear implant experience be improved.

The parents provided a varied journey through the world of cochlear implantation. Some parents felt that they were well informed by the cochlear implant team, while others were given very little information about the cochlear implant, deafness, hearing loss, etc. and felt ill-equipped to make an informed decision. Early intervention services were ideal for some parents in this study as a professional was dedicated to coming to the home several times a week for early intervention services, while other parents received services "once a week or every other week." The data also varied as it relates to speech-language and reading outcomes. Many of the children of the parent participants were at or above grade level for reading and were able to communicate verbally and with good speech intelligibility. Other children were significantly below reading levels compared to their hearing age peers. Parents also reported that the IEP process is potentially overwhelming, acknowledging the need for additional help as parents go through this process. Parents expressed great satisfaction and joy with their child's experiences with the cochlear implant. While another parent expressed dissatisfaction and frustration. Finally, most parents feel that the cochlear implant process could be significantly enhanced if parents had access to more information so that they could educate themselves about the cochlear implant device, and thus place themselves in a better position to educate and advocate for their child who has a cochlear implant(s).

| Child | Consistent use of cochlear device since implantation | Speech intelligible to unfamiliar listeners | Current reading level |
|---|---|---|---|
| Sebastian | Yes | Yes | Reading at grade level |
| Bryce | Yes | Yes | Reading at grade level |
| Shane | Yes | Yes | In 1st grade reading at pre-k level |
| Joseph | No | No | In 7th grade reading at 3rd grade level |
| Alicia | Yes | Yes | Reading at grade level |

Table II shows each child discussed by each parent participant, whether the child had consistent use of cochlear implant, whether the child's speech is intelligible to unfamiliar listeners, and the child's current reading level.

# CHAPTER V

# DISCUSSION

## Research Questions

The overarching research question is what differences is what differences have occurred in the parental cochlear implant journeys that may account for the differences in their child's outcomes?

### ***Research Question 1***

*What are the similarities and differences in these told stories that may explain differences in the child's language outcomes?*

There were several similarities and differences in the stories told by the participants in this story. In each case, the parents expressed devastation over the diagnosis of deafness. Each parent expressed that they made the decision to have their child/children implanted because they wanted them to be able to both hear and speak. None of the parent participants had any family members with a diagnosis of any severity of hearing loss prior to their child's diagnosis. All of the parents noted that this was another factor that played a part in their decision to have their child implanted. They believed that by having their child implanted with a cochlear device, there would not be this "burden" to have all close family members (i.e., grandparents, cousins, aunts, and uncles) learn American Sign Language. In addition, each parent believed that their deaf child would be better off and more capable of functioning independently in society if they had the ability to hear and speak; their only chance of that was the cochlear implant.

There were extreme differences in the early intervention, follow-up care, amount of therapy received, and the use of the cochlear implant across the studies. Three of the four parents have children who have excellent speech and language skills (Sebastian, Bryce, Shane). One of the four parents have children whose oral language is virtually unintelligible. Joseph has speech that is not easily understood by unfamiliar listeners. Yolanda explained that her son, Joseph, went through long periods of time (years) in which he did not wear his external processor. Though all parents expressed frustration due to broken and lost parts for the cochlear device, only one parent reported having long stretches of time where her deaf child did not utilize his cochlear device. It is very much possible that those long stretches of time where the child was not using his cochlear implant had a significant impact on the language outcomes. This lack of consistent use of the cochlear implant is a contributing factor in the variability seen between the one child who did not consistently use his cochlear device and the other 4 children who consistently used their cochlear devices. There needs to be a sufficient level of motivation from the parent in order to maximize the benefits of the cochlear implant (Waltman, 2000).

The parent of the child with unintelligible speech also reported that before her son had been implanted with a cochlear device, it was explained to her in such a way that she believed it would be a “cure” for his hearing loss. She was not explained in complete detail how a cochlear implant works and what she would need to do for him to be successful with his implant. She thought the surgery would "fix" his hearing loss. The cochlear implant team failed to explain that the cochlear implant is not a cure and there would still be a lot of work to be done in order for him to be successful with it, she did not follow through on her end. All professionals on the cochlear implant team should be responsible for educating the family on the things which are necessary for successful speech and language outcomes with a cochlear implant. "Professionals working with families in early-intervention programs need to ensure that parents have the knowledge and competence to provide their children with the necessary language learning activities" (DesJardin et al., 2006). All professionals on the cochlear implant team should be responsible for educating the family on what to expect after surgery. Two of the four parents were not provided with the full picture when the cochlear implant was presented to them. What differences exist which divided the four parents into two separate groups?

Early intervention has been shown to be effective in improving early language outcomes in children with congenital hearing loss, as a population. Not having access to the amounts of early intervention services may hinder the benefits of early intervention when compared to others. Research has also found that the benefits of early intervention increase as the frequency of early intervention increases (Geers et al., 2019). This is likely another reason the parents of children with CIs in this study who involved their children in consistent and frequent early intervention programs had better speech and language outcomes than the child whose parent did not have him in consistent and frequent early intervention.

### *Research Question 2*

*What are the similarities and differences in these told stories that may explain differences in the child's academic outcomes?*

The same differences that may have influenced language outcomes may have also had an impact on academic outcomes. "Academic performance depends not only on a students' ability to learn the material, but also on their ability to understand spoken and written language, their ability to convey their knowledge both verbally and written, as well as their literacy skills such as reading, writing, and spelling. Kids start developing the precursor skills needed to read, write, and spell as young as two years old. If those skills are later developing or do not develop, students' performance will suffer. This is because reading and writing are both language-based academic skills" (Gillam & Johnston, 1992).

There were differences in the early intervention, follow-up care, amount of therapy received, and the use of the cochlear implant across the studies. There was also a difference in some of the parents having an advocate to assist them during IEP meetings whereas others did not have this available to them. There are many benefits to having an advocate help with the IEP. He or she may; (1) advise the parent about services and accommodations that meet their child's individual needs; (2) help parent interpret reports and evaluations as well as explain their implications; (3) provide assistance in establishing goals for the child; and (4) give a boost of confidence during the meeting. Both similarities and differences were found in the told stories of the parents of children with cochlear implants which helped to shed some light on possible explanations for the differences in the child's language and academic outcomes. It is the hope that with these identified differences, trained professionals are better able to help create more successful outcomes in children who are implanted with cochlear devices.

## Recommendations for Clinical Practice

Most parents feel that they could have benefitted from additional information about the cochlear implant device and the processes involved from surgery to therapy that lasts years after the cochlear implant surgery.  There must be close collaboration between CI clinics and local educational services in order to ensure the best management and continuing use of the cochlear implant technology.

There should be greater use of the experiences of deaf and hard of hearing people in support of the decision-making process. It is important for information about sign language and the Deaf community to be more accessible to families both before and after their children's implantation. Parents should be made aware that choice of a communication mode need not be an either/or option, and that sign language exposure is not solely something to be resorted to if children fail to develop oral/aural communication proficiency. Instead, it can be used to provide fuller access to cognitive development and communication competence across a range of situations and social settings, therefore maximizing the child's life experience and potential.

Implant programs should continue to advise with caution about the range of likely outcomes, but also be aware that families are likely to be influenced by their hopes and aspirations for their children as much as by the information they have received. As a result, information giving processes should be regularly repeated, extended, and evaluated through ongoing discussion and counseling.

Results from the teachers' surveys report that 70% of their children with cochlear implants fall below the median level of their class in academic achievement. However, findings from the parents' surveys suggest that they were unaware of this outcome. As a result, there needs to be more communication and collaboration between parents and the teachers to ensure that the parents are aware of their children's academic achievement, particularly in literacy and mathematics. This will help to ensure that the children's scholastic achievements correspond with their communication potential and language acquisition.

It should be required for teachers involved with children with cochlear implants, both teachers of the deaf and general classroom teachers, to have access to professional development and training about CI device equipment and the needs of the children with CI. In addition, the maintenance of the cochlear implant necessitates strong communication between teachers, parents, and implant professionals.

The clear connections found between families' localities and parental stress and children's communications outcomes indicate that for children to receive optimal benefits from their implants and for the demands and stress on parents to be reduced, it is imperative that ongoing attempts are made to better access to audiological, rehabilitation, and continuous device maintenance services for families who live far away from cochlear implant centers.

Even with the availability of cochlear implants and early intervention, deaf children are behind their normal hearing peers when they enter school. Additionally, there is much language learning that lies ahead for them. As a result, there is need for us to enhance our intervention with deaf children during the early elementary grades.

## Recommendations for Future Research

Differences in socioeconomic status and race both should be further explored when looking at factors that lead to variability in the outcomes of children with cochlear implants.

It would also be beneficial if additional methods that are used in teaching deaf children to read could be explored. Cochlear implants have been available for children who are born deaf in the United States for three decades, yet deaf children, even with the use of cochlear implants continue to lag behind hearing children in literacy development. Studies that examine the science of teaching deaf children to read are needed to attempt to close the literacy gap.

## Limitations of the Study

The findings of this study have to be seen in light of some limitations. The first is that the sample size for this study was small (number of parents of children with CIs = 4). Analyses with such a small sample should be interpreted conservatively. It should be noted that although the sample size was small, saturation was reached. Indicating that an adequate sample size was obtained. The second limitation of this study to be noted is the researcher's personal experience on the topic which can lead to biases. To overcome this bias, participants with varying experiences were used to ensure that a neutral tone was maintained. Finally, the third limitation of this study worth mentioning is time restriction. The time available to examine the research problem and to measure change or constancy over time was constrained by the dates of a single semester. In the future, a longitudinal study would help to resolve this limitation.

# REFERENCES

American Speech-Language-Hearing Association. (n.d.). *Effects of hearing loss on development*. American Speech-Language-Hearing Association. Retrieved January 22, 2022, from https://www.asha.org/public/hearing/effects-of-hearing-loss-on-development/

Baldassari, C. M., Schmidt, C., Schubert, C. M., Srinivasan, P., Dodson, K. M., & Sismanis, A. (2009). Receptive language outcomes in children after cochlear implantation. *Otolaryngology–Head and Neck Surgery*, *140*(1), 114–119. https://doi.org/10.1016/j.otohns.2008.09.008

Belsky, G. (2014). *What is an IEP*. Understood. Retrieved March 22, 2022, from https://www.understood.org/en/articles/what-is-an-iep

Bridges for the Deaf and Hard of Hearing. (n.d.). *Deaf history*. bridgesfordeafandhh. Retrieved February 15, 2022, from https://www.bridgesfordeafandhh.org/deaf-history

Busetto, L., Wick, W., & Gumbinger, C. (2020). How to use and assess qualitative research methods. *Neurological Research and practice*, *2*(1), 1-10.

Calderon, R., & Greenberg, M. T. (2011). Social and emotional development of deaf children: Family, school, and program effects. *The Oxford Handbook of Deaf Studies, Language, and Education*, *1*(2). https://doi.org/10.1093/oxfordhb/9780199750986.013.0014

Center for Devices and Radiological Health. (n.d.). *Benefits and risks of cochlear implants*. U.S. Food and Drug Administration. Retrieved February 12, 2022, from https://www.fda.gov/medical-devices/cochlear-implants/benefits-and-risks-cochlear-implants

Ching, T. Y. (2015). Is early intervention effective in improving spoken language outcomes of children with congenital hearing loss? *American Journal of Audiology*, *24*(3), 345–348. https://doi.org/10.1044/2015_aja-15-0007

Ching, T. Y., Dillon, H., Day, J., Crowe, K., Close, L., Chisholm, K., & Hopkins, T. (2009). Early language outcomes of children with cochlear implants: interim findings of the NAL study on longitudinal outcomes of children with hearing impairment. *Cochlear implants international*, *10 Suppl 1*(Suppl 1), 28–32. https://doi.org/10.1179/cim.2009.10.Supplement-1.28

DesJardin, J. L., Eisenberg, L. S., & Hodapp, R. M. (2006). Sound beginnings. *Infants & Young Children*, *19*(3), 179–189. https://doi.org/10.1097/00001163-200607000-00003

Gallaudet University/. (n.d.). *American deaf culture*. Laurent Clerc National Deaf Education Center. Retrieved February 22, 2022, from https://clerccenter.gallaudet.edu/national-resources/info/info-to-go/deaf-culture/american-deaf-culture.html

Galletta, A. & Jr, Cross,. (2013). Mastering the semi-structured interview and beyond: From research design to analysis and publication. 1-245.

Geers, A., Moog, J., & Rudge, A. (2019). Effects of Frequency of Early Intervention on Spoken Language and Literacy Levels of Children Who are Deaf or Hard of Hearing in Preschool and Elementary School. *The Journal of Early Hearing Detection and Intervention*, *4*(1), 15–27. https://doi.org/https://doi.org/10.26077/7pxh-mx41

Gillam, R. B. & Johnston, J. R. (1992). Spoken and written language relationships in language/learning-impaired and normally achieving school-age children. Journal of Speech and Hearing Research, 35, 1303 – 1315.

Hall, M. L., Hall, W. C., & Caselli, N. K. (2019). Deaf children need language, not (just) speech. *First Language*, *39*(4), 367–395. https://doi.org/10.1177/0142723719834102

Hauser, P. C., & Marschark, M. (2008). What we know and what we don't know about cognition and deaf learners. *Deaf Cognition*, 439–457. https://doi.org/10.1093/acprof:oso/9780195368673.003.0016

Hyde, M., & Punch, R. (2011). The modes of communication used by children with cochlear implants and role of sign in their lives. *American Annals of the Deaf*, *155*(5), 535–549. https://doi.org/10.1353/aad.2011.0006

Hyde, M., Punch, R., & Grimbeek, P. (2011). Factors predicting functional outcomes of cochlear implants in children. *Cochlear Implants International*, *12*(2), 94–104. https://doi.org/10.1179/146701010x12677899497317

Hyde M, Punch R, Komesaroff L. A comparison of the anticipated benefits and received outcomes of pediatric cochlear implantation: parental perspectives. Am Ann Deaf. 2010 Summer;155(3):322-38. doi: 10.1353/aad.2010.0020. PMID: 21138045.

Hyde, M., Punch, R., & Komesaroff, L. (2010). Coming to a decision about cochlear implantation: Parents making choices for their deaf children. *Journal of Deaf Studies and Deaf Education*, *15*(2), 162–178. https://doi.org/10.1093/deafed/enq004

Isaacson, B. (2020, August 30). *Cochlear implants for hearing loss: How they work, benefits, risks*. WebMD. Retrieved February 22, 2022, from https://www.webmd.com/healthy-aging/understanding-cochlear-implants

Knoors, H., & Marschark, M. (2012). Language planning for the 21st Century: Revisiting bilingual language policy for deaf children. *Journal of Deaf Studies and Deaf Education*, *17*(3), 291–305. https://doi.org/10.1093/deafed/ens018

Kyle, F. E., & Harris, M. (2011). Longitudinal patterns of emerging literacy in beginning deaf and hearing readers. *Journal of Deaf Studies and Deaf Education*, *16*(3), 289–304. https://doi.org/10.1093/deafed/enq069

Lane, H., & Bahan, B. (1998). Ethics of cochlear implantation in young children: a review and reply from a Deaf-World perspective. *Otolaryngology--head and neck surgery : official journal of American Academy of Otolaryngology-Head and Neck Surgery*, *119*(4), 297–313. https://doi.org/10.1016/S0194-5998(98)70070-1

Marschark, M., Shaver, D. M., Nagle, K. M., & Newman, L. A. (2015). Predicting the academic achievement of deaf and hard-of-hearing students from individual, household, communication, and educational factors. *Exceptional Children*, *81*(3), 350–369. https://doi.org/10.1177/0014402914563700

May-Mederake, B. (2012). Early intervention and assessment of speech and language development in young children with cochlear implants. *International Journal of Pediatric Otorhinolaryngology*, *76*(7), 939–946. https://doi.org/10.1016/j.ijporl.2012.02.051

Merriam, S.B., Tisdell, E.J. (2016). Qualitative research: A guide to design and implementation (4th ed.). Hoboken, NJ: John Wiley.

Nittrouer S. (2016). Beyond Early Intervention: Supporting Children With CIs Through Elementary School. *Otology & neurotology : official publication of the American Otological Society, American Neurotology Society [and] European Academy of Otology and Neurotology*, *37*(2), e43–e49. https://doi.org/10.1097/MAO.0000000000000906

Ohio University. (2009, July 27). *Cochlear implants, the deaf culture, and Ethics*. Cochlear Implants, The Deaf Culture, And Ethics | The Institute for Applied & Professional Ethics. Retrieved February 22, 2022, from https://www.ohio.edu/ethics/2001-conferences/cochlear-implants-the-deaf-culture-and-ethics/index.html

Perfetti, C. A., & Sandak, R. (2000). Reading optimally builds on spoken language: Implications for deaf readers. *Journal of Deaf Studies and Deaf Education*, *5*(1), 32–50. https://doi.org/10.1093/deafed/5.1.32

Punch, R., & Hyde, M. (2010). Children with cochlear implants in Australia: Educational settings, supports, and outcomes. *Journal of Deaf Studies and Deaf Education*, *15*(4), 405–421. https://doi.org/10.1093/deafed/enq019

Punch, R., & Hyde, M. (2011). Social Participation of children and adolescents with cochlear implants: A qualitative analysis of parent, teacher, and child interviews. *Journal of Deaf Studies and Deaf Education*, *16*(4), 474–493. https://doi.org/10.1093/deafed/enr001

Schauwers, K., Gillis, S., & Govaerts, P. (2005). Language acquisition in children with a cochlear implant. *Developmental Theory and Language Disorders*, 95–119. https://doi.org/10.1075/tilar.4.07sch

Svirsky, M. A., Robbins, A. M., Kirk, K. I., Pisoni, D. B., & Miyamoto, R. T. (2000). Language development in profoundly deaf children with cochlear implants. *Psychological science*, *11*(2), 153–158. https://doi.org/10.1111/1467-9280.00231

U.S. Department of Health and Human Services. (2016, February). *Cochlear implants*. National Institute of Deafness and Other Communication Disorders. Retrieved April 22, 2022, from https://www.nidcd.nih.gov/health/cochlear-implants

U.S. Department of Health and Human Services. (n.d.). *Quick statistics about hearing*. National Institute of Deafness and Other Communication Disorders. Retrieved January 22, 2022, from https://www.nidcd.nih.gov/health/statistics/quick-statistics-hearing

Vermeulen, A. M., van Bon, W., Schreuder, R., Knoors, H., & Snik, A. (2007). Reading comprehension of deaf children with cochlear implants. *Journal of Deaf Studies and Deaf Education*, *12*(3), 283–302. https://doi.org/10.1093/deafed/enm017

Waltzman SB. Variables affecting speech perception in children. In: Waltzman SB, Cohen NL, editors. Cochlear implants. Thieme Medical; New York: 2000. pp. 199–206.

# APPENDIX

Interview Questions - Semi- Structured Interview

1. What is your child's date of birth?
2. What grade is your child in?
3. When did you find out about your child's hearing loss?
4. Anyone else in the family with hearing loss?
5. Do you know the cause of the hearing loss?
6. Did the child receive early intervention?
7. What did the EI services look like? Did someone come to your home? How often?
8. At what age did the child receive a cochlear implant?
9. Did you ever feel as it the surgery was being pushed on you? How? What did the CI team say to make you feel one way or the other?
10. Were alternatives discussed with you?
11. Did you know about all the appointments necessary for receiving a cochlear implant prior to agreeing to the surgery?
12. Why did you decide on the cochlear implant for your child?
13. What information did you wish you knew prior to your child's surgery?

14. When did the child start speech therapy?
15. How much speech therapy is your child getting now? How many days? Where? How much are they getting at school? Group? Individual?
16. Do you want more therapy for your child?
17. Has the child consistently attended speech since they started?
18. What grade level is your child reading on right now?
19. How comfortable are you at the IEP meetings? Do you offer any suggestions or ask for additional services?
20. What are you worried about in your child's overall development?
21. How would you rate your child's vocabulary on a scale of 1-5?
22. Are you happy with the result of the cochlear implant? Did it meet your expectations?
23. Tell me one way the process can be improved for future cochlear implant recipients born with hearing loss.