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UNIVERSITY OF NORTHERN COLORADO

Greeley, Colorado

The Graduate School

RURAL COCHLEAR IMPLANT SERVICES:  
REFLECTIONS FROM PARENTS AND  
(RE)HABILITATION PROFESSIONALS

A Dissertation Submitted in Partial Fulfillment  
of the requirements of the Degree of  
Doctor of Philosophy

Natalie J. Austin

College of Education and Behavioral Sciences  
School of Special Education

December 2020

This Dissertation by: Natalie J. Austin

Entitled: *Rural Cochlear Implant Services: Reflections from Parents and (Re)Habilitation Professionals*

has been approved as meeting the requirements for the Degree of Doctor of Philosophy in the College of Education and Behavioral Sciences in the School of Special Education.

Accepted by the Doctoral Committee

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## ABSTRACT

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The idea of what “rural” means and the influence of this setting is very complex. The impact on the resources and services available to the family, school district, and community goes beyond geographic barriers. Despite there being known problems with service provision for children with hearing loss in rural areas, little is being done to improve the support offered to families and professionals working to meet the needs of children who have cochlear implants.

The purpose of this phenomenological qualitative study was to take a deeper and more intimate look at service provision for children with cochlear implants in rural areas from the perspective of parents and the professionals who serve them. Seven parents and seven professionals were interviewed about their experiences. Open-ended interview questions were asked with the goal of identifying themes around the overall impact, challenges, and systems of support related to living and working outside of a city center with children who have cochlear implants.

Findings related to the overall experiences of living and working in a rural setting were discussed in terms of the simplicity of rural life, benefits of small class sizes, the added commitment for parents, the importance of family involvement, and the need to be creative to meet students’ unique needs. When looking at the challenges with rural services, issues surrounding logistics, parent motivation, local resources, school support, and local teams were

highlighted as causes of difficulty. There were many sources of support discussed including positive opportunities for family advocacy, school services, local professionals, outside support services, and the enhancement of peer connections.

Due to the paucity of research on service improvement for children with cochlear implants in rural settings, this study will contribute to the body of inquiry on this topic and in turn highlight meaningful implications for the field. Participants in this study were from rural counties within one midwestern state. Future studies would benefit from looking at participants from a range of rural locations throughout the country.

Keywords: cochlear implants, rural, deaf, hard-of-hearing, habilitation, rehabilitation, multidisciplinary team

## DEDICATION

*What works for your child is what makes the choice right.  
-Hands & Voices*

This is dedicated to Hands and Voices and all of the families and professionals who work tirelessly to provide unbiased support and love to children who are deaf and hard of hearing. To the parents and service providers who graciously helped with recruitment and participation in my research, I am immensely grateful for the time and energy you took to make this study happen. I truly appreciate the trust you placed in my vision for this research by sharing your unique and beautiful stories. To my Pops and Mama Austin; as parents of a child with a hearing loss who gave you more grey hairs than you can count, I thank you for more than you will ever know and dedicate these next hundreds of pages to you.

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## CHAPTER I

### INTRODUCTION

*I am the youngest of five farm kids, born and raised on the rural plains. As a kindergartner, I went through the obligatory vision and hearing screening that all students experience at the start of school. I can remember the screener looking confused, scribbling some notes, and then sending me back to class. A few days later, I could hear my mom and dad talking in the kitchen, my mom saying that I was being a stinker at school, not following the directions for the hearing screening, and not raising my hand for the beeps. Now the school had sent a form home saying I failed the screening and have to make an appointment to see an audiologist.*

*My busy mother had to take the time to drive me three hours to see a clinical audiologist. The results from that test produced an audiogram exactly the same as the one from school. In disbelief, my mom asked for the test to be repeated, two more times. Being by my side every day for the past five years and also having a background in childhood education, my mother knew me well and never had any reason to think I might not be able to hear everything.*

*This was the start of my hearing loss journey and navigating the medical and educational implications that go along with being a “different” kid. I still despise the sound booth at the audiologist’s office to this day, the silence inside is deafening. I hated being pulled out of my classroom to meet with who I now know as the itinerant teacher of the deaf who worked for all the rural area schools. As soon as I saw her face in the doorway, I knew she was there for me, and so did everyone else. Even as a young child, I always felt like I was just a check mark on her list: “Met with the girl who has a hearing loss, made sure she is sitting in the front row: CHECK.” And that was about the extent of my accommodations and support through school.*

*For several years, my family made weekly trips to the “big” cities, between five and seven hours round trip, to meet with every different hearing specialist my parents could find. I hated those appointments. I remember electrodes being placed through my ear drums, being strapped to a rotating table to trigger my vertigo, and a hospital stay as I underwent surgery to have my eardrum replaced. I can remember clearly, sitting with the doctor at my final appointment, and him telling us there were no solutions to restore my hearing or to prevent my vertigo and tinnitus. What he did tell us is that my life needed to be drastically different to preserve the hearing I had left. No more sports, no more band, no putting my head underwater, and a continued list of stark limitations. And that was it. I can remember vividly the walk to the elevator with my folks. The doors closed; I was in shock. My mother is an incredibly strong and composed woman. The sight of tears running down her cheeks from frustration and not knowing what to do to help her daughter is still a memory that breaks my heart.*

*Throughout my high school journey, I wrote research papers and learned everything I could about the world of deaf education. I told my high school guidance counselor that I wanted to be a therapist for parents of children who are deaf. I wanted to use my experience with hearing loss to make sure no parent ever had to endure that feeling of despair, isolation, and helplessness. I have been working toward achieving that goal ever since.*

## **Personal Reflection**

In my professional life, I have been involved in the field of deaf education and deaf services for over twenty years. There was no degree that specialized in being a therapist for parents of children who are deaf / hard of hearing (DHH) at the time of my graduation from high school, so I found and fell in love with a small college that focused on oral deaf education. I knew that I wanted to have a well-rounded and diverse skill set at the completion of my program, so I enrolled in sign language classes at the school next door and sought out classroom observation opportunities and student teaching placements in settings that used sign language. During my senior year at college, they announced the launch of a master's degree in early intervention in deaf education. Finally, a name for my dream job.

With a bachelor's degree in deaf education with an emphasis in speech-language pathology and a master's in early intervention in deaf education, I knew in every moment of every class, every observation, every student teaching placement, and every session working with families that I had found the perfect fit for my skills, ambitions, and personal passion. Through the years, I worked in an array of settings with a variety of families of children with hearing loss. I loved being able to show both the parents and the children I worked with my hearing aids and share stories of living a happy, successful, and productive life as an adult with hearing loss. So many families experience a wide range of conflicting emotions when it comes to raising a child with a hearing loss and not knowing what to expect for their future. Many parents shared that until we started working together, they never knew their child would be able to drive, have a boyfriend, go to college, hold down a job, and on and on. For me, this was passion and purpose perfectly realized.

Regarding the hearing aids I wore, I have tried the gamut of assistive technology options when it comes to my hearing loss, spending the majority of my life not using devices, relying mainly on lipreading and context clues. I started with different run of the mill behind the ear models that just made the mumbling louder. Then in grad school, my audiology teacher asked to share my audiogram with the class. Viewing my hearing levels shocked both my teacher and classmates. My teacher could not believe I did not utilize any assistive technology and convinced me to look into some different amplification options, which I tried several models through the years, and still no success. I have also gone through two implant surgeries to try different models of bone anchored hearing aids, which lead to some of the worst medical complications I have ever experienced in my life. Always the eternal optimist, I look to these experiences for the lessons they taught me that I can pass on to the families I work with.

My career led me back to those rural plains where I was born and raised, and I worked as the teacher of the deaf for the twelve school districts in the area. At one point I lived in the area and delivered services in person. Several years later I worked as their teacher of the deaf remotely, delivering my daily and weekly sessions with students through distance technology since I was living three hours away from the area. I drove out to the schools about once a month to meet face-to-face with the educational teams and students.

I have been lucky to work in and experience a variety of educational settings, communication approaches, and service delivery models during my career in this field. Working with children who have cochlear implants (CIs) and pursuing Listening and Spoken Language Specialist (LSLS) certification, I have garnered an in-depth understanding and exposure to all that is required and involved in not only the decision making process parents go through, but also the educational and (re)habilitation considerations involved in meeting the needs of a child with

a CI. Growing up with a hearing loss in a rural community and then returning and working with a diverse group of children who were DHH in the area both in person and remotely showed me first-hand, the myriad of challenges faced by not only these students, but by their families, (re)habilitation teams, and local communities to meet their unique needs.

For the purpose of this paper, the term (re)habilitation will be used to encompass both rehabilitation and habilitation services and professionals (American Speech-Language-Hearing Association [ASHA], 2020). Since habilitation refers to teaching a new skill to someone who has never developed that skill, and rehabilitation indicates regaining lost skills or function, both terms are applicable when discussing service provision for children who are DHH (ASHA, 2020). Some children are born with hearing loss and others acquire a hearing loss later in life. The services they receive would then be classified as either habilitation if their hearing loss is congenital, or rehabilitation if the hearing loss is acquired.

### **Statement of Problem**

Research has shown that there is a need to focus on specific, smaller subsections of parents of children with CIs, such as families from varied socioeconomic and cultural backgrounds including families from rural areas (Humphries et al., 2012; Huttunen & Valimaa, 2012; Punch & Hyde, 2010; Sorkin & Zwolan, 2008). Families are very diverse, and some outlying groups of parents are not represented in the research. Oftentimes parents in these smaller groups have unique needs and concerns that cannot be addressed in the same way as the general population of parents who have been featured in other more generalized studies.

Accessing many different services in rural areas is a challenge, and this includes specialized medical and educational services for children who have CIs. When looking further into this issue, I found that there are few studies that look specifically at the challenges faced by

children with CIs and the parents and professionals who are charged with serving them in rural settings. Barr, Dally, and Duncan (2019) found in their systematic review of eight government documents and sixteen articles, that despite there being known problems with the service provision in rural areas, little is being done to research improvements in service delivery specifically for children with hearing loss in these communities.

It has been shown that parents who live in less populated areas experience unique challenges related to their child with a CI (Checker, Remine, & Brown, 2009; Humphries et al., 2012; Huttunen & Valimaa, 2012; Punch & Hyde, 2010; Sorkin & Zwolan, 2008). It is often the case that services available to these families in more rural areas are not as consistent or high quality when compared to services available in more populated areas (Checker et al., 2009; Graham, & Underwood, 2012; Huttunen & Valimaa, 2012; Sorkin & Zwolan, 2008). Families living in these outlying areas often have to travel a great distance to obtain the services their child needs (Barr et al., 2019; Bush et al., 2015; Elpers, Lester, Shinn, & Bush, 2016; Gallego et al., 2016; Hopkins, Keefe, & Bruno, 2012; Sibon-Macarro et al., 2014). Research on this subgroup would help guide future practice for professionals on how best to serve children with these unique needs and to also help guide families in their decision-making process to get an implant for their child, knowing the extra challenges they may encounter.

### **Purpose of the Study**

The purpose of this qualitative study was to take a deeper and more intimate look at service provision for children with CIs in rural areas from the perspective of parents and the (re)habilitation professionals who serve them. The questions guiding this study started by obtaining an overview of how the CI experience is impacted by life in a rural setting. There are also many challenges in addition to opportunities with obtaining high quality, specialized

services in rural areas. I was interested in examining the parents and (re)habilitation professional's perspective on what these specific challenges and opportunities are and how they have worked to address them to meet the needs of students who have CIs. Then the current systems of support that are being utilized within these rural settings by parents and professionals were examined to garner an understanding of strategies and approaches that are being applied.

### **Research Questions**

The following questions guided my research:

- Q1a How does living in a rural setting impact the overall CI experience for parents?
- Q1b How does working in a rural setting impact the overall CI experience for professionals?
- Q2a What are the challenges and opportunities for parents receiving support services for their child with a CI in a rural setting?
- Q2b What are the challenges and opportunities for professionals providing support services for a child with a CI in a rural setting?
- Q3a What are the systems of support in rural settings for parents to support a child with a CI?
- Q3b What are the systems of support in rural settings for professionals to support a child with a CI?

### **Significance of the Study**

This study is significant for parents and professionals working with children who have CIs in rural settings and will contribute to and inform the field of DHH services by providing insight into how best to meet the needs of this unique population of students. A fair amount of research has been done on the general population of children who have received a CI, but there is a paucity of research related to how having an implant is impacted by living in a rural setting.



The minimal research that has been done on this unique subgroup includes studies that focus solely on parental views of services and support (Bush et al., 2015; Checker et al., 2009; Elpers et al., 2016). The studies by Bush et al. (2015) and Elpers et al. (2016) focus mainly on the initial diagnosis and early treatment and intervention challenges living in a rural area, which does provide valuable insight into this specific aspect of service provision. There are other studies that focus solely on very small samples of school professionals (Pedersen & Beste-Guldborg, 2019; Sibon-Macarro et al., 2014). The researchers in the Pedersen and Beste-Guldborg (2019) study looked at the application of collaborative consultation with three school professionals in a rural setting. Sibon-Macarro et al. (2014) surveyed two rural and two urban service providers to determine what services are available for children who are DHH in these varied settings. These two pieces of research provide great insight into a small sampling of the professionals' perspective of meeting the unique needs of children who are DHH in rural settings. I will be taking a more in-depth look at each of these studies in the following chapter.

Parents are such an integral part of the education and (re)habilitation for their child who has a CI. Valuable insight can be garnered by looking at the collective experiences of parents and support service professionals when working to meet the unique needs of a child who has a CI in a rural setting. Previous research that has been done based solely on parent experiences and based solely on professional experiences can be built upon by taking a look at the collective experiences of both the parents and (re)habilitation professionals.

### **Definition of Terms**

*Cochlear Implant:* surgically implanted electronic hearing device that is designed to provide a sense of sound for a person who is profoundly deaf or severely hard of hearing (United States Food and Drug Administration [USFDA], 2018).

*Listening and Spoken Language:* the goal of this approach is to combine early identification and intervention with appropriate hearing technology to enable a child with hearing loss to develop language skills comparable to their hearing peers (AG Bell, 2020).

*Rehabilitation and Habilitation:* Rehabilitation helps people relearn skills they have lost, such as children or adults who lose their hearing later in life. Habilitation applies to skills that are learned as opposed to relearned, such as for someone who was born with hearing loss (ASHA, 2020).

*(Re)habilitation Team:* A multi-disciplinary team that provides patient-centered support to allow for collaboration among the CI recipient, family, therapists, doctor, audiologist, educators, and other professionals to establish a path to success (Johns Hopkins Medicine, 2019).

*Rural:* all population, housing, and territory not included within an urban area; which is considered 50,000 or more people (United States Census Bureau, 2019).

*Telepractice:* application of telecommunications technology to the delivery of speech language pathology and audiology professional services at a distance by linking clinician to client or clinician to clinician for assessment, intervention, and/or consultation (ASHA, 2019).

*Universal Newborn Hearing Screening:* a mandatory test to check a baby's hearing after birth before leaving the hospital. If a baby is born at home, a hearing test should be completed before he or she is 1 month old (Boys Town National Research Hospital, 2019).

### **List of Acronyms**

CI	Cochlear Implant
DHH	Deaf / Hard of Hearing
LSLS	Listening and Spoken Language Specialist
SLP	Speech-Language Pathologist
TOD	Teacher of the Deaf
UNHS	Universal Newborn Hearing Screening

### **Summary**

To provide some background into the catalyst for this research project, I shared a small portion of my own experience growing up as a child with a hearing loss in a rural community. Through the personal reflection that followed, I discussed my professional journey in the field working with children who have CIs and providing services for children who are DHH in rural settings. This led into the statement of the problem related to service provision for children with CIs in rural settings. Taking a deeper look at the services provided to children with CIs in rural areas from the parent and (re)habilitation professional's perspective was laid out as the purpose of the study. Six specific research questions that guided this process were established, focusing on the parents and professionals involved. The significance of the study and how it will impact the field was discussed. A definition of terms and list of acronyms was provided to help guide the reader and provide clarification throughout this paper.

The following chapter contains a review of literature on children with CIs and their families in rural settings. General challenges of service provision in rural areas is discussed with a deeper look at how having a CI in this setting is impacted. A general overview of children who are DHH and have CIs is provided, again culminating into a discussion on how the unique

(re)habilitation and service needs of this group is affected by being in a setting outside of an urban center. The perspectives of professionals are explored in addition to potential solutions for everyone involved. The third chapter will outline the methodology used in this study. Chapter four will present the key findings from the interviews with parents and professionals on service provision for children with CIs in rural settings. There will be a discussion surrounding the overall categories, themes, and subthemes that emerged from the data. And chapter five will summarize these results and provide implications for future practice for parents and professionals in the field. The paper will conclude with a discussion of the limitations of this study and suggestions for future research.

## CHAPTER II

### LITERATURE REVIEW

This review of literature will take an in-depth look at the current levels of service being provided to children with cochlear implants in rural settings. As a starting point for this discussion, it is important to define what is meant by rural, the challenges presented with living in a rural setting, and how these specific challenges may impact a child who is DHH with a CI living in these areas. An overview of children who are DHH, specifically in terms of UNHS and educational trends is provided. Specific information is discussed related to CIs; expectations and variance of outcomes; parent experiences after implantation including outside sources of support; and the CI (re)habilitation process.

The review then focuses specifically on literature related to children who have CIs in rural settings. Impact of rural life on UNHS and subsequent diagnosis delays are discussed. Reduced access to appropriate services and resources in rural settings is reviewed with specific discussions on how information and communication; funding and health insurance; and travel demands are impacted by rural life. Educational placements and the professionals working in rural settings with children who have CIs are the next areas examined. The review concludes with possible approaches for meeting the unique needs and challenges of educating children with CIs in rural areas including the use of visiting specialists and short-term contractors; grants and increased funding; and telepractice.

### **Scope of Review**

To gain a better understanding of the current research on rural CI services, an online search of the literature was conducted and the key words “Deaf,” “cochlear implants,” and “rural” were used in the initial search. A title and abstract review helped identify articles relevant to the current review and then they were sorted by date.

Articles published in the last ten years were prioritized and the reference list of each article was reviewed for additional related information on the topic. An additional search of literature that cited these prioritized articles was also conducted and reviewed for relevant sources of information. Other literature that was older than ten years but that still presented information that was historically relevant to the topic was also included.

CIs are used around the world and subsequently, research is being conducted in various countries where implants are available. This synthesis contains research from a range of countries around the world including Australia, Canada, Belgium, Brazil, and Japan to name a few. Addressing each specific country’s cultural nuances related to cochlear implantation is beyond the scope of this review, but is something to be mindful of when considering parental and professional experiences working with a child who has a CI, specifically how these nuances relate to the service provision in rural versus urban settings.

### **Defining Rural**

In the United States, a significant portion of the population lives in areas considered to be rural (Barr et al., 2019). There are many different definitions used when discussing the term ‘rural’, and round the world, different groups and organizations characterize what it means to live in a rural setting in a variety of ways. One aspect that is agreed upon is that a single measure such as population cannot fully define rural (Barr et al., 2019). Some of the diverse

characteristics that have been looked at are the density of housing and land use, road distance to a major center, and population density (Ratcliffe, Burd, Holder, & Fields, 2016; Statistics Canada, 2017). Often, rural is looked at in exclusionary terms, as in an area outside an urban setting (Ratcliffe et al., 2016; United States Census Bureau [USCB], 2019). For the purpose of this study, rural will be defined as all population, housing, and territory not included within an urban area; which is considered 50,000 or more people (USCB, 2019). Together with this guiding definition, the diverse and unique characteristics of this setting must remain a significant part of the conversation.

There are many positive aspects to rural life and reasons why people stay over many generations and relocate to smaller communities to raise their families. Some reasons given for why small towns are preferred over larger urban areas are the community values, family life, safety, and connection to nature (Struthers & Bokemeier, 2000). Although some have a romanticized image of what life in a small-town entails, there are also significant challenges and limitations that come with rural living.

### **Rural Challenges**

The large land size of the U.S. presents unique challenges for the provision of a variety of services in rural areas. When compared to their urban peers, children in rural areas struggle to access the same needed services and supports (Barr et al., 2019; Barr, Duncan, & Dally, 2018; Baxter, Hayes, & Gray, 2011; Graham & Underwood, 2012). In a qualitative study that included focus groups and interviews of parents in two rural communities, Graham and Underwood (2012) found that parents' experiences accessing human services such as social and health support for their children were impacted by several aspects of rural life and location issues. Some of these include a desire to have specialized and everyday services close to their homes and

within their community; issues such as travel which brings along with it additional financial costs, other family logistics, and time commitments, including time away from work for the travel; and the cliquish nature of small towns and how new members can feel unwelcome or like they are an outsider. Graham and Underwood (2012) were also sure to highlight that the prevailing notion of everybody knowing everybody could also be considered a benefit of living in a small town when it came to personal connections with professionals in the community because these people were also their friends and neighbors.

It has been established that accessing various services in rural areas is a challenge, but there are few studies that look specifically at the challenges faced by children who are DHH in rural settings. Barr et al. (2019, 2018) found that despite there being known problems with the service provision in rural areas, little is being done to research improvements in medical and educational service delivery specifically for children with hearing loss in these communities. After a discussion surrounding trends in Deaf Education with a focus on CIs, specific issues related to services for children who are DHH and have CIs in rural communities will be further explored within this review of literature.

### **Children Who are Deaf/Hard of Hearing**

Early access to specialized services is vital for the development of child who is DHH. Individualized hearing technology, early intervention, and consistent educational, audiological, and family support is paramount (Ching, 2015; Moeller, Ertmer, & Stoel-Gammon, 2016). This is explicitly essential for families of children with CIs who have a goal for their child to develop listening and spoken language skills (Knoors, 2016; Yoshinaga-Itano, 2013).



## **Universal Newborn Hearing Screening**

The implementation of Universal Newborn Hearing Screening (UNHS) is now established in 43 states providing identification of a hearing loss at birth (CI Candidacy Information, 2017; Mayo Clinic, 2018; Nelson, Bougatsos, & Nygren, 2008). During this past decade, the diagnosis of hearing loss has greatly increased, and infant hearing screening has improved to 98% across the U.S. (Boys Town National Research Hospital, 2019). While the rate of UNHS has experienced a steady increase, the rate of follow-up diagnosis of hearing loss has decreased (Curry & Gaffney, 2010). One study that examined the reasons for this decrease found one contributing factor to be living in a rural setting (Bush et al., 2014).

## **Education Trends**

Inclusive education, where all students regardless of specialized needs are placed in general education classrooms in their neighborhood schools, is an increasing trend for students who are DHH (Checker et al., 2009; Shaver, Marschark, Newman, & Marder, 2014). Simply placing a student who is DHH into an inclusive classroom setting does not provide automatic access to meet this student's unique needs. Students who are DHH are highly varied and their access to accommodations, modifications, and specialized instruction is essential for student success (Scheetz, 2012).

For students who are focused on acquiring listening and spoken language skills, such as some children with CIs, simply being exposed to spoken language does not provide adequate opportunities to garner language fluency (Humphries et al., 2012). The educational team working to serve these DHH students must ensure they have the knowledge and skill set to develop listening and spoken language, and in turn, parents are seeking out professionals who have their LSLS Certification to meet their child's needs (Goldberg, Dickson, & Flexer, 2010). Finding

professionals who fit these requirements can be tough, especially in a rural setting where specialized resources are limited.

### **Cochlear Implants**

The availability and use of CIs are changing the face of Deaf education. Many parents are considering CIs for their child who is DHH because of reported positive spoken language and listening outcomes. When a child is born with a significant bilateral hearing loss, intervention will be necessary for the child to develop language (Knoors, 2016; Moeller, 2000; Yoshinaga-Itano, 2013). If the goal of the family is for the child to develop spoken language and listening skills, appropriate amplification and therapy are necessary to meet this goal (Knoors, 2016; Yoshinaga-Itano, 2013). CIs are one amplification option available for these children.

The National Institute on Deafness and Other Communication Disorders (NIDCD) reports that more than 90% of DHH children are born to hearing parents (2016). This indicates that the majority of parents faced with decision-making for their child who is DHH have little to no prior experience with hearing loss. When a person who is DHH receives a CI, hearing is not automatically restored to the same levels as those who do not have a hearing loss (Niparko, 2009; Sorkin, 2013). There is an intense (re)habilitation process involved for any person receiving a CI who has the goal of achieving listening and spoken language abilities (Niparko, 2009; Waltzman & Roland, 2015). When young children receive CIs, parents play a vital role in this (re)habilitation process (Hyde, Punch, & Komesaroff, 2010; Leigh, Dettman, Dowell, & Briggs, 2013; Niparko, 2009).

CIs are surgically implanted electronic hearing devices that are designed to provide a sense of sound for a person who is profoundly deaf or severely hard of hearing (USFDA, 2018). Since a requirement of the CI process warrants the recipient to undergo surgery under general

anesthesia, those electing to get the device themselves or making the decision on behalf of another, must consider the risks involved in an elective surgery for a condition that is not life threatening. This is one of the many reasons this type of surgery is controversial and a hard decision for families to make.

Since the introduction of CIs in the 1970s, the criteria by which children are considered eligible has expanded significantly from the time of the initial approval by the United States Food and Drug Administration in 1990 (USFDA, 2017). The age at which children are eligible to receive an implant has reduced significantly in addition to changes in criteria related to the severity of hearing loss (Mayo Clinic, 2018). Implantation is now performed on children as young as 4-6 months (Colletti, Mandalà, & Colletti, 2012; Holt & Svirsky, 2008; Valencia, Rimell, Friedman, Oblander, & Helmbrecht, 2008) and at some centers, even younger when it is determined that hearing aids would not provide sufficient auditory gain (Birman, 2009; Colletti et al., 2012).

The reduction in age of implantation is largely related to UNHS implementation in 43 states and the detection of a hearing loss at birth (CI Candidacy Information, 2017; Mayo Clinic, 2018; Nelson et al., 2008). Medical professionals inform parents shortly after birth if their child did not pass the newborn hearing screening. Parents are charged with making numerous critical decisions for their child from the moment of conception, and the decision of what steps to take regarding their child's hearing loss is one of critical importance to their child's development.

An increase in the prevalence of CIs can also be attributed to the changing criteria of implanting children who have less severe levels of hearing loss. Some children who have moderately-severe to severe hearing loss and do not benefit from hearing aids are receiving implants (Mayo Clinic, 2018). Many parents believe that CIs are superior to hearing aids, so

often push to have their child implanted even when the child has substantial residual hearing (Fitzpatrick et al., 2009).

Implantation can either be bilateral or unilateral, and if bilateral, the surgery is either performed simultaneously or consecutively. During the 1990s, unilateral cochlear implantation was the standard of care for children with profound deafness, and it was believed that this provided adequate auditory information for children to develop listening and spoken language skills (Nicholas & Geers, 2007; Niparko et al., 2010). Since that time, it has been found that because hearing is binaural in nature, bilateral implantation can provide more of a natural hearing experience (Gordon, Valero, & Papsin, 2008). Limitations from unilateral hearing include trouble localizing sound, difficulties understanding speech in background noise, and having to put greater effort into listening (Brown & Balkany, 2007; Ching, Van Wanrooy, & Dillon, 2007; Eapen & Buchman, 2009; Murphy & O'Donoghue, 2007). Bilateral access to hearing, either with two implants or with a CI and a hearing aid, is advocated by many as the current standard of care (Ching, Massie, Van Wanrooy, Rushbrooke, & Psarros, 2009; Papsin & Gordon, 2008).

### **Expectations of Outcomes**

The growing incidence of cochlear implantation, roughly 58,000 adults and 38,000 children in the United States alone (NIDCD, 2016), and the increased trend of CIs being considered the best response to profound and sometimes severe cases of hearing loss, result in parent expectations of their child's performance with a CI to be quite high (Christiansen & Leigh, 2002; Huttunen & Valimaa, 2012; Hyde et al., 2010; Weisel, Most, & Rinat, 2007; Zaidman-Zait & Most, 2005). According to the United States Food and Drug Administration, approximately 324,200 registered devices have been implanted worldwide as of December 2012

(NIDCD, 2016). It is essential to identify, study, and analyze the experiences of parents of children who have gone through the implant process and how their expectations compare to the outcomes they have experienced. Practitioners must look at information on parent experiences as a way to shape and guide the provision of future services to children with CIs and their families.

It is vital that professionals provide realistic expectations to parents regarding the variance seen in children with CIs and not just highlight the success stories. The importance of realistic parent expectations is highlighted by Weisel et al. (2007) in emphasizing that if parent expectations are set so high regarding their child's potential implant success, it is possible that the parents will experience just as high a level of stress if their child does not succeed. Within the media and online sources, parents might obtain unrealistic portrayals of CI success (Komesaroff, 2007; Power, 2005). This emphasizes the need for professionals working with these families to continue to be realistic and forthcoming with families regarding the range of possible outcomes their child may experience.

### **Varied Cochlear Implant Outcomes**

The outcomes of children who receive CIs can be highly individualistic although many parents have the same shared hope of their child functioning at equal levels to their hearing peers (Huttunen & Valimaa, 2012; Sach & Whynes, 2005). Professionals must continue to prepare families for the individualistic outcomes children achieve and cater their services to meet these unique needs. This requires professionals taking the time to get to know the individual strengths, needs, and goals of the families they are working with and help families to recognize and identify these qualities as well.

There are many factors that contribute to the variance seen in outcomes of children with CIs. Niparko et al. (2010) conducted multivariable analyses to identify several areas that

contribute to a child's overall CI performance. The researchers in this study looked specifically at rates of improvement in the participants' comprehension and expression when assessing their spoken language development. Some of the areas identified that had an impact on development were socioeconomic status, parent-child interactions, and residual hearing prior to implantation. Parents need to be informed regarding these variables that can impact their child's progress with a CI.

In a paper written by Humphries et al. (2012), the authors highlight that there is great variability in the success rate of implanted children and even greater variance lies in what constitutes "success." They categorized children who received CIs into five groups: those who receive no discernible auditory benefit from their CIs, those who are more responsive but do not gain linguistic benefit, those who only gain minimal access to speech but are not able to distinguish words, those who can converse with family members and close friends using speech reading and context clues, and then "stars" who can converse with strangers and use speech reading and context to aid the auditory information provided by their CIs. From their review of perceived CI success story studies, the authors note that the percentage of implanted children who fall into each of the above-mentioned groups is a point of great controversy in the literature. This article warns that the true benefit of a CI is only an educated estimate and that promoters of CIs must provide parents making the decision to implant their child with understandable and reliable information regarding projected success for their child.

In a critical analysis of empirical studies assessing educational achievement levels of children with cochlear implants, Marschark, Rhoten, and Fabich (2007) found that students showed initial gains in speech production and perception but that these gains were not maintained as children progressed through school. The authors highlight that the variability of

success for implanted children could be related to a variety of factors such as consistency of implant use and the age at which the child was implanted, which would have an impact on language and reading abilities prior to implantation. Parents must be made aware of the impact of age of implantation and consistent implant use on their child's educational development.

Mayer and Trezek (2018) examined peer reviewed research on the literacy achievement of children who have a CI. The researchers reported that there is a wide range of variability in reading comprehension for implanted children. Two of the three studies they reviewed related to writing achievement for children with CIs reported low scores for the group of participants. These authors identified similar factors that have been previously discussed for varied outcomes of CI users. These factors include communication modality, age of implantation, consistency of CI use, and the presence of additional disabilities. The findings of this review align with previous parent reports regarding the factors that impact achievement in children with CIs.

Genetic variants were identified as a cause for poor CI outcomes in a study conducted in Asia (Wu et al., 2015). Noticing the significant variance seen in the outcomes of CI recipients, the researchers looked at children with subpar CI outcomes and compared them to those with positive outcomes. Auditory/speech performance, imaging, and audiological features were compared with each child's genetic diagnosis. These authors found two specific mutations in the deafness genes that negatively impact the neurons of auditory nerves, which directly affect CI outcomes. Due to the identification of genetic variants in the subjects with poor outcomes, the authors propose that all CI candidates considering surgery receive genetic examinations to test for the identified genes.

It is vital to explore the variance of outcomes experienced by individuals with CIs due to the invasive nature of implantation. It is also important to discuss the depth of emotional and

resource investments made by families so they can be prepared for what the future might hold. Punch and Hyde (2010) looked at the range of communication, academic, and social outcomes in implanted children from the perspective of their teachers. One area explored by the researchers regarding varied outcomes is the impact of interpreters in the classroom with some students who have a CI and if students are being provided with appropriate communicative and curricular access. Another area identified as impacting outcomes for some students is the risk of missing out on learning in certain environments such as group activities. It was found that often, students are reluctant to speak up and advocate for themselves if they are missing information in these settings.

The teachers in this study (Punch & Hyde, 2010) also identified heightened difficulties for families in remote areas and that additional stress and demands could be found with these groups, resulting in an impact on student outcomes. The overall findings in this study are similar to previous research showing that reported outcomes of children with CIs are varied and that overall, this group of students lag behind their hearing peers in academic and social development.

### **Parental Experiences After Implantation**

It is common that parents put a great deal of stress on their child's future development and need to instead remain patient with the implant process (Archbold, Sach, O'Neill, Lutman, & Gregory, 2008). This is an issue that can be greatly alleviated by more appropriate service provision from the child's team. The possible issues that may arise from a CI must be addressed at the forefront. There is worry that parents may experience an initial period of high hopes and expectations for the child's CI, but after time, they come to realize that their child is still deaf and that there is a long road of (re)habilitation ahead (Hyde et al., 2010). Children may continue to



experience struggles with communication and hearing after receiving a CI (Huttunen & Valimaa, 2012; Zaidman-Zait, 2008).

**Outside sources of support.** It takes a village to raise any child, and a child with a CI is no different, often requiring many outside resources to achieve successful developmental milestones. Parents identified collaborative partners in the journey with their implanted child as professionals, spouses, and other parents of children who are DHH (Zaidman-Zait, 2008). Professionals must ensure they provide highly individualistic intervention services to meet each family's unique needs and recognize that these needs evolve over time (Archbold, Sach, Lutman, & Gregory, 2006; Huttunen & Valimaa, 2012). Due to more universal detection of hearing loss at birth, timely implementation of early intervention services is occurring (Declau, Boudewyns, Van den Ende, Peeters, & Van den Heyning, 2008). This earlier intervention is found to be beneficial to the child's overall development (Nelson et al., 2008).

### **(Re)habilitation Process**

The (re)habilitation and education of a child with a CI involves many professionals from various disciplines. This can include but is not limited to: Teachers of the Deaf (TODs), Audiologists, Speech-Language Pathologists (SLPs), LSLS Certified Auditory Verbal Therapists, Implant Surgeons, Early Interventionists, Case Managers, Social Workers, and others depending on the child's individual needs and the age of the child at implantation. After implantation, the (re)habilitation process is ongoing, and parents play a critical role in this process. Parents become responsible for their child's use and maintenance of the CI device, especially when their child is very young. Parents must become advocates, particularly in the early years, for the services and accommodations their child needs.

During the initial stages of parent education, parents must be educated regarding the road ahead, including their integral role in their child's CI (re)habilitation process. Parents are critical observers of their child's everyday life and they are able to assess day-to-day outcomes rather than just what is achieved in a clinical situation (Archbold, Lutman, Gregory, O'Neill, & Nikolopoulos, 2002; Sach & Whynes, 2005). Having a child who is DHH has a significant impact on the entire family and parents must recognize the impact this whole process has on everyone in their child's life.

Early intervention professionals play a crucial role in the explanation, initiation, and speed at which diagnostic and treatment services are provided. In a retrospective survey of 300 parents, Sorkin and Zwolan (2008) uncovered that families felt a need for early intervention program improvement. Parents expressed a desire to be provided more comprehensive information on all communication options and technology, including, but not limited to CIs. Most of the families in the study received audiology, speech, and home-based early intervention services. Many families did not receive all needed services and were forced to obtain additional outside services that required out of pocket expenses. They found that many communities do not or are not able to provide the kind of spoken language support children with CIs need (Sorkin & Zwolan, 2008). Access to high quality (re)habilitation and support services is imperative. The availability of resources in a family's community and remote services such as telepractice must be taken into consideration and discussed when making the decision to implant their child.

### **Children Who are Deaf/Hard of Hearing in Rural Settings**

Studies reviewed thus far have touched on the impact that living in a rural location has on the development and education of students who have a CI (Bush et al., 2014; Punch & Hyde, 2010; Sorkin & Zwolan, 2008). Some issues children who are DHH experience are of course

seen globally, regardless of the student's location. But there are some challenges specific to being a child with hearing loss who lives in a rural community. Some of the overarching issues that impact children with hearing loss in rural settings include delays in diagnosis, allocation of hearing technology, and access to specialized services (Barr et al., 2019, 2018; Ching, 2015).

### **Universal Newborn Hearing Screening and Diagnosis Delays**

A key predictor of long-term successful outcomes for children who are DHH is early diagnosis. Barr et al. (2019) found that children living in rural areas often received a delayed diagnosis of their hearing loss. One study conducted in rural Kentucky found that families of babies living in these areas are not attending their follow-up appointments to confirm a hearing loss (Bush et al., 2014). This same study found that when compared to urban peers, children living in rural areas took significantly longer to obtain a hearing loss diagnosis. Their findings showed that children living outside of Appalachia received a diagnosis in 31 weeks on average and those living in the rural Appalachian area took 53 weeks to obtain a diagnosis (Bush et al., 2014). A delay in diagnosis results in slower access to critical intervention services.

The communication of results from their child's UNHS test is an area of frustration for rural families. In a study conducted by Elpers et al. (2016), rural participants highlighted poor communication about their child's hearing screening results. Many families reported that they did not receive the results of this screening while they were still in the hospital after delivery. Results were delivered to families several days to several weeks after they were discharged. The participants in this study expressed a high level of concern with the lack of communication and heightened confusion regarding the test results they received. The authors highlighted that this confusion is connected to the lower education levels seen in some families from rural settings.

Follow-up appointments to confirm the presence of a hearing loss after UNHS results are received are critical. Many UNHS programs in the U.S. struggle with consistent follow-up for families (Miller, 2015). Distance from a testing facility was found to be a major contributing factor to this lack of follow-up (Holte et al., 2012; Krishnan & Van Hyfte, 2014). Many families in rural settings also reported a significant variation in the instructions they received on what to do after their child failed their screening test at the hospital. Some families were referred directly to specialized hearing centers while others were left to navigate the system on their own (Elpers et al., 2016).

### **Reduced Access to Appropriate Services and Resources**

All children with hearing loss require consistent specialized intervention to develop successful communication skills. In rural areas, families report barriers to accessing the same DHH specialized services as their peers living in urban areas. This impacted the timing of diagnosis, obtaining hearing technology, and receiving ongoing support (Barr et al., 2019; Bush et al., 2014; Elpers et al., 2016). Parents in rural settings report overall reduced access to appropriate services, and this limited service provision can negatively impact the outcomes for children who are DHH (Checker et al., 2009).

This reduced access to specialized services also impacts children with hearing loss receiving hearing technology. Bush, Burton, Loan, and Shinn (2013) found in their research of 40 children born with congenital hearing loss that there is a correlation between the distance a family lives from a hearing specialist to the time it took for their child to receive hearing aids or a CI. They found that the average distance an urban family had to travel for hearing services was 13.5 miles and that rural families had to travel an average of 96 miles. This correlated to urban area children receiving hearing aids around six months and rural area children receiving theirs at

42 months. With CIs, urban children were implanted at the average age of 23 months and it took almost twice as long, 42 months, for rural children to receive their implants.

In a study conducted by Hixon, Chan, Adkins, Shinn and Bush (2016), the researchers looked at CI recipients from urban, moderately rural, and extremely rural areas to compare their experiences. The greatest areas of impact for participants living in rural areas were overall lower income, longer commutes to a CI center, and higher levels of Medicaid use. The rural participants had a much longer delay in their hearing loss diagnosis to the time they received hearing technology. Rural CI users also reported socioeconomic characteristics that impacted the treatment of their hearing loss.

In a database review of 133 pediatric patients who received a unilateral CI, it was found that there was no significant difference between patients who were insured through Medicaid and those who had private insurance in relation to age of referral, age of implantation, and the odds of initial implantation (Chang, Ko, Murray, Arnold, & Megerian, 2010). This study found that areas of difference in these two groups were that Medicaid patients were found to have medical complications at a five times higher rate and that they missed substantially more follow-up visits when compared to patients with private insurance. The findings of this study support the need for CI centers to focus attention on educating Medicaid patients on the issues of postoperative complications and consistent attendance at follow-up appointments.

Recommended follow-up support after hearing assessments such as therapy services and timely maintenance of hearing technology were noted as major challenges for families living in rural settings (Sibon-Macarro et al., 2014). The authors went on to note that as a result of this delay, rural children with hearing loss went for extended periods with no or lower quality access to communication and intervention services. Audiological equipment in rural areas was found to

not be well maintained and intervention attendance by families was less regular (Fulcher, Purcell, Baker, & Munro, 2015).

**Professionals and parent education.** Access to information in rural areas has an impact on hearing services received by children who are DHH. Several studies emphasize that families in rural areas have less access to information about hearing loss than urban families (Barr et al., 2019), that parents from rural settings are not as informed about possible interventions when compared to metropolitan families (Sibon-Macarro et al., 2014), and rural pediatricians are often less aware of support services available for children who are DHH (Elpers et al., 2016). The research from Elpers et al. (2016) went on to point out that 50% of the rural participants in their study had no knowledge of available treatment options for hearing loss, including CIs.

Many rural families report a lack of information and repeated miscommunications when it came to their child's disability (Brown & Remine, 2008; Dew et al., 2013; Hussain & Tait, 2015; Tait & Hussain, 2017). Families in the Bush et al. (2015) study highlighted that they wanted more information about specific services available for their child with hearing loss in addition to sources of financial support. Elpers et al. (2016) pointed out that improving access to high quality care and minimizing misinformation must be prioritized to prevent any delays in hearing loss treatment.

Families in rural areas often turn to the internet to gather information on their child's hearing loss (Barr et al., 2018; Boudreaux, Gonzales, Blewett, Fried, & Karaca-Mandic, 2016). When looking at the information provided on the internet, it should be equitable to all, but websites of rural agencies were found to have limited information about the services available in their communities and funding support available for families (Barr et al., 2019). Even with parents turning to the internet for information, Bush et al. (2015) noted that a high level of rural

parents had never heard of a CI. It was found that low levels of parent education in addition to lack of health insurance negatively impact timely access to hearing support services for families in rural settings (Bush et al., 2015; Elpers et al., 2016).

Primary care providers in rural areas were found to have limited knowledge of hearing loss which made it difficult for them to make appropriate referrals for families to seek necessary additional support (Bush et al., 2015). This lack of information seen in rural areas is compounded by communication difficulties between government departments and other organizations in these areas (Barr et al., 2019). Large government departments, such as those in the health and education sectors, were reported by families as providing poor coordination and communication (Sibon-Macarro et al., 2014).

**Travel demands.** Families of children with CIs in rural areas must often travel long distances to support their child's medical and educational needs. Successful intervention and (re)habilitation services are difficult to achieve within smaller communities that have less resources compared to more populated, urban areas (Barr et al., 2018; Gallego et al., 2016; Hussain & Tait, 2015; Lai, Serraglio, & Martin, 2014; Tait & Hussain, 2017). Specific issues such as the hazards of country driving (Barr et al., 2018; Hopkins et al., 2012), limited or absent public transportation access (Sibon-Macarro et al., 2014), financial implications of travel (Elpers et al., 2016), and no consistent mode of transportation (Gallego et al., 2016) were highlighted by several researchers when looking at travel challenges faced by rural families.

Follow-up testing after a child fails their newborn hearing screening, such as an Auditory Brainstem Response, requires infant hearing testing to be performed when the child is sleeping. Elpers et al. (2016) highlights that this can pose diagnostic challenges when a child has just been in the car 1-4 hours for travel to the appointment. The long distance traveled for these

appointments poses additional challenges and burdens on rural families because parents have to take time off work, juggle the needs of their other children, pay for meals on the road, and sometimes overnight hotel accommodations (Dew et al., 2013; Elpers et al., 2016; Gallego et al., 2016; Tait & Hussain, 2017).

The challenge posed by travel constraints in rural communities is not just felt by the families of children with CIs, but also by the professionals who serve them. Professionals working in these rural settings have to be prepared for a range of road conditions, longer commutes, and weather constraints. This calls for the need to purchase a sturdier and more reliable car to meet these travel demands, different than urban colleagues who do not have the same issues to confront and who can also rely on public transportation to meet their travel needs (Gallego et al., 2016). To provide services to rural CI clients, professionals frequently have to pay for overnight accommodations which are often not reimbursed by their employer (Dew et al., 2016). The travel demands experienced by both parents and professionals working with children who have a CI has a significant impact on access to services (Barr et al., 2018; Lai et al., 2014; Sibon-Macarro et al., 2014).

### **Educational Placements**

Educating students with CIs is complex for many reasons and trying to meet their specialized education and (re)habilitation needs in a rural setting compounds these complexities. When looking at the evolution of educational placements for students who are DHH, including those who have CIs, before 1975, more than 85% of these students attended specialized schools whereas currently, more than 85% of these students attend school in general education settings (Shaver et al., 2014). Children with CIs in rural locations are spread out amongst their local,



home schools where incidence levels of hearing loss are even lower and the availability of specialty staff is even more limited (Pedersen & Beste-Guldborg, 2019).

Deafness and hearing loss are considered low incidence disabilities. Children who are DHH compose only 1% of the school population and this low incidence has a significant impact on resource and logistic challenges that influence the timing and quality of interventions provided, made even more dire in rural settings (Sibon-Macarro et al., 2014). Based on the findings of The National Association of State Directors of Special Education (2011), students who are DHH in rural areas spend more than 60% of their time in a mainstreamed classroom being educated by general education teachers using curriculum focused on hearing students. This approach to education does not automatically meet these students' unique literacy development and language needs. When looking at children who have CIs, just being exposed to spoken language in their classroom setting does not automatically facilitate language fluency, and without consistent access to language acquisition, these children will experience language deprivation (Humphries et al., 2012).

In taking a deeper look at parents of children who are DHH in rural settings, Checker et al. (2009) conducted a qualitative study of 34 parents to gauge their level of satisfaction with their child's services. Parents highlighted that they wanted a mix of specialist support for their child and that collaboration between this team of specialists, the classroom teacher, and parents should be the focus of their child's services. In looking at specialist support, parents identified that they wanted professionals familiar with listening and spoken language development on their child's team. Parents advocated for a more established policy to be implemented to ensure parental involvement in their child's education and for specialists and classroom teachers to meet at least twice a year to further discuss their child's whole program, ensuring a focus on social

skill development. An increase in the frequency and duration their child's TOD worked with them on specific skill development was another area identified by parents. They also discussed the need for specific policy development that clearly established role clarification and service delivery parameters for the team working with their child. This study highlights that parents in rural settings have high expectations for the services their child receives and the need for rural professionals to obtain the training and support services needed to deliver high quality instruction and intervention.

**Professionals working in rural settings.** Having a CI in a rural setting not only impacts children and their families, but these devices also have a significant impact on the professionals working to serve these students and meet their unique communication and education needs. Professionals in rural settings serve children with CIs much less frequently than their counterparts in urban settings (Sibon-Macarro et al., 2014). This leads to many of the professionals in these rural areas not having the specialty skill set needed to adequately serve these students.

The recruitment and retention of special educators is a nationwide concern, made even more dire when looking at professionals who specialize in working with children who have CIs in rural areas (Dolman, 2010; Marlatt, 2014; Paul, 2015). It is estimated that 40% to 50% of first year special education teachers will leave the profession within their first five years of working in the field (Potemski & Matlach, 2014). It is well documented that there is high workforce turnover of qualified professionals in rural areas and this is a result of lack of resources, unrealistic demands, overwhelming caseloads, insufficient financial incentives, travel challenges, lack of professional development opportunities, limited administrative support, and social

isolation (Dew et al., 2016; Gallego et al., 2016; Hussain & Tait, 2015; Pedersen & Beste-Guldborg, 2019; Veitch et al., 2012).

Sibon-Macarro et al. (2014) surveyed education service providers in two rural and two metropolitan areas to gain a better understanding of the services available to children who are DHH in these two differing settings. They found that the educators in rural areas used a wider range of assistive technology but had less access to maintenance if something needed to be repaired with the devices. The rural schools and professionals did not have the same level of access to highly trained professionals. Travel distance was found to be a barrier when it came to obtaining this specialized support. It was also found in this study that parents in rural areas were less informed about possible interventions available for their child when compared to parents in metropolitan locations. The recommendations made by the authors focused on the need for more collaboration between service providers and an increase in specialized professional development.

Rural students who use CIs are at risk for academic, communication, vocational, and social failure when they have limited or no access to high quality, specially trained professionals who are equipped to address their unique educational and communication needs (Pedersen & Beste-Guldborg, 2019). Educational teams in rural settings must work together to develop possible solutions to address the individualized needs of every child with a CI they see on their caseload. This will require collaboration with the child's family, school, local resources, and possible outside sources to achieve these goals.

### **Sources of Support**

The unique communication needs and specific educational challenges of children who have CIs have been examined. A deeper look has been taken into how living in a rural area

further compounds these needs and challenges for a myriad of reasons. Children with CIs will continue to live and need to be educated in areas of our country that are not near implant centers, specialized hearing medical professionals, trained service providers, and a range of other resources that are available in urban areas. Because of this, solutions must be discussed on possible ways to meet these needs and set up children, families, and professionals for future success.

To support students with CIs in rural settings, the professionals working with them on a consistent and continued basis must adjust their existing skill set for service provision and acquire new skills to meet the unique and changing needs of these students (Miller, 2015). The specific knowledge base professionals need to obtain or improve centers around enhancing the development of communication, often listening and spoken language. Parents from all parts of the world, regardless of living in rural versus urban settings, are seeking professionals to work with their child who are able to focus on their listening and spoken language development and are often specifically looking for someone with LSLS Certification. This specific certification ensures that professionals such as TODs, audiologists, and SLPs have the skills and knowledge necessary to develop spoken language and listening abilities in children who have CIs (Goldberg et al., 2010; Miller, 2015).

SLPs are often a very important part of the educational team for a child who has a CI and their responsibilities may include addressing speech, language, and aural (re)habilitation. Miller (2015) found that many SLPs often lack confidence working with a child who has a CI. This is often the result of preparation programs not adequately training these professionals to meet the needs of this unique population. Training programs are required to provide coursework in aural (re)habilitation and offer clinical experience to SLP students, but these requirements might not

be adequate given the specialized needs of children who have CIs. Due to the lack of coursework and practicum experiences available for future SLPs to hone their skills in CI technology and subsequent aural (re)habilitation, institutes of higher learning such as Nazareth College in Rochester, New York have developed specialty programs to provide SLP students with the needed skills to work with children who have CIs (Brown & Quenin, 2010). SLPs who have completed their post graduate education and are currently working in the field in rural settings must seek out specialized training opportunities when a child with a CI is added to their caseload.

Okalidou et al. (2014) collected data from 313 SLPs specifically related to their knowledge, experience, and practice working with children who have CIs. Only 37% of the SLPs surveyed had received any kind of CI specific course training. The majority of SLPs in this study stated that they wanted further training and supervision working with children who have CIs. The conclusion of the authors is that there is a growing need for SLPs to be made a part of well-organized professional training so they can better meet the needs of this unique population of children they serve.

**Visiting specialists and short-term contractors.** Much of the literature suggests the use of specialized contractors as a potential solution to meeting the needs of children with CIs in rural settings and supporting the professionals who work with them (Barr et al., 2019; Dew et al., 2013; Fulcher et al., 2015; Jacups, Newman, Dean, Richards, & McConnon, 2017; Pedersen & Beste-Guldborg, 2019; Sibon-Macarro et al., 2014). Outreach visits from professionals who specialize in communication development, often listening and spoken language, and who have an intensive knowledge set surrounding the CI device itself can be highly beneficial. The specialists can not only be used to provide direct service to the children with CIs, but they can in turn train

therapy assistants and other members of the child's educational team on strategies to best meet the needs of these students (Dew et al., 2013).

In the findings of Sibon-Macarro et al. (2014), they highlighted the use of outside specialized service providers as a possible solution to meet the needs of CI students in rural settings. One area they emphasized was the value members of smaller communities place on visiting professionals prioritizing building relationships with the families and local team members they work with when they come to town. The researchers also stressed the importance of strong communication and collaboration between the local team of service providers and short-term contractors. If these outside specialized service providers work to develop long-term relationships with the communities they serve, they can help to improve the authenticity of communication while developing strong relationships and enhancing the knowledge of the overall community.

Rural families who have children with CIs would benefit from multiple opportunities to network with one another while hearing information from specialists. Families can work together to pool their funding resources to be able to pay for specialists to drive or fly in to their rural areas to provide community education and training opportunities (Dew et al., 2013; Jacups et al., 2017). Rural school districts can also work together to combine their allocated resources to create regional service provider centers (Ault, Bausch, & McLaren, 2013) that include professionals who have specialized listening and spoken language training to meet the communication and education needs of children with CIs. With this assistance from outside specialty contractors, general educators and related service providers in these rural communities must work together to understand and implement the specific strategies they were taught into all educational settings (Pedersen & Beste-Guldborg, 2019).

**Grants and increased funding.** Financial constraints of obtaining high level services for children with a CI in rural settings is not only a burden on families, but on professionals, school districts, and small community resources. Creative solutions such as families and school districts pooling their money and resources to address shortages have been discussed as a possible solution for funding needs. Looking at additional resources such as grants and increased funding from various sources is another possibility worth exploring.

In looking at ways grants can be used to provide funding relief to rural areas in their support of children who have CIs, Curle (2015) discussed the use of funding grants to update websites in an attempt to increase the access to information for both parents and professionals in rural settings. The author also went on to emphasize that these grants could also be used for the provision of consistent and reliable high-speed internet that can be used at home and in schools for the application of service support for students. Access to high quality and robust information for these families is critical and the provision of internet services to ensure this ability to obtain educational materials is vital.

Barr et al. (2019) points out that government agencies, insurance companies, and service providers could streamline their services and develop simplified and improved communication to reduce the indirect cost of professional services and reduce costs to families in rural areas who have children with CIs. Medicaid and other insurance providers need to ensure that their hearing professionals are receiving the industry standard rates of pay so rural families have a larger work force of professionals to choose from who provide high quality specialized hearing services for their child with a CI (McManus, Lindrooth, Richardson, & Rapport, 2016).

**Telepractice.** To address the challenges of meeting the unique communication and education needs of children with CIs in rural settings, many families and professionals have

implemented the use of telepractice (ASHA, 2019). There are many names used when discussing the delivery of specialized services through distance technology. A few of these labels include telepractice, teletherapy, teleintervention, teleaudiology, telespeech, speech teletherapy, telesupervision, telerehabilitation, telehealth, and telemedicine. The term telepractice will be used in this paper to describe this approach to service delivery.

The American Speech-Language-Hearing Association (ASHA) defines telepractice as the “application of telecommunications technology to the delivery of speech language pathology and audiology professional services at a distance by linking clinician to client or clinician to clinician for assessment, intervention, and/or consultation” (ASHA, 2019). Their website goes on to expand on the other activities that service providers can perform through this distance technology approach including mentoring, supervision, pre-service, and continuing education. They outline that telepractice can take place in a variety of locations such as schools, client homes, childcare centers, medical centers, and many other settings. It is stated that there is not a limit to where telepractice services can be implemented as long as state, national, professional, and institutional regulations and policies are followed.

Speech-language pathology and audiology are not the only types of telepractice services that can be delivered to support children with CIs living in rural settings. Services focused on early intervention, social emotional development, and sign language instruction are examples of some of the other areas that telepractice can address for this population of students. A wide range of health and education services focused specifically on the unique needs of children with CIs can be provided through distance technology (Barr et al., 2018).

There is tremendous support by both families and professionals for the implementation of telepractice as a successful way to bridge the gap of services and meet the needs of children with



CIs in rural settings (Barr et al., 2019, 2018; Boudreaux et al., 2016; Constantinescu, 2012; Edwards, Stredler-Brown, & Houston, 2012; Elpers et al., 2016; Goldberg et al., 2010; Hopkins et al., 2012; Houston & Stredler-Brown, 2012; Juenger, 2009; McCarthy, Duncan, & Leigh, 2012; Miller, 2015; Rourke, Kong, & Bromwich, 2016; Veitch et al., 2012). Some of the specific benefits of telepractice include reduced travel for families and professionals, which provides a cost-benefit when compared to in person services (Barr et al., 2019), enhanced early diagnosis and intervention (Rourke et al., 2016), social-emotional support (Hopkins et al., 2012), and supervisor or professor supervision of student teachers (Houston & Stredler-Brown, 2012) to name a few. Some of the other benefits of telepractice outlined by Houston and Stredler-Brown (2012) include fewer appointment cancellations, timely delivery of services, more effective use of time, and a more successful approach to parent coaching. They go on to expand on the parent coaching point stating that telepractice requires parents to take a more active role in the intervention session since there is no teacher or therapist present in the room, so parents must learn how to reinforce language and listening targets for their child.

There are some inherent challenges of using a telepractice approach for the service provision of students in rural areas who have CIs. Funding is noted as one of the major issues seen with the implementation of telepractice. Barr et al. (2019) highlights that increased funding to support telepractice expansion in the U.S. could positively impact outcomes for children with CIs. Some rural areas of the country do not have reliable internet connectivity or have lower connection speed which cause problems when trying to conduct intervention services using distance technology (Hamron & Quigley, 2012).

Hopkins et al. (2012) provided an overview of their program serving families in rural Maine using telepractice services. They laid out the essential equipment necessary and optional

elements that can be used for distance therapy sessions. Some of the required elements include a computer, webcam, high speed internet, and shared software. Social emotional benefits and community activity training were two areas the authors focused on that were successfully addressed through the implementation of telepractice. Students in rural areas were able to connect with other peers who were DHH with a focus on improving identity development. Local community leaders were able to learn strategies on how they could successfully include children who are DHH into community activities such as Boy Scouts and sports. To address the issue of funding, the authors suggest grants as a viable way to develop telepractice programs and acquire the technology required to ensure success.

The use of telepractice as a means to meet the needs of children with CIs in rural areas is not just a tool that can provide solutions within the school or classroom, but its' application can be used at home, within the child's community, and beyond. There are endless possibilities for how telepractice can have a positive impact serving this population of students. Delivering service using this approach can help to ensure that all families, professionals, and children are provided with consistent, reliable, and high-quality information and services, regardless of their location.

### **Conclusion**

Being a parent can be an overwhelming endeavor, one met with daily challenges that will impact their children for the rest of their lives. Add to this already present complexity being a parent of a child with a CI in a rural area that has sparse availability of support services to meet their child's unique needs. Professionals who are a part of this process, from the nurse who gives the initial screening, to the implant surgeon who does the procedure, and every professional in

between and to come, must strive to work together to make this process as supportive and nurturing as possible.

Parent expectations for their child after implantation are understandably high, regardless of location and access to services. Information about CIs is becoming much more commonplace in the media and online. More often than not, the success stories are highlighted, oftentimes presenting an unrealistic picture of life after implantation achieved by all children. Having high expectations for their child's achievement is wonderful, parents should want nothing but the best for their child. The key is that parents must be educated on the wide range of outcomes they can expect after their child is implanted and the challenges inherent to living in an area that may not have close or immediate access to the vital services their child needs. It is also important to emphasize to parents what is required of them if they choose to have their child implanted and the long, continuous road of (re)habilitation ahead that they are an integral part of.

CIs are viewed by some as a magical quick fix to restore hearing for an individual who is DHH, but this is not the reality. The actuality of what the implant process entails must be made explicitly clear from the very beginning. The road after implantation is challenging enough and should be entered into with a clear understanding of what lies ahead.

## CHAPTER III

### METHODOLOGY

#### **Introduction**

To successfully investigate the service provision of children with cochlear implants in a rural location, a closer and more detailed look must be taken at the shared and diverse experiences of the parents and professionals in these settings. A majority of past research has focused on the general population of children who have CIs. That research does not account for the unique challenges and barriers to service provision in areas outside of an urban setting. The limited research that has been done on the services available for children who are DHH in rural settings has centered mostly on the parent perspective of the general population of children with hearing loss, often focusing only on diagnosis and initial treatment. Research that has been done with service providers in these settings has explored only small samples of professionals and the overall DHH population of students, not accounting for the unique needs of children with CIs. All of this previous research is meaningful and provides great insight into areas that need further exploration.

As stated in the first chapter, the purpose of this qualitative study was to take a deeper and more intimate look at the service provision for children with CIs in rural locations from the perspective of their parents and (re)habilitation professionals. The questions guiding this study started by obtaining an overview from parents and professionals of how the CI experience is impacted by life in a rural setting. Then the current systems of support that are being utilized within these rural settings by parents and professionals was examined to garner an understanding

of strategies, resources, and approaches that are being applied. There are also many challenges in addition to opportunities with obtaining high quality, specialized services in rural areas. I was interested in examining the parents and (re)habilitation professional's perspective on what these specific challenges and opportunities are and how they have worked to address them to meet the needs of students who have CIs.

### **Research Questions**

The following questions guided my research:

- Q1a How does living in a rural setting impact the overall CI experience for parents?
- Q1b How does working in a rural setting impact the overall CI experience for professionals?
- Q2a What are the challenges and opportunities for parents receiving support services for their child with a CI in a rural setting?
- Q2b What are the challenges and opportunities for professionals providing support services for a child with a CI in a rural setting?
- Q3a What are the systems of support in rural settings for parents to support a child with a CI?
- Q3b What are the systems of support in rural settings for professionals to support a child with a CI?

### **Research Approach**

Phenomenology is the exploration of a phenomenon within a group of individuals who have all experienced it (Creswell, 2013). This framework is best suited for situations when the goal is to understand several individuals' common or shared experiences of a phenomenon. For the purpose of this study, the phenom of interest is support for children with CIs in a rural setting. The individuals of interest are parents and (re)habilitation professionals. Phenomenology

focuses on the experience itself and how that is transformed into consciousness, and the essence of the shared experience is the core meaning (Merriam, 2009).

It is my belief that the nature of multidisciplinary teamwork among parents and professionals that is necessary to successfully meet the needs of a student with a CI is ideally suited to a phenomenological framework. A successful team in this setting should share the vision of the goals established through their (re)habilitation and education plans. This framework provided a clearer understanding of how the experiences of working with and supporting children who have CIs in rural settings could shape further training and support for multidisciplinary professionals and the families they serve. Interviews are the primary source of data in phenomenological research, although other approaches can also be used (Creswell, 2013). Data for this study were collected through semi-structured open-ended interview questions.

### **Researcher Stance**

In the first chapter of this paper, I shared a small part of my personal experience as a child with a hearing loss in a rural setting. I went on to provide a personal reflection that expanded upon my professional background in the fields of deaf education and deaf services. My background includes in-depth work with families of children who have CIs, and another part of my professional journey included working as an itinerant teacher of the deaf in rural settings, both on-site and remotely.

Because of my diverse background, I have garnered an in-depth understanding both personally and professionally of the unique challenges to service provision in rural areas. My involvement working with children who are DHH and my training with CIs has led me to recognize the unique nature of the technology and the depth of knowledge required to successfully support these children through a requisite team approach. Parents are vital members

of their child's (re)habilitation and educational team and their input is critical to shaping future practice.

It is my hope to use my personal and professional experiences in this field to make a positive contribution to improving the level of service received by children with CIs in rural settings. I want to have an impact on the experiences of professionals in these areas who often have very little to no prior training or experience working with a child who has a CI. And I strive to continue with my ongoing goal of ensuring parents feel supported and empowered in the ever-changing journey of having a child with hearing loss.

## **Methodology**

### **Participants and Setting**

Participants were recruited on the criteria laid out in chapter one for what constitutes a rural setting. The United States Census Bureau (2019) defines rural as all population, housing, and territory not included within an urban area; which is considered 50,000 or more people. I worked with contacts I have from the Hands and Voices organization via email communication to connect with parents and professionals across the state of Colorado who work with a child who has a cochlear implant in a rural setting as outlined by the United States Census Bureau definition. Hands and Voices is a non-profit, parent-driven organization dedicated to supporting families of children who are DHH (Hands and Voices, 2012).

As another method of recruitment of parents and professionals, I reached out by email to educational audiologists from the Colorado Department of Education (CDE) directory.

Educational audiologists are hired or contracted throughout the state of Colorado by school districts to provide comprehensive management and support for children who are DHH (CDE,

2019). I focused on connecting with educational audiologists who serve students located in rural areas of Colorado.

I reached out via email to contacts through Hands and Voices and the CDE educational audiologist directory and shared the details of my research and participant criteria. A recruitment letter was provided outlining details of my background and information on my study to potential participants. If a potential participant was suggested, I gave the option of having the prospective parents contact me directly through email. If the parent preferred that contact them and was comfortable sharing their contact information, I reached out to them directly by whatever means they preferred.

Once this connection was made, I asked the interested parents if they had a professional on their child's educational team who they thought would be interested and willing to participate. Again, the option was given for this professional to contact me directly through email, or if they preferred to have their contact information shared with me, I reached out to them to start the process. For both parents and professionals, I initiated the process by sharing the details of my research project through my recruitment letter, answered any questions they had, and obtained signed consent forms before proceeding.

In collaboration with Hands and Voices and educational audiologists across the state, I recruited parents from a variety of counties around Colorado. The Colorado Official State Web Portal (2020) has identified the following counties that meet the criteria for rural established in this study: Alamosa, Archuleta, Baca, Bent, Chaffee, Cheyenne, Clear Creek, Conejos, Costilla, Crowley, Custer, Delta, Dolores, Eagle, Elbert, Fremont, Garfield, Gilpin, Grand, Gunnison, Hinsdale, Huerfano, Jackson, Kiowa, Kit Carson, La Plata, Lake, Larimer, Las Animas, Lincoln, Logan, Mesa, Mineral, Moffat, Montezuma, Montrose, Morgan, Otero, Ouray, Park, Phillips,



Pitkin, Prowers, Pueblo, Rio Blanco, Rio Grande, Routt, Saguache, San Juan, San Miguel, Sedgwick, Summit, Teller, Washington, Weld, and Yuma. When contacting potential parents and professionals, I used this list of counties to guide recruitment.

I found parents who had a child between the ages of eight and eighteen who have had their CI a minimum of three years. There were no additional exclusionary or inclusionary requirements for parents related to issues such as their child's cause of hearing loss, congenital versus acquired hearing loss, second language households, socioeconomic levels, hearing status of the parents, or having multiple children with hearing loss. All of these diverse factors were a positive addition to this research and may have had an impact on the parent's experience, but were not the focus of participant inclusion or exclusion in this study.

My goal was to have a minimum of six parents participate, and I was able to recruit and interview seven. I worked to find parents who had a service provider on their child's team who was willing to participate in the study. In total, I had fourteen participants which included seven parents and seven professionals. The service providers I focused on recruiting were audiologists, SLPs, TODs, general education teachers, and any other service provider on the child's educational team the parents thought would offer valuable insight. There were no additional exclusionary or inclusionary requirements for professionals related to years in the field, degrees obtained, or experience with CIs. All of these diverse factors might have been a positive addition to this research and may have had an impact on the professional's experience, but were not the focus of participant inclusion or exclusion in this study.

After parents and professionals agreed to participate and a signed consent form was obtained, a demographics form was sent to collect background information prior to conducting the interviews. Due to the small sample size of this easily identifiable population and to protect

the confidentiality of participants, demographics will be reported in ranges and not individually for participants (See Table 1). Participants were from seven different rural counties across one midwestern state. Each of the counties was very diverse and representative of seven very different perspectives based on their location throughout the state. Some rural locations were more agricultural, and others were focused on the mountain and tourist industry. Travel across the state is greatly impacted by weather and terrain which had greater impacts based on location. Some participants could rely on paved highway and interstate travel while others had to deal with the added challenge that comes with rough terrain and dirt roads.

Families lived in their rural communities between 14 and 45 years. Town population for participants ranged from 387 to 16,750 residents and distance from a city center and their CI service providers ranged from 75 to 278 miles. Demographics collected on families centered around their child and specific information related to their CI. The students were between the ages of 11 and 17, were diagnosed with hearing loss between the ages of birth and age seven, and have been implanted between four and 14.5 years. Given the student age requirements for this study, having pre-teen and teenage participants was shown to have a significant impact on the findings, implications, and suggestions for future research.

The professionals interviewed were a mix of TODs, audiologists, SLPs, and general educators. They have worked in the field between four and 32 years and have worked in a rural setting between four and 28 years. The percentage of students who had a CI on each professional's caseload ranged from one to 90 percent and the percentage of the day each professional spent working with children who have a CI ranged from four percent (1.5 hours per week) to 100 percent.

Table 1

<i>Demographics</i>	
Parents	
Miles from a city center	75 - 278
Town population	387 - 16,750
Student	
Age	11 - 17
Age of diagnosis	Birth - 7
Age at implantation	2.5 - 8
Years implanted	4 - 14.5
Unilateral or Bilateral	All Bilateral
Professionals	
Years in the field	4 - 32
Years in a rural setting	4 - 28
% of students with cochlear implants	1 - 90
% of day with cochlear implant students	4 - 100

In response to the demographics questions regarding training, the seven professionals responded with the following information:

*What formal coursework was offered/required in your training program on working with children who have CIs:*

- 1) Embedded in class  
No specific class for CIs  
Discussed along with different modalities
- 2) None
- 3) Clinical Audiology I  
Anatomy and Physiology of Speech and Hearing  
Speech and Hearing Sciences  
Amplification Systems and Aural Rehabilitation for Children  
Evaluation Techniques for Children Who are DHH  
Courses that focused on language, speech, counseling, and development
- 4) Doctorate of Audiology degree  
Required continuing education courses of at least 20 hours annually
- 5) None in college
- 6) None
- 7) I don't think we had anything directly relating to CIs

*What additional training have you sought out on working with children who have CIs outside of your formal training:*

- 1) CI conference  
State department of education  
Licensure credit
- 2) Professional development training  
Mentor program with the state department of education
- 3) State department of education mentors
- 4) National and international conferences  
Consistent research reviews on pediatric cochlear implantation
- 5) Conferences  
Webinars  
Trainings  
LSLS instruction
- 6) None
- 7) CI tech support  
Professional development at CI center  
State department of education

*What additional training has your employer offered on CIs:*

- 1) CI training not required  
Nothing offered on CIs
- 2) Professional developing on CIs  
Mentoring program with state department of education
- 3) I have taken on the responsibility of finding my own training and information
- 4) Continuing education attendance  
Team collaboration with colleagues
- 5) Trainings  
Conferences
- 6) Training on FM systems  
Letting teachers see what a cochlear implant sounds like
- 7) I haven't had any training from them

## **Data Collection**

Institutional Review Board (IRB) approval was obtained from the University of Northern Colorado prior to proceeding with this study. Purposeful sampling was used in the selection of participants who are involved with children who have CIs in rural settings. Participant consent forms were completed prior to data collection.

Participants were asked a series of interview questions to explore how living and working in a rural setting impacts the CI experience, the challenges and opportunities of providing and receiving support services, and the systems of support in rural settings to support a child with a CI. These interview questions can be found in the appendix of this paper. When interviewing parents for this study, I wanted to get to the heart of their CI experience. My goal was to lead them in reflecting back on their journey, sharing their success stories, what surprises and challenges they encountered, and what they wished they knew at the start of their CI experience.

With the professionals, I wanted to get similar information through having them reflect back on their experience from the beginning. Sharing what their knowledge base was prior to working with a child who has a CI, what training they realized they needed to obtain, and how they went about gaining the skills required to successfully serve a student with those unique needs.

Interviews were conducted by phone or online video (e.g. Zoom or FaceTime) and took between 30 minutes to one hour. I sent a follow-up email within 48 hours after the conclusion of the interview to see if there was anything additional participants thought of that they would like to share. The interviews were recorded and transcribed to ensure reporting accuracy and all recordings and transcripts were kept in a password protected computer in a locked cabinet in a locked room. Transcripts of the interview were emailed to each of the participants to give them

the option to review their responses and make any changes if needed. Recordings were discarded after transcription and consent forms will be destroyed three years after the study is completed.

Based on my personal and professional experiences with hearing loss, CIs, and receiving and providing services in rural settings, I recognized that I must make a concerted effort to maintain objectivity. In an attempt to mitigate this, I worked to ensure that my questions were as open-ended as possible and not in any way leading. During the interview process, I was mindful of not interjecting my personal experiences or any kind of bias upon the answers provided by the participants.

### **Data Analysis**

Interviews were transcribed by a transcription service. They were coded by the researcher and peer reviewer to ensure accuracy. Answers were analyzed to determine trends among parents and professionals regarding their experiences with children who have CIs in rural settings. All data were handled through a process of horizontalization which allowed for all responses to be treated as having equal value during initial analysis. Responses were reviewed for what would be considered significant statements and used to create what Moustakas (1994) calls *clusters of meaning* across the participants. This allowed for themes to be developed across the data. Following the guidance from Creswell (2013), I looked for topics readers will expect to find based on previous literature and common sense, surprising codes that were not anticipated at the beginning of the study, unusual codes that are of interest, and codes that will serve to address the larger theoretical perspective of the research.

Inductive coding was used to identify the themes of my research (Yi, 2018). I started by doing initial coding where I read through my data to get familiar with it to garner a general idea

of what the overall data looks like. Notes were made during this process to develop some broad codes for future reference. Line-by-line coding was used to review the data with a closer eye and more details were added to my codes. After this step, I sorted and analyzed my codes into categories to identify predominant and consistent themes. I kept a journal through this coding process, being mindful to note any biases that were recognized and any questions I had about the codes I was developing.

This served as a basis to engage in meaningful discussions when dialoguing and working with my peer reviewer. I worked together with my peer reviewer to independently code the first two transcripts so a list of codes could be created. We reviewed our codes together to ensure we agreed on which ones should be used moving forward. After the remainder of the transcripts were coded, I continued to work with my peer reviewer to establish themes.

The use of thematic analysis aimed to identify common themes that represented the shared experiences of the parents and professionals working with children who have CIs in rural settings. Braun and Clarke (2012) promote the use of this popular method of qualitative data analysis because it is flexible, accessible, and can be used with any theoretical framework.

### **Credibility and Trustworthiness**

**Self-reflection of bias.** In qualitative research, it is important to establish credibility to ensure validity of the results gathered. It was vital to keep an open mind throughout the interview process and be aware of potential bias that may have influenced the data collection. By making a concerted effort to identify any biases I know I have, this helped me ensure my personal perspectives did not have any impact on the results of this study. Having such rich personal and professional experiences in the areas I researched added great depth to the study because I was able to remain mindful of any potential bias. Creswell (2013) highlights the importance of

including several different procedures to provide evidence for the delivery of consistent and accurate results in a study. In addition to *self-reflection of bias*, other specific measures that were taken to ensure validity and reliability in my research included *member checks*, *peer reviewing*, an *audit trail*, and the use of *rich, thick description*.

**Member checks.** Member checking is also referred to as respondent or participant validation and is used to verify the credibility of the results to make sure they are accurate and resonate with the experiences of the participants (Birt, Scott, Cavers, Campbell, & Walter, 2016). To accomplish this, I reviewed my findings with participants to ensure they felt the findings were accurate. The option to participate in member checking was available for each participant. I contacted participants within 48 hours after I conducted their interview to see if there was anything additional they would like to add. Transcripts of their interview were emailed to each of the participants to give them the option to review their responses to ensure accuracy and make any changes if needed. Member checking was especially important due to the phenomenological nature of this work to ensure the research results were an accurate telling of the shared stories and experiences of the parents and professionals in this study.

**Peer reviewing.** Peer reviewing was applied by sharing my study with a colleague to obtain feedback and ensure my study resonates with people other than myself. This colleague is highly knowledgeable in qualitative research and is familiar with the topic of interest. Peer reviewing is also called analytic triangulation and is the process by which a researcher seeks out a peer who is not involved in the study to challenge the researcher's thinking and chosen approaches in all parts of the research process (Given, 2008). The process of coding and developing my specific themes for data analysis was greatly enhanced through the focused work and collaboration with my peer.



**Audit trail.** An audit trail was established by including a transparent description of how I collected and analyzed my data to help establish confirmability of my findings. Establishing an audit trail is a strategy recommended by many researchers for establishing trustworthiness of a qualitative study to give readers the ability to follow the logic of the researcher to determine if the findings from the study can be relied upon as a basis for further inquiry (Carcary, 2009). The audit trail for this study included detailed descriptions of how decisions were made throughout the study, how interviews were conducted, and how data were analyzed.

**Rich, thick descriptions.** Rich, thick descriptions are used to convey my findings in an effort to provide results that are prolific and realistic. One of the goals of implementing the use of rich, thick description is to transport the reader and give the discussion an element of shared experiences which can add to the validity of the findings (Creswell, 2013). This also involved the importance of paying attention to contextual details while I observed and interpreted meaning during this research (Mills, Durepos, & Wiebe, 2010).

### **Conclusion**

The idea of what rural means and the influence of this setting is very complex. The impact on the resources and services available to the family, school district, and community goes beyond geographic barriers. I wanted to identify what parents and professionals do not have in rural settings that is critical for future success in the lives of children with CIs. In addition, I wanted to explore the victories experienced and what creative solutions have been developed to meet these unique challenges to influence future practice. In the end, I wanted to help answer the question, what is the impact of ruralness on the lives of children with CIs, and what can be done to mitigate it.

In the following chapter, I will present the key findings from the interviews with parents and professionals on service provision for children with CIs in rural settings. There will be a discussion surrounding the overall categories, themes, and subthemes that emerged from the data. In the final chapter I will summarize these results and provide implications for future practice for parents and professionals in the field. I will then conclude the paper by discussing the limitations of my study and suggestions for future research.

## CHAPTER IV

### RESULTS

The purpose of this phenomenological qualitative study was to take a deeper and more intimate look at service provision for children with cochlear implants in rural areas from the perspective of parents and the professionals who serve them. Seven parents and seven professionals were interviewed about their experiences. Open-ended interview questions were asked with the goal of identifying themes around the overall impact, challenges, opportunities, and systems of support related to living and working outside of a city center with children who have CIs. To gain a better understanding and take a deeper look at these issues, the following research questions were posed:

- Q1a How does living in a rural setting impact the overall CI experience for parents?
- Q1b How does working in a rural setting impact the overall CI experience for professionals?
- Q2a What are the challenges and opportunities for parents receiving support services for their child with a CI in a rural setting?
- Q2b What are the challenges and opportunities for professionals providing support services for a child with a CI in a rural setting?
- Q3a What are the systems of support in rural settings for parents to support a child with a CI?
- Q3b What are the systems of support in rural settings for professionals to support a child with a CI?

This chapter presents the key findings from the interviews with parents and professionals. The data collected revealed similar themes and results from parents and professionals, so in turn, results for both groups will be reported together. In addition, data related to opportunities and sources of support revealed tremendous overlap when analyzing the data and will be reported together for clarity and conciseness. Findings will be discussed related to the categories of *living and working in a rural setting*; *challenges with rural services*; and *sources of support in rural settings* (See Table 1). Themes related to living and working in a rural setting emerged surrounding (a) the simplicity of rural life, (b) small class sizes, (c) added commitment, (d) parent involvement, and (e) the need to be creative to meet students' unique needs. Themes related to challenges with rural services were connected to difficulties with (a) logistics, (b) parents, (c) resources, (d) schools, and (e) local teams. Themes related to sources of support in rural settings emerged surrounding positive opportunities for (a) families, (b) schools, (c) local professionals, (d) outside services, and (e) peer connections. Following is a discussion of these overall categories with the themes and subthemes that emerged from the data. Illustrative quotes from participants and rich, thick descriptions are used to better support and expand upon these findings.



Figure 1. Themes and Categories

## **Living and Working in a Rural Setting**

The overall sense from the participants interviewed reflected a very positive outlook on living and working in a rural setting. Many of the parents and local professionals grew up in the area themselves and spoke fondly of their overall experiences. There were some common themes that many of the participants brought up when discussing their experiences with rural life, specifically as it pertained to raising or working with a child who has a CI. Themes emerged surrounding (a) the simplicity of rural life, (b) small class sizes, (c) added commitment, (d) parent involvement, and (e) the need to be creative to meet students' unique needs.

### **Simplicity of Rural Life**

Not having to deal with the hustle and bustle of big city life was highlighted by several participants as one of the many positive aspects that life outside of an urban center brings. One parent stated that she loved that when driving her children to and from school, "you don't have to deal with big city traffic every day." The majority of participants echoed this sentiment and shared their appreciation for the quiet and simplicity that comes with rural living. Participants expanded upon this sharing that they moved back to their small community or purposefully relocated to a rural setting to take advantage of all the benefits that come with living outside a city center, specifically the connection to the outdoors and nature, open space, and the security they felt letting children safely play outside.

### **Rural School Experience**

When discussing their child's school experience, many parents looked at the inherent small class sizes that rural education brings as a definite bonus for their child with a CI. One mother shared that "it is a smaller school and they're very good about accommodating her, and

the kids are pretty good with just knowing about [her CI].” The benefit of small class sizes was echoed by another mother:

I feel like the school reached out and looked for answers, that's good. I'm gonna say the school as a whole was a source of support...I kind of feel like my daughter became kind of a project. She had more attention. The school has one gen ed teacher and a para in every classroom, so that I feel is very beneficial...I think in a [bigger] setting, if our daughter had been in that setting, I think she would have been lost...I think our daughter would have been overlooked because she would have been the child to sit in class and behaved and not throw a fit and drew attention to yourself. And I really do, I love our teachers, I love our principal, but I honestly do not think, she wouldn't have the value of education issued in another school.

The majority of the parents shared that because they lived in a small town, many teachers and coaches took a much more personal interest in their child's success. One mom mentioned that “we've been pretty lucky with her teachers and through sports too, they know her, so as she goes up in school, there's somebody there who gets it.” Another parent echoed this personalized experience when it came to her son with a CI playing sports in a small town:

We have had amazing support from coaching staff that treat my son like another one of the kids, but yet have patience with him. They want to see him succeed at the sport and try to help in any way to prevent his implants being the reason why he can't play a sport.

### **Added Commitment**

Most of the parents shared that they knew before their child received an implant about the added commitment that was involved with raising a child with a CI in a rural setting; including travel involved with their child's CI appointments and the financial implications involved with living far from a city center. One mother expanded upon this:

I would say that one impact of rural life is the commitment, we made the commitment knowing our son had the hearing loss, knowing he just was implanted, and he would need all of this therapy, we made the commitment for the travel and the expenses.

Many of the parents discussed that they came to realize that their family would be paving the way for other children with CIs who might go through the school system in their rural

district. One mom highlighted that “being the first student in our school district with implants allows us to pave the way for future students with implants.” Families also looked at this experience as a chance to educate and inform their small communities about CIs. This was explained by one participant that “every time someone asks him what they are, it gives him a chance to educate them about his implants.”

### **Parent Involvement**

Having parents who are highly involved in their child’s education was highlighted by all of the professionals as being important for any family, regardless of location, but they emphasized how vital this was, especially for children with CIs living outside a city center. One professional stated that “the three parents that are here with CIs are super on top of it.” Another professional echoed this point in her explanation about the parents she worked with:

They just wanted them to just have the best life, so they’ve been so involved, still are so involved, and that was really the key to her success that has nothing to do with me, I just went along for the ride with this fun family.

Another participant shared a similar perspective on a family of a child with a CI she worked with, that “because that family is so involved and really they were the ones just like steam rolling this train for her with everything.”

### **Thinking Outside the Box**

The realization that local systems of accessing and sharing information differed when compared to what is available in urban settings was made evident by all of the participants interviewed. They spoke of the necessity of looking to resources outside of their rural backyards and the need to be willing to do things a little differently than they are done in bigger cities. One mom shared that “you have to think outside of the box in these little towns, and you just have to

be as creative and somewhat flexible as possible, you must have creativity when living in a small town.”

The theme of creativity and the need to think outside the box when working to meet the needs of students with CIs in rural settings was discussed by all participants in this study. One professional pointed out, “oftentimes it requires a little more creativity about how we can get support services for those students in their local home communities.” There was also a discussion around the need to be aware of the additional level of attention that must be taken for students in these smaller school districts. When discussing her work with students with CIs who live outside a city center, one professional stated, “I think that it mostly adds another layer of consideration about how we can optimize the best outcomes for all of our students.”

### **Challenges with Rural Services**

Several challenges were discussed by participants, and themes emerged surrounding difficulties with (a) logistics, (b) parents, (c) resources, (d) schools, and (e) local teams. When looking at logistical challenges, issues such as time commitment, travel, and isolation will be explored. Parent challenges will be discussed in terms of the undue burdens that are placed upon parents, and professional challenges working with parents. Access to resources was another challenge area discussed, specifically as it relates to technology. Challenges with the school tapering off support as the student progresses through school and not having in-person, physical support will be explored. Additionally, challenges with local teams in terms of lack of local skilled professionals, professionals pushing their own agendas, conflicting team members, professional turnover, and teacher licensure will be discussed in more detail in this section.



## Logistical Challenges

A logistical challenge shared by many of the participants with serving students in rural schools who have CIs was the slower pace that things move in smaller towns. Professionals who have previously worked in more urban areas noticed this impact the most. One service provider shared that “often times, for some of these kids who live in more rural locations, I think ‘quick’ becomes a very relative sort of term, that things don't go at the speed that I would prefer them to.”

In rural settings, because students who are DHH were so spread out and professionals must serve students with a range of needs, all of the professionals pointed out that the students they serve were much more diverse compared to students served in more populated areas where more “like” students were able to be grouped and served together. One service provider shared her experience working in a bigger school compared to her current work in a rural setting:

The diversity of students that we get, like when I was in a bigger school, they had special classrooms, where all the autism students would go within one autism classroom, whereas now all of our highest severe needs students are in one classroom here, so just the variety of students that I get.

It was reported that students being so spread out resulted in students with CIs in rural schools often being the only student with a CI in their district and sometimes even the only student with hearing loss.

Many participants mentioned that one aspect of living in a small town was the sense of familiarity. One professional stated that “the most difficult part about working in a rural setting is protecting confidentiality. Everybody knows everything about everybody.” This sentiment was echoed by another professional who explained:

It's interesting how privacy doesn't seem to matter to most people, but as a professional, it matters so much to me and it is my job to protect my students! People often think I am

being rude or not understanding what they're talking about, but I am truly just protecting my students and their privacy.

**Time commitment and travel.** All of the participants brought up the issue of travel and the time commitment involved as one of the service provision challenges of having a child with a CI in a rural setting. This issue was explained in more detail by one of the parents:

Anything just to know the time commitment, I mean they do kind of tell you, yeah you have to come up for mappings, and you have to do this, but I think just knowing that time commitment, I mean it's days. We were going to the city every week, every two weeks before she got those implants, and you didn't realize just how much of that you would have to do.

An additional impact of travel, specifically for mapping and visiting the child's implant audiologist, often resulted in their child often having to miss a full day of school. One parent expanded on this impact:

It's a day trip to go to an appointment. I mean you just can't go downtown, it's a three hour trip to do a remapping one way. So I mean that's a full day of school, a full day of travel for mapping. Parents who have different jobs and are in different situations are even more complicated 'cause it's a day trip up there.

This need to travel to an urban center so frequently for their child's CI appointments was also said to negatively impact work and other areas of family life in addition to having a negative financial impact on the family. A participant explained:

The financial commitment is huge. As a parent, you've got to realize that. That life, I worry about that, it's lifelong for her, we were driving to the city all the time, it was every couple weeks.

The majority of the professionals shared that they also experienced travel and time commitment challenges that come with working in a rural setting where students are spread out quite a distance from one another. This was said to have an impact on the need for heavy drive time which limited the amount of face-to-face time professionals were able to spend with students. One participant expressed her frustration and shared that "I think the most difficult

thing is time with kids, and that's where my heart is. I do a lot of driving.” Another professional expanded on how this impacted high quality service provision:

That's why it would be another challenge for the rural areas finding a teacher of the deaf, it's been challenging, and then also I feel like their caseloads and the area that they have to serve down here is so big that it's hard for them to provide great service.

**Isolation.** The feeling of isolation was a common theme discussed by all participants through the course of the interviews. The isolation that was discussed was not only from the parents wishing they could connect with other parents of children who have CIs, but the sadness families and professionals felt that students did not have any close peers with CIs to connect with. Many of the parents stated that they realized that this was part of living in a rural community where their child with a CI was viewed as a minority.

Most all of the parents reported that often their child was the only person in their community with a CI and they felt as if their son or daughter was alone in their rural setting. They stated that because of this, community members were not always understanding. One mother shared her wish for her rural community: “just the understanding and the educating. I wish more people in this community had more knowledge.” Not only did participants share that their child was the only child with a CI in the community, but many parents stated that their child was the first person to ever have a CI in their small rural setting.

From what most parents reported, this small-town mentality sometimes resulted in community members overstepping because everyone is in everyone else's business. One mom shared the following negative encounter she experienced:

I had a guy from church drive to my home, he came on the idea that he was gonna help me with sign language, then he came up here twice to our home to tell me that I didn't have the right to take her rights away by getting her a CI.

The majority of parents expressed a desire to have more interaction with other families who have children with CIs as well as for their children to have connections with peers who have CIs. One mom shared this desire with me:

Exposure for her with other kids with implants, there just isn't any. I don't know that she's interacted with a kid with implants yet, I mean honestly, I don't know that there has been a child she has interacted with implants yet. Period. We'd love to just expose her to other kids, and she hasn't had that in five years. That's probably the biggest challenge, there are just not people around here.

Several of the participants mentioned that it was a challenge to attend any of the gatherings that were happening throughout the state for families of children with CIs due to the drive and distance from these events. One mom talked about this issue as well as the social emotional impact not having interaction with peers who have CIs has on her son:

Well the social emotional piece I think is probably something that maybe we're not always thinking about. You know the peer relations. I think having maybe a little bit more of a system around that. We kind of get these notices, this barbecue's happening over in another town which is like 2 hours from us, or whatever, and you just don't feel connected to a bigger group so much. And I can only imagine how my son might feel about it. I think just from a day-to-day perspective, how can we support these kiddos that often kind of get left out or dismissed if they're not catching things going on or understanding what's going on. And so I think that for me and my experience, a big challenge is the social emotional.

All of the professionals also brought up the lack of like-peer experiences in rural settings for students who have CIs. They stated that this as a major challenge for their students with CIs in smaller school districts. One of the participants shared that “it’s even more challenging providing like-peer experiences because all of my students are different ages. I have and do bring my DHH students together, but connectivity can be difficult because their maturity levels are so different.”

Professional isolation was also discussed by the majority of professionals as being a major issue. One teacher discussed her challenge that “it's a little isolating and my kids are

spread out all over the place.” Many of the other participants shared the same frustration, and one professional stated that “it's definitely me all by myself, and so knowing... it's me, myself, and I making all the decisions, and you can't have more than one because there's not enough kids to warrant that, and especially with cochlear implants.” Only having one professional in the area to serve all the students left them feeling like they sometimes could not provide the services their student needs when they need it. This was expressed further by one professional:

Instead of just being right there in the same vicinity as the kids, I have to drive to get to them, that's probably my biggest frustration with working with DHH kids and kids with cochlear implants in the rural areas is just getting to them when they need me.

### **Undue Burden on Parents**

Living in a rural setting was reported by the majority of participants to place an undue burden on the shoulders of the parents of a child with a CI. Parents stated that there is some support, but that they often had to do things that were not their job, but they did it because their child needed it. One mother shared her experience with this:

I do plan with her starting high school this next year on putting together my own email, to reach out to each one of her teachers individually and say, “in a classroom setting, she's gonna look normal, but these are the things she's gonna miss,” and remind them in a nice way that she has some accommodations to her IEP, note taking, an outline, captioning, all of those little pieces. I don't feel comfortable it is going to be done unless I do it.

Many of the parents shared that they did not want to have to be the main provider all the time. They expressed that they wanted and needed support and that sometimes they wanted to just be a mom. One of the participants expressed her feelings about this:

And I don't know how it will play out, we had an audiologist after the implant, and she was an audiologist who worked at a big clinic and worked with a lot of kids and she said “when we do this you really have to work with him”, which we have, like all the time, and I'm to the point where I'm like, I just really got to be a mom sometimes, right?

All of the parents also expressed that they wished they had more confidence in their local education team and that these professionals would step up so the burden would not always fall on the shoulders of the parents. One mom shared:

I wish from a professional, an educator, I wish that I felt more confident in her deaf hard of hearing teacher, because truly I feel like a lot of this next year would come better if it was coming from her versus coming from me.

Another parent expressed the undue burden placed on rural parents to lead the team and advocate for her daughter:

It's all parent driven here you know...I mean we're the ones that have to tell the teachers and we're the, we're the ringleaders of having to be that support for her wherever she goes in whatever she does. I think just knowing that we're kind of it out here. I mean you can't just run downtown and do something. So just knowing it's all on us.

With all of the many implications COVID-19 has had on families, the need for children who have hearing loss and rely on lip reading was discussed by several families as being a big challenge and one they wished they had more support from local teams on. One mom expressed:

It is a big difference. We were just talking the other day about how the school district is going to look now with all these changes coming in and how everybody is required to wear a face mask, and I don't think they think about this. The CI center said, "right away get ahold of your superintendent and you need to order teachers masks with a clear part so that your son can read lips" and I was like, I will cuz my kid needs it, but that's not my job.

Many parents reiterated that it became frustrating when all of the educating, therapy, and fighting for their child's needs falls on them. This frustration was expressed in more detail by one of the mothers:

I was told things in the beginning like she wouldn't read past a second grade level, and I had to fight with our school district to be able to take her to a program in preschool for deaf and hard of hearing children, and I was told if I tried to do that past kindergarten or past preschool they would fight me on it. I've had to, we've had to fight quite a bit to get things done and I've had to educate myself a lot.

Another parent echoed this frustration of feeling like she had to fight her child's local schools to get the services they need:

I think it was one of the hardest things to advocate or to come up against the school and say this is a need, and I'm not backing down at this point, but I kind of wish I would have done it sooner because great things came from it you know. So advocating earlier and understanding all of that, it's overwhelming and it's a lot, but if I had another parent or an advocate I could have reached out to, maybe I would have done it a little sooner you know?

It was articulated by several parents that they often do not know what they do not know.

When they were the sole advocate for their child's needs, they often did not know what training needed to be provided to solve a problem or to meet their child's needs. This was expanded upon by one of the mothers:

I think for me, you just don't know what you don't know, and I think unfortunately you're thinking, oh we can get through this IEP, it's OK, I don't have a huge need so I wouldn't reach out for that advocate.

**Challenges with parents.** Professionals reported some challenges in working with the parents of students who have CIs in the rural school districts they serve. It was made clear that any issues professionals had working with parents did not seem to be from a place of ill intent, but mainly from parents getting busy and needing to switch their priorities from their child's CI needs to other pressing matters. One professional expanded upon this point:

It seems like in the beginning, they're like, "yeah, we're going to do speech. We're gonna go every couple of months down to the city and get the implant remapping done." And it just falls through the cracks slowly because they have other things. If they have a farm, if they have all that. Life takes hold and they have other kids typically.

All of the professionals also recognized that distance and travel were major factors contributing to parents following through and remaining consistent with their child's CI needs. One professional explained that "it is a hurdle for families to travel to the CI center, but oftentimes it's a hurdle for parents to just get to the school sometimes, so I see that distance is the

really big challenge.” Another professional echoed this sentiment with what she had experienced:

In the more of the rural setting, it's kind of that they start to lag off and not continue to be involved. I think just because it's so far to go to the city, and now life on the farm, and it's busy. And it's not that they don't care about their kids or they're not trying to do what's right, they just don't have the time.

Many professionals expressed that this need for parents to travel so often is coupled with the financial implications that come with having a child who has a CI. One professional shared:

It's hard for these families out here, especially if there's a financial burden for them to get to their mappings at times. And I did have a family, the parents just wouldn't get her to her cochlear implant mapping you know, “our car broke down,” so it's that distance that makes it hard a little bit for parents.

Another issue that many of the professionals reported seeing with parents is that once their child has intelligible speech, they stopped following through on the necessary support services for their child with a CI. One professional mentioned that “when their speech is intelligible and they're like “OK like they're fine.” [Therapy] becomes a small thing.” One of the professionals explained that if parents start decreasing their support at home, that means the local team must provide more support at school. She explained:

I know my kids, especially when they're young, when there is an issue, we need to go in, that sound they're dropping, that I'm talking to my speech therapist, and so when it does come up, I think if it's a family that's dropping off and not doing as much at home, we just know we have to hit it harder when they're at school.

### **Access to Resources**

Access is another area that every participant brought up as lacking in their rural communities. Access to qualified local professionals, to Listening and Spoken Language Specialists (LSLS), and to CI specific information were just a few of the areas participants highlighted as being lacking in terms of access. One of the mothers shared more about this challenge:



First of all, I wish there were more therapists that had auditory verbal training. But there's not even anybody in the closest "bigger" city. I was trying at one time to reach somebody who was in the process of getting their final education in it, but she was not willing to take it on, they felt it was not in their realm. Just that piece, not being able to have a speech therapist in this area that had knowledge of cochlear implants or even auditory verbal therapy.

In terms of information access and sharing, parents expressed frustration in rural communities with their local professionals having no knowledge of deafness, let alone CIs. This was expanded upon by one of the mothers:

I think that access has been the hardest part. Again, our audiologist isn't in town, and the educators don't have very much, if any, experience to understand and meet my son's hearing needs without our support.

**Technology challenges.** Frustration with technology in rural settings was a prominent theme shared by many of the participants. The main issue that was faced was the delay in obtaining replacement parts and repairs for the CIs of the students. One of the professionals described her experience:

If there's an issue with their implant, with the processor, or cords, or something like that and they call and say, "hey I need you." I sometimes can't get there right then and sometimes I have to say, "can you wait till tomorrow?", and that's a bad deal, especially for CI kids because they really are deaf deaf if their CI is not working.

Most of the professionals also discussed the challenge of constantly changing technology and that each student they served used differing equipment they had to learn about. This frustration was shared by one teacher that "every kid's equipment is different every year, and from a different company, and it's hard to keep all the track of it." Another professional discussed her experience with this technology challenge:

I think the biggest thing is that the new technology that is available to aid or assist students with the cochlear implants, we just don't know about. So either we have to kind of actively research that or [parents] find out about that when they have their appointment with their audiologist and that kind of gets brought back to the district level.

Funding in smaller school districts to support purchasing equipment for students that represent such a small population was also a point of technology frustration for many of the professionals. This was expanded upon by one teacher who said that “finding funding to purchase that equipment or troubleshoot it, sometimes it's a little bit difficult when you only have one person in the district.” Another professional echoed this sentiment by stating that “I would say probably the biggest thing is just knowing the newer technology that's out there and having the funding to even have access to that.”

### **School Challenges**

Many parents expressed the challenges they encountered as their student progressed through school. They stated that it became an issue when one set of teachers is trained, then the next year their child has a whole new set of teachers and it often fell on their shoulders as a parent in a rural setting to provide training and the information their child's new set of teachers needed to be successful. It is not surprising that many parents brought up the issue of moving to high school and the challenges that poses for their student's CI needs. Given the age and duration of implantation requirement for participants in this study, it makes sense that many students are older and transitioning into middle and high school. Many parents reported that educators in their child's younger years were much more willing to be trained and learn about their child's CI needs. The frustration of working with professionals in their child's later years was discussed by one of the mothers:

High school is gonna be more challenging for her and I. I'm not very positive about that piece right now. I asked to try to pick a case manager for her, and I was told if I ask for a specific case manager I would be refused. So already just on that note, I already feel the resistance.

This frustration and the challenge of working with their child's higher-grade teachers was echoed once again:

Her 4th grade teacher was told that I was a bear cat. After halfway through the year I was in there picking up homework and the teacher said, "I was told you were a real bear cat, but you're not, you're just an informed mom." I feel like that's the face I've had to put on. It took, I think I counted nine phone calls and several emails just to get two meetings set up with the high school for me to be able to go in. And the same scenario again that I had to put it in writing and bring in outside people to even get a time. I pulled in her counselor because that's what I had to do to even be heard. So a lot of resistance, it's honestly: "we're too busy, your problem is little." And it's not. It's my child and my child's education.

Another issue discussed by many of the parents was the frustration of local team support tapering off and completely going away as their child progressed through school. One mother shared:

I wish we had more support like we did in the beginning. In the beginning we had people reaching out, now I feel like we've got to this point that she's done so well and I'm worried that she's going to be overlooked.

One mother echoed this frustration with the lessening of support: "we took him off of an IEP and put him on a 504...and when we did that, everybody disappeared. Nobody was around." Even the tapering off of outside resources was expressed by another mother as a source of frustration:

The mentor program through the state department of education coming down and helping the school out, I wish that was still a part, I wish the high school would be involved at that level, but they don't. I'm going to ask, but I don't see it going anywhere.

Another school issue that was brought up by the majority of participants was often not having a physical, in-person, consistent professional to support students. Participants reported that visiting professionals and service provided via telepractice was at least something, but not the same. One mother shared her experience:

We didn't really have anybody here physically to really come be consistent. We had the online telehealth going, and of course as parents, we would sit in on those sessions and try to carry things through at home, but I don't know, just you know, nothing takes the place of that in-person, and practicing, and that kind of stuff.

## Local Educational Teams

The main challenge that all participants brought up were issues with the child's local educational team. This frustration reached a breaking point with one mother, and because of this she shared that "I'm actually probably going to home school next year because I feel like he can get serviced better at home." Another mother shared this same level of frustration and expressed:

I don't know how to say things any nicer and I don't want you to think that, but we don't, there's NO support at school, which surprised me for a 504. I still thought the special ed teachers would follow him, check-in every once in a while. I didn't even know the one [special ed] teacher until I asked for a reevaluation.

A struggle that several parents often encountered was that when their child was successful and appeared "normal," that their local rural school districts did not seem to understand that the student still needed support and accommodations. Parents stated that local, rural professionals would often forget their child was deaf, which often resulted in lack of needed support. One mother shared her perspective on this:

I talk to the teachers and let them know that she can't hear, but I just don't think they get the extent of that. Our teachers are really good, but they just assume since she has implants, she's good to go. I think they just don't quite get it. And they just assume with the implants and with the FM system, and she does read lips, she does very well. I think just some training that some of those kids, they just struggle. I mean in general. She has adapted, it's deceiving because she doesn't appear to really have a problem ever, or let them know she does.

All parents highlighted that there was a lack of local expertise and skilled professionals working with their children. They said that often their local team was not involved in their child's education to the extent needed. Several parents expressed frustration specifically around the Teacher of the Deaf (TOD). One mother stated: "the teacher of the deaf, of the hearing impaired, she didn't know anything. She kept sending me links to read all this stuff, and I was like, isn't this your job?" Another parent shared frustration with their child's audiologist:

The audiologist, this school audiologist did come and was there to answer questions I suppose. But her equipment, she hasn't been able to check my son for years since he's had his implant. I mean his equipment doesn't work with her technology.

Many of the parents shared that even when there was a school audiologist assigned to their child's team, that often this local audiologist was not well informed or educated about CIs.

Because of this paucity of knowledge from the local professionals, families were forced to do everything through the big city audiologists. One participant shared a story of her son's experience with his school audiologist:

There was this little girl who had hearing aids at his school, and they got her an FM system, and they tried to get my son to test out her FM system, and my son was like playing along. And they asked, "does it work?" And he said, "nope, can't hear anything." And I asked, "did you tell them you can't connect to anything other than with your cochlear implants," and he was like "no, that's their job, they should know that. It's not my job to tell them. I feel like I'm not supposed to tell people how to do their job." The ones who are supposed to be telling us what to do don't know how to do their job either. It is what it is.

The difficulty of finding quality local support was also highlighted by all of the professionals as a barrier to providing the services children with CIs need in rural settings.

Working to find support locally that does not involve traveling service providers who must come in from outside settings is a challenge. One professional discussed her perspective:

I think the biggest challenge is really trying to find out who can provide the most support locally for that child, so it's distance to professionals with the time and the resources sometimes to address the needs of any specific child. I really do think that that is the biggest challenge.

Many of the local professionals who were on site discussed their frustration with not feeling confident to adequately serve students with CIs and did not feel savvy when it came to their student's technology. One participant shared that "specific to cochlear implants, just having that background knowledge and then the resources to be able to serve them, so that was definitely a challenge." Another professional shared that her confidence levels were much higher

when working with hearing aids, but not as much with CIs: “I definitely feel confident with hearing aids. I feel like with implants, if it's an issue, I'm like power it on, power it off. And then kind of beyond that ... not as confident for sure.”

Many of the professionals discussed the need to take on roles that are outside of their job description or expertise area when working in rural settings. When there were not qualified professionals to fill all of the roles on a child's educational team, other service providers had to fill in. This experience was expanded upon by one professional:

I think the biggest impact of it being all down here, we try and do our best, and we only have a part time audiologist, so she just comes in when I need her, and so really I'm [serving as the] audiologist as well, fixing all the devices and having to learn everything and all the FM and sound fields and everything is all on me.

The lack of formal training of local professionals was brought up by many participants as a big challenge in rural communities. Some participants brought up the issue of formal training that happened several years ago, and as a result, did not include in-depth CI training.

Additionally, professionals shared that training that is currently happening is not adequately preparing professionals to work with students who have CIs. One teacher shared that she is a recent graduate and that her program was lacking in CI content:

I mean even when I was going through the Masters, it wasn't really, CIs weren't really taught...we really didn't learn the tech side. And I would say that's a bad thing, but it's changing every six months so by the time you teach it, it wouldn't be relevant.

When discussing the CI training of the educational audiologist who served students in her rural school, one teacher shared:

No, not at all. I mean she does the hearing aid side and she helps with all the testing or whatever I need, but hasn't really learned [about CIs]. I think is starting to in her Masters or whatever she's working on now, is starting to learn more, but I don't think that was at all in her school.

Another service provider shared that she went through her college training over thirty years ago and that the world of CIs looked very different at that time:

We didn't talk about cochlear implants at all in college, that was 33 years ago, and then when I did my practicum there was a kid with a CI, and I remember it was so early on and I remember just being like "what is that, that is the craziest thing." My mentor teacher had to explain it to me. And they've come so far with the cochlear implants now obviously, but it wasn't a real successful implant for that little girl, so I was like, "what's the point." And I would have never known what to do.

**Professionals pushing their own agenda.** Many of the parents pointed out that they often encountered local professionals who pushed their own agendas and did not take the parent's and child's wishes into consideration. The following was a story that was shared by one of the participants:

Because my son was identified as a student that is deaf/hard of hearing, he was seen by a provider from the state school for the deaf and blind. Since they only met with him once a month, my son wasn't able to make a connection with that person and he didn't really understand why they were coming to see him. They came and wanted to make suggestions that didn't really work for my son, such as including sign into instruction. Once my son realized that he could hear like everyone else, he wanted to communicate like everyone else around him and we respected that choice. So, when they wanted to incorporate sign language into his instruction, he was getting frustrated because he was paying more attention to the signs, more as a distraction, and was missing the majority of the lecture.

Another mother shared an encounter she had with a teacher that led to passing shame on the family's decision to get an implant for their son:

The TOD's counsel to me was... "you know even if you get him implanted, he'll still pick his heart language. So regardless, you might need all this." Kind of like a little bit of shame, that was her description. I think her way of belief is that it isn't healthy for kids.

A similar story was shared by another parent:

It's been frustrating, that TOD actually learned from somebody who had no knowledge of cochlear implants, and the little bit of knowledge she had was negative. She's the one that drove to my home and told me I was making a huge mistake to implant, and risking her life, and I was shocked. Because I had no knowledge of the deaf community and how much resistance I got.

Many of the parents shared that they often received judgment from professionals regarding the communication choices they made for their child and that their child made for themselves. Parents reported that many professionals passed harsh judgment and tried to force sign language on their child, sometimes after parents and their child were very clear that was not what they wanted. This issue was discussed further by one mother:

His para would talk to him in sign language as the lectures were going and he's like, "I can't, that's too much." So we tried to have her kind of like back off a little bit, but then it was never a happy medium. What we wanted wasn't enough for what she needed to do I guess or what she felt she needed to do.

One mother shared that the desire to not communicate in sign language also came directly from her daughter: "when she started preschool she quit signing, and told me right there, 'I do not want to live in this world, I don't want to be the only person in the class that speaks this way.'"

**Conflicting team members.** It was reported that it is very hard for all participants when professionals on the same educational team disagreed with one another. Many of the parents shared that they were already feeling lost and overwhelmed and were looking to their team of professionals for guidance. When professionals disagreed and offered conflicting advice, parents expressed that this is very hard on them. One mother talked about her experience with this conflict:

So she was saying "try to get rid of all the things that you're doing that aren't helpful, things that won't let him use the implants." Right. So okay, and then when this gal came in from the special education agency, she's like "he needs to learn sign." And I'm like, "I wish you two people would agree, right? Because what am I supposed to do?"

This was another story that was shared by a participant that echoed the frustration of conflicting local professionals:

Here we have the audiologist who we love and trust, adore, and then this woman who was his education liaison. And then she started fighting for things that I thought were good ideas, but it didn't work well. She wanted him to have an aide, and the child psych came in. She said "he doesn't need an aide, what do you guys think?" I'm like "well if the



aide could make him more independent, yeah I'd be all for it, but if you just get an aide because nobody else is willing to put in the work to make sure he's understanding." I was just confused, and they couldn't even agree, and they're the team! So I think the majority stayed with the child psych because that's the school team and the other gal was on the outside coming in, so I said, "you know what, forget it, I'll figure it out, and I'll let you know what we want to do."

Conflicting team members was also a major concern that was raised by several professionals. One professional shared that "I think that teaming has been challenging and I think it is challenging anywhere, but maybe more challenging when we're not always able to meet as a team and be on the same page together." This was expanded upon by another service provider who shared her experience with conflicting team members:

We have our school based team, which is good, but then we have the teacher of the deaf and the audiologist that all don't live in town, they come in and they don't always come on the same day, and sometimes like the teacher of the deaf will tell us one thing, and my audiologist will tell us something different, sometimes conflicting messages.

Another professional shared her frustration with team members who did not communicate well with other members of the student's team:

I don't know that we've had a successful solution! I think we've tried to have more team meetings. Our current teacher of the deaf has not, has been something. She's been difficult to communicate with and kind of has her own agenda, and then we try and are there on the same page, or we think we're maybe on the same page, and then she's off over here again.

**Professional turnover.** The issue of high turnover of local professionals in rural settings was also something several participants shared as a point of frustration. Participants stated that this turnover sometimes resulted in an improvement in services, but other times it went from good to bad. One mother shared an experience she had with this frustrating situation:

A lot of that was the principal and I, she was my biggest support system at that time. And then she retired and then the principal that came, we didn't have a great experience, so I had to write his 504 with a teacher and he signed off on it.

Another parent discussed the situation at her daughter's school when there was a personnel turnover: "but then she didn't stay and we got this other woman, who I've not seen her get along well with the teachers, she's a little abrasive I think, I don't know, it just wasn't a good fit."

Several of the professionals in this study also discussed that one of the biggest challenges in terms of the local teams was staff turnover. One support service professional expressed her frustration with this: "I would say we have gone through five or six teachers of the deaf since I've been here, and we had one that was really good and strong, but the rest haven't been very good resources for me." Another professional echoed this same challenge with the fluctuating nature of rural educational teams:

And then me professionally, it's just a matter of identifying a small group of people that really I can best collaborate with and often times that takes time and it can change several times through a school year. Even so it's often a moving target. You may have a contact in August that come January, that's no longer the person that's best able to get to you, so I think that's a big hurdle, is just knowing who to contact for what issues and the best way to get things remedied quickly.

**Teacher licensure.** Along with the issue of high turnover in rural settings, teacher licensure in these communities was also identified by many participants as an issue. Participants shared that their rural districts struggled to get qualified and skilled professionals to move to and work in their small towns. They often took a general special ed teacher and worked to get them a DHH teaching license, and participants shared how this was not even close to the same thing as getting a TOD with a four year BA or six year MA degree. One mother shared the issue of education for her daughter's current TOD:

Our TOD got her licensing, it was in an unconventional manner. The deaf and hard of hearing teacher had been here for years and she tried to retire and no one stepped up. So then the school district contracted with her, and during that time she was a para working with another little boy who has a lot of health issues. She did her schooling completely online. And I see now where she doesn't have the knowledge that I wish she had, the knowledge, the experience, I feel like she has some of it at book value but not at face value, we've had some battling.

Another parent struggled with a similar situation in her school district:

I think I recognized early on in that process that not everybody is really cut out to be a teacher of the deaf. And so I really struggled with it. It's like, you're a special ed teacher, so now we think you can handle any type of ability difference. And quite frankly, that was a frustration, because unfortunately for her, she didn't have the luxury to say no, we need a teacher of the deaf, she was trying her darnedest, but I think that was a huge challenge to make sure that what she was being taught for interventions and that actually translated the same as it would have looked if we were actually with a trained professional.

**Outside support.** Since local professionals were often not able to meet their child's needs, the majority of parents stated that they had to go elsewhere to get these needed services, resulting in having to pay out of pocket for what their child needed. Parents not only had to pay for these critical services, but also had to drive to a city center to get this support and shoulder the additional financial burden that comes with travel. One mother shared her experience with obtaining speech and language services for her son:

So then right after his implants, and he got cleared, we stuck to speech therapy at his implant center instead of the school, because it didn't go well with the school and we couldn't get, [the school Speech Language Pathologist (SLP)] didn't even go to his IEP meetings or anything. So we took on all that.

**Service challenges.** Many of the participants shared that rural professionals were spread too thin and spread out over large areas. They explained that they knew these professionals have to wear lots of different hats in these small rural districts. Several of the parents reported that they feel as if professionals thought they were doing a good job and providing the services their child needed, but often they were not. One mother described her struggle with this issue:

I don't even know what she does, she comes in and helps kids with, I think she's a liaison between the school and special education agency because she's not there a lot. I think she's really spread out. They would call her, but she was always doing other things.

Many of the parents shared that they realized that professionals are overwhelmed and that it is hard to obtain the needed training for a small and unique population of students. One mother

explained that “everyone's to the max, like nobody can do another in-service for this population. Professionals are maxed out.”

One issue that was highlighted by the majority of participants was the need for professionals in these rural areas to understand that not only are all children with hearing loss different, but even all children with CIs are very different. Many professionals were reported to apply a one size fits all approach, when that was not appropriate to meet their child's needs. One mother summarized this feeling by stating that “it would be good for them to have a chance to see that not every child with CIs or hearing loss are the same. They may require different equipment, different accommodations, and different ways of communicating.”

### **Sources of Support in Rural Settings**

Parents and professionals discussed the support that is currently in place to help them serve students with CIs in rural school districts and had some great ideas for possible solutions that could be implemented in their own school districts, as well as advice for other rural communities on meeting the needs of students with CIs. Themes emerged surrounding systems both on a local level as well as outside sources of support. More specifically, themes related to sources of support in rural settings were connected to positive opportunities for families, schools, local professionals, outside services, and peer connections.

#### **Family Support**

It was discussed by several professionals how impressed they have been with the knowledge base of several of the rural families of students with CIs. The majority of participants shared that parents were a very important system of support for meeting the unique needs of children with CIs in rural settings. One professional shared her experience working with a well-informed family:

A lot of my families are so savvy themselves that usually the problems don't happen at school, it's at their home, and then they're just absolutely the most fantastic family, so they'll be like, you know we just called the implant manufacturer and we're going to get this taken care of, I mean they're just so good about it.

Several professionals also discussed the positive impact of parents advocating for their children in these smaller districts. One professional shared:

Honestly, parents who advocate for their children were a huge benefit, because not just on the school front, but when they would go to those appointments with an audiologist or they would have those yearly evaluations, just advocating for their kids on what the recommendations are coming back to school was important also.

Related to parent advocacy, it was discussed by several of the professionals at the local schools how vital it was for parents to help relay information between the school team and outside professionals, especially the child's CI center. One professional mentioned the impact of parent communication and how important it was for families to be an involved member of their child's educational team:

Her mom will send me the report, the [school] audiologist will get the report too. It's just that her family is so on top of it, but I think that's a first step specific to a cochlear implant kid is making sure that that's all working, that's the first step, right? If that's not working, then what are you doing? So making sure that that's perfect, and then that second piece of us all continuing to be communicating regularly, working together.

Many of the parents were very aware of what was needed in terms of parent opportunities. One topic that came up often is that parents shared that they needed to feel like they have the ability to say no. This was coupled with the sentiment that the professionals working with their child did not always know what is best. One mother emphasized the point that "I wish I would have known that I could have said 'no' sooner. No to the things that I didn't feel were beneficial for my son but was told he 'needed' because he became deaf." Many parents shared that they encourage others to realize they know their child best and to fight and not settle for care that does not fit their child's needs. One parent shared a powerful suggestion:

The best advice I could give to parents would be to do what's right for your child no matter what any provider might say (as long as your child is safe). You know your child the best, you see them day in and day out. Fight for your child and don't give in to mediocre, because your child deserves the best.

Many of the participants suggested the need for more parent education and classes prior to making the decision to implant their child. Parent training on accountability in terms of what is involved with implanting your child, learning everything there is to know about CIs, and the opportunity to interact with others who have CIs would in turn improve outcomes for the student.

One mother shared:

I think I would have liked to have some type of an actual class for parents. That actually trained us, that we had to attend, that held us accountable for knowing information. I feel like we made a medical decision that we were like, "okay, this is the best thing," but then we felt ill prepared to handle it. And accountability. It was kinda like, "okay, make yourself learn this." There's so many opinions out there, we don't know which one to follow. So yeah, I think a class, like an actual class that you have to enroll and be accountable, learn something, and interact.

Considering the overall sentiment from participants on potential opportunities they saw for rural school districts to improve their service provision for students with CIs, one mother's perspective was quite powerful:

For the professionals that serve DHH students, learn and never stop learning. Ask questions, get the parents involved, have patience and have an open mind. What you read in a book might not fit every student you come across in your class or office, and you need to take the time to learn about that child.

When looking at the future and recognizing the impact of her advocacy for her son on the greater good of students to come, one mother stated:

Your research is huge because my son is not gonna be the last one in this district with cochlear implants, right? And who knows what the break is going to be in between. And I don't want them to forget what it's like to have a kid with hearing loss or even cochlear implants.

## School Solutions

One theme that was brought up by several of the professionals was the need for higher level administration to be supportive of the work that is being done with students who have CIs in small district schools. This relates often to equipment and support services students need to be successful in the classroom. One professional who works with the schools expanded upon this point:

Our director and our assistant director...we've had their support too. With funds, we've gotten some good equipment, but the equipment, it's almost like your cell phone, it lasts like three to five years. And then we're also using it every day in a high school setting, multiple teachers, multiple people, when they take that microphone and they're winding it and its' wire cracks and breaks and you have to replace that, we need funds. Schools always need funds and the fact that they're going to be getting cut, that's just concerning. We're a high need group, that's a nice cost for the district and that's a little scary for us for next year.

Many professionals working in a variety of roles within the child's educational team brought up the benefit of using an FM system. It was discussed that these systems not only benefited the students with CIs in rural classrooms, but that all students benefited from this increase in auditory access. One professional explained her positive experience using an FM system:

I think the FM systems honestly, I felt like was the biggest impact not only for the hard of hearing students, but really any student in the class benefited from that, and I could be more strategic about seating arrangements and put the hard of hearing students closer in relation to that FM system. And that didn't always mean that it was right up front next to me. Unfortunately, preferential seating and hard of hearing students need to be closer to the teacher, to the board, sometimes that also means they're closer to more distracting students who are up there because they can't focus, or they don't want to get their work done. I think that was good.

Another successful solution that was brought up by some of the professionals as a system of support for CI student classroom success was presenting their assessments and exams orally. Participants shared that due to some vocabulary and reading deficits, this approach to testing

proved successful for students who had CIs. One teacher shared her experience using this approach:

I felt like another strategy that was important with this was oral presentation of their assessments so that we could rephrase the question if they didn't understand it. Hearing it read to them was helpful because of that vocabulary deficit that they have compared to their peers. The ability to rephrase the question and the choices was very beneficial for them, especially in science when it's such vocabulary rich content.

Overall, all of the participants emphasized the need to approach services a little differently than might be done in other settings. There is a need to be creative and look for solutions in places you might not normally look. One participant summarized this point by sharing that "it takes thinking outside of the box and doing things a little different than you would normally do is how you make it work."

### **Local Support**

One of the biggest opportunities for student success from the perspective of all participants was focusing on the local team. The majority of participants stated that everyone must work together to ensure their local team is solid, has clarified roles, identifies a team lead, and has a strong and developed plan. Most of the professionals shared that teams must realize students and parents are counting on them, they must be prepared, and they must reach out to obtain knowledge. It was emphasized that local teams must communicate regularly, work together, and ensure they are including the parents on all communication. All participants shared how different every small-town team looks and that the role each team member fills can look different in every setting.

Having a strong local teacher or professional get on board, regardless of their role on the child's team, was highlighted by many of the participants as often being the key to getting the services and support the student needs. Many participants stated that they were often surprised at



who that person ended up being. It was brought up that this was often a result of not having an active or knowledgeable TOD on the team. One mom shared that she was really grateful for the vested interest her son's general education team took in making sure his CI needs were met: "some of his gen ed teachers were the ones who were amazing advocates." When general education teachers were on board, savvy, and willing to take the time to learn about the needs of students with CIs, many of the participants emphasized what a difference this made in the student's education.

Many of the participants highlighted the need for local schools to have someone on their team who is highly educated, able to provide connections and resources, has no agenda, is flexible, and can be an advocate for both the student and family. One participant shared that "I think schools and communities could benefit from having someone locally that is highly educated in hearing loss and deafness in children from birth through high school." The emphasis must be on a team approach that puts the students first. One mother who had a very positive local team experience expressed what she thinks other districts need: "gosh, a team like ours. Putting the kids first and having a team approach of what the kid needs."

One professional highlighted how the diverse skill set that each team member brings to the table works to best serve students with CIs:

I would say the school audiologist for the actual technology piece and then me for the auditory verbal piece and supporting auditory and language needs for sure. I feel like we're a good team, she has expertise in the areas that I don't.

Another professional echoed this sentiment and expanded upon how important a strong local team was, especially when a student is not receiving the needed support at home:

Successful solutions, that team, that collaboration. If we're on it, and parents maybe aren't or had just started dropping the ball...if we keep staying on it, most parents at least are going to respond to you. I really haven't had a parent that's just flat out ignoring us or not at least trying, you can just see that it's maybe not as diligent as they once were, but if

we're all communicating, working together as a team, and making sure that the student is hearing everything, their speech isn't slipping, they're processing, they're getting the auditory information, and we're following their accommodations in their IEP.

All participants agreed that at least one strong, knowledgeable, and savvy professional must lead the team for the student with a CI. Some participants identified this professional as the school audiologist, and others thought it needed to be the TOD. One professional shared her perspective on getting the school audiologist on board to lead service provision:

To be able to get that audiologist, you know some districts have a .2 audiologist, or they're contracting with somebody, but if they were able to have someone to be able to kind of lead that, having relationships with the students, and make sure that they're making sure everything's working and getting the best equipment for them while they're at school, is just going to help them to be more successful, I think that's it.

Another participant expressed her perspective on having the TOD lead the way to ensure needs are met for students who have CIs in rural schools:

I really do think I would probably encourage you to, I mean obviously each person is going to be in their different role, but the teacher of the deaf has got to get on board really fast, and anybody that would be willing to go with her to get some [CI] trainings right away, access as many trainings that they can.

**Local Teacher of the Deaf.** Almost every participant in this interview emphasized the importance of a strong local TOD to lead the team for a student with a CI in a rural setting. Participants discussed this both in terms of positive experiences they have had when their team was being led by a knowledgeable TOD, and also from a place of struggle when there was not a competent TOD on site. Overall, a much-needed system of support for the local team that was agreed upon was a savvy, motivated, and educated TOD.

Often team members identified their TOD as the person who was or should be the most knowledgeable about the needs of their students with CIs. One professional highlighted:

I would say that the teacher for the deaf obviously has the most [knowledge] and she would be in and work with those students at least once a week, and so we could touch

base either through email or when they were in to kind of run ideas by or troubleshoot or talk through things.

The participants in this study reported that the TOD in their small school districts would take on tasks such as providing whole staff in-services on CIs, playing hearing loss simulations for general education teachers to get buy-in, teaching students strong self-advocacy skills, being in continuous contact with classroom teachers to ensure follow-through, and finding a local, in-house professional such as a special education teacher or paraprofessional to assist with teaching daily auditory verbal tasks for students with CIs.

One of the TODs who was interviewed for this study emphasized the importance of committing to continually learning and being connected to the individual needs of each child with a CI she worked with. That was her most important piece of advice for other TODs serving students in small communities. She expanded upon this by sharing how she worked to ensure she was doing this through collaborative practice with her student's CI center:

Whenever I can, I like to go on visits with the kids and with their audiology appointments, and then if they have any therapy appointments afterward I like to go see what's going on so that I can keep going in the same direction and ride out on whatever they're doing so that we're collaborating.

It was brought up by the TODs how important it is to be connected with other TODs around the state, especially those who also work within rural school districts. The encouragement and idea sharing among fellow professionals was said to be a vital system of support for serving students with CIs. One participant shared a story about her involvement in a small cohort of fellow TODs that was created in her area:

We had a cohort and we came together like once a month because we thought all of us are all here all alone, right? So really saw a need for coming together, brainstorming just those weird things that happen that you're like, "what do I do?" And just getting advice from the other TODs...it's pretty cool.

Having an on-site TOD is something that many parents emphasized as being of vital importance for rural school districts working to meet the needs of a child with a CI. Participants added that this local, knowledgeable TOD must provide support, training, and education. One mother shared that if she could go back and do something differently, “I would have advocated for a teacher of the deaf way earlier.” Another parent shared:

Communities need someone that is there to support, not necessarily with an agenda, someone that is flexible in their ideas and approaches, that understands that not everyone learns the same way. They need to have someone that understands the technology that can be beneficial to students that are deaf or hard of hearing and be willing to advocate for students to get the equipment that they need.

Many parents pointed out that having a skilled, knowledgeable, and active TOD on board made all the difference in their student’s school experience. One mother had to fight for years to get a TOD for their school district and emphasized that “I just think it's really important that we had an on-site teacher of the deaf.” Another mother was feeling extremely frustrated at the lack of leadership and advocacy for her son from his local team and shared the positive experience she had when a skilled and knowledge TOD finally got involved:

The teacher of the deaf from the local special education agency, it was quite a beautiful thing when she spoke up, I was like, where have you been? She said, “he’ll never test well on math, it's not appropriate to where he is right now, you guys need to make some changes in investigating in some curriculum that will be helpful, you’re going to have to change it all and serve this child well,” and I wanted to get up and hug her.

**Local audiologist.** Another professional that was brought up by several participants as being a vital member of the local team was the school audiologist. Again, the majority of participants discussed the need for a knowledgeable audiologist, specifically about CIs, in terms of positive experiences having a strong one as well as negative experiences when they were not a strong source of information and support. When identifying a strong system of support in her local school, one professional shared, “I would say our audiologist is most knowledgeable and

usually when she comes over we touch base and talk, and then if something arises, I'll call or email her.” Another professional echoed this sentiment by stating that “the educational audiologist, here's a resource, the audiologist for the [local special education agency] is amazing.”

The collaboration between the school audiologist and the student’s CI audiologist was brought up by almost all of the participants as being a vital part of ensuring success for the child in a rural school setting. One professional highlighted the importance of every person’s role on the team, but that the school audiologist holds a special responsibility:

We all lean on each other, but I would defer after trying those simple tricks to the [school] audiologist, then she has been the one that will contact the student’s private audiologist, so I kind of put that responsibility on her to be in touch with the private audiologist...I mean I think that [school] audiologist is huge in their collaboration between the public setting of school and the private audiologist and making sure that they have a good working relationship, that we can share data and information, and that, “oh I just reprogrammed her, here's the data that I got, share that with the teacher of the deaf, share that with families.”

**New staff.** Staff turnover was discussed by several participants as a common occurrence in rural settings, and that this sometimes led to a positive change in personnel. One professional shared that “I think this next year we are going to have a new teacher of the deaf, so I'm hopeful that it's going to improve.” Getting new professionals with fresh perspectives and more current training, specifically related to CIs, was discussed by participants as a possible positive system of support.

**Learning experiences.** There were several opportunities for professional learning experiences highlighted by participants. Many participants suggested having professionals go with students to audiology appointments, observing mappings, job shadowing, and visiting a bigger school with a successful CI program. One professional shared:

I'd love to see a mapping. My student that will be a senior, she's had the same paraprofessional this whole time her K through twelve experience, and so she's gone several times with her for the remapping of her implants and she's been like, "it's so cool to watch it." It's not that I would know what she's doing, I don't know, maybe just that conversation and hearing from the audiologist.

In regards to observing a bigger school with a successful CI program, one professional shared that "spending time in another school where there's a couple of implant kids would be a really great thing for a team to do to get an idea of where they need to go next or things that would help kids."

**Trainings.** Attending trainings specifically related to CIs was brought up by all participants as a vital opportunity for local service providers to take part in to successfully serve their students who have CIs. These trainings are not only beneficial for school staff, but for the rural community as well. One professional expanded upon this educational opportunity:

I think a general understanding of the challenges that come with wearing a CI is important for individuals in the school as well as community members recognizing the dos and don'ts. I have provided a staff training on this but haven't provided one for the community yet. Something I've been wanting to provide since I've been here. Education could provide more understanding and patience for those who wear a CI.

Another professional expressed a desire to take a more in-depth audiology course as a way to better meet the needs of her students with CIs: "I was always in love with my audiology class, it is all so fascinating, so I mean even just like a refresh on that."

The majority of participants highlighted the realization that school training must occur every year as the student with a CI progresses through the grades and that the training of school professionals must be ongoing. A vital thing that many participants emphasized is the importance of realizing that you are never done learning. One professional stated that "technology is constantly changing. I would always love a refresher course on all of the new devices for students who are DHH."

All of the participants stated that professional training and obtaining at least a general comprehension of CI knowledge must occur for every district that has a student with a CI. One participant explained that “I would love teachers, educators, principals, support staff, the superintendent, to attend conferences that are specific for students with CIs, ones that have students present that have CIs themselves.” A more in-depth explanation was provided by another parent:

I think just a little more knowledge on implants, like I said, she's the only one out here so it's hard to say, “yeah, they should be experts.” But it would be nice if they just had a basic knowledge for some of that, where I don't think they do, because they just aren't around it.

Ongoing training for local team members was emphasized by all participants as a critical system of support to ensure success for students with CIs in rural school settings. Some of the training that was highlighted as critical was professional development specific to CIs, listening and language training, information on how to contact CI manufacturers, and auditory simulations on what CIs and FMs sound like. Participants shared that this training could be provided by local knowledgeable professionals such as the TOD, school audiologist, or SLP. It was also discussed that outside professionals could be brought in to provide this training and support. These training and support options will be discussed in more detail in the section on outside resources.

Several of the participants shared that an opportunity for enhancement of services would entail local teams putting together a packet of information and trainings for general education teachers working with children who have CIs. One participant expanded upon this point by sharing that rural school districts need “someone that can assist the parents and students in educating the school staff. And providing professional development so the parents aren't trying to do it themselves.”

**Emulate successful programs.** Many of the participants thought an opportunity local school professionals could pursue would be to emulate successful urban DHH programs. One mother suggested that “talking with teams that aren't rural and seeing what works and what doesn't work and seeing how you can best replicate that.” Another participant shared that one possible approach would be to figure out the ideal services your child needs and build from there, “you know, what ideally you need and then how to best get that the best way you can.”

The majority of participants stated that teams who work in rural settings must be flexible and open to making changes as they go. One mother shared her thoughts on an opportunity for improving services in smaller communities:

Being open to make changes as you go because...if that doesn't work, we'll go back, it's okay, we can try it. Having a team that's willing to try different things. Having a team that actually work together and see each other and physically be there.

Another parent echoed this same sentiment and emphasized the need to be willing to look at resources outside your rural community:

I think just tapping into all the resources that you possibly can and asking questions around what your services are really looking like at school. And just getting that advocate to call and say that I'm thinking about this. If you know you can get teachers on board or you have that teacher of the deaf that's going to be that advocate for that professional development piece. Get someone on board. You have to be committed to finding those bigger resources and finding that professional team that might not be in your backyard right now.

## **Outside Resources**

Several additional outside resources were listed as potential opportunities for local service providers in rural schools to utilize to help professionals better serve students in their districts who have CIs. One professional had a suggestion for better supporting local teams:

They really need some sort of quick and easy way to find out the professionals that can support them best. So whether this is developing a sheet that families can give in an IEP meeting with a rundown of who the child works with for any variety of things. So who their speech language pathologist is, who their mapping audiologist is, who their



educational audiologist is. All of the people so that they could get to us more quickly and easily.

The strongest theme that was emphasized by all participants was that local school professionals must seek out and welcome outside support. It is important to not view the use of outside services as a sign you are doing something wrong. One participant stated that “schools can support a great deal by welcoming these kind of meetings with some of the [outside] professionals in small groups. We have to really get that background support so that children can be as successful as possible.” Participants shared several sources of outside support their schools have utilized such as the state department of education, the student’s CI center, DHH specific magazines, LSLs resources, and CI specific conferences and workshops.

The emphasis on having live, in-person, on-site support within the rural schools was made by many of the participants. They shared that outside professionals coming in was an incredible opportunity for local teams to really enhance and focus their service provision for students with CIs. One of the professionals shared her thoughts on doing this:

And seriously, I think the best thing to do is just have somebody come, a teacher of the deaf that is well versed in what that looks like, and just being able to see somebody else do it and know that’s the expert. Just to me, that’s the best teaching tool and readiness tool that they could ask for is to have somebody just showing, this is how it’s done, and this is what you need to have in place.

**State department of education.** Support from the state department of education was brought up by almost all of the participants as a great source of education and guidance for working with students who have CIs. The CI mentorship program that connects rural schools with knowledgeable CI professionals was a positive system of support for many participants. One professional shared:

My mentors really helped me feel confident in my position. I am the first teacher of the deaf [here] so I felt a lot of pressure when I accepted the job. My mentors reminded me that I was the expert and that I was doing everything correctly.

Another participant shared more details about what the mentoring program looked like for her school:

I would say like five years ago, they set up a mentorship program down here. They did the big trainings for all the SLPs in our area, it was very helpful. And then one SLP specifically met with me, and so that has been very helpful in my working with student's with cochlear implants. The first year, it was a three year mentoring program. In the first year I think it was ten hours, and then the second year went down to five hours, and the third year, or maybe it was 15/10/5, something like that.

The state department of education's yearly conference was highlighted as a support opportunity by one professional: "the cochlear implant conferences in January that the state department of education has put on have been great, there's a lot of research, there's a lot of data." Many participants shared their encouragement for rural school districts to get involved with the state department of education's CI mentor program. One professional offered assurance that seeking out help does not mean you are doing something wrong:

Tap in. Don't be scared of the department of education, because there's the one side of "I don't want them coming in and seeing what we're doing because then they're gonna say we're doing it wrong." Well we're all doing it wrong, you can't do it right by the books. So I really think not being afraid of asking for help. We did a mentoring program with [them] for three years and ended up doing an extra year because I was finishing my Masters. So they were doing an extra year for me. That was super because they would come down and do trainings, they come down and go around to the kids and see what we're doing and kind of give us feedback.

In addition to the CI mentor program set up by the state department of education, one participant shared that they also provided weekly webinars during the months when schools were shut down due to COVID-19:

The state department of education has been amazing, and especially in the last four months of COVID, they've done weekly training, or like weekly webinars, with all of us for like 2 hours, amazing. So for them to go and, that was a whole bunch of extra work for them, but it was helping us to troubleshoot technology, troubleshoot how to record different things in different programs. They've really, really been amazing in all their training.

**Cochlear implant center and team.** Almost every participant interviewed put a strong emphasis on the ongoing support they received from the student's CI team. A strong connection to the CI center, CI audiologist, and the team at the CI center was a common theme and source of support. One mom shared that "we have had such wonderful results and my son has grown so much and is doing things that we never thought he could, and he did that by us and his CI team advocating for his rights." Another participant had similar positive accolades:

Our audiologist and team at the CI center has the most knowledge about our son's CIs. We have always been able to reach out to his team at the CI center via phone, email, or in person for any questions about his CIs or support at school. We always get an amazing response, and they always go above and beyond to get us the answers we need.

Many parents indicated that the support and resources received from their CI center are what they wish they received from their local teams. One mother expressed great frustration for the local resources and support for her daughter in their rural community. She highlighted what a saving grace their relationship with the CI center has been:

The CI center and especially the family consultant, she has been a huge inspiration, just her knowledge and her experiences and explaining. One time she gave us a story about herself and hearing the dog's toenails on the floor and not knowing what that sound was, just those things, those are the little pieces of information that I don't think our TOD gets.

Several families brought up the family consultant from their child's CI center as being an incredibly positive resource and support for them. One participant shared the following sentiment:

We also work with the family consultant at the CI center and we LOVE her. She's amazing. So if his CI audiologist doesn't know, then the family consultant does. And if she doesn't know, she find's somebody that does.

The CI team was also brought up by many families as being vital in the training that they provided to local teams. One mother discussed her experience with this training:

At the very beginning, the CI center came down and met with kindergarten, first grade, second grade, and they met with the whole team. It's a small school so there's only one

class per grade with the classroom teachers, the nurse, the PE teacher, speech therapist. At the time everybody that was involved, and they just kind of gave a rundown of what was necessary, I mean what she would look like. They provided a mentor clear up through her starting middle school.

IEP and 504 support, speech language pathology (SLP) services, and telepractice were some of the additional resources highlighted by participants that came through the student's CI center. In discussing the frustrations they encountered with their local team and their child's educational plan, many parents shared that the guidance and support they received from their child's CI team was invaluable. One mom shared:

Every time we were trying to figure out how to fix his IEP, someone for the CI center came down themselves and sat in my meetings. They were like, "this is why we do it this way. This is why he needs speech therapy this way."

Another mother echoed this sentiment and described her experience with the CI center providing educational plan support:

So it really was better, and even this last time when I wanted to reevaluate his 504 to see if he would qualify for an IEP, the CI center very much gave me a guideline: "these are the things you can ask for, these are the things you don't have to ask for, and we can pick and choose." But I really don't know where we would be without them.

Telepractice was another resource that many participants discussed in terms of systems of support for their child. They stated that the majority of this telepractice support was implemented by their CI center:

Yeah [telepractice] was huge. It was like after six months of being implanted with the second implant and for speech therapy they wanted him to be able to talk on the phone. So this happened about month three and it was amazing, it really did go fairly fast. My son picked it up really well. We can still use it every once in a while, and that's how he did a lot of his like distance learning was through Zoom. So telepractice has been good. He said it's pretty easy, he doesn't really struggle with it he said.

Another mother also shared her experience with relying on her daughter's CI center for the support they need, including telepractice:

When she did first get them, we did online speech therapy with her implant center, so we didn't have to go up there twice a week, so they've been accommodating there. Basically everything we do is through her implant center. If we need anything we go there.

Many parents also emphasized how grateful they were to their CI centers that were located in urban settings for working to schedule appointments together to reduce family travel time, knowing they were a rural family. One mom talked about this experience:

The CI center has been really good. Like for appointments, we can meet with the audiologist and the surgeon at the same time, they're pretty good about realizing how far we come and helping with appointments and getting them together or even at surgeries, do we want morning, do we want afternoon? I mean they've been knowing that we come that far away, they've been pretty adapted to what we need for that.

**Cochlear implant manufacturer.** The majority of participants highlighted the CI manufacturer as an invaluable resource for meeting the unique technology needs of students. One professional stated, “the manufacturers have been really very valuable to us in providing some of that education and support for local providers.” This sentiment was highlighted by another professional: “because I am a learner... I am calling the implant manufacturer and troubleshooting with them directly if something is going on.” Most participants shared that this has been a highly effective way to meet their students’ needs within rural areas where there was limited access to resources.

Trainings directly from the CI manufacturer were discussed by participants as a potential opportunity for professionals to receive more in depth knowledge on managing their students’ devices. Many of the professionals highlighted that learning from these experts was a much better way to access the information than trying to learn from a book. One professional discussed this training opportunity in more detail:

I think that it has been manufacturer specific support training that can be very helpful. Pre COVID, a lot of the manufacturers would have parent and support person workshops every so often, or have made themselves available to rural school districts so that they can really get to the heart of the concerns that local rural educational teams have and

really provide that entry level support so that people, if nothing else, they can walk away with a telephone number and an email address so that they know who to contact when issues come up, but I really find that it is some specific training by a highly knowledgeable professional around cochlear implants in a small group setting that really can be very, very helpful.

The CI manufacturer for their child's implant came up often as a consistent resource and theme that parents also felt they could turn to and get the support they needed when it came to the technology and troubleshooting involved with their child's device. Many of the parents felt that local professionals were not knowledgeable when it came their child's CI, so they had to seek out other sources of support. One participant discussed how the implant company directly provided the support and knowledge their family was seeking: "the CI support team, tends to be actually pretty good, if you call them, they can walk you through."

In the interviews, the fathers were often mentioned as the ones who took the lead on any type of troubleshooting for their child's device and were the ones who reached out to the CI company for any issues that needed resolved. One participant shared his experience working with the CI company:

I have also been very pleased with our CI company. With troubleshooting, I've been able to pick up the phone and everybody there was right on board. If we've needed a piece or something, I mean it's within a day or two that we get what we need, it's very quick, it has been very positive, just the CI company and just having them. Picking up the phone, and we need new magnets, these got sand in it, whatever we need.

**Conferences and workshops.** Most of the professionals discussed the benefit of attending outside conferences and workshops that focused on topics surrounding CIs. They shared that often there was funding available to attend continuing education events, and that local professionals should seek out opportunities to attend conferences and workshops that provide specific CI training. One professional expanded upon her experiences:

Any training that you can get on CIs, maybe some audiology conferences too, that's always a good thing. I mean it helps to know that technology side and the more technical

piece of it. Technology changes so often and I would go every once in a while, I'd go to some audiology conferences. I think we miss out if we think that those conferences are just for audiologists, we need to have that information as well. It's really important. So any trainings or conferences for audiology, AV therapy, any of that stuff is super helpful.

**Listening and spoken language resources.** Systems of support that focus specifically on listening and spoken language development were highlighted by the majority of participants in rural settings as useful resources for meeting the needs of students with CIs. Workshops and online resources were emphasized as useful support tools. Private LSLS therapists and organizations in urban centers were also brought up as positive systems of support that parents sought out to meet their students' unique listening and spoken language needs that were not successfully met by local providers. These specialists provided support through in-person auditory verbal sessions at their clinics, telepractice sessions, and coming to the child's classroom and doing observations and working with local staff. One mom shared that her son "meets online with an SLP from the private LSLS clinic and has been doing therapy with her for years on Mondays, and they are super helpful and supportive."

### **Telepractice**

The use of telepractice was brought up by many participants as not only a successful approach for them to provide services to students, but also as a means to obtain training and mentoring from outside support services. Many professionals brought up the impact of COVID-19 and service delivery switching to being completely on-line. This opened their eyes to the possibility of the continued use of telepractice for addressing their student's needs. One professional pointed out that "that's one good thing about using Google Meets and Zoom and stuff like that with students, having to, I really learned how to become a more effective provider using those venues." Another service provider expanded upon this possibility:

Even knowing more about some of the resources to get patients to the CI center, and COVID has taught us an awful lot about telehealth services, so maybe this is an avenue where we can start to expand our ability to reach professionals and these local settings through some of these telehealth support means.

Many professionals also discussed the use of telepractice as a possible solution to long drive times and weather issues. One participant expanded upon the use of telepractice as a way to approach these problems:

As far as the time thing, I really just need to use more virtual meetings when I can't get there. Some of my kids, it's an hour and a half to get there, it's a long drive. And if I'm working five hours with this student, I'm not going to be able to get there, yeah it's just rough, it's rough. I really feel like this would not be a hard thing for students now. Because I don't know that I would have had a student before that would know how to get into a Google Meet or a Zoom meeting or whatever, so now I feel like I can use that a lot more...It's interesting, if it's a bad weather day please don't go, we'd rather have you guys stay home, we know that there's things that you could do and if you want to do some remote meetings or whatever...that is a blessing as much as I hated this COVID, it's like, okay I do see some perks.

The use of distance services was an opportunity many parents also suggested to meet the unique needs of this diverse group of students. A few of the students successfully used telepractice services prior to their school districts moving to remote learning during the COVID-19 pandemic, but being forced to only be educated via distance technology opened the eyes of many parents to other potential opportunities for long distance service delivery. One mother emphasized this point that “now even with the COVID you're realizing, hey, this is something you can do long distance, right?”

### **Peer Relations**

Many participants discussed possible opportunities for helping to meet student social-emotional needs by providing peer connections with other students who have CIs. One professional brought up the option of implementing telepractice to address like-peer connections:

Especially now that we, and kids, and teachers, and myself know a little bit more about how to use Zoom and Google Meets and all that good stuff, I feel like it will be easier to



set up times to collaborate with other kids from other districts so that they can at least see them face to face a little bit, you know, via technology. I think that will be extremely helpful.

Another teacher discussed reaching out to professionals in other school districts to set-up potential like-peer interactions via remote means:

I think that I'll use that more, plus I do I think it'll be easier to collaborate with other students, it'll just be finding out who the students in other areas are and talking to some of my other friends that are teachers of the deaf in other areas so that we can get those set up.

All of the parents emphasized the need for more opportunities for their child and family to interact with others who have CIs. This was discussed more in depth in terms of challenges, and many parents brought this up when discussing opportunities for improvements in service provision. They shared that there needs to be peer relations established and that day-to-day socialization needs to occur, not just once a year.

### **Conclusion**

The results from these interviews revealed valuable insight from parents and professionals into their experiences living and working in rural settings with students who have CIs. An in-depth look at overall experiences, challenges, and sources of support led to themes and subthemes emerging throughout this chapter to provide valuable insight into the experiences of parents and professionals living and working in school districts outside of a city center. Findings related to participant experiences living and working in a rural setting centered around the simplicity of rural life, benefits of small class sizes, the added commitment for parents, the importance of family involvement, and the need to be creative to meet students' unique needs. When looking at the challenges with rural services, issues surrounding logistics, parent motivation, local resources, school support, and local teams were highlighted as causes of difficulty. There were many sources of support discussed, including positive opportunities for

family advocacy, school services, local professionals, outside support services, and the enhancement of peer connections. The following chapter will take a deeper look at the results of this study. Discussion will occur surrounding implications for future practice, limitations of the study, and suggestions for future research.

## CHAPTER V

### CONCLUSIONS

In the review of literature in chapter two on service provision for children with cochlear implants in rural settings, it was made clear that when compared to their urban peers, children in rural areas struggle to access the same services and supports (Barr et al., 2019, 2018; Baxter et al., 2011; Graham & Underwood, 2012). Despite there being known problems with the service provision in rural areas, Barr et al., (2019, 2018) emphasized that little is being done to research improvements in medical and educational service delivery specifically for children with hearing loss in communities outside a city center. These previous findings served as a catalyst to conduct research into the service provision in rural settings for children with CIs and the parents and professionals who work with them.

#### **Discussion**

The purpose of this phenomenological qualitative study was to take a deeper and more intimate look at service provision for children with CIs in rural areas from the perspective of parents and the professionals who serve them. Seven parents and seven professionals were interviewed about their experiences. Open-ended interview questions were asked with the goal of identifying themes around the overall impact, challenges, opportunities, and systems of support related to living and working outside of a city center with children who have CIs. There was consistency in the themes and data from the parents and professionals and similarities in the challenges identified, systems of support, and potential opportunities for improving the services provided to students with CIs living in rural areas.

The findings discussed were related to the categories of *living and working in a rural setting*; *challenges with rural services*; and *sources of support in rural settings*. Themes related to living and working in a rural setting emerged surrounding (a) the simplicity of rural life, (b) small class sizes, (c) added commitment, (d) parent involvement, and (e) the need to be creative to meet students' unique needs. Themes related to challenges with rural services were connected to difficulties with (a) logistics, (b) parents, (c) resources, (d) schools, and (e) local teams. Themes related to sources of support in rural settings emerged surrounding positive opportunities for (a) families, (b) schools, (c) local professionals, (d) outside services, and (e) peer connections. In this section, these themes and subthemes will be further explored and their relation to previous research will be discussed.

### **Living and Working in a Rural Setting**

When answering research question one, a general look was taken at the effect rural life has on the overall CI experience. Parents and professionals reported a positive overall experience living and working in a rural setting. This is in-line with the findings of Struthers and Bokemeier (2000) who found that reasons small towns are preferred over larger urban areas are the community values, family life, safety, and connection to nature.

When children receive CIs, research shows that parents play a vital role in the (re)habilitation process (Hyde et al., 2010; Leigh et al., 2013; Niparko, 2009). Participants in this study echoed the critical importance of parent involvement on the student's educational team, especially when living outside of a city center where resources are limited. Parents in this study recognized the added commitment that comes with raising a child who has a CI in rural setting and shared that they see the importance of being willing and active members on their child's

educational team. Professionals emphasized that it makes a significant difference when parents are involved in the education of the students they serve in rural schools.

The need to be creative and think outside the box was an overarching theme that came out of this study when looking at the impact a rural setting has on meeting the needs of a child with a CI. Since there is reduced access to appropriate services in rural settings (Barr et al., 2019, 2018; Baxter et al., 2011; Graham & Underwood, 2012), participants realized that they must look to resources outside of their own backyards to meet the unique needs of students. This signified that an extra level of consideration must be given to rural students and the impact of living outside of a city center and away from specialized services when compared to their urban peers.

### **Challenges with Rural Services**

When answering research question two, access to high quality, trained, local professionals was a major issue highlighted by all participants in this study. It is well documented that there is high workforce turnover of qualified professionals in rural areas. This is a result of lack of resources, unrealistic demands, overwhelming caseloads, insufficient financial incentives, travel challenges, lack of professional development opportunities, limited administrative support, and social isolation (Dew et al., 2016; Gallego et al., 2016; Hussain & Tait, 2015; Pedersen & Beste-Guldborg, 2019; Veitch et al., 2012). Professionals in the current study supported these findings and shared their frustrations specifically around travel, lack of resources, and the need for additional CI specific training and support.

Because of the lack of local support and resources, many parents in this study were forced to obtain outside services that required out of pocket expenses. Research shows that many communities do not or are not able to provide the kind of spoken language support children with CIs need (Sorkin & Zwolan, 2008). This ties into the need for families to travel to obtain

services. The long distances traveled for appointments posed additional challenges and burdens on rural families because parents had to take time off work, juggle the needs of their other children, pay for meals on the road, and sometimes overnight hotel accommodations (Dew et al., 2013; Elpers et al., 2016; Gallego et al., 2016; Tait & Hussain, 2017).

Often, a child with a CI is perceived as being able to function at the same level as their hearing peers without any additional accommodations, but research shows that this is not the case (Scheetz, 2012). This is especially a problem in rural settings where professionals and community members were not familiar or did not have exposure to many people with CIs. Parents reported that professionals tended to forget their students were deaf and appropriate support services got overlooked. Findings from the current study support previous research which shows that rural students who use CIs are at risk for academic, communication, vocational, and social failure when they have limited or no access to high quality, specially trained professionals who are equipped to address their unique educational and communication needs (Pedersen & Beste-Guldborg, 2019).

Many parents talked about the pressure and judgement they received from various professionals. When a parent made the hard decision to implant their child, it was reported in this study that some professionals told families that they harmed their child by giving them implants. Additionally, when a parent and their child decided that they did not want to use sign language, parents shared that the pressure and disapproval from professionals was extremely hurtful. It was made clear through this study that there are still many professionals working in the field who think that when a child is DHH, it equates to the automatic need for sign language instruction. Many of the parents reported having to fight to get sign language instruction removed from their child's educational plan, even after both the parent and the student made it explicitly clear that

this was not something they wanted. This emphasizes the need for professionals to be respectful of not only the families wishes, but the child's request as well (Archbold et al., 2006; Huttunen & Valimaa, 2012).

### **Sources of Support in Rural Settings**

To answer research question three, parents and professionals discussed ways students receive support to meet their CI needs and ideas to improve service provision moving forward. A finding that applied both to systems of support and challenges is the ebb and flow of local support many families had. Some families had strong support at one time and later had nothing. Other parents shared stories of past terrible experiences, but that services improved. This speaks to the findings in previous research of the transient nature of professionals, specifically special education service providers in rural settings (Dolman, 2010; Marlatt, 2014; Paul, 2015). Reports in this study were very participant specific. There was not one profession identified by all families that was the key source of support, it depended on each family's individual experience. This is supported by what has been found in previous research, which emphasized the need to focus services on the individualized needs of each child and family (Archbold et al., 2006; Huttunen & Valimaa, 2012).

Parents and the role they play on their child's educational team were highlighted by all participants as a major system of support. Research shows that parents are critical observers of their child's everyday life as they are able to assess day-to-day outcomes rather than just what is achieved in a clinical situation (Archbold et al., 2002; Sach & Whynes, 2005). In addition, participants emphasized how vital it was for parents to help relay information between the school team and outside professionals, especially from the child's CI center.

Research has shown that there is a need for more collaboration between service providers and an increased need for specialized professional development (Sibon-Macarro et al., 2014). All participants in this study emphasized the importance of both team collaboration and the need for local service providers to seek out additional training to meet the needs of the students they serve. Participants shared both local and outside sources of support professionals could utilize to obtain this focused training to meet the needs of students who have CIs within their rural schools. This echoed past research that the educational team working to serve students who are DHH must ensure they have the knowledge and skill set to develop listening and spoken language when this is the goal for a child with a CI (Goldberg et al., 2010).

Telepractice was a resource many participants only recently became familiar using on a consistent basis due to the mandate for remote education and COVID-19. In addition to educational and (re)habilitation support, literature shows that service providers can provide mentoring, supervision, pre-service, and continuing education through telepractice. And this distance approach to services can take place in a variety of locations such as schools, client homes, childcare centers, medical centers, and many other settings. (ASHA, 2019). Many parents and professionals in this study also discussed the potential of meeting the unique social-emotional needs of students with CIs in rural settings through the use of telepractice. This is supported by the findings in the study by Hopkins et al. (2012) where social-emotional benefits were successfully addressed through the implementation of telepractice and students in rural areas were able to connect with other peers who were DHH with a focus on improving identity development.



## Implications

The parents and professionals who participated in this study provided invaluable insight into improving service provision for children with CIs in rural settings. These findings have tangible implications for the field that can be applied by parents and professionals going forward. By providing in-depth descriptions of the current systems of support they have in place, the challenges they face on a daily basis to meet students' needs, and the identification of potential opportunities for improvement, ideas and solutions that may lead to potential student success have been identified.

One of the biggest takeaways from this research is how willing local people are to learn and be a part of successful service provision for students with CIs in their small communities and schools. The important part is identifying these individuals who are willing to be team players, and then develop a plan on how best to communicate and collaborate together. This will require work on the part of current service providers to take the time to seek out these individuals and connect them with the training necessary to contribute to student success.

Several of the parents mentioned their disappointment in the lack of services and support as their child moved into middle and high school. A very tangible implication from this study is for professionals to ensure that CI specific support continues for students as they progress through school. Ensuring that students have a strong start by focusing on early intervention and providing CI specific training to their elementary school team is critical, but this continued support and training must also be provided to middle and high school staff to ensure student success through the entirety of their school experience.

Focusing on developing self-advocacy skills is critical for any student, but this study revealed how important it is for student's with CIs in rural settings. Since often the responsibility

of educating school level staff and professionals through the years falls on the shoulders of the family, and implication of this study would be to focus on enhancing the self-advocacy skills of students as they progress through school to be able to advocate for what they need to be successful themselves. The National Deaf Center has resources available to provide direct training for teens who are DHH. This would help students become more engaged in their own education and identifying and promoting their own needs.

It was a bit surprising how many times parents stated: “I don’t know who she was,” “I’m not sure what her role was,” “I don’t know what she did,” and other similar sentiments when discussing service providers who worked with their child. Parents were unfamiliar with the role of some of the service providers on their child’s team. Information and resources must be provided to ensure parents know who is providing support services for their child. One example provided by a participant to address this need was developing a sheet of outside service providers for parents to be able to present to their local team at their child’s IEP meeting. This sheet could provide a rundown of all the outside service providers who work with the student with their role and contact information. It could include professionals such as their mapping audiologist, private SLP, and any other outside professionals who provide support services. Then local team members could be added to the sheet. It would of course need to be a working document that could be added to and edited through the years as the child’s team changes.

When looking at CI specific training for local service providers, an implication from this study showed that training cannot be viewed as being “one and done.” Professionals cannot be given one training, one mentoring session, one in-service on meeting the needs of their CI students and think that is sufficient. Many things are constantly changing: the students’ needs change, the team that serves the student changes, etc. The on-going nature and evolution of

services requires consistent commitment and reconsideration. Professionals must work to ensure they are continually seeking out training on how to best serve students with CIs to meet their changing needs.

An action item that service providers can implement going forward is having members of rural teams visit successful urban CI school programs to see what is working for them. They can then bring this back to their local school districts and try and emulate practices with the resources they have available. This approach takes it a step beyond having outside professionals coming to their school to observe and give suggestions. Having local professionals observe the schools of their visiting experts and setting up a potential partner program would be a possible suggestion for expanding the knowledge base and skill set of service providers from rural schools.

Many parents and professionals commented on the need to transition everything online due to COVID-19. There were very few successful solutions shared around the actual implementation of telepractice prior to the quarantine and mandated shift to remote services. Parents and professionals shared how they are figuring out so many successful solutions remotely now. This is a critical time in service provision for students in rural settings to have support services looked at through a lens of remote service delivery. Another implication of this study is that now that students, parents, and professionals were somewhat forced to get comfortable with service delivery being given through telepractice and the technology that goes along with it, this will potentially open many doors for remote service provision for children with CIs in rural settings.

Establishing peer connections were an important issue identified in this study. Parents and professionals alike emphasized the need for focused attention on providing like-peer relationships for students with CIs in rural settings. Professionals can help spearhead this cause

by collaborating with other professionals from districts around their state who have similar aged students with CIs. Since so many students, parents, and professionals are now feeling extra savvy when it comes to technology and distance services, it is the perfect time to establish more connections with other students who have CIs across their state and even nation. This will help in providing the critical social-emotional support that all students need as they progress through school.

A very impactful finding and future implication of this study is that parents can say “no” to professionals. Several parents mentioned this issue of not feeling empowered as a parent to speak up. Parents must trust what they know to be best for their child. Professionals do not always know or do what is right for their child, and unfortunately service providers can sometimes come in with their own agenda or one size fits all approach. Parents must trust what they know to be best for their child.

A major takeaway is that someone must take the lead with families and provide them with access to the myriad of CI specific resources that are available. This person must be unbiased and cannot push their own agenda. For each family, that person may look a little different. This professional needs to commit to additional trainings, doing the research on each child’s individual device, to being in constant and collaborative communication with the implant center, and accept the help and resources available to support them in this journey. There are countless support resources through the state department of education and content specific curriculums available that can help empower parents and coordinate with schools.

### **Limitations and Future Research**

The findings from this study have provided meaningful insight into service delivery for students with CIs in rural settings. Due to the paucity of research on service improvement for

children with CIs living outside of a city center, this study has the potential to provide a significant contribution to the body of inquiry on this topic and in turn highlight meaningful implications for the field. With this in mind, it is important to also discuss the limitations present in the current study. These limitations will in turn lead to suggestions for future research to further this line of inquiry.

This study included parents and professionals from a wide variety of rural counties. However, all of the participants were located in the same state. This is a limitation of the study because it only gave information from the perspective of parents and professionals from one state. Future research that includes participants from a variety of states would provide more robust information representative of different parts of the country. Support services vary from state to state and it would be beneficial to have the chance to learn from the challenges and successes of more of the population.

All of the professionals in this study were female and all but one of the parent participants were mothers. Adding the perspective of male professionals who work in rural settings as well as the perspectives of more fathers would be a valuable direction for future research. Many of the mothers in the study did mention the contribution of their husbands, especially around the area of technology. Hearing from them directly would help to understand their perspective better.

The participants in this study were professionals and parents of children who have CIs. This provided a strong starting point for capturing the overall CI experience in a rural setting, but is limited to the perspective of these two groups. Future research would benefit from interviewing students directly. This would greatly enhance the understanding of the student perspective in terms of self-advocacy. It is important to hear from the students directly what they

want and not just what their parents want for them. This would help to better understand the facilitation of like-peer relationships and what students truly desire.

The overall CI experience was positive for families in this study. Professionals would likely have been hesitant to provide referrals to families who have had a negative CI experience. One way that this was countered was by adding the perspective of professionals. This gave the service providers a chance to talk about parents and students they have worked with through the years who perhaps did not experience high levels of success to give a more well-rounded perspective. Only having families with overall positive CI experiences is a limitation of this study and future research would benefit from identifying and interviewing families who have had negative CI experiences.

### **Conclusion**

As stated previously, despite there being known problems with service provision in rural areas, little is being done to research improvements in medical and educational service delivery, specifically for children with hearing loss in these communities (Barr et al., 2019, 2018). This study provides insight into some potential approaches for improving services for families, professionals, and students with CIs who live and work in these rural settings.

It is my hope that the findings from this study, both those that were known previously in addition to new information revealed, can be used to shape future practice. Both parents and professionals can benefit from the information shared by participants in this study. Experiences shared surrounding challenges, systems of support, and potential opportunities can provide valuable insight into the overall improvement of service provision for students with CIs in rural settings.

As an adult with hearing loss who was born, raised, and educated in a rural school setting; went through the implant process; and worked as a service provider both remotely and on-site with children who have CIs in rural settings, I know how critical research on this topic is for children, families, and service providers. It is my hope that this study provides tangible action steps that parents and professionals can take to improve the services for students with CIs in rural settings.

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**APPENDIX A**  
**PARENT DEMOGRAPHICS FORM**



**Parent Demographics**

**Age of your child:**

**Age of hearing loss diagnosis:**

**Age at implantation:**

**Unilateral or bilateral implants:**

**Population of your town:**

**How long have you lived in this town:**

**Distance from your child's**

**Audiologist:**

**Implant surgeon:**

**Other specialists:**

**APPENDIX B**  
**PARENT QUESTIONS**

## **Parent Questions**

### ***Tell me about living in a rural community.***

- How does living in a rural setting impact your life, especially as it pertains to having a child with a cochlear implant?

### ***Tell me about your cochlear implant experience.***

- Are you able to confidently troubleshoot problems with your child's CIs when they occur?
- Who on your child's team has the most knowledge when it comes to CIs and how do you collaborate with them to meet your child's needs?
- What additional training do you think would be useful for professionals working with children who have CIs?

### ***Tell me about your (re)habilitation and education experience.***

- What have been some of the challenges of meeting your child's needs related to their CI living in a rural setting?
- What are some successful solutions that have been implemented to meet these needs?
- Which professionals and resources have been the most supportive and valuable in this experience?
- What resources and professional support do you think schools and communities need to have in place to meet the needs of a student who has a CI in a rural setting?

### ***Final thoughts.***

- Looking back, is there anything you wish you would have known or done differently related to your child's CI experience?
- What advice do you have for rural parents considering a CI for their DHH child and for the professionals who will serve them?
- Anything else you would like to add?

**APPENDIX C**  
**PROFESSIONAL DEMOGRAPHICS FORM**

**Professional Demographics**

**What is your current position:**

**How many years have you worked in this field:**

**How long have you worked in a rural setting:**

**What percentage of your students have CIs:**

**What percentage of your week or day is spent working with students who have CIs:**

**What formal coursework was offered/required in your training program on working with children who have CIs:**

**What additional training have you sought out on working with children who have CIs outside of your formal training:**

**What additional training has your employer offered on CIs:**

**APPENDIX D**  
**PROFESSIONAL QUESTIONS**

## Professional Questions

### *Tell me about working in a rural community.*

- How does working in a rural setting impact your service provision for students who have cochlear implants?

### *Tell me about working with children who have cochlear implants.*

- Are you able to confidently troubleshoot problems with CIs when they occur?
- Who on your team has the most knowledge when it comes to CIs and how do you collaborate with them to meet your students' needs?
- What additional training do you think would be useful to working with children with CIs?

### *Tell me how your work is impacted by a rural setting.*

- What have been some of the challenges of meeting students' needs related to their CI living in a rural setting?
- What are some successful solutions that have been implemented to meet these needs?
- Which professionals and resources have been the most valuable in this experience?
- What resources and professional support do you think schools and communities need to have in place to meet the needs of a student who has a CI in a rural setting?

### *Final thoughts.*

- Looking back to your start of service for students with CIs in rural settings, is there anything you wish you would have known or done differently?
- What advice do you have for other rural school districts who may get their first child with a CI or who are currently struggling to meet the needs of this unique group of students?
- Anything else you would like to add?

**APPENDIX E**  
**RECRUITMENT POST FOR PARENTS**





Hello,

My name is Natalie Austin and I am a doctoral student in the School of Special Education at the University of Northern Colorado. My studies and research are focused on deaf education and I have a specific interest in students who have cochlear implants in rural settings. Professionally, I have worked as a teacher of the deaf both on site and remotely in rural settings. Personally, I grew up as a child with a hearing loss in a rural setting.

For my dissertation, I am conducting interviews with parents and professionals to take an in-depth look at their experiences with services for children who have cochlear implants in rural settings. My aim is to find parents who have children between the ages of eight and eighteen and have had their cochlear implant a minimum of three years. The goal is to find parents who have a service provider on their child's educational team willing to participate in the study. The service providers I will be focusing on recruiting are audiologists, speech-language pathologists, teachers of the deaf, general education teachers, special education teachers, or any other service provider on your child's educational team you think would offer valuable insight. This research will be used to inform parents and professionals on strategies and approaches that can be used to meet the unique needs of children who have cochlear implants in rural settings. The interview should take between 30 minutes to one hour and will be completely confidential with no identifying information used.

Please do not hesitate to reach out via email if you are interested in participating, have a participant you would like to nominate, or I can answer any additional questions regarding my study.

Thank you for your time and I look forward to hearing from you,

Natalie Austin  
aust0479@bears.unco.edu  
Doctoral Student  
School of Special Education  
University of Northern Colorado

**APPENDIX F**  
**RECRUITMENT POST FOR PROFESSIONALS**



UNIVERSITY OF  
**NORTHERN**  
**COLORADO**

Hello,

My name is Natalie Austin and I am a doctoral student in the School of Special Education at the University of Northern Colorado. My studies and research are focused on deaf education and I have a specific interest in students who have cochlear implants in rural settings. Professionally, I have worked as a teacher of the deaf both on site and remotely in rural settings. Personally, I grew up as a child with a hearing loss in a rural setting.

For my dissertation, I am conducting interviews with parents and professionals to take an in-depth look at their experiences with services for children who have cochlear implants in rural settings. In addition to parent participants, my aim is to find professionals on their educational team who have a student on their caseload between the ages of eight and eighteen and have had their cochlear implant a minimum of three years. The service providers I will be focusing on recruiting are audiologists, speech-language pathologists, teachers of the deaf, general education teachers, special education teachers, or any other service provider on the child's educational team the parents think would offer valuable insight. This research will be used to inform parents and professionals on strategies and approaches that can be used to meet the unique needs of children who have CIs in rural settings. The interview should take between 30 minutes to one hour and will be completely confidential with no identifying information used.

Please do not hesitate to reach out via email if you are interested in participating, have a participant you would like to nominate, or if I can answer any additional questions regarding my study.

Thank you for your time and I look forward to hearing from you,

Natalie Austin  
aust0479@bears.unco.edu  
Doctoral Student  
School of Special Education  
University of Northern Colorado

**APPENDIX G**  
**INSTITUTIONAL REVIEW BOARD**  
**APPROVAL LETTER**



UNIVERSITY OF  
**NORTHERN COLORADO**

**Institutional Review Board**

Date: 06/04/2020  
Principal Investigator: Natalie Austin

Committee Action: **IRB EXEMPT DETERMINATION – New Protocol**

Action Date: 06/04/2020  
Protocol Number: [2005003227](#)

Protocol Title: RURAL COCHLEAR IMPLANT SERVICES: REFLECTIONS FROM PARENTS AND (RE)HABILITATION PROFESSIONALS

The University of Northern Colorado Institutional Review Board has reviewed your protocol and determined your project to be exempt under 45 CFR 46.104(d)(702) for research involving

Category 2 (2018): EDUCATIONAL TESTS, SURVEYS, INTERVIEWS, OR OBSERVATIONS OF PUBLIC BEHAVIOR. Research that only includes interactions involving educational tests (cognitive, diagnostic, aptitude, achievement), survey procedures, interview procedures, or observation of public behavior (including visual or auditory recording) if at least one of the following criteria is met: (i) The information obtained is recorded by the investigator in such a manner that the identity of the human subjects cannot readily be ascertained, directly or through identifiers linked to the subjects; (ii) Any disclosure of the human subjects' responses outside the research would not reasonably place the subjects at risk of criminal or civil liability or be damaging to the subjects' financial standing, employability, educational advancement, or reputation; or (iii) The information obtained is recorded by the investigator in such a manner that the identity of the human subjects can readily be ascertained, directly or through identifiers linked to the subjects, and an IRB conducts a limited IRB review to make the determination required by 45 CFR 46.111(a)(7).

You may begin conducting your research as outlined in your protocol. Your study does not require further review from the IRB, unless changes need to be made to your approved protocol.

Sincerely,

A handwritten signature in black ink that reads "Nicole Morse". The signature is written in a cursive, flowing style.

Nicole Morse  
Research Compliance Manager

University of Northern Colorado: FWA00000784

**APPENDIX H**  
**PARTICIPANT CONSENT FORM**



**Consent Form for Human Participants in Research  
University of Northern Colorado**

**Project Title:** Rural Cochlear Implant Services:  
Reflections from Parents and (Re)Habilitation Professionals

**Researcher:** Natalie Austin, Doctoral Student

**Research Advisors:** Dr. John Luckner and Dr. Sandy Bowen

**Email:** aust0479@bears.unco.edu  
John.Luckner@unco.edu  
Sandy.Bowen@unco.edu

I am researching the experiences of parents and professionals working with children who have a cochlear implant (CI) in rural settings. In this study, parents and professionals will be interviewed regarding the impact of a rural setting on the CI experience, what systems of support are available, and the challenges and opportunities of providing and receiving support services.

The interview will be conducted by phone or online video (e.g. Zoom or FaceTime) and should take between 30 minutes to one hour. I will send a follow-up email within 48 hours of our interview and send a copy of the interview transcript to see if there is anything additional you would like to share and to ensure your responses have been reflected accurately. The interviews will be recorded and transcribed to ensure reporting accuracy and all recordings and transcripts will be kept in a password protected computer in a locked cabinet in a locked room. Recordings will be discarded after transcription and consent forms will be destroyed three years after the study is completed.

There are minimal risks for this study and all information collected will be kept strictly confidential. No identifiable information such as names will be used and only the researcher and research advisors will have access to the data. This research will be used to inform parents and professionals on strategies and approaches that can be used to meet the unique needs of children who have CIs in rural settings.

Participation is voluntary. You may decide not to participate in this study and if you begin participation you may still decide to stop and withdraw at any time. Your decision will be respected and will not result in loss of benefits to which you are otherwise entitled. Having read the above information and having had an opportunity to ask any questions, please sign below if you would like to participate in this research. A copy of this form will be given to you to retain for future reference. If you have any concerns about your selection or treatment as a research participant, please contact the Office of Research and Sponsored Programs, Carter Hall, University of Northern Colorado, Greeley, CO 80639, 970-351-1907.

Participant Signature: \_\_\_\_\_ Date : \_\_\_\_\_

Researcher Signature: \_\_\_\_\_ Date : \_\_\_\_\_