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An overwhelming journey: Mothers of children cochlear implant users experiences with speech-language pathologists

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An Overwhelming Journey: Mothers of Children Cochlear Implant Users Experiences with
Speech-Language Pathologists

by

Jennifer Beebe

Thesis

Submitted to the Department of Special Education

Eastern Michigan University

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for the degree of

MASTER OF ARTS

in

Speech-Language Pathology

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Ypsilanti, Michigan

Running head: AN OVERWHELMING JOURNEY

Dedication

To my grandmother, Shirley Wallace, for being our family leader and advocating for and encouraging us all, especially Jeffrey.

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Acknowledgments

This project would not have been possible without the support of many important individuals. First, I want to thank my husband for understanding my dream of continuing my education by pursuing a master's degree in speech-language pathology. Greg, thank you for fully supporting me through my graduate school journey. I also must thank my parents for all of the sacrifices you made for me to live a privileged life full of opportunities, and instilling a strong work ethic in me. Mom, you know I wouldn't be able to get through anything in life without sharing some tears with you, thank you for always being there when I am stressed out, but more importantly for always being just as excited as me in celebrating my accomplishments. Pops, thank you for showing me how to work hard and for always telling me how proud you are—I live for those words. I am so grateful for all of your support in everything that I do.

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I would like to give a special thanks to the participants of this study. I appreciate each of you giving up your precious time to share your stories with me. I am so grateful for your willingness to open up and share your perspectives.

I also want to share my deepest appreciation and thanks to Mr. and Mrs. Brehm for your support of my research project through the award of the Delores Soderquist Brehm Endowed Scholarship in Special Education.

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Abstract

This study shares themes identified across the experiences of mothers of children cochlear implant users with speech-language pathologists. Parents describe learning that their child has a hearing loss as an overwhelming journey with much to learn and many decisions to make, especially in their child's first year of life. Parents rely on professional support in developing their child's listening and spoken language development. A phenomenological framework of qualitative research was utilized to understand the perspective of the mothers who participated in this study. The intent of this study is to improve the partnership between parents and professionals of children with hearing loss working towards an outcome of spoken language, by better understanding the perspective of parents of this unique population.

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Chapter 1: Introduction

Background Information

Children with hearing loss are able to acquire spoken language comparable to their same-age peers with typical hearing, when their hearing loss is identified early and they receive advanced hearing technology and timely early intervention services, especially when they have access to well-trained professionals (Houston & Perigoe, 2010). With family-centered practice being best practice in early intervention services, parents play a vital role in supporting their child's development of spoken language. Professionals must understand how to support parents of children cochlear implant users in facilitating their child's language development. This study focuses on parents of children cochlear implant users and their experiences with speech-language pathologists (SLPs) who have provided services to their family.

Purpose of the Study

The purpose of this thesis project was to describe the experience of parents of children cochlear implant users receiving speech and language services from SLPs. The participant narratives have been analyzed to create a better understanding of the experience of mothers of children cochlear implant users. Professionals must listen to the perspective of families to provide services that are appropriate.

Research Questions

The goal of this research project was to understand and share the experiences of parents of children cochlear implant users receiving speech and language services from SLPs. The following research questions guided the work:

- What experiences do parents have with discovering their child's hearing loss?

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- What experiences do parents have with choosing an outcome of listening and spoken language for their child?
- What experiences do parents have with professionals influential to their child's development of listening and spoken language?
- What experiences do parents have specifically with SLPs who have provided services to their child?

Chapter 2: Literature Review

Children with hearing loss are being identified younger than ever before due to the Early Hearing Detection and Intervention (EHDI) Act (2000). The EHDI guidelines recommend screening every newborn's hearing before they leave the hospital. In addition, any child who fails their newborn hearing screening should receive a diagnostic hearing evaluation before three months of age and, if necessary, be enrolled in an early intervention program by six months of age (ASHA, n.d-c). While approximately only 45% of newborns in the United States were screened for hearing loss prior to the passage of the original EHDI legislation in 2000, today more than 95% of newborns have their hearing screened (Alexander Graham Bell [AG Bell] Association, n.d-b). In the past, many children born with a severe or profound hearing loss were not identified until age 2.5 to 3, and therefore, they were not provided the opportunity to receive appropriate speech and language services during a critical time to develop spoken language skills (National Institutes of Health, 2013). With the current standard that children born with hearing loss receive proper intervention by six months of age, spoken language is a possible outcome. Due to the fact that 95% of children born with hearing loss are born to parents with typical hearing, more parents are choosing cochlear implantation and an outcome of spoken communication for their child (Compton, Tucker & Flynn, 2009; Mitchell & Karchmer, 2004). As more children are being identified with hearing loss and more families are choosing listening and spoken language as an outcome, there is a need for more professionals qualified to provide services to families of children cochlear implant users (AG Bell Association, n.d-b).

Children with hearing loss are able to acquire spoken language comparable to their same-age peers with typical hearing, when their hearing loss is identified early and they receive advanced hearing technology and timely early intervention services, especially when they have

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access to well-trained professionals (Houston & Perigoe, 2010). Children cochlear implant recipients require rigorous listening and spoken language support to achieve maximal success with their device (Ertmer et al., 2002). According to the American Speech-Language-Hearing Association (ASHA, 2016), the scope of practice of speech-language pathologists (SLPs) includes speech, language, communication, and listening skills impacted by hearing loss and deafness. SLPs with the appropriate experience, knowledge, and skills play an important role in developing the communication skills of children with hearing loss (Carney & Moeller, 1998; Houston & Perigoe, 2010). To be effective, SLPs must have knowledge about current hearing amplification technology and the impact it can have in helping young children with hearing loss acquire age-appropriate spoken language communication (Cole & Flexer, 2007).

Early intervention for young children with hearing loss should include a strong emphasis on developing their language skills in the context of their families (Joint Committee on Infant Hearing [JCIH], 2007; Moeller, Carr, Seaver, Stredler-Brown, & Holzinger, 2013). In addition to understanding cochlear implants, effective SLPs must understand the value of and provide family-centered intervention to support parents in facilitating their child's language acquisition (ASHA, n.d-a; Cosby, 2009). Family-centered intervention, which recognizes parents as the more important instrument of change in their child, compared to service providers, is one of the foundational recommendations of early intervention (Dempsey & Keen, 2008; Moeller et al., 2013). A child's daily routine is regarded as an important learning context; therefore, service providers must emphasize to parents the critical role they play in promoting their child's language development. As many families do not know how to facilitate their child's language development, SLPs must educate parents on how to provide a language-rich environment and

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ideas for how to encourage the development of their child's spoken language skills within activities of a typical day (JCIH, 2007; Moeller et al., 2013; Yoshinaga-Itano, 2014).

Parents of pediatric cochlear implant users rely on professionals to educate and guide them in supporting their child's language development, yet many SLPs are not confident in providing services to cochlear implant users. In a survey of SLPs employed in North Carolina, Compton et al. (2009) found 79% had little to no confidence in their ability to manage cochlear implant technology or to provide services to children with cochlear implants. SLPs who provide services to children with cochlear implants and their families require specific training (Arehart & Yoshinaga-Itano, 1999; ASHA, n.d-a). SLPs interested in working with children cochlear implant users and their families must take the initiative to educate themselves on evidence-based practices for this specific population. In addition, SLPs can benefit from understanding the perspective of the parent journey outside the training they receive (DesGeorges, 2003). An important component of expertise is the first-hand experience of families of children cochlear implant users.

Very few studies have looked at the parent perspective of working with SLPs. Current findings indicate that parents feel favorably about speech and language services related to cochlear implant rehabilitation; however, there is a lack of information on the specific services parents find helpful, especially in regard to collaboration with professionals (Kelly, 2013). In his dissertation study on parent's perceptions of audiology and speech-language services for their child cochlear implant user, Kelly (2013) found that parents felt positive about services received and preferred a family-centered approach but favored services that directly benefitted the child over supporting the parent.

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Few researchers have used surveys to gather information on the perspective of parents of children cochlear implant users. A common finding across several studies was that parents did not feel they were being provided unbiased information from professionals (Decker & Vallotton, 2016; Jackson, 2011; Sorkin & Zwolan, 2008). Parents also described difficulty in accessing appropriate services for their child. In Sorkin and Zwolan's (2008) survey of 148 parents of children with cochlear implants, 58% indicated at least some difficulty in obtaining appropriate services for their child. In a questionnaire of parents of children with hearing loss by Jackson (2011), parents emphasized the importance of informational resources, social-emotional support, and educational advocacy as well as connections to other families of children with hearing loss. Hands & Voices, a national non-profit organization dedicated to supporting families of children with hearing loss, has a Guide By Your Side program which connects parents of children newly diagnosed with hearing loss to parents of children who are deaf or hard of hearing (Hands & Voices, 2017). Parent guides understand the experience of discovering a child has a hearing loss, and they are trained to provide education and emotional support to families of children recently diagnosed with a hearing loss.

Decker and Vallotton (2016) used qualitative methodology to look at the information parents receive from early intervention service providers in general, not specifically SLPs, in regard to supporting their child with hearing loss' language development. Parents felt that service providers made it clear that the parents played a strong role in their child's development, and service providers emphasized the importance of parents following through with suggestions made by service providers, taking advantage of available resources, and being an advocate for their child. Parents felt that service providers had many suggestions for promoting their child's speech and language development; however, they desired additional, more specific information

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to meet their child's unique needs. The information provided to parents in regard to encouraging language development is critical and has the potential to influence how parents communicate with their child (Decker & Vallotton, 2016).

There is a lack of research on the perspective of parents of children receiving speech and language services. Families of children cochlear implant users are a unique population with distinct needs. Families of children with hearing loss working towards an outcome of listening and spoken language require counseling from professionals in the areas of hearing device care and management, realistic expectations, listening strategies, community resources, and support groups (ASHA, n.d-a). Families who choose for their child to undergo surgery for a cochlear implant must make a commitment to their child's development, as a critical component for children cochlear implant recipients to successfully develop spoken language is the continuous involvement of the family. It is essential for professionals in the field of speech-language pathology to understand and learn from the experiences of families of children cochlear implant users in order to provide the most effective intervention. Many of the previous studies on parent perspective have solely utilized surveys. There is a need for qualitative research to provide parents of children cochlear implant users a voice. Both parents and professionals possess knowledge and experience that when combined can create services that work successfully. Understanding the experiences of families of children cochlear implant users can help to create a system that offers services based on professional expertise and training as well as a family-orientated experience (DesGeorges, 2003).

Chapter 3: Methodology

The chosen methodology for this study was qualitative research, to give participants a voice and better understand their experience. The theoretical framework utilized was phenomenology. Phenomenology seeks to understand the experience of an individual from their own perspective. Phenomenology is used to identify, appreciate, explain, and make meaning of the experiences that participants share in their own words (Munhall, 2007). Participation in this study was open to parents of children with hearing loss using cochlear implants and receiving services from a speech-language pathologist (SLP). Participants were recruited through the principal investigator and contact with a parent professional support group for children with hearing loss.

Four participants were interviewed regarding their experiences with SLPs. Table 1 shows participant information. All participants were mothers of children cochlear implant users. No participants were excluded based on age, gender, race, or disability. All participants were between the ages of 18 and 65. The participants children ranged in age from 3 to 12 years at the time of data collection. All children were diagnosed with hearing loss very early after birth but received cochlear implants at differing ages. All of the mothers expressed that they are pleased with their choice of cochlear implantation for their child. The participants have had experiences with multiple SLPs in the Early On, public school, and medical setting. Each participant has also received services from SLPs with listening and spoken language Auditory Verbal therapy certification.

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Table 1

Participant Information

| Participant's Name | Child's Name | Child's Age | Hearing Aids | Cochlear Implant(s) | # of SLP Providers |
|---------------------------|---------------------|--------------------|------------------------|---|---------------------------|
| Alyssa | Lexi | 12 | Bilateral: 4 months | First CI: 14 months Second CI: 6 years | 7+ |
| Jessica | Justin | 10 | Bilateral: 6 months | Unilateral: 8 years | 6+ |
| Andrea | Jaxon | 5 | Bilateral: 4 months | Bilateral: 15 months | 5 |
| Maria | Max | 3 | Bilateral: 10 weeks | Bilateral: 14 months | 4 |

Note. CI = cochlear implant.

Interviews took place at locations decided by participants within a mid-west state. Open-ended, semi-structured interviews ranging from 45 to 90 minutes in length were conducted with participants until data saturation was reached. All interviews were audio-recorded with permission from the participants. Participants were asked the following broad interview questions:

- Tell me about your child and what a typical day looks like for your child currently.
- Tell me about your experience with discovering your child's hearing loss.
- Tell me about your experience with choosing a cochlear implant and an outcome of listening and spoken language for your child.
- Tell me about your experiences with the professionals who have helped support your child's development of listening and spoken language.

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- Describe your experiences specifically with SLPs who have provided services to your child and your family.

Interviews were transcribed and analyzed for meaning related to the research questions.

Chapter 4: Presentation of Data

This chapter will introduce the participants, Alyssa, Jessica, Andrea and Maria, and identify themes present across the participant's interviews.

Alyssa

Alyssa's face lights up when she talks about how much her daughter Lexi enjoys being in sixth grade this school year. She speaks of how Lexi loves all of the changes, especially the ability to participate in theatre, a new interest discovered from attending a summer camp for kids with hearing loss for the first time this year. Lexi's teacher consultant for children who are deaf or hard of hearing (DHH TC), who has supported Alyssa since Lexi was three months old, encouraged Alyssa to send Lexi to the camp. Alyssa expressed that the DHH TC "actually tried a few years before, and [Alyssa] was too nervous. [She wishes she] would have because Lexi had such a great time."

It was not always easy though. When Lexi, Alyssa's second child, was born she failed her newborn hearing screening. Lexi failed another screening a week later, and after that she failed a hearing test. An auditory brainstem response was recommended, and Alyssa went through with it although she was reluctant to have Lexi sedated for the test at three months of age. Alyssa shared, "It was hard...it was very overwhelming at first." There was no family history of hearing loss, and she had never known anyone with hearing loss. She contacted Early On after the hospital provided her with the information, and she describes their first service provider, the DHH TC as a "godsend." Alyssa said the DHH TC made her feel comfortable as she came in and thoroughly explained the different services and options for a child with hearing loss. Services from an Early On SLP began a month or so later, and Alyssa shared that the DHH TC and speech-language pathologist (SLP) collaborated and "worked well together." However,

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frustration comes across Alyssa's face as she describes Lexi's school SLP from kindergarten to fifth grade as a "bully-type personality." Alyssa shared that the school SLP "was very stern and stuck in her ways and not looking at the reason Lexi is different, so what type of therapy she needs is different than any other kid that just needs speech therapy."

Jessica

Jessica leads a very busy life, but amidst the chaos, she appears calm. She balances supporting four actively involved elementary school-aged children, her full-time working husband, and a young and energetic puppy. Jessica's life changed drastically when her first children, triplets, were born at 26 weeks. It seemed as though she had shared the story many times before, as she was calm in describing her son Justin's traumatic first several months of life. All three of her children had brain bleeds at five days of life, and she recalled all of Justin's medical diagnoses and treatments by name. Jessica shared:

... his was actually the best case. He had a grade II-III and a grade I on the other side, and his resolved so he does not have a shunt but his PDA valve didn't close right and so, he needed the libation for that and after he had that, he got very sick and had sepsis, and so, he was on Gentamicin and Vancomycin and he was fully intubated, and he was on the jet oscillator...and all those things that we were told upfront that with them, you often have hearing loss and vision loss. So, we kind of knew that there was a high probability that he would face something along those lines.

Jessica described feeling overwhelmed in those early years and voiced her struggle with remembering every detail, as she had triplet children with special needs, receiving medical treatments and services in multiple areas from numerous professionals. While she had support services in place very early on, she expressed disappointment that several service providers

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throughout her family's journey may not have done everything they could have to benefit her children.

Andrea

After five years, Andrea has finally settled into enjoying her role of staying home with her two children, Jaxon and Nolan. A former high school math teacher, Andrea quit her job to spend enough time supporting her son Jaxon with his language development. Andrea had never heard of a cochlear implant before her son was born. She remembers feeling very overwhelmed by everything to learn and all of the decisions to make within the first year of his life. She went back to work the year after he was born, but she felt extremely overloaded with the amount of appointments and struggled to find time to research information on hearing loss, amplification options, and language development. She attended conferences and sought out information from cochlear implant companies when trying to make the decision of what cochlear implant brand to choose. Andrea shared, "my professional background kind of pushed me to look for more of those professional options of where to get information" and that it "is kind of my personality to try to keep learning more about all of it."

Andrea shared that she had a terrible experience with the first SLP provided to her family through Early On. She expressed:

When they started, they just gave us a speech pathologist who had never worked with a deaf child and had no clue what to do with him and so it was kind of frustrating. Her suggestion was to bang pots and pans and see what he does. He is profoundly deaf... so once I kind of got my feet under me and understanding the process, I had to advocate this is not working and I think when he was just over a year, I got a teacher of the deaf involved in his Early On.

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Andrea is now a parent guide supporting families when their child is first diagnosed with hearing loss. Her goal is to help families have a better experience than she did.

Maria

Maria, a teacher with a master's degree in learning disabilities, labels herself as "very Type A, very organized." In recalling when she first learned that her son Max had a hearing loss, she wishes the professionals would not have brushed off the fact that he failed three hearing screenings in his first three days of life. She was told, "Don't worry, it is probably just fluid. Really don't worry. Here is a number, give them a call when you have a chance..." With Max joining a two and half year-old sister at home, Maria and her husband were busy and did not worry about it until about six weeks later, when an auditory brainstem response confirmed that Max had a severe to profound sensorineural hearing loss.

Maria remembers being devastated thinking about the whole time he was in the womb: "He couldn't hear me talking to him. I would sing to him and he wasn't hearing that... the whole time." Maria did not know anyone with a hearing loss prior to her son Max being diagnosed. She had a difficult time, she shared, "It is so hard, in a hearing world, to feel like you are connecting with your deaf child."

Maria was offered a parent guide from a parent and professional support group when Max was eight weeks old. However, she turned down the parent guide due to feeling so overwhelmed. Maria shared, "I wish I hadn't because I think it would have made the process a little easier for us to have someone else who has been there to just kind of say, 'It's okay. I've survived and so will you, and this is how we do it together.'" Fast forward 10 or so months later, Maria attended a conference put on by the group, and after being somewhat bored in a presentation on individualized education programs (IEPs), she asked if she could help provide

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support to parents. Maria is now a parent guide and president of this very parent and professional support group for children with hearing loss. Maria is currently pregnant with twins and knows that one or both of them could have hearing loss. She feels “prepared and ready” if that is the case, as she has a “different support system this time” around.

Analysis of the participant interviews reviewed several themes. Data within the themes of knowledge, support, and communication will be shared.

Theme: Knowledge

The theme of knowledge was present across all participant interviews. Knowledge refers to the understanding of a topic an individual has gained through education and experience. Within the broad theme of knowledge, several sub-themes were uncovered. Most of the participants had no experience with an individual with hearing loss prior to their child being diagnosed. The participants expressed a lack of knowledge regarding hearing loss and the impacts of a hearing loss. The participants all had a need to learn about the options and realistic expectations and outcomes for their child. The participants also expressed disappointment in the lack of knowledge many SLPs had regarding hearing loss. Additionally, participants shared that they noticed a huge difference in the knowledge and ability listening and spoken language specialist (LSLS) certified Auditory Verbal (AV) therapists had to support their child’s development of spoken language compared to SLPs without the certification. The sub-themes of parent need for knowledge, service provider lack of knowledge, and difference in AV therapist knowledge level will be explored.

Subtheme: Parent need for knowledge. None of the participants had a family history of hearing loss, and most of the participants had never known an individual with hearing loss prior to their child being diagnosed. The participants all expressed feeling overwhelmed after

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receiving their child's diagnosis of a hearing loss. Andrea shared, "We had no idea what a cochlear implant was. Our idea was that we were going to have to sign and that was the only option and what does that mean and what is Deaf culture?" Andrea and her husband first heard of a cochlear implant when their son Jaxon's hearing loss was officially diagnosed around three months of age. After the official diagnosis, she began exploring to learn more about cochlear implants. Andrea shared that it was a "struggle to find the time to find the information."

Now in her role as a parent guide, Andrea is able to meet with families of children with hearing loss and listen to their experiences. Andrea is thrilled when she hears that families have someone who specializes in hearing loss, such as a DHH TC to support them early on. She recalled from her own journey, "...definitely [feeling] lost for a while there on the appropriate services that you should be getting." Jessica similarly described "...going in blind trying to learn all this..." Jessica, being a first-time mother to triplets with special needs remembered not really knowing what milestones were to be expected. She recalled, "I knew they had delay and all that but I didn't really know what they should be doing." Maria had some knowledge through her own experiences of being a teacher, but shared that "it is just so different when you are working with your own child on a specific need." Maria recalled seeing their Early On SLP so little that it was not even enough time for her to wrap her head around her son Max's hearing loss. She shared, "We saw her once a month for half an hour which wasn't enough for me to even understand that he wasn't hearing me." It didn't make sense to Maria. She remembered thinking, "I mean, he has hearing aids, what do you mean he is not hearing me?" Maria credits their AV therapist as the one to help her truly understand the degree of her son's hearing loss.

Jessica shared her expectation that professionals provide parents with knowledge. She stated, "You are the professional and we don't know, and we are going in blind trying to learn all

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this so the more that can be provided, the better.” Jessica felt that whatever information could be provided to parents would be helpful, “especially ones that if you can tell they would do the work with [their child] at home and want to know more.” Alyssa recalled the Early On DHH TC explaining everything very well and educating her on “the different services that are there and about the cochlear implants and different things” her family could do. Maria shared that her family began AV therapy before her son Max had access to sound as she had a need for knowledge on how to connect with him. Maria expressed to their AV therapist, “I just need things that I can learn from you so I feel like I can connect with him right now.” The AV therapist taught her how to play with her son Max so she didn’t feel so disconnected.

The participants also discussed seeking out information themselves. Maria shared that her and her husband attended a state-wide conference put on by a parent professional support group for children with hearing loss when Max was 12 or 13 months old. Andrea also shared that her and her husband attended a conference at one point. Andrea found the conference helpful, “to kind of get just a little more professional information instead of just hodge-podge information clumped from the internet.” Andrea credits her professional background as pushing her to professional sources for information. She enjoyed having the opportunity to talk with representatives from the different cochlear implant companies to aid in the decision of which cochlear implant brand to choose for her son Jaxon. Jessica remembered “just researching online and trying to figure it out.” She also asked questions on the parent professional support group Facebook page and communicated with another parent in the same educational program as her son Justin. Each of the participants had a huge need for knowledge and sought out information in varying ways.

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Subtheme: SLP lack of knowledge. While all of the participants had a great deal of knowledge to gain regarding hearing loss, they were disappointed by the lack of knowledge service providers held. The participants described a lack of knowledge in regard to supporting the speech and language needs of a child with a hearing loss from professionals serving their child, whether that be an Early On SLP or school SLP. Andrea shared that she had a “rough time with Early On.” She explained that she was a teacher and so she generally understood the IEP process. However, Andrea shared that when Early On services began around the time her son Jaxon was three months old:

They just gave us a speech pathologist who had never worked with a deaf child and had no clue what to do with him and so it was kind of frustrating. Her suggestion was to bang pots and pans and see what he does.

Andrea was frustrated: “[I] had no teacher that knew how to deal with a child with hearing loss... I mean a significant hearing loss.” She went on to explain that with the little knowledge she had, she took charge and had to “advocate this is not working.” When Andrea’s son was just over a year old she fought to get “a teacher of the deaf involved in his Early On.”

Andrea not only advocated for a DHH TC through Early On but for a different SLP service provider as well. Andrea shared that their second SLP still did not have extensive knowledge of children with hearing loss but “was at least supportive in like you know willing to learn... do a little sign.” She expressed, “The second [SLP] was at least open to learning more about a child with hearing loss than the first.” For example, Andrea recalled asking their second Early On SLP, “What do you do when a deaf kid runs out in the road?” Her son was becoming a toddler and she was worried for his safety. The SLP replied, “I don’t know but maybe we should try and figure that out.”

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Maria had a similar experience of feeling disappointed with the lack of knowledge their Early On SLP had regarding hearing loss. Maria shared that it “was a struggle to find it [speech and language services] valuable.” Maria described the Early On SLP as “very young; she just graduated from college and this was her first job out of college.” She went on to say, “I think the lack of experience showed greatly, but I remember feeling like the goals that she would set for his individualized family service plan... were not appropriate.” She remembered thinking, “I don’t think she gets it. You can’t set a goal of four-word utterances at 95% for a two and a half year-old who has hearing loss, who has only been hearing for one year. You can’t really do that.” While Maria was frustrated by the situation, she chose not to speak up about the lack of knowledge the SLP displayed as it could result in loss of service,

You are given what you are given and if you don’t like it, then you can excuse yourself but then you are not given any more services. They won’t exactly give you a new provider. Because it is Early On and they are stretched as it is.

Maria felt that the breakdown with this Early On SLP was her attitude of, “She just got out of school, she learned everything she needs to know versus, ‘I’m willing to keep learning because I realize that I don’t know everything.’... and that just comes with age and experience.” Maria recalled, “There were some times when it was very apparent... that they just didn’t quite understand.” She remembered having an SLP that provided services to her family for a little more than two years tell her, “I love coming to play with Max because he actually plays with me versus some of the other children who are under my caseload who are nonverbal autistic...” Maria told her, “Whoa, whoa, whoa! These are two different... I know you are not saying that he is like a nonverbal autistic child; however, you have these kids on your caseload

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and I hope you have an understanding how they differ.” Maria had to spend sessions with the Early On SLP educating her on how to work with a child with hearing loss. She shared:

So occasionally, I would take what we would learn in AV therapy and... when that Early On therapist would come to the house, I would carry over what we would work on in AV therapy with her so that we were consistent but then also so she would learn that this is not a nonverbal kiddo. This is just a kiddo who just didn't have access...he is not nonverbal.

Having to educate her son's service providers on how to support him is something Maria has had to continue to do as Max transitioned into his preschool setting. Maria shared, "...he is not getting the amount of access that we would like but it is going to be a slow process.”

Jessica felt that the SLPs her family received services from may not have done enough to help support her son Justin's language development. Jessica emphatically shared, “I *know* that they never used the Picture Exchange Communication System with any of [my] kids at all which might have been beneficial since he was delayed.” She continued, “Especially just building his vocab even...because that is still one area that he still lacks is vocab and just building those categories up.” She felt that because the SLPs' lacked knowledge of techniques, Justin missed out.

Andrea shared that she noticed a huge difference in the knowledge that the Early On SLP and Early On DHH TC possessed. She felt that having a “focused idea of just a child with hearing loss and not the broad spectrum of speech delays” was a huge benefit in supporting her son Jaxon's spoken language development. Andrea's younger son has typical hearing but still has a speech delay. She shared that it has “been a whole different world” comparing the difference in speech services between her two sons. She shared, “At least with Jaxon, I had a

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reason and I understood why and he really hasn't had any speech problems, it has just been slightly delayed due to the delayed hearing." For Jaxon they first had to focus on the hearing and listening, and with her other son, he had access to sound and just had to work on his expressive speech and language skills. Andrea shared, "So, I think speech pathologists for him is great but having someone to specialize in the hearing part first- the listening part first- and then developing the speech was, I think, really beneficial for him."

When asked what her advice for SLPs was, Andrea shared, "Understanding that the hearing loss is a big difference compared to kids that just have speech delays—the approach is definitely different in how all that will be developed and just kind of understanding that, being patient with the process." Maria shared similar thoughts. While she felt it was unfair for her to say, she believes,

A lot of speech therapists feel like they are one-size-fits all, so they get a little bit of training in hearing loss and they get a little bit of training in apraxia and they get a little bit of training in... general speech delays and they get a little bit of everything so when they are put in those school situations especially, they feel they can work with just about anybody very successfully...

As a parent of a child with hearing loss who uses cochlear implants, Maria felt that in her experience SLPs may have not fully understood hearing loss or cochlear implants. She shared, "I don't think they understand that cochlear implants are very different from a hearing aid in the way that the recipient actually hears with them." Maria remembered that it took a long time for her to understand that her voice does not sound the same to Max as it does to someone with typical hearing, "that eventually it will sound closer to it but it will take a long time because his brain is still developing, but it is still very robotic and you still have to keep that in mind."

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Maria knows that Max requires a different type of therapy. Max “is not a child that has a speech delay; he is a child with hearing loss who has a speech delay. So different.” She has been frustrated by SLPs who “often take their general knowledge of hearing loss specifically and try different strategies or evidence-based practices on Max and they don’t work because it is not what he needs.” She shared,

[SLPs] are great in what they do and I think probably 85% of the time, their strategies will work for most of their caseload, but then they need to take a step back and either if they don’t understand, either be willing to listen to us as parents who live this with him or be willing to research a little bit outside of their day to help them to understand a little bit more about his disability.

The participants felt frustrated by the lack of knowledge many SLPs had regarding hearing loss, especially Early On SLPs.

Subtheme: Difference in AVT knowledge level. Each of the participants commented on a huge difference in the knowledge level and ability of AV therapists to support their child’s listening and spoken language development compared to other SLPs. Alyssa described the difference between the AV therapist and other SLPs that her and her daughter Lexi encountered as, “...just getting it; just understanding how the hearing plays a role in her speech and missing different parts.” Jessica shared that she felt the AV therapist could support her son Justin in all areas and not just with his hearing, stating, “So even though she is a speech therapist, she kind of gets the vision part too and so encompassing all of that in what she is working on with him.” Maria has had a great experience with their AV therapist from the start. She remembers the AV therapist being “very knowledgeable about what [her son] needed based on his speech evaluation.” Maria remembered feeling, “Oh, she really knows what she is doing. We never for a

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minute thought, ‘I wonder if there is someone else out there that is better and that could give us better results.’” Maria shared that their AV therapist will often ask if she can answer questions about anything Maria is noticing at home and whether that is developmental or related to hearing loss, which she appreciates, stating, “I don’t always understand if what I am hearing currently is hearing loss or just a typical three-year-old issue.” While Max’s current school SLP knows what to expect developmentally, she relies on the AV therapist’s knowledge and will ask Maria “to ask the private therapist if [something] is developmental or hearing loss related.”

Maria feels that her son Max, who graduated from AV therapy at age three, would not be where he is now if their family did not follow through with the AV therapy. Maria shared that with the AV therapist, “it is kind of different because she works with children with hearing loss and she has a different understanding of what he needs ...” Maria shared, “...it is just very evident that when you work with a speech therapist through the school district, they are kind of a one-size-fits-all and then when you work with someone specific to hearing loss, they know exactly how to work with him.” Maria feels that both SLPs are fantastic tools, but that it would be very difficult for her son to have developed the speech and language skills he has without a specialist in hearing loss. Maria would love if there were more AV therapists available in the schools to support children with hearing loss. She feels that “the kids with hearing loss would see huge gains just by having someone who just gets it.”

Andrea shared similar feelings. Her family actually moved so that her son could attend a full-time program for children with hearing loss working towards an outcome of spoken language, in which the teachers all had AV educator certification. If they had remained in their home district, her son would have attended a program for children with hearing loss ranging from ages 3 to 7 all in one classroom, which she felt “doesn’t really get a lot of educational

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benefit for anyone.” She shared that their decision to move was “to give him another option of being able to support the cochlear implants and having the school program that knows how to help kids with implants develop that speech.” Andrea felt that it was “amazing to have that focused therapy every day. And, it is just different than having an hour in a room with a speech pathologist.” The program made it possible for her son Jaxon to begin kindergarten in a mainstream setting. The participants emphasized how much greater AV therapists or AV educators were able to support their child’s spoken language development over SLPs without the certification.

Theme: Support

The participants described discovering their child’s hearing loss as very overwhelming. Maria shared, “I remember being devastated thinking the whole time, he was in the womb, he couldn’t hear me talking to him. I would sing to him and he wasn’t hearing that...the whole time.” Alyssa expressed, “It was hard...it was very overwhelming at first.” Andrea shared, “It is an overwhelming journey and it is a lot of decisions to make within the first year of your child’s life.” The theme of support was present across all participant interviews. Feeling support refers to receiving approval, comfort and encouragement. The participants each discussed different sources of support after receiving their child’s diagnosis of hearing loss and working towards an outcome of listening and spoken language.

Maria had a very unique story of support received from the AV therapist providing services to their family. Maria struggled to figure out how to connect with her son Max because of his hearing loss. She shared, “You feel like there is no way you would not be connected with your child just because they have a disability.” She voiced, “I think it is different when you have all the senses and you have a child that is missing one...how can you connect with them in that

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way?” Maria recalled one of her first meetings with the AV therapist when Max was about nine months old: “I remember crying in her office and saying, ‘I feel like I can’t play with my baby. I don’t know him. I can’t connect with him.’” The AV therapist suggested beginning therapy before Max had access to sound to support Maria in building a relationship with him. The AV therapist would give her ideas and explain how to connect with Max using his other senses, using bright-colored picture books, facial expressions, visuals, and objects. Maria shared that the AV therapist explained that it is more than just hearing, and taught her how to play with him so she didn’t feel disconnected. The AV therapist has been a great support system; Maria even shared that “coincidentally, [the AV therapist] has the same last name as us and we joke about that—how we are not related but she basically is our family now.” Maria explained that the AV therapist has supported her in all areas of Max’s life: “She has taught me about being a parent and she has supported me during some really tough decisions of what the best thing would be to do with Max or for Max.”

Alyssa also feels support from their AV therapist, as she visits Lexi’s school every year and provides recommendations for Lexi’s IEP goals and services. Alyssa described the AV therapist as very comfortable to work with. But, for Alyssa, no one can compare to the DHH TC that has been in her life since her daughter Lexi was three months old. Alyssa described the DHH TC as a “godsend” and “an amazing person.” Alyssa shared that she continues to feel well supported by the TC even as Lexi has transitioned into middle school: “Any questions I have, she is always very open to talk to me, and answer anything.” Unfortunately, Alyssa cannot say the same about the school SLP, who has consistently been argumentative and unwilling to think about how Lexi’s hearing loss makes her different. Alyssa has felt a lot of resistance from the school SLP. She shared, “[The SLP] always tried to fight with what I was fighting for” and

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always wanted to cut back on services despite Alyssa's proof that Lexi needed the services. The school SLP would not even take into account the reports from the AV therapist. Jessica also shared that her son's school SLP has not really taken into account or supported recommendations from the AV therapist. Jessica shared that her son Justin receives speech and language evaluations about once every six months from the AV therapist, and she takes the information from his performance "back to the school team and that is usually addressed through his goals and what not, but... [she feels] like the school SLP isn't quite at the same level as everyone else with really encompassing that." Additionally, Jessica has shared her personal concerns with Justin's social language and felt that the SLP did not recognize or support her with these concerns. Because of Justin's complex medical history, Jessica has interacted with many professionals. She shared that there have been professionals who have not listened or provided the support she needed, but she also described very supportive relationships with their audiologist and ear, nose, and throat doctor. She shared, "[The audiologist] was definitely helpful and we have a very good relationship with her, being able to really talk to her about my thoughts and feelings." She shared that the audiologist would listen and understand her perspective and reservations. In regard to her relationship with the ear, nose, and throat doctor, she shared, "We can totally trust him," and she always feels that she is being heard. Jessica also shared that it was a very difficult period of time when her family was trying to decide whether Justin should receive a cochlear implant or not, and she did not receive the support she was hoping for from her son's teacher of the deaf. The teacher very vocally disapproved of the idea of implantation. Jessica shared, "That was really hard because she was someone that I really trusted." Maria also experienced a similar situation with the AV therapist in regard to her family using sign language with Max. Maria wanted to supplement speech with sign language, which is not a principle of the

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listening and spoken language approach. Maria shared that her and the AV therapist “have had a lot of arguments about sign language being appropriate for someone who is going through AV therapy.” The AV therapist was always very professional, but clearly expressed that she did not support the use of sign language with Max. While the AV therapist has no reservations about Max using signs now that he has graduated from AV therapy, Maria wishes she could have been more supportive and accepting of her trying to support Max’s communication in any way possible from the beginning.

In addition to sharing the support they did and did not receive from professionals, the participants all mentioned connecting with a large support group for parents and professionals of children with hearing loss. Jessica shared that she connected with the group through social media and has asked questions of other parents. Maria recalled first attending one of the groups’ annual conferences when Max was about one year old. She shared, “Before that, we didn’t really have a lot of support. We didn’t know how to get that support.” In addition to an online presence and annual conference, the group has various events throughout the state for families of children with hearing loss to get together, as well as provides parent guides. Parent guides are parents of children with hearing loss connected to families of children newly identified with hearing loss to provide information and support. While all of the participants are part of the support group, Andrea was the only one to have a parent guide herself. However, she was not able to have that “mom-to-mom connection of having similar situations,” as her guide had a child who could not receive a cochlear implant. Maria was offered a parent guide when Max was about eight weeks old but turned it down due to feeling overwhelmed. Looking back, she wishes she would have received the support from a parent guide. Maria and Andrea both discussed their role as parent guides now. Maria described her feelings with supporting other parents as, “I’m with you, I’ve

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been there but I don't know how I can help you in this moment and I really want to." Andrea shared, "It is fun to kind of be supportive and then trying to help make sure they have a better experience than I did." The participants each had very unique stories of support received as well as thoughts on how they could have been better supported.

Theme: Communication

The theme of communication was present across all participant interviews.

Communication refers to the exchange of information between a sender and receiver, including spoken or written via face-to-face, phone conversation, or a physical note. Each of the participants discussed the communication they have participated in with their child's SLPs.

Alyssa's daughter Lexi received speech and language services from the same school SLP kindergarten through fifth grade, in which her service time included pull-out sessions 30 minutes two-to-three times a week. When asked if she knew what the school SLP was working on during Lexi's most recent sessions, Alyssa shared, "I am not quite sure to be honest." Alyssa expressed that it was a difficult relationship with Lexi's school SLP, stating she "was good at what she did... but just her personality, she was not the friendliest." Alyssa shared that the SLP sometimes communicated with her, but during Lexi's fifth grade school year, Alyssa began keeping track of when the SLP was seeing Lexi, and she discovered that the SLP had missed a lot of sessions. She shared, "Lexi wasn't receiving what she was supposed to be receiving." Alyssa brought this issue up, resulting in the SLP having to make-up the sessions, which "made hard feelings."

Jessica expressed similar feelings regarding communication from her son Justin's school SLP. She shared, "I don't feel like I have good communication to really know what is happening." She expressed that communication was an area she wanted to discuss at Justin's next IEP meeting, to ensure that what the SLP is targeting is really beneficial, as well as her

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desire to receive more feedback on his speech service time. Jessica shared, “I have not really been sure of what is really being addressed through her, I guess...and maybe she is doing more than I think that she is... it is just not really communicated well to know.” Jessica shared that the SLPs she has worked with “are the ones who [she just hasn’t] had as good communication, just really knowing what they are doing.” She expressed that the lack of communication stems back to her son Justin’s preschool years:

We really didn’t have a whole lot of communication with [the SLP] at that level either.

I didn’t really feel like there was stuff where I was told, “Oh we are doing this at school and this works well so do that at home...”

Maria also shared, “I don’t know a whole lot of what they are working on right now at school.” She expressed, “I wish communication was better with the school; it’s not great.” Maria shared that the service providers are very vague at the IEP meetings and say they will see her son Max “this” amount of time:

And then every once in a while, I will get a weekly report... about what they worked on, what we should work on at home with him, what we need to watch out for. If he comes home and says “this,” this is what he is talking about.

Maria shared that she really appreciates when she does get a note from the school SLP, “as too often you get kids who come home from school and you say, ‘What did you do today?’ ‘Nothing.’”

Maria shared that her preferred communication would be a daily report or a quick summary of what the SLP did with Max each week:

I am very type A, very organized...I would like a daily report; it doesn’t have to be typed out, just a two-line this is what we did today and these are some things we

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worked on...the end. It doesn't have to be a lot- just so I can make sure that they are also following through with what they are supposed to be doing as far as service times and he is not losing service for whatever reason.

When notes are sent home, Maria is aware of what Max is doing at school and can help to facilitate the same language between school and home. Jessica shared that she would have appreciated if SLPs could have provided some direction and specific tasks she could do to support her son Justin's language development at home. Jessica would have liked to know about certain things:

More just what they are working on, what they are seeing as helping or if they see there is an area specifically to work on...like if they had told me specifically, "Work on food groups this week" and you can target specific things and know what to work on, I think that would have helped him and us.

While most of the participants expressed that they would have appreciated more communication from their child's school SLP, Andrea shared that she has been very pleased with the level of communication from her son Jaxon's SLPs. Her son received services from an SLP with AV therapy certification from 17 to 30 months of age in which his speech and language skills "progressed pretty quickly." Andrea recalled the SLP being "very good about talking about things we could do at home or very positive, like 'Oh I can tell you worked on this at home!'" Andrea's son Jaxon attended an auditory-oral program for students with hearing loss from age two and a half until he transitioned to a mainstream setting for kindergarten. She noted the difference in level of communication between the two settings. Andrea shared that while her son was at the auditory-oral program, "[she] was getting feedback every day, what they were doing, that kind of thing, where this year [she more has] to rely on what he says is going on." Her son is

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not receiving any services from an SLP in his kindergarten setting, and all of her communication from his kindergarten teacher and DHH TC has been “really positive and good so [she hasn’t] been too worried about getting a ton of information.” Each of the participants expressed their feelings about the communication received from their child’s SLPs, whether that be a desire for more communication and preferred level of communication, or in one participant’s case, satisfaction with the communication received.

Chapter 5: Analysis of Data

The themes of knowledge, support, and communication emerged from the participants narratives on their experiences with speech-language pathologists (SLPs). These themes will be analyzed in relation to current literature.

Knowledge

Parent need for knowledge. The participants each expressed a need to acquire knowledge, as many of them had never known an individual with hearing loss prior to their child being diagnosed. The participants recalled not understanding the impact of hearing loss, being unfamiliar with hearing amplification options, and the difficult task of making time to gain new information. Andrea remembered having no idea what a cochlear implant was before her son Jaxon's diagnosis of hearing loss, feeling lost about what services he should be receiving, and struggling to find the time to find the information. Jessica shared that she knew her son Justin had a delay, but she didn't really know what milestones were to be expected. All of the participants described the time immediately following diagnosis of their child's hearing loss as "overwhelming." Fitzpatrick, Angus, Durieux-Smith, Graham, and Coyle (2008) state that families of children with hearing loss describe feeling overwhelmed and need to hear information more than once, with a strong need for information following diagnosis, as well as a need for ongoing, current information, particularly in regard to amplification technology. Discovering that they have a child with a hearing loss comes as a shock to most parents. In this challenging situation, parents rely on experts, such as medical professionals, to help them understand hearing loss, its impacts, and realistic outcomes for their child (Anmyr, Larsson, & Olsson, 2016). The participants within this current study recalled receiving information from professionals. Jessica expected the professionals to educate her as she felt she was "going in

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blind trying to learn all of this.” Accurate information from professionals is necessary for parents to make informed decisions about their child’s communication (Decker, Vallotton, & Johnson, 2012). The information that professionals provide must be current and unbiased, as research shows that parents may internalize the opinions of professionals, which can influence the manner in which they interact with their child (Decker & Vallotton, 2016).

The most common sources of information for parents of children with hearing loss include medical professionals, audiologists, SLPs, and the internet (Decker et al., 2012). In addition to seeking information from professionals, the participants in this current study described how they obtained knowledge from searching on the internet and social media sites. Jessica remembered searching for answers to her questions online as well as asking questions to the members of the parent professional support group’s Facebook page. Andrea also described finding information online. Fitzpatrick et al. (2008) found parents of children with cochlear implants cited websites and online discussion groups as a valuable way to gain information. Many parents look to the internet for information and to learn about resources but feel that medical professionals could better support their use of the internet as a source of knowledge. Parents are interested in receiving guidance from professionals on which internet sites provide credible information (Fitzpatrick et al., 2008).

SLP lack of knowledge. The participants expressed disappointment in the lack of knowledge Early On or school-based SLPs had regarding hearing loss. Andrea remembered feeling extremely frustrated with the Early On SLP they were provided, as she had never worked with a child with a hearing loss and had no clue what to do with him. Maria shared it was hard to find the services from their Early On SLP valuable, as the SLP did not understand hearing loss or cochlear implants and was not even able to create appropriate goals for her son, Max. Maria

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recalled having to spend time educating the SLP about children with hearing loss; when in reality, being completely new to hearing loss, she was the one who needed the SLP to share knowledge with her. Jessica also felt frustrated that if SLPs providing services to her family had been more knowledgeable about hearing loss, they could have better supported her son Justin's language development. There is a lack of well-trained professionals available to support the development of listening and spoken language in children with hearing loss (Houston & Perigoe, 2010). Additionally, SLPs are not adequately prepared to work with children with hearing loss. Compton et al. (2009) found a significant lack of training and preparation in cochlear implants and hearing rehabilitation for SLP graduate students, causing the school-based SLPs to have very low confidence in supporting children cochlear implant users. SLPs are qualified to work with students with hearing loss but must commit to ongoing education to provide services following best practices for students with hearing loss working towards an outcome of listening and spoken language (Houston & Perigoe, 2010).

Difference in AVT knowledge level. All of the participants received services from an Auditory Verbal (AV) therapist in addition to therapy from an Early On SLP or school-based SLP. The participants noted many differences between SLPs with AV therapy certification and those without the certification in their ability to support their child's development of listening and spoken language. Alyssa shared that she felt a huge difference in how AV therapists understood the impact that hearing loss played in her daughter Lexi's acquisition of speech and language. Maria also emphasized that when working with someone with a specialization in hearing loss, they truly understood how to support her child's needs. Maria and Andrea both expressed that they did not feel that their children would have the speech and language skills they currently have without services from their AV therapist. The participants had

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overwhelmingly positive remarks about AV therapists ability to support their child's speech and language development.

Maria also shared her understanding that SLPs are trained to generally support any speech and language disorder, but that does not mean that all SLPs are equipped to support the needs of children with hearing loss. She expressed her frustration with SLPs who have taken their general knowledge of hearing loss and have not been able to support her son Max. SLPs are certified by the American Speech-Language Hearing Association. Training to become an SLP includes coursework and clinical experience related to the prevention, screening, assessment, and treatment of all communication disorders across all age groups (Rosenzweig, 2014). SLPs are trained as generalists, prepared to support a wide range of individuals and their communication needs. Families of children with hearing loss working towards an outcome of listening and spoken language require support from professionals knowledgeable about supporting their unique needs (Houston & Perigoe, 2010; Rosenzweig, 2014). The Alexander Graham Bell Association for the Deaf and Hard of Hearing provides specialty certification for listening and spoken language specialist (LSLS) certified AV therapists or AV educators. Most LSLSs are SLPs who go on to pursue the specialized certification. The LSLS certification process involves 900 hours of mentored auditory verbal practice, 80 additional hours of continuing education coursework, a passing score on a rigorous examination, and a commitment to continuing education in the area of listening and spoken language (Rosenzweig, 2014). LSLSs understand and use the most current best practices in the area of listening and spoken language, guide and coach families to use listening and spoken language strategies and techniques, include families in decision making, and recognize caregivers as the child's first and most important teacher

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(Hearing First, n.d.). The LSLS certification allows professionals to support the unique needs of families of children with hearing loss.

Support

In addition to having a need for knowledge, the theme of support was prevalent across the participants' narratives. The diagnosis of hearing loss in a child can cause parents to feel distress, uncertainty, and grief (Kurtzer-White & Luterman, 2003). Parents of children with hearing loss are faced with many challenges and decisions to make. In addition to accepting that their child has a disability and cannot hear, parents must simultaneously decide what communication outcome they desire for their child and immediately begin taking steps working towards the chosen communication outcome. The literature shows that parents of children with disabilities experience more stress than parents of typically developing children (Britner, Morog, Pianta, & Marvin, 2003; Davis & Carter, 2008). This is concerning as higher levels of parental stress are related to lower language functioning levels in children with hearing loss (Dirks, Uilenburg, & Rieffe 2016).

Most of the participants of this current study highlighted the support they received from professionals. Maria felt fortunate to build a very strong relationship with their family's AV therapist and felt a great deal of support from her in building a connection with her son Max. Alyssa described feeling very well supported by the deaf and hard of hearing teacher consultant that came into their lives when her daughter Lexi was three months old. Jessica described supportive relationships with the audiologist and ear, nose, throat doctor. These examples demonstrate that most of the participants of this study described the support received from professionals and did not focus on support coming from friends or family members. The literature shows that parents of children with hearing loss find family and friends as the most

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important source of support (Anmyr et al., 2016). In addition, the literature shows that parents of children with hearing loss have had difficulty receiving the support they desired from professionals. In a qualitative study of 12 parents of children cochlear implant users, the participants expressed that they sought out support from professionals but had difficulty receiving the support they desired. The participants had to fight against professionals for their child to have opportunities with their desired communication choice (Anmyr et al., 2016). While the participants of this present study felt supported by many of the professionals they encountered, they did also describe a lack of support from professionals similar to what is seen in the current literature. Jessica described the difficult time period of deciding whether her son Justin should receive a cochlear implant or not and not receiving support from his teacher of students who are deaf or hard of hearing, someone she really trusted. Alyssa described the ongoing resistance she felt from Lexi's school SLP regarding services. Maria also shared the frustration she experienced when the AV therapist did not support her in using sign language with her son Max.

Alyssa shared that the AV therapist visiting her daughter Lexi's school to observe, provide information to the school team, and support her in making recommendations for Lexi's individualized education program goals, services, and accommodations was very helpful. Jessica discussed taking information from the AV therapist's assessments to her son's school team to guide their goals and services. Archbold, Lutman, O'Neill, and Nikolopoulos (2002) found that parents feel there should be a connection between the cochlear implant center and their child's school program. Parents found support from the implant team to their child's educational setting very valuable (Archbold, Sach, O'Neill, Lutman & Gregory, 2006).

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Maria described not knowing how to get support or ever feeling a great deal of support until she attended a conference put on by a group for parents and professionals of children with hearing loss. One of the components of this group is connecting parents of children newly diagnosed with hearing loss with a parent guide. Parent guides are parents of children with a hearing loss who can provide information and support from a parent perspective. While Andrea was the only participant to have a parent guide after discovering her son's hearing loss, all of the participants have interacted with the group members in some way. For example, Jessica would ask questions on the group's Facebook page, and seek support from another parent in her son's educational program. Parent-to-parent support is an important component of a support system. Research on the perspective and experiences of parents of children with hearing loss shows there is a need for parental support (DesGeorges, 2003; Fitzpatrick, Graham, Durieux-Smith, Angus, & Coyle, 2007; Jackson, 2011), and that parent support must come from experienced parents and is not something that can be reduplicated by professionals. Professionals providing services must be aware of resources for parental support and recommend these to families. Henderson (2014) created a conceptual framework for parent-to-parent support of children with hearing loss through review of the current literature on the parent perspective. Some of the components of the framework include the need for support in the areas of information, decision-making, parenting, and that parent's social, emotional, and educational needs must be addressed. The exchange of parenting knowledge gained through the experience of raising a child with a hearing loss is an essential component of peer parental support. Parent guides can answer questions and teach parents of children newly identified with hearing loss how to navigate the process and understand the roles of each of the different professionals they will encounter. Parent-to-parent support provides parents with the opportunity to access knowledge, information, and resources

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for informed decision-making. Receiving emotional support from other parents helps parents to feel more confident in creating their opinion and making decisions related to their child's language development (Henderson, 2014).

In a study with graduate students and professionals in audiology, speech-language pathology, and deaf educators as participants, all felt that talking to parents about their emotional concerns would help the parent to better support their child (Munoz, Nelson, Blaiser, Price, & Twohig, 2015). However, one third of the participants felt that there was not enough time to address parent's emotional concerns during an appointment. In addition, 95% of the professionals and 100% of graduate students desired training on how to effectively support parents (Munoz et al., 2015). Service providers must be cognizant of parent's level of stress and know that the information and support they can provide to parents may help to reduce their stress (Dirks et al., 2016).

For professionals to truly provide supportive, family-centered services they must be aware of the social support families have in place, and also align their support with each family's unique values and goals (Dirks et al., 2016). SLPs have an important role and bring crucial information on services, support, and the intervention process to families, but they need to partner with families to effectively support parents of children with hearing loss (Munoz et al., 2015).

Communication

The majority of the participants in this study did not feel they had strong communication with their child's school-based SLP. Participants did not know exactly what SLPs were targeting during sessions with their child and expressed a desire for more communication to carry over and practice speech and language skills at home. In discussing the lack of communication from SLPs,

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the participants mostly referred to their child's school-based SLPs and not Early On SLPs or SLPs with AV therapy certification. Early intervention and AV therapy services follow a family-centered practice model, but in the school setting, children are typically seen without their parents present for the session. The ASHA (n.d-d) position statement on the roles and responsibilities of SLPs in schools includes partnering and collaborating with families to meet student needs. However, there are no practical guidelines that define how school-based SLPs should communicate with families. Parents are provided information on their student's goals during individualized education program meetings but may not receive any follow-up communication from the SLP besides district required quarterly or triannually progress reports. A few survey studies have been completed to understand the communication and collaboration between school-based SLPs and caregivers of children on their caseloads. Pappas, McLeod, McAllister, and McKinnon (2008) found SLPs working in school settings to have fewer caregiver interactions compared to SLPs in other clinical settings, such as hospitals or private practice. Many SLPs feel that communication with caregivers is valuable and important, but also acknowledge that it does not always happen enough (Pappas et al., 2008). School-based SLPs shared that consistent communication with families is challenging (Tambyraja, Schmitt, & Justice, 2017). Communication between school-based SLPs and caregivers was found to be highly variable across several studies, with some families receiving no communication in a school year to other families receiving communication on almost a weekly basis (ASHA, 2014; Pappas et al., 2008; Tambyraja et al., 2017). The variability in communication was found to be dependent on many factors, including the SLPs length of experience, caseload size, workload, and self-efficacy as well as demographic factors of school location and family's socioeconomic status. Families of lower socioeconomic status were communicated with less than families of

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children of higher socioeconomic status (Tambyraja et al., 2017). In a survey of 277 SLPs, school-based SLPs noted that much of their communication to parents happens through the child's classroom teacher (Pappas et al., 2008). In another study looking at the communication of 73 school-based SLPs of children kindergarten through second grade with language impairments, the most common communication type was found to be information sent through a homework folder (Tambyraja et al., 2017). In this same study, it was found that increased communication between SLPs and caregivers resulted in increased improvement with grammar in an academic year. The literature shows that more frequent communication can lead to progress with the development of language skills. The homework folder could be utilized to communicate not only the goals targeted and progress made in a session but also to communicate what families can do to support their child's speech and language development at home, a desire of the participants of this present study.

Chapter 6: Conclusions

Summary of Results

This study shares the experiences of mothers of children cochlear implant users, working towards an outcome of listening and spoken language with speech-language pathologists (SLPs). The themes found in this study include knowledge, support, and communication.

Within the theme of knowledge, the following sub-themes emerged: parent need for knowledge, SLP lack of knowledge, and a difference in the knowledge level of SLPs with Auditory Verbal (AV) therapy certification. The participants expressed a need to gain knowledge, as many of them had never known an individual with hearing loss prior to their child being diagnosed. Parents of children with hearing loss acquire knowledge from medical professionals, audiologists, SLPs and the internet (Decker et al., 2012). The participants were disappointed in the lack of knowledge that Early On and School SLPs had regarding hearing loss. The participants felt that the SLPs limited knowledge prevented their children from gaining language skills. There is a lack of well-trained SLPs adequately prepared to support the speech and language needs of children with hearing loss (Houston & Perigoe, 2010). All of the participants received services from AV therapists in addition to Early On and school-based SLPs. The participants shared that they felt their children would not have developed the speech and language abilities they have without support from a professional with listening and spoken language specialist AV therapy certification. SLPs are trained to generally work with clients with any communication disorder, while AV therapists are trained to specifically support the unique needs of families of children with hearing loss working towards an outcome of listening and spoken language.

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The theme of support was prevalent across the participant interviews. The diagnosis of hearing loss in a child can cause parents to feel distress, uncertainty, and grief (Kurtzer-White & Luteran, 2003). The participants described feeling very overwhelmed following their child's diagnosis of hearing loss. The participants described the support they received from AV therapists, teachers of students with hearing loss, and other professionals, as well as the resistance they experienced from professionals related to their child's development of listening and spoken language. The participants also described their association with a support group for parents and professionals of children with hearing loss. Parents of children with hearing loss need support from other parents who have undergone the same experience. Parent support must come from experienced parents and is something that cannot be reduplicated by professionals (DesGeorges, 2003; Fitzpatrick et al., 2007; Jackson, 2011). Professionals feel that supporting parents emotionally would help the parent to better support their child but desire more training on how to support the emotional needs of parents. SLPs must be aware of the supports parents have in place and also have the ability to identify the support parents need.

Each of the participants shared information about communication with their child's SLPs. Most of the participants shared that they would have preferred more communication from their child's school SLP. Many SLPs feel that communication with caregivers is valuable and important but find it challenging to provide consistent communication. SLPs acknowledge that communication with families does not always happen enough (Pappas et al., 2008; Tambyraja et al., 2017). More frequent communication with parents can lead to progress in the child's development of language skills.

Potential Clinical Implications

Professionals have much to learn from the experiences shared by the participants of this study. When parents discover that their child has a hearing loss, they often feel very overwhelmed. Feeling overwhelmed can impact an individual's comprehension. Professionals must acknowledge and understand the impact of their client's feelings and always provide ongoing, up-to-date information. Parents may internalize the information that professionals share with them; therefore, professionals must be sure to provide information that is not only current, but unbiased. Parents not only rely on information from professionals but seek out information from the internet. Professionals should support parents of children with hearing loss in finding information on the internet, and provide reliable internet sources to families.

Most SLPs do not feel confident in providing services to children with hearing loss. University programs that train SLPs need to provide training and experiences in hearing loss and hearing rehabilitation. In addition, SLPs interested in working with the population of children with hearing loss must pursue education in the area to be well-qualified to support this unique population. SLPs who do not have the appropriate education to support children cochlear implant users working towards an outcome of listening and spoken language need to refer families to a specialist.

Parents of children with hearing loss need support from other parents who have undergone the same experience. Professionals providing services must be aware of resources for parental support and be able to recommend these resources to families.

Parents and professionals both feel that communication about speech and language services could be better. More frequent communication from professionals to families can lead to growth of the child's language skills. SLPs should be communicating more frequently with

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families. To provide the communication families desire, clinicians should ask families about their preferred mode and level of communication.

Limitations/Delimitations of the Study

All of the participants of this study were from the same midwestern state. This study focused on the experiences of a small group of mothers of children with cochlear implants. For this study to have greater clinical implications, it would be necessary to include parents of children from other locations. Exploring the experiences of a larger and more diverse participant group would yield more valuable information for professionals to support parents of children cochlear implant users working towards an outcome of listening and spoken language.

Directions for Future Study

Analysis of the narratives provided by the four participants of this study revealed several factors to consider in speech and language services to children cochlear implant users and their families. Findings from this study reveal that parents expect professionals to educate them on hearing loss and how they can support their child's listening and spoken language development. Parents of children with hearing loss are overwhelmed and have a huge need for support from professionals and other parents of children with hearing loss who have undergone similar experiences. In addition, parents would like to receive more communication from professionals, specifically school-based SLPs, regarding their child's service time and progress towards their goals. The current literature shows that SLPs understand the value of emotional support for parents of children with hearing loss as well as the importance of consistent communication with families. SLPs would like more training in supporting the educational and emotional needs of parents of children with hearing loss. There is a need for more qualitative studies from the

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perspectives of SLPs and listening and spoken language specialist certified AV therapists providing services to the families of children cochlear implant users.

References

- Alexander Graham Bell Association for the Deaf and Hard of Hearing. (n.d-a). *Glossary of terms*. Retrieved from <http://www.agbell.org/Document.aspx?id=1039>
- Alexander Graham Bell Association for the Deaf and Hard of Hearing. (n.d-b). *Position statement: Early hearing detection and intervention reauthorization act of 2008*. Retrieved from [http://www.agbell.org/Position_Statements/Position_Statement __Early_Hearing_Detection_and_Intervention_Reauthorization_Act_of_2008/](http://www.agbell.org/Position_Statements/Position_Statement__Early_Hearing_Detection_and_Intervention_Reauthorization_Act_of_2008/)
- American Speech-Language-Hearing Association. (n.d-a). *Cochlear implants for children* [Practice Portal]. Retrieved from http://www.asha.org/PRPSpecificTopic.aspx?folderid=8589943349§ion=Key_Issues
- American Speech-Language-Hearing Association. (n.d-b). *Configuration of hearing loss*. Retrieved from <http://www.asha.org/public/hearing/Configuration-of-Hearing-Loss/>
- American Speech-Language-Hearing Association. (n.d-c). *Early hearing detection and intervention*. Retrieved from <http://www.asha.org/Advocacy/federal/Early-Hearing-Detection-and-Intervention/>
- American Speech-Language-Hearing Association. (n.d-d). *Roles and responsibilities of speech-language pathologists in schools* [poster]. Retrieved from <https://www.asha.org/uploadedFiles/Roles-Responsibilities-SLPs-Schools-Poster.pdf>
- American Speech-Language-Hearing Association. (2014). *2014 Schools Survey report: SLP caseload characteristics*. Retrieved from <http://www.asha.org/research/memberdata/schoolssurvey/>
- American Speech-Language-Hearing Association. (2016). *Scope of practice in speech-language pathology* [Scope of Practice]. Retrieved from

AN OVERWHELMING JOURNEY

<http://www.asha.org/policy/SP2016-00343/>

- Anmyr, L., Larsson, K., & Olsson, M. (2016). Parents' stress and coping related to children's use of a cochlear implant: A qualitative study. *Journal of Social Work in Disability & Rehabilitation, 15*(2), 150-167, doi:10.1080/1536710X.2016.1162123
- Archbold, S. M., Lutman, M. E., Gregory, S., O'Neill, C., & Nikolopoulos, T. P. (2002). Parents and their deaf child: Their perceptions three years after cochlear implantation. *Deafness & Education International, 4*(1), 12-40, doi:10.1179/146431502790560962
- Archbold, S., Sach, T., O'Neill, S., Lutman, M., & Gregory, S. (2006). Deciding to have a cochlear implant and subsequent after-care: Parental perspectives. *Deafness & Education International, 8*(4), 190-206, doi:10.1179/146431506790560094
- Arehart, K. H., & Yoshinaga-Itano, C. (1999). The role of educators of the deaf in the early identification of hearing loss. *American Annals of the Deaf, 144*(1), 19-23.
<https://doi.org/10.1353/aad.2012.0167>
- Britner, P. A., Morog, M. C., Pianta, R. C., & Marvin, R. S. (2003). Stress and coping: A comparison of self-report measures of functioning in families of young children with cerebral palsy or no medical diagnosis. *Journal of Child and Family Studies, 12*(3), 335-348.
- Bruder, M. B. (2000). Family centered early intervention: Clarifying our values for the new millennium. *Topics in Early Childhood Special Education, 20*(2), 105-115.
<https://doi.org/10.1177/027112140002000206>
- Carney, A. E., & Moeller, M. P. (1998). Treatment efficacy: Hearing loss in children. *Journal of Speech, Language and Hearing Research, 41*(1), S61-S84. doi:10.1044/jslhr.4101.s61

AN OVERWHELMING JOURNEY

- Cole, E., & Flexer, C. (2007). *Children with hearing loss: Developing listening and talking birth to six*. San Diego, CA: Plural Publishing.
- Compton, M. V., Tucker, D. A., & Flynn, P. F. (2009). Preparation and perceptions of speech-language pathologists working with children with cochlear implants. *Communication Disorders Quarterly*, 30(3), 142-154. doi:10.1177/1525740108325554
- Cosby, J. (2009). Pediatric cochlear implants: Knowledge and skills of speech-language pathologists. *The ASHA Leader*, 14(2), 6-18. doi:10.1044/leader.FTR1.14022009.6
- Davis, N. O., & Carter, A. S. (2008). Parenting stress in mothers and fathers of children with autism spectrum disorders: associations with child characteristics. *Journal of Autism and Developmental Disorders*, 38(7), 1278-1291.
- Decker, K. B., & Vallotton, C. D. (2016). Early intervention for children with hearing loss: Information parents receive about supporting children's language. *Journal of Early Intervention*, 38, 151-169. doi:1177/1053815116653448
- Decker, K. B. Vallotton, C. D., & Johnson, H. A. (2012). Parents' communication decision for children with hearing loss: Sources of information and influence. *American Annals of the Deaf*, 157(4), 326-339. doi:10.1353/aad.2012.1631
- Dempsey, I., & Keen, D. (2008). A review of processes and outcomes in family-centered services for children with a disability. *Topics in Early Childhood Special Education*, 28, 42-52. doi:10.1177/0271121408316699.
- DesGeorges, J. (2003). Family perceptions of early hearing, detection, and intervention systems: Listening to and learning from families. *Mental Retardation and Developmental Disabilities Research Reviews*, 9(2), 89-93. doi:10.1002/mrdd.10064
- Dirks, E., Uilenburg, N., & Rieffe, C. (2016). Parental stress among parents of toddlers with

AN OVERWHELMING JOURNEY

moderate hearing loss. *Research in Developmental Disabilities*, 55, 27-36.

doi:10.1016/j.ridd.2016.03.008

Ertmer, D. J., Young, N., Grohne, K., Mellon, J. A., Johnson, C., Corbett, K., & Saindon, K.

(2002). Vocal development in young children with cochlear implants: Profiles and implications for intervention. *Language, Speech and Hearing Services in Schools*, 33(3), 184-195. doi:10.1044/0161-1461(2002/016)

Fitzpatrick, E., Angus, D., Durieux-Smith, A., Graham, I. D., & Coyle, D. (2008). Parents needs following identification of childhood hearing loss. *American Journal of Audiology*, 17, 38-49. doi:1059-0889/08/1701-0038

Fitzpatrick, E., Graham, I. D., Durieux-Smith, A., Angus, D., & Coyle, D. (2007). Parents' perspectives on the impact of the early diagnosis of childhood hearing loss. *International Journal of Audiology*, 46, 97-106. doi:10.1080/14992020600977770

Fitzpatrick, E., Grandpierre, V., Durieux-Smith, A., Gaboury, I., Coyle, D., Na. E., & Sallam, N. (2016). Children with mild bilateral and unilateral hearing loss: Parent's reflections on experiences and outcomes. *Journal of Deaf Studies and Deaf Education*, 21(1), 34-43. doi:10.1093/deafed/env047

Hands & Voices. (2017). Guide by your side. Retrieved from

<http://www.handsandvoices.org/gbys/index.htm>

Hearing First. (2017). *What is listening & spoken language (LSL)*. Retrieved from

<https://hearingfirst.org/lsl/what-is-lsl>

Houston, K. T., & Perigoe, C. B. (2010). Speech-language pathologists: Vital listening and spoken language specialists. *The Volta Review*, 110(2), 219-230.

Hycner, R. H. (1985). Some guidelines for the phenomenology analysis of interview data.

AN OVERWHELMING JOURNEY

Human Studies, 8(2), 279-303.

Jackson, C. W. (2011). Family supports and resources for parents of children who are deaf or hard of hearing. *American Annals of the Deaf*, 156(4), 343-362.

Joint Committee on Infant Hearing. (2007). Year 2007 position statement: Principles and guidelines for early hearing detection and intervention programs. *Pediatrics*, 120, 898-921. doi:10.1542.peds.2007-2333

Kelly, P. M. (2013). *Parent perceptions of audiology and speech-language services and support for young children with cochlear implants* (Doctoral dissertation). Retrieved from <http://scholarcommons.sc.edu/etd/2530>

Kurtzer-White, E., & Luterman, D. (2003). Families and children with hearing loss: Grief and coping. *Mental Retardation and Developmental Disabilities Research Reviews*, 9(4), 232-235.

Mitchell, R. E., & Karchmer, M. A. (2004). Chasing the mythical ten percent: Parental hearing status of deaf and hard of hearing students in the United States. *Sign Language Studies*, 4, 138-163.

Moeller, M. P., Carr, G., Seaver, L., Stredler-Brown, A., & Holzinger, D. (2013). Best practices in family-centered early intervention for children who are deaf or hard of hearing: An international consensus statement. *Journal of Deaf Studies and Deaf Education*, 18, 429-445. doi:10.1093/deafed/ent034

Munhall, P. L. (2007). A phenomenological method. In Munhall, P.L. (Ed.), *Nursing research: A qualitative perspective* (pp. 145-210). Sudbury, MA: Jones & Bartlett Learning.

Munoz, K., Nelson, L., Blaiser, K., Price, T., & Twohig, M. (2015). Improving supports for parents of children with hearing loss: Provider training on use of targeted

AN OVERWHELMING JOURNEY

- communication strategies. *Journal of the American Academy of Audiology*, 26(2), 116-127. doi:10.3766/jaaa.26.2.2
- National Association of the Deaf. (2017). *Community and culture: Frequently asked questions*. Retrieved from <https://www.nad.org/resources/american-sign-language/community-and-culture-frequently-asked-questions/>
- National Institutes on Deafness and Other Communication Disorders. (2016). *Quick statistics about hearing*. Retrieved from <https://www.nidcd.nih.gov/health/statistics/quick-statistics-hearing>
- National Institutes of Health. (2013). *Cochlear implants*. Retrieved from <https://report.nih.gov/NIHfactsheets/ViewFactSheet.aspx?csid=83>
- Pappas, N. W., McLeod, S., McAllister, L., & McKinnon, D. H. (2008). Parental involvement in speech intervention: A national survey. *Clinical Linguistics & Phonetics*, 22(4-5), 335-344. doi:10.1080/02699200801919737
- Rosenzweig, E. (2014, September 2). For children with hearing loss, not just any SLP will do. *Auditory Verbal Therapy*. Retrieved from <https://auditoryverbaltherapy.net/2014/09/02/for-children-with-hearing-loss-not-just-any-slp-will-do/>
- Seidman, I. (2006). *Interviewing as qualitative research: A guide for researchers in education and the social sciences*. New York, NY: Teachers College Press.
- Sorkin, D. L., & Zwolan, T. A. (2008). Parental perspectives regarding early intervention and its role in cochlear implantation in children. *Otology & Neurotology*, 29(2), 137-141. doi:10.1097/mao.0b013e3181616c88
- Tambyraja, S. R., Schmitt, M. B., & Justice, L. M. (2017). The frequency and nature of communication between school-based speech-language pathologists and caregivers of

AN OVERWHELMING JOURNEY

children with language impairment. *American Journal of Speech-Language Pathology*, 26(4), 1193-1201. doi:10.1044/2017_AJSLP-16-0235

Yoshinaga, C. (2014). Principles and guidelines for early intervention after confirmation that a child is deaf or hard of hearing. *Journal of Deaf Studies and Deaf Education*, 19, 143-175. doi:10.1093/deafed/ent043

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Appendix: Human Subjects Approval Letter

Oct 8, 2017 8:28 PM EDT

Jennifer Beebe
Special Education, Users loaded with unmatched Organization affiliation.

Re: Exempt - Initial - UHSRC-FY17-18-68 The Experience of Parents of Children Cochlear Implant Users with Speech-Language Pathologists

Dear Dr. Jennifer Beebe:

The Eastern Michigan University Human Subjects Review Committee has rendered the decision below for The Experience of Parents of Children Cochlear Implant Users with Speech-Language Pathologists. You may begin your research.

Decision: Exempt

Selected Category: Category 2. Research involving the use of educational tests (cognitive, diagnostic, aptitude, achievement), survey procedures, interview procedures or observation of public behavior, unless: (i) information obtained is recorded in such a manner that human subjects can be identified, directly or through identifiers linked to the subjects; and (ii) any disclosure of the human subjects' responses outside the research could reasonably place the subjects at risk of criminal or civil liability or be damaging to the subjects' financial standing, employability, or reputation.

Renewals: Exempt studies do not need to be renewed. When the project is completed, please contact human.subjects@emich.edu.

Modifications: Any plan to alter the study design or any study documents must be reviewed to determine if the Exempt decision changes. You must submit a modification request application in [Cayuse IRB](#) and await a decision prior to implementation.

Problems: Any deviations from the study protocol, unanticipated problems, adverse events, subject complaints, or other problems that may affect the risk to human subjects must be reported to the UHSRC. Complete an incident report in [Cayuse IRB](#).

Follow-up: Please contact the [UHSRC](#) when your project is complete.

Please contact human.subjects@emich.edu with any questions or concerns.

Sincerely,

Eastern Michigan University Human Subjects Review Committee