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Parent Perceptions of Audiology and Speech-Language Services and Support for Young Children with Cochlear Implants

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PARENT PERCEPTIONS OF AUDIOLOGY AND SPEECH-LANGUAGE SERVICES
AND SUPPORT FOR YOUNG CHILDREN WITH COCHLEAR IMPLANTS

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DEDICATION

This work is dedicated to my parents who instilled in all of their children the love of learning and the value of a good education. I also dedicate this paper to my sister, Nancy, who continues to teach me about the intricacies and beauty of Deafness. Finally, to my wife, Margaret, without your enduring love and support this accomplishment would not have been possible.

ACKNOWLEDGEMENTS

A lesson I learned in the dissertation process is that whereas the endeavor is an act of single authorship, successful completion of the work would not be possible without a community of support. In my case that includes my dissertation committee: Dr. Erik Drasgow, chair, and committee members Dr. Kathleen Marshall, Dr. Christine DiStefano, and Dr. Wendy Potts. I am grateful to each one of them for the hours of conversation, guidance, and reading that helped shape the final product. I especially appreciate Dr. Drasgow's patience and persistent prompting from the earliest stages of the work to the final submission. It has been an honor to be an apprentice to a master scholar.

This dissertation would be merely an idea without the participation of professionals in the field who put me in touch with parents of young children with cochlear implants. I am indebted to colleagues across the country that provided feedback, publicized the study, and/or distributed the survey. I am grateful to Dr. Alys Young and colleagues at the University of Manchester, United Kingdom, for permission to modify their survey instrument that was central to the study. Ms. Anne McNally, my dear friend and colleague for over 30 years, offered insights about families and Deafness, served as a sounding board for my ideas, and helped me connect with parents and professionals. I deeply appreciate her support.

Without parental participation in the study there would be no findings. I am honored that so many gave so willingly of their time and shared their thoughts, feelings, and stories. Their contribution to the study is the essential element.

ABSTRACT

Parents of children diagnosed with severe-profound sensorineural hearing loss are selecting cochlear implants at an increasing rate and when their children are very young. Audiologists and speech-language pathologists are typically involved in habilitation activities following implantation in an effort to increase children's access to listening and spoken language. These clinicians depend upon parents to participate in habilitation activities that may lead to favorable outcomes for children. However, little evidence exists regarding parents' perspectives on the services and supports audiologists and speech-language pathologists provide in this team effort. Parents can offer valuable feedback to clinicians regarding the type and quality of services they receive. Data gathered systematically from parents can aid in the design and delivery of services. The purpose of my study was to investigate parents' perceptions about the importance of various services and to measure their satisfaction with the support provided to them. Results of the study revealed that parents were overwhelmingly positive about audiologists' and speech-language pathologists' services and support, but preferred services that directly benefitted the child over those that supported the parent. Parents favored a family-centered approach in services, but indicated that the greatest overall positive difference in services and support was for their child, followed by the positive difference for themselves, and then for other family members. Implications for future research and practice are discussed.

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CHAPTER I

INTRODUCTION

Nearly 4,000 American children are born annually with a profound hearing loss (DesJardin, Eisenberg, & Hodapp, 2006). There is evidence that the auditory portion of the brain depends upon early and frequent input for the development of normal patterns of language and speech (Cole & Flexer, 2007; Kuhl & Rivera-Gaxiola, 2008). Thus, the effects of a profound hearing loss at birth are far-reaching and present significant challenges to individuals and their families (Kral & O'Donoghue, 2010). Paramount among the effects is a delay in the development of language with corresponding difficulties in speech perception and production (Cole & Flexer, 2007). Further, children who are born with a profound hearing loss, or become deaf before acquiring spoken language, typically fall behind their hearing peers on measures of written and spoken language (Svirsky, Robbins, Kirk, Pisoni, & Miyamoto, 2000; Svirsky, Teoh, & Neuburger, 2004; Yoshinaga-Itano, Sedey, Coulter, & Mehl, 1998). These children also tend to demonstrate long-term deficits in reading that adversely affect overall academic achievement (Wake, Hughes, Poulakis, Collins, & Rickards, 2004).

Even though a severe to profound hearing loss is a threat to a child's full development, there is evidence that early intervention and the use of technology can mitigate the impact on communication and academic achievement. (Baldassari, et al., 2009; Bergeson, Pisoni, & Davis, 2003; Nicholas & Geers, 2007; Tomblin, Barker, Spencer, Zhang, & Gantz, 2005). Professionals in the field, such as audiologists and

speech-language pathologists (SLPs), endorse early detection and early intervention in response to a diagnosis of hearing loss (American Speech-Language-Hearing Association [ASHA], 2007; Joint Committee on Infant Hearing, 2007). Early detection of hearing loss through universal newborn hearing screenings (UNHS) has become a routine procedure in United States hospitals (Centers for Disease Control and Prevention [CDC], 2010). A major goal for parents is to find ways to manage hearing loss early so that pathways for neural development occur resulting in a child's increased access to listening and spoken language. Neural pathways are essential for the transmission of acoustic signals that are processed in the auditory center of the brain and contribute an individual's perception of sound (Cole & Flexer, 2007; Nicholas & Geers, 2007).

Cochlear Implants for Children

Individuals with severe-profound sensorineural hearing loss require the use of a listening aid to access sound for communication and auditory environmental cues. There are, however, individuals whose hearing loss is so severe that even amplified sound delivered through powerful hearing aids provides little meaningful information (Boothroyd, Geers, & Moog, 1991; Niparko, et al., 2010). A promising intervention in such instances is the cochlear implant (CI), a device that picks up sound, converts it to electrical signals, and transmits the signals to implanted electrodes that directly stimulate the auditory nerves (Svirsky, Robbins, Kirk, Pisoni, & Miyamoto, 2000). The CI device has internal parts inserted surgically into the cochlea and external parts worn on the head and ear(s).

Over the past two decades, parents of children with severe-profound sensorineural hearing loss have increasingly chosen CIs when hearing aids provide little

or no benefit (Bat-Chava, Martin, & Kosciw, 2005; Belzner & Seal, 2009). Surveys of deaf and hard of hearing school programs in the United States showed an increase in students who have a CI from 5.3% ($N = 2,199$) in 1999-2000 to 15.0% ($N = 5,562$) in 2009-2010 (Gallaudet Research Institute, 2011). As of December 2010, about 28,400 children had received CIs in the US (National Institute on Deafness and Other Communication Disorders [NIDCD], 2011). CI eligibility has expanded since 2000 to include children as young as 12 months for profound hearing loss and 24 months for children with severe hearing loss (Belzer & Seal, 2009).

The Newborn Infant Hearing Screening and Intervention Act of 1999 established universal newborn hearing screenings (UNHS) as a standard practice in nearly every U.S. hospital. Data collected by the Centers for Disease Control and Prevention (CDC) show that 660,639 (46.5%) infants among the total births in 1999 were screened for hearing loss. By 2007, the CDC survey showed that 3,345,629 (97%) infants were screened (CDC, 2010). Congenital hearing loss now is reliably detected in the majority of cases within weeks after birth, thus giving parents the option to consider a CI for eligible cases by a baby's first birthday.

There are several aspects of cochlear implantation that differ from other interventions for hearing loss. One is that CIs require elective surgery under general anesthesia. Hearing aids do not require surgery except for bone-anchored models that require a less invasive procedure than CIs and, even so, these hearing aids are not typically surgically inserted until near five years of age (Cole & Flexer, 2007; Tjellstrom, 2005). Unlike other interventions, such as the use of a hearing aid, parents undergo a candidacy process for CIs with a team of professionals. The purposes of the process are

to consider: (a) the nature of a child's hearing loss (type, degree, and configuration), (b) previous interventions such as the use of hearing aids, (c) the child's overall health status, (d) the parents' commitment to aural rehabilitation, and (e) the parents' expectations for realistic outcomes with the CI (DesJardin, Eisenberg, & Hodapp, 2006; Winter & Phillips, 2009; Zaidman-Zait & Most, 2005).

Another distinguishing feature of CIs compared to other interventions is cost. CI expenses, which may be covered in part by private or government insurance, can exceed \$40,000 whereas expenses for hearing aids, usually excluded from insurance coverage, range up to several thousand dollars (ASHA, 2013; Christiansen & Leigh, 2002). Presently the average cost of a digital hearing aid is approximately \$1,500 to \$2,000. The most advanced digital aids range up to about \$5,000 each (National Institutes of Health, 2013). The total cost of an implant, including evaluation, surgery, the CI device, and subsequent habilitation may be \$100,000 or more (American Academy of Otolaryngology – Head and Neck Surgery, 2013).

Whereas the CI candidacy process and cost may inhibit some families, a growing body of evidence shows developmental and academic gains realized by CI implementation. Current research associates CIs with gains on language measures not commonly seen for children with severe-profound hearing loss without implants. For example, children with CIs have outpaced children with hearing aids on a measure of adaptive behavior related to communication (Bat-Chava, Martin, & Kosciw, 2005). In other studies children with CIs were found to have higher education attainment than peers with hearing aids (Stacey, Fortnum, Barton, & Summerfield, 2006; Thoutenhoofd, 2006). Measures of expressive language for children with CIs suggest that early implantation,

combined with oral education, may lead to their fluency in spoken language being comparable to hearing children as both groups enter kindergarten (Nipkaro, et al., 2010; Svirsky, et al., 2000). Early implantation and the use of oral communication are associated with positive outcomes on measures of speech perception (O'Donoghue, Nikolopoulos, & Archbold, 2000; Spencer, 2004).

When parents select cochlear implantation for their child, they face a lengthy aural habilitation process (Zaidman-Zait & Most, 2005). Post-implantation audiology and speech-language therapy sessions typically occur over years and include fitting of the CI device, mapping sessions, maintenance and troubleshooting of the speech processor, and speech-language-auditory therapy (Winter & Phillips, 2009). The initial fitting session involves hooking up the external parts of the CI by an audiologist (Christiansen & Leigh, 2002). Subsequent mapping sessions are necessary to fine-tune the auditory signal provided by the implant (Bradham, Snell, & Haynes, 2009). The speech processor requires daily checks for sound quality at home by parents and by staff members at school, and frequent battery integrity checks are essential (Chute & Nevins, 2006). Speech, language, and auditory therapy sessions following cochlear implantation may continue into the early years of elementary school (Braham et al., 2009). These activities will likely begin within months after parents receive confirmation of their child's hearing loss and while they are still coping with the diagnosis and with their revised expectations for their child's future (Zaidman-Zait, 2007).

Deafness, CIs, and Parents' Needs for Support

The diagnosis of deafness of a child is an upsetting event in the lives of most hearing parents, contributing to an initial sense of loss and mourning and subsequent

periodic stress for them and their families (Hintermair, 2006; Meadow-Orlans, Mertens, & Sass-Lehrer, 2003; Scheetz, 2001). The evidence regarding the impact of deafness on families is complex and highly variable (Feher-Prout, 1996; Hintermair, 2006; Jackson & Turnbull, 2004; Koester & Meadow-Orlans, 1990; Lederberg & Golbach, 2002; Meadow-Orlans, Mertens, Sass-Lehrer, & Scott-Olson, 1997; Morton, 2000; Quittner, Steck, & Rouiller, 1991). The common denominator is that most families experience distress at the time of diagnosis followed by varied responses that seem to be influenced by multiple factors. Jackson and Turnbull (2004) reviewed literature on deafness and family life concluding that factors influencing the impact of deafness may include the severity of the loss, the presence of co-existing disabilities, family ethnicity, parents' hearing status and educational levels, communication modes and proficiency in those modes, and the access the family has to social supports and parenting models. They include the caveat, though, that the results they found were drawn from studies with small samples of homogenous groups (white and middle class) and focused on hearing parents of children with severe-profound hearing loss who used hearing aids and sign language.

Studies have narrowed the focus on parents' experiences with deafness through investigations of those who have chosen CIs for their children. For example, a small group of studies examined parents' expectations for the device, their views of the CI process, and stressors related to everyday life with a CI (Archbold, Sach, O'Neill, Lutman, & Gregory, 2006; Burger, et al., 2005; Hyde, Punch, & Komesaroff, 2010; Spencer, 2004; Steinberg, et al., 2000; Zaidman-Zait & Most, 2005; Zaidman-Zait, 2007; Zaidman-Zait, 2008). The collective evidence is that parents generally have realistic expectations for outcomes, find the CI process most stressful around the time of surgery,

and have varying degrees of stress depending upon child characteristics (such as the presence or absence of additional disabilities) and family circumstances (such as support from family or friends and the presence or absence of typical stressors such as financial problems). Interventions for young children with early hearing loss require parental involvement but CIs represent the only one that explicitly requires a commitment to habilitation through a candidacy process. A search of the literature, though, reveals no standardized, empirically-sound method for predicting or assessing parent commitment.

Whereas parents' commitment to CI habilitation is hard to predict or assess, parental involvement is essential because implantation is an elective procedure that requires their permission, as well as resources, including time and money. Parental participation in mapping sessions and speech-language therapy is a key element during the candidacy process (Ambrose, Hammes-Ganguly, & Lehnert, 2009). Parent involvement is an avenue to successful outcomes for speech and language development through habilitation activities with audiologists and SLPs, whose services are among the most frequently provided for young children with CIs (Christiansen and Leigh, 2002; Fitzpatrick, Graham, Durieux-Smith, Angus, & Coyle, 2007; Spencer, 2004). This frequency of contact provides audiologists and SLPs an opportunity to support parents in habilitation, thus leading to positive outcomes for children learning to listen and speak through use of the CI. Despite this emphasis on the importance of parents' roles in the process, little attention has been given to how audiologists and SLPs support parents' participation in habilitation activities following CI surgery.

Rationale and Purpose

For CIs to result in positive outcomes, parents' involvement in the CI process is important, if not critical. However, there is relatively little known about parents' perceptions of audiology and speech-language habilitation activities and satisfaction with the service delivery from professionals. Little evidence is available regarding how frequently parents access services with audiologists and SLPs, and how they evaluate the content of sessions. For example, do parents value a family-centered process in their sessions or do they prefer a child-focused approach? How satisfied overall are parents with the services and support from audiologists and SLPs? Data collected from parents could address these questions and help audiologists and SLPs develop practices that enhance parents' roles in habilitation leading to improved outcomes for children.

In sum, technological advances in cochlear implantation for children with severe-profound hearing loss have made a significant impact on treatment options (Bradham & Jones, 2008). Children with severe-profound sensorineural deafness are receiving CIs at an accelerating rate and at an early age. The system of services and support is still developing (Kral & O'Donoghue, 2010). Further development of the service system would be enhanced by feedback from parents because they and their children are the consumers of these services. As consumers, parents are in a position to inform professionals about the type and quality of services they receive. Their feedback about services and support can guide researchers and practitioners in the design of CI audiology services and speech-language therapy, leading to potentially better outcomes for deaf children.

The purpose of my exploratory study was to examine the perspectives of parents of young children with CIs about the services and support provided to them by audiologists and SLPs. The study addresses the following research questions:

- First, what is the average amount of time per month that parents of children with CIs between the ages of two and six years old estimated they spent with audiologists and SLPs within a twelve-month period?
- Second, how do parents rate (a) the importance of the services and support received from audiologists and SLPs and (b) their satisfaction with the services and support?
- Third, how do parents rate (a) audiologists' and SLPs' performance on family-centered practice dimensions in delivered services and how do they rate (b) the importance of family-centered practices to them as part of audiologists' and SLPs' services and support?
- Fourth, how do parents rate the overall impact of the support provided by audiologists and SLPs?
- The study will contribute to the literature by measuring parents' perceptions of elements of audiologists' and SLPs' practices. The data collected in the study can clarify what works for parents in terms of services and support from professionals and how the CI habilitation process can continue evolving with a family-centered focus.

Definition of Terms

Audiologist. Audiologists diagnose and treat patients' hearing and balance problems using advanced technology and procedures (ASHA, 2012).

Auditory-verbal therapy (AVT). Auditory-verbal therapy is a systematic intervention involving a diagnostic teaching process that promotes the use of listening as the main modality for acquiring language by deaf children (Goldberg, Dickson, & Flexer, 2010).

Cochlear implant (CI). A surgically implanted device designed to bypass damaged or missing cells in the cochlea and electronically stimulate the auditory nerve of individuals who do not benefit from acoustic amplification (Eisenberg, 2009). It is comprised of two major systems: external parts that are attached or worn on the body and the internal parts that are implanted during surgery. The external parts include a microphone, a sound (or speech) processor that is powered by a power source or battery, and an external transmitter contained in a headpiece and attached with a magnet. The internal parts of a CI are comprised of an internal coil, internal receive-stimulator, and an electrode array that is inserted into the cochlea. A second magnet on the inside of the skin near the insertion point secures the external transmitter and the internal receiver together on the head (Christiansen & Leigh, 2002).

Hearing loss (Severe-to Profound) – Degrees. A severe hearing loss falls in the range of 71-90 decibels where even loud speech is hard to understand. A profound loss falls in the 91+ decibel range. At this level the individual is considered deaf and must use assistive listening devices to access oral communication (ASHA, 2001).

Sensorineural hearing loss. Sensorineural hearing loss is a hearing loss that involves the cochlea and can be mild, moderate, severe or profound and is usually permanent. Mild to moderately severe sensorineural hearing loss can usually be helped

with hearing aids whereas severe or profound hearing loss can usually be helped with cochlear implants (ASHA, 2001).

Speech-language pathologist (SLP). SLPs assess, diagnose, treat, and prevent communication and swallowing disorders in patients (ASHA, 2012).

CHAPTER II

LITERATURE REVIEW

Research about the use of CIs to ameliorate the effects of early, severe-profound deafness has grown steadily over the past two decades. However, within this literature, few studies address parents' perspectives of the cochlear implant process that follows surgery. This emerging body of literature can potentially inform the practices of professionals who depend upon parents to bring children to audiology and speech therapy appointments and to follow through with home-based activities. Understanding parents' perspectives of the habilitation process and discerning their level of satisfaction with professional practices can enhance the evolving system of services and supports for parents of young deaf children.

My literature review begins with a description of the cochlear implant procedure. The review examines parents' roles in obtaining an implant and in participating in habilitation activities. Next, I examine studies investigating parents' perspectives on the CI process. The findings include information specifically related to the services of audiologists and SLPs, who are also referred to as clinicians. The review includes parental reports of everyday problems with CIs and highlights their needs for support. There is an examination of family-centered practices in relation to CIs. My review concludes with a discussion of areas of needed research.

Cochlear Implant Procedures for Children

The decision to use a CI requires justification since implantation is a more medically invasive procedure and a more costly one than any other form of intervention for severe-profound sensorineural hearing loss (Geers, 2006). Thus, a team convenes to determine if the implant is a suitable intervention for an individual (Chute & Nevins, 2002). Winter and Phillips (2009) state “in the approximately 20 years that children have been receiving multichannel cochlear implants, it has become standard practice for pediatric implant centers to use a team approach in determining candidacy” (p. 18). Teams vary in composition but include at a minimum an otologist/otolaryngologist, audiologist, and parents in the case of a child or adolescent. Other team members, such as a speech-language pathologist (SLP), education professional, psychologist, or social worker may participate depending upon the age and needs of the recipient (Balkany et al., 2002; Christiansen & Leigh, 2002; Chute & Nevins, 2002; Lutman, M.E., Archbold, S., Gibbin, K.P., McCormick, B., & O’Donoghue, G.M. 2004; Niparko, Lingua, & Carpenter, 2009). Families may choose to link with other professionals or continue to work with members of the CI team following implantation (Zaidman-Zait, 2008).

CI teams are not limited to a single protocol for determining candidacy. In the United States, the Food and Drug Administration (FDA) oversees the marketing, labeling, and distribution of cochlear implants as medical devices (Zwolan & Thomas, 2009). The FDA provides guidelines on candidacy considerations, and manufacturers also specify suggested candidacy criteria. Individual CI teams make a determination regarding candidacy using the guidelines and recommended criteria (ASHA, 2004b). The candidacy process is a fluid one because advances in technology and ongoing

research on outcomes influence decisions about candidate selection (Cole & Flexer, 2007). CI teams are typically convened to consider implantation for individuals ranging from infancy into late adulthood.

Surgery is scheduled after an implant team has reviewed audiological, medical, and radiologic evaluations and determined that an individual is suitable for a CI. The surgery, performed under general anesthesia, involves the insertion of an electrode array deep into the cochlea, installation of the internal receiver components, and securing the electrodes and receiver to prevent migration of the components (Lucker, 2002). The techniques for cochlear implantation in infants and very young children are similar to that of adults. The rate of major complications, such as an adverse reaction to anesthesia or facial paralysis, is low. Francis et al. (2008) report an 8.6 % incidence of unexpected consequences of cochlear implant surgery in 209 ears of 188 children. These unexpected consequences included wound infections, incomplete insertions, and otitis media. The children were younger than six years of age and enrolled in a multicenter study following cochlear implantation. This rate is nearly the same as that observed for older patients (Hoffman, 1997).

Parental Roles Following Surgery

Parents face practical tasks following implantation surgery. Transporting a young child to and from clinic visits may involve special arrangements and costs, especially when private transportation is not available or the travel distance is considerable (Sach & Whynes, 2005). Family routines and work schedules may be altered for therapy appointments. Parents must decipher technical language and concepts involving CIs as well as troubleshoot device failures (Incesulu, Vural, & Erkam, 2003).

As clinical practice emphasizing language activities in natural environments has evolved, parents are encouraged to report information from home observations to therapists (Spencer, 2004; Weisel, Most, & Michael, 2007). Clinicians encourage parents to participate in therapy sessions and to seek ways to reinforce techniques used in therapy within the home environment.

Families may interact with a variety of service providers following CI surgery, depending upon the child's age at implantation. Infants receiving a CI may have an early interventionist trained in auditory-verbal therapy on the team, whereas children closer to school age (four or five years and older) may have a teacher of the deaf as a team member. Two professions that commonly serve all young children with CIs and their parents are audiology and speech-language pathology (Christiansen & Leigh, 2002; Sorkin & Zwolan, 2008). These professionals are involved with the technical aspects of a CI, such as fitting, mapping and troubleshooting for audiologists, and speech, language, and listening therapies, as well as device troubleshooting, for SLPs.

Approximately three to four weeks after surgery, the CI recipient attends mapping sessions with an audiologist. In some clinics, these appointments occur on two consecutive days and last for one to two hours each session (Zwolan & Stach, 2009). Tests with specialized software are conducted to collect information for programming the speech processor. During this visit, the CI device is activated and thresholds for hearing sounds (soft, loud, and comfortable) are established. A common recommended schedule of follow-up visits following activation is at 2, 4, 8, and 12 weeks as well as 6 and 12 months post-activation but the schedule is variable because individual circumstances dictate the need for appointments (Bradham et al., 2009; Zwolan & Stach, 2009). These

benchmark appointments vary from clinic to clinic but four to six audiology appointments in the first year are common (Eisenberg, 2009).

Setting the parameters for the speech processor, also known as mapping the processor, is a critical element in postoperative care (Sillon et al., 2004). The procedure requires the child to respond to various inputs as the audiologist conducts telemetry testing and psychophysical testing. The former allows the audiologist to send and receive information to the implant. The latter involves the creation of the initial program for the speech processor. Zwolan and Stach (2009) emphasize the importance of teamwork between audiologists and parents prior to mapping sessions since young children must be conditioned to respond to sound input. A trip to the implant center may involve considerable travel because centers often are associated with medical or university settings and thus distant from families outside those immediate areas. Thus, careful planning and preparation are essential to a productive visit.

For many parents, the primary goals for using a cochlear implant for their children are: (a) to increase access to sound and (b) to improve listening skills and spoken language production (Archbold et al., 2006; Christiansen & Leigh, 2002; Geers, 2006; Inceselu et al., 2003; Perold, 2001; Sach & Whynes, 2005; Yuelin, Bain, & Steinberg, 2004). These goals may be similar to those for children with hearing aids but may be out of reach for many of them with severe-profound hearing loss, given the severity of their deafness and the lack of benefit gained from hearing aids. Postoperative therapy services usually begin with, or continue, auditory discrimination activities followed by training in identifying sounds and associating them with objects. Comprehension of auditory messages and speech production are other broad categories that SLPs undertake

in therapy. SLPs provide informal and formal evaluation services, often at 6-month and 12-month intervals following surgery, to assess progress on language goals. Therapy schedules may include appointments as often as twice weekly during the first year following implantation but vary depending upon parents' schedules and transportation needs (Geers & Brenner, 2003).

Parental Needs for Postoperative CI Services and Support

Between 90 to 95% of children with congenital deafness are born to hearing parents who have little to no experience with the technologies and methods used to develop communication between them and their child (Cole & Flexer, 2007; Mitchell & Karchmer, 2004). Thus, parents may need support as they cope with the reality that communication with their child will require unexpected adjustments to daily life (Weisel, Most, & Michael, 2007). They may require professional services and guidance regarding communication choices and the implications for the method(s) they select (Ingber & Dromi, 2009). Parents may need professional support as they shape their expectations for their child's progress as well as for the expectations of other family members regarding life with a deaf family member (Spahn, Richter, Burger, Lohle, Wirsching, 2003). These are needs for support that many hearing parents of deaf children have regardless of the communication options and aids they select, such as sign language, hearing aids, cued speech or cochlear implants (Eleweke, Gilbert, Bays, & Austin, 2008; Jackson, Traub, & Turnbull, 2008; Jackson, Wegner, & Turnbull, 2010; Meadow, 1980).

Whereas there is evidence that parents of deaf children need support, there remain questions about parents' needs for support given that many of them have successively, and in a short period of time experienced: the diagnosis of deafness, the decision-making

and candidacy process for a CI, and their child's surgery. Parents then enter a lengthy habilitation phase during which audiologists and SLPs may see them more frequently than other professionals and are engaged with them in activities designed to maximize the benefits of the CI. Information from parents about their needs for support and preferences in service delivery following implantation is important because clinicians depend upon parental involvement to carry out treatment plans, including the proper use and maintenance of the CI device (e.g., the child wearing it during all waking hours and using viable batteries). SLPs enlist parents in listening, speaking, and language activities at home (Geers & Brenner, 2003). Parents' reports on the course of these activities enable SLPs to craft treatment goals to advance listening and speaking skills for CI children. Thus, parental perspectives collected in research endeavors can inform clinicians regarding the quality of fit between their practices and parents' needs.

Parents' views about audiology and speech-language services are found in response to sections of surveys about the overall process. For example, Archbold, Lutman, Gregory, O'Neill, and Nikolopoulos (2002) reported results from an investigation of parent perceptions three years after their children received CIs. The study involved parents of 30 children with CIs. The researchers used an open-format schedule of questions consisting of 17 prompts. The prompts evoked responses that were organized into sections grouped under child functioning, parental implications, family implications, and the process of implantation. The schedule of questions did not directly address parent satisfaction with services or support.

The results from the Archbold et al. (2002) study suggest that parents had variable needs for support at varied times, such as support with the CI technology. More than

one-half of the parents reported worrying about device failure and the effect that would have on their children. All parents emphasized the need for on-going technical support, including updates on technology. As children approached school age, the majority of parents stressed the importance of connection between the implant center and officials at school. Parents used terms such as “necessary, essential, or invaluable” to describe the liaison between clinic personnel and school personnel. Nearly all parents mentioned the value of speech therapy.

Archbold et al. (2006) conducted a second study in the United Kingdom (UK) using the 74-item questionnaire, *Children with Cochlear Implants: Parental Perspectives*, to assess parents’ perspectives on the process and outcomes from implantation after three years of use ($N = 101$). Among the findings was a broad consensus (90%) among parents regarding the need and importance of an experienced team to guide the CI process. The same level of agreement applied to the need for regular checking and tuning of the device as well as the importance of contact between the CI team, parents, and school personnel (at least once per year). Parents (74%) also wanted advice from professionals on the implant team regarding their child’s future.

Huttunen et al. (2009) obtained similar results using the same 74-item survey questionnaire to study the experiences of parents in Finland whose children ($N = 36$) had used CIs between two and three years. Parents overwhelmingly (greater than 90%) agreed that ongoing monitoring and tuning of the implant system was important. Parents were also in strong agreement (greater than 80%) with the notion that only experienced teams should carry out CIs and they depended upon the team for advice about implant matters. In a third study regarding parent perspectives of the CI process, Incesulu et al.

(2003) devoted 6 items out of 58 on a survey to the services of the implant center. The questions focused on information provided by the CI center, cooperation between the CI center and other service providers after surgery, and the role of the CI team members at the center regarding follow-up services. Parents ($N = 27$) strongly agreed that they depended upon the implant center for assistance, including advice about the future.

In a different approach to discerning parents' needs for support, Fitzpatrick et al. (2007) employed a qualitative methodology to investigate Canadian parents' preferences for clinical services (including audiology and speech-language therapy) related to CIs and hearing aids. The researchers used conjoint analysis to explore parents' preferences for services for their deaf children. They examined parents' preferences based upon hypothetical clinical models and drew upon their actual experiences retrospectively to discern what parents would have preferred.

In the case of CIs, Fitzpatrick et al. (2007) found that the key attributes of services parents selected as important were: the location of the therapy services (clinic preferred over home-based) and the amount or frequency of them. The results did not specify the amount or frequency of services that parents' desired, only that these attributes were important to them. Parents of CI children in their study ($N = 28$) expressed their desire for: (a) coordinated services through one agency compared with either services that were not coordinated or a model without psychosocial services, (b) access to parent support independently rather than through health services, and (c) access to information through their clinical programs.

Other studies have included parents' experiences with clinical services as individual items or sections in surveys that dealt with related issues. For example,

Christiansen and Leigh (2002) surveyed 439 parents of children with CIs regarding a range of topics from pre-implant through postoperative services and included questions about educational matters. When asked specific questions about postoperative audiology and speech language services, 95% of the parents cited audiology as a profession that facilitated the use of the CI and 75% of the parents cited speech pathology as facilitative. Similarly, in a study of early intervention services conducted by Sorkin and Zwolan (2008), parents cited audiology and speech-language pathology as two of most frequently mentioned services related to CIs and two they valued highly among 12 categories. Parents ($N = 27$) in a study by Incesulu et al. (2003) also endorsed the positive impact of the implant center, including audiology and speech-language services, by unanimously underscoring the importance of advice from audiology and SLP professionals on the implant team.

Whereas parents rely on professionals for advice about pediatric CIs, there is little evidence in the literature regarding the specific kinds of situations that are troublesome for parents. Problems that parents identify with CIs are relevant concerns for audiologists and SLPs because parents are the consumers of these services. Familiarity with parents' concerns about aspects of the CI enables clinicians the opportunity to support parents during valuable appointment and therapy time. Zaidman-Zait (2008) examined these issues in a study of Canadian parents' needs for support as they coped with everyday problems and stress. She explored the specific types of everyday problems parents faced and the interpersonal relationships they identified as resources for problem solving.

Everyday Challenges and CIs

Zaidman-Zait (2008) asked an open-ended question regarding the everyday problems encountered when parenting a child with a CI. Parent responses ($N = 31$) were based upon experiences with 28 deaf children ranging in age from 12 months to 13 years ($M = 6.32$ years). The mean age of implantation was 3.53 years. All children received audiology and speech- language therapy services in the first year post-implantation. Parents submitted 137 problem descriptions that Zaidman-Zait and a colleague analyzed for content and organized into nine domains. The nine domains cited in the study were: (a) implant drawbacks, (b) communication difficulties, (c) child's behavior and character, (d) socialization, (e) habilitation demands and parenting roles, (f) financial difficulties, (g) services, (h) educating others and/or advocacy, and (i) academic concerns. These domains are also represented in the findings of other researchers, and serve as a good outline of challenges and needs of parents of children with CIs. The results of the Zaidman-Zait study and related research in each domain is reviewed below.

Implant drawbacks. The domain containing the highest percentage of problem nominations (58.1 %) in Zaidman-Zait's (2008) study was implant drawbacks described as "equipment breakdowns and failures, maintenance of parts, and troubleshooting, device's limitations (e.g., can't be used in water, at playground, or during night; effect of background noise)" (p.144). Similar concerns about device failure and related problems emerged from a study by Archbold, Lutman, O'Neill, and Nikolopoulos (2002) in which they interviewed parents in the UK three years after their children received a CI. Actual device failure or the threat of failure was cited by nearly half of the parents in the survey as a source of worry and concern. Sach and Whynes (2005) found that about 33% of 216

parents in their study cited device failure as one of the unexpected outcomes in the CI process. The results from these studies suggest that parents of CI children may have needs for support related to the functioning of the device and concerns when there are problems with it. Device failures directly affect communication between children using CIs and others and thus are especially important matters, according to parents' feedback.

Communication difficulties. Device malfunctioning or failure falls into the purview of an audiologist's practice. SLPs consider device efficacy, including proper programming, when a child's communication progress is slow. But parental concerns about communication extend beyond the device itself to the development of language (written and spoken) as well as listening skills. There is a significant amount of variability in outcomes for listening and spoken language with CIs, and parents have varied experiences and expectations regarding their child's communication progress (Eisenberg, 2009; Perold, 2001). .

Communication difficulties contained the second highest percentage (38.7%) of responses in Zaidman-Zait's (2008) study. The author defined this domain as "communication breakdowns in child-parent-interactions, children's speech perception and production competence, language level, and home language considerations" (p. 144). According to parents in the study, these difficulties were major sources of every day difficulty. Notably, about 45% of the parents' in Zaidman-Zait's study indicated that they used sign language to support spoken language attempts. These parental reports stand out since audiologists and SLPs typically encourage parents engaged in auditory-verbal therapy with CIs to eschew signs in learning language in favor of using auditory stimuli as the main sensory input (Fairgray, Purdy, & Smart, 2010).

Parents' concerns about communication issues following implantation notwithstanding, the passage of time since implantation appears to have a mediating effect on parents' worries about communication progress. For example, Incesulu et al. (2003) reported that 63 percent ($N = 27$) of their parents reported communication difficulties between their CI children and normal-hearing persons a year after CI surgery. But Archbold et al. (2006) found that 89% of parents surveyed in their study ($N = 101$) noted that spoken language had developed greatly three years after CI surgery. Improvement in spoken language seemed to have contributed to improvements in all areas of communication.

Child's behavior and socialization. Nearly one-third of the parents in Zaidman-Zait's (2008) study identified one or more problems in the areas of child behavior or socialization. The description of child behavior focused on the child's behavior and temperament and the term socialization involved "social competence, social status, peer relationships, and social inclusion" (p. 144). Behavior issues for young deaf children are part of the developmental process and not unique to those who use CIs. Difficulties with communication are common sources of misunderstanding and frustration. However, some parents of CI children hold relatively high expectations for their children in terms of communication skills, social relationships, and overall outcomes because they hope the device will give them and their children a mutually accessible form of communication through listening and spoken language (Meadow-Orlans et al., 2003; Nicholas & Geers, 2006). Researchers consistently emphasize the importance of professionals' roles in guiding, supporting, and informing parents regarding the progress of deaf children,

including not only hearing, but functioning in their daily environments as well (DesJardin et al., 2006; Eleweke et al., 2008; Incesulu et al., 2003; Zaidman-Zait & Most, 2005).

Habilitation demands. Robbins (2009) describes rehabilitation after cochlear implantation as “...the training or retraining of a patient’s auditory system to be alert to and interpret signals transmitted by the implant, with the goal of achieving communication competence” (p.269). Children who have prelingual deafness and receive CIs as infants or toddlers typically are considered in *habilitation* for audiology and speech-language services since they are learning to use their hearing for the first time. Habilitation demands on parents usually take the form of audiology and therapy appointments and practice with communication methods at home. Zaidman-Zait (2008) found that nearly 25% of parents found the habilitation demands associated with a CI as especially challenging. Traveling to appointments, following through on therapy homework, and monitoring the device were examples parents cited that interfered with other important home activities such as parenting other children. Geers and Brenner (2003) reported that parents worked with their CI children on therapy-related activities every day for the first two years following implantation and between daily and weekly after the third year following implantation.

Financial difficulties. About 23% of the parents in Zaidman-Zait’s (2008) study reported financial challenges associated with the CI. Notably, the parents in the study received services in Canada where access to health care is organized differently than in the US. The former is delivered through a national health care model whereas in the latter CIs for children tend to be financed through private insurance plans, as well as the Medicaid governmental program. Comparisons in CI costs in both countries are difficult

given the varied plans. Financial strain is felt for some families not only for batteries and some repairs but also, in some instances, for an increased number of appointments associated with CI mapping and speech-language therapy compared to the regimen for hearing aids.

Services. About 20% of the parents in the Zaidman-Zait (2008) study indicated difficulties locating qualified clinicians. These results are from parents in Canada. Studies in the US tend to lend support to these findings. For example, about 40% of SLPs responding to a survey in a relatively large longitudinal study of CI children ($N = 181$) conducted in the US indicated that they had no CI experience/specific training prior to serving CI children (Geers & Brenner, 2003). Similarly, Compton, Tucker, & Flynn (2009) reported that 79% of SLPs in North Carolina ($N = 190$), surveyed about their preparation for working with children with CIs, felt little to no confidence in managing technology or working with this clientele.

Advocacy and Education. Deafness is a low incidence condition with severe to profound bilateral sensorineural loss occurring in about 1 per 1000 births (Eisenberg, 2009). Thus, as some parents (about 20%) in Zaidman-Zait's (2008) study indicated, they often find themselves in a position of explaining their child's needs and advocating for services in settings where professionals have little knowledge and experience with the condition. These circumstances are stressful for them because they spend time and energy educating professionals before conversations can begin about services. Parents (10%) in the study also expressed concerns about the implanted child's academic performance. The small sample of children whose parents participated in the study and the spread of their ages may have influenced the degree of concern about academics since

challenges for CI children in school tend to emerge as language and vocabulary demands become more complex (Sach & Whynes, 2005).

Zaidman-Zaid concluded that parents of CI children experienced difficulties and stressors associated specifically with the device. She stated that her findings could aid audiologists and SLPs by helping them to anticipate the types of issues that parents might bring to appointments and therapy sessions. In the study, Zaidman-Zaid found that parents cited professionals as the most frequently accessed (90.3%) resource for collaborative problem solving compared to spouses (80.6%) and others. The next closest group was other parents of deaf children (48.4%) followed by family members other than spouses (38.7%) and friends (32.3%). Parents, it appears from literature, not only value clinicians generally but also depend upon them for specific advice in relation to daily CI use.

Parents' experiences with audiology and speech-language services, especially those delivered by experienced clinicians on a CI team appear to be positive as evidenced by these studies. Yet a search of the literature revealed no studies reporting detailed measures of parental satisfaction with the combination of audiology and speech-language services following implantation, thus revealing a gap in the literature. Measurement of parental satisfaction with services and support can inform clinicians regarding what aspects of their practices are helpful to parents. There are examples of surveys of parent satisfaction in other areas of pediatric medicine such as neonatal intensive care (Mitchell-DiCenso et al., 1996), physicians' delivery of pediatric care (Lewis, Scott, Pantell, & Wolf, 1986), and pediatric hematology/oncology (Varni, Quiggins, & Ayala, 2000). A thread in the parent satisfaction literature in some medical settings involving young

patients is that satisfied parents are more likely to establish therapeutic alliances with providers and thus follow through on treatment regimens (Brinkmeyer, Eyberg, Nguyen, & Adams, 2004). Pediatric cochlear implantation is a process beginning with screening and diagnosis, followed by surgery, and requiring parent follow through, thus befitting scrutiny regarding parent satisfaction with services.

Family-Centered Practice and CIs

A medical definition of deafness views the condition as a deviation from typical or normal functioning that needs correction (Paul and Jackson, 1993). Yet a growing body of literature documents a shift away from a pathogenic view of deafness as a disability, centered on the individual, toward a family-centered orientation accentuating their resources for coping and empowerment (Hintermair, 2006; Ingber & Dromi, 2009). This change in emphasis from a child-focused deficit model of support and services to a family-centered empowerment model has taken place in early intervention practice over the past three decades (Dunst, 2002; Dunst, Trivette, & Hamby, 2007; Guralnick, 2001; Ingber & Dromi, 2010). In the field of deafness, a family-centered focus for support has been influenced by developments in universal newborn hearing screening (UNHS). Since the 1990s the momentum to screen every newborn for hearing loss has accelerated with improved technologies (Fitzpatrick, et al., 2008).

Dunst et al. (2007) highlight what they consider as essential characteristics of family-centered care for parents who have young children with disabilities. They emphasize practices that foster parent/professional collaborations and partnerships. They promote practices that are respectful of families and that provide information enabling them to make informed decisions. They maintain that families should help determine the

choices available to them for services rather than simply selecting from choices dictated by professionals.

Trute and Hiebert-Murphy (2007) couched choice-making and related family-focused practices within the context of consumer satisfaction in their study of 111 families of children with identified disabilities in Manitoba, Canada. They examined the implications of a concept from the field of psychotherapy – working alliance – and how it relates to family-centered practice (FCP) and parent satisfaction. The idea of working alliance is that parents in a professional helping relationship care for each other and work toward goals they set together. They found a strong relationship between working alliance and consumer satisfaction with childhood disability services.

Bailey (2011) emphasized that family-centered practices now are almost universally endorsed in the literature of professionals working with families of young children with disabilities. Further, FCP in early intervention is now a well-established concept in programs that serve families and children with a variety of needs, including childhood deafness. Brown and Remine (2008) summarize some of the seminal research in family-centered practice and describe it as both a philosophy and a way to gauge quality in early intervention services. They stress these elements of FCP:

(a) families' strengths are valued, (b) parental choice and control over decision-making are promoted, (c) professionals and families have a collaborative relationship, (d) everyday family activities are considered when planning interventions, and (e) characteristics of practitioners' expertise include sensitivity, responsiveness to diversity, and flexibility.

As Brown and Remine (2008) note, these elements have special significance in early childhood deafness since parental choices about communication and language development are fundamental to all intervention efforts that follow.

Audiologists and SLPs serving parents and children in the CI process have multiple opportunities to engage in FCP. Those who are members of cochlear implant teams may accompany parents from the diagnosis of deafness as early as several days after birth, through choices about communication methodologies, and into the cochlear implant process from surgery through post-surgery therapies. Audiologists and SLPs may also join with parents on their journey at different entry points, for example, after implantation has occurred. Whenever the professionals first encounter families with young deaf children, they likely serve parents who are in an on-going process involving decision-making about interventions, family dynamics surrounding the presence of a child with a disability, and emotions related to these dynamics. Thus, family-centered practices potentially fit well with parents' needs in the CI process.

The American Speech-Language-Hearing Association (ASHA, 2008) includes FCP as a core knowledge and skill for practitioners. The Joint Committee on Infant Hearing (JCIH, 2007) promotes a family-centered approach as one of the principles of early intervention with young deaf children. The practice of auditory-verbal therapy (AVT) places parents in a central role for facilitating language development in the home (Rotfleisch, 2009). Instead of sitting in a waiting room during speech-language appointments, parents engaged in AV therapy actively participate in sessions with SLPs and audiologists. They carry out language activities in the home and other natural settings and collaborate with clinicians in AVT sessions. Audiologists and SLPs who

are certified in AVT have the designation of a listening and spoken language specialist (certified AVT), since they usually work one-on-one with the child and family members in contrast with listening and spoken language specialists (AV educators) who tend to work in group or classroom settings (Goldberg, Dickson, & Flexer, 2010).

Practitioners of AVT subscribe to the tenet that even children with profound hearing loss can learn to use spoken language through early identification, appropriate amplification, and intensive therapy emphasizing listening and speaking where parents are the primary language models (Eriks-Brophy, 2004). AVT is not limited to CI users exclusively. Early implantation that gives infants and young children access to sound, combined with parents' desires to see their children fully integrated into hearing society, makes the therapy an especially good fit with CIs. It may be CI parents who participate in AVT therapy enjoy the benefits of family-centered practices along with the technical skills that clinicians bring to listening, speech, and language development. The literature is sparse, though, regarding parents' feedback on family-centered practices within the context of early intervention services for CI families.

I located one study in the literature that incorporated the construct of family-centered practice within the context of early intervention services for parents of deaf children. Bamford, et al. (2009) explored the views of parents of deaf children in the UK regarding characteristics and quality of early intervention services. The core cohort of the 3-year longitudinal investigation consisted of 82 parents of 82 young deaf children (9 of the 82 deaf children used CIs). The authors examined a variety of variables, such as family characteristics, the provision of services for young deaf children, and measures of developmental milestones, such as language skills. One of the instruments used in this

endeavor, *My View of Services* (MVOS), measured parents' ratings on 18 items associated with family-centered practice in terms of the extent that professionals engaged in these and the importance of the items to parents at the time of the rating. The MVOS also measured parents' estimates of the type and amount of services received in early intervention and their ratings of the importance of the services to them and their satisfaction with service delivery.

Gascon-Ramos, Campbell, Bamford, and Young (2010), analyzed results from the Bamford et al. (2009) report and described specific aspects of parents' preferences and satisfaction. The early intervention services examined in the Gascon-Ramos et al. (2010) study included audiology, family support workers (typically teachers of the deaf), and other specialists such as SLPs, social workers, deaf role models, and allied health providers. Using the MVOS, the researchers surveyed parents at entry to the study and then six and twelve months later. Their analysis focused on parents' ratings of the amount and importance of specific types of services and supports, as well as their satisfaction with each content item in the survey.

The Gascon-Ramos et al. (2010) study did not report parents' ratings on the family-centered practice scale (the process of intervention). But the study does contain information about parents' ratings of the content of services. The study collected this information from items on the survey derived from a literature review on early intervention practices in deafness, an expert review of items developed from the review, and focus groups comprised of hearing and deaf parents. The authors report that whereas parents regarded all content of intervention as important, they attributed more importance and satisfaction to services by professionals that equipped them to support their child

than services that addressed parents' needs for personal support. The findings also indicated that audiologists and teachers of the deaf were the professions most frequently involved with parents (parents could also nominate additional providers beyond the 17 choices). SLPs were "prominent" in terms of amount of service provided, according to parent reports.

Summary

Parents of young deaf children diagnosed with severe-profound sensorineural hearing loss are selecting CIs at an increasing rate and when their children are very young. The decision to use a CI involves a team of professionals who typically assess not only child characteristics but also parental characteristics, including their expectations for the device and their commitment to habilitation activities involving audiology and speech-language therapy. The habilitation process typically takes place over several years. Parents are expected to commit resources such as time, money, and follow-through with home-based activities to reinforce therapy. Habilitation after implantation, that includes accurate mappings, device checking and maintenance, speech-language therapy, and parental support, makes a positive difference for children in terms of outcomes for speech and listening skills, language development, and academic achievement.

Universal newborn hearing screening in the US has led to early and reliable diagnosis of congenital hearing loss enabling eligible children to receive CIs as early as 12 months of age. Thus, parents of these children may experience a range of emotions beginning with the birth experience followed by shock, grief, and mourning upon learning of the diagnosis of deafness. They also encounter experiences with

professionals and learn about treatment options, technologies, and interventions within a narrow window of time following diagnosis. Parents who select CIs for their children begin the habilitation process within several weeks after surgery. Despite the emphasis on the importance of parental participation in the process, there is limited research evidence regarding their perspectives on two central aspects of it: audiology and speech-language therapy. Parental perspectives on audiology and speech-language services can inform practices in the developing system of services and support.

Researchers have examined parental perspectives regarding audiology and speech-language services in the CI process in a small number of studies. However, their consideration of parental viewpoints is typically only an aspect of multiple sections within surveys. Whereas current findings suggest that parents' view audiology and speech-language services in the CI habilitation process favorably, there is a lack of specificity regarding what services are particularly helpful. Further, the accumulated evidence does not provide clarity about the kinds of support that parents find beneficial as they team up with professionals. Evidence from one study (Zaidman-Zait, 2008) does elucidate the types of everyday problems that parents face in the habilitation process. The two domains containing the most frequently cited areas of concern for them – implant drawbacks and communication difficulties – are squarely within the professional scope of practice for audiologists and SLPs.

For audiologists and SLPs to collaborate effectively with parents in the CI habilitation process, it is especially important to identify what aspects of clinical services are valued and what kinds of support parents need from professionals. Several points warrant consideration. First, it is unclear from the literature how often parents access

services of audiologists and SLPS in the early years following CI surgery. Second, as parents participate in therapy sessions with their child, it becomes increasingly important for professionals to determine how to maximize their time with parents and children to obtain positive outcomes. Moreover, the field can benefit from the perspectives of parents of CI children regarding family-centered practice. Whereas family-centered practice has become a central tenet in early intervention efforts, specific data from the subset of parents of young deaf children with CIs can add to the literature of CI habilitation. Finally, a small sample of SLPs indicates that their training and experience is insufficient for effective practice with young CI children. Parental perspectives on services can add data and a need consumer perspective on the CI process. These needs for information in the field frame the research questions in this study.

My study incorporates the use of a published survey questionnaire, *My Views on Services (MVOS)*. This instrument is specifically tailored for use with parents of young children with hearing loss. It is designed to measure parent perceptions of early intervention services and thus fits well with my research questions. I explain the modifications I made to the instrument in the chapter that follows.

Research Questions

The purpose of my study was to examine the views of parents of young children with CIs about the services and support provided to them by audiologists and SLPs. The study addresses the following research questions:

- First, what is the average amount of time per month that parents of children between the ages of two and six years old with CIs estimated they spent with audiologists and SLPs within a twelve-month period?

- Second, how do parents rate (a) the importance of the services and support received from audiologists and SLPs and (b) their satisfaction with the services and support?
- Third, how do parents rate (a) audiologists' and SLPs' performance on family-centered practice dimensions in delivered services and how do they rate (b) the importance of family-centered practices to them as part of audiologists' and SLPs' services and support?
- Fourth, how do parents rate the overall impact of the support provided by audiologists and SLPs?

CHAPTER III

METHOD

To address the research questions, I modified a published survey questionnaire, *My Views on Services* (MVOS) (Young, Gascon-Ramos, Campbell, & Bamford, 2009), to collect the perspectives of parents of young children with CIs about specific practices of audiologists and SLPs serving their children. This chapter contains a description of the parent recruitment procedure, details about modifications to the survey questionnaire, and the data collection procedures for this study.

Parent Recruitment

The target population for this study was parents of children with cochlear implants between the ages of two and six years of age. For parents to qualify for participation in the study, their child was required to meet the following conditions: (a) between the ages of two years and six years old, inclusively, (b) a minimum of one year of CI involvement at the time of the data collection, and (c) actively using a CI (single or bilateral) at the time of the study. The reason for the minimum age of two is that children implanted at age one, the current recommended minimum age in the United States, would be age two with one year of CI experience. The upper age limit of six was selected because children are enrolled in school by age six and typically receive school-based services. The focus of this study was on early intervention services. The period of one year of CI use was selected for two reasons: (a) to allow for a sufficient number of interactions between parents and clinicians to study and (b) to guide parents' recollection

of their reactions to those services within a specified time frame. I chose the restriction of current CI use in order to identify parents' experiences that were recent and thus fresh for recollection.

The study used purposive sampling to contact parents via contact persons at the respective sources. I recruited parents of children with CIs from three sources: (a) CI teams affiliated with a hospital or clinic, (b) schools, and (c) support groups for parents of deaf children. I identified the three sources after conversing with audiologists and speech-language pathologists regarding potential sources for recruitment of parents. These conversations took place at national conventions focused on early intervention services for deaf children and parent support. I sought settings that offered the possibility of finding groups of parents of children with CIs in a reasonably expeditious manner from a variety of locations in the United States.

I contacted individuals in a supervisory position at a mix of settings who could commit to my request for assistance in contacting parents. I spoke with each person by phone with a subsequent letter summarizing our conversation. Each contact agreed to assist in the study through written communication. The benefit of this approach was that I was able to identify (a) settings serving parents and (b) individuals at the settings who agreed to assist me disseminate the survey link and/or materials to parents. Table 3.1 summarizes the recruitment sources, the type of setting, and an estimated number of parents projected by the contact person.

Table 3.1

Parents Recruitment Data

| Source | Setting | Projected Number of Parents |
|--|-----------------------------|-----------------------------|
| University of South Carolina Speech & Hearing Center | CI Team | 5 |
| Medical University of South Carolina | CI Team | 5 |
| John Tracy Clinic, Los Angeles CA | Clinic | 10 |
| Atlanta Area School for the Deaf | School | 3 |
| Atlanta Speech School | School | 5 |
| South Carolina School for the Deaf | School | 5 |
| Hands & Voices National Organization | Parent Support Organization | 10 |
| Parent Support Group – North Carolina | Parent Support Organization | 5 |
| Total | | 48 |

Instrument

Survey research can provide statistical information about a population as well as qualitative data regarding specified phenomena (Fink, 2009). I used the survey instrument, *My Views on Services* (MVOS) (Young et al., 2009). This instrument was previously used to study aspects of early intervention services for parents of deaf children in the United Kingdom but not limited to parents who chose CIs. The MVOS is predominantly quantitative in nature with 11 questions, some consisting of multiple parts, as well as one open-ended question and 10 demographic questions. Table 3.2 summarizes descriptions of the four main sections of the original MVOS survey questionnaire.

Table 3.2

My Views on Services (MVOS)

| Sections | Description |
|------------------------------------|---|
| 1. Professionals work with child | Professional services evaluated according to timelines and availability |
| 2. Services and support received | Content of intervention evaluated according to quantity, importance, and satisfaction |
| 3. How support is provided | Process of intervention evaluated according to extent of professionals' performance on family-centered practice dimensions and importance of the support to parents at the time of the rating |
| 4. Effects of the support provided | The overall impact of the intervention |

The content of intervention section of the original MVOS consists of 22 items divided into two subscales or clusters: (a) supporting a child and (b) supporting parents. The authors stress that these content items refer to elements of intervention as a whole rather than practices of individual professionals (Young et al., 2009). There are 18 items in the process of intervention section of the MVOS based on the construct of family-centered practice. These items focus on how clinicians deliver services instead of what they deliver (the content). Appendix A presents the content of intervention subscales. The overall impact of the intervention section consists of one scaled question plus one open-ended question.

In a study of the validity characteristics of the MVOS, investigators reported that their sample size ($N=82$) was not sufficiently large to conduct a meaningful factor analysis (Young, et al., 2009). However, they report on an exploratory cluster analysis of the 22 questions in the content of intervention scale. By using hierarchical cluster analysis and two-step cluster analysis they identify two main clusters underlying the structure of the questions: *supporting the deaf child* and *supporting parents*. The former

includes 10 items relating to behaviors associated with parenting a deaf child. The latter contains 12 items that are less specific to deafness and more generally related to supporting parents as individuals or supporting the family when coping with challenging life circumstances. This is the extent of the reported validity data on the MVOS.

The MVOS has high internal consistency (Cronbach's $\alpha = 0.88$) on the content of intervention scale (Gason-Ramos et al., 2010). Reliability was established with 6-month test-retest correlations ($\rho = 0.88$, $r = 0.68$) and 12-month test-retest correlations, ($\rho = 0.60$, $r = 0.82$). The two subscales within the content of intervention scale demonstrated internal consistency (Cronbach's $\alpha = 0.88$ and 0.86) for supporting the deaf child and supporting parents, respectively. The correlation between the subscales was adequate ($r = 0.75$). Internal consistency on the process of intervention scale is also high (Cronbach's $\alpha = 0.93$). Reliability was established with a test-retest administration (6-month test-retest correlations, $r = 0.64$ and 12-month test –retest correlations, $r = .82$).

Modifications to the MVOS

To address the research questions of interest, I modified the MVOS to collect information about parents' views on services received from audiologists and SLPs after young children received a CI. I modified it to create a focus specifically on parents of young children with CIs. The designation for the modified version is the MVOS-M. Parents rated items about services during the past **year** rather than a 6-month period as in the MVOS. As time elapses from CI surgery, appointments with audiologists tend to become less frequent (Bradham et al., 2009). Thus, a one-year reporting period captured more information about services than a 6-month period.

The original version of the MVOS lists 18 professionals that parents may check as service providers to their children. I limited the number of choices of professionals for this study to audiologists and SLPs since it is the services of these two types of professionals that are the focus of this investigation. Modified instructions in the MVOS-M simplified the language and reduced the complexity of the graphics. Wording was changed for instructions, scales and anchors. The phrase and column “Please tick if you would like to have contact with this service” were eliminated since this information is not within the purview of this study.

I added two questions which asked: (a) if either clinician is a member of the parents’ original CI team, and (b) whether the audiologist or SLP is certified in auditory-verbal therapy (AVT). My rationale for adding these was to determine if parents knew background information about their audiologists’ and SLPs’ membership on the original CI team because earlier research showed a parental preference for such (Archbold et al., 2006). Also, I sought information about parents’ awareness of clinicians’ skills and training in the principles of AVT, which includes an emphasis on family-centered practice. I examined parents’ perspectives on family-centered practices as part of the study.

I added three additional items to the section on the services and support received from audiologists and SLPs. Two of the items - “information on cochlear implant functioning and repair” and “information on cochlear implant failure and recalls” - are cochlear implant-specific and not in the original MVOS. A third item is “help to encourage my child’s listening and spoken language”. Listening and spoken language are not exclusive concerns of parents with CIs but tend to be a major focus and reason

why they select CIs for their children (Fink et al., 2007; Nikolopoulos, Dyar, Archbold, & O'Donoghue, 2004). The MVOS does not explicitly include an item related to listening and spoken language. The addition of this item in the MVOS-M gave parents an opportunity to rate the importance of the concept and their satisfaction with the services of audiologists and SLPs related to listening and spoken language activities.

Parents rated 22 items in the MVOS where items are organized into three dimensions: importance, amount of services received (rated from nothing to too much), and satisfaction. Parents rated an expanded item pool of 25 items in the MVOS-M on only two of those three dimensions: importance and satisfaction. Parents could choose to respond to an open-ended question listing any of the items they would rate as *no support* or *too little*. The question in the MVOS-M that addresses this issue is: “For any aspects listed in a-y of the previous question did you receive NO support or TOO LITTLE support from your audiologists or SLPs? If so, identify those aspects”.

There are two reasons for this change. First, parents estimate the average amount of monthly services from audiologists and SLPs in questions two and three of the MVOS-M. The responses to these two questions address the first research question in the study. Second, the designers of the MVOS included questions about the amount of certain services and support because they were interested in how the need for these might change over time (measured in six-month intervals). The present study is not concerned with studying change over time and thus, parents' ratings of how much they received is not included.

Changes to Scale Structure

I made changes in the number of scales and the scaling descriptions used in the MVOS. There are five scale points in the MVOS in section 2 for the satisfaction measure. The descriptions *not at all* and *very much* anchored the end points on the scale and there were no labels for the other three scale points. The descriptions were changed to four scale points, where each point was labeled using anchors of: (1) *not satisfied*, (2) *somewhat satisfied*, (3) *satisfied*, and (4) *very satisfied*.

Two reasons support these changes. First, the MVOS-M focuses on two professions in contrast with 18 professions in the MVOS. The narrowing of the number of professions requires fewer gradations in the satisfaction measure because there is less variability in service delivery between two professions and 18 professions. Second, the MVOS-M focuses specifically on parents of children with CIs. The designers of the MVOS used it with a wide range of children with hearing loss including those with mild losses and those using no amplification or hearing aids in addition to children using CIs. These changes reduce variability by focusing on children only with CIs, thus obviating the need for finer gradations in the scales.

The number of scale points in section three was reduced from seven points to four points. Seven gradations were too fine to discriminate differences for this population of parents receiving services from two professions. Parents might have difficulty distinguishing between *to a very small extent* of services and *to a small extent*. Similarly, differences between *to a fairly great extent* and *to a great extent* might be too difficult to discern in the cases of clinical services. Parents from two families with young deaf children enrolled in the South Carolina Hands & Voices chapter confirmed these

conclusions in a field test of the instrument in January 2012. They reported difficulty distinguishing among the seven choices and suggested that fewer choices would improve the question. Thus, for these items, item anchors were limited to: (1) *not at all*, (2) *somewhat*, (3) *about right*, and (4) *great*.

Other minor changes to the MVOS include several stylistic ones. These involve wording used in the UK (e.g., “please ‘tick’ if you were offered this service”). This phrase was changed to “please ‘check’ if you were offered this service”. Also, the term “cochlear implant” was added to emphasize that the questions are exclusively for parents of deaf children with CIs. Finally, a demographic section was created as part of the MVOS-M and placed it at the end of the survey (section five). Table 3.3 presents a summary of the changes to the MVOS. Appendix B presents the full survey.

Table 3.3

Summary of Changes to the MVOS

| Section | Original Format | Revised Format |
|--------------|--|--|
| Instructions | Support in past 6 months | Support in past year |
| Instructions | Deaf child | Child with a CI |
| Instructions | “Bubbles” contain instructions and examples of how to fill out survey | Removed bubbles and inserted instructions to simplify format |
| Section 1 | 18 choices of professional services Glossary described the 18 professional services | 2 choices of professional services (audiology and speech-language therapy) |
| Section 1 | No questions about AVT certification and CI team membership | 2 questions added regarding AVT certification and CI team membership |
| Section 1 | 4 columns about service | 3 columns about service |

Table 3.3 (Continued)

Summary of Changes to the MVOS

| Section | Original Format | Revised Format |
|-----------|---|---|
| Section 2 | 22 questions | 25 questions |
| Section 2 | Scales for importance, amount, and satisfaction | Importance and satisfaction scales; added open-ended question |
| Section 2 | 5 scale points 2 scale descriptions | 4 scale points 4 scale descriptions |
| Section 3 | 7 scale points | 4 scale points 3 scale descriptions changed |
| Section 4 | 2 questions regarding the differences services made | 1 question combines the original 2 questions |
| Section 5 | No section 5 in original | Section 5 added to collect demographic information |

Parents who opened the survey, but whose child had not received both audiology and speech-language services in the past year, were redirected out of the survey because the child did not meet the inclusion criteria.

Data Collection

I used an online survey questionnaire. Parents who could not or chose not to use an electronic format had the option of using a paper version of the survey. Parents had the option to provide an email address if they wanted to receive summary information about the study.

I published the MVOS-M using Survey Monkey, a commercial web-based tool. Survey Monkey is US Federal Section 508 certified, meaning that it satisfies federal requirements that make online information and services accessible to users with disabilities. I supplied a recruitment packet electronically, or in a paper format, to each contact person in the study with a description of the study, examples of the types of

questions asked, and a letter of invitation for parents. Contact persons disseminated the survey link via their databases to prospective parents. Parents who completed the survey online used a link to an exclusive account. Those who completed a paper copy returned those via the postal service. I provided paper copies of the survey with postage paid return envelopes to contact persons who supplied those to prospective parents as needed. Two paper copies were distributed by one source (University of South Carolina Speech & Hearing Center CI team) and seven copies were distributed by a second source (the CI team at the Medical University of South Carolina).

Contact persons sent a reminder notice to prospective parents two weeks and four weeks after initial contact was made with them. The contact persons sent reminders at two weeks and four weeks to parents who requested a paper copy but did not return the survey within a four-week time frame.

Data Analysis

There are a total of 22 items in the MVOS-M plus one optional question. Information from nine items in the survey questionnaire directly addressed the four research questions in the study. The survey gathered information about the qualifications of service providers and their relationship to the original CI team through two items. Items 13 – 23 collected demographic information. Table 3.4 presents the research questions, corresponding survey items, and the method of analysis for each question.

Table 3.4

Research Questions, Survey Items & Analysis Methods

| Research Question | Survey Item | Data Analysis Method |
|---|---|--|
| Q1. Average amount of time monthly with audiologists and SLPs | Item 2 (audiologists) and Item 3 (SLPs) | Means and Standard Deviation (SD) |
| Q2. Parent ratings of importance of services and support from audiologists and SLPs and Parent ratings of satisfaction with services and support from audiologists and SLPs | Item 6 Items 7 and 8 | Paired t-test for 2 subscales Means and SD 5-point summary Paired t-test for 2 subscales Means and SD 5-point summary |
| Q3. Parent ratings of extent of audiologists' and SLPs' performance on family-centered practices and | Item 9 | Means and SD 5-point summary |
| Parent ratings of importance of family-centered practice as part of audiologists' and SLPs support | Item 10 | Means and SD 5-point summary |
| Q4. Parent ratings of overall impact of audiologists' and SLPs' support | Item 11 | Frequencies and percentages Cross-tabulation (child, family, self) |
| Biggest difference for parent and family from audiology and SLP services | Item 12 | Content analysis of responses |

Note. SLP = Speech-language pathologist

Types of Analysis

Data screening. I imported data into SPSS- version 18 from Survey Monkey for statistical computations. I analyzed the number of responses in each section of the survey. Some parents completed part but not all sections of the survey. The total number of parents responding in each section of the survey is reported in the analysis. I created four variables to address part of the second research question by summarizing the parents' responses to the Likert items in mean scores on four subscales: (a) perceived

importance of services for the child, (b) perceived importance of services for the parent, (c) satisfaction with services for the child, and (d) satisfaction with services for the parent. Appendix C presents a summary of the composition of these variables drawn from survey items in the MVOS-M.

Descriptive statistics analysis. I analyzed the distribution of responses for the four survey questions. Means are reported as the most sensitive measure of central tendency, thus reflecting the contribution of each data point. Standard deviations are reported to show the average distance of responses from the mean. Large standard deviations show a greater variation in parent responses whereas small values indicate a greater degree of homogeneity in responses. I used five-number summaries (minimum score, 1st quartile, median, 3rd quartile, and maximum score) to describe central tendency and variation in the distribution of values for the second and third research questions. The five-number summary concisely describes the distribution of responses including the spread from the median and the range from minimum to maximum.

Frequency data expressed the number of times a particular value or response was recorded in various items in the survey. I used percentages to describe the share of values per variable and Likert scales to gather data for the four research questions. I used an open-ended question to gather information in addition to quantitative data for the fourth research question. I coded the responses on the basis of key terms and used a rank order procedure to rate the percentages of responses in each code. I also used cross-tabulation analysis to look for patterns of interaction in research question four. The two variables of interest in this question were: (a) the effects of audiology and speech-language pathology services on (b) various members of the respondents' families.

Group comparisons. I conducted group comparisons to address the following research question: How do parents rate (a) the importance of the services and support received from audiologists and SLPs and (b) their satisfaction with the services and support? Within this question are two scales that reflect the focus of the services and support in terms of importance and satisfaction: (a) support for the child and (b) support for parents. A paired t-test was used to test the significance for the average difference in ratings between services and support for the child and services and support for the parents and for the average difference in ratings between satisfaction with services for the child and satisfaction with services and support for parents. The predicted differences among these variables were: (a) that parents would rate support for their child from audiologists and SLPs as more important than support for themselves and (b) that parents would rate their satisfaction with services and support from audiologists and SLPs for their child higher than their satisfaction with services and support for themselves.

CHAPTER IV

RESULTS

My primary goal in the study was to quantify and analyze the perspectives of parents of young children with CIs regarding audiology and speech-language services that they received following their child's surgery. Question one in the study sought to establish how frequently parents used the services of audiologists and SLPs, on a monthly basis, within a twelve-month period. The second research question collected data on parents' views on the content of the services delivered by audiologists and SLPs on the dimensions of importance and satisfaction. The third research question sought parents' views on how professionals delivered services in terms of family-centered practice. This question involved parental estimates of how important these practices were to them at the time of the rating and the extent to which clinicians engaged in them. I also sought parents' ratings of the overall positive effects of audiology and speech-language services for their child, themselves, and for other family members. This chapter begins with a description of parents in the study and follows with the results obtained for each research question.

Participants

A total of 94 parents began the questionnaire and 71 completed all items through the demographics section at the end of the survey. A total of 84 parents provided information regarding the average amount of services received monthly from audiologists and speech-language pathologists. A total of 78 parents completed the section of the

survey addressing importance and satisfaction with services and support. A total of 72 parents completed the section of the survey addressing the extent and importance of family-centered practices of audiologists and SLPs serving them. A total of 71 parents supplied information from the first to the last item in the survey. Thus, I analyzed sections of the survey containing from 84 to 71 responses to use all the available data. A total of seven out of nine parents who received a paper copy of the survey returned it in the supplied prepaid envelopes via the United States postal service. The information from the paper copies of the survey was transcribed into the online format through Survey Monkey.

For simplicity and clarity, all persons who completed the survey are identified as parents. The education level for the majority of the parents went beyond high school with 39 (55%) reporting some college and 25 (35%) reporting graduate level training. The great majority of the parents were hearing persons ($n = 67$, 96%). Parents supplied information on 71 children who met the criteria for CI use, thus enabling those parents to participate in the study.

The sample included parents of more children implanted between the ages of one through two ($n = 58$, 82%) than between ages three to six ($n = 13$, 18%). The sample included more parents of children currently between the ages of three to six with at least one year of CI experience ($n = 62$, 87%) than those age two or younger with one year of CI experience ($n = 9$, 13%). The sample included slightly more parents of girls ($n = 39$, 55%) than parents of boys ($n = 32$, 45%). The great majority of children (93%) belonged to families with 1-3 children. Table 4.1 contains the details regarding the persons who completed the questionnaire and characteristics of their children.

Table 4.1

Demographics, n = 71

| Child's age at implant | Age 1 | Age 2 | Age 3 | Age 4 | Age 5 | Age 6 | Total |
|--|-------|-------|-------|-------|----------|-------|-------|
| Frequency | 33 | 25 | 6 | 3 | 4 | 0 | 71 |
| Percentage | 47% | 35% | 8% | 4% | 6% | 0% | 100% |
| Child's age at survey | | | | | | | |
| Frequency | 0 | 9 | 10 | 19 | 14 | 19 | 71 |
| Percentage | 0% | 13% | 14% | 27% | 20% | 26% | 100% |
| Number of children in family | | | | | | | |
| | 1 | 2 | 3 | 4 | 5+ | | |
| Frequency | 18 | 30 | 17 | 3 | 2 | | |
| Percentage | 26% | 43% | 24% | 4% | 3% | | |
| Parent's Hearing Status | | | | | | | |
| Neither parent deaf or hard of hearing | | | | | 67 (96%) | | |
| One parent deaf or hard of hearing | | | | | 3 (3%) | | |
| Both parents deaf or hard of hearing | | | | | 1 (1%) | | |
| Role of person completing survey | | | | | | | |
| Mother | | | | | 56 (79%) | | |
| Father | | | | | 9 (13%) | | |
| Grandparent | | | | | 6 (8%) | | |
| Parent's highest level of education | | | | | | | |
| Elementary (1-8) | | | | | 0 (0%) | | |
| High school (9-12) | | | | | 7 (10%) | | |
| College (13-16) | | | | | 39 (55%) | | |
| Graduate school (17+) | | | | | 25 (35%) | | |

The racial distribution of the sample is largely White ($n = 54$, 76%). Black or African-American respondents ($n = 6$, 8%), Asians ($n = 5$, 7%), and those of Hispanic or Latino ethnicity ($n = 6$, 8%) are distributed fairly evenly for the remaining percentages. One respondent selected the Non-Hispanic/Latino category for race/ethnicity. Figure 4.1 depicts the racial distribution of the sample.

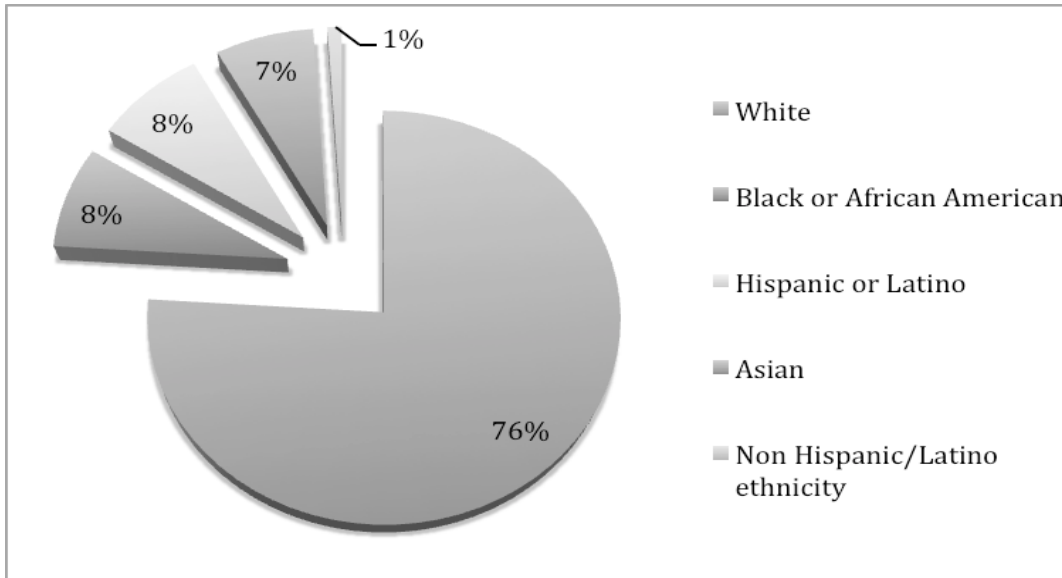


Figure 4.1 Racial distribution (Excludes non-responses)

Amount of Services

My first research question asked “What is the average amount of time per month that parents of children between the ages of two and six years old with CIs estimated they spent with audiologists and SLPs within a twelve-month period?” A majority of respondents who began the survey ($n = 89$, 95%) indicated that children received both audiology and speech-language services. The remaining parents either indicated that their children received only audiology services ($n = 3$, 3%) or that no services were received in the past year ($n = 2$, 2%). These five cases were eliminated from further consideration leaving a total of 84 parents. The remaining parents estimated the amount of services received from audiologists and SLPs in survey items 2 and 3, respectively.

About 77% ($n = 65$) of parents indicated that they received audiology services ranging from less than 1 hour to 4 hours per month on average. About 75% ($n = 63$) of parents estimated that speech-language services occurred within a range of 1 to 12 hours

on average per month. Table 4.2 provides a summary of parents' responses regarding estimated amount of services.

Table 4.2

Hours of Service Received Per Month in Past Year, N = 84

| Range of Hours Received | Service | Number of Parents Selecting Range/Service | Percentage of Parents Selecting Range/Service |
|-------------------------|-----------|---|---|
| Less than 1 | Audiology | 29 | 34.5 |
| | SLT | 2 | 2.4 |
| 1 – 4 | Audiology | 38 | 45.2 |
| | SLT | 26 | 31.0 |
| 5 – 8 | Audiology | 7 | 8.3 |
| | SLT | 22 | 26.2 |
| 9 – 12 | Audiology | 6 | 7.1 |
| | SLT | 11 | 13.1 |
| 13 – 16 | Audiology | 2 | 2.4 |
| | SLT | 4 | 4.8 |
| 17 – 20 | Audiology | 0 | 0.0 |
| | SLT | 3 | 3.6 |
| 21 – 24 | Audiology | 0 | 0.0 |
| | SLT | 2 | 2.4 |
| 25+ | Audiology | 2 | 2.4 |
| | SLT | 14 | 16.7 |
| Total | Audiology | 84 | 100.0 |
| | SLT | 84 | 100.0 |

Note. SLT = speech-language therapy

Parents also answered questions about two variables related to the audiologists and SLPs serving them in the past year: (a) whether the clinician was certified in AVT and (b) whether the clinician was a member of the original CI team. Results for the certification question indicated that at least one of the two professionals serving them in the past year held AVT certification in about 65% ($n = 55$) of the cases. Nearly 20% of

the parents ($n = 17$) reported that neither professional held AVT certification and 15% of the parents ($n = 13$) did not know if the clinicians held AVT certification. Parents' responses indicated that over 70% ($n = 61$) of either audiologists, SLPs, or both, who served them in the past year, were members of the original implant team. About 22% ($n = 19$) of the parents indicated that neither the audiologist nor the SLP serving them in the past year was on the original implant team. About 6% ($n = 5$) of the parents were unsure about whether or not their clinicians in the past year were on the original CI team.

Importance and Satisfaction with Services and Support

A total of 78 parents completed items in the survey that addressed the second research question: "How do parents rate (a) the importance of the services and support received from audiologists and SLPs and (b) their satisfaction with the services and support." The ratings on both of these qualities are based upon a 1 (lowest) to 4 (highest) Likert scale. The response options for importance were: (1) *not important*, (2) *somewhat important*, (3) *important*, and (4) *very important*. The response options for satisfaction were: (1) *not satisfied*, (2) *somewhat satisfied*, (3) *satisfied* and (4) *very satisfied*. Means, standard deviations, and a five-point summary (minimum score, 1st quartile, median, 3rd quartile, and maximum score) are reported for importance and satisfaction.

Table 4.3 summarizes parental ratings of importance and satisfaction with services using descriptive statistics. The table depicts the descriptive statistics for each item in regular type for importance and in bold for satisfaction. The majority of ratings for both importance and satisfaction fall at a mean of 3.00 or greater. These findings indicate that parents rated the majority of the items as important or very important and

they were satisfied or very satisfied with the delivery of services and support. Parents provided an overall rating of satisfaction with services ($M = 3.44$, range= 3.52 - 2.67).

Table 4.3

Ratings of Importance and Satisfaction with Services, $n = 78$

| Survey Item | Mean | SD | Min | 1 st Q | Median | 3 rd Q | Max |
|--|---------------------|---------------------|---------------------|---------------------|---------------------|---------------------|---------------------|
| Information about available services | 3.54 3.32 | 0.80 0.78 | 1.00 1.00 | 3.00 3.00 | 4.00 3.00 | 4.00 4.00 | 4.00 4.00 |
| Information about deaf children's needs and potential | 3.65 3.32 | 0.67 0.74 | 1.00 1.00 | 3.00 3.00 | 4.00 3.00 | 4.00 4.00 | 4.00 4.00 |
| Information about deafness | 3.07 3.23 | 1.02 0.81 | 1.00 1.00 | 2.00 3.00 | 3.00 3.00 | 4.00 4.00 | 4.00 4.00 |
| Information about how to communicate with my deaf child | 3.43 3.39 | 0.92 0.71 | 1.00 1.00 | 3.00 3.00 | 4.00 4.00 | 4.00 4.00 | 4.00 4.00 |
| How to play with and enjoy my deaf child | 3.12 3.29 | 1.06 0.75 | 1.00 1.00 | 2.00 3.00 | 3.50 3.00 | 4.00 4.00 | 4.00 4.00 |
| Knowledge about how deaf children grow up | 3.16 3.09 | 1.02 0.84 | 1.00 1.00 | 2.00 2.00 | 4.00 3.00 | 4.00 4.00 | 4.00 4.00 |
| Help to encourage my child's communication skills | 3.82 3.52 | 0.53 0.66 | 1.00 1.00 | 4.00 3.00 | 4.00 4.00 | 4.00 4.00 | 4.00 4.00 |
| Comprehensive assessments (e.g., language, development, hearing, etc.) | 3.78 3.52 | 0.42 0.72 | 3.00 1.00 | 4.00 3.00 | 4.00 4.00 | 4.00 4.00 | 4.00 4.00 |
| Referrals to other professionals and services | 3.23 3.26 | 0.87 0.80 | 1.00 1.00 | 3.00 3.00 | 3.00 3.00 | 4.00 4.00 | 4.00 4.00 |
| Help to understand how professional support systems work | 2.90 3.12 | 1.06 0.87 | 1.00 1.00 | 2.00 3.00 | 3.00 3.00 | 4.00 4.00 | 4.00 4.00 |
| Advocacy (e.g., professionals that help me make my needs known) | 3.45 3.20 | 0.85 0.88 | 1.00 1.00 | 3.00 3.00 | 4.00 3.00 | 4.00 4.00 | 4.00 4.00 |
| Assistance to claim insurance benefits | 2.93 3.13 | 1.04 0.84 | 1.00 1.00 | 2.00 3.00 | 3.00 3.00 | 4.00 4.00 | 4.00 4.00 |
| Coordination of all services and professionals involved with my child and family | 3.24 3.20 | 0.92 0.88 | 1.00 1.00 | 3.00 3.00 | 4.00 3.00 | 4.00 4.00 | 4.00 4.00 |

Table 4.3 (Continued)

Ratings of Importance and Satisfaction with Services, n = 78

| Survey Item | Mean | SD | Min | 1 st Q | Median | 3 rd Q | Max |
|---|---------------------|---------------------|---------------------|---------------------|---------------------|---------------------|---------------------|
| Respite care (e.g., support for childcare to enable caregivers to take a break) | 2.26 2.74 | 1.24 1.12 | 1.00 1.00 | 1.00 2.00 | 2.00 3.00 | 3.25 4.00 | 4.00 4.00 |
| Consideration of my whole family's strengths and needs | 3.09 3.15 | 0.88 0.86 | 1.00 1.00 | 3.00 3.00 | 3.00 3.00 | 4.00 4.00 | 4.00 4.00 |
| Support for my whole family, not just me and my deaf child | 2.93 3.07 | 0.91 0.86 | 1.00 1.00 | 2.00 2.50 | 3.00 3.00 | 4.00 4.00 | 4.00 4.00 |
| Support to make decisions about my deaf child and my family | 3.15 3.20 | 0.87 0.82 | 1.00 1.00 | 3.00 3.00 | 3.00 3.00 | 4.00 4.00 | 4.00 4.00 |
| Emotional support for me and other family members (partner, siblings) | 2.99 3.04 | 0.97 0.93 | 1.00 1.00 | 2.00 2.00 | 3.00 3.00 | 4.00 4.00 | 4.00 4.00 |
| Confidence-building in parenting a deaf child | 3.00 3.16 | 0.98 0.87 | 1.00 1.00 | 2.00 3.00 | 3.00 3.00 | 4.00 4.00 | 4.00 4.00 |
| Contact with other parents of deaf children | 3.27 3.02 | 0.88 0.99 | 1.00 1.00 | 3.00 2.00 | 4.00 3.00 | 4.00 4.00 | 4.00 4.00 |
| Contact with deaf people | 2.78 2.67 | 1.05 1.02 | 1.00 1.00 | 2.00 2.00 | 3.00 3.00 | 4.00 4.00 | 4.00 4.00 |
| Support to help others understand my child's deafness | 2.87 2.99 | 1.04 0.93 | 1.00 1.00 | 2.00 2.00 | 3.00 3.00 | 4.00 4.00 | 4.00 4.00 |
| Information on cochlear implant functioning and repair | 3.58 3.45 | 0.68 0.72 | 1.00 1.00 | 3.00 3.00 | 4.00 4.00 | 4.00 4.00 | 4.00 4.00 |
| Information on cochlear implant failure and recalls | 3.58 3.38 | 0.64 0.79 | 2.00 1.00 | 3.00 3.00 | 4.00 4.00 | 4.00 4.00 | 4.00 4.00 |
| Help to encourage my child's listening and spoken language | 3.82 3.52 | 0.48 0.72 | 1.00 1.00 | 4.00 3.00 | 4.00 4.00 | 4.00 4.00 | 4.00 4.00 |
| Overall, how satisfied are you with the support you are getting? | 3.44 | 0.68 | 1.00 | 3.00 | 4.00 | 4.00 | 4.00 |

Note. 1st Q = 1st Quartile; Min = Minimum; 3rd Q = 3rd Quartile; Max = Maximum. Ratings of parental satisfaction are in boldface.

The group means for parents' ratings for the importance of services and supports and their satisfaction with these are displayed in table 4.3 to clearly highlight the means

and to order them from highest to lowest. Table 4.4, for example, shows parents' ratings for help encouraging the child's listening, spoken language, and communication, along with the assessments of those skills, are at the top of their list for importance.

Table 4.4

Rank Ordering of Group Means for Importance of Services

| Survey Item | Group Mean (<i>M</i>) |
|---|-------------------------|
| Help to encourage my child's listening and spoken language | 3.82 |
| Help to encourage my child's communication skills | 3.82 |
| Comprehensive assessments (e.g., language, development, hearing, etc.) | 3.78 |
| Information about deaf children's needs and potential | 3.65 |
| Information on cochlear implant functioning and repair | 3.58 |
| Information on cochlear implant failure and recalls | 3.58 |
| Information about available services | 3.54 |
| Advocacy (e.g., professionals that help me make my needs known and fight for things if necessary) | 3.45 |
| Information about how to communicate with my deaf child | 3.43 |
| Contact with other parents of deaf children | 3.27 |
| Coordination of all services and professionals involved with my child and family | 3.24 |
| Referrals to other professionals and services | 3.23 |
| Knowledge about how deaf children grow up | 3.16 |
| Support to make decisions about my deaf child and my family | 3.15 |
| How to play with and enjoy my deaf child | 3.12 |
| Consideration of my whole family's strengths and needs | 3.09 |
| Information about deafness | 3.07 |
| Confidence-building in parenting a deaf child | 3.00 |
| Emotional support for me and other family members | 2.99 |
| Support for my whole family, not just me and my deaf child | 2.93 |
| Assistance to claim insurance benefits | 2.93 |
| Help to understand how professional support systems work | 2.90 |

Table 4.4 (Continued)

Rank Ordering of Group Means for Importance of Services

| Survey Item | Group Mean (<i>M</i>) |
|--|-------------------------|
| Support to help others understand my child's deafness | 2.87 |
| Contact with deaf people | 2.78 |
| Respite care (e.g., support for childcare to enable caretakers to take a break | 2.26 |

Parents' satisfaction with audiologists' and SLPs delivery of services and supports is closely aligned at the top and at the bottom of their ratings. Table 4.5 shows their ratings for satisfaction. Help with a child's communication skill development is again at the top of the list and, similar to the importance scale, contact with deaf people and respite care are the lowest ranked items.

Table 4.5

Rank Ordering of Group Means for Satisfaction with Services

| Survey Item | Group Mean (<i>M</i>) |
|--|-------------------------|
| Help to encourage my child's communication skills | 3.52 |
| Comprehensive assessments (e.g., language, development, hearing, etc.) | 3.52 |
| Help to encourage my child's listening and spoken language | 3.52 |
| Information on cochlear implant functioning and repair | 3.45 |
| Information about how to communicate with my deaf child | 3.39 |
| Information on cochlear implant failure and recalls | 3.38 |
| Information about available services | 3.32 |
| Information about deaf children's needs and potential | 3.32 |
| How to play with and enjoy my deaf child | 3.29 |
| Referrals to other professionals and services | 3.26 |
| Information about deafness | 3.23 |

Table 4.5 (Continued)

Rank Ordering of Group Means for Satisfaction with Services

| Survey Item | Group Mean (<i>M</i>) |
|--|-------------------------|
| Advocacy (e.g., professionals that help me make my needs known) | 3.20 |
| Coordination of all services and professionals involved with my child and family | 3.20 |
| Support to make decisions about my deaf child and my family | 3.20 |
| Confidence-building in parenting a deaf child | 3.16 |
| Consideration of my whole family's strengths and needs | 3.15 |
| Assistance to claim insurance benefits | 3.13 |
| Help to understand how professional support systems work | 3.12 |
| Knowledge about how deaf children grow up | 3.09 |
| Support for my whole family, not just me and my deaf child | 3.07 |
| Emotional support for me and other family members | 3.04 |
| Contact with other parents of deaf children | 3.02 |
| Support to help others understand my child's deafness | 2.99 |
| Respite care (e.g., support for childcare to enable caretakers to take a break) | 2.74 |
| Contact with deaf people | 2.67 |
| Overall satisfaction | 3.44 |

The subscales addressing the perceived importance of services for a deaf child (IMP_C) and perceived importance of services for the parent (IMP_P) demonstrated adequate internal consistency (Cronbach's Alpha = 0.88 and 0.91), respectively. The subscales addressing the satisfaction with services for a deaf child (SAT_C) and satisfaction with services for the parent (SAT_P) were higher (Cronbach's Alpha = 0.96 and 0.96), respectively. Correlations within scales were positive, high, and statistically significant, $r(76) = .86, p = .01$ for IMP_C and IMP_P; $r(76) = .88, p = .01$ for SAT_C and SAT_P. Correlations were not significant between IMP and SAT subscales. Table 4.6 summarizes paired samples correlations.

Table 4.6

Paired Samples Correlations, n = 78

| | IMP_C | IMP_P | SAT_C |
|-------|-------|-------|-------|
| IMP_P | .86* | | |
| SAT_C | .12 | .08 | |
| SAT_P | .08 | .12 | .88* |

Note. IMP_C = Importance for deaf child; IMP_P = Importance for parent; SAT_C = Satisfaction for child; SAT_P = Satisfaction for Parent *p = .01

I conducted a paired-samples t-test to compare parents' ratings of the importance of audiologists' and SLPs' services for a child with a CI and ratings of the importance of those services for the parent. There was a significant difference between the importance scores for services for a child ($M = 3.36$, $SD = .60$) and services for a parent ($M = 2.96$, $SD = .69$); $t(77) = 9.84$, $p < 0.001$, 95% CI [.32, .48]. Similarly, I conducted a paired-samples t-test to compare respondents' ratings of satisfaction with audiologists' and SLPs' services for a child and satisfaction with services for a parent. There was a significant difference between satisfaction with services for a child ($M = 3.33$, $SD = .64$) and services for a parent ($M = 3.06$, $SD = .75$); $t(77) = 6.71$, $p < 0.001$, 95% CI [.19, .35].

Extent and Importance of Family-Centered Practice

The third research question asked "How do parents rate (a) audiologists' and SLPs' performance on family-centered practice dimensions in delivered services and how do they rate (b) the importance of family-centered practices to them as part of audiologists' and SLPs' services and support?" The ratings on both dimensions are based upon a 1 (lowest) to 4 (highest) Likert scale. The response options were: (1) *not at all*; (2) *somewhat*; (3) *about right*; and (4) *great*. Means, standard deviations, and a five-point summary (minimum score, 1st quartile, median, 3rd quartile, and maximum score) are reported for the two survey scales addressing these questions.

The mean ratings for the extent of clinicians' performance on family-centered practices fell between *about right* to *great* on the four-point Likert scale for this question. Table 4.7 presents ratings on the extent and importance of audiologists' and SLPs' engagement in family-centered practices (the process of intervention). The table depicts the descriptive statistics for each item in regular type for the extent to which clinicians deliver these practices and in bold for the importance that parents ascribe to the practices.

Table 4.7

Ratings of Extent and Importance - Family-Centered Practice, n = 72

| Survey Item | Mean | SD | Min | 1 st Q | Median | 3 rd Q | Max |
|---|---------------------|-------------------|---------------------|---------------------|---------------------|---------------------|---------------------|
| Flexible in arranging meetings that take into account family's availability | 3.36 3.63 | .87 .52 | 1.00 2.00 | 3.00 3.00 | 4.00 4.00 | 4.00 4.00 | 4.00 4.00 |
| Adapting to your needs | 3.49 3.55 | .71 .56 | 1.00 2.00 | 3.00 3.00 | 4.00 4.00 | 4.00 4.00 | 4.00 4.00 |
| Trusting you as the 'expert' on your child | 3.46 3.64 | .77 .56 | 1.00 2.00 | 3.00 3.00 | 4.00 4.00 | 4.00 4.00 | 4.00 4.00 |
| Providing enough time to talk about child without feeling rushed | 3.49 3.70 | .73 .57 | 1.00 1.00 | 3.00 3.00 | 4.00 4.00 | 4.00 4.00 | 4.00 4.00 |
| Working together with you in designing and deciding the support you want for child and family | 3.42 3.61 | .77 .49 | 1.00 1.00 | 3.00 3.00 | 4.00 4.00 | 4.00 4.00 | 4.00 4.00 |
| Taking into account family's culture and lifestyle for support plans | 3.36 3.22 | .78 .83 | 1.00 1.00 | 3.00 3.00 | 3.50 3.50 | 4.00 4.00 | 4.00 4.00 |
| Planning in a coordinated fashion | 3.38 3.63 | .80 .57 | 1.00 2.00 | 3.00 3.00 | 4.00 4.00 | 4.00 4.00 | 4.00 4.00 |
| Providing positive feedback that makes you see your strengths in parenting your child | 3.49 3.37 | .69 .71 | 1.00 2.00 | 3.00 3.00 | 4.00 4.00 | 4.00 4.00 | 4.00 4.00 |
| Treating you as an individual rather than just a typical parent of a deaf child | 3.60 3.51 | .63 .61 | 1.00 2.00 | 3.00 3.00 | 4.00 4.00 | 4.00 4.00 | 4.00 4.00 |

Table 4.7 (Continued)

Ratings of Extent and Importance - Family-Centered Practice, n = 72

| Survey Item | Mean | SD | Min | 1 st Q | Median | 3 rd Q | Max |
|--|---------------------|-------------------|---------------------|---------------------|---------------------|---------------------|---------------------|
| Working towards building up your understanding of information | 3.50 3.60 | .68 .61 | 1.00 2.00 | 3.00 3.00 | 4.00 4.00 | 4.00 4.00 | 4.00 4.00 |
| Able to see your viewpoint | 3.47 3.50 | .71 .56 | 1.00 2.00 | 3.00 3.00 | 4.00 4.00 | 4.00 4.00 | 4.00 4.00 |
| Providing a safe and caring atmosphere for you and your child | 3.71 3.69 | .58 .47 | 1.00 2.00 | 3.75 3.75 | 4.00 4.00 | 4.00 4.00 | 4.00 4.00 |
| Following up on things discussed at previous visits | 3.50 3.54 | .75 .59 | 1.00 2.00 | 3.00 3.00 | 4.00 4.00 | 4.00 4.00 | 4.00 4.00 |
| Communicating high expectations for your child and family | 3.67 3.54 | .62 .59 | 1.00 2.00 | 3.00 3.00 | 4.00 4.00 | 4.00 4.00 | 4.00 4.00 |
| Working in partnership with you and your family | 3.60 3.67 | .68 .50 | 1.00 2.00 | 3.00 3.00 | 4.00 4.00 | 4.00 4.00 | 4.00 4.00 |
| Providing updated and comprehensive information in a planned way | 3.46 3.55 | .68 .53 | 1.00 2.00 | 3.00 3.00 | 4.00 4.00 | 4.00 4.00 | 4.00 4.00 |
| Providing an optimistic view of the future for your child | 3.70 3.64 | .58 .51 | 1.00 2.00 | 3.00 3.00 | 4.00 4.00 | 4.00 4.00 | 4.00 4.00 |

Note. 1st Q = 1st Quartile; Min = Minimum; 3rd Q = 3rd Quartile; Max = Maximum. Ratings of the importance of family-centered practice are in boldface.

Table 4.8 breaks out the group means from highest to lowest for the extent to which clinicians provide support in a family-centered context. Notably, the range of group means is narrow – from a high of 3.71 to a low of 3.36.

Table 4.8

Rank Ordering of Group Means for Extent of Family-Centered Practice, n = 72

| Survey Item | Group Mean (<i>M</i>) |
|---|-------------------------|
| Providing a safe and caring atmosphere for you and your child | 3.71 |
| Providing an optimistic view of the future for your child | 3.70 |
| Communicating high expectations for your child and family | 3.67 |
| Working in partnership with you and your family | 3.60 |
| Treating you as an individual rather than just a typical parent of a deaf child | 3.60 |
| Answering your questions fully | 3.57 |
| Following up on things discussed at previous visits | 3.50 |
| Working towards building up your understanding of information | 3.50 |
| Adapting to your needs | 3.49 |
| Providing enough time to talk about child without feeling rushed | 3.49 |
| Providing positive feedback that makes you see your strengths in parenting your child | 3.49 |
| Able to see your viewpoint | 3.47 |
| Providing updated and comprehensive information in a planned way | 3.46 |
| Trusting you as the 'expert' on your child | 3.46 |
| Working together with you in designing and deciding the support you want for child and family | 3.42 |
| Planning in a coordinated fashion | 3.38 |
| Flexible in arranging meetings that take into account family's availability | 3.36 |
| Taking into account family's culture and lifestyle for support plans | 3.36 |

Table 4.9 shows the rank order of group means for the importance parents ascribe to family-centered practices listed in the survey. As noted for the scale on the extent to which clinicians engage in family-centered practices, the range of group means is relatively narrow – from 3.70 to 3.22.

Table 4.9

Rank Ordering of Group Means for Importance - Family-Centered Practice, n = 72

| Survey Item | Group Mean (<i>M</i>) |
|---|-------------------------|
| Providing enough time to talk about child without feeling rushed | 3.70 |
| Answering your questions fully | 3.69 |
| Providing a safe and caring atmosphere for you and your child | 3.69 |
| Working in partnership with you and your family | 3.67 |
| Providing an optimistic view of the future for your child | 3.64 |
| Trusting you as the 'expert' on your child | 3.64 |
| Flexible in arranging meetings that take into account family's availability | 3.63 |
| Planning in a coordinated fashion | 3.63 |
| Working together with you in designing and deciding the support you want for child and family | 3.61 |
| Working towards building up your understanding of information | 3.60 |
| Providing updated and comprehensive information in a planned way | 3.55 |
| Adapting to your needs | 3.55 |
| Following up on things discussed at previous visits | 3.54 |
| Communicating high expectations for your child and family | 3.54 |
| Treating you as an individual rather than just a typical parent of a deaf child | 3.51 |
| Able to see your viewpoint | 3.50 |
| Providing positive feedback that makes you see your strengths in parenting your child | 3.37 |
| Taking into account family's culture and lifestyle for support plans | 3.22 |

Table 4.10 places the rank order of group means for the extent of family-centered practices alongside the importance parents assign to these practices. For example, parents ranked the importance of the statement "Providing enough time to talk about child without feeling rushed" highest on the list of 18 items in terms of importance. The

group mean for this same item in terms of the extent to which clinicians provided it was lower in a list of highest to lowest means, falling at the 10th position. Other items were ranked more closely on both dimensions such as: “Working in partnership with you and your family” that fell at the 4th position in terms of both importance and the extent to which it was practiced by clinicians.

Table 4.10

Comparison of Group Means for Importance and Extent by Rank Order, n = 72

| Survey Item | Rank by Importance of Services | Rank by Extent of Service Delivery |
|---|--------------------------------|------------------------------------|
| Providing enough time to talk about child without feeling rushed | 1 | 10 |
| Answering your questions fully | 2 | 6 |
| Providing a safe and caring atmosphere for you and your child | 3 | 1 |
| Working in partnership with you and your family | 4 | 4 |
| Providing an optimistic view of the future for your child | 5 | 2 |
| Trusting you as the ‘expert’ on your child | 6 | 14 |
| Flexible in arranging meetings that take into account family’s availability | 7 | 17 |
| Planning in a coordinated fashion | 8 | 16 |
| Working together with you in designing and deciding the support you want for child and family | 9 | 15 |
| Working towards building up your understanding of information | 10 | 8 |
| Providing updated and comprehensive information in a planned way | 11 | 13 |
| Adapting to your needs | 12 | 9 |
| Following up on things discussed at previous visits | 13 | 7 |
| Communicating high expectations for your child and family | 14 | 3 |
| Treating you as an individual rather than just a typical parent of a deaf child | 15 | 5 |
| Able to see your viewpoint | 16 | 12 |

Table 4.10 (Continued)

Comparison of Group Means for Importance and Extent by Rank Order, n = 72

| Survey Item | Rank by Importance of Services | Rank by Extent of Service Delivery |
|---|--------------------------------------|--|
| Providing positive feedback that makes you see your strengths in parenting your child | 17 | 11 |
| Taking into account family's culture and lifestyle for support plans | 18 | 18 |

Overall Impact of Support

My fourth research question asked “How do parents rate the overall impact of the support provided by audiologists and SLPs?” Parents rated how much audiologists’ and SLPs’ services made a positive difference for themselves, for the child, and for family members over the past year. Four response options were offered with two named anchor items: (1) *not at all* and (4) *very much*. Frequencies, means, and percent of responses to the survey item were tabulated. Table 4.11 presents these results.

Table 4.11

Positive Difference Made by Audiologists and SLPs in Past Year, n = 72

| | <i>Not at all</i> n (%) | n (%) | n (%) | <i>Very Much</i> n (%) | n (M) |
|---------------------------------------|----------------------------|---------|-----------|---------------------------|-----------|
| Your child | 0 (0.0) | 2 (2.8) | 4 (5.6) | 66 (91.7) | 72 (3.89) |
| Yourself | 0 (0.0) | 3 (4.2) | 14 (19.4) | 55 (76.4) | 72 (3.72) |
| Your family (e.g., partner, siblings) | 3 (4.2) | 7 (9.7) | 18 (25.0) | 44 (61.1) | 72 (3.43) |

The data show the highest ratings for the positive difference for the deaf child, followed by the positive difference for the parent. Positive differences for other family

members are rated highly (a mean score of 3.43 out of 4.0) but with fewer ratings at the top of the scale.

An open-ended question in the survey was included in the same section (the effects of the support provided). A total of 58 responses were recorded. I analyzed the responses for major themes using content analysis. The survey software program, Survey Monkey, included a tool for creating categories and assigning parents' comments to each. Six thematic categories emerged from the analysis along with one category of "other" containing responses that did not fit in any of the six. A definition of each category and sample quote follows. All quotes are verbatim from the survey.

The category with the most responses ($n = 15$) is the one describing personal and professional characteristics of the audiologists and SLPs – Characteristics of Providers. An example from the submissions: "Knowing we are in good hands with our audiologist and that we can trust her expertise. Like the fact I can email her when I have questions and she usually gets back to me very quickly." Parents wrote about the positive effects they experienced as a result of working alliances with audiologists and SLPs. For example, one parent wrote "They've helped us get to where we are today. They've taught me, guided me, comforted me, and given me the confidence that I can do this; the confidence that my son will be okay."

A total of 14 comments were grouped into the category of Communication Outcomes. The common theme in this category was the communication benefits for the children with CIs associated with audiology and speech-language services. An example of a comment for this category is this one: "We have learned to effectively communicate with our daughter and we are seeing such huge improvements in her speech and language

development because of consistent speech therapy and appointments with her audiologist.”

The category of Effect on Parents contained 12 comments from the overall total of 58 responses. One parent stated “They’ve helped us get to where we are today. They’ve taught me, guided me, comforted me, and given me the confidence that I can do this; the confidence that my son will be okay”. Another comment highlighted an example of family-centered practice: “their willingness to support our decisions and not forcing us into AVT when we chose Total Communication”.

Parents provided positive descriptions of a program or facility where they received services. This category of Positive Program Descriptions includes six of the comments submitted. One parent wrote: “Enrolling my child at the center even though it meant moving the family” (made the biggest difference). Another parent named the specific facility: “Being at John Tracy’s clinic made the biggest difference”.

The category, Positive Outlook, included five comments such as these examples: “To realize my child has the potential to have a normal life. To give us the tools to help him and allowing us to actively participate” and “To learn what to do! How to talk and how to live a normal life. How to go through all the deep and sad moments. How to be happy about every single step.”

Parents also cited specific actions of audiologists and SLPs on behalf of their children. This category, Advocacy, included two of responses. An example of a comment from this category is this one: “The availability and willingness of the team to be there for my child and the love and concern they have for the lifelong well-being of

my child.” Appendix D contains a verbatim transcription of the parents’ responses by category from the most to the least number of responses in each.

Summary

The responses for the survey questionnaire used in the study extended from a high of 94 persons who entered the survey to 71 who continued through the last section containing demographic information. Whereas the survey was divided into sections, each section was analyzed on the basis of the number of parents who completed the items in the section. Data from these responses provide the results for each of the research questions. Parents ($N = 84$) reported contact with clinicians at a rate of approximately three hours per month on average for audiology and nearly five hours per month on average for speech-language pathology services. A majority of parents indicated that they received audiology services ranging from less than 1 hour to 4 hours per month on average. A majority of parents estimated that speech-language services occurred within a range of 1 to 12 hours on average per month.

The data demonstrated a highly favorable parental view of the content of intervention (what was delivered). Parents placed the highest value on services that helped them to help their child. They valued, but less so, services that provided them personally with support. In fact, there was a statistically significant difference between services supporting the child and services supporting the parent.

Parental ratings of the extent of clinicians’ performance on family-centered practices were closely aligned with their ratings of the importance of these practices. Parents’ mean ratings for both dimensions were high with scores falling between third and fourth scaling points on the four-point scale. Parents’ views of the overall positive

impact of audiology and speech-language pathology services were most highly rated for the impact on the CI child. The positive impact felt by the parent was a close second in the ratings. The overall positive impact made by audiologists and SLPs for other family members, such as a spouse or siblings of the CI child, was rated lower than for the child and parent. This rating, nonetheless, was high as evidenced by the mean score falling between the two highest points on the scale.

An analysis of parents' responses to an open-ended question regarding the biggest difference in services found the development of speech, language, and listening for the child as a category that had the most comments. Parents also emphasized the importance of support they received from clinicians. They commented on the positive characteristics of the clinicians as frequently as they wrote about the effects of the support they felt. Results from this question and the data collected from the other questions in the survey form the basis for the discussion that follows in the next chapter, including limitations of the study and suggestions for future research.

CHAPTER V

DISCUSSION

The increasing rate of cochlear implantation for children with severe-profound sensorineural deafness at increasingly earlier ages links parents and clinicians in the important habilitation phase following CI surgery. However, there is little information in the literature regarding parental perspectives on services and support from audiologists and SLPs and limited information regarding parental satisfaction with the manner in which services and support are delivered. This study employed a survey questionnaire designed for use with parents of young deaf children to explore the views of those who chose cochlear implantation as an intervention. Parents confirmed that they received audiology and speech-language services over a defined period of time and in many cases from clinicians who were on their original CI team. Their ratings for audiology and speech-language services were overwhelmingly positive with a statistically significant preference for services that directly supported the child versus supporting the parent. Parents rated clinicians' performance on family-centered practices favorably and provided high ratings for the overall positive impact of services for their children, themselves, and other family members, in that order. The implications of these findings for clinicians' practice and for future research endeavors are offered.

Amount of Services

The first research question in this study created a context for CI parents' views on audiology and speech-language services and support by asking them to estimate the

average amount of services received per month in a 12-month period of time. The majority of parents (77%, $n = 65$) reported receiving audiology services from less than one hour to about four hours on average per month. About 75% of parents ($n = 63$) estimated engagement in speech-language services within a range of 1 to 12 hours on average per month during the past year.

The estimate in this study for speech-language services is slightly less than the estimate Geers and Brenner (2003) found in their three-year longitudinal study of CI children. In that study parents estimated receiving speech-language services about 1.5 hours per week (6 hours per month). The average amount of audiology services parents reported receiving was about 3 hours per month. Whereas there is a published protocol for a recommended schedule of audiology visits in the first year of CI use (Bradham et al., 2009), the actual frequency of audiology visits for children may vary due to a variety of factors such as the age and health of the child, the presence of additional disabilities, changes in the mapping of the CI, fitting adjustments, and device functioning, as examples (Winter & Phillips, 2009).

These reports on the frequency of contact with clinicians establish a foundation for the other research questions in this study. The data provide a perspective regarding parents' estimates of how frequently they and their children saw audiologists and SLPs following implantation. The findings are consistent with results from Sorkin and Zwolan (2008) where parents cited audiologists and SLPs among the most frequently accessed professionals for their CI children following implantation. This study goes further than others by providing specific estimates of the range of services received from audiologists and SLPs over a 12-month period. Additionally, parents' estimates of the amount of

services they received combined with the demographic profile of children in the study show that speech-language services tend to be more frequently accessed than audiology services as children age with their implants. The majority of children in the study received CIs before the age of two and they were four years old or older at the time of the survey.

Importance of Services and Parental Satisfaction

My second research question examined parents' perspectives on the importance of specific early intervention services, as delivered by audiologists and SLPs, and parents' satisfaction with the service delivery. Results demonstrated that parents rated the majority of items in a survey of early intervention services, designed specifically for parents of young deaf children (Bamford et al., 2009), as *important* to *very important* and they were *satisfied* to *very satisfied* (overall satisfaction $M = 3.44$) with services as a whole. An examination of the 24 content items that parents rated on two qualities – once for importance and a second time for satisfaction - revealed that when the means were rank ordered, the highest three ratings for importance and satisfaction were: (a) help to encourage the child's listening and use of spoken language, (b) help to encourage the child's communication skills, and (c) comprehensive assessments of these skills. Thus, on average, parents gave the highest ratings to those services directly related to their children and, more specifically, those services related to enhancing communication, especially listening and speaking.

These findings are unique since no other published studies focus exclusively on parents' perspectives regarding the importance of audiologists' and SLPs' services for children with CIs, along with parents' satisfaction with those services. The findings do

support other research suggesting that parents seek CIs because their primary goal is to help their child access sound, thus leading to improvements in listening and spoken language (e.g., Archbold et al., 2006; Christiansen & Leigh, 2002; Geers, 2006). Yet, there is evidence that communication challenges following CI surgery are an everyday concern for some parents (Zaidman-Zaid, 2008). Given that the majority of parents of deaf children are hearing persons (Mitchell & Karchmer, 2004), it is not surprising that listening, spoken language, and communication assessments are rated so highly. The indication that parents in this study, 96% of whom are hearing, were *satisfied* to *very satisfied* with audiologists' and SLPs' services related to communication items reinforces this point.

Whereas parents gave high ratings for the importance of services related to their child, those services less directly related to supporting the child and more oriented toward the parent or other family members were rated lower. For example, support to help others understand the child's deafness ($M = 2.87$), contact with deaf people ($M = 2.78$), and respite care ($M = 2.26$) received the three lowest ratings, respectively, in terms of importance to the parents. It is noteworthy that these services were not seen as unimportant by parents as evidenced by group means falling between descriptors on the Likert scale of *somewhat important* to *important*. I speculate that parents' lower ratings for the deafness items may relate to their higher ratings for spoken language and communication items. That is, parents may not place as high a value on understanding deafness or contacting deaf people because the goal for their child is to become, in essence, a hearing person. Regarding respite care, I speculate that mothers in the study, predominantly college-educated, may have resources that obviate the need for respite

care and thus allow them to focus instead on therapy and the promotion of their child's communication skill development.

Targeting the survey exclusively to parents of young children with CIs enabled me to modify the original MVOS to add CI-specific items. The additional items for this study were: (a) "Help to encourage my child's listening and spoken language", (b) "Information on cochlear implant functioning and repair" and (c) "Information on cochlear implant failure and recalls." I added these items for two reasons: (a) previous research noted that these were important concerns for parents of children with CIs (Archbold et al., 2002; Archbold et al., 2006; Geers, 2006; Huttunen et al., 2009; Zaidman-Zait, 2008) and (b) these were not included in the original MVOS. The survey results suggest that the addition of these items was useful in delineating parents' perspectives because communication and device related-matters ranked among the four highest group means for importance and satisfaction. These items appear to have face validity for survey purposes. Practitioners and researchers may find these results worthy of consideration when using the MVOS-M with families of young children with CIs.

A visual inspection of the rank ordered means for parent ratings of importance and satisfaction is informative. Previously noted was the similarity in the highest rated items on both qualities. Similarly, the three lowest items for both importance and satisfaction were: (a) "Support to help others understand my child's deafness," (b) "Contact with deaf people" and (c) "Respite care." One common denominator among these three is that each is potentially a source of support for parents and/or other family members but not directly related to supporting the child.

The group means on the middle items for importance and for the satisfaction tended to be close when compared to each other. One exception to this congruence between importance and satisfaction is the item: “Contact with other parents of deaf children.” The group mean ($M = 3.27$) for importance fell at the 9th position for all means on this scale; the group mean ($M = 3.02$) for satisfaction was at the 21st position for means on this scale. Parents have emphasized the importance of making connections with others who share similar circumstances in terms of parenting a child with a CI (Zaidman-Zait, 2007). The group means in this study both fall above the third scale point (*important* and *satisfied*); nevertheless, clinicians may take note of this finding that parents valued connections with other parents of deaf children, especially in these circumstances where all parents’ children used CIs.

The data also document parents’ reports on clinicians’ training and membership on CI teams. The majority of parents sampled in this study indicated that at least one of their clinicians (audiologist or speech/language pathologist) was certified in AVT and a majority noted that at least one of them was a member of the original implant team. Thus, parents’ satisfaction with services is in accord with the emphasis in AVT on spoken language and active parent participation. Earlier research also indicated that parents’ prefer clinicians who are experienced with the CI process as was the case for a majority of the parents in this study (Archbold et al., 2006; Huttunen et al., 2009).

Extent and Importance of Family-Centered Practices

Another purpose of the study was to assess parents’ views regarding clinicians’ performance on aspects of family-centered practices. The family-centered approach is established as a central tenet in working with families who have children at-risk for

developmental delay as well as children identified with disabilities (Bailey, 2011; Dunst, 2002; Dunst et al., 2007; Guralnick, 2001). Family-centered practice is found at the confluence of early identification through universal newborn hearing screening, early cochlear implantation, and the use of auditory-verbal therapy, as all three of these place parents in a central role for decision-making and subsequent action. Measuring CI parents' views on the importance of family-centered practice is instructive in light of the previous findings (Gascon-Ramos et al., 2010) regarding parents' preference for services that support the child. That is, clinicians are challenged to find a balance between delivering services to address the child's needs while simultaneously considering the needs of parents and other family members affected by the child's condition.

Parents in this study placed a high value on the importance of family-centered practices as evidenced by the range of means for the 18-item scale measuring this construct (M range = 3.22 to 3.70). Items that clustered near the top ratings on the importance scale focused on positive, high quality aspects of face-to-face interactions, such as having enough time to talk within a setting that was safe and caring. Parents valued clinicians' optimistic outlook for the deaf child's future. They also gave high ratings to items that emphasized having a partnership with professionals along with the acknowledgement that have their own expertise – as a parent. These findings reinforce previous research detailing essential elements of family-centered practice such as collaborative relationships between parents and professionals and informed decision-making (Brown & Remine, 2008; Dunst et al., 2007).

Audiologists and SLPs provided a safe and caring atmosphere for families, were optimistic about the future for the child, and communicated high expectations for the

child and the family, according to parents' ratings regarding the extent of clinicians' engagement in family-centered practices in this study. Clinicians demonstrated skills in partnering with families and treating parents as individuals, according to the results. These are qualities that require no specific expertise in CIs. Thus, while parents value technical skills related to CIs, and some clinicians worry about a lack of specific training with CIs (Compton et al., 2009; Geers & Brenner, 2003), these results highlight the value of "soft" non-technical skills as an important element of effective clinical practice.

Parents' ratings of the extent to which clinicians engaged in these family-centered practices also reveal two noteworthy sets of items when compared with their ratings of importance. Keeping in mind that the overall ratings for extent are above the third of four scaling points (3.0 or above on a 4.0 scale) or *about right*, the first group consisted of items that parents rated lower, relatively speaking, on extent compared to importance: (a) "Provided enough time to talk about child without feeling rushed", (b) "Flexible in arranging meetings that take into account family's availability", and (c) "Planning in a coordinated fashion". The differences in ratings are a more a function of the position of the rankings for extent versus importance than the group means. Previous research findings indicate that nearly a quarter of parents found habilitation demands (e.g., travel, multiple appointments, rearranging home schedules) a concern (Zaidman-Zait, 2008). The results in this study suggest that, flexible and coordinated planning leading to sessions with sufficient time to talk and listen, are important priorities for parents and thus relevant goals for clinicians seeking to engage in family-centered practices.

The second set of items that reflected a notable difference between importance and extent was: (a) "Trusting you as the 'expert' on your child" and (b) "Working

together with you in designing and deciding the support you want for child and family”. Again, within the high overall ratings for these items, parents rated the extent of clinicians’ engagement in these behaviors relatively lower than the importance of these items. Family-centered practice literature emphasizes collaboration and partnerships between professionals and parents (Brown & Remine, 2008; Dunst et al., 2007). Parents in this study value these practices as evidenced by their rankings of importance. Audiologists and SLPs work in a technical field that includes mappings, the complexity of the CI device, and techniques for developing speech and language. Nonetheless, their challenge is to recognize the expertise that parents bring to therapy appointments and to help maintain a balance among the various experts on the team.

Overall Impact of Support

Most parents of young deaf children encounter challenging circumstances as they cope with the diagnosis of deafness and the effect of the condition upon their child, their families, and themselves (Ingber & Dromi, 2009; Spahn et al., 2003; Weisel et al., 2007). Although the literature recommends early intervention for parents and children delivered in a family-centered manner (ASHA, 2008; JICH, 2007), little is known about parents’ views on the support provided by audiologists and SLPs, especially within a family-centered context. These professionals are among those most likely to encounter and serve families when a young child receives a CI. Thus, a fourth purpose of the study was to assess the overall impact of services and support provided to parents of young children with CIs by audiologists and SLPs.

The results of the study demonstrate that parents were overwhelming positive about the amount of difference audiologists and SLPs made for children with CIs. Out of

the 72 parents who rated the clinicians' performance on the positive difference they made, 66 parents (92%) indicated *very much* as the description. Some parents' comments touched upon the "normalization" they sought for their child with the CI: "to realize my child has the potential to have a normal life" and "my daughter's world opened up after her implant and all of our audiologists and speech therapists helped with this process." Another comment focused on the unique needs of the child: "treating my child as an individual and considering her strengths and weaknesses when determining appropriate services." A parent's comment also demonstrated how clinicians' efforts may affect the child directly as well as provide significant benefit to the parent:

My son was having problems with his cochlear implant. One audiologist had no idea what to do, so we switched (audiologists) and they got my son to wear his processor again. I hope they know how important that was to us and lifted a big weight off of my shoulders.

This comment reinforces findings from Zaidman-Zait (2008) wherein parents expressed concerns about equipment issues as well as the findings from Compton et al. (2009) regarding SLPs' self-reports about their lack of expertise and training with CIs.

Parents' ratings for the positive difference audiologists and SLPs have made were second highest for the effect on themselves. Over 75% of the parents indicated that the clinicians had made *very much* of a positive difference – the highest rating on the 4-point scale. One comment captures the depth and breadth of the clinicians' impact: "They helped us get to where we are today. They taught me, guided me, comforted me, and given me [sic] the confidence that I can do this: the confidence that my son will be okay." Another emphasized the collaboration between the clinicians and parents that is

characteristic of family-centered practice (Brown & Remine, 2008): “Their encouragement that our child’s success was based on how much we as parents were willing to do. They gave us the tools and put us to work. We have been so pleased with our audiologist and SLP.”

Parents’ ratings for the positive difference clinicians made for family members (partner, sibling) were rated lowest when compared to positive differences for the child and the parent. This category was the only one of the three that included responses ($n = 3$) of *not at all*. Nonetheless, slightly more than 60% of the parents chose *very much* as their rating for this category. One parent emphasized the effect on family by including the impact of profound deafness: “understanding of the profoundness of the hearing loss; being positive about my child’s potential; their interaction with all members of my family.” Another parent stressed the importance of communication between clinicians and how the information they shared helped the family make decisions – another hallmark of family-centered practice (Turnbull and Turnbull, 1997): “having the audiologist and speech therapist communicate with each other and the family. Giving all information so that we, as the family, could make the best decision for my child and family.”

Finally, whereas parents’ overall ratings were positive, there were comments that indicate shortcomings in the service delivery system. For example one parent noted “... the S/LP provided through the school district has no current or relevant training in order to meet the needs of oral deaf children.” This sentiment was echoed by another parent who added an emphasis on differences between professionals in their approach: “... Now I find the new professionals significantly [sic] lacking in experience, and one support sign

and speech and the other dismisses sign. My child still needs sign support with a late cochlear implant.” One response captures both the big picture when encountering deafness for the first time as well as the practical challenges involved in a family’s response to the condition:

When we were told that our child was deaf you are thrown into a world where we didn't really know anything. We had never been around anyone who was deaf. We didn't know the services that were needed across the board--SLP, audiology and educationally. Parents are relying [sic] our audiologist and SLPs to help them navigate in this new world. We know that our SLP and audiologist are busy but at times it is very frustrating to send an e-mail and not get a response back. I think sometimes the professionals need to step back and think what if this was my child.

Implications for Practice and Research

This study contributes to the body of literature regarding early intervention services for parents of children with CIs. The specific focus on parents’ perspectives on audiology and speech-language services is unique. I used an established survey questionnaire to sample the views of parents of young deaf children on early intervention services and modified the instrument to gather information relevant to those who chose CIs as an intervention for their child’s hearing loss. Thus, the study offers practitioners findings for reflection, or even a change in their work with parents, and provides data to researchers that may stimulate ideas for future research.

One implication for pediatric CI practice drawn from the study is that parents need support but prefer support in the form of activities that have a direct impact on their

child. Further, they place a high priority on services and support directed toward improving their child's communication skills. Parents appear to favor clinician behaviors that are aimed at helping them to help their child over clinician behaviors directed at supporting them through other related matters, such as locating respite care or assistance with insurance claims. Yet parents also highly value a safe and caring atmosphere in the audiology booth or therapy room where their expertise is acknowledged and they sense a partnership between them and clinicians. Parents want clinicians to practice the "soft" skills that lead to a sense of being heard, validated, and comfortable but not at the expense of clinical skills that result in the child learning to listen well and speak clearly.

Related to the clinical skills necessary to meet parents' varied needs is the issue of training for audiologists and SLPs serving families of children with CIs. The curriculum for audiologists and SLPs emphasizes family-centered practices (ASHA, 2008). Evidence from this study indicates that parents value these practices. The feedback from parents regarding the clinicians serving them was positive on this dimension. Yet parents also highly value technical skills and experience directly related to CIs. This finding has significant implications for trainers and for professional development given evidence that some clinicians do not feel prepared to address the needs of CI users (Compton et al., 2009).

Another implication for practice is that clinicians need to be vigilant about interpreting parents' needs even when feedback from them is highly positive. For example, parents in this study were overwhelmingly positive about audiologists' and SLPs' services and support. Yet on the item involving contact with other parents of deaf children, parents ranked clinicians' performance on this item relatively low when

compared with the importance they ascribed to it. Arranging contact with other parents may be challenging for clinicians or they may not view it within their area of clinical responsibility. Nonetheless, the data suggest that contact with other parents is important. Another potentially challenging implication for clinicians is that the highest rated item for family-centered practice was having sufficient time to talk without feeling rushed. Parents rated clinicians' practice in this area in the lower half of the list of items suggesting that this important (to parents) area needs attention from systems.

A final implication for practice emerging from the study is the use of the MVOS-M. Clinicians may consider using this version of the MVOS to measure satisfaction and family-centered practices those parents find important over time. Measuring parents' input over time is in keeping with the original intent of the MVOS (Bamford et al., 2009). This modified version of the instrument may be appealing to clinics and other settings with a dedicated CI practice. Related to this matter is the need for further study regarding instrument reliability given the changes I made to the MVOS. This study provides a starting point given the similarity of findings in it and Young et al. (2009) regarding paired samples correlations for satisfaction and importance.

A further implication for research dovetails with a limitation of this study. The results from this study are based upon the responses of a largely white and well-educated sample of individuals, suggesting likely membership in at least the middle position on the socioeconomic continuum. Thus, parents in this study who rated respite care lowest in terms of importance may not be representative of individuals who have greater needs and fewer resources than the study sample. Similarly, parents from this study rated consideration of their lifestyle and culture the lowest among the items for importance of

family-centered practice. Parents from minority backgrounds and/or lower socioeconomic status may rate these items differently. More research is needed to discern the views of parents of young children with CIs from diverse racial, ethnic, and socioeconomic backgrounds regarding audiologists' and SLPs service and support delivery.

Summary

In summary, the results of this study have relevance for audiologists and SLPs serving parents and families of young children with CIs. Parents, who are increasingly selecting CIs for children with severe-profound sensorineural hearing loss at early ages, placed a high value on the services and support they receive from these clinicians. Data from this study are consistent with other research in the field in that parents tend to prefer services that support the needs of the deaf child more than services to support the parent. Parents emphasized the importance of services that enhanced their child's use of listening and spoken language and gave high ratings to clinicians' efforts to develop those skills. Parents also gave high ratings to practices consistent with family-centered services and commented not only the benefits of audiology and speech-language services for the child but also on the support parents received.

This study quantified parents' views on services and support thus serving as a bridge between empirical evidence and what occurs in audiology booths and speech-therapy sessions through several key findings. First, the study demonstrates in a systematic way that parents value both the content and the process of services and support from clinicians. Second, the results emphasize that whereas parents are overwhelmingly positive in their feedback, they place the highest value on particular

services that directly impact the deaf child's development of listening and spoken language skills. Third, the results add to the literature on family-centered practice by demonstrating that a specific group of parents – those of young children with CIs – place a high value on characteristics of that model of service, such as collaboration and shared decision-making, within a safe and caring environment.

Broadly stated, the findings add to the literature of parent satisfaction and early intervention services for children with disabilities. That is, the study examined services delivered by audiologists and SLPs, the construct of family-centered practices, and a parent satisfaction measure. More specifically, the study focused on the experiences of parents of young children with CIs. These findings are specific to this particular sample of parents thus calling for additional data collection with parents who represent diverse socioeconomic, cultural and hearing backgrounds.

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APPENDIX A-Content of Intervention Subscales

Table A.1

Content of Intervention Subscales

| Supporting a Deaf Child | Supporting Parents |
|--|--|
| Information about how to communicate with my deaf child | Help to understand how support systems work |
| Help to encourage child's communication skills | Advocacy, e.g. professionals help me to make my needs known and to fight for things if necessary |
| Comprehensive assessments (e.g. language development, hearing) | Referral to other professionals and services |
| Knowledge about how to play with and enjoy my child | Contact with other parents of deaf children |
| Knowledge about how deaf children grow up | Contact with deaf people |
| Confidence in parenting a deaf child | Assistance to claim welfare benefits |
| Information about deaf children's needs and potential | Emotional support for you and your family (partner, siblings) |
| Information about deafness | Support for my whole family, not just me and my deaf child |
| Coordination of all the services and professionals involved with my child and family | Support to make decisions about my deaf child and my family |
| Information about available services | Support to help others understand my child's deafness |
| | Full consideration of my whole family's strengths and needs |
| | Respite care e.g. support for childcare to enable caretakers to take a break |

APPENDIX B-My Views on Services Modified (MVOS-M)

Consent to Participate in Research

Project Title: Parent Perspectives of Audiology and Speech-Language Services and Support for Young Children with Cochlear Implants

Introduction: Please accept my invitation to participate in a doctoral dissertation study. My interest is parents' views of the services they receive from audiologists and speech-language pathologists. The study is limited to parents of children who have used a cochlear implant for at least one year. Children may have a single implant or bilateral implants. The children's ages must be between two years and six years old.

Purpose: The proposed study explores parents' ratings of the amount and importance of the services and support they receive from audiologists and speech-language pathologists following cochlear implantation. The study explores parents' satisfaction with these services and supports. The study also examines the extent to which the professionals' services are family-centered. The survey takes approximately 20 minutes to complete. I recognize that this is valuable time for any parent to give and I appreciate your willingness to consider participation.

Procedures: If you agree to be in the study, you will be asked to:

- Complete this brief, twenty-minute survey.
- The survey includes questions about your experiences with audiology and speech-language services. There are questions about your education and general questions about your family such as the number of children and if there are other persons in your family who are deaf or hard of hearing.
- You will not be asked to include your name or any other personal information.

Risks/Benefits: There are no foreseeable risks involved in participating in this research beyond those experienced in everyday life. There are no direct benefits to you from participation, but your participation will help the field understand what parents value in the services they receive.

Confidentiality:

- No identifying information such as your name or birth date is required.
- Confidentiality will be maintained to the degree permitted by the technology used. No absolute guarantees can be made regarding the confidentiality of electronic data.

Voluntary Participation:

- Participation in this study is voluntary. If you do not want to be in this study, you do not have to participate. Even if you decide to participate, you are free to not answer any question or withdraw from the survey at any point. However, if you do participate in the study, it is helpful if you answer all questions. If you agree, please proceed.

Section One: Professionals working with you and your child

You and your deaf child with a cochlear implant (CI) between 2 and 6 years old could be involved with many services. Please answer the following questions about the PAST YEAR for you, your deaf child, and your close family (partner, siblings.) The survey is divided into these sections:

1. Professionals working with you and your child
2. Services and support you are getting
3. How support is being provided
4. The effects of the support provided
5. Required demographic information

1. Did your child have audiology and speech-language pathology services in the past year?

- ☐ Yes, both ☐ Audiology only ☐ Speech-language pathology only ☐ Neither

If your answer to previous question is "Neither"

If your child received NO audiology and NO speech-language pathology in the past year please STOP here. All the remaining questions are about receiving those services. Thank you!

2. Over the past year how many hours of audiology services on average did your child receive per month?

- ☐ 0 ☐ Less than 1* ☐ 1-4 ☐ 5-8 ☐ 9-12 ☐ 13-16 ☐ 17-20 ☐ 21-24 ☐ 25+

(*if less than 1 hour per month on average then estimate the total number of hours in the past year)

3. Over the past year how many hours of speech-language pathology services on average did your child receive per month?

- ☐ 0 ☐ Less than 1* ☐ 1-4 ☐ 5-8 ☐ 9-12 ☐ 13-16 ☐ 17-20 ☐ 21-24 ☐ 25+

(*If less than 1 hour per month on average then estimate the total number of hours in the past year)

4. Is your audiologist or speech-language pathologist a certified Auditory Verbal Therapist (AVT)?

- ☐ Speech-language pathologist is an AVT
☐ Audiologist is an AVT
☐ Neither are AVTs
☐ Both are AVTs
☐ Don't know

5. Were any of the audiologists and speech-language pathologists who served you in the past year members of your child's original cochlear implant team?

- ☐ A speech-language pathologist
☐ An audiologist
☐ Neither
☐ Both speech-language pathologist and audiologist
☐ Unsure

Section Two: Services and support you are getting

We would like to know what services and support are important to your family.

6. How IMPORTANT was each aspect for you in the past year?

| | Not important | Somewhat important | Important | Very important |
|---|-----------------------|-----------------------|-----------------------|-----------------------|
| a. Information about available services | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| b. Information about deaf children's needs and potential | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| c. Information about deafness | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| d. Information about how to communicate with my deaf child | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| e. How to play with and enjoy my deaf child | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| f. Knowledge about how deaf children grow up | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| g. Help to encourage my child's communication skills | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| h. Comprehensive assessments (e.g. language, development, hearing etc.) | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| i. Referrals to other professionals and services | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| j. Help to understand how professional support systems work | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| k. Advocacy (e.g. professionals that help me make my needs known and fight for things if necessary) | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| l. Assistance to claim insurance benefits | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| m. Co-ordination of all services and professionals involved with my child and family | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| n. Respite care (e.g. support for childcare to enable caregivers to take a break) | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| o. Consideration of my whole family's strengths and needs | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| p. Support for my whole family, not just for me and my deaf child | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| q. Support to make decisions about my deaf child and my family | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| r. Emotional support for me and other family members (partner, siblings) | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| s. Confidence-building in parenting a deaf child | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| t. Contact with other parents of deaf children | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| u. Contact with deaf people | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| v. Support to help others understand my child's deafness | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| w. Information on cochlear implant functioning and repair | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| x. Information on cochlear implant failure and recalls | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| y. Help to encourage my child's listening and spoken language | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |

7. How SATISFIED are you with these services and support from your audiologists and speech-language pathologists?

| | Not satisfied | Somewhat satisfied | Satisfied | Very satisfied |
|---|-----------------------|-----------------------|-----------------------|-----------------------|
| a. Information about available services | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| b. Information about deaf children's needs and potential | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| c. Information about deafness | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| d. Information about how to communicate with my deaf child | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| e. How to play with and enjoy my deaf child | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| f. Knowledge about how deaf children grow up | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| g. Help to encourage my child's communication skills | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| h. Comprehensive assessments (e.g. language, development, hearing etc.) | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| i. Referrals to other professionals and services | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| j. Help to understand how professional support systems work | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| k. Advocacy (e.g. professionals that help me make my needs known and fight for things if necessary) | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| l. Assistance to claim insurance benefits | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| m. Co-ordination of all services and professionals involved with my child and family | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| n. Respite care (e.g. support for childcare to enable caregivers to take a break) | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| o. Consideration of my whole family's strengths and needs | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| p. Support for my whole family, not just for me and my deaf child | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| q. Support to make decisions about my deaf child and my family | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| r. Emotional support for me and other family members (partner, siblings) | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| s. Confidence-building in parenting a deaf child | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| t. Contact with other parents of deaf children | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| u. Contact with deaf people | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| v. Support to help others understand my child's deafness | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| w. Information on cochlear implant functioning and repair | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| x. Information on cochlear implant failure and recalls | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| y. Help to encourage my child's listening and spoken language | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| z. OVERALL, how satisfied are you with the support you are getting? | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |

8. For any aspects listed in a - y of the previous question did you receive NO support or TOO LITTLE support from your audiologists or speech-language pathologists? If so, identify those aspects. For example, if you received no support on item "t" ("contact with other parents of deaf children") put: "t" in the "No support" box below. List all that apply.

No support for these aspects

Too little support for these aspects

Section Three: How support is being provided

Please let us know your views on how audiologists and speech-language pathologists worked with you over the past year.

9. To what EXTENT were your audiologists and speech-language pathologists:

| | Not at all | Somewhat | About right | Great |
|---|-----------------------|-----------------------|-----------------------|-----------------------|
| a. Flexible in arranging meetings that take into account your family's availability. | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| b. Adapting to your needs (e.g. reconsidering what they had planned to do with you on a particular appointment to meet your needs). | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| c. Trusting you as the 'expert' on your child. | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| d. Providing enough time to talk about your child without feeling rushed. | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| e. Working together with you in designing and deciding the support you want for your child and family. | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| f. Taking into account your family's culture and lifestyle when working out support plans. | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| g. Planning in a co-ordinated fashion (so you, audiologists, and speech-language pathologists all work in the same direction) | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| h. Providing positive feedback that makes you see your strengths in parenting your child. | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| i. Treating you as an individual rather than just a typical parent of a deaf child. | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| j. Working towards building up your understanding of information (explaining its full meaning and its relevance at each stage). | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| k. Able to see your viewpoint. | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| l. Providing a safe and caring atmosphere for you and your child. | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| m. Following up on things discussed at previous visits. | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| n. Answering your questions fully. | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| o. Communicating high expectations for your child and your family. | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| p. Working in partnership with you and your family. | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| q. Providing updated and comprehensive information in a planned way. | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| r. Providing an optimistic view of the future for your child and family. | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |

10. How IMPORTANT is each aspect for you?

| | Not important | Somewhat important | Important | Very important |
|---|-----------------------|-----------------------|-----------------------|-----------------------|
| a. Flexible in arranging meetings that take into account your family's availability. | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| b. Adapting to your needs (e.g. reconsidering what they had planned to do with you on a particular appointment to meet your needs). | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| c. Trusting you as the 'expert' on your child. | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| d. Providing enough time to talk about your child without feeling rushed. | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| e. Working together with you in designing and deciding the support you want for your child and family. | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| f. Taking into account your family's culture and lifestyle when working out support plans. | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| g. Planning in a co-ordinated fashion (so you, audiologists, and speech-language pathologists all work in the same direction) | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| h. Providing positive feedback that makes you see your strengths in parenting your child. | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| i. Treating you as an individual rather than just a typical parent of a deaf child. | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| j. Working towards building up your understanding of information (explaining its full meaning and its relevance at each stage). | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| k. Able to see your viewpoint. | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| l. Providing a safe and caring atmosphere for you and your child. | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| m. Following up on things discussed at previous visits. | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| n. Answering your questions fully. | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| o. Communicating high expectations for your child and your family. | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| p. Working in partnership with you and your family. | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| q. Providing updated and comprehensive information in a planned way. | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| r. Providing an optimistic view of the future for your child and family. | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |

Section Four: The effects of the support provided

We are interested in knowing the results of audiologists' and speech-language pathologists' support for you, your child, and your family over the past year.

11. Overall, how MUCH have audiologists and speech-language services made a positive difference for the following members of your family?

| | Not at all | | | Very much |
|---------------------------------|-----------------------|-----------------------|-----------------------|-----------------------|
| Your child | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Your family (partner, siblings) | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Yourself | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |

12. What has made the biggest difference for you and your family relative to receiving audiology and speech-language pathology services?

Section Five: Required demographic information

Demographic information will only be used in the aggregate.

13. Age of your child with a CI:

| | 1 month to 1 year old | 2 years | 3 | 4 | 5 | 6 years | Older than 6 |
|---|--------------------------|-----------------------|-----------------------|-----------------------|-----------------------|-----------------------|-----------------------|
| How old was your child when he/she received a cochlear implant? | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| How old is your child now? | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |

14. Did you and your child with a CI receive any of these educational services in past year? Check all that apply.

- ☐ Early intervention (birth to age 3)
- ☐ Educational services (ages 3 to 6)
- ☐ Auditory Verbal Therapy (from someone other than your audiologist or speech-language pathologist)
- ☐ Parent Education

15. Does your child with a CI have any other special needs? Check all that apply.

- ☐ None ☐ Vision loss ☐ Physical challenges ☐ Developmental concerns ☐ Health conditions ☐ Other

Other (please specify)

16. What gender is your child with a CI?

- ☐ Boy ☐ Girl

17. What is the total number of children in your family?

- ☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5+

18. Please tell us your position in the family.

- ☐ Mother ☐ Father ☐ Grandparent ☐ Other relative acting as parent ☐ Guardian

19. Are you or the other parent of your child with a CI deaf or hard of hearing?

- ☐ Neither parent is deaf or hard of hearing ☐ One parent is deaf or hard of hearing ☐ Both parents are deaf or hard of hearing

20. What is your highest level of education?

- ☐ Elementary (1-8) ☐ High school (9-12) ☐ College (13-16) ☐ Graduate school (17+)

21. What race/ethnicity do you use to describe yourself? Check all that apply.

☐ American Indian or Alaskan Native

☐ Other

☐ Asian

☐ White

☐ Black or African American

☐ Hispanic or Latino ethnicity

☐ Native Hawaiian or Other Pacific Islander

☐ Non Hispanic/Latino ethnicity

22. What U.S. state do you live in?

State:

23. OPTIONAL: Provide your email address if you wish to be informed of results.

Email Address:

Thank you for contributing to research on young children with cochlear implants and their families. Please consider forwarding this survey link to parents you know who are eligible to participate. Please make sure to press the "Done" button when you are finished.

APPENDIX C-Variables Created for Importance and Satisfaction

Table C.1

Variables Created for Importance and Satisfaction-Section 2 of MVOS-M

| Variable | Section/Item in Survey | Likert Item |
|--|------------------------|-------------------------|
| Importance of services to child (IMP_C) | Section 2, Item 6 | a,b,c,d,e,f,g,h,m,s |
| Importance of services to parent (IMP_P) | Section 2, Item 6 | i,j,k,l,n,o,p,q,r,t,u,v |
| Satisfaction with services for child (SAT_C) | Section 2, Item 7 | a,b,c,d,e,f,g,h,m,s |
| Satisfaction with services for parent (SAT_P) | Section 2, Item 7 | i,j,k,l,n,o,p,q,r,t,u,v |

APPENDIX D-Parent Responses Regarding Biggest Positive Difference-Services

Characteristics of Providers

1. Our audiologist has made the biggest difference, The S/LP has made little or a negative difference for us. Our audiologist is highly skilled and trained, while the S/LP provided through the school district has no current or relevant training in order to meet the needs of oral deaf children. The most significant service that has been provided has been by our AVT who communicates directly with our audiologist.
2. Having an audiologist who has worked with us since my son was diagnosed with hearing loss, through both CI surgeries, and now that my child is school aged has been very beneficial to us.
3. Having the audiologist and speech therapist communicate with each other and the family. Giving all information so that we as the family could make the best decision for my child and family.
4. They are smart and knowledgeable people!
5. The level of expertise of our audiologist and speech pathologist. i believe I have two of the best qualified and most effective members in my team in the entire region (not just state). The "above and beyond" level of care and thought put into helping my child, where I know they were thinking about my child between appointments and researching what could help. They are very flexible in helping her at whatever state she was at.
6. When we were told that our child was deaf you are thrown into a world where you didn't really know anything. We had never been around anyone who was deaf. We didn't know the services that were needed across the board--SLP, audiology and educationally. Parents are relying our audiologist and SLPs to help them navigate in this new world. We know that our SLP and audiologist are busy but at times it is very frustrating to send an e-mail and not get a response back. I think sometimes the professionals need to step back and think what if this was my child.
7. I've been very well informed by my Audiologist Department in terms of choices. I wasn't connected too much with other families that have gone through it but that would have been nice. I have great relationships with his SLP and Aud. and that has made a tremendous difference. They have educated me, been patient, were genuine with my concerns and not once treated my child like a patient but a family member. I felt so comfortable discussing practically everything with them and they have also been a world of resources for me in many other areas such as school district and references.

8. My son was having problems w/his cochlear implant. One audiologist had no idea on what to do, so we switched and they got my son to wear his processor again. I hope they know how important that was to us and lifted a big weight off of my shoulders.

9. Having experts to guide us through the process; we had no experience, but they helped us find our way.

10. Consistent weekly speech with accountability and encouragement to work hard at home promoting language for my son every day. Also the availability of our audiologist to answer questions at any time.

11. We changed my son's speech pathologist in the past year and he talks all the time. He feels very comfortable and she makes speech fun and interesting for him. His audiologist always gives us helpful info and we have her email so we can get her help any time. My son has come a long way with all this help!

12. The clinicians have been the primary sources of information since surgery. We depend upon both our audiologist and speech-clinician greatly.

13. Ability to coordinate visits between different services (we have 2.5+ hr commute to audiologist, ENT, etc)

14. Knowing we are in good hands with our audiologist and that we can trust her expertise. Like the fact that I can email her when I have questions and she usually gets back to me very quickly.

15. My daughters world opened up after her implant, and all of our audiologists and speech therapists helped with this process.

Communication Outcomes

1. My son has learned how to hear and will build on this as the beginning of communication.

2. would not have been able to do it without them. Had no clue where to start in this hearing journey. Our Maddie has went from no speech to now being able to communicate with people in her daily life, church, school, family, and outside activities. She is learning something new every day.

3. Other than learning to communicate with our daughter better we are grateful for them updating her maps to keep her up to date and teaching us new tools as parents.

4. Daughter has started speaking and recognizing sounds.

5. Being given the information on how to incorporate learning (speech & language) into everyday routines and everyday life. Because therapy time alone is not sufficient to help children reach potentials. Also, audiology appointments are too rushed.
6. We have learned have to effectively communicate with our daughter and we are seeing such huge improvements in her speech and language development because of consistent speech therapy and appointments with her audiologist.
7. Assurance of proper adjustment of implant and maximizing use.
8. When their goal is oral-verbal, then it makes a great different for a child with a CI(s). If not, then they are more a hinderance than a help.
9. My child had the understanding of word & picture but could not speak after the surjury & the 2-3 month of the AVT my child started to speck
10. How to go about teaching child various activities to increase listening/communication/verbal skills.
11. My child's continued progress and the provision of practical tools to reinforce his continued language development.
12. My daughter has improved a lot in the past one year with regards to speech. Progress is slow and steady. A year ago she couldn't even say the ling sounds.
13. I learned early after the implant that aggressive speech-language therapy was necessary for my grandchild to benefit from the implant. It doesn't just happen when it is turned on!
14. Being able to have a normal conversation with my child! Seeing and watching her come into her "hearing". It's just awesome to know she will be able to live and communicate the with the whole world!

Effect on Parents

1. They've helped get us to where we are today. They've taught me, guided me, comforted me, and given me the confidence that I can do this; the confidence that my son will be okay.
2. Their encouragement that our child's success was based on how much we as parents were willing to do. They gave us the tools and put us to work. We have been so pleased with our audiologist and SLP. They have a great relationship with our son and he had grown so much in his listening and speaking skills. They are our "go to" people whenever we need help making a decision or have questions. Our weekly SLP will be AVT certified in October 2012. We see an AVT certified SLP twice per year.

3. Getting educated about how to work with and enjoy my child.
4. Being able to fully explain to the professionals my fears of the uncertain, and they making my questions and concerns feel warranted
5. Encouragement, professionalism, success for my child
6. As a parent, a few years into this journey, you develop a "gut feeling" as to where your child is at, what the next step needs to be, what strategies to employ, what to expect, what to ask for, but at the end of the day, I am just the parent and not the professional and I need affirmation and confirmation grounded in facts and research and the professionals' own past experiences working with families of d/Hoh children. I need to a) feel like I'm heard and understood and b) to have verified that my instincts are correct and then c) take those ideas to the next level so that I can learn more. That has made the biggest difference to me - having these professional "partners" to support me and help me to grow and keep learning in order to help my child as best I can.
7. their willingness to support our decisions and not forcing us into AVT when we chose Total Communication.
8. All the detailed explanations that increased my knowledge and understanding on how to best help my child. And any information on recent research.
9. Knowledge and understanding of information I would not have been able to fully comprehend without their help and support.
10. to learn what to do! how to talk and how to live a normal life. how to go through all the deep and sad moments. how to be happy about every single step.
11. Finding services that agree with my point of view. I have gone through a few and once i have found the ones who see my point of view it has been a wonderful experince and i have seen such amazing growth in my son since all of us are on the same page.
12. Having services available closer to home.

Positive Program Descriptions

1. Attending Atlanta Speech School has by far made the biggest positive impact on our family. We are/were able to streamline services in one location with a group of professionals that cover the whole spectrum of needs for students with cochlear implants.
2. Having daily (5 days a week) Speech has been the best thing. We have been very lucky to have an audiologist at our school, so she has been able to do some testing weekly in small time frames that has allowed us to get good results and a great map. I am disappointed in my normal Kaiser Audiologist for dropping the ball once we started working with the school Audiologist. She has not been a team player and in fact I feel

she is passing us off to the school audiologist. Luckily we love our school audiologist. As for Speech, we have been able to keep the same Speech teacher for three years, and this has been helpful to work with one person. Usually they will change up every two years, but we pushed for some constance since we were also changing teacher. My son goes to the CCHAT Sacramento 5 days a week for 4 1/2 hours per day, which includes a 1/2 hour of speech. This is an oral school and has been the best choice we could choose for our family. Audiology and Speech support is everything. Without a good program, we would not know for sure he is hearing, and without the pull thru of speech, he would not know how to talk. Techology is great!!

3. Our audiologist care has been through CCCDP at Chapel Hill. These ladies have been so laid back and helpful and informative. Their outlook calmed us and we always felt like we had a plan, we had a goal.

4. The biggest difference is to take part in the unique John Tracy Way

5. My son has made much progress and is talking after one year. Being at JTC's preschool

6. Enrolling my child in the Moog Center for Deaf Education in St Louis, even though it meant moving the family. The support we get there, and the sheer number of hours with certified AVTs a week, is astounding. One hour a week with our previous AVT was ok, but now our child is about a year ahead of even normal-hearing children in his language skills.

Positive Outlook

1. understanding of the profoundness of the hearing loss; being positive about my child's potential; their interaction with all members of my family.

2. finding providers who have an optimistic, sky is the limit-style view of a child's future and helping us make our way there

3. To learn what to do! How to talk and how to live a normal life. How to go through all the deep and sad moments. How to be happy about every single step.

4. to realize my child has the potential to have a normal life. To give us the tools to help him, and allowing us to actively participate

5. Treating my child as an individual and considering her strengths and weaknesses when determining appropriate services.

Advocacy

1. The availability and willingness of the team to be there for my child and the love and concern they all have for the lifelong well being of my child.

2. PROVIDERS WHO ARE WILLING TO GO THE EXTRA MILE TO MEET OUR SONS NEEDS. MY SON IS BI LATERAL COCHLEAR IMPLANTS AND HAS BEEN ASSIGNED A PARA IN SCHOOL WHO SIGNS. HE ALSO IS ASSIGNED A SPEECH THERAPIST, SENSORY INTEGRATION THERAPIST, AUDIOLOGIST AND WILL BE EXCELLING INTO THE 1ST GRADE NEXT YEAR. HE GETS ALL OF THESE SERVICES IN THE SCHOOL. I AM VER BLESSED

Other

1. This is a tough survey to answer, since the audiologist available in our community has changed, and the experienced speech therapist at the centerbased program retired. Now I find the new professionals significantly lacking in experience, and one support sign and speech and the other dismisses sign. My child still needs sign support with a late cochlear implant. Very frustrating to have to ask them what to do when I have only been "in the field" just a few years myself, and as a parent, not a professional.

2. Everything

3. Nothing

4. Teacher of D/HH is a very strong advocate for my child and is very flexible to use different approaches to help my child communicate. She (my daughter) also has Autism Spectrum Disorder and her teacher (D/HH) has been in close contact with other professionals and found the best techniques to help my child