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**PARENTAL EXPERIENCES WITH EARLY CHILDHOOD SERVICES FOR
THEIR CHILD WITH HEARING LOSS**

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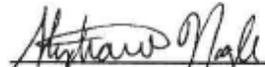
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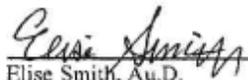
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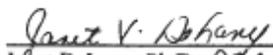
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Abstract

PARENTAL EXPERIENCES WITH EARLY CHILDHOOD SERVICES FOR THEIR CHILD WITH HEARING LOSS

Emily J. Garrett

The field of audiology lacks research regarding parental satisfaction with the audiological services their child received during the diagnosis and management of their child's hearing loss. Additionally, it is crucial to obtain parental feedback regarding specific aspects of the Early Hearing Detection and Intervention (EHDI) that could be improved in order to increase parental satisfaction and involvement within these services. It is widely known and accepted that parental satisfaction and involvement with the EHDI services lead to more successful outcomes for the children with hearing loss. This study utilized a questionnaire to probe parental experiences. 97 respondents filled out the online-questionnaire regarding their experiences with the newborn hearing screening, audiological services, and early intervention services. The questionnaire involved both closed and open ended questions to allow respondents to expand upon their answers. Overall, results from responses indicated dissatisfaction with the newborn hearing screening process, satisfaction with services received from five different types of audiologists, ENT, and early intervention speech-language pathologist, and satisfaction with early intervention services. Respondents indicated suggestions for areas that needed improvement as well as areas that have exceeded expectations. Results from this study highlight the importance of parental input as well as the importance of positive interactions between parents and professionals. This would improve parent experiences and maximize the possible benefit of the program for the children with hearing loss.

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KEY TO ABBREVIATIONS

- A-ABR:** Automated Auditory Brainstem Response
- AAP:** American Academy of Pediatrics
- ADD:** Attention Deficit Disorder
- ADHD:** Attention Deficit Hyperactivity Disorder
- ASR:** Acoustic Stapedius Reflex
- BAHA:** Bone Anchored Hearing Aid
- CDC:** Center for Disease Control
- CI:** Cochlear Implant Audiologist
- CMV:** Cytomegalovirus
- DPOAE:** Distortion Product Otoacoustic Emission
- EHDI:** Early Hearing Detection and Intervention
- EI:** Early Intervention
- EIA:** Early Intervention Audiologist
- EI SLP:** Early Intervention Speech-Language Pathologist
- ENT:** Ear, Nose and Throat Physician
- ESA:** Educational/School Audiologist
- FM:** Frequency Modulation
- GA:** General Audiologist
- HA:** Hearing Aid Audiologist
- HL:** Hearing Loss
- IDEA:** Individuals with Disabilities Education Act
- IRB:** Institutional Review Board
- JCIH:** Joint Committee on Infant Hearing
- NICU:** Neonatal Intensive Care Unit
- PED-ENT:** Pediatric Ear, Nose and Throat Physician
- TEOAE:** Transient Evoked Otoacoustic Emissions
- UNHS:** Universal Newborn Hearing Screening

CHAPTER 1

Introduction

Congenital hearing loss has been diagnosed in two infants per every 1,000 infants who have received a newborn hearing screening (Center for Disease Control [CDC], 2014). As a result of the newborn hearing screening and early detection program, infants have been diagnosed with hearing loss as early as one month of age (American Academy of Pediatrics [AAP], 2007). This led to earlier implementation of intervention services which provided earlier access and development of speech and language for children with hearing loss. Yoshinaga-Itano, Sedey, Coulter, & Mehl (1998) reported that children who received intervention services prior to six months of age had better language development, better socio-emotional development and better emotional well-being when compared to children who received intervention services after six months of age.

The negative effects of a late-diagnosed congenital hearing loss have been well documented in the literature. Prior to the development of these programs, children with hearing loss were not being identified until around two years of age (Yoshinaga-Itano, 1999). This meant that the children had limited exposure to language, which delayed speech and language skills until they were almost 3 years old (Yoshinaga-Itano, 1999). In addition to the speech and language delays, children with hearing loss typically exhibited increased behavioral issues, low psycho-social development, and lower educational progress when compared to normal hearing children (AAP, 2007).

Research has indicated that success of the early detection and intervention program was highly dependent on parental-involvement and positive parental-professional relationships throughout the programs (Danahauer, Pecile, Johnson, Mixon,

& Sharp, 2008; DesGeorges, 2003; Eleweke, Gilbert, Bays, & Austin, 2008; Fitzpatrick, Angus, Durieux-Smith, & Graham, 2008; Larsen, Muñoz, DesGeorges, Nelson, & Kennedy, 2012). Parents play a critical role in ensuring successful outcomes of early intervention services for their child (DesGeorges, 2003; Eleweke et al., 2008; Fitzpatrick et al., 2008). Therefore, application of a family centered approach during the early detection and intervention process, has been highly recommended throughout the literature (Crais, Roy, and Free, 2006; Eleweke et al., 2008; Fitzpatrick et al., 2008; Muñoz, Bradham, & Nelson, 2011). The family centered approach promotes self-efficacy and confidence in the parents which lead to increased parental involvement in the services (Eleweke et al., 2008; Fitzpatrick et al., 2008). Increased parental involvement has led to higher follow up rates and better long-term outcomes for the children with hearing loss (Fitzpatrick et al., 2008).

Since parents play such a critical role in the success of the early detection and intervention program for their children, the goal of this study was to evaluate parental feedback regarding their experiences with the newborn hearing screening, audiological services, and early intervention services. This study assessed: (a) the effect of demographic factors on parent satisfaction with the audiologists or intervention services; (b) the effect of the type of interaction (positive or negative) with audiologists on parental satisfaction/involvement with early intervention services; (c) the effect of parental involvement with their child's early intervention services on positive feedback about the program; (d) overall themes of parental feedback. Results from this study will be used to educate professionals on parental needs to facilitate better developmental outcomes for the children with hearing loss.

CHAPTER 2

Review of the Literature

Early Hearing Detection and Intervention

The Early Hearing Detection and Intervention program (EHDI) was created to minimize the impacts of congenital hearing loss on speech and language development and socio-emotional development of the child (AAP, 2007; Moeller, White, & Shisler, 2006; Yoshinaga-Itano, 2004; Yoshinaga-Itano, Coulter, & Thomson, 2001). The goal of this program was to screen all infants by one month of age, evaluate and diagnose infants who did not pass the screening by three months of age, and implement intervention services by six months of age (AAP, 2007). These guidelines were established to allow for the development of speech and language skills, socio-emotional skills and academic skills similar to their normal hearing peers (AAP, 2007). In order to meet these goals and ensure successful outcomes, research has suggested that professionals involve the children's parents and families throughout the entire process (Danhauer et al., 2008; DesGeorges, 2003; Eleweke et al., 2008; Fitzpatrick et al., 2008; Larson et al., 2012). When families are educated and involved throughout the EHDI process, developmental outcomes for children are more successful (Fitzpatrick et al., 2008). There is a lack of research regarding parental satisfaction with their child's audiological services as well as the influence of these audiological services on feelings of satisfaction with their child's early intervention services.

Universal Newborn Hearing Screening

The screening process identifies newborn infants with a potential hearing loss. Professionals conducting the hearing screenings refer those infants for diagnostic testing

in order to diagnose a hearing loss as early as possible (Moeller et al., 2006). Early identification of hearing loss is imperative for earlier implementation of intervention services (Yoshinaga-Itano, 2004; Yoshinaga-Itano et al., 2001). When intervention services are provided prior to three years of age, a child with hearing loss has a better chance of developing normal speech and language development (Yoshinaga-Itano, 2004; Yoshinaga-Itano et al., 2001).

Yoshinaga-Itano et al. (2001) assessed the speech and language development of 25 children with bilateral hearing loss who were born in hospitals with a UNHS program and 25 children with bilateral hearing loss born in hospitals without a UNHS program. Investigators wanted to determine if the UNHS program outcomes were being met. In order to compare language abilities and speech scores, participants were matched for age and degree of hearing loss. They further divided the children into groups based on if they received their diagnosis before or after six months of age. When compared to the children born in a hospital without the UNHS program, children born in hospitals with the program had better receptive and expressive language, a larger variety of consonants in spontaneous language, and better speech intelligibility. Additionally, children who received a newborn hearing screening were twice as likely to have language in the normal range when compared to the children who were not screened at birth.

Screening protocols. The UNHS consists of otoacoustic emissions (OAEs), an automated auditory brainstem response (A-ABR), or a combination of both audiological tests (Johnson, et al., 2004; Rhodes, Margolis, Hirsch & Napp, 1999; Widen, Bull & Folsom, 2003). The one stage screening protocol utilizes one audiological test measure where as a two stage screening protocol utilizes both OAEs and an A-ABR (AAP, 2007;

Widen et al., 2003). Although every program can be set up using either protocol, some programs choose a two stage protocol in order to decrease referral rates and the need for follow up screenings (AAP, 2007). However, a two stage screening protocol is recommended for infants in the NICU due to the increased chance of neural hearing loss in this population (AAP, 2007). The A-ABR/OAE combination allows professionals to differentiate between sensory and neural hearing problems (Widen et al., 2003). The OAE examines the integrity of the peripheral auditory system extending to the outer hair cells of the cochlea whereas the A-ABR tests the integrity of the peripheral auditory system, the eighth nerve, and the brainstem auditory pathway (AAP, 2007; Widen et al., 2003). If OAEs are absent but an A-ABR is present, this is indicative of a sensory problem (Widen et al., 2003). If the OAEs are present but the A-ABR is absent, this is indicative of a neural problem known as auditory neuropathy (Widen et al., 2003).

Rhodes et al. (1999) evaluated screening methods to determine whether a single method or combination of methods was the most effective for identification of infants with hearing loss as well as identification of those without hearing loss. They performed A-ABR, transient evoked otoacoustic emissions (TEOAE), distortion product otoacoustic emissions (DPOAE) and acoustic stapedius reflex (ASR) tests on 173 ears. A combination of DPOAEs and the A-ABR were found to be the most efficient. When the A-ABR was used as a follow up test, 90% of infants that initially failed the screening received a pass result.

Clinical professionals. The success of the newborn hearing screening program is highly dependent upon the support and knowledge base of the professionals involved (Danhauer et al., 2006; Goedert, Moeller & White, 2011; Shulman et al., 2010).

Professionals such as Otolaryngologists (ENTs), audiologists, nurses, midwives, and pediatricians play key roles in the screening process as well as the follow up process (Danhauer et al., 2006; Goedert et al., 2011; Larsen et al., 2012; Shulman et al., 2010).

Pediatric-ENTs (n=233) were surveyed to assess their opinions of the newborn hearing screening process and their roles in the process (Danhauer et al., 2006). It was theorized that PED-ENTs may not be aware of the importance of their role in the screenings. Although PED-ENTs demonstrated adequate knowledge of the newborn hearing screening program and supported the program, they requested additional information regarding national benchmarks such as the one-three- six rule. By providing professionals with more information about the process and the national requirements, the “wait and see” attitudes of professionals was discouraged (Danhauer et al., 2006; Shulman et al., 2010). Danhauer et al. (2006) recommended that audiologists collaborate with PED-ENTs in order to increase follow up rates for infants who are referred for further testing. Primary care physicians also felt under- informed and in need of current information regarding hearing screenings, diagnostic testing and early intervention to appropriately counsel parents on what to do next (Arnold et al., 2006).

Attitudes of midwives regarding newborn hearing screenings and their role in the screenings were surveyed by Goedert et al. (2011). Only 68% of the midwives in this survey believed that it was important to have a universal newborn hearing screening program. Midwives were uneducated regarding the screening process, steps for referral and availability of resources for the families. When asked if they were involved in the screening process, 89.1% of the midwives said no but 91% knew that their state mandated some form of a newborn hearing screening. The midwives surveyed felt that

the newborn hearing screening was not their responsibility and they lacked knowledge on where and how to properly refer for a hearing screening or diagnostic testing.

Test results. Parents and professionals have reported significant miscommunications during discussions of the screening results. This miscommunication stemmed from professionals who were unaware of proper terminology and lacked adequate knowledge of results, tests and potential impact of pediatric hearing loss (Danhauer et al., 2008). It also occurred when parents misunderstood the purpose of the screening or what the terms, pass and refer, actually meant (Hewlett & Walsbren, 2006; Widen et al., 2003).

When conveying results, professionals expressed uncertainty regarding appropriate terminology for describing the results to the parents. Most programs did not have standard protocols in place for presenting the results of the screenings (Shulman et al., 2010). Widen et al. (2003) designed a tutorial to educate professionals and interventionists on the newborn hearing screening process and how to appropriately present results. This tutorial encouraged standardization of terminology used to counsel parents on the screening results and what they mean. Widen et al. (2003) recommended using the terms, pass and refer, to describe the results of the screening. A pass result meant, at the time of the test, the infant had results consistent with normal hearing. A refer result indicated the need for additional diagnostic testing to confirm or rule out the presence of a hearing loss. The word, fail, was highly discouraged when discussing screening results with parents.

Danhauer et al. (2008) surveyed thirty-four parents to evaluate their experience with the professionals who conducted their infants' newborn hearing screening. They

investigated the influence of parent-professional interactions on follow up rates.

Investigators reported that parents often misunderstood the results of the screenings.

Investigators suggested that professionals avoid giving false hope of normal hearing after the infants failed the first screening.

Parents should be encouraged to ask questions about the screening process and results. Poon, Jamieson, Buchanan and Browne (2008) examined how hearing screening results were conveyed in a two-stage UNHS program. They observed twelve interactions between four mothers and one screener. The screener only used yes or no questions, requests and declarative statements when communicating with the parents. This type of interaction between the parents and the screener led to less parent initiated questions. Researchers suggested that communication between parents and the screeners be facilitated in a way that encourages parents to ask questions to gain a better understanding of the screening process and results.

If professionals conducting the screenings felt more confident in their knowledge about the process and how to present the results, the emotional burden on the parents would be reduced. Through a comprehensive review of current literature, Hewlett and Waisbren (2006) found that false-positive screening results could generate stress and anxiety in the mothers. They suggested that informational material on the UNHS process and proper ways to convey screening results should be provided to professionals. Another suggestion was the creation of an advisory board consisting of parents, primary care providers and pediatricians. The board would be responsible for publishing educational materials for parents and professionals regarding the UNHS program and process.

Early Detection of Hearing Loss

Follow up. The CDC stated that 45.9% of infants who received a referral for additional diagnostic testing did not follow up (2014). Several studies have confirmed that follow up rates for infants who received a “refer” result on their screenings were unacceptably low (Danhauer et al., 2006; Danhauer et al., 2008; Fitzpatrick et al., 2008; Goedert et al., 2011; Holte et al., 2012, Larsen et al., 2012; Shulman et al., 2010). A variety of factors were established as causes for the low follow up rates. Factors included: lack of service system capacity, family constraints, lack of provider knowledge and insurance company complications (Danhauer et al., 2006; Danhauer et al., 2008; Fitzpatrick et al., 2008; Goedert et al., 2011; Holte et al., 2012, Larsen et al., 2012; Shulman et al., 2010). Failure to follow up for those who did not initially pass and failure to screen universally were shown to be two major threats to the UNHS program (Goedert et al., 2011).

Lack of service system capacity was one the of the most frequently cited reasons for low follow up rates (Fitzpatrick et al., 2008; Holte et al., 2012; Larsen et al, 2012; Shulman et al., 2010). Shulman et al. (2010) surveyed fifty-five program coordinators and conducted site visits of eight universal newborn hearing screening programs across the United States of America. They identified factors that created barriers along each step of the EHDI program. Facilities that participated in their study stated that their facility had insufficient screening equipment and lacked appropriate screening protocols. Programs did not have sufficient equipment and protocols partially due to a lack of funding to purchase and sustain equipment and qualified professionals (Holte et al., 2012). In addition to those factors, a lack of pediatric audiologists was noted as a major

contributor to low follow up rates (Fitzpatrick et al., 2008; Larsen et al., 2012; Shulman et al., 2010). The shortage of pediatric audiologists made timeliness of service delivery a challenge to the program (Fitzpatrick et al., 2008; Larsen et al., 2012).

Family constraints were also recognized as key factors in loss of follow up (Danhauer et al., 2008). Through a retrospective chart review, Danhauer et al. (2008) reported that 60% of infants who did not pass the screening were lost to follow up. They surveyed thirty-four parents to identify their reasoning for not following up. Parents experienced difficulty attending the follow up appointment because they had to rearrange their schedules, find childcare for siblings and find transportation. Fitzpatrick et al. (2008) surveyed twenty-one parents whose children were identified either by the newborn hearing screening program or traditional referral. Families in this study cited distance to the audiologist's office as a major barrier to follow up. Larsen et al. (2012) found similar results in which parents stated that the long distance required to travel to a qualified facility was a challenge.

Additional deterring factors included lack of provider knowledge, complications with insurance and variability in follow up protocols (Fitzpatrick et al., 2012; Holte et al., 2012; Larsen et al., 2012; Shulman et al., 2010). Larsen et al. (2012) reported that professionals conducting the screenings felt that they did not have accurate information regarding where the infant could go for diagnostic testing. Professionals also felt that they had insufficient patient populations needed in order to develop expertise of both the UNHS program and early detection program (Shulman et al., 2010). Additionally, complications with insurance companies have delayed follow up or discouraged families from follow up altogether (Holte et al., 2008; Larsen et al, 2012).

Referral to early intervention. The audiologist is legally required to refer a child with hearing loss to a Part C early intervention program within two business days following the diagnosis (Muñoz et al., 2011; Widen et al., 2003). Once a child is diagnosed with hearing loss, intervention services should immediately follow (Yoshinaga-Itano, 1999). According to the 2012 CDC Summary of National EHDI data, only 84.6% of children diagnosed with hearing loss were referred for early intervention services (CDC, 2014).

Parental experiences. Arnold et al. (2006) identified what parents and professionals considered important for efficient communication between parents and professionals regarding the newborn hearing screening program. They conducted twenty-nine focus groups and twenty-three individual interviews. Participants included both English and Spanish speaking parents of infants (<18 months) who had experienced the screening process and interacted with a variety of professionals during the process. Arnold et al. (2006) reported that it would have been helpful if the importance of following up was conveyed to the parents in their own language. Parents stated that they wished they had been educated about the hearing screening process prior to giving birth.

Larsen et al. (2012) examined parental experiences with the diagnostic evaluation process. Professionals seemed to have difficulty communicating and connecting with parents regarding the next step following diagnosis of a hearing loss. This led to parents feeling overwhelmed and lost when trying to navigate the system themselves. Parents were unsure of which professionals to contact for information on what to do next. When surveyed, 91% of parents received information on hearing loss, 58% received information on hearing aids and 56% received information on early intervention.

Jackson, Wegner, and Turnbull (2010) surveyed family members to assess their perception of the quality of their lives following the early identification of their child's hearing loss. Although most families were generally satisfied with the audiologic services they had received, a majority of them had low satisfactory ratings in the emotional well-being category. It was recommended that families receive counseling/emotional support from early intervention programs in addition to the services the child with hearing loss receives.

Early Intervention for Children with Hearing Loss

Purpose. Children with hearing loss exhibit increased behavioral issues, lower psycho-social well-being and lower educational progress when compared to children with normal hearing (AAP, 2007). Several different professions have provided services to children with hearing loss to ensure that they received the most appropriate medical, audiological, speech and language, and educational interventions possible (Nelson, Bradham, & Houston, 2011). In addition to professional services, the early intervention component also encompassed technology and rehabilitation for a child with hearing loss (Fitzpatrick et al., 2008). The services aimed to encourage language development, parent-child communication, development of social skills and if possible, use of residual hearing (Eleweke et al., 2008).

Early intervention must follow early detection in order to enable the child to be successful in every-day life and in their educational career (Eleweke et al., 2008; Fitzpatrick et al., 2008; Nelson et al., 2011). An important goal of the early identification program is to facilitate effective parent-child communication as soon as possible following the diagnosis of hearing loss (Eleweke et al., 2008). Effective communication

between the parent and child is a strong predictor for successful overall development of a child with hearing loss (Eleweke et al., 2008).

Federal mandates. Early intervention services have been federally mandated by Part C of the Individuals with Disabilities Act (Nelson et al., 2011; Proctor, Niemeier, & Compton, 2005). President George W. Bush re-authorized IDEA to require states to develop their own eligibility criteria as well as develop their own plans on how services are rendered (Nelson et al., 2011). It is the responsibility of the state to ensure positive outcomes for the children and their families (Proctor et al., 2005). Systems need to be developed that allow adequate communication between audiologists, physicians and early interventionists to facilitate a smooth transition between early detection and early intervention (Nelson et al., 2011).

Recommended Protocols

Family centered approach. A family centered approach has been recommended as the best option for creating a successful early intervention plan for a child with hearing loss (Crais et al., 2006; Eleweke et al., 2008; Fitzpatrick et al., 2008; Muñoz et al., 2011). Parents have reported feeling overwhelmed with the process which creates a strong need for information, guidance and emotional support through the child's early intervention program (Muñoz et al., 2011). Intervention services should encourage the family, as a whole, to educate themselves on childhood hearing loss and its potential impacts on the development of the child and on the family structure (Eleweke et al., 2008; Fitzpatrick et al., 2008, Muñoz et al., 2011).

Fitzpatrick et al. (2008) surveyed twenty-one parents of children under the age of five years who were identified through the neonatal screening and through traditional

referrals. Investigators wanted to categorize strengths and weaknesses of the early intervention program and allow parents to express what they felt they needed during the process. Through this study, investigators concluded that appropriate support for the families of children with hearing loss impacts the success of the early detection and intervention programs. More specifically, programs that took a family centered approach promoted self-efficacy in the parents, which resulted in higher follow-up rates and better outcomes for children with hearing loss, due to increased involvement in the early intervention services. Fitzpatrick et al. (2008) suggested that programs consider aligning services with parent expectations to encourage better outcomes.

Crais et al. (2006) examined whether professionals and families agreed upon which family centered services were actually implemented and which services were considered essential for future assessments. They surveyed one hundred and thirty-four early intervention professionals from various professions as well as fifty-eight family members. Participants were asked to categorize forty-one family centered practices as either actual practices, ideal practices, or both. Crais et al. (2006) found that professionals' and families' agreement was fairly high regarding practices that were implemented and essential practices. However, they did find that the practices that were considered important for success were not the practices that were actually being implemented in early intervention programs.

Conveying information. An early intervention program should provide unbiased information that provides parents with enough evidence to guide their decision making regarding services and communication options (Decker, Vallotton, & Johnson, 2012; Eleweke et al., 2008; Fitzpatrick et al., 2008; Nelson et al., 2011). Eleweke et al. (2008)

suggested that families receive timely and unbiased information to allow them to respond to their emotions in an appropriate manner. Families have reported a need for more specific information on childhood hearing loss such as etiology, severity, and amplification options (Eleweke et al., 2008; Fitzpatrick et al., 2008). They have also reported a need for information on the consequences of hearing loss, prognosis, therapy options, communication options and education options (Eleweke et al., 2008; Fitzpatrick et al., 2008). Families wanted access to information that would allow them to educate themselves on services and resources available to themselves and their children with hearing loss (Fitzpatrick et al., 2008).

Families should be receiving this information from their audiologist, physician and/or early intervention service providers (Decker et al., 2012; Nelson et al., 2011). However, Nelson et al. (2011) reported that early interventionists felt that they lacked the knowledge to appropriately provide families with the most accurate information. This ignorance resulted in inadequate service delivery for the child and their families during early intervention services. In order for families to be properly educated, service providers should have had access to appropriate, unbiased information to provide to the families as well. Families tend to internalize and highly respect opinions of professionals; therefore, when professionals are properly educated, families can receive more accurate, up-to-date information that can help guide them through the intervention process (Decker et al., 2012).

Service coordination. As mandated by Part C of IDEA, each enrolled family should be assigned a service coordinator who is responsible for communicating with the agencies providing services to the child and the family (Bruder et al., 2005). The service

coordinator is the main point of contact for the family to help them navigate the system and ensure they are receiving the necessary services in a timely manner (Bruder et al., 2005; Jackson et al., 2010). Part C of IDEA did not designate a certain profession responsible for the service coordinator role (Bruder et al., 2005). Bruder et al. (2005) stated that, according to Part C of IDEA, a service coordinator should:

coordinate the performance evaluation and assessments, facilitate and participate in developing, review and evaluation of individualized family service plans (IFSP), assist families in identifying available service providers, coordinate and monitor the delivery of available services, inform families of the availability of advocacy services, coordinate with medical and health providers, facilitate development of a transition plan for preschool services, if appropriate. (p. 178)

A majority of states did not mandate that service coordinators attend training on how to effectively coordinate services (Bruder et al., 2005). Therefore, service coordinators were unaware of how to effectively perform their job in a way that allowed families to receive full benefits from their services.

Bruder et al. (2005) identified areas of service coordination that could potentially be measured to evaluate the effectiveness of this component of early intervention. Due to the emphasis on outcomes and evidence based practices in early intervention, Bruder et al. (2005) focused their study on measurement of the service coordination outcomes as a way to evaluate the effectiveness of early intervention services provided under Part C of IDEA. They surveyed families and providers who had participated in early intervention in order to examine their knowledge of and experiences with the service coordination component of the program. They found that family members were unaware of a service

coordination system in their communities or state. Service providers stated that funding, personnel, caseload and service structures played a significant role in the ability to provide coordinated services to the child with hearing loss and their family. Fitzpatrick et al. (2008) reported similar difficulties regarding funding and access to coordinated care for families. They also reported a lack of coordination between the clinics and providers which can lead to inadequate service being provided to families enrolled in early intervention.

Parental role. Parents play one of the most important roles in determining the success of early intervention services for their child with hearing loss (DesGeorges, 2003; Eleweke et al., 2008; Fitzpatrick et al., 2008). DesGeorges (2003) emphasized the fact that success was impacted by the parents' reactions, acceptance, and advocacy for their children during diagnosis and early intervention. The parents should be willing to be actively involved in the early intervention services (Fitzpatrick et al., 2008). It is important for professionals to encourage familial involvement to help foster parent-child communications (Eleweke et al., 2008). When the professionals took the time to understand parental opinions and experiences, it increased the chance of success for the child with hearing loss (DesGeorges, 2003).

Benefits. Developmental outcomes were highly dependent on the age in which the child with hearing loss began receiving intervention services (Yoshinaga-Itano, 2004). Hearing aids used to be fit around thirteen to sixteen months of age; however, through the implementation of the early intervention program, hearing aids are now being fit at five to seven months of age (Yoshinaga-Itano, 2004). Children who had early intervention implemented prior to six months of age had better language development,

better socio-emotional development, and better emotional well-being, at 12 and 24 months of age, compared to children who were not identified prior to six months of age (Yoshinaga-Itano, 1999).

Yoshinaga-Itano et al. (1998) compared the receptive and expressive language abilities of early identified children with hearing loss (prior to six months of age) and later identified children with hearing loss (after six months of age). Investigators reported that regardless of test age, communication mode, degree of hearing loss and socioeconomic status, children who were identified prior to six months of age had significantly better language scores compared to children who were identified after six months of age. Through intervention, children who were screened at birth and identified earlier, were twice as likely to have language abilities in the normal range compared to children with hearing loss who were not screened and identified later in life (Yoshinaga-Itano et al., 2001). Additionally, the screening group of children who were identified with hearing loss earlier, had better receptive and expressive language, larger variety of consonants in spontaneous language and better speech intelligibility (Yoshinaga-Itano et al., 2001).

Nelson et al. (2011) have identified the benefits that the early intervention program provides for families and children with hearing loss. First the provided services encouraged (a) physical; (b) cognitive; (c) communicative; and (d) social/emotional development of the infants and toddlers that were enrolled. Participation in the program increased the potential for the child to live independently when he or she was older. The program was designed to educate the families on how to facilitate development in these various areas when the child was in his/her natural environment. The early intervention

program, when successful, ultimately reduced the financial burden to society by eliminating the need for specialized services when the children reached school age.

Short comings. Numerous studies have identified areas in which early intervention programs could be improved (Bruder et al., 2005; Fitzpatrick et al., 2008; Jackson et al., 2008, Nelson et al., 2011). Several components of the early intervention program such as communication policies, government funding and service providers who lacked adequate knowledge of the impact of hearing loss, were identified as areas that needed improvement (Bruder et al., 2005; Fitzpatrick et al., 2008; Jackson et al., 2008, Nelson et al., 2011).

Nelson et al. (2011) reported that EHDI communication policies and procedures regarding the referral process were inadequate and ineffective. Audiologists and physicians were not communicating with early intervention agencies when making referrals and they were not communicating with each other. Additionally, Nelson et al. (2011) observed that services were being compromised due to early interventionists' lack of specialized training regarding the effects of hearing loss. Jackson et al. (2008) examined parents' experiences with early intervention services. They stated that parents felt that early interventionists were unaware of the impact that hearing loss had on the family as a whole. Fitzpatrick et al. (2008) stated that families felt that their social worker was uninformed regarding technical and medical aspects of the screening, diagnosis and intervention programs and therefore could not provide appropriate recommendations or information for the families. Bruder et al. (2005) reported that additional areas needed improvement including obtaining both funding and enough personnel to handle the large

caseloads. State policies also needed to be more specific regarding the requirements of a service coordinator position.

Purpose of this Study

The success of the early hearing detection intervention program has been proven to be highly dependent on parental involvement and positive parent-professional interactions. The purpose of this study is to evaluate parental satisfaction with the professionals and services received as part of their child's hearing health care. The focus of this survey is their satisfaction with the audiological services. Results from this study will be used to educate professionals on parental needs in order to improve parent-professional relationships and involvement during the diagnosis and management of the child's hearing loss.

CHAPTER 3

Methodology

Survey Development

This study was concerned with parents' experiences with the quality of services provided during the diagnosis of hearing loss and/or intervention services given to their child. The survey consisted of a mixture of qualitative and quantitative questions. The survey questions were selected and modified from previously conducted studies (Crais et al., 2006; Danhauer et al., 2008; Harrison, Dannhardt, & Rousch, 1996; MacNeil, Liu, Stone & Farrell, 2007; Mazlan, Hickson, & Driscoll, 2006). The survey consisted of questions with a closed set of response options. However, open set response items were available for certain questions in order to allow the participant to provide an additional answer or an explanation for the answer they gave. The first page of the survey informed the participants of the purpose of the survey as well as the projected use for results of the survey. Participants were not required to answer every question. They had the option to skip questions that they felt uncomfortable answering or felt did not pertain to their previous experiences. It was formatted for online dissemination using Towson University's Campus Lab survey system. A link was provided for the participants to access the survey online.

The first section of the survey pertained to the participants' demographic information. Demographic questions included: (a) person filling out the survey in relation to the child with hearing loss, (b) level of education completed by participant, (c) parent's hearing status and (d) type of health insurance the participant's child carries. All of the demographic questions included check-boxes with specific categories for the participant

to choose from. The last two questions provided an “other” option for the participant to fill in if they felt none of the options appropriately described them.

The second section of the survey contained questions specific to the child and his/her hearing loss. All of the questions contained check boxes with a closed set of responses for the parent to choose from. Some questions had an “other” check box in which the parent was able to write in a response. The purpose of this section was to collect information on the child to examine if any of these factors had an influence on the type of answers the parents gave.

The third section of the survey included questions regarding the participants’ experience with their child’s universal newborn hearing screening process and results. All of the questions, with the exception of the reason for the NICU stay, provided check-boxes to check with a closed-set of responses. The question regarding who presented the screening results provided an “other” check box which allowed the participant to provide an additional person if a certain professional was not listed as an option. This section served to provide information regarding any possible factors from the screening that impacted parental satisfaction during the diagnosis and management of their child’s hearing loss.

Section four consisted of questions regarding the audiological services and professionals that were part of their child’s hearing health care. This section evaluated the parent’s satisfaction regarding their interactions with different types of audiologists, Speech-Language Pathologist and Ear, Nose, and Throat physician. The section linked questions depending on which professionals the parents indicated that they had interacted with. Parents were first asked to use a strongly agree to strongly disagree scale regarding

specific descriptive characteristics of the each professionals they had interacted with. They were also asked to indicate, using a closed set of responses, what types of information each professional provided to their family. They were given an elaboration box to provide additional information regarding their interactions with the ENT and audiologists. This section was used to evaluate the quality of interactions between the families and the professionals. It was also used to provide overall themes of suggestions from families regarding how to improve their experiences with these professionals.

The final section pertained to the participants' experience with the early intervention program and familial involvement with these services. This section contained a combination of closed and open set responses. This section was used to compare satisfaction with intervention services with satisfaction of audiological services. It was also used to identify overall themes of parental suggestions for areas of strength and weakness of the early intervention program. The complete questionnaire can be found in Appendix C.

Participants

Participants were recruited from local Infants and Toddlers programs, local support groups for parents of children with hearing loss and local educational groups. Additional recruitment occurred through the use of fliers and social media networks (i.e. Facebook). Participation in the survey was completely voluntary. Consent was assumed when the participant filled out the survey. IRB approval was waived by the Towson IRB. The IRB approval can be found in Appendix A.

In order to participate in the survey, the participant had to be the parent of a child (7 years old or younger) with hearing loss. The participant had to read at a 3rd grade level

and had to be proficient in English. If the participant had more than one child with hearing loss, they were instructed to fill the survey out regarding their youngest child with hearing loss. There were screening questions the participant had to answer prior to accessing the survey. This was aimed to ensure that the participant met the criteria.

Demographic information collected included: age and gender of the child, state where the child was born, state where the child received services and other general health questions related to the child's birth and development.

A pilot survey was conducted through a parental support group at Maryland School for the Deaf. The purpose of this pilot survey was to assess the thoroughness of the survey and to gain feedback on what information needed to be added or removed.

Statistical Analyses

This study utilized a qualitative research design in the form of a questionnaire. A total of 96 respondents completed the questionnaire. Answers to the online survey were aggregated for analysis purposes. Frequency counts and percentages were calculated for each response option for every question.

CHAPTER 4

Results

The exact number of recipients was unknown due to online distribution of the questionnaire. Therefore, a response rate was unable to be calculated. Questions 1-3 of the questionnaire were utilized as screening questions to ensure the respondents met the criteria. Respondents had to answer “yes” to all questions in order to access the rest of the survey. A total of 176 people attempted to take the survey but only 97 online surveys were actually completed. A summary of the responses, including the number of respondents per question, can be located in Appendix D. Due to IRB specifications for research involving surveys, respondents were not required to answer every question. Additionally, certain questions were only accessible if the respondents answered “yes” to previous questions. Therefore, the number of respondents per question ranged from 14-96 throughout the questionnaire. There were several questions in which multiple answers were allowed; therefore, when statistics regarding these questions are reported, they are reported in regards to the number of responses rather than the number of respondents unless otherwise specified.

Demographic Information

The demographic information pertaining to the respondent consisted of question 4-6. Figure 1 illustrates the responses to questions 4-6. Examination of the responses revealed that the majority of respondents were mothers of the children with hearing loss (89.58%, $n=86$), considered themselves hearing parents (91.75%, $n=89$) and held a bachelor’s degree or higher (62.89%, $n=61$).

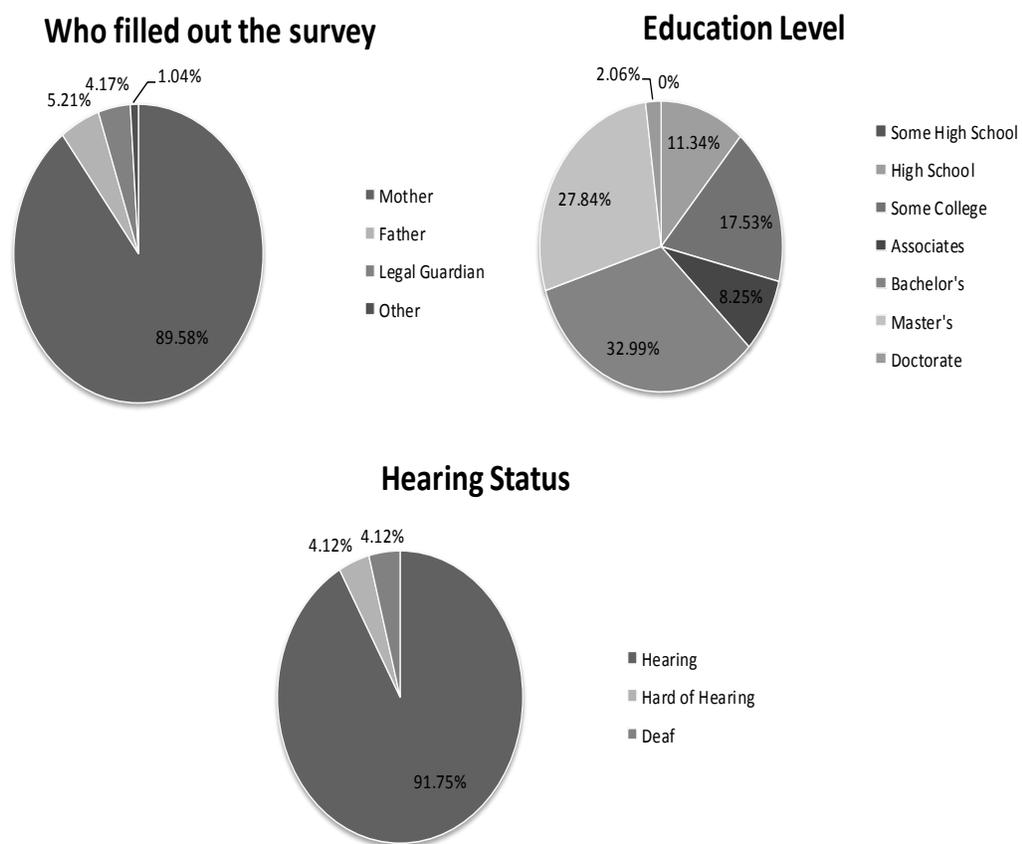


Figure 1. Percentage (%) of respondents regarding specific demographic information including: who filled out the survey, level of education completed, and hearing status.

Table 1

Demographic Information responses regarding the child with hearing loss and the diagnosis and management of their hearing loss

	n (%)		n (%)
Gender		Cause of Hearing Loss*	
Female	49 (52.13)	Genetic	16 (41.03)
Male	45 (47.87)	Complications during pregnancy	3 (7.69)
		Bacterial Meningitis	3 (7.69)
Current Age		Ototoxic Medications	2 (5.13)
Less than a year	1 (1.08)	Complications during birth	1 (2.56)
1 year old	13 (13.98)	Other	16 (41.03)
2 years old	11 (11.83)		
3 years old	17 (18.28)	Devices used or currently using*	
4 years old	12 (12.90)	Hearing Aids	70 (75.27)
5 years old	12 (12.90)	Cochlear Implants	47 (50.54)
6 years old	13 (13.98)	FM System	28 (30.11)
7 years old	14 (15.05)	BAHA	3 (3.23)
Age of Diagnosis		Other	1 (1.08)
0-2 months	43 (47.25)	None	6 (6.45)
3-5 months	11 (12.09)		
6-8 months	6 (6.59)	Professionals seen as part of hearing loss care*	
9-11 months	5 (5.49)	Audiologist	93 (98.94)
12-17 months	5 (5.49)	Otolaryngologist/ENT	83 (88.30)
18-24 months	4 (4.40)	Speech/Language Pathologist	78 (82.98)
25-36 months	3 (3.30)	Pediatrician	77 (81.91)
36 months or older	14 (15.38)	Early Intervention Worker	63 (67.02)
Type of Insurance*		Geneticist	33 (35.11)
Self-Pay through Parent's Employer	63 (64.95)	Physical Therapist	27 (28.72)
State Provided/Government Assisted	28 (28.87)	Occupational Therapist	25 (26.60)
Private Policy	11 (11.34)	Developmental Pediatrician	16 (17.02)
Other	6 (6.19)	Psychologist	12 (12.77)
Cause of Hearing Loss known		Social Worker	11 (11.70)
No	54 (56.84)	Psychiatrist	2 (2.13)
Yes	41 (43.16)	Other	16 (17.02)

Note. ENT= Ear, Nose, and Throat Physician, BAHA = Bone Anchored Hearing aid, FM= Frequency modulation. Demographic categories marked with an (*) are questions that multiple answers were allotted. For the categories with an (*), percentages are reported in percentage of respondents, not percentage of responses.

Demographics of the child. The demographic information pertaining to the child as well as information regarding their hearing loss diagnosis and management consisted of questions 7-18. Table 1 reflects the responses to a majority of the questions in this section. It should be noted that multiple answers were allowed for several questions. These questions are marked with an asterisk (*) in Table 1. Therefore, the percentages add up to more than 100% because the number reported reflects the percentage out of the total number of respondents rather than the total number of responses. A majority of the children were female (52.13%, $n = 49$), diagnosed with hearing loss by 0-2 months of age (47.25%, $n = 43$), had self-paid insurance through their parent's employer (64.95%, $n = 63$) and had or were currently utilizing hearing aids (75.27%, $n = 70$).

Universal Newborn Hearing Screening

Table 2 represents the responses to questions 21-27 regarding where the child was born, NICU stay and his/her newborn hearing screening process and results. A majority of respondents indicated their child was born in a hospital (97.80%, $n = 89$), did not require a NICU stay in the first 2 months of life (79.12%, $n = 72$) and had a newborn hearing screening (100%, $n = 92$).

Comorbidities with Hearing Loss

When respondents were asked to indicate if their child had any additional diagnoses other than hearing loss, 34.04% ($n = 32$) reported they did. Table 3 indicates if there were additional diagnoses and if it was a confirmed diagnosis or a parental concern. Table 4 displays the co-morbidities of the child's hearing loss that respondents stated were present. Conditions included: (a) various degrees of cerebral palsy; (b) global

Table 2

Responses to questions regarding the birth of the respondent's child and their newborn hearing screening

	n (%)		n (%)
Where was your child born?		Were you informed of the results?	
Hospital	89 (97.80)	Yes	89 (97.80)
Birthing Center	1 (1.10)	No	2 (2.20)
At Home	0 (0)	Unsure	0 (0)
Other	1 (1.10)		
		Screening Results-Right Ear	
Did your child spend time in the NICU?		Fail	36 (39.56)
No	72 (79.12)	Pass	31 (34.07)
Yes	19 (20.88)	Refer	22 (24.18)
		Unsure	1 (1.10)
		I was never told	1 (1.10)
Why did your child spend time in the NICU?*		Screening Results-Left Ear	
Premature	5 (26.32)	Fail	37 (41.11)
CMV	2 (10.53)	Pass	27 (30.00)
Jaundice	2 (10.53)	Refer	24 (26.67)
Hypothermia	2 (10.53)	Unsure	1 (1.11)
Meconium Aspiration	2 (10.53)	I was never told	1 (1.11)
Low oxygen levels	1 (5.26)		
Total Body Cooling	1 (5.26)	Who presented the results?	
Low blood sugar	1 (5.26)	Nurse	30 (33.33)
Low platelets, enlarged liver & spleen	1 (5.26)	Audiologist	18 (20.00)
Subdural Hematoma	1 (5.26)	Technician	11 (12.22)
Floppy Airway, trach, and GT	1 (5.26)	Pediatrician	7 (7.78)
Heart condition and feeding difficulties	1 (5.26)	Physician	3 (3.33)
		Student Intern	0 (0)
Did they receive a newborn hearing screening?		Unsure	16 (17.78)
Yes	92 (100)	Other	5 (5.56)
No	0 (0)		
Unsure	0 (0)		

Note. NICU = Neonatal Intensive Care Unit, CMV = Cytomegalovirus

Table 3

Additional diagnoses, categorized as a confirmed diagnosis or parental concern, of the child with hearing loss

	Confirmed Diagnosis		Parental Concern	
	n	%	n	%
Speech and Language Disorders & Delays	15	19.23	2	2.56
Developmental Delay	11	14.10	2	2.56
Orthopedic Challenges	7	8.97	1	1.28
Visual Impairment	7	8.97	0	0.00
Learning Disability	5	6.41	0	0.00
Intellectual Disability	4	5.13	0	0.00
Behavioral Challenges	3	3.85	2	2.56
Traumatic Brain Injury	3	3.85	0	0.00
ADHD/ADD	2	2.56	2	2.56
Emotional Disturbance	1	1.28	0	0.00
Autism	1	1.28	0	0.00
Other	n 10		% 12.82	

Note. ADHD = Attention Deficit Hyperactivity Disorder, ADD = Attention Deficit Disorder.

Table 4

Reported comorbidities with hearing loss

	n
Cerebral Palsy	3
Hypotonia	2
Speech Delay	2
Sensory Issues	2
Heart Defect	2
Downs Syndrome	1
Pachygyria	1
Global Delay	1
Reading difficulties	1
Oral Motor	1
Dysphagia	1
Expressive-Receptive Disorder	1
Meningitis	1
Coat's Disease	1
Cortical Visual Impairment	1
Lazy Eye	1
Nystagmus/Progressive myopia	1
CHARGE syndrome	1
Cleft Lip and Palate	1
Hepatoblastoma	1
Sleep Apnea	1
Ushers Type 1B	1

developmental delay; (c) sensory processing issues; (d) coats disease; (e) pachygyria; (f)

CHARGE syndrome; (g) Usher's syndrome; (h) hepatoblastoma; (i) nystagmus; (j)

cortical visual impairment; (k) Down's syndrome; (l) meningitis; and (m) speech delay.

Question 22 asked respondents to indicate the reasoning for their child's NICU stay.

Respondents reported reasons such as: (a) prematurity; (b) cytomegalovirus (CMV); (c) subdural hematoma; (d) heart condition; (e) cleft palate; (f) jaundice; (j) low oxygen levels; (l) meconium aspiration; and (m) total body cooling.

Satisfaction with Different Audiologists

Respondents were asked to indicate their level of agreement with statements regarding specific characteristics of five different types of audiologists. The types of audiologists included: General Audiologist (GA), Hearing Aid Audiologist (HA), Cochlear Implant Audiologist (CI), Early Intervention Audiologist (EIA), and the Educational/School Audiologist (ESA). Utilizing the Likert Scale, respondents indicated their level of agreement with the specific audiologist being: knowledgeable, argumentative, open-minded, caring, trustworthy, unfriendly, supportive, insensitive, and a good listener. It should be noted that in order to access the questions regarding specific audiologists, respondents had to indicate those specific audiologists on Question 29. Therefore, not every respondent rated every audiologist so the number of respondents per question for the different audiologist varied from 22-67. For the purposes of analysis, the characteristics were grouped into two categories: positive characteristics and negative characteristics. The positive characteristics group included: knowledgeable, open-minded, caring, trustworthy, supportive, and a good listener. The negative characteristics group included: argumentative, unfriendly, and insensitive. The levels of agreement were

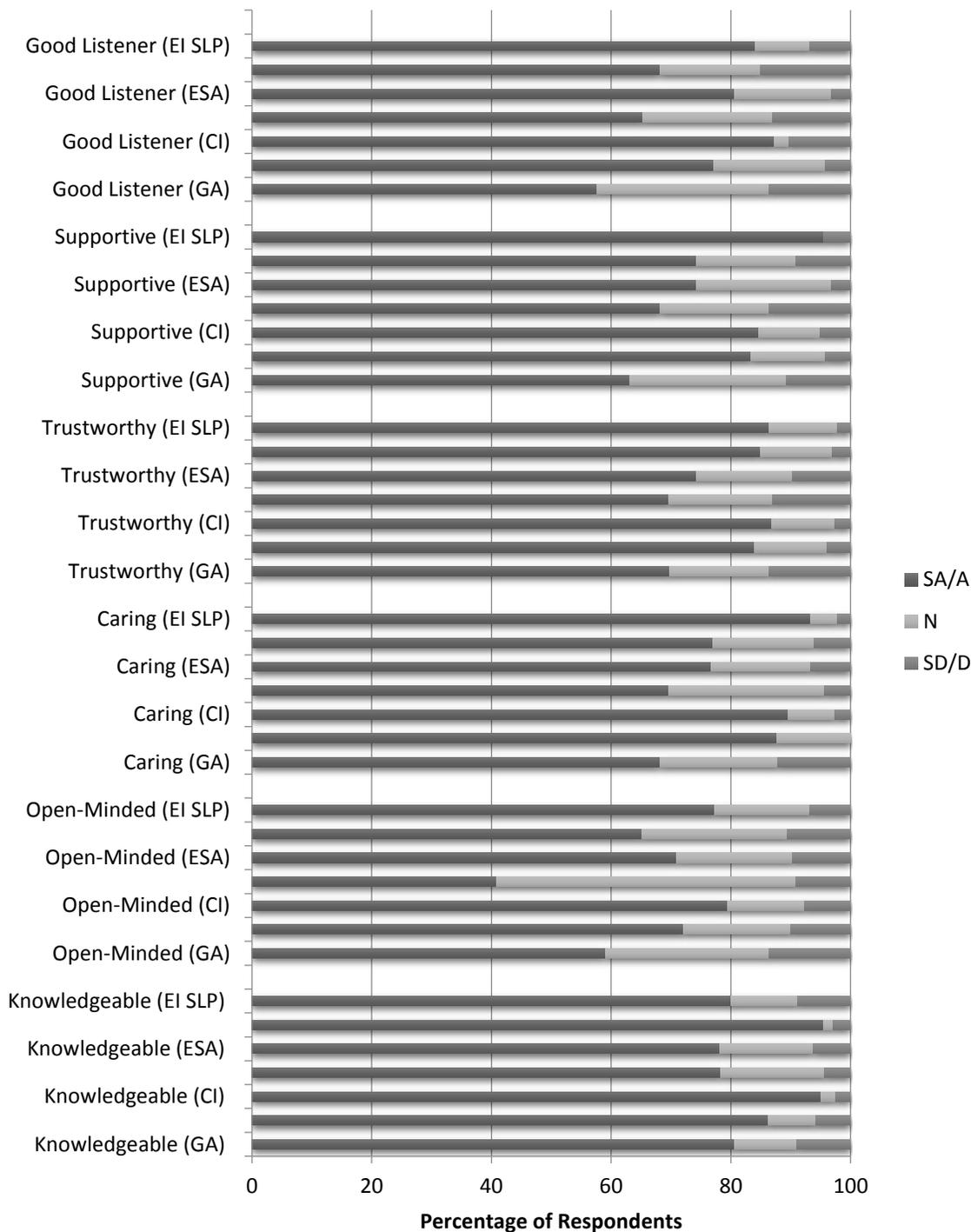


Figure 2. Level of agreement, in percentages, with positive characteristics of different professionals respondents interacted with part of their child's hearing health care. GA= General Audiologist, HA= Hearing Aid Audiologist, CI= CI Audiologist, EIA= Early Intervention Audiologist, ESA= Educational/School Audiologist, ENT= Ear, Nose, and Throat Physician, EI SLP= Early Intervention Speech-Language Pathologist.

grouped into the following categories: agree (strongly agree or agree), neutral and disagree (strongly disagree and disagree).

Positive characteristics of audiologists. Figure 2 illustrates the responses for each positive characteristic between the different professional respondents interacted with as a part of their child's hearing health care. When respondents were asked to indicate their level of agreement with the positive characteristics, a majority of respondents indicated that they strongly agreed or agreed with that statement for all of the types of audiologists. When respondents were asked to rate their level of agreement with the statement: "my [audiologist] was knowledgeable", the percentage of respondents who agreed with the statement ranged from 73.13%-95.00%. The Cochlear Implant audiologist had the highest percentage of agreement (95.00%, $n = 38$) and the Educational/School audiologist had the lowest percentage of agreement (78.13%, $n = 25$). When asked to indicate their level of agreement with the statement: "my [audiologist] was open-minded", the percentage of respondents who agreed with that statement ranged from 40.91%-79.49%. The Cochlear Implant audiologist had the highest percentage of agreement (79.49%, $n = 31$) and the Early Intervention audiologist had the lowest (40.91%, $n = 22$). The percentage of respondents who agreed with the statement ranged from 68.18%-89.48% when respondents were asked to indicate their level of agreement with the statement: "my [audiologist] was caring". The Cochlear Implant audiologist had the highest percentage (89.48%, $n = 34$) while the General and Early Intervention audiologist had the lowest percentages (68.18%, $n = 45$; 69.56%, $n = 16$). Responses regarding the statement, "my [audiologist] was trustworthy", ranged in percentages from 69.57%-86.84%. The Cochlear Implant audiologist had the highest percentage (86.84%,

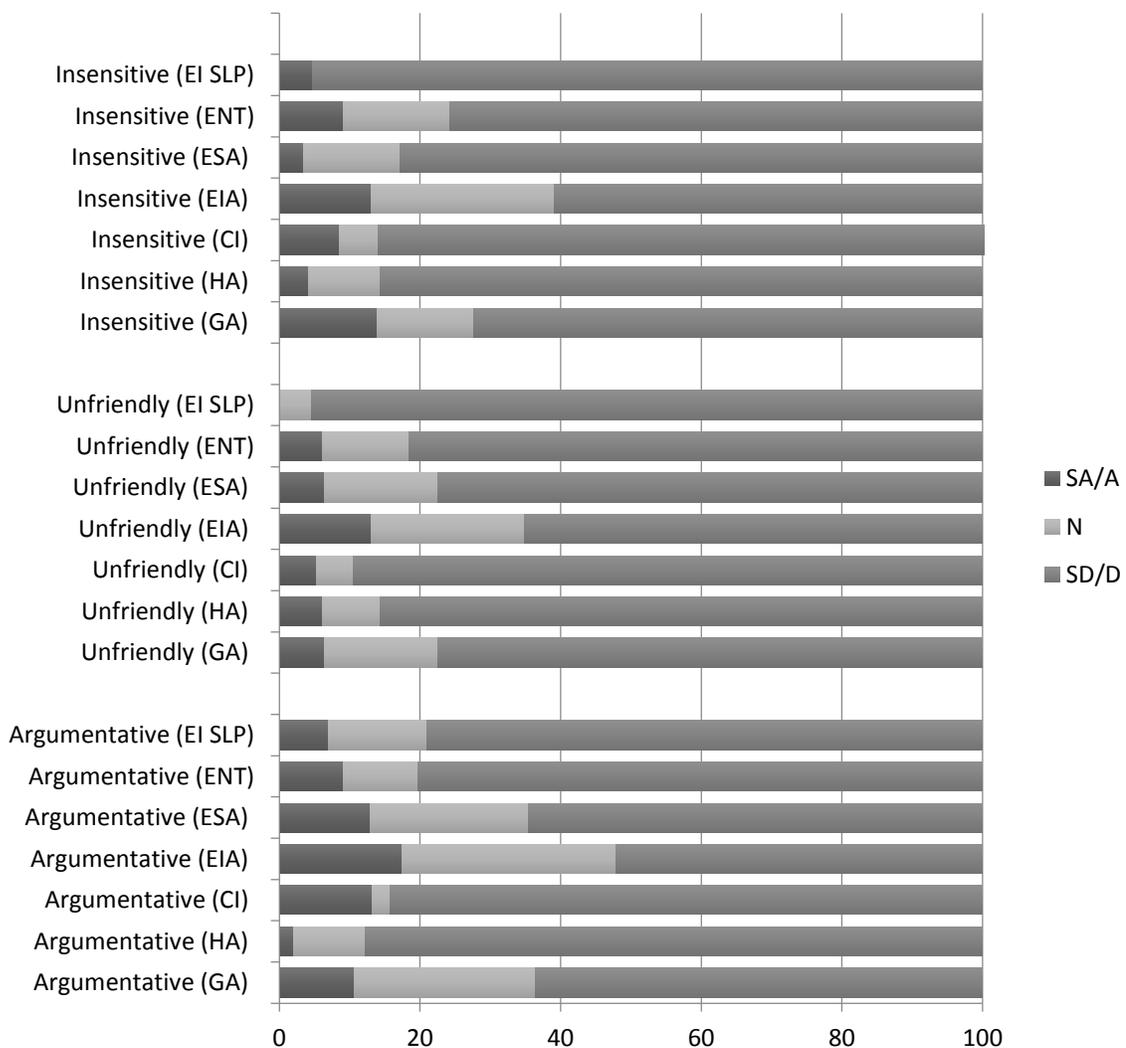


Figure 3. Level of agreement, in percentages, with negative characteristics of different professionals respondents interacted with part of their child's hearing health care. GA= General Audiologist, HA= Hearing Aid Audiologist, CI= CI Audiologist, EIA= Early Intervention Audiologist, ESA= Educational/School Audiologist, ENT= Ear, Nose, and Throat Physician, EI SLP= Early Intervention Speech-Language Pathologist.

$n = 33$) and the Early Intervention audiologist and General audiologist had the lowest percentages, 69.57% ($n = 16$) and 69.69% ($n = 46$), respectively. When asked to indicate their level of agreement with the statement, “my [audiologist] was supportive”, the level of agreement ranged from 63.08%-84.61%. The Cochlear Implant audiologist had the highest percentage (84.61%, $n = 33$) and the General Audiologist and Early Intervention audiologists had the lowest percentages of agreement, 63.08% ($n = 41$) and 68.18% ($n = 15$) respectively. The percentage of responses in agreement with the statement, “my [audiologist] was a good listener”, ranged from 57.57%-87.18%. The Cochlear Implant audiologist had the highest level of agreement (87.18%, $n = 34$) and the General audiologist and the Early Intervention audiologist had the lowest level of agreement with 57.57% ($n = 38$) and 65.22% ($n = 15$), respectively.

Negative characteristics of audiologists. Figure 3 illustrates the responses for each negative characteristic between the different types of audiologist. When respondents were asked to specify their level of agreement with the negative characteristics, a majority of respondents indicated that they strongly disagreed or disagreed with that statement for each type of audiologist.

When respondents were asked to indicate their level of agreement with the statement, “my [audiologist] was insensitive”, the percentage of respondents who disagreed ranged from 57.17%-87.75%. The percentage of disagreement for this statement was highest for the Hearing Aid audiologist (87.75, $n = 43$) and the Early Intervention audiologist had the lowest level of disagreement (57.17%, $n = 12$) followed by the General audiologist (63.63%, $n = 42$). When asked to indicate their level of agreement with the statement, “my [audiologist] was unfriendly”, the percentage of

respondents who disagreed ranged from 65.22%-77.42%. The Cochlear Implant audiologist had the highest percentage of disagreement (89.47%, $n = 34$) and the Early Intervention audiologist had the lowest percentage (65.22%, $n = 15$) followed by the General audiologist (77.42%, $n = 48$). The level of disagreement ranged from 60.87%-86.71% regarding the statement, “my [audiologist] was insensitive”. The Cochlear Implant audiologist had the highest level of disagreement (86.11%, $n = 31$) and the Early Intervention audiologist had the lowest percentage (60.87%, $n = 14$) followed by the General audiologist (72.31%, $n = 47$).

Satisfaction with Different Professionals Involved in Hearing Health Care

Respondents were asked to indicate their level of agreement with statements regarding specific characteristics between different types of audiologists, the ENT physician and the Early Intervention Speech-Language Pathologist. Utilizing the Likert Scale, respondents indicated their level of agreement with the specific audiologist being: knowledgeable, argumentative, open-minded, caring, trustworthy, unfriendly, supportive, insensitive, and a good listener. It should be noted that in order to access the questions regarding these professionals, respondents had to indicate interaction with those professionals on Question 29. Therefore, not every respondent rated every professional so the number of respondents per question for the different professionals varied. For the purposes of analysis, the characteristics were grouped into two categories: positive characteristics and negative characteristics. The positive characteristics group included: knowledgeable, open-minded, caring, trustworthy, supportive, and a good listener. The negative characteristics group included: argumentative, unfriendly, and insensitive. The

levels of agreement were grouped into the following categories: agree (strongly agree or agree), neutral and disagree (strongly disagree and disagree).

Positive characteristics of audiologists versus ENTs, and SLPs. As shown in Figure 2, the ENT and SLP had similar ratings to the audiologists for most of the characteristics. Regarding the professional being knowledgeable, the ENT had the highest percentage (95.22%, $n = 64$) and the EI SLP fell in the middle of the range with 80.00% ($n = 36$). When respondents were asked to indicate their level of agreement with the professional being open-minded, the ENT and Early Intervention SLP fell in the middle of the percentages range with 65.15% ($n = 43$) and 77.27% ($n = 34$), respectively. Related to the level of agreement with the professional being caring, the Early Intervention SLP had the highest percentage (93.34%, $n = 42$) and the ENT's percentage of agreement fell in the middle with 76.92% ($n = 50$). Regarding the professional being trustworthy, the Early Intervention SLP (86.36%, $n = 38$) and the ENT (84.85%, $n = 56$) had two of the highest percentages compared to the different audiologists. When asked if their professional was supportive during their interactions, the Early Intervention SLP had the highest percentage (95.56%, $n = 43$) and the ENT's percentage of agreement was 74.24% ($n = 49$) which was in the middle of the percentage range. Regarding the professional being a good listener, the ENT had the third lowest percentage of agreement (68.18%, $n = 45$) and the Early Intervention SLP had the third highest percentage of agreement (84.09%, $n = 37$).

Negative characteristics of audiologists versus ENTs, and SLPs. As shown in Figure 3, respondents were asked to specify their level of agreement with the negative characteristics, a majority of respondents indicated that they strongly disagreed or

disagreed with that statement for each professional. When respondents were asked to indicate their level of agreement with the professional being argumentative, the ENT had 80.31% ($n = 53$) of respondents disagree and the EI SLP had 79.09% ($n = 34$) disagreement which was in the middle of the percentage range. Regarding the professional being unfriendly, the EI SLP had the highest percentage of disagreement (95.34%, $n = 41$) and the ENTs percentage of disagreement was 81.53% ($n = 53$). When asked their level of agreement with the professional being insensitive, the EI SLP had the highest percentage of disagreement (95.24%, $n = 29$) and the ENTs percentage of disagreement fell in the middle with 75.76% ($n = 50$).

Information Provided by Professionals

Respondents were asked to indicate where they received different types of information that pertain to the diagnosis, treatment, and management of their child's hearing loss, the impact of hearing loss on their family or their child's development, and the programs and therapies available for children with hearing loss. It should be noted that, for questions regarding the information provided by professionals, respondents were able to choose more than one option. Therefore, for the purposes of comparison, the responses were reported in percentages of respondents that chose each option. It should be noted that respondents answered this question for the professional only if they indicated they interacted with this professional on question 29. Additionally, for purposes of comparison, options were combined into three different categories: 1) diagnosis, management and causes of hearing loss; 2) impact of hearing loss; and 3) programs and therapies for hearing loss.

Diagnosis, management, and causes of hearing loss information. Figure 4 illustrates the percentage of responses indicating which professionals provided information on degrees of hearing loss, management and treatment options, genetic testing, genetic causes of hearing loss and non-genetic causes of hearing loss. When respondents were asked what information each professionals provided them, respondents were able to choose more than one answer. Regarding degrees of hearing loss, 83.75% ($n = 31$) of respondents received information from the Cochlear implant audiologist, 80.65% ($n = 50$) received information from the General audiologist and 70.83% ($n = 34$) received this information from the Hearing Aid audiologist. Regarding treatment and management options, the highest percentages of respondents indicated they received information from the Cochlear Implant audiologist (91.89%, $n = 34$), the ENT physician (91.23%, $n = 52$), and the Early Intervention audiologist (88.89%, $n = 16$). The largest percentage of respondents indicated that the ENT physician provided information on genetic testing (40.35%, $n = 22$), genetic causes of hearing loss (40.35%, $n = 23$) and non-genetic causes of hearing loss (38.60%, $n = 22$).

Impact of hearing loss information. Figure 5 illustrates the percentage of respondents that indicated which professionals provided information regarding the impact of hearing loss on the family, the child's speech and language development, social development and emotional development. Overall, the largest percentage of respondents indicated that their Early Intervention SLP provided information regarding this section of information followed by the cochlear implant audiologist. Respondents indicated that a majority of information on the impact of hearing loss on the family came from: Early Intervention SLP (61.90%), Cochlear Implant Audiologist (56.76%, $n = 21$), and the

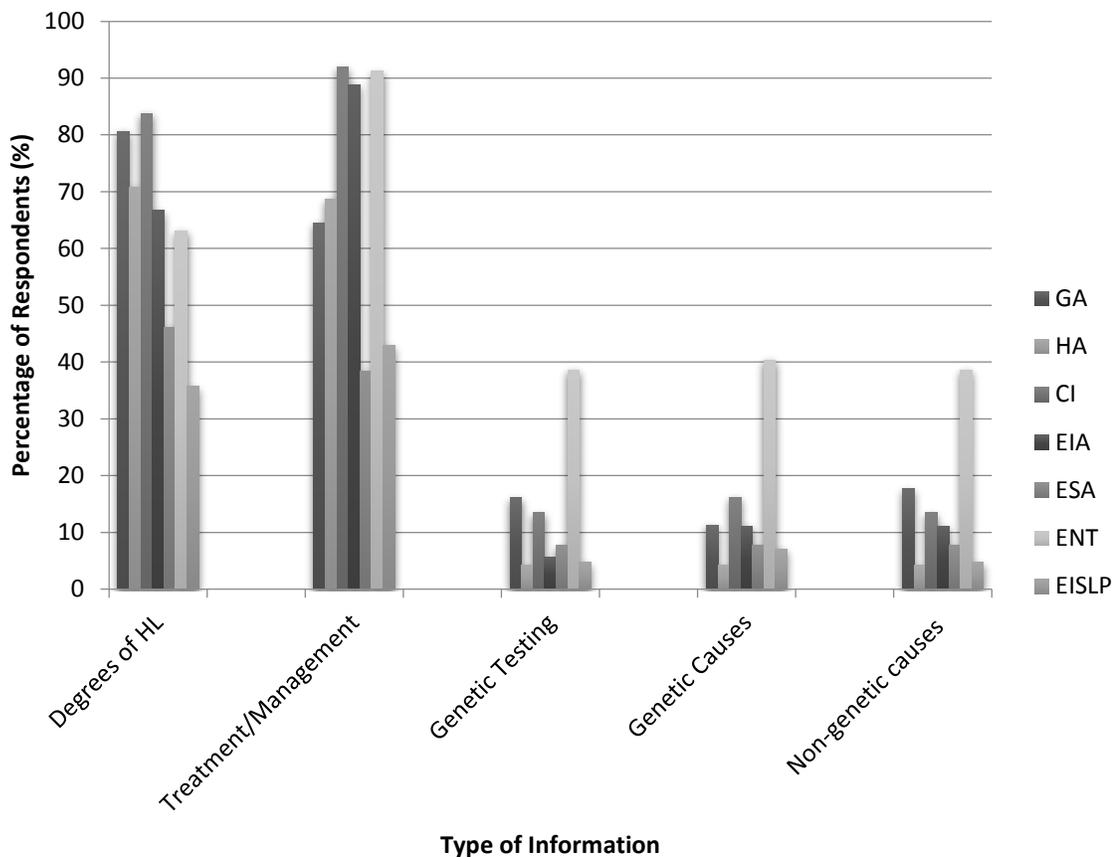


Figure 4. Percentage (%) of respondents who indicated which professionals provided information regarding diagnosis, management and cause of hearing loss. GA= General Audiologist, HA= Hearing Aid Audiologist, CI= CI Audiologist, EIA= Early Intervention Audiologist, ESA= Educational/School Audiologist, ENT= Ear, Nose, and Throat Physician, EI SLP= Early Intervention Speech-Language Pathologist.

Early Intervention Audiologist (50.00%, $n = 9$). The leading percentage of respondents indicated that information regarding the impact of hearing loss on the child's speech and language development came from the Early Intervention SLP (83.33%, $n = 35$).

Regarding information on the impacts of hearing loss on the child's social and emotional development, the Early Intervention SLP had the highest percentages, 69.05% ($n = 29$) and 59.52% ($n = 25$), respectively.

Program and therapy information. The program and therapy information grouping includes information on: communication modes and options, programs for financial assistance or funding, local therapy related services and local services for family and emotional support. Figure 6 represents the percentage of respondents, per professional, who provided program and therapy information for those with hearing loss. A majority of this information came from a professional involved in the early intervention process. The EI SLP had the highest respondent's percentages regarding the communication modes and options (85.71%, $n = 36$), local therapy related services (73.81%, $n = 31$) and local services for family and emotional support (59.52%, $n = 25$). The Early Intervention audiologist had the highest percentage regarding programs for financial assistance or funding (33.33%, $n = 6$) followed closely by the Early Intervention SLP (28.57%, $n = 12$).

Qualitative Analysis

Free response boxes were provided, in each section of the survey, to allow respondents to provide additional comments. Appendix E consists of the free response answers for each free response box provided throughout the survey. In Appendix E, the

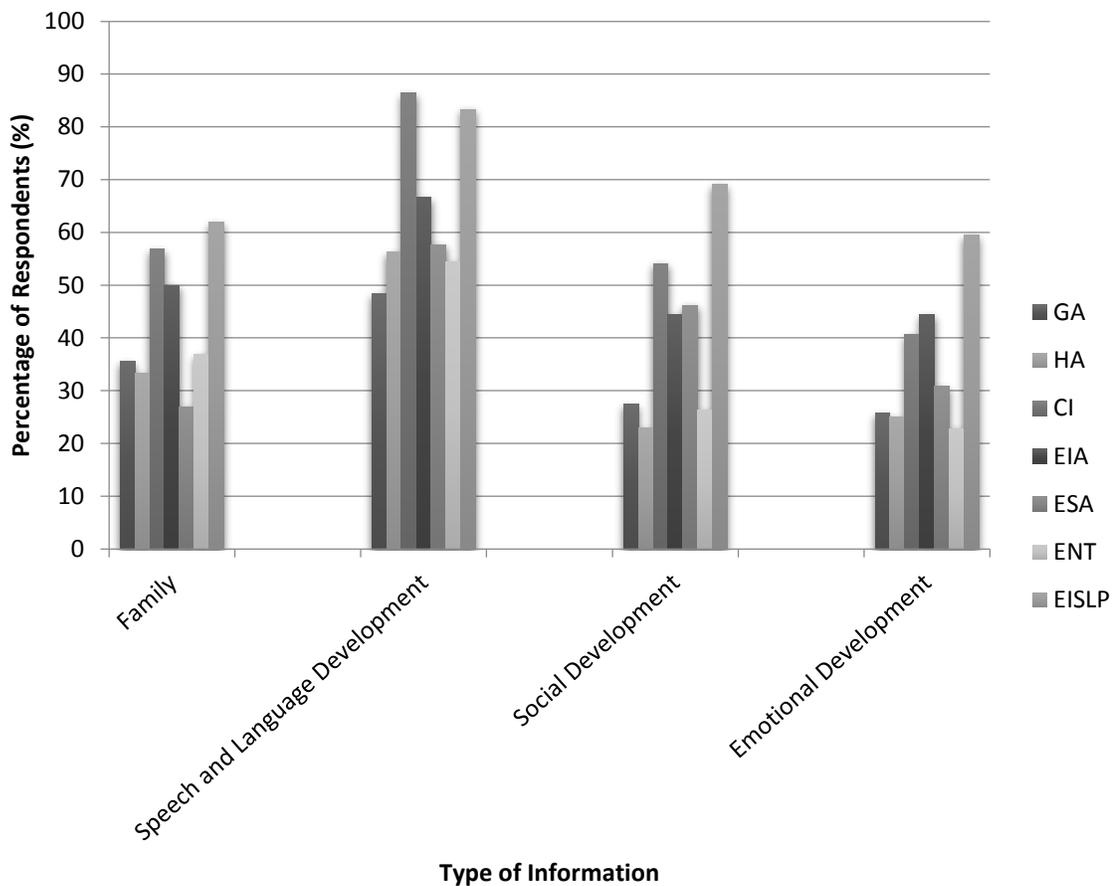


Figure 5. Percentage (%) of respondents who indicated which professionals provided information regarding impact of hearing loss. GA= General Audiologist, HA= Hearing Aid Audiologist, CI= CI Audiologist, EIA= Early Intervention Audiologist, ESA= Educational/School Audiologist, ENT= Ear, Nose, and Throat Physician, EI SLP= Early Intervention Speech-Language Pathologist.

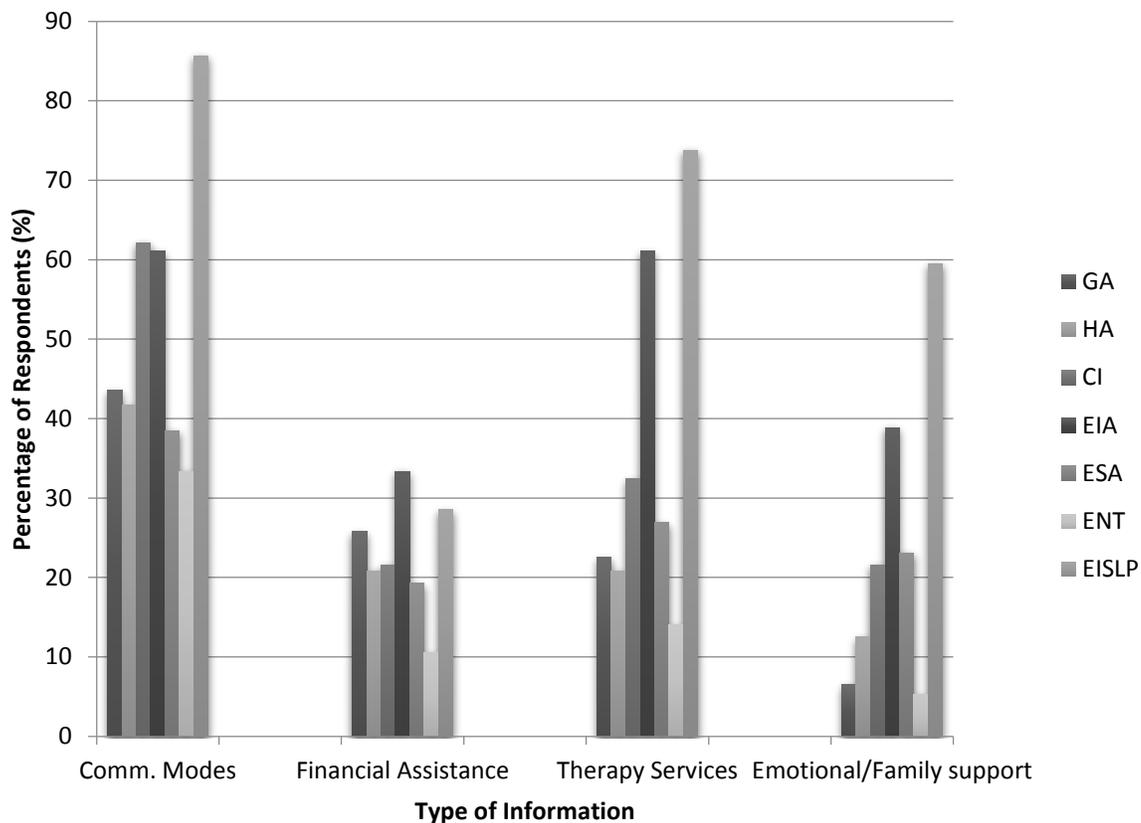


Figure 6. Percentage (%) of respondents who indicated which professionals provided information regarding therapy and program options for children with hearing loss. GA= General Audiologist, HA= Hearing Aid Audiologist, CI= CI Audiologist, EIA= Early Intervention Audiologist, ESA= Educational/School Audiologist, ENT= Ear, Nose, and Throat Physician, EI SLP= Early Intervention Speech-Language Pathologist.

free responses answers appear exactly as they were worded by respondents. Free responses were examined to identify different positive and negative themes throughout the responses in each section. The number of responses for the free responses questions ranged from 6-50.

Newborn Hearing Screenings

Question 28 gave respondents the opportunity to provide additional information related to their experience with the newborn hearing screening. A total of 50 responses were given for this question. Overall, respondents indicated dissatisfaction with their newborn hearing screening experience. Out of the 50 responses, 15 had positive feedback and 35 had negative feedback. Common themes of responses regarding the newborn hearing screening were: (a) poor delivery of results, (b) lack of explanation and information provided, and (c) multiple screenings were completed before a referral for audiology services was made. Several comments ($n = 23$) indicated that the delivery of results was very poorly done. One comment representative of this was:

“At the hospital I was told by the nurse not to worry and that babies fail all the time. She gave me a referral list for audiologists but not with any urgency at all”

Respondents also indicated that there was a lack of information or explanation regarding the results of the screening or what they meant ($n = 11$). One comment representative of this theme was:

“We were simply handed a piece of paper that indicated she did not pass and that is referred us for further evaluation follow up. There was no discussion at all with the nurse or medical staff at the hospital; they just gave us a piece of paper”

Several respondents ($n = 16$) also indicated that it took several re-screens before they were referred for an audiological evaluation. One comment that represented this theme was:

“My son was given 3 newborn hearing screenings before we were referred to an audiologist. He failed both ears the first time. They told us it was a fast delivery and he probably had fluid in his ears. When he failed one ear and pass one ear the second time, they told us the machine probably wasn't working correctly. The third time he failed, the technician said we should probably see a specialist.”

Hearing Devices

Question 17 gave respondents the opportunity to provide positive or negative feedback regarding hearing devices their child currently uses or has used in the past. Comments were divided into positive and negative feedback in order to generate common themes throughout the responses. The total number of responses for this question was 49. Some responses included both negative and positive feedback; therefore, the number of positive and negative responses combined is higher than 49. Regarding the positive aspects of the devices, respondents indicated that: hearing aids and cochlear implants gave their child access to sound that enabled appropriate development and the cochlear implant provided access to sound when a hearing aid provided little to no benefit. There were a total of 33 positive responses regarding hearing devices used. The negative aspects of the devices included: difficulty keeping the hearing aids or sound processors on their children and hearing aids did not provide benefit but were still a requirement for the cochlear implant process. There were a total of 21 negative responses regarding devices used. Numerous respondents ($n = 16$) stated that the hearing aid and/or cochlear

implant provided their child with access to sound necessary for appropriate development.

One comment representative of this was:

“All positive his hearing aids are great and provide him with the necessary tools for learning”

The second positive theme was that cochlear implants provided their child with benefit when the hearing aid did not ($n = 8$). One comment that was representative of this was:

“No response through trial of digital hearing aids both ears, cochlear implanted left side now 8 months hearing can babble, make a range of sounds and beginning to form some basic words”

Respondents indicated that they had difficulty keeping hearing devices on their child regardless of type of device ($n = 6$). Respondents indicated difficulty keeping hearing aids in, sound processors of the cochlear implant on as well as one respondent indicated trouble keeping a bone anchored hearing aid on (BAHA). One comment representative of this was:

“Keeping a CI on a baby is HARD. Difficulty level +1000 if you have other child at home”

Respondents expressed frustration regarding use of a hearing aid (s) that provided no benefit because it was part of the cochlear implant process ($n = 8$). One comment representative of this was:

“We tried hearing aids to rule them out before insurance would pay for cochlear implants. The hearing aids did not work well at all.”

Audiological Services

For the purposes of analysis of themes, responses to Q. 40 ($n = 25$), Q.51 ($n = 14$), Q.62 ($n = 8$), Q.73 ($n = 6$) and Q. 84 ($n = 8$), were combined to find commonalities regarding responses about audiological services. There were 29 positive responses and 32 negative responses. Responses were themed into positive and negative responses.

Positive themes throughout the responses included: caring demeanor and professional played a supportive role for the family. Negative themes included: Lack of information provided regarding hearing loss and management options and lack of good bedside manner. Several respondents indicated that they felt the audiologists were caring in their demeanor ($n = 10$). One comment representative of this was:

“Our audiologist always goes above and beyond when it comes to caring for our daughter. She made a very difficult time a little easier to handle. I don’t know what we would have done without her.”

Respondents also indicated that their audiologist played a supportive role during the management of their child’s hearing loss ($n = 10$). One comment representative of this theme was:

“Audiologist that fit daughter for first hearing aids was awesome! She was very kind, warm, caring and took time to listen to my concerns. She spent a lot of time explaining the type of hearing loss my daughter had and the impact of it on developing speech and language. I felt like she was part counselor- which was really needed at that time as I was an emotional wreck and so afraid of the future.”

A negative theme that occurred throughout the free responses was that there was a lack of information provided by audiologists regarding hearing loss and management options ($n = 10$). One comment representative of this was:

“Almost everything I learned in the beginning process about deafness and cochlear implants, I taught myself through my own research. Her birth to three providers auditory verbal therapist was always much more helpful than her audiologists. I never had a bad experience with her audiologist; she just wasn’t as informative as I wish she was looking back on the very beginning.”

Another theme found throughout the free responses was that respondents felt they lacked positive interactions with the audiologists ($n=9$). One comment representative of this was:

“Another distant, quiet, disinterested & unfriendly one. Even with our family history, that doesn’t mean I don’t want to know details. They didn’t act interested in my child. It was business & I rarely saw a smile. Poor ‘bedside manner’”

Other Professionals

Responses to question 95 ($n = 14$) and question 106 ($n = 11$) were combined in order to theme responses regarding other professionals involved in hearing loss health care. This combined free responses regarding the ENT and the Early Intervention SLP. There were 10 positive responses and 15 negative responses. Common themes included: (a) lack of bedside manner, (b) disagreement with parental decisions, (c) not specially trained to work with children with hearing loss and (d) supportive and informative. Respondents stated that they felt these professionals, more specifically the ENT, lacked good bedside manner ($n = 5$). One comment representative of this is:

“Only have had to see ENT twice initially, he was smart but not very friend/lacked bedside manners”

They also felt that the professionals disagreed with the decisions they, as parents, made for their children regarding management of their hearing loss ($n = 4$). One comment representative of this is:

“My most unpleasant experiences have been with ENT doctors. They were shocked with my decision not to proceed with the implant process. They asked questions in a way that implied I was erroneous in these decisions. These experiences were thoroughly offensive and I went away every time questioning my decisions, even though I came to these decisions by many hours of researching, reading, and discussing the “choices”. And why are they called “choices”? There are many options out there that can be mixed and matched. There was a strong “either or else” mentality in the ENT offices. I would be perfectly pleased if I never have to go back.”

Several respondents indicated that they felt the professionals, mostly the EI SLP, were not appropriately trained to work with children with hearing loss ($n = 5$). One comment representative of this was:

“SLP from Early Intervention was very kind and made therapy fun for my daughter but she did not specialize in hearing impaired children. I pushed EI for my daughter to be seen by SLP who specialized in hearing loss and was much happier afterwards.”

Numerous respondents also reported that they felt the professionals were supportive and informative ($n = 8$). One comment representative of this was:

“We love our SLP. She’s sweet and works well with our family. She does a great job of working at his level & keeping me informed of what she sees. LOVE her.”

Early Intervention Services

Questions 112 ($n = 39$) and 113 ($n = 34$) were examined for themes related to satisfaction with early intervention services for hearing loss. Question 112 consisted of the positive feedback and question 113 consisted of the negative feedback. The themes were separated into negative feedback and positive feedback related to the early intervention services. Negative feedback included: services being cut off when the child turns three years old and the number or duration of sessions were not adequate. Positive feedback included: inclusion of family in services provided and good coordination between professionals for their child's services. Respondents indicated that they disliked that early intervention services are discontinued when the child turns three ($n = 3$). One comment representative of this was:

“EI transitions children the day that they turn 3 regardless if there are continuation services available or not. In our case little bit turned 3 before preschool started and there were no services available until school started unless we were financially capable of paying for private services. I think this is a sad hole in state services. If I chose to keep her out of school that would be one thing, but I think if the child is going to go into the public school system then services should be provided until the school program picks up”

Respondents also expressed that they felt the amount or duration of early intervention sessions were too few or short ($n = 8$). One comment representative of this was:

“They are not specific for children with hearing loss. Too infrequent, too short in duration for each meeting”

Several respondents stated they felt that their family was included in their child's early intervention services ($n = 14$). One comment representative of this was:

“I liked that we, as parents, were included as part of my son’s ‘team’. I felt like I was treated with respect and that the staff took time to teach me about the therapy they were performing so that I could continue it after they left for the week.”

Additionally, several respondents felt like there was good coordination between professionals during their child’s early intervention services ($n = 6$). One comment representative of this was:

“I love that we have a team that all works together and develops plans for our daughter that work together”

CHAPTER 5

Discussion

A total of 97 online surveys were completed using Towson University's Campus Labs survey system. The majority of the current sample identified themselves as mothers of a child with hearing loss, hearing parents, and held their Bachelor's or Master's degree. Prior to completion of the survey, respondents were informed that the survey was completely anonymous which in turn allowed them to respond to the questions with honesty. Participants also had the ability to skip questions or were not given the option to answer every question.

Newborn Hearing Screenings

Overall, respondents indicated dissatisfaction with their experience with the newborn hearing screening. Respondents felt that screening results were inappropriately delivered which caused a lack of urgency related to follow up on the parents' part. Unfortunately, there is no universal protocol in place for delivery of screening results (Shulman et al., 2010). Some respondents indicated that the nurse or technician told them the results whereas other respondents indicated that there was a note left in their child's bassinet. The Joint Committee on Infant Hearing (JCIH) has recommended a face-to-face delivery of results that are presented in a caring way (AAP, 2007). Several respondents also reported that they were told that it is common for babies to refer and attributed the refer result to fluid in the ears. This type of assurance caused parents to assume there was no urgency in the follow up testing. One respondent stated:

“a nurse came in during the middle of the night and told me he failed. They minimize the results by saying 'there's probably fluid in his ears.’”

Respondents also felt there was a lack of explanation regarding the purpose of the screening, the tests completed for the screening and what the results meant. Danhauer et al. (2008) reported similar findings and attributed them to professionals' lack of knowledge regarding the results, tests and potential impact of hearing loss. They also stated that professionals were unaware of proper terminology to use when relaying results to parents (Danhauer et al., 2008). It has been suggested that the terms "pass" or "refer" be used, with an explanation of what both terms mean, when relaying results to the parents (Widen et al., 2003). This lack of explanation caused anxiety in the parents because they were unsure of what to do next. Hewlett and Waisbren (2006) suggested that stress and anxiety could be reduced if professionals improved the education and communication provided to parents at the time of the newborn hearing screening. In order to improve the education of parents regarding the results, we need to improve the education of professionals providing the results to the parents.

Additionally, several respondents stated that multiple screenings were completed before they were referred for diagnostic testing. Multiple screenings were completed while at the hospital or required parents to come back to the testing facility to receive the screenings. Respondents indicated frustration with this component of the newborn hearing screening. The recommended guidelines set forth by the Joint-Committee on Infant Hearing (JCIH) suggested completion of one re-screening utilizing the same equipment for well-babies who do not pass the initial newborn hearing screening (AAP, 2007). This re-screen should be completed on both ears even if one ear already passed

(AAP, 2007). If the baby fails the OAE rescreen, JCIH recommended performing an A-ABR screener prior to discharge from the hospital. If the baby spends time in the NICU, an A-ABR should always be used. If the baby does not pass the A-ABR in the NICU, JCIH recommends an immediate referral to an audiologist for a re-screen and additional diagnostic testing rather than an outpatient rescreening (AAP, 2007). These guidelines were set in place to ensure a timely and proper diagnosis. However, Holte et al. (2012) indicated that these guidelines were not always being implemented. They stated that multiple screenings were a contributing factor to a delayed diagnosis of hearing loss for children who do not pass their newborn hearing screening (Holte et al., 2012). JCIH has stressed how important the guidelines are for a timely diagnosis and appropriate intervention to occur in order to ensure the best possible outcomes for the child with hearing loss (AAP, 2007).

Hearing Devices

Overall, a majority of respondents expressed satisfaction with their child's hearing aids or cochlear implants with minimal amounts of negative feedback regarding the devices. The hearing aids or cochlear implants provided their children with access to sound that was necessary for speech and language development. One respondent stated that:

“Cochlear implants are amazing. Both of my children were born almost 100% deaf and both have received bilateral cochlear implants. At 4 my son is now on the same level of speech development as his hearing peers. My daughter is well on her way to the same.”

Respondents expressed frustration that a trial with hearing aids was required before their child could get a cochlear implant. The hearing aids did not provide any benefit and

some respondents seemed a little unsure as to why they were required to go through this as part of the process. One respondent stated:

“Hearing aids were a waste of time and effort. It seems to be the process towards cochlear implants to start with hearing aids. They never helped at all. His loss was moderate/severe.”

However, respondents were very appreciative for their child’s cochlear implant even though they were dissatisfied with the hearing aid trial. The cochlear implant provided access to sound for their child when the hearing aid was unable to do so. Several respondents indicated that since implantation, their child had begun to vocalize and respond to speech at close to normal hearing levels.

Satisfaction with Audiologists

Respondents were asked to indicate which types of audiologists they had interacted with as part of their child’s hearing health care. They were given the options of General Audiologist, Hearing Aid Audiologist, Cochlear Implant Audiologist, Educational/School Audiologist, and the Early Intervention Audiologist. A majority of respondents interacted with the General Audiologist and the Hearing Aid Audiologist and about half of the respondents interacted with the Cochlear Implant Audiologist. About a third of the respondents interacted with the Educational/School and Early Intervention Audiologists. However, it should be noted that there were not always clear cut differences between audiologists because one audiologist may serve several roles for a family. For example, the General Audiologist and the Hearing Aid Audiologist may be the same person for some respondents. Additionally, the General Audiologist may have

encompassed multiple audiologists if the respondent was not sure so this could have contributed and influenced ratings for this subset of audiologists.

There is a lack of research regarding parental satisfaction with their child's audiological services. However, Jackson et al. (2010) reported that most families were typically satisfied with the audiologic services they received but audiologists had the lowest ratings of satisfaction in the emotional well-being category. This survey not only looked at their quality of interactions with different types of audiologists but also gave respondents the opportunity to freely discuss anything they felt was great about their audiologist or ways that their experience could have been improved.

When parents were asked to indicate their level of agreement with positive characteristics, the cochlear implant audiologist overwhelmingly had higher percentages of agreement compared to the other audiologists. When they were asked to indicate their level of agreement with negative characteristics, cochlear implant audiologists had the highest percentage of disagreement. These results could be due to the fact that cochlear implant audiologists spend more time with their patients due to the time requirements for counseling, programming and follow up. Cochlear implant audiologists see their patients more often and typically have longer appointments for programming.

However, when asked to indicate their level of agreement with the positive characteristics for the General audiologist and the Early Intervention audiologist, respondents indicated the lowest percentage of agreement for these two groups of audiologists. The General audiologist and the Early Intervention audiologist also had the lowest percentage of disagreement for the negative characteristics. These results could be due to the fact that General audiologists are typically the one who makes the initial

hearing loss diagnosis which can be a traumatic experience for a parent. Additionally, the Early Intervention audiologist typically monitors hearing status and does not interact as much with the family as much as the Hearing Aid audiologist or Cochlear Implant audiologist would. Respondents were asked to indicate which audiologists gave them certain types of information. Additionally, they were given the chance to provide additional information regarding their interactions with the five types of audiologists. This will be discussed in more detail in a later section.

Satisfaction with Other Professionals Involved in Hearing Health Care

In addition to audiology services, respondents rated interactions with the ENT physician and the Early Intervention SLP. The responses for the ENT and EI SLP were compared to those responses for the different types of audiologists. Overall, the percentage of agreement with positive characteristics for the ENT and SLP fell in the middle of the percentage ranges when compared to the audiologists. However, the EI SLP had the highest level of percentage regarding being caring and supportive. Respondents were also asked to indicate their level of agreement with negative characteristics of the professionals. The ENT typically fell in the middle of the percentage range with a few exceptions. The EI SLP had the highest percentage of disagreement with the professional being unfriendly and insensitive. The results for the EI SLP were expected based on the amount of time and commitment the EI SLP spends with the child with hearing loss to work on speech development. The EI SLP typically goes to their home multiple times a week and spends one on one time with the child.

Respondents were generally satisfied with the services they received from their child's ENT and EI SLP. They felt like these professionals were supportive and

informative but could have been better equipped and trained to work with children with hearing loss. This is consistent with the findings reported in the study conducted by Nelson et al. (2011). They found that services were compromised due to the fact that several early intervention providers did not have specialized training for children with hearing loss (Nelson et al., 2011).

Information Received

Fitzpatrick et al. (2008) stated that families needed more information on etiology of hearing loss, severity of hearing loss, hearing aids and cochlear implant options, therapy related information, and prognosis information. Families should have received this information from their audiologist, physician and/or early intervention service providers (Decker et al., 2012; Nelson et al., 2011). Therefore, the questionnaire tried to identify if this information was being given and what professional was disseminating it. Therefore, Respondents were asked to identify which professional provided them with specific types of information. This information was broken up into three sections: 1) diagnosis, management and causes of hearing loss; 2) impact of hearing loss; and 3) programs and therapies for hearing loss.

A majority of the information regarding the diagnosis, management and causes of hearing loss came from the General Audiologist, Cochlear Implant Audiologist, Hearing Aid Audiologist. The ENT physician provided a majority of the information on genetic testing, genetic causes of hearing loss and non-genetic causes of hearing loss. However, the overall percentage of respondents who received information regarding genetic testing, genetic causes of hearing loss and non-genetic causes of hearing loss, was very low. This could be because audiologists are either unaware of what information to give the family

or they are cautious about giving out this information because it typically comes from an ENT physician.

Information regarding the impact of hearing loss on various developmental areas or the child's family mainly came from the Cochlear Implant Audiologist or the Early Intervention SLP. Families received a majority of the developmental impacts from their Early Intervention SLP. Although this was expected given that the EI SLP's sole responsibility is to work on developing speech and language, parents and families would benefit from receiving this information prior to working with an SLP. Families have reported a need for access to information that would allow them to educate themselves on services and resources available to themselves and their children with hearing loss (Fitzpatrick et al., 2008).

The last section was information related to program and therapy options for children with hearing loss. A majority of respondents indicated that the EI SLP provided them with information regarding local therapy related services, local services for family and emotional support and communication modes and options. Regarding programs for financial assistance or funding, the EI Audiologist and the EI SLP were indicated as the providers of this information. All audiologists should be educated on and providing options for the family regarding therapy and funding options.

However, free response answers indicated that several respondents still had a need for more information regarding hearing loss and management options for hearing loss. Several studies have found similar results regarding parent's need for additional information (Eleweke et al., 2008; Fitzpatrick et al., 2008). Eleweke et al. (2008) explained that parents need information that would educate parents and families about

childhood hearing loss and the consequences of this hearing loss as well as information on specialized support, communication and education options. When parents and families have insufficient access to a wide range of information, it resulted in inadequate service delivery for the child with hearing loss (Nelson et al., 2011). Although respondents expressed a need for more information from audiologists, they also expressed an appreciation for the supportive role the audiologist played for their family. Fitzpatrick et al. (2008) highlighted the importance of appropriate support for the family of the children with hearing loss. It impacts the success of the early intervention services for the child with hearing loss (Fitzpatrick et al., 2008).

Early Intervention Services

It has been well-established that early intervention programs that have taken a family centered approach tend to have better parental involvement which increased the success of early intervention for the child with hearing loss (Crais et al., 2006; Danhauer et al., 2008; DesGeorges, 2003; Eleweke et al., 2008; Fitzpatrick et al., 2008, Larson et al., 2012; Munoz et al., 2011). Parents were able to freely comment about their experiences regarding what they liked or did not like about their child's early intervention services. A majority of respondents indicated that they liked that their family was included in the services for their child and that it allowed them to carry over the services into their home and daily life. One response very clearly articulated the sentiment of a majority of respondents in regards to family inclusion:

“I liked that we, as parents, were included as part of my son's ‘team’. I felt like I was treated with respect and that the staff took time to teach me about the therapy they were performing so that I could continue it after they left for the week.”

Multiple studies have reported that coordination between professionals was necessary in order for early intervention services to be successful (Bruder et al., 2005; Fitzpatrick et al., 2008). Respondents did feel like there was appropriate coordination between professionals that provided the best possible outcome for their child. Nelson et al. (2011) stated that positive communication between EHDI stakeholders was a critical component of the EHDI program. Respondents to this survey seemed to be in agreement with Nelson et al. (2011).

Respondents indicated two main components of early intervention programs that could be improved. First, respondents indicated that the duration and/or number of sessions their child received were not adequate. Second, they stated that they disagreed with the rule that early intervention services end the day the child turns three years old. Respondents felt like services should not be cut off when the child turns three years old, mainly because it caused a lapse in services until the child starts school. Parents felt like they did not receive a lot of guidance or education on how to obtain services or what to do once their child aged out of early intervention. One respondent highlighted this by saying:

“That after he turned 3 years old they ended and we are basically on our own with the whole starting school, we will be putting him in Mainstream classes and we hope its what’s best for him.”

Early Intervention programs should be educating and guiding parents in a way that makes them feel confident in the decisions they are making for their child once early intervention ends. If there is a large gap in time between when the child turns three years

old and when school starts, there should be transition protocols that ensure that the child does not regress in the services they have received.

Limitations and Future Research

There were several limitations of this study that could be improved upon in future research. First, respondents consisted primarily of mothers rather than fathers. Day and Brice (2014) reported a majority of their respondents were mothers as well so they cautioned about assuming that fathers would view the interactions in the same way as the mothers. This could have been due to the fact that the survey instructed that only one parent per household fill out the survey. Future research should encourage both parents to fill out the survey in order to obtain a larger number of respondents who are the fathers of the children with hearing loss. Additionally, a significant effort was made to distribute the questionnaire through email and Facebook to as many participants as possible. However, parents from the Deaf community were still largely under-represented. The Deaf community could have possibly been represented if the survey had been distributed in person to parent groups. Second, the survey was very long and time consuming to complete which resulted in a smaller amount of respondents for the questions towards the end of the survey. The survey started out with around 97 respondents and towards the end of the survey, the number of respondents dropped to almost half of that. Future surveys should be broken up into separate surveys for each component of the EHDI process. More specifically, additional research is needed to evaluate satisfaction with different types of audiological services and identify possible reasons why parents are more satisfied with one type of audiologist such as the Cochlear Implant audiologist versus another type of audiologist such as the Early Intervention audiologist. Lastly, this study

relied on respondents' recollections of the newborn screening, diagnosis process, and early intervention process. Several studies have indicated this as a limitation to their questionnaires regarding parents' experiences with hearing loss services (MacNeil et al., 2007; Munoz et al., 2012). It has been reported that patients remember about 50% of the information that health care professionals provide them with (Margolis, 2004). It is likely that parents accurately remember some of the information or events, but that some of their recollections may not be completely accurate (Munoz et al., 2012). Margolis (2004) stated that patient satisfaction is enhanced when they remember and understand the information that was given to them. Future studies in this area should attempt to have a follow up questionnaire distributed at a later date to evaluate the consistency of the recollection of the events.

Conclusion

This study evaluated parental feedback regarding parents' experiences with the newborn hearing screening, audiological services, and early intervention services for their child with hearing loss. Since there is a lack of research in the field of audiology regarding parental satisfaction with the services their child received during the diagnosis and management of their hearing loss, this study aimed at assessing this. Overall, respondents seemed satisfied with their interactions with professionals and services their child received during the identification, diagnosis, and intervention services. Results from this survey highlighted that parents' and families need emotional support beginning during the newborn hearing screening process. Another theme from the results of the survey is families have an overwhelming need for information at each step of the EHDI process. This information needs to be up-to-date and unbiased. The information needs to

be provided in a way that allows the family to comprehend it and learn from it.

Additionally, children need a better transition between Early Intervention services and services provided once school starts.

Appendices

**Appendix A:
IRB Approval**



EXEMPTION NUMBER: 15-X024

To: Emily Garrett
 From: Institutional Review Board for the Protection of Human
 Subjects, Patricia Alt, Member VS
 Date: Friday, October 10, 2014
 RE: Application for Approval of Research Involving the Use of
 Human Participants

Office of Sponsored Programs
 Et Research

Towson University
 8000 York Road
 Towson, MD 21252-0001

t. 410 704-2236
 f. 410 704-4494
www.towson.edu/ospr

Thank you for submitting an application for approval of the research titled,
*Parental Experiences with Early Childhood Services for their Child with
 Hearing Loss*

to the Institutional Review Board for the Protection of Human Participants
 (IRB) at Towson University.

Your research is exempt from general Human Participants requirements
 according to 45 CFR 46.101(b)(2). No further review of this project is
 required from year to year provided it does not deviate from the submitted
 research design.

If you substantially change your research project or your survey
 instrument, please notify the Board immediately.

We wish you every success in your research project.

CC: Stephanie Nagle
 File

Appendix B:
Informed Consent Letter

September 4, 2014

Dear Participant,

My name is Emily Garrett and I am a doctoral student in the Department of Audiology at Towson University. As part of the research for my doctoral thesis, I will be conducting a survey to evaluate parental experiences with services received during the diagnosis and intervention for their child with hearing loss. This survey will allow me, as a future pediatric audiologist, to better serve the children and parents I will be working with. I am passionate about making these experiences and interactions as positive and beneficial for all involved. I am hopeful that this study will educate other professionals and prompt them to make changes in their interactions with families as well. This program is more successful when there is parental involvement, positive parent/professional relationships and open lines of communication. The only way to know what changes are needed for improvement is to gain your valuable feedback.

Participation in this study is voluntary. If you choose to participate in my project, you will be asked to complete a short survey. It is not necessary to answer every question, and you may discontinue your participation in the project at any time. If you do choose to participate in the study, your participation will be completely anonymous. Neither anyone reading the results of the survey nor I will be able to identify you. Please do not put your name or any other identifying marks on the survey form.

If you have any questions about the project, you may contact me at egarre7@students.towson.edu, my faculty advisor, Dr. Stephanie Nagle at (410) 704-3920, or the Chairperson of Towson University's Institutional Review Board for the Protection of Human Participants, Dr. Debi Gartland, at (410) 704-2236. A copy of the results of the survey, reported in aggregate form, will be available to you upon completion of my project, if you would like to see it.

The link for the survey is: <http://studentvoice.com/towson/hearingprofessionalsurvey>

Thank you for your time.

Sincerely,

Emily Garrett
Doctoral Student

Appendix C:

Parental Experiences with Early Childhood Services for their Child with Hearing Loss Questionnaire

Screening Questions (Can only access survey if answers to all of these questions are yes):

1. Do you have a child with hearing loss who is 7 years old or younger?
 - Yes
 - No
2. Have you completed your education at least through middle school?
 - Yes
 - No
3. Are you fluent in English?
 - Yes
 - No

Survey Questionnaire

Note: If you have more than one child with hearing loss, please fill this survey out on the youngest child.

Demographics- YOU (person filling out the survey)

Who is filling out the survey?

- Mother
- Father
- Legal guardian
- Other (please specify)

What is your highest level of education?

- Some High school
- High school/GED
- Some College/ No degree
- Associate's Degree
- Bachelor's Degree
- Master's Degree
- Doctoral Degree

What is your hearing status?

- Hearing
- Hard of hearing
- Deaf
- Other: _____

Demographics- YOUR CHILD

In what state was your child born? (**Drop-down Menu of all 50 states, territories, and “other”**)

In what state did your child receive services? (**Drop-down menu of all 50 states**)

What type of health insurance does your child have? (**Check all that apply**)

- State provided/ government assisted (i.e., Medicaid)
- Self-pay through parent’s employer
- Private Policy
- Other: _____

What is the gender of your child?

- Male
- Female

How old is your child currently?

- Less than a year old
- 1 year old
- 2 years old
- 3 years old
- 4 years old
- 5 years old
- 6 years old
- 7 years old

How old was your child when he/she was diagnosed with hearing loss?

- 0-2 months of age
- 3-5 months of age
- 6-8 months of age
- 9-11 months of age
- 12-17 months of age
- 18-24 months of age
- 25-35 months of age
- 36 months or older

Describe your child’s hearing loss (for example: mild, bilateral, sensorineural hearing loss): (**Free Response**)

Is the cause of your child’s hearing loss known? (**If yes, link it with the next question**)

- Yes
- No

If yes, what is the cause(s) of hearing loss? **(Check all that apply)**

- Genetic (confirmed through genetic testing)
- Complications during pregnancy (i.e. Toxoplasmosis, Rubella, Maternal Diabetes)
- Complications during birth (i.e. lack of oxygen)
- Bacterial Meningitis
- Medications that are harmful to hearing (i.e. Gentamicin, chemotherapy)
- Other: _____

My child now uses or has used in the past (Check all that apply)

- Hearing Aid(s)
- Cochlear Implant(s)
- An FM system
- BAHA
- Other: _____
- None of the above

If NOT None of the above - Please share additional information and/or any positive or negative experiences regarding the devices your child has used or is currently using.
(Free Response Box)

Which of these professionals has your child seen as part of their hearing loss care?
(Check all that apply)

- Audiologist
- Speech/Language Pathologist
- Pediatrician
- Otolaryngologist/ Ear, Nose, and Throat Physician (ENT)
- Occupational Therapist
- Physical Therapist
- Psychologist
- Social Worker
- Geneticist
- Developmental Pediatrician
- Early Intervention Worker
- Developmental Pediatrician
- Psychiatrist
- Other:

Does your child have any additional challenges or diagnoses?

- Yes
- No

If yes, which of the following additional challenges or diagnoses does your child have?
(Check all that apply)

- Autism
 - Parental concern: _____
 - Confirmed diagnosis: _____
- Emotional disturbance
 - Parental concern: _____
 - Confirmed diagnosis: _____
- Intellectual disability
 - Parental concern: _____
 - Confirmed diagnosis: _____
- Orthopedic challenge
 - Parental concern: _____
 - Confirmed diagnosis: _____
- Learning disability
 - Parental concern: _____
 - Confirmed diagnosis: _____
- Speech and Language Disorder or Delays
 - Parental concern: _____
 - Confirmed diagnosis: _____
- Traumatic Brain Injury
 - Parental concern: _____
 - Confirmed diagnosis: _____
- Visual Impairment
 - Parental concern: _____
 - Confirmed diagnosis: _____
- Developmental Delay
 - Parental concern: _____
 - Confirmed diagnosis: _____
- Behavioral Challenges
 - Parental concern: _____
 - Confirmed diagnosis: _____
- ADHD/ADD
 - Parental concern: _____
 - Confirmed diagnosis: _____
- Other: _____

Screening and Results

Where was your child born?

- Hospital
- Birthing Center
- At Home
- Other: _____

Did your child spend any time in the NICU in the first 2 months of life?

- Yes
- No

If Yes, Why did your child spend time in the NICU? (**Free response**)

Did they receive a newborn hearing screening?

- Yes
- No
- Unsure

If yes:

Were you informed of the screening results?

- Yes
- No
- Unsure

What were the results of the screening in the right ear?

- Pass
- Fail
- Refer
- Unsure
- I was never told

What were the results of the screening in the left ear?

- Pass
- Fail
- Refer
- Unsure
- I was never told

Who presented the results?

- Audiologist
- Nurse
- Physician
- Pediatrician
- Technician
- Student Intern

- Unsure
- Other: _____

Please share additional information or comments regarding your child's newborn hearing screening (free response)

Audiology/Audiological Services

I have interacted with: **(Multiple answers are allowed; when they click on an answer, we need to link it to bring up questions 1, 2, and 3 for each professional they click on)**

- General Audiologist
- Hearing Aid Audiologist
- Cochlear Implant Audiologist
- Early Intervention Audiologist
- Educational Audiologist/School Audiologist
- Ear, Nose, and Throat Physician (ENT)
- Early Intervention SLP
- None of the above

If General Audiologist is selected:

1). Please indicate your level of agreement with the following (Strongly Agree, Agree, Neutral, Disagree, Strongly Disagree):

The General Audiologist was:

- Knowledgeable
- Argumentative
- Open-minded
- Caring
- Trustworthy
- Unfriendly
- Supportive
- Insensitive
- A good listener

2. The general audiologist provided information on? (Check all that apply) (Multiple answers allowed)

- Degrees of hearing loss
- Impact of hearing loss on family
- Impact of hearing loss on child's speech and language development
- Impact of hearing loss on child's social development
- Impact of hearing loss on child's emotional development
- Communication Modes and Options (i.e. verbal, sign language)
- Treatment/Management options (i.e. Cochlear Implants, Hearing Aids)

- Programs for financial assistance or funding
- Genetic testing
- Genetic causes of hearing loss
- Non-genetic causes of hearing loss
- Local services- Therapy related
- Local services- Emotional/ Family support related

Other: _____

3. Is there any additional feedback, information, or suggestions you want to share about the general audiologist? (open/free response)

If Hearing Aid Audiologist is selected:

1) Please indicate your level of agreement with the following: (Strongly Agree, Agree, Neutral, Disagree, Strongly Disagree):

The Hearing Aid Audiologist was:

- Knowledgeable
- Argumentative
- Open-minded
- Caring
- Trustworthy
- Unfriendly
- Supportive
- Insensitive
- A good listener

2. The Hearing Aid audiologist provided information on? (Check all that apply) (multiple answers allowed)

- Degrees of hearing loss
- Impact of hearing loss on family
- Impact of hearing loss on child's speech and language development
- Impact of hearing loss on child's social development
- Impact of hearing loss on child's emotional development
- Communication Modes and Options (i.e. verbal, sign language)
- Treatment/Management options (i.e. Cochlear Implants, Hearing Aids)
- Programs for financial assistance or funding
- Genetic testing
- Genetic causes of hearing loss
- Non-genetic causes of hearing loss
- Local services- Therapy related
- Local services- Emotional/ Family support related

Other: _____

3. Is there any additional feedback, information, or suggestions you want to share about the Hearing Aid audiologist? (open/free response)

If Cochlear Implant Audiologist is selected:

1). Please indicate your level of agreement with the following(Strongly Agree, Agree, Neutral, Disagree, Strongly Disagree):

The Cochlear Implant Audiologist was:

- Knowledgeable
- Argumentative
- Open-minded
- Caring
- Trustworthy
- Unfriendly
- Supportive
- Insensitive
- A good listener

2. The Cochlear Implant audiologist provided information on? (Check all that apply) (multiple answers allowed)

- Degrees of hearing loss
- Impact of hearing loss on family
- Impact of hearing loss on child's speech and language development
- Impact of hearing loss on child's social development
- Impact of hearing loss on child's emotional development
- Communication Modes and Options (i.e. verbal, sign language)
- Treatment/Management options (i.e. Cochlear Implants, Hearing Aids)
- Programs for financial assistance or funding
- Genetic testing
- Genetic causes of hearing loss
- Non-genetic causes of hearing loss
- Local services- Therapy related
- Local services- Emotional/ Family support related

Other: _____

3. Is there any additional feedback, information, or suggestions you want to share about the Cochlear Implant audiologist? (open/free response)

If Early Intervention Audiologist is selected:

1). Please indicate your level of agreement with the following(Strongly Agree, Agree, Neutral, Disagree, Strongly Disagree):

The Early Intervention Audiologist was:

- Informative
- Argumentative
- Approachable
- Caring

- Trustworthy
- Abrasive
- Supportive
- Inconsiderate
- A good listener

2. The Early Intervention audiologist provided information on? (Check all that apply)
(multiple answers allowed)

- Degrees of hearing loss
- Impact of hearing loss on family
- Impact of hearing loss on child's speech and language development
- Impact of hearing loss on child's social development
- Impact of hearing loss on child's emotional development
- Communication Modes and Options (i.e. verbal, sign language)
- Treatment/Management options (i.e. Cochlear Implants, Hearing Aids)
- Programs for financial assistance or funding
- Genetic testing
- Genetic causes of hearing loss
- Non-genetic causes of hearing loss
- Local services- Therapy related
- Local services- Emotional/ Family support related

Other: _____

3. Is there any additional feedback, information, or suggestions you want to share about the Early Intervention audiologist? (open/free response)

If Educational/School Audiologist is selected:

1). Please indicate your level of agreement with the following(Strongly Agree, Agree, Neutral, Disagree, Strongly Disagree):

The Educational Audiologist was:

- Knowledgeable
- Argumentative
- Open-minded
- Caring
- Trustworthy
- Unfriendly
- Supportive
- Insensitive
- A good listener

2. The Educational/School audiologist provided information on? (Check all that apply)
(multiple answers allowed)

- Degrees of hearing loss
- Impact of hearing loss on family

- Impact of hearing loss on child's speech and language development
- Impact of hearing loss on child's social development
- Impact of hearing loss on child's emotional development
- Communication Modes and Options (i.e. verbal, sign language)
- Treatment/Management options (i.e. Cochlear Implants, Hearing Aids)
- Programs for financial assistance or funding
- Genetic testing
- Genetic causes of hearing loss
- Non-genetic causes of hearing loss
- Local services- Therapy related
- Local services- Emotional/ Family support related

Other: _____

3. Is there any additional feedback, information, or suggestions you want to share about the Educational/School audiologist? (open/free response)

If ENT Physician is selected:

If ENT is selected:

1). Please indicate your level of agreement with the following(Strongly Agree, Agree, Neutral, Disagree, Strongly Disagree):

The ENT was:

- Knowledgeable
- Argumentative
- Open-minded
- Caring
- Trustworthy
- Unfriendly
- Supportive
- Insensitive
- A good listener

2. The ENT Physician provided information on? (Check all that apply) (multiple answers allowed)

- Degrees of hearing loss
- Impact of hearing loss on family
- Impact of hearing loss on child's speech and language development
- Impact of hearing loss on child's social development
- Impact of hearing loss on child's emotional development
- Communication Modes and Options (i.e. verbal, sign language)
- Treatment/Management options (i.e. Cochlear Implants, Hearing Aids)
- Programs for financial assistance or funding
- Genetic testing

- Genetic causes of hearing loss
- Non-genetic causes of hearing loss
- Local services- Therapy related
- Local services- Emotional/ Family support related

Other: _____

3. Is there any additional feedback, information, or suggestions you want to share about the ENT Physician ? (open/free response)

If Early Intervention SLP is selected:

1). Please indicate your level of agreement with the following (Strongly Agree, Agree, Neutral, Disagree, Strongly Disagree):

The Early Intervention SLP was:

- Knowledgeable
- Argumentative
- Open-minded
- Caring
- Trustworthy
- Unfriendly
- Supportive
- Insensitive
- A good listener

2. The Early Intervention SLP provided information on? (Check all that apply) (multiple answers allowed)

- Degrees of hearing loss
- Impact of hearing loss on family
- Impact of hearing loss on child's speech and language development
- Impact of hearing loss on child's social development
- Impact of hearing loss on child's emotional development
- Communication Modes and Options (i.e. verbal, sign language)
- Treatment/Management options (i.e. Cochlear Implants, Hearing Aids)
- Programs for financial assistance or funding
- Genetic testing
- Genetic causes of hearing loss
- Non-genetic causes of hearing loss
- Local services- Therapy related
- Local services- Emotional/ Family support related

Other: _____

3. Is there any additional feedback, information, or suggestions you want to share about the Early Intervention SLP? (open/free responses)

Early Intervention

Was your child referred for early intervention services for their hearing loss?

- Yes
- No
- Unsure

Did your child participate/receive early intervention services?

- Yes
- No
- Unsure

If they did not participate in early intervention services, why not?

If yes, what services is your child receiving through early intervention? (**Check all that apply**)

- Audiological
- Speech and Language Therapy
- Occupational Therapy
- Physical Therapy
- Behavioral Therapy
- School for the Deaf
- Specialized instruction or preschool other than School for the Deaf
- Other: _____

How long has your child been receiving early intervention services for their hearing loss?

- 0-6 months
- 6-11 months
- 1 year
- 2 years
- More than 2 years

If they received early intervention services, were you satisfied with your child's early intervention services?

- Yes
- No

If they received early intervention services, what did you like about the services your child received? (**Free Response**)

If they received early intervention services, what did you dislike about the services received? (**Free Response**)

Please feel free to share any additional information regarding your experiences during the diagnosis and management of your child's hearing loss (**Free response**)

Appendix D

Table 5

Responses for who filled out the survey

	n	%
Mother	86	89.58
Father	5	5.21
Legal Guardian	4	4.17
Other	1	1.04

Note. Total number of respondents=96

Table 6

Responses for highest level of education completed

	n	%
Some High School	0	0
High School/GED	11	11.34
Some College/ No Degree	17	17.53
Associate's Degree	8	8.25
Bachelor's Degree	32	32.99
Master's Degree	27	27.84
Doctoral Degree	2	2.06

Note. Total number of respondents=97

Table 7

Responses for hearing status

	n	%
Hearing	89	91.75
Hard of Hearing	4	4.12
Deaf	4	4.12

Note. Total number of respondents=97

Table 8

Responses for state the child was born in

State	n	%	State	n	%
Alabama	3	3.09	New Hampshire	4	4.12
Alaska	0	0.00	New Jersey	5	5.15
Arizona	2	2.06	New Mexico	0	0.00
Arkansas	0	0.00	New York	6	6.19
California	4	4.12	North Carolina	3	3.09
Colorado	1	1.03	North Dakota	0	0.00
Connecticut	3	3.09	Ohio	2	2.06
Delaware	1	1.03	Oklahoma	0	0.00
Florida	0	0.00	Oregon	0	0.00
Georgia	3	3.09	Pennsylvania	0	0.00
Hawaii	0	0.00	Rhode Island	0	0.00
Idaho	0	0.00	South Carolina	0	0.00
Illinois	3	3.09	South Dakota	1	1.03
Indiana	0	0.00	Tennessee	0	
Iowa	3	3.09	Texas	4	4.12
Kansas	0	0.00	Utah	2	2.06
Kentucky	4	4.12	Vermont	0	0.00
Louisiana	1	1.03	Virginia	4	0.00
Maine	0	0.00	Washington	2	2.06
Maryland	13	13.40	Washington D.C.	0	0.00
Massachusetts	4	4.12	West Virginia	0	0.00
Michigan	1	1.03	Wisconsin	2	2.06
Minnesota	6	6.19	Wyoming	0	0.00
Mississippi	6	6.19	Guam	0	0.00
Missouri	0	0.00	Northern Mariana Islands	0	0.00
Montana	0	0.00	Puerto Rico	0	0.00
Nebraska	0	0.00	US Virgin Islands	0	0.00
Nevada	0	0.00	Other	4	4.12

Note. Total number of responses= 97

Table 9

Responses for state the child received early intervention services in

State	n	%	State	n	%
Alabama	2	2.11	New Hampshire	5	5.26
Alaska	0	0.00	New Jersey	3	3.16
Arizona	2	2.11	New Mexico	0	0.00
Arkansas	0	0.00	New York	6	6.32
California	4	4.21	North Carolina	3	3.16
Colorado	2	2.11	North Dakota	0	0.00
Connecticut	3	3.16	Ohio	3	3.16
Delaware	3	3.16	Oklahoma	0	0.00
Florida	1	1.05	Oregon	0	0.00
Georgia	2	2.11	Pennsylvania	1	1.05
Hawaii	0	0.00	Rhode Island	0	0.00
Idaho	0	0.00	South Carolina	0	0.00
Illinois	3	3.16	South Dakota	1	1.05
Indiana	0	0.00	Tennessee	1	1.05
Iowa	3	3.16	Texas	3	3.16
Kansas	0	0.00	Utah	2	2.11
Kentucky	3	3.16	Vermont	0	0.00
Louisiana	1	1.05	Virginia	1	1.05
Maine	0	0.00	Washington	2	2.11
Maryland	13	13.68	Washington D.C.	0	0.00
Massachusetts	3	3.16	West Virginia	1	1.05
Michigan	1	1.05	Wisconsin	2	2.11
Minnesota	5	5.26	Wyoming	0	0.00
Mississippi	7	7.37	Guam	0	0.00
Missouri	0	0.00	Northern Mariana Islands	0	0.00
Montana	0	0.00	Puerto Rico	0	0.00
Nebraska	0	0.00	US Virgin Islands	0	0.00
Nevada	0	0.00	Other	3	3.16

Note. Total number of responses= 95

Table 10

Responses for child's type of health insurance

	n	%
State Provided/ Government Assisted	28	25.93
Self-pay through parent's employer	63	58.33
Private Policy	11	10.19
Other	6	5.56

Note. Total number of respondents=97; Total number of responses=108. Respondents were able to choose more than one answer for this question. The n and percentage reflect the number of responses for that option, not the number of respondents.

Table 11

Responses for gender of child

	n	%
Male	45	47.87
Female	49	52.13

Note. Total number of respondents=94

Table 12

Responses for current age of child

	n	%
Less than a year old	1	1.08
1 year old	13	13.98
2 years old	11	11.83
3 years old	17	18.28
4 years old	12	12.90
5 years old	12	12.90
6 years old	13	13.98
7 years old	14	15.05

Note. Total number of respondents=93

Table 13

Responses for the child's age at the time of diagnosis

	n	%
0-2 months	43	47.25
3-5 months	11	12.09
6-8 months	6	6.59
9-11 months	5	5.49
12-17 months	5	5.49
18-24 months	4	4.40
25-35 months	3	3.30
36 months or older	14	15.38

Note. Total number of respondents=91

Table 14

Reponses for Is the cause of your child's hearing loss known?

	n	%
Yes	41	43.16
No	54	56.84

Note. Total number of respondents=95

Table 15

Responses for the cause of their child's hearing loss

	n	%
Genetic	16	39.02
Complications during pregnancy	3	7.32
Complications during birth	1	2.44
Bacterial Meningitis	3	7.69
Medications harmful to hearing	2	4.88
Other	16	39.02

Note. Total number of respondents=39; Total number of responses=41. Respondents were able to choose more than one answer for this question. The n and percentage reflect the number of responses for that option, not the number of respondents.

Table 16

Responses for devices the child currently uses or has used in the past

	n	%	
		Respondents	Responses
Hearing Aid (s)	70	75.27	45.16
Cochlear Implant (s)	47	50.54	30.32
An FM system	28	30.11	18.06
BAHA	3	3.23	1.94
Other	1	1.08	0.65
None of the above	6	6.45	3.87

Note. Total number of respondents=93; Total number of responses=155. Respondents were able to choose more than one answer for this question. The n and percentage reflect the number of responses for that option, not the number of respondents.

Table 17

Responses for professionals seen as part of their child's hearing loss care

	n	%	
		respondents	responses
Audiologist	93	98.94	17.35
Speech-Language Pathologist	83	88.30	15.49
Pediatrician	78	82.98	14.55
Otolaryngologist/ENT Occupational Therapist	77	81.91	14.37
Physical Therapist	63	67.02	11.75
Psychologist	33	35.11	6.16
Social Worker	27	28.72	5.04
Geneticist	25	26.60	4.66
Developmental Pediatrician	16	17.02	2.99
Early Intervention Worker	16	17.02	2.99
Psychiatrist	12	12.77	2.24
Other	11	11.70	2.05
	2	2.13	0.37

Note. Total number of respondents=94; total number of responses=536. Respondents were able to choose more than one answer for this question. The n reflects the number of responses given.

Table 18

Responses for Does your child have additional challenges or diagnoses?

	n	%
Yes	32	34.04
No	62	65.96

Note. Total number of responses=94

Table 19

Responses for child's additional challenges or diagnoses

	Parental Concern		Confirmed Diagnosis	
	n	%	n	%
Autism	0	0	1	1.28
Emotional Disturbance	0	0	1	1.28
Intellectual Disability	0	0	4	5.13
Orthopedic Challenge	1	1.28	7	8.97
Learning Disability	0	0	5	6.41
Speech and Language Disorders or Delays	2	2.56	15	19.23
Traumatic Brain Injury	0	0	3	3.85
Visual Impairment	0	0	7	8.97
Developmental Delay	2	2.56	11	14.10
Behavioral Challenges	2	2.56	3	3.85
ADHD/ADD	2	2.56	2	2.56

Note. Total number of respondents=30; total number of responses=78. Respondents were able to choose more than one answer for this question. The n and percentage reflect the number of responses for that option, not the number of respondents.

Table 20

Responses for Where was your child born?

	n	%
Hospital	89	97.80
Birthing Center	1	1.10
At home	0	0.00
Other	1	1.10

Note. Total number of respondents=91

Table 21

Responses for Did your child spend any time in the NICU in the first 2 months of life?

	n	%
Yes	19	20.88
No	72	79.12

Note. Total number of respondents=91

Table 22

Responses for Did your child receive a newborn hearing screening?

	n	%
Yes	92	100
No	0	0
Unsure	0	0

Note. Total number of respondents=92

Table 23

Responses for Were you informed of the results?

	n	%
Yes	89	97.8
No	2	2.2
Unsure	0	0

Note. Total number of respondents=91

Table 24

Responses for newborn screening results in the right ear

	n	%
Pass	31	34.07
Fail	36	39.56
Refer	22	24.18
Unsure	1	1.10
I was never told	1	1.10

Note. Total number of respondents=91

Table 25

Responses for newborn screening results in the left ear

	n	%
Pass	27	30.00
Fail	37	41.11
Refer	24	26.67
Unsure	1	1.11
I was never told	1	1.11

Note. Total number of respondents=90

Table 26

Responses for Who presented the results?

	n	%
Audiologist	18	20.00
Nurse	30	33.33
Physician	3	3.33
Pediatrician	7	7.78
Technician	11	12.22
Student Intern	0	0.00
Unsure	16	17.78
Other	5	5.56

Note. Total number of responses=90

Table 27

Responses for professionals respondent has interacted with

	n	%	
		Respondents	Responses
General Audiologist	76	82.61	19.10
Hearing Aid Audiologist	67	72.83	16.83
Cochlear Implant Audiologist	48	52.17	12.06
Early Intervention Audiologist	31	33.70	7.79
Educational/School Audiologist	37	40.22	9.30
ENT	83	90.22	20.85
Early Intervention SLP	56	60.87	14.07
None of the above	0	0	0

Note. Total number of respondents=92; total number of responses=398. Respondents were able to choose more than one answer for this question. The n reflects the number of responses given.

Table 28

Responses for the level of agreement with statements regarding the General Audiologist

	n	Level of Agreement				
		Strongly Agree (%)	Agree (%)	Neutral (%)	Disagree (%)	Strongly Disagree (%)
Knowledgeable	67	34 (50.75)	20 (29.85)	7 (10.45)	6 (8.96)	0 (0)
Argumentative	66	2 (3.03)	5 (7.58)	17 (25.76)	14 (21.21)	28 (42.42)
Open-Minded	66	16 (24.24)	23 (34.85)	18 (27.27)	7 (10.61)	2 (3.03)
Caring	66	27 (40.91)	18 (27.27)	13 (19.70)	6 (9.09)	2 (3.03)
Trustworthy	66	24 (36.36)	22 (33.33)	11 (16.67)	5 (7.58)	4 (6.06)
Unfriendly	62	1 (1.61)	3 (4.84)	10 (16.13)	17 (27.42)	31 (50.00)
Supportive	65	28 (43.08)	13 (20.00)	17 (26.15)	5 (7.69)	2 (3.08)
Insensitive	65	3 (4.62)	6 (9.23)	9 (13.85)	20 (30.77)	27 (41.54)
A Good Listener	66	20 (30.30)	18 (27.27)	19 (28.79)	7 (10.61)	2 (3.03)

Note. Total number of respondents, between the statements, ranged from 62-66

Table 29

Responses for Information provided by the General Audiologist

	n	%	
		respondents	responses
Degrees of Hearing loss	50	80.65	17.99
Impact of HL on Family	22	35.48	7.91
Impact of HL on speech and language development	30	48.39	10.79
Impact of HL on social development	17	27.42	6.12
Impact of HL on emotional development	16	25.81	5.76
Communication modes and options	27	43.55	9.71
Treatment/Management Options	40	64.52	14.39
Programs for financial assistance or funding	16	25.81	5.76
Genetic Testing	10	16.13	3.60
Genetic causes of HL	7	11.29	2.52
Non-genetic causes of HL	11	17.74	3.96
Local services-Therapy related	14	22.58	5.04
Local services-Emotional/Family Support	14	22.58	5.04
Other	4	6.45	1.44

Note. Total number of respondents=62; total number of responses=278. Respondents were able to choose more than one answer for this question. The n reflects the number of responses given. HL stands for hearing loss.

Table 30

Responses for the level of agreement with statements regarding the Hearing Aid Audiologist

Item	n	Level of Agreement				
		Strongly Agree (%)	Agree (%)	Neutral (%)	Disagree (%)	Strongly Disagree (%)
Knowledgeable	51	30 (58.82)	14 (27.45)	4 (7.84)	2 (3.92)	1 (1.96)
Argumentative	49	0 (0)	1 (2.04)	5 (10.20)	17 (34.69)	26 (53.06)
Open-Minded	50	18 (36.00)	18 (36.00)	9 (18.00)	4 (8.00)	1 (2.00)
Caring	49	26 (53.06)	17 (34.69)	6 (12.24)	0 (0)	0 (0)
Trustworthy	50	24 (48.00)	18 (36.00)	6 (12.00)	2 (4.00)	0 (0)
Unfriendly	49	1 (2.04)	2 (4.08)	4 (8.16)	16 (32.65)	26 (53.06)
Supportive	48	20 (41.67)	20 (41.67)	6 (12.50)	1 (2.08)	1 (2.08)
Insensitive	49	1 (2.04)	1 (2.04)	5 (10.20)	14 (28.57)	28 (57.14)
A Good Listener	48	16 (33.33)	21 (43.75)	9 (18.75)	2 (4.17)	0 (0)

Note. Total number of respondents, between the statements, ranged from 49-51

Table 31

Responses for Information provided by the Hearing Aid Audiologist

	n	%	
		respondents	responses
Degrees of Hearing loss	34	70.83	18.18
Impact of HL on Family	16	33.33	8.56
Impact of HL on speech and language development	27	56.25	14.44
Impact of HL on social development	11	22.92	5.88
Impact of HL on emotional development	12	25.00	6.42
Communication modes and options	20	41.67	10.70
Treatment/Management Options	33	68.75	14.65
Programs for financial assistance or funding	10	20.83	5.35
Genetic Testing	2	4.17	1.07
Genetic causes of HL	2	4.17	1.07
Non-genetic causes of HL	2	4.17	1.07
Local services-Therapy related	10	20.83	5.35
Local services-Emotional/Family Support	6	12.50	3.21
Other	2	4.17	1.07

Note. Total number of respondents=48; total number of responses=187. Respondents were able to choose more than one answer for this question. The n reflects the number of responses given. HL stands for hearing loss.

Table 32

Responses for the level of agreement with statements regarding the Cochlear Implant Audiologist

Item	n	Level of Agreement				
		Strongly Agree (%)	Agree (%)	Neutral (%)	Disagree (%)	Strongly Disagree (%)
Knowledgeable	40	31 (77.50)	7 (17.50)	1 (2.50)	1 (2.50)	0 (0)
Argumentative	38	1 (2.63)	4 (10.53)	1 (2.63)	10 (26.32)	22 (57.89)
Open-Minded	39	16 (41.03)	15 (38.46)	5 (12.82)	3 (7.69)	0 (0)
Caring	38	24 (63.16)	10 (26.32)	3 (7.89)	0 (0)	1 (2.63)
Trustworthy	38	24 (63.16)	9 (23.68)	4 (10.53)	0 (0)	1 (2.63)
Unfriendly	38	1 (2.63)	1 (2.63)	2 (5.26)	8 (21.05)	26 (68.42)
Supportive	39	25 (64.10)	8 (20.51)	4 (10.26)	2 (5.13)	0 (0)
Insensitive	36	1 (2.78)	2 (5.56)	2 (5.56)	5 (13.89)	26 (72.22)
A Good Listener	39	21 (53.85)	13 (33.33)	1 (2.56)	3 (7.69)	1 (2.56)

Note. Total number of respondents, between the statements, ranged from 36-40

Table 33

Responses for Information provided by the Cochlear Implant Audiologist

	n	%	
		respondents	responses
Degrees of Hearing loss	31	83.78	14.09
Impact of HL on Family	21	56.76	9.55
Impact of HL on speech and language development	32	86.49	14.55
Impact of HL on social development	20	54.05	9.09
Impact of HL on emotional development	15	40.54	6.82
Communication modes and options	23	62.16	10.45
Treatment/Management Options	34	91.89	15.45
Programs for financial assistance or funding	8	21.62	3.64
Genetic Testing	5	13.51	2.27
Genetic causes of HL	6	16.22	2.73
Non-genetic causes of HL	5	13.51	2.27
Local services-Therapy related	12	32.43	5.45
Local services-Emotional/Family Support	8	21.62	3.64
Other	0	0.00	0.00

Note. Total number of respondents=37; total number of responses=220. Respondents were able to choose more than one answer for this question. The n reflects the number of responses given. HL stands for hearing loss.

Table 34

Responses for the level of agreement with statements regarding the Early Intervention Audiologist

Item	n	Level of Agreement				
		Strongly Agree (%)	Agree (%)	Neutral (%)	Disagree (%)	Strongly Disagree (%)
Knowledgeable	23	10 (43.48)	8 (34.78)	4 (17.39)	1 (4.35)	0 (0)
Argumentative	23	0 (0)	4 (17.39)	7 (30.43)	3 (13.04)	9 (39.13)
Open-Minded	22	5 (22.73)	4 (18.18)	11 (50.00)	2 (9.09)	0 (0)
Caring	23	7 (30.43)	9 (39.13)	6 (26.09)	1 (4.35)	0 (0)
Trustworthy	23	6 (26.09)	10 (43.48)	4 (17.39)	3 (13.04)	0 (0)
Unfriendly	23	0 (0)	3 (13.04)	5 (21.74)	5 (21.74)	10 (43.48)
Supportive	22	6 (27.27)	9 (40.91)	4 (18.18)	3 (13.64)	0 (0)
Insensitive	23	0 (0)	3 (13.04)	6 (26.09)	5 (21.74)	9 (39.13)
A Good Listener	23	6 (26.09)	9 (39.13)	5 (21.74)	2 (8.70)	1 (4.35)

Note. Total number of respondents, between the statements, ranged from 22-23

Table 35

Responses for Information provided by the Early Intervention Audiologist

	n	%	
		respondents	responses
Degrees of Hearing loss	12	66.67	11.32
Impact of HL on Family	9	50.00	8.49
Impact of HL on speech and language development	12	66.67	11.32
Impact of HL on social development	8	44.44	7.55
Impact of HL on emotional development	8	44.44	7.55
Communication modes and options	11	61.11	10.38
Treatment/Management Options	16	88.89	15.09
Programs for financial assistance or funding	6	33.33	5.66
Genetic Testing	1	5.56	0.94
Genetic causes of HL	2	11.11	1.89
Non-genetic causes of HL	2	1.11	1.89
Local services-Therapy related	11	61.11	10.38
Local services-Emotional/Family Support	7	38.89	6.60
Other	1	5.56	0.94

Note. Total number of respondents=18; total number of responses=106. Respondents were able to choose more than one answer for this question. The n reflects the number of responses given. HL stands for hearing loss.

Table 36

Responses for the level of agreement with statements regarding the Educational/School Audiologist

Item	n	Level of Agreement				
		Strongly Agree (%)	Agree (%)	Neutral (%)	Disagree (%)	Strongly Disagree (%)
Knowledgeable	32	14 (43.75)	11 (34.38)	5 (15.63)	1 (3.13)	1 (3.13)
Argumentative	31	1 (3.23)	3 (9.68)	7 (22.58)	6 (19.35)	14 (45.16)
Open-Minded	31	9 (29.03)	13 (41.94)	6 (19.35)	3 (9.68)	0 (0)
Caring	30	14 (46.67)	9 (30.00)	5 (16.67)	2 (6.67)	0 (0)
Trustworthy	31	12 (38.71)	11 (35.48)	5 (16.13)	3 (9.68)	0 (0)
Unfriendly	31	0 (0)	2 (6.45)	5 (16.13)	6 (19.35)	18 (58.06)
Supportive	31	10 (32.26)	13 (41.94)	7 (22.58)	1 (3.23)	0 (0)
Insensitive	29	0 (0)	1 (3.45)	4 (13.79)	6 (20.69)	18 (62.07)
A Good Listener	31	10 (32.26)	15 (48.39)	5 (16.13)	1 (3.23)	0 (0)

Note. Total number of respondents, between the statements, ranged from 29-32

Table 37

Responses for Information provided by the Educational/School Audiologist

	n	%	
		respondents	responses
Degrees of Hearing loss	12	46.15	12.24
Impact of HL on Family	7	26.92	7.14
Impact of HL on speech and language development	15	57.69	15.31
Impact of HL on social development	12	45.15	12.24
Impact of HL on emotional development	8	30.77	8.16
Communication modes and options	10	38.46	10.20
Treatment/Management Options	10	38.46	10.20
Programs for financial assistance or funding	5	19.23	5.10
Genetic Testing	2	7.69	2.04
Genetic causes of HL	2	7.69	2.04
Non-genetic causes of HL	2	7.69	2.04
Local services-Therapy related	7	26.92	7.14
Local services-Emotional/Family Support	6	23.08	6.12
Other	0	0.00	0.00

Note. Total number of respondents=26; total number of responses=98. Respondents were able to choose more than one answer for this question. The n reflects the number of responses given. HL stands for hearing loss.

Table 38

Responses for the level of agreement with statements regarding the Ear, Nose, and Throat Physician (ENT)

Item	n	Level of Agreement				
		Strongly Agree (%)	Agree (%)	Neutral (%)	Disagree (%)	Strongly Disagree (%)
Knowledgeable	67	48 (71.64)	16 (23.88)	1 (1.49)	1 (1.49)	1 (1.49)
Argumentative	66	2 (3.03)	4 (6.06)	7 (10.61)	15 (22.73)	38 (57.58)
Open-Minded	66	21 (31.82)	22 (33.33)	16 (24.24)	3 (4.55)	4 (6.06)
Caring	65	27 (41.54)	23 (35.38)	11 (16.92)	3 (4.62)	1 (1.54)
Trustworthy	66	37 (56.06)	19 (28.79)	8 (12.12)	1 (1.52)	1 (1.52)
Unfriendly	65	0 (0)	4 (6.15)	8 (12.31)	17 (26.15)	36 (55.38)
Supportive	66	32 (48.48)	17 (25.76)	11 (16.67)	5 (7.58)	1 (1.52)
Insensitive	66	3 (4.55)	3 (4.55)	10 (15.15)	15 (22.73)	35 (53.03)
A Good Listener	66	22 (33.33)	23 (34.85)	11 (16.67)	7 (10.61)	3 (4.55)

Note. Total number of respondents, between the statements, ranged from 65-67

Table 39

Responses for Information provided by the Ear, Nose, and Throat Physician (ENT)

	n	%	
		respondents	responses
Degrees of Hearing loss	12	46.15	12.24
Impact of HL on Family	7	26.92	7.14
Impact of HL on speech and language development	15	57.69	15.31
Impact of HL on social development	12	45.15	12.24
Impact of HL on emotional development	8	30.77	8.16
Communication modes and options	10	38.46	10.20
Treatment/Management Options	10	38.46	10.20
Programs for financial assistance or funding	5	19.23	5.10
Genetic Testing	2	7.69	2.04
Genetic causes of HL	2	7.69	2.04
Non-genetic causes of HL	2	7.69	2.04
Local services-Therapy related	7	26.92	7.14
Local services-Emotional/Family Support	6	23.08	6.12
Other	0	0.00	0.00

Note. Total number of respondents=57; total number of responses=273. Respondents were able to choose more than one answer for this question. The n reflects the number of responses given. HL stands for hearing loss.

Table 40

Responses for the level of agreement with statements regarding the Early Intervention Speech-Language Pathologist

Item	n	Level of Agreement				
		Strongly Agree (%)	Agree (%)	Neutral (%)	Disagree (%)	Strongly Disagree (%)
Knowledgeable	45	27 (60.00)	9 (20.00)	5 (11.11)	3 (6.67)	1 (2.22)
Argumentative	43	1 (2.33)	2 (4.65)	6 (13.95)	9 (20.93)	25 (58.14)
Open-Minded	44	19 (43.18)	15 (34.09)	7 (15.91)	2 (4.55)	1 (2.27)
Caring	45	30 (66.67)	12 (26.67)	2 (4.44)	0 (0)	1 (2.22)
Trustworthy	44	26 (59.09)	12 (27.27)	5 (11.36)	0 (0)	1 (2.27)
Unfriendly	43	0 (0)	0 (0)	2 (4.65)	8 (18.60)	33 (76.74)
Supportive	45	31 (68.89)	12 (26.67)	0 (0)	2 (4.44)	0 (0)
Insensitive	42	1 (2.38)	1 (2.38)	0 (0)	7 (16.67)	33 (78.57)
A Good Listener	44	27 (61.36)	10 (22.73)	4 (9.09)	2 (4.55)	1 (2.27)

Note. Total number of respondents, between the statements, ranged from 42-45

Table 41

Responses for Information provided by the Early Intervention Speech-Language Pathologist (SLP)

	n	%	
		respondents	responses
Degrees of Hearing loss	15	35.71	5.79
Impact of HL on Family	26	61.90	10.04
Impact of HL on speech and language development	35	83.33	13.51
Impact of HL on social development	29	69.05	11.20
Impact of HL on emotional development	25	59.52	9.65
Communication modes and options	36	85.71	13.90
Treatment/Management Options	18	42.86	6.95
Programs for financial assistance or funding	12	28.57	4.63
Genetic Testing	2	4.76	0.77
Genetic causes of HL	3	7.14	1.16
Non-genetic causes of HL	2	4.76	0.77
Local services-Therapy related	31	73.81	11.97
Local services-Emotional/Family Support	25	59.52	9.65
Other	0	0.00	0.00

Note. Total number of respondents=42; total number of responses=259. Respondents were able to choose more than one answer for this question. The n reflects the number of responses given. HL stands for hearing loss.

Table 42

Responses for Was your child referred for early intervention services for their hearing loss?

	n	%
Yes	58	78.38
No	15	20.27
Unsure	1	1.35

Note. Total number of respondents=74

Table 43

Responses for Did your child participate/receive early intervention services?

	n	%
Yes	61	81.33
No	13	17.33
Unsure	1	1.33

Note. Total number of respondents=75

Table 44

Responses for services the child received through early intervention

	n	%	
		Respondents	Responses
Audiological	27	45.76	17.2
Speech and Language Therapy	50	84.75	31.85
Occupational Therapy	15	25.42	9.55
Physical Therapy	17	28.81	10.83
Behavioral Therapy	1	1.69	0.64
School for the Deaf	14	23.73	8.92
Specialized Instruction other than School for the Deaf	20	33.9	12.74
Other	13	22.03	8.28

Note. Total number of respondents=59; total number of responses=157. Respondents were able to choose more than one answer for this question. The n reflects the number of responses given.

Table 45

Responses for How long has your child been receiving early intervention services for their hearing loss?

	n	%
0-6 months	4	6.78
6-11 months	4	6.78
1 year	10	16.95
2 years	12	20.34
More than 2 years	29	49.15

Note. Total number of respondents=59

Table 46

Responses for Were you satisfied with your child's early intervention services?

	n	%
Yes	51	85
No	9	15

Note. Total number of respondents=60

Appendix E

Free Response Comments:

Q4. Who is filling out the survey?

(Other- please specify):

- *Adoptive mother*

Q9. Type of Health Insurance:

(Other- please specify):

- *Live in UK so N.A.*
- *NHS united kingdom*
- *Tricare*
- *Union provided*
- *US Army Tricare so maybe government one? Kinda government self-pay combo.*

Q13. Describe your child's hearing loss:

- *ANSD, bilateral profound*
- *Bilateral*
- *Bilateral*
- *Bilateral*
- *Bilateral*
- *Bilateral*
- *Bilateral-Profound >85DB*
- *Bilateral almost complete deafness at birth*
- *Bilateral auditory neuropathy spectrum disorder*
- *bilateral aural microtia and atresia (conductive) - unaided audiogram was in the "severe" range until about a year ago and now is in the moderate range*
- *Bilateral conductive*
- *Bilateral Profound*
- *Bilateral Profound*
- *Bilateral profound hearing loss*
- *Bilateral profound hearing loss.*
- *Bilateral profound loss*
- *Bilateral profound sensorineural*
- *Bilateral profound sensorineural*
- *Bilateral profound sensorineural hearing loss*
- *Bilateral profound sensorineural hearing loss*
- *Bilateral profound, sensorineural loss due to congenital cytomegalovirus (CMV). Progressive loss from 15-18 months.*

- *Bilateral profoundly deaf*
- *Bilateral sensorineural moderate to severe hearing loss*
- *Bilateral sensorineural*
- *Bilateral sensorineural*
- *Bilateral sensorineural hearing loss...mild/moderate in one ear, severe/profound in the other*
- *Bilateral sensorineural severe to profound*
- *Bilateral sensorineural, moderate to severe on right side, severe to profound on left side*
- *Bilateral sensorineural*
- *Bilateral sensorineural. At time of diagnosis right ear was severe-profound, left ear was moderate-moderately severe. Right ear implanted at 2 yrs 2 months, left ear implanted 1/26/15 activation scheduled for 3/6/15*
- *Bilateral severe sensorineural*
- *Bilateral severe to profound sensorineural*
- *Bilateral severe to profound sensorineural*
- *Bilateral, profound sensorineural*
- *Bilateral, sensorineural, severe/profound*
- *Bilaterally completely deaf (sensorineural)*
- *Conductive, middle ear dysfunction*
- *Initially unilateral with mild to moderate loss in the left ear. It has now progressed to bilateral hearing loss with moderate to severe loss in left ear and mild to moderate in right ear.*
- *Mild*
- *Mild*
- *mild*
- *Mild bilateral sensorineural*
- *Mild bilateral sensorineural*
- *Mild R ear/ Moderate L ear*
- *Mild to moderate bilateral high frequency neurosensorial hearing loss*
- *Mild to moderately severe, sloping sensorineural hearing loss in at least the better ear. We haven't had an ABR done yet, so we don't know the exact status or the ears individually.*
- *Mild, bilateral*
- *mild-moderate bilateral*
- *mod/severe sensorineural*
- *moderate- severe bilateral sensorineural*
- *moderate bilateral*
- *Moderate, bilateral, sensorineural*
- *Moderate, bilateral, sensorineural*

- *Moderate, bilateral, sensorineural*
- *neuro bilateral sensorineural reverse slope hearing loss moderate to severe*
- *Normal sloping to mild right ear, normal sloping to severe left ear. Sensorineural*
- *Profound bilateral*
- *Profound bilateral and Auditory Neuropathy Spectrum Disorder*
- *Profound bilateral due to Auditory Neuropathy*
- *Profound bilateral hearing loss due to meningitis infection at 6 mos old*
- *Profound bilateral sensorial*
- *Profound bilateral sensorineural*
- *Profound bilateral sensorineural*
- *Profound bilateral sensorineural*
- *Profound bilateral sensorineural hearing losd*
- *Profound bilateral sensorineural hearing loss*
- *Profound bilateral*
- *Profound deafness bilateral*
- *Profound sensorineural due to connexin 26*
- *Profound to severe- sensorineural*
- *Profound, bilateral, sensorineural*
- *Profound, sensorineural hearing loss in right ear. Moderate to severe loss in left ear.*
- *Profoundly Deaf- Family History*
- *Profoundly deaf both sides*
- *Progressive hearing loss. EVAS*
- *Progressive sensorineural hearing loss. Profound in L ear, severe in R ear.*
- *sensorineural*
- *Sensorineural mild to server in both ears*
- *Sensorineural moderate/severe bilateral*
- *Sensorineural unilateral moderate/severe*
- *Sensorineural bilateral profound*
- *Severe bilateral sensorineural*
- *Severe profound. Bilateral.*
- *Severe sensorineural*
- *Severe to profound bilateral sensorineural*
- *Severe to profound bilateral SNHL*
- *Unilateral (left) profound loss (mainly low tones).*
- *Unilateral sensorineural*
- *Unilateral sensorineural hearing loss (high frequency)*
- *Unilateral SNHL high frequency moderate sloping to severe progressive loss due to LVAS defect is bilateral*

Q15. What is the cause(s) of hearing loss?

Other (please specify):

- *Chronic fluid build up/ enlarged adenoids*
- *CMV*
- *Cmv*
- *Cold and congestion, fluid in the ears*
- *Enlarged vestibular aqueduct*
- *EVA*
- *FSHD*
- *Genetic but confirmed through testing. There is a long history of hearing loss in the maternal side. Every generation has more than one individual with a hearing loss since the 1800s*
- *Not fully formed cochleas*
- *Sever jaundice*
- *Specialist states it genetic. We did not have the genetic test done do to the amount it cost. Its not going to change anything at the end of the day we still have a hearing loss.*
- *Stroke*
- *Suspected genetic because of parental history*
- *Unknown*
- *Vestibules damaged in vitro*

Q16. My child now uses or has used in the past:

Other (please specify):

- *Streamer*

Q17. Please share additional information and/or positive or negative experiences regarding the devices your child has used or is currently using:

- *Advanced Bionics Naida. Bi-Lat implanted at 10 months of age*
- *All are difficult due to her severe cerebral palsy which usually leads to her head rubbing against her wheelchair/stander/the floor -- and then whatever device she's wearing comes off. Keeping them on consistently is extremely difficult.*
- *All is fine*
- *all positive his hearing aids are great and provide him with the necessary tools for learning*
- *All positive with CI*
- *All positive, but that may be because, I, the mother have used the same devices and knew what to expect*

- *background noise and distance in public school classroom is unacceptable. No access to deaf Ed specialist*
- *Best thing we gave our little boy was the gift of cochlear implants*
- *Cis (cochlear brand) are working well for him*
- *Cochlear implants are amazing. Both of my two children were born almost 100% deaf and both have received bilateral cochlear implants. At 4 my son is now on the same level of speech development as his hearing peers. My daughter is well on her way to the same*
- *Got good auditory access from hearing aid on left ear for a long time. Easy adjustment to cochlear implant. FM does improve hearing when working properly, but it's not always easy to use properly or monitor. Ear level receiver got lost in preschool and later in the year teacher stopped using it because receiver kept falling out and she wasn't sure it was working properly and there was no point person in the school district*
- *Has also caused issues with balance/equilibrium*
- *He loves his ha's*
- *He's worn HAs since he was 9 weeks old. There were times between 14 months-24 months that it was difficult to keep the HAs in, but now he prefers to wear them.*
- *Hearing aid from 5 months to 1 year with no benefit*
- *hearing aids didn't provide benefit but were required for testing for his cochlear implants. His CIs work great! Advanced Bionics has been wonderful replacing cables & other equipment often.*
- *Hearing aids offered no benefit whatsoever. No response to sound at all while aided. However, with bilateral cochlear implants, he hears at 10 db.*
- *Hearing aids were a waste of time and effort. It seems to be the process towards cochlear implants to start with hearing aids. They never helped at all. His loss was moderate/severe.*
- *His current hearing aids are great. They cover a huge range of sounds, and the Phonak nonlinear frequency compression has greatly increased the range of accessible sounds for him. His first audiologist pushed us toward an adequate, but not great pair of basic aids, which did not give him access to nearly as much sound as these do. Parents should be allowed to see what is available and not just directed to the cheapest option, even if you think the family cannot afford a nicer set of hearing aids.*
- *I can't say as I have anything negative to say about the devices other than the actual surgical procedure and cost of the equipment.*
- *It took my daughter a good 9+ months to keep her aids in all day long.*
- *Its always getting filling with wax! Teachers and family have no idea the importance of using it.*

- *keep them, it has been pretty good but we have went through a few stages of refusal, the worst was at about 20 months, 1 month of total refusal to wear them.*
- *My child is happy with her Phonak hearing aids*
- *My daughter has bilateral auditory neuropathy. Prior to her cochlear implant in her right hear, she had all if her natural/residual hearing. It took us almost a year to get a diagnosis as she passed all hearing tests, including her newborn hearing screening, until she had her ABR at 3 years old. We are struggling with the decision to implant the other ear. She has made great progress with the one implant, we are just not sure if we are ready to damage the residual hearing in her other ear.*
- *My son wore hearing aids until 15 months old. We did not see any benefit from them even though he wore them all waking hours. He was implanted at 15 months. He's currently 2.5 and is caught up and even exceeding some peers receptively. His expressive skills are only 5 months behind on his last evaluation.*
- *My sons wear hearing aids. My youngest do not. My eldest does not want to wear them nor does he benefit from them. My second child wears them daily at school and his hearing goes all the way from 100+ db to 30 db when using the aids.*
- *No problems what so ever . He loves his Hearing Aids . But does remove them in Very loud places ,like gyms,public restrooms,around screaming children . Which worries me when he starts School . We do comfort him now and encourage him to keep them on when he feels like taking them off at these times / places . Other than that we are very blessed for his hearing aids .*
- *No response through trial of digital hearing aids both ears,cochlear implanted left side now 8 months hearing can babble,make a range of sounds and beginning to form some basic words eg mum,shush,baba,puppy etc,very good at sign language.*
- *Our son is 9 months post activation on one ci (7months on the other) and it progressing wonderfully with lots of speech therapy and intervention*
- *POSITIVE: The CI is amazing (We have a Nucleus 6)! My son is beginning to vocalize and respond to the same sounds as my hearing children. NEGATIVE: Keeping a CI on a baby is HARD. Difficulty level +1000 if you have other children at home*
- *She does extremely well with her CI's and does not currently use an FM system in her preschool of 16 children in a class.*
- *She has the Oticon Safari and we have been very pleased with both the hearing aids and the service.*
- *She is doing great with the implants and loves her FM. I feel like they could be made a bit more kid friendly.*
- *She loves it but the lack of coordination between her ENT and audiologists is frustrating*

- *She uses AB implants. While they seem delicate, AB is prompt with replacement parts and they are absolutely amazing.*
- *She was implanted at 11.5 months and has taken to hearing well, she asks for her processors when she wakes up*
- *Sometimes the fm will randomly turn off or sound static-y. Implants allow her to function as if she had normal hearing.*
- *String connecting Baha to shirt has wrapped @ her neck cutting into her neck. BAHA helps her but she refuses to wear it except at preschool.*
- *there is a lot of fear mongering on the Internet about cochlear implants that are completely inaccurate.*
- *Uses a speaker w/ teacher using a microphone in class. DHH teacher says it helps, but I notice NO difference in the room. Maybe its only noticeable through his aid?*
- *We are having technical issues that no one can explain*
- *We had a tried period of the most powerful hearing aids available from age 4-8months with no response before deciding to move forward with CIs. Continued HA use until surgery at 13 months.*
- *We have dogs who are attracted to the aids so have had to use a bonnet in the house to ensure they stay on and out of harms way.*
- *We just got the HA and most of the time they work great but we're having issues right now with the left that seems not to work all the time*
- *We love the cochlear implants. I love hearing my daughter talk and sing. I love her look of curiosity when she hears a new sound.*
- *We tried hearing aids to rule them out before insurance would pay for cochlear implants. The hearing aids did not work at all.*
- *We will be getting tubes*
- *Works great - she hears at normal levels mostly -- but could not have afforded without help of foundations -- devices are about to go out of warranty and I am terrified about cost of repairs which we need every so often -- not covered by insurance.*

Q18. Which of these professionals has your child seen as part of their hearing loss care?

- *Audio Verbal Therapist*
- *Auditory Verbal Therapist (special SLP)*
- *AV Therapist*
- *AVT*
- *Consultant to school*
- *Deaf/ HH itinerant teacher*

- *In our state, our daughter also qualified for state-funded preschool at the age of 3. She has been in preschool for nearly 3 full years also receiving speech and developmental therapy services through the school system*
- *Itinerant teacher*
- *Listening and Spoken Language Specialist*
- *Neurologist*
- *Physical Therapist- his vestibular system is damage and therefore he hasn't begun to walk yet.*
- *Sensory Therapy*
- *Teacher of the deaf*
- *Teacher of the Deaf*
- *Teacher of the Deaff*
- *Teachers from MSD and MCPS*

Q20. Which of the following additional challenges or diagnoses does your child have?

Intellectual Disability- confirmed diagnosis:

- *Down Syndrome*
- *Pachygyria*

Orthopedic challenge- parental concern:

- *Global delay*

Orthopedic challenge- confirmed diagnosis:

- *Hypotonia and delayed gross motor function due to vestibule damage*
- *Mild cerebral palsy*
- *Mild CP*
- *Severe quad cerebral palsy*

Learning Disability-confirmed diagnosis:

- *Pachygyria*
- *Struggles in reading*

Speech and Language Disorder or Delays- parental concern:

- *Delay in speech poss due to CP*
- *Oral motor*

Speech and Language disorder or Delays- confirmed diagnosis:

- *~6 month speech delay*
- *Low muscle tone paired with extreme tongue thrust*
- *Mixed expressive-receptive disorder*
- *Non verbal / tracheostomy / dysphagia*
- *Pachygyria*
- *Speech Delay*

Traumatic Brain Injury- confirmed diagnosis:

- *MRI post meningitis revealed multiple, small stroke spots scattered throughout his brain*

Visual Impairment- confirmed diagnosis:

- *Coats disease*
- *Cortical visual impairment / retinopathy of prematurity*
- *Lazy eye*
- *Nystagmus, progressive myopia*

Developmental delay- confirmed diagnosis:

- *Global delay*
- *Global developmental delay*
- *Pachygyria*

Behavioral challenges- parental concern:

- *Sensory issues*

Behavioral challenges- confirmed diagnosis:

- *Sensory processing disorder*

Other (please specify):

- *Balance Issues- Overcoming*
- *CHARGE syndrome, Bilateral cleft lip and palate, major heart defect requiring open heart surgery. Asthma, hospitalizations..*
- *Delayed in gross motor skills*
- *Global delay, hyperactivity, sleeping problems, hypermobility*
- *He is in long term f/u with oncology for met hepatoblastoma. 12 total rounds chemo from age 8mo-2.5 years.*
- *Heart defect*
- *Obstructive sleep apnea*
- *Sensory Integration Dysfunction, Migrane Disorder*
- *Sensory processing*

- *Usher Syndrome Type 1b. Currently just has hearing loss, but will lose vision during adolescence.*

Q21. Where was your child born?

Other (please specify):

- *Unknown- abandoned in China*

Q22. Why did your child spend time in the NICU?

- *24w preemie*
- *47 days*
- *Born at 29 weeks*
- *Born at 35 weeks. Was in the NICU for 8 days.*
- *Born with CMV and needed daily platelet transfusions*
- *Born with low platelets, enlarged liver and spleen*
- *Developed a subdural hematoma within hours of birth*
- *Floppy airway, trach & gt*
- *Heart condition and feeding difficulties due to cleft*
- *Low birth weight, prematurity, jaundice, maintain body temperature*
- *Low blood sugar, jaundice, hypothermia*
- *Low oxygen levels and trouble breathing immediately after birth. Both of my kids had this issue.*
- *She was 5 weeks early and spent 10 days on NICU*
- *Swallowed meconium, risk of pneumonia*
- *Symptomatic cytomegalovirus infection at birth*
- *Total body cooling*

Q27. Who presented the results?

Other (please specify):

- *Adoption agency*
- *Card left on her nicu isolette*
- *No one we had to ask*
- *The “refer card” was placed in my sons bassinet and he was rolled into our room. No explanation until I started yelling*
- *We had to ask multiple times for the results.*

Q28. Please share additional information or comments regarding your child’s newborn hearing screening:

- *a nurse came in during the middle of the night and told me he failed. They minimize the results by saying 'there's probably fluid in his ears'.*
- *After what was considered unsuccessful screenings as a newborn, we were told to bring him back in 2 weeks and given information on when and where to go. At the 2 week follow-up, he failed again. We were given the choice to come back in a week or be referred to an ENT. We chose to see an ENT.*
- *At the hospital I was told by the nurse not to worry and that babies fail all the time. She gave me a referral list for audiologists but not with any urgency at all.*
- *audiologist did screening in my presence and got no response to OAE and the second attempt was done the next day in the nursery and my son was brought back with a note in his bassinet that he didn't pass the hearing screening.*
- *Despicable wording was used ("passed" "failed") by all audiological professionals except one audiology intern from Gallaudet. She, instead, said "results show that the baby showed a hearing level of a deaf person. If I had this result instead, that would mean the baby has a hearing similar to hearing people." Impeccable word choices, much more representative of the results. My 3 children "failed" all hearing tests, and they are all wonderful human beings.*
- *Due to a cousin that has severe loss my husband requested, and was granted, a total of 3 hearing screenings; our child failed all three.*
- *Failed 2 newborn screening*
- *Failed initial test. Passed the retest. No idea how considering every doctor we have seen said he was born with severe loss.*
- *failed newborn hearing test. But no concerns. Told ears too wet. Ward too noisy. Equipment playing up. Audiologist told us after multiple tests at 5 weeks old.*
- *Failed was told possibly gunk from birth tried again next day still failed*
- *Had we not asked for the results of our child's screening we would have been sent home with a piece of paper saying "referred". Even just asking no one was able to give us any kind of information.*
- *He "failed" the first time, but they did it a second time and he "passed"*
- *failed in both ears on three separate occasions*
- *He failed the newborn test giving at the hospital .. 1 week later he went back to get it checked again and they said he passed*
- *He failed the test at the hospital and then passed all screenings at the pediatrician and school district when they tested him due to his speech and language delay so I was still concerned and took him to a private ENT where I got the diagnosis of the hearing loss*
- *He still passes today, reverse ski slope*
- *His pediatrician disregarded the results and run OAE in his office, that he passes. As ANSD kids often have OAEs present, he wasn't diagnosed until 10 months.*

- *I didn't think much about the newborn hearing screening as hearing loss did not run in either of our families and she was not premature.*
- *I have one son who is deaf and two sons that are hearing; when my daughter was born and failed the newborn screening I was upset. The nurses assured me (even though I disagreed) that she could hear and they would retest her... she's deaf...which is fine but I think we need to educate nurses on what to say on a failed result.*
- *I remember being told that he failed the new born hearing screen and that it might had been fluid , it was a mix of inner and outer loss coming up on the results . So we took him back a few weeks later . And he failed that one . They did note that he was not completely asleep . So the requested a sedated ABR and we did that . And he failed that . The results were worse because after the abr we discovered he had so much wax impacted in his ears ,which I felt like the professionals should have cleaned out his ears before the ABR . Days after the ABR we saw his ENT and she removed it , she said she couldn't even see his ear drum it was so impacted that that could also show hearing loss on test results . That day he took a booth test after the wax was removed and his results in the booth were better than the ABR ??.*
- *I say 'refer' because that's what ended up happening, but in fact the results were actually inconclusive. The machine did not give a response. We eventually managed to get in for a sedated ABR.*
- *I was told at discharge when my husband was pulling ur vehicle around to load us up to go home*
- *I was told she did not pass the hearing screen but that it probably was nothing...probably just too much amniotic fluid, but that I did need to follow-up with an audiologist.*
- *I was told the “refer” was likely fluid due to my c-section.*
- *If we wouldn't have asked about our daughters screening they would have just sent us on our way with just a piece of paper saying "referred"*
- *It was done at Lawrence General Hospital in Massachusetts and done in the hospital room. (This was a pilot program.)*
- *It was repeated numerous times over the first week of his life with different results. The technician was inexperienced and kept telling us it was an equipment failure. It was a third party company hired by the hospital performing the test and we do not have anything positive to say about them.*
- *Lacked substantial information or explanation. Just to follow up with an audiologist in 3 weeks.*
- *My child did not FAIL. She is just DEAF*
- *My son passed the hearing test several times. only when he had an ABR test did we find he had LVA with moderate hearing loss at 3 years old*

- *My son was born with normal hearing.*
- *My son was given 3 newborn hearing screenings before we were referred to an audiologist. He failed both ears the first time. They told us it was a fast delivery and he probably had fluid in his ears. When he failed one ear and passed one ear the second time, they told us the machine probably wasn't working correctly. The third time he failed, the technician said we should probably see a specialist.*
- *Our hospital performed the OAE hearing screening. It is thought that our daughter did have auditory neuropathy from birth, and had she had an ABR, it probably would have been caught then instead of 3.*
- *Overall, we had a positive experience with the newborn hearing screening test. The initial test - right after our daughter was born - was conducted by an intern young woman at GBMC hospital where I gave birth. The intern came into my room - after my 32 hour labor - and shocked us by coldly saying in a very matter of fact manner that our daughter failed her newborn hearing screening test. We were completely shocked - which doesn't begin to express how we felt. A few weeks later a more conclusive ABR was conducted by an Audiologist who was much more sensitive. The intern wasn't mean - it just seemed as though she had no experience with delivering this kind of news. Now our daughter's Deafness is a beautiful thing - but that first moment - a great deal more sensitivity was needed.*
- *Since we have an older child born with hearing loss, I had been in touch with the audiology department at the birthing hospital ahead of time to ensure that they were ready to do a hearing test when our youngest was born. I am sure that the infant screening program would have caught him anyway, but I wanted to bypass unnecessary re-screens in the event that he did not immediately pass. Since they were ready, we were able to get him diagnostic testing quickly when the screen failed*
- *The audiologist never said what it was, I had to wait for a report. She said "well, there's something weird" and left before we could ask more questions. We assumed she was coming back, but never did.*
- *They blew it off - treated it like it wasn't a big deal. Stated that with c-sections, it is very common to fail because of fluid in the ears.*
- *They said it was probably fluid in his ears and not to worry about it. He would need to have another test at some point though.*
- *They were not able to explain much just that she didn't pass in one ear on two tests spaced a few days apart. They immediately referred to an ENT and audiologist.*
- *This is my second hearing impaired child so I was expecting the results and was not as panic-y as the first.*

- *Traumatic to hear results. Expected lots to happen from NICU, but never thought of deafness. Audiologist performing test suggested toxic levels of vancomycin and gentamycin might have something to do with loss. Never been confirmed.*
- *Was in hospital one week after birth given a screening four times to rule out mucus etc from birth, left with a referral for the outpatients and an ABR test*
- *Was told that results were most likely due to congestion from a rapid delivery. Hospital also stated they would send to ENT for follow up and they never did*
- *We failed the second round of testing two weeks later. A month later we found out she was deaf.*
- *We insisted and harped about the newborn screening as my son did not receive the screening and really should have as he was in fact deaf.*
- *we were simply handed a piece of paper that indicated she did not pass and that it referred us for further evaluation follow up. there was no discussion at all with the nurse or medical staff at the hospital, they just gave us a piece of paper.*
- *We were told it was likely fluid. After 3 failed tests over his first month of life, we did first ABR where we discovered it was profound in both ears.*
- *We were told that this was fairly common and could be because of fluid in the ears or that she may not have been sound asleep during the screening. We were not concerned.*
- *Wish it would have been more accurate so we could have got him an aid right away, as his speech is somewhat affected.*
- *you have to wait 24 hours, I would have went home soon but they asked that I stay at least 24 hours so I agreed to stay*

Q39. The General Audiologist provided information on:

Other (please specify):

- *birth to three providers*
- *doctor to contact*
- *none of the above*
- *NOTHING!! She did testing for the ENT and sent him the results.*

Q40. Is there any additional feedback, information, or suggestions you want to share about the General Audiologist?

- *After the extended ABR she looked at me and said "well, the results say your son wouldn't hear a jumbo jet next to him". She was cold and insensitive. We paid for her services up front only to find out that they are 100% covered by the state so then it was a 3 month battle to have our \$300 refunded. She said that cochlear implants can work but are susceptible to meningitis and other frightening consequences. We have not seen her again since the first visit.*

- *Almost everything I learned in the beginning process about deafness and cochlear implants, I taught myself through my own research. Her birth to three providers auditory verbal therapist was always much more helpful than her audiologists. I never had a bad experience with her audiologist, she just wasn't as informative as I wish she was looking back on the very beginning*
- *best Audiologist we have seen was at the MS school for the deaf. She was awesome. she spent more time helping us than anyone in the Dr. office's that we went to. I have been to several even had 5 hearing screenings before they confirmed my child had a hearing loss. It the questions that come later that the dr. office does not help you with, and the struggles that the kids are facing in school. were to go for help. MS. has a law that does require the insurance companies to pay anything on hearing Aids. Keri's hearing aids cost 4,600. Families need to know where to go for help and assistance. I do not receive any government assistance.*
- *During daughter's first sound booth hearing test at age 2 years, Audiologist told us she was not being cooperative and to return in 3 months. 3 months later we had new Audiologist for soundbooth test and he immediately informed us after test that she had a hearing loss and needed an ABR and talked about hearing aids. I was in shock and upset and didn't feel a lot of comfort or concern. I understand Audiologist must shave to report these results often but to parent it's devastating. I did not know where to turn to for support!*
- *First audiologist we saw misdiagnosed my son at 5 months and was told he had no hearing loss. A few months after we went to a new audiologist and we learned he had profound hearing loss and the 1st test was given incorrectly.*
- *General audiologist mostly just suggested we see a specialist since little bit's loss was so profound that no testable decibel level would register. Very caring but no suggestions were offered outside of our statement that the next appointment would be a children's specialist hospital*
- *I have dealt with multiple audiologists in navigating my sons hearing loss as a result of staff turnover and different care needed and switching centers as needed (totally unrelated to the competency of the audiologists)*
- *It is important that both parents attend the appointment if you are going to tell them the news that their new baby is deaf.*
- *More information would have been helpful*
- *Our audiologist always goes above and beyond when it comes to caring for our daughter. She made a very difficult time a little easier to handle. I don't know what we would have done without her.*
- *Ours administered the test incorrectly and falsely stated that she could hear.*
- *She did the testing for the ENT. ABR testing was inconclusive in one ear but my son seemed to respond to the testing in the booth. Ent took that as he could hear*

in at least that ear. He said lots of people have only hearing in one ear. He patted me on the head and sent me home.

- *She directed the answers to my husband's questions to me which was off putting to him.*
- *She gave us wrong information saying we didn't need hearing aids. She also was very vague in what my daughter couldn't hear, only told us a cricket she couldn't hear. Never explained how it would effect speech. Also referred us to a program that we weren't eligible for. Did not suggest early intervention.*
- *she is a pediatric audiologist, and she does both hearing aids and cochlear implants. she was actually the person that did the ABR at the hospital and she was amazing to us...she also has a private not for profit practice and she has been with us every step of the way*
- *The general audiologist didn't share as much as she normally would've because I had told her what I knew already.*
- *The general audiologist stated he could test children, but after visiting a pediatric audi, I know that he did not have the correct equipment.*
- *There was way too much emphasis on cochlear implants and nothing on Deaf role models and MSD. I had to politely and insistently decline the option to implant my children.*
- *This assessment is for our first audiologist, who was quick to refer us back to our pediatrician with the thought that our daughter could be autistic or have ADHD. She was not interested in pursuing additional testing and auditory neuropathy as a possibility was not even discussed. She was convinced that hearing was not the problem, but rather it was behavioral. We did see a second general audiologist who was much more patient and caring and really listened to our issues with our daughter. It was she that thought our daughter could have auditory neuropathy and referred us to another facility that could perform the sedated ABR to confirm her medical opinion.*
- *Understanding of where "we were" as a family would have helped.*
- *We have a family history of deafness so were provided with info but didn't need much of it.*
- *We have had 2 pediatric audiologists. The second has been much more informative and supportive than the second. She has been willing to listen to my concerns and answer my questions. She has taken the time to make sure we understand the testing she does and the equipment my kids are using.*
- *We only got the audiologist after getting the cochlear implants*
- *We worked with Alicia White at JHU's Listening Center. When our daughter was first born we thought that we were interested in cochlear implants. We have since changed our minds. Alicia was a great audiologist for us.*
- *wish they had more information to share*

Q50. The Hearing Aid Audiologist provided information on:

Other (please specify):

- *Hearing aid care*
- *The general audiologist and the hearing aid audiologist-same person*

Q51. Is there any additional feedback, information, or suggestions you want to share about the Hearing Aid Audiologist:

- *After our diagnosis, this audiologist was wonderful and continues to not only be our audiologist, but a good family friend.*
- *Audiologist that fit daughter for first hearing aids was awesome! She was very kind, warm, caring and took time to listen to my concerns. She spent a lot of time explaining the type of hearing loss daughter had and the impact of it on developing speech/language. I felt like she was part counselor - which was really needed at that time as I was an emotional wreck and so afraid of the future.*
- *for question 37, when my daughter was diagnosed we got a one inch book with lots of info and later a large 3 ring binder in the mail with more info so the audiologist did not verbal provide much info and I did searching on my own so when I had questions I asked the audiologist or early intervention team*
- *had a couple hearing aid audiologists as a result of the original one leaving her position*
- *More information*
- *My hearing aid audiologist is also my CI audiologist*
- *same person as the General Audiologist*
- *She suggested that her clinic might not be able to meet my sons needs as it was a "teaching" institution and they were going on break for the summer.*
- *The general audiologist didn't share as much as she normally would've because I had told her what I knew already.*
- *This is the same person as the General Audiologist*
- *We used MSD's audiologist for my children's aids. She is WONDERFUL. She is honest and open. She didn't push anything on us and instead served as a great resource for our children's educational development.*
- *We were her first infant case that tested profoundly deaf. She had no idea how to handle our feelings or questions but she was very kind and cried with us.*
- *We were required, for insurance purposes, to trial aids; our hearing aid audiologist, who we still keep in contact with, was honest in telling us that any type of hearing result would be just shy of miraculous with aids. She, like every specialist we have dealt with thus far, was supportive and would go out of her way to answer questions or make short notice appointments any time we felt we needed assistance.*

- *While our HA audiologist was never a "bad" audiologist, we decided to change centers before our son was implanted.*

Q62. Is there any additional feedback, information, or suggestions you want to share about the Cochlear Implant Audiologist:

- *Had multiple CI audiologist as a result of moving center in NY and then moving to MD where we live now*
- *The general audiologist didn't share as much as he normally would've because I had told him what I knew already. And we've worked together previously*
- *This audiologist was nice as long as you didn't question her. She gave limited information on many subjects.*
- *This is the same person as listed as General Audiologist*
- *We had a negative experience with our first CI audiologist and switched clinics when our son was 4. My answers above were for the first team.*
- *We love Dr. Mike Scott!!!*
- *We see an audiologist that is part of an implant team, barring relocations or any changes in the audiologist's employment, our child will probably see the same group of people for her entire childhood,*
- *We went through 3 different audiologists at JHH. They were TERRIBLE! My husband's were fine but with my child - they were distant, disinterested & disorganized.*

Q72. The Early Intervention Audiologist provided information on:

Other (please specify):

- *Nothing really*

Q73. Is there any additional feedback, information, or suggestions you want to share about the Early Intervention Audiologist:

- *Another distant, quiet, disinterested & unfriendly one. Even with our family history, that doesn't mean i don't want to know details. They didn't act interested in my child. It was business & i rarely saw a smile. Poor "bedside manner"*
- *Overlap between HA audiologist and EI audiologist*
- *The early intervention audiologist was through the local school district and only tested my son with his hearing aids in and determined that he was not hearing impaired. After extensive arguments, a retest was done w/out the aids and he failed the test.*
- *They just didn't have much experience with Cis*
- *Waste of time and quite upsetting*

- *We were forced to use the implant audiologist for most services. However, MSD sent their audiologist out to visit. She allowed me to ask questions and even call her any time.*

Q84. Is there any additional feedback, information, or suggestions you want to share about the Educational/ School Audiologist:

- *He has just started nursery so we have had not much dealings with this as yet*
- *Please see my description for hearing aid audiologist. Same goes for this.*
- *See previous question*
- *the only Audiologist that really helped us was at the school of deaf. Which she was also a deaf education teacher also. I can not thank her enough for all she did.*
- *The response given here is with regard to our current educational audiologist from the school district. When we lived in NY the audiologist had no involvement with us because she would not touch a child with a cochlear implant (those were her words), and then she retired and I never found out who replaced her, if anyone*
- *There is an audiologist in Baltimore County schools system but I can't tell you anything about the person really. I only met her during the IEP process briefly.*
- *We opted to go to the school rather than deal with JHH. They are kind but don't seem as familiar with CIs because it's MSD.*
- *While she is knowledgeable about sound field testing and hearing aids, she admits to not knowing about cochlear implants*

Q94. The ENT physician provided information on:

Other (please specify):

- *Did nt discuss the speech b/c she had already learned to talk*
- *Referred for CAT scan, EKG, and genetic testing*

Q95. Is there any additional feedback, information, or suggestions you want to share about the ENT:

- *Had difficulty setting up the referrals for CAT scan, EKG and genetic testing. Staff wasn't particularly helpful either so had to go through my pediatrician who works with JH hospital system. The GBMC system and JH hospital system don't work well together so had to chase down my results myself.*
- *He is great. Even gave us his personal cell #*
- *he sent us to a specialist that deals with the inner inn to have the test confirmed that we had a hearing loss.*
- *He told me that my son could hear and sent us on our way. My son is the 5th child in our home. I kept saying there was something wrong. He humored me with the inconclusive testing and then told me he was fine. I wanted the dr. to be right but I*

knew he was NOT!!! So I went to another facility. There was a mix up in the scheduling. They scheduled a BSR instead of an ABR. AND THIS IS THE POINT!!! My son passed the booth test with in NORMAL limits. He was smart!! He figured out the system and beat it. However, he failed every ABR.

- *He wanted to do Sequential bilateral CIs. We disagreed and after some talking he agreed to do simultaneous*
- *He was an insensitive jerk*
- *I always feel like our ENT has our daughter and our family's best interest in mind.*
- *Initial ENT was horrible. 2nd one was much better. (from a referral)*
- *Love Dr. Choo*
- *My most unpleasant experiences have been with ENT doctors. They were shocked with my decision not to proceed with the implant process. They asked questions in a way that implying I was erroneous in these decisions. These experiences were thoroughly offensive and I went away every time questioning my decisions, even though I came to these decisions by many hours of researching, reading, and discussing the "choices". And why are they called "choices"? There are many options out there that can be mixed and matched. There was strong "either or else" mentality in the ENT offices. I would be perfectly pleased if I never have to go back.*
- *Only have had to see ENT twice initially, he was smart but not very friendly/lacked bedside manners*
- *Seemed like he was in a hurry to get in and out, not sure if he has dealt with a lot of children*
- *Very straightforward man dr toner, tells it like it is but we preferred that approach, we felt he was very in control and professional*
- *We dealt with many ENTs in NY due to insurance changes and reputation of affiliated cochlear implant program.*

Q106. Is there any additional feedback, information, or suggestions you want to share about the EI SLP:

- *Current SLP is private practice and wonderful in helping us guide through school services. 1st SLP was argumentative, insensitive and didn't value our time.*
- *EI therapist was great but had limited experience with CI kids. The SLP was very nice but not as effective as a therapist that had other CI clients may have been*
- *Not specialized in therapy services for hearing loss - oral or sign*
- *Our EI slps didn't know my son has hearing loss.*
- *She has been our best advocate*
- *SLP from Early Intervention was very kind and made therapy fun for my daughter but she did not specialize in hearing impaired children. I pushed EI for daughter*

to be seen by SLP who specialized in hearing loss and was much happier afterwards.

- *They are AWESOME!!! They provide the critical bridge to formal educational settings. I was at a loss as a mama to deaf kids many times, and those SLPs came to rescue every time.*
- *They just didn't have a lot of experience with CI's*
- *they were nice, I can't wait until my daughter is three and we don't have to use the early interventionist. In one way it was nice to have some one to check on general development but I don't like getting quizzed for an hour about all aspects of development when my daughter only has hearing loss. It was helpful when the early interventionist started giving us the developmental checklists so we could be prepared for her visits. My least favorite part of all the hearing loss things we need to do.*
- *We have had MANY SLPs over the years throughout Early Intervention, pre-school and then kindergarten*
- *We love our SLP. She's sweet & works well with our family. She does a great job of working at his level & keeping me informed of what she sees. LOVE her!*

Q108. Did your child participate/receive early intervention services?

No (Why not?):

- *Did not decide weather to do tubes or not*
- *He did not qualify for birth to 3 but is currently in the PPT phases for preschool intervention services*
- *It was not until he was 3 about to be 4 years old that it was clear he was hearing impaired.*
- *Late diagnosis. Age 4 at time of diagnosis*
- *MS has a deaf school and determines that any hearing impaired child must go there to receive benefits. Since my child has partial hearing, i wanted a speech path to work with him not a sign language teacher that would address his speech development future.*
- *Not at first! After he was 18 months and I had to fight for it. MSD was a great resource.*
- *Not offered*
- *She received early intervention until she turned 3 years of age.*
- *The hearing loss was discovered until he was 5 years old*
- *Was too late when we found out she had a hearing loss*
- *We originally signed up for it but it was a joke I hated that they were not specified for hearing loss*

Q109. What services is your child receiving through early intervention?

Other (please specify):

- *Aged out*
- *ASL teacher comes to house every other week*
- *AV therapy*
- *AVT type therapy*
- *BSL teacher*
- *Hardly anything*
- *Has DHH services at Preschool*
- *Nutrition*
- *Quarterly general early intervention visits*
- *Teacher of the D/FF*
- *Teacher of the deaf*
- *Teacher of the Deaf, ASL support*
- *TOD services*

Q112. What did you like about the services your child received?

- *A wholistic approach to family life Always supportive*
- *after my son was diagnosed with hearing loss, he want sent to Villa Cresta Elementary School for the hearing impaired students program 3 to 5 years old*
- *at home, the staff are nice and help us with what we need*
- *Both of our therapists were associated with the Heuser Speech and Language Academy in Louisville KY and were great at evaluating our daughter overall and coordinating services between them*
- *Caring people who really wanted to help our family & provide options. They find resoures or funding that might interest us. They are proactive & organized.*
- *Early intervention contracts with a local speech school to provide therapy, which is great*
- *Everyone was very friendly and always happy to see us. They included family in everything, and communication between home and school was a constant.*
- *Flexibility and in home*
- *Gave me insight into what he needed and didn't need*
- *Good services once I finally got them to provide them.*
- *Help. Informative. Enjoyable.*
- *His SLP is great.*
- *I feel we have the right people working with her and a good balance of support*
- *I liked that we, as parents, were included as part of my son's "team". I felt like I was treated with respect and that the staff took the time to teach me about the therapy they were performing so that I could continue it after they left for the week.*

- *speech therapy, in early intervention has been wonderful*
- *I live near NYC where professionals are trained*
- *I love that we have a team that all works together and develops plans for our daughter that work together.*
- *It has proven useful in that my daughter is right where she should be with her speech.*
- *Nothing*
- *Our SLP is great, and if she doesn't know something, she will always find out for us.*
- *People at MSD are wonderful. My kids are at above grade level across the board, and MSD staff are a huge part of this success. They never treated my kids as if they are disabled, but instead focused on how to maximize their abilities as deaf children. The tools and strategies they use were unique, innovative and targeted.*
- *Services received were incredible! Daughter went to Emerson College's Thayer Lyndsley program for hearing impaired toddlers where she received speech therapy and attended a toddler class 3 mornings a week. There was also a parent support group which was so helpful!*
- *So much out there and they all want to help him*
- *speech therapist outside of school is helpful, has noted improvement.*
- *speech therapy, in early intervention has been wonderful*
- *Tailored to as much or as little as we required*
- *tailored to his needs*
- *They came to my home*
- *The best was that they came to our home which was a relief considering he had therapy everyday*
- *The level of care and concern was unbelievable! We felt that our child & family were very supported and our child excelled during this time.*
- *The TOD, now a close friend, was very supportive and offered assistance outside of early intervention parameters. I could call or text whenever I had, or still do have, questions or concerns. Early Intervention therapists were also helpful in supporting me as I struggled with some of the unexpected differences in raising a deaf child.*
- *They are excellent at teaching me how to teach my son. Most of the team genuinely cares about my entire family.*
- *They have been very helpful in guiding us to resources.*
- *They understood listening and spoken language*
- *They was caring and tried to give advice on hearing aids and then cochlear implants and was not pushed into anything.*
- *They were all awesome!*

- *They were very helpful for the Whole Family . We learned the importance of early intervention.And at the same time How to deal and act about our sons hearing loss .*
- *Understanding*
- *Very friendly and knowledgeable. They help my children learn to speak.*
- *Very helpful and caring*

What did you dislike about the services your child received?

- *At the beginning we wanted to start BSL and the teacher of the deaf was against us doing it, but so glad we did as he uses this as his first language at the moment.*
- *Because of my work schedule and the early intervention persons schedule, I could not always be there. Most took place at daycare unless it was summer and I was off of work.*
- *because of what I perceived as apathy on the part of his early intervention physical therapist and occupational therapist, I switched his OT and PT to private at Children's Hospital. Since that change she has made unbelievable games.*
- *Before my child received more help. As she is getting older I feel she is receiving less individual instruction as she works in a preschool setting. I feel like I have to be argumentative in order for her to receive the help she deserves & needs.*
- *EI transitions children the day that they turn 3 regardless if there are continuation services available or not. In our case little bit turned 3 before preschool started and there were no services available until school started unless we were financially capable of paying for private services; I think this is a sad hole in state services. If I chose to keep her out of school that would be one thing, but I think if the child is going to go in to the public school system then services should be provided until the school program picks up.*
- *general early intervention, lots of development questions and things to keep track of*
- *Half were home visits. The other half were office visits and the office was over an hour and a half drive away.*
- *He is in a busy loud classroom with other high needs kids, still feel he has a hard time hearing because they want to retest for developmental delay.*
- *I can't say that I had any dislikes. I wish that services were provided after age 3.*
- *I feel like we are not receiving services often enough (3x month), but we are being reevaluated next week. We didn't know about her hearing loss when EI started, it was just for speech delay.*
- *I had to fight to get services.*
- *I needed to still understand that they were not cured or a hearing person and how to continue to help them advocates in all environments*

- *No AVT or speech therapy*
- *Non applicable*
- *None at MSD. And "intervention services". Could we please call this process differently? It sounds as if we are saving those children from a life of alcoholism/drugs or something. These services were more of a modified vehicle to fit a unique set of learning processes. Parents new to Deaf world definitely would benefit from these programs, especially the linguistic and emotional aspects, but it isn't really an "intervention". It's more like an early start.*
- *Nothing*
- *Nothing- very happy with all services received!*
- *Original EI coordinator was not a subject matter expert in hearing loss, we have received one now who is and it is a huge improvement*
- *Provider wasn't as knowledgeable as I'd preferred*
- *Some of the therapists sent were not a good fit (rude, one smoked and put her hands in his mouth - yuck!)*
- *some very basic testing and some responses recorded to sound when we knew the child only happened to turn in that general direction of his own accord, we were told he could hear sounds we knew for certain he couldn't*
- *Sometimes I felt like my child was under a magnifying glass and that my parenting was on display*
- *That after he turned 3 years old they ended and we are basically on our own with the whole starting school, we will be putting him in Mainstream classes and we hope it's what's best for him*
- *That is only lasts a short amount of time.*
- *That they were unknowledgable*
- *The school is less organized & proactive.*
- *The teacher for his early intervention who has been coming to our house since he was 3 mos old was not wholly supportive of our decision to perform CI surgery at 6.5 mos old. she highly recommended we wait until his 1st bday. He was activated at 7.5 mos. he is now 2 years and 3 months and in normal range with hearing peers. My biggest observation of services we've received is that many of the timelines, expectations and therapies are a bit outdated. The technology has come a long way and early implantation is also key. The professionals from audiologists, to SLPs and early interventionists from my experience haven't caught up.*
- *There did not seem to be a coherent plan or goal. Several agencies were involved as well, so while there was some communication between the therapists, they did not really work together.*
- *They are not specific for children with hearing loss. Too infrequent, too short in duration for each meeting*

- *They really didn't have a lot of knowledge when it came to cochlear implants*
- *They've hardly done anything. In the 18 months since my daughter was referred they've seen her four times. It is a waste of time.*
- *we had 6 slp's and no one knew he had hearing loss*
- *We live in a rural area and therapists are hard to come by. We just lost our speech and language therapist due to retirement and so my son is without a therapist until she is replaced.*
- *Which he could receive more time weekly*

Please feel free to share any additional information regarding your experiences with the diagnosis and management of your child's hearing loss:

- *ANSD is not a very well understood diagnosis in the best of cases. In our case, with a lot of co-existing disabilities, it has meant that hearing/coping with hearing loss has not always been a prime focus of our attention and efforts.*
- *Could we please stop calling this "hearing loss" and instead call it "hearing level"? audiologists serve a very important component in deaf children's development, but hearing levels are not purely pathological. It has linguistic, cultural and emotional implications, so it is important for those in the audiological community to understand they are a component to the whole development process, and not a start-to-end resource person.*
- *I had to see several ENTs before i found a good one. Others were unkind. No one told me about EI, I actually applied for it by myself. They helped me find better ENTs and Audiologists. They pushed to get aids as well. I have been very satisfied with our EI team. Our new ent and audiologist are great.*
- *I was in shock/disbelief when daughter was first diagnosed at age 2 years, 3 months. I knew she had a speech delay as I referred her myself at around 22 months old to Early INtervention due to concerns about lack of age appropriate language. Her first soundbooth test was inconclusive and we were told to return 3 months later. When we returned at age 2 years 3 months I was devastated to hear she had a hearing loss and needed hearing aids. My daughter lost 3 precious months when she could have been aided and hearing language. I wish Audiologist would have said come back in a week or 2 weeks to try soundbooth test again instead of waiting 3 months. Also, diagnosis was given to us with little emotion and care. I was devastated and was afraid of her future as I didn't know any deaf people. I would have loved more information on parent support.*
- *MN Hands and Voices has been an AWESOME resource.*
- *My child received early intervention services from about 4 months of age until 2.5 years of age.*

- *Our daughter's case is unique, and I have found that many professionals do not know about auditory neuropathy, which is why it took us so long to get diagnosed. I feel that more professionals in audiology need to be informed about this disorder. We have also had a year long fight with our school system to transition our daughter from simply developmentally delayed to hearing impaired. I actually had a deaf and hard of hearing teacher argue with me that my daughter would not qualify for hard of hearing or deaf services because she was not, according to her audio gram. As the parent, I had to advocate and plead my case for my daughter and just recently now have her qualified for hard of hearing services. I think there is quite a bit to be done in the field of auditory neuropathy in both medical and education fields for this reason. In addition, we have no idea why our daughter is the way she is. Our family does not have a history of hearing loss, and she presented none of the risk factors associated with this disorder.*
- *The diagnosis and management is stressful and we rely heavily on our implant team for continued support and expertise. The continued management is simple in comparison to our child's continued education. Our daughter hears but does not yet speak and so we rely on ASL. Early Intervention provides 16 two hours sessions of ASL but nothing further for the parents; our daughter learns ASL in her total comm class and, at the age of 3 1/2, has "words" we do not know. I feel that this is another hole in the "education" system.*
- *We have been very lucky as our team have been excellent and always got back to us with any questions or problems.*
- *We were going old that we so of mainstream to public school with out much need for sped and I that was not the case*
- *We were told for the first 5 years that cochlear implants were not an option because of his brain malformation (pachygyria). We finally found a surgeon willing to implant our son so he missed all those years of hearing, unfortunately.*
- *While we were in California, we were told implants were not an option. We had better learn sign as it would be his only mode of communication. Moved to SE Georgia where we were encouraged for oral/aural communication w/implants. Implanted in north FL, tons of AVT therapy, deaf ed - hearing at 10 db, completely oral, only 1 year behind same age peers. Remarkable! Where would he be if we had listened to the "experts" in California?!*
- *Would of liked to receive more info @ beginning when she was born on the more emotional/behavioral/effects on family when she was born. Just given a book to read rather than someone talking with me.*
- *You can't trust the school district. You have to fight for services*

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