“¡Ya Entiendo! Now I Understand!” Parents' Perceptions of the Diagnosis Process and Early Intervention Services

Jenna Hudson

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“¡YA ENTIENDO! NOW I UNDERSTAND!” PARENTS’ PERCEPTIONS OF THE DIAGNOSIS PROCESS AND EARLY INTERVENTION SERVICES

By

Jenna Hudson

A Dissertation
Presented in Partial Fulfillment of Requirements for the Degree of Doctor of Education
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Kennesaw, GA
July, 2015
PARENTS’ PERCEPTIONS

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“¡Ya Entiendo! Now I Understand!” Parents’ Perceptions of the Diagnosis Process and Early Intervention Services

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ABSTRACT

“¡YA ENTIENDO! NOW I UNDERSTAND!” PARENTS’ PERCEPTIONS OF THE DIAGNOSIS PROCESS AND EARLY INTERVENTION SERVICES

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This qualitative research study examined parents’ perceptions on the diagnosis process that identified their children as deaf or hard of hearing and the early-intervention services provided after the diagnosis. It explored how culture influenced the parental perception of information given to them and the ways in which their cultural backgrounds swayed their individual reactions. As a convenience sample, interviews were conducted with six families in the participants’ homes for ease and comfort. The interviews, which contained open-ended questions, were conducted as a dialogue rather than a simple question-and-answer session. After each interview, an observation was conducted to collect data on the family’s interactions during leisure time, focusing on how the parents and their child communicated with one another. The study revealed that half of the mothers were alone when the diagnosis was delivered. The parents reported that the diagnostic medical information had been conveyed to them in a negative manner, as if their child had purposefully failed the hearing test. The parents also perceived the diagnosis process as long and cumbersome and experienced a variety of emotions throughout the process. The
study examined the families’ varying grieving phases from the initial doctor’s visit to their continuous daily struggle in interacting with their child. The children whose parents were interviewed had different amplification and communication modes, and some were candidates for cochlear implants. In spite of their frustration and overwhelming emotions, the study concluded that the parents were ultimately grateful for the interventions and services provided for their children.

Key Words: hearing loss, deaf and hard of hearing, parent perceptions’, diagnosis, early intervention services
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CHAPTER ONE: INTRODUCTION

The diagnosis process of a hearing loss often begins with the Universal Newborn Hearing Screening (UNHS). Hearing loss is considered one of the most common disabilities in the United States (Jackson, Traub, & Turnbull, 2008). Before the UNHS was widely implemented in 1990s, physicians, medical personnel, and teachers were responsible for detecting hearing loss through a long referral process (Fitzpatrick, Angus, Durieux-Smith, Graham, & Coyle, 2008). Now, the UNHS helps identify children with hearing loss as infants to improve their learning and communication outcomes (Fitzpatrick et al., 2008). After children are screened, follow-up assessments are given and early intervention services are provided to the child (Fitzpatrick et al., 2008). Thus, infants are identified as being deaf or hard of hearing at an earlier age with the use of the UNHS (Fitzpatrick et al., 2008), and the resulting early intervention services increase the speech and language development in children who are deaf and hard of hearing (Fitzpatrick, Graham, Durieux-Smith, Angus, & Coyle, 2007). As UNHS became more widespread, both the parents of children who were identified through the referral process and parents of those identified with the UNHS were advocates for the screening procedure (Fitzpatrick et al., 2007). However, studies have found that the parents whose children were diagnosed later through the referral process usually have a harder time
accepting the diagnosis because they tend to focus on the cause of the hearing loss (Fitzpatrick et al., 2007). In contrast, parents of children identified early through UNHS had more success accepting their child’s diagnosis and were able to form a plan for treatment sooner (DesGeorges, 2003). Even with this parental acceptance, determining the next step is difficult for parents whose children did not pass the UNHS; children who are covered by Medicaid are more likely to be lost in the system than those covered by private insurance (Larsen, Munoz, DesGeorges, Nelson, & Kennedy, 2012). Scheduling a follow-up evaluation before the family leaves the hospital helps avoid losing children in the system (Larsen et al., 2012). Finding a pediatric audiologist who has the appropriate equipment can be a challenge for families, especially those on Medicaid, and as a result many times the diagnosed child will not get the follow up care that is recommended (Larsen et al., 2012).

Unfortunately, many doctors and medical professionals are not trained in methods to effectively deliver “bad news” in a sympathetic manner. As a result, parents suffer a range of emotions as they deal with this unexpected diagnosis (Gilbey, 2010). “Although there is a lack of information specifically regarding the delivery of the bad news of the detection of hearing loss, there is abundant information regarding other medical disorders” (Gilbey, 2010, p. 266). Many parents indicated that doctors did not want to be the ones to tell the parents that their child had hearing loss and would often refer the child for additional testing in order to avoid delivering the final diagnosis (Gilbey, 2009). Examining the effectiveness of delivering the information about hearing loss may be beneficial to those professionals working with the families of children who are deaf and hard of hearing. The way that the information is delivered to the parents of children with
hearing loss can have either a negative or positive effect on the parents’ reaction to the diagnosis (Gilbey, 2009); this reaction in turn impacts the effectiveness of the child’s early intervention services and, ultimately, the child’s language development (Fitzpatrick, Graham, Durieux-Smith, Angus, & Coyle, 2007).

Thus, the parents’ reception of the information and the diagnosis relating to their child’s hearing loss can have a positive or negative effect on the intervention services their child receives (Matthijs et al., 2012). To complicate matters, the manner in which the diagnosis is presented to the parents may be perceived in a variety of ways depending on the parents’ age, gender, ethnic background, education, socio-economic status, previous experience, and support systems (Kampfe, 1989). Consequently, the diagnosis of hearing loss in a newborn can be devastating news, and as a result parent-friendly vocabulary by medical professionals regarding diagnosis information is beneficial to the parents (Tattersall & Young, 2006). Parents expressed that professionals who delivered the diagnosis used mostly a medical discourse instead of discussing the child’s prognosis in a relatable manner (Matthijs et al., 2012). This information often causes parents to feel confused and anxious when it is presented in a cold manner that lacks compassion (Fjord, 2001).

After receiving news of this sort, parents often experience different stages of grief. The different stages of grief range from shock, anger, and depression, to denial (Kampfe, 1989). According to Gilliver, Ching, and Sjahalam-King (2013), common feelings in addition to denial and shock are confusion, grief, sadness, and disbelief. In addition, parents may experience the different stages of grief over and over again throughout various milestones, or lack thereof, in the child’s life (Kampfe, 1989). Many
parents have expressed the desire to know experiences of other parents of a child who is deaf and hard of hearing through the diagnosis process, which can help them to picture a possible future for their own child (Jackson et al., 2008). Moreover, the parents’ stage of grief can have a negative impact on the early intervention services due to the delayed start (Kampfe, 1989). Consequently, identifying and addressing the parents’ emotions is important for the child’s education: “Depressed parents lack the energy to deal with daily life, much less the energy to make decisions, seek intervention or offer emotional support to the child and family” (Kampfe, 1989, p. 256). On the other hand, providing the parents with psychological and emotional support during and after the diagnosis helps parents accept their child’s hearing loss (Boison, 1987).

In spite of more use of UNHS for early diagnosis, the lack of information in a relatable format provided to the parents and medical professionals can cause a delay in early intervention services (Eleweke, Gilbert, Bays, & Austin, 2008). In some studies, parents indicated they were given insufficient information from the medical professionals during the diagnosis process and that they did not receive support from professionals (Eleweke et al., 2008). As a result, parents who do not have enough information about the scope of their child’s hearing loss and the cause often begin looking for cures, do not fully understand hearing loss, and do not know what they can do to meet the child’s immediate communication needs (Eleweke et al., 2008). Thus, they may delay finding the early intervention services that their child needs.

These early intervention services are vital to a deaf or hard of hearing child’s language development. A child’s hearing impairment has a direct impact on language development, the type of communication used, and communication between the child and
his or her family (Boison, 1987). These early intervention services begin shortly after a child is identified as deaf or hard of hearing and before the age of six months old (DesGeorges, 2003). Early intervention services focus on language and social skills (Freeman, Dieterich, & Rak, 2002). Without these services, children who are deaf and hard of hearing may continue to communicate at home using gestures and created signs (Steinburg, Davila, Collazo, Loew, & Fischgrund, 1997). Ideally, early intervention services align with the parents’ expectations (Fitzpatrick et al., 2008), and parents of children who are deaf and hard of hearing are provided with information regarding early intervention services that focus on the family’s and child’s needs (Eleweke et al., 2008). Since most children are being identified earlier and when early intervention services are being implemented sooner, these children are entering school with a smaller gap in their language development (DesGeorges, 2003).

Early intervention services are also referred to as parent-infant programs since they address the needs of both the child with hearing loss and his or her parents who are learning to help the child begin to communicate (Marriage, 2013). These programs that bring in the families also promote parent participation (Fitzpatrick et al., 2008). Ideally, the person providing the services uses the family-centered model, which treats the parents as equals and with respect (Marriage, 2013). In addition to helping the child learn to communicate, providing families with resources and information about how to best work with and for their child allows the parents the opportunity to become an advocate and accept the hearing loss (Eleweke et al., 2008). Although the main reason for early intervention services is to provide effective learning experiences for children who are deaf and hard of hearing (Eleweke et al., 2008), parents want to be provided with
strategies to use to help their child’s language development. Even with widespread use of UNHS and early intervention programs, significant gaps may exist in the parents’ understanding and emotional acceptance of the diagnosis of deaf and hard of hearing for their child. This study explored these possible gaps.

**Purpose Statement**

The purpose of this study was to explore a) what the parents’ perceptions were regarding their experience during the diagnosis process as they learned that their child was deaf or hard of hearing and b) examine the early intervention services that followed the diagnosis. The study investigated how the diagnosis information was delivered to a variety of people from different backgrounds in order to help share different families experiences. The study researched the parents’ perceptions regarding the information pertaining to communication modes and resources for early intervention services, and their perception of the manner of delivery. This study explored the parents’ perception of the timing and effectiveness of early intervention services, as the parents’ perceptions are critical for language development to prevent significant delays for children who are deaf and hard of hearing (Gilliver, Ching, & Sjahalam-King, 2013). This study investigated the parents’ perceptions of the early intervention services that followed the diagnosis.

**Significance of Study**

According to Jackson and colleagues (2008), “more information is needed about families’ experience with deafness to identify helpful supports and areas in which families desire additional support” (p. 83). The participants in this study described in detail their experience with the life-changing event of learning their child was deaf or hard of hearing. The surveyed parents’ experiences help build literature by showing the
impact that hearing loss has on a family and illustrate the complex experiences the parents endure and the types of decisions parents have to make throughout the process (Jackson et al., 2008). The way in which the information was received from the parents’ perspective has a direct impact on the child’s education and language development (Boison, 1987). If the parents perceived the information to be negative, they may not seek early intervention services in a timely manner, which increases the likelihood for language delay (Matthijs et al., 2012). In addition, the type of communication mode information given to the parents (for example, American Sign Language, cued speech, spoken language, or total communication) impacted the decision of which mode the child communicated with from the start. If the child is limited to one communication mode and is unsuccessful, then the child must learn a new way to communicate causing the language delay to increase (Fjord, 2001). Consequently, early intervention services are vital for a child who is deaf and hard of hearing’s language development and academic success (Fitzpatrick et al., 2007).

In addition, the language development in children who are deaf or hard of hearing is influenced by when they are diagnosed as hearing impaired (Fitzpatrick et al., 2008), how early they are enrolled in early intervention services (Larsen et al., 2012), and how involved their parents are with their intervention and education (Jackson et al., 2008). The earlier the child is diagnosed, the earlier the intervention can begin to promote language development (Larsen et al., 2012). Lederberg and Everhart (2000) indicate that older children who are deaf and hard of hearing lag behind their hearing peers in dialogic and pragmatic skills. This study interrogated these factors as indicated by the research questions, listed below. There are a variety of modes of communication options available
to the children. It is important to determine which one or which combination works best for the individual child.

**Language Development**

The advances in technology and early identification, children who are deaf and hard of hearing have a better chance at developing age-appropriate language development skills (Jackson & Schatschneider, 2014). Even with these advances some children who are deaf and hard of hearing vary in their language development. Children who are deaf and hard of hearing range in language outcomes; even those with cochlear implants. These language outcomes range from age appropriate to very delayed. Research shows that the age of identification, which sensory device is used, age at implantation, length of implant use, communication mode, cognitive skills, gender, and the variety of education options all impact the language development of children who are deaf and hard of hearing (Jackson & Schatschneider, 2014). “This gap in language development may be observed to greater or lesser depending on children’s sensory device use and early access to auditory input” (Jackson & Schatschneider, 2014, p. 541). According to a study reported on by Jackson and Schatschneider (2014), children with hearing aids had higher receptive vocabulary scores than those children with cochlear implants. These results were influenced by the hearing thresholds the children had prior to implantation. The children with hearing aids were exposed to more incidental language exposure early on, whereas the children with cochlear implants were exposed later on after implantation. Research shows that the hearing age, or the age the child received their sensory device, is a better predictor for language development than the sensory device used (Jackson & Schatschneider, 2014). Moeller (2000) stated that children with sensorineural hearing loss
who receive early intervention services by six months of age achieve language abilities similar to those of their hearing peers.

A wide variety of communication modes are available for children who are deaf and hard of hearing and families (Jackson & Schatschneider, 2014). The method used depends on the individual child’s needs. One method available to children is gestures. Gestures occur using fingers, hands, bodies, facial expressions, and movement (Crais, Watson, & Baranek, 2009). There are two types of gestures, deictic and representational (Crais, Watson, & Baranek, 2009). Deictic gestures are divided into two categories, contact and distal gestures. Contact gestures require more hands on and touching between a child and adult. Distal gestures require less touching and can be pointing (Crais, Watson, & Baranek, 2009). Deictic gestures develop as early as seven to nine months of age. Representational gestures often begin around 12 months of age during games and routines. These gestures “establish reference and indicate a particular semantic content” (Crais, Watson, & Baranek, 2009, p. 96).

Total communication is a philosophy used for children who are deaf and hard of hearing to succeed. Total communication is a combination of any and all modes of communications in English word order to acquire language (California Department of Social Services, 2007). One method is the auditory-verbal approach or oral method. The auditory-verbal approach focuses on spoken language and listening skills. Children are discouraged from using visual cues (Jackson & Schatschneider, 2014). Children who use the oral method use speechreading or lipreading along with their residual hearing (California Department of Social Services, 2007). Another form of communication is cued speech. Cued speech uses gestures that are paired with spoken language to visually
see the different sounds on the mouth (California Department of Social Services, 2007).

There are three different types of manual modes of communication. The first manual mode of communication is American Sign Language (ASL). ASL is considered its own language composed of a unique grammatical structure consisting of movements by the hands, body, and facial expressions (California Department of Social Services, 2007). Manual English uses ASL signs but in English word order to assist with reading and writing. Seeing Essential English, Signing Exact English, and Sign English are manual modes of communication. The last form of manual communication is fingerspelling. Fingerspelling is a code for numbers and letters. Each manual mode of communication contains some aspect of fingerspelling. Fingerspelling is often used for counting and spelling out names (California Department of Social Services, 2007)

**Figure 1: Modes of Communication**

![Modes of Communication diagram]

(California Department of Social Services, 2007)
Definition of Terms/Abbreviations


*ASHA*: American Speech Language Hearing Association is the national association for “audiologists; speech-language pathologists; speech, language, and hearing scientists; audiology and speech-language pathology support personnel; and students” (American Speech-Language-Hearing Association, 1997-2015a).

*Auditory Neuropathy*: Sound enters the ear normally but the signal from the ear to the brain is damaged. Affects people of various ages. (National Institute on Deafness and Other Communication Disorders, 2011)

*Auditory Verbal Therapy*: Endorses early detection of the hearing loss, assists parents facilitate their child’s use of their hearing and creating language rich environments that integrate listening and spoken language, and help children self-monitor their communication through listening (The ASHA Leader Blog, 2012, March 29).

*Cochlea*: Snail shaped, fluid-filled organ that transforms sound waves to electrical impulses (Medline Plus, 2015)

*Decibels*: Unit of loudness of a sound (Earinfo.com, 2015)

*DFCS*: Department of Family and Children Services

*EHDI*: Early Hearing Detection and Intervention

*ENT*: Ears, Nose, and Throat doctor

*JCIH*: Joint Committee on Infant Hearing

*NICU*: Newborn Intensive Care Unit
OAE: Otoacoustic Emissions

Profound: Hear sounds 95 decibels or louder; most rely on lip-reading and/or sign language (Hear-it, n.d.)

Progressive Loss: The existing hearing loss becomes worse over time. (About Health, 2015)

Severe: Hear sounds 70-95 decibels; most people rely on lip-reading and/or sign language (Hear-it, n.d.)

SPIKE: Setting, perception, invitation, knowledge, emotions, strategy

UK: United Kingdom

UNHS: Universal Newborn Hearing Screening

US: United States

Literature Search Strategies

A list of relevant terminology regarding the diagnosis process of children who are deaf and hard of hearing, stages of grief for parents of children who are deaf and hard of hearing, and the parent’s perceptions was compiled. Terminology was also determined through the literature. The following descriptors were used during the search: deaf, hearing loss, hard of hearing, diagnosis procedure, diagnosis process, diagnosis guidelines, levels of stress, stages of grief, parent reactions, parent perceptions, parent perceptions, doctor protocol, doctor procedures, parent attitudes, emotional responses, parent coping, parent experiences, family adjustment to disability. Search engines included Academic Search Complete, Proquest, MEDLINE, EBSCO Host, and KSU SuperSearch.
Conceptual Framework

Since the parents are from different backgrounds and cultures, it is vital to identify common themes and responses to their reactions when learning that their child is deaf or hard of hearing and the resulting stages of grief and acceptance (Eleweke et al., 2008). The manner in which the parents recall the diagnosis process may be impacted by their backgrounds, whether it is a positive or negative memory (DesGeorges, 2003). However, the courses of action taken by individual families to plan for the child’s education might be fairly universal. While medical professionals strive to remain impartial, the truth remains that the parents’ culture, language, ethnicity, and gender may affect how doctors present parents with information regarding the child’s hearing loss (Eleweke et al., 2008). The parents’ background could also affect the support given to the parents, the language used by the doctors, and the people present at the diagnosis.

Investigating parental perceptions and stages of grief is crucial for a child who is deaf or hard of hearing because knowledge of these processes may provide insight into the experience a child has had with professionals who work with children who are deaf and hard of hearing (audiologists, doctors, ENTs, early intervention service providers, teachers, etc.). Professionals who know the parents’ current grief stage may be able to adjust how they interact with, approach, and provide information to the parents (Tattersall & Young, 2006).

In addition, understanding the theories about the ways people understand their experiences can be helpful to professionals. For example, constructionists contend that an object or phenomena cannot be described without considering the person’s unique experience/interaction; therefore, people of different cultures and backgrounds can
interact with the same object or phenomena, but have completely different experiences (Crotty, 1998). A person’s background influences his or her understanding of those experiences: “Moving from one culture to another provides evidence enough that strikingly diverse understandings can be formed of the same phenomenon” (Crotty, 1998, p. 47). Constructionists believe there is not one true and final answer since different perceptions can be obtained from the same experience. Consequently, a person’s background and culture impact how he or she sees the world and experiences it. Each person’s perceptions of his or her experiences is valid and the culture influences the way he or she interprets or acknowledges the phenomenon (Crotty, 1998). Furthermore, constructionists believe that an experience cannot be described without the person and that his or her background has an impact on the individual’s perception of the phenomenon (Crotty, 1998).

For this study, I was interested in the parents’ perception of the process they encountered when they learned their child was deaf or hard of hearing. In conjunction with the constructionism theory, each family had a different idea of the process since each was influenced by their personal cultures. In this study, I analyzed their perceptions and common themes in their diagnosis experiences. Common themes evolved even though the people were from different backgrounds: “As a direct consequence of the way in which humans have evolved, we depend on culture to direct our behavior and organize our experience” (Crotty, 1998, p. 53). I listened to each family’s story and learned from their experiences. The reason I included people from different backgrounds is summed up with this statement, “cross-culture comparisons should make us very aware that, at
different times and different places, there have been and are very divergent
interpretations of the same phenomena” (Crotty, 1998, p. 64).

In addition, family stress theory can be helpful in understanding parents’ struggles
when processing this difficult-to-hear diagnosis. McCubbin and McCubbin (1989) state
the importance of family stress theory is that the type and strengths of the family play a
role in defining the family’s behaviors. This theory looks at how families adapt to and
deal with stressful crisis situations, focusing on the strengths of the family and their
ability to withstand difficult situations. Because of the many factors that play into their
makeup, including their culture and background, some families adjust better and adapt to
crisis scenarios. The two phases related to this theory are the adjustment phase and the
adaptation phase. The adjustment phase was the family’s transition into the crisis
scenario, and the adaptation phase was the family’s reaction to the crisis (McCubbin &
McCubbin, 1989).

**Research Questions**

The following are the open-ended questions that I used to investigate the reactions
of the parents as they experienced their children’s diagnoses:

1. What were the parents’ perceptions regarding the diagnosis process of their deaf or
   hard of hearing child?
   - How the parents’ culture played a role in the way the diagnosis information
     was delivered?
   - What kind of information was received during this process?
   - What information regarding mode of communication was shared with the
     parents?
2. What were the parents’ perceptions of early intervention services and providers?
   - How the parents’ culture played a role the way the diagnosis information was delivered?
   - What kind of information was received during this process?
CHAPTER TWO: LITERATURE REVIEW

Universal Newborn Hearing Screening

The universal newborn hearing screening (UNHS) is an intervention that aims to improve outcomes for children who are deaf or hard of hearing and for their families (Fitzpatrick, Angus, Durieux-Smith, Graham, & Coyle, 2008). Ninety-seven per cent of babies are being screened using the UNHS, and 43 states and District of Columbia have required UNHS for newborns (Larsen, Munoz, DesGeorges, Nelson, & Kennedy, 2011). One out of every 2,000 babies born in the United States have a moderate to profound hearing loss; consequently, hearing loss is considered one of the most common disabilities in the United States (Jackson et al., 2008). Eleweke et al. (2008) stated, “Hearing loss has been described as the most common childhood disability in the United States (US), United Kingdom (UK), and other countries (p. 194). Roughly between 16,000 and 18,000 babies and toddlers are diagnosed as deaf or hard of hearing each year (Eleweke et al., 2008). More than 90 per cent of children who are deaf or hard of hearing are born to hearing parents (Feher-Prout, 1996). The majority of children with hearing loss lose their hearing prelingually or before they develop language (Eleweke et al., 2008).
Benefits of the UNHS

Prior to the UNHS, detection of a hearing loss was identified by health, education, and social services (Fitzpatrick et al., 2008). The UNHS is part of the early hearing detection and intervention (EHDI) programs (Fitzpatrick et al., 2008). The implementation of UNHS varied depending on the creation of the state laws (National Conference of State Legislatures, 2011). UNHS lead to early detection for children (Hardonk et al., 2011). Fitzpatrick et al. expressed, “UNHS constitutes the first step in a comprehensive system of care aimed at preventing or reducing the negative consequences of childhood hearing loss” (2008, p. 38, 39). The Maternal Child Health Bureau of the U.S. Department of Health and Human Resources and the American Academy of Pediatrics promotes the use of a “medical home” or a method of providing cost-effective and high-quality medical care from trusting physicians to families and children (DesGeorges, 2003). As partners in the medical home, pediatricians and parents are able to receive medical and non-medical services necessary for their child and family to reach their highest potential (DesGeorges, 2003). The UNHS is part of a system of such comprehensive services that provides the screening, family support, fitting of appropriate technology, maintenance of technology, and counseling services (Fitzpatrick et al., 2008; Matthijs et al., 2012).

After the child has been screened, he or she must receive follow up interventions including services and technology in order to succeed to their highest potential (Fitzpatrick et al., 2008). Consequently, EHDI programs set up follow-up referrals within two days of screening an infant (Larsen et al., 2011).
Several studies point to the benefits of the UNHS. The UNHS helps identify children early in order to begin early intervention services (Fitzpatrick et al., 2007; Marriage, 2013). Evidence shows that the UNHS detects hearing loss earlier than the traditional referral process (Fitzpatrick et al., 2007). Children who are deaf and hard of hearing who are identified and given an early start have the capabilities to meet their highest potential and have access to language from the beginning (DesGeorges, 2003). Children who are diagnosed early also have a better opportunity to reach their highest potential with language and educational development than those who are diagnosed later (Gilliver, Ching, & Sjahalam-King, 2013). Children who were diagnosed earlier had an easier time getting audiological testing done (Fitzpatrick et al., 2007). Those children whose hearing loss was detected early also had more environmental awareness (Fitzpatrick et al., 2007). Prior to UNHS, the average age of detection was two years, now the average detection is two to three months of age (Larsen et al., 2011; Tattersall & Young, 2006). Children who were identified late and did not receive a newborn hearing screening had significant delays in communication, academics, and social development (Fitzpatrick et al., 2007; Larsen et al., 2011). Families that had children diagnosed later wanted to know the etiology of the deafness, whether it was present at birth or if something happened in early childhood before the loss was detected (Fitzpatrick et al., 2007).

**Challenges to Follow-up Procedures**

There are challenges to connecting parents of those who did not pass the UNHS to the next step. If a child does not pass the UNHS, the next step is diagnostic hearing evaluations. Some parents look forward to fitting their children with the correct
amplification devices and starting a new adventure, while other parents may not be ready to accept the diagnosis and delay the process (Sjoblad, Harrison, & Roush, 2001). Infants who are covered by Medicaid are more likely to be lost in the process and not receive early intervention services than those who have private insurance (Larsen et al., 2012). Babies identified after three months old were also more likely to be lost in the system and not receive intervention services than those identified before three months old (Larsen et al., 2012). Professionals scheduling a follow-up appointment before the family leaves the hospital helps avoid children being lost and not receiving intervention services. When the task is left up to the parents, they often have a difficult time trying to figure out which office and with which doctor to make the appointment (Larsen et al., 2012). Thus, hearing loss specialists provide EHDI professionals with up to date information on where comprehensive audiological services and assessments occur for those infants who did not pass the UNHS. For example, some parents of children born between 2006 and 2009 indicated they had a difficult time understanding the UNHS results and knowing whether to go for further testing or not (Larsen et al., 2012). On the other hand, Tattersall and Young (2006) recommend that parents wait four weeks between the last screening and the first appointment with audiology. In addition, EHDI coordinators indicated it is difficult to get consistent reporting from audiologists; therefore, it is difficult to determine how many babies do not get a follow-up diagnostic hearing evaluation (Larsen et al., 2011).

The American Speech Language Hearing Association (ASHA) and the Joint Committee on Infant Hearing (JCIH) have set up guidelines for audiologists (Larsen et al., 2011). The JCIH goal is for infants with hearing loss to be identified and begin
receiving early intervention services by six months old (Sjoblad et al., 2001). This goal may be difficult to implement. Krishan found that even though children are receiving hearing tests by three months of age, they are not receiving amplification and early intervention services by six months of age (2009).

According to EHDI programs, there is a shortage of pediatric audiologists to perform diagnostic hearing assessments (Larsen et al., 2012). Unfortunately, some audiologists do not have the appropriate equipment, especially pediatric equipment (Larsen et al., 2011). Since hearing screenings and test results are critical in determining correct intervention services, it is important for the audiologist to have the correct array of tests to perform (Larsen et al., 2011). In addition to providing technology and amplification to children, audiologists must also provide support to the family while they are grieving. If parents are going through the grieving process, they may not use the amplification correctly (Marriage, 2013).

**Information Parents Receive**

**Prior to UNHS**

Prior to the UNHS, given that hearing loss is not a physically noticeable disability, most parents did not often think of it as a possibility prior to the diagnosis. The audiologist is usually the parents’ last resort after several other attempts at different diagnoses (Boison, 1987). The period of time in which the hearing loss is suspected, but not confirmed, is vital since it lays the ground work for how parents will make decisions later (Matthijs et al., 2012). A diagnosis puts a name to what is happening with the child and gives the parents a name to continue researching (Fjord, 2001). There was an assumption that parents would notice the child’s hearing loss immediately and seek help,
but this is not the case (DesGeorges, 2003). Boison explained, “It took the parents several steps to reach a diagnosis of their children’s hearing loss, i.e. through pediatric examination, trips to witch/local herbalist, spiritual churches; ontological/audiological evaluation” (1987, p. 222). Before the UNHS, the delay between the parents’ first suspicion and the hearing diagnosis was two years. Many doctors told parents to wait and see what happens (DesGeorges, 2003). Doctors indicated that if a small child came to their practice with a hearing loss, they would be able to detect it right away (DesGeorges, 2003). On many occasions, if audiological assessments were not available, doctors have dismissed the parents’ suspicion of a hearing loss by clapping their hands behind the child’s head, especially if there are additional disabilities (Fjord, 2001).

**Diagnosis Process**

Before diagnosis, parents of deaf children often unintentionally communicated visually to the child through gestures and touch; after the diagnosis, the visual communication seemed to disappear due to the feeling of incompetence (Fjord, 2001). The diagnosis usually takes place with the parents and the medical professional with the highest level of cultural authority. The first test given is the otoacoustic emissions (OAE) which inserts small probes into the baby’s ear. If a baby does not pass the first OAE, then another OAE is performed; if the baby still does not pass, then an auditory brainstem testing (ABR) is administered (Tattersall & Young, 2006). Many parents and professionals consider the ABR as the definitive moment of diagnosis (Gilbey, 2009). Babies in the Newborn Intensive Care Unit (NICU) routinely get both the OAE and ABR, unlike the well babies who usually only get the OAE (Tattersall & Young, 2006). Although parents view the process with deep emotion (Gilbey, 2009), few children are
found to have difficulty. Tattersall and Young state, “Less than 3% of all babies screened are referred to audiology and of that group only around 10% are found to be deaf” (2006, p. 34). During diagnosis, audiologists and ENTs perform diagnostic interventions that require specific knowledge and equipment (Hardonk et al., 2011). Audiologists often fit children with hearing aids based on the ABR results (Marriage, 2013).

Informing the parents of a diagnosis or “breaking the bad news” to parents is difficult and challenging to do; this task is often done by doctors. Bad news is considered information that causes one to feel like there is no hope, a person’s mental or physical health is threatened, or it upsets a lifestyle (Gilbey, 2009). There is information on delivering bad news for other medical disorders to parents, but there is a lack of information related to hearing loss (Gilbey, 2009). Doctors often have a difficult time using both a caring and competence technique together. What the parents hear during the diagnosis period is vital (Fjord, 2001). The information they are told has in impact on how the parents interact with and raise their deaf children (Matthijs et al., 2012). Parents felt that if the doctors gave them good explanations, they were good communicators. A good explanation was one that used parent-friendly vocabulary, used examples, and confirmed whether the parents understood or not (Tattersall & Young, 2006).

Family Supports

Giving the parents psychological and emotional support during and after the diagnosis is crucial to parents’ acceptance of their child’s hearing loss (Boison, 1987). Additional research needs to be conducted exploring the families’ experiences with deafness to determine which supports are helpful. Most of the research that has been conducted has been limited to close-ended questions, surveys or scales (Jackson et al.,
This study found that parents respected professionals who were able to deliver the diagnosis in a sensitive way and were aware of the parents’ feelings (Tattersall & Young, 2006). When parents are able to receive support from the beginning, they are able to cope easier with their child’s hearing loss (Freeman et al., 2002). Having at least one supportive relationship also helps the coping process. Family members often provide support for one another during stressful times (McNee & Jackson, 2012). The problem and the support may both be enhanced for Hispanic parents, who felt their child was referred to as the disability, and he or she was losing an individual identity. However, the Hispanic community tends to have deep religious beliefs. Thus, the Hispanic community often provides more support and comfort to the family of children with a disability (Steinburg et al., 1997).

Parents of newly diagnosed children tend to be flooded with emotions and questions for the doctors. Parents want to know what the etiology or cause of the hearing loss is (DesGeorges, 2003), whether the hearing loss was present at birth (Fitzpatrick et al., 2007), and what are other associated disabilities, as well as information and explanation regarding the degree of hearing loss, different amplification options and communication choices, and the educational impact (DesGeorges, 2003). Parents had questions regarding the Deaf community, as to how to teach their child to have a positive self-esteem, financial concerns, sibling struggles, and language development (DesGeorges, 2003).

**Difference or Disability**

There are mixed feelings on whether a hearing loss is considered a disability. Many feel that since children who are deaf or hard of hearing are often able to develop a
language, either spoken or signed, and become a complete person, that there is a communication difference, but not a communication disability (DesGeorges, 2003). Deafness is thus referred to as a cultural phenomenon and not a disability. The culture is referred to as Deaf, and the audiological condition is referred to as deaf (Steinburg, et al., 1997). Those who do not have experience with hearing loss often think of it as a disability or disease. This becomes a problem for parents since most of them are hearing. Thus, the “hearing world” often refers to deafness as an impairment that requires intense auditory and speech therapy in order to live in society. On the other hand, the concept of Deaf is known as a cultural-linguistic model or constructionist model. Being deaf just makes the child part of a cultural minority group, not a disability group. Consequently, professionals require training on more regarding cultural-linguistic issues so that the parents receive as much information as possible (Matthijs et al., 2012).

**Unbiased Information**

DesGeorges (2003) expressed that several of her participants had audiologists apologize for the child’s hearing loss and then proceed to fit the child with the incorrect hearing amplification technology. In addition to apologies, parents often hear biased opinions on information related to hearing loss and modes of communication (DesGeorges, 2003). Important suggestions may not be given to the family because professionals are concerned about the family. Other professionals focus on only the child’s disability and not the child’s and family’s needs (Eleweke et al., 2008). For the past hundred years, professionals have argued and debated the different communication modes for children who are deaf and hard of hearing, making unbiased information difficult to obtain. Fortunately, a shift has begun over the past few years to focus on the
mode that works for each individual child, in order to allow each child the opportunity to communicate. (DesGeorges, 2003). Eleweke et al. (2008) stated, “The literature indicates that early exposure to sign communication can facilitate the linguistic, cognitive, social, emotional and educational development of children with hearing loss” (p. 197). Establishing an effective, elaborate form of communication early in life that fits the individual child’s needs is crucial for cognitive and social development as well as forming relationships (Decker, Vallotton, & Johnson, 2012).

Therefore, providing parents with unbiased information about support services and options available in early intervention programs helps make educated decisions about their child, especially those with no prior experience with hearing loss. When given relevant information, parents may feel more obligated to participate in their child’s education and acquire more resources (Eleweke et al., 2008). DesGeorges (2003) expressed that parents felt there needs to be more comprehensive, coordinated and culturally sensitive services provided for children with hearing loss. In addition, parents want to receive information regarding possible options for their child in order to avoid any bias (Matthijs et al., 2012).

Information from Multiple Sources

In order to make the best decisions for their child, parent seek information from other parents, members of the deaf and hard of hearing community, professionals and teachers working in the field of deafness. By receiving input from multiple sources and a variety of perceptions, the parents get balanced information to assist their child in achieving success (DesGeorges, 2003; McNee & Jackson, 2012). Parents who received information from these varied sources felt more appreciated by professionals when they
involved themselves in their child’s education. These parents sought additional speech therapy and were able to learn sign language to communicate with the child, as well as management of hearing aids (Eleweke et al., 2008). In addition, providing information and demonstrating the benefits of amplification on residual hearing by audiologists is beneficial (Marriage, 2013). In order for parents to make the appropriate, educated decision for their child regarding communication and technology, they need to be provided with the information and support they require (DesGeorges, 2003). By not providing the family with information regarding supportive services, the system may limit the family’s ability to adapt to the child’s hearing status (Eleweke et al., 2008).

Unfortunately, parents of children who are deaf or hard of hearing are still not receiving satisfactory information or support during the early years and do not know how to help their children at home (Eleweke et al., 2008).

Furthermore, parents and professionals often have their own opinions regarding certain methods causing biased information to be shared. Both groups have their own cultural backgrounds and perceptions that influence their decision making and work practices (Matthijs et al., 2012). Parents also hear information based on the current politics and geographical region (Trapp Petty, 2011). In addition, the family’s cultural background plays a part in how the family will react to the hearing loss diagnosis. The manner in which people from different ethnic groups treat disabilities differs based on gender, language, family structure, beliefs about health, the role of stress, intervention services, and treatment of the disability (Steinburg et al., 1997). Ideally, the information parents receive should “educate them about childhood hearing loss and its consequences, about the specialized support these children will require to ensure optimum development,
Parent and Professional Collaboration

Effective elements of collaboration are mutual respect, clear communication, understanding and empathy, shared decision making, information sharing, accessibility, both parties’ evaluation of the progress, and no blaming or pointing fingers (DesGeorges, 2003). Within this framework of collaboration, parent participation can range from being a parent-consultant to providing workshops for families who are newly identified. The increase in parent participation has changed the way information is delivered to parents and tends to provide a better quality of life for children who are deaf and hard of hearing. Parents and professionals working together continues to build a future where children who are deaf and hard of hearing can be identified early and begin their journey right away so their language can develop. While the medical part of a hearing loss diagnosis is important, there is additional information that families require in order to make choices for their child who is deaf and hard of hearing along the journey (DesGeorges, 2003). Thus, sharing information between families who have similar experiences can be an important way for families to learn from one another.

Furthermore, collaboration between the parents and the professionals is important so the professionals can understand what information the parents know and can work together to find the best services for the child. Consequently, families can begin to take control over their child’s diagnosis process through collaboration. Collaboration can also determine the goals the child works on and the strategies to obtain these goals. In addition, the relationship between families and the professionals is ultimately
strengthened through collaboration (Eleweke et al., 2008). Collaborating and communicating information between parents and involved professionals would be beneficial during the child’s rehabilitation (Gilliver, Ching, Sjahalam-King, 2013). However, parents want to receive unbiased information in order for collaboration to work correctly. As will be discussed later in this chapter, parents in some studies do not feel that they have received unbiased information.

Several studies have shown that the degree to which parents are involved and informed affects the child’s educational success. These parents work with their children to become good communicators. The involvement of parents has been reported to be a predictor of the child’s communication ability by age five (Fitzpatrick et al., 2008). However, parental involvement in the case of children who are deaf and hard of hearing may still be limited due to the lack of information. By participating and making decisions related to their child’s hearing loss the parents are able to cope and receive support to help meet their child’s needs (Eleweke et al., 2008). Hispanic parents may have limited involvement with supportive services due to their intimidating factors (Steinburg et al., 1997). Families feel empowered by knowing what they want regarding the needs of the child with hearing loss and how to reach that goal.

Several factors that play a role in the information parents receive from professionals are communication difficulties, absence of knowledge on the topic for professionals and parents, the differences in what the professionals understand and what the parents understand and believe, and the parents’ misunderstanding of the professional vocabulary (Eleweke et al., 2008). The misunderstanding of information can cause families to be confused regarding the cause of the disability, not sure what can be
done to help the child, and cause the parents to look for a cure (Eleweke et al., 2008).

Parents who receive the first information in a medical setting are more likely to consider only medical information in further decision-making processes. Surveys of parents indicated the medical perspective of deafness was a major theme in early discussions (Matthijs et al., 2012).

**Different Perceptions**

Later on some parents may learn about different perceptions and methods although they may not often be given the chance to see the socio-cultural view associated with deafness (Matthijs et al., 2012). Eleweke and colleagues (2008) suggests that to prevent the possibility of a solely medical view of deafness, packets of relevant unbiased information are gathered by the government in order to give to parents of children with hearing loss the support they require. Providing these packets at audiology clinics, health centers, and schools along with encouraging parents to ask questions to clarify misunderstood information helps parents learn different perceptions. In addition, the internet has become an important resource of information to parents since accurate information can be acquired quickly to assist with decision making. Equally important, provide literature and videos to the parents soon after the diagnosis in order for the parents to reference them many times (Eleweke et al., 2008).

Others have suggested that parents could be visited by a range of professionals working with children who are deaf or hard of hearing from speech and language pathologists, audiologists, and professionals with hearing loss, teachers, and social workers. These medical professionals could benefit from hearing different perceptions as well in order to broaden the horizons outside of what they learn at in-services. Looking at
the diagnosis outside of just the professional prospective is helpful to medical professionals (DesGeorges, 2003). These professionals provide information pertaining to counseling, assessments, communication strategies and options. Planning and scheduling meetings with the family helps with consistency (Eleweke et al., 2008).

Moreover, give parents unbiased information so they feel empowered, as well as the chance to ask questions of the professionals (Eleweke et al., 2008). Understanding the family’s culture, value, structure, and routines helps professionals. Include information regarding and contact information for deaf role models for parents. This study suggests that there are three major overlapping stages that occur after diagnosis: separation, liminality, and reincorporation (Fjord, 2001). Separation happens when the parents first hear about the diagnosis and includes a break in social interrelations. Then, liminality occurs when parents are trying to determine how to cope with this new diagnosis, and often parents may be left to do this step on their own. The final step is reincorporation and is not always possible if the second step does not end. Reincorporation involves the mainstreaming of deaf children due to what society expects of them (Fjord, 2001).

**Parent Support Groups**

Eleweke et al. (2008), suggest that parents be given information on how to contact other parents with children newly diagnosed as deaf or hard of hearing in order to share support, stories and experiences, and learn from one another. Parents who have been through similar situations may be able to give the newly diagnosed parents the support they need. Those parents who are in contact with other families and have support may be better able to overcome new obstacles as they arise in the child’s life. Parents who receive support from other parents may also be able to better interact with their child and
recognize more fully the child’s communication needs. Parents who form these informal support groups tend to be welcoming of new parents as they learn from one another and reap the benefits of each other’s support (Eleweke et al., 2008). Unfortunately, most parents of young children with hearing loss do not receive information regarding parent-to-parent support groups (Eleweke et al., 2008). The packets that are suggested for care after the diagnosis contain information regarding how to find parent-to-parent support groups. The amount of social support mothers receive significantly impacted the mother-child interactions later (Feher-Prout, 1996). Parent support groups can provide the parents with the ability to share information regarding hearing amplification devices and resources, can help parents understand prognoses information, and lend a helping hand. The emotional piece for parents may also be met through the parent-to-parent support groups, as well as giving the children the opportunity to see peers with the same type of communication (Fitzpatrick et al., 2008).

**Early Intervention**

As noted before, a child’s hearing impairment has a large impact on his or her language development, mode of communication, and communication with the family. With the help of early detection, early diagnosis, and early hearing assessments, the child’s needs are addressed and rehabilitation and early intervention services are implemented right away (Boison, 1987; Freeman et al., 2002). After an infant is identified as deaf or hard of hearing, the next step is for him or her to be enrolled in an early intervention program (Larsen et al., 2012). Children should be identified and begin early intervention services before six months of age (Decker, Vallotton, & Johnson, 2012; DesGeorges, 2003). DesGeorges stated, “Historically, children who are deaf or
hard of hearing have entered the public school years with significant language delays due to late identification, followed by underachievement as substantiated through nationally standardized tests scores of this student population” (2003, p. 89). The cognition and categorizing abilities stem from language (Fjord, 2001). When early intervention services are implemented immediately, there is a definite improvement in speech and language development (DesGeorges, 2003). Children whose hearing loss is detected early have a better change of entering school with normal levels of language development (DesGeorges, 2003).

As noted before, the success of children who are identified as deaf or hard of hearing depends largely on the parents’ reactions, acceptance, and their advocacy for their child (DesGeorges, 2003). Likewise, early intervention for children who are deaf or hard of hearing promotes language acquisition as well as social skills. Those children who are identified early are able to communicate better with the peers and family (Freeman et al., 2002). In addition to the possible lack early intervention, Deaf children from Hispanic families have more severe problems in communication and academics than those from non-Hispanic families (Steinburg, Davila, Callazo, Loew, & Fischgrund, 1997). The inconsistent linguistic signals may impede the communication skills of Hispanic deaf children (Steinburg, et al., 1997). Thus, early intervention becomes even more critical for these families because without these services, communication for a deaf or hard of hearing child may continue to be gestures or home signs (Steinburg et al., 1997). A key component of language acquisition, parents who engage in dialogue with the children are promoting this acquisition and laying the foundation for more language to build (Freeman et al., 2002). However, parents often feel stressed trying to use
language stimulation strategies throughout the day (Jackson et al., 2008). At the same

time, the mother’s ability to problem-solve is positively related to the child’s emotional
understanding, reading achievement, and cognitive problem-solving skills (Feher-Prout,
1996). Underscoring the importance of early intervention, studies have found that
children who are identified as being deaf and hard of hearing as infants have a better self-
concept of accepting themselves as a child with a hearing loss (Fitzpatrick, et al., 2007).

Because of the importance of early intervention, aligning services with the
parents’ expectations and preferences ensure the early intervention outcomes are as
successful as possible (Fitzpatrick et al., 2008). As part of the services after the diagnosis,
providing parents with information about the child’s specific hearing loss, development
needs, and additional supportive services assists the parents in a way in which they
understand and remember (Eleweke et al., 2008). Parents of children with hearing loss
require information related to supportive services (Eleweke et al., 2008). Eleweke et al.
explain, “Supportive services are flexible forms of assistance that should enhance a
family’s ability to care for a child with hearing loss” (2008, 191). They also suggest that
providing information about supportive services will promote inclusion and the
likelihood that children who are deaf and hard of hearing will stay with their families
(Eleweke et al., 2008). Supportive services provide parents with information regarding
their child’s needs and formal and informal family support services (Eleweke et al.,
2008). Studies have found that the number and quality of support the parents receive are
more important than the type or quantity (McNee & Jackson, 2012).
Family-Centered Models

Early intervention programs are also referred to as parent-infant programs since they focus on the family needs in addition to the child’s needs. These programs are becoming more family-centered to help provide the child and family with the correct support (Marriage, 2013; Fitzpatrick, et al., 2008). Family-centered models draw from the strengths and information of each member of the group to meet the needs of the child and family. Thus, family-centered models emphasize the whole family, and professionals become active listeners, models, and coaches through the process (Eleweke et al., 2008). These programs focus on language development, parent-child communication, social skills development, and maximization of any residual hearing the child may have. This family-centered approach promotes self-efficacy in parents and higher participation rates in early intervention services (Fitzpatrick, et al., 2008). Family-centered models also provide the parents with a sense of equality and as a member of the team (Marriage, 2013). Strategies for educational development, learning sign language, and speech training skills are also included in these early intervention programs (Eleweke et al., 2008; Marriage, 2013).

Parents’ Role

As mentioned earlier, parents are key participants in early intervention. Eleweke et al. stated, “Effective parent-child communication is the best single predictor of success in virtually all areas of development of children with hearing loss, including academic achievement” (p. 194). Early interventionists are able to enhance the families’ well-being early on due to earlier detection and services (Jackson et al., 2008). After the identification of their child’s hearing loss, parents have important roles to fulfill. Parents
providing recommendations for the development of early hearing detection and intervention (EHDI) systems, help develop educational materials, support other families through the identification and diagnosis process, and listen and learn from the parents’ experiences (DesGeorges, 20003).

**Role of Supportive Services**

By providing families with supportive service information, professionals will enable families with the resources needed to seek the correct services in order to deal with and accept their child’s hearing loss in a positive manner (Eleweke et al., 2008). Jackson et al., (2008) stated that the participants in their study were highly involved in the intervention services their child received. By learning about supportive services, parents of children with hearing loss obtain further information regarding additional resources pertaining to their child’s development and coping strategies (Eleweke et al., 2008). Early intervention services thus provide parents with the knowledge and skills to manage the hearing impairment and corresponding technology (Freeman et al., 2002). Parents who are knowledgeable regarding their child’s hearing loss have more positive interactions with their child (Freeman et al., 2002). When interactions occur in the child’s appropriate mode of communication, then the child is given the chance to be involved in normal social and academic activities (Eleweke et al., 2008). The interactions of the family and the environment are referred to as the family ecosystem theory because the family nurtures the child and the environment (McNee & Jackson, 2012). In addition, friends, neighbors, community workers, media, and politics influence the family dynamic. Sibling involvement in these early intervention services is beneficial.
Thus, effective and timely early intervention programs provide successful learning experiences for children who are deaf or hard of hearing. Early intervention programs promote development and future capabilities (Eleweke et al., 2008). Children who receive early intervention services before nine months of age have better language development than those identified and provided services after nine months of age (Eleweke et al., 2008). Since parents are the primary decision-makers for their child, their participation is imperative for their child’s success. When family members create positive relationships with professionals and are involved in the assessment procedures and implementation of the early intervention services, then the child is more likely to succeed (Eleweke et al., 2008). Thus, information regarding early intervention services can be found at health centers, hearing and speech clinics, and educational centers in the community. Parents should also be provided with strategies for improving their child’s language development, parent-child communication, social skills, using their child’s residual hearing, and parent support groups (Eleweke et al., 2008). When professionals provide parents with information regarding early intervention and support services, the parents are able to make education decisions and participate fully in the development of their child (Eleweke et al., 2008). According to Eleweke et al., “Literature indicates that information about supportive services could make the biggest differences in the lives of families of children with hearing loss by enhancing their empowerment” (2008, p. 198).

In spite of their challenges, holding children who are deaf or hard of hearing to high expectations gives them the same opportunities to learn so they are able to be as
independent as possible. Those children who are not held to these same high expectations often begin to feel isolated and become dependent on other people (Eleweke et al., 2008). The correct services, provided early, can enhance the potential of children who are deaf or hard of hearing. However, with a lack of information, early intervention services are often delayed (Eleweke et al., 2008). When information or services are not provided to the parents during identification, then the screening and intervention process are less effective (Matthijs et al., 2012). Other factors that delay early intervention services include how far the family lives from the testing facility, the type of hearing loss and severity of the loss, and whether the hearing loss is unilateral or bilateral (Larsen et al., 2012).

Parents’ Perceptions

Understanding the parents’ experiences assists with moving toward a more collaborative approach between parents and professionals. Collaborating allows the professionals to see the parents’ perspective regarding the UNHS, identification process, and early intervention services (DesGeorges, 2003; Eleweke et al., 2008). Since many parents tend to be the long-term case managers for their child, their involvement in the decision-making process for their child is vital. Parents speak up to ensure their voices are heard and views are addressed by professionals (DesGeorges, 2003). Due to their negative experiences, these parents want to be involved in the identification process and intervention services so that in the future other parents of children who are deaf and hard of hearing will not have the same experiences (DesGeorges, 2003; Jackson et al., 2008). Fortunately, DesGeorges found that there are families who have positive experiences and want their voice heard as well. Early intervention services should therefore be family-
centered with experiences that work in real life settings as well as in the professional clinic. In this way, professionals and parents can each bring a different piece to the puzzle which is important due to the uniqueness of deafness and hearing loss (DesGeorges, 2003; Eleweke et al., 2008).

**Parent Reactions to UNHS**

Since parental involvement is key to child success, it is important to discover their reactions to UNHS. As noted above, accurate and early detections of hearing loss can help with decision-making and planning for choices with amplification and educational programs (Larsen et al., 2011). Parents who have been surveyed generally seem to be aware of this need. Fitzpatrick et al. stated, “All parents expressed the view that newborn hearing screening services should be an important part of the overall service delivery model for children with hearing loss” (2008, 41). In another study, parents also expressed that continuing the use of the UNHS helps detect hearing loss at the earliest possible age (Fitzpatrick, Graham, Durieux-Smith, Angus, & Coyle, 2007).

Moreover, Jackson et al. stated, “With newborn hearing screenings, babies are identified earlier and parents are introduced to issues related to deafness within a few months after their child’s birth” (2008, p. 82). However, some parents did feel as if they did not receive any emotional support during the diagnosis process, only when they reached the therapeutic process (Fitzpatrick et al., 2008). Fitzpatrick et al. found, “The success of newborn screening is largely dependent on the implementation of adequate support programs for children and families” (2008, p. 45). As several studies have found, the support given may not be adequate. Some parents expressed that finding out their child was deaf or hard of hearing interfered with the normal early parent-child bonding
(Young & Tattersall, 2007). However, other parents stated that finding out their child had a hearing impairment later gave the parents more time to bond with their child (Fitzpatrick et al., 2007; Gilliver, Ching, & Sjahalam-King, 2013). The parents in this study also expressed that the need for early intervention was more important than the emotional bond. The parents in the study shared that a later diagnosis did not necessarily mean a delay of diagnosis by months or years but simply just a few days or a week to allow the parents time to adjust to the new baby’s arrival (Gilliver, Ching, & Sjahalam-King, 2013).

In addition, parents of children with hearing loss and those with normal hearing tend to report positive perceptions toward the UNHS process and prefer it over the traditional referral process (Fitzpatrick et al., 2007). Both sets of parents (those whose children were screened and those who were not) felt that children who were diagnosed early had a better long-term prognosis and more opportunities with the speech and language development than those who were diagnosed later in life (Fitzpatrick et al., 2007).

Surveys of parents of children identified through the UNHS found that these parents had more success with their reactions, acceptance, and advocating for their child (DesGeorges, 2003). In this context, advocating for the child can mean fighting for the child’s options and services and being an active participate in decision-making (Jackson et al., 2008). Those parents whose children went through the UNHS indicated a smooth transition to the audiological assessments although they reported that waiting for the results was nerve-racking (Fitzpatrick et al., 2007). In this study, those parents whose children were screened using the UNHS were less frustrated about the lack of
coordination between services, since they were not racing against the clock as much as parents of children identified later (Fitzpatrick et al., 2007). Studies have found that the diagnosis often solidifies the parents’ suspicion of a hearing loss (Tattersall & Young, 2006) but is still a scary event (Trapp Petty, 2011).

**Parent Perceptions of the Information Prior to UNHS**

Before the UNHS was widely used, parents described their diagnosis scenarios and began to feel frustrated since they felt as if the professionals were not listening to what they wanted (Freeman et al., 2002). Another study found that parents often become frustrated at the lost time between recognition and actual diagnosis (DesGeorges, 2003). In addition, parents of children who were diagnosed with a hearing loss through the referral process tended to express that they were frustrated, confused, and often anxious waiting on the results of the audiological assessment (Fitzpatrick et al., 2007). Much of the frustration from these parents came from having to convince the doctor that they were concerned and wanted further testing (Fitzpatrick et al., 2007). Consequently, the parents in this study whose children were diagnosed later felt strongly about the importance of the UNHS and its use by public health services (Fitzpatrick et al., 2008). Many parents were confused by the referral process. Some parents thought the referral was to determine the child’s level of hearing loss, not to confirm the child had a hearing loss (Tattersall & Young, 2006). Other parents saw the follow-up appointment with audiology as the next step in the screening process, not as a step to define their child’s hearing loss (Tattersall & Young, 2006). As these studies indicate, the referral process went well for some, and for other parents it was a challenge to learn how to work the system.
Physician and Parent Perceptions on the Given Information

In the study conducted by Larsen and colleagues (2012), primary care physicians indicated they were comfortable telling the parents the results of the hearing evaluations, but were not confident and knowledgeable in the steps that followed if the child did not pass. Physicians stated they would like more evidence based, concise information that uses familiar terminology across medical practices as well as education materials for parents (Larsen et al., 2012). Research has found the importance of audiologists keeping physicians up to date on hearing loss and the diagnosis process since physicians do not see deaf and hard of hearing patients frequently. Parents and physicians have both indicated concern for the fact that hearing evaluation results and recommendations are not given to parents in a timely manner, if they are given (Larsen et al., 2012).

In one study, parents tended to perceive that the doctors did not want to be the ones responsible for telling the parents the results, and therefore, would refer for further testing in hopes that someone else would deliver the bad news to the parents (Gilbey, 2009). Parents in this study had a variety of perceptions related to who is responsible for delivering the diagnosis (Gilbey, 2009). Another study suggested that parents wanted physicians to stop providing them with inaccurate information regarding hearing screenings and hearing loss (DesGeorges, 2003). Parents in another study also expressed their frustration about the uncertainty of who was supposed to report the details of the hearing loss to the family (Fitzpatrick et al., 2007). A majority of the parents in this study thought that it was vital for audiology and therapy services to be provided to children with hearing loss regardless of their severity of hearing loss (Fitzpatrick et al., 2008). On the other hand, some parents who were surveyed felt as though they did not expect the
physicians to be informed enough about the ear to deliver the information; others wanted
doctors to focus on the information, not the supportive side (Gilbey, 2009). Fitzpatrick et
al. (2008) also pointed out that some of parents were dissatisfied with the communication
used during the diagnosis. Another study reported that some parents expressed that the
professionals who delivered the diagnosis used mostly medical dialogue and that very
few used a combination of medical and cultural-linguistic discourse (Matthijs et al.,
2012). An additional study found that the information parents hear during the diagnosis
process may cause them to feel confused and anxious. Other parents also indicated they
were left on their own and given little to no help through the process (Fjord, 2001).
Gilbey's study (2009) showed that 50 per cent of these parents were dissatisfied with how
the process went and that only 21 per cent were happy with how the information was
presented to them.

The role of extended family members may also be crucial, but challenging.
Another study found that parents expressed it was difficult for extended family members
to learn how to sign in order to communicate with their child. However, some extended
family members experienced a similar grieving process as the parents and grew closer to
the family and child (Jackson et al., 2008). The three factors that tend to influence the
relationship of extended family members are physical proximity, ease of communication,
and the strength of the relationship. Some challenges, especially for grandparents, are the
physical distance, poor health, and lack of knowledge about hearing loss and early
intervention services (McNee & Jackson, 2012). Studies have found that some parents
felt that having another person present when the diagnosis was delivered was extremely
helpful since the other person was able to give support and ask important questions that
the parents did not think of due to their emotions (Gilbey, 2009; McNee & Jackson, 2012). Thus, family-oriented support is important after the diagnosis of a hearing loss (Jackson et al., 2008).

After diagnosis, providing parents with counseling regarding negative feelings and emotional support, factual information about the child’s hearing loss, and directions on how to work on auditory training with their child is valuable (Boison, 1987). Unfortunately, Matthijs et al. (2012) suggest that parents often are provided with biased information. Parents in this study are aware that they are not getting the information they require and the information they are receiving is biased (Matthijs et al., 2012). In another study, parents also expressed that the therapist told them that if they did not listen to the provided communication options their child would not succeed (DesGeorges, 2003). Because of such negative perceptions, audiologists should listen carefully and without judgment to the parents and focus on their current priorities (Marriage, 2013). As another study shows, parents usually expressed their major concerns as regarding communication and education (Feher-Prout, 1996). Parents like these in another study, who did not receive various options, including alternative options, felt angry (Jackson et al., 2008).

An additional study found that parents expressed they felt they were left alone to deal with their grief after the diagnosis (Freeman et al., 2002). Other surveyed parents felt that they found information on their own, instead of professionals giving it to them (Jackson et al., 2008). This study found that parents who were given information regarding other parent contacts felt this was a vital part of the process. These parents indicated the best thing they could do was talk and learn from other people who are going through the same experiences. Many of these parents expressed that they felt lonely
through the process and would have liked to be given more information about parent contacts and deaf social events (Jackson et al., 2008).

**Parent Reactions to Early Intervention**

As noted above, parent perceptions and practices have an impact on how beneficial the early intervention services will be (Freeman et al., 2002). The parents in the Fitzpatrick et al. (2008) study discussed how important the emotional support and coaching on language development was for their family and their child. These therapy sessions were weekly in order to provide the families with additional support throughout the therapy. After overcoming some initial obstacles, most parents in an additional study expressed positive experiences with support services (Jackson et al., 2008).

As studies indicate, one key reason for the delay of early intervention services is the lack of information, which greatly affects the child’s development. Surveyed parents felt they were provided with inadequate information during the diagnosis process and were thus unable to make educated choices for their children (Eleweke et al., 2008). Furthermore, studies indicate that the biggest complaint for parents is the lack of information and support from professionals (Eleweke et al., 2008; Jackson et al., 2008). In addition, some parents want information repeated to them multiple times in a variety of different ways at several different times to ensure they understand and follow through with services (Larsen et al., 2012). Consequences for lack of information can be misconceptions of the cause of the hearing loss, lack of knowledge about interventions, and the search for a cure (Eleweke et al., 2008).

According to Boison, parents of children who are deaf and hard of hearing tended to be overprotective of their children and often made excuses for the late developers
hoping they would outgrow it (1987). Some parents also expressed they had a hard time finding information about their options relating to their child’s hearing loss (Jackson et al., 2008). Jackson et al., (2008) reported that they had parents in their study who were not satisfied with the early intervention services due to the lack of informational resources they were provided. In an additional study, some parents often became confused after receiving contradictory opinions and information (Feher-Prout, 1996). Other parents also felt as if they were being pulled in different directions by the professionals (Jackson et al., 2008). In order to try to clear the confusion, parents in another study begin asking questions about the child’s future; when professionals were uncertain about the answer, these parents become more frustrated and stressed (Feher-Prout, 1996). Furthermore, parents who did not receive information regarding supportive services and the individual needs of their child tended to report more stress and thought of their involvement more as a required job (Eleweke et al., 2008). Another study found that the uncertainty and the impact on language development were areas in which stress and anxiety were created in the family (Fitzpatrick et al., 2007). When surveyed, some parents of children who are deaf or hard of hearing often begin to question the reason behind this unexpected life event (Feher-Prout, 1996). Matthijs and colleagues (2012) stated, “Psychological issues, such as adjustment to the diagnosis, may also have an important influence. Supporting families of newly diagnosed babies is therefore not only about providing information” (p. 388). However, parents want to be provided with accurate information so that the child who is deaf or hard of hearing can be included in the family with as few obstacles as possible (Eleweke et al., 2008). Complicating matters, some parents only listen to the information they want to hear, depending on their
emotions and the stage that they are in the grieving process with the diagnosis of a hearing loss (Matthijs et al., 2012). When too much information is given right away, the parents tend to get confused, to question how to parent the children, and to refuse to take responsibility for decisions that are made (Matthijs et al., 2012).

**Reactions to the Presentation of Information**

The way in which the information is delivered to the parents has an effect on their emotions. Studies show that the experiences families had were often reduced and considered an exception, not the rule (DesGeorges, 2003). Gilbey (2009) also found that a majority of parents felt the diagnosis was delivered in a blunt way which caused the parents to feel anger and shock. Medical professionals dumped the diagnosis on some surveyed parents without warning, without making sure the parents understood the diagnosis, with a lack of empathy and knowledge, and used confusing medical terms the parents did not understand (Gilbey, 2009). Most parents in another study felt the diagnosis process to be confusing and anxiety filled (Tattersall & Young, 2006). The audiologists tend to be abrupt and the parents get frustrated when they leave the diagnosis without any information, according to another study (Jackson et al., 2008). Consequently, the diagnosis should be presented to the parents using a level of vocabulary they can comprehend. Parents in this study want to be treated as an equal and included in the diagnosis dialogue (Tattersall & Young, 2006). Some of these parents also felt excluded during the process because they were not given explanations regarding the equipment, testing procedures, and testing results (Tattersall & Young, 2006).
Reaction to Delivering Diagnosis

Often times in one study, the person delivering the bad news lacked empathy or the ability to put himself or herself in the other person’s shoes. This lack of feeling fueled the disconnect for these parents. Until recently, there was no training during medical school or residency regarding methods to deliver the dreadful news to parents. In addition, there is no information on the training audiologists go through to learn how to deliver such a diagnosis (Gilbey, 2009). This study suggested that the way in which parents interpreted the information is “in the eye of the beholder,” and no one can predict how the information will impact the parents without first understanding the parents’ expectations (Gilbey, 2009, p. 269). The research also suggested that the person who is delivering the diagnosis must have a plan in order to not cause the parents more emotional pain than necessary (Gilbey, 2009). Many parents in this study expressed that more emotional and informational support should be provided to any parent who receives this diagnosis. After the diagnosis, these families felt it was important to create an action plan for their child (Jackson et al., 2008). Specifically, Gilbey (2009) illustrated the SPIKE model, which was developed by Buckman to deliver bad news. SPIKE stands for setting, perception, invitation, knowledge, emotions, strategy and summary. A private and uninterrupted setting is crucial for the parents as well as comfortable; the medical professional recognizing how the parents perceive the diagnosis is important; the medical professional require the patient’s invitation to disclose the diagnosis; breaking the information and knowledge given to the parents into small chunks, while checking for understanding is beneficial; professionals should address the parents’ emotions and
provide treatment options while coming up with a plan together (strategy and summary) (Gilbey, 2009).

While knowledge is necessary, some parents felt they were presented with too much information at the time of diagnosis and were required to make decisions about a variety of options they were not prepared for (Matthijs et al., 2012). Parents in other studies were also overwhelmed and had a difficult time sorting through the information (Jackson et al., 2008; Fitzpatrick et al., 2008). At the same time, the initial information sets the trajectory of care for the child (Matthijs et al., 2012). In spite of its importance, the parents’ perspective in regards to care for the child does not receive as much attention in research (Hardonk et al., 2011).

**Reactions to Communication Modes**

During early intervention services, some parents expressed that they felt forced to make a certain decision related to mode of communication. According to Decker, Vallotton, and Johnson (2012), 90 per cent of parents said their decision regarding communication method was influenced by professionals. Tremendous pressure was felt by these parents choosing communication modes. Parents in this study who chose to use some amount of sign language with their child sought information from professionals outside the medical field in addition to those in the medical field more than parents who chose not to use sign language (Decker, Vallotton, & Johnson, 2012). As the child gets older, parents of children in an additional study who used sign language to communicate often felt inadequate due to their sign skills. These parents also got frustrated when they had a difficult time expressing their thoughts and ideas to their child (Jackson et al., 2008).
As studies have shown, the preschool and school-aged child’s ability to succeed and adjust is related to how successful the family is at adjusting (Feher-Prout, 1996). In this survey, the mother tended to be the primary decision-maker regarding mode of communication (Feher-Prout, 1996). Other also parents expressed that they began to feel distressed when they were faced with many decisions related to language and education models and the feeling that these choices had to be made immediately (Fjord, 2001). Another study found that parents without experience with hearing loss felt they had to meet set timetables for decisions in order to benefit from early intervention services (Matthijs et al., 2012). Jackson et al. (2008) illustrated that some parents only realized through trial and error the appropriate mode of communication for their individual child. As another study reported, some parents feel inadequate when they leave the audiologist office and an issue arises with their child’s hearing amplification device. These parents feel as if they have no control over the issue (Marriage, 2013).

**Parents’ Stages of Grief**

As noted above, parents often begin to go into crisis mode, and feelings of shock, denial, grief, anger, guilt, sadness, and anxiety builds up upon learning of their child’s hearing loss (Boison, 1987). Studies show that such negative reactions are often associated with the diagnosis of a hearing impairment as frustration and aggression build up (Boison, 1987; Matthijs et al., 2012). Since finding out that their child has a hearing loss can be emotionally devastating, parents naturally begin to mourn, as other studies show (Fitzpatrick et al., 2007; McNee & Jackson, 2012). Other surveyed parents were also traumatized after the diagnosis of having a deaf or hard of hearing child (Freeman et al., 2002). Complicating matters, some parents often felt guilty for not being aware that
their child had a hearing loss (Fitzpatrick et al., 2007). These parents of healthy babies felt shock when they learned of their child’s hearing loss, more so than parents of children in the NICU or parents who were suspecting the loss (Fitzpatrick et al., 2007). From the beginning, parents began to worry about the child’s future with speech, school, jobs, ensuring they have an equal opportunity in life (Eleweke et al., 2008; Jackson et al., 2008). As discovered in an early study, parents are often the children’s main therapist for working with the child on speech and language delays (Boison, 1987). Studies also show that if the parents deal with their emotions in the correct way, then these feelings are considered normal and healthy (Eleweke et al., 2008; Feher-Prout, 1996).

**Impact on Family Members**

The diagnosis of a hearing loss not only affects the parents but the whole family; since decisions may have to be made regarding career, finances, and where to live (Fitzpatrick et al., 2008). Another study found that siblings often feel that they do not receive as much attention due to their sister or brother having a hearing loss (Jackson et al., 2008). The parents in this study also indicated that the needs of the child with hearing loss feel like a job and subsequently changed the dynamics of the family relationship (Jackson et al., 2008). On the other hand, some families expressed that they had a stronger bond after this journey. These parents want to be treated with respect since they are the experts on their child (DesGeorges, 2003). For some parents in an early study, anger was directed at the child, wondering why they had to be deaf and not like other normal hearing children. These parents who had to go through long diagnosis procedures began to feel anger toward the physician. These parents then began to feel tired as they tried to keep the anger from becoming apparent (Boison, 1987). Even parents within the
same family can react differently to the diagnosis, as a study by Jackson et al. showed. These mothers felt as if they were solely responsible for raising the child, which created additional stress. Some parents ignored the diagnosis and hoped the hearing loss would go away if they pretended it was not there. Several of these parents indicated some level of conflict with their spouse due to determining each person’s responsibilities (Jackson et al., 2008). As another study showed, hearing parents often experience large amounts of pressure having a deaf child (Feher-Prout, 1996).

Some parents reported that their experience with the diagnosis process was unpleasant due to the fact that the pediatrician did not know much about hearing loss (DesGeorges, 2003). However, these parents’ experiences have begun to change since the medical professionals’ education has increased in regard to hearing loss (DesGeorges, 2003). Another study showed that parents and families of children with hearing loss often begin to cope with the loss after their feelings of grief (Eleweke et al., 2008). This study suggested that it is important for families to experience these feelings of grief in order to accept the diagnosis and the change in their daily lives. Thus, parents who receive the support they require are then able to change their emotions into positive feelings and are able to think more clearly regarding their child’s needs. Those families who receive support from other parents and professionals are able to deal with their emotions and learn how to raise a child with hearing loss (Eleweke et al., 2008). As studies show, the parents who indicated they experienced low levels of stress were the ones who received support and information about available resources (Eleweke et al., 2008; McNee & Jackson, 2012). The opposite was true for those who received little support or information: according to this study, these parents experienced large amounts of stress.
and thought of their involvement with their child as a required task (Eleweke et al., 2008). As an early study indicated, many parents expressed that they began treating their deaf or hard of hearing child differently after the diagnosis, often making excuses for the child’s inappropriate behaviors. In addition, parenting a child with a hearing impairment may require more physical communication and discipline (Boison, 1987).

As studies show, parents may often experience a roller coaster of emotions as they cope with stress (Feher-Prout, 1996; Jackson et al., 2008). These parents may experience stress, disorganization and coping, followed by a period of recovery and the new normal (Feher-Prout, 1996). Thus, medical professional’s awareness of the grief process is helpful when working with parents who are grieving (Freeman et al., 2002). Professionals providing the families with support must also be aware of the family’s culture, values, and structure (Eleweke et al., 2008). Since 1970s, researchers have come to understand more about the impact a hearing loss has on a family and professionals are beginning to appreciate the complexity in family’s reactions (Feher-Prout, 1996).

**Coping Families**

Feher-Prout (1996) expressed that most psychologists use a cognitive model for stress and coping that was created in 1979 by Folkman, Schaefer, and Lazarus. Coping is considered the method in which a person changes his or her thoughts and actions to adjust to the external and internal sources of stress and is an ongoing process. The three types of appraisals are primary, secondary, and reappraisal. Primary includes how the person evaluates the event to himself or herself, secondary looks at the options relating to the event, and reappraisal occurs when new information is received (Feher-Prout 1996). Each person looks at the event differently; something that is stressful to one person may
not be considered stressful to another person. When it comes to the diagnosis of a hearing loss, most of the hearing parents consider the event to be stressful, whereas deaf parents do not find the event to be stressful (Feher-Prout, 1996). This study found that deaf parents of deaf children communicate with their children from birth and do not go through the grieving process after the diagnosis. Deaf parents are able to share first-hand experiences with their child about being a deaf person in a hearing world. Communication between the deaf child and parents impacts how the child will react to their own deafness (Feher-Prout, 1996).

The coping process begins after an event is considered stressful. Feher-Prout (1996) stated, “Coping processes consist of information search, direct action, inhibition of action, and intrapsychic (thought) processes, all of which vary over time” (p. 156). Coping also helps regulate emotions and is considered “emotion-focused,” “problem-focused,” or both (Feher-Prout, 1996). The effectiveness of coping depends on the “goodness-of-fit” model which is “an appropriate fit between (1) reality and appraisal, (2) appraisal and coping, (3) coping strategies and task demands and constraints, and (4) coping strategies and one’s other agendas” (Feher-Prout, 1996, p. 156, 157).

Research relating to family stress began in 1930s by Reuben Hill and his ABC-X model. In stress-free environment, families usually know each person’s role and who does what, share perceptions of everyday events, and share the same values in life (Feher-Prout, 1996). When a family has a child with hearing loss, the family may not have rules regarding hearing loss and methods to communicate with the child; these missing rules and strategies may lead to stress. If stress continues, crisis may occur and each family member enters individual survival mode (Feher-Prout, 1996). Feher-Prout indicates that
hearing loss and Reuben Hill’s ABC-X model, “the degree of family stress/crisis is the outcome (X) of a provoking event or stressor (A), the family’s resources or strengths (B), and the meaning attached to the event by the family (C), that is, A + B + C = X” (1996, p. 158). In 1994 Burr and Klein discussed different levels of coping strategies. Level I strategies are when the family tries to change the family rules, level II strategies are changes of rules about rules, and level III strategies are changes to the family’s beliefs and values. Families adjusting to the diagnosis of hearing loss may use the three levels of strategies (Feher-Prout, 1996).

Consequently, parents of children with hearing loss may acquire new roles and responsibilities after the diagnosis process. These new responsibilities may restrict the parents from spending more time with others in the family and can be a source of stress (Eleweke et al., 2008). “The varied demands of these roles, coupled with parents’ lack of prior experience leave them highly dependent on hearing professionals for information on how best to support their child” (Gilliver, Ching, & Sjahalam-King, S10, 2013). Another study showed that parents felt unprepared for knowing and taking the next steps after the diagnosis (Jackson et al., 2008). Prior to the 1970s, little research had been done on the family and deaf child’s interactions since families were not often mentioned in the research (Feher-Prout, 1996). After the 1970s, researchers began to pay attention to the impact that deafness had on families and the corresponding impact of families on the child. As studies have shown, some initial feelings that parents have related to the diagnosis may include denial, rationalization, shock, guilt, anger, helplessness, and acceptance (Feher-Prout, 1996; Gilbey, 2009; Marriage, 2013). These emotions may occur and reoccur throughout the child’s life based on new milestones (Marriage, 2013).
In turn, these emotions may affect the future of the child and the family (Feher-Prout, 1996). As studies have confirmed, the period of time right after the diagnosis is considered to be the most stressful and burdensome for the parents’ and child’s quality of life (Gilbey, 2009; Trapp Petty 2011). However, professionals on hearing loss may expect the parents to begin making decisions right away without proper support and information (Trapp Petty, 2011). Additionally parents may often be overwhelmed with information about amplification, modes of communication, education options, and legal issues (Feher-Prout, 1996). In addition, Fitzpatrick and colleagues found that “few parents of children who used hearing aids expressed the view that the focus on cochlear implants in hospital clinics led to perception that their child’s less severe hearing loss was somehow less important” (2008, p. 42).

Summary

Due to the UNHS, children are being diagnosed as deaf and hard of hearing at an earlier age. After the screening, additional tests are usually done to confirm the hearing loss and determine the degree of hearing loss. Early intervention services may begin immediately in order to promote and build the child’s language development. Through early intervention services, children who are deaf and hard of hearing may not have as big a language delay as children who are diagnosed later. The way in which the information is presented to the parents affects their reactions and feelings. How the information is presented is vital when presenting the deaf and hard of hearing diagnosis to the family.
Implications and Suggestions for Future Research

A majority of the studies summarized here look at the parents’ perceptions, but more studies are needed to investigate how the parents’ culture played a role in the type and way the information was presented. “Culture comprises the norms and patterns of behavior that are consecrated by tradition and obligatory for representatives of an ethnos” (Drach, 2014, p. 109). Culture includes age, gender, ethnicity, language and more. Studies were also conducted investigating the parents’ perceptions of children newly diagnosed, but should be done for children of various ages and children who used differing modes of communication. Responding to the gaps in research, I have chosen to explore the perceptions of parents of children who are deaf and hard of hearing regarding the services that they received using a qualitative case study.
CHAPTER THREE: METHODOLOGY

Research Questions

1. What were the parents’ perceptions regarding the diagnosis process of their deaf or hard of hearing child?
   - How the parents’ culture played a role in the way the diagnosis information was delivered?
   - What kind of information was received during this process?
   - What information regarding mode of communication was shared with the parents?

2. What were the parents’ perceptions of early intervention services and providers?
   - How the parents’ culture played a role the way the diagnosis information was delivered?
   - What kind of information was received during this process?

Research Design

This study utilized the qualitative case study approach to research, which looks in depth into a specific topic through the use of interviews, questionnaires, and surveys (Creswell, 2013). Qualitative research is also characterized as in-depth interviewing consisting of open-ended and flexible questions (Bodgan & Biklen, 2007). In addition,
Qualitative research illustrates the actual experiences by providing the participants with a voice to share their stories (Fitzpatrick, et al., 2008; Merriam, 2009). The naturalistic setting is suggested to collect the most accurate data in qualitative studies (Bodgan & Biklen, 2007; Merriam, 2009). Furthermore, Bodgan and Biklen (2007) describe a case study as, “a detailed examination of one setting, or a single subject, a single depository of documents, or one particular event” (p. 59). Qualitative research then determines common themes through deep analysis and rich descriptions. In addition, the words used in qualitative studies illustrate pictures of the events studied instead of numbers (Bodgan & Biklen, 2007). The purpose of analyzing data in a qualitative study is not to prove or disprove the research question. Instead, qualitative researchers focus on accurately capturing their participant’s perceptions (Bodgan & Biklen, 2007).

Researchers have expressed the need for additional qualitative studies investigating the experiences of parents with diverse perceptions, parents of children who are deaf and hard of hearing of various ages and who use different modes of intervention (Jackson, Traub, & Turnbull, 2008). The parental experiences have been present in research prior but were limited to close-ended questions, surveys, and scales (Jackson, Traub, & Turnbull, 2008). The qualitative approach of this study focused on the parents’ perceptions of their experience during the diagnosis process of their child’s hearing impairment. The research investigated whether the families’ culture had an impact on the diagnosis process. The stages of grief that each family went through were also addressed in this study. Since the researcher was the key instrument, the qualitative method was the best fit for this study (Creswell, 2009). One advantage to the researcher being the key instrument was the ability to look at both the nonverbal and verbal communication; a
down side was the researcher’s biases were identified and monitored to ensure they did not impede the data (Merriam, 2009). The study determined what type of information the parents received from the professionals and how their culture impacted this information, as well as the parents’ past and current stages of grief. One issue with case study designs was the ability to generalize the results of the study (Bogden & Biklen, 2007). Using parents from a variety of backgrounds helped increase the generalizability of the information, but it was still limited.

**Case Selection**

This qualitative study took place in the southeast in a suburban area outside a major city. Six families of children that are deaf and hard of hearing were recruited for the study. The participants each had differing experiences with the diagnosis process. The participating parents were voluntary and part of a convenience sample where they knew the researcher from their child’s school prior to the study.

**Participants**

The participants were from a variety of diverse backgrounds and socioeconomic statuses in order to increase the ability to generalize the results. The following backgrounds were represented in the study: teen parents, parents of a child diagnosed later due to an illness, parents of a child with multiple disabilities, parents of an adopted hard of hearing child, parents from an underrepresented US group, and international parents. Of the six families, two were Mexican, one was Puerto Rican, one was African American, and two were white. One of the families required a Spanish interpreter to participate in the interviews. One of the mothers was hard of hearing but did not require a sign language interpreter.
Each family had a child that was deaf or hard of hearing. One family had three children that are hard of hearing. Majority of the children attended a public school in which the deaf and hard of hearing satellite program was housed. The children ranged in age from 5 to 11. The parents ranged in age from mid-20’s to late 40’s. Majority of the children had profound hearing loss diagnosis. Five out of the six mothers worked at least part time. Five out of the six fathers worked, one was a full-time student.

**Positionality**

**Researcher’s Background**

I was hired as a deaf and hard of hearing teacher in the district in which the study was conducted. The deaf and hard of hearing program was established at a school in the southeast of the United States prior to when I was hired. I was a deaf and hard of hearing preschool teacher in the school in which most of the parents’ students attend. Prior to being a deaf and hard of hearing preschool teacher, I taught kindergarten and second grade deaf and hard of hearing students at a different school in a resource classroom. The students spent a majority of their day in the general education classroom and were pulled into a small group classroom for specific subjects. After one year, I moved to the school which the majority of the children in the study attended and taught fourth and fifth grade students for part of the school year. The previous preschool teacher moved, and I took over the position. I had a self-contained deaf and hard of hearing special education preschool classroom. I was beginning my fourth year of teaching preschool students who are deaf and hard of hearing during the study.
Researcher’s Bias

My relationships with the participants contributed to the possible bias in the study. I taught five out of the six participants’ children. Two of the participants’ children I taught for two years, and three of the participants’ children I taught for one year. I taught American Sign Language to one of the families to help facilitate communication with their daughter.

Since the researcher is the key instrument in a qualitative study, I conducted the research (Creswell, 2013). After several years of meeting families at different stages of acceptance and listening to their knowledge regarding hearing loss, I became intrigued with what parents learn and experience during the diagnosis process. The researcher’s responsibility is to focus on the participants’ information about the problem and not what the researcher contributes (Creswell, 2013). I strived to do this in my analysis of the data.

Since the researcher was the key examiner, bracketing must occur. Bracketing occurs when the researcher is aware of and makes notations of his or her personal bias, assumptions, hypothesis, preconceived notions and beliefs related to the study (Tufford & Newman, 2010; Thompson, Locander, & Pollio, 1989). “Bracketing is also a method to protect the researcher from the cumulative effects of examining what may be emotionally challenging material” (Tufford & Newman, 2010, p. 81). Through bracketing, the researcher was able to recognize her own pre-existing thoughts and set them aside, which allows the researcher to continue analyzing with an open-mind (Tufford & Newman, 2010). Researchers use bracketing in memos, reflective journals, and interviews with an outside source. (Tufford & Newman, 2010). For this study, the use of memos was the best form of bracketing. Bracketing can occur throughout the research process, but
escalates during data analysis. The analysis led to thick descriptions of the themes that were pulled from the experience of the parents learning the child was deaf or hard of hearing. “The research goal is to a thematic description of experience” (Thompson, Locander, & Pollio, 1989, p. 137).

**Data Collection**

After approval from the Institutional Review Board (IRB), the researcher sought and received consent from the parents of the children that are deaf and hard of hearing that participated. She provided specific information regarding the study to the parents who indicated they would participate. Data was collected using interviews and parent/child observations. The researcher also asked the parents to indicate where they wanted the interviews conducted. The interviews took place at a location and time that was convenient and comfortable to the parents. The parents were interviewed regarding their experience during the diagnosis process of their child’s hearing impairment. The study took place over a five-month period to allow time for the interviews and data-saturation to occur. The interview sessions were videotaped in order to transcribe the information more easily, as well as make note of the body language and gestures of the parents. The goal of the study was to determine common themes related to the information parents received through the diagnosis process. In addition, the researcher investigated whether the parents’ culture played a role in the delivery of the hearing impairment diagnosis and the diagnosis information they were given. The stages of grief were also explored during the study.
Parent Interviews

The interview lengths ranged from 21 to 55 minutes, with an average of 32 minutes per interview. The interviews took place in the family’s home and were videotaped. The questions were asked during a semi-structured interview with open-ended circular questions that occur during a dialogue rather than a question and answer session (Thompson, Locander, & Pollio, 1989). The questions were designed to acquire information about the parents’ experiences with the deaf and hard of hearing diagnosis process and early intervention services. Interviews are the most common data collection method in qualitative research (Starks & Trinidad, 2007) because they are “the most powerful means of attaining an in-depth understanding of another person’s experience” (Thompson, Locander, & Pollio, 1989, p. 138).

Parent/child Interaction Observations

The observation lengths ranged from 16 to 36 minutes, with an average of 28 minutes per observation. Furthermore, the researcher observed each child who was deaf or hard of hearing and the parents’ interactions. The researcher observed the parents’ and children’s mode of communication during their interactions. The researcher took notes on the mode through which wants and needs were expressed by the child to the parents as well as the mode that the parents used to make requests of their child.

Data Analysis

The researcher read over and organized the research documents before she began to analyze the information. The researcher used content analysis to analyze the data collected in the parent interview and parent/child observations. The parent interviews consisted of open-ended questions which allowed the parents to provide in depth
information to their answers. The transcribed interviews and observations were uploaded into Atlas Ti. The researcher analyzed the information to determine which themes were reoccurring. While the researcher analyzed the interviews and observations line-by-line and codes emerged using open codes. “Open coding involves identifying concepts within the text and labeling them according to their properties” (Mueller & Buckley, 2014, p.123). The codes were then collapsed into seven families allowing the common themes to develop (1) complex information, (2) passive doctors, (3) beneficial services, (4) long, intense process, (5) ever changing feelings, (6) against doctors’ wishes, sign language, (7) cochleas present then cochlear implant surgery. The researcher also created 15 memos containing insight from the interviews and observations. The document files, codes, and memos were stored in a Hermeneutic Unit for easy retrieval at a later date. After the analysis of the data, a deep understanding of the parents’ perceptions of the diagnosis process and early intervention services, the manner in which the parents’ culture impacted the diagnosis, and parents’ stages of grief emerged.

Limitations

The limitations to this study included the convenience sample in which the parents of the children were previous or current students from one public elementary school. Delimitations were that the elementary school was the deaf and hard of hearing satellite school for the county, and the researcher was a deaf and hard of hearing teacher at the school as well. Another delimitation was that only the parents’ perception of the diagnosis process was heard and not the medical professionals or early invention providers. Therefore, the parents indicated the information they heard during the diagnosis process, which may have been influenced by the stages of grief.
Member Checking Procedures

To ensure the validity of the research several validation strategies were used. The researcher used triangulation of the data sources to make sure the information was correct, observed the parent/child interactions, interviewed parents, and used the literature. The researcher also used member checking to increase the validity of the study. The member checking partner was a mother of a child who was deaf who participated in the study. The results of the study were validated by using these strategies.

Summary

This study investigated the parents’ perceptions of the diagnosis process. It explored the type of information the parents received during the diagnosis process and whether their culture played a role in how the information was delivered to the parents. The way the information was provided to the parents during the diagnosis process can set the direction for the family toward early intervention services, as shown by studies discussed in chapter two. The study also looked into the different stages of grief and the parents’ current stages. Determining this information will help future parents realize that prior families have gone through similar scenarios and learn from the information those parents received.
CHAPTER 4: EXPERIENCING THE DIAGNOSIS PROCESS THROUGH THE EYES OF PARENTS

In this chapter I examined the parents’ perceptions of learning the diagnosis of their child’s hearing loss and their insights on the early intervention services they received. The parents’ feelings during the process as well as the steps to the diagnosis process are discussed within this chapter. I investigated six families for my study. Each case “examines a different theme or takes up a different aspect” of living with children that are deaf and hard of hearing (Biklen and Casella, 2007, p. 82). Each family’s story represents a theme discovered by the researcher. The way in which each family reacts to the diagnosis varies. One family indicated, “It was shocking. It was definitely like it wasn’t real. It was like ‘no, no, no.’ We knew it, but it was like ‘no’—it was like when we heard she had DS (Down syndrome)” (Rebecca, personal communication, May, 10, 2014). Another family had a different initial experience, “I just felt kind of lucky to have him. I didn’t feel any, any, um like guilt or bad for him or anything. Like I just thought we were lucky, and that he’s lucky (Natalie, personal communication, July 19th, 2014).” These diverse stories are told pertaining to a theme present in their data.

This study supported existing research on the length of the diagnosis process and on the necessity that information be given in a more timely manner (Larsen et al., 2012);
on the negative connotation toward not passing the hearing test prolonging early intervention services (Matthijs et al., 2012); on the range of feelings the parents felt after diagnosis and the lack of empathy the doctors used while delivering the diagnosis (Gilliver, Ching, & Sjahalam-King, 2013); on the majority of children who are deaf having hearing parents (Feher-Prout, 1996); and on the problem that parents still are not receiving adequate information about hearing loss and early intervention services (Eleweke et al., 2008). As suggested by previous studies, the family’s background impacted the diagnosis process, the diagnosis delivery, and the parents’ reactions. Many of the families in Gilbey’s study (2010) had undesirable experiences learning about their child’s hearing loss or did not understand the diagnosis. Unfortunately, many doctors and medical professionals are not trained in how to effectively, and in a sympathetic manner, deliver “bad news” to parents suffering from loss or dealing with an unexpected diagnosis (Gilbey, 2010). In this study as well as in the Gilbey study, the way in which the information was relayed to the parents about their child’s hearing loss influenced their reaction to the process (2010). Several parents in this study as well as in the Gilbey study indicated that their doctor prolonged the information by referring to future tests in order to delay the inevitable. Many parents pointed out that they believed doctors did not want to be the ones to tell the parents that their child had hearing loss and would often refer the child for additional testing in order to avoid delivering the final diagnosis (Gilbey, 2009). The parents in this study as well as Gilbey’s study (2009) indicated they had undesirable experiences with the diagnosis process and were often referred for additional testing which impacted their reaction to the process. The similar findings of this study and Gilbey (2009) increased the generalizability of both.
The themes exposed while data was collected in this study are broken down by each family which allows the reader to completely experience each diagnosis process and learn more about the individual family. The families represented in the study are from a variety of backgrounds with varying levels of education and socioeconomic statuses.

I have named the stories revealed by the parents as a way of categorizing the major themes that emerged, as follows:

- The first family illustrated the ups and downs felt by the parents during the diagnosis process, “Rollercoaster Ride of Emotions.”
- The second family explored the diagnosis process through the eyes of adoptive parents who suspected hearing loss prior to finalizing the adoption, “The Chosen Child.”
- The third family described how taking the positive outlook from the beginning impacted the process of accepting the hearing loss, “God’s Blessing—The Lucky Ones.”
- The fourth family explained how information was misunderstood when language barriers were present, “No Entiendo—Communication Barrier.”
- The fifth family traveled through the diagnosis process of a family of a postlingual child affected by spinal meningitis, “Critical Condition—Spinal Meningitis.”
- The last family illuminated how a family with genetic etiology of hearing loss experienced the diagnosis process, “Runs in Family—Genetic Hearing Loss.”
In the sections that follow, the summary narrative for each family was presented, integrated with discussion, and then followed with threads across the cases. A table that summarizes the demographics of the participants follows.

Table 1

Summary Demographics of the Participants Part 1

<table>
<thead>
<tr>
<th>Child</th>
<th>Mode of Communication</th>
<th>Parents’ Names</th>
<th>Age Diagnosed</th>
<th>Present at Diagnosis</th>
<th>Age of Mother at Diagnosis</th>
</tr>
</thead>
<tbody>
<tr>
<td>Rebecca</td>
<td>Beginning American Sign Language, gestures</td>
<td>Hannah and Antonio</td>
<td>1.5</td>
<td>Mother and Father</td>
<td>36</td>
</tr>
<tr>
<td>Lily</td>
<td>Beginning sign language, gestures</td>
<td>Lynn and Scott</td>
<td>4</td>
<td>Mother and Father</td>
<td>37</td>
</tr>
<tr>
<td>Jack</td>
<td>American Sign language</td>
<td>Natalie and Charles</td>
<td>Failed UNHS, finalized 1.5</td>
<td>Mother on phone</td>
<td>19</td>
</tr>
<tr>
<td>Alex</td>
<td>Spoken language with sign support</td>
<td>Rachel</td>
<td>2.5</td>
<td>Mother</td>
<td>30</td>
</tr>
<tr>
<td>Ryan</td>
<td>American Sign Language</td>
<td>Lisa and Richard</td>
<td>4</td>
<td>Mother</td>
<td>35</td>
</tr>
<tr>
<td>David</td>
<td>Spoken language and Sign language</td>
<td>Gabriella and Carlos</td>
<td>Birth</td>
<td>Mother and different Fathers</td>
<td>30</td>
</tr>
<tr>
<td>Trevor</td>
<td>Spoken language</td>
<td>Gabriella and Carlos</td>
<td>4</td>
<td>Mother and different Fathers</td>
<td>31</td>
</tr>
<tr>
<td>Rose</td>
<td>Spoken language</td>
<td>Gabriella and Carlos</td>
<td>3</td>
<td>Mother and different Fathers</td>
<td>33</td>
</tr>
</tbody>
</table>
Table 2

*Summary Demographics of the Participants Part 2*

<table>
<thead>
<tr>
<th>Child</th>
<th>Degree of Hearing Loss</th>
<th>Ethnicity</th>
<th>Free and Reduced Lunch</th>
<th>Present at Interview</th>
<th>Present for Observation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Rebecca</td>
<td>Profound</td>
<td>White</td>
<td>No</td>
<td>Mother and Father</td>
<td>Mother, Father, Sister</td>
</tr>
<tr>
<td>Lily</td>
<td>Profound</td>
<td>Lily: Chinese Family: White</td>
<td>No</td>
<td>Mother and Father</td>
<td>Mother, Father, 3 siblings</td>
</tr>
<tr>
<td>Jack</td>
<td>Profound</td>
<td>Mexican</td>
<td>Yes</td>
<td>Mother and Father</td>
<td>Mother and Father</td>
</tr>
<tr>
<td>Alex</td>
<td>Severe to profound</td>
<td>Mexican</td>
<td>Yes</td>
<td>Mother</td>
<td>Mother</td>
</tr>
<tr>
<td>Ryan</td>
<td>Profound</td>
<td>Puerto Rican</td>
<td>No</td>
<td>Mother and Father</td>
<td>Mother, Father, Aunt</td>
</tr>
<tr>
<td>David</td>
<td>“Low”</td>
<td>African American</td>
<td>Yes</td>
<td>Mother</td>
<td>Mother</td>
</tr>
<tr>
<td>Trevor</td>
<td>Progressive</td>
<td>Auditory Neuropathy</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

“Rollercoaster Ride” of Emotions: Feelings Experienced during Diagnosis Process

“Rollercoaster Ride” to Diagnosis

Even with the Universal Newborn Hearing Screening (UNHS), many children are often diagnosed with a hearing loss later on for a variety of reasons (Larsen et al., 2012). After leaving the hospital, some children do not attend follow-up audiology
appointments, and therefore do not receive an official diagnosis. Other newborns pass the UNHS, but later develop a hearing loss (Larsen et al., 2012). This was the case for Rebecca. Ten days after Rebecca was born, her parents learned about diagnosis number one, Down syndrome (DS). The DS diagnosis made the parents feel lost and unsure of the future. Her father, Antonio stated, “We were a little unclear because of the Down syndrome. So we weren’t sure how she would—what delays she would have there” (personal communication, May 10, 2014). Rebecca’s parents were celebrating the birth of a new baby girl but also grieving with the new information of DS, or an extra 21st chromosome.

Rebecca passed the UNHS, and there were no indicators of deafness, but the parents have since learned that this screening is not always accurate. After a year, her parents started to recognize that she was not responding to sounds that her sister and other infants would detect and acknowledge. “We just noticed that we would call her, or she would not respond to sound about a year old, which most kids were already responding to a couple months before,” Antonio stated. Hannah, Rebecca’s mother, interjected “Antonio would go up to where she would be asleep and he would clap very loud. He came down and was like, ‘she’s deaf,’ and I was like, ‘oh, no, she’s asleep.’ You were like ‘no, she’s deaf’” (personal communication, May 10, 2014). Hannah shared that Rebecca began to say a few sound and words including “Mama;” Antonio wonders if “Mama” was actually just sounds she was making and not intentionally producing the word. The observations showed Rebecca making only grunting noises when her parents spoke to her.
Hannah and Antonio shared their concern with their pediatrician regarding Rebecca’s hearing, which started the referral for the diagnosis process. “It was Antonio; Antonio was definitely the one who said we need to get her tested. So we did get her tested, and they said they couldn’t tell because she had tiny, tiny ear canals with Down syndrome,” Hannah recalled. Antonio explained that Rebecca’s level of cognition may have been a concern rather than an actual hearing loss. Antonio and Hannah continued with the referral process for Rebecca, and the next step was the Auditory Brain Response (ABR). Rebecca received her first of many sedated ABRs.

A doctor was the only person present while informing both parents that Rebecca had limited hearing. The doctor indicated that Rebecca may be able to hear at 90 dB. According to her mother, “she hears a lawnmower starting next to her ear.” The parents were shocked at the level of hearing loss she had. Hannah stated, “It was definitely like it was real. It was like, ‘no, please no.’ We knew it, but it was like—now, it was like when we heard she had DS (Down syndrome).” The doctor stated that Rebecca had excessive earwax and Myringotomy Tubes would correct the problem. Her parents tried the Myringotomy Tubes and instantly thought the deafness was eliminated. After the Myringotomy Tubes procedure, the family went out to eat, and Rebecca reacted when a waitress dropped a tray full of plates. Hannah exclaimed, “She can hear; they cleaned her ears out!” During the Myringotomy Tubes procedure, the doctors cleaned earwax out of Rebecca’s ears. Unfortunately, a little while later her parents realized this was not the case. Rebecca responded to the vibrations that occurred when the plates dropped but not the sound.
Soon after the Myringotomy Tubes, Hannah indicated they began to notice she was not responding to sounds. A follow-up ABR was scheduled with a different person. The results of this ABR were the opposite from the first ABR. This time both parents were told, “There isn’t a lot working there.” With these contradictory results, the parents scheduled a Magnetic Resonance Imagining (MRI) at the children’s hospital to allow an audiologist to thoroughly examine Rebecca’s ear structure. The audiologist indicated to Hannah and Antonio that Rebecca’s ears did not contain cochleas. The cochlea is the snail shaped, fluid-filled organ that transforms sound waves to electrical impulses (Medline Plus, 2015). These cochleas had not formed in Rebecca’s ears. Hannah questioned the doctor’s results and relived the conversation with the doctor.

That’s so weird because I know she heard. I know she had heard. I know she reacted to sound, just not very acutely. I do know she said mama at one point, and it was very clear. It was very clear. He did the big test. He said, “No, I don’t see cochleas.” And he called me and said, “But sign language is a beautiful thing and eventually Europe is going to have a thing where they can go through the head and do this whole thing, but don’t worry it’s beautiful, sign language.” I was like ‘no, it’s beautiful but I really know she heard and if she had no cochleas, she couldn’t have heard a peep.’ There would be nothing. (Hannah, personal communication, May 10, 2014)

Hannah decided to follow her hunch and kept moving forward.

They got a second opinion by another audiologist who stated he did see cochleas. Hannah excitedly relayed the information about the cochleas, “I was like, ‘oh my gosh, thank goodness that I questioned it.’ Thank goodness that I questioned it and went with my gut as a mom and kept fighting.” At this appointment, the audiologist and his assistant presented the diagnosis and were “very nice.” The audiologist had a folder ready to give to the parents about options for a child with a hearing loss. The folder had
information about hearing aids and implants for the parents to read and resources to research more themselves.

**“Rollercoaster Ride” with the Cochlear Implants**

Rebecca and her parents were then told their next step would be to travel to a hospital in a different state to receive specialized tests to determine the strength of her newly discovered cochlear nerve endings. If they were strong enough, then cochlear implants would be an option. The specialized results indicated both of Rebecca’s cochlear nerve endings were strong enough for implants, indicating Rebecca was a cochlear implant candidate. Antonio stated,

> What I remember most was, him telling us it really depends on her cognitive ability. No question that the implants would work, but how much she was going to be able to take advantage of it is yet to be determined. (Antonio, personal communication, May 10, 2014).

Rebecca’s mom focused on a different aspect of the information, “He had high hopes, or he said he wouldn’t do it. You know, he said ‘I think she’s pretty bright.’” Rebecca’s father indicated the audiologist was conservative and would not have done the surgery if he did not think it was going to work or give some kind of benefit. Rebecca’s parents proceeded with the decision to try cochlear implants for her.

After the decision that Rebecca was a candidate for cochlear implant was made, the family had to follow certain steps. Her mother stated, “We had to report back to the insurance and the surgeon saying, ‘we aren’t joking.’” They had to drive down to the local school for the deaf and take specific tests and receive therapy. The family had to make this drive every week for a year to demonstrate their persistence, and they were going to do the therapies and maintenance of the implant. Rebecca’s mother said, “They had to see if we were psychologically ready; we did a psychological eval.” This eliminates families
who are not going to follow through with the intense auditory verbal training after the implantation. The mother said she did the prerequisites for the implants. One day while attending a therapy session at the school for the deaf, Hannah was asked to give a speech in front of “big wigs” from several of the large hospitals in the area about her experience through the diagnosis process, including the misdiagnosis of no cochleas. This experience allowed medical professionals to hear a real life experience with the diagnosis process.

Moreover, Rebecca had to wear hearing aids for a year before the cochlear implant surgery. This was to show that she could tolerate objects behind the ear, as well as demonstrate the family’s dedication and commitment. After the insurance determined she could tolerate these, she received her first cochlear implant and the surgery went smoothly.

A year after the first implant surgery, Hannah read how beneficial bilateral implantation was and wanted to try it with Rebecca. Antonio was unsure since it would mean Rebecca would have two “knobs” (cochlear implant magnets) on each side of the back of her head. Eventually, they decided it was a good idea and moved forward with a second cochlear implant for Rebecca. One hour into the second implant surgery the doctor called the mother from the operating room on the emergency telephone line. Hannah identified her fear when she received this call, “I’m like ‘she’s dead because surgeons do not call,’ and I started passing out. Antonio was not there because the first surgery was so easy. I started getting really woozy.” Before the surgery, the nurses told Hannah that the doctor would not be the one calling, and the nurses would update on how the surgery was going. When she received the call straight from the doctor, Hannah began experiencing a variety of emotions. The doctor was calling her to explain that
Rebecca had too many nerves covering her cochlea and that he could not successfully perform the surgery. He shared that he had already destroyed half the taste buds on her tongue and if he continued he would paralyze her face. Hannah made the ultimate decision to end the surgery and not put Rebecca at any more risk.

While Rebecca was in recovery from the second surgery, Hannah asked the surgeon what other options were available for Rebecca. The surgeon informed her that she could talk to her audiologist and get a high powered hearing aid. Hannah relentlessly called the audiologist from the hospital to set up an appointment to get her a new high powered hearing aid. Unfortunately, the large high powered hearing aid bothered Rebecca on her tiny ear with a large amount of interference between the hearing aid and the cochlear implant.

Hannah and Antonio were told by her implant surgeon that he saw “a light in her eye” and that they should allow her time to adjust to the cochlear implant. The parents were instructed to expose her to as much spoken language as possible. Spoken language was the primary mode of communication. The doctor had really high hopes for Rebecca, according to her mother. The father reiterated the fact that he remembered the doctor indicating her success with communicating and the cochlear implant depended on her cognitive ability. The parents indicated they know she is hearing and can tell a difference between her reactions to sounds with her waterproof implant versus her normal everyday implant. Hannah shared that the difference is instant; whereas, Antonio said it is almost instant but not always. Hannah interjects the reason for it not always being instant is that Rebecca is choosing to ignore. Rebecca was observed responding to loud noises that caught her interest. Other times Rebecca did not respond to voices or her name.
After the successful cochlear implant surgery, the doctor told the parents to try to avoid using sign language to communicate with Rebecca. The doctor indicated she needed to learn how to listen with her “very expensive device” and rely on the implant instead of sign language. Hannah pointed out, “We didn’t really want to sign truly because we are like, ‘we want her to talk to us. Let’s make her use it.’” The parents began to recognize that after two years of shoving thousands of words at Rebecca and her producing one or two, Rebecca was beginning to show signs of frustration.

We were listening to a guy who is fantastic, and I mean, I don’t know how much he knows deeply about delay. I know he knows a bit, but as far as Downs, or how long that it would really take them to speak and such. He really recommended shoving the words in, try to make her express herself. Shoving words and a lot of speech therapy were the two things recommended the most for communication. (Hannah, personal communication, May 10, 2014)

The parents were only offered information about sign language one time prior to Rebecca being thought to be a candidate to receive cochlear implants. Since she received the cochlear implants, sign language was not considered an acceptable mode of communication.

However, the family began learning a new mode of communication, sign language, in order to eliminate some of the frustration Rebecca was feeling when she was unable to express herself verbally. The parents recognized that Rebecca was beginning to show signs of frustration and knew they needed to do something in order to communicate. Antonio stated, “We think sign language has been huge.” Hannah and Antonio decided to go against the surgeons recommendations and began learning sign language. Antonio said, “Just being able to communicate is the biggest thing. She loves it because she tells us as much as possible. Now obviously, if we had to do it again, we
would start sign language from the very beginning.” Both parents agree that they have made a lot of progress communicating with Rebecca through sign language.

During observations, the family was seen using differing amounts of sign language and different modes of communication. Hannah did the most signing with Rebecca. She signed a lot of what she spoke, but not every sentence. Antonio signed a few words, but mainly used spoken language with Rebecca. Rebecca’s sister communicated primarily through gestures but would use a basic sign occasionally. Rebecca’s mother spends the most time with her and thus was the family member who signed the most with Rebecca. She was able to explain to Rebecca their activity and what was next in their daily routine.

“Rollercoaster Ride” Receiving Services

Rebecca began receiving early intervention services through the state program from the time her mother registered her, around the age of one, until she turned three years old. The building to sign up for early intervention services was shared with Department of Family and Children Services (DFCS). Hannah indicated that signing up for the services was an internal struggle, “It just felt dirty. Ahh, I don’t know if that’s the right word, but it didn’t feel good going to DFCS with people that were on food stamps. I’m just being very honest. We work really hard, and here I am at DFCS.” After the initial struggle, Hannah was grateful for the services Rebecca received and for the information she learned from the therapists.

In most cases, information regarding early intervention services is given to the parents at the hospital before they were released. Information about early intervention services for hearing loss is also included, but since Rebecca passed the UNHS,
professionals did not arrange for those services to start along with the others. Rebecca received early intervention services for occupational therapy, speech therapy and physical therapy from one to three years old. At three, services were provided through the school system. When Rebecca was about one and a half years old, the parents suspected the hearing loss and began the evaluation process for those early intervention services.

Once the services began, the mother’s attitude towards the therapies was mixed. She thought the services provided to Rebecca were fantastic but dreaded the therapists coming to her house several times each week. She could not stand the occupational therapist, physical therapist, and the speech therapist coming into her house each week as she was trying to bond with her newborn daughter. The in-house services were great so the family did not have to travel to receive the services. “I just didn’t want them in my house. Quite honestly, I was like ‘this is not normal.’ I just wanted normal again, boring not boring, but regular without any problems. No medical problems.”

Although the services provided to Rebecca were helpful, the mother just felt invaded and that she had to be “on” whenever services were provided. Hannah indicated she was grateful and thankful, but at the same time she did not want Rebecca to require services. Hannah stated that the speech therapist taught her some of the most beneficial strategies.

I didn’t want my kid’s tongue to be hanging out of her mouth the whole time. That is one of the biggest things they taught me was to gently tuck it back in. I know that sounds funny, to use a straw, to really make her use a straw to strengthen her mouth for words. (Hannah, personal communication, May 10, 2014)

The occupational therapist also taught the mother ways to help Rebecca hold her bottle. Hannah expressed her thoughts on the therapists.
They were fantastic; I mean it was more selfish. It was three days a week, Monday, Wednesday, and Friday. I was really trying to get to know my kids, and yet all these strangers were in my home a lot. So for me it was hugely helpful, but dreaded. (personal communication, May 10, 2014)

Antonio was at work during the early intervention therapies. He would come home at the end of the day and assist with any remaining activities and chores.

After Rebecca received the cochlear implants, intense Auditory Verbal Therapy began. Auditory Verbal Therapy endorses early detection of the hearing loss, assists parents facilitate their child’s use of their hearing and creating language rich environments that integrate listening and spoken language, and help children self-monitor their communication through listening (The ASHA Leader Blog, 2012, March 29). Auditory Verbal Therapy focuses on spoken language as the primary mode of communication The ASHA Leader Blog, 2012, March 29). For this therapy, she would go to another specialized school for children with hearing loss a couple of days a week when she was young. This specialized school did not use sign language and worked on intense spoken language communication. The audiologist who performed the cochlear implant surgery recommended the specialized school since they help increase the use of the implant and specifically use Auditory Verbal Therapy to teach children how to rely on the device for listening. At this school, Rebecca received speech therapy for one year. The family was planning on her attending the school full time until the school was not willing to provide anything but speech therapy for Rebecca. Thus, she began attending her neighborhood school at the age of three. After school, Hannah would drive Rebecca down to the specialized school for private Auditory Verbal Therapy.
“Rollercoaster Ride” Handling Emotions

From the beginning of the diagnosis process, the parents of Rebecca had different reactions and emotions. Hannah felt very lonely in the beginning of the process. She explained, “It was lonely hearing someone tell you that your kid may never hear.” Antonio did not feel lonely. He expressed that because his wife was organized and educated, he felt it was more of just a hurdle to overcome. Hannah agreed with the feeling of overcoming hurdles.

I pushed so hard to give her every opportunity. I felt like when I would come to wall, I was like ‘oh no, no, no.’ I gotta push this one over. I got to give her every chance. Sometimes it felt really lonely because I was like is this ever going to work? (Hannah, personal communication, May 10, 2014)

One benefit stressed by both parents was the amount of people they were introduced to throughout the diagnosis process that they still are in contact with today. The uncertainty of the next step was the point at which the mother felt the loneliest and most emotional.

A word used by the parents to describe the post implantation phase of Rebecca’s story was “hopeful.” Hannah indicated that other stresses seemed to disappear, and she was able to move forward. With the implant surgery, the parents were hopeful Rebecca would be able to hear again. Their main goal was safety because they wanted Rebecca to be able to hear them yell “watch out” since they are a very energetic and do many activities outside. Hannah shared, “So, for me it as a huge victory, getting an implant and having her turn around. I felt like all my hard work was definitely worth every second as a mom.” Hannah reiterated that she would like to share with other parents the importance of using their intuition, and if they question a diagnosis, to continue moving forward receiving second and third opinions. This mother indicated at the beginning of the
process, she was stressed and lonely, and now at the end, her perceptions have changed to hopeful and thankful.

Rebecca’s father stated his current perceptions are hopeful mixed with a sense of this is the new normal. “Honestly, looking in it probably doesn’t look very normal, but for us it just feels like it is.” Hannah expressed that Antonio was the rock of the family during the whole diagnosis process. There were nights when she was not able to sleep, and he was there to support her and the family. Antonio shared that he saw the whole process as another hurdle to overcome and he was there to support Hannah as much as possible. “It’s just gotten easier. I don’t know; maybe we are just getting used to it.”

Throughout the process, there was a “rollercoaster” of emotions ending in their being hopeful and thankful for the whole experience.

**Chosen Child: The Unique Journey of the Diagnosis of an Adopted Child**

**Chosen Child to Diagnosis**

The diagnosis process for this child who has been adopted from a different country was a unique journey. The file Lynn and Scott, her parents, had on Lily, indicated she had auditory nerve damage. This note left Lynn and Scott feeling unsure of what her capabilities would be when they finally adopted her. Lynn indicated “We just felt that she was our daughter, so we just went forward with the adoption process” (personal communication, July 9, 2014).

Lynn explained the adoption process once they got to the foreign country:

You go there, and you get them. You have about one hour with them there, and then you bring them home with you forever. So we walked into the hotel room, and she had had pictures of us, and we had pictures of her. (personal communication, July 9, 2014)
Lily’s sister showed her around the hotel room and showed her the crib where she could sleep. Lynn stated that Lily immediately started shaking her head as a natural gesture indicating she did not want to sleep in the crib. Scott recalled that Lily was very expressive and they could tell when she was mad or upset (personal communication, July 9, 2014).

The family started signing with Lily the day they met her in July. They started teaching her animal signs and acting out what the animals do with noises. Lily picked up on the animal signs quickly, so Lynn and Scott started teaching her signs relating to family members (mom, dad, etc.). Lily showed an interest in sign language right away. At the family’s first introduction, Lily’s primary mode of communication was pointing and gestures. The family incorporated sign language with her gestures from the beginning. Lynn recalls, “My daughter was with us, and we would say ‘where’s dad?’ and she would look at him. She would do it.” Lynn indicated that sign language was innate for Lily. The parents were astonished at Lily’s cognitive abilities because she picked up sign language so quickly after having not been given sign language or any mode of communication for almost four years. During the observation, Lynn continued to sign the important words in a conversation with Lily. Lily has three hearing siblings who are not adopted. Her siblings participated in parallel play with Lily by playing an activity beside her, but did not include her in the activities they were doing.

Based on their time with her, her parents already assumed she could not hear. There were some loud banging that Lily would respond to, but otherwise that was it. Before an ABR was done on Lily, the doctors told Lynn and Scott there was a possibility it was fluid in her ears. Lynn confessed, “It’s kind of what they always tell you, every
time.” Scott added, “It might just be fluid, and if you put in tubes, it might clear it out, and there might be some kind of improvement, but there may not, so.” Lynn and Scott tried tubes: no improvement. Lynn’s piece of advice for ENTs was not to tell a parent, especially one who already speculated for a year that her child was deaf, that it may just be fluid in the ear; it gives the parents a false sense of maybe it is fluid. It would have been very difficult as a parent of a newborn whose world is already “turned upside down, to then give this glimmer of hope. Cause I think that’s pretty rare, that’s what’s causing it.”

After the tubes did not work, the parents received a folder with various types of information. The audiologist offered to give the parents information for support groups of parents with children who are deaf or hard of hearing. Lynn and Scott did not reach out to any of the recommended parent support groups since they were already members of support groups of parents who adopted children with special needs. For support, they had other families through the adoption world, even other families of children with hearing loss. The parents also stated that because they have four children and work full time, they honestly did not have time to attend any more support groups. Lynn said she talked to two other mothers of children with cochlear implants. She got some good advice, but then they started telling her their opinions. She did not like that because it was causing her stress. She had to realize she needed to make the best decision for her family.

After a few months of having Lily as part of their family, Lynn and Scott had an MRI and ABR done in September. The audiologist and a couple of other people came in after the ABR, and “they were like really tentative, just to like share with us the final word or whatever.” The audiologist informed the parents that Lily was profoundly deaf
even at the highest decibel. Lily’s brain was not responding to any sounds. Lynn and Scott stated they were not shocked by the results of a hearing loss. They were already assuming she could not hear since she had already been with them. They shared that their experience is different than a typical family experiencing the diagnosis with a newborn baby. A week later the doctor called the family to let them know the results of the MRI and that Lily was a candidate for a cochlear implant.

**Chosen Child with Cochlear Implants**

Scott stated that they did not think about cochlear implants at first because they did not know about them. Cochlear implants were not on the parents’ radar. Scott initially thought “we will learn how to do sign language and everything will be fine.” Both parents indicated they were naïve and thought that sign language would be easy to learn. However, the family has only learned roughly 300 signs.

Lynn and Scott learned that Lily was a candidate for a cochlear implant after the MRI that was done a few months after she came to America. Prior to the completion of the MRI, the doctor explained the implant surgery to the parents in preparation for the possibility that Lily would be a candidate. The doctor called them the next week to let them know she could get the complete replacement. The doctor examined the MRI results and told Lynn and Scott that Lily had both auditory nerves and they looked normal, so there was no reason not to try the surgery.

The doctor told the parents that it would be a long process for language development and that they should not expect that she would begin talking immediately after the implant. Scott expressed that people who did not see Lily often but knew that she got implants, would ask if she were talking yet. He explained that he compared the
process to a baby learning to talk and that for at least the first year, the child is listening and learning the communication game. Then the child starts trying to say words; it’s a process.

Lynn explained that they did not feel the cochlear implant surgery was something they had to do, a “do or die” scenario. She indicated they were not trying to “fix” Lily, but decided to give the implants a try after evaluating the child’s future in their community. Lynn explained, “we don’t have a big Deaf community at all, like we don’t know very many.” She stated they do not think one way is better and they do not feel passionately either way, implant or no implant. “It is whatever your personal choice happens to be and whatever fits your family best.” Scott interjected, “We just thought that like if she could, let’s give a chance.” Lynn added that Lily appeared to be the type of child who would embrace it since she is a little fighter (personal communication, July 9, 2014).

After Lily received the implant, Lynn and Scott were told they needed to go to the auditory verbal center or to auditory verb therapy (AVT) at one of the local children’s hospitals. The audiologists were encouraging the parents to bring Lily to AVT and not send her to school yet. Lynn indicated she had to weed through the information given to her to tweak it to the approach that would work best with a four-year-old adopted child. The audiologist did not say anything to the parents about a local school that specializes in teaching children to listen and speak. The audiologist continued to push AVT. The doctors also encouraged the parents not to sign with Lily after the implants. They did not want her to become dependent on the sign language, but preferred Lily’s primary mode of communication to be spoken language. Scott said that they told the doctors they
thought they were going to have to use some sign language because they could not rely strictly on speaking.

After two teachers at Lily’s school saw her cognitive abilities, they pointed out to the parents that the information given to them by the surgeon is usually given to parents of deaf and hard of hearing eight month olds receiving cochlear implants. The teachers reminded Lynn and Scott that Lily was now four years old and with her amazing cognitive abilities, the parents should be using a combination of both spoken and sign language.

Since Lily did not understand speech yet, and there were so many obstacles and scenarios throughout the day that they needed to communicate with her, they used some sign language. Sign language came easiest to Lily. The doctors continued to recommend speech only but told Lynn and Scott to do what they felt they need to do. Scott stated that when they first adopted Lily, they used the signs, but since she received her cochlear implants they do not sign as much so that she learns how to rely on speech. Lynn shared, “I mean sign has been a life line for us. It has been amazing. And we totally don’t regret using it.” Currently, Lily’s primary mode of communication is a combination of spoken language, sign language, and gestures. Scott and Lynn expressed that it took Lily awhile to start signing in context, but once she did it was really exciting and that any form of communication was exciting. Lynn said,

I think they are so into the AVT stuff which is fine, for an eight month or a 13 month old, you know, because they are still a baby. And that’s how a baby learns language. But a four year old to me, needs more. (personal communication, July 9, 2014)

At the time of the implant, Lily was already set in her ways and had her own way of coping which is different than a baby learning language. Lily also had to learn what a
mother and father were and how to depend on them since she was adopted. In this context, communication by any means was vital for her.

**Chosen Child Receiving Services**

Lily was too old to receive early intervention services since she was adopted at the age of four. Before Lily was adopted from a different country, she lived in a foster home as well as attended and participated in “normal” preschool. Lily’s foster home documented her developmental milestones for the family. Lily had three signs before she came to America, but that was what formal language she had. Lily began getting services when she started school two months later.

After receiving many recommendations from audiologist and other parents, Lynn and Scott combed through the information and made sure they were making the best decision for their four-year-old adopted child, who recently became part of their family. Scott and Lynn were considering AVT, a local school that specializes in teaching children to listen and speak, as well as the local school system with a deaf and hard of hearing satellite program. After much consideration, they decided on the local school system with the satellite program. Lynn and Scott felt this option best fit their family’s hectic lifestyle. Lily still had not received her hearing amplification devices yet when they made this decision.

Lynn discussed the individual education program (IEP) experience. Lynn and Scott had no prior experience with an IEP. When they went to the initial meeting, the team debated putting her in a classroom that used primarily sign language to communicate since Lily did not have any access to sound. Lynn suggested that because
they had decided to go the cochlear implant route they wanted Lily to start right away in a classroom that focused primarily on spoken language. Lynn stated that,

Knowing her personality and the way she is, she’s resistant to a little change and all that. And like I can see her getting confused. And cause like if we go down this path, you know, they are telling me over here that we need to start on this path. And we need to go ahead and sign up for this AVT now, even though we don’t have the sound in. (personal communication, July 9, 2014)

Lynn proposed to the IEP team that Lily start half day. While at school, Lily received speech and language services as well. Lynn said that she advocated for Lily to get her the services that were appropriate for her current needs. Lynn indicated that she would advise parents to advocate for their individual situation since each scenario is different. Scott specified he thought there needs to be more of a mentoring or education program to inform parents of what their options are and what they can do to help themselves.

Lily received private AVT every other week. On the off weeks, the family had some auditory verbal education. A teacher would come into the house and teach the parents techniques to use in order to facilitate and require more communication from Lily. Lynn learned to label objects with sign and/or the word in order to build Lily’s vocabulary. The teacher showed her strategies she never would have thought to use, instead of just getting by. Lynn shared that “it’s amazing how much in your daily activities you can teach so much language.” During the observation, Lynn used selecting which ice cream the children wanted as a language lesson for Lily. Scott incorporated a language teachable moment into swinging encouraging Lily to request a push. Lily did not receive private speech and language services in order to avoid overwhelming her already rigorous day and the family as well. After a long day at school, Lily comes home
and prefers to relax and play before participating in any structured language stimulating activities.

**Chosen Child Handling Emotions**

Adopting a child with hearing loss was not something Lynn and Scott had set out to do, but when they received the file regarding this little girl, they were open to the idea. Lynn shared her thoughts regarding adopting a child with hearing loss.

The day we got the call that they were going to present us with a file, and they felt like it—they thought of us—it matched our criteria. Umm, they said, you know, are you open to hearing loss? And I was like ‘sure.’ So, ‘cause we’re just kind of like whatever God like—our vision for like, whatever God has for us, you know. And we were open to that. (personal communication, July 9, 2014)

Even though they did not feel like they were equipped for a child with a hearing loss, they were still open to the idea. Lynn remembered that she soon realized that Lily would never hear music or hear the sound of her voice.

The parents felt they were an anomaly. Lynn explained she can see why parents become really emotional because it is not something they were expecting. Lynn reminisced about her first child having the UNHS, “I remember being just like terrified. And when they were doing the little puff and everything, and I was like what if she can’t hear, you know, what if we have a deaf child?” Their experience with Lily was unique because they chose to add to their family and to parent a deaf child. After the ups and downs with raising children, Lynn came to the conclusion that true happiness does not come from perfection. Knowing that happiness does not come from perfection helped Lynn and Scott be less emotional about Lily’s hearing loss.

After Lily had her cochlear implant surgeries, the audiologist’s prognosis was guarded and not overly optimistic. They were trying to be cautious about her outcome.
with listening and spoken language. The doctor’s prognosis made Lynn feel nervous, but she knew Lily’s outcome was dependent on she and Scott following through with what they were supposed to do. Scott shared that he understood it’s a process and to take one day at a time because it was not going to be immediate. Scott said, “That’s one thing that you have to go in to it understanding, and I think that helps.” He said that it was very difficult, the first night after the surgery, explaining to friends because they had certain preset expectations.

The diagnosis process is arduous as well as long and intense according to Lily’s mother. At times the process was overwhelming, especially at the beginning, since they were dealing with a newly adopted child who was unable to communicate her wants and needs. Lily’s parents shared it was hard adjusting their schedules to make the doctor’s appointments and therapies as well as learning about hearing loss.

Through Lily’s hearing loss diagnosis, Lynn and Scott have met many interesting people they would have never met otherwise. Lynn reiterated the fact that they were naïve and had a lot of learning to do in order to meet Lily’s needs. “I guess that’s why ours is different. We weren’t disappointed because we already knew.”

**God’s Blessing—The Lucky Ones: A Family Accepting the Hearing Loss**

**God’s Blessing to Diagnosis**

Jack’s hearing loss was discovered through the UNHS at the hospital by the on-call pediatrician. His parents were told by the on-call pediatrician he had failed the hearing test, but not to worry because it was common. Jack’s young parents were told he could have fluid buildup in the ears causing him to fail the UNHS. A follow-up visit was scheduled for a few days after Jack was released from the hospital. Jack was seen by his
pediatrician and received another hearing test that he also failed. His pediatrician then referred Jack and his parents to see an audiologist. The pediatrician still did not indicate any reason to be concerned about a hearing loss.

The next appointment was scheduled with an audiologist. The audiologist checked Jack’s ears to eliminate the possibility of fluid buildup. Jack’s ears showed no signs of fluid. The audiologist then performed a more extensive hearing test involving the brain stem’s response to sound (ABR). Jack went back for three different ABRs, one of them being sedated, before a diagnosis was given. The audiologists continued to refer for additional testing.

After Jack received several hearing tests that came back as “failing,” the audiologist fitted him with a pair of hearing aids. The audiologist had Jack wear the hearing aids because they were unsure of the cause and degree of hearing loss at the time. Jack wore the hearing aids for one year. The parents noticed there was never a response to sound while he was wearing the hearing aids. At this point Natalie, Jack’s mother, and Charles, Jack’s father, knew their son had a hearing loss, but did not know the extent of the loss yet. Natalie remembers, “We didn’t know that he was completely deaf or anything. So we still talked to him like he was hearing” (personal communication, July 19, 2014). The parents decided to request another sedated ABR since Jack was not responding with the hearing aids. The final ABR was performed when Jack was a year and half. The doctors informed his parents that he still did not pass the ABR and he had a severe to profound hearing loss.

With the severe to profound hearing loss, Natalie and Charles thought he could hear loud noises like a fire truck or airplane. Jack’s parents interacted with him as if he
was a hearing child and he seemed to respond to them. “We always did the hearing aids because the Ears Nose Throat specialist (ENT) said if there is some hearing at least he’s getting something, some awareness of sound.” Jack would always know when his parents were laughing, mad, or sad. Natalie and Charles thought Jack was hearing them. Jack’s parents were teenagers when they had Jack and had not been around young babies. Natalie stated that looking back Jack reactions to the parents’ emotions was more than likely his noticing facial cues and body language, not his hearing.

**God’s Blessing with Cochlear Implants**

Jack’s parents were considering cochlear implants in order to increase his hearing since he was so visual. To determine if he were a candidate, a MRI needed to be done. Jack was a year and a half when his parents took him for a MRI. A cochlear implant specialist performed the MRI. The specialist called Natalie at work to deliver the results. When the doctor called Natalie, he did not ask her to come in and review the MRI results; he told them to her over the phone. Natalie considers this call the final diagnosis. Natalie stated that she was confused by the specialist calling her to share the results since, while she was at the MRI appointment, she had scheduled a follow-up visit for the results to be reviewed and explained.

Through this phone call, they learned the exact cause of Jack’s hearing loss. Jack did not have cochlear nerves; his nerves never formed. He was profoundly deaf and was not a candidate for cochlear implants. “I remember he told me on the phone, and I just started crying.” Natalie stated she wanted more details than these blunt words: he was not a candidate and did not have a cochlear nerve. The doctor told her over the phone that in a year Jack could come back for another MRI. A year later, when she called back to
schedule the follow-up MRI, the doctor informed her she actually did not need to bring him in for an addition test. “I don’t know if he was giving me, hope then. Then saying ok, don’t.”

After the doctor delivered the news over the phone with no further explanation, Natalie took Jack’s MRI results to a different Ears, Nose, and Throat specialist (ENT). The new ENT clarified everything for her. This doctor used an illustration of the ear (see Figure 2) and showed her the parts that Jack was missing. The new ENT also explained to Natalie about research that was being conducted in different countries that may eventually come to America, cochlear nerve implants. Natalie emailed the researcher to conduct her own research about the new implant and discovered that it was being tested on animals first and would not be conducted on children for at least another ten years.

**Figure 2: Diagram of the Ear**

(Hearing Haven, n.d.)

When asked if they would consider this surgery for Jack now, Natalie stated, “I don’t know at this point. I guess I would leave that up to him. If that’s something he wanted, ‘cause ultimately we know that that’s not going to give him hearing like us.”
Natalie stated the only reason she would possibly proceed with the cochlear nerve implant in the future was for awareness and safety. Jack’s parents have taught him about the importance of safety since he cannot hear. If Jack starts to walk off, not looking both ways, or not being as careful, then his parents get angry, and he learns from his mistake.

The new ENT also told Natalie about different modes of communication. He told her she had to pick one and could not use a mixture because this would be Jack’s primary route for communication. Natalie recalls the doctors telling them, “we would have to learn sign language and that was the only option really.” Natalie described that she had hoped Jack would have some degree of speech. She expressed that every mother wants to hear her child talk and she wanted him to be able to hear her voice. No prognosis was given to Jack’s parents regarding his future and his ability. Natalie shared the doctors assumed she knew how to raise a child with hearing loss and did not inform her that Jack could live a normal life without hearing. Since Natalie was a teenage mother with a lower socioeconomic status, she had the double challenge of learning to raise a new baby, in addition to learning that he was deaf.

**God’s Blessing Receiving Services**

Jack’s pediatrician told Natalie and Charles about different early intervention services available for him. Through the early intervention services, Natalie received information about parent support groups and how to get in contact with other families of children with hearing loss. The early intervention therapists were helpful for Natalie and provided her with additional support since they knew other families and their struggles. Being a young new mother, Natalie was hesitant to reach out and talk to other parents and
learn from their obstacles. Eventually, she realized it would benefit Jack, and she was able to reach out.

According to Jack’s mother, he received four different early intervention services through the state programs: music therapy, play therapy, physical therapy, and a deaf mentor. The therapists would come over to the house and do different exercises with Jack and show his parents different strategies as well. A music therapist would come to their house and work with Jack incorporating sound through the use of guitars and other objects that focused on his senses. A play therapist came to the house and taught the parents different strategies to use with Jack through play with animals. Jack’s motor skills were a little delayed in addition to the hearing loss. Natalie stated, “I think it all had to do with his hearing, like not balancing well.” A physical therapist came to the house to show Natalie different techniques to work on Jack’s motor skills.

One of the most beneficial support systems provided through the state early intervention services was a deaf mentor. Also coming to the house, the deaf mentor introduced the family to the Deaf culture and taught them their first signs to use with Jack. Natalie stated, “The deaf mentor was the most helpful because I didn’t know anything about Deaf culture. I didn’t even know there was a Deaf culture.” The deaf mentor provided the parents with information about other parents and resources that were out there for their family and Jack. Natalie expressed, “I think that made me more passionate about the Deaf culture because I don’t want him to learn how to read my lips, I want to learn how to speak his language.” Jack will eventually learn to read some words on the lips, but his parents felt they should learn more about his culture and not demand that he accommodate to the hearing world. The deaf mentor “opened our eyes,” she
added. Natalie had to request the information, but it was readily available for her. She asked for information regarding churches and daycares that would help a young new mom with a child with hearing loss.

Natalie stated that she and Charles found the different therapy sessions to be helpful. “I would suggest it to other moms that go through it.” Since Natalie and Charles were teenage parents, the therapists demonstrated for them different activities that would be beneficial to Jack. Natalie indicated that they learned the most sign language and built their vocabulary through games and play. The therapists came to the house once every two weeks for an hour to work with Jack and his parents. The therapists would come separately. “They would change, like, we didn’t have the four therapists; we didn’t have them all throughout. They changed but it, everything, all of them helped.” These services were provided until Jack was three years old and started preschool at the local elementary school. The last person who came to the house was the deaf mentor.

The parents expressed that their sign language is improving. Natalie would like to go back to school to increase her sign language skills and become a sign language interpreter. She wants to help families going through similar situations. Natalie stated that for the most part she understands everything that Jack is trying to communicate, but if she does not understand then she tells him to slow down and tell her again. She stated that he will sign it again really slow. If she still does not understand, which is not frequently, then he will show her what he wants, but she has him sign it again in order to learn more from him. Charles and Natalie currently know the same amount of sign language. Natalie shared that when she goes to school to become an interpreter, she will teach Charles everything she learns so he continues to learn sign as well.
Based on the observation done at Jack’s house, his parents use sign language each time they talk to Jack because they understand that this is Jack’s primary mode of communication. Natalie included Jack in on an organizational calendar activity she was doing and used it as a time to teach Jack his numbers and how to find the numbers in a planner. She also had him write the person’s birthday on the specific day so he practiced his writing and she was able to practice her fingerspelling. Charles joined Natalie and Jack after he finished making dinner.

**God’s Blessing Handling Emotions**

Jack’s parents explained that the diagnosis process was something they would do again. They viewed the process as something they “went through” and “just had to do it.” They did not find the experience stressful. It was right after learning that Jack was not a candidate for the cochlear implant and the degree of hearing loss over the phone that his parents accepted that he was deaf. Natalie explained that it was not something they were expecting, but that they accepted it right away. The diagnosis was difficult for that initial moment. Natalie explained, “Just the moment when he told us, but after that we were like okay, well now we have to accept it and move on.”

From the beginning, the parents had started to learn and teach Jack sign language since they knew he had some degree of hearing loss. Natalie and Charles stated that when they learned that Jack was profoundly deaf with absent cochlear nerves, “We decided not to go with the hearing aids anymore and just use sign language.” When asked about her perceptions of the diagnosis process, Natalie stated,

Hmmm, I wouldn’t change it for anything. It’s weird because the only time I felt like sad about it was when I initially found out. Like that first moment, but after that I was like, ok. I just felt kind of lucky to have him. I didn’t feel any guilt or bad for him or
anything. I just thought we were lucky and that he’s lucky.  
(personal communication, July 19, 2014)

Natalie shared that she has seen other families’ reactions to the news of their child’s hearing loss and their experience was different. Other families may feel like “why did this happen to me?” However, she and Charles never felt that way.

During the interview, Natalie was pregnant with her second child, and she joked that they were not sure they were prepared for a hearing child since they were accustomed to having a deaf child. She said that the doctors completed some preliminary testing to determine if the new baby would have hearing loss. So far it did not appear so, but even if it does she said, “I don’t care ‘cause it wasn’t something that was so hard for us, and like I see other parents that have other situations that are way, way, way worse.”

Natalie and Charles said that it has not been difficult or changed their life. Natalie stated,

I hear about other families still in denial or who have not accepted the hearing loss and I’m like ‘aww.’ I know about this family who has a baby with a hearing loss and that is how she feels. I just want to talk to her and just explain to her that you don’t have to; it’s nothing bad. (personal communication, July 19, 2014)

The members of Charles and Natalie’s extended family have also learned sign language. They do not know as much as the parents, but they are able to communicate and understand Jack. Both Natalie and Charles are from native Spanish speaking families that have learned English as well. Learning new languages was second nature for these families. Natalie exclaimed, “So that’s, I guess, it’s another reason why it’s so easy for us.” Every member of their families has accepted Jack’s hearing loss. “Everybody wants to, like, even like the older people in our family know.” Jack’s new sibling will also learn sign language as he grows up in order to communicate with him.
His parents feel that Jack can do anything. Natalie and Charles explained that Jack is more alert than they are sometimes. Natalie expressed that she is in awe of him. She explained that in the beginning she had many questions about what he would be able to do, but she never doubted that he could strive to do whatever he desired. Natalie expressed that she now feels that God chose her for a reason and that she and Charles are lucky to be Jack’s parents. Charles and Natalie never had any doubts and were always in it together.

No Entiendo—Communication Barrier: A Diagnosis Journey for a Spanish Family

No Entiendo to the Diagnosis

Right after Alex was born the doctors performed the UNHS on him. Alex’s mother, Rachel, stated, “They did audition test for him and one ear came back fine and the other, it was not” (personal communication, July 25, 2014). The communication barrier between the parents and the doctors was evident throughout the entire interview with the researcher. The doctors told Rachel that Alex had a “hearing problem in one ear.” After being released, Rachel was taking him back and forth to specialist appointments at the hospital. Alex was also born prematurely with several health complications that were later resolved.

Alex has an older brother, Juan, who was born with Cerebral Palsy. When Juan was a baby, he also had problems with his ears, but “he recovered from his problem.” The doctors “diagnosed his hearing, but they told me that he was going to recover and with time he has been getting better.” A different doctor saw Juan through the diagnosis, but told Rachel that he did not need to go anymore because he was fine. Juan’s doctor informed Rachel that he had a little hearing loss but he was going to improve. “He wasn’t
going to go down; it was going to be going up. If he was having more hearing infections, he was going to get worse, but he didn’t have anymore.” Juan had Autism as well and was nonverbal. Juan’s experience occurred before Alex was born.

According to Alex’s mother, the specialist did not inform her that he could not hear—only that he had a “hearing infection.” Alex was going to the specialist every six months. While Alex was receiving early intervention services, one of the therapists asked Rachel how she felt about the appointments with the specialists. Rachel informed the therapist that she was worried because Alex was having so many “hearing infections.”

The therapist assisted Rachel with scheduling an appointment at the children’s hospital in the city.

Alex was two and half years old by the time his mother took him to a different hospital for additional testing. While at the children’s hospital, the doctors did an ABR; Rachel referred to this as an audiogram test. The results of the ABR indicated that Alex was deaf in both ears. The ENT at the hospital was the person who delivered the diagnosis to Alex’s mother. In the room with the ENT was another audiologist and a nurse. Rachel was alone with Alex when she was informed about his hearing loss. The ENT informed her that “because he was very premature that the ear didn’t develop very well. The ear didn’t have the chance to develop.” Rachel indicated that she was provided with partial information besides the cause of his hearing loss. She did not receive any information about parent support groups or different modes of communication.

The doctors also gave Rachel limited information regarding Alex’s prognosis for the future. Rachel relayed that the doctor told her Alex was going to need to attend a special school where he would learn how to communicate and to hear things. The school
would teach him how to listen since the sounds he was hearing were different than the
sounds other people were listening to and could hear.

**No Entiendo with Cochlear Implants**

The audiologist who performed the ABR at the hospital was the first doctor to
discuss cochlear implants with Rachel. The audiologist “told me that the way to help him
was getting the surgery with implant.” After receiving the news regarding Alex’s hearing
loss, Rachel began to cry. The doctors told Rachel there was no need to be sad because
science is much more advanced now and he could get cochlear implants.

Rachel remembers the doctors informing her, “Now they have the cochlear
implant that it would be very good for him. And it will help him, but also exists the
possibility that sometimes it doesn’t work.” Rachel had prior knowledge of cochlear
implants since an acquaintance’s daughter had cochlear implant surgery. Unfortunately,
the daughter did not benefit from the implants. Rachel said she was hesitant about doing
the implant surgery for Alex since her friend’s daughter’s hearing did not improve with
the cochlear implants. “I was thinking about the lady with her daughter, and I was
thinking about what happened if Alex is in the same situation and he would not be able to
hear with implants.”

Later on Rachel saw a video about cochlear implants; she could not recall the title
of the video. The video made her feel much better about the whole concept. She decided
she was going to try implants for Alex. Rachel told the doctor she was going to continue
with the cochlear implant surgery and that she “agreed with him and his surgery.” Alex
received first cochlear implant at the age of three.
A couple of weeks after the surgery was completed, Rachel took Alex back to the doctor to test the implant. Rachel shared, “they test him and he could hear. I was so happy, and he was happy too.” Since the first surgery was a success, Rachel decided on proceeding with the second implant for Alex. Alex received his second cochlear implant when he was four years old. This surgery went just as smoothly as the first one. Alex feels very comfortable with both of his implants now. His mother stated, “He can hear very well, and when he cannot hear, he tells me.” If Alex is sweaty from playing or if the battery is dead in his implant, then he lets his mother know so she can dry it or change the battery. Alex tells his mother in Spanish when there is a problem with the cochlear implants. Alex’s primary mode of communication is spoken English with some spoken Spanish with sign language support.

Cochlear implants are gradually turned up and more access to sounds are added at each doctor’s visit. Since the implants, Alex goes to the audiologist every six months to make sure the implants are still working. At the audiologist appointments, the implants are mapped. Mapping an implant refers to tweaking and adding sounds to ensure that Alex is hearing at the highest level he can.

**No Entiendo Receiving Services**

Alex received three different early intervention services. He received speech therapy, physical therapy, and services for a visual impairment. Neither Rachel nor Alex were taught any sign language from these therapists. The therapist for his visual impairment would work with objects of different colors and lights to help determine what Alex could see. Alex has glasses now and can see within normal limits.
The early intervention services began when Alex was eight months old until he was five years old. Traditionally, early intervention services end at the age of three when the child enters preschool. The therapists would come once a week for 30-minute sessions on different days. Rachel was very happy with the services provided for Alex because “they helped him a lot.” Rachel focused on the fact that the therapists helped Alex more than the question of whether these services helped her.

When Alex began preschool at the age of three, he began to learn sign language in addition to English. Sign language provided as an additional mode of communication for Alex. Rachel report that the school occasionally provided sign language classes for the families and had a Spanish interpreter attend. Rachel and sometimes her husband took advantage of these classes and attended in order to learn basic sign language to communicate with Alex. Rachel is the primary caregiver for Alex since his father works several jobs to provide for the financial needs of his family.

**No Entiendo Handling Emotions**

Through the diagnosis process, Rachel felt very bad. When she learned Alex was deaf in both ears, she felt “terrible” since she had only been informed about a problem with one ear, but not the other. Rachel was by herself with Alex when she learned about his hearing loss. She began to cry, and the doctors tried to comfort her. “The doctor told me to don’t feel sad because—I was told to don’t feel sad and upset because here there were many resources to help Alex with his—um—condition in different ways.” Rachel now feels better about the whole diagnosis process and early intervention services since “he’s trying to talk, and he’s also trying to talk in Spanish, and the sign language helped a lot.”
During the observation at the house, Alex was doing his favorite activity, drawing and coloring. Alex’s younger cousin interacted with Alex the most. Juan, Alex’s brother, requires most of their mother’s attention. Juan can become physical while playing and has injured his brother and cousin before. Rachel shared she prefers to keep the brothers separate to avoid injury. She spends a lot of the day making sure Juan is taken care of since Alex and his cousin are more independent. The cousin often habitually acted as Alex’s Spanish interpreter when he did not understand what his mother was saying. When Alex had a spelling question for his mother, she provided the spelling in English and sign language.

Alex’s sign language vocabulary is greater than his mother’s. If Alex signs a word and cannot physically show her the object, she often has to go look up the sign in order to know what he is trying to tell her. To look up the signs on certain websites, she has to have her brother-in-law help her use the internet. The majority of the time her brother-in-law is at work outside of the home, so she has to wait for his assistance. Rachel explained that Alex primarily communicates in English, but tries Spanish, and if he cannot recall the word, then he will use sign language. Overall, Rachel and Alex understood each other’s form of communication and used gestures, or the cousin interpreted when the meaning was lost.

**Critical Condition - Spinal Meningitis: Typical Child who Becomes Deaf**

**Spinal Meningitis to Diagnosis**

The diagnosis process of finding out Ryan was deaf was secondary to the spinal meningitis. Ryan became sick with spinal meningitis while living in Puerto Rico. With the spinal meningitis, Ryan had hydrocephalies and traumatic brain injury. In order to
provide better medical care for Ryan, Lisa, Ryan’s mother, moved to a southeastern state with Ryan.

Richard, Ryan’s father, described how the neurosurgeon was the only doctor willing to give them a second opinion (personal communication, July 10, 2014). The neurosurgeon evaluated Ryan and determined his shunt valve worked and recommended they see a neurologist. The neurologist decided Ryan was responding and suggested they see another specialized doctor. The specialized doctor decided to start Ryan on an aggressive therapy for three months. During the three months of therapy, Ryan started breathing on his own without the help of the tracheotomy.

After they moved, the doctors performed an “evaluation study” to check his ears. Ryan’s father had not moved here from Puerto Rico yet, so his mother was alone. The day the doctors performed the hearing test and explained to Lisa that Ryan was totally deaf, she was “alone, alone, by herself, no one else.” Lisa called Richard in Puerto Rico to relay the diagnosis to him. Richard expressed his reaction as, “I was like, ‘oh my God; I felt cold water going through me.’ So that’s my best memory.”

Lisa explained that the ENT performed a normal hearing test on Ryan and then decided to do a more extensive test, the ABR (personal communication, July 10, 2014). Ryan was sedated, and the doctors completed the test to see his brain’s reaction to the sound waves. By doing the ABR, the doctors discovered Ryan had a bilateral profound hearing loss. Ryan was four years old when his parents learned he was deaf. The ENT, and his nurse delivered the diagnosis news to Lisa. At that moment, the ENT’s main concern was how Lisa was going to react to the diagnosis information.
Eventually, the doctors provided Lisa with different types of information on how to help Ryan through the meningitis recovering and regarding his hearing loss. Within the information was a list of parent support groups that Lisa could attend.

Ryan’s doctors did not provide any prognosis information to Lisa or Richard after the first six months post illness. The doctors educated Lisa and Richard that children who suffer from meningitis typically reach their development peak within six months after onset. That was not the case for Ryan; he was still exceeding expectations by learning new things, so the doctors stopped making prognosis predictions. The neurologist was amazed at Ryan’s progress. Ryan recovered full function of both hands and was continuing to get better. However, due to the traumatic brain injury brought on by illness, Ryan learns at a slower rate than other children. The doctors are unsure of Ryan’s future since he has already exceeded their previous expectations.

**Spinal Meningitis with Cochlear Implants**

Lisa remembered the doctor telling her that Ryan’s only chance of communicating and primary mode of communication would be sign language. He was not a candidate for a cochlear implant since his cochleas were ossified due to the meningitis. Richard explained,

> It was a mix of things; meningitis damaged the liquid inside the cochlea, and the antibiotic he was using back then burnt all the hair inside the cochlea. So that process together make the, um, cochlear bone too ossified within six months. So, if they did that procedure at the hospital six months earlier to that, probably would have a full functional cochlear. *(personal communication, July 10, 2014)*

Unfortunately, the cochlear implant surgery was not possible then because Ryan was in a coma, and the doctors did not want to do that type of elective surgery on him.
The first ENT did not want to perform cochlear implant surgery on Ryan, so Richard began looking for second opinions. Several doctors informed him that they did not want to do the surgery. The original ENT recommended the family visit a specialized otologist if they were still interested in having the cochlear implant surgery. The specialized otologist was the doctor who agreed to perform the surgery, but did not guarantee the results. Richard agreed to that and the surgery was completed.

The specialized otologist suggested Ryan have bilateral cochlear implants. Ryan had a shunt valve that goes down the other ear. In order to complete the second cochlear implant surgery, Ryan’s neurosurgeon would have to assist with the surgery to make sure there were no complications with the shunt. Lisa and Richard decided against proceeding with the second cochlear implant due to how dangerous the surgery would be to Ryan. They were happy enough with the results of the first implant.

After Ryan received his cochlear implant, the doctor told Lisa and Richard that Ryan was not hearing like other children with cochlear implants and suggested they still use sign language. The doctor was unsure if the cause was from the ossification of the bone or the traumatic brain injury, but one of them was affecting the way he was responding to sounds. Richard stated that Ryan hears. Cochlear implant processor technology continues to upgrade and allowing Ryan more access to sound.

**Spinal Meningitis Receiving Services**

Ryan was too old for early intervention services through the state department because he was already four years old when he became sick. Lisa indicated that enrolling Ryan in school was an easy process because everyone was so helpful. She explained that she still remembers the teacher. The teacher was the one who recognized that Ryan was
learning some language. Since Ryan exhibited signs of learning language and a desire to communicate, he was moved from a special needs preschool class to a preschool class that worked specifically with children who were deaf and hard of hearing and whose primary mode of communication is sign language.

At school Ryan needed speech therapy, physical therapy, and occupational therapy. After school, Lisa would drive Ryan down to the children’s hospital where he had “special therapies” with his first audiologist including speech. In addition to receiving private speech therapy, he also had private physical and occupational therapy. Ryan had aquatic therapy and hippotherapy. Aquatic therapy is physical therapy that takes place in the water and hippotherapy is physical, occupational, and speech therapy that uses the horse’s movement for sensory and motor input (American Hippotherapy Association, Inc., 2014). He also attended a special gym that focuses on alternative therapy.

Ryan’s mother drove him to the specialized therapy appointments. Therapy appointments have been a regular for Ryan since he was released from the hospital at the age of four. Ryan’s parents’ perceptions toward the therapy services he has received were excellent. Lisa stated that “It’s hard; that’s the reason why I can’t work evenings, I mean, afternoons ‘cause I take him to different therapies.” The family had a full schedule but were happy with the services Ryan received.

**Spinal Meningitis Handling Emotions**

Richard describes his memory of the experience as everything happening so quickly. During the first year, he was still living in Puerto Rico. He traveled back and forth in order to provide his wife and son with support. Richard decided until final
decisions were made, he and Ryan’s older brother would remain in Puerto Rico. “We tried to play on a safe basis back then ‘cause 50/50 chances. So we said, ‘you stay here with him, if he improve, I move there. If he don’t improve you move back to Puerto Rico.’” Richard stated he helped provide for his family in both locations until a solid outcome was identified. Ryan started to make more progress when he began school and continued to move forward. Richard and Ryan’s brother ultimately moved from Puerto Rico to join Ryan and Lisa.

Lisa expressed that the diagnosis made her feel terrible. She was not prepared for the process especially being alone. Richard stated he also felt terrible about the diagnosis. Ryan was a completely normal speaking child who lost everything due to illness. Suddenly, his life changed. Lisa stated that it was very hard to receive the diagnosis information, going from completely normal at birth to deaf at four. Richard shared the first thought that cross his mind was he would never hear Ryan say “Papa” again and that was a difficult thought to grasp. Lisa indicated the diagnosis was the “strongest news ever” so they focused on providing Ryan with an opportunity for a better recovery and education. They decided to stay in the new state permanently instead of going back to Puerto Rico. Richard and Ryan’s older brother moved from Puerto Rico to settle down. The diagnosis was depressing for both Lisa and Richard. The process got easier once Ryan was released from the hospital. Ryan started school soon after arriving back home.

Ryan’s parents shared that they thank God every day for the services he has been receiving. If they had still been living in Puerto Rico and he was discharged from the hospital, his experience would have been the complete opposite. Lisa said the doctors told them, “He would do nothing; just provide him with a nice bed, make him
comfortable, left him there ‘cause he’s—you know. So, thanks to our curiosity, we started looking for different alternatives, and God brings us here.”

Since receiving the cochlear implant, Ryan has started producing a few words. He was able to say “Papa” again which pleased his father. Ryan was also able to produce the word water in Spanish. During the observation, the family used a combination of communication modes. While speaking with Ryan, his father used sign language and English, whereas his mother communicated using Spanish and sign language. If his parents were speaking to one another, they only spoke in Spanish. Lisa and Richard were thrilled with the progress Ryan has made and continues to make.

**Runs in Family—Genetic Hearing Loss: Diagnosis for a Hearing Impaired Family**

**Runs in Family to Diagnosis**

For the family with three children with hearing loss, each experience was unique. Identifying the hearing loss in the oldest child, Trevor, was the most challenging experience. Trevor passed the UNHS at the hospital, “His was the only odd one since he passed his test” reported his mother, Gabriella (personal communication, October, 13, 2014). When he was about three years old, his mother started noticing that he was not hearing as well. “We did not know he was hard of hearing until right before we moved here, and I think he was like three or four years old.” When Gabriella began noticing a possible hearing loss, she scheduled an appointment with the pediatrician.

“Hearing loss runs in our family, so I already knew sign language. It mostly interfered with the girls, not the boys. They say it’s hereditary.” Gabriella, her grandmother, her mother, her aunts, one uncle, and a majority of her cousins have identified hearing loss. Gabriella stated that her hearing loss has gotten worse, and she
has a progressive hearing loss. Since hearing loss run in the family, Gabriella paid close attention to Trevor’s development. She mentioned to the pediatrician that she did not think he was hearing very well. Gabriella then scheduled an appointment with the ENT that the pediatrician recommended. The ENT identified this oldest child’s hearing loss as moderate to severe.

Right after Trevor was diagnosed as hard of hearing, the family moved to a new state. Trevor’s father was taken aback by the diagnosis. Gabriella expressed, “It was an easy process; once I transferred to the ears nose specialist here, he got hearing aids.” Gabriella reiterated the fact that the diagnosis process for Trevor was long, but smooth. Everyone assisted her and told her where she needed to go for the next step. After multiple trips to the audiologist over a span of several years, Trevor’s hearing loss was identified as progressive.

The second child, David, was identified early at the hospital through the UNHS. Gabriella stated that the process for David was easy as well. David’s hearing loss was identified as “low.” With the family history of hearing loss, the discovery of two children with hearing loss was not a surprise. “It wasn’t really shocking. The only shocking one was, I guess, it was Trevor.” David had seizures when he was born so his parents went to the doctor more often with him. During the more frequent doctor visits, David received several hearing tests. He had more tests done that Trevor or Rose. David did not have a progressive hearing loss; his was stable.

For Rose, the youngest child, the process has been hard. Rose passed the UNHS at the hospital. The pediatrician never did any further testing. The school system contacted Gabriella about Rose since the older two siblings attended school. The school
system suggested that Gabriella explore having Rose’s hearing tested again. “We did the test, and I think it came back that they couldn’t tell if she was hard of hearing or not. I don’t know; everybody thinks she can hear.” Rose’s hearing loss appears to vary based on the day; some days she can hear better than others. A doctor and two nurses presented the information about Rose’s hearing loss as Auditory Neuropathy to Gabriella and Carlos, her husband. “They couldn’t tell whether she was; they are calling it Auditory Neuropathy. Her hearing goes in and out, and so I guess there’s nothing we can do about that.” The exact degree of hearing loss was unknown for Rose. Carlos is Rose’s father but not the father to Trevor or David. Rose was Carlos’s first child with hearing loss.

With three children, the doctors encouraged the family to use sign language as their primary mode of communication. Gabriella knew sign language from communicating with her extended family. After his mother learned about Trevor’s hearing loss, he started sign language classes. With David, she used the sign language she knew, and when he started school, he also started to learn more sign language. The doctor told Gabriella and Carlos to start using sign language with Rose when she was a baby. “They said use sign language. They’ll learn sign language before they’ll learn how to talk.” They started incorporating simple words. David definitely learned how to sign before he learned how to talk. Gabriella remembered that when they moved here, David was not talking yet.

Gabriella stated that David and Trevor sign to each other and to Rose at home. Due to the degree of hearing loss and not wearing hearing aids at home, David and Trevor must sign in order to fully grasp a conversation. Sign language is David and Trevor’s primary mode of communication. Rose tries to sign with her brothers but often
uses made up signs, so her brothers do not understand what she was saying. Rose’s primary mode of communication was spoken language. During the home observation, David signed and spoke everything. Gabriella would speak and sign almost everything she said to David, but only spoke to Rose. Carlos did not know sign language. Gabriella shared that she explained to Carlos he needed to learn sign language in order to communicate with the children more affectively.

**Runs in Family with Cochlear Implants**

Doctors have informed Trevor that because he has a progressive hearing loss, he requires cochlear implants. Without cochlear implants, Trevor will go completely deaf. However, Trevor does not want them. He is scared according to Gabriella. Trevor is nervous about the surgery and wonders if he would be able to play football with the implants. The doctors showed Trevor pictures of football players with cochlear implants. Gabriella shared that Trevor is more than likely scared because when he was nine or ten he had surgery to correct a hole in his ear. He did not have a pleasant experience or recovery from this surgery. Gabriella reminisced, “They took some skin from behind his ears to patch the holes up. And it didn’t do good. I think that’s when the left ear went really bad. It got infected real bad.” Trevor remembers this surgery and is nervous that the cochlear implant surgery may turn out the same way. Gabriella stated that she would like Trevor to get cochlear implants, but she is only slightly pushing it. She is ultimately leaving the final decision up to him since it is his body.

For David right now, the doctors indicate he does not require cochlear implants. Hearing aids work well for him with his degree of hearing loss. Currently, David’s
hearing aids are broken. The family plans to get David new hearing aids as soon as Medicaid is resolved. Later on, he may need cochlear implants.

Whether Rose needs hearing aids or implants is still unknown. Gabriella indicated the doctors told her that they have to wait until Rose is a little older to do the sound booth hearing test to get a better picture of her hearing loss. The doctors have a difficult time assessing Rose’s hearing loss since she does not sit still long enough to be fully evaluated. Gabriella was in the process of exploring the possibility of getting Rose hearing aids for at home, but had to wait until Medicaid problems were settled.

**Runs in Family Receiving Services**

David is the only one of the three children that received early intervention services. Trevor was too old before his parents suspected his hearing loss, and it was officially diagnosed. Rose did not receive any early intervention services either. David received speech therapy through the state’s early intervention program. He received speech services since he was a late talker. He also received services though the program for children who were deaf or hard of hearing. The therapist would come to the house, and she knew sign language. Gabriella explained that the therapist would “go over pictures. I think she called it motor skills. And she asked with the pictures to get him to say the words and stuff. So she worked with him basically on speech, to get him to talk.” The therapists would come twice a week for an hour each time.

Gabriella found the services to be very helpful. She stated that they taught David, helped her find doctors, and told her who to go to in order to get hearing aids. The therapists also gave Gabriella advice on how to work with Trevor. David received the early intervention services right away since he did not pass the UNHS. Rose passed the
UNHS, therefore not requiring early intervention services. Since no one from the hospital contacted Gabriella about Rose, she did not receive any services. Gabriella explained that the pediatricians never did more hearing tests with Rose after she passed the first UNHS.

**Runs in Family Handling Emotions**

Each of the children’s fathers had a different reaction to the identification and diagnosis of their hearing loss. Gabriella reported that Trevor’s father did not say much about the diagnosis, “He just looked at me and said okay.” David’s father, a different man than Trevor’s, did not have experience with hearing loss so his response was “What?”

Gabriella shared that the diagnosis for Trevor and David was not a surprise for her since she has such extensive family history of hearing loss. She said that she did have the feelings of “What you do wrong? What I did wrong? Why my kids have to have hearing loss?” She used to question herself about it, but she no longer does. She has accepted the fact that they lack one sense. Gabriella explained that because they are lacking one sense, their other four senses are stronger; what they lack in one sense they gain in the others. She said, “I see better than a lot of other people see. So I feel like I might lack in hearing, but my eyesight is better, so I try not to make it a big deal.” Gabriella tells Trevor, David, and Rose that their hearing loss does not make them who they are and to not let it break them. She conveys to them that they just have to work a little bit harder than a “normal person.” They can still do things. She tries not to focus on the hearing loss, so the boys learn to put their feelings aside and keep moving forward. Gabriella shared that she tells the children that there will come a time where they may be teased for their hearing loss, but they just have to overlook it like she did growing up.
She is going to be shocked if Rose does not have a hearing loss after Trevor and David both did. Gabriella said that she has had a difficult time with Rose’s diagnosis since it has been so unknown. Gabriella explained that Rose’s hearing loss has been a surprise because she passed her hearing test too and she appeared to be hearing what her mother was saying. Carlos was also not surprised by the diagnosis, but he took the diagnosis harder than Gabriella. Since Trevor and David had hearing losses, he assumed Rose might have one too. Gabriella had experience with hearing loss and was accustomed to a hearing loss diagnosis. After some time and the inconsistency of Rose’s hearing loss, Carlos doubted the diagnosis and kept saying, “She can hear. She can hear.” Still skeptical about the hearing loss, Carlos does not understand why he needs to learn sign language because he feels that Rose can understand him without it. Gabriella explains to him that even though Rose may not need it each time she is spoken to, she and the boys benefit from it since he mumbles his words and does not look at them when he talks.

Currently, Trevor is the child that Gabriella is worried about the most. His hearing loss is the worst and continues to progressively decline. Since he is older, he is becoming more sensitive to his hearing loss. Gabriella indicated that as long as David’s hearing loss stays where it is and does not get worse, she is fine with where it is. With Rose’s, the mother is rather skeptical. She questions why doctors are unable to tell her exactly what the hearing loss is. Gabriella questioned, “I’m like what? Is it a blockage? Why can’t they tell me yet?”
CHAPTER 5: DISCUSSION AND IMPLICATIONS

The purpose of this study was to explore the parents’ perceptions of the diagnosis process finding out their child was deaf or hard of hearing. These parents shared their experiences in regards to how they felt throughout the complicated and lengthy diagnosis process. This study also investigated the parents’ perceptions of the intervention services provided for their child following their diagnosis. This chapter analyzes the shared experiences among the six families and the role each family’s background played in their individual experiences.

As discussed in chapter two, research has shown that the manner in which the doctor delivers the “bad news” and the family’s background may affect the parents’ emotions as they relive the diagnosis process. The current stage of grief and the presence of any additional disabilities also contributed to how a family might relay their diagnosis experience. As reported in chapter four, each individual family in this study had a unique experience during the diagnosis process. The interviews took place at the families’ homes in order to provide comfort to the parents. Unfortunately, only four fathers were able to participate in the interviews. Two of the fathers were working during the interviews. Table 2 shows the common themes that emerged from analyzing the data.
Table 3

*Common Themes Emerging from the Data*

<table>
<thead>
<tr>
<th>Theme</th>
<th>Meaning</th>
<th>Quote</th>
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<tbody>
<tr>
<td>Complex Information</td>
<td>The information the parents received from the ENT during the delivery of the diagnosis was either wrong, misunderstood, or provided false hope to the parents.</td>
<td>• First doctor told Hannah, “No, I don’t see cochleas.” The doctor providing the second opinion saw cochleas.</td>
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<td></td>
<td></td>
<td>• Rachel did not understand Alex to be deaf only that he “has hearing infections.”</td>
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<td></td>
<td></td>
<td>• Doctors told Lynn and Scott, “It might just be fluid, and if you put in tubes, it might clear it out.”</td>
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<tr>
<td>Passive Doctors</td>
<td>A theme present among the parents is the doctors did not want to be the ones to deliver the “bad news” so they would refer for further testing.</td>
<td>• Scott shared, “You know they were like really tentative just to like share with us the final word or whatever.”</td>
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<td></td>
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<td>• Lisa explained the ENT performed a normal hearing test on Ryan and then decided to do a more extensive test.</td>
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<td></td>
<td></td>
<td>• Natalie said Jack went back for three different ABRs.</td>
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<tr>
<td>Beneficial Services</td>
<td>The parents felt the early intervention services were helpful for themselves and their child. They learned new strategies to implement for increasing language development.</td>
<td>• Hannah stated, “It was hugely helpful but dreaded.”</td>
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<tr>
<td></td>
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<td>• Natalie shared, “The deaf mentor was the most helpful…. I would suggest it to other moms that go through it.”</td>
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<td></td>
<td></td>
<td>• Lisa expressed that the process was easy because everyone was so helpful.</td>
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<tr>
<td>Long, Intense Process</td>
<td>The parents felt the diagnosis process was long and required many doctors appointments. Several parents shared they met people they would not have met if it were not for this process.</td>
<td>• Gabriella said the diagnosis process for Trevor was long but smooth.</td>
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<tr>
<td></td>
<td></td>
<td>• Lynn shared that the diagnosis process is arduous as well as long and intense.</td>
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<tr>
<td></td>
<td></td>
<td>• Hannah stated that one benefit was the number of people they were introduced to through the process that they are still in contact with today.</td>
</tr>
</tbody>
</table>
### Ever Changing Feelings

The parents shared at the beginning they were emotional, lonely, and stressed, as well as it was terrible news; toward the end their feelings shifted to hopeful and thankful; they were the lucky ones as they began to accept it and move on.

- Rachel expressed she felt “terrible” when she found out Alex was deaf in both ears.
- Hannah shared, “It was lonely hearing someone tell you that your kid may never hear.”
- Natalie stated, “I just felt kind of lucky to have him.”

### Against doctors’ wishes, sign language

Each family uses some degree of sign language to communicate with their child. Some used strictly sign language while others use sign as support for the spoken language. Doctors advised them not to sign but to focus on listening with the expensive cochlear implants.

- The doctor told the parents to try to avoid using sign language to communicate with Rebecca.
- The doctor did not want Lily to become dependent on the sign language.
- Prior to implants, Lisa remembers the doctor saying Ryan’s only chance of communicating and primary mode of communication would be sign language.

### Cochleas present then cochlear implant surgery

If the child had a cochlea, then implant surgery was performed. The only child who did not have cochlear implant surgery did not have cochlear nerves.

- Doctor called to tell them Lily was a candidate for a cochlear implant and schedule the surgery date.
- Rebecca was a cochlear implant candidate. Antonio stated, “What I remember most was, him telling us it really depends on her cognitive ability.”
- Jack did not have cochlear nerves; his nerves never formed. He was profoundly deaf and was not a candidate for cochlear implants.

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**Parents’ Perceptions Regarding the Diagnosis Process**

Learning about a child’s hearing loss can be quite devastating to a family (Gilliver, Ching, & Sjahalam-King, 2013). The parents of the children in this study had a variety of reactions to the diagnosis process of finding out their child is deaf or hard of hearing. The perceptions ranged from these parents feeling they were the lucky ones to
parents indicating they had received terrible news. DesGeorges (2003) shared that most parents have a negative experience with the diagnosis process. This study found that parents thought the experience was long and had mixed feelings toward the diagnosis. This study’s results were similar to DesGeorges (2003) who found that parents thought it was a long and wasted time between identification and the final diagnosis. Larsen and colleagues (2012) also found that parents and doctors surveyed appreciated when hearing test results were delivered in a timely manner. The majority of the parents in this study felt terrible, shocked, or lonely during the diagnosis process. Another study found that shock is a common feeling for this sample of parents experiencing this new diagnosis (Fitzpatrick et al., 2007). As another study showed, denial is also a shared reaction to hearing loss for parents and families (Gilliver, Ching, Sjahalam-King, 2013). In addition, there are other contributing factors that affect how parents perceive and accept the hearing loss diagnosis. For instance, the period of time in which the hearing loss is suspected, but not confirmed, is vital since this uncertainty lays ground work for how the parents will react and make decisions later (Matthijs et al., 2012). The doctors in this study presented this information to parents as failing the hearing test; this terminology provides new parents with an immediate negative connotation toward hearing loss. Thus, negative reactions by the family are often associated with a hearing loss diagnosis in this study (Matthijs et al., 2012). This finding supports Fjord’s study (2001) that doctors have a difficult time using both caring and competence techniques together. For most parents in another study, this diagnosis is their first experience with hearing loss, and learning their child “failed” the screening can be devastating. Since parents are often experiencing
 Researchers have found that the sample of parents who were studied cope with the diagnosis of a hearing loss in many ways. Fjord (2001) discussed the three stages that occur after a diagnosis as separation, liminality, and reincorporation. In this suggested progression, separation happens immediately after the diagnosis when parents take a break from social interrelations, liminality happens when parents are trying to cope with the new diagnosis, reincorporation is the final stage as parents re-associate with society and have accepted their deaf child (Fjord, 2001). In this study, only two families have reached the final stage. The majority of the families are still struggling with the diagnosis and its effects on their everyday life. The two families who have reached the reincorporation stage have accepted the hearing loss, and it no longer affects their day to day life. The parents in this study agreed with Boison (1987) that they had feelings of shock, denial, grief, anger, guilt, sadness, and anxiety after their child was diagnosed with a hearing loss.

Diagnosis of a hearing loss affects the whole family and also includes career, finances, and the choice of where to live (Fitzpatrick et al., 2008). This broad effect was evident with Ryan’s family, who moved here from Puerto Rico in order to guarantee better health care services (Richard, personal communication, 2014). Parents in the same family may react differently when a child is diagnosed with a hearing loss (Jackson et al., 2008). Rebecca’s parents reacted differently; the mother felt alone and shocked through the initial diagnosis, and her father thought of it as another obstacle to overcome (Hannah & Antonio, personal communication, 2014). Rose’s parents also reacted differently to the
Parents’ perceptions

Diagnosis. Rose’s mother had two children who had previously been identified with a hearing loss and expected Rose to have one, too. Rose’s father (who is not the father of Rose’s half siblings) had not had experience with a child with hearing loss diagnosis and had a more difficult time overcoming the information (Gabriella, personal communication, 2014). As studies show, when parents receive the correct support, then their grief may dissolve and acceptance of the hearing loss may happen faster than those parents who do not receive the correct support (Eleweke et al., 2008). Parents in my study expressed the same findings as Feher-Prout (1996) that their life with a child with hearing loss is now their new normal. The emotions these families felt started as denial, and as they took the diagnosis “rollercoaster ride” their feelings began to change to acceptance.

Preschool teachers of children who are deaf and hard of hearing taught information regarding the experiences the parents have during the diagnosis process, amplification devices, and the stages of grief associated with a crisis are well prepared. Being a preschool teacher of children who are deaf and hard of hearing in addition to the researcher, I frequently encounter parents of newly diagnosed children. Knowing the types of feelings the parents are currently exhibiting will help me during meetings with the parents to determine the best educational path for their child. Also, being aware of the parents’ perceptions of the diagnosis and the information they have already learned would help me to plan how much education they require regarding their child’s diagnosis and prognosis. I have encountered parents who are still in stage of denial with their child’s hearing loss and do not want to accept the fact that their child cannot hear as well. These parents are not ready to discuss intervention strategies or amplification devices. I have also taught children whose parents have had more time to deal with their child’s
diagnosis and have fully accepted the child’s hearing loss. These parents tend to be more involved in the education program and are ready to work with the professionals to determine appropriate strategies, learning language development techniques, and to educate themselves more about their child’s level of hearing loss. I used the conceptual framework of constructionism to determine the general range of responses that parents of children who are deaf and hard of hearing may have at the time of the diagnosis. Learning what these parents heard and how they perceived the diagnosis process was enlightening. I also used constructionism to analyze the parents’ experiences with early intervention services.

**UNHS**

As discussed in chapter one, the universal newborn hearing screening (UNHS) is an intervention that aims to improve outcomes for children who are deaf or hard of hearing and their families (Fitzpatrick et al., 2008). This early test is important because children who are deaf and hard of hearing who are identified and given an early start have the capabilities to meet their highest potential and have access to language from the beginning (DesGeorges, 2003). Out of the six families that participated in my study, only three experienced failing scores on the UNHS. The other children passed the UNHS, and their hearing loss was detected later on the same way it was prior to the UNHS, by health, education, and social services (Fitzpatrick et al., 2008). One of the children in Rose’s family with genetic hearing loss discovered her loss with the UNHS; the other two were discovered at an older age (Gabriella, personal communication, 2014).

The current study contradicts the research done by Larsen and colleagues (2011) and Tattersall and Young (2006) that found since the UNHS, children are identified
around two to three months of age. According to what the parents consider to be the final identification, the average age in the current study was two and a half years old. This research supports the findings of Fitzpatrick et al. (2007) and Larsen et al. (2011), who determined that children identified late and did not receive a newborn hearing screening had significant delays in communication, academics, and social development. This study also supports the findings of DesGeorges (2003) that parents do not immediately notice a child’s hearing loss and seek help. Rebecca’s parents are the prime example; she was approximately one year old when they discovered she was not hearing as well (Hannah & Antonio, personal communication, 2014). Fitzpatrick and colleagues (2007) stated that parents of children diagnosed later wanted to know the etiology of the deafness, whether it was present at birth or if something happened later to cause the deafness. The parents during this study did not mention wanting to know the etiology. Two of the families know the cause; the others do not. One of the children in the study was older and lost his hearing due to illness at the age of four. This research supports data by Eleweke and colleagues (2008) that the majority of children with hearing loss lose their hearing prelinguially or before they develop language.

**Diagnosis Delivery**

The current study found that the number of parents present during the diagnosis delivery may have contributed to the type of information given. Out of the six families, three of the mothers were alone when they learned their child was deaf or hard of hearing. Jack’s mother was called by the doctor at work and was told the final diagnosis over the phone (Natalie, personal communication, 2014). This study supports Gilbey (2009) that professionals deliver the diagnosis in a blunt way without empathy. Gilbey
suggested that doctors provided the families with prior notice to bring emotional support with them to the doctor’s appointment. Boison (1987) had previously found that providing families with emotional support during the diagnosis delivery helped the parents accept the hearing loss more quickly. Professionals could deliver the diagnosis in a more empathetic way to parents who are still processing their child’s diagnosis and provide more support and encouragement; unfortunately this does not happen often (Gilbey, 2009). Boison (1987) and Freeman et al. (2002) shared that giving parents psychological and emotional support during and after the diagnosis could help the parents accept their child’s hearing loss. Two of the three families in the current study that had both parents present accepted their child’s hearing loss quickly, and one of the three mothers who was alone also accepted the hearing loss quickly. In addition, this study found that the families which had both parents present during the diagnosis delivery were given more information regarding hearing loss and services than those who only had the mothers present. When two people were there, they were able to ask more questions in order to better understand the hearing loss and lend support to one another. Having emotional support allows for each person to listen and take in the information first hand from the doctor; it is also crucial for accepting the hearing loss (Boison, 1987).

The parents’ background may also have had an impact on the information delivered to them by the doctors. This statement is supported by Matthijs et al. (2012); parents and professionals have their own cultural background and perceptions that influence their decision making and work practices. Three of the six families in this study spoke Spanish as their primary mode of communication. Of these families, only one did not speak and has limited understanding of English. Hearing the information from
doctors who do not speak Spanish may have impacted how the information was received in this case. Gilbey (2009) expressed that doctors use medical terms that are confusing, and parents do not understand. None of the families had a Spanish interpreter present to translate the information for them at the doctor’s appointments. Alex’s mother, who is Mexican, understood that her son had “hearing infections,” not that he was deaf in both ears. Her understanding came from a situation she had with her older son, whom the doctor said had a “hearing infection” and that if he continued having them then it could become a hearing loss (Rachel, personal communication, 2014). This example supports Eleweke et al. (2008): the misunderstanding of information can cause families to be confused regarding the cause of the disability, not sure what can be done to help the child, and to look for a cure. Much of the information regarding the diagnosis may have been lost in translation in this example.

As discussed previously, doctors often provide diagnosis information in medical terms that are complicated for the average person to understand (Gilbey, 2009). The current study found that doctors were not good communicators, in accordance with the findings of Tattersall and Young (2006) since the doctors did not use parent friendly vocabulary. Trying to understand medical terms from a language that the parents do not speak was challenging. This finding supports Matthijs and colleagues (2012), who expressed that professionals used medical dialogue to deliver the diagnosis. Breaking down the information for parents using layman’s terms would be beneficial for parents, as Gilbey (2009) suggests.

In addition, Steinburg and colleagues (1997) found that the family’s cultural background plays a part in how the family will react to the hearing loss diagnosis. In this
study, the family with the genetic aspect of hearing loss was African American. Since 
hearing loss was so prevalent in the family and the mother had experience with her own 
hearing loss, she was able to accept the hearing loss much faster than the average African 
American family may. Before this mother accepted the hearing loss, she stated she did 
question what she did wrong for her children to have their own hearing loss (Gabriella, 
personal communication, 2014). This finding supports Feher-Prout’s (1996) study that 
parents of children with hearing loss often begin to question the reason for the 
unexpected hearing loss. Regardless of the parents’ background, they may grasp only 
desired information from the doctors and ignore unwanted information. Matthijs and 
colleagues (2012) suggest that parents only listen to the information they want to hear 
depending on their emotions and their progression through the grieving process.

**Diagnosis Information**

A packet of information regarding resources and support groups available to 
families with children with hearing loss was given to three out of the six families in this 
study. Eleweke et al. (2008) supports the packets of information and suggests they 
include unbiased information with literature and videos. By providing parents with 
unbiased information, professionals will introduce them to different perceptions (Matthijs 
et al., 2012). Such unbiased information allows the family to feel empowered (Eleweke et 
al., 2008). Information regarding deaf role models and mentors should be included in the 
packet of information given to parents (Fjord, 2001). However, Jack’s parents are the 
only parents in this study who received information about deaf mentors and had one 
come to their house. This development may have been because Jack was the only child 
who was profoundly deaf and was not a candidate for a cochlear implant. In addition,
Lily’s parents expressed that they conducted research themselves and learned more about hearing loss that way instead of the packet; this finding supports Jackson and colleagues (2008) as well as Fjord (2001), who found that parents were expected to learn the information on their own with little help during the process.

In addition to mentors, Eleweke and colleagues (2008) and DesGeorges (2003) determined that providing information about parent support groups is beneficial since parents learn from other parents who have previously gone through a similar experience. These parent support groups may help the parents to overcome new obstacles as they arise. Parent support groups may also benefit the child by allowing him or her to see other children who communicate in a similar way (Fitzpatrick et al., 2008). The current study supports the findings of Eleweke et al. (2008) since only two of the families received information regarding parent support groups. One family, after much thought and consideration, contacted other families. This family has accepted their child’s hearing loss and felt blessed to have him as their child; Jackson et al. (2008) expressed families who contact other families are able to picture a similar future for their child. Another family took advantage of support groups that they were a part of through the adoption world. This family was able to receive support through other families who have adopted children as new obstacles arise. This finding correlates to those of Eleweke et al. (2008), who stated sharing stories and experiences with other families assists with the diagnosis process.

Socioeconomic status may also have been a complicating factor in the perception and acceptance of the diagnosis process. Three of the six children whose parents participated in the study receive free and reduced lunch. Two of the families whose
children do not receive free and reduced lunch were initially told by doctors to try Myringotomy tubes before the hearing loss was confirmed. These families also happen to be the only white participants. One family was told that fluid buildup was a possible cause for hearing loss while the other was also told that it could be an accumulation of earwax and that once cleared out the hearing loss may solve itself. One family who does receive free and reduced lunch, was told a possible cause for hearing loss could be fluid, but was never told about Myringotomy tubes. Parents in DesGeorges’ (2003) study had similar experiences to these families where doctors told them to wait and see what happened with their child’s hearing loss. By referring the family for Myringotomy tubes instead of diagnosing the hearing loss, the doctors were able to push the responsibility of delivering the “bad news” to the next medical professional and prolonged the inevitable diagnosis (Gilbey, 2009). Having white parents present at the initial diagnosis may have influenced the doctor to recommend trying Myringotomy tubes instead of delivering the diagnosis of a hearing loss. These families were provided with a false hope during the early diagnosis steps.

**Additional Testing**

Within two days of an infant being screened, a follow-up referral is sent to the state Early Hearing Detection and Intervention (EHDI) program (Larsen et al., 2011). The current study found that doctors continued to ask for additional follow-up hearing tests or ABRs in order to put the diagnosis responsibility on the next professional, as also found by Gilbey (2009). Previous research has found that children who were diagnosed earlier had an easier time getting audiological testing done (Fitzpatrick et al., 2007). In addition, some audiologists do not have the appropriate pediatric equipment to perform
vital accurate hearing screenings and tests (Larsen et al., 2011). Even with earlier audiological testing, these parents in this research were still referred for several additional unnecessary tests. Parents were told their child required an additional test to confirm the hearing loss. Even the family who adopted their child and was aware of a possible hearing loss was still referred to several rounds of hearing tests (Lynn & Scott, personal communication, 2014). The family with a genetic aspect of hearing loss was referred for several additional tests even though hearing loss was prevalent in their family (Gabriella, personal communication, 2014). Unlike the study performed by Gilbey (2009), the parents in this study did not feel the ABR was the definite moment of diagnosis; an ABR was often the last hearing test given, but actually hearing the doctors present the results was the definite moment.

In addition to requesting further testing, doctors also referred parents in this study to specialists. By referring for additional testing or recommending specialists, the inevitable diagnosis of a hearing loss was delayed and early intervention services were postponed (Gilbey, 2009). Each parent in the study expressed how long and drawn out the diagnosis process was; similar to those in DesGeorges (2003) they were irritated with the time between recognition and final diagnosis. Gilbey (2009) supports the idea that referring for additional testing is putting the diagnosis responsibility on the next doctor and thus prolonging the expected diagnosis. This study supports Gilbey (2009) that delivering the diagnosis or “breaking the bad news” was difficult and done by a doctor. If the child was a possible candidate for a cochlear implant, then the process was even longer. Five out of the six families had children that were candidates for cochlear implants. Determining whether the child was a candidate and the additional insurance
requirements elongated the process for these families which in the end may have delayed the language development even more.

Similar to doctors referring for additional testing to avoid delivering the hearing loss diagnosis (Gilbey, 2009), parents may often continue seeking additional opinions until they receive the preferred diagnosis. Gilliver, Ching, and Sjahalam-King’s research supports the parents seeking second opinions: “when parents are experiencing grief emotions, they may be particularly prone to seek out positive advice and focus only on this” (2013, S15). As research has shown, some parents look forward to fitting their children with the correct amplification devices and starting a new adventure, while other parents may not be ready to accept the diagnosis, and thus, they delay the process (Sjoblad, Harrison, & Roush, 2001). One family in the current study was not satisfied with the idea of their son not being a cochlear implant candidate and began searching and meeting with doctors until they found one who agreed to perform the risky, unguaranteed surgery (Richard, personal communication, 2014). In addition to the doctors using complicated language (Tattersall & Young, 2006), parents were also provided with inaccurate information (DesGeorges, 2003). The following example supports the Eleweke and colleagues’ study (2008) that accurate information is important in order to prevent as many obstacles as possible. Hannah was told that her daughter did not have cochleas. After following her initial feeling and requesting additional testing, she learned that her daughter did in fact have bilateral cochleas. Her daughter received one cochlear implant but the doctors determined the second cochlea was unable to be implanted due to the placement of the nerves (Hannah, personal communication, 2014).
Accepting the Hearing Loss

The age of the parents may influence how they accept the hearing loss diagnosis and information (Kampfe, 1989). In the current study, Jack’s parents were teenagers during the diagnosis process which may have helped them accept the hearing loss more quickly. These young parents were the only family who stated they accepted the hearing loss diagnosis right away and felt as if they were “chosen by God” to be this child’s parents.

In addition, Jack’s family is Mexican. According to Steinburg and colleagues (1997), Hispanic families tend to have deep religious beliefs and provide more support and comfort to the family. Out of the two Mexican and one Puerto Rican family in the current study, this is the only family who expressed anything about religion. They stated they were the fortunate ones and that their child was also lucky. This mother compared her family’s situation to other families she had seen in the community growing up and realized that the hearing loss diagnosis was minuscule (Natalie, personal communication, 2014). Natalie’s statement coincides with Gilliver, Ching, and Sjahalam-King’s (2013) research that some parents had feelings of relief or acceptance when comparing hearing loss to other family obstacles. The Puerto Rican family also expressed they were thankful to God that they moved here and continued their search for more advanced medical care (Richard, personal communication, 2014).

The amount of support the extended family provides may also be a contributing factor to how accepting the immediate family is to the hearing loss (Jackson et al., 2008). In the current study, Jack’s extended family was also accepting of the hearing loss and immediately wanted to learn more about the loss in order to educate themselves and
provide the best for their family member. Jack’s entire family has learned sign language to communicate with him. Thus, the communication between these family members came easily. This example contradicts the findings of Jackson and colleagues (2008), but the rest of the families support the previous research findings in that the extended family has a difficult time learning how to sign. However, Jack’s family realized that if they wanted Jack to understand them and if they wanted to understand him, then a visual mode of communication must be used since he is profoundly deaf (Natalie, personal communication, 2014). Rose, Trevor, and David’s mother was also more accepting of the hearing loss due to the genetic aspect. She had experienced and been around hearing loss and sign language growing up, which was a benefit. The majority of the family members in this family were also able to sign and communicate with one another. Thus, communication was not a barrier for these children, parents, or extended family. Rose, Trevor, and David’s family was the only family in the study that had a parent and extended family with hearing loss (Gabriella, personal communication, 2014). According to Feher-Prout (1996), more than 90 per cent of children who are deaf or hard of hearing are born to hearing parents. Through the observations conducted in this study, fluid communication between parent, child, siblings, and extended family was not always evident. Those that had better communication were no longer in denial of the hearing loss.

**Amplification**

Marriage (2013) agrees with the importance of emotional support while providing children with the correct amplification technology, so the parents may be able to move through the grieving process and use the amplification devices correctly. The type of
amplification information provided to the parents impacted the communication mode the parents chose. Matthijs and colleagues (2012) shared that the information given to parents affected how the parents interacted with and raised their deaf child. The current study supports that finding because parents who were told information regarding cochlear implants often had a negative feeling toward using sign language with their child and were advised not to sign with their child (Hannah & Antonio; Lynn & Scott, personal communication, 2014). Two out of the six families were steered towards the cochlear implant route by the doctors. One of the Spanish speaking mothers was at the hospital alone, which may have impacted why the doctor pushed the surgery right away. Rachel focused on the information about the implant; other information regarding the hearing loss was lost due to the language barrier (personal communication, 2014). Two of the families had children with multiple disabilities. One of these children became deaf due to illness; this family went to several doctors until they found one who was willing to perform the surgery, Richard and Lisa focused on the positive information and ignored the previous doctors, similar to the families in Gilliver, Ching, and Sjahalam-King’s study (2013). The other family was told their child could have an implant, but the doctors were unsure how much she would benefit from it due to cognitive ability (Hannah & Antonio, personal communication, 2014).

In this research, the families with children who received cochlear implants were encouraged not to use American Sign Language. This finding supports the results of a study conducted by DesGeorges (2003) that parents may often hear biased opinions and information related to hearing loss and communication modes. Unbiased information is difficult to find due to the years of debates (DesGeorges, 2003). Jackson et al. (2008)
found that parents have to realize through trial and error the correct communication mode for their child. In this study, Rebecca’s parents and Lily’s parents eventually decided to go against the doctors’ suggestions and began using sign language to meet their individual child’s needs after trying the strictly oral method and talking with several professionals. DesGeorges (2003) suggests that parents and medical professionals consult a range of professionals who work with children who are deaf and hard of hearing to broaden the horizons and see the options and opportunities for the children. The parents’ decision to add sign language coincides with the new shift in the communication mode debate that using the mode that works best for the individual child to allow for the highest level of communication is the most important decision (DesGeorges, 2003). If the children had not been cochlear implant candidates, then sign language would have been an adequate mode of communication similar, to Jack’s scenario, but since they were candidates, sign language was not considered acceptable. Feher-Prout (1996) found that mothers were the primary decisions makers regarding communication mode. This study supports these findings. Out of the six families who participated, four of the mothers were observed to communicate and interact with the child the most. In the two exceptions, the fathers were equally capable at communicating and involved as the mothers.

**Parents’ Perceptions Regarding the Early Intervention Services**

Of the six families and eight children involved in this study, four families and four children received early intervention services. Two families and four children did not receive any early intervention services due to the age when diagnosed. Each child received therapy of some sort, whether it was through the state’s early intervention program, private therapy, or the school system. As previous research has found, parents
of children with hearing loss acquire new roles and responsibilities after the diagnosis process (Eleweke et al., 2007). The parents in this study became therapists, taxi drivers from appointment to appointment and therapy session to therapy session, counselors, researchers, and advocates, in addition to being mom or dad. Thus, they were performing as other parents who were found to be the child’s first and main therapist working with the child on their speech and language delays (Boison, 1987).

**Receiving Services**

Larsen and colleagues (2012) stated that after an infant is identified as deaf or hard of hearing, the next step is to enroll in early intervention services. This identification and enrollment ideally happens before six months of age (DesGeorges, 2003). Unfortunately in this study, only two children began receiving services at a young age, but the earliest was eight months old. Early intervention services may often be postponed due to the distance the family lives from testing facilities, the type of hearing loss and its severity, as well as whether the hearing loss was unilateral (one ear) or bilateral (both ears) (Larsen et al., 2012). The type and severity of the hearing loss was evident in Rose’s case since she was not diagnosed until she was three. The school system suggested a follow-up test due to the family history (Gabriella, personal communication, 2014).

According to Larsen and colleagues (2012), babies that were identified after three months of age were more likely to get lost in the system and not receive services than those that were identified prior to three months of age. The Joint Committee on Infant Hearing’s goal is for babies identified with a hearing loss to begin receiving early intervention services by six months of age (Sjoblad et al., 2001). This goal was difficult
for those babies, like three of the children in this study, that have a progressive hearing loss and initially passed the UNHS. For Hannah, signing up to get services was a struggle due to the location of the early intervention office. Even though Rebecca’s hearing loss was not discovered with the UNHS, it was identified in enough time to receive early intervention services. Rebecca’s mother humbly admitted that she was hesitant to sign up for early intervention services since the office was attached to the Division of Family and Children Services (DFCS). These honest feelings regarding DFCS may have slowed the start of the early intervention services by a few months (Hannah, personal communication, 2014). Infants who were covered by Medicaid were more likely to get lost in the system and not receive early intervention services than those we had private insurance (Larsen et al. 2012). Fortunately, in this study even those children who were on Medicaid and were diagnosed in enough time received early intervention services.

**Information Received**

The importance of the type of information received is highlighted by Eleweke and colleagues (2008), who found that parents who received unbiased information about support services and early intervention program options were able to make educated decisions about their child even if they had no previous experience with hearing loss. In this study, the type of information the parents indicated they received was biased, depended on the type of their child’s hearing loss, and their eligibility to be a cochlear implant candidate. For example, Jack, who is profoundly deaf and was not a candidate for a cochlear implant, was introduced to a deaf mentor who began teaching the family sign language and Deaf culture. They were the only family in this study who received services
from a deaf mentor and learned about Deaf culture (Natalie, personal communication, 2014).

In addition to receiving information from doctors and those providing early intervention services, families receive information from existing members of the deaf and hard of hearing community, professionals, and teachers in the field as previous research has shown (DesGeorges, 2003; McNee & Jackson, 2012). However, in the current study, Jack’s family was the only family who received information from an adult in the deaf and hard of hearing community (Natalie, personal communication, 2014). Lily’s family reached out to parents of children who had been identified with a hearing loss (Lynn, personal communication, 2014). Those children in this study that were diagnosed later and were unable to receive early intervention services interacted with and relied on the teachers of the deaf more than those who received early intervention services. Parents in this study, as well as DesGeorges (2003) and McNee and Jackson (2012), who received information from multiple resources, were able to see a variety of perceptions.

According to Eleweke and colleagues (2008) parents of children who are deaf or hard of hearing are still not receiving adequate information regarding proper supports during the early years and do not know how to effectively support their children at home. One major complaint from parents in previous studies is the lack of information provided to them (Eleweke et al., 2008). The parents in this study did not indicate this was an issue they felt strongly about, but they were grateful for the information and services they received. Eleweke et al. (2008) shared that parents who did not receive information regarding supportive services for the child’s needs became more stressed and saw their role as a job providing for the child with a hearing loss. One mother in this study
expressed that it can be stressful to choose which activities in their daily lives they turn into language building moments without overwhelming the deaf or hard of hearing child, the siblings, and the parents (Lynn, personal communication, 2014). This finding correlates with those of Jackson and colleagues (2008), who discovered parents become stressed deciding when to use language stimulating activities. As other research has shown, language development and the associated delays can often be areas that cause stress and anxiety for newly diagnosed families (Fitzpatrick et al., 2007).

Collaboration

As discussed in chapter two, collaboration between the parents and professionals is important so the professionals know what information the parents have heard and they can work together to provide the best services for the child (Eleweke et al., 2008). DesGeorges (2003) also found that collaboration is vital since parents and professionals each bring a difference piece of the puzzle to the table. Only one example from this study stands out in support of this previous research. Alex’s mother was assisted by a therapist in making second opinion doctor’s appointments at a different hospital. This assistance may have been due to her inability to speak English and her lack of understanding the diagnosis. This mother found the collaboration to be extremely helpful (Rachel, personal communication, 2014). The families in this study that actively participated in the early intervention services had stronger relationships with the therapists, which support the findings by Eleweke et al. (2008). Similar to collaboration between early intervention therapists and parents, the parents should continue to be involved in the child’s educational decisions as the child enters the school system, other research has suggested (Jackson et al., 2008).
According to Fitzpatrick and colleagues (2008), a child’s ability to communicate by the age of five is affected by the involvement of the parents. This study supports these findings; majority of the parents are actively involved in the child’s education services. One of the parents attends the meetings, but does not question or provide much input to the teachers. This nonparticipation may be due to her Mexican culture. In previous research, Steinburg et al. (1997) found that Hispanic parents may have limited involvement due to their intimidating factors. However, when provided with family-centered early intervention services, the parents may feel like equal members of the team (Marriage, 2013). Some of the parents in this study felt like members of a team, while others just agreed with the information provided to them.

**Quality of Services**

Three out of the six families in the current study received more than one intervention service. Previously, McNee and Jackson (2012) illustrated in their research that it is not the number or type of services the child receives, but the number and quality of supports the parents receive. For example, Ryan was too old when he recovered from spinal meningitis and was not able to receive early intervention services, but he was provided with occupational therapy, physical therapy, and speech therapy in the school setting. Ryan also received private occupational therapy, private physical therapy, private speech therapy, and he attends an alternative gym (Lisa, personal communication, 2014). In addition, Rebecca received physical therapy, occupational therapy, and speech therapy through the early intervention services for her hearing loss and Down syndrome. When she entered into the school setting, she continued these services. Rebecca also received private speech therapy as a young child (Hannah, personal communication, 2014). The
last child who received more than one service was Alex. As a young child, early intervention services for a visual impairment were also provided. Alex’s visual impairment has since been corrected with eye glasses (Rachel, personal communication, 2014). Many parents, including the majority of the ones in this study, may seek out additional speech therapy, learn sign language to communicate, and troubleshoot hearing aids (Eleweke et al., 2008).

The families in this study were pleased with the services they were provided, especially those services provided in the home. In-home services eliminate travel, especially since traveling with a young child may be a difficult task and allows for the families to continue strategies in the home environment (Eleweke et al., 2008). Early intervention programs are usually provided in the home since they are becoming more family-centered to address the family’s needs in addition to the child’s (Marriage, 2013; Fitzpatrick et al., 2008). Even though the parents in the current study were pleased with the early intervention services provided at the home, one mother stated she felt her space was invaded and she had to be prepare each time they came (Hannah, personal communication, 2014). For a new mother who is trying to bond with her infant, having a therapist come into the home and try to explain strategies can be overwhelming (Young & Tattersall, 2007). Creating and enjoying the new bond between parent and baby without worrying about hearing loss explains why some parents in Gilliver, Ching, and Sjahalam-King’s study expressed a desire for later diagnosis (2013). DesGeorges (2003) found one way to ameliorate this feeling is with effective elements of collaboration including mutual respect, clear communication, understanding and empathy, shared decision making, sharing of information, and no blaming.
Language Development

In previous research, Steinburg and colleagues (1997) discovered that deaf children from Hispanic homes tend to have more severe problems in communication and academics than those from non-Hispanic families. The inconsistent linguistic signals may interfere with the communication skills (Steinburg et al., 1997). Three of the families that participated in this study have Mexican or Puerto Rican parents. One of the children is profoundly deaf and has no access to sound. These parents have learned sign language to communicate with him; therefore, his linguistic abilities are not impacted by the fact he is from a Spanish speaking family like those in Steinburg and colleagues’ (1997) research.

The experiences of other two children do support the findings of Steinburg and colleagues. Both these children have access to some sound. They hear Spanish at home, as well as English and sign language in the school setting. During the observation it was clear that trying to decipher the Spanish, English, and sign language was a challenge for these students and does impact their language and academic abilities.

The families in this study expressed that the early intervention therapist that came to the house worked on different strategies with the children and taught them vocabulary, which supports findings by Eleweke and colleagues (2008), who suggest that parents be provided with strategies for language development at home. The children in this study have delayed language development compared to hearing children their age. This finding supports research by Boison (1987) and Freeman et al. (2002), who found that a child’s hearing impairment has a large impact on the language development, mode of communication, and communication with the family. When detection and intervention services are provided early, the child’s language development is higher than those
identified later (DesGeorges, 2003); the current research found the same to be true. For example, Jack’s mother did not fully grasp the early intervention services provided and could not explain the therapists’ roles. She expressed they were helpful to both Jack and the parents, but thought there were four different therapists when they could have been therapists taking over for one another. She was a very young mother and stated she did not fully understand each person’s role (Natalie & Charles, personal communication, 2014). The communication barrier may have played a role in interactions between therapists and the Spanish speaking mothers. The therapist did not speak Spanish and could not fully communicate with Alex’s mother. Providing strategies for the mother to work on with Alex was a challenge since Rachel did not understand English. She would have to watch what the therapists were doing in order to learn.

**Perceptions**

This research supports the study done by Jackson et al. (2008) which stated that parents expressed positive experiences with the supportive services after some initial obstacles. The parents in this study have positive and encouraging comments to say regarding the early intervention, private, and school based services they were provided. Importantly, the parents’ perceptions and practices have an impact on how beneficial the early intervention services will be for the child (Freeman et al., 2002). Jackson and colleagues’ (2008) study found that the therapy sessions were weekly in order to provide the families with additional support throughout the therapy; the families in the current study support the weekly therapy sessions. For those children that received several services, this support meant multiple days each week of therapists coming into the home.
Previous research has found that children with hearing loss identified early are better able to communicate with peers and family (Freeman et al., 2002). A child’s success also depends on the parents’ reactions, acceptance, and their advocacy for their child (DesGeorges, 2003). Without proper early intervention services, communication may continue to be gestures and home signs (Steinburg et al., 1997). These previous findings rang true for the children and families who participated in the current study. Many of the children in the current study did not receive proper early intervention services due to the family’s unacceptance of the hearing loss or the advice received from the doctors. Early intervention services may often be aligned with the parents’ expectations and preferences (Fitzpatrick et al., 2008). These families in the current study were observed to have limited communication with their child through gestures, home signs, and basic sign language.

The choice of the primary mode of communication by parents of children who are deaf and hard of hearing is also tied to early intervention, as previous research shows. Decker, Vallotton, and Johnson (2012) stated there are numerous communication modes to choose from: spoken or visual, unusual form of spoken or visual, or a combination of both spoken and visual. For the parents in the current study who took longer to accept their child’s hearing loss and see that sign language was their child’s primary mode of communication, sign language is emerging and now acting as a catalyst for various modes of communication in the house. In summary, Eleweke et al. (2008) found early intervention services promote language development, and the current research supports that finding.
Cochlear Implants

The children in the current study who were cochlear implant candidates had to go to even more doctors’ and therapist appointments. Prior to receiving the implants, Hannah expressed she had to go to a year of therapy sessions to show the doctors and the insurance companies that they were committed to the follow through requirements (personal communication, 2014). After a child receives the cochlear implant, he or she must go to additional doctors’ appointments to get the device activated and programmed also known as mapped (American Speech-Language-Hearing Association, 2015c). As the child gets older and can troubleshoot the implants himself, the audiologist appointments will become annual (American Speech-Language-Hearing Association, 2015c). Children with cochlear implants often attend auditory verbal therapy sessions to fully benefit from the new hearing apparatus (The ASHA Leader Blog, 2012, March 29). Gabriella, the mother of the family with genetic hearing loss, was interested in getting a cochlear implant for her oldest son with a progressive hearing loss. She is leaving the final decision up to him since he is old enough to advocate for himself, but if he is interested in getting a cochlear implant, then she will be open to the idea. This attitude is interesting since Deaf parents often reject cochlear implants and view them as trying to “fix” their child (Steinburg, et al., 1997). Because Gabriella and her family members with hearing issues are not fully involved in Deaf culture and identify with the hearing world, this outcome is not as shocking.

Limitations of Findings

This study only focused on six families who lived in the same southeastern suburb. The students had at one point attended the same school within a public school
system. The parents were from different backgrounds. The students had varying degree of hearing loss. The students used American Sign Language to communicate but ranged from experienced signer, learning to sign, to sign support.

Another limitation to the study was that the researcher was a teacher at the school the students attended. The researcher knew the families who participated in the study. This role may have impacted the information the parents provided. For some families having built a rapport with the researcher allowed them to feel comfortable to provide constructive criticism regarding the hearing loss diagnosis process whereas other families did not. Parents provided honest factual information, but some provided more than others. It is unknown whether another researcher who is not seen as an authority figure would have elicited more candid responses.

For the Spanish speaking family, using an interpreter was a challenge. The researcher was not sure if the questions were truly understood by the mother and if the information the mother said was relayed to the researcher. The mother would communicate with the interpreter, and then the interpreter would express what the mother said. The interpreter used for the study was a trained Spanish interpreter for the public school system. The information this mother provided was limited compared to the other parents.

One limitation regarding the observations was that the activities may have been staged. The researcher went into the family’s natural setting, but the families may have felt they needed to do activities they do not normally do since the researcher was there. The researcher informed the parents that she was watching their normal everyday interactions with one another. The majority of the families did normal everyday activities
even if it involved the parents rarely interacting with the child. Other families participated in activities that felt more staged.

**Implications for Future Parents**

The findings from this study have implications for future new parents whose child did not pass the UNHS or whom they suspect has a hearing loss. These findings will illustrate for parents how previously affected parents reacted to and accepted the diagnosis of a hearing loss. Four inferences from the parents in this study that will help future parents going through similar situations are discussed in the following paragraphs.

The first inference from the study is for parents to bring someone with them to the doctors’ appointments. Half of the mothers were by themselves when they were presented with the final hearing loss diagnosis. The families that had both parents present were able to ask more clarifying questions since they had more than one person listening and digesting the information. Also, family members were able to provide each other with emotional support when the information was delivered from the doctors. Having at least two people listen to the diagnosis helps since each parent may have a different perspective of the experience.

The second suggestion from the study is for the parents to take advantage of the information provided for them, including the parent support groups. Those parents that were able to contact parents who had previously had a child diagnosed as deaf or hard of hearing saw real life examples of their future. By sharing their experiences with one another, parents are able to accept the diagnosis sooner and meet new friends that understand their struggles.
The third recommendation from the study is for parents to participate in the early intervention services provided to their child. The parents that experienced the family-centered early intervention services learned what strategies the therapists were using with their child and were able to continue using the same or similar techniques when the therapists were not there. The parents who participated learned more about hearing loss and different resources available for children who are deaf or hard of hearing.

The final conclusion from the study is in regards to communication modes. The parents who had waited until their children were unsuccessful with only spoken language and cochlear implants wished they had started communicating using sign language in addition to spoken language. The parents regretted not beginning implementing manual and spoken communication earlier. The suggestion is for new parents to go with their instincts instead of following direct orders from the doctors. Each child is different, and communication is vital. It is easier to drop sign language or use it as a manual communication support than to wait for a child to be unsuccessful with spoken language and then to try to learn and overcome the already established language delay.

**Implications for Preservice Teachers**

As a new teacher of children who are deaf and hard of hearing, I was unaware of the exact process the parents and children encounter as they discover the hearing loss. It was not until I was working with other teachers of children who are deaf and hard of hearing and parents that I learned the steps of the diagnosis process. It is important for preservice teachers to learn the diagnosis process and shadow a doctor during the experience to assist in interacting with families. Knowing the families’ experiences can
help the teacher empathize with the individual families by understanding the cumbersome process.

Another piece of information that would be beneficial for preservice or first year teachers of children who are deaf and hard of hearing is the process through which the parents and doctors fit the child for hearing aids. Understanding how the hearing aids are fit for the child’s specific hearing loss and the cost of the hearing aids is helpful to know as a teacher since the teacher is often the person teaching the child how to correctly wear the hearing aids. Recognizing the steps the parents have taken with the insurance company to get the correct amplification device is eye opening. As a teacher of children who are deaf and hard of hearing, I learned that some insurance companies will pay for cochlear implants, but will not pay for hearing aids. Both amplification devices are vital for a child’s language development. The process to determine if a child is a cochlear implant candidate requires additional doctor’s appointments. The insurance companies and doctors want to ensure the parents are going to fulfill the post-operative requirements and necessary therapies.

The parents in this study indicated that they received information regarding parent support groups, but only one family reached out to other families of children who are deaf and hard of hearing. As a teacher of children who are deaf and hard of hearing, it would be beneficial to be aware of the parent support groups available for parents. Research shows that interacting with other families who have similar experiences allows families to overcome new obstacles (Eleweke et al., 2008). Parent support groups also allow the child to see other children with hearing impairments (Fitzpatrick et al., 2008). Knowing which groups are available in the surrounding community and providing that
information to the parents would help encourage them to reach out to others. In addition to knowledge about available parent support groups, discovering the different locations that offer sign language classes will assist the parents. Parents are often unaware of the churches, colleges, community centers, or schools that offer sign language courses and do not know where to look in order to find the available resources. When parents are aware of the opportunities in their surrounding communities, then there is a greater chance in parents taking advantage of them.

As a teacher of children who are deaf and hard of hearing, the researcher found that it is important to be aware of the different information and forms the doctors are providing. Since doctors are often using medical terminology in their explanations (Gilbey, 2009), helping the parents understand and complete medical forms or where to go for assistance is important. The information the doctors give the parents set the expectations. As a deaf and hard of hearing teacher, I have learned that parents tend to trust the doctors more so than the teachers. Building onto what the doctors have said helps build the relationships with the parents. In addition to the medical information provided to the parents, information regarding Deaf culture and informing teachers to be sensitive to the beliefs and traditions of Deaf culture is beneficial. Becoming involved in Deaf culture may help provide an identity for children who are deaf and hard of hearing and provide support for their families. A teacher who points families in the direction of Deaf culture events will be reassuring.

The transition from early intervention services provided in the home to receiving services in the school setting can be intimidating for parents. Providing comfort and reassurance to the families will help make the transition smoother. Families participate in
an Individual Family Service Plan (IFSP) determining the strengths, weaknesses, and goals for the child until the age of three when a transition meeting to an Individualized Education Program (IEP) occurs. Collaboration between the early intervention providers and the preschool teachers is vital for the continued success of the child. The early intervention providers can supply the preschool teachers with much needed background information regarding the child and the family. Preschool teachers want to know what questions to ask and understand and explain the process from an IFSP to an IEP.

Annually, a child who is deaf and hard of hearing is given an audiological test, and an audiogram illustrates the hearing results. These results are explained to the parents by the audiologist. As a teacher of students who are deaf and hard of hearing, the research found that it is important to be able to read an audiogram and understand how to take the information and use it in the classroom. The audiogram shows the teacher what sounds and at what frequency the child will be able to hear. The last thing benefitting a preservice teacher is the differences in types of hearing loss and levels of hearing loss. Children are different and accommodating to meet the individual child’s needs is crucial in his or her language and academic development.

**Implications for Health Education**

Interviewing the parents allowed for in-depth conversations to occur regarding the diagnosis process they experienced. Several reoccurring themes arose regarding the healthcare professionals. The themes were poor bedside manner, medical terms too high, and not understanding the information.

The parents indicated that the healthcare professionals delivered the medical diagnosis and handed them a packet of information but then they were left on their own.
It is important to remember that these parents have just been presented with life changing information regarding their child. Perfecting the bedside manner is vital for the success of healthcare professionals. Allowing the parents time to grieve, provide emotional support, assist with grasping the diagnosis, and allow the parents time to ask questions or come back with more questions.

The next two themes go together, medical terms too high and not understanding the information. Similar to teachers, medical professionals start presenting information to parents at a level that is too high. These parents have just received a diagnosis that they are grieving over and the information is being presented in a way in which they do not fully understand. Parents often leave the doctors appointment confused and not grasping the information given to them. When the parents do not understand they are not able to assist their child correctly. Healthcare professionals should present the information to parents using more common known words paired with examples and pictures. When information is presented in multiple ways it is more likely to be understood. To make sure the parents understand the information presented to them allow them to ask as many questions as needed as well as asking the parents clarifying questions. Since the parents feel overwhelmed during this initial period, having them go home and digest the information and come back in the near future to ask more questions is helpful. Approaching the diagnosis as a team method allows the parents to feel more involved and needed during the initial stages.
## Table 4

### Implications

<table>
<thead>
<tr>
<th>What?</th>
<th>How it looks?</th>
<th>How to do?</th>
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</thead>
<tbody>
<tr>
<td><strong>Parents</strong></td>
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<tr>
<td><em>Emotional Support</em></td>
<td>During the initial doctors visits having another person present allows the parent to receive emotional support. The second person present also brings another perspective allowing for more questions to be asked.</td>
<td>Spouse</td>
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<td></td>
<td>Grandparent</td>
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<td></td>
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<td>Family member</td>
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<td>Friend</td>
</tr>
<tr>
<td><strong>Participate</strong></td>
<td>Parents should take advantage of all the provided resources for them ranging from parent support groups to early intervention services. The more involved the parents are the easier the hearing loss is for them to accept.</td>
<td>Parent support groups</td>
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<td>Play groups</td>
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<tr>
<td></td>
<td></td>
<td>Therapy sessions</td>
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<tr>
<td><strong>Research</strong></td>
<td>There are many resources out there for parents regarding communication modes. Researching the different types and receiving nonbiased information is key for the child’s language success.</td>
<td>Oral communication</td>
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<td></td>
<td></td>
<td>Manual communication</td>
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<td></td>
<td></td>
<td>Total communication</td>
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<tr>
<td><strong>Preservice Teachers</strong></td>
<td>Taking the time to get to the know the families and discover their path to diagnosis will allow the teacher insight on the families background and feelings. Connecting with the family personally helps build a trustworthy relationship.</td>
<td>Ask questions</td>
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<tr>
<td><em>Learn the Families</em></td>
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<td>Read files</td>
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<tr>
<td></td>
<td></td>
<td>Home visits</td>
</tr>
<tr>
<td><strong>Learn the Medical Aspect</strong></td>
<td>As a new teacher, trying to apply all the newly acquired information into your first classroom can be</td>
<td>Shadow a doctor</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Experience a hearing test</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Participate in the child’s doctors appointment</td>
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</tbody>
</table>
stressful. Students who are deaf and hard of hearing have several doctors appointments. Observing similar doctors visits will help the teacher see the experiences the children and families have as well as learn the medical terms. The teachers can then prepare the students for the appointments.

### Healthcare Professionals

#### Bedside Manner
Parents want healthcare professionals who will provide emotional support as well as the medical information.

- Offer support
- Allow time to grasp the diagnosis
- Allow time for plenty of questions

#### Layman’s Terms
Medical terms are often difficult to understand so providing parents with easier vocabulary and examples assists with understanding.

- Simplify terms
- Provide examples
- Provide visuals

#### Clarification
Medical information and the initial diagnosis is overwhelming. Ask the parents for clarification, provide plenty of opportunities to ask questions, and allow the parents time to think and call back with more questions.

- Simplify terms
- Ask questions

### Implications for Future Research

After completing this study, several recommendations arise for future research studies. Future qualitative research studies should use a broader sample of parents. The parents in this study lived in the same suburb in the same southeastern state. Opening up
the sample to parents from different parts of the same state or different states would provide the researchers with a broader view. The researcher would be able to generalize the information better. Future research should also focus on families of children who are deaf and hard of hearing who have additional disabilities. Focusing on these families will help future families as well as professionals learn from these parents’ experiences. Researchers should also focus on Spanish speaking families. A researcher who is fluent in Spanish would be able to learn directly from the parents their experiences instead of relying on an interpreter and the difficulties of the communication barrier.

Future researchers should interview parents immediately following the diagnosis time period. The parents in this study were able to relive the experience, but an interview closer to the actual diagnosis could get the raw feelings and details. Taking the medical professionals (ENTs, audiologists, pediatricians, etc.) perceptions into the diagnosis process could be an insightful topic for future research as well. Researching the transition phase from early intervention services to the school setting and the experiences the parents had with this change in services could be another future research topic. Several of the children in this study did not receive early intervention services due to the age of diagnosis; focusing a study on participates who were diagnosed at a later age could be beneficial as well.

Open-ended questions were used in this study. This type of interview question is recommended for future qualitative research studies on similar topics. The parents were able to share their experiences without being limited to answering a certain question. This study used more of the dialogue interview method than actual question and answer. The interviews took place in the parents’ natural setting. This setting is also recommended for
future research since parents may feel more comfortable in their own environment and be more willing to share their stories. Since the participants knew this researcher, they were more open to sharing their experiences and perceptions than if the researcher were a stranger.

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**APPENDIX A**

PARENTAL CONSENT FORM WITH CHILD ASSENT STATEMENT
Title of Research Study: Parents' Perceptions of the Diagnosis Process and Early Intervention Services

Researcher's Contact Information: Jenna Hudson, 678-549-5029, jmaster4@students.kennesaw.edu

Your child is being invited to take part in a research study conducted by Jenna Hudson of Kennesaw State University. Before you decide to allow your child to participate in this study, you should read this form and ask questions if you do not understand.

Description of Project

The purpose of the study is to explore what the parents’ perceptions are regarding their experience during the diagnosis process as they learned their child was deaf or hard of hearing and with the early intervention services. The study will also look at the parent and child interactions to learn more about the modes of communication used.

Explanation of Procedures

The researcher will get consent from the parents of children who are deaf and hard of hearing that will be participating. The researcher will ask the parents to indicate where they would like the interviews and observations to take place. The researcher will provide specific information regarding the study to the parents who indicated they will participate. Data will be collected using interviews and parent/child observations. The study will take place over a five-month period to allow time for the interviews to occur. The interview sessions will be videotaped in order to transcribe the information easier, as well as make note of the body language and gestures of the parents.
Time Required
The parents are asked to participate in an interview and parent/child observation. The total time for both will be around two hours. The children will be asked to participate in the parent/child observation for about thirty minutes.

Risks or Discomforts
There are no known risks or discomforts during this study.

Benefits
The benefits to the parents will be that they will get more clarity of the events that occurred during the process of diagnosis of their child's hearing loss and how communication is used during their parent/child observations. This study will help assist professionals working with children who are deaf and hard of hearing as well as their parents.

Compensation
No compensation will be given to the participants.

Confidentiality
The results of this participation will be anonymous. When the researcher is writing up the findings of the study, she will use pseudonyms for the parents. The documents and data will be kept in a locked filing cabinet when not in use by the researcher. After one year the videotapes will be erased and after three years the documents will be destroyed.

Inclusion Criteria for Participation
The parents will be over the age of 18. The participants will be voluntary. The children will be observed during the parent/child interactions but the focus will be on the parents.

**Parental Consent to Participate**

I give my consent for my child, ____________________________________________, to participate in the research project described above. I understand that this participation is voluntary and that I may withdraw my consent at any time without penalty. I also understand that my child may withdraw his/her assent at any time without penalty.

__________________________________________
Signature of Parent or Authorized Representative, Date

__________________________________________
Signature of Investigator, Date

PLEASE SIGN BOTH COPIES OF THIS FORM, KEEP ONE AND RETURN THE OTHER TO THE INVESTIGATOR

**Child Assent to Participate**

My name is Jenna Hudson. I am inviting you to be in a research study about hearing loss and how you talk with your parents. I will watch you and your parents talk
and play together. Your parent has given permission for you to be in this study, but you get to make the final choice. It is up to you whether you participate.

If you decide to be in the study, I will ask you to play and talk with your parents like you normally do. I will just be sitting here watching and videotaping. It will help me see how you and your parents are able to talk with one another.

You do not have to answer any question you do not want to answer or do anything that you do not want to do. Everything you say and do will be private, and your parents will be talking and playing with you during the study. When I tell other people what I learned in the study, I will not tell them your name or the name of anyone else who took part in the research study.

If anything in the study worries you or makes you uncomfortable, let me know and you can stop. No one will be upset with you if you change your mind and decide not to participate. You are free to ask questions at any time and you can talk to your parent any time you want. If you want to be in the study, sign or print your name on the line below:

_____________________________________________
Child’s Name and Signature, Date

Check which of the following applies

☐ Child is capable of reading and understanding the assent form and has signed above as documentation of assent to take part in this study.
☐ Child is not capable of reading the assent form, but the information was verbally explained to him/her. The child signed above as documentation of assent to take part in this study.

_____________________________________________
Signature of Person Obtaining Assent, Date
APPENDIX B
SIGNED CONSENT FORM

Title of Research Study: Parents' Perceptions of the Diagnosis Process and Early Intervention Services

Researcher's Contact Information: Jenna Hudson, 678-549-5029, jmaster4@students.kennesaw.edu

Introduction
You are being invited to take part in a research study conducted by Jenna Hudson of Kennesaw State University. Before you decide to participate in this study, you should read this form and ask questions about anything that you do not understand.

Description of Project
The purpose of this study will be to explore what the parents’ perceptions are regarding their experience during the diagnosis process as they learned their child was deaf or hard of hearing and with the early intervention services.

Explanation of Procedures
The researcher will get consent from the parents of children who are deaf and hard of hearing that will be participating. The researcher will ask the parents to indicate where
they would like the interviews to take place. The researcher will provide specific information regarding the study to the parents who indicated they will participate. Data will be collected using interviews and parent/child observations. The study will take place over a five-month period to allow time for the interviews to occur. The interview sessions will be videotaped in order to transcribe the information easier as well as make note of the body language and gestures of the parents.

**Time Required**

The parents are asked to participate in an interview and parent/child observation. The total time for both will be around two hours.

**Risks or Discomforts**

There are no known risks or discomforts during this study.

**Benefits**

The benefits to the parents will be that they will get more clarity of the events that occurred during the process of diagnosis of their child's hearing loss. This study will help assist professionals working with children who are deaf and hard of hearing as well as their parents.

**Compensation**

No compensation will be given to the participants.

**Confidentiality**

The results of this participation will be anonymous. When the researcher is writing up the findings of the study, she will use pseudonyms for the parents. The documents and data
will be kept in a locked drawer when not in use by the researcher. After one year the videotapes will be erased and after three years the documents will be destroyed.

**Inclusion Criteria for Participation**

The participants will be over the age of 18. The participants will be voluntary.

**Signed Consent**

I agree and give my consent to participate in this research project. I understand that participation is voluntary and that I may withdraw my consent at any time without penalty.

__________________________________________________
Signature of Participant or Authorized Representative, Date

__________________________________________________
Signature of Investigator, Date

PLEASE SIGN BOTH COPIES OF THIS FORM, KEEP ONE AND RETURN THE OTHER TO THE INVESTIGATOR

Research at Kennesaw State University that involves human participants is carried out under the oversight of an Institutional Review Board. Questions or problems regarding these activities should be addressed to the Institutional Review Board, Kennesaw State University, 1000 Chastain Road, #0112, Kennesaw, GA 30144-5591, (678) 797-2268.
APPENDIX C

Dissertation Interview Questions

1. Tell me about the diagnosis process you went through with your child.
   a. Questions to ask if parents do not provide enough information
      i. Who told you about the hearing loss?
      ii. How many people were present?
      iii. What information was provided for you?
          1. Regarding hearing loss
          2. Regarding parental support
          3. Communication modes
      iv. What prognosis information was given to you?
      v. What were your perceptions/feelings of the diagnosis process?

2. Tell me about the early intervention services your child received.
   a. Questions to probe for if parents do not provide information
      i. When did your child start receiving services?
      ii. What were the services?
      iii. Who provided the services?
      iv. Did you hear about services but were unable to receive? If so, why not?
v. How long were these services provided?

vi. What were your perceptions/feelings of the early intervention services?

3. How did you feel during the diagnosis process and early intervention services?
   a. Can you explain this further?
   b. What about the process made you feel that way?
   c. Why would you interpret your feelings that way?
   d. How do you feel about communicating with your child?

4. When can we get together for the observation during leisure time?
APPENDIX D

Parent and Child Observation

1. What activities are the parent and child engaging in?
   ◦ Is the parent engaging with the child?
   ◦ Is the parent on the child’s physical level?
   ◦ How does the parent stimulate the child’s interest?
   ◦ Does the parent show the child new, imaginative ways to play?

2. How does the parent communicate during teachable moments with the child?
   ◦ How does the parent explain things to the child?
   ◦ How does the parent provide suggestions?
   ◦ How does the parent build the child’s language?
   ◦ How does the parent communicate during play?
   ◦ How does the parent teach the child new vocabulary?

3. How does the parent communicate with the child?
   ◦ What is the parent’s mode of communication?
   ◦ What is the child’s mode of communication?
   ◦ What is the parent’s tone of voice?
   ◦ Are smiles and praise given to the child?
   ◦ What is the parent’s physical presence?
   ◦ Is communication positive or negative?
4. How does the parent provide encouragement/praise to the child?
   ◦ How are suggestions given?
   ◦ How is approval shown to the child?
   ◦ How are directions or requests relayed to the child?
   ◦ How does the child ask for assistance or express wants?
   ◦ How does the parent encourage independence?

5. How attentive is the parent to the child?
   ◦ Does the parent notice when the child is bored with an activity and provide new suggestions?
   ◦ Parent allows child to lead the activity?
   ◦ How does the parent respond to the child’s emotions?
   ◦ Does the parent make eye contact with the child?
   ◦ How does the parent comfort the child?

6. How attentive is the parent to the child?
   ◦ Does the parent notice when the child is bored with an activity and provide new suggestions?
   ◦ Parent allows child to lead the activity?
   ◦ How does the parent respond to the child’s emotions?
   ◦ Does the parent make eye contact with the child?
   ◦ How does the parent comfort the child?