University of Alberta

Infant hearing programs: Parents' experiences with newborn hearing screening and the Canadian context

by

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ABSTRACT

Infant Hearing Programs: Parents' Newborn Hearing Screening Experience and The Canadian Context

The purpose of this qualitative study was to describe the current Canadian Infant Hearing Program (IHP) context and to describe the experiences of parents who had been involved with a Canadian universal newborn hearing screening program. For the first part of the study, representatives from four Canadian provinces and one territory were contacted and interviewed. On-line, published, and unpublished documentations were also used as a source of information. For the second part of the study, four mothers and one father, who had experiences in a UNHS program, were interviewed using an open-ended, semi-structured approach. Parents described their experiences with universal newborn hearing screening, diagnostics, and access to intervention services.

The findings from this research suggest that parents have valuable insights for professionals and program developers involved with IHPs. It concludes with recommendations for developing, future Canadian IHPs, and with implications for professionals.

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CHAPTER I - INTRODUCTION

Statement of the Problem and Purpose of the Study

It is estimated that one to six babies per one thousand are born with hearing loss in Canada and the United States (Watkin, Baldwin, & McEwen, 1991). This range can be further broken down by category of hearing loss. It is estimated that the prevalence of bilateral, severe to profound sensorineural hearing loss is one per one thousand, two per one thousand including infants with unilateral hearing loss, and five to six per one thousand if all infants with sensorineural hearing loss of at least a mild degree are included (Hyde & Riko, 2000). The average age that hearing loss is identified is between eighteen months and two and a half years for children with severe to profound hearing loss and five to six years for children with mild to moderate loss (Calderon & Naidu, 2000; Yoshinaga-Itano & Apuzzo, 1998).

Hearing loss in the early years of an infant's life can have a "significant impact on a child's development" (Carney & Moeller, 1998, p. 63). A child with an undiagnosed and undetected hearing loss in the first three years of life is at risk of being delayed in his/her language and communication skills. This delay can negatively affect social, academic and emotional skills (Carney & Moeller, 1998; Vaccari & Marschark, 1997). Approximately 90% of children with severe to profound sensorineural hearing loss have parents with normal hearing (Northern & Downs, 1991).The majority of these parents have little experience with signing, if any (Vaccari & Marschark, 1997). These hearing parents, without any knowledge of hearing loss, who have a baby born with an undetected hearing loss, spend much of their child's early development without a common mode of communication. These infants are unable to take the sounds from their environment and transform them into meaningful words. Undetected severe to profound hearing loss prevents infants from having the opportunity to learn language implicitly and effortlessly. It doesn't allow a child to pick up on the incidental learning which occurs from overhearing adult voices or being exposed to sign language. These infants, who are underexposed to language, haven't had the same opportunity as an infant exposed to spoken or signed language to develop their world knowledge. Delays in vocabulary and language development can result in difficulty acquiring literacy skills (Carney & Moeller, 1998). Delays in communication "can also affect a child's self esteem and socialization" (Carney & Moeller, 1998, p. 64). It also has an impact on family dynamics, siblings and husband-wife relations (Luterman, 1991). Discipline becomes difficult because children don't hear the warning before the punishment. Expressions of love, and other related "vehicles for socialization" (Scheetz, 2001, p. 67) are unheard, causing the children to miss a crucial component of the bonding process between mother and child.

When considering the number of children with hearing loss, the late age of identification and the negative consequence of late identification and intervention, it becomes evident that these children are facing serious risks in terms of their ability to develop on par with children who have normal hearing. More needs to be done at an earlier age for children born with a hearing loss. The United States has taken a leadership role in the implementation of Early Hearing Detection and Intervention (EHDI) programs. These programs are comprised of universal newborn hearing screening (UNHS), timely diagnostics and connections to intervention programs or developmental services (Finitzo & Crumley, 2000). Research, mainly from the United States, has addressed all three of these areas and EHDI programs are prevalent, although still in their infancy. There is a great deal of research that has focused its attention on the practicality, effectiveness, and possibility of the implementation of a program that screens all infants at birth. These UNHS programs are being implemented in almost every hospital in the United States. Accompanying many of these are the EHDI programs that include diagnostics and facilitation to intervention services. Little research has focused on Canadian programs, their implementation, their impact on professionals and, more importantly, their impact on parents and families. Comprehensive programs in Canada have been referred to, mainly in the literature, as Infant Hearing Programs (IHPs) which are the Canadian equivalent of American EHDI programs. Both comprise all three components: 1) UNHS, 2) diagnostics and 3) facilitation to intervention services.

The purpose of this investigation was two fold. First, I wanted to find out about the current Canadian IHP context. Second, I wanted to discover and understand the experiences of parents who had been involved with a Canadian UNHS program. I specifically focused on the screening component, their experiences in receiving the diagnosis of hearing loss, and seeking follow up services and intervention.

Personal Perspective

My personal experiences and learning have lead me to want to explore the topic of these parents' experiences in universal newborn hearing screening, receiving diagnostics, and in seeking out intervention services. I have always been interested in the helping professions and I have become extremely interested in working with infants with hearing loss. As I got involved in the field of deafness studies, I obtained more exposure to all areas: aural rehabilitation, ASL, Deaf culture, and the differing views and arguments in the literature. This literature sensitized me to all the divergent perspectives.

Through volunteered and practicum experiences, in numerous programs for children who are deaf and hard of hearing, I began to see how children who are late identified struggle more with their communication than do children who are earlier identified. I also wanted to learn as much as possible about the divergent perspectives arguments regarding communication methodology. There are many varying philosophies; parents have to make very difficult choices during a very emotional time and I wanted to come to a better understanding of parents' experiences.

When I came across the literature on the early diagnosis of and intervention for hearing loss in infants, I felt that this was the area in which to invest myself further. I became very interested in how the implementation of UNHS provides families with the possibility for earlier intervention. IHPs require that all children with a hearing loss be diagnosed at an early age, meaning that more can be done for children at optimal ages in terms of language/ communication development. At earlier ages, parents will be able to make decisions regarding what type of communication mode they want to provide their child and will be able to work earlier at establishing their chosen method of communication.

My personal experiences: volunteer work, graduate learning, and investigation into the literature, led me to want to talk with parents and discover more about their experiences and feelings in regard to a universal program that could identify children at birth with a hearing loss. I also wanted to talk with parents and hear their perspectives on how professionals could create an IHP that really meets their needs while going through a very individual process.

Overview of the Study

The study consists of two parts. The first part involved looking at the current Canadian IHP context and the second part explored parents' experiences in a Canadian UNHS program. In order to address the first research question, representatives from four Canadian provinces with IHP or UNHS programs were interviewed in order to determine the specifics of each program. In order to address the second research question, five parents of children diagnosed with a hearing loss through a Canadian UNHS program were asked to respond to letters of invitation. I interviewed each parent and asked them about their experiences with universal newborn hearing screening, receiving the diagnosis, and seeking intervention services.

Chapter II contains a review of the literature pertaining to the three components of infant hearing programs: universal newborn hearing screening, diagnostics, and facilitation to intervention services. Criticisms and concerns pertaining to all three components are also presented in Chapter II. The chapter concludes with a brief discussion of past research and a statement of the research questions and aims of the current study.

Chapter III contains a description of the specific design of basic qualitative research. It discusses the data gathering and analysis methods used for each part of the research question. I also include my personal perspective and issues related to credibility, trustworthiness, and ethics. The purpose of basic qualitative research is to describe, interpret and come to understand others' experiences and perspectives. The focus was to find the meaning that parents attributed to their experiences.

Chapter IV includes a description of what four Canadian provinces and one territory have implemented in terms of an IHP, specifically the UNHS component, how infants are being diagnosed and what is being done to facilitate families access to intervention services.

Chapter V tells the stories of each parent then describes the themes that were common throughout all the interviews. Quotes are used from parents to illustrate each theme. This provides a richness and depth because the reader can access the parents' own words.

Chapter VI discusses the findings with reference to the existing literature and the implications for the implementation of future IHPs. Considerations and suggestions for future research conclude the chapter.

CHAPTER II – REVIEW OF THE LITERATURE

This literature review will define an Infant Hearing Program (IHP) by looking at all three of its components in detail: 1) universal newborn hearing screening, 2) diagnostics, and 3) facilitation to intervention services. It will also address some of the major criticisms and concerns that have arisen surrounding the component areas. In terms of the universal newborn screening, researchers have been critical of the number of false positives, high referral rates, screener qualifications, and parental anxiety surrounding screening results. Previous literature surrounding diagnostics has highlighted the importance of professionals' awareness of the emotions associated with the diagnosis of hearing loss and the sensitivity required of those professionals who are conveying that diagnosis to parents. In terms of the intervention component, previous literature has emphasized the need for stronger evidence supporting the benefit of early intervention for children with hearing loss. Research has also addressed the concern that exists surrounding the sensitivity of the professionals involved in facilitating parents' access intervention. There has also been concern surrounding the waiting period that exists for parents who have received the diagnosis and are waiting to access appropriate intervention services.

Overview of IHP

Historical Overview: United States and Canada

In the United States, national and federal agencies, state departments and consumer and professional organizations of health joined together to develop goals and principles intended to guide the development and implementation of EHDI programs (Culpepper, 2003). In 1993, the National Institute for Health (NIH) published a Consensus Statement in which they criticized the identification statistics and standards of that time as being unacceptable. When they released their statement, the screening standard in most hospitals was to screen only infants who were placed on High Risk Registries (HRR). That screening standard was put in place in 1982, when the Joint Committee on Infant Hearing (JCIH) issued their first position statement, in which they recommended that any infant with one of seven specific high-risk factors should be referred for audiological follow up (Isaacson, 2000; Johnson, 2002). Then, in 1990, they recommended a specific protocol for the hearing screening for those high risk infants (Johnson, 2002). The risk factors identified for the HRR include a "significant family history of infant or early childhood hearing loss; the presence of craniofacial abnormalities; hyperbilirubinemia levels requiring blood transfusion; a birth weight of less than 1 500 grams; congenital or prenatal infections; prolonged mechanical ventilation for five days or longer; a diagnosis of bacterial meningitis; and a five-day course of ototoxic medication" (Zochodne, Brown, & Dort, 2001, p. 25). But, this type of screening misses between 30-50% of children with hearing loss (NIH Consensus Statement, 1993). So, in 1993, the NIH recommended screening all infants prior to discharge from hospitals and that the screening process should be completed by six months (NIH Consensus Statement, 1993). They also recognized that, in recommending screening for *all* infants, adequate diagnostics and follow up appointments would be necessary and that "comprehensive intervention and management programs must be an integral part of a universal screening program" (NIH Consensus Statement, 1993, p. 22). In 1994, the Joint Committee on Infant Hearing (JCIH) endorsed the recommendations put forth by the NIH. In response to the endorsements and recommendations regarding early detection of hearing loss and intervention, Bess and Paradise (1994), an audiologist and pediatrician respectively, wrote an article in the journal of Pediatrics, in which they expressed criticisms and concerns in regard to the implementation of UNHS programs. Their 1994 article was titled, "Universal Screening: Not Simple, Not Risk Free, Not Necessarily Beneficial and Not Presently Justified." In response to their article, literature has sought to provide stronger evidence in order to dispute their concerns; this research deals with safety, acceptability, reliability, validity, cost, practicality, efficacy, and availability of early hearing detection and intervention.

In 2000, the JCIH published a position statement, in light of the additional research, in which they recommended eight principles that should guide the implementation of EHDI programs. The first four principles stated that 1) all infants should be screened before one month, 2) all diagnostics should occur before 3 months, 3) intervention should begin before 6 months, and 4) if a child passes the screening but exhibits risk factors, that child should be followed. The final four principles stated that 5) families should have the right to informed decision making, 6) results from the screening should be protected like any other health information, 7) regions should monitor their programs effectiveness, and 8) regions should monitor their programs to ensure quality, practicality, and cost-effectiveness (JCIH, 2000).

In 2001, the Canadian Association of Speech-Language Pathology and Audiology and the Canadian Academy of Audiology published their position statements supporting the recommendations of the JCIH (1995, 2000) and the NIH

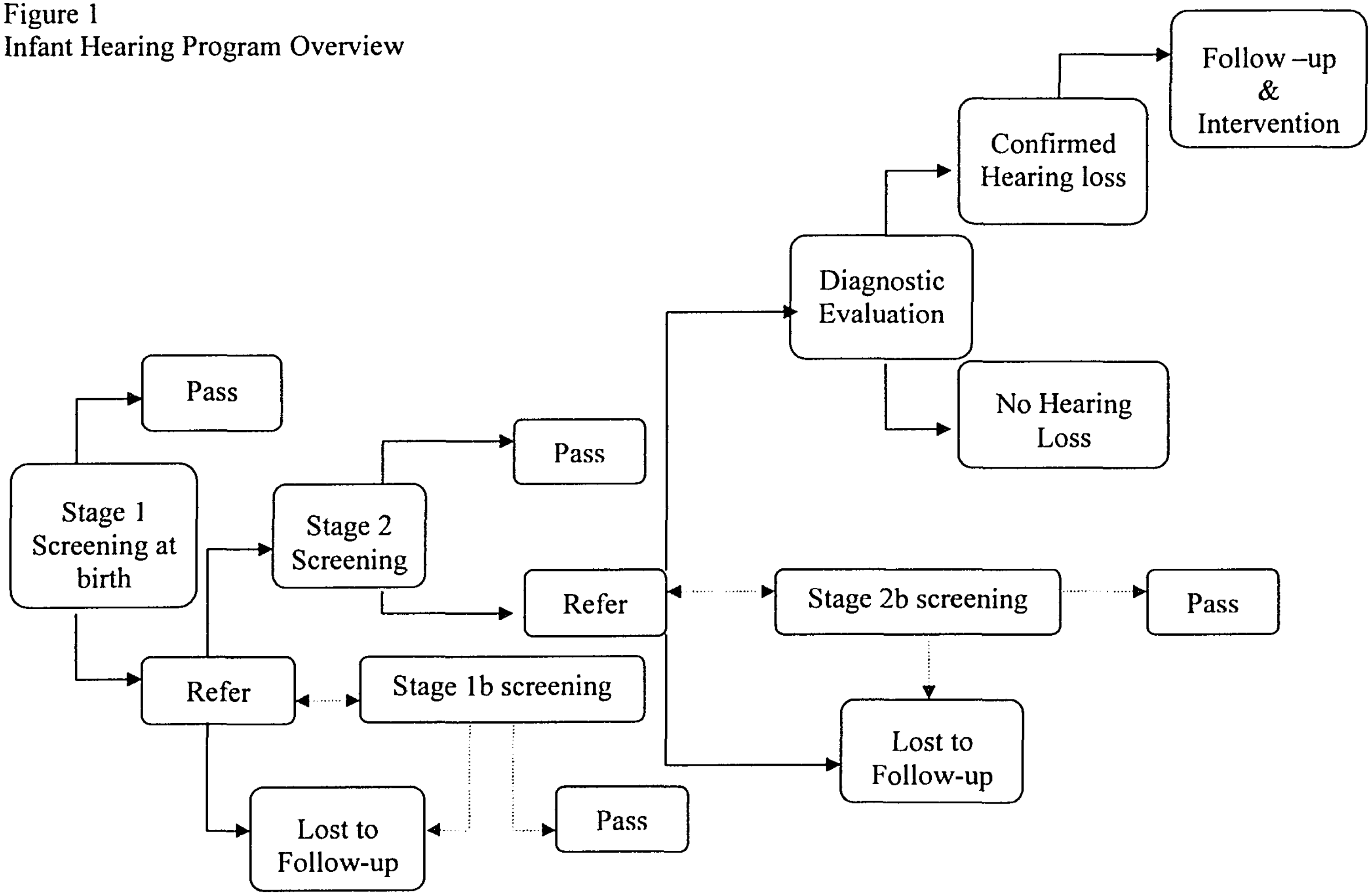
(1993). The position statement also recommended that IHPs be implemented so that parents are provided with seamless transitions from screening to intervention (Durieux-Smith, Seewald, & Hyde, 2001).

The following section will include a brief description of the three components of an IHP (see Diagram 1 for an IHP overview). While there is some variability in programs, there is a great deal of similarity as all programs seek to follow the above-mentioned guidelines.

Screening

The aim of the first component of an IHP is to provide all infants at birth with universal newborn hearing screening. Infants' hearing used to be assessed by an audiologist through behavioral observation audiometry for children who are less than 6 months, and visual reinforcement audiometry for children from 6 months to 2 years of age (Mauk, Barringer, & Mauk, 1995). Behavioral observation audiometry has resulted in many false positives and false negatives. It is limited in its ability to determine thresholds and is highly subjective, limiting its effectiveness as a hearing screening method for newborns (Mauk et al., 1995). Currently two technologies are being used in order to conduct the hearing screening. The two recommended methods for screening are evoked otoacoustic emissions and auditory brain stem response and they are available in automated commercial devices (Meier, Narabayshi, Probst, & Schmuziger, 2004).

Figure 1
Infant Hearing Program Overview



Note: Dotted lines and arrows represent possible stages in some, but not all, screening programs.

The following is a description of the technologies that are being used, how they are used and the variability that exists in a screening program.

Evoked Otoacoustic Emissions

Otoacoustic emissions (OAEs) are sounds that are generated in the cochlea spontaneously or in response to a sound (Bess & Humes, 2003; Hayes, 2003; Hyde 2002). The outer hair cells in the cochlea can spontaneously produce OAEs in a normally hearing ear but not necessarily all normally hearing ears produce spontaneous OAEs (Hayes, 2003). For these reasons, spontaneous OAEs are not used for audiological purposes (Bess & Humes, 2003; Hayes, 2003). Two types of evoked OAE (EOAE) are most commonly used in screening infants: transient evoked otoacoustic emissions (TEOAE) and distortion product otoacoutic emissions (DPOAE) (Bess & Humes, 2003; Hayes, 2003; Hyde 2002). EOAEs are measured by placing a probe with a microphone in the infant's ear canal. The sound stimulus is delivered through the probe. The sound stimulus then travels through the middle ear to the inner ear where it reaches the basilar membrane which moves and causes a shearing of the outer hair cells (Bess & Humes, 2003). The microphone inserted in the probe picks up the EOAE, which is the echo that has traveled back from the inner ear to the outer ear in response to the stimulus. This testing is not perfect; some children who do have a mild degree of hearing loss may still produce EOAEs and some children who have no hearing loss may not produce any EOAEs because they have some fluid that could be blocking the response from coming through their middle ears (Hyde, 2002). EOAEs "are all analyzed relative to the noise floor;

therefore, reduction of physiologic and acoustic ambient noise is critical for good recording" (Campbell & Mullin-Derrick, 2002, p 2).

EOAEs can also be measured through the use of automated technology, where the system produces "pass" or "refer" results and takes 3 to 5 minutes to conduct (Hyde, 2002).

TEOAEs are produced in response to a short acoustic signal: a click or a tone burst (Hayes, 2003). A click carries sound energy over a wide range of frequencies that stimulate the basilar membrane in the cochlea (Bess & Humes, 2003). The basilar membrane responds first to high frequencies and, as the wave moves to the apex of the basilar membrane, to low frequencies. If a TEOAE were plotted on an amplitude-over-time graph, first the click stimulus would appear followed by a brief period of silence, then a different waveform would emerge showing the echo of the click stimulus as it comes back into the ear canal from the inner ear (Bess & Humes, 2003). Generally there are no emissions produced if a child has a hearing loss approximately greater than 30-40 dB. TEOAEs are best at detecting a hearing loss in the high frequencies (Hayes, 2003).

DPOAEs are produced in response to two differing, continuous frequencies which are presented to the ear simultaneously (Hayes, 2003). In DPOAE, the two frequencies stimulate the corresponding outer hair cells, which then stimulates a third set of outer hair cells between the two frequencies. This stimulation creates a separate tone which is known as the distortion product (Yuskow, 2004). The distortion product is the tone that echoes from the cochlea approximately ½ an octave below the second frequency generated (Gorga, Norton, Sininger, Cone-

Wesson, Folsom, Vohr, Widen, & Neely, 2000). Due to the fact that a DPOAE is created in response to a frequency-specific signal,

> There is a tendency to use the response to predict frequency specific hearing sensitivity. Although this practice is imperfect, there is often a good correspondence between pure tone audiograms and DPOAE amplitude, at least at the higher frequency regions" (Hayes, 2003, p. 69).

Generally moderate intensity signals are used to evoke a DPOAE. Higher intensities can produce DPOAE in ears with a hearing loss as great as 50 dB HL, meaning that a child with a moderate hearing loss could pass the screening.

Auditory Brainstem Response

ABRs record the brain's response to an external sound (Hyde, 2002). Electrodes are placed on an infant's head and an insert earphone is placed in the child's ear or a bone oscillator is placed on the mastoid. The earphone or oscillator delivers a repeated sound stimulus for a specified amount of time, either in the form of clicks or tone bursts, which are frequency specific. The electrodes then pick up and measure the electrical potentials. They are averaged together to produce an electrical waveform (Bess & Humes, 2003). These ABR electrical potentials are analyzed by latency, "the time period in which they emerge following the acoustic stimulation" (Hayes, 2003, p. 67). The peaks of the waveforms are labeled I-V and correspond to different sites in the brain involved with hearing; the eighth nerve (I), a distant portion of the eighth nerve (II), the cochlear nucleus (III), the superior olivary complex (IV) and the lateral lemniscus (V) (Bess & Humes, 2003). The waveform that develops shows the progression of electrical activity as a result of the sound stimulus moving thought the cochlea to the auditory cortex (Bess & Humes, 2003). It should take longer for a sound to affect the fifth waveform because, the intensity of the signal decreases and the sound wave has to travel further back along the basilar membrane. If the wave V latency increases a lot, it is indicative of something abnormal (Hodgetts, 2003). If an infant has a sensorineural hearing loss, the waveform V will be prolonged. If an infant has a conductive hearing loss the latencies will be elevated by air, but not by bone, and the absolute latencies will increase but not the interpeak latencies (Hodgetts, 2003). ABRs require a great deal of subject preparation and also test interpretation (Hayes, 2003). Today many screening programs employ the use of automated ABRs (AABR). They are computerized and don't require the interpretation of a trained professional. Rather, they produce an automatic “pass” or “refer” result (Mauk et al., 1995; Saville & Mahon, 2000). Automated ABRs take 5 to 10 minutes to complete.

Both AABRs and EOAEs can be done while the child is sleeping or quiet. They are quick and non invasive. Most universal newborn hearing screening programs are designed as a two staged process. The infant is usually screened in the first 24 to 48 hours. The testing produces a “pass” or “refer” result. After the first screen, if a child received a “refer” result, he/she undergoes the second stage of screening. In most UNHS programs, it is recommended that professions inform parents about the result of the screening and insert the results in the infant’s chart (Zochodne et al., 2001).

There is variability in who performs the screen, where and when it might be done, and what the referral process is. There can also be a certain degree of variation within the design of the screening component at a hospital or at provincial/state level. Some hospitals screen infants more than twice before they are referred for audiological evaluation (Hyde, Friedberg, Price, & Weber, 2004). Different personnel might also perform the screening. In some regions it is the responsibility of audiologists; in other regions it can be nurses, technicians, volunteers or other personnel (Brown, Dort, & Sauve, 2000). There can also be variation in where and when the screening takes place. Some regions perform the first screening in hospitals and the second screening is performed in community clinics (Prieve, Dalzell, Berg, Bradley, Cacace, Campbell, DeCristofaro, Gravel, Greenberg, Gross, Orlando, Pinheiro, Regan, Spivak, & Stevens, 2000). Other hospitals try to do all the screening before the infant leaves the hospital (Messner, Price, Kwast, Gallagher, & Forte, 2001). In some programs parents will be asked to return for re-screening four weeks after their first screening; in other programs parents will be contacted to schedule another screening appointment. Still other programs require parents to initiate the re-screening. Finitzo and Crumley (2000) identified the importance of arranging the following appointment for families whose infant needs to be re-screened or to receive diagnostic evaluations. The authors stated that, "Parents are more likely to keep an appointment that you give them than they are to identify a provider, call a hospital and make an appointment on their own" (p. 137). These authors also identified the importance of a tracking and follow-up systems to ensure a high quality screening program (Finitzo & Crumbley, 2000).

Diagnosis

When a newborn receives a "refer" result on both screens, follow-up should occur as soon as possible. The hospital personnel should stress the importance of follow-up evaluations to parents as a precaution to rule out hearing loss (National Center for Hearing Assessment & Management, 2001). The purpose of the diagnostic evaluation is to determine more specific information pertaining to the infant's hearing loss (Widen, Bull, & Folsom, 2003). Diagnostic results of hearing testing indicate the type of hearing loss, which ear the hearing loss is in, and the degree of the hearing loss. The type of hearing loss which can be diagnosed is sensorineural or conductive. Sensorineural hearing loss occurs when there is a problem within the inner ear or along the nerve pathway to the brain (Scheetz, 2001). Conductive hearing loss occurs in the outer or middle ear while the inner ear remains normal. Conductive hearing loss occurs when there is a blockage in the ear canal, when the ear drum is not working well or when the ossicles, the bones in the middle ear, are restricted in movement (Scheetz, 2001). Either type of hearing loss can occur in one ear, unilaterally, or in both ears, bilaterally.

Hearing is also categorized by the degree of loss. Zero to 15 dB HL represents the level at which individuals with normal hearing are able to detect a sound at a variety of frequencies. The following are the categories of the degrees of hearing loss which are typically used by audiologists: 15 to 30 dB HL is a mild hearing loss, 31 to 60 dB HL is a moderate hearing loss, 61 to 90dB HL is a severe hearing loss and 90 dB HL or greater is a profound hearing loss (Carney & Moeller, 1998). Individuals with mild to severe hearing loss are more often classified as being hard-of-hearing while individuals with profound hearing loss are often called deaf (Carney & Moeller, 1998).

Each state/province has its own guidelines for the diagnostic component for an IHP. The following are assessments that may be used in the diagnostic evaluation: an auditory brainstem response, immittance testing (tympanometry and acoustic reflex testing), evoked otoacoustic emissions and behavioral audiometry (Widen et al., 2003).

Immittance testing refers to evaluations of the middle ear. These may include tympanograms and acoustic reflexes. These assessments look at the mobility of the ear drum and give an indication as to whether there may be fluid or debris in the middle ear causing a conductive hearing loss (Widen et al., 2003). When EOAEs are conducted during the diagnostic audiological evaluation, the audiologist is required to interpret the results as opposed to the automated machinery.

Information from parents can also be used in the diagnostic evaluation (Hyde & Riko, 2000). Some parents are also referred to an ear, nose, and throat (ENT) specialist for a medical diagnosis. ENTs examine an infant's head, neck and ears and sometimes can require an infant to undergo CAT scans and magnetic resonance imaging. ENTs can also provide clearance for a parent to proceed with amplification (Widen et al., 2003).

Diagnostic ABRs can either be conducted while the infant is sedated or while the infant is asleep. It is of extreme importance that the infant is still, so that he/she does not interfere with the screening by producing noises, which interfere with recording the brain's response. During the diagnostic stage, automated machinery is not used. The audiologists must interpret the results of the ABR by looking at the latency of the waveforms. The sounds used to evoke the latency response are clicks or tones. Clicks test the structure of the brain stem and the strength of the transmission along the auditory nerve. This allows the audiologist to estimate the degree of hearing loss. Tones allow the audiologist to test certain frequencies by air and bone conduction (Hyde & Riko, 2000). This part of the testing may take an hour (Hayes, 2003; Widen et al., 2003).

Many states have specific protocols for how to inform parents about their child's diagnostic results. In some programs audiologists are advised to talk to parents; topics might include the results of the assessments and the implications, amplification options, information regarding the importance of early intervention, the need for medical follow-up, or the availability and importance of support groups for parents. As well, audiologists may discuss parents' needs to obtain services from other providers such as geneticists and child development specialists (Alberta Universal Newborn Hearing Screening Project, 2001-2004).

Intervention

Upon completion of audiological diagnostic testing, if the infant has a confirmed hearing loss, the goal of an IHP is to facilitate the child's and family's access to the most appropriate follow-up and intervention services before the child is 6 months. The primary focus of this early intervention is to support a family in their ability to develop their infant's communication and language skills, to enhance the family's understanding of their infant's strengths and needs and to promote the ability of the family to advocate on behalf of their infant (Gracey, 2003).

At opposite ends of a continuum, being deaf can be viewed within two frameworks: a medical framework and a cultural framework. In a medical framework being deaf is viewed as a disability or deficit when compared to others who have normal hearing. In a cultural framework being Deaf is viewed as belonging to a unique group of people who share the same language, American Sign Language (ASL), hence the capital "D" in Deaf (Carney & Moeller, 1998). Being hard-of-hearing can sometimes signify the degree of a hearing loss, as was previously mentioned, or it can signify that the individual has some residual hearing and uses spoken language with or without amplification (Marschark, Lang, & Albertini, 2002). These two separate frameworks can provide some insight into "one of the most disheartening philosophical conflicts…: the controversy over signed and spoken communication methods" (Marschark et al., 2002, p. 21).

The two main communication methods, at extreme ends of the continuum, are that 1) children can successfully be taught to communicate through speech only and can successfully be mainstreamed into hearing society and 2) children can successfully learn to communicate through sign language only and can become a part of Deaf culture. In very broad terms, people who subscribe to the extreme end of the spoken language continuum seek an intervention program within the medical framework that enables the development of spoken language only. Those who align themselves within the cultural framework of Deafness seek intervention services that enhance the development of a visual language. It is important to note that broad generalizations are being made here. Not all families find themselves polarized at one end of the continuum nor do they all find themselves faced with professionals who advocate only one framework. Some parents may seek out intervention services that offer a combination of spoken language as well as visual language, and, therefore don't fit into one particular framework for how they view their child's hearing loss. Many professionals are also providing intervention services that consider the individual child as opposed to any one particular framework and are willing to do whatever it takes to assist that child to develop language and communication. It is important, however, to be aware that this continuum exists and that various professionals find themselves at various places upon this continuum.

The goal of early intervention is to help families to develop their child's communication abilities and there are many choices for parents in terms of what that method of communication should be. Spoken language intervention services consist of speech language therapy, auditory verbal therapy and auditory oral programs. The goal of these types of programs is to develop spoken language through the use of aided residual hearing and have children mainstreamed and included in the hearing community (Gravel & O'Gara, 2003). Auditory perception is aided with either hearing aids or cochlear implants. Technology is improving and advancing rapidly in both areas and children can be fitted or implanted well before they are 12 months old (Gravel & O'Gara, 2003).

Visual language intervention services often include the use of American Sign Language and the Bilingual- Bicultural approach. These intervention programs focus on the development of a visual language that is distinctly different from English but still a language in its own right. These programs also provide infants born with a hearing loss an opportunity to interact with members of the Deaf culture.

Again, these represent ends of a continuum, many families find themselves somewhere in the middle; they would like their child to develop spoken language but they also want to provide him/her access to a visual form of communication or a visual language. Intervention services that offer a combination of both those approaches are called Total Communication (TC) programs. In some of these programs ASL or Signing Exact English (SEE, SEE II) are used. SEE is not a true language in itself but is rather English on the hands. Some signs are borrowed from ASL but SEE follows the exact sentence structure as for English and highlights some of the grammatical morphemes that are difficult for children with hearing loss to hear (Gravel & O'Gara, 2003). In these TC programs both modes of communication are used and children can be exposed to both visual and spoken languages.

Intervention services are not only concerned with a child's communication. White (2003) identified that intervention should include medical, educational and audiological components. White (2003) also stated that, according to state EHDI coordinators, appropriate education intervention isn't as available as it should be in the U.S., because most intervention programs have been developed for infants with severe to profound hearing loss. These children only represent one third of the babies being identified through universal newborn hearing screening. Less is known about the intervention needs of children with mild to moderate hearing loss and conductive hearing loss. In addition, prior to UNHS, early interventionists were providing services for infants who were late diagnosed and delayed in language. However, with this early identified population, early interventionists are required to provide these infants with a different type of intervention. The goal with the early identified infants is to prevent a delay from developing as opposed to "remediating" an often large delay (White, 2003). White (2003) also identified that educational and medical intervention must be, “accessible, family-centered, comprehensive, continuous, coordinated, compassionate, and culturally effective” (p. 85).

Literature is sparse in terms of how information pertaining to intervention services is shared with parents. Some EHDI programs in the U.S. have indicated that they recruit "veteran parents" of children with hearing loss to work with parents of the newly diagnosed infant; these “experienced” (p. 256) parents have already been through what the new parent is about to embark upon (Widen et al., 2003). Other U.S. EHDI programs indicated that there are regional coordinators who work with families and provide them with information about communication options, programs in their community, funding and other forms of consultation (Hayes, 2001). Some Canadian literature has stated that it is the audiologist who provides the information and habilitation services in IHPs (Dort, 2000). Because choices are complex and decisions often difficult to make regarding intervention for a child with a hearing loss, it is of extreme importance that professionals provide parents with all the necessary information so that they can make informed decisions on their child’s behalf.

Concerns and Criticisms in the Literature

The following section will discuss the concerns and criticisms in the literature relating to the screening, diagnostics and intervention component of UNHS programs.

Screening

False Positives

In the 1994 article by Bess and Paradise, they criticized the guidelines for

UNHS stating that the recommended screening protocol of OAE and ABR screening would result in high false positive rates. False positives occur when an infant receives a “refer” result on the screening but does not have an actual hearing loss. Bess and Paradise (1994) suggested that automated technology would be a better tool because it was less difficult to interpret, less time consuming, and required less training.

Two properties that are important in evaluating screening protocols are test sensitivity and specificity. "Sensitivity is the probability that an individual with the target disorder will fail the screen and specificity is the probability that an individual without the target disorder will pass" (Hyde & Riko, 2000, p. 112). For at least moderate hearing loss, AABRs have a sensitivity of approximately 85% and a specificity of 90-95% and OAEs have a sensitivity of 80% and a specificity of 90% (Hyde & Riko, 2000). The more sensitive and specific the screening tool, the more likely referral rates will be kept to the lowest possible number and the more likely that parents’ levels of anxiety will remain at a minimum.

Part of the reason that there is so much variation in screening protocol is that different hospitals and regions are trying to deduce the best screening protocol by implementing multiple stage screenings with both automated screening technologies, AABRs and EOAEs, which will yield the lowest false positive rates. Current literature reports that false positive rates range from 2-8% (Clemens & Davis, 2001; Kennedy, 1999).

Referral Rates

High referral rates can place an unnecessary strain on hospitals and on the services for diagnostic evaluations (Bess & Paradise, 1994). Many hospitals or regions employ different combinations of screening protocols in order to keep their referral rates as low as possible. High ranking UNHS programs have a referral rate that is under the American Academy of Pediatrics recommended referral rate of 4% (Hyde, 2002). Some hospitals have found that referral rates can be lowered if they do more than two screenings. Hyde (2002) reported that referral rates can be dropped to as low as 1-2% when an additional AABR screening is added to a two-stage, two-technology, screening protocol before infants are referred for diagnostic testing. Other researchers have found similar results with an additional screen (Clemens & Davis, 2001). Cox and Toro (2001) reported a 1.65% referral rate with their two-tiered screening program in which the first screen was conduced with a DPOAE and the second screen was an AABR. Lemons, Fanaroff, Steward, Bentkovewr, Murray, and Diefendorf (2002) reported that AABRs were the best screening technology to use because they result in the lowest referral rate at hospital discharge. Hyde and Riko (2000) reported that the most successful screening protocol was the combination of EOAEs followed by AABRs. Screening hospitals and regions are continuing to investigate the best protocol in order to make UNHS more feasible and to keep the strain off diagnostic and intervention services.

Parental Anxiety

Another major concern in relation to false positives and high referral rates is the level of anxiety and concern experienced by parents as they wait for audiological diagnostics (Clemens & Davis, 2001; Hergils & Hergils, 2000; Poulakis, Barker, & Wake, 2003; Weichbold & Welzl-Mueller, 2001; Weichbold, Welzl-Mueller, & Mussbacher, 2001). Many parents will not be aware that hearing loss is a low prevalence condition. The low prevalence of hearing loss results in the screening which have a low positive predictive value, meaning that there will be a small number of infants who receive a "refer" result on the screening who actually do have a hearing loss (Keren, Helfand, Homer, McPhillips, & Lieu, 2002; Weichbold, Welzl-Mueller, & Mussbacher, 2001). If infants' receives "refer" results on all screening, parents may interpret that to mean that there is a strong chance that their infant has a hearing loss and they may become extremely worried (Poulakis et al., 2003; Weichbold, Welzl-Mueller, & Mussbacher, 2001). Not only are parents worried but they may also feel "negative emotions" toward their child (Poulakis et al., 2003, p. 20). Some researchers have also suggested that this may cause a disruption in the infant-parent relationship (Hergils & Hergils, 2000).

Several studies have looked at parents' attitudes towards UNHS programs (Clemens & Davis, 2001; Hergils & Hergils, 2000; Poulakis et al., 2003; Watkin, Beckman, & Baldwin, 1995; Weichbold & Welzl-Mueller, 2001; Weichbold, Welzl-Mueller, & Mussbacher, 2001). In 1995, Watkin et al. conducted a retrospective study of parents of infants with hearing loss, who were not identified through screening, in order to survey their opinion on UNHS programs. The majority of parents in their study would have liked a hearing screening test at birth. Many of the parents surveyed had the opinion that, although parents may be anxious and worried, having a screening test would be the best thing possible for their child. In 2000, Hergils and Hergils conducted another retrospective study of parents who had been involved in a UNHS program. Again, the majority of parents surveyed had a positive view of UNHS because they felt "reassured by it" (Hergils & Hergils, 2000, p. 321). Some parents were anxious about the repeated testing and found some comfort in receiving information about the testing. Other parents, who experienced some anxiety, felt as though they would have liked more information about the UNHS process. Weichbold, Welzl-Mueller, & Mussbacher (2001) reported that parents found comfort in even the most basic information about infant hearing screening. The information gave parents a more positive view of the screening. The authors of this study deduced that, if more parents were better informed about the UNHS process, the number of individuals who support UNHS would increase.

Kennedy (1999) found that, in terms of the parent-child relationship, the anxiety that parents feel regarding their infant was similar both to parents whose infant passed the screening and to those who received a “refer” (Kennedy, 1999). In 2003, Poulakis et al. found that parents viewed screening tests as a positive tool for identifying hearing loss. While parents reported that they did experience negative feelings when their child was a false positive, some said their feelings were resolved upon diagnosis.

There appear to be some common trends in the literature: more information about the hearing screening process helps to increase its acceptance and the benefit of a hearing screening is greater than the anxiety it causes the parents.

Screeners' Ability and Training

Newborn hearing screening requires a degree of heightened sensitivity from professionals who are sharing the information about an infant's potential hearing loss with parents. Parent-infant bonding is important for the child's development and attachment. Opponents of UNHS are critical that the bond may be upset by the early diagnosis of hearing loss, especially if it is insensitively delivered (Gracey, 2003). The concern in the literature focuses on who screens each infant and what his/her training and level of awareness is surrounding the issues of deafness (Hyde & Riko, 2000; Kileny, 2000; Mauk & White, 1995). As many of the above studies mention, importance is placed on how the screening procedure is handled due to the impact that it has on the UNHS program's acceptance.

In UNHS programs, there is a great deal of variability in who is responsible for the initial screening and informing parents about their child's need for a second screening. In some UNHS programs, screeners are volunteers (Messner et al., 2001). Messner et al. (2001) reported that volunteers receive training in working with ABR machines and testing procedures, but there is little mentioned about counselling, sensitivity, how to inform parents about the UNHS process, or the fact that their child might have a hearing loss. It has also been reported that the automated technology that is now available has allowed for "lay people" to do the screening (Knott, 2001, p. 25). But the literature is again non-specific in regard to what type of training a "lay person" has when it comes to being delicate about the sensitive issue of hearing loss. With all of the different personnel responsible for the screening (nurses, volunteers, dedicated screeners, technicians and audiologists), research has been critical of the protocols that are in place in order to adequately prepare those individuals to share the information about the screening with parents and to inform them of the results. The following section will speak to the reported impact that the diagnosis of hearing loss has on parents, which is influenced by how parents are told.

Diagnosis

Reaction to Deafness

There has been a great deal of research and concern surrounding parents' reaction to the diagnosis of hearing loss. Luterman (1991) has studied parents' emotions upon receiving their child's diagnosis. Some of the feelings which parents might experience are "grief, shock, anxiety, anger, depression, guilt, resentment, vulnerability, confusion, panic and denial" (Poon, 1999, p. 17). Corcoran, Stewart, Glynn, and Woodman (2000) developed a questionnaire and did a study in which parents' explained their reactions to the diagnosis of their child's hearing loss. One mother in the study explained that it was "the most important thing to overcome" and that "it became [her] life" (p. 168). Another mother expressed being "full of fear" upon receiving the diagnosis (p. 169).

The coping mechanisms that parents develop in dealing with the diagnosis of deafness are unique to each parent. Some may choose to deal with it by accepting it, not acknowledging it, fighting it, or letting it entirely consume them (Scheetz, 2001).

The process that some parents go through is described as cyclical. At any point parents may be on an inward journey of despair, or detachment or protest or on an outward journey of exploration, or hope, or investment (Martin & Elder, 1991). In some cases parents may blame themselves for their child's hearing loss and that can have a huge impact on families. In some situations, mothers may take on a more active role and fathers may remain passive, uninvolved, and in denial. This can put a significant strain on families and marriages (Luterman, 1991). Corcoran et al. (2000) quoted a father explaining that he would distance himself from his child and would remain removed from the entire situation to avoid dealing with the emotions of it. Siblings can also be affected by a new infant with a hearing loss in the family because they may not understand all the extra time and attention that the new baby receives.

Literature, therefore, indicates that finding out that your child may have a hearing loss has a profound effect on parents and may have long-lasting effects on the family and the child. All professionals involved in an IHP need to be aware of all these potential feelings and processes that parents may experience.

Returning for Follow-up

Another notable concern in the literature surrounds the number of families that don't bring their child in for follow-up diagnostic appointments. Bess and Paradise (1994) reported on research findings that indicate 25% to 80% of infants have not returned for follow-ups. Therefore many children fall through the cracks of the system and Bess and Paradise (1994) reported that regardless of "cost saving incentives" and "aggressive recruiting efforts" it remained an issue for some UNHS programs (p. 332).

Sensitivity of Professionals

Many qualitative research studies have been critical of the professional's ability to sensitively share the diagnosis of hearing loss with parents (Bamford, Davis, Hind, McCracken, & Reeve, 2000; Luterman & Kurtzer-White, 1999; Roush, 2000).

In Roush's (2000) survey parents reported feeling as though audiologists were unaware of their grief and were non-supportive once they first learned about their child's hearing loss. Parents expressed wanting "more consideration" given to these matters (p. 163). Luterman and Kurtzer-White (1999), in their retrospective survey, found that parents wanted to learn about their child's hearing loss "by an audiologist who is not only a skilled clinician but also an empathetic, supportive counsellor" (p. 16). Other qualitative studies have found that parents often don't understand the language used by professionals. Parents have also expressed feeling hurt and upset when, after learning of their child's hearing loss, they are treated in a manner that they deem insensitive (Corcoran et al., 2000). Some research has also indicated that there are delays between when parents suspect that there is a problem with their infant's hearing and when the family physician takes the concern seriously (Prendergast, Nelson Lartz, & Casson Fiedler, 2002).

Research has also stated that there may be communities in regions where no qualified professionals are available to provide the counselling that should be offered to parents upon diagnosis (Bess & Paradise, 1994; Paradise, 1999). Studies have also highlighted, however, that audiologists, who are often in the position of sharing the diagnosis with parents, have not received enough training in counselling in their graduate programs in order to take on the counselling position (Luterman & Kurtzer-White, 1999).

Intervention

In 1994, Bess and Paradise criticized another recommendation, put forth by the NIH, which addressed the efficacy of early intervention for children with hearing loss. Bess and Paradise (1994) stated that there was "no direct evidence that demonstrates conclusively that intervention appropriate by current standards results in more good than harm to the child and the family" (p. 332).

Many past studies were considered flawed because of poorly defined variables, too much variability, too small a sample size and too many intervening variables (Calderon & Naidu, 2000). Studies have also failed to meet "the criteria for a true scientific experimental design" (Calderon & Greenberg, 1997, p. 458). Randomly assigning infants to intervention and non-intervention, in order to have control groups, is unethical and thus an impossibility. While many professionals feel as though early intervention for a child with hearing loss is a significant contributor to positive outcomes in speech, language, and audition, this valid criticism by Bess and Paradise (1994) called for more empirical research to be conducted. Subsequently, many researchers began to provide stronger evidence (Calderon & Naidu, 2000).

Evidence for Early Intervention

In 2001, the U.S. Preventative Service Task Force (UPSF) conducted an assessment of UNHS. They rated three different studies as "fair evidence" for improved language and communication as a result of early identification and intervention (Thompson, McPhillips, Davis, & Helfand, 2000).

A study by Appuzo and Yoshinaga-Itano (1995) was one of the three studies cited. In their study, the authors examined 69 children's language ability at 40 months who were separated into age-of-identification groups. The age-of-identification groups were 1) 0-2 months, 2) 3-12 months, 3) 13-18 months and 4) 19-25 months. All children had different degrees of hearing loss but, all were enrolled in the same early intervention program after their hearing loss was diagnosed. Apuzzo and Yoshinaga-Itano(1995) found that all children who had been identified and in intervention before three months had higher language abilities.

Moeller's (2000) study was another cited as providing fair evidence. In her study, children's vocabulary and verbal reasoning skills were examined at five years of age. These children were enrolled in intervention programs at different ages. Her results found that children who were enrolled earliest in intervention had higher vocabulary and verbal reasoning than children who were enrolled later in an intervention program.

The third study, mentioned in the UPSF assessment of UNHS, was Calderon and Naidu's (2000) study. Their longitudinal study examined children who entered an early intervention program prior to 12 months, between 13-24 months, and between 26-36 months. Even with controlling for the degree of hearing loss, children who entered intervention prior to 12 months had greater speech, language and auditory skills when they left the intervention program.

Researchers, at the University of Colorado, have conducted numerous research studies, which indicate that regardless of the type of intervention program, children enrolled earlier in intervention do better on language and communication measures (Yoshinaga-Itano, 1999; Yoshinaga-Itano, 2003; Yoshinaga- Itano & Apuzzo, 1998; Yoshinaga-Itano, Coulter, & Thomson, 2000; Yoshinaga-Itano, Sedey, Coulter, & Mehl, 1998). UNHS was established in Colorado in 1992. Of the children identified with hearing loss through this program, over 90% enter the Colorado Home Intervention Program (Yoshinaga-Itano, 2003). This unique situation has given Yoshinaga-Itano and colleagues the opportunity to study a large number of children who are early identified and seek immediate intervention. Their research looks at the outcomes in relation to age of identification, and examines variables that influence outcomes.

In order to measure language, speech, and developmental outcomes, Yoshinaga-Itano and colleagues often use the Minnesota Child Development Inventory (MCDI). This screening tool is used to identify children who are delayed in a number of developmental areas. It is a test normed on different populations and in a previous study "the validity and reliability of this instrument for use with deaf and hard of hearing children was reported" (Yoshinaga-Itano & Appuzo, 1998, p. 384). Infants' results on the Expressive Language scale and Comprehension-Conceptual scale are used as speech and language outcome measures. From these scales, in order to examine a child's language ability, language quotients are calculated for each child. Language quotients are calculated by dividing a child's chronological age by their score on the MCDI scales of interest and multiplying it by 100 or by averaging the two scales (Yoshinaga-Itano et al., 2000). From this test, one can also calculate cognitive quotients and discrepancy quotients. Cognitive quotients are calculated with results from the non-verbal scale and the child's chronological age. Discrepancy quotients are calculated in order to determine how an infant's language level compares to his/her cognitive ability (Yoshinaga-Itano et al., 2000).

The research of Yoshinaga-Itano and colleagues has demonstrated that children identified with hearing loss prior to six months have significantly higher discrepancy quotients on expressive language and comprehension-conceptual subtests than do children who are identified after six months (Yoshinaga-Itano & Appuzzo, 1998). Her studies indicate that the discrepancy quotients of the early-identified children were within the low average level when compared to children with normal hearing (Yoshinaga-Itano &Apuzzo, 1998). This means that children appear to have language levels comparable to their cognitive ability and in the same range as children with normal hearing. Their studies have also examined outcomes for children who were identified before six months and children who were identified between 7-12 months, 13-18 months, and 19-24 months. Infants identified prior to six months had higher language quotients than infants in the last three categories (Yoshinaga-Itano et al., 1998). Yoshinaga-Itano and colleagues (1998) also reported that there was no significant difference in the language development of the three later-identified categories of children. This resulted in the hypothesis that there is a sensitive period for language development that ends after six months of age (Yoshinaga-Itano, 1999).

The positive language outcome, as a result of early identification and immediate intervention services, has been termed the early identification effect (Yoshinaga-Itano, 1999). The studies of Yoshinaga-Itano and colleagues indicate that, regardless of gender, age at testing, socioeconomic status, degree of hearing loss, mode of communication, and presence or absence of an additional disability, the early identification effect is present.

The original concerns of Bess and Paradise (1994) have served to be greatly beneficial, especially in this area because researchers heard the criticisms and concerns and professionals are now being provided with the evidence that was missing in this literature.

Sensitivity and Ability of Professionals

Qualitative research studies have also shown that there is a concern surrounding a professional's ability to help inform, guide and coordinate intervention services for parents (Bamford et al., 2000; Luterman & Kurtzer-White, 1999; Roush, 2000). Sass-Leher (2003) reviewed guidelines put forth by a number of researchers for professionals involved in early intervention programs. Seven guidelines were identified; early identification must be followed by comprehensive family-centered early intervention programs; the family centered aspect must serve to enhance family adaptation and decision making; family support must be offered to promote family well being and to enhance parent-child interaction and the child's developmental outcomes; the programming needs to be culturally, developmentally, and individually appropriate; the family must be encouraged to be involved and taught effective communication in order to promote language acquisition and academic achievement for their child; and programs should involve deaf and hard-of-hearing professionals.

Culpepper (2003) stated that, with the advent of EHDI programs in the US, the "rapid advances in technology and program implementation have created a knowledge and practice gap between those who are familiar with early intervention and state-of-the art methods being used in the early identification of hearing loss and those who were taught before these rapid shifts occurred" (p. 117). That knowledge-to-practice gap is experienced by parents, whose infant's are identified through UNHS and who are receiving services from professionals who have had little preparation in deafness and its implications (Stedler-Brown & Arehart, 2000). Families have reported that health care professionals do not seem to have a full understanding of the experiences of deaf adults and those professionals are making the surgical recommendations (i.e. cochlear implant surgery) without being able to consider the individual needs of the child (Bodner-Johnson & Sass-Leher, 2003). In a medical setting there can be a pairing of a "medical solution" to a "medical problem". In these situations, parents may sometimes make choices when they are grief ridden, not fully aware of all the implications of their decisions, and less aware of alternate interventions (Kluwin & Stewart, 2000, Mauk & White, 1995).

When parents are looking at what their next step should be after receiving the diagnosis, they seek guidance and positive encouragement from the professional counselling them regarding their child's hearing loss (Durieux-Smith & Ericks-Brophy, 2002). There is a delicate balance to be reached concerning how to provide parents with sufficient information and yet not overwhelm them (Durieux-Smith & Ericks-Brophy, 2002).

Professionals must also provide parents with information that is unbiased towards any particular philosophy. This can be challenging when considering that most professionals have a personal bias (Gravel & O'Gara, 2003). Parents have expressed the need for unbiased information especially surrounding communication options. Parents also wanted more information about available services and financial assistance (Roush, 2000).

In Corcoran et al.'s (2000) study, parents were concerned with the professionals' lack of respect towards their wishes when it came to intervention decisions for their child. In Roush's (2000) study, parents also expressed a need for professionals to be more supportive and to allow them to make their own choices for their children. Luterman & Kurtzer-White (1999) found that parents expressed a need for professionals to put them in touch with other families who are going through or have gone through the same process.

Waiting Periods for Intervention Services

As with other areas of an IHP, there are wait-list concerns when it comes to infants' accessing early intervention. Bess and Paradise (1994) reported that some families were waiting eight to nine months before receiving intervention services. Harrison and Roush (1996) reported that some parents have experienced up to one year delay before accessing intervention services.

Kileny and Lesperance (2001) reported that universal detection of hearing loss cannot be equated with timely intervention. They stated that there is no guarantee that there will not be "bureaucratic delays with funding agencies" (p. 67) or that the "economic situations of families" might limit access to intervention (p. 67). In many locations, before IHPs can be implemented, there needs to be a restructuring of health care systems so that parents can immediately access intervention services, audiological and medical management, and family counselling

(Mencher and DeVoe, 2001). It seems wrong to alert parents to a potential problem and then not be able to provide them with the necessary resources to have that problem addressed (Mencher and DeVoe, 2001).

Mencher and DeVoe (2001) listed as one of their concerns with UNHS, that being *able* to identify hearing loss at birth doesn't mean that professionals are prepared for the consequences of doing so. One such area where professionals may not be prepared is pediatric hearing aid fitting. This is a pediatric specialty, and most audiology students do not receive training for this in their graduate programs. This has resulted in a shortage of qualified and experienced pediatric audiologists who can fit hearing aids as early as desired (White, 2003).

Summary and Limitations of Past Research

The concerns in the literature clearly indicate that there is not yet a seamless transition between the screening, the diagnosis and facilitation to intervention components of an IHP. There are also many variables that come into play when evaluating the success of an IHP. As of yet, in the literature, there is no "best IHP protocol" that outlines how the three main components can be implemented in order to maximize the benefits of an IHP. One limitation is that the literature that focuses on the sensitivity of professionals is not based on professionals working within IHPs. Perhaps there is a difference in the sensitivity of professionals who work with newborns and those who do not. This study seeks to look directly at parents' perspectives of UNHS experiences and this includes their contact with professionals.

Another limitation of the literature is that much of the research surrounding these areas is based on programs in the United States. As previously stated, the

United States has taken a leadership role in the implementation of EHDI programs; currently at least 41 states have passed legislation, five states have achieved EHDI programs without legislation, and others still have it pending (Yoshinaga-Itano, 2003). Canada is lagging far behind in the implementation of programs that identify infants, diagnose hearing loss before six months, and facilitate entry into early intervention programs, referred to in Canada as Infant Hearing Programs. Ontario has developed a comprehensive IHP program. New Brunswick, P.E.I., and Yukon have implemented UNHS programs, and Alberta has just completed a UNHS study. As provinces are beginning to bring IHPs into fruition, there is a need to focus on those Canadian IHP specifics and on what parents' experiences are within those programs. As these programs are just beginning, many of the Canadian provinces have not yet developed a comprehensive IHP. Therefore this study will explore parents' UNHS experience, their encounters with professionals during the process of receiving the diagnosis, and their initial access to intervention services.

Statement of Research Question and Aims of the Current Study

The aims of the current study are to examine the Canadian IHP situation and gain a better understanding of what parents' experiences are. It is of extreme importance to determine if parents are finding these first Canadian programs to be helpful, informative, and positive. The challenges, successes, or failures of these programs can provide some valuable insights into what needs to be done to make the programs work more smoothly, what needs to be implemented in other upcoming programs, and what needs to be entirely avoided. Professionals could also potentially gain a deeper understanding of how the services that they offer affect parents' experiences. To date, no research explores these issues from the perspectives of parents in a Canadian IHP.

A basic interpretive methodology was used to explore, through open ended interviews, the experiences of parents who have had an infant diagnosed with a hearing loss through a Canadian UNHS program, and their subsequent experiences in receiving the diagnosis and seeking intervention services. Chapter III provides a further description of the basic interpretive research approach and, specifically, the techniques used for data collection and analysis.

CHAPTER III – METHODOLOGY & METHOD

Basic Qualitative Research

Basic qualitative research serves to describe, interpret, and aid in the understanding of "a phenomenon, a process, or the perspectives and worldviews of the people involved" (Merriam, 1998, p. 11). In the analysis of basic qualitative research the goal is to identify patterns that reoccur throughout the data collected; these reoccurring patterns can then be presented in the form of themes (Merriam, 1998). The investigator is the primary instrument and is therefore responsible for collecting and interpreting the data (Merriam, 2000, 1998). The result of this type of study is considered to be very descriptive and detailed, in order to demonstrate how the understanding of another individual's experience was reached, providing a trustworthiness of the data.

Basic qualitative research was chosen for this study because it fits well with what this study seeks to do: "talk with people about their experiences and perceptions" (Patton & Westbury, 1992, p. 3). This study sought to find the meaning that parents attributed to their experiences in Canadian UNHS programs. The methods of basic qualitative research propose to allow the investigator to discover the experiences of participants by connecting with them and allowing them to share their experiences. In three articles, (Corcoran & Stewart, 1995; Corcoran & Stewart, 1998; Corcoran et al., 2000) Corcoran and colleagues explained that, by listening to participants' experiences, they could find "the meaning this experience had for them, as well as describe its impact on a variety of relationships and life choices" (Corcoran et al., 2000, p. 167). They go on to describe the impact that this type of research can also have on the professionals who play a contributing role in the experiences of these individuals. Qualitative findings can, therefore, contribute to basic knowledge and theory (Patton, 1990).

The researcher is critically important at all stages of the process. Ellis (1998) points out that investigators are required to be "self-conscious about [their] efforts to develop and further [their] understanding" (Ellis, 1998, p. 6). The investigator must seek to maintain empathetic neutrality (Patton, 1990). In Patton's words, "this simply means that the investigator does not set out to prove a particular perspective or manipulate the data to arrive at any predisposed truth"(Patton, 1980, p. 52). He describes empathetic neutrality as an investigator's empathy towards the people he/she encounters and neutrality in respect to the findings. The nature of qualitative inquiry requires that the investigator be open to design flexibility, as the design tends to "unfold as the field work unfolds" (Patton, 1990, p. 58).

Part 1: Current Canadian Context

The first part of this study sought to describe existing Canadian IHPs. Discovering what has worked well for Canadian provinces and territories, and where difficulties have been encountered, will benefit upcoming IHPs. Understanding the current Canadian context can also provide insights into which UNHS protocol to use, who should be counselling parents, as well as how best to facilitate access to intervention services.

Implementation of the Study

Selection of Participants

There were two sources of information involved in the first part of the study:

a) professionals in IHP/UNHS programs and b) on-line, published, and un-published documentation.

The professionals above were professionals involved in the implementation and running of current IHP/UNHS programs in Alberta, New Brunswick, P.E.I, Yukon, and Ontario. They were contacted in order to gather information on their current Canadian situation. Through Internet searches, the names of managers or coordinators of Canadian IHP programs were found. These professionals were contacted and were informed of the study. They were then asked to be key informants on the specifics of their provincial UNHS program. Professionals were asked a series of related questions attached in Appendix A.

The reason for the selection of these managers and coordinators was that they were either the experts on the provincial knowledge required or they would be able to direct me to the appropriate person. They were contacted, because some of the specific IHP information was not in any published literature, on-line or widely available to the public.

The second source of information for UNHS program specifics (web sites, web documents, published, and unpublished documents) required the investigator to use creative thinking and to have an open mind in terms of what documents might prove to be useful (Merriam, 1998). Information, such as the origin of the documents, their reasons for being written, the name of the author and under what context it was written, was obtained for all relevant documentation possible. This information was gathered in order to ensure authenticity of the documentation (Merriam, 1998).

The specific types of documentation used for this study were: unpublished manuals, press releases, electronic papers, provincial government web sites, and specific UNHS web sites. All information was free, and contained information that could have taken an enormous amount of time to gather from differing sources (Merriam, 1998). These documents and sites are listed in Appendix B.

Description of Participants

The following is a description of all the professionals who were interviewed in order to gather information on the specific programs in the Yukon, New Brunswick, P.E.I., Ontario, and Alberta.

In order to gather information pertaining to the Yukon's IHP, two certified audiologists working within the program were contacted. One audiologist had been involved with the program since its implementation in 2002. The other audiologist received her training through the IHP in Ontario and had been working in the Yukon for quite some time.

The information pertaining to New Brunswick was gathered by contacting a Health Care Consultant, who was the provincial lead for the New Brunswick Infant Hearing Screening Program. This Health Care Consultant was a speech language pathologist (SLP) and had been involved with the program for one year and a half.

In order to gather information pertaining to the IHP in Prince Edward Island, the provincial audiologist in charge of the IHP, who focuses in pediatrics, was contacted. This audiologist ran the Infant Hearing Program and had been with it since its inception. This audiologist was also in charge of overseeing the running and tracking of the program.

The information regarding the Ontario IHP was gathered from an audiology consultant to the Ministry of Children and Youth Services in Ontario. This consultant was a part of a specialized interdisciplinary team created to implement, administer, and evaluate preschool speech and audiology programs including the Infant Hearing Program (IHP).

In order to gather information from Alberta, the provincial coordinator of the Alberta Newborn Hearing Screening Study was contacted. The provincial coordinator is an academic audiologist and had been with the Alberta project since it began.

Data Collection

Information from these participants was collected through telephone contact or over secured e-mail. Each professional was telephoned initially, explained the purpose of the study, and asked if they would like to participate. Professionals either agreed to participate on the spot or a time was arranged for the interview to take place. One professional had to cancel the telephone interview and responded to the questions via e-mail. Discussions lasted between 30 and 45 minutes.

Information from the second source of information was collected through printing the selected relevant documentation from on-line sites or receiving them from IHP coordinators. The date of each download and printing from on-line source of information were recorded for future referencing.

Interview Procedures

Interviews occurred with the professional participants, following a standardized list of questions pertaining to the issues of relevance in the literature review. The first set of topics covered were issues pertaining to the screening, such as, how the screening was conducted and by whom, the number of infants being screened, and referral rates. The second set of topics included the diagnosis, the protocols in place, who diagnosed infants, how many infants have been diagnosed, who informs the family, and whether there is any special protocol for informing parents. The third topic area was intervention services. Professionals were asked about what services were available to families, how they were informed about those options, what funding was available to families, and about what provisions and systems are in place for tracking data. Also of special interest were the challenges and successes that each UNHS program faced over the course of its implementation.

During the interview, notes were taken of the professionals' responses and these were compiled at the end of the interview. Follow-up questions were conducted either by phone or over a secure e-mail in order to clarify certain issues.

Part 2: Parents' Experiences in a Canadian UNHS Program

The second research question in this study was: What are parents' experiences in a Canadian UNHS program? The experience of parents will provide valuable insights and shed light on whether the concerns expressed in the literature are shared by parents who have experienced a Canadian UNHS program. Their insights will provide information beneficial to other parents and also to professionals who are developing and maintaining newborn hearing screening programs and comprehensive infant hearing programs.

Four health regions in one province were contacted to participate. One health region declined to participate, stating they did not have sufficient time or resources to become involved with this study. To obtain participants, two separate recruitment strategies were employed in this study. In two health regions, the first recruitment strategy, discussed below, was used. In the third health region, a separate ethics submission with a new recruitment strategy was required for ethics approval.

Implementation of the Study

Selection of Participants

The selection of participants, both professionals and parents, was based on purposeful sampling (Patton, 1990). This allows for selection of information rich cases (Patton, 1990).

In the first two participating health regions, to recruit parent participants, health region coordinators were contacted and sent an information letter informing them about the study. The information letter to health region coordinators is attached as Appendix C. In the information letter they were asked to assist this research by contacting parents who met the specified criteria.

In order for parent participants to be invited to participate in the study, the specified criteria were as follows: 1) parents had to be hearing parents and 2) must have had their infant diagnosed with a hearing loss through a Canadian UNHS program. The requirement for parents to be hearing was that they would probably have a different experience in a UNHS program than would parents who are Deaf in terms of their reaction to the diagnosis of their child's hearing loss and to the information they receive. Possible reasons for the difference may be as a result of a Deaf parents' perspective in regards to what it means to be Deaf as well as their previous knowledge of hearing loss. The other criteria enabled the study of a system that had never been explored and might, in many ways, be different from the programs or perspectives in the United States.

Parents who met this criteria were contacted by the health region coordinators, informed of the study and asked if they might be interested in participating. In one health region, the clinical audiologist in charge of the UNHS contacted two parents who agreed to participate. The clinical audiologist tried to contact another family, but they had moved out of the area therefore were unable to be reached. Other families who had been screened were not included because the audiologist had yet to verify the hearing loss.

In the other health region, the audiologist in charge of the UNHS program identified six families who had children diagnosed through newborn hearing screening. All six were contacted and four agreed to participate. Reasons pertaining to why two families did not agree to participate are unknown. Two of the four families who agreed to participate were selected for this study. The other two were excluded because they didn't meet the criteria of the study due to additional medical complications.

Parents, who expressed interest in participating, were asked if they would like my contact information or if their contact information could be passed on to me. In all cases, parents agreed to let the health region coordinator pass on their telephone numbers to me.

I contacted the parents to ask if they were still interested in participating or if they had any additional questions. All parents continued to express interest. They were mailed out an information form as well as a consent form, also attached in Appendix D and Appendix E.

The third health region that agreed to participate required some changes in terms of how the study was implemented; this required the study to go through another local ethics committee. In order for this ethics approval, a local investigator of that region had to be a part of the ethics application. A local investigator was contacted and agreed to participate. The local investigator, my supervisor and I prepared another ethics application. Before the new ethics application could be submitted to the third health region, the original ethics with the procedural changes included, needed to be resubmitted at the ethics review board affiliated with University of Alberta. Upon approval of the changes from the University of Alberta, the other ethics document was submitted to the third health region. Once that approval was obtained, a UNHS health region coordinator in this third region was contacted by the local investigator and given an information letter informing him/her about the study. This information letter to health region coordinator is attached in appendix F. In this information letter they were asked to assist this research by mailing a letter to parents who met the specified criteria.

In this third health region, in order for parent participants to be invited to participate, the specified criteria were as follows: 1) parents had to be hearing parents with English as a first language and 2) must have had their infant diagnosed with a sensorineural hearing loss that was detected by the UNHS program. The changes to the recruitment criteria were suggested by the local investigator who was familiar with the ethical procedures in that health region and recommended that wording and participant criteria be made as specific as possible.

Parents who met these criteria were mailed an information letter and consent form by the health region coordinator. The letter informed parents about the study and asked if they were interested in participating. The letter and consent form are attached in Appendices F and G. Parents were also sent a stamped envelope with a return address to the local investigator. The letter also informed parents that if they were interested in participating they could send in their signed consent form with a contact phone number. Of the eight parents who met the criteria and were mailed out the study's information, only one parent expressed interest in participating but, because her response came so late in this project I was unable to use the interview data.

Description of Participants

Five parents, representing four families, (i.e. married parents of one child) from the first two health regions were selected for this study: four mothers and one father (see Table 1 for participant description). Three of the five parents were married at the time of the interview and a fourth was just about to get married a month after the interview. Two parents were homemakers, one parent was an instructor at a college, and one was self employed. Information for one parent was unavailable. Two children were female and two were male.

The age at which infants were first screened ranged from birth to three and a half weeks. The time that the infants were officially diagnosed ranged from six weeks to nine months. The age of each infant at the time of the interview also ranged from one year to three years old. Two children in this study were diagnosed with a sensorineural hearing loss and two were diagnosed with a conductive hearing loss. One child, who was first diagnosed with a sensorineural hearing loss, was found to have a conductive hearing loss later on. The degree of the hearing loss for the children ranged from mild to profound. Two children possessed a health concern in addition to their hearing loss.

All children were developing spoken communication. Two infants with conductive hearing loss had tube surgery to drain the fluid in their ears. Of those infants, one accessed speech language pathology services and the other accessed no regular services. The third infant with a conductive hearing loss received a bone anchored hearing aid (BAHA), and accessed no regular intervention services. The infant with a sensorineural hearing loss was first amplified with hearing aids, then implanted with a cochlear implant. This infant received sign language intervention as well as oral/aural intervention service.

Table 1
Description of Parents

	Name of child	Parents' professions	Age of parents	Age of child at interview	Age at 1st screening	Age diagnosed	# of children in the family	Birth order of child with HL	Type of hearing loss	Degree of hearing loss	Amplification	Communication System
Rachael	Joey	Home maker	20-25	11 months	2 days	6-8 weeks	3	2	Sensori-neural/ Conductive	Moderate	Wore HA for a short time	Speech
Julie	John	Home maker	30-35	3 years	3 1/2 weeks	6 weeks	2	1	Sensori-neural	Profound	Hearing aids and CI	Speech + ASL
Morgan	Samantha	Piano and voice teacher	30-35	17 months	At birth	5 months	3	3	Conductive	Mild-moderate	BAHA	Speech
Paul	Samantha	College instruct-tor	30-35	17 months	At birth	5 months	3	3	Conductive	Mild moderate	BAHA	Speech
Susan	Ella	N/A	N/A	21 months	1 1/2 weeks	9 months	3	3	Conductive	N/A	None	Speech

Note: Names have been changed in order to ensure participant confidentiality.

Data Collection

As previously stated, five parents from the first two health regions agreed to have the investigator contact them directly and the health region coordinators passed on their contact information. The first phone conversation consisted of describing to the parents the purpose of the study and what was required in participation. If parents continued to agree to participate, they were sent an information letter with a consent form attached. Parents were informed that they were free to change their minds at any time in regard to participation. No one refused to participate. An interview time was arranged with parents. Two of the interviews took place in person at the participants' homes, two were conducted in a university office and one interview was conducted over the phone. Informed consent for the first four participants was signed prior to commencement of the interview and the consent form for the fifth participant was mailed out and returned before a time was set for the interview. Confidentiality was assured. All interviews lasted between 60-90 minutes and were tape recorded.

The same procedure was followed for the one parent in the third health region. The parent was contacted by phone, asked if he/she had any additional questions and a time was arranged for the interview to be conducted over the phone.

Interview Procedures

According to Patton (1990), the purpose of interviewing is to "access the perspectives of the person being interviewed" (p. 278). Understanding our experiences is different from understanding the experiences of others. By allowing individuals to offer information without putting ideas of the correct answer into their minds (Patton, 1990), we come as close to understanding our participants' experiences as possible.

According to Merriam (1998), there are three types of interviewing procedures in qualitative research. The three interview structures are 1) highly structured interview, 2) semi-structured interview, and 3) unstructured or informal interview. The method used for interviewing in this study was the semi-structured interview. In this type of interviewing there is a guiding line of questions or issues that the investigator wants to explore. The guide identifies areas or topics of interest, specific questions to be asked, and open-ended questions to be explored (Merriam, 1998). This approach allowed me to follow the flow of the conversation, to follow where parents led the discussion, and at the same time ensured that all areas of interest and relevance were covered during the interview. Merriam (1998) suggests that this type of interviewing is especially beneficial for the novel interviewer, due to the fact that he/she has a guide sheet and is thus able to feel more confident and assured in his/her interviewing skills.

All semi-structured interviews lasted approximately 60-90 minutes. The questions in the interview guide were based on issues highlighted in previous research, which addressed how parents have experienced their children being diagnosed with a hearing loss. The interview guide included questions covering the particulars of the screening process, parents' reactions to the screening and diagnosis, the type of information received, and parents' needs and access to intervention services. The interview guide is attached in Appendix I. Parents were, most importantly, able to direct the conversation and talk about the experiences that were most pertinent to their individual experience. Each interview began by asking parents to tell the investigator about their child. Parents began to describe their experiences. Each interview was slightly different from the other as parents had differing experiences. Issues raised in one interview caused additional questions to be asked in subsequent interviews.

Interviews were audio taped and transcribed verbatim and the investigator transcribed those interviews. Each of the transcribed interviews were sent to parents with a letter thanking them for participating and explaining that they would be contacted again after the analysis of the interviews. After the analysis of the interviews parents were sent another letter with a description of the topics discussed. The second letter, that identified the topics of our interview, was sent so that I could ask the parents "to clarify and amplify the themes that had emerged during the first interview" (Corcoran & Steward, 1998, p. 91). I also informed parents that I would be contacting them again to collect some demographic information and follow-up on the UNHS experience. Follow-ups were conducted by mail and over the phone because all families were outside of the city and therefore direct personal contact at these regular intervals could have been difficult for the investigator.

Data Analysis

Analysis in basic qualitative research involves searching the data for themes to emerge (Merriam, 1998). This analysis is affected by the theoretical framework of the study (Merriam, 1998). The goal of this type of thematic analysis is to understand rather than to know (Barnard, 1997). Understanding comes from reading and re-reading the data to look for the different themes that arise.

The first step of analysis in this study, after the data were transcribed, was to read carefully through each interview numerous times. After the initial readings, “interesting” and “significant” issues or quotes were marked in the margins or highlighted. Next, memos were written commenting on the possible themes and significant insights that emerged from the first reading (Barnard, 1997). These were recorded so that significant themes could be reflected upon. Data analysis was conducted as the data collection was ongoing; this affected subsequent interviews because it led to additional lines of questioning.

In order to manage the data, each interview was printed off the computer in a separate colour in order to facilitate the coding process. According to Merriam (1998), “coding occurs at 2 levels- identifying information about the data and interpretive constructs related to the analysis” (p.164). I began by coding all passages of the interview by creating one to three key words that accurately summed up the sentiment of what a particular section was about. These codes were “informed by the study's purpose, the investigator’s orientation and knowledge and the meaning made explicit by the participants” (Merriam, 1998, p. 179). After this process was completed for each interview, I cut out each coded section and made piles on the floor of each section. Each section of the interview that received the same code as another section, was placed on the same pile. For each section that received a different code, a different pile was created. This process continued for each individual interview. Once all the interviews were separated into like-labeled piles, the entire coded interview was considered. The relationship between the different coded piles was considered continually. Codes were compared with other codes, resulting in some codes being merged and some separated until a grouping of codes emerged into a theme.

Once analysis was completed for the individual interviews, all interviews were compared to each other. This permitted the investigator to understand what “processes and outcomes” occurred by looking across many cases (Merriam, 1998). There was a constant re-visiting and comparing of every interview and the analysis was continued in this manner until no new themes emerged from all interviews.

Personal Perspective

According to Patton (1990), “the qualitative analyst's effort at uncovering patterns, themes and categories is a creative process that requires making carefully considered judgments about what is really significant and meaningful in the data” (p. 406). The individual who makes those types of decisions in qualitative research is the investigator, and therefore it is important to have an awareness of what the investigator brings with him/her to the study, what personal biases and presuppositions there are. If these are brought to light, then the investigator can more objectively handle the data. My biases regarding those things relevant to the study are personal beliefs and understandings that I have developed from reading the literature in this field.

One understanding that I carried with me into this study is that hearing parents generally have a negative reaction to the diagnosis of their child's hearing loss. Literature has led me to believe that parents are very emotional during this time and professionals aren't always adequately trained in order to help parents through this very difficult time. Having stated that, I still believe every family must be viewed on its own and within its own context.

Through my own observations and practicum visits to various deaf and hard-of-hearing childhood settings, I discovered I had my own personal biases in regard to how professionals deal with parents and educate deaf children. These biases are rooted in my view that parents have the right to be sensitively informed about their child's hearing loss and that they have every right to make informed choices that aren't biased in any direction. It is also my belief that professionals should focus on the individual child and provide intervention appropriate for that individual, as opposed to intervention that adheres to one methodology. These biases guide my research, but by highlighting them here, I will allow the reader to become aware of them. I hope to be able to put them aside as I listen to the participants' perspectives in the interviews.

In doing this research I was able to construct a more sophisticated understanding of how parents' needs are being met. I have a more representative idea of what state Canadian programs are in, what is being done well, and what can be done even better. My goal is not to judge parents' experience as good or bad but to understand their perspectives of their experiences.

Credibility/ Trustworthiness

In order to assure the quality of work for this study there are a number of ways in which I tried to ensure the credibility. The first method used in order to establish trustworthiness of this study, was "analyst triangulation" (Patton, 1990, p. 468). Analyst triangulation involves two or more people independently analyzing the same data. One method of analyst triangulation is to have participants review the findings of a study (Patton, 1990). Analysis triangulation was used with the participants of the study when they received the transcripts of their interview. Participants also received a copy of the major topics that emerged from their interview as a result of the analysis. This was conducted to ensure interviews were accurately analyzed and appropriately portrayed parents' experiences.

An audit trail was also kept throughout the entire study. Merriam (1998) defines this as "a detailed account of the methods, procedures and decision points carrying out the study" (p. 31). This detailed account, all contacts, phone conversations and interviews were documented so that, at all times, that type of information would be available. I also kept a journal throughout the interpretation of the data, recording my personal views, insights and issues that arose when dealing with the research, which serve to explain how I arrived at the results.

Ethics

Before beginning the research, a research proposal was submitted to my thesis supervisor. Upon her approval, an ethics application was compiled and then submitted to the University of Alberta's Department of Educational Psychology Ethical Review Committee. When approval was obtained from this committee, health region coordinators were contacted, informed of the study and asked to participate. Their participation required professionals to nominate parents who met the specified criteria.

One health region required a separate submission for ethics approval, therefore a different proposal was created for that health region. A second ethics application was compiled with the help of a principal investigator and thesis supervisor. This ethics proposal was an application for scientific, administrative, and ethical review of clinic trial/health research and was submitted to that particular health region. All the same rights to confidentiality and protection were guaranteed in this health region and consent was also required before the audio-taped interviews began.

Every parent, who participated, provided his/her informed consent before participating in the study, and every parent agreed to be audio taped in the consent form and before the interview began. Each parent was also informed that their identity would be protected as would the name and location of the participating health region and professionals involved.

This chapter provided an overview of the basic qualitative research techniques that were applied to discovering the Canadian IHP context and the five parents' experiences in a UNHS program. Chapter four describes infant hearing programs, specifically the UNHS protocol, diagnostic protocol, and facilitation to intervention services, for four Canadian provinces and one territory.

CHAPTER IV – CANADIAN IHP CONTEXTS

Five Canadian provinces, since 2000, have begun to implement some of the recommendations made by the many task forces and organizations who support the implementation of IHPs. Durieux-Smith and Stuart's (2000) article reported that two provinces, Ontario and Alberta, had announced funding for a program and a pilot project respectively. Yukon implemented a screening program in 2000 (The Hearing Foundation of Canada). New Brunswick implemented an IHP in April of 2002 (Roussel, 2003). Since then, the Hearing Foundation of Canada reported, in February 2003, that Prince Edward Island has also implemented an IHP. The following will entail a discussion of the specifics of these programs in terms of their screening, diagnostics and facilitation to intervention services.

The following is a description of the birth statistics from Statistics Canada for each province from 2003-2004. Taking into consideration six out of 1000 infants will have some form of hearing loss (Watkin et al., 1991), the number of infants born with a hearing loss was calculated for each of the following provinces. In Yukon there were 355 births in 2003-2004, meaning that there were approximately two infants born that year who have a hearing loss. In the province of New Brunswick there were 6, 927 births, meaning that there were approximately 42 infants born that year with some degree of hearing loss. In Prince Edward Island, there were 1, 325 births in 2003-2004, meaning that there were approximately eight infants who were born with some degree of hearing loss. In the province of Ontario, there were 128, 455 babies born in 2003-2004, meaning that in this province there were approximately 770 infants born with hearing loss that year. In the province of

Alberta, out of the 39, 042 children born that year, there were approximately 234 infants born with some degree of hearing loss.

Diagnostic findings of these children have been problematic. A 1998 study, looking only at the province of Alberta estimated that, based on the number of births for that year and considering six per 1000 babies are born with a hearing loss, only eight infants out of a potential of 227 were actually diagnosed with a hearing loss before the age of three (Alberta Universal Newborn Hearing Screening Project, 2000).

In terms of identifying all these children with hearing loss, Canada currently has a "wait and see approach," (Brown, Dort, & Zochodne, 2001, p. 23) meaning that only when a problem is perceived by educators or parents, does an investigation into the child's hearing take place. In Canada, during the last 35 years, the importance of early identification and intervention has been a subject at many conferences and the objective of many task forces (Durieux-Smith & Stuart, 2000). Recommendations were made by these differing task forces and associations in order to improve the late age of identification, providing access to programming and screening infants born in Well Baby Nurseries (WBN) as well as Neonatal Intensive Care Units (NICU) and infants on High Risk Registries (Durieux-Smith & Stuart, 2000). It was also recommended that there be a system in place to track infants and ensure that they receive sufficient follow-up (Brown et al., 2000). These recommendations also were intended to create an awareness of hearing loss in parents and in medical professionals (Durieux-Smith & Stuart, 2000). Unfortunately, in 2000, Durieux-Smith and Whittingham reported that Canada still had "no systematic approach to early diagnosis and management of hearing loss in infants" (p. 60). Durrieux-Smith and Stuart (2000) stated that "it is time that Canada moves beyond the recommendation stage" (p .47)

In 2000, Brown et al. published a survey conducted in 1998, which assessed infant hearing screening programs and the number of infants that were screened in Canadian birthing hospitals. Their survey indicated that approximately 10% of all birthing hospitals that responded to the survey had some type of newborn hearing screening. Most programs were based on HRR or NICUs (Brown et al., 2000). They reported that this accounted for 25% of births in Canada (Brown et al., 2000). This study only served to further support research which has indicated that the identification and intervention provided in Canada is insufficient for infants with hearing loss.

Yukon

In September 2002, an infant hearing screening program was implemented in the Yukon. There are two birthing hospitals, although the one based in Whitehorse delivers the majority of babies. There are approximately 360 births a year. Approximately 15 births a year occur out in the community. The Yukon Hearing Services of Yukon Health and Social Services, based in Whitehorse, service all ages, including infants and children.

Screening

Approximately 95% of infants born in the Yukon are screened. The infants who are not born at Whitehorse General Hospital generally are not screened unless referred by a nurse or doctor who knows what the risk factors are.

Yukon has implemented a two-stage screening program using Otodynamic's Echocheck, a Transient Evoked Otoacoustic Emissions device. The first stage of screening is preformed by nurses at the hospital, alongside other infant screenings such as that for phenylketonuria (PKU). Nurses were trained by Hearing Services staff at the onset of the screening program. As part of the training, audiologists at the Yukon Hearing Services compiled a training manual and provided hands-on training to all the nurses on the maternity ward at the time. The manual educated nurses in regard to hearing loss and how best to inform parents about the screening results. Audiologists at the Yukon Hearing Services clinic were unsure as to how exactly the nurses tell parents about the screening, but many parents already know about the program. Nurses are told to tell parents that the screening is routine, along with all other screenings done on infants. They know that there any many reasons for an infant to receive a "refer" result on the screening and share that information with parents. The audiologist explained that nurses don't need training on how to share the screening results, as they are the professionals who screen for all sorts of health risks. Nurses were encouraged to call the audiology clinic at any time with questions or problems. Parents are informed that their child is about to have his/her hearing screened and they are given handouts. Parents have the right to refuse a screening. Only two families have refused to have their child's hearing screened since the implementation of the program.

The babies who do not pass the first stage of screening at the hospital are screened again at the audiology clinic as soon as possible. The same screening technology, from the same manufacturer, is used for the second screening. The second screening is conducted by any of the staff who work at the Yukon Hearing Services, i.e. two audiologists and a hearing instrument practitioner. The staff at the Yukon Hearing Services conduct the second stage of screening in a sound-proof booth and are able to spend more time ensuring that they get an accurate result. If the result of the second screening is a "refer," only the audiologist at the clinic will sit down and inform parents about their child's hearing loss and the next step in the process. Waiting list issues are not a concern for the second stage of screening due to the short amount of time it takes to conduct an OAE and the availability of staff members. Parents also appear not to be anxious when they come in for their second screen. Approximately one third of infants screened require a second screen. The high referral rate is due in part to the noise level in the hospital and the nurses' heavy work load. If an infant exhibits risk factors for a later onset of hearing loss, he/she is screened again at about six months of age using Diagnostic Otoacoustic Emissions rather than using an automated screener.

Diagnosis

During the first two years of the program there have been no children identified with a sensorineural hearing loss. Although the Yukon Hearing Service has an audiologist trained to do diagnostic ABR, there are no doctors in the Yukon who have agreed to do sedated ABRs if a child were ever to need it. Since the program has never encountered a child who has received a "refer" result for the second screening, the exact procedure for what will be done, in order to diagnose that child, remains to be determined. If there is no one competent to provide diagnostics, the physician will be asked to refer outside of Whitehorse. Referrals tend to go to British Columbia or Alberta.

Intervention

There are very limited services in the Yukon for children who are deaf and hard-of-hearing. If parents choose to have their child receive amplification, audiologists at the Yukon Hearing Services fit pediatric hearing aids using an accepted prescriptive formula. Chronic Diseases provides funding for amplification for children from birth to 16 years. This source does not include funding for FM systems. Funding is relatively easy to obtain, but does require the family to follow through with certain paperwork, which at times can be problematic. Families also can access the Child Development Center for speech language pathology services, although there are no SLPs in the Yukon who are trained specifically for dealing with children with hearing loss. Many families from remote communities in the Yukon move to Whitehorse for services while some move to other provinces where there are more options available to them.

Yukon manages their data to ensure quality by following all children who are screened until they "pass" the screening tests or ultimately obtain a "refer" result. There are so few children it does not take a great deal of effort to track the data. The hospital uses "Meditech" and prints a copy for Yukon Hearing Services clinic which tracks "pass", "pass with risk indicators", or "refer" status. If a child were to be diagnosed with a hearing loss he/she would be provided services by the audiology clinic whenever possible.

Children are also re-screened before they enter kindergarten. While there are cases of children not being identified until four or five years of age, the hope is, as the program becomes established and routine, late identifications will stop. There is also a higher transient population in the Yukon and because screening programs are so inconsistent across the country, the ones who are identified late usually come from outside of the Yukon or from one of the more remote communities of the Yukon and Northwest Territories.

One of the biggest challenges faced by the IHP in the Yukon is the fact that no doctors have said they will participate in the IHP by doing sedated ABRs. Another challenge is the remoteness of some communities, which makes it hard to screen every baby. A positive aspect of the IHP program in the Yukon is that there are so few births, which makes it easier to track all infants. Therefore relatively few infants in the Yukon are not screened.

New Brunswick

An infant hearing screening program (IHSP) commenced in New Brunswick in 2002. As of April 1st, 2004, all eight regional health authorities had implemented the program. There are approximately 7, 800 births per year in New Brunswick. There are between 25 to 30 hospitals in these eight health regions. All audiology clinics are situated in the hospital. Each region uses the same technology and equipment. While there are provincial standards in place, there is a great deal in the New Brunswick program that varies from region to region. The following is a description of a mix of the provincial perspective and one major metropolitan hospital's program.

Screening

The program in New Brunswick is a two-stage screening program. The first screen is conducted with OAE technology, specifically the ABaer from Bio-logic, and is preformed within the first 48 hours of the infants' life. The location of the first screen depends on each health region. The majority of screening takes place in nurseries, as opposed to the mother's bedside. The rationale for screening in the nurseries is that a sleeping infant is most likely to be in the nursery. Parents are informed about the screening before it occurs and they are given the right to refuse. Parents have refused the screening on the rare occasion, but no specific reasons for the refusals are recorded. If the infant receives a "refer" after the first screening the family is contacted by the audiology clinic and an appointment is made for the infant's second, Level-two, screening. The second screening uses both OAE and AABR technology, with ABaer equipment from Bio-logic.

The benchmark for New Brunswick is to have 95% of infants screened. The benchmark for the return rate for Level-two screening is at 90%, and the benchmark for the referral rate to diagnostics is 4%. Currently the provincial referral rate is being lowered through different training initiatives, use of designated screeners, and equipment quality assurance checks.

The individual performing the screening varies from region to region. Nurses, support personnel or, occasionally audiologists perform the Level-one screen. The professional who does the screening might affect whether or not the screening occurs prior to discharge. Support personnel and audiologists work a regular Monday to Friday work schedule; therefore, if they are the designated screeners in a region, babies born on the weekend are often discharged before they can be screened. These families are then contacted by the audiology department and are asked to bring in their child for outpatient screening.

Screeners received their training from audiologists. Each region has compiled different training packages to meet the need of their identified screeners and regional needs. The most extensive package includes a great deal of hands on training as well as some theoretical information and support. The goal of the training package is to help the screeners develop a comfort level with the screening equipment. If the infants receive a "refer" result after the Level-one screening, in most cases, the regions try to have the audiologist impart the information to parents. The audiologists are primarily responsible for Level-two screenings and any further audiological assessment required. The provincial perspective is that there are no wait-list issues, considering the goal is to screen all infants as soon, after birth, as possible.

At the inception of the IHSP, one regional hospital had given the screening responsibility to nurses. Many babies were missed and nurses required support to take on this additional responsibility. Recently, in February 2004, the same hospital hired a "nurse screener" who coordinates the screening program. This individual works Monday-Friday and does all the screening. She received her training from the audiology staff. This nurse is responsible for informing parents about their child screening results and books the diagnostic appointment for infants requiring a diagnostic appointment.

Diagnosis

The diagnostics occur either after the infant receives a Level-two "refer" result or an appointment is scheduled for the family to come in at a later time. The benchmark for the percentage of children that the program would like to have diagnosed by four months is 95%. There is a different protocol in each region regarding the diagnostic component of their program. After the diagnostic testing, audiologists counsel parents regarding the results and refer families to other medical services if needed. Currently, a professional development workshop is scheduled for May 2005 to help audiologists province wide develop sensitivity when it comes to sharing information with parents about hearing loss.

Since August 2004, 18 children have been diagnosed with a sensorineural hearing loss ranging from mild to profound. Cases of conductive loss have also been picked up along the way. Currently, no information is available in regard to the number of infants with additional disabilities. The number of false positives is unavailable provincially. One regional hospital reported that out of the 19 infants that were sent for audiological diagnostics, six were diagnosed with a hearing loss.

A challenge being faced by all regions is getting parents to return for their follow-up appointments. In one regional hospital, approximately 30% to 40% of families do not bring their infant in for their follow- up appointment, however, further education with parents and public health staff is expected to assist in reducing this number. Health regions are in communication through meetings and teleconferences in order to determine how best to deal with this current challenge and to share the successes of each regional service.

Intervention

The benchmark for referring children to the appropriate childhood initiatives within the first six months is 100%. The benchmark for amplification within the first six months is 95%. There are multiple intervention options for a newly diagnosed infant in New Brunswick. One option is for parents to access the Atlantic Provinces Special Education Authority (APSEA) which provides services in New Brunswick. APSEA offers services in English. APSEA can provide parents with auditory verbal therapy, sign language instruction, and additional support as the child reaches school age. There is a French service offered through the provincial Department of Education. The services are offered to children from birth to 21 years. The government of New Brunswick's Department of Health and Wellness also has a program called the Extra-mural Program. It, along with hospital based speech language pathology services, provides speech language pathology and occupational therapy to families of a newly diagnosed infant. Both of these programs and their services are offered to parents free of charge.

One of the biggest challenges in the implementation of the IHSP in New Brunswick has been getting the support of the required organizations for implementation in all regions. Based on their experiences, one recommendation made for upcoming programs is to have an audiologist from each region be a front-line representative to help direct the program, create guidelines and address implementation issues. These front-line individuals could then form a working group to support the implementation of an IHSP.

To ensure the quality of the program in New Brunswick, program coordinators are now focusing on the tracking and managing of the data. They are working to create a provincial system in which all data can be tracked, collected and analyzed which will be running by April 1st, 2005.

Prince Edward Island

An IHP was implemented in P.E.I. in January 2004. The province has two health regions which are both participating in the program. There are approximately 1, 500 births per year in the two hospitals. It is unknown how many births occur out in the community. Discussions between public health and the IHP coordinator suggested that there were few, if any, births outside the hospital. This screening program therefore only screens those infants who are born in either of the two hospitals.

Screening

The screening protocol in P.E.I. is a two- staged screening process. The technology employed is AABR for both stages, specifically the ALGO 2 from Natus Medical. The first AABR screen takes place, ideally, 12 hours after birth. The location of the screening varies in hospitals and is situation dependent. One birthing hospital has mother-infant care and the other has nursery-infant care, therefore screening may take place either at the mother's bedside or in the nursery, respectively. Parents are informed that their infant is about to have his/her hearing screened before it occurs; that it is a routine practice. The second stage of screening is also done with AABR technology. This screening is done before discharge, but the exact time that it occurs is variable and at the discretion of the screeners.

Nursery nurses are responsible for screening in the hospital. They were given start-up training and on-site support for the first few months from the audiologists. Start up training entailed hands on experience with the equipment and provided nurses with the appropriate language to be used while talking to parents about the screening. Once the initial training was over, screeners received monthly support visits unless there were situations which required the audiologist's presence more frequently. Nursery nurse screeners also have been given instructions composed by the audiologist, which they can reference at any time. All screening results are forwarded to the audiology center.

If an infant receives a "refer" result on both stages of the screening, the nursery nurse informs the parents that they need to see the audiologist. The nursery nurse contacts the audiology clinic to make a referral. The audiology clinic will contact the family to schedule an appointment.

Ninety-nine-point-nine percent of infants born in the hospital have been screened. There is only one child who has remained un-screened because, when the AABR machinery broke down in the hospital, they had to track down all the parents, whose infants were missed. One family was unable to be recalled because they had already relocated. Estimates of the number of infants who receive "refer" results for the second stage of screening are compiled regularly. Percentages have ranged from as low as 5% to as high as 8%. Initially, when the program was just getting started, some mothers were being discharged before the second screening could take place. The learning curve experienced by nursery nurses has been steep, but the program is now running more smoothly as all those involved are better accustomed to the screening procedures and therefore more accurate screenings are occurring.

Diagnosis

There is only the one clinic that services all the infants that are screened in the two hospitals and only the audiologist in charge of the program is responsible for testing infants. The referral rate for infants needing diagnostic audiology is 1.2% (approximately 18 babies). Of those 18 infants, three are identified with permanent hearing loss. There are a battery of tests which make up the diagnostic protocol. Examples of such tests are: OAEs, diagnostic tone burst ABR by air conduction, as well as by bone conduction. Clicks are sometimes used in order to determine if further investigation is required. Diagnostic assessments are scheduled within a month of discharge from the hospital. The audiologist reported that this is the best time to conduct diagnostics on babies as they sleep most soundly during their first month. The audiologist does not conduct any middle ear testing with the infants that she sees for diagnostics. Only if they become regular clients and once they are a little older does the audiologist conduct middle ear testing. There are no wait-list issues for screened infants to access audiologists for diagnostics because they have priority in P.E.I. Prioritizing infants has caused waiting list issues for other populations of children waiting to have audiological testing. The clinic has not had any issues in getting families to attend their diagnostic audiology appointments.

Three infants have been diagnosed with a hearing loss thus far. All have been diagnosed with a sensorineural hearing loss. One infant was diagnosed with a unilateral profound hearing loss, another with a profound bilateral hearing loss, and the third infant with a moderate high frequency hearing loss in both ears. One of these infants might have a disability in addition to his/her hearing loss but it has yet to be confirmed.

The audiologist informs parents that their child has a confirmed hearing loss. After the diagnostic appointment, the audiologist does one of two things. If she feels as though parents are able to handle the information and discussion, she will give them a confirmed diagnosis and proceed with the intervention which, in P.E.I., involves taking ear impressions, ordering hearing aids and beginning oral/aural habilitation. If she feels as though parents are unable to handle the information, she will schedule a follow-up session which may involve more or repeated diagnostics for confirmation and counselling. Usually, the second session is scheduled 2 weeks later; some tests may be redone and then the family and the audiologist discuss the results, go into detail about the implications, and takes ear impressions. The audiologist explained that parents' readiness to handle the information is something she "gets a feel for" while working with the families.

Intervention

Once a child is diagnosed, he/she is closely followed. There is a program for habilitation called the Hearing Education Auditory Resource where parents can access the services of an auditory verbal therapist (AVT), a SLP, an ENT and often a pediatrician. Parents can also access a program for hearing aid funding. There is no sign language alternative for families in P.E.I. that the audiologist was aware of. She suggested that the SLPs could provide some training in the area, but that it would be very limited. Parents are informed upon diagnosis about the services that are available to them in P.E.I. Parents thus far have not asked or been informed about the out-of-province intervention services that might be available to them with the exception of information on cochlear implant programs and candidacy. The audiologist expressed her preparedness to inform parents of other options outside of P.E.I., if that information were requested.

Parents are responsible for coordinating their own services for their child. The audiologist and AVT work together, but all other services function independently. The AVT usually conducts home visits and can act as case coordinator although that is not her primary role.

Funding for services in P.E.I. is cost shared on a sliding fee scale, meaning that funding responsibilities of the family will vary depending on the family's income. Funding covers hearing aids, earmolds, repairs, equipment maintenance and batteries. Funding also covers sound detecting devices such as flashers, silent call alert systems and TTYs. These are available until 21 years of age. SLP and AVT services are part of a publicly funded program so there is no fee attached to these services. Funding does not cover FM systems.

The audiologist uses an ALGO tracking system that Natus Medical, a screening equipment manufacturer, provides. It is a database and analysis program. This program allows the audiologist to track the number of infants tested, the results of the initial and final referral and the average time taken to screen each infant. False positives and other measurements must be done manually.

Some of the biggest challenges that the P.E.I. Infant Hearing Program has faced its implementation have been 1) getting the funding to set up the program and

2) bringing the nursing staff on board initially, because of the additional time and commitment that was required of them to implement the program for no additional salary. A positive aspect of the IHP implementation was the multidisciplinary team that was created to advocate for the program. The team assembled gave a high profile to the program. It was composed of two representatives from each health region in the following areas: nursery nurses, public health representatives, ENTs, pediatricians, hospital administration and the department of health and social services. The audiologist and AVT were also a part of the interdisciplinary team. Another factor that the audiologist attributed to the success of the program was the screening technology. The audiologist stated that the AABR screenings keep referral rates low so that excess time is not spent doing diagnostic audiology on babies with normal hearing. Also, once the nurses were on board their commitment contributed to success of the program. The IHP is unique in that, the size of the province makes it relatively easy for all families, with infants born in the hospital, to be screened and referred to the audiologist. The greatest distance that families would ever have to travel is two hours in order to get to the audiology clinic. The audiologist believes that this factor also helped to make the program more feasible.

Ontario

An infant hearing program (IHP) was implemented in the province of Ontario in the neonatal intensive care unit in February, 2002, and in the well baby nursery in October, 2002, by the provincial government of Ontario (now the Ministry of Children and Youth Services). The Ontario IHP is a very comprehensive program composed of three parts; the universal newborn hearing screening, audiology services and communication development. There are 12 different districts in Ontario and all districts are screening all newborns in hospital, predischarge from the birth admission. There is also a protocol in place for midwives to screen newborns born in the community.

Screening

For well babies, the IHP uses a two-stage screening protocol, but in the first stage of screening the infant is screened with two different types of screening technology. Stage-one screening occurs either in a nursery, the mother's room, or in a special screening room. The first screen is done with an automated DPOAE and, if the child receives a "refer" result on that screening they are re-screened with an AABR. The DPOAE screening equipment is AuDX, and the AABR equipment is ABaer, both by Bio-logic. The second screening in Stage-one occurs either right after the first screen or before the child is discharged from the hospital. Stage-one screening occurs at least 18 hours after a child is born (if possible) and after 34 weeks gestation for infants born prematurely. For infants who receive a "refer" result, Stage-two screening takes place two to four weeks later with an AABR. This screening occurs in community screening clinics in a variety of settings in the community (Hyde, Friedberg, Price & Weber, 2004). The Ontario IHP reports that there are no wait-list issues concerning the screening component. Any baby who misses the screening before he/she leaves the hospital will have an appointment automatically made for him/her if the parent agrees. Information on babies missed in the hospital is sent to the regional IHP offices, and the family is contacted to book an appointment. Babies that meet one of a list of risk indicators for congenital or late onset/progressive permanent hearing loss are screened at birth with an AABR and if they received a "refer" result on the first screen, full diagnostics are preformed by IHP audiologists.

Last year in the province of Ontario, 85% of all infants born in the hospital were screened, but many babies that year were not screened due to SARS, a syndrome that created complications for hospitals in Ontario. Approximately 10% of those infants screened required the second stage of screening.

Parents are given information about the hearing screening process in prenatal classes, by their physicians, and then by the hospital and screening staff. The government has also developed brochures to explain and describe every step of the screening process. These brochures are produced in 13 different languages. Parents are given these brochures when they are admitted to the hospital and after the screen; there is also a video that plays on the TV channel in their rooms while in hospital.

The screening staff is composed of nurses and some dedicated screeners. Midwives also screen their own patients. The screening staff is responsible for informing a parent of their infant's screening result and if they must see the audiologist. All individuals involved in the IHP have received standardized training on the program, equipment and in communicating with parents. An Ontario government consultant team created the standardized training protocol with a variety of experts, with their respective specialties from all around the world. Audiology staff from the equipment manufacturer helped with screening equipment training. Audiology experts in assessment of physiologic tests of hearing helped with the protocol for diagnostics, and an audiologist from Kansas helped create the visual reinforcement audiometry protocol. Individuals from the Colorado Home Intervention Program helped to train the audiologists and social workers.

Diagnosis

Last year, the referral rate to diagnostics was 1.5%. Hyde (2000) attributed the low referral rate to the additional screening in stage one of the screening protocol. Each health region is responsible for collecting information pertaining to the number of families that don't bring their infants in for follow-up audiological appointments. In order to get a confirmed diagnosis, the infants undergo a battery of tests. Audiologists conduct tone pipe ABRs in order to determine frequency specific information, DPOAE, middle ear tests encompassing reflexes and tympanometery. Cochlear mircrophonic testing is also conducted, if required, in order to detect auditory neuropathy. In some situations more than one visit might be required in order to conduct the battery of tests.

In order to inform parents that their child has a confirmed hearing loss, audiologists work as a part of a team with specially trained social workers. The audiologist gives the information to families and discusses results. The support of the social worker is optional for families. Infants with an identified hearing loss are referred to a pediatric otolaryngologist or physician for a medical evaluation. Infants are seen by the audiologist for diagnostics between 8 to 12 weeks corrected age.

Last year 147 infants were identified with a hearing loss, an increase from the 15 who were identified in 2002-2003 (Toronto Preschool Speech and Language Services, 2003). Last year, 14% of infants were diagnosed with unilateral hearing loss, 17% had a mild hearing loss, 10% had a moderate, 16% had a moderate to severe, 25% had a severe and 8% had a profound hearing loss. Approximately one third of all children screened have a developmental challenge in addition to their hearing loss. It is estimated that one out of five infants sent to the audiologist had normal hearing.

Intervention

Communication development is an important component of the IHP. The IHP is a non-profit program and services are provided to families free of charge for up to two and a half years after the diagnosis is made. The funding for the program pays for all the services that families receive as well as service providers' salaries. By controlling the funding, the IHP is able to ensure standardized service delivery. After that, children are transitioned to other services in the community. Another very important element in the Ontario IHP is that parents receive unbiased and evidence based information about communication options and they are able to make informed choices (Hyde et al., 2004). The IHP has produced numerous video programs and brochures in order to provide information about all communication options available. Each health region also has a family support worker (FSW) who provides parents with unbiased information about their options and offers counselling services to help them through the diagnosis. The FSWs have varying credentials in each health district and are trained on the standardized IHP protocol. Initially, the position of the FSW was to be filled by an individual who had little knowledge about hearing loss and had worked outside the field to ensure that he/she wasn't biased towards one communication methodology. The IHP then trained the FSWs in hearing, hearing loss and communication issues to ensure they are able to help parents most effectively.

Audiologists refer families to the FSW as soon as the diagnosis is made and he/she contacts the families, within 48 hours of receiving the referral, to set up an appointment to meet with parents to discuss their options (Toronto Preschool Speech and Language Services, 2003). Parents can choose when they would like to set up the meeting. Meetings may take place at the family's home, or a mutually agreed upon community location. Parents are supported through the diagnostic process and are provided counselling for their concerns. As appropriate for the needs of the child, parents may be given videos on two differing methods of communication to watch and discuss with the FSW. Parents can also request to meet with professionals from the different communication methodologies. The FSW has a resource binder that he/she brings to the parent meetings, which was designed by the IHP, explaining all the different options available to parents.

The communication development services that are available to families in Ontario are: auditory verbal therapy, American Sign Language, Langue de Signe de Quebec, the dual approach (sign and oral language), and a home visiting program from the provincial School for the Deaf, as well as other services as required by the child and family. For parents who choose to have their infant's hearing amplified or aided, the hearing aid assessment is preformed by a specialized pediatric audiologist who has had special training in servicing infants. Some children might also obtain speech pathology services from any of the 32 preschool programs that are in the province (Ontario; Early Year, 2002). All screening, audiology and communication development services are provided through program funding for children age 0 - 2 ½. Some funding for hearing aids is provided through another provincial program - Assistive Devices Program, but parents have to pay some portion themselves.

The tracking of data is also an important component of the IHP. The IHP continuously evaluates their outcomes and the quality of the program in order to constantly make improvements. A customized data tracking system is used throughout the province, which tracks every baby served by the program, provides service and wait list information, and provides all of the information needed to evaluate program outcomes both regionally and provincially. One of the challenges faced by the IHP is in providing families with evidence-based information regarding communication development services for their infants because, good evidence in this area is lacking in the world community. Since the implementation of the IHP, over 300, 000 babies have been screened in Ontario and, of those infants identified with permanent hearing loss, the first of them are being transitioned out of the program with age-appropriate language skills – enabling them to reach school ready to learn on par with their hearing peers.

Alberta

The situation in Alberta is different from other provincial programs discussed thus far. Alberta currently doesn't have a provincial UNHS program. In 2000, a Health Innovation Fund application was submitted to the government of Alberta Health and Wellness, from the University of Calgary's Auditory Research Program, proposing the implementation of a UNHS pilot project in Alberta Regional Health Authorities (RHA). The goal of their project was to screen infants born in RHAs in the first three months and provide seamless access to more comprehensive diagnostic testing (Dort, 2000).

The Alberta Hearing Screening Study was implemented in four RHAs in Alberta from a total of 17 RHAs, which shrunk to nine during the course of the funding due to provincial restructuring. Out of the four RHAs that agreed to participate in the study, there were 14 birthing hospitals involved in the UNHS program. The information in this section, on the Alberta situation, is somewhat vague because the government has not yet approved the numbers from this research and the findings of the pilot project have yet to be published.

The study began in May 2001 and ran until 2003. All regions have continued to do the screening after the research completion date was passed, although one hospital in Calgary has scaled back its screening while they are developing a new screening model. In one region they have expanded their screening to the cover the additional hospitals which were incorporated during the shift in the region boundaries. There were approximately 1, 500 to 2, 000 infants that were born in each hospital in Calgary and approximately 20, 000 infants screened from 2001-2003.

Screening

The Alberta Hearing Screening Study uses a two-stage, two-technology screening system. The first screening is done with an OAE, specifically the Ero-Scan from Etymotic Research. There is no specified protocol pertaining to where the screening must take place and, therefore, there are a multitude of places where the screening occurs, depending on each region. Typically the screening takes place at the mom's bedside. The screening occurs a minimum of 12 hours after birth.

If an infant receives a “refer” result on the first screen, he/she is brought in as an outpatient for a second screening with an OAE, using the same equipment as the first screen, the Ero-Scan from Etymotic Research. If the infant receives another “refer” result, he/she is directly screened with an AABR, specifically the ABaer from Bio-Logic Systems. Depending on the region and where the equipment is set up, families take their infant either back to the hospital or into an audiology clinic. The second stage of screening usually occurs within the first month. Initially there were some waiting issues experienced in the large metropolitan region.

The project is overseen by the Provincial Screening Coordinator, who is an audiologist. Each RHA is comprised of regional coordinators who are all also audiologists. Each region determines who will do the first and second screening in their region. The screenings are conducted by either nurses or dedicated screeners. The bigger the hospital the less likely it is that the screening is being conducted by nurses. Screeners were trained by the regional coordinators. Sometimes the coordinators would train either all the screening staff or just one individual who would then train all others involved in the screening. Staff were trained on the care and use of the equipment and the UNHS protocol. The protocol explains overall what needs to be done in the program and how. Its execution is variable in each region so long as the major criteria are met. Training time is spent on educating screeners about how to talk to parents, so that the results of the screening don’t alarm the parents too much; but screeners do emphasize to parents the importance of returning for their next appointment.

Parents are not always informed that their child is about to undergo a hearing screening test. Some regions require parents to sign a consent form while other regions view the hearing screening as being covered under a blanket standard-of-care policy and therefore do not inform parents prior to screening. Parents in Alberta have been educated about the infant hearing screening through different awareness efforts. Pamphlets about hearing screening are sent to doctor's offices, and parents are educated through prenatal classes. Nurses and dedicated screeners also perform the second screening and are responsible for informing parents that their infants needs to have his/her hearing assessed further with an audiologist. Approximately 70% of the infants who went on to stage-two screening had normal hearing.

It is difficult to estimate the exact percentage of infants screened in the Alberta UNHS study because of the difficulty in determining the exact number of infants born in each hospital. This difficulty is a result of different hospitals using different tracking systems. Only two regions were able to integrate their hospital database with the projects. The different databases or tracking systems made it harder to determine the denominator (number of babies born at a facility) as well as to track infants requiring follow-up. In the regions where each birth was tracked and reported to the pilot project, there were a very high percentage of infants screened.

Diagnosis

The Alberta Universal Newborn Hearing Screening Project is not a comprehensive IHP; its mandate was only to implement the screening portion of an IHP. That is not to say that the Alberta UNHS study was not concerned with the diagnostics and intervention services for infants. Although not a formal part of their protocol, program creators established guidelines for each of these areas, but could not enforce the recommendations made.

The pilot project has a 2% referral rate and .5% of those children have a confirmed hearing loss. Out of over 20, 000 infants screened, 880 did not come back at various stages for a follow-up appointment. Recorded reasons for infants not returning for the appointments have been listed as follows: some parents moved out of the region covered by the project; some parents could not to be contacted; some parents declined; and for over half of all parents who didn't attend their appointment, no reasons were given.

The diagnostic component is at the discretion of the audiologist. There are recommended guidelines, but because audiologists are not being paid through the Alberta Hearing Screening Study, the program can not tell audiologists what to do. The guidelines for audiologists are a two-step process. The guidelines for the first step, the initial consultation and audiological diagnostic assessment, recommends that infants undergo an unsedated tone ABR, OAEs, and middle ear measurements. The guidelines for the second step, the confirmed hearing loss assessment, recommends that audiologists talk to parents about the results of the testing, the importance of early intervention, possible amplification and available support groups. Recommendations are also made regarding how to make referrals for medical evaluations and specialty evaluations (Alberta Universal Newborn Hearing Screening Project).

Intervention

In the documents containing Alberta's UNHS pilot project guidelines and protocols, there are numerous recommended procedures for early intervention. One recommendation is that all children receive appropriate intervention between the first three to six months. Other recommendations suggest that infants with hearing loss must be assessed in terms of their language, speech, communication, cognitive, motor and personal-social skills. It is also recommended that the infant-parent interaction be assessed and that parents be informed about intervention options. Next, families should be enrolled in their chosen intervention. Another recommendation is that infants and families progress should be monitored and evaluated, and changes to the program should be applied when needed (Alberta Universal Newborn Hearing Screening Project).

When asked, the co- investigator of the Alberta study said that tracking was the key to any successful UNHS program. The project developed a centralized computer tracking system. After every test, the results are downloaded and sent to a central database at the University of Calgary. At birth, each infant is labeled with a unique lifetime identifier and regardless of the location or stage of the infant's hearing assessment, his/her results are uploaded to the same database. Once a week program implementers print off a list of all the results. This enables them to ensure that appropriate follow-up is attained by all families for whom it is required. Each RHA is also required to report on all the following information: number of live births, number of infants screened, number of infants returning for follow up, number of infants referred for diagnostics, number of infants with diagnostics by three months, number of infants with confirmed hearing loss, number of infants with permanent congenital hearing loss aged 0 to 7, average median age in months of infants diagnosed hearing loss, and number of infants receiving intervention by six months (Alberta Universal Newborn Hearing Screening Project).

Through the project, the cost of the screening was covered for all infants. The cost of the diagnostic assessment was covered through global funding provided to the RHA for audiological assessments. The cost of the hearing aid (if required) was covered on a cost-shared basis with the province; however, parents pay a considerably larger portion than the province for the aids. Intervention costs, although not a part of the study, are a mixed bag. Some services are covered by Alberta Health and some by provincial early intervention services.

One of the biggest concerns, for some RHA, was that all the infants identified through UNHS and needing diagnostics would flood their system and create enormous wait-list issues. Participating RHAs have found that the screening actually saves them diagnostic time because they no longer get as many referrals from family doctors, and they have, in fact, saved money by doing the infant screening. The Alberta UNHS program has kept referral rates low with their two-stage, two-technology screening protocol and that has been a very positive aspect of their program.

The co-investigator of the Alberta UNHS Study identified that one major challenge faced in the implementation of the program was the inability of all regions to be a part of the same tracking system. Another challenge resulted when it came to educating people on all sides of the issue regarding the need for an IHP. The co-investigator explained that some of the resistance encountered was from parents, who he perceived were afraid of the technology and the unknown, and that they didn't want the screening to hurt their child. The co-investigator also explained that some resistance was encountered from physicians who were also not 100% on board because of the negative aspects in the literature pertaining to the screening. A recommendation that the co-investigator made for helping to create a successful UNHS program would be to have one "champion" in each region, meaning someone who supports the concept of UNHS and is willing to work hard at educating those involved about its benefit.

Summary

This chapter provided a brief look into the current Canadian IHP context. An overview of each program is presented in Table 2. Programs from Yukon, New Brunswick, Ontario, P.E.I., and Alberta have been described according to their universal newborn hearing screening protocol, diagnostic protocol, and the protocols established to ensure facilitation to early intervention services. The funding opportunities, the challenges and successes faced in the implementation of each program have also been described.

Chapter five will describe parents' experiences in one of these Canadian programs. Parents' individual stories will first be described, followed by each of the nine themes that emerged through the analysis. Quotes are used to illustrate each theme.

Table 2
Overview of Canadian IHPs

	Yukon	**Alberta**	**Ontario**	**New Brunswick**	**Prince Edward Island**
Year Implemented	December 2002	2001-2003	October 2002	2002-2004	January 2004
Total Number of Health Regions/ Birthing Hospitals	2 Birthing Hospitals	9 Health Regions	12 Districts 5-27 Birthing Hospitals per Region	8 Health Regions 25 – 30 Hospitals	2 Health Regions 2 Birthing Hospitals
Number of Health Regions/ Birthing Hospitals Screening	1 Birthing Hospital	4 Health Regions 13 Hospitals & 1 Health Unit	12 Districts 5-27 Birthing Hospitals per Region	8 Health Regions 25 – 30 Hospitals	2 Health Regions 2 Birthing Hospitals
Total Number of Births 2003-2004	355	39 042	128 455	6 927	1 325

Stage 1 Screening :					
Technology	TOAE	DPOAE	DPOAE AABR	OAE	AABR
Manufacturer	Echocheck Otodyanmics	Ero* Scan Etymotic Research	AuDX- Biologic ABaer- Biologic	ABaer Biologic	ALGO 2 Natus Medical
Time of Screen	First 24 hours	Min. 12 hrs after birth	First 18 hours	24-48 hours	First 12 hours
Location	Bedside or quietest place	Varies: Most common location is mom's bedside	Nursery, Beside, screening room	Nursery	Nursery or bedside
Screener	Nurse	Nurse, Dedicated Screener	Nurse, dedicated screener	Nurse, Support Staff, Audiologist	Nursery Nurse

	Yukon	Alberta	Ontario	New Brunswick	Prince Edward Island
Stage 2 Screening:					
Technology	TOAE	DPOAE AABR	AABR	OAE AABR	AABR
Manufacturer	Echocheck Otodyanmics	Ero*Scan Etymotic Research ABaer- Biologic	ABaer- Biologic	ABaer- Biologic	ALGO 2 Natus Medical
Time of Screen	6 weeks- 1 month	Within 1st month	2 weeks later	Varies	Varies, before discharge
Location	Outpatient	Outpatient	Outpatient	Outpatient	Nursery or bedside
Screener	Audiologist or *hearing instr. Spec.*	Nurse, Dedicated *Screener*	Nurse, dedicated screener	Audiologist	Nursery Nurse

Diagnostics and Intervention					
Number of Infants Diagnosed	0	Unavailable	147	18	3
Counsels Families Regarding Implications of Hearing Loss (HL)	Audiologist	Audiologist	Family Support Worker	Audiologist	Audiologist
Intervention services available for Infants 0-5	Child Dev. Center, Chronic Disease, Audiology	Audiology, SLP, ENT, AVT, Early Intervention	Family support, AVT, ASL, dual approach, etc...	APSEA, Extra-Mural, Audiology	Hearing Ed. Auditory Resource, SLP, ENT, Audiologist
Tracking Program	Audiologist tracks by hand	Centralized Computer Tracking	Customized Data Tracking System	In Development	AGLO Tracking System
False Positives Rates	0	Unavailable	1/5 have no HL	Unavailable	15/18 have no HL
"Refer" Rates	0%	Benchmark is 2%	1.5%	Benchmark is 4%	1.2%

Note: Not all provinces have a comprehensive Infant Hearing Program; some provinces have implemented only a newborn screening program.

CHAPTER V- PARENTS' PERSPECTIVES

The intent of part two of this study was to better understand and learn from the experiences of parents whose children had been diagnosed through a UNHS program. Analysis of the data determined the themes of each parent's interview and then the common themes across all interviews. While each parent's experience with a UNHS program is very individual, similarities were made evident by the nine themes that emerged through the analysis: 1) the impact of the diagnosis, 2) the ways of coping, 3) the amount, nature and impact of the information provided, 4) the individual needs for information, 5) the impact of professionals, 6) the decision making process, 7) the services provided, 8) recommendations and, finally, 9) support and praise for UNHS. Each theme is presented and summarized followed by a description in the parents' own words of their experiences that relate to the theme. This provides the reader with a richness of the significantly impacting UNHS experiences that parents underwent. This chapter will begin with a description of the stories of the parents who participated in this study.

Parents Stories

I interviewed five parents of four children who were diagnosed with a hearing loss through UNHS. The following is a brief description of each parent's experience in the program. Their stories outline their experiences with newborn hearing screening, receiving the diagnosis of hearing loss, and their initial attempts at seeking intervention services. Names have been changed to preserve confidentiality.

Rachael

Rachael's child, Joey, is a little over a year old. Rachael's labour was induced by a serious three car accident and she was rushed to her hospital with injuries and to deliver. After her child's birth, on the second night at ten o'clock, a nurse came in to check on Rachael and Joey about feeding issues. The nurse questioned how Joey was feeding and Rachael explained that, after feeding was finished, there was a large amount of formula that had leaked on to the bib and therefore that Joey wasn't getting down a great deal of food. After she had finished questioning Rachael, the nurse took the baby and when she returned she had the pediatrician with her. The pediatrician informed her that Joey had cleft palate and that there was a potential that Joey also could have a hearing loss. The next morning a nurse came in and screened Joey's hearing. When asked about the information she was given about the hearing screening Rachael replied, "They didn't, because I had it done with my first son so I kind of knew they tested hearing, all babies get it done and that was about it". The nurse tested Joey's hearing three times and he received a "refer" result on all three tests.

Six to eight weeks later Joey was screened again and he was referred on the screening. Following that, an appointment was made for a diagnostic ABR. At this appointment the audiologist informed Rachael that Joey had a hearing loss and she was told that the hearing loss was not congruent with a conductive hearing loss that is usually associated with cleft palate; it might be in the inner ear or the middle ear. Basically, the ENT said, "He was just deaf".

The ENT recommended amplification immediately, but informed Rachael that Joey would never speak. When Joey was six months, he began to get ear infections. At eight months, he went to the ENT to have tube surgery to drain the fluid that was in his middle ears. At this appointment, Rachael reported that she thought her child's hearing was improving and had been since he had cleft palate surgery. She informed the ENT:

> I actually noticed after he had his cleft palate surgery and … oddly enough it seems like ever since he has had his palate surgery he's hearing better but they didn't do anything to his ears. I asked, "How does fixing the roof of his mouth together affect his ears?" The doctor said, "Well oddly enough, the muscles in your cleft palate, like when you yawn, they stretch and they pull down on your Eustachian tubes, which drains fluid." He said. "So there could have been mucus or something in there and as soon as we got that fixed and he yawned for the first time, it pulled and it drained and he was hearing better."

The ENT then informally tested Joey, assessing whether or not he would turn to loud noises, and commented that it was possible that he may not have a sensorineural hearing loss. They proceeded with the tube surgery. An hour and a half after surgery, they tested Joey and found he had normal hearing. After this testing the ENT said, "Now that I look at those results you know those peaks aren't very big so maybe he had fluid from the very beginning…"

During the time that she was dealing with her child's hearing loss, Rachael was very proactive. She incidentally found out about a teacher of the deaf whom she saw two or three times over a period of four months. She also contacted a speech language pathologist but was informed that he/she wouldn't see her child until he was eighteen months. Of the eight months that her child was diagnosed with a hearing loss, he wore his hearing aids for only three months, because there were so many problems with fitting them, with them breaking down and with her child's ear infections.

Susan

Susan's infant, Ella, is two years old. Susan's child also has some additional health issues but they were not discussed during the course of this interview. Susan learned about newborn hearing screening when she was at the hospital for a visit unrelated to her pregnancy. The hospital staff:

> just mentioned that it was just coming into effect as my due date was coming up and that they would probably stop in to see me while I was in the hospital and do early infant hearing screening. So they'd actually given me the pamphlet but it was through speech language hearing services.

Her child was first screened when she was a week and a half old because she was missed before being discharged from the hospital. Ella was referred on her first screening and the screeners told Susan "Well, there's nothing to be concerned about. Just bring her back in a few weeks and we'll try again". Susan's reaction to this was, "Okay, not a problem. I'm flexible." A week later Susan "brought her back in [for a second screening] and she failed that one. Again she got the excuses, 'Well you know she's really rattly.' And I didn't think too much of it." Again Susan was told that she should come in for another screening. Another week later, her baby was screened again, and received another "refer" result. The screeners this time blamed it on faulty machinery. Susan said that "there was always an excuse as to why it wasn't working. Instead of the possibility existing that she actually had a hearing problem."

At this point Susan demanded to see an audiologist:

> By this time I am a little upset. And I just said, "Okay." I said, "Listen, I'm not coming in again, obviously. Either there is something wrong or this is not working for her so I want to get in to see an audiologist to find out exactly what is going on."

She went to see her pediatrician and told the doctor of her suspicion, the doctor clapped loudly behind the baby and the baby didn't flinch. The pediatrician then made the referral to the audiologist. Susan got into audiology by the time her child was three months old. In Susan's situation, her audiologist wanted to have Ella sedated in order to conduct the diagnostic ABR but the pediatrician refused to sedate her young baby. Because Ella wasn't sedated, when she woke up during testing and made a movement or a slight noise, the testing had to start all over again and therefore the hearing test wasn't completed in one visit. "We went back, I don't know how often between then and the time that she was nine months old" to see the audiologist to determine why her child was receiving "refers" on the screening tests. Susan described her experiences in finally receiving the diagnosis of Ella's hearing loss:

> We went to the doctor and asked to see the ENT, totally for an unrelated, or so I thought, an unrelated problem, that's when [the audiologist] from the

hospital asked if he could send a report in to the ENT. The ENT took a look at the report and then said, "So I see we're going to need some tubes."

As the ENT was looking over Ella's audiology file, looking over some of Ella's reports, he determined that Ella had a middle ear infection; therefore, a conductive hearing loss and, in his opinion, Ella needed tube surgery to drain the fluid in her middle ear and help to clear up her conductive hearing loss. All of this information was new to Susan and something she had never heard of before. Susan described her reaction to finally hearing about the status of her child's hearing, "It was like ... okay, it was one of those... I guess so. But I said, no that's not the reason we're here." When Ella was having tube surgery to drain the fluid in her middle ear, Susan also found out that Ella's hearing loss was secondary to a sub-mucous cleft.

During the entire time that Susan was waiting for the diagnosis, she was also very proactive and sought out information for herself about hearing loss in general. Susan acquired information about an infant health and development service in her region. This service offers therapeutic and education activities for infants with developmental delays, disabilities, emotional or behavioral problems. Professionals involved in providing services are physical therapists, occupational therapists, speech language and hearing specialists, home based development coordinators and professionals involved in parent training.

Susan learned about the infant health and development service by walking past their location in the hospital. She copied the number and contacted them to ask questions regarding hearing loss in general. From the infant health and development service, Susan was provided with intervention services from a home based coordinator, speech language pathologist and occupational therapist for Ella's other health issue, while she was waiting to learn about her child's hearing status. These services were involved with the family from three months onwards.

Julie

Julie's child, John, is a little over three years old. He was born just before the newborn hearing screening program was implemented in her region, but all the equipment was there, set up and the program was just waiting to be implemented. Julie had a very hard delivery and forceps were used bruising John's head significantly. At John's two-week check up, Julie mentioned to her pediatrician that she was suspicious of her child's hearing abilities. At her doctors office she asked the doctor to check her baby's ears to see if there was something abnormal with them and she explained:

> My doctor told me his ears were fine when I had him there for my two week checkup. When he told me that his ears were fine I knew there was something wrong. My doctor told me I had to wait and see because John was too young to know.

After her appointment with the pediatrician, a public health nurse came for a routine home visit. Julie described this visit saying:

> I was telling her about [his hearing] and she held [John] up and she spoke to him and he responded and she said, "I think he's fine." I said, "Well I don't." She left and she called me about an hour later and said she was talking to her supervisor and that the majority of her job is to actually make sure the mothers are satisfied with things. And she said, "You don't seem to be that

> way." So she gave me the name of the audiologist, and I made the appointment through her myself.

The public health nurse concluded their conversation by telling her that, "You have nothing to worry about." Julie then contacted the audiologist and was told, "I needed *a* [doctor's] referral." She continued to explain her interaction with the audiologist:

> I said, "Well I can't get one." And I guess because I was very distraught, it's hard to understand how distraught I actually was… and I guess when she said that I needed a doctor's referral, I guess then I got really upset. She said that she would take us and then when I explained to her what was going on she said, "Well we can do the test but I really don't think you have anything to worry about."

When John was three and a half weeks he was screened with an AABR and then with an OAE. John's was referred on each screen. Two weeks later he was scheduled for a diagnostic ABR. Julie found the time between appointments to be very hard to deal with. She described her child's diagnostic appointment:

> Right before it happened and I suppose I'm kind of nosy or kind of pushy, whatever you want to say because, of course, once she was hooking him up to these electrodes, I wanted to know what she was doing. So she was explaining to me what she was doing and she was saying, "On the screen it'll come up and down and that represents the child's brain waves." So, of course, when we were doing [the testing] there was no up and down. So, when she said it, we already knew what she was going to say, before she said

> it. And the thing was she ended up doing it so loudly that [John] was asleep but we could actually still hear it and she said, "We can't go any louder because the vibrations are going to wake him up." So that was at 95dB and we didn't get any response at that.

John was diagnosed with a profound sensorineural hearing loss. Once the family found out about the hearing loss, Julie's husband requested that his employer transfer him so that they could be closer to a place that provided more intervention services. Her husband was transferred back to their original home town where all their family resides "eight weeks tops" after the diagnosis. In the meantime their audiologist sent them to a variety of other professionals for assessments and services. Julie's audiologist sent them to the city to have all the testing redone. The doctor in the city informed Julie that "the chances are [John's] deafness is so severe that we should go with sign language because [John] would never speak." The family decided to pursue amplification, but had to wait over three weeks in order to get hearing aids for their child and they didn't know the cause of the delay. When they moved back to their original home town, things happened more quickly. John was wearing hearing aids by the time he was ten weeks old. The audiologist who diagnosed their child had also set up appointments with numerous service providers for intervention when the family got to their new home. Julie described this situation:

> [The audiologist] just had appointments set up for us to do all these things and we actually did them as soon as we got here. We went through the School for the Deaf and got sign language classes. I made everybody go, actually, grandparents and all... I made everybody go. And [my child]

> actually had 30 -35 signs before he was a year old because that was what we were constantly doing with him.

Their decision to use signing with his hearing aids was made because with his hearing aids, "He wasn't getting much from them."

After having considered all the information that they had gathered from all the different professionals in their new location, Julie and her husband then decided to have her child implanted with a cochlear implant (CI). He was implanted at twelve months and three weeks and is now two years post implant. Julie and her husband have:

> decided that we would phase out the sign until he got the speech and then we would bring the sign back in again. But [John] still, he's almost three and he speaks just incredibly but we still actually have an appointment with the School for the Deaf once a week.

Although they still go to the school for the deaf:

> We don't do any signing, actually, none. We discussed it with the School for the Deaf and the thing was, the CI doesn't change the fact that he is deaf and I still wanted him to have a sense of the fact that he is not different from everyone else. There are other kids out there that are the same as him...So we actually kept up on that and we will keep up on the sign and that's what we've always said. We gave him the cochlear implant but if he chooses down the road to not use it and go back to sign, well that's his choice, but we wanted to give him that choice...

Morgan and Paul

This was a mother and father who participated in the same interview, but had differing experiences. Paul was born with a conductive hearing loss that was the result of a hereditary condition. They were informed before they began having children that there was a possibility that they could pass on this condition to their children and therefore they needed to have their children screened. When asked to tell me about their child, Samantha, Morgan responded:

> She is seventeen months old and we pretty much knew that there was a problem right from day one. We also knew there was a risk with her inheriting the same condition that her father has, the congenital atresia of the ear canals and, with the newborn screening that was confirmed.

Samantha was their third child and the only one of the three who inherited this hearing loss. She described what happened after she was born and was being washed by the nurse:

> The nurse actually noticed when she was cleaning her ears that the canal seemed to be very small. That was before she was even aware that there may be a problem. When she came back, I asked her about the newborn screening, "When were they going to do it?" She talked about it and explained that it would be done soon and then she asked me why I was asking. I then explained to her [Paul's] congenital problem with his ears. That's when she said to me, "Well you know when I was giving her a bath I did notice that one of her canals did seem to be really small". She went and made a note of

> that right away on the charts and asked for the pediatrician to come and see her right away when we were there and so that's what we did.

This visit with the nurse alerted Morgan and Paul to the fact of a potential problem even before the screening. They reported being in a region that "screened in the first 24 hours." Morgan explained that, "At the time [of the first screening], I had a room full of visitors so they just took her in the next room and did it. I was fine with that."

When the nurse came back she reported that their child had been referred on the screening. The second screening occurred in their rural community:

> They had said to go back in three weeks just to have the newborn hearing screening done again to make sure that it wasn't a fluid buildup or something that might clear up on its own. So I did that and that one came back as a "refer" also but we were told it was because their machine was acting up. [The audiologist] said, "Well, we are going to see if we can get a different machine and come back in a couple of weeks." They tried to say that there was something wrong with the machine, that it was not working properly, and so we scheduled another appointment. At our new appointment, the result of that screening also came back as "refer" and then the screener said, "Okay, we need to go the next step and not to delay it too much longer."

By the time that their child was seven months, they had been referred to the city where a diagnostic ABR preformed by an audiologist, which confirmed that she had at least a moderate hearing loss.

Morgan and Paul were then given a great deal of information from their audiologist to the point that they were overwhelmed. Although feeling overwhelmed, they still recalled receiving information on intervention services and support groups. They stated that, due to their frame of minds, they were not in a position to take advantage of all the information that was given to them.

Based on the information they received from the audiologist in their home town, Morgan and Paul made the decision to proceed with a headband bone conduction hearing aid. While they were pursuing that option, Paul had an appointment with his audiologist in regard to his bone anchored hearing aid. While they were waiting for Paul's audiologist to commence their appointment, they were speaking to the nurses about Samantha, how they had decided to amplify her and their concern with using the headband which was hard and could leave permanent grooves on Samantha's head. Paul's audiologist ended up overhearing the majority of the conversation standing in the doorway, and informed Morgan and Paul that there was a new technology on the market, a bone anchored hearing aid for babies, which might be a better option for them. Morgan and Paul went back to their infant's audiologist and informed her that they were interested in pursuing this amplification option for their child instead. Paul explained that their decision to go with the bone anchored hearing aid came down to, "a relationship with [my audiology clinic], my own BAHA processor that I'm wearing, that good relationship and that was the deciding factors."

They have not sought out any other intervention services other then having Samantha assessed by a speech language pathologist "a few times" in their home town. Morgan and Paul explained that they are finally in the position were they feel as though they would be able to take advantage of information sessions and other information pertaining to the education of their child.

Summary

From the description of all the participants' UNHS experience, it becomes very evident that the experiences of each parent are very individual. The focus of this study has been on parents' experiences during the screening, their initial experiences after the screening with diagnostics, and their ability to access intervention services; it is not on the intervention that parents chose for their infants. In comprehensive IHPs, the goal surrounding the early intervention component is not to tell parents what intervention they should enroll their child in or to evaluate the intervention services. The goal is rather to provide parents with adequate information and facilitate parents' access to early intervention services. It is important to remember that these participants had their infants screened in a region where this facilitation component was not established.

Table 3 and 4 illustrate the roles of the professionals who were involved with each family throughout their entire experience with the screening, diagnostics and search for intervention services. Table 3 presents the information per family. Table 4 lists all the professionals involved in these families' experiences and what their responsibilities were at various stages of the process.

Table 3

Parents' interaction with professionals and the roles they played

Parents	Professionals Involved	Role
Rachael & Joey	Nurse	Noticed Feeding Issues + contacted pediatrician
	Pediatrician	Diagnosed cleft palate + indicated potential hearing loss
	Audiologist	Screened her child + diagnosed Sensorineural hearing loss (SNHL)
	ENT	Recommended Amplification + discovered hearing loss was conductive
	Teacher of the deaf	Provided 3-4 home visits
	Hearing Aid Clinician	Fit hearing airs & ear molds and provided some resources
	Speech Language Services	Delayed Services until Joey was 18 months
Susan & Ella	Audiology technicians	Screened infant
	Pediatrician	Referred to the audiologist
	Audiologist	Preformed diagnostic ABR
	ENT	Dealt with additional health issues and diagnosed Ella with a conductive loss
	Home Based Coordinator	From an infant health and development service, provided information and support
	Speech language pathologist	Provided speech therapy for Ella
Julie & John	Pediatrician	Minimized concern for John's hearing
	Public Health Nurse	Provide contact number for the audiologist
	Audiologist	Screened, preformed diagnostic ABR, diagnosed SNHL, and set up numerous appointments
	Rural Audiologist	Repeated test results
	Hearing aid clinician	Fit John with hearing aids
	Deaf Role Models	At the school for the Deaf acting as a deaf role model for John: in hometown
	Sign Language Instructors	Taught sign language to the family: in home town
	Auditory Verbal Therapist	Provided AV therapy to the family: in home town
	Cochlear Implant Team	Involved in John's cochlear implantation: in home town
	SLP	Provided speech therapy for John: in home town
Morgan & Paul & Samantha	Nurse	Noticed small ear canal
	NHS nurse	Screened baby
	Rural Audiologist	Diagnostic ABR
	Home town Audiologist	Counseled parents
	Paul's Audiologist	Counseled parents in regards to new amplification Technology
	SLP	Assessed Samantha a few times

Table 4
Professional's roles in parents' UNHS experience

Professionals	Approximate Time of Contact	Role	Parent who Accessed Professionals
Nurses	Prior to & Screening	Screeners	Rachael. Morgan & Paul
		Observed addition health concerns	Rachael, Morgan & Paul
		Provided parent with an audiology contact	Julie
		Advised parents about screening results	Rachael. Morgan & Paul
Pediatricians	Prior to Screening	Diagnosed additional health issues	Rachael
		Dismissed parental concern about hearing loss, "you're looking for problems that aren't there"	Julie
		Identified potential hearing loss by clapping behind the baby	Susan
		Inspected infant's outer ears	Julie
ENTs	Unrelated Appointment	Diagnosed hearing loss incidentally	Susan
	Diagnosis	Diagnosed additional health concern	Susan
		Recommended only amplification	Rachael
		Speculated on reasons for hearing loss	Rachael
		Advised parents that their child will never speak	Rachael
	Intervention	Performed tube surgeries to drain middle ear fluid	Rachael, Susan

Audiology Technician	Screening	Screened infant	Susan
		Attributed "refer" result to equipment malfunction	Susan

Audiologists	Screening	Performed the screening	Rachael
		Would not perform a sedated ABR	Susan
		Attributed "refer" result to equipment malfunction	Susan
	Diagnosis	Performed Diagnostic ABR	Susan, Rachael, Morgan, Paul & Julie
		Diagnosed hearing loss	Rachael
		Counseled parents	Julie, Morgan & Paul
		Informed parents of intervention options by providing sufficient and insufficient information	Julie, Morgan, Paul, Rachael & Susan
	Intervention	Coordinated service providers	Julie
		Fit infants with special hearing aids (BAHA)	Morgan & Paul

SLPs	Intervention I	Assessed infant and/or provided speech therapy	Susan, Julie, Morgan & Paul
		Delayed seeing infant until they were older	Rachael

Teachers of the Deaf	Intervention	Provided families with information on sign language	Rachael, Julie

Hearing Aid Technician	Intervention	Fits infant with hearing aids	Rachael, Julie

AVT	Intervention	Provide auditory verbal therapy	Julie

Themes

Themes emerged from the parents' experiences in the screening component, the diagnostic component and their initial exploration into intervention. The following will be an in-depth look at each of the themes as they relate to each component of an IHP experience. Some themes apply to all components of an IHP whereas other themes are specific to one of the three components of an IHP.

Theme 1: Amount and Nature of the Information Provided and Its Impact

The giving and receiving of information was a significant component throughout the entire UNHS experience. Parents expected and received information throughout the screening, diagnostic and initial exploration of intervention components. Parents talked about the amount of information they received, the nature of the information and the impact that the information had on them.

Amount of Information

Parents described two kinds of experiences: some in which they felt as though they had received a lack of information and some where they felt that they had received sufficient amounts of information. The experiences occurred at all points throughout their experience: before the screening, during and after the screening, the diagnosis, intervention, and in response to the questions addressed to the professionals who were involved in their child's care.

The following section describes the stages of the process, where parents received with sufficient information, enough, or too little information. Some parents reported receiving both a lack of information and sufficient amounts of information in the same stage. This is possible because parents encountered numerous professionals throughout one stage who, they perceived, provided them with differing amounts of information. Parents found that the more information they received when they were ready for it, the better it made them feel.

Before the Screening: Sufficient Information

With the advent of screening programs, health regions are undertaking efforts to make parents aware that hearing screenings are occurring at birth in the hospital. Awareness efforts are occurring through different initiative such as word of mouth, service providers, in prenatal classes and before the screenings. Morgan and Susan described situations in which they received sufficient information before the screening of their child. Morgan said that, before the screening she was "fine" with the information that she was given from the hearing screening nurse about the screening that would be preformed on her child. She described that they "explained how it all worked and what they were going to do." Morgan also felt appreciative of the information that she was given from the nurse who bathed her child and noticed that she had a really small ear canal before the screening even happened. When asked if she appreciated the information she replied, "I really did, we really did."

Before the birth of her child, Susan appreciated the information she received about the new universal newborn hearing screening program from an SLP. Her first reaction to hearing about the screening was, "that the experience in itself would be cool. I thought it was a great thing."

Rachael was not told anything before her child was actually screened by said that she knew about infant hearing screening from her older child's experiences. Julie's experience was different in that she did not have the screening done at birth;

rather, she was suspicious of her child's ability to hear and had to seek out the screening.

After the Screening: Sufficient Information

Each parent involved in a UNHS program began their UNHS experience with the screening component. Jamie's child was screened by an audiologist, Susan's child was screened with by an individual working with her audiologist, Rachael, Morgan, and Paul's child, were screened by a nurse. After each infant was screened the parents received information from the nurse, audiologist or technician, about the screening. When Morgan and Paul were asked if they appreciated how the information about Samantha receiving a "refer" result was shared with them by the nurse screener, Morgan replied:

> Yeah. Our doctor was aware too that there was a possibility. He had said already that he would take care of everything. He had requested already that the pediatrician come and look to double check himself before we left the hospital. So then when the nurse came in she just added that to her chart and the pediatrician came in within a couple of hours and took a look.

After the Screening: Lack of Information

Rachael described her experience after the screening by stating that the nurse who screened her infant simply didn't know what information to impart to her in regard to Joey's results:

> She just came in, tested it, and she just did it again and again and again. She just handed me a little pamphlet and, it leaves a space for me that says "[your

> child] passed" but she didn't fill it in. She said, "He didn't pass. He'll need further testing." She just didn't know what to say to me.

Julie, who went to the audiologist to have John screened, felt that the information that she received after John received a "refer" on his second screening was not a complete description of what a "refer" result means. The audiologist said that a "refer" result on a screening test does not automatically indicate a hearing loss. Julie's description of her experience reflects that she wasn't given enough information about the screening results in order to fully comprehend what a screening test indicates:

> After the screening I said, "That means he failed." All she would tell me was, Well no, no that doesn't mean he failed, it just means that we need more information." So I didn't really get anything from her. Nobody actually told me that he had a hearing loss until he had the test at the hospital.

Susan also described how she felt as though she had received a lack of information after the screening. For Susan, the most difficult part for her was the "not knowing" during her child's first nine months, whether her child had a hearing loss or not. The "not knowing" component and lack of information that she was given were worse for Susan than the possibility of a hearing loss:

> To have her fail it and I don't know how many kids actually did, but to fail it three times and just be left to our own devices. I couldn't do that as a parent. I couldn't do that. I said to myself, I'm going to find out and I'm going to find out now and if she ends up hearing impaired then she ends up hearing

> impaired and we'll deal with it. Not a big deal. But the not knowing drove me nuts.

Susan also said that if she had been provided with some source for getting information about hearing loss and the screening results, she would have been better prepared to deal with the potential diagnosis:

> If somebody had said, even after she'd failed the third one, if someone had said that [this infant health and development service] can provide you with some information just in case of a hearing loss or hearing impairment, that would have helped, but no they don't do that.

Diagnosis: Sufficient Information

Diagnostics is the stage of the process when the infants, who have received "refer" results on their hearing screenings, attend an appointment with an audiologist for a diagnostic ABR. This should confirm the status of their hearing. These parents' experiences included them taking their children to have the diagnostic ABR and then speaking with audiologists about the results of the test. The information about the diagnosis can come from the audiologists. In Susan's experience, due to the lack of information she was getting as a result of her infant's screening, she independently found out about an infant health and development service. She received information from the professionals there about her infant's potential diagnosis.

Morgan and Paul received the information about Samantha's diagnosis from their audiologist. While they received a great deal of information, to the point that they felt overwhelmed, in terms of the information they had received, Morgan said:

> at the time I felt quite okay with it. Of course right away I remember thinking... I think I should have a multitude of questions to ask but I just couldn't think any more at that point.

From the infant health and development service, Susan felt as though she received sufficient amounts of information about the potential of a diagnosis. She also described the relationship she had with the home base coordinator whom she dealt with and whom she felt that any time she needed a question answered this individual would get back to her. She explained:

> Right from my first actual phone conversation with her, things just took right off. If I needed to know something, I could phone and leave her a voice mail and she would get back to me, even after hours, if that is what it took. She'd phone me at 9:30 at night and say, "Hi it's just Linda getting back to you with the information that you wanted." There were no waiting days, it was almost immediate. If she wasn't in the office she'd call me as soon as she got the message and if she didn't know the answer she'd find out.

Susan was very happy with the amount of information that the infant health and development service provided her surrounding the difference between a conductive hearing loss and sensorineural hearing loss and if her child was diagnosed with a sensorineural hearing loss what she would need to do in order to help her child:

> I was asking them the differences and if it wasn't conductive, if she'd need hearing aids, if she would need different things to communicate, if she'd be able to learn to speak with the help of a speech language pathologist, if she'd

> … yeah all these questions I'm just throwing out left right and center and they were coming back with answers.

Susan also described how the infant health and development service provided her with information in regard to communication options for her child once she was diagnosed. Susan again appreciated this information, because it helped to prepare her even before a diagnosis was made.

> She did say that, "Well you know, if Ella can't hear there is sign language a whole bunch of different ways to teach her to communicate, whether it be by pictures or by …." I mean she laid it all out on the line so that when I went in there I was prepared for them to say, your daughter can't hear anything and if she couldn't hear anything that was fine. By that time I wasn't scared anymore.

Diagnosis: Lack of Information

As previously mentioned, Susan felt that there was a lack of information provided to her from the audiologist. Even once she was told that the screenings indicated that her child had a hearing loss, there was still a great deal of information that wasn't imparted to her and that lack of information left her "spinning circles":

> Even after they found that there was a hearing loss I didn't know why, what, how, and for how long. Nothing. None of those questions were answered and I was left spinning circles. In the whole meantime my daughter can only hear parts of what is going on, different tones or louder voices. You couldn't whisper, you couldn't sing really lowly to her and that kind of stuff. I know that now and I didn't know that then.

Rachael said that once her audiologist diagnosed Joey she was told:

> that they figured it was his middle ear or his inner ear and they weren't sure... They said with his hearing aids he would only hear cars, horns, trains, planes, and fire alarm. He'd only hear really loud things. Hearing aids were just precautionary, that was the only reason we were getting them...They were giving us books on sign language, saying, "He's going to need special schooling and he's going to need all these things for in the classroom and here's all this funding information and blahblah blah."

Julie described her experience when she received information from her audiologist after the diagnostic ABR:

> Well, once she told us about the hearing loss, she kept saying," Profound hearing loss." And not knowing anything about hearing loss, that didn't register to me. I kept saying, "He's Deaf." And she said, "No, he has a hearing loss." And apparently, Deaf, I've learnt since then, is not the appropriate terminology (laughter). But back then that was the only way that I understood.

Intervention: Sufficient Information

The guidelines for the intervention component in an IHP try to ensure that infants and families access appropriate intervention by the time the babies are six months old. All the parents in this study were able to contact professionals in order to discuss intervention options, to ask questions, or to learn how best to help their newly diagnosed child. Advice and suggestions varied, however. Susan accessed intervention services through an infant health and development service before Ella was six months. Julie also accessed speech services, amplification services, and sign language services before John was six months. But Morgan and Paul have not enrolled in any regular early intervention services, and Rachael was also told that she needed to wait until Joey was eighteen months.

Parents described how obtaining information about the intervention options available made them feel more able to deal with the diagnosis, less scared, and more able to cope. Julie described her experience after receiving the diagnosis. In her experience, she received sufficient intervention information from her audiologist without even having to ask for it. She explained that after having met with her audiologist to discuss the diagnosis, she provided her with information and appointments to see all sorts of different specialists who would assess her child:

> The audiologist called me back the next day and said that there was a teacher that knew sign language and she offered to get us in contact with her. She got us an appointment with a Child Development Specialist at the hospital and she also set up appointments for us at the Kid's Hospital in [the city]. In [the City], the children's hospital was really great. We went through all the tests again and they even went so far as to get a library card if we wanted to take out any books on different things. She also sent us to [a rehabilitation hospital] and we went to the hearing clinic in [our town]. She made an appointment for me to see the teacher and a speech language pathologist in [our town].

When Julie was asked about the information that she received from all the professionals she encountered, she explained that her audiologist was so helpful and that she had provided her with all the information that she needed in order to be able to understand what all the subsequent professionals that she visited were talking about:

> We had dealt with the audiologist so much when I was in [a town]. I used to speak to her everyday. So speaking with her, you find out pretty much everything you need to find out so that when we went to the city, I kind of knew what they were talking about so we didn't have any issues with that.

Intervention: Lack of Information

During parents' experiences seeking intervention services, they described that there was also a lack of information received from professionals in terms of the intervention options and services that were available to parents. The lack of information that parents received in regard to intervention services made parents feel very confused and unsure about where to go and what to do.

Rachael described her experience after she had received the diagnosis and sat down with the audiologist where she really felt as though there was a lack of information imparted to her in regard to what to do next and where she could turn for information. She explained:

> I left feeling really uninformed, I was like, well what do I do? I don't know what to do. I don't know who to see or how to go about doing this.

Rachael also described a situation in which she received information from a Teacher of the Deaf whom she contacted and, although the information that she received gave her a little bit of hope, it still wasn't sufficient information in order to give her an indication of what to expect:

> I had already met with the teacher and she had given me some ideas on how to like teach sign language and she lent me the video and the book. It was so cute it showed little babies… (made signs) … It gave me some hope but I still didn't know what to expect.

Julie also had expected to hear more about other alternatives and implications but was not informed of any:

> We didn't really get anywhere with anything. The only thing we found out is the things that we already knew, that he had a profound hearing loss and that we should get hearing aids and start sign language.

Morgan explained that she had not been given information about other intervention services and she explained that this information was not given to her because it wasn't important for her child at the time that she was diagnosed. When asked if she was given information about intervention she replied:

> No ... well very very briefly but because she was still a newborn that was something that wasn't really pertinent right now. If she was an older child that definitely would have been more pertinent.

When Morgan was asked about how she felt in regards to the lack of information that was given to her after her child was diagnosed she replied, "We really haven't looked into it much and we haven't been given much."

When parents asked questions, sometimes audiologists didn't have the information available to them or they simply didn't know the answers. In Morgan and Paul's experience, Samantha's first audiologist wasn't aware that a bone-anchored hearing aid for babies existed and therefore didn't recommend or suggest that option to Morgan and Paul:

> And so other audiologists weren't even aware that it existed for babies. So then when I had talked to our audiologist in [our home town], she had said, "Well had I known that it existed, that would have been my number one recommendation for you."

Morgan continued on to say that she, "Wouldn't have said that that was a fault or an oversight on anyone's part."

Rachael described two situations she encountered where she went to see Joey's audiologist in order get answers to her questions but the audiologist didn't have the answers to information that she was looking for. In both situations, Rachael was looking for information in regard to how to handle the hearing aids, when her child should wear them and when they should be turned off:

> I had questions like, "What about a toque? If the car seat makes it squeal is he just never supposed to wear his hearing aids in the winter? How is he supposed to go tobogganing? Is he just supposed to be completely deaf when he goes tobogganing or something?" I didn't know. [The audiologist] said, "I don't know, I guess you'll just have to try and see if it squeals." And it's just like ... oh ... thanks...

In the second situation, Rachael was asking the audiologist questions about what to do if the hearing aids got wet, because they were put in her child's mouth. The audiologist referred her to a hearing aid clinic, because he didn't have the answers, but in the end Rachael decided to look up the information on her own:

> [The hearing aids] are not supposed to get wet and every two seconds they are in his mouth. So when I went to the audiologist to find out what I should do, he didn't have a clue either. He was like, "Well I don't know. Well maybe the Hearing Aid Clinic can help you". So I looked it up on the Internet and they said to use wig tape because it's two sided and doesn't irritate the skin, just stick it to the back of his head behind his ears . The Internet had all these suggestions on things to do and that helped but I had to do that all on my own.

Nature of Information

While the amount of information that parents received had an impact upon their entire experience, from the screening to the diagnosis to receiving information about intervention, it is evident that the nature of that information had an impact upon on parents' experiences as well. The nature of the information refers to the manner and type of information that was provided from professionals. The different nature of the information evoked certain feelings and reactions in parents. As was mentioned previously, although some parents received sufficient information and the nature of that information was helpful, often the nature of the information was viewed as negative. Parents found that the information that they received from professionals was sometimes, inaccurate or incomplete, and also that it minimized their concern for their child. This may not have reflected a lack of training and may have been very unintentional.

Screening: Inaccurate

Parents felt that the information that they received was inaccurate, because they didn't receive the information about the child's screening results in a straightforward manner. When Susan's child, Ella received a "refer" result on the screening she was told the reason was due to:

> faulty this, too heavy breathing that, too mucousy. There was always an excuse as to why it wasn't working. Instead of the possibility existing that she actually had a hearing problem.

Susan described her experience of waiting nine months and not getting any information that she felt was accurate in nature about the screening and having to finally take matters into her own hands in order to get a confirmed diagnosis. She explained her feelings of how the nature of the information she received was not representative of what was really going on with her child:

> So it all ended up getting to where an answer was but it took nine months to get there and that was the hardest part. Had they told me at three months, well she has fluid behind her ears, and this is what we are going to do. They didn't. Everything was, well this computer wasn't working right or the test didn't run long enough or she was too fussy to finish it. All the excuses kept coming and coming and coming and I finally just took matters into my own hands and said enough's enough; I'm not doing this anymore.

Susan also felt as though her audiologist knew about her child's conductive hearing loss for "six months he knew and never said a word."

Morgan also received many excuses about the reasons that Samantha received a "refer" result on the hearing screening. While a "refer" result does not immediately indicate a hearing loss it does suggest that the cause may be a hearing loss and, in Morgan and Paul's experience, the cause of the "refer" result was first attributed to machinery malfunctions:

> That one came back as a "refer" also but their machine was acting up and [the screener] said, "Well we are going to see if we can get a different machine and come back in a couple of weeks again." We did that and they tried again to say there is something wrong with their machine, "It's not working properly."

Dismissing Parental Concerns

Parents also said that the nature of the information that they received in regards to their concern for their child's hearing minimized their concern. Susan and Julie encountered this during the screening phase while Rachael said that it happened to her when she was seeking intervention services.

Screening: Dismissing parental concerns.

Susan said that she felt as though no one was taking her concern for her child's hearing seriously. She described her experience in taking her child back for the third screening and having her "refer" yet again. Finally she demanded that someone take the fact that her child has received "refer" results on three screenings seriously and that perhaps something more should be done. She described her reaction after that third appointment, "To take her in and say what's going on here, there's something going on here and nobody is taking it seriously enough."

Julie described the response of her pediatrician and then her audiologist when she first contacted each of them about her concern for John's hearing. From her pediatrician she was told, "I was an overanxious mom who had a difficult pregnancy and I was looking for problems that weren't there." When Julie contacted the audiologist and asked if she would screen John's hearing, she was initially turned down. When the audiologist finally agreed to screen John she said, "Well we can do the test but I really don't think you have anything to worry about."

Intervention: Dismissing parental concerns.

Rachael described her experience when she went to obtain speech and language services for Joey; Joey was then six months old and had been diagnosed five months before. She was told that Joey was too young for speech service, that she shouldn't worry about her child's speech ability and that she should wait until he was eighteen months. She described the response that she got from the speech language pathology service, "They were just going to leave him. They were like oh he's just too little. Don't worry about it."

Impact of the Information Provided

Parents who received a lack of information described the impact that the information had on them. Susan described how the limited information that she received regarding the results of her infant's screening caused her to feel increased levels of alarm. The impact of the information also caused Susan, Morgan and Paul to make assumptions and excuses about their child's hearing potential. Either they believed the excuses given to them from the professionals or they made their own assumptions about broken equipment which allowed them to believe that their infant couldn't really have a hearing loss. Susan went on to expressed feelings of distrust towards the professionals due to the lack of information she received.

Screening: Increased Levels of Alarm

Another impact of the amount and nature of information received was that it caused increased levels of alarm. Susan described that after multiple screenings she felt an increased level of alarm, because she hadn't received any information about the potential hearing loss:

> It was to the point that not knowing...As somebody doing the testing, you are probably thinking that it could be this or that or whatever... but as a parent when you take your child in twice and they fail both times it kind of raises an alarm.

Screening: Making Assumptions and Excuses

The incomplete information that parents received about their child's potential hearing loss also enabled parents to make assumptions and excuses about their child's hearing loss. Morgan said that, because of all the excuses they had been given about her infant's screenings results, she and her husband continued to hold on to the hope that Samantha's diagnostic ABR would reveal that she did not have a hearing loss:

> Until, you know, over all those months, until we had a definite diagnosis, there's always a hope that we are going to get to the ABR and they are going to say, "You know what she really is O.K." but that's not what we heard right?

Paul also explained how the excuses that he was given about Samantha's screening results allowed him to hold on to the hope that she didn't actually have a hearing loss:

> Yeah I just kind of wanted to... I guess it my mind I just kind of ruled it out. I guess it could be a hearing loss but I bet more on thinking that it was equipment malfunctions, maybe there are some environmental factors; maybe something's just not quite right but [Samantha's] fine.

Susan, also, received excuses as to why Ella received a "refer" result on the screening. Instead of assuming that Ella didn't have a hearing loss, Susan went on the assumption that she did have a hearing loss and she informed herself regarding all the possibilities. She explained her rationale for making this decision:

> See I went on the assumption that, yes, there was a problem and I just didn't know severity. I didn't know if it was something that could be fixed or if it was just something that I was going to have to live with. Nobody was telling me anything so I went on the assumption that she... to say I went on the assumption that she couldn't hear wasn't exactly right but I went on the assumption that she couldn't hear everything .... Like I sit back now and think about what she went through for the first year and it's like ... wow...

Distrust

Susan also said that because she felt as though she didn't receive complete and accurate information about her child's screening results, all her future interactions with health care professionals were influenced by a general distrust. Her screening experience taught her that, “You never know what’s going to happen and what they are not telling you”.

Theme 2: Impact of the Diagnosis

Reactions to the Diagnosis

Regardless of the way that parents received the diagnosis of hearing loss, the reactions and the range of emotions felt were similar. Parents described their reactions to the diagnosis by discussing their feelings of panic, acceptance, how their reaction was affected by current life circumstances, their need to know what to blame, the differences between the maternal and paternal reaction, the perceived lifelong impact and feelings of being upset.

Panic

Susan and Rachael had no experience with hearing loss whatsoever and reported feelings of panic upon receiving the diagnosis. Susan recalled the first phone call that she made after learning that her child had a hearing loss:

> When I made that first phone call it was in the grasp of a panicking parent. I just thought…oh my god this is happening to me… what does this mean? I have had two healthy children up until now and now I’m going to have one that is hearing impaired. And of course the panic button’s been hit right.

Rachael also shared the same feelings of panic when she was told her child was deaf:

> All you’re thinking is, oh my god my baby is deaf. That’s the only thing that I thought… oh my god, oh my god…

Acceptance

Morgan, whose spouse, Paul, has a hearing loss, was aware of the fact that they may pass on his hereditary condition to their children. This had a big impact on her reaction. She described her reaction to the diagnosis as one of initial acceptance. She described this acceptance as coming from her previous experience in dealing with her husband's hearing loss:

> When she had that ABR done, and they gave a definite diagnosis, there was part of me that said, "I'm okay with this." We've talked through a lot of hearing loss with [Paul] and we had a little bit of understanding of how that all went and thought we can get a child through this.

Grief

Morgan however, also reported feeling a significant amount of grief upon receiving the diagnosis. "There's the other side that really grieves. That you have a child that's not… that's born with a lifetime problem".

Surprisingly, perhaps, Paul described his reaction to learning about their child's hearing loss as like a death to him, because it was a death of his dream to not pass on his hereditary condition to his children and it had happened with his third child:

> Well it's like a death, it's really like a death. I mean [Samantha] is still alive of course but to have some of your hopes crushed… I had always hoped that I would never pass that on to my children and when it did happen, it was a death of that dream and with that comes the experience of loss and with that comes the experience of grieving. You know. Very real

Impacted on by Life Circumstances

Parents also expressed that their reactions to the diagnosis depended a great deal on their current life circumstances. For some parents the information about their child's hearing loss was secondary to other health issues that their child was facing. Rachael for example had learned the night before that Joey had a cleft palate and she explained that, "I don't think anything could have shocked me more than the night before... I think I was just kind of in a daze." Susan, on the other hand, treated Ella's hearing loss as a completely separate issue to the other health problems that she was facing. During the interview she was very specific in talking only about Ella's hearing loss and explained that she wasn't going to get into the other health issues.

Morgan, Paul and Julie had just recently been through very emotionally challenging times in their lives. Morgan and Paul said:

> We had actually just walked through a very difficult time as a family and my dad had passed away just two weeks before that. There was a big job change for [Paul] too which came with its fair share of losses involved in that too.

They found that the diagnosis of their child's hearing loss just added to the other significantly upsetting issues that they had to come to terms with. Morgan reported that, "It's hard to kind of separate emotions at that time." Paul said that, "It hit us very heavy because it was another one of these losses that we experienced throughout 2003."

Julie said she and her husband, "We were going through so much" and that, "I had such a bad pregnancy and I was so sick after that. It was just a lot to deal with at that time" because there was so much that she was dealing with in addition to the diagnosis of her child's hearing loss.

Blame

Rachael and Julie spoke of their need to know the cause of their child's hearing loss once they received the diagnosis. It seemed important to know the cause. Rachael turned to her ENT for an explanation of her child's hearing loss. She asked the ENT if her child's hearing loss was due to the car accident, which induced her labour. The ENT responded:

> Well it's not the same type of hearing loss that cleft palate babies have because there's no fluid... It could either be genetic or if you had any illness in your pregnancy or the accident because it was on my due date.

Once Julie received the diagnosis she recounted looking back on her pregnancy and the choices that she made, thinking that any of her previous decisions could have been the cause of John's hearing loss:

> You go back through and think, "What have I done? What did I do while I was pregnant that would cause that?" I had such a hard pregnancy. I had so many ultrasounds done, time after time, and people were telling me, "Oh god, ultrasounds are really bad, their rays are really bad" and you're thinking, "Oh my god. Is that what did it?" Then I went into premature labour and they pumped me full of drugs to stop the labour and you think, "Oh god is that what did it?"

Julie also looked at the particular circumstances of the child's birth and wondered if those circumstances, a difficult labour and the use of forceps, were the cause of her child's hearing loss. "I had a really hard pregnancy and [John] was overdue and they bruised up his head a lot during delivery so I just assumed it was that."

Different Coping Styles of Husbands and Wives

Morgan, Paul, Julie and Rachael all spoke of the differences in how they and their husbands received the news of their child's diagnosis of hearing loss. Rachael described her husband as being in complete denial about their child's cleft palate and hearing loss which was confirmed by multiple failed testing:

> We had three and a half hours of testing and he failed it all... My husband kept saying, he's not deaf, he's not... because he was in denial about the cleft palate, he was in denial. He wouldn't feed him. He was just, "No." He wasn't his perfect baby anymore so he was just in denial about everything.

Julie described the differences in reaction between herself and her husband:

> [We had] extremely different ways of dealing with things. That's why we actually had trouble at first. I deal with things and the fact is I like to know what's the problem and how do I fix it whereas [my husband] in that point and time wanted to just forget. It was so easy to pretend he wasn't deaf because he was so observant. I remember him telling his mom that he had a slight hearing loss and I remember thinking, "That's not true. How can you say that?" But we just dealt with things differently. It just took [my husband] a lot longer to come to terms with it, I guess, then it did with me. I don't know if that's a mother instinct or what it is. But I guess everybody deals with things differently.

Morgan talked about how her husband had a really difficult time accepting the diagnosis and coming to terms with it. She described her experience in needing to talk him into acceptance:

> At one point I said, "Look as a father, you're either going to teach her she's okay the way she is by your accepting this or, if you don't accept this, she'll never accept it for herself..."

Paul also spoke of how his feelings in regard to receiving the diagnosis differed from his wife's, and he expressed his difficulty in coming to terms with the diagnosis. He states, "As far as the information that came, I still kind of chose…it took me a while, it took a long time emotionally to catch up with the facts. It really did."

In regard to his non-acceptance, he explained that, "It might have been a pride thing too." Paul didn't want to believe and be faced with the fact that he passed on his hereditary condition to his child. He further explained by stating his disbelief that he had passed on his condition:

> I couldn't, I couldn't have passed this on yet the facts were staring me in the face... yes it has happened. I think Morgan had to give me a pep talk and I had to kick myself up, I had to kick myself in the pants!!! My ignoring of the issues, the fact of her hearing loss, I'm not doing her any favors. I'm not helping her by doing that and it's my problem. It was my problem not hers in the sense that I just had to get myself emotionally ready to act, help her, serve her, read the resources and go to these kinds of appointments. Just do it

> because me just sitting on the fence there, choosing inactivity, that's not helping her at all.

Julie spoke of how the differences in the way that she and her husband dealt with the diagnosis really had an impact on their marital relationship. She said, "We were having a really hard time of it. Even just relationship wise it was really stressful."

Perceived Lifelong Impact

Another common reaction of parents in regard to the diagnosis of their child's hearing loss was their concern for the perceived lifelong impact that this would have on their child's life and their difficulty in coming to terms with that. Morgan described her experience, after receiving the diagnosis, in which she came to the realization that her child's hearing loss was something that the medical system couldn't fix:

> You know with the medical system there is always a lot of... there is so many things the medical system can do to fix problems and at this point we realized that this was a lifetime issue. This is not something at this point that the medical system can fix so that she can have normal hearing. There was the whole thought of even adjusting to seeing her with an apparatus on her head for possibly the rest of her life. There were emotions through that.

Rachael described her realization that her child's hearing loss could have a lifelong impact when she reflected on how dependent she perceived her child would always be on others. She had this realization when she had little information about hearing loss and felt as though there was no one there to give her any answers. She said:

> You're thinking about it, you're just sitting there all by yourself and you're like, "Am I going to have to be there everyday of his life to wake him up or have someone wake him up for school? How does he become independent and move out on his own? If no one is there to tell you then you don't know. At least if you know then you can prepare yourself for it and you feel better you're not so ...oh my god...this is lifelong.

Upset

Another experience among parents in this study was their feeling of being upset in reaction to the diagnosis of their child's hearing loss. Feelings such as sadness, dismay, and fear were all the different emotions that parents expressed. Julie described some of her reactions when she had learned about John's hearing loss by saying, "Right and then I started to cry...I was a new mom, I was frightened to death." She also described how doctors told her that she should feel after hearing about John's hearing loss:

> In [an urban city] there was so many kids that were so sick and [John] was basically a happy healthy child and they were saying, "Well consider yourself lucky." But at the time we didn't consider ourselves lucky.

Paul described his feelings by saying, "I think we were in a sense of not quite shock but dismay."

Coping: After the Diagnosis

Another common theme that emerged across all parents' experiences was their ability to cope with the news of their child's hearing loss. In this category, coping encompasses parents' initial efforts to cope with the diagnosis and obtain assistance for their child. The common experiences in the coping category were parent's new roles as an advocate, parent's initial efforts to obtain assistance for their child, parent's struggles when it came to trying to cope, and the support groups that parents turned to.

Becoming an Advocate

After having their child diagnosed with a hearing loss, parents not only became the "parent of a deaf child" but they also gained another new role as an advocate for their child. For some parents becoming an advocate was the only thing that they felt they could do in order to deal with the diagnosis. Susan, Rachael, and Julie spoke about their realization that they were responsible for obtaining the information that they felt they needed in terms of hearing loss, services, programs that were available and all the different professionals that could be involved with their child.

Susan felt as though she needed more information in order to better cope with the potential of her child's hearing loss and she found a service she could contact in order to gain answers to all of her questions. She recognized the importance of acting on behalf of herself and her child and getting the information that she wanted when she needed it:

> It was actually just walking by the hall seeing their sign in the hall, [for an infant health and development service]. I picked up the phone and I said to them, "I don't know if you can help me but I am looking for information." A conversation opened up. Had I not done that I would have been sitting back, not knowing anything, and playing the waiting game. I'm not a person to sit back and play the waiting game at all, at all, and I don't know too many parents that would be.

Julie described also attempting to get answers about her child's potential hearing loss on her own by continually testing her child's hearing at home while she was waiting for her child's diagnostic ABR. She reported testing her child at home "by [dropping] a pot or [setting] off the smoke detector" and nothing worked. Julie was just trying to inform herself as much as possible so she would be prepared if her child failed the diagnostic testing. She explained that, "We went so long those two weeks that I had tested him and tested him myself so that I knew."

Rachael described how she felt that she needed to get the information for herself because no one was providing it for her:

> I was like whatever I would just do it myself. I'll just find out ways to do it myself.

Susan and Rachael also turned to the Internet in order to access information that would help them to advocate on their child's behalf. Susan's reading on hearing loss helped her to prepare for a definitive diagnosis:

> I read up a lot on hearing loss at the time, what services are available and what equipment is available to children with hearing impairments and stuff

> like that so I was prepared for it to go either way in terms of hearing loss, whether it could be repaired or if it was something that she would have forever. I was just seeing what services were available to help her. I was prepared for the worst and anything better was awesome. That's always been my theory, anything better is awesome.

Rachael turned to the Internet also to find out information that she hadn't received from any other professionals. She explained that because she didn't have any professionals tell her the right or wrong way to do things, she took it upon herself to look for information sources. Rachael was specifically uncertain about how to work with amplification equipment and needed more information:

> I didn't have anyone tell me if I was doing it right or wrong or to give me suggestions. I went on the Internet to look things up because I was like, "Well how do you keep hearing aids on babies?"

Rachael also turned to the Internet for more information to prepare her for advocating for services for her child. She used the information from the Internet to advocate for early intervention services for her child:

> I read on the Internet and it really scared me. I read on the Internet, I think it was a University study and I think they might have found that if a baby wasn't diagnosed and didn't have intervention by six months that they'll never progress past a grade six level for reading and I was like, "Well how do people go to school?" I was really adamant about the fact that I'm not going to leave him until he's a year or eighteen months to get hearing aids if that will prevent him from progressing past grade six.

Parents in this study commented on how they felt as though they were immediately thrust into their advocacy roles as soon as the first screening occurred. Although parents didn't name this experience as *advocating*, their descriptions of their roles throughout the UNHS process are just that of advocates. Rachael reported feeling that as soon as the second screening occurred and from that point onward she "had to push to have anything done with [her child]." Rachael expressed how she felt having to get all the information for herself caused additional anxiety:

> Everyone seems so scared [to give out information], which is sad because you shouldn't have to worry about finding the information yourself when you're dealing with it.

Susan also found that all the responsibilities of being an advocate was really hard on her while she was dealing with all of her emotions related to being a new "parent of a deaf child". She states, "It was all me doing the leg work trying to find the answers. And I mean it was tough."

Susan continued to talk about how she felt a need for more information in order to advocate for Ella but getting that information on her own was extremely difficult for her:

> I needed to get as much info as possible in case it doesn't go for the positive. If it can't be fixed and we're left with a hearing impairment, what services are there for her? How can I deal with that? How can I explain to the other two kids why she doesn't look at them? It was all questions and it was just finding those answers and it was finding them on my own which was the hardest.

On the other hand, although Julie expressed her frustrations at the lack of information that she had received at different points throughout her experience, she appreciated what the lack of information did for her role as an advocator for her child:

> If anything, actually, [this city] was really good on the fact that it made me go find the answers that I wanted instead of waiting for someone to tell me.

Obtaining Assistance

Another common experience in the coping category was the efforts that parents undertook to obtain assistance for their child. Parents' efforts to obtain assistance were represented by their attempts to find resources and seek and speak to professionals who work with infants with hearing loss. Unfortunately for the parents in this study, they were not directed to such services after receiving the diagnosis. In Susan, Rachael, Morgan and Paul's experiences, they were left to their own devices to make contact with intervention services. They said that their contact with intervention services occurred by luck or coincidence.

Rachael had numerous situations that she described as being "fluky" when it came to her obtaining assistance from professionals. In one such situation, Rachael went to a sale that her older child's playgroup was having and found a book on signing with babies. A woman noticed her looking at the book and to Rachael's surprise she found out that she was a teacher of the deaf. Rachael described this experience, stating how she was surprised at how, "Just by fluke I happened to come across a teacher for hearing impaired children at a play school where there is not a single kid with a hearing problem."

She went on to describe how it was even more of a coincidence that this woman was still in their health region, because she was hired to work a long time ago with a child who was diagnosed with a hearing loss whose family didn't want to send their child away to a residential school, even though that was what they were being told to do:

> So it's only by fluke that one child's parents said no to what everyone else was saying which is what you need to do. And then that's how I ended up meeting her because she was still around because of that. So it's complete fluke situations that brought everything together.

Rachael described another chance situation that she found herself in at the hearing aid clinic when it came to obtaining assistance for her child:

> The hearing aid lady, she and her husband have the hearing aid clinic, and I'm not sure I think he fixes and repairs the hearing aids or fits them, he does something but he just by chance happened to see that I'm sitting in the waiting room with a baby with hearing aids. He said to me, "Oh I have something for you if you want." He went to the back and he brought this little package; a video and pamphlet about kids who speak but have hearing loss so that we could see what they are going to sound like and how they deal with school. It was a whole bunch of kids between five and twelve talking. You could hear their speech; see how they were interacting. You could get some sort of sense of what your kid was going to be like. He just by chance one day offered it to me and [the hearing aid lady] had never before offered it to me.

Rachael described yet another situation where she obtained some assistance for her child by complete “fluke.” In another city, at a doctor’s appointment for her child, she noticed that this doctor was wearing hearing aids. She explained the encounter:

> One doctor, we've had complete flukes, fluky situations everywhere we turn. When [my child] had his cleft palate surgery we had to go to [an urban city] and we had to stay there for three days. This doctor was working in the N cluster which was where all the newborns were and he had bilateral hearing loss and he was wearing hearing aids. I could sit there and see him talking and obviously he's a doctor, obviously he passed grade six if he can be a doctor. He's passed grade six reading. He's talking, I'm listening to him and I'm like, “Wow.” I didn't get a chance to talk with him because he left but I wanted to ask him what his residual hearing was, to find out if it was anything like what [my child’s] was. Then after we got back from [the urban city], Joey had a check up with his pediatrician [in our town] and that same doctor was a resident there now following our pediatrician.

Morgan and Paul also described their experience in obtaining appropriate amplification for Samantha as having occurred by chance:

> Then we had this appointment for [Paul] through [his hearing aid clinic] just for a routine analysis check up and I had [Samantha] with me in there. I don't know how we got on to it, we started talking about [Samantha] and the nurses were there waiting for [the audiologist] to come in to look at [Paul] and anyway they started telling me about this brand new package that they had

> gotten for babies with the bone anchored hearing aid and as we were talking [the audiologist] had come to the door. He just stopped there and listened. We didn't realize he was there listening at first until, finally, he came in and he said, "You know, I think we can help you. With her type of hearing loss being a conductive hearing loss, this might be a route for you to go; it might be a better option."

Morgan and Paul were so appreciative of this assistance and considered this a chance occurrence. Morgan explained:

> Making that contact with [Paul's hearing aid clinic] that was a real turning point for me because we already knew the team and they knew us and in that sense we already had a personal relationship with them. Then I just kind of went, "Oohhhh, somebody knows us and understands and we already have a relationship". Then I kind of breathed a sign of relief and went, "Aahhhhhh. Okay maybe we can get some help and get this underway and somebody is kind of rooting for us." That's been very positive for us with [Paul's hearing aid clinic] ever since....

Susan also recounted her experience in obtaining assistance and attributed her connection to intervention service to luck. She was also not initially provided with any information in terms of intervention. Susan undertook her own efforts by calling an intervention service provider when she caught sight of a poster advertising their serrivces. She contacted them and asked if they would be able provide her with some information about hearing loss. "Luckily" they were able to do a great deal more for Susan and her child than just provide her with information:

> I just found it bizarre because it wasn't why I phoned. I just phoned to see if they had any information, any literature. Then, all of a sudden, I have all these people swelling to my help saying, "This is what we are going to do if or you know..." And they still are involved. They followed us from three months of age. We are so lucky.

Obtaining assistance was also an issue for some parents when it came to trying to access funding after they had received the diagnosis and decided to provide their child with amplification. Morgan and Paul had applied to the provincial funding group for hearing aids and never heard back from them:

> The only thing that has never come through is whatever happened to [our hearing aid funding]. We still have not heard a thing back. Nothing has ever come back, so now the [non for profit organization] has said that, "If that never comes through we will cover it."

Morgan and Paul also were not informed from any other professionals about avenues for funding other than the provincial funding and learnt "by accident" about the other options from "our oldest daughter who in her kindergarten class had a grandparent that was [a member], who we had gotten to know."

Struggling to Cope

Another common experience in the category of coping after the diagnosis were parents' struggles to cope with the information provided. Struggles were encountered by parents when they received the diagnosis and when their efforts to obtain information or services ended leaving them feeling discouraged.

Paul expressed his extreme difficulty in coping with the diagnosis because of his own experiences with his conductive hearing loss. He said, “I was just thinking of my own pains I experienced growing up. For the most part I had wonderful supportive teachers but sometimes I had classmates that weren't as supportive.”

Paul’s struggles to cope also made it very difficult for him to deal with the intervention information because he wasn’t prepared to face it:

> A lot of those emotions and memories, well not so much the memories but the emotions tied to the memories, rose to the surface and I went, “I'm not really ready to do this yet. I'm not ready to read through the information. I'm not ready to read through the resources.”

Rachael described her struggles when it came to trying to get information and answers from her audiologist. She described her discouragement:

> Sometimes I’d go to a doctor or an audiologist and I’d have a short little appointment and I’d have a zillion questions and half of them you feel like an idiot for asking, like, “Do you take their hearing aids out when you feed them because babies are messy or are they always suppose to associate eating with totally quiet or are there any techniques or advice?” Just little things that you feel like an idiot for asking a professional and they'll just be like, “Oh, well, take them out.” And they'll get all snotty about it but it's a legitimate question that you don't know the answer to.

Having and Not Having Support Networks

A final common experience in the coping category was the support networks that parents turned to in order to assist them in coping with their new role as a “

parent of a deaf child" and all its implications. As is evident thus far, each parent is very individual and although supports were a common experience, the individuals that provided the support for parents were different in each family. Morgan and Paul turned to their family, their faith, and their faith community for support. Morgan explained, "We had a lot of family support. Both our families are well aware and very supportive. Definitely with [Paul] pastoring at the time there were definitely other Christians around us who were a hug and a good support."

At multiple other points during the interview, Morgan and Paul also made reference to the huge role that prayer played in their ability to get through the challenging decision making. They described their experience in learning about the bone-anchored hearing aid as, "More or less a God moment," which speaks to the importance of faith in their lives.

Susan also said her support was family, specifically, her mother. She expressed her gratitude towards her mother for all her help and support by saying, "Had it not been for my mom, I don't know if I would have been able to keep it together, it was just, it was all at once and just getting nowhere." Susan also described one of her supports as the professional who she encountered through the infant health and development service, who was very supportive and invested in helping her. She described this professional stating, "She was such an advocate for [Ella]… She was right in there and had she not been… I don't know where we'd be today."

Julie did feel greatly supported from the audiologist that was involved with her child and praised her numerous times for everything she did for her child and family. When asked what was “most helpful” after having learnt about the diagnosis, Julie replied, “Oh, the audiologist. A hundred and thousand times over.”

Two parents, Rachael and Julie, did not have as positive an experience with support networks. Rachael expressed her experience in which she felt that she had a lack of a support around her. She said, “Even family didn’t want to hold him, didn’t want to baby-sit him because his hearing aids. They’d fall out, they couldn’t get them back in, they’d squeal if they rubbed up against his hearing aids.”

Julie described how, because she and her husband were not living in their home town, they didn’t really have the same amount of support that they would have had, had they been living with their family and friends in their home town:

> It might not have been so difficult if we were home because someone would know of somebody else with a deaf child that they could put you in contact with. But when you don't know anybody you have nobody to call and you have nobody to talk to.

Theme 3: Individual Needs for Information

Another very significant theme that emerged was that each parent expressed that they had individual needs in regard to the information that they received from the professionals who counselled them after they received the diagnosis. The reaction to the information that parents received is based on the reaction to the diagnosis, how they individually coped with that information, and all the life changing implications that the diagnosis of a hearing loss involved. The similarity in this category comes from not what parents had to say about the information that they received but that they all expressed individual needs for how they would have liked the information to be imparted to them. Parents described their individual need for being informed. For Rachael and Susan, their need was to hear all the information upfront right after their child was diagnosed. On the other hand, Morgan and Paul described their need to be given more time before they were told about their next steps and intervention options in order to deal with the diagnosis.

Receiving Information Up-Front

Rachael was one parent who described her appreciation for receiving a lot of information up front, about her amplification options after her child was diagnosed. When asked if she thought the information she received was helpful, she responded, “Yeah, especially when you are so concerned about it. It's such a shock, you don't know what to expect. As you deal with it you get more comfortable to a certain extent, that's just the way it is.”

Susan, although she said the information she received from the home based development coordinator from the infant health and development service was a little overwhelming, she appreciated knowing everything there was to know. She described her experiences in receiving the information:

> [The home base development coordinator] gave it all to me to the point where I was a little overwhelmed because it was so much. But on the opposite side of things it calmed my nerves down enough to actually be able to absorb things and that's what I needed at the time.

Needing More Time

Morgan and Paul, however, said they needed more time to cope with the diagnosis before they were faced with all the information. Right after Samantha was diagnosed, Morgan was counselled by her audiologist about all the implications, options and the next steps in terms of intervention. She described her experience, her reaction to the information, and how she would rather have dealt with the information:

> At the time I felt quite okay with it. Of course right away I remember thinking, "I should have a multitude of questions to ask you." But I just couldn't think anymore at that point. There was a lot of information at that point that's thrown at you and not in a bad way but just because these are the things you need to do, these are the steps you need to take, here's a folder of information and you can get online with these organizations and support and that kind of thing. Just with the whole nature of everything that had been going on in our lives, I went home and I put it all away (laughter) because I was just feeling, I was personally overwhelmed, with everything. And I needed to just slow down. I felt like, "I will take out this book, this, one piece of paper at a time, when I am ready to take it out and read it but don't push me right now."

Paul also described how he, too, was overwhelmed with the information that they had received about what their next steps and intervention options were, immediately after Samantha was diagnosed. He explained, "You know what? We just didn't get on the ball with it partially because we just were so overwhelmed with everything else that had just happened. Looking back I wish that, at the time, I had pursued that more."

Morgan's individual need for information was different than what her actual experience was. Morgan described how her individual needs could have been met had she been given more time to come to terms with the diagnosis first. She made some suggestions for how an audiologist could meet her individual needs:

> I think, something that could be done, is even to just say once the diagnosis has been made, you give an opportunity to talk about information and what all that means, is to just give the family a little bit of space, a little bit of time to go home and to come to terms with it. Even a month or two and then to phone parents up and say, "What can we do for you now. These are your options, you need to start." I understand they need to be firm and they need to be pushing parents to move forward but even at the beginning just to be given a little bit of space and time without being pushed to, you need to go do this now, you need to go do this, you need to go do this. For me, after a little while, I just went, "Hold it!"

Julie described her experience of being counselled after she had received the diagnosis of her child's hearing loss. Her experience reflects the needs of Morgan and Paul. The audiologist with whom Julie dealt gave her some time to cope with the diagnosis before she provided Julie with all the information about implications, next steps and intervention options. She explained how the audiologist handled them after the diagnosis:

> What she went and did was say, "I'll let you go home now and I'll give you a call tomorrow afternoon." She went on and said, "It's a lot for you to deal

> with right now. I'll just give you a chance to come to terms with it and I'll give you a call tomorrow afternoon." And that's what she did.

Theme 4: Impact of Professionals

Another major theme that emerged from parents UNHS experiences was the impact that professionals had on parents during screening, at the time of the diagnosis and again later on as the child and family sought intervention services. Professionals had both a negative and positive impact on parents. Factors that had a negative impact on parents were professionals' ability to convey the diagnosis, their professional skills and their interpersonal skills. Other professionals' interpersonal skills had a positive impact on parents when it came to providing parents with information about intervention in a supportive and caring manner; this helped parents significantly in their UNHS experience.

Ability to Convey the Diagnosis

When it came to conveying the diagnosis, parents expressed how professionals' ability to share that information had an impact on them. Parents were impacted on by what information professionals gave to them and by how sensitively that information was delivered.

Rachael and Morgan shared their reaction to the information that professionals shared with them. Rachael explained what she needed from her audiologist after she received Joey's diagnosis:

> I needed [the audiologist] to speak in layman's terms a little more because the audiologist goes through things in decibels but you're just like, "What

> does it mean?" and "What does frequencies mean?" And they don't go over that. They act like they expect you to know.

Morgan explained that after Samantha failed the diagnostic ABR, the audiologist was providing her with specific information about her child's hearing loss and she, too, did not understand the information that was shared. Morgan spoke of a chart that was used, an audiogram which shows frequencies and decibels and how she didn't understand it:

> I think she showed me the chart when we were there too. She talked about what frequencies she didn't hear, which ones she was fairly good with. I didn't understand it all... I didn't understand all the charts. I could tell you the high frequencies [my child] is not going to hear but to see it on a chart with all the numbers and things, I didn't quite understand all that.

Three parents described experiences where they found professionals who were insensitive when it came to conveying the diagnosis to them. The insensitivity of professionals made dealing with the diagnosis even more difficult for them. Rachael described an interaction, where she felt as though the audiologist was very blunt when he diagnosed Joey. She explained how she was told:

> They figured it was his middle ear or his inner ear and they weren't sure and it just, "He was deaf." And at first they said, "With his hearing aids he would only hear cars, horns, trains, planes, and fire alarms. He'd only hear really loud things; it was just precautionary that was the only reason to get hearing aids."

Julies recalled receiving John's diagnosis in an insensitive manner from another audiologist in the city, as opposed to the town that she had the screenings conducted in:

> At the hospital in [the city] it was almost like, "We have told you that your child has a hearing loss. We have told you what to do, what more do you want from us?" And I guess, looking back on it now, I don't know what I really wanted them to do, I just wanted them to do something.

Based on Susan's experiences, where she had to wait nine months before receiving Ella's diagnosis, she expressed her opinion about how professionals need to carefully consider how they convey the diagnosis of a child's hearing loss to parents:

> They can't be scared to tell you what they think and I know a lot of professionals nowadays are scared to tell you what they think, they only want to tell you what they know but I honestly think that when it comes to that, if they think it's a hearing loss then say it may be. Further testing is needed ... that's all it would have taken, that's all they would have to do. For the next person that's in my shoes, you know, "Eeek." I feel sorry for them... I think they have to take at least that into consideration, not the testing itself but how do you convey the results to parents or not convey in my case.

Diagnosis: Professional Skills

Parents talked of professionals' abilities in terms of their skills when it came to interpreting the results of the diagnostic ABRs or reports they received. Parents also wondered whether or not professionals were taking the appropriate amount of time and attention required to accurately interpret the results.

Rachael's experience, having her child diagnosed with a sensorineural hearing loss only to later find out it was conductive, caused her to question the ability of the ENT who looked over Joey's chart and diagnosed him:

> I don't think it was the newborn hearing screening that caused all the problems, it was the ENT being too lazy to really look over his chart. They used the exact same test to test [my older child] and they knew with that it was fluid.... So it wasn't that the test said he was deaf, it was the doctor being too rushed or negligent to look at the chart.

Susan's experience also caused her to question the ability of the professional that interpreted her child's screening and diagnostic results:

> I had the bad experience, but not with the screening itself. The screen itself was very accurate but I had the problem with the professionals interpreting those results.... The test itself was awesome but the professionals interpreting it just didn't know how to interpret what they were reading, I don't think, or at least how to convey what they were reading.

Intervention: Professional Skills

Rachael's experience in seeking out intervention services for her newborn also caused her to wonder about professionals' abilities in dealing with infants who are so young:

> I got attitude and I got a lot of...like they didn't seem to know a whole lot about it. It almost seemed like everyone in that center hadn't dealt with a

> baby. Even the audiologist who did the hearing aids, she said that she had never put hearing aids on a baby so young. He was three months old when he got his hearing aids and she said they had never done it that young before. And I was like, "Why had you never?" I asked her about the earmolds, "Well how often are you going to have to do the earmolds?" And she said, "I don't know we usually do them once or twice a year." I said, "He's going to grow a lot in once or twice a year." She replied, "I don't know, I've never done it on a baby this little before so we are just going to have to see."

Intervention: Negative Interpersonal Skills

Some of the interpersonal skills of the professionals also had a negative impact on parents through their UNHS experience. Interpersonal skills refer to the manner in which professionals interacted with parents, when it came to providing them with information about intervention options and other services.

Morgan explained how she felt as though some of the professionals who she was dealing with were passing judgment on her for deciding not to move into a major city for services for their daughter:

> The one thing that came out with over the last year was on some of our appointments there was a real push that you should be moving to the city and I came out of that going, "Not every hard of hearing child in the world is going to be moving to the city and you know there are other services available even in small centers." And that I got a little bit tired of... Even almost to the point of where if they would ask us, "Are you considering moving to the city?" And if I said, "No," it was almost frowned upon. That

> bothered me. We are close to [a major town] and there are services in [our home town] with the speech language pathologist. I would think at the time, "She's not deaf. It's not like she has to be in a deaf school. Yes she does need help but we can get that help. We don't need to uproot everything and move to [the city]." So that would have been the one thing that I would have said that probably did not need to be said.

Morgan also spoke about how she felt pressured by professionals when it came to starting intervention. Unfortunately, Morgan and Paul were in a situation where they had to wait for funding and weren't getting any feedback; meanwhile professionals were giving them a hard time for not proceeding with intervention. This situation for parents didn't make coping with their child's hearing loss any easier for them:

> We had applied for funding knowing that she needed hearing aids. We weren't hearing anything, we weren't hearing anything, we weren't hearing anything and yet the medical professionals that are saying look we need to get on the ball with it and I was saying there is nothing coming through with funding for her.

Julie described one encounter with professionals, in the city as opposed to her home town, where she didn't appreciate how the professional didn't take the time to communicate with her at a time when she was feeling vulnerable and unsure:

> The hospital that we dealt with in [the city] didn't even seem like they had the time to deal with us. They were just so busy and I don't really know if the doctor had a bad day that day or what it was but he really didn't give us any

> time really. And I know [my husband] got really mad and stormed out because we had been down there for three days and we didn't really get anywhere with anything. The only thing we found out is the things that we already knew.

Intervention: Positive Interpersonal Skills

Parents also identified some positive experiences that they had as a result of some professionals interpersonal skills. Parents had kind words for the care, and support that some professionals demonstrated toward their child. Parents also expressed how appreciative they were of these professionals who helped them through coping with the diagnosis and accessing intervention services.

Although Morgan and Paul felt overwhelmed by the information that they had been given from their audiologist after the diagnosis, they still explained that they felt as though the audiologists "were very very good, and kind," and that all the information that they received was "certainly from the professional side, it was well meaning."

Julie expressed her sincere appreciation for the care and support that she received from the audiologist who first screened John. That audiologist was a constant for Julie and John. Julie sincerely appreciated how, even though they no longer used her services and moved out of the province, this audiologist still had a genuine interest in the well being of John:

> She actually took an interest in what we were going through. When I would call her I would usually get her machine because she was working, obviously,

> but she would always make a point of calling back. She was just there at that point in time.

Susan also felt as though the professional that she contacted, through the infant health and development service, was very supportive when it came to Ella's care as was made evident in a previous quote.

Theme 5: Decision Making

Decision making was another theme that emerged from all parents' experiences. Parents also had both negative and positive experiences when it came to making decisions. The negative experiences parents experienced were a result of the impact that professionals had on their decision making process and the challenges that parents faced in trying to make decisions. The positive experiences in the decision making process were attributed, again, to helpful professionals.

Making Decisions: Impact of Professionals

One challenge described by parents was that, in some cases, they felt like the professionals were making the decisions about intervention for their child without any parental input. Rachael explained that one professional told her that Joey would have, "No speech, he's going to need hearing aids and sign language and that was it."

Julie described her experience with an audiologist in the city. After diagnosing John, his only recommendation was to amplify; from this professional there was no mention of sign language at all. Julie explained, "His exact words in the report were, 'From our standpoint we expedite amplification.' That's what he said."

Julie also described how, before she moved out of province, back to her original home town, no one mentioned to her any other alternatives like cochlear implants. She explained, "Nobody mentioned any other alternatives for us at that point. I don't know how popular cochlear implants are but until we got home, nobody ever mentioned it. I didn't even know there was such a thing."

Based on Rachael's experience of trying to access audiology and speech language intervention services and having been told that Joey was too young, she felt that when it comes to decision making:

> at least let the option be to the parents. It shouldn't be up to the doctor, the audiologist; it shouldn't be up to speech therapy. It should be up to the parent if they want to start. They should be able to make suggestions, say this is what we normally do but it should be up to the parents. Some parents may not want to waste their time with a six month old trying to start training but other parents might look at it thinking start young as opposed to late because mom and dad are more comfortable with it.

Retrospectively, Rachael and Julie, also explained that she would have liked information about all intervention options so that they could make educated decisions. Rachael would have liked:

> the newborn hearing screening nurse to give more information about what to expect and what your options are. Like, "You can go get hearing aids, you can do sign language, you can do this and you can do that." Give you, even though your child is a day old or two days old, give you options.

Julie also said that she would have appreciated it if professionals provided her with more information so that she could make an informed decision. She explained that she didn’t feel as though she were around enough to get all the information before she moved away:

> There are so many different routes to go that if you find out about all of them; it's not hard to make a decision because there is so many different ways. I didn't find all that out in [the city] but we weren't there long enough to find that out.

Supportive Professionals

Decision making was described as positive when parents had experiences with professionals who had positive interpersonal and professional skills. Julie had the opportunity to work with a professional who was able to assist her in an unbiased way in the decision making process by providing her with access to all the different methodological approaches. Morgan and Paul also described that their decision making process, was positively affected by the power of prayer and that learning about the bone-anchored hearing aid came to them by “a divine appointment and answer to our prays.”

Theme 6: Professional Services

All parents had the experience of accessing professional services for their infant. In this category, professional services encompassed any type of service that was provided to the parent and infant in order to confirm the diagnosis and obtain intervention services. These professional services were a significant issue when it came to many different areas of the UNHS experience. The trends that emerged when it came to professional services were: the impact of waiting for services, the degree to which services were coordinated and professionals collaborated with one another, the delay of professionals to provide information and services, the fittings of pediatric hearing aids, parents' opinions of rural services and their additional needs for services that went unmet throughout their experiences.

Waiting for Services

A common experience of parents was waiting in order to get services for their infant. Parents talked about waiting for services when it came to the time between when their child was screened and when their child received a diagnostic ABR. Morgan reported that it took four months for Samantha to get in for a diagnostic ABR. She described the emotional upheaval that the waiting time caused her:

> That waiting time where you don't really know... where we didn't have a diagnosis yet and we were not sure... You can't really accept it yet because you don't have the diagnosis so it's like a little bit of a no man's land time.

Julie, who had to wait two weeks in order for John's diagnostic ABR, said, "Two weeks is not a long time but when you're waiting for something like that it is forever and for parents that are waiting to hear that kind of news, [two weeks] is not a good thing." In regards to the wait period, Julie stated, "It's really, it's really quite hard to go through that."

Susan also had to wait an extremely long time in order to get a diagnosis and she described how the wait for information caused her to feel frustrated and anxious:

> To even explain my level of frustration at that time. To take your baby, anybody's baby and have [the screeners] administer the test and your baby is sleeping. They're not moving, yeah they're breathing but everybody breaths right and have them say, "No we can't get a reading, maybe she's breathing

> too loudly." Right from day one something didn't sound right, even about why the test wasn't working and to have to go through the whole process and find out that they knew what was wrong and nobody was doing anything about it… I was really, really anxious and frustrated, very frustrated. Very hesitant about taking her in again. I just wanted to forgo all the little steps and go for the main testing. I understand that there is a process to follow too but it was frustrating, so frustrating as a parent to sit back and hear excuses like my baby was breathing to loud or was too mucousy.

Rachael did not express anxiety concerning her waiting periods between screening and diagnosis. Joey was screened when he was two days old and then an appointment was scheduled for her six to eight weeks later. She said:

> The audiologist phoned me within two to three weeks and set up a date. They wanted him to be at least six weeks because some babies are just not mature when they are born. That's what they told me, for some babies it just takes longer for their hearing to completely mature. So they wanted to wait, give it a least a month and then it would be a clear indication; it was a hearing loss or not.

Coordination and Collaboration of Professionals

Once a child receives a "refer" on his/her first screening, parents became involved with a numerous professionals. Some of the parents in this is study were involved with multiple audiologists, otolaryngologists and public health services such as nurses and SLPs. The collaboration amongst these different service providers was difficult at times because parents described a lack of coordination between all the different service providers who were, in part, responsible for the care of their child. As is evident in Table 3, Morgan and Paul are an example of a family that had multiple service providers involved with their child, Samantha. Morgan expressed feelings of confusion and awkwardness as she was not sure if it was her responsibility to coordinate the professionals or if the professionals were actually doing it themselves:

> I found there really was a time when things got really confusing because you are working with so many professionals. Between the SLP, the public health and three different audiologists, after a while, I was asking questions like, "I don't know if I am supposed to contact these people myself or whether they contact each other or whether I am suppose to phone the SLP or are they going to make that connection for me?"

Morgan also described being worried about "stepping on people's toes."

Julie felt that the process of getting hearing aids was more complicated than it needed to be because "the ear molds and the hearing aids are not done at the hospital," which means parents cannot go to one place to get molds fitting as well as the hearing aids. Rachael felt as though there really wasn't any coordination of services in her experience. After Joey was diagnosed, she was left to her own devices to find out about services that he may require. Rachael described how it was that she ended up contacting speech and language services:

> He had his needle, was it the three months or six months needle, and the nurse giving him his needle said, "Is he in speech therapy?" And I said, "No." She asked, "Has he been referred yet?" And I said, "No." This nurse, her

> niece is actually the one that the teacher of the deaf was brought in for. The nurse said, “He needs speech therapy, you've got to start young.” She called and made a referral.

Julie had the opposite experience when it came to the collaboration of professionals for other intervention services. She found that her audiologist was really helpful in setting up appointments for her where she was, in her town and in the city and also in her home town that she moved back too. This coordination of services contributed to the, retrospective, overall positive UNHS experience that Julie described. She described her feelings:

> You're up there and you didn't know where to be going and you didn't know what to be doing and it was just… you really had nowhere to go and no one to turn to and I mean I've thanked the audiologist there, oh my god, a million times and I mean she still keeps in contact with my husband, myself and [John] and he’ll be three. We've been home for almost two and a half years. She said, “You were just so distraught”. And like I said earlier, it was a really bad time but, then again, it's really good now.

Delay of Information and Services

Another common experience expressed by parents was that many encountered challenges when it came to professionals who, for whatever reasons, delayed giving information or services to parents and their infant. Parents experienced this delay from a number of different professionals at the screening component and intervention component of their UNHS experience.

Screening: Delay of Information and Services

Susan encountered a delay receiving service at the screening level when her audiologist requested a sedation order be put in for Ella's diagnostic ABR but Susan's pediatrician refused. Due to the fact that Ella wasn't sedated, she woke up during the screening, turned or made noises which produced a "refer" result on the screening. Susan spoke of the delay she encountered:

> So we went back, I don't know how often between then and the time that she was nine months old and they knew right from the get go what the problem was and refused, refused to do anything.

Intervention: Delay of Information and Services

Rachael encountered a delay when it came to providing intervention services for Joey. Professionals delayed providing amplification services as well as speech and language services. After Rachael had the confirmed diagnosis from her audiologist, she went to get Joey hearing aids. From the hearing aid clinic she was told that she should wait before getting the hearing aids and have Joey tested again in three months. Her reaction to this information was:

> why delay the amplification? Everything, they wanted to delay everything and I was like why? That's fine that's dandy if that's your kid but this is my kid and I want to start now. I don't want to waste any time and they were like, "No, no, no, nope. We're going to wait; we're just going to wait."

When Rachael went to obtain speech and language services in her home town, she also received the same frustrating reluctant attitude. When she contacted them to set up an appointment, "They phoned me three weeks later and they were like, No he's too young, we won't come out until he's a least eighteen months."

Pediatric Hearing Aid Fitting

The other challenge that parents described when it came to intervention services was the fitting of pediatric hearing aids, specifically the ear molds. Rachael and Julie described the experience of getting hearing aids as a really long process, where they had to wait an extremely long time to get their infant's ear molds and then by the time that they had arrived, their child had already out-grown them. This was the experience of both Rachael and Julie. Neither of these parents knew the reason for the delay in receiving their infant's ear molds but Rachael expressed her frustration:

> By the time he got them they didn't fit...Then in about a week I went back and said, "I can't get them to stay in, they just like fall right out and the [hearing aid technician] said, "He needs new ones already?" I think he had them for a little over a week but they had taken the impression two weeks early so it had been three weeks and within three weeks they didn't fit.

Rachael continued to describe her frustrations with Joey's hearing aids. At one point she noticed that Joey's hearing aids weren't working and she took them in to the hearing aid technician:

> So [the hearing aid technician] sent it away and I think it took three weeks for it to come back. I think he had his hearing aids from three months until eight months is when he had his tube surgery but a little past six months he was

> starting to get ear infections so I think he had them for three months. I think he wore them for a total of three weeks.

Rural Services

Another common trend that emerged was that all parents made some comments about rural services. All parents in this study lived in rural areas and believed that the services they received were affected because of where they lived. Three parents felt that their rural location was, in part, a disadvantage for services while three parents believed that there were some positive aspects to their child's receiving rural intervention services.

As previously mentioned, Rachael's experience caused her to question professionals' abilities to provide intervention services for her child. Susan also questioned whether or not her challenges were due in part to inexperienced professionals who hadn't diagnosed very many children in their rural setting. She felt that professionals' lack of experiences in servicing this new young population caused her daughter to suffer and, although being concerned about sounding negative about her city, said, "When it comes to what I've been through and what is best for her. I would take her out of town anytime." Julie also commented on the lack of service providers that were available in her rural community. "There are really no facilities for a deaf child up there which is really why we moved."

On the positive side, Morgan and Paul, because of how they were pressured to move out of their rural community and refused, obviously did not feel that their child was at a disadvantage because of her rural address. Susan, who had a negative experience in trying to receive a diagnosis, greatly appreciated the intervention service that she accessed in her rural community and felt that, because her daughter was in a smaller town, she was able to receive more one on one attention:

> I think living here... I'm just trying to put this in perspective. I think living here she gets more services provided for her than she would if we lived in a bigger city. The patient load here isn't quite so heavy. She gets more. In a smaller city there is more funding available for the services that [my child] even needs today. Everybody said, "You're lucky you don't live in [a larger urban setting], you might get therapy once a month and right now she gets therapy once a week."

Additional Needs for Services

The final sub theme in this category was that all parents expressed their needs for additional services. Some of the additional needs that parents identified were accessed, such as genetic counselling while the majority of their additional needs were not met in parents' UNHS experience but, rather, were thought of retrospectively as services that would have been helpful, such as access to veteran parents, counselling services and their individual need for services. As parents were identifying their additional needs, they were also making recommendations for future UNHS programs. By identifying their needs, they hoped to be speaking for other parents who may have similar needs as they did and who may benefit a great deal from the provision of the services that they received or would have liked to receive.

Genetic Counselling

Two parents over the course of our interview expressed their need, after their child was diagnosed, to see a genetic counsellor. As was discussed in the impact of the diagnosis, these parents wanted to know the cause of their child's hearing loss and they sought situations that they could blame for their child's hearing loss. As a result, Rachael and Julie ended up accessing the services of a genetic counsellor. Both parents who obtained services from a genetic counsellor had a family that was still growing and therefore had the additional concern of whether or not this was something that could be passed on to future family members. As Rachael was going through her UNHS experience with Joey, she became pregnant again and it became really important for her to know whether or not Joey's hearing loss was genetic. While she was waiting to get in to see the genetic counsellor and was collecting her family history, she found out about other health issues in her family history and was informed by others that she was at risk for cerebral palsy, which all made her feel extremely "paranoid." She described a great deal of relief upon her visit to the genetic counsellor, who told her she had a 25% chance of having another baby with a hearing loss although it still didn't minimize the impact:

> I was like, "At least I know what I'm dealing with." At least it's not I have a 25% chance of having a baby with three legs or something. At least I know what I'm dealing with but I was still like "phewww" that's a lot to deal with.

Julie was completely surprised to have a son born with a hearing loss, having never even considered that it could be a possibility. She said:

> Well that's just it, you don't think about it at all. We did find out it was genetic. It was both on my side and [my husband's] side, both of us are carriers but there is no history on either side. We went back as far as we

> possibly could, there's no history and that's what the geneticists told us. It was like winning the lottery that you just got two carriers together.

Knowing that she and her husband were carriers, when she became pregnant again she immediately set things up so that when her daughter was born her hearing would be tested immediately:

> And my little girl, her hearing is perfect. I've had her tested, she's eight months old and I have had her tested three times because I'm really paranoid about it now and her hearing is perfect, she obviously doesn't carry the deaf gene.

Veteran Parents

Four parents expressed their need to access "veteran parents" who have been through the process before and who can help advise them in regard to what the experience was like, what to expect, and what the possible outcomes are. Parents felt as though, by talking to other parents, they would be provided with more useful and understandable information, that it would be more comfortable, and that there would be more time to be able to spend with them compared to busy professionals. Rachael felt that speaking to a "veteran parent:"

> could have saved a lot of stress, a lot of not knowing and especially having someone come in who's dealt with hearing impaired children and who's taught them or who's been a mother or somebody who's first hand, not somebody who's read about it because [the professionals] don't understand.

Rachael also felt that parents would be better able to answer the questions that she had:

> You want to ask and you don't want to sit there for five hours with someone in an office with a huge list and half the time you forget half the questions that you wanted to ask anyway because you don't write them down. You get home and you think, "Why didn't I ask that one...I totally forgot?" You know it would be nice to have someone you can talk to and who can give you those answers.

Morgan also felt that access to "veteran parents" would also be beneficial to her:

> I think at the time what would have been good for me was to have some one-on-one interaction with other parents who have also gone through this same thing and I'm not actually sure if that was made available, if that was suggested at the time or not but looking back I think that would have been something really good for me just to see. I think it would have been a comfort at that point.

Julie was put in touch with parents who had a child with a hearing loss, once she moved back to her home town after John was diagnosed. She appreciated, not only the information they shared, but also the support that these parents were able to offer her and how the contacts between parents were made:

> That was one of the biggest things that I found great down here was that they put me in touch with everybody that was going through the same thing that I went through. They did it in a way that was helpful because it's not that easy to pick up the phone and talk about it when you are first going through it so they did it through e-mails. I e-mailed a lot at two or three in the morning

> when you couldn't sleep, you couldn't call anybody and I used to e-mail people and ask how did you get through that? Or how did you deal with this? What did you find was the best way to go about it? Things like that which I think would have been a benefit in [the city my child was diagnosed in]. It may very well be there but we just didn't get it.

Counselling Services

Another need for services that was expressed by parents was a need for counselling services to be provided to parents after the diagnosis. Morgan and Paul both felt as though they would have benefited from talking to someone who could validate their feelings, a counsellor who was informed about deafness, who could help them deal with their emotions and move on. Morgan explained:

> One thing that I think could have been offered on the more personal side was to ask us, "Would you like to be connected with say a counsellor who can deal with parents with children with a disability?" Just to help us through some of that grieving process and be where we are at and explain how to move on from there.

Paul also described that he would have appreciated having access to "someone who can guide parents through their own thoughts and emotions and help them be the best support they can to their children with disabilities. I think would be really helpful, really helpful."

Theme 7: Individual Needs for Services

Parents also expressed many individual needs for services, depending on their individual experiences and their reactions to the information that they received.

Based on Morgan's experience, where they had so many different professionals involved and she felt awkward when it came to keeping each of them informed, she expressed her need for “a professional that coordinates the professionals (laughter) so we didn't have to do that.”

Paul spoke about his need for more information about all the different services that were available to them, specifically, now that he was prepared to deal with his child's hearing loss, what type of services were available to his family at this time. Paul stated, “I think, honestly, the thing for me at this point would be, to start getting into some seminars and workshops and to start talking to other parents.”

Paul continued, explaining the other information he would like to access. He said, “Something else is to be up on the latest research and technology. Even to be sent information on what's happening for programs”

Morgan also wanted more information on what would be happening in the schools. She explained she would like information on “what kinds of things public schools or preschools are doing for hearing impaired children and what kinds of things can be implemented to work with them.”

Theme 8: Recommendations

Parents had varying recommendations that they wanted to share based on the individual circumstances of their UNHS experience. Parents' recommendations came from their experiences and struggles, and were based on what they felt could be done better for future parents' UNHS experiences. These recommendations are in addition to the needs for services that parents highlighted in the previous section. The recommendations in this section focused on how an IHP could be improved.

One Place of Contact

Two parents made the specific recommendation that there should be one contact person that parents can go to in order to get more information, who can direct them to where they can get more information or who can direct them to services. As has been made evident by the parents shared experiences, four of the five parents felt as though they were left to their own devices when it came to getting information or services and, because of that, parents felt as though their experience could be improved if more support were given to help transition them from diagnosis to intervention.

Julie's recommendation came from her experience of giving birth to her child in a region were there was no screening program. When she had a concern about her infant's hearing ability, she didn't know where she could go to get the diagnosis and, even after that, where to get information. Her concern was for other parents who find themselves in that same situation. She recommended:

> Some kind of hot line, that people could phone just to find out from somebody where they go from there. I don't even know how that would work or even if it would work, not only for deaf children but for anything. If you have a child and you don't know where to go from there, there should be someone you can call and say, "Look, this is what I think is wrong, where do I go?" Then they'd be able to direct you in some direction. That would probably be my biggest thing...That's the scary part, not knowing where to go. That was our scariest part I guess.

Susan also made a similar recommendation based on her experience of not getting the answers and information that she needed from the professionals who were screening her baby. Susan recommended that there be one facility that parents can contact in order to get more information about the services that are available:

> Anyone looking for information that is medically related can go into this place, parent services or hospital services and say, "This is the problem I am having and I really don't know where to go, and who do I talk to? Who can tell me who the best person to go to is?" I would love to have somebody say, "This is where you go and this is who you talk to." That's what I would give anything to see… I would love to see just one medically based organization in town that can deal with any number of things that can send you in the right direction.

Funding Information

Parents also made the recommendation that they be given more information about all of their options for funding or that there should be some sort of funding in place for some parents who can't financially cover the costs associated with getting a child with a hearing loss diagnosed. Parents struggled with not knowing how they would be able to provide the help for their child that the health care providers were recommending.

During Julie's interview, she mentioned the challenges that she could foresee for parents who are from rural communities, who have to travel great distances to attend appointments that span three or four days, having to spend a great deal of money on hotel bills and food bills on top of dealing with the impact of a potential diagnosis. Julie explained, "It is really stressful and if you have money issues it would be that much harder, again, if you couldn't afford to be down there to get the appointments."

Julie saw this as potentially being a big concern for some parents and that there should be some type of financial assistance in place to help these parents. Rachael felt that it was extremely important for parents to be provided with information on funding options when they are being counselled by the audiologist about the diagnosis and intervention, otherwise parents are left feeling as though they will not be able to provide the very best for their child. Rachael recommended:

> Professionals need to tell you that the government will pay for [your child], for all their special needs for their schooling, if they need special hearing aid monitors, the government pays for it. You're thinking, "I don't have money for it. My kid is going to suffer because I'm not a doctor I'm not rich." Give parents information about the funding available, that schooling is available, that these are the options and you can do this or you can do that.

Individual Recommendations

Susan strongly felt that professionals should be honest and open with parents about the results of the screening performed on their child. She felt that, as long as professionals kept parents informed in regard to what they know when they know it, the relationship between parent and professional would be sound. But if professionals keep information to themselves, this would create problems with that relationship. Her recommendation was:

> disclosure. You disclose to me what you know and what you think is going on and we'll have a good relationship. If you just want to keep it all to yourself and muddle on by, we're going to have a problem you know.

Again with Julie giving birth to John in a region that didn't have their UNHS program up and running, her final recommendation is for those parents, and it is a powerful and important one. Julie's message to other parents was:

> if you have any inclination that something is not just right, don't stop, no matter what somebody tells you, just don't let it go. I think that's what the biggest thing is, you take your child to the doctor and they tell you, "Oh that's fine. Don't worry about it." And you tend to take that wholeheartedly. Obviously doctors aren't perfect either, they are only human but parents should have the confidence that parents know best.

Theme 9: Support and Praise for Universal Newborn Hearing Screening

Despite all the challenges and struggles that parents experienced as part of a UNHS program, all parents expressed their deep gratitude towards the early diagnosis of their infants hearing loss. Parents were thankful because of the fact that it allowed them to proceed with intervention services earlier, which made them more hopeful that their child's language outcomes would develop on par with hearing children.

In Julie's UNHS experience, she did not know where or to whom to turn in order to have her child's hearing assessed and she encountered professionals who did not seem to have the time to deal with her concerns. Yet, despite these hardships, she still had words of praise for UNHS:

> I'm very thankful that we found out as early as we did. Even the other kids that have CIs, when I compare them to [John], he is just so much ahead of them … I really believe, I know he didn't get much from his hearing aids but I know he got something, whereas if he didn't have them and we didn't get into the system until he was a year old, then he would have been so much further behind than he is right now.

Paul, who had already experienced living with hearing loss, related his experiences with Samantha's identification of hearing loss to his father's experience with his own hearing loss. He was thankful that his child had the experience of being diagnosed earlier and had the opportunity to seek intervention at an earlier age as opposed to falling behind:

> Dad knew that I had a hearing loss there, he knew it within six weeks of my birth and yet it took him three to four years to convince the medical establishment that it was a hearing problem and not brain damage or a disability of that nature. With this screening program, we would definitely recommend it in the sense that children could get the help, intervention and diagnosis earlier. When I was in grade one, I was developmentally behind. In speech, everything, I was playing catch up. And I caught up by the end of grade two. Yeah and we are, oh boy we are so thankful that we are in a region that was doing it and that she was caught as early as she was.

Rachael's infant was misdiagnosed and she too encountered many challenges but she also spoke of her thankfulness for the screening program. Despite everything she went through she said:

> I'd rather know because, if there is no intervention by six months and some people would be like, "Oh no, no, he's fine. Look he's listening to you he's smiling." And I said, "Well yeah, he's looking at you." And then other people would say, "Well he didn't even hear the blender." So I felt like, "How are you supposed to know if your child has a hearing loss?" The only other thing to do would be wait and leave it until they are two or three and they're not talking.

Susan, who waited nine months to receive a confirmed diagnosis, voiced her appreciation for the UNHS program. Had it not been for the screening she would have had no reason to suspect a hearing loss:

> I absolutely support UNHS because, had it not been for her failing [the screening], it wouldn't have been, probably, until later that it was picked up. I do, I totally thought it was the best idea going yet. I do. I'm just... I'm so thankful.

Morgan also expressed her appreciation for UNHS because she really felt that Samantha's diagnosis could have been significantly delayed had it not been for the screening program:

> [The screening] was our only clue that she was not hearing properly. As a newborn she didn't startle, newborns have a typical reaction to startling to sudden or sharp noises and she did not do that. That was our only clue and it was something that could have been easily overlooked. She's a content baby and with the moderate hearing impairment that she has, she could have been missed until she was significantly delayed in school and in her speech.

Two parents in this study explained that they heard about the fact that the UNHS program in their region was ending and it allowed them to voice their utmost support for its implementation. When Julie heard that the program was ending, "I sent up pamphlets and I sent up a letter. In the letter I said if there is anything in the world I can do, I would because [UNHS] is the best thing in the world." Rachael also described her reaction to the discontinuing of the UNHS program:

> They had a thing in the paper that said they were going to discontinue the hearing screening because they didn't have enough funding for it and that they had to fight the mayor for it. This was about two months after [my child] was born and [the paper] said, "Hearing screening has been here for three years and they've only identified four kids with hearing loss. So is it worth it?" And I was like, "For the mothers of those four babies, yes it is worth it. Just because every other baby has normal hearing, for the mother of those babies it is worth it, if they can prevent a two year delay in every aspect."

Summary

The participants talked about their experiences with universal newborn hearing screening, the diagnosis process, and what type of facilitation was provided as they accessed intervention services. Parents described both positive and negative experiences as they went though each stage. Positive and negative experiences were attributed to: individual ways families dealt and coped with the diagnosis, the amount and nature of information, and numerous different professionals that parents encountered.

As a result of their experiences, the participants had recommendations about how infant hearing programs could be most successfully implemented. Each parent supported universal newborn hearing screening as a positive tool for identifying hearing loss in newborns but their experiences provide some insight into implications for best practices. The following chapter will address implications for best practice based on parents' experiences and the Canadian context.

CHAPTER VI - DISCUSSION

This chapter emphasizes what I consider to be the most salient aspects of the findings presented in the previous chapter. The findings discussed in this chapter have been chosen to highlight areas where we can draw the most significant implications for best practices for new IHPs. The implications discussed are not directed towards a specific group of professionals, i.e. SLPs, audiologists, or teachers of the deaf but, rather, represent the qualities that any one of those professionals should demonstrate in order to make parents' UNHS experiences more positive. These implications also represent the needs of parents whose children are diagnosed with any degree of hearing loss, from mild to profound. Parents who participated in this study had infants diagnosed with hearing loss that varied considerably; however, they all had common concerns. These areas of discussion are: 1) parents' needs for accurate information about the screening, 2) parents' individual needs for information, 3) professionals' impact on parents and 4) empowering parents through the process of collaboration.

Implications for Best Practices

Screening: Parents' Needs For Accurate Information

In this study, some parents described how they felt as though they received little information during the screening component of their UNHS experience. Susan, Rachael, Morgan, and Paul encountered problems obtaining a diagnosis once their child had been referred on a screening test. Susan, Morgan, and Paul were told that the "refer" results of their infant's screening were due to equipment malfunction or blamed on their infant's noisy movement. In Rachael's experience, her child was diagnosed with the wrong type of hearing loss. These parents, who had a difficult time obtaining the diagnosis after their screening, became critical of the information that they were given about their child's screening tests. They indicated that they needed more information about what a "refer" result could potentially mean, as opposed to having screeners tell them that the machinery was malfunctioning or that their child was breathing too loudly. In Susan's story, her screening experience was made even more difficult due to the fact that the possibility of hearing loss wasn't even mentioned to her after her child's screening resulted in a "refer".

Research has addressed the concern that screening tests are imperfect and can result in false positives, where a child receives a "refer" result on a stage of screening but doesn't actually have a hearing loss. The concern is that this causes parents too much anxiety and stress to warrant the implementation of a UNHS program (Hergils & Hergils, 2000; Poulakis et al., 2003; Watkin et al., 1995; Weichbold & Welzl-Mueller, 2001; Weichbold, Welzl-Mueller, & Mussbacher, 2001). Research has also addressed how professionals can best share the results of screening tests; it is a fine balance between creating a significant enough concern in parents so that they bring their child in for the follow-up appointment but not so much concern that they experience a great deal of anxiety and stress (Hergils & Hergils, 2000; Magnuson & Hergils, 1999; Poulakis et al., 2003; Watkin et al., 1995; Weichbold & Welzl-Mueller, 2001; Weichbold, Welzl-Mueller, & Mussbacher, 2001). There has also been research directed toward the influence of the amount of information that parents are given about the screening procedures and the parental attitudes towards the hearing screening experience. Research has shown that the more informed mothers are of the screening, the higher their acceptance and the lower their maternal concern (Hergils & Hergils, 2000; Weichbold, Welzl-Mueller & Mussbacher, 2001).

Canadian Situation

In addition to information learned from the literature, program creators and coordinators of Canadian IHPs are also very concerned with how best to inform parents about a "refer" result on the first stage of screening. Manuals for Yukon, Ontario, and Alberta's screening programs have sections which describe how parents should be informed about the screening results. In the Yukon, the newborn hearing screening manual makes suggestions to screeners about what to tell the parent:

> **If there is a questionable emission or no emission:**
>
> "I wasn't able to get a good screening this time. It was too noisy in the room/ the baby's ears are still wet/ the baby was moving too much during testing. We will try to re-screen the baby's hearing again before you leave the hospital."
>
> **If still no clear emission following re-screening:**
>
> "We weren't able to get a clear screening result yet. This could be caused by many things including background noise, the baby's movements, or debris in the baby's ear canal. Hearing Services will be contacting you in the next few weeks to schedule follow-up testing. They have a quiet booth and will be able to check for wax and debris in the ear canal" (Yukon Guidelines for Newborn Hearing, 2002)

In Ontario, screeners are educated on what the results of the screening indicate and therefore, how to answer parents' questions. Pertaining to a "refer" result, the Ontario screening training manual informs screeners to answer the following questions accordingly:

> **If the result is "No Result" what does it mean?**
>
> "No Result" means that the screening test could not be completed for some equipment related reason. If the baby was too active and the noise levels are too high, the computer will not be able to recognize a response. There could be a problem with the probe, or probe fit, or with the computer software, although that would be rare. Whatever the reason, a "No Result" means that the screening will have to be repeated in order to determine whether the true result for that baby is "Pass" or "Refer".
>
> **If there is a "Refer" result, what is the Stage 2 screen?**
>
> Parents usually want to know the results of the test right away. If there is a pass in both ears, there is usually no problem. If one or both ears give a "refer" result, then it is important to reassure the parent(s) that all this means is that a more detailed hearing check-up would be a good idea, preferably within a few weeks. The word "fail" is never used in connection with a screening result, because it alarms parents unnecessarily and because it does not capture the true significance of not recording an OAE… If the baby does indeed fail, what it means is that there is an increased *risk* of a hearing problem, but not that there *is* a hearing problem. The odds are that a baby who fails the screen will have normal hearing, but virtually ALL babies who DO have hearing loss will fail.

If the result is "Refer" from Stage 2, the next step is an Audiology Assessment.

> If a baby doesn't pass the screen, the parents should be informed in a low-key manner that there will be a follow-up contact for an audiology assessment within a few weeks, to be done at a time convenient to them and provided the general health of the baby is satisfactory. The parents should be reassured that the pre-discharge test does NOT mean that the baby is deaf. There are many possible causes of screening failure, such as fluid in the middle ear that will resolve naturally in some cases or with medical management. Most infants who fail the pre-discharge screen will turn out to have normal hearing. However, the "refer" screening result does indicate increased risk and it should be indicated that a hearing check-up would be a good idea after the acute-care stage is passed. (Ontario Ministries of Health and Long Term Care, 2002)

In the Alberta UNHS study, parents are given a pamphlet with their child's results and information concerning, "Taking care of your child's hearing." If the child gets referred the pamphlet tells parents that, "We need to repeat your baby's screening." It goes on to say:

> Your baby, __________________, needs to have a second hearing screening. It is common to have fluid in the middle ear following birth. When babies do have fluid in their middle ear, they often need to have their hearing screening repeated (Alberta Universal Newborn Hearing Screening Project).

It also tells parents that they will be contacted in 30 days for a re-screening.

Implications for Best Practices

Based on the parents' experiences in this study and what the literature shows, more information and training needs to be given to screeners as to how best to inform parents of a "refer" result on a screening. At the very least, all parents should be given very clear verbal explanations, emotional support and written information about the screening and what the next step is in the program. Some consideration should be given to informing parents about the entire screening procedure. If parents are told at the same time that they are in the hospital for delivery, important information about the hearing screening may be missed because there are so many other things going on. But if parents were told in Lamaze classes or at one of their obstetrician appointments, parents would be better educated in order to understand what the screening means. Professionals might also feel less of a need to protect parents by sharing only partial information with them about the hearing screening.

The potential of a hearing loss should always be mentioned. Parents in this study expressed that the "not knowing" and the excuses they received were more difficult to deal with then the mention of the possibility of a hearing loss. The parents' experiences in this study signify that parents are stronger than professionals give them credit for and, therefore, perhaps a more complete and all encompassing description of the screening procedure and all the potential results should be shared honestly with parents.

Giving Information: Parents' Individual Needs

Parents in this study indicated that they each had individual reactions to their child's hearing loss. The literature indicates that it is important that all professionals who are involved in UNHS programs are very aware of this individuality (Edwards, 2003; Meadow-Orlans, Mertens, D., Sass-Leher, & Scott-Olson, 1997; Sjoblad, Harrison, Roush, & McWilliam, 2001). Edwards (2003) discussed the importance of professionals' awareness of parents' ability to respond to change when it comes to counselling them about their newly diagnosed child with a hearing loss. She stated that generally most human beings "do not invite change into their lives" (p. 4). People function according to the pattern of their lives and when something unexpected happens, most individuals are resistant to that change. She described that for parents of a newly diagnosed child with a hearing loss, this resistance can take the form of:

> delaying, needing more detail, intellectualizing, moralizing or impulsive action- [convincing yourself] everything is suddenly fine, [thinking] "I need a solution fast"...sustained confusion or denying the impact...[experiencing a] lack of questions or [having] a desire to talk about the same concerns repeatedly. (p. 5)

Parents in this study described how they greeted this life changing event (learning that their child had a hearing loss), when they talked about their individual needs for information. Susan described her need to know everything that professionals knew as soon as they knew it. For her, knowing every detail kept her from being afraid. Rachael also felt that it was helpful to know the information upfront. She felt that, by having and dealing with all the information, she was eventually comfortable with her child's hearing loss and its implications. Paul was resistant to accepting his child's hearing loss. His resistance took form in his inability to attend medical appointments. Morgan was also resistant to the life changing news by initially lacking questions to ask the professionals and then feeling so overwhelmed with information that she had to put it out of her mind. Jamie described two different reactions to the life changing diagnosis. First she explained that she immediately wanted to fix the problem and find a solution. Secondly, she stated that she felt as though she needed more of an opportunity to talk repeatedly over her concerns with professionals. For many parents in this study, how they were informed about their child's hearing loss and the individual ways they dealt with the diagnosis of their child's hearing loss, were not the same. This incongruency only compounded their difficulty in dealing with the diagnosis.

Canadian Situation

In one province, after parents receive the diagnosis, it is up to them to set up an appointment for counselling with the Family Support Worker, about the implications of their child's hearing loss. By having that decision rest in the hands of parents, those who want to deal immediately with the diagnosis can make the appointment the day after their child is diagnosed, whereas parents, who need more time, can take a full two weeks before they begin scheduling and attending appointments. While, in another province, consideration is given to how ready a parent is to receive the diagnosis, the audiologist makes the decision about when the parents receive the news. In this situation, some parents may be upset if the professional withholds their child's health information for sometime.

Implications for Best Practices

The parents in this study demonstrate that parental need for information is very individual and dynamic. I have heard this used as an argument against *universal* newborn hearing screening; if parents are individuals, how can professionals ethically create a program that is designed to be *universally* applied. I think the answer lies in the need to better educate professionals regarding how to communicate with parents. If professionals listen to families to determine how each family greets change and where they are in the process of change, then parents will guide professional practice concerning how and when to share information. An important distinction needs to be made; by no means am I suggesting that professionals should decide what they share and what they withhold from parents. Based on data from these interviews and other interactions with parents, I believe parents have the right to know everything that the professionals know when they know it, but it should be parents who set the pace for how they want to deal with the information after they have received the diagnosis.

By understanding this individuality, professionals will be better able to work with parents to meet their needs, as opposed to following a standard protocol. A protocol that *universally* specifies how and when professionals are to counsel parents would be too rigid for the individual needs of each family that is affected by an IHP. Each individual reaction to the diagnosis and whether or not it is resisted or accepted requires a different response from the professionals who are to counsel parents. Audiologists have expressed that, in their busy work schedule, it is difficult to find the time to spend with one family trying to figure out what their needs are. Later I will suggest that infant hearing programs need to include in their program design an individual who is dedicated to spending sufficient time with families in order to meet their individual needs after the diagnosis.

The parents in this study echo the sentiment that parents want to know what the professionals know when they know it regarding the diagnosis of their child. When it comes to information pertaining to the implications, next steps, and the intervention and programming, that could better be shared with parents in the manner that parents express they want to hear it. When dealing with families in this very vulnerable time, it is important that if an IHP is to be implemented, the infant and family must be the number one concern and priority. Unfortunately, historically, parents and families have been under-represented at the level where the decisions are being made about the program and services (Bodner-Johnson, 2001; DesGeorges, 2003).

Telling Parents: Professionals' Impact

The parents in this study all encountered and dealt with some professionals who were perceived to be insensitive to the emotions they experienced upon receiving the news of their child's hearing loss. This perceived insensitivity towards parents, in this vulnerable time, is supported in previous research, where parents have stated that they too were displeased with the way the identification of their child was handled. Parents have expressed their wishes to receive counselling from a skilled empathetic audiologist (Bamford et al., 2000; Bruder, 2000; Corcoran et al., 2000; Harrison & Roush, 2000; Luterman & Kurtzer-White, 1999; Russ, Kuo, Poulakis, Barker, Rickards, Sauders, Jarman, Wake, & Oberklaid, 2004; Sjoblad et al., 2001). In a study conducted by Bamford et al. (2000), the authors stated that, "It must not be overlooked that the identification of newborns and very young babies brings heightened sensitivity to the process" (p. 152). Luterman and Kurtzer-White (1999) identified that, "The current level of counselling training does not prepare audiologists for meeting the increased emotional demands that UNHS would precipitate" (p. 17). Roush (2000) identified that the extent to which a family centered approach is taught during graduate training affects the degree to which those methods are accepted and implemented by the practicing professional. Oyler and Matkin (1987) looked at parent-professional relations and asked audiologists to evaluate their training in pediatric audiology. This survey identified that:

> Three out of four respondents indicated that their graduate programs offered no course work that dealt specifically with counselling parents and family members. Among new audiologists, fewer than one in four had taken courses related to working with families (p.160).

More recently, Crandell (1997) published a study, "An Update on Counselling Instructions within an Audiology Program," and he found that only 18% of graduating audiologists had completed one course in counselling.

The parents in this study described experiences in which professionals did not treat them with the sensitivity that they felt they required. Jamie described how, when she found herself very emotional, upset and needing something that she could not articulate from the professional at the hospital in an audiology appointment, the audiologist acted as though he had no time for her family. In Rachael's experience, she described being told about her child's hearing loss in a very blunt manner; she felt the audiologist who was in the UNHS program wasn't very sensitive to the impact that the news would have on her. Rachael and Morgan also described how the professionals who counselled them regarding their child's hearing loss and its implications used language and terminology that they were unable to understand.

Canadian Situation

Of the five Canadian programs, four programs have audiologists who have the role of counselling parents regarding the diagnosis and intervention services. In New Brunswick, IHSP implementers are in the process of compiling a training session for audiologists to help them develop sensitive ways to diagnose an infant with a hearing loss. In Ontario, the audiologist does share the diagnosis with the family and a family support worker counsels the family about intervention options and implications. Some Canadian audiology training programs are beginning to re-evaluate the counselling training that they are providing to future audiologists.

Implications for Best Practices

The implications of these findings are that, in order for IHPs to be successful, special attention needs to be given to the counselling training that audiologists and other professionals receive, either in audiology programs, as additional workshops or as a requirement before they take a position within a UNHS program. As Berg and Spivak(1999) stated:

> Professionals with demonstrated competencies in early identification and interventions of hearing-impaired infants are much needed and at present not available in every community or region. Mandated universal newborn hearing screening will increase the demand for such expertise and skill. Programs in

> audiology will be forced to meet this challenge and tailor their educational training to meet this need (p. 351).

If infant hearing screening programs are to become a reality in every province, university programs should begin to train and develop professionals who have the requisite skills to take positions in such programs. Harrison and Roush (2000) found that audiologists who specialized in pediatric audiology are most likely to be aware and sensitive to the needs of families. These professionals, whether they are audiologists, speech language pathologists, teachers of the deaf, or early interventionists, who are trained in deafness and in working sensitively with families, should be the professionals who are responsible for coordinating Infant Hearing Programs.

Empowering Parents: The Process of Collaboration

Parents in this study described their experiences of being left to their own devices after they had received the diagnosis of their child's hearing loss. Benedict and Raimondo (2003) stated that the major component of collaboration with families is communication. Literature suggests that there has been a lack of collaboration in infant hearing programs when it comes to 1) accessing information about intervention, 2) receiving support services, and 3) obtaining assistance in transitioning (Bamford et al., 2000; Bodner-Johnson, 2001; Corcoran et al., 2000; DesGeorges, 2003; Harrison & Roush, 1996; Luterman & Kurtzer-White, 1999; Russ et al., 2004; Sjoblad et al., 2001). Parents in this study shared experiences where a lack of collaboration was evident, and said that this contributed to negative feelings towards their NHS experiences.

Access to information: intervention options

When it came to professionals collaborating with parents, participants in this research indicated that they needed to receive more information about the intervention options available. The literature also indicates that parents have expressed their need for more detailed information after their child has been identified, and a need for unbiased information about intervention options (Bamford et al., 2000; Corcoran et al., 2000; Luterman & Kurtzer-White, 1999).

It was apparent that parents in this study received insufficient information or details regarding intervention from the way they discussed how they came to make the decisions regarding the intervention services for their child. Morgan and Paul were not told about the importance of sending their child to speech and language therapy, nor were they informed about all the amplification options that were available to their child. Rachael and Susan were left to their own devices when it came to accessing intervention services. When it came to the intervention that Susan's daughter Ella received, Susan expressed that her service providers always were able to answer why it was that they were providing one particular intervention for Ella but Susan was never a collaborative partner in creating that intervention. Jamie was the only parent who had a positive, coordinated experience when it came to accessing information about intervention and intervention services.

In terms of the need for unbiased information, Harrison and Roush (2000) surveyed questioning pediatric audiologists as to what their priorities were a few months after an infant was diagnosed. They indicated that the priority is, "assisting a child in learning to listen and speak"(p. 238). This can be viewed as problematic when an audiologist is in the position of counselling parents regarding intervention options, because the audiologist might have a different priority and agenda than the parents may have. When interviewing the parents in this study, it became evident that not all parents were equally informed about all the intervention options that were available to them. For example, in Rachael's experience, she was told she should provide her child with amplification but received little information from medical professionals regarding any sign language intervention programs. The same was true for Morgan, Paul and Susan. The literature states that many professionals in the field of deafness have their own personal biases, which sometimes are allowed to influence parents (Gravel & O'Gara, 2003). This is insufficient practice for a successful IHP.

Canadian situation.

In the Canadian IHP programs, Ontario is one province that claims to be doing its best to ensure that parents are receiving information that is not biased towards one methodology or another. I have insufficient information to comment on the other provinces. In Ontario, in order to prevent professionals exerting external pressure on parents towards one methodology, IHP implementers at first decided that the individual who should counsel parents regarding intervention should not have a great deal of formal training in the field of deafness. The reason for this decision was that it was thought that this individual would not have biases. Recently, however, Ontario professionals are considering changes to this policy.

Another factor that has influenced what parents are told regarding intervention options has been the number of services that are available in the province. In P.E.I the audiologist in charge of the infant hearing program explained that he/she informs parents only of the options that are available to them in their area and, in P.E.I., that does not include any intervention options for sign language. In Yukon, one audiologist explained that some parents choose to leave Yukon if their child is diagnosed, to pursue different intervention options. In New Brunswick, the parents referred to APSEA are introduced to a program that offers all intervention options under one roof. Alberta too offers options for parents, though coordination at the provincial level does not happen.

Implication for best practices.

In a successful IHP, parents need access to all information regarding intervention in an unbiased manner, in order to make informed choices. Parents need to be made aware that sometimes the information they are receiving is the opinion of the professional that they are dealing with, and, if they speak to another professional, they will receive different information and advice. For those parents who feel they will benefit from the literature, professionals could direct them to the most recent research on how best to communicate with infants who are deaf and hard-of-hearing or professionals could select valid and user friendly material that can be distributed to parents.

Upcoming IHP programs need to carefully consider the qualifications of the professionals that they choose to counsel parents. Literature has identified that all professionals, (audiologists, SLPs, AVTs, teachers of the deaf) working with children who have a hearing loss have their own biases (Gravel & O' Gara, 2003). While other health care workers may have expertise in one area, i.e. counselling, they may not have expertise in working with hearing loss. Therefore, perhaps, instead of making decisions based on a particular profession, the individual person should be considered based on his/her unique qualifications, past experience and the program's design.

Parents should be allowed to access whatever services are available in the community. Funding and structures need to be in place in order for that to occur. Parents should not be made to feel as though they have to make a choice between intervention services as a result of funding constraints or methodological limitations. In order to accomplish this ideal, it may be necessary to include, in the implementation of an infant hearing program, a restructuring of the current services and structures for parents to access. Future IHP programs also need to carefully evaluate the intervention programs that are established in their provinces. All existing service providers need to work together in order to do what is best for families.

Support Services

Parents in this study described their need to be connected with parents who have gone through similar experiences. This need is also expressed in the literature as a means of empowering parents. The process that other parents have gone through can help parents determine what their own needs are as well as learn about relevant issues from other parents who have experienced them (Bodner-Johnson, 2001; Edwards, 2003; Meadow-Orlans et al., 1997; Sass-Lehrer, 2003).

The parents in this study indicated that a very positive addition to an infant hearing program would be if all parents, upon diagnosis, were provided with access to a support group. Rachael, Morgan, Paul, and Jamie all expressed that they would have appreciated talking to parents who had gone through a similar experience. Jamie also discussed how, for her, it would have been helpful if she had been able to make contact with a Deaf adult, who could have served as a successful Deaf role model for her child and herself. Parents in this study also discussed how sometimes professionals didn't have the answers to their questions because they didn't live their lives with a child who had a hearing loss. Parents also described feeling uncomfortable around professionals who thought their questions were silly and who didn't have the time to spend answering them.

Research has found that, once parents of a child newly diagnosed with a hearing loss, realize they are not alone in the process and make contact with other parents, they are given hope (Corcoran, et al., 2000). Other studies in this area have found that when parents are asked what services were lacking for them once their child was diagnosed, many identified that they wanted more contact with other parents (Roush, 2000).

Implications for best practices.

"Veteran parents" have a great deal to offer because, as opposed to many professionals who don't have a child with a hearing loss, these parents do and therefore have developed many techniques, skills and tools that help to make life a little easier. Infant hearing programs should consider ensuring that some sort of parental support service is available to parents and either point them in the direction of an existing program or include this as a part of the implementation of an IHP. Some parents in this study vaguely recalled being told about support services, but the information was shared in a way that they didn't retain it. Careful consideration should also be given to how parents are provided with this information. Perhaps, as opposed to simply being told about a support group, parents might be given a pamphlet about the services, or as was Jamie's experience, be provided access to an Internet discussion group. Another possibility would be to ask parents if they agree to have their name given to a support group, and that group can contact parents at a later time to determine whether or not they would like to participate.

Obtaining Assistance Transitioning from Diagnosis to Intervention

Advocating for the child is an important and positive skill that many parents develop as a result of having a child diagnosed with a hearing loss, as was the case for many parents in this study. Parents need to know to how to advocate for their child because it is an essential life long activity (Benedict & Raimondo, 2003; DesGeorges, 2003). While learning to become an advocate for a child is important, more needs to be done for parents to ease them through the early UNHS experience. Dealing with the diagnosis of hearing loss at birth can be a very emotional and vulnerable time for parents in addition to just dealing with the birth of a new baby; parents, therefore, could benefit from more support (Beneidct & Raimondon, 2003; Sjoblad et al., 2001).

In this study parents reported that they struggled with being left to their own devices in trying to find answers, information, services and coordinating all professionals who were involved in the care of their child. Morgan and Paul specifically expressed their need for an individual who could coordinate all the professionals involved in the care of their child. For Jamie, who had her audiologist, and for Susan, who had her home based development coordinator, their experiences were made more positive because they had those individuals acting on their behalf. Currently, more needs to be done for parents in order to provide them with a seamless transition from screening to diagnosis to intervention services in an infant hearing program.

This is a sentiment that is also expressed in the literature (Bamford, et al., 2000; Russ et al., 2004; Sjoblad et al., 2001). Corcoran et al. (2000) identified that many parents of a child newly diagnosed with a hearing loss have found that their initial efforts at obtaining assistance, "were met by a decentralized and confusing system of care." (p. 169) Russ et al. (2004) explained that parents have expressed that they have had "communication difficulties and misunderstandings with providers which negatively impacted their child's care." (p. 356). Edwards (2003) has made the recommendation that in order to empower and support parents throughout this process, there should be the determination of a case manager so that a trusting relationship can be built and parents can deal with one person who can coordinate all that needs to be done.

Canadian Situation

One effective position in an IHP is the Ontario's Family Support Worker, whose responsibility is, in part, to help parents coordinate the services involved with their child to the extent that parents would like them to. In P.E.I., the contacted audiologist mentioned that the AVT sometimes acts as a case manager for some parents but not in all cases and it is not her primary role. More information is needed from the other provinces.

Implications for Best Practices

Based on these parents' experiences, a recommendation can be made that, for all UNHS programs, there should be a position created for an individual to manage and service the needs of all parents who have a child diagnosed with a hearing loss. This individual would be more than a first point of contact, he/she would also act to assist the family with their individual needs. His/her name should be given to parents immediately after the first screening and he/she would be available to parents at any time throughout the process to answer any questions that parents may have about a "refer" on the screening or next steps. As parents indicated in this study, without this individual, parents were left with many questions and no one available to answer them. This caused them a great deal of additional stress and frustration.

This individual could also be available to meet with the parents after they have received the diagnosis, at a time that is best suited for them. This individual should be well informed about hearing loss, the emotions that are involved in learning about hearing loss and, most importantly he/she should be able to provide unbiased information to a parent about all the intervention options that are available to their child. This could alleviate some of the negative experiences that the parents encountered in this study.

This individual could also act as the case load manager for parents: he/she could set up appointments for parents, connect them to professionals who could address individual additional needs for services, be the liaison between all the different professionals and assist the family in evaluating their child's progress. This could also assist the family in evaluating and adjusting the goals that the family has set out for their child and themselves. This professional would be able to provide parents with more information; he/she would be able to help parents through the coping process by listening to their stories and by providing them with additional support. This professional would be dedicated to help families in whatever decision it was that they made about their child's future and he/she would be dedicated to helping facilitate and guide families through the UNHS process. Above all he/she could call in other professional as needed.

Again some parents in this study, such as Jamie and Susan, had the experiences of having a professional who really became involved and took a genuine concern in the welfare of their child and family. Those parents reported what an enormous positive effect that those professionals had on their lives and how much those professionals were able to help them cope. Other parents such as Rachael, Morgan, and Paul, did not have such a professional involved in their child's welfare and suffered from that. By having a professional either provide or provide access to these services one could expect that fewer parents would have a negative UNHS experience.

Summary of Implications for Best Practices for Professionals

It is important to highlight, again, that the recommendations and implications presented in this study are not directed toward one profession nor are they directed toward dealing with any specific degree of hearing loss. These implications and recommendations are suggested for the benefit of every family whose child is diagnosed through universal newborn hearing screening, whether the hearing loss is mild or profound. These implications and recommendations are also recommended for any professional, regardless of their background, who works well within an infant hearing program. The following are the implications and recommendations that have arisen based on these parents' experiences.

1. Careful consideration should be given to the information pertaining to the screening and results, and especially the manner in which that information is delivered to parents.
2. Parents usually always want to know what the professionals know, when they know it, regarding health information pertaining to their infant.
3. Professionals need to take the time to deal individually with parents. Parents want to be asked what their needs are at different points throughout their infant hearing program experience and how they would like to proceed with the next steps.
4. Professionals need to limit the amount of jargon that they use when talking to parents about their child's hearing loss.
5. Professionals also need to sensitively and empathetically counsel parents. More training or, perhaps, educational streams, could look at providing pre-service professionals with such sensitivity training.
6. Professionals need to ensure that they provide parents with all the information available regarding intervention options and that they don't try to let their personal biases influence a parent's decision making process.

7. Professionals need to support parents in their decision making process and provide guidance were guidance is sought. Professionals need to make sure that they are not unduly critical of the decisions that parents make.
8. Professionals also need to provide parents with different support systems once their child is diagnosed with a hearing loss and expose families to other Deaf adults.
9. Infant Hearing Program implementers need to ensure that if they are prepared to identify infants at birth with hearing loss, then they are also prepared to facilitate parents' access to intervention services and the collaboration of service providers in a timely manner.
10. Infant Hearing Program implementers need to carefully consider the skills and qualifications of the individuals they hire to work within their programs.

Considerations for the Study

This section addresses considerations for the two research questions: what are the current Canadian IHP/UNHS contexts? and what are parents' experiences in a Canadian UNHS program?

These data clearly indicate that there is much more to learn about the Canadian situation. Although phone interviews were quite in-depth only one professional, in each context was contacted. That person discussed only parts of each program from his/her perspective. Certain information wasn't available at the time of the interview because the tracked IHP data hadn't yet been analyzed. In some government run programs, the data had not yet been released to the public. The reader must keep this in mind. In addition, changes in each province may have also taken place during the period of this research. Although I have tried to update information, some may have been missed.

I also remind the reader that interviews took place with five parents who lived in rural areas. Access to services in rural areas is different compared to urban centers. Rural communities have a lesser population and attract fewer professionals. Therefore, professionals working there may have less experience when compared to professionals in an urban center. Due to the fact that rural centers attract fewer professionals, there could be fewer choices when it comes to accessing intervention. The reader must keep in mind that this influences parents' UNHS experience.

It is also important to keep in mind that each parents' UNHS experience was very unique. Each parent faced different circumstances that surrounded the diagnosis of his/her child and reacted to life changing news in different ways. There were also commonalities among the parents and one would expect that other parents will identify with their stories. Parents did however, express many of the same needs for services, the same impact that professionals had on their experiences, the same recommendations and the same support and praise for UNHS programs.

Future Research

This section presents potential areas for future research pertaining to parents' experiences in a Canadian IHP. This is a very exciting and new area of health care research with many aspects that have yet to be investigated. The following are some suggested areas for future research.

1. In the future a similar study could be conducted with an increased number of participants and be expanded to include parents with experiences in urban centers.
2. Future research could explore parents' experiences in different programs or do a comparison of parents' experiences within a UNHS program and parents' experiences within a comprehensive IHP program.
3. A comprehensive comparison of provincial IHPs could be conducted with surveys and by speaking at length with the different professionals involved with the program.
4. Future research could investigate why most Canadian provinces are reluctant to implement an IHP and explore what measures need to be put in place in order to make IHPs across Canada a provincial reality.

Conclusion

In my opinion one of the most significant implications of this study, based on these parents' experiences, and consistent with the literature, is that we, as professionals, can't talk about newborn hearing screening without including plans to develop a system for parents to access intervention services. Young, Tattersall, Uus, Bamford, & McCracken (2004) stated, "To be blunt, newborn hearing screening is of little significance unless it is the catalyst for high-quality, multidisciplinary early intervention" (p. 870). It is not enough that intervention programs exist in regions that are doing the screening. Professionals undertaking the implementation of an IHP need to ensure that parents are able to enter an intervention system that is easy to navigate and access. With that said, although the parents in this study had negative experiences from not having had facilitated access to intervention systems, all parents still spoke words of praise for the newborn hearing screening, which identified their child at an early age. As Rachael put it when she was asked,

> *So is it worth it? Yes, for the mothers of those four babies [identified], yes it is worth it. Just because every other baby has normal hearing, for the mother of those babies it is worth it, if they can prevent a two year delay in every aspect.*

REFERENCES

Alberta Universal Newborn Hearing Screening Project (2001-2004). Available from http://www.babyhear.ucalgary.ca/

Appuzo, M., & Yoshinaga-Itano, C. (1995). Early identification of infants with significant hearing loss and the Minnesota Child Development Inventory. *Seminars in Hearing, 16*(2), 124-139.

Barnard, S. (1997). Qualitative data analysis: Content and thematic analysis. Power Point Presentation. Retrieved from http://www.sohp.soton.ac.uk/moi301/thematic.htm.

Bamford, J., Davis, A., Hind, S., McCracken, W., Reeve, K. (2000). Evidence on very early service delivery: What parents want and don't always get. . In R.C. Seewald (ed.), *A sound foundation through early amplification: Proceedings of an international conference,* (pp.151-159). Switzerland; Phonak, AG.

Benedict, B., & Raimondo, B. (2003). Family rights, legislation and policies: What professionals need to know to promote family involvement and advocacy. In B. Bodner-Johnson and M. Sass-Leher (eds.), *The young deaf or hard of hearing child: A family centered approach to early education* (pp. 61-95). Washington, DC: Paul Bookes Publishing Co.

Berg, AL., & Spivak, L. (1999). Universal newborn hearing screening: Should we leap before we look? Letter to the Editor. *Pediatrics, 104*(2), 351-354.

Bess, F., & Paradise, J. (1994). Universal screening for infant hearing impairment: Not simple, not risk-free and not presently justified. *Pediatrics*, *93*(2), 330-334.

Bess, F., & Humes, L. (2003) *Audiology. The Fundamentals. Third Edition.* Baltimore, MD: Lippincott Williams & Wilkins.

Bodner-Johnson, B. (2001). Parents as adult learners in family centered early education. *American Annals of the Deaf, 146*(3), *263-270.*

Brown, D., Dort, J., & Sauve, R. (2000). Newborn hearing screening programs: A truly Canadian perspective. *Journal of Speech -Language Pathology and Audiology, 24*(3), 48-53.

Brown, D., Dort, J., & Zozhodne, B. (2001). Universal newborn hearing screening programs. *The Canadian Nurse*, *97*(4), 23-26.

Bruder, M.B. (2000). Family centered early intervention: clarifying our values for the new millennium. *Topics in Early Childhood Special Education, 20*(2), 105-115.

Calderon, R., & Naidu, S. (2000). Further support for the benefits of early identification and intervention for children with hearing loss. In C. Yoshinaga-Itano & A.L. Sedey (Eds.), *Language, Speech and Social Emotional Development of Children Who Are Deaf and Hard-of-Hearing: The Early Years*, *The Volta Review, 100*, 53-84.

Calderon, R., & Greenberg, M. (1997). The effectiveness of early intervention for deaf children with hearing loss. In M.J. Guralnick (Ed.), *The effectiveness of early intervention* (pp. 455-482). Baltimore: Brookes.

Carney, A.E., & Moeller, M.P. (1998). Treatment efficacy: hearing loss. *Journal Speech Language and Hearing Research, 41*(Suppl.1), 61-84.

Campbell, K., & Mullin-Derrick, G. (2002). Otoacoustic Emissions. Retrieved March 3, 2005 from www.emedicine.com.

Crandell, C. (1997). An update on counselling instructions within audiology programs. *Journal of the Academy of Rehabilitative Audiology, 30*, 1-10.

Clemens, C., & Davis, S. (2001). Minimizing false-positives in universal newborn hearing screening: A simple solution. *Pediartics, 107*(3), 1-3.

Corcoran, J.A., & Stewart, M. (1995). Therapeutic experiences of people who stutter. *Journal of Speech Language Pathology and Audiology, 19*, 89-96.

Corcoran, J.A., & Stewart, M. (1998). Stories of stuttering: A qualitative analysis of interview narratives. *Journal of Fluency Disorders, 23*, 247-264.

Corcoran, J.A., Stewart, M., Glynn, M., & Woodman, D. (2000). Stories of parents and children with hearing loss: A qualitative analysis of interview narratives. In R.C. Seewald (ed.), *A sound foundation through early amplification: Proceedings of an international conference* (pp. 167-174). Switzerland; Phonak, AG.

Cox, L. C., & Toro, M. R. (2001). Evolution of a universal infant hearing screening program in an inner city hospital. *International Journal of Pediatric Otorhinolaryngology, 59*, 99-104.

Culpepper, B. (2003). Identification of permanent childhood hearing loss through universal newborn hearing screening programs. In B. Bodner-Johnson and M. Sass-Leher (eds.), *The young deaf or hard of hearing child: A family centered approach to early education* (pp. 99-122). Washington, DC; Paul

Bookes Publishing Co.

DesGeorges. J. (2003). Family perceptions of early hearing, detection, and intervention systems: listening to and learning from families. *Mental Retardation and Developmental Disabilities Research Reviews, 9*, 89-93.

Dort, J. (2000). Universal Newborn Hearing Screening Program in Alberta. *Health Innovation Fund Application.* Unpublished Manuscript

Durieux-Smith, A., & Stuart, A. (2000). Newborn hearing screening: A Canadian historical perspective. *Journal of Speech-Language Pathology and Audiology, 24*(3), 44-47.

Durieux-Smith, A., & Whittingham, J. (2000). The rationale for neonatal hearing screening. *Journal of Speech Language Pathology & Audiology, 24*(2), 59-67.

Durieux-Smith, A., Seewald, R., & Hyde, M. (2001). CASLPA - CAA Position on universal newborn and infant hearing screening in Canada. *Journal of Speech-Language Pathology and Audiology, 24*(3), 139-141.

Durieux-Smith, A., & Ericks-Brophy, A. (2002). *A needs assessment for the development of decision aids to help parents of Deaf and Hard of Hearing children choose an intervention option.* Unpublished Manuscript.

Edwards, C. (2003). Reflections on counselling: Families and hearing loss. *Loud and Clear: A cochlear implant rehabilitation newsletter, 2*, 1-8.

Ellis, J. (1998). *Teaching from understanding: teacher as interpretive inquirer.* New York : Garland Pub.

Finitzo, T., & Crumley, W. (2000). A model universal newborn hearing screening program for hospitals and birthing facilities. *Journal of Speech and-Language Pathology and Audiology*, *24*, 130-138.

Gorga, MP., Norton, S., Sininger, Y., Cone-Wesson, B., Folsom, RC., Vohr, BR., Widen, J., & Neely, S. (2000). Identification of neonatal hearing impairment: distortion product otoacoustic emissions during the perinatal period. *Ear & Hearing, 21*(5), 400-424.

Gracey, K. (2003). Current concepts in universal newborn hearing screening and early hearing detection and intervention programs. *Advances in Neonatal Care, 3*, 308-317.

Gravel, J., & O'Gara, J. (2003). Communication options for children with hearing l loss. *Mental Retardation and Developmental Disability Research Reviews, 9*, 243-251.

Harrison, M., & Roush, J. (1996). Age of suspicion, identification, and intervention for infants and young children with hearing loss; A national study. *Ear and Hearing, 17*, 55-62.

Harrison, M. & Roush, J. (2000). Information for families with young deaf and hard of hearing children: Reports from parents and pediatric audiologists. In R.C. Seewald (ed.), *A sound foundation through early amplification: Proceedings of an international conference,* (pp. 233-250). Switzerland; Phonak, AG.

Hayes, D. (2001). Newborn hearing screening: Selected experience in the United States. *Scandinavian Audiology, 30*, 29-32.

Hayes, D. (2003). Screening methods: Current status. *Mental Retardation and Developmental Disabilities Research Reviews*, *9*, 65-72.

Hergils, L. & Hergils, A. (2000). Universal neonatal hearing screening- parental attitudes and concern. *British Journal of Audiology, 34*, 321-327.

Hodgetts, B. (2003). *Otoacoustic emissions and auditory brainstem response.* Lecture, University of Alberta, Department of Speech Language Pathology.

Hyde, M. (2002).Ontario's Infant Hearing and Communication Development Programs. *Public Health and Epidemiology Report Ontario.* Retrieved from http://www.tbdhu.com/audiology/PHEROArticle.htm.

Hyde, M. L., & Riko, K. (2000). Design and evaluation issues in universal newborn hearing screening programs. *Journal of Speech-Language Pathology and Audiology, 24*(3), 102-118.

Hyde, M., Friedberg, J., Price, P., & Weber, S. (2004). Ontario Infant Hearing Program: program overview, implications for physicians. *Ontario Medical Review*, *71*(1). Retrieved from http://www.oma.org/pcomm/OMR/jan/04toc.htm

Isaacson, G. (2000). Candidate thesis: Universal newborn hearing screening in an inner-city, Managed care environment. *Laryngoscope, 110*(6), 881-894.

Johnson, A. (2002). Update on newborn hearing screening programs. *Pediatric Nursing, 22*(3), 267-270.

Joint Committee on Infant Hearing. (1995). Joint Committee on Infant Hearing 1994 Position Statement. *Pediatrics, 95*(1), 152-156

Joint Committee on Infant Hearing. (2000). Year 2000 Position Statement: Principles and Guidelines for early hearing detection and intervention programs. *American Journal of Audiology*, *9*(1), 9-29.

Kennedy, C.R. (1999). Controlled trial of universal neonatal screening for early identification of permanent childhood hearing impairment; coverage, positive predictive value, effect on mothers and incremental yield. *Acta Pediartic Supplement, 432,* 73-75.

Keren, R., Helfand, M., Homer, C., McPhillips, H., & Lieu, T. (2002). Projected cost-effectiveness of statewide universal newborn hearing screening. *Pediatrics, 110*(5), 855-864.

Kileny, P. (2000). Is UNHS worth the cost? *Hearing Journal.* Retrieved October 14, 2003 from http://findarticles.com/cf_0/m0BPK/11_53/67885922/print.jhtml.

Kileny, P., & Lesperance, M. (2001). Evidence in support of a different model of universal newborn hearing loss identification. *American Journal of Audiology, 10*, 65-67.

Knott, C. (2001). Universal newborn hearing screening coming soon: “Hear's” Why. *Neonatal Network, 20*(8), 25-33.

Kluwin, T., & Stewart, D. (2000). Cochlear implants for younger children: A preliminary description of the parental decision process and outcomes. *American Annals of the Deaf, 145*(1), 26-32.

Lemons, J., Fanaroff, A., Steward, E., Bentkovewr, J., Murray, G., & Diefendorf, A. (2002). Newborn hearing screening: Cost of establishing a program. *Journal of Perinatology, 22*, 120-124.

Luterman, D. (1991). *Counselling the communicatively disorder and their* family (2nd Ed). Austin, Texas: Pro-Ed.

Luterman, D. & Kurtzer-White, E. (1999). Identifying hearing loss: Parents' needs. *American Journal of Audiology, 8,* 13-18.

Magnuson, M., & Hergils, L. (1999). The parents’ view on hearing screening in newborns: Feelings, thoughts and opinions on otoacoustic emissions screening. *Scandinavian Audiology, 28*(1), 47-56.

Marschark, M., Lang, H., & Albertini, J. (2002). Educating deaf students: From research to practice. Oxford, New York, Oxford University Press.

Martin, K., & Elder, S. (1991). Pathways through grief: A model of the process. In J.D. Morgan (Ed.), Personal care in an impersonal world; A multidimensional look at bereavement (pp. 73-86). Amityville, NY: Baywood.

Mauk, G. W., Barringer, D. G., & Mauk, P. P. (1995). Seizing the moment, setting the stage, and serving the future: Toward collaborative models of early identification and early intervention services for children born with hearing loss and their families Part I: Early identification of hearing loss. *Infant-Toddler Intervention, 5*(4), 367-393.

Mauk, G. W., & White, K. R. (1995). Giving children a sound beginning: The promise of universal newborn hearing screening. *The Volta Review, 97*(Winter), 5-32.

Meadow-Orlans, K.P., Mertens, D., Sass-Leher, M.A., & Scott-Olson, K. (1997). Support services for parents and their children who are deaf or hard of hearing: A national survey. *American Annals of the Deaf, 142*(4), 278-293.

Meier, S., Narabayashi, O., Probst, R., & Schmuziger, N. (2004). Comparison of currently available devices designed to fit newborn hearing screening using automated auditory brainstem and/or otoacoustic emission measurements. *International Journal of Pediatric otorhinolaryngology, 68*, 927-934.

Mencher, G. and DeVoe, S. (2001). Universal newborn screening: a dream realized or a nightmare in the making? *Scandinavian Audiology Supplement, 53*, 15-21.

Merriam, S. (1998). *Qualitative research and case study applications in education* (2ed). San Francisco : Jossey-Bass Publishers.

Merriam, S. (2002). *Qualitative research in practice: examples for discussion and analysis*. San Francisco : Jossey-Bass Publishers.

Messner, A. H., Price, M., Kwast, J., Gallagher, K., & Forte, J. (2001). Volunteer-based universal newborn hearing screening program. *International Journal of Pediatric Otorhinolaryngology, 60*, 121-130.

Moeller, M.P. (2000). Early intervention and language development in children who are deaf and hard of hearing. *Pediatrics, 106*, 1-9.

National Center for Hearing Assessment & Management. (2001) When do I refer for audiological and medical evaluation? *Sound Ideas Newsletter,3(3).* Retrieved March 4, 2004, from http://www.infanthearing.org/newsletter/v3n3/whentorefer.html

National Institute of Health. (1993). Early identification of hearing impairment in infants and young children. NIH Consensus Statement, *11*, 1-24.

Northern, J., & Downs, M.P. (1991). *Hearing in children (4th Ed).* Baltimore, MD: William & Wilkins.

Ontario Ministries of Health and Long Term Care (2002). *Infant Hearing Program: Well-baby (DPOAE) Screening Protocol and Training Manual.* Unpublished Manuscript

Ontario; Early Years (2002). Identifying Permanent Hearing Loss in Infants. [Brochure]

Oyler, R.F., & Matkin, N.D. (1987). National survey of educational preparation in pediatric audiology. *American Speech Hearing Association, 29*(1), 27-33.

Paradise, J. L. (1999). Universal newborn hearing screening: Should we leap before we look? *Pediatrics, 103*(3), 670-672.

Patton, M. (1980). *Qualitative evaluation and research methods.* Beverly Hills, CA: Sage Publications.

Patton, M. (1990). *Qualitative evaluation and research methods* (2ed.). Newbury Park, CA: Sage Publications.

Patton, M., & Westbury, C., (1992). Ethnography and research: A qualitative view. *Topics in Language Disorders,12*, 1-14.

Poon, B. (1999). *Parental reaction to deafness in children: A grounded theory investigation.* Unpublished master's thesis, University of Alberta, Edmonton, Alberta, Canada.

Poulakis, Z., Barker, M., & Wake, M. (2003). Six month impact of false positives in an Australian infant hearing screening program. *Archives of Disease in Childhood, 88 , 20-24.*

Prendergast, S., Nelson Lartz, M., & Casson Fiedler, B. (2002). Age of diagnosis, amplification, and early intervention of infants and young children with hearing loss: Findings from parent interviews. *American Annals of the Deaf, 147*(1), 24-30.

Prieve, B., Dalzell, L., Berg, A., Bradley, M., Cacace, A., Campbell, D., DeCristofaro, J., Gravel, J., Greenberg, E., Gross, S., Orlando, M., Pinheiro, J., Regan, J., Spivak, L., & Stevens, F. (2000). The New York State universal newborn hearing screening demonstration project: Outpatient outcome models. *Ear and Hearing, 21*(2), 104-117.

Roush, J. (2000). Implementing Parent-Infant Services: Advice from Families. In R.C. Seewald (ed.), *A sound foundation through early amplification: Proceedings of an international conference,* (pp. 159-166). Switzerland; Phonak, AG.

Roussel, M. (2003). NB provincial universal newborn & infant hearing screening program. *Caslpa Update in Echo.* Electronic Reference. Retrieved Oct, 2003 from www.communicationnb.ca

Russ, SA., Kuo, AA., Poulakis, Z., Barker, M., Rickards, F., Sauders, K., Jarman, FC., Wake, M., & Oberklaid, F. (2004) Qualitative analysis of parents' experience with early detection of hearing loss. *Archives of Disease in Childhood, 89,* 353-358.

Saville, D., & Mahon, B. (2000). Newborn and infant hearing screening and early identification program. *Public Health and Epidemiology Report Ontario, 11*(5). Retrieved from http://www.health.gov.on.ca/english/providers/pub/phero/phero_052600.html

.

Sass-Leher, M.(2003). Programs and services for deaf and hard of hearing children and their families. In B. Bodner-Johnson and M. Sass-Leher (ed.), *The young deaf or hard of hearing child: A family centered approach to early education* (pp. 153-180), Washington, DC; Paul Bookes Publishing Co.

Scheetz, N. (2001). *Orientation to deafness- 2nd Ed.* Needham Heights, Massachusetts, Allyn and Bacon.

Sjoblad, S., Harrison, M., Roush, J., & McWilliam, R.A. (2001). Parents reactions and recommendations after diagnosis and hearing aid fitting. *American Journal of Audiology, 109,* 24-31.

Statistics Canada. (2003-2004) Births and birth rate, by provinces and territories. Available at http://www.statcan.ca/english/Pgdb/demo04a.htm.

Stedler-Brown, A., & Arehart, K.H. (2000). Universal newborn hearing screening: Impact on intervention services [Monograph]. In C. Yoshinaga-Itano & Sedey (Eds.), Language, speech, and social-emotional development of children who are deaf and hard of hearing: The early years. *The Volta Review, 100*(5), 85-117.

The Hearing Foundation of Canada. Available from http://www.thfc.ca/screening.html

Thompson, D.C., McPhillips, H., Davis, R.L., & Helfand, M. (2000). UNHS: summary of evidence. Journal of AMA, *286*(16); 2000-1020.

Toronto Preschool Speech and Language Services (2003). 2002-2003 Annual Report Summary.

Vaccari, C. & Marschark, M. (1997). Communication between parents and deaf children: Implications for socio-emotional development. *Journal of Child Psychology, 38,* 793-801.

Watkin, P., Beckman, A., & Baldwin, M. (1995). The views of parents of hearing impaired children on the need for neonatal hearing screening. *British Journal of Audiology, 29,* 259-262.

Watkin, P., Baldwin, M., & McEwen, G. (1991). Neonatal at risk screening and the identification of deafness. Archives of Disease in Childhood, *66,* 1130-1135.

Weichbold, V., & Welzl-Mueller, K. (2001). Maternal concern about positive test results in universal newborn hearing screening. *Pediatrics, 108*(5), 1111-1116.

Weichbold, V., Welzl-Mueller, K., & Mussbacher, E. (2001). The impact of information on maternal attitudes towards universal neonatal hearing screening. *British Journal of Audiology, 35,* 59-99.

White, K. (2003). The current status of EHDI Programs in the United States. *Mental Retardation and Developmental Disabilities Research and Reviews, 9,* 79-88.

Widen, J., Bull, R.W., & Folsom, R.C. (2003). Newborn hearing screening: What it means for providers of early intervention services. *Infants and Young Children, 16,* 249-257.

Young, A., Tattersall, H., Uus, K., Bamford J., & McCracken W. (2004). To what extent do the characteristics of the object of evaluation influence the choice of epistemological framework? The case of universal newborn hearing screening. *Qualitative Health Research, 14*(6), 866-874.

Yoshinaga- Itano, C. and Apuzzo, M. (1998). Identification of hearing loss after age 18 months is not early enough. *American Annals of the Deaf, 143,* 380-387.

Yoshinaga-Itano, C. (1999). Benefits of early intervention for infants with hearing loss. *Otolaryngology Clinics of North America, 32*(6), 1089-1102.

Yoshinaga-Itano, C. (2003). From screening to early identification and intervention: discovering predictors to successful outcomes for children with significant hearing loss. *Journal of Deaf Studies and Deaf Education, 8,* 11-30.

Yoshinaga-Itano, C., & Apuzzo, M.(1998). The development of deaf and hard of hearing children identified early through the high-risk registry. *American Annals of the Deaf, 143*(5), 416-424.

Yoshinaga-Itano, C., Coulter, D., & Thomson, V. (2000). The Colorado newborn hearing screening project: Effects on speech and language development for children with hearing loss. *Journal of Perinatology, 20*, 131-S136.

Yoshinaga-Itano, C., Sedey, A.L., Coulter, D.K., & Mehl, A.L. (1998). The language of early- and later-identified children with hearing loss, *Pediatrics*, *102*, 1161-1171.

Yoshinaga-Itano. (2003). Early intervention after universal newborn hearing screening: Impact on outcomes. *Mental Retardation and Developmental Disabilities*, 9, 252- 266.

Yuskow, K. (2004). *Otoacoustic Emissions*. Power point presentation, University of Alberta, Department of Speech Language Pathology.

Yukon Guidelines for Newborn Hearing (2002). Unpublished Manuscript.

Zochodne, B., Brown, D., & Dort, J. (2001). Making the case: Universal newborn hearing screening programs. *Canadian Nurse*, 93, 23-26.

APPENDIX A

1. When was the program implemented?
2. How many health regions or hospitals are screening?

Screening

1. How is the screening done?
2. What screening technology used? What is the name of the equipment and manufactures?
3. When and where does the 1st screening take place?
4. Who performs the first screening and what training are they given?
5. When and when does the second screening take place?
6. How many children are referred on for the 2nd screening?
7. What is the percentage of infants being screened?
8. What is the referral rate for diagnostics?
9. Are parents given any information about the screening process? If yes, when, by who and is special training provided to these individuals?
10. Who informs the parents that their infant has failed both screens? How are parents told and is there any special training given to these individuals?
11. Are there any wait list issues with the screening component?

Diagnosis

1. How many parents don't show up for their follow up appointments? Are there any known reasons for why these parents don't show up?
2. Is there any special program/system in place for informing parents that their child has a confirmed hearing loss?
3. What battery of tests do infants undergo for a confirmed diagnosis?
4. Are there any wait list issues, provincially or for each health region, for families to get in for a diagnostic ABR?
5. How many false positives are there? How many infants have a confirmed hearing loss?
6. What is the break down in terms of type and degree of hearing loss (if known) and how many children have a disability in addition to a hearing loss?

Intervention

1. What services are in place in order to inform parents about their options?
2. What services are available to families in the province?
3. Is there any funding in place to help parents?
4. Whose job is it to inform them of their funding possibilities?
5. What tracking system do you have in place in order to ensure quality and outcomes of your program?
6. What are the biggest challenges that have been faced in the implementation of the infant hearing program? What has been a major factor that has led the program to being so successful?
7. Is there anything that I should be asking or that I have missed in order to get an accurate description of your provinces UNHS program?

APPENDIX B

Documents and Websites for the Current Canadian Contexts

Ontario

Hyde, M., Friedberg, J., Price, P., & Weber, S. (2004). Ontario Infant Hearing Program: program overview, implications for physicians. *Ontario Medical Review*, 71(1). Retrieved from http://www.oma.org/pcomm/OMR/jan/04toc.htm

Ontario Ministries of Health and Long Term Care (2002). *Infant Hearing Program: Screening Training Manual.* Unpublished Manuscript

Ontario Ministries of Health and Long Term Care (2002). *Infant Hearing Program: Well-baby (DPOAE) Screening Protocol and Training Manual.* Unpublished Manuscript

Ontario Ministries of Health and Long Term Care (2002). *Infant Hearing Program: Universal Infant Hearing Screening Assessment & Communication Development. Local Implementation Support Document.* Unpublished Manuscript.

Ontario; Early Years (2002). Identifying Permanent Hearing Loss in Infants. [Brochure]

Toronto Preschool Speech and Language Services (2003). 2002-2003 Annual Report Summary.

Weber, S. (2003). Identifying permanent hearing loss in infants: Ontario's Infant Hearing Program. *Canadian Academy of Audiology Newsletter.* Retrieved from www.canadianaudiology.ca

Alberta

Alberta Universal Newborn Hearing Screening Project (2000). Universal Newborn Hearing Screening Program in Alberta: A Pilot Project. Protocols and Guidelines. Retrieved from www.babyhear.ucalgary. ca

Yukon

Yukon Guidelines for Newborn Hearing Screening (2002). Unpublished Manuscripts

Yukon: UNHSP Informing Parents of Screening Results (2002). Unpublished Manuscripts

www.thfc.ca

New Brunswick

NB Newborn Screening. (2000). *Canadian Academy of Audiology Newsletter.* Retrieved from www.canadianaudiology.ca

Roussel, M. (2003). NB provincial universal newborn & infant hearing screening program. *Caslpa Update in Echo.* Electronic Reference. Retrieved Oct, 2003 from www.communicationnb.ca

Health and Wellness. (2003). Update on Universal Newborn and Infant Hearing Screening Program. *News Release- Communications New Brunswick.* Retrieved Sept.10, 2003 from www.gnb.ca/cnb/news

News Release (2002).Retrieved Sept 9, 2003 fromwww.communicationnb.ca/page4.html

Prince Edward Island

The Hearing Foundation of Canada. Prince Edward Island Becomes the third province to implement Universal Newborn Hearing Screening to Identify Canada's most common birth defect. Retrieved Jan. 15th, 2004 from www.thfc.ca/home.html

Ellis, P. (2000). Status of Hospital Based Infant Hearing Screening. *Canadian Academy of Audiology Newsletter.* Retrieved Aug. 28, 2004 from www.canadianaudiology.ca/member-service/past-issues/spring_2000_5.html

www.babyhear.ucalgary.ca
www.stats.can.ca
www.thfc.ca
www.apsea.ca

APPENDIX F

INFORMATION LETTER TO HEALTH REGION FACILITATORS

Project Title: Parents Experiences in Canadian Universal Newborn Hearing Screening Programs: Diagnosis and Intervention

Principal Investigator: David K. Brown, Ph.D.,
Auditory Research Program, Department of Surgery,
University of Calgary

Co-Investigators: Sarah McDermid, MEd Candidate,
Mary Ann Bibby, Ph.D. Professor
Department of Educational Psychology, University of Alberta

Dear Newborn Hearing Screening Coordinator,

We are conducting a study to understand and learn from the experiences of parents who have been involved in Universal Newborn Hearing Screening programs. The information gathered from parents will provide valuable insights to other parents and also professionals who are involved in the implementation of upcoming and current Universal Newborn Hearing Screening provincial programs in Canada. Parents will be interviewed and asked to describe their experiences in going through the diagnosis and to talk about their needs for intervention information and services. Anonymity will be maintained at all times.

We would like to request your assistance in the recruitment of participants. It would be greatly appreciate if you could distribute a letter, 2 consent forms and self-addressed, self-stamped envelope to parents in your health region that fit our criteria. Please note that their participation in this study is completely voluntary.

Parent participants must meet the following criteria:

1. Parents must be hearing with English as their first language
2. Parents must have had an infant diagnosed with a sensorineural hearing loss that was detected by the Alberta Universal Newborn Hearing Screening program.

Parents who are interested in participating in this study will be asked to return one of the consent forms. When we receive the consent form, a time for an interview will be arranged. We will then conduct an interview with those who agree to participate. The interviews will take place at a location that is most convenient for the parents or over the phone. A copy of the research proposal is attached, which will give you more information about the details of this project.

APPENDIX G

INFORMATION LETTER TO PARENTS

Project Title: Parents Experiences in Canadian Universal Newborn Hearing Screening Programs: Diagnosis and Intervention

Principal Investigator: David K. Brown, Ph.D.,
Auditory Research Program, Department of Surgery, University of Calgary

Co-Investigators: Sarah McDermid, MEd Candidate,
Mary Ann Bibby, Ph.D. Professor
Department of Educational Psychology, University of Alberta

Dear Madam or Sir:

This letter is being sent to you on behalf of the above-mentioned researchers who are doing research on parent's experiences with a Universal Newborn Hearing Screening Program. The purpose of the research is to describe what is happening in Canadian Universal Newborn Hearing Screening programs and to understand and learn from the experiences of parents who have been involved in those programs. The information gathered from parents will provide valuable insights to other parents and also professionals who are involved in the implementation of upcoming and current provincial Universal Newborn Hearing Screening programs in Canada. Parents want the very best for their children and because Universal Newborn Hearing Screening is new, these researchers are trying to gather information as to how to help parents and professionals in this process.

You have been sent this letter because you have been through the UNHS experience and have had your child diagnosed with a hearing loss that could have only been detected from the UNHS program. Your anonymity has been maintained and will be maintained at all times.

What is required in participating in the research project is a one hour interview during which you will be asked questions about your experiences with the screening program, receiving the information about your child's hearing loss, your feelings and opinions, your needs for services and any other pertinent information you are willing to share about your child and your experience.

Again, your confidentiality has been maintained at all times and will be through out this process. Two consent forms are attached following this letter. If you are interested in participating in this study, please fill out the consent form and send one back in the supplied envelope. The other consent form is for your files. If you have

APPENDIX H

CONSENT FORM FOR PARENTS

Title: **Parents Experiences in Canadian Universal Newborn Hearing Screening Programs: Diagnosis and Intervention**

Investigators: Dr. David K. Brown (Principal Investigator), Mrs S. McDermid-Kelly, Dr. M.A. Bibby (co-investigators)

This consent form is only part of the process of informed consent. It should give you the basic idea of what the research is about and what your participation will involve. If you would like more detail about something mentioned here, or information not included here, please ask. Take the time to read this carefully and to understand any accompanying information. You will receive a copy of this form.

BACKGROUND

With the advent of Universal Newborn Hearing Screening (UNHS) in four Regional Health Authorities in Alberta, more young children are being diagnosed with a hearing loss and are requiring intervention services at a much younger age than prior to UNHS. Information from parents will provide valuable insights to other parents and also professionals who are involved in the implementation of upcoming and current Universal Newborn Hearing Screening Programs.

WHAT IS THE PURPOSE OF THE STUDY?

The purpose of the present study is to talk with parents who have experienced the Alberta Universal Newborn Hearing Screening program.

WHAT WOULD YOU HAVE TO DO?

Participants will take part in a one-on-one interview with Mrs. Sarah McDermid-Kelly, a Master's student in Deafness Studies at the University of Alberta as part of her research thesis. Of interest are what parents' experiences have been in going through the screening process, receiving the diagnosis, and seeking help from intervention services. Also of interest are any insights and opinions that parents have in regards to their experience in the program. This interview will take place at the location that is most convenient to participants, either in person or over the phone at a time that is convenient for you and will take about one hour of your time. This interview will be audio-recorded so that a transcript can be created. You will be mailed a printed transcript of the individual interview for you to review for accuracy. After transcribing and ensuring the accuracy of your interview themes will be identified. At that point, you will be contacted again by Mrs. McDermid-Kelly to ensure that responses were interpreted as you intended.

WHAT ARE THE RISKS?

There are no known physical risks to participating in this study.

APPENDIX I

INTERVIEW GUIDE

Project Title: Parents Experiences in Canadian Universal Newborn Hearing Screening Programs: Diagnosis and Intervention

Questions Addressing Topics of Interest

1. Tell me about you child. What's happening now for you and your child?
2. Describe your experiences in the UNHS program?
   i) Initial screening experience:
      - Were you aware that your child was undergoing a hearing screening?
      - Did you feel you were adequately informed? Who informed you?
      - Who performed your child's screening?
      - How was it done? Where was it done? When was it done?

   ii) Diagnosis:
      - Tell me what was your experience in receiving the diagnosis?
      - Who were the people involved?
      - How did you feel about the manner in which you received the information?
      - When did you receive the diagnosis? What was the wait time was like for you between screening and receiving the diagnosis?
      - What suggestions or recommendations would you suggest in order to make this a positive experience for all parents.

   iii) Intervention Services:
      - Tell me about your experience in accessing intervention services and the choices that you have made?
      - Tell me about your decision making process.
      - What are your needs- for yourself, your child and your family?
      - Were there any support networks involved? Talk about your supports.
      - Describe some either positive or negative experiences when it came to intervention services.

   iv) Are there any changes or recommendations that you can make.

APPENDIX J

Glossary of Acronyms

AABR = Automated Auditory Brainstem Response

ABR = Auditory Brainstem Response

APSEA = Atlantic Provinces Special Education Authority

ASL = American Sign Language

AVT = Auditory Verbal Therapy

BAHA = Bone Anchored Hearing Aid

CI = Cochlear Implant

DPOAE = Distortion Product Otoacoustic Emissions

EHDI = Early Hearing Detection and Intervention

ENT = Ear Nose and Throat Doctor

EOAE = Evoked Otoacoustic Emissions

FSW = Family Support Worker

HRR = High Risk Registry

IHP = Infant Hearing Program

JCIH = Joint Committee on Infant Hearing

MCDI = Minnesota Child Development Inventory

NICU = Neonatal Intensive Care Unit

NIH = National Institute of Health

OAE = Otoacoustic Emissions

PKU = Phenylketonuria

RHA = Regional Health Authority

SEE, SEE II = Signed Exact English

SLP = Speech Language Pathology

TOAE = Transient Otoacoustic Emissions

UNHS = Universal Newborn Hearing Screening

UPSTF = U.S. Preventative Service Task Force

WBN = Well Baby Nursery