PARENTS’ EXPERIENCES OF COCHLEAR IMPLANTION FOR COCHLEAR NERVE DEFICIENCY

by

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Abstract

This research study investigated the experiences of two parents whose child was diagnosed with severe-to-profound hearing loss due to the congenital inner ear abnormalities of cochlear nerve deficiency and bilateral common cavity deformity. Despite her diagnoses, the child received a cochlear implant in her second year of life. Parents’ experiences regarding their child’s hearing loss were explored using a narrative approach to qualitative interviewing. Each parent was interviewed separately and the resulting transcripts were analyzed both separately and together as a dyad. Principles of qualitative description were followed in describing results to privilege the voice of the parents. The parents’ experiences are presented first as a chronologically-organized joint narrative; themes that emerged from one or both interviews are then discussed. Results of this study add valuable insight to the research literature regarding cochlear implantation outcomes for children with cochlear nerve deficiency. This study also supports the value of dyadic analysis in qualitative research, particularly for the fields of speech-language pathology and audiology. Finally, the parents’ experiences depicted in this study draw attention to issues that have important clinical implications for audiologists and other professionals who counsel families of children with hearing loss.
Preface

This study was reviewed and approved by the Behavioural Research Ethics Board of the University of British Columbia. The certificate number of the ethics certificate obtained is H10-03382.
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<tr>
<td>BCEHP</td>
<td>BC Early Hearing Program</td>
</tr>
<tr>
<td>CHARGE Association</td>
<td>Coloboma of the eye, Heart defects, Atresia of the posterior nasal apertures, Retardation of growth and/or development, Genital and/or urinary abnormalities and Ear abnormalities and/or deafness.</td>
</tr>
<tr>
<td>CI</td>
<td>Cochlear Implant</td>
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<td>CND</td>
<td>Cochlear Nerve Deficiency</td>
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<td>CT Scan</td>
<td>Computed Tomography Scan</td>
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<td>MRI</td>
<td>Magnetic Resonance Imaging</td>
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Finally, I give all thanks and praise to Jesus Christ for His unending grace, love, and peace in my life.
This thesis is dedicated to parents—firstly to my parents, John and Devon de Putter, who embody selflessness in their love for my brothers and me—secondly to the parents in this study, who inspired me with their determination to give the world to their daughters—and thirdly, to all parents who give of themselves continuously to provide stability, love and opportunities for their children.
Chapter 1: Introduction

In the present age of rapid technological advances, no device has so changed the communication options for children and adults with severe-to-profound hearing loss as the cochlear implant (CI). This device represents a common procedure in which individuals with hearing loss who do not receive benefit from hearing aids are provided access to sound, and subsequently speech, through electrical stimulation of their auditory nerve. Concurrently with these advances, the advent of universal hearing screening programs across North America provides parents with the detailed auditory profile of their child only a few months after birth. For parents of deaf and hard-of-hearing children, this quickly sets into motion a necessary and often difficult journey of weighing the available options and deciding which therapeutic interventions to initiate with one’s child.

A number of studies have investigated the experiences of parents who, after discovering their child has severe-to-profound hearing loss, decide to initiate the process of exploring CI candidacy and eventual implantation for their child. This body of research seeks to understand how parents experience the process of diagnosis, decision-making, and implantation, including their emotions and key factors that affected their choices along the way. Most of this research, however, investigates the population of parents whose children have severe-to-profound sensorineural hearing loss but an intact auditory nerve with which to conduct electronic signals to the brain. In fact, this description covers the majority of children who are candidates for cochlear implantation. As implantation becomes more established and frequent, a newer cohort of children is being implanted whose neurophysiology is not normal. This study investigates the experiences of parents who are faced with the decision to have their child implanted or not, but with the added complication of knowing that their child
has been diagnosed with cochlear nerve deficiency (CND) and that potential outcomes for children with this condition are uncertain.

The following literature review discusses the available research on a variety of topics pertaining to the current study. It begins with a discussion of cochlear implantation—what it is, who it is for, and how the demographics of CI recipients have changed over time. It then briefly discusses the variable results of cochlear implantation and factors that have been identified as influencing implant success, namely age of implantation and educational placement. Incorporated into this section is a discussion of the Deaf community over time and the tension between proponents of oral communication and advocates of manual communication. In addition to the factors of education and age at implantation, the neurophysiology of the potential CI recipient is of great importance in predicting implant success because CIs rely on intact structures of the inner ear and nervous system to work as designed. To illustrate some neurophysiological conditions that may affect implant success, the review then looks at the literature on CND and other inner ear abnormalities including congenital conditions and auditory neuropathy spectrum disorder. Cochlear nerve deficiency is of particular relevance in this review as it represents the primary inclusion criterion for participation in the current study, i.e., only parents of a child with CND were eligible to participate. To illuminate this condition in regards to cochlear implantation, the review discusses available literature regarding identification of CND, types of CND and outcomes of children with CND who have received a CI. Finally, literature describing issues in counselling, best practice guidelines for intervention, and elements of experiences of parents whose child undergoes cochlear implantation are reviewed.
Following the literature review, an overview of the qualitative methodology used in this particular research study is described. This includes a discussion of qualitative description, narrative interviewing, and case study research. Methods specific to this study are then reported including how participants were recruited, an overview of the participants themselves, how data was collected and a description of the data analysis process. Results of the study are depicted first in a chronological narrative that is presented from the perspective of both parents and supplemented by documentation from the child’s health record and researcher observations noted during the storytelling. The second portion of the results is a discussion of themes that emerged from one or both parents’ interviews. Finally, results are discussed in terms of their significance, their contribution to the research literature, and the implications they hold for parents, professionals and involved others.
Chapter 2: Literature Review

2.1 Introduction

This review discusses prior research that has been conducted in areas relevant to the topic of the current research study. It begins with a brief discussion of what cochlear implantation is and how candidacy for cochlear implantation is determined. Outcomes of cochlear implantation and factors that are influential in the “success” of the child’s habilitation to the device are then presented. Within this section, literature on the topics of Deaf\textsuperscript{1} culture, education for children with hearing loss and sign language as they relate to the current case study are discussed. Next is a description of literature on the topic of CND as it pertains to cochlear implantation, followed by a brief explanation of other neurological conditions that implicate implant success, specifically cochlear anomalies and auditory neuropathy spectrum disorder. After this, issues in counselling parents regarding CIs from the viewpoint of audiologists are discussed, as well as intervention standards and guidelines for best practice. Finally, research investigating the experiences of parents who choose cochlear implantation for their child with hearing loss is summarized. These topics form a foundation for the current research study which explored two parents’ experiences of cochlear implantation for their daughter who was diagnosed with CND and common cavity deformation of the inner ear.

2.2 Cochlear Implantation

In a normal auditory system, delicate hair cells in the cochlea of the inner ear convert acoustic energy into electrical impulses which are sent to the cerebral cortex by way of the

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\textsuperscript{1} When written with a capital “D,” Deaf is referring to a cultural label; lower case “d” deaf refers to the audiological condition.
auditory nerve (Scheetz, 1993). Damage to these fragile hair cells disrupts input to the auditory pathway to the brain and results in sensorineural hearing loss (Scheetz, 1993). Many children with mild-to-severe hearing loss are able to detect and understand speech through hearing aids, but many others may receive little or no benefit from such amplification (O’Donoghue, Nikolopoulos, Archbold, & Tait, 1999). Cochlear implants compensate for sensorineural hearing loss by bypassing the damaged hair cells in the cochlea and directly stimulating the auditory nerve with implanted electrodes (Nikolopoulos & Vlastarakos, 2010). The sensory stimulation received by the auditory cortex from the cochlear implant is not equivalent to normal hearing, but many individuals can learn to interpret signals from the implant in understanding speech (Balkany et al. 2002). The perception of speech then lays the foundation for the development of spoken language (O’Donoghue et al., 1999; Calmels et al., 2004). Therefore, for children with severe-to-profound sensorineural hearing loss who do not benefit from hearing aids, a CI may be the most reasonable way to stimulate their auditory nerve, provide them access to sound, and subsequently enable them to develop oral communication (Nikolopoulos, Lloyd, Archbold, & O’Donoghue, 2001).

An eight-point scale called The Categories of Auditory Performance is often used to describe auditory abilities of cochlear implant users (Archbold, Lutman, & Nikolopoulos, 1998). The scale ranges from a score of zero, meaning the CI user has no awareness of environmental sounds, to a score of seven, meaning the CI user can converse over the telephone with a familiar speaker (Nikolopoulos, Archbold, & O’Donoghue, 1999). Unfortunately, not all CI users reach the highest level of speech perception and production; there remains a wide variance in outcomes among children with CIs (Tait, Lutman & Robinson, 2000). Many factors influence the potential success of cochlear implantation
including pre-operative conditions, such as age at implantation (Tomblin, Barker, Spencer, Zhang & Gantz, 2005; Svirsky, Teoh & Neuburger, A., 2004), level of residual hearing loss (Dowell, Blamey & Clark, 1997; Gordon, Twitchell, Papsin & Harrison, 2001) and child learning style (Nikolopoulos, Gibbin, & Dyar, 2004), as well as post-operative factors, such as quality of device mapping (Moog, 2002), and mode of education (Geers, Nicholas & Sedey, 2003; Tobey & Buckley, 2004; Geers, Brenner & Davidson, 2003). Because these, and other factors, are influential in the potential success of cochlear implantation, a number of criteria have been developed for determining whether an individual child with severe-to-profound sensorineural hearing loss is a candidate for implantation or not.

### 2.3 Cochlear Implant Candidacy

Not every individual with hearing loss is a candidate for a CI. The general criteria are determined by the manufacturers of CIs, and specific criteria are set by cochlear implant centres (Gifford, 2011). As such, criteria vary somewhat depending on world location and on device brand (Gifford, 2011); however, a number of core criteria are used fairly uniformly in North America. Francis & Niparko (2003) maintain that CI candidacy must include holistic consideration of factors related to the child in question including developmental factors, educational options and family support. Subsequently, determining pediatric implant candidacy is a complicated process, involving assessments of audiometric thresholds, monitoring progress with conventional amplification (i.e., hearing aids), speech recognition performance (for older children), etiology of hearing loss, and availability of appropriate (re)habilitation programs and therapy (Gifford, 2011). Confirming structural integrity of the inner ear and assessing other medical conditions are also important in determining implant candidacy (Balkany et al., 2002). Dowell (2005) suggests that two questions should guide CI
candidacy: “Does a particular candidate have a good chance (let us suggest >75%) of improved auditory skills?” and “Can the implant device be placed safely into the cochlea and will it have the potential to generate an auditory percept?” (p.10). Table 1 describes the current CI candidacy criteria for children in British Columbia (British Columbia Children’s Hospital, 2010), which is a typical example of the set of criteria used to define CI candidacy.

Table 1: BC Children’s Hospital Unilateral CI Candidacy Criteria

<table>
<thead>
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<th>BC Children’s Hospital Unilateral Cochlear Implant Candidacy:</th>
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<tr>
<td>Age range of 12 months through 18 years</td>
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<tr>
<td>A bilateral severe-to-profound sensorineural hearing loss</td>
</tr>
<tr>
<td>Little or no benefit from consistent use of appropriately fitted hearing aids worn at least 3-6 months as shown through minimal progress in auditory development</td>
</tr>
<tr>
<td>Inner ear which can accommodate the implant device/ integrity of auditory nerve, as determined by MRI/ CT Scan</td>
</tr>
<tr>
<td>No medical contra-indications, including active middle ear disease or ossification of cochlea, which would interfere with implant surgery or the post-implant (re)habilitation process</td>
</tr>
<tr>
<td>Family and/or child with good motivation and realistic expectations about the cochlear implant (i.e., in cases where there are co-operative families who have effectively participated in the habilitation of their child, have demonstrated the ability to manage hearing aids and other amplification devices and recognition of limitations that the cochlear implant may have for their child)</td>
</tr>
<tr>
<td>Family prepared for the time and travel costs associated with cochlear implant follow-up as well as the continuing costs of speech processor supplies and upgrades</td>
</tr>
<tr>
<td>Enrolment in an appropriate educational program with emphasis on development of auditory/oral skills</td>
</tr>
<tr>
<td>No additional conditions which could interfere with a child’s implant use and (re)habilitation</td>
</tr>
</tbody>
</table>

The first criterion in Table 1 is the age at which a child is eligible for implantation. In British Columbia, a child must be at least 12 months old; elsewhere, some children are being implanted prior to one year of age (Valencia, Rimell, Friedman, Oblander, & Helmbrecht,
Secondly, to be considered for a CI, an individual must have bilateral severe-to-profound sensorineural hearing loss (British Columbia Children’s Hospital, 2010). In most cases, any milder degree of hearing loss is likely to benefit from hearing aids and thus the risk and expense of CI surgery is not appropriate. Furthermore, CIs work by bypassing the damaged hair cells in the cochlea, not any other portion of the auditory pathway, and thus they are only suitable for a sensorineural type of hearing loss. A third criterion is that the child must have shown little or no benefit from consistent use of appropriately fitted hearing aids that have been worn for three to six months as shown through minimal progress in auditory development. This ensures that the child’s condition is severe enough to warrant such a surgery, and that sufficient access to sound cannot be provided by traditional non-invasive means (i.e., hearing aids). A fourth criterion that is particularly relevant to the current study is that the individual must have an inner ear which can accommodate the implant device as determined by Magnetic Resonance Imaging (MRI) or Computed Tomography (CT) scan. An MRI is a procedure that utilizes a powerful magnetic field and radio frequency fields to obtain detailed images of the soft tissues of the scanned areas of the body (Radiological Society of North America, 2011). A CT scan uses X-ray images taken around an axis of rotation to provide a three dimensional image of bodily structures (Nordqvist, 2009). Both of these imaging methods enable medical professionals to analyze structures of the inner ear, skull and brain before any invasive procedures are attempted. In determining CI candidacy, MRI and CT scans provide imaging of the internal auditory canal, the temporal bone, the cochlea, and the auditory nerve to make sure that the inner ear and the cochleovestibular nerve are present and appear grossly normal (Francis & Niparko, 2003). (As a caveat to this criterion, although MRI and CT scans are the
gold standard for investigating the integrity of inner ear structures, it is acknowledged that even these are not 100% guaranteed to pick up all abnormalities that may affect the success of the implant.) CIs rely on intact structures along the auditory pathway in order to transmit signals reliably to the cortex (Francis & Niparko, 2003). If other structures besides the hair cells in the cochlea are affected by pathology, the cochlear implant may not be able to work as designed. For example, meningitis can cause severe-to-profound hearing loss by damaging the spiral ganglion cells of the cochlea, but it also causes ossification of the cochlea (Francis & Niparko, 2003). Children with hearing loss due to meningitis are therefore an urgent priority for cochlear implantation in order to place the electrode in the cochlea before ossification occurs (Dodds, Tyszkiewics, & Ramsden, 1997). A fifth criterion is that there must be no medical contra-indications or additional conditions that could interfere with the surgery, implant use, or post-implant (re)habilitation. Contra-indications for implantation include agenesis of the inner ear, absence of the cochlear nerve, and illness that precludes surgery or general anesthesia (Balkany, 2002).

The next few criteria focus not on characteristics of the child’s hearing loss and neurophysiology, but on the child’s support network. To begin with, the family and/or the child to be implanted must be motivated and have realistic expectations about the cochlear implant (British Columbia Children’s Hospital, 2010). They must realize that a CI is not a magical device that will “fix” the hearing impairment right away; rather, it provides a signal that takes a lot of work and prolonged rehabilitation before the full potential of the implant is realized (Nikolopoulos et al., 2001). The family must also be prepared for the time and travel costs associated with cochlear implant follow up and the cost of speech processor supplies, repairs and upgrades. Although children with cochlear implants in Early Intervention
programs are eligible for funding through the Ministry of Children and Family Development, the cost of travel, the time required of parents and other additional costs are still substantial. Additionally, the family must enrol their child in an educational program that emphasizes the development of auditory/oral skills. The purpose of a cochlear implant is to provide access to hearing and speech; therefore, in order to make the most of the device, the child with the CI must be trained to use the signal in understanding speech and then in the expression of spoken language. To make certain that a child has the best possible chance of developing speech perception and spoken language, it is essential that their family is committed to participating fully in post-surgery implant follow-up and providing ongoing auditory/oral therapeutic intervention. Inability of the family to commit to such follow-up is a contraindication to surgery (Francis & Niparko, 2003). All of the criteria described above serve to make certain as much as possible that getting a CI is the best choice for an individual with severe-to-profound hearing loss and his or her family.

2.3.1 Candidacy Criteria Expansion

Although the fundamental criteria for cochlear implant candidacy are described above, these criteria are not static, but expanding as the field matures and the devices evolve (Gifford, 2011). Since the approval of the device by the Federal Drug Administration in 1990, candidacy has expanded in terms of degree of hearing loss and age of the client—in both directions. First created for post-lingually deafened adults, CIs are now used with pre- and post-lingually deafened children with significant benefits (Florian, 2003). Furthermore, CI candidates can now have as high as 50% word discrimination scores with a hearing aid and still qualify for implantation (Florian, 2003; Zeng, 2004). Word discrimination is an audiological test in which an individual hears a word at a comfortable volume and must
repeat that same word (Bauman, 2005). A score of 50% on this test indicates that some residual hearing is available for amplification. At one time, this score would have precluded CI surgery for the particular candidate (Gifford, 2011); currently, however, if other factors support implantation, a CI may still be an option for these individuals who benefit somewhat from hearing aids (Dowell, 2005; Francis & Niparko, 2003). In addition to degree of hearing loss and client age, candidacy is expanding to include clients with abnormalities of the inner ear and auditory nerve (Balkany et al., 2002). As mentioned above, an inner ear that can accommodate the device is one of the fundamental criteria for implant candidacy. However, as the device develops and the surgery is refined, it is not known whether clients with certain abnormalities of the inner ear may in fact benefit to some extent from an implant. Indeed, clients with a common cavity of the cochlea have been implanted with success (Ito, Sakota, Kato, Hazama & Enomoto, 1999; Beltrame, Frau, Shanks, Robinson, & Anderson, 2005) and other conditions may also benefit from surgical intervention (Balkany, 2002; Odabassi, Mobley, Bolanos, Hodges, & Balkany, 2000; Lenarz, 1998). Clients with abnormalities present significant challenges for health professionals on CI teams, for they must advise families on the potential benefits of implantation given the increased surgical risk and the uncertainty of post-operative outcomes (Balkany et al., 2002); nonetheless, the potential benefits may be worth the risks in some cases. The current study attempts to address this issue from the parents’ point of view for one particular case, a child with CND and common cavity deformity.
2.4 Outcomes of Cochlear Implantation

2.4.1 Introduction

Despite the established nature of cochlear implantation, there remains huge variability among children with CIs in regards to their post-operative speech perception and production outcomes (O’Donoghue, Nikolopoulos, & Archbold, 2000). Outcomes range from achieving open-set speech recognition with an unfamiliar speaker to using the implant signal only to detect environmental sounds, to ceasing to wear the implant completely. This variability is a matter of significant concern because cochlear implantation involves surgical risk and an ongoing time commitment from the family, the client, and the professionals involved. To better advise potential clients on the probable outcomes of implantation, it is necessary that factors involved in the relative success of the implant are identified and discussed. In fact, this variability has been the focus of much research, and a number of factors have been identified that contribute to probable outcomes.

2.4.2 Age at Implantation

The first key variable noted in the literature is age of implantation. For pre-lingually deafened children, it is well substantiated that earlier age at implantation is correlated with better speech perception and production (Florian, 2003; Geers, Tobey, Moog & Brenner, 2008; Sarant, Blamey, Dowell, Clark, & Gibson, 2001; Tomblin et al., 2005; Svirsky et al., 2004). This is similar or equivalent to duration of deafness in post-lingually deafened adults and children (Sarant et al., 2001). For both then, younger age at implantation or shorter duration of deafness is associated with better outcomes. Intuitively, length of implant use is also associated with better outcomes as the longer an individual has had access to the speech
signal, the greater facility they will have in using it to understand their environment and for producing speech (Tomblin et al., 2005; O’Donoghue et al., 2000; Mondain et al., 1997).

2.4.3 Intervention Programs and Mode of Communication

Two interconnected factors that have been investigated at length are type of intervention program and mode of communication. A study by Geers (2002) reported that type of intervention was the single most significant variable associated with outcomes in speech perception, production, spoken language, and reading for children implanted before age five. More specifically, those children in oral communication environments scored higher on these linguistic and academic measures than their peers in total communication environments (Geers, 2002). Differences between children in oral communication and total communication intervention programs had also been investigated using a measure of percentage consonants correct (Tobey, Wiessner, Sundarajan, Buckley, & Sullivan, 2007). As the primary goal of implantation is to learn to recognize novel speech and speak intelligibly, this measure is suggested to be a sensitive measure of children’s oral communication ability (Tobey et al., 2007). Again, children in oral communication programs were found to produce higher percentages of accurate phonemes than their peers in total communication programs. Other studies have found differing results (Connor, Hieber, Arts, & Zwolan, 2002) but, overall, current research suggests that implanted children who are placed in an oral communication setting will develop greater levels of speech perception and spoken language intelligibility than those in total communication programs (Geers, 2002; O’Donoghue et al., 2000).

Relatedly, Geers, Nicholas & Sedey (2003) investigated the degree to which language development after cochlear implantation was affected by educational intervention and
classroom communication mode. Educational factors that they identified and investigated were hours of therapy, therapist experience, parent participation, public or private school, special or mainstreamed school, and communication mode. Assessment scores were combined into two component scores, spoken language and total language. After child and family characteristics had been removed from the analysis, the six educational variables accounted for 7% of variance in the total language scores, and 12% of variance in the spoken language component score (p. 55S). The most significant variables were class placement, where mainstreamed children displayed better language, and communication mode, where children with an oral emphasis displayed better language. When educational factors were considered individually, some of the other variables also became significant. Specifically, the number of hours of therapy became a significant predictor of spoken language competence. When all predictors were included, however, the effects of classroom type and communication mode overcame the therapy effects.

The results of this study introduce an important consideration. Although mode of communication and type of intervention are two of the most consistent predictive variables in the literature regarding cochlear implantation outcomes, intervention must be implemented consistently and frequently in order to result in the best outcomes.

2.4.3.1 Communication Options

Although there are two primary communication options denoted in the literature, oral communication and total communication, these terms are often used as categorical labels for programs that focus entirely on oral communication training and those that incorporate some signs into the language instruction. Within these overarching categories of communication style are a number of distinct sub-types or variations. Gravel and O’Gara (2003) describe the
communication options as ranging along a continuum from spoken language to visual language. Furthest towards spoken language are two communication methods, auditory-verbal and auditory-oral. The auditory-verbal approach aims for the development of spoken language exclusively through the uses of aided residual hearing and the integration of the child with hearing loss into the hearing world (Gravel & O’Gara, 2003). Similarly, the auditory-oral approach aims to facilitate the development of spoken language through residual hearing and mainstreamed education; however, children also learn to use speechreading, facial expressions and naturally occurring gestures to aid their comprehension of speech. The next method along the continuum, cued speech, uses spoken language and visual cues. This approach teaches distinct handshapes that represent groups of consonants, and different locations around the face that represent vowels. By observing a speaker’s hand pattern, location and lip movements, the child with hearing loss learns to distinguish speech sounds that are difficult to distinguish through speechreading alone. The next category of communication methods described by Gravel and O’Gara (2003) are those that use spoken language and signs. This category includes manually coded English, total communication and simultaneous communication. Manually coded English utilizes signs and fingerspelling to represent spoken English. It is often used as the signed component of total communication and simultaneous communication. Total communication teaches the use of multiple modalities in communication; in this environment, communicators would speak in a loud conversational voice, accompanying their words with manually coded English. The child learns to use their residual hearing and their understanding of signs for language comprehension. Simultaneous communication differs from total communication only in that it does not require amplification of a child’s residual hearing. The next communication
method, American Sign Language, falls entirely on the visual language side of the spectrum and is considered the “natural” language of the Deaf community. This is a visual language in its own right that has a grammatical system and syntactic structure that are completely distinct from those of English. Lastly, the bilingual-bicultural approach teaches children American Sign Language as a first language, and spoken English as a second language. Amplification is not required for learning American Sign Language, but may be used for the development of spoken language.

Although these variations are described in the literature, there may not be intervention programs of all varieties in a given location, so parents who are choosing a communication method for their child with hearing loss are often limited by the availability of programs in their locality. Overall, the issue of immediate and future mode of communication is shown to be an important factor in the minds of parents considering an implant for their child. Typically, the decision to get an implant reflects a desire of parents for their child to develop spoken language, but often the adopted mode of communication changes over time as the child gains more experience with the implant and moves more towards oral language.

2.4.3.2 Sign Language, Oral Therapy and the Deaf Community

At this point, it is important to mention that there has been and continues to be quite a debate over mode of communication and type of intervention for deaf children. As discussed above, many studies have investigated the outcomes of children placed in oral communication environments compared to those in total communication programs. The issue of communication mode and intervention program for deaf children is multifaceted and has generated a lot of tension between oral communication advocates and manual, or signed,
communication advocates for centuries. From the early 1800s, after the first deaf school was established in the United States until the current day, methodological “wars” have been fought across the nation (Luterman, 1999). In his summary of these “wars,” Luterman (1999) describes that the clear-cut battle between oralists and manualists in the nineteenth century continues even today but in a much more subtle manner. He expresses that advocates of oral intervention believe deafness is a condition that needs to be fixed in order to make the deaf child as similar to a hearing child as possible (Luterman, 1999). The advocates of sign language, however, believe that the first goal of intervention is to have a well-adjusted deaf child who is able to communicate using his or her “natural” language of signs (Luterman, 1999).

The idea that sign language, more specifically American Sign Language, is the “natural” language of deaf children is a view espoused by the Deaf community (Dolnick, 1993). The Deaf community is primarily made up of deaf individuals who consider that their deafness is a cultural difference, rather than a disability. They are referred to as “Deaf” when referencing this cultural difference as opposed to “deaf,” which is the audiological condition (Poitras Tucker, 1998; Dolnick, 1993). Like other cultures, Deaf people have their own language (Dolnick, 1993). Unlike other cultures, however, the majority of people in the Deaf community have hearing parents (Dolnick, 1993); thus they learn about Deaf culture from peers and Deaf adults as opposed to their own family. With the advent of cochlear implantation in North America, parents of profoundly deaf children have the option of giving their child access to auditory input through the implant. The Deaf community was traditionally opposed to implantation as it meant fewer deaf children would learn their “natural” language, American Sign Language, and become a part of the Deaf community.
(Dolnick, 1993). Some members of the Deaf community even considered cochlear implantation of children to be akin to cultural killing (Poitras Tucker, 1998). Although this is an extremist position, the nature of cochlear implantation does imply that deafness is a medical condition to be “fixed.”

Currently, parents of deaf children do not feel the political tension of the past century when they choose the intervention program and mode of language instruction for their child, as shown by the absence of this factor in literature exploring parental decision-making regarding CIs and communication approach (Johnston et al., 2008); however, their decisions may be influenced by interactions with deaf adults (Li, Bain & Steinberg, 2004). Many hearing parents of deaf children choose to have their child implanted out of a desire for their child to develop spoken language and therefore become part of the hearing world (Incesulu, Vural & Erkam, 2003; Kluwin & Stewart, 2000; Hyde, Punch, & Komesaroff, 2010). The majority of these children are educated in oral communication environments as this is a required commitment in determining CI candidates (Francis & Niparko, 2003; British Columbia Children’s Hospital, 2010). Some children, however, receive a CI and for some reason the implant is not successful. The issue of mode of communication and type of intervention program is particularly important for these children who have limited or absent auditory perception and for whom oral communication programs may not result in significant gains in communication.

2.4.4 Learning Style

In addition to age at implantation and mode of communication, Nikolopoulos, Gibbin & Dyar (2004) reported that the learning style of children with CIs is a significant factor in the relative success of cochlear implantation. In this study, 41 pre-lingually deafened
children, who were implanted between ages 21 months and 5.8 years, were assessed at three and four years post-implant. Their speech perception abilities were assessed using Connected Discourse Tracking and according to the Categories of Auditory Performance. Connected Discourse Tracking is a test in which a child is read an age-appropriate story phrase by phrase, and must repeat each phrase back to the examiner without speechreading (Nikolopoulos, et al., 2004). As described previously, the Categories of Auditory Performance is an eight-point holistic ranking of the child’s auditory abilities in daily life (Archbold, Lutman, & Nikolopoulos, 1998). The Nottingham Children’s Implant Profile (Nikolopoulos et al., 2004) was completed prior to implantation and documented the following 12 factors: chronological age, duration of deafness, medical/radiological, audiological assessment, speech and language abilities, multiple handicap, family structure and support, educational environment, availability of support services, expectations of family/child, cognitive ability and learning style. For each of these categories, the child was given a classification of “No concern,” “Mild to moderate concern,” or “Great concern” (Nikolopoulos et al., 2004). Statistical analysis revealed that the most consistent predictor of outcomes was the child’s learning style, accounting for up to 29% of the variance (Nikolopoulos et al., 2004). Learning style was assessed using the following three questions: Does the child have an internal or an external locus of control?; What is the child’s temperamental style?; And how does she/he cope with change, novelty or ambiguity? A delineation of “No concern” indicated that the child had a satisfactory learning style and was able to attend well to self- or adult-chosen activities. A description of “Mild to moderate concern” indicated a learning style that was developmentally delayed in which the child attended well to self-chosen activities, but gave variable attention to adult-chosen activities.
Finally, a delineation of “Great concern” indicated that the child had limited ability to sustain attention in new or unfamiliar tasks (Nikolopoulous, Gibbin et al., 2004). The label of “Learning Style” seems somewhat misleading as it is more common to talk about learning style in terms of how one best learns new information in an academic environment (Dunn, Griggs, Olson, Beasley, & Gorman, 1995); nevertheless, this study suggests that the child’s personality, way of interacting with the others, and ability to sustain attention, will affect the potential success of the implant.

2.4.5 Other Factors

Other factors that have been investigated regarding the relative success of cochlear implantation include parental involvement in therapy (Moeller, 2000), nonverbal intelligence, family size, socioeconomic status, number of active electrodes in the array, and type and frequency of intervention services. These are typically denoted in the literature as less important variables than age of implantation and mode of communication (eg. Nikolopoulos et al., 2004; Geers, 2002). A final factor, and one that plays a significant role in the probable success of an implant is the presence of neurophysiological conditions that implicate implant surgery and electrode placement and performance (Francis & Niparko, 2003). Cochlear nerve deficiency is one such condition (Govaerts et al., 2003; Bradley, Beale & Graham, 2008).

The goal of this study is to understand more fully the experiences of parents whose child has CND and yet receives a CI. The following section discusses research literature that has investigated aspects of cochlear implantation for children with CND.

2.5 Cochlear Nerve Deficiency

Cochlear nerve deficiency is a condition in which the cochlear nerve is reduced in size or absent. A small cochlear nerve indicates that fewer-than-normal auditory fibres are
present to conduct sound from the cochlea to the auditory cortex (Adunka, 2007). It can also be referred to as hypoplasia of the auditory nerve, or as “wispy” auditory nerves. The literature relating to cochlear implantation and CND, which is the focus of the current study, is reviewed below.

### 2.5.1 Importance of MRI in Establishing CND

In 1998, Gray et al. reported the complete failure of cochlear implantation in the case of a young child who had unidentified hypoplasticity of the auditory nerve prior to implantation. The child had a CT scan to determine implant candidacy; however an abnormality of the internal auditory canal was not noted until a post-operative detailed examination of the scan. The conclusion of this study was cautionary in nature and suggested that all CI candidates without absolutely clear auditory responses should be screened with MRI before determining candidacy to ensure that there is a functioning cochleovestibular nerve. The cochleovestibular nerve is made up of the vestibular nerve and the cochlear nerve which together form the eighth cranial nerve.

Bamiou, Worth, Phelps, Sirimanna, & Rajput (2001) also confirmed the importance of MRI imaging by reporting that it was very effective in determining the presence and characteristics of the cochleovestibular nerve in a number of cases prior to implantation. They described one patient who, despite the MRI showing hypoplasia of his cochleovestibular nerve, presented with responses and vocalizations that indicated some hearing was present. The child was implanted and his post-operative thresholds were within normal limits as determined by electrical stimulation of his cochlear nerve through the CI. Therefore, they concluded that candidacy for implantation should be determined with both MRI and electrophysiologic studies, such as auditory brainstem response testing and
otoacoustic emissions testing, especially when the child’s results indicate that some hearing may be present (Bamiou et al., 2001). An auditory brainstem response test is an objective test that measures the neural response of the auditory brainstem pathway to auditory stimuli (Bhattacharyya, 2011). It is used to estimate hearing thresholds in infants by measuring the neural responses to brief tone stimuli at specific frequencies (Bhattacharyya, 2011). Otoacoustic emissions are low-intensity sounds produced by the hair cells in the cochlea (Campbell, 2010). This test is used in newborn hearing screening to determine cochlear functioning, specifically the status of the hair cells in the cochlea (Campbell, 2010).

Magnetic resonance imaging and CT scans are now standard in establishing CI candidacy; however, candidacy criteria have also widened to allow some children with CND to receive CIs depending on other factors and indications of potential benefit.

2.5.2 Types of Hypoplasia

One such indicator of potential benefit is the type of hypoplasia. A retrospective case review by Govaerts et al. (2003) investigated implanted children with abnormalities of the cochlear nerve and found that cochlear implants could be of use in some cases of hypoplastic cochlear nerves, depending on the type of aplasia. Four cases were examined as to type of aplasia and outcome of implantation in terms of audiological findings and recognition of auditory stimuli. Types of aplasia are indicated by the visibility of the cochleovestibular nerve on MRI. Type I aplasia is shown by a narrow internal auditory canal where no cochleovestibular nerve can be visualized. Type IIa aplasia is recognized by the presence of the cochlear branch of the cochleovestibular nerve at the cerebellopontine angle and the middle third of the internal auditory canal, but absent at the level of the lateral third
concurrently with an abnormal canal. Type IIb is similar to Type IIa but with a typical internal auditory canal.

The first child, who presented with Type IIa aplasia, was implanted at age three years. His overall outcomes were thresholds of 45 dB HL and auditory discrimination of 18/22 phoneme pairs at 70 dB HL. The child in case two presented with Type I aplasia and some response to electrical stimulation of the outer ear canal in the left ear. Post-operative electrical stimulation failed to elicit perception. Case three described a child with Type IIa hypoplasia who was implanted at age four years. The postoperative audiogram for this child revealed thresholds at 65-70 dB HL. He made moderate progress in terms of speech development, but his primary mode of communication remained sign, although he could discriminate some phonemes. Finally, the child in case four presented with Type IIb aplasia. She was implanted at the age of two years, but did not appear to benefit from the implant and discontinued use after one year.

It was concluded that aplasia or hypoplasia of the cochleovestibular nerve is not a complete contraindication for implantation; if the electrode can be placed in the vicinity of the nerve, it may be beneficial to consider implantation, especially in cases of Type II hypoplasia or aplasia (Govaerts et al., 2003).

2.5.3 Long-Term Outcomes of Implanted Children with CND

Little research exists that has investigated long-term receptive and expressive language outcomes of children who have a CI and confirmed CND. A few studies have been published, however, that do explore this topic.
2.5.3.1 Cautionary Outcomes: Six Children with CND

Bradley et al. (2008) reported that even though some children with hypoplastic cochlear nerves may have clear responses to sound when aided, long-term results are often less encouraging. This study looked at outcomes of six children with confirmed hypoplasticity of the cochleovestibular nerve. Outcome measures reported included consistency of audiometry conducted in the sound field at specific levels, Category of Auditory Performance level, and Speech Intelligibility Ratings. Characteristics of their internal auditory canals were also described.

The first child was aided at 12 months and found to have clear auditory responses to sound up to 1000 and 2000 Hz in the left and right ear, respectively. Her CT scan and MRI showed narrowing of the internal auditory canal, but normal cochleae. The cochleovestibular nerve on the left was visible, but hypoplastic, and absent on the right. She was implanted at age 5;11 (years;months). Five years later, behavioral thresholds for warble tones in the sound field were 40 dB HL, but she could not distinguish between the Ling 6 sounds. The Ling 6 sounds are a range of speech sounds made up of maximally distinguishable frequencies (“ee,” “oo,” “m,” “sh,” “s,” “ah”; Agung, Purdy, & Kitamura, 2005). They are used frequently with children with hearing loss to test their ability to detect or identify these sounds (Agung et al., 2005). This child was able to identify 100% of words on a listening identification test while speechreading and listening, but no better than chance without the visual support. Although she clearly received more sound with the implant than without it, it served mainly as an aid to speechreading, and had done little to develop her spoken language. She is educated in a total communication environment and uses sign to communicate.
The second child was found to have profound hearing loss at 12 weeks of age and his hearing deteriorated over the next few years. At age 2;9 aided responses at levels considered not to be vibrotactile were found between 500 and 2000 Hz. A CT scan showed narrowing of the internal auditory canal on both sides, with abnormal inner ear physiology on both sides. As the cochleovestibular nerve was absent on the right, but hypoplastic on the left, he was implanted in the left ear at age 3;11. Four years later he had behavioral thresholds of 30-40 dB HL to warble tones presented in the sound field with inconsistent responses. He could detect the presence of the Ling 6 sounds, but not discriminate among them. He was able to correctly identify 7/20 environmental sounds. He remains in a signing environment and uses sign to communicate. Nevertheless, he chooses to use his implant and states that it helps him to hear.

The third child was found to have a profound sensorineural hearing loss at six months. At 13 months, aided behavioral thresholds were identified in the right ear from 250 to 1000 Hz at auditory levels. CT and MRI showed common cavity malformations in both ears. MRI showed a possible strand of the cochlear nerve in the left internal auditory canal; however, the cochlear nerve was not visible on the right. Because of his clear behavioral responses to sound in his right ear, he was implanted at age 2;6. Three years later, his sound field thresholds were at 35 to 40 dB HL between 500 and 4000 Hz. Again, he could detect but not distinguish among the Ling 6 sounds. His Categories of Auditory Performance score of 4 revealed that he could discriminate at least two speech sounds. His Speech Intelligibility Rating score was 2, meaning that connected speech was unintelligible. The authors note that with the minimal benefit he appears to receive, he is likely to become a non-user (Bradley et al., 2008).
The fourth child was found to have profound sensorineural hearing loss at eight months and fitted with hearing aids. At 13 months of age, he demonstrated aided responses to sound in his right ear at 500 to 2000 Hz. MRI revealed normal internal auditory canal width on both sides, but hypoplasia of the cochleovestibular nerve on both sides, more severely on the left. He was implanted at age 2;3. Three years post implant, his sound field thresholds were 30 to 40 dB HL at 250 to 4000 Hz. He could detect the Ling 6 sounds, but could not distinguish between the vowels. Interestingly, his Categories of Auditory Performance score was 5, showing that he could understand common phrases without speech reading. He correctly identified 9/12 items with auditory presentation alone at 70 dB HL. His Speech Intelligibility Rating score was between 2 and 3, revealing poor intelligibility, even though he spoke in five to eight word utterances. In this case, the implant was clearly providing some measurable benefit to the user, and he was educated in a mainstream classroom with support.

The fifth child was found to have profound sensorineural hearing loss at four months, but clear behavioral responses to sound were noted in the left ear. CT and MRI showed narrow internal auditory canals on both sides, a hypoplastic cochleovestibular nerve on the left and an absent cochleovestibular nerve on the right. He was implanted at age 1;10. Progress at six years showed behavioral thresholds to speech in the sound field to be between 30 and 50 dB(A). He could detect the Ling 6 sounds, but had limited ability to discriminate or understand speech. His Categories of Auditory Performance score was level 2 showing an ability to discriminate at least two speech sounds, and a Speech Intelligibility Rating of 2 showing very poor intelligibility. He uses sign to communicate, but shows an awareness of sound through his implant.
Finally, the sixth child was diagnosed with profound sensorineural hearing loss at 18 months. She had unaided responses up to 4000 Hz in both ears and aided responses up to 2000 Hz although her auditory awareness was poor (levels of auditory presentation were not described). A CT scan and MRI showed narrow internal auditory canals, a severely hypoplastic cochleovestibular nerve on the left, and an absent cochleovestibular nerve on the right. She was implanted at 3;6. Two years later, she had behavioral thresholds at 30 to 40 dB HL in the sound field from 250 to 6000 Hz. She could detect all phonemes but could not distinguish among them. She showed no sound awareness in daily life and used sign to communicate. She became a non-user two and a half years after the surgery.

In sum, Bradley et al. (2008) reported long-term outcomes for six implanted children with CND and found that although all cases demonstrated an awareness of sound pre- and post-implant, their implant only minimally affected their perception and development of spoken language. Most professionals and parents would agree that one of the primary purposes of cochlear implantation is to optimize the development of speech and language comprehension and production (Geers, 2006; Incesulu et al., 2003), which in the majority of these cases was not realized. Nevertheless, two of the children clearly indicated that they preferred to wear their implant and found that it helped them with language comprehension.

2.5.3.2 Promising Outcomes: Four Children with CND

Zanetti et al. (2006) described a more favourable outcome of cochlear implantation for a child with CND. The child in this study was evaluated for potential hearing loss at 18 months when a significant delay of speech production became apparent. He underwent a full audiological, otoneurological and imaging investigation and was subsequently diagnosed with profound bilateral congenital hearing loss and bilateral hypoplasia of the
cochleovestibular nerve. The child was fitted with binaural hearing aids and provided with intensive acoustic training for ten months; nonetheless, only minimal progress was gained. Finally, at 29 months, he received a cochlear implant in his poorer ear and resumed participation in an intensive habilitation program. He continued to wear a hearing aid in his other ear.

Four to six months after implant activation, this child’s speech perception appeared to have improved and his expressive vocabulary had increased. Furthermore, his demeanor had improved, showing more signs of cheerfulness and desire for peer contact and relationships. Ten months post-activation, he showed further improvement in all areas of auditory perception. An electrically-evoked auditory brainstem response test was repeated at that time, but no recognizable waveforms could be elicited despite the improvement in auditory perception. An electrically-evoked auditory brainstem response test differs from an acoustically-evoked auditory brainstem response test only in the type of stimuli presented (Voll, 2005). Typically an auditory brainstem response test records neural responses to click or tonal stimuli; an electrically-evoked auditory brainstem response test measures neural responses to electrical current delivered preoperatively to the promontory of the inner ear or postoperatively through the CI (Kileny, Zwolan, Zimmerman-Phillips, & Telian, 1995). To determine the relative effect of the CI and the hearing aid, the child was tested for word identification in a closed set, and word recognition in an open set, in the conditions of hearing aid only, CI only, and then hearing aid and CI together. Interestingly, performance with the CI alone was very poor, and performance with the hearing aid was better, but performance with both the CI and the hearing aid exceeded the simple sum of the previous two scores. Ten months post-implant, the child achieved 90% word identification in a closed
set, and 50% word recognition in an open set with bimodal amplification (CI & hearing aid). Furthermore, his neurocognitive scores showed substantial improvement in his cognitive abilities in areas of expressive and receptive language as well as locomotor, hand-eye coordination and performance competencies. His mental age according to this evaluation actually exceeded his chronological age by three months.

This study reported an important finding: despite many contraindications to implantation, this child received benefit from his cochlear implant, beyond what might have been expected. Although his abilities with his CI were poor without the amplification from his hearing aid in his other ear, the CI still boosted his word identification and recognition abilities. Furthermore, this study highlights that for some children, despite abnormal imaging and poor electrophysiological testing results, there remains the possibility of a satisfactory auditory outcome after cochlear implantation.

Warren, Wiggins, Pitt, Harnsberger & Shelton (2010) also reported positive auditory outcomes for three children with CND who underwent cochlear implantation. The first child was diagnosed with CHARGE syndrome and underwent audiological and otoneurological assessment. CHARGE syndrome is a complex cluster of genetic birth defects that tend to occur together in a recognizable pattern. These defects include: Coloboma of the eye, Heart defects, Atresia of the posterior nasal apertures, Retardation of growth and/or development, Genital and/or urinary abnormalities and Ear abnormalities and/or deafness (Zanetti et al., 2006). Her acoustically-evoked auditory brainstem response was attenuated at high stimulation levels, which was attributed to a cochlear microphonic. A cochlear microphonic is a recorded potential that is thought to be generated by the outer hair cells in the cochlea (Santarelli, R., Scimemi, P., Dal Monte, E. & Arslan, E., 2005). Imaging revealed no
cochlear nerve on either side and an abnormal positioning of the facial nerve. Nevertheless, the child wore a hearing aid on one ear and the family reported responses to environmental sounds. The right ear was determined to be a marginal CI candidate and the family was counseled to keep a hearing aid on that ear. One year later, the child stopped responding to sounds to which she had previously responded and cochlear implantation was subsequently performed at 43 months of age. Six months after implantation, she was able to discriminate single-syllable words. Nine months after implantation, she showed responses to sound at 20 dB HL. Her preschool teacher reported expressive utterances of up to five words where four out of the five words were intelligible.

The second child reported in this study was also born with some congenital abnormalities and was referred from a newborn hearing screen. An acoustically-evoked auditory brainstem response test conducted at one month revealed a minimal response to high intensity stimuli in the left ear, but no recordable response on the right. Imaging revealed no identifiable cochlear nerves and no clear cochlear nerve canal. A hearing aid was worn on the left ear and the family reported sound awareness and attempts to mimic sound. She then received a CI in her left ear. Five months post-operation, this child responded to her name and other words, attempted sounds, and showed progress on the Infant-Toddler Meaningful Auditory Integration Scale (Zimmerman-Phillips, 2001). The Infant-Toddler Meaningful Auditory Integration Scale is a structured interview schedule in which parents assess the child’s spontaneous responses to sound in everyday environments.

The third child described in this study also had CHARGE association and was referred from a newborn hearing screen. She showed some response to high stimulation levels on the right side. Imaging results revealed no identifiable cochlear nerve. Auditory
brainstem response testing revealed responses on both sides. At 19 months, this child underwent cochlear implantation. Four months later, she showed a 14 point improvement on the Infant-Toddler Meaningful Auditory Integration Scale.

This study concludes that although these cases are uncommon, an inability to visualize the cochlear nerve or the cochlear nerve canal on radiologic imaging tests does not rule out innervation of the cochlea. Imaging results must be verified by electrically-evoked auditory brainstem response testing to confirm the presence or absence of the cochlear nerve. Furthermore, CND does not guarantee that a child will not benefit from cochlear implantation; indeed, a number of cases have now been documented in which children with CND achieved enhanced auditory skills due to their CI.

The limited and variable nature of the outcomes reported for these children raises questions as to whether implantation for children with CND is warranted. Although these studies do not address parental factors, we can assume that there is a story behind every case that is multifaceted, involving complicated processes of decision making, expectations, and emotions on behalf of the parents. More research is needed to investigate the cohort of parents whose children have CND and their experiences of implantation in order to inform professionals and parents in the future who are looking at candidacy and weighing the potential risks and benefits involved for children with similar physiology.

2.5.4 CND Conclusion

The few studies that have investigated outcomes of CIs for children with CND point out that although the presence of a typical cochleovestibular nerve is ideal in establishing CI candidacy, abnormalities are not a complete contraindication to implantation. Furthermore, determination of the type of hypoplasia through MRI may add some predictive value to
potential outcomes, but should be reviewed cautiously given the small number of cases investigated and the modest gains described therein. It is clear that parents whose children have CND are in a very difficult situation. Like other parents of children with severe-to-profound hearing loss, they must weigh the risks and benefits of cochlear implantation and decide which intervention route to go with their child. Unlike others, however, parents of children with CND have less research to guide their decision-making process and provide them with realistic expectations. Furthermore, the few studies that look at long-term outcomes in this population reveal quite limited results; thus the probable gains of cochlear implantation for their child are truly unknown.

CND is one neurophysiological condition that affects the potential outcomes of cochlear implantation and complicates the decision-making process for parents of children in this situation. There are other neurophysiological conditions, however, for which research is also limited and outcomes are also unknown. The parents in the current study are therefore in a comparable position to other parents whose child is diagnosed with a condition other than CND but one that still implicates the probability of implant success. Some of these comparable conditions are described below.

2.6 Other Neurophysiological Conditions that may Affect Implantation Outcomes

There are many neurophysiological conditions of the inner ear that may have an effect on the success of cochlear implantation (Balkany et al., 2002). Physiologically, CIs typically require the presence of the cochlea to enable placement of the electrodes as close to the core of the cochlea as possible, which ensures their proximity to the spiral ganglion cells of the cochlear nerve (Francis & Niparko, 2003). Neurologically, CIs require the presence of spiral ganglion cells and cochlear nerve fibres to carry the electrical signals of the implant to
the auditory cortex (Francis & Niparko, 2003). Abnormalities that interfere with the development of inner ear structures have been classified by Jackler (1987) into two primary categories; malformations limited to the membranous labyrinth, and malformations of the osseous and membranous labyrinth. The second category is of particular relevance as it denotes conditions that can be identified by radiographic imaging such as MRI or CT scan (Jackler, 1987), which means these conditions would be identifiable during CI candidacy testing. Malformations of the osseous and membranous labyrinth, including Michel’s aplasia, cochlear aplasia, cochlear hypoplasia, incomplete partition, and common cavity will be briefly described below as well as the neurological condition of auditory neuropathy spectrum disorder.

2.6.1 Congenital Inner Ear Abnormalities

The congenital inner ear abnormalities described here are depicted according to Jackler’s (1987) classification. The first is a very rare and severe deformity of the membranous and osseous labyrinth known as complete labyrinthine aplasia or Michel’s aplasia. In this condition, there is a complete absence of inner ear structures, resulting in uniform deafness. The next four conditions are anomalies of the cochlea. First is cochlear aplasia, in which the cochlea is completely absent. Again, this is a rare condition and ears with this abnormality are devoid of auditory function (Jackler, 1987). Secondly, cochlear hypoplasia is a deformity where the cochlea consists of one or fewer turns. In these ears, hearing is variable. Thirdly, an incomplete partition or Mondini dysplasia is a cochlea that consists of 1.5 turns. It is the most common type of cochlear malformation, making up approximately 50% of such deformities. The cochlea in these cases is smaller in size than normal and hearing is again variable. Finally, the common cavity malformation is a condition
where the cochlea and the vestibule form one conjoined space. Neural populations are typically sparse or absent, but spiral ganglion cells may be scattered peripherally around the walls (Jackler, 1987). Auditory function is usually poor.

Malformations of inner-ear structures have implications for the success of cochlear implantation depending on their severity. Furthermore, they may present complications during the actual surgery, the most common of which are an aberrant facial nerve and/or a cerebrospinal fluid gusher (Ito et al., 1999). For a common cavity malformation in particular, it may be difficult for the surgeon to place the electrode optimally within the cochlear-vestibular space (Ito et al., 1999).

2.6.2 Auditory Neuropathy Spectrum Disorder

Another condition with similar implications for implant success is auditory neuropathy spectrum disorder, which is a group of disorders in which the hair cells in the cochlea appear to be functioning normally, but there are abnormal responses in the auditory pathway from the cochlea to the brainstem (Dowley et al., 2009). It is further characterized by poorer speech perception than would be expected given an individual’s audiometric thresholds, especially in noise (Schramm & Harrison, 2010). When tested, these ears produce normal otoacoustic emissions and cochlear microphonics, but have abnormal or absent auditory brainstem responses. Furthermore, responses on a pure-tone audiogram are extremely variable (Dowley et al., 2009). Potential sites of dysfunction that may create the characteristics of auditory neuropathy include the inner hair cells, the hair cell-nerve junction, the cochlear nerve, or the central auditory nervous system (Schramm & Harrison, 2010). The speech and language prognoses for individuals with auditory neuropathy spectrum disorder is still uncertain given the variability in speech and language outcomes.
post-implant; however, a growing body of research is documenting children with auditory neuropathy spectrum disorder who show significant speech perception gains after cochlear implantation (Schramm & Harrison, 2010; Trautwein, Sininger, & Nelson, 2000; Madden, Hilbert, Rutter, Greinwald & Choo, 2002; Buss et al., 2002).

All of the abovementioned conditions have implications for cochlear implantation. The goal of presenting the current research on these conditions is to illuminate the experiences of parents for whom the outcome of cochlear implantation for their child is uncertain. Any parents of a child or individual undergoing CI candidacy evaluation who is identified with one of these malformations or conditions will have to be counselled as to the potential complications that these conditions may cause during surgery and the effect they may have on probable implant success. The same holds for any child diagnosed with CND, which is the focus of the current exploratory study. The next section explores literature on the topic of counselling parents regarding CIs from the perspective of health professionals.

2.7 Counselling Parents Regarding Cochlear Implants

Sharing information and advising parents of children with hearing loss regarding CIs is not an easy task for audiologists and other involved health professionals. Luterman (2003) refers to this difficulty as the audiologist’s dilemma. He describes that CIs, if implemented correctly, can mitigate many of the negative effects of deafness. Many audiologists, in their unbridled enthusiasm for cochlear implantation and in their desire to alleviate parents’ grief, may suggest an implant too quickly before parents are truly ready to make the decision on their own. Luterman (2003) suggests that this persuasion method of counselling is detrimental to parents as it reinforces feelings of inadequacy, it allows them to blame others if the outcome is not as they expected, and it causes them to rely on professionals to make
their decisions for them. Instead, audiologists must learn to let the parents grieve and to wait for them to be in a place where they can make the right choice for their family, whether the audiologist agrees with their choice or not (Luterman, 2003).

The choice to implant one’s child or not is a complicated decision for parents of children with hearing loss. For many parents, it is a voluntary surgery for a child who may already have coexisting medical conditions or have endured a difficult birth (Luterman, 2003). Furthermore, it is a choice that must be made without the child’s input, but will alter their lives significantly. Luterman (2003) reports that many parents feel they are “flying blind” having to make decisions about implantation, communication and intervention so early in the child’s life. Parents of children diagnosed with hearing loss often ask questions regarding their child’s future speech development and educational placement, but audiologists are unable to predict or guarantee future outcomes based on their diagnostic test results. This inability of professionals to answer questions about the future definitively leaves parents in a place of uncertainty and unpredictability in regards to their child’s future (Kurtzer-White & Luterman). Harrison & Roush (2001) described several studies in which parents report their desire for factual information from the audiologist including realistic expectations for the future. Therefore, in counselling parents of children with CND, audiologists are in a complicated position due to the lack of factual information available for them to share with parents regarding possible implantation outcomes. The next section describes guidelines for best practice that have been developed to help professionals who are in the position to counsel families of children with hearing loss.
2.8 Standards and Best Practice Guidelines for Intervention

As mentioned above by Luterman (2003), professionals who counsel parents of children with hearing loss have a difficult responsibility. In order to ensure that parents are being counselled in the most appropriate manner, a number of mandatory service standards and guidelines for best practices in the field have been developed. The standards and guidelines developed for the British Columbia Early Hearing Program (BCEHP) are detailed here.

The BCEHP has developed five mandatory standards, which are based on current research literature, for professionals who provide service to families of children with hearing loss (BCEHP, 2008). The first standard specifies that children with hearing loss should receive intervention services by six months of age or earlier. This is based on a timeline in which children are screened by one month of age, diagnosed with hearing loss before three months of age and have begun to receive appropriate intervention less than three months later. This standard is founded upon research studies that report early intervention results in better outcomes (i.e., Yoshinaga-Itano et al., 1998). The second standard for service provision describes that parents must be provided with full and unbiased information about the options available for their child. This standard is fulfilled by providing parents with an information package regarding hearing equipment, communication options, programs and intervention approaches, as well as giving parents access to unbiased information on the BCEHP website. Additionally, no communication method is promoted through the BCEHP, and training is provided to audiologists and interventionists regarding promotion of informed choice and understanding of bias. The third standard for practice in British Columbia specifies a series of steps from referral to intervention that must be followed to ensure that all
children suspected of having hearing loss are referred for further testing and that all families of children with hearing loss have access to appropriate support and services. This step-by-step process details the responsibilities of the diagnostic audiologist and the intervention coordinator at BCEHP to ensure that no family is lost to the system, but that all families experience the same degree of follow-up, support and guidance. The fourth standard prescribes an assessment protocol and schedule that service-providers must follow in order to develop an individualized family service plan, to promote monitoring of progress, and to make timely adjustments to the plan when necessary. Finally, the fifth standard relates specifically to the individualized family service plan and specifies how, when and by whom the service plan should be created. Additionally, this standard explains how often the service plan must be reviewed and amended in order to ensure that the expected progress is being made.

In addition to the BCEHP mandatory standards for intervention, there are also guidelines for best practice in intervention. These guidelines are composed of the following five core elements: Evidence-based practice, family-centred care, individualized and flexible intervention services, communication and collaboration, and family support. The first guideline, evidence-based practice, requires that decisions about intervention planning are based on evidence from current research, valid assessments and family observations and values. On a practical level, this requires that the interventionists carry out regular assessments of the child’s progress and that they develop an individualized family service plan based on these results and with family input. The second element of best practice is the concept of family-centered care. Family-centered care means that parents are considered partners in the rehabilitation process, that their competence is acknowledged and encouraged,
and that families are enabled to make their own choices for their child. Also included in family-centered practice is the responsibility of professionals to respect family diversity and to identify strengths in the family that can be used as a resource. The third guideline for best practice details that intervention services are individualized and flexible. This means that the professionals acknowledge that no one program or approach will meet the needs of all children; therefore, an individualized service plan must be created for each family that takes into account the various factors that describe this child and this family. The fourth guideline for professionals working with children with hearing loss stresses the importance of communication and collaboration between early interventionists and audiologists in service provision and in the creation of the individualized family service plan. Although audiologists are often not included in the creation of the service plan, BCEHP suggests that this does not represent best practices in intervention and that audiologists should be included and involved. Finally, the fifth guideline specifies that all efforts should be made to ensure that families receive all the support that they need. This section describes resources available to parents, including an informative website and a parent advisory group. In addition to parent-to-parent support, professional counselling is provided free of charge for families in British Columbia who have family members with hearing loss.

The standards and guidelines espoused by BCEHP have been created to ensure that families are adequately supported from the time their child is referred to further hearing testing, to diagnosis of hearing loss, to intervention, and beyond. Furthermore, they provide explicit guidance to professionals who are involved in providing intervention to families of children with hearing loss. The next section explores elements of parent experiences that
have been described in the research literature regarding their experiences of the cochlear implantation process for their children with hearing loss.

2.9 Parent Experiences

To begin with, much research has investigated the experiences of parents who after discovering that their child has severe-to-profound hearing loss decide to get a CI for their child. Several key factors stand out in the literature as being important in understanding elements of parents’ life stories as they make decisions and cope with the ramifications of their child’s hearing loss post-diagnosis.

2.9.1 Emotions

Just after diagnosis of one’s child, common beliefs and feelings emerge in parents who are faced with decisions that will have a lifetime impact on their disabled child (Duncan, 2009). Not only must they make a decision for their child, a process that many parents find very difficult given the uncertainty of their child’s future agreement with their choice (Okubo, Takahashi, & Kai, 2008; Archbold, Sach, O’Neill, Lutman & Gregory, 2006), but the complex decision-making process begins concurrently with the shock and vulnerability of receiving the initial diagnosis (Duncan, 2009). After confirmation of a child’s hearing loss, many parents may enter a grief cycle including emotions of sadness, guilt, shock, loss, disbelief, anger, despair and numbness (Anagnostou, Graham & Crocker, 2007). Initially, grief is often experienced in the emotions of shock, denial, anger, guilt and depression, but later on these often give way to acceptance and growth (Anagnostou et al., 2007). Learning to accept the disability, implement adaptations within the family, navigate complex changing emotions and gather information to guide their decision is not an easy task and it is one that takes time. It is crucial that parents are given as much time as they need to deal with their
emotions and process the information they have gained, as well as reflect upon their own beliefs and expectations in order to avoid future regret at a hasty decision (Duncan, 2009).

2.9.2 Decision Making

Recent research by Hyde, Punch and Komesaroff (2010) combined qualitative and quantitative means to investigate influences on the parent decision-making process. They explored both the extent to which parents’ decisions are based on informed choice and comprehensive advice, and the other sources of information that are employed in the decision-making process. Quantitative data from a survey given to 247 participants in this study was subsequently confirmed and probed in-depth by qualitative findings from 27 follow-up interviews. The authors found that parents primarily received information regarding implantation from cochlear implant teams, ear, nose and throat specialists, and some audiologists. This prepared them with information from a medical point of view, but did not address implications for their child’s social and emotional health or alternative intervention options, a concern that is paramount in many parents’ minds (Sach & Whynes, 2005). Over half of the parents surveyed, however, also had contact from other parents or children with implants, which was considered very valuable due to the personal stories they heard and the emotional support they received through these interactions.

Archbold, Sach, O’Neill, Lutman & Gregory (2006) also describe research in which parent experiences were explored through the lens of a questionnaire. In this study, a questionnaire titled “Children with cochlear implants: parental perspectives” (Archbold et al., 2006; O’Neill, Lutman, Archbold, Gregory & Nikolopoulos, 2004) was given to 101 parents of implanted children. Results indicated substantial consensus on some aspects of parent experiences, but a fair amount of diversity on other topics. One main area of agreement was
the importance of gaining as much information prior to decision-making as possible (Archbold et al., 2006). All parents agreed or strongly agreed with this item. Though this finding appears intuitive, it is not always the case; a subset of parents in Hyde et al.’s (2010) study revealed that they had made the decision as quickly as possible given the understanding that early implantation leads to better outcomes, and the feeling that there was “no other option” for their child. There was also a fair amount of diversity found in Archbold et al.’s (2006) research regarding the amount of stress parents experienced in the decision making process. Only 55% agreed or strongly agreed that making the decision to implant or not was the most difficult part, whereas 41 percent disagreed or strongly disagreed (Archbold et al., 2006). After correlation analysis of items, it was found that difficulty making the decision to implant or not was negatively correlated with the desire for their child to become a part of the hearing world and learn to talk. In other words, those parents who struggled the least with the decision to implant their child placed the highest priority on their child’s development of oral communication.

2.9.3 Communication

Another theme that comes up repeatedly in research regarding parent experiences is in relation to their child’s present and future mode of communication. Research conducted by Wheeler, Archbold, Hardie & Watson (2009) looked in depth at the experiences of 12 families in the choices that they made prior to and post cochlear implantation. This was a follow-up investigation of families that had previously taken part in a parent-questionnaire regarding pre- and post-implant choices (Watson, Archbold & Nikolopoulos, 2006).

One theme that emerged from the interviews, common to all parents, was their desire to use the most effective way of communicating with their child pre-implant, whether this
was formal sign language, speech, or a mix of sign and speech (Wheeler et al., 2009). Parents simply wanted to communicate with their child in any modality necessary; therefore, there was diversity in the modes adopted. For many parents, their main motivation for choosing a CI was to enhance their child’s development of speech and language (Wheeler et al., 2009). Therefore, although any effective mode was assumed pre-implant in order to begin communicating, their eventual goal in getting the implant was the development of spoken language. Changing in favour of an oral mode of communication is often an expectation of parents initiating the implantation process (Huttunen & Valimaa, 2010). Post-implant, therefore, parents in Wheeler et al.’s (2009) study noted a reduction in the use of signing as the development of oral language progressed, supported by auditory input from the implant. Finally, once oral skills were established, for some there was a regained interest in using signed communication in addition to oral language (Wheeler et al., 2009).

Although the development of spoken language is a major purpose of implantation (Geers, 2006; Incesulu et al., 2003), not all parents value this outcome to the same extent. Archbold et al. (2006) reported that 25% of parents who responded to their survey did not expect their child to talk after implantation, and 13% felt neutrally. Furthermore, 73% of parents agreed or strongly agreed that signing support is helpful for a considerable time after implantation.

As discussed in the previous section regarding intervention for children with hearing loss and modes of communication, much research has been conducted on the relative efficacy of oral communication versus total communication environments. The overall results of this literature support an oral mode of intervention for children with CIs, although there are other studies that support total communication programs (eg. Connor et al. 2000). Additionally,
Asberg, Vogel & Bowers (2008) reported that parents using only oral or only sign were significantly more stressed than those using total communication. Consequently, parents of children with CIs must negotiate the advice of professionals, their own beliefs, values and hopes for the future, and the conclusions presented in the research literature in order to decide which communication route to travel with their child.

2.9.4 Interactions with Professionals

A final theme often mentioned in exploring parents’ perspectives on the implantation process is their experiences interacting with various professionals. Archbold et al. (2006) reported that most parents agreed on core elements of services expected from professionals. These core elements included expectations that only experienced teams carried out implantation, that regular checkups were essential and that members of the CI team visited the child at least once a year. Most parents also wanted advice from the implant center on aspects of their child’s future (Archbold et al., 2006).

Wheeler et al. (2009) found that some parents were upset with the advice they received from professionals in relation to managing their child’s hearing loss and communication. Nine parents experienced conflict over communication strategy, typically with teachers of the deaf. Only three families felt adequately supported by local professionals. One parent also reported being frustrated with the unwillingness of professionals to comment on the oral communication potential of their child. Finally, a number of parents reported feeling overly advised to go the route of the professional’s own philosophy, which may not have fit with what they felt was best for their child (Wheeler et al., 2009).
A study by Tattersall and Young (2006) investigated the experiences of parents of deaf children who were identified through newborn hearing screening. In this qualitative study, interactions with professionals also emerged as a theme that was important to many parents. Qualities of good professional communication described by these parents included good explanations, sensitivity, inclusiveness in order to make parents feel like partners in the process, and honesty/openness. Good explanations were identified as having three characteristics: they used appropriate language that was understandable to the parents, they used examples in context, and they were thorough so that parents were not left with unanswered questions. Sensitivity in professional interactions was important to parents, for they wanted their needs to be met not only at a practical level, but also at an emotional level through a gentle professional approach. Inclusivity in professional communication meant that parents were engaged in the testing process, being informed about how things worked and what expected results would look like. Finally, honesty and openness was valued in professional communication as parents wanted to know where the professionals stood and the whole truth about their child even if it was hard to hear.

2.10 Summary

The topics described in this literature review serve as a foundation to understanding what parents learn and experience after their child is diagnosed with severe-to-profound hearing loss. Although much research has looked at the experiences of parents who decide to have their child with hearing loss receive a CI, no study to date has described the experiences of parents whose child receives a CI in spite of having a diagnosis of CND. This study begins to fill the gap in the research literature by investigating the experiences of two parents whose daughter received a CI despite having CND and common cavity deformity. Their experiences
are presented as close to the data as possible, with minimal interpretation, so that the voices of the parents speak louder than the voice of the researcher. Results of this study increase our understanding of the experiences of parents who decide to get a CI for their child with abnormal neurophysiology of the auditory system. Furthermore, the results of this study can be applied to other situations in which professionals have little research evidence to guide their counselling of parents who must make decisions regarding their child’s health, wellness and intervention.
Chapter 3: Methodology

3.1 Introduction

The current research study attempts to explore and understand more fully the experiences of parents whose child has severe-to-profound hearing loss, CND and common cavity deformity of the inner ear. As discussed earlier, very little research has been conducted on this topic, in part because there are very few families who find themselves in this situation, creating a very small pool of potential participants. By nature then, this is an exploratory case study and one that requires detailed investigation in order to add to the research literature. Due to the exploratory nature of this research, the rarity of the situation to be explored, the subsequent scarcity of potential participants, and the depth of information required in order to shed light on the situation in question, qualitative methods offer the most appropriate paradigm for this study (Creswell, 1998). More specifically, qualitative description with a narrative approach to interviewing single case studies is the methodological platform from which the research questions were investigated.

This chapter begins with an explanation of the qualitative methodology including qualitative description, narrative interviewing and case study research. This is followed by a description of the recruitment process, participants, data collection and data analysis procedures.

3.2 Overview of Qualitative Methodology

The methodology employed in this study is qualitative description that incorporated a narrative approach to single case study interviews. The methodological elements of qualitative description, narrative interviewing, and case study research are each described below, beginning with qualitative description.
3.2.1 Qualitative Description

Qualitative description is well suited to studies in which a clear description of events and experiences is desired (Sandelowski, 2000). Rather than looking deeper into and beyond the language of participants, qualitative description stays closer to the data and towards the surface of words and events (Sandelowski, 2000). As such, it produces a kind of interpretation that is more likely to be agreed upon by researchers as accurate (Sandelowski, 2000). Furthermore, qualitative description is very concerned with descriptive and interpretive validity. Descriptive validity necessitates that events are conveyed accurately and in appropriate sequence; interpretive validity ensures that participants’ viewpoints, intentions, statements and experiences, and the meanings attributed to events by participants are accurately reported and attributable to the correct source (Johnson, 1997).

Qualitative description is an appropriate methodology for the current study for a few reasons. First of all, the goal of the current study is to describe and understand more fully the events, thoughts, emotions and reflections of parents in regards to their child’s unique life situation; therefore, a clear and unembellished depiction of participants’ experiences is desired. Secondly, this is an exploratory study because very little research has been conducted in this topic area and the number of potential participants is small. In contrast to other qualitative frameworks that delve beyond surface-level data, qualitative description facilitates depiction of the informational content of the data that allows readers to draw their own conclusions from the information presented. Again, because of the rarity of this situation and the paucity of research on this topic, every story and every experience of parents in this situation provides a valuable learning opportunity for professionals, parents and other stakeholders. By describing the experiences of parents clearly and in their own terms the
participants’ voices are primarily represented in the data, thus allowing the reader to consider and reflect upon the meanings attributed therein. In sum, qualitative description supplies a good methodological fit with both the topic and the goals of the current research study.

### 3.2.2 Narrative Interviewing

In addition to qualitative description, the current methodology incorporated aspects of narrative interviewing in the data collection process. In his book *Research Interviewing*, Mischler (1986) discussed that storytelling is a significant way in which people express and give meaning to their own understanding of their experiences. Similarly, Gee (1985), a linguist stated that “one of the primary ways—probably the primary way—humans make sense of their experience is by casting it in narrative form” (p.11). These two quotes highlight the importance of narrative as a framework through which we make sense of our human experiences and share this meaning with others.

One type of narrative, in which an individual tells all or part of his or her life story, can be described as a biographical narrative. To elicit such biographical narratives, Wengraf (2001) describes a particular technique which restricts interviewer participation in the interview to a minimum. Wengraf’s strategy, which he calls the biographic-narrative-interpretive-method approach, is designed to elicit a biographical narrative in response to a single initial narrative question. The researcher then declines to give any more direction to the interviewee until his or her story is completed. This resistance by the interviewer to enter into the interviewee’s narrative for the purposes of clarification or redirection is motivated by the *Gestalt* principle, in which participants must be given room to fully express their conceptualization of the story in its entirety (Wengraf, 2001). The concept of narrative interviewing, and in particular the biographic-narrative-interpretive-method approach
described above, held particular merit for the study at hand because the research question focuses on a portion of an individual’s life history. Furthermore, it was critical that the events and themes of importance in these life histories emerged from the individual’s own conceptualization of the past, present and anticipated future, rather than prescribed by the researcher. In sum, the incorporation of Wengraf’s approach to narrative interviewing in this qualitative case study ensured that the participants were given the freedom to tell their story from their own perspective, including whatever topics and events that stood out in their mind as part of the story to be told.

3.2.3 Case Study Research

Lastly, the research methodology in this study consisted not only of qualitative description with a narrative approach to interviewing, but on a more fundamental level, it comprised a single case study. Case study research is a preferred method when the focus is on a current phenomenon within a real-life context and when the researcher cannot exert control over the events to be explored (Yin, 1994). Further to that, Creswell (1998) states that “a case study is an exploration of a ‘bounded system’ or a case (or multiple cases), over time through detailed, in-depth data collection involving multiple sources of information rich in context” (p. 61). In this study, the “bounded system” is a family and the “multiple sources of information” include both parents and the reports from professional personnel that provided services to their particular child. Case study research literature often espouses the concept of purposeful sampling in which cases are chosen for reasons that may include their uniqueness, ordinariness, accessibility, or unusualness, depending on the purpose of the study (Creswell, 1998). In the present study, unusualness, but also accessibility, played a large role in the choice of case. On one hand, because there were so few potential participants, each family
that met the inclusion criteria for the study was naturally an unusual case, and therefore a valuable case to be explored. On the other hand, due to the very fact that there were so few potential participants, access to these families was limited and resulted in only a single case consenting to participate.

3.2.4 Qualitative Methodology Summary

In summary, the current research study is a single case study design. Our case consists of a family unit from which individual parent interviews made up the bulk of the collected data. Other data sources included health reports from the two agencies that provided service to their hard-of-hearing child. Parent interviews were collected using an interview strategy that elicits a biographical narrative with minimal interviewer intervention. This allowed each parent the freedom to express his or her story in its fullness according to their own understanding of the past, present and expected future. Finally, the over-arching qualitative methodology that forms the foundation of this study is qualitative description in which data are presented in a clear, straightforward manner, in which the views of the participants are clearly seen, and in which the reader is able to consider, reflect upon, and make conclusions based on the experiences, events and viewpoints presented.

3.2.5 Reflexivity

In qualitative research, it is important to note that the researcher is “a central figure who influences the collection, selection, and interpretation of data” (Finlay, 2002, p. 531). How the researcher acts and responds during the data collection process will always affect the participants’ responses to some degree, therefore affecting the findings (Finlay, 2002). Reflexivity is a tool in which the researcher engages in thoughtful self-awareness in order to acknowledge and understand that he or she is an active participant in the construction of
knowledge during the data collection and analysis processes. By acknowledging this fact and stating one’s position and bias as a researcher, the trustworthiness of the data presented is increased (Finlay, 2002).

Thus far in the description of this research methodology, I have only mentioned the theoretical framework that guided my inquiry. Additionally, the narrative approach to research interviewing depicted in this study was chosen because it makes the researcher more of a listener to a story than an interviewer who directs the flow of conversation. This allows the participant to engage in storytelling without being constrained or redirected by researcher questions. Despite the goal of this strategy, my presence, my appearance, and my interaction style undoubtedly influenced the way that the participants interacted with me and told their story of their child’s hearing loss. Furthermore, one of the participants asked repeatedly for more direction during the interview and thus I was more directive than I intended to be. Field notes that I took during the interview and afterwards noted my own reactions to what was said as well as my observations of the participants, their apparent emotions, body language and gestures, during the telling. In the results presented below, I occasionally include my own voice in the storytelling regarding the way in which the participants’ story affected me in the moment and how I interpreted their stories during the data analysis process.

3.3 Methods

3.3.1 Recruitment Process

Ethics approval for this study was granted by the UBC Behavioural Research Ethics Board. Participants for this study were recruited through the British Columbia Children’s Hospital Cochlear Implant Team. Recruitment packages were given to a member of the CI Team who passed them on to potential participants who met the study inclusion criteria. In
order to participate in this study, the participants had to be a parent of a child with the following characteristics:

1. The child must have CND with at least one hypoplastic auditory nerve with the other being absent, or also hypoplastic as confirmed by diagnostic imaging
2. The child must have been implanted with a cochlear implant before the age of 3;0;
3. The implant must be in an ear with confirmed CND.

The CI Team identified fewer than ten families who met the criteria to participate in this study. Two of these contacted the primary researcher of this study; after being sent more information, however, only one family consented to participate.

3.3.2 Participants

Participants in this study included two parents, the father and mother of two children. Although their youngest child did not have her hearing screened at birth, she was diagnosed with severe-to-profound hearing loss at nine months of age. She was also diagnosed with bilateral CND and common cavity deformity. Despite her diagnoses, she had received a CI nearly three years prior to this study. She was approximately four years old at the time of the parent interviews. The family will be henceforth referred to as Geoff (father), Kate (mother), Madison or Maddy (eldest daughter) and Ellie (daughter with CI)².

3.3.3 Data Collection

The primary source of data collected in this study consisted of two in-depth, semi-structured narrative interviews conducted separately with each parent, by the same interviewer, on different days (See Appendix A Interview Guide). Eisikovits and Koren (2010) suggest that conducting separate interviews while using the dyad as the unit of

² Names changed to preserve confidentiality.
analysis allows each person to tell the story from their own perspective without considering the reaction of their partner to criticisms, differences or sensitive topics. The partner is, however, present in the virtual space due to their participation in the life events being discussed. Furthermore, because the dyad is the unit of analysis, separate interviews allow the examination of overlaps and contrasts between the individual stories (Eisikovits & Koren, 2010). This will be further discussed below when explaining the process of data analysis.

Interviews were recorded using a Marantz digital recorder. Field notes were taken during the interview and afterwards to supplement the recordings with researcher observations. Recordings were then transcribed verbatim using the transcription conventions described in Appendix B. Although I attempted to transcribe the recordings precisely, I acknowledge that transcribing interactions requires decision-making on the part of the researcher. My own biases are therefore present in the way that the interviews were transcribed. For example, I decided when to code a feature of speech such as laughing or pretending to shout, and when it was unimportant to describe such prosodic contours. A second researcher listened to the recordings and provided a reliability check for the transcriptions. All names of individuals and agencies were changed during transcription to preserve confidentiality and anonymize the transcripts.

In addition to the two interviews, other sources of data include audiological reports both pre- and post-implant, medical files from the cochlear implant team responsible for the implantation of the child in question, and assessment and treatment reports from the two agencies that provided speech and language services to this family. Before the interviews were conducted, each parent signed a consent form to participate and a consent form to release their child’s health record information to the primary researcher in this study. Each of
the two agencies that provided speech-and-language services to their child was contacted and asked for any reports, assessments, therapy documents, and other pertinent notes regarding the child in question. The CI team was also asked for all reports and documentation pertaining to this child. Both service agencies and the CI team provided their information to the researcher. This documentation supplied a record of the child’s hearing, speech, and language progress from professional viewpoints and is a source of data triangulation along with the parent interviews.

3.3.4 Data Analysis

Data from the interviews in this study were analyzed in three stages; in the first stage, each interview was analyzed individually; the second stage investigated the two interviews together, pulling out overlaps and contrasts between them; and the third stage incorporated the professional reports as a source of triangulation with the events and timelines presented in the two parent interviews. Exactly how the process was conducted is described below.

The first stage of analysis consisted of analyzing each parent interview individually. As the very first portion of the analysis, each transcript was coded line by line according to Luborsky’s method of identifying topics, themes and patterns in qualitative research. Luborsky (1994) considers that topics are labels used when summarizing the content of utterances. Themes, however, are defined as “the manifest generalized statements by informants about beliefs, attitudes, values or sentiments” (Luborsky, 1994, p. 195). Themes can be identified either by tagging statements that are repeated, or noting statements that are marked as being of great importance to the informant. The first method is simply a matter of counting frequency of similar utterances. The second method of identification requires paying attention to discourse markers such as causal conjunctions, intensifiers, and
evaluative clauses. Evaluative clauses express moral language such as judgments about responsibility, blame, cause, and right or wrong actions or beliefs (Luborsky, 1994). These give “direct insights into the primary cultural and personal frameworks of value and belief that shape motivations and the ways people plan and react to events and conditions in their lives” (Luborsky, 1994, p. 199). Another discourse marker that appeared in one transcript was laughter. As the interview was transcribed, it quickly became apparent that laughter served to highlight statements of importance or to change the way that the participant’s spoken words were interpreted by the listener. The third term that Luborsky uses in analyzing qualitative data is a pattern. Patterns describe findings that emerge from the researcher’s perspective and observations of the data. These could include analyses of inferences, regularities, or structures, but they are less concerned with the meaning of these patterns to the informant (Luborsky, 1994). Because the objective in presenting these data is to illuminate the participant’s perspective and experiences according to the meaning they attribute to situations and events, such patterns observed by the researcher are not explored in detail in this study.

In the first pass of analysis, line-by-line codes consisted primarily of topics and salient themes. Interview transcripts were subsequently analyzed in an iterative process whereby codes were combined into higher level topical categories and themes. The analysis of each individual interview resulted in a list of compiled topics and themes for each parent.

The second phase of analysis looked at the transcripts together and examined overlaps and contrasts between them. Eisikovits and Koren (2010) maintain that analyzing separate interview transcripts together as well as individually creates an account that is more than just the sum of both parts. The situation of interest in this research study is one that is
experienced jointly by both parents, but not in the exact same way due to individual differences. Such a shared experience lends itself well to dyadic analysis because individual versions are captured without relinquishing the dyadic perspective, effectively creating a “we-oriented perspective” in addition to an “I-oriented perspective” (Eisikovits & Koren, 2010, p. 1644). These multiple perspectives strengthen the data and increase trustworthiness as they provide a type of triangulation regarding specific shared life experiences from different data sources. In view of the suggestions by Eisikovits & Koren (2010), each transcript was analyzed separately to discover individual perspectives, and together in order to explore congruencies and discrepancies in the shared experiences of the dyad.

As codes were revisited numerous times across the two interviews, it became apparent that the emergent categories and themes from both parents fell into a narrative framework that included multiple phases and clear turning points in this period of their lives. Many themes were common to both parents, for example both made use of powerful metaphors to convey their understanding of events; however, there were also some differences in their experiences and recollection of events that were noted as contrasts. As a result of the second stage of analysis, lists of themes common to both parents, lists of themes only apparent in one interview or the other, and lists of overlaps and contrasts between the two interviews were compiled.

As a third component of our data analysis, the professional medical and service documents regarding the participants’ child were reviewed. One of the purposes of triangulation is to provide confirmation of a single construct (Breitmayer, Ayers & Knafl, 1993). The analysis of the transcripts together yielded a joint narrative that referred to specific events and moments in time. By comparing medical reports with events depicted in
the interviews, a clear timeline of diagnosis, implantation, and follow up therapy for this family was created. Their experiences and thoughts at those points in time, as depicted in the interviews, were then organized chronologically. A second purpose of triangulation is related to the goal of completeness (Breitmayer et al., 1993). By gathering information from multiple data sources, it was possible to “reveal the varied dimensions of an area of interest; each measure, source or investigator contribut[es] another piece to the puzzle” (Breitmayer et al., 1993, p.238). Although the specific voices of the medical professionals were absent in that they were not interviewed in person, their perspective was represented to some extent through their written reports. In summary, reviewing the professional documents provided a documented timeline of tests, meetings and appointments for the participating family; this was used to create a chronological framework for the overall story and the smaller vignettes that the parents told in their interviews. The documents also offered a source of triangulation with the parents’ recollections of interactions with various professionals.

The final step of data analysis comprised member-checking with the participants. Both parents received a copy of the results section below and confirmed that their opinions and intended meanings had been represented accurately in the data below. A few minor changes that they suggested were made, and both parents gave consent to have their information, as presented below, to be published in this thesis.
Chapter 4: Results

4.1 Overview

Results of the current study are presented below in two sections. The first section is organized chronologically as a narrative account of the parents’ experiences. Direct quotes from the parents form the foundation of this narrative in order to adhere to the format of qualitative description in which data is presented clearly and without embellishment. Omission of content in direct quotes, as noted by ellipses, consist of the researcher’s back-channeling and the participants’ revisions, false starts, hesitations and interjections such as “um” and “ah.” Occasionally more substantial content is omitted, for example in the case of long digressions, and this is noted in the line numbers recorded after the quote. These omissions serve to make the quotes more understandable to the reader while attempting to keep the meaning and message of the content the same. Throughout the story, some interpretative statements are included to draw the reader’s attention to themes and moments of importance that emerge from the quotes. The second section is a discussion of themes that emerge from the two interviews.

4.2 The Story of Ellie’s Parents in Response to her Hearing Loss

4.2.1 Introduction

The following is the story of the participants, Kate and Geoff, in relation to their daughter Ellie’s hearing loss. It is told at times from a number of perspectives including individual perspectives, their joint perspective, from the perspective of medical professionals as gleaned from medical documentation, and from the perspective of the researcher. Exactly whose perspective is being depicted at each point in the storytelling is made explicit.
4.2.2 Initial Suspicions of Hearing Loss to Diagnosis

When Ellie was quite young, just a few months old, both parents describe that she kept her head to one side. When they brought her to a doctor, she was diagnosed with torticollis, which is an in utero condition where the neck muscles on one side are longer than the other. To correct this, they began some physiotherapy for their baby. Kate described how not long afterwards, when Ellie was about five months old, she was going through a monthly checklist of development, and when she came to the item “Startles at sound” she realized that Ellie did not do it. Thus she began to wonder at Ellie’s ability to hear and informed Geoff of her suspicion that Ellie may be deaf in one ear. Geoff remembered that their first inkling of something potentially being wrong with Ellie’s hearing was that she did not seem to be responding to her name. Both recall that they did their own home experiment together, popping a paper bag behind Ellie’s head while she was distracted. Kate remembers her seeming to respond a little bit, but Geoff remembers there being no response. In any case, Geoff recalls that they visited a family physician who hit a metal cup with a hammer on both sides of Ellie’s head and confirmed their suspicions that there seemed to be a problem. The next step in a diagnosis of hearing loss is to estimate the child’s hearing thresholds using the auditory brainstem response, so both parents described how Kate brought Ellie in for auditory brainstem response testing, but it was unsuccessful as Ellie would not go to sleep. The second auditory brainstem response appointment, Kate describes as a disaster because Ellie was initially sleeping, but woke up when the electrodes were being attached. Geoff explains that after this (See Appendix for Transcription Conventions),

“There was a, quite a discussion about tranquilizing her, or sedating her in some form…and there seemed to be some sort of confusion as to, how much sedation was
actually required…and, different people had different ideas, without actually consulting with each other. So…it took a long time for the tests to actually be done.”

(IG: 177-181).

He reports experiencing a lot of uncertainty and frustration at this time, saying that

“It took us, probably three months for the ABR (auditory brainstem response), because every time we made an appointment and got in there, it would not work. And then it’d be like another, you know four weeks ‘til the next appointment was available, right? And so, you know, when you’ve got like a seven month old baby, a month is a long time, you wanna do it now…You know, like “Look, give her the shot, let’s get her to sleep, let’s do this, like come on come on come on.”

(IG: 915-921)

According to Ellie’s medical record, she was nine months old by the time the sedated auditory brainstem response was conducted and the initial results were available. Geoff recalls that she was nine or ten months before they received the auditory brainstem response results, but Kate remembers it taking until Ellie was eleven months old. This discrepancy in time simply highlights the fact that for this family, waiting for a concrete diagnosis of their baby’s hearing status felt like a very long time. The audiologist’s report of the initial sedated auditory brainstem response testing tentatively diagnosed Ellie as having moderate-to-severe hearing loss. To confirm these findings, according to the medical record, behavioral audiometry testing was conducted a week later. Both parents attended this session and Kate reported:

“Well then my husband and I went and…we thought she heard something that time. And the audiologist just looked and she just went “Nooooo {shakes head slowly back and forth}”’. And just moved her head from side to side. So that was it.”

(IK:48-52)
The medical record from this time documents that Ellie was officially diagnosed with severe-to-profound hearing loss after the behavioral audiometry testing. This was a clear turning point in the stories told by Geoff and Kate as it finally solidified the level of Ellie’s hearing loss and set into motion a new phase of coping with and learning to raise a deaf child. In summary of this time period, Geoff recounts that after conducting their home testing of Ellie’s hearing and realizing that there might be a problem:

“…we worked our way up through the chain of doctors, and uh, service providers to find out that she was, possibly deaf, actually hard-of-hearing, and then extremely and absolutely deaf…it’s like each step along the way, was sort of, another level of bad news. It seemed like.”

(IG: 12-15)

The above quote illustrates a theme that emerged from both of the transcripts—the theme of increasing despair as every step towards diagnosis and every interaction with professionals simply resulted in another level of bad news. Kate expressed:

“It’s as my husband said it, he said it just never got better. It just kept getting worse. [{laughs} and]…it was just like, every time we’d go see somebody, it would get worse. It would get worse and worse and worse.”

(IK: 59-62)

The above paragraphs have described the experiences of these parents from the time they noticed something was wrong with their baby, to the time she was diagnosed with severe-to-profound hearing loss. The process lasted approximately four to six months and was a time of increasing frustration, uncertainty and despair. As the researcher listening to their stories, I was able to experience the depth of emotion that these memories invoked in both Kate and Geoff. The uncertainty of not knowing Ellie’s true condition and the frustration of failed
appointments contributed to the stressfulness and difficulty of these months for their family. The following section details the months following her diagnosis.

4.2.3 Service Providers and Cochlear Implant Candidacy

After the assessment in which Ellie was diagnosed as having profound hearing loss, Kate recounts, “So that was it. “Here’s your pamphlet.” [laughs] so we had our pamphlet” (IK: 52). The pamphlet she is referring to here is one that describes the three service providers available in this area for children with hearing loss. One specifically provides auditory-oral therapy to children with hearing aids or to children with working cochlear implants (Rod Bay Auditory Oral School); the second is on the other end of the spectrum from auditory-oral therapy, providing children with sign language instruction and an introduction to the Deaf community (Deaf Kids Resource Centre); the third attempts to be middle-of-the-road, teaching some sign language, but tending to focus more on auditory-oral therapy (Maple Lake Therapy). Again, being given the pamphlet represented the turning point from possibly having a deaf child to definitely having a deaf child and the options of what to do now.

Kate and Geoff decided to start out middle-of-the-road with Maple Lake Therapy and began to take sign language classes. Kate remembered that “we kind of talked things through…and then we, I can’t remember how we find out first information about cochlear implants, but that was, that was the next big thing, right?” (IK: 52-54). Geoff also recounted that “once we knew she was profoundly deaf, we pretty much were committed to an implant… I didn’t want her being the last deaf person out there…” (IG: 229-231).

Once a family has decided to pursue cochlear implantation for their child, implant candidacy criteria necessitates that their child has a CT scan and an MRI in order to ensure
the presence of an inner ear that can accommodate the device (British Columbia Children’s Hospital, 2010). Ellie’s imaging results proved to be devastating for this family. Regarding this experience, Geoff joked:

“Um, and ah, once they got the results to that we were invited to consult. And ah, as a joke I tell people, any doctor’s appointment begins, that begins with “This is what a normal something or other looks like…” is probably not going to go well.”

(IG: 20-22)

Kate further described:

“We got the call to, a call to go see Dr. Chang. And we thought, oh, he’s just going to talk about the surgery…Well he sits us down, and my husband will fill you in on this and you’ll really need a box of Kleenex then. And um, he says ok, “This is what a normal cochlea looks like. [crying] and this is your daughter’s]. At that point, Geoff got up and left the room. [laughs] Cuz he was like, he just lost it completely.”

(IK: 63-69)

According to both parents, this was their lowest point since they first began to investigate Ellie’s hearing. It is important to note that Kate punctuated this quote with laughter despite the fact that she was describing a very dark moment for both her and Geoff. Throughout the entirety of Kate’s story, laughter emerged as an important marker of her troubles-telling. Jefferson (1984) writes that in an environment of troubles-talk, which is when an individual talks about personal trials to another, there are two orderings of laughter: one is where the teller laughs and the recipient does not laugh, responding seriously instead; the other is where the teller laughs and the recipient laughs also. She purports that when a troubles-teller laughs in the course of troubles-telling, he or she is showing a resistance to the troubles, that he or she is in a position to take it lightly. A troubles-recipient who is “properly aligned” with the storyteller, doesn’t treat the laughter as an occasion to join in, but instead
exhibits receptiveness to the trouble and responds to the seriousness of the matter (Jefferson, 1984). Jefferson’s description of laughter during troubles-telling fits the pattern of laughter that we see in Kate’s storytelling. Often her laughter marks events or times of particular difficulty, but the fact that she punctuates them with laughter shows that at the time of the telling, she is in a position to take these past troubles in a light-hearted manner. In other words, she is showing resilience in the face of past troubles, that she has moved on and they no longer hold the same grip on her that they did at the moment they occurred.

In Ellie’s medical record, the radiologist reported that Ellie has a common cavity of the inner ear on both sides, meaning there are no discernible cochleae, nor semicircular canals, which are the organs of balance. Furthermore, in Ellie’s case, there is no identifiable cochlear nerve or vestibular nerve on the left side, and on the other side, what looked to be the cochlear nerve was visualized, but the vestibular nerve was again absent. When shown the pictures of a normal inner ear and Ellie’s inner ear, Kate remembered that it looked like a hole. She recalled “I think that was the lowest point, was just to find out that she was broken, broken…and I think…irretrievably broken” (IK: 1175-1180). Similarly, Geoff relayed the following:

“Um, I think the worst thing was the ah, common cavity, and the wispy nerves, because, all of the information we had about cochlear implants basically resolved, revolved around an inner ear being available, a cochlea being available…so we had been, I shouldn’t say denial, but we had been basically holding out a lot of hope for the implant. We saw that as our…salvation I guess. And we, until, essentially that moment, um, there was… an ongoing belief that technology would save us, that our beautiful little girl wasn’t actually going to be deaf. {long pause} I think that was a major blow.”

(IG: 211-216)
Again later on in the interview he responded:

“Um, I think my own particular lowest point was ah, after the MRI…issue, um, I actually, took her, I took Ellie with me and left the room. I was quite upset and I basically had a good cry out in the hallway.”

(IG:728-731)

This depicted another clear turning point in their story; since the diagnosis of Ellie’s hearing loss, a cochlear implant had been the best option to provide Ellie with access to sound. With the further diagnosis of abnormal inner ears, Kate and Geoff were shifted into yet another phase of deciding what to do given Ellie’s inner ear situation. After their initial shock at seeing the images of Ellie’s inner ear or lack thereof, both parents remembered that Dr. Chang informed them that he would still do the implant. Geoff recalled as follows:

“When they informed us of the common cavity and the um, actual, reduced number of nerves, not actually the wispy nerve situation, it was um, quite distressing. Um, the doctor said that…he had minor experience with the um, common cavity issue. Ah, and he said there was essentially a fifty fifty chance that it would work. Um, so we decided to go with it. And um, until, it, I’m not sure if it was at that time or later that we discovered the wispy nerves.”

(IG: 24-28)

Later on in the telling, Geoff referred again to this time saying:

“So then through that we were talking about the cochlear implant and uh, the MRI and the CT Scan, and…then they came back, and uh, not only was she, you know, completely without inner ears, um she was also missing two actual nerves on one side of her face, head, and one on the other. So, it was, even, you know, like I say, just every new discovery was something worse. So um, I mean, fifty fifty odds is essentially that it will work or it won’t work. Yes no. Right? So, proceeding on that, we’d decided to go for the cochlear implant cuz it was pretty much already in the
Both parents teared up when telling this part of the story. The rawness of that moment in Dr. Chang’s office was so vivid that even each parent telling the story to me over three years later was enough to bring back the emotions they felt at that point in time. I myself, listening to each of their depiction of this appointment, could not help my tears from welling up also just from experiencing some of the emotional impact that this new information had on each of them.

The previously depicted portion of this story described the process of choosing a service provider and determining cochlear implant candidacy. Following on that, the next section depicts the time period of the actual implantation and the months of follow-up appointments and therapy.

4.2.4 Cochlear Implantation, Further Frustration

According to Ellie’s health record, she was a year and a half old when she underwent cochlear implant surgery. Four weeks later the implant was activated for the first time. The surgeon had inserted twenty-two electrodes into the common cavity and the audiologist was able to identify some neural responses to eleven out of the twenty-two. Regarding the time of implantation, activation and follow-up, Kate stated:

“And uh, and then, she had the surgery, and then like things looked good sort of in the booth, like oh, well there’s some response and there’s this response and that response. And there’s um eleven out of twenty-two electrodes were showing some response…Um, but she never seemed to respond to sound. She never responded to sound.”

(IK: 84-89)
Further to the above quote, Geoff related that after implantation:

“It was um, became apparent that the implant was not performing up to expectations. Um, we have been back and forth to the ah, audiologist, a number of times, and it took a long time for the cochlear implant to actually indicate that it was working, like through his testing… at the same time, there didn’t seem to be any noticeable effect on her. So, after a drawn out series of conversations, in which they continued to say that it appeared to be working, while we were saying that it doesn’t seem to be showing any effect, we essentially came to the agreement that it works intermittently, which is not a great situation for a communication system.”

(IG: 29-35)

In contrast with Geoff’s quote above, the audiologist reports in Ellie’s health record do not explicitly state that the implant took longer than normal to indicate that it was working. Furthermore, there does not seem to be any documentation of Geoff’s conclusion that the implant worked intermittently. It appears that there is some discrepancy between the professional’s understanding of “not working” and what the parents meant by “not working.” It is plausible that when the medical professionals insisted that the implant was working, they meant that the actual equipment of the CI appeared to be functioning. In contrast, when Ellie’s parents say “not working,” they may have meant that it was not having an effect on Ellie, or rather that it did not appear to be providing her with a discernible auditory signal. To identify specifically what each person meant at each moment in time by “not working” is merely speculation; however, the potential discrepancy is important to note as there are a number of different interpretations that could influence the intended meaning behind these individual perspectives.

In the months following implantation, there are numerous audiologist reports in Ellie’s health record that describe each mapping session post-implant. Mapping is a term
used to describe the process of digitally programming the cochlear implant. In a mapping session, the audiologist turns on each electrode individually and increases or decreases the electrical current to find the patient’s most comfortable listening levels and the level at which one can only just hear a sound (Sislian, 2008). A cochlear implant user needs to have their MAPs frequently updated as they adapt to the old MAP and as tissue growth changes the amount of electrical stimulation needed (Sislian, 2008). According to Ellie’s audiologist reports, turning up the current on certain electrodes sometimes resulted in facial nerve stimulation as evidenced by the involuntary twitching of her facial muscles. This indicated the current levels were too high. One time, Ellie was noted in the report to take the implant off while playing with a noisy toy, possibly indicating discomfort from the stimulation level; however, she was not reported to participate in the session to the extent of responding when she heard a sound through the implant.

Although the audiologist reports indicate that there is some neural activity in response to the electrical stimulation through the implant, Geoff and Kate both expressed that they were not noticing any effect of the implant on Ellie at this time. Subsequently, Kate reported that after implant activation:

“I think we sort of kept trying, and at this point, I really started to hate Maple Lake Therapy {laughs}. Because, um, it was, we were supposed to take her out on hearing walks and say “Oh, do you hear that?” and do sound practice with her and it was kinda like…it’d sorta take on a surreal quality? Like if you really wish and hope hard enough and click your heels three times! {laughs}. [{laughing} There’s no place like hearing, you know?]. And I just, and I just thought like, well she doesn’t hear. And it started to get, as I said, it it wasn’t frustrating as much as it was surreal. You know, like, if it’s not there, it’s not there.”

(IK: 89-100)
Again, the moments of laughter in this quote are meaningful and served to influence what I heard as the intended meaning behind her words. Although Kate used the harsh notion of hatred in regards to Maple Lake Therapy, her laughter directly afterwards toned down her words so that I interpreted her words to be more of irritation with or disappointment towards the service provision than an actual hatred of the therapists there. Kate remembered voicing her doubts about Ellie’s hearing to the audiologist, but she recalled that he kept being hopeful and would not conclude definitively that the implant did not work. Again there emerges the potential discrepancy between what each party might mean by “not working” in regards to Ellie’s implant. It was at this point in time that Kate remembered beginning to search for information about Ellie’s condition in regards to cochlear implantation, stating:

“Um, and ah, you know and at that point I started to really really research. And there’s nothing out there, as you know. There’s no information. And I was, I joined, um I tried a Facebook group, I set one up, and nobody joined. I set up a group in in the cochlear, the um, Cochlear Americas um had a has a posting page. But um, and I just never went back … Um, then, um so there was no information available.”

(IK: 105-117).

Despite the lack of information, Kate recalled reading a book called “The Brain that Changes Itself\(^3\),” which she found very interesting. In light of what she read, she consulted with a doctor in the United States, recalling the following:

“So I looked up some names and I and I talked to the doctor, a doctor down in the states who recommended implanting the other side. And he recommended we talk to a doctor in Toronto. So I left a phone message with him. And then he, I wasn’t home when he called, but he talked to Geoff and Geoff said that {sniff} I gather he lost it [{laughs} on the phone]. And and was quite upset and the doctor in Canada said, you

know, no. There’s nothing you can do. And then the doctor in Toronto made a social worker [{laughs} call Geoff to make sure he was ok].”

(IK: 120-127).

In the examples of laughter in the above quote, the researcher did not respond with laughter in kind, responding instead according to the gravity of the event depicted in Kate’s words. According to Jefferson (1984), this would indicate a recipient that is properly aligned with the troubles-teller, who recognized that laughter signaled a moment of troubles-telling rather than a moment of humor.

Geoff also talked about the experience of consulting a doctor in the United States, but he remembered it pertaining to the potential option of an auditory brainstem implant, saying:

“Myself I, continued to ah, sorta hold out hope for a, brainstem implant or the possibility of it. We ended up consulting an American doctor, um, a phone interview, and then sort of a second opinion was a Canadian doctor who was an associate of his, or, you know, somebody who knew, who explained to us that um, the two different philosophies between medicine in Canada and the United states is that, in Canada “Will it work?” and in the United States “Do you have money to pay for it?” And ah, so again, that was another, I think a particular um, blow to me. And ah, sort of the explanation that um, brainstem implants were not being done on children in Canada anymore and that it could be done in Italy, there was a particular doctor who was doing them in Italy, but I mean it, it was, just very much guinea pigging on children which I was not willing to do.”

(IG: 217-226)

After it became apparent that the implant was not having the desired effect of providing a consistent speech signal to Ellie, and after consulting with the doctor in the USA and in Toronto about other potential solutions, Kate recalled a conversation where she and her husband inquired about another solution:
“Um, and at that point, I mean, we’re we’re big we’re big technology people…And we both read science fiction and and uh, and we um, um, I said, “Look, they implant, they can transplant faces now, cadaver?” {laughs}. And uh, and Jared, or Chang, I can’t remember who told us said “No, ah when they touch the bones of the ear, poof! They just they just dissolve.” So that wasn’t an option.”

(IK: 129-136)

Listening to their stories, it became clear that this family was willing to try anything to provide their little girl with a chance at hearing; anything reasonable, that is, that would not put her at unnecessary risk or be nothing more than experimenting on her. As these potential options or hopes for hearing continued to be dashed—first the cochlear implant, then the suggestion of a second implant, then an auditory brainstem implant, and then their idea of an inner ear transplant—it appeared that slowly they were forced to accept that Ellie was a deaf girl, at least for the foreseeable future before more technology became available, or until Ellie herself decided to try more surgeries at a later age.

Kate describes how after exhausting all the options and realizing that none were workable for their daughter at this time, other people continued to suggest other ideas to her. She recalled the frustration of this, saying:

“I think I think my big issues are, in dealing with family and stuff, um, you know how everybody everybody’s an expert?...Um people go, “well what about their growing cells? And they’re doing this and they’re doing that.” And I and I usually say, “Well no… we’ve done our research, and and no, there there is nothing, you know…this is our lives.” And then…they’ll keep at it. They’ll keep at me about it because people wanna hope right? And that at that point I go, “Look, you know, we’re waiting for the aliens to come with their superior technology because that’s the only thing that’s going to give her hearing, ok?” And eventually I came to my line, which is that, you know, there’s a point, there’s a point when hope becomes denial. Because you are
hoping so much, you’re denying who she is and how her life is and and how it will continue.”

(K: 163-179)

Kate’s line of hope becoming denial emerged as an important theme throughout her interview as a phrase that encapsulated her journey of acceptance of Ellie’s deafness. It was apparent from Kate’s story how she and Geoff had put their hope in the options that may have provided Ellie with the ability to hear. When it became clear that the implant did not work, and the other ideas proved to be unrealistic, Kate realized that all the hoping for something else, the striving after hearing, was actually keeping her in a state of denial of Ellie’s real condition, which she took to be profound deafness in spite of the CI. Kate eventually concluded that Ellie’s implant does not provide her with any distinguishable sound. This view, however, is not necessarily the opinion of Geoff or of the audiologist.

Both Geoff and Kate expressed in the interviews how they experienced much anxiety during the time after implantation and how it was a very difficult period for them. A particular worrisome topic for Geoff, as mentioned a number of times throughout his interview, is expressed in the following quote:

“My own thought was, that I was very nervous about Ellie being like the last deaf person in the room. Um, as every other deaf person out there got a cochlear implant and it functions. Um, I’m still trying not to think about that, a lot.”

(IG: 135-137).

He further explained this fear by relating the following:

“Um, as I said before, I didn’t want her being the last, deaf person out there because we, ah, apparently Deaf culture has, there’s a lot of factions within it. And, for a long time the Deaf community was was very much against the implants. And, there was a, documentary of, of, a deaf family and one of the children ah, getting an implant. And
everyone was against it, and yet at the end of the film there was a post-script that said essentially, that they did get the implant and that in the ten years since then, a lot of the people that were against the implant have had them, as well. And…it’s one thing if it’s not uncommon, if there is a society available. I don’t want my child to be completely isolated by a particular disability that is really, not apparent.”

(IG: 230-238)

In looking at this quote, it seems that Geoff is looking ahead into the future, and thinking of the possibility that the Deaf community will cease to exist or will shrink incredibly as the majority of children born deaf and deaf adults receive CIs and subsequently enter the hearing world as opposed to the Deaf community. For Ellie, this would mean a future with a very small community, or even the absence of such a community, because her implant does not provide her access to the hearing world. The root of this worry seems to be a fear that Ellie will be alone, without a strong community support system of others like her.

One of Kate’s major worries was in terms of what she loved to do with their first child. She stated:

“I talk to Maddy all the time, and I tell her everything, and I let her watch movies and then I explain them, and ah, we have lengthy lengthy discussions and, and I worry that I can’t do that with Ellie. That was the, I think the hardest thing, was that, I read to Madison. I used to sit Maddy in the chair and I’d do a personal story time for her for thirty minutes every [{laughing} day]…And not being able to share that, and I I made up songs for Maddy, like with her name in the lyrics and stuff. You know, like the Oscar Meyer Wiener song and you know. And to not have that with Ellie, that was just crushing.”

(IK: 502-518)

Another fear that Kate felt was that of not being able to communicate danger to Ellie adequately. She explained:
“It’s a lot easier to ah, to hold the door open to the poison cupboard and go
[(pretending to shout] “THIS STUFF WILL KILL YOU!”] {laughs} to a hearing child…Um, than it is with a deaf child, you know, “This bad, make sick, sick you, bad, you sick, you no move, bad.” [ {laughs} you know, like] you know, which is more effective right? So that’s that’s a worry.”

(IK: 539-547)

Although both parents expressed that the period of time post-implantation was a very difficult one, both Kate and Geoff remembered a particular meeting with a social worker that was a high point for them in a very low time. Geoff described it as follows, beginning with a description of the stress and uncertainty of the time:

“We were having a lot of stress, and um, because as I say, when you have disabled children you, you don’t know where things are going, you don’t know what’s expected of you…we’re sitting there thinking, well this is our little girl, and like what are what are we supposed to do? What are we going to do?...And, I mean, it is such a broad based question but it actually is a very broad based situation. Where are we going to send her to school? Who will her friends be? What will she do when she grows up? What kinds of activities are available for her or not available for her because of her handicap? And you, just like this whole giant vast unknown of what are we going to do? …And…the lady who we talked to…she basically painted in some very broad strokes that gave us a little bit of perspective on, what we could do and what she would do. Um, and instead of sort of like floating in the middle of an ocean, we were floating just off the coast or just off the beach or something, you know, we were within reach of help and some ideas of what was going to happen.”

(IG: 419-440)

Geoff’s use of metaphor in this quote to express his thoughts and experiences is quite powerful. The future for him was so unknown that he felt they were floating in the middle of an ocean without any concept of where they were or land in any direction. The most helpful
thing for them at this point was for someone to come in and give them an idea of the future and what their role would be. Throughout the storytelling, both Geoff and Kate use such metaphors to explain their experiences in an in-depth, understandable manner. Kate also recalled that:

“I think one of the most useful pieces of information I got was from the social worker when we all sat down, {sniff} who said “Ah, she’ll text you.” {laughs}. That was actually probably one of the best things I heard.”

(IK: 547-549)

Expanding on this encounter, Geoff remembered:

“We were essentially thinking to ourselves that we are, having to teach our child to speak a language that we don’t actually know yet. And uh, that was very uh, there was a lot of anxiety involved. And, she explained to us that we had the idea reversed. We would probably not be teaching Ellie very much; she would be teaching us a great deal. And she also pointed out that a lot of the uh current technology, common current technology, like texting and email and such, is um, every much suited to Ellie.”

(IG: 51-57)

Both parents expressed in their separate interviews, that this meeting with the social worker served to relieve a lot of anxiety that they had been experiencing regarding Ellie’s and their future. “For a very long time,” Geoff remembered, “it was just one negative thing after another. And then all of a sudden here was this woman saying that you know, it’s not that bad, you will be able to deal with it, she is going to help you” (IG: 649-651). When each parent was asked whether there were any high points in their story when they look back, this was the first high point both of them mentioned and one that made a difference to each of them.
4.2.5 Moving Forwards and Looking Back

Another episode that Kate recalled as being important to my understanding of her story was a meeting with Dr. Chang. This meeting was also a turning point for the family and perhaps even the beginning of Kate’s understanding of Ellie as a Deaf person. She described:

“So the last time we went to see Chang was last September and he said, very very matter of factly which kind of blew me away…And um, Chang goes, “and the implant doesn’t work so we’re not doing that. And just keep up with your signing and she’ll be fine.” Which was kind of, “Thanks!” {laughs}. Don’t get me wrong, we love Dr. Chang…Um, but it was it was kind of nice to to have sort of a definitive. So at that point we we left Maple Lake Therapy, because obviously we had to make a decision and Geoff had originally wanted to integrate Ell into school and, I said no, that um…ok no, she’s gotta go to the deaf school. She’s gotta be with her peers.” (IK: 136-148, 155).

Also in regards to service provision, Geoff stated:

“Deaf Kids Resource Center is more biased towards deafness…Um, teaching them to, teaching them sign language is a foundation of, of language. Um, you are, you literally give them language and otherwise you know what are they gonna do? They’re just standing around waiting for these other things to happen right? And essentially, once we, you know, came to accept that Ell was deaf and was not going to change, that she was like, completely deaf. Um, and then it became, you know, Maple Lake Therapy was like, not in the position to provide what we needed. (IG: 783-790)

After the meeting with Dr. Chang, Kate described that she and Geoff made the official switch from their original service provider to Deaf Kids Resource Centre, believing that they were more in a position to meet their and Ellie’s needs. According to publically available information on the three service providers available in the area, Deaf Kids Resource Centre offers a preschool five mornings a week during the school year, in addition to speech-and-
language therapy, sign language instruction, and other related programs for children with hearing loss. The preschool is primarily available for children with hearing loss, but if space allows, they will also include siblings of deaf children, and children of deaf adults. Most children at the preschool are between the ages of three and five, but depending on their date of birth, some may be a bit younger or a bit older. Regarding Ellie’s entry to Deaf Kids Resource Centre preschool, Geoff remembered:

“She was only two and a half when she started the preschool which I thought was quite young, um before actually going and sitting in the class one day, with her. And it turns out, deaf children are very well behaved…I was very impressed with that.”

(IG: 109-111)

He continued to say, correcting Ellie’s age of preschool entry by a few months, that:

“Um, so it was like two and three quarters I guess, but, very early by my thinking to you know, start her in this thing, but her mom wanted her to…have society, to have ah social interactions and it did work out quite well. And ah, it was not very long before I was like, completely reversed my thinking.”

(IG: 550-556)

The period of time described above, from when Ellie was implanted at age eighteen months, through the follow-up therapy and questioning of the implant, to three months after she began attending preschool is a time that Kate described as complete darkness and despair. She stated:

“IT started out with despair. Despair at at, 18 months, and then like I said, like Geoff said, it just kept going down down down down down down. Then it started, a little bit of a glimmer of of signing, and her getting a little bit, little bit, little bit. And then she started school. And then like three months of school and then Boom! She’s off.”

(IK: 1373-1378)

When asked what helped her to walk out of this despair, she answered the following:
“You know what, putting her in the school, in the, in school at Deaf Kids. And then she could do, you know, she could do and she could communicate and no matter what I could teach her at home, I mean I just didn’t have the skill and the and the capability. When she was out in the world and she was like, struttin her stuff and doing her thing, and then and now, she’s she’s just, you know/pccwww/ {taking off motion}.”

(IK: 1340-1347)

Looking back on this time of despair and then preschool entry from where she was at the time of the interview, Kate reflected:

“It’s…like wading through a black black river of despair. And then now it’s just once in awhile, stars wink out…but, you know, to go from that complete and total utter darkness to just occasionally brown outs, {laughs} You know…I wish I had known, that it wouldn’t be that bad.”

(IK: 1303-1312)

4.2.6 Preschool and Beyond

Ellie began preschool at the age of two and three quarters. Regarding her experience at the preschool, Geoff responded:

“The whole social aspect of it has been really positive because, she is a little kid, she does wanna make friends, she does wanna play with people. And when we go to the park, um, she will stand there trying to convince the other kids to notice her and play with her. And, again, it’s like the vast majority of people don’t speak sign language so she has to find some way to allow them to communicate with her. To communicate with them right. Um, and as a very little girl without the ability to lipread, she um, she’s somewhat excluded, is no isolated. She’s somewhat isolated. You know there’s only so many other um extremely small children that ah, um, speak sign language and if they don’t happen to be in your neighborhood then you have to figure out a way to, you have to figure out a way to find them for one and connect with them for another.
And that’s what the preschool has provided.”
(IG: 558-570)

Further to that, he described a benefit of the preschool to himself, saying:

“You meet deaf adults as a result of you know, um, and they’re married they have children they have ah, jobs, mortgages, all the you know, I guess hallmarks of a of a participating citizen in our society. And ah, you know basically they show you that those things are available to your child too.”
(IG: 799-801)

Geoff described that early on in the story of Ellie’s deafness, a huge source of anxiety was simply not knowing what would become of her in the future. At the time of the interview, however, he stated:

“I remain quite, positive and hopeful for the future, for Ellie’s future. She is very energetic, she’s very outgoing and uh, she is pretty damn smart. I’m constantly amazed at just, you know, how smart she is. And she is very social, very positively social. She has very little, she makes friends very easily. She’s quite cute, and people respond to that. And she’s also very outgoing.”
(IG: 59-62)

Kate also expressed her confidence in Ellie’s future saying, “So, I don’t think she’s going to have any problems {laughs}” (IK: 447). Further to that, she described Ellie’s life currently, stating:

“She has special powers. She charms people. You know, she works as a volunteer at an old folks home on Fridays, and you know, they they make her, they make her presents…she’s well loved. She’s a very popular child…People will like, they’re attracted to her so they’ll talk to her and I’ll and I’ll usually have to say like “Uhh, she can’t hear you. She’s deaf.” And…sometimes they’ll go “Oh! Oh my God I’m so sorry.” And I’m like “Pff, don’t be. [{laughs} you know]. Feel sorry for yourself because, man she’s happy. She’s spoiled rotten, super popular, you know, loves life,
has everything she’d ever hope and want. And uh, really, there’s nothing to be sorry for.”

(IK: 343-351)

When asked about some of the high points along the way, both Geoff and Kate mentioned the helpful meeting with the social worker. In addition to that, they both noted that the other high points were little things, little moments that meant a lot. Geoff described, “I think that the ah, the high points are smaller, but there’s more of them” (IG: 733). He goes on to tell a vignette in which Ellie had a bike with training wheels for a long time but did not have any interest in riding it, preferring her tricycle. When he brought the bike to the bicycle shop to get tuned up, however, and Ellie came with him to pick it up, she was suddenly interested in it. He recalled that she rode it from the bicycle shop to the park, and then around a monument in the park dozens of times, and then rode the bike home, and then up and down the lane, and then she finally went to bed and was asleep before her head hit the pillow. Geoff reflected on this, stating:

“You know, you wouldn’t think it associates with ah, with her deafness, but again, it’s like one of those things is that, she’s a child, she’s making these different way points, and um, each time she does it is a, is another victory. You know another, another high I suppose.”

(IG: 750-754)

Kate recalled that one particular high for her was watching the promotional video for Deaf Kids Resource Centre where Ellie is featured as a very cute little signer. Other highs for Kate were “little things along the way, like little little communication things that just have, like ah, that have blown me away… And just some of the leaps of logic that she’s made” (IK: 1187-1190). She recalled a particular high point was a recent story that both Kate and Geoff
mentioned in which Ellie saw a man with a missing finger. Immediately she turned to her mom and signed “Phone girl.” Confused for a moment, Kate eventually realized that she was asking her mom to look on her iPhone, which has an American Sign Language dictionary application where a girl will demonstrate on the screen how to sign particular words. Ellie had realized there must be a word for “missing a finger” and so they looked up the word “amputated,” providing her with the vocabulary item that she wanted.

Another astounding thing about Ellie that both Geoff and Kate recalled with pride and amazement is the fact that she has recently been teaching herself to lipread and speak. Geoff expressed:

“We joke that Ellie is deaf so that she won’t take over the world and to allow the rest of us to keep up. Um, through, I mean she’s four and a half, she is teaching herself to lipread and speak.”

(IG: 40-43)

Kate further described:

“But, she’s taught herself to speak as I said. She says, um, I should write it down, she says “purple, open, finished, broken, (a name that resembles the name of her older sister), um, I want dat, um fall” mostly plosives, plosives and fricatives. She’s not good with, um like /m/ and /n/. Um, but a lot of words. And uh, “all finished” and “all.” And sometimes I’ll I’ll say, you know, “use your voice.” And I can tell her, I’ll say I’ll say “say goodbye” and she’ll go “bubhuh.” And I’ll say, “No use your voice,” and she’ll go “Bye bye!””

(IK: 640-650)

From the attitudes of both parents when relating their current thoughts about Ellie and in the positive stories that they tell about her, I can see how much their expectations of the future have changed over time. Kate describes a year and a half long period after cochlear
implantation where they were walking through a “black black river of despair.” Currently, however, they are upbeat and positive about Ellie’s future and proud of who she is, her level of intelligence, and her progress with sign language, lipreading and speaking. Kate acknowledged her acceptance of Ellie’s deafness as part of who she is, and even professed to have made a “cultural shift” herself, from the hearing world to the Deaf world (IK: 380) in order to accommodate her daughter. Regarding Ellie’s cochlear implant use currently, she confessed:

“Now, I I have to say I’m not, don’t tell Jared this, I’m not very responsible about putting her implant on her. In fact, it’s in my purse right now, not on her head. Um, she wears it at school. On the weekends, sometimes we remember but mostly it’s it’s something to worry about, like what if it gets lost? What if it gets wrecked? What if it gets wet? So we don't always put it on her because, mm she’s fairly active, she’s very active.”

(IK: 305-311)

Further to that in terms of Ellie’s hearing, she expressed:

“So I guess, you know, like well we’ll see Chang again in in the fall and and we’ll see Jared and again and I, you know. And I guess at some point she’ll be able to tell us if she hears anything. She says she hears things but I think it’s her imagination or she feels things. We stomp on the floor to get her attention. Um, but every once in awhile she’ll say “Oh I heard that” and it’s never when she has the implant on. {laughs}. Whether that’s her version of hearing, or. She seems to understand as best she can the difference between hearing and deaf... so I guess, you know, we’ll see. It’ll be up to her if she wants to continue to wear it or not. I suspect she won’t.”

(IK: 858-878)

Regarding how Ellie is progressing with sign language, Geoff described:
“This very moment she’s at a quite a, I would almost say a breakthrough. Um, and as my wife described it, she’s learned about a year’s worth of language in two days at the camp. Um, I’m not so sure that she learned more language but she has become a lot more assertive with it…And um so she’s a lot more assertive in her signing and…she just signs a lot more. It’s like it’s not, she’s not tentative about it…other people have shown her that they can understand her language. It, just because mummy and daddy can’t, doesn’t necessarily mean that there’s an issue with her. So now she will just sign up a storm to us and we have really no idea what she’s saying. Except you know, maybe sorta get hints at what she’s saying…I’m sure she will get more frustrated later, but she’s not particularly frustrated now.”

(IG: 804-819)

Reflecting on her experiences with the preschool and sign language, Kate considered that simply giving parents a pamphlet with a summary of each service provider is not sufficient for parents trying to decide between options because the Deaf community is so foreign to most people. As a better approach, she proposed:

“They almost need to give you a tour. You know, these are the children that succeed at this. These are the children that succeed at this. Um, because to make that choice without that information, most people don't know Deaf people, you know.”

(IK: 750-755)

Further to that she suggested:

“They they could almost do a video, you know, or like or a DVD of of different people’s experiences. Like “Little Billy hears quite well with his implant. Here he is at the oral school” {laughs}. You know…Um, “Little Suzie did ok with the implant and she’s learning some sign language as a backup. And…little Ellie can’t hear diddly, so she’s learning sign, but look how well she’s doing with it!”

(IK: 1113-1117)
From these quotes, I gathered that Kate felt the majority of parents of deaf children are biased towards the non-Deaf service providers, simply because they are unfamiliar with any persons in that lifestyle or community. Sign language may appear foreign and daunting, and so is the unknown of how to communicate with deaf adults. From a piece of paper, “the pamphlet,” it is difficult to illustrate the benefits of sign language and the Deaf community. Kate therefore proposed that a video approach may be a more unbiased way to present the three options to parents of deaf children so that Deaf intervention and education is not be seen as a last resort, but as a good option that provides a foundation of language through American Sign Language, that incorporates social interaction with peers, and that actually complements and enhances the development of spoken language.

In conclusion, when asked what his best hopes for Ellie are, Geoff responded:

“Just a full and happy life. I think that ah, she is not particularly handicapped. You know, there are tools available to her and she is learning to use them. Right now, she is teaching herself to use them. Um, society will label her as handicapped but it’s not what people call you it’s what you answer to. And I think I hope that she will never feel limited by this. I hope that she will do what she wants in her life, I, and just enjoys it. You know, I essentially I I hope it doesn’t bring her pain.”

(IG: 949-953)

The above paragraphs have described the experiences of Ellie’s parents in relation to Ellie’s deafness from the time they first suspected something was wrong with her hearing, through the diagnostic process, through cochlear implant candidacy, implantation and follow-up, to her entry into deaf preschool and the subsequent couple of years until the time of the interview. Both parents explained situations, shared stories and described metaphors that helped to clarify their experiences, illustrate how they made sense of them, and reveal how
they coped with the realities of having a deaf child. This section has attempted to present their story in their own words, staying close to the surface level of their data by presenting it primarily in the form of quotes with little interpretation. The following section details themes that emerge from the interviews.

4.3 Themes Emerging from the Parents’ Stories

Throughout the interviews, a number of salient themes emerged, some of which were common to both parents and some that only appeared in the experiences of one or the other. These do not fit cleanly into the story chronology as they are threads woven through the entire storytelling as opposed to isolated events. The most prominent themes are detailed below.

4.3.1 Hope

The first element of the storytelling that was quite pervasive in both accounts was the idea of hope, and how hope appeared in different ways as the story progressed. First of all, hope emerged as a theme woven throughout the diagnostic process. It was apparent when Kate and Geoff popped a paper bag behind Ellie’s head and Kate remembered that she might have responded a little bit. Hope is again evident when Ellie is being tested with behavioral audiometry in the booth and Kate expressed that both she and Geoff thought she heard something that time. Once Ellie’s diagnosis of profound hearing loss was confirmed, hope was evident in the technological options that might save their child from deafness; first the cochlear implant, then perhaps another implant, an inner ear transplant, or even an auditory brainstem implant. At some point along the way, Kate seems to recognize that continuing to hope for Ellie’s hearing is actually denying the reality of her deafness. This realization resulted in the emergence of Kate’s “line” that “there comes a point where hope becomes
denial.” Interestingly, both parents identified a particular phrase about hope that they used to conceptualize their experiences. Kate’s understanding of hope becoming denial is illustrated below.

As mentioned briefly in the previous story section, one of the phrases that Kate used repeatedly to both make sense of her experiences and to explain her viewpoints to other people is that hope can become denial. She articulated the emotion of anger that she feels when she sees other parents of deaf children denying their child’s deafness, and only pursuing oral intervention without sign language. One such encounter is expounded below:

“Um, the hospital referred somebody to me...because their, I guess their child...was um, deemed to be in a similar situation to Ellie. And uh, the hospital had basically turned them down for an implant. So they flew to another country...and had binaural; they had two implants done. And I think they have their child in in oral school. You know, just this complete rejection of of Deaf culture...and to put your child through this for like, what, which which to me is a a forlorn hope...and I was really upset about it. I went to Ellie’s school and I I was telling, um, her head teacher. And I just started crying. And I said “I just feel so bad.” And the teacher said, “Well you know, I hate to do this Kate, but I have I have to confirm your your views on this because” she says “I will see that child. I will see that child in four or five years with no language, with no social skills, behind behind behind.” Because there’s so much hope, that it becomes denial.”

(IK: 210-228)

Related to this frustration, Kate used the following imagery to explain:

“People are so, people people are just, “Hearing at any cost”...And it reminds me of my brother...had had told me about, um, when he was a teenager he had a friend who had a dog. And he taught the dog to speak by manipulating its jaw. Wh, so the dog could sort of approximate a couple words in human speech, but I mean you gotta know, it must have been agony [{laughs} for that dog] for his his jaw to be wrenched
and and twisted and turned. And and that’s the image that comes to mind when people just really push that, “Speaking at any cost. Hearing at any cost.” You know, fly to Italy and have somebody drill into your kid’s brain.”

Expressing her views on the ideas of “hearing at any cost” and that there is a point when hope becomes denial suggests that Kate is now at a place of acceptance of Ellie’s deafness. Although initially she was willing to do whatever it takes to give Ellie hearing, she now has realized that learning sign language and integrating with Deaf culture is the appropriate place for Ellie to be. In talking about Ellie, she affirmed:

“Ell’s like all, a hundred percent girl. Um, but, um and but and, she’s just, she’s a Deaf person. You know, and she’s, she’s not less…Um, {sniffs} but um, but people do, people do push their kids to be, and you know, and like this implanting at any cost like that one family. Like why, why?”

In summary, Kate’s hope appeared to change from hoping that Ellie will hear, to simply hoping that Ellie will do well socially, academically and communicatively at the deaf preschool and beyond. It was quite clear to me from the interview that Kate has fully committed herself to Ellie’s deafness. Although others may have believed that the implant was still working or doing something good for Ellie, Kate preferred to fully accept Ellie’s deafness rather than allow herself to hope for hearing any longer. She did not want to be stuck in a fairy tale land, just wishing and hoping that things would happen (remember her metaphor of wishing and clicking your heels three times; “there’s no place like hearing!”). Rather, in her own experience, she tried the options, she researched diligently to find anything that would help Ellie, to “save” her from deafness; but in the end, it came down to the fact that Ell is deaf, that there is not anything currently available to help her to hear, and
that Kate has come to accept and appreciate the implications of this fact. Consequently, Kate is learning sign language, she has learned to feel comfortable around Deaf people, she has made a “cultural shift,” and in her own words, “it’s been nothing but rewards” (IK: 910).

This does not eliminate the fact that the day-to-day aspects of raising a disabled child can be difficult—she mentions numerous stories that illustrate this—but she is no longer holding out a false hope that Ellie will one day hear, and thus neglecting the language that Ellie can learn, the way that Ellie can communicate, and the community that Ellie can be a part of right of now.

In contrast to Kate’s quote of hope becoming denial, Geoff’s repeated quote about hope is “hope for the best, prepare for the worst.” This underlies his explanation of some of the choices that they made along the way and even seems to encompass his view of Ellie’s deafness overall. For example, he initially uses this phrase to shed light on why they began to take sign language lessons before Ellie’s cochlear implantation, even though they knew that they were intending to have her implanted. In this case, he was hoping the implant would work for her—the best case scenario—but in case it did not, he was preparing for the worst—that she continues to be profoundly deaf—by learning sign language. In other words, he prepared for the worst by learning sign, but he is hoping he will not have to use it. The next place that he talked about hoping for the best but preparing for the worst is in relation to Ellie’s future, stating: “I sometimes wonder about the future, but I also pretty much am waiting for it to happen, and trying not to…predispose myself to negativity” (IG: 47-49). He explains that sometimes in thinking about the future, we pre-position ourselves for something terrible to happen, which can in fact create our own reality. Furthermore, “if you start thinking ahead, as often as not you’ll imagine problems” (IG: 373). He continued:
“Once you’ve made your preparations for the worst, it’s important to get on with the living. And you know, not necessarily waiting for the worst thing to happen, but you know, you’re you have prepared for it. And as often as not, preparing for it will um, it it’s no longer a disaster.”

(IG: 374-377)

In the example above, hope appears as the best case scenario for the future. Geoff seems to be looking ahead and hoping that the future will bring the best it could possibly bring; nevertheless, he wants to be prepared for the worst case scenario in the event that his hopes are not realized.

Although it appears that Kate has shifted her hope from hearing to the Deaf community, it is less clear the degree of acceptance of Ellie’s deafness that Geoff feels or whether he continues to hope that something else will come along. Kate professed at one point that “I think my husband still holds that hope that it’ll work or something will work or something will come along” (IK: 336-337). Furthermore, Geoff also referred to his knowledge of current technology, including how biotechnology is advancing and how there is some science that says the scar tissue barrier could be passed or that nerves could be replaced (IG: 1009-1011). Additionally, he remarked that Ellie could have the brainstem implant if she wants to once she is twenty years old or so. Although this does not mean that he has not accepted Ellie’s deafness, the fact that he rarely mentions himself in relation to Deaf society suggests that he has not committed himself to the Deaf community in the same way as his wife has done. This is most likely related to parenting roles and work schedules; Geoff’s job is one that takes him out of town quite often and consequently he described how he misses sign language classes and has frequent chunks of time where he does not practice his signing with Ellie or anyone else. Furthermore, according to both him and Kate, he is
doing less well than his wife and daughters in sign language, and thus is not able to communicate with Ellie as well as he would like. In fact, Geoff often expressed how difficult it is for him to learn sign language and how frustrated he is with his slow progress. Additionally, he acknowledged that he does not have a particular aptitude for languages; the only thing that would help him advance quickly, hours of study, is simply not possible with his work schedule. Understandably then, it seems that Geoff has not given up on hoping for Ellie’s hearing; according to him, hoping for the best is acceptable as long as one also prepares for the worst. He himself appears to be preparing for the worst by learning sign as well as he can, but it does not negate his hope that she will one day hear and he will be able to talk to her.

During the process of member-checking where the participants were invited to comment on or change how their opinions were presented, Geoff described his surprise when he realized how he appeared to be less accepting of Ellie’s deafness. As we discussed this, it became apparent that Geoff’s hope in technology was not so much an issue of accepting Ellie’s’ deafness, but a reflection of his own fear of isolation, and his fear that Ellie will be isolated. Whereas Kate has come to accept the Deaf community and to see opportunities for Ellie within that society, Geoff still has some anxiety that she will be isolated, even within that community. Regardless of how well he accepts her condition and accepts who she is, he felt that without the ability to hear, she is cut off from other people, and to some extent, from him. He considered that contact with other people is very important and the majority of people in the world will not speak her language. This connection with others is something that he cannot give her, and something that he continued to find distressing; therefore, he
continued to hope that she will one day be able to connect with the rest of the world who do not communicate in sign language.

Another theme that emerges from Kate’s interview also relates to the concept of hope in a phrase she shares with other people to help them get through difficult times. Kate shared the following story:

“You know there’s a…joke in a, I I think it’s Yiddish originally…it’s one of those apocryphal stories, and then it was also turned into a joke. But the punchline basically is, um, this…wise king asks all the men in his kingdom to compile all the knowledge for his sons, so the sons can, you know be knowledgeable. Well, ten years passed and there’s a room full of books. He goes, “No no no no, narrow it down, narrow it down.” So another ten years pass and they condense it down to two huge thick books. He goes, “No no, my sons aren’t that bright, just you know narrow it down narrow it down.” Another ten years pass. And they say “Ok, we’ve distilled it down to four words, all the knowledge you need to know.” He says “Ok, what is it?” “This too shall pass.”… Everything changes. So when you have children, and they’re screaming their heads off with colic, just think, “This too shall pass.” I tell people that when they’re when they’re having babies, I said, “Let me give you the four words you need to know. This too shall pass.” And that’s it.”

(IK: 1315-1334)

The wisdom in this quote and the ability to share it with others only comes from the fact that Kate has endured the dark days and difficulties after Ellie’s diagnosis and implantation and she has come out the other side realizing that everything changes, and the fears that once clouded the future with uncertainty have dispersed, and she now regards Ellie’s future with confidence and positivity.

Another way in which the theme of hope emerged from Geoff’s interview is his depiction of how he coped at different points in time. To illustrate this, Geoff described the
idea of “sometimes you have to look at the horizon and sometimes you have to look at your feet” (IG: 431-432). As mentioned above in the story, when talking about the helpful meeting with the social worker, Geoff described how he felt like they were floating in an ocean with no idea of what was going to happen; if they looked up at the horizon to look ahead into the future, there was just nothing, only sky. The social worker, however, painted in some broad strokes of what was going to happen, their roles and her role, and suddenly instead of being in an endless ocean, they were within sight of land, or just off the coast, with some definition to their skyline. Another instance when this metaphor was meaningful to him is during the frustration of potty training. He described:

“It’s like when you’re potty training them and it’s frustrating and it’s not working and it’s not working and then you have to stand back and say “Well you know, they’re probably going to be going to high school one day, and I’m practically positive that they won’t be wearing a diaper or peeing in their pants when they do it.” So…again, there’s the time you look at your feet, and you know, your boots are covered in mud and you’re not getting what you want. And that’s the time to maybe look up and see that you’re in a beautiful mountain place and the, you know the trail does actually extend way over there. And you know, that is where you’ll be at some point in the future right?”

(IG: 667-675)

This metaphor is very meaningful in describing a way to cope with life’s difficulties and a way to cling to hope when life is overwhelming. According to this metaphor, sometimes looking ahead into the future is full of anxiety because the way is not clear and the future is completely unknown and potentially formidable. At those times, Geoff would suggest to look at the place that you are in right now, and “live in the moment” regardless of what the future may hold (IG: 370). At other times, the day-to-day is overwhelming and exhausting; at that
time it may be appropriate to look up and see that the road does extend in the distance to other places that you will eventually get to. These would be points to remember Kate’s message of hope that “This too shall pass” (IK: 1328).

Finally, in relation to the idea of hope, both parents expressed in their interviews that they are very hopeful for Ellie’s future, and that they do not anticipate many problems for her. Geoff mentioned a couple of times that he simply wants to put opportunities in front of her and hopes she finds something that she likes. He stated:

“I, you know, want to put options in front of her, things that she might like to do. Um, the horse-back riding, she loves the horse-back riding. She likes her gymnastics, um…My parents provided me with a lot of different opportunities to do things. And ah, I would like to do that with her, sort of. She doesn't have to follow through on all of them, but it’s just…champion motorcycle racers have to have talent, but they also have to have a parent who puts them on a motorcycle when they’re three years old. You know, so it’s gotta be both…put a bunch of things in front of her and hopefully she finds things that she likes and is able to do you know…I mean, it’s the thing you do with all children I guess, hope that they find something that they like.”

(IG: 400-414)

In addition to the previous quote, he explained:

“So, I think that again providing the, her with opportunities to do things, to essentially try things out, to succeed, to enjoy things, um, helps her you know, develop her own self-confidence, self-image, and ah, hopefully, you know, helps her, you know, make her own choices.”

(IG: 868-870)

This idea of putting opportunities in front of Ellie and hoping she finds something she likes illustrates the normality of their expectations for her future. As both parents said, Ellie is not
particularly handicapped; therefore, their hopes for her are fundamentally the same as those of all parents—that their child will succeed and find joy in life.

The way that hope is expressed when relating their story of Ellie’s diagnosis and deafness and the way that hope is described when talking about the current day are quite different. At first, both Geoff and Kate’s hope was that she would hear, that technology would assist her to hear—essentially, as Geoff stated, “that our beautiful little girl wasn’t actually going to be deaf” (IG:216). As time has progressed, however, their hopes have become less about Ellie’s physical abilities and more about her emotional development and attitude towards life. In essence, they seem to hope that she will be confident in who she is a person, comfortable making her own decisions, and that she will be able to accomplish what she desires in life, regardless of her hearing status.

In summary, the theme of hope is woven through Kate and Geoff’s storytelling in a number of different ways, but the frequency with which it emerges in the story proves it to be an important piece in understanding their experiences.

4.3.2 Technology as Salvation

In the section above, the parents’ hope is often tied up in the technological options that may save their daughter from deafness; when the technological options are exhausted, however, both parents felt plunged into a deep and long-lasting despair. The theme of technology as salvation is discussed below.

To begin with, Kate described herself as follows:

“Um, I am I am pro-medicine, I am pro-doctors, I am I am pro-vaccination, I am I am I am down with that. I take my meds. [{laughs} I’m a I’m a contributing member of society]. Um, so I’m not, I’m not crunchy granola at all.”

(IK: 280-284)
This initial quote reveals that Kate believes in modern medicine and the medical approach to controlling disease through vaccinations and medications. Understandably then, when Ellie was diagnosed with a chronic condition, both she and Geoff put their hope in modern medicine, in medical technology, to “save” her. Shortly after Ellie was definitively diagnosed with hearing loss, Geoff stated: “We’d decided to go for the cochlear implant ‘cause it was pretty much already in the pipeline” (IG: 203). This quote of the cochlear implant being “already in the pipeline” implies that implantation was imminent, that Kate and Geoff could not see themselves not trying the implant because of their trust in technology, even if the procedure was not common for children with Ellie’s inner ear condition. In reference to that decision, Kate explained that their motivation was “whatever is best for my child…And that that’s I think why we went for it. You know, was that, you know, we’ve got to take that chance” (IK: 1789-1791)

Another way in which the theme of technology as salvation emerged from the transcripts is found in how Kate researches in response to new information. At a number of specific points in time in telling her story, one after Dr. Chang said he would still do the implant and another when the therapy at Maple Lake took on a surreal quality, she recalled that “at that point I started to really research” (IK: 105). In researching, she hoped to find out the latest technology or the latest research regarding Ellie’s condition. Unfortunately, as she stated, “There’s nothing out there” (IK: 106). As another attempt to find information from others, she described starting a Facebook group and a posting page on the website of one of the CI Manufacturers for people with children like Ellie, but no one joined either group.

Throughout Kate and Geoff’s storytelling, technology also appeared as their hope for salvation after the CI was not performing up to expectations. As discussed in the theme of
hope, the technological options that they considered after the cochlear implant included bilateral implantation, their own idea of an inner ear transplant from a cadaver, which proved to be unrealistic, and then the possibility of an auditory brainstem implant. The brainstem implant is the only option that is still somewhat available, as Geoff expressed as follows:

“There’s even sort of the opportunity for a brainstem implant, at some point in the future, but I mean, the information that we have suggests that, that the, hearing part of her brain, the part that would actually process sound systems and vocal language, oral language will be co-opted by other parts. So that, you know, it’s quite possible that even if, when she’s older she was to have a brainstem implant, that um, that it wouldn’t be, ah, completely um, it wouldn’t be completely successful. I read a lot of science fiction. I see a lot of opportunity in technology, um, my friend…sees the brain as being very resilient and malleable, like changeable, so, but I think the next bit of surgery will have to have Ellie participating in it. You know like, ‘Do you want to do this?’”

(IG: 137-147)

When it became apparent that none of these ideas were realistic options for the immediate future, (although the brainstem implant may be an option later on) both parents had to deal with the fact that for the present time, technology would not save Ellie from being deaf or cure her condition. This leads to the next major theme, the emotion of despair that Kate expressed characterizes the time period from implantation to after Ellie starts preschool.

4.3.3 Despair

In addition to the themes of hope and technology as salvation, the theme of despair is woven throughout their story, often as a result of uncertainty, hopes being crushed, and regrets at decisions made.
As mentioned in the story chronology, Kate described that the year and a half from when Ellie was 18 months old to a few months after she started at the preschool was a time of deep despair. Both Kate and Geoff remembered that after suspecting something with Ellie’s hearing, it never got better but just continually got worse and worse. Even before eighteen months, however, both Kate and Geoff recalled some very difficult and worrying times. Geoff expressed, in relation to the process of diagnosis and CI candidacy, that “it’s like each step along the way, was sort of, another level of bad news it seemed like” (IG: 14). Likewise, Kate compared their experiences to Homer Simpson falling off a cliff. She portrayed:

“It’s not really a journey when [{laughing} it goes straight down hill]. It’s not much of an adventure, /whhhccck, pow!/ /pow pow pow/. It’s like, you know when Homer Simpson falls off a cliff? And then hits the cliff on the other side and then he hits a tree and then he hits another tree and it keeps going down hitting the different trees all the way down, you know, there’s never a break. That’s what it was like {laughs}.” (IK: 808-819)

Further to that, she stated that “It started out with despair. Despair at at, 18 months, and then, like like, like I said, like Geoff said, it just kept going down down down down down down” (IK: 1372-1374). Geoff recalled that his main emotions at that time were distress, unhappiness, uncertainty and frustration, as he thought “just oh my god what are we gonna do, what is to, will become of her?” (IG: 912-914). Along the same lines, he illustrated his anxieties with the following quote:

“You know, Khalil Gilbran said in The Prophet that parents are a bow and children are an arrow and your desire is to shoot them as high in the air as you can. Um, you know, is, how much is [her hearing loss] gonna drag her back or hold her back?...Just, you know, is she gonna be able to get a job? Is she gonna be able to meet
people...will the world take advantage of her, will people take advantage of her?”
(IG: 845-851).

Kate reflected on her own worries during that time saying:

“But um, I just I didn’t think she was gonna walk. I didn't think she’d be able to communicate and I thought, and she wouldn’t have any friends. [{laughing} and you know like]. Just the worst case scenario, and it’s completely untrue.”
(IK: 685-688)

When asked what helped to move forward from this time of despair, Kate recalled:

“It started a little bit of a glimmer of of signing and her getting a little bit little bit little bit. And then she started school and then like three months of school and then Boom! She’s off. And, we were all happy.”
(IK: 1374-1377)

To further explain the switch from despair, Kate expressed that she just did not have the capability to teach Ellie enough sign at home. Once she was at the preschool for a few months, however, she started to be able to communicate and was “struttin her stuff” (IK: 1346) out in the world, they began to see glimmers of hope and that darkness of despair start to lift.

The year and a half long period that Kate describes as a time of despair begins just after implantation and continues through the year of follow-up CI mapping sessions and therapy at Maple Lake. The next theme is closely related to the theme of despair because despair was often the result of the interactions with professionals that happened during this time period.

4.3.4 Questioning Professional Motivations

In talking about interactions with professionals and reflections back on service provision, a theme that emerges from Kate’s interview is a regret that they decided to go for
the cochlear implant, and dissatisfaction with, even distrust of, the medical motives behind giving Ellie the implant. Involved in this is a desire for more concrete facts and more transparency in the way that the odds were communicated to them. She reflected:

“I just want to say on the outset, I am very, you know, we would’ve gone for whatever surgery, done whatever we needed to do…um, you know what NIMBY stands for right? Not In My Backyard… I would’ve liked to know that it really wasn’t likely, and whether or not they knew and they’re not going to tell me anywhere are they? {laughs}. That it wasn’t likely to work. I don't know if I would’ve gone for it if I’d known it was a five percent or a ten percent or as it turns out, zero percent.”

(IK: 295-303)

Along the same lines she continued:

“And and the reason I bring up Not In My Backyard is like, thinking about it now I realize that, somebody has to provide the statistics, somebody has to be the guinea pig, somebody, you know. And you’re all for cadaver research and you’re all for this research and that research…But, I really wish it wasn’t my child. Because now, she’s got this chunk of stuff in her head. You know. It’s kind of like the tattoo regret, but slightly worse. So, you know…on the plus side she furthers medical research, but it’s my child. So there’s your moral hopes and obligations vs. your personal. And and, now I’m wandering, but you see what I’m saying?”

(IK: 313-322)

In company with this desire for better illumination of the actual probabilities, Kate expressed how the information they received from the audiologist and Maple Lake service providers were less than adequate. She considered:

“Um, well, you know Jared’s this really sweet man…but I wish he had, when he said, “well it’s… working” I wish he had said then, as opposed to sort of much later on that—because maybe my understanding of it wasn’t clear enough—that “sure she’s getting sound, but what she’s getting isn’t ‘lalala,’ what she’s getting is /kkkkkkkkkkk/
{laughs}. You know. I wish I’d had a better understanding of that…With Maple Lake Therapy, um, I wish that they had couched their terms less positively. And I wish they said “If she hears” or “You could try seeing if she hears this” as opposed to “When she hears!” And keeping a log. [{laughs} Which would be painful if she can actually have heard!]…I like rules. You know. I like rules and boundaries and borders and pie charts. {laughs}. You know. Probabilities, um, yeah. I didn’t feel that I guess I was informed enough about about that. Um, You know and I guess nothing’s definite and they’re collecting data. Maybe this data [{laughs} will be useful for the future] with with other children…I mean maybe Jared really doesn’t know. Maybe I’m just being overly critical.”

(IK: 928-955)

In summary, I sensed an overall feeling of regret and of being shortchanged when Kate spoke about her feelings looking back on the information they received about the implant and the therapy post-implantation. She felt that the odds of implantation success were not communicated clearly enough, possibly because the medical community wanted to try an implant for Ellie, just to see whether it would work or not. Likewise, she suspected that their incentive for doing the implant may have been research-motivated, rather than motivated by what is best for her family. From the audiologist, she felt that they were not informed enough about what kind of signal Ellie was getting. She realized later that there was a discrepancy between what the audiologist may have meant by “it’s working” and what she understood that to mean. This was likely a source of false expectations and lasting frustration when the professionals continued to say that the implant was working, but to Kate, it actually was not “working” as they expected it should. Finally, Kate regrets spending so long at Maple Lake therapy before entering the Deaf community. This may relate to a feeling that they should have known and accepted Ellie’s deafness earlier on in the therapeutic process. Because they continued at Maple Lake, false hopes were dragged out longer than they should have been.
Overall, it appears that in looking back at the choices they made for Ellie’s rehabilitation, Kate felt that were she more informed, the choices she made would have been different, and would have been better for Ellie and for her family.

Interestingly, this theme of questioning professionals’ motivations did not emerge from Geoff’s interview. He mentioned that he did not want his child to be a guinea pig for the medical community (IG: 148), but this statement was not in reference to the professionals that performed the implant on Ellie, but in regards to other surgeries in the future that she may elect to have. Furthermore, when asked about how his experiences were with the different service providers, Geoff answered that both of them were very good (referring to Maple Lake Therapy and Deaf Kids Resource Centre). He acknowledged that Maple Lake was more biased towards helping people hear, whereas Deaf Kids was more biased towards deafness (IG: 781-783), but he did not express any regret at being with Maple Lake for as long as they did. Instead, he simply recognized that once they accepted that Ellie was deaf and was not going to change, Deaf Kids Resource Centre became a more appropriate service provider (IG: 788-789).

4.3.5 Does Deafness Need a Cure?

Another topic that Kate mentioned a number of times as something she tries to communicate with others is the concept that cochlear implants are not “cures” for deafness. She professed the following saying “I’d say that the ongoing thing for me is is disabusing people of the notion that that there’s a cure, or even that deafness needs to be cured” (IK: 457-460). She continued to say:

“I kind of don’t like the fact that it leads people to think that she can hear. I wish they’d stop sort of touting it as a cure. You know, it’s an assistive device, you know.
And I don’t think that’s too much for the average Joe to get their head around. You know, it’s an assistive device. Like, when they have it off, they’re still deaf. Nobody sleeps like the deaf. {laughs}”

(IK: 878-884)

It may be that Kate viewed cochlear implants as a cure for deafness before her own personal knowledge of the situation, as many people do. After her experiences with Ellie, however, she realized that marketing a CI as a cure for deafness is misleading; an implant assists deaf persons to hear, but it does not cure their deafness. Further to that, she communicated strongly that deafness itself should not be represented as a condition that needs to be “cured” per say. Through her experiences with Deaf Kids Resource Centre, Kate has come to really appreciate sign language and Deaf people; therefore, their language and the condition of being deaf, has come to mean something special to her. Understandably then, she feels that that part of who they are, their deafness and/or their Deafness, is not something that needs to be “cured” but rather appreciated. She spoke the following in relation to this:

“We were talking about this the other day at uh, at the…AGM for Deaf Kids, was…there has to be a a way of making people—and I guess I should be on the forefront of that when I find the time—um, make that cultural shift. To say that this is an inclusive life, this is an inclusive thing, that sign language doesn't mark them for different-ness. And that it actually makes their lives better.”

(IK: 703-715)

Where Kate professed that deafness does not need a cure, Geoff discussed this theme in a different light. He stated the following:

“And ah, like I say, if ah, you know, it’s one thing if it’s not uncommon if there is a society available. I don’t want my child to be completely isolated by a particular disability that is really, not apparent. You know, you look at her and she’s a very pretty and outgoing little girl and, um, you know, it’s not until you pay attention to
her for any period of time and how she interacts with other people that you realize that she’s deaf. So um…how’s she going to interact with the rest of the world?..It’s not up to the rest of the world to change for her. You know, how is she going to adapt to it?”

(IG: 236-242)

From this quote, it is apparent that Geoff thinks deafness does need a cure if it is an uncommon condition without a society available. In other words, if the Deaf community shrinks due to increasing cochlear implantation, then his daughter will be left without a society of people who share her condition. In that situation, Geoff would consider her condition as one that needs to be “cured.” To further illustrate this, he explained:

“I, my own thought was that, I was very nervous about Ellie being like the last deaf person in the room. Um, as every other deaf person out there got a cochlear implant, and it functions. Um, I’m, still trying not to think about that, a lot.”

(IG: 135-137)

In summary, where Kate has made a cultural shift to the Deaf community, seeing Ellie as belonging to the society of other Deaf individuals, Geoff’s view of the Deaf community is more transient, believing that it has the potential to shrink or even disappear in the future. As such, he considered that deafness does not need a cure at this point in time, while Ellie still has peers and a vibrant community to become involved in. In the future, however, if this community ceases to exist as it does currently, then her condition will be one that needs a cure so that she can follow the rest of her community into the “hearing” world.

4.3.6 Bringing the Child into the Family

An additional theme that emerged is the idea of bringing the child into the family. Kate used a number of metaphors and illustrations to convey the meaningfulness of moments
where Ellie showed herself to be just like them and how important it was to bring Ellie into the family.

The first metaphor Kate used to describe what it was like to have a deaf child was a piece of prose work called “Welcome to Holland” by Emily Perl Kingsley (1987). She explained that this piece is often handed out at various conferences to help people understand what it is like to have a disabled child. It was written by Kingsley after she had a child with Down Syndrome. Kate described it as follows:

“It’s a piece of prose work where she talks about, you plan for Italy, you buy the guide books for Italy, you learn a bit of Italian, you get on the plane and, you’re in Holland. You know? And and it’s horrible! This isn’t what you wanted. Where’s where’s where’s the ah beautiful Italian villas? Where is the wine and the crusty bread? And {sniff} and it’s just awful. But eventually, um, you ah, you look around and and Holland has its own beauty, and you meet some really nice people that are travelling there with you. And and after awhile, you know it’s it’s not so bad, and you start to really enjoy Holland. I mean, you’ll always have that piece in your heart that says, “Well I could’ve been in Italy.” But you know, you’re in Holland, and there there you must stay, and and you know, there’s good things too there.”

(IK: 561-571)

This piece describes the shock and disappointment, but also the eventual acceptance, of having a child with an unexpected condition. Kate further described her experiences by relaying a story from a cartoon in the seventies. In this cartoon episode, a man is waiting outside the delivery room for his baby and when it comes out, the baby is green and has little antennae. He is mortified to bring it outside because it communicates with ants and people scream and run away when they see it. When the baby is inside their house, however, it draws the Einstein theory on the chalkboard and proceeds to build a rocket ship after seeing
one on the television. Soon afterwards the parents get a telegram from aliens on Mars saying that their babies got switched. Meanwhile, the alien baby takes off in his rocket ship and the parents cry for it to come back so that they can receive their baby in exchange. The man eventually wakes up and realizes it was just a dream. The point of Kate telling this story, however, she expressed as follows:

“But the reason I get back to this, is because this is what it was like. We thought we were getting a baby and oh my God, we got something else. You know, I tell people it’s like, it’s just it’s just like that, you know. It’s it’s like the Holland thing, and um, and ah, or sometimes I tell people that she’s a fairy changeling. {laughs}. Because she looks like it. And she acts like it. She’s she’s a fairy changeling baby.” (IK: 1068-1073).

A fairy changeling refers to European mythology where occasionally a fairy child would be left in place of a human child (Munro, 1991). These three metaphors—that of living in an unexpected place, having an alien baby, or receiving a fairly changeling child illustrate the idea of having a child who is different from the rest of the family in some way. These three examples illustrate how initially Ellie appeared to be somebody different than the rest of her family, someone other than the baby they were expecting. The parents at this point experienced much anxiety because their future and the future of their baby was completely unknown. As Geoff described, they were floating in an ocean without any land in sight or ideas of what would happen. As time went on, however, and Ellie grew older, Kate recalled meaningful moments where Ellie showed that her similarities to her family were much more than her differences. One particular story related to Kate’s sense of humor. A number of times throughout the interview she mentioned how her family’s culture leans towards the
grotesque in their humor. In other words, she has an off-beat sense of humor that others may find rather earthy. With that in mind, Kate recalled the following:

“Um, a couple of months ago, and this is astounding, um Ellie came up to me, and there was, this is gross, there was a lump in her pants and I just looked at her and I went “You are too old! You are too old to be pooping your pants.” And I reached down and I pulled her pants out a little bit and I reached down and pulled out, a wad of Kleenex. And then she started laughing laughing laughing laughing. So she pranked me! She deliberately made a fake poop stuck it in her pants… I mean, that’s pretty smart, you know, to be able to at four, come up with just the idea of like ‘I know how to really freak mom out.”

(IK: 241-258)

She went on to talk about this event as a high point in her story, saying:

“But yea, but so, so for Ell to to fake me out with this fake poo was just, “Yes! You are my baby! Muah! Muah! {pretending to kiss her}”… just little points…when she just proved herself to be one of us. And, and and to be as funny as us, and and just like us, and to show the same preferences as us, and like to do the same things.”

(IK: 1227, 1235-1238)

Kate further expressed the meaning behind this small episode, saying:

“Yeah, the, you know, the little, little things…the humor, that she is, she is one of us. She’s not a changeling. She’s not an alien baby. She’s obviously our child. {laughs} Particularly the poo prank. That was just, that was, that was practically tradition!”

(IK: 1193-1199)

The above quotes illustrate how Ellie proved herself to be part of the family, through the development of her sense of humor and personal preferences. Another way in which the theme of bringing the child into the family emerged was in Kate’s portrayal of service
provision. She described how after Ellie was diagnosed, the primary decision that she and Geoff had to make was in terms of Ellie’s education, not in terms of family. She described:

“You know, it really is education education education…It’s not, a very family…centered approach. It’s not, “How will you bring this child into your family?” How will you integrate this child into your family? Um, which I think is the most important thing. Like, how far are you willing to go to meet your child. You know? Are you willing to say, no…they have to meet me on my field, my language, my turf. Or will I say, I’ll meet them halfway. Or will I say, no, I will cross over, you know, whither thou goest I will go. Which is what we end up doing…in the end.”

(IK: 1004-1012)

Further to that she stated:

“It needs to be more of of a family first, education second…Not education, not society, not what society wants or society needs. It’s bringing the baby into the family and saying “How will you make this work?” within that first. Because once you have that, you know, and and then she can see the world.”

(IK: 1033-1035, 1075-1079)

To understand where she was coming from in terms of her ideas of family, the following quote may help illustrate:

“When I see the other parents…and they don’t have that, camaraderie and that communication, and they’re like, their children are—mind you it might also be a different parenting approach too—their children are sort of adjunct to them. They’re not, um…we’re really big on our family. We’re a family. We’re a unit. We’re a cohesive unit and we all talk together and everybody has an opinion.”

(IK: 1020-1026)

The high value Kate puts on cohesiveness within her family shows how worrying it must have been for her when she was not sure how Ellie would fit into the family. This deep-
seated value of togetherness was the springboard for how passionately she felt about bringing one’s deaf child into the family before thinking about how he or she is going to be educated.

4.3.7 Summary

This chapter has described the results of the current case study in two primary sections. The first section was the story of Ellie’s parents in relation to her deafness, which was presented chronologically and made up primarily of direct quotes from both of her parents. The story was supplemented by reports from medical professionals and occasionally included a description of the researcher’s observations and experiences while listening to the storytelling. The second section was a discussion of prominent themes that emerged throughout the story as topics of importance for one or both parents. The salient themes that emerged from both Geoff and Kate’s transcripts included the themes of hope, technology as salvation, despair, questioning of professional motivations, whether deafness needs a cure, and bringing the child into the family. Overall, the results of this study consist of an in-depth case study of the experiences of parents who have their child with cochlear nerve deficiency and common cavity deformity receive a cochlear implant. How this study fits within the research literature, its contribution to the body of research on this topic, reflections of the researcher on this study, and potential applications of this research are discussed in the following chapter.
Chapter 5: Discussion

The goal of this study was to gain greater understanding of the experiences of parents who chose to have their child with cochlear nerve deficiency receive a cochlear implant. This case study both supports existing literature on cochlear implantation and parent experiences, and adds to what is known about implantation for children with CND and common cavity deformity. Qualitative methods in this study add valuable insight to the research literature on how to investigate the topics of CIs and parent experiences and cochlear implantation for children with CND. The in-depth nature of qualitative description and the inclusion of dyadic analysis proved to be enriching methods of inquiry for this type of case study.

As described in the literature review, candidacy criteria for CIs have expanded to the point where Ellie, a little girl with CND and common cavity deformity, was considered a potential CI candidate. Although she had abnormal neurophysiology, other factors known to support positive implant outcomes were present. For example, the age at which she was implanted, 18 months, is correlated with greater speech production and perception outcomes than children implanted later in life (Florian, 2003; Geers et al., 2008; Sarant et al., 2001). Additionally, she was originally educated in a program that emphasized the development of oral skills, which is substantiated in the literature as corresponding to better speech perception and spoken language than children educated in total communication programs (Tobey et al., 2007; Geers, 2002; O’Donoghue et al., 2000). For this particular child, however, both the implantation itself and the enrolment in an oral intervention program proved to be frustrating and disappointing for both of her parents. According to Jackler’s (1987) classification of congenital inner ear abnormalities, individuals with common cavity deformity may have some spiral ganglion cells scattered around the walls of the cavity,
which are essential for the CI to work, but he noted that auditory function in cases of common cavity deformity is usually poor. In Ellie’s case, it appeared that the combination of her common cavity and the fewer-than-normal cochlear nerve fibres present to transmit the implant’s signal to the auditory cortex contributed to her lack of auditory progress with the implant. Furthermore, Kate was so frustrated by the nature of her oral therapy that they eventually switched to a sign-language based program and became involved in the Deaf community, realizing that it was a better fit for their child. Despite some of the positive outcomes reported in the literature for children with CND who received cochlear implants (Zanetti et al., 2006; Warren et al., 2010), Ellie’s auditory progress with the implant was more comparable to the children in Bradley et al.’s (2008) study, the majority of whom used sign to communicate and received little or no benefit from their CI. This is a cautionary outcome that should be considered by other parents of children with CND and by professionals in the position to counsel parents in similar situations.

In regards to parents’ experiences of CIs, both of the parents in this study explained elements of their experiences that were comparable to those described in the research literature. For example, some of their described emotions, shock, loss, disbelief, and despair, are substantiated in the literature as part of the grief cycle that parents often enter after the diagnosis of their child (Anagnostou et al., 2007). Additionally, Geoff depicted that once the extent of Ellie’s deafness was known, he and Kate were committed to an implant as they did not want Ellie to be the last deaf person in the world. In fact, the decision to have Ellie receive a cochlear implant did not emerge from either of their stories as a major milestone. From this it appears that the actual decision to implant was not very difficult, which corresponds to the parents in Archbold et al.’s (2006) study; the parents for whom the
decision to implant was the easiest were those who placed the highest priority on their child learning to hear and speak. Nevertheless, after it became apparent that Ellie’s auditory progress with the CI was minimal at best, her parents’ hope that she would learn to hear and speak shifted to a hope that she would simply be able to communicate in whatever modality worked for her. Another theme that emerged from the literature review is parents’ experiences interacting with professionals. Wheeler et al. (2009) found that many parents experienced conflict over communication strategy with involved professionals and few felt adequately supported. The family in this study also experienced some conflict regarding communication strategy, particularly when they were not seeing any effect of the implant, but their therapists continued to suggest auditory-oral based activities to improve Ellie’s sound perception. Furthermore, this family did not feel adequately supported by their professional team. Conversely, they felt like Ellie’s future was completely unknown and that they did not have any ideas of what was going to happen to her or to them. A single meeting with a helpful social worker stood out for them as providing more support and encouragement than all their meetings with professionals up to that point. In sum, many of the themes that emerged in the literature review regarding parents’ experiences of cochlear implantation for children with hearing loss were also present to some extent in the experiences of parents in this case study.

In addition to substantiating the literature on parent experiences of CIs for children, this study also adds to the literature in the methodological area of dyadic interview analysis, and in the topical area of cochlear implantation for children with CND. Data analysis of the two interviews in this case study revealed the value of dyadic analysis for investigating an experience shared between two partners. As espoused by Eisikovits and Koren (2010),
separate interviews allow us to hear each partner’s story without the influence of the other person in the physical space, but the dyadic analysis of both interviews together reveals something more than the sum of the two parts. By analyzing the transcripts together, a number of qualities emerged that would have been absent from individual analysis alone.

First, the cohesion between Geoff and Kate’s stories was a notable characteristic. Although they were interviewed separately, there was considerable overlap between the two stories and it was clear that the other partner was present in the virtual space of the one being interviewed. Consequently, both stories had the feel of being a co-constructed story with the other partner. The way in which this co-construction emerged was both in the content of the story they told and in the way that each mentioned the other person’s experiences of particular events and situations. For example, in terms of content, both parents mentioned many of the same events and marked the same moments as particular turning points. Furthermore, in telling of a particular event, both included how the other felt at times, whether similarly or in contrast to him or herself. Occasionally one would also mention how the other partner would give more insight into the situation, or that the other would tell me more about a certain time. Obviously, in this dyad, both individuals have communicated together, and each has a voice that is recognized as meaningful by the other. This was further evidenced by the way in which each talked about their children; it was clear that both of their children have a voice within the family that is recognized as important by both of their parents.

Dyadic analysis also revealed similarities in how each parent told their story. One of these similarities is the way in which both used compelling metaphors to explain their experiences to the researcher. These metaphors, although different to each parent, served to
increase the power and meaning behind their described emotions and situations. 
Mastergeorge (1999) reports that “metaphoric language is used when literal language is felt to be inadequate” (p.245). Furthermore, it is used to help a listener better understand an unfamiliar emotional experience (Mastergeorge, 1999). As the listener in this research study, I did not have personal experience with having a deaf child. Because the explicit purpose of the interviews was to gain a better understanding of parents’ experiences, both Kate and Geoff used metaphors to better explain their experiences and emotions to me. In her study of family perceptions of diagnosis and disorder through metaphor, Mastergeorge (1999) discovered four uses of metaphor: metaphors relating to diagnosis, to personal coping, to personify experiences and to describe ambivalence. Interestingly, the metaphors used by both Geoff and Kate are comparable to the metaphors reported in Mastergeorge’s study, especially in the areas of diagnosis and coping. For example, over half of the participants in Mastergeorge’s study reported that after diagnosis, there was “no light at the end of the tunnel” (p.249). This is similar to Kate’s metaphor of walking through a “black black river of despair” (IK: 1304) or her explanation that it just got worse and worse (IK: 61). In addition to metaphors pertaining to diagnosis, Mastergeorge (1999) found that metaphors of fairy tales were also used by the parents in her study to describe their life stories in regards to coping. She reported that the story often began with typical events of watching their child pass milestones, but then a disaster took place, hopelessness ensued, and a resolution with a happy ending eventually occurred after a period of time (Mastergeorge, 1999). This is quite comparable to the way in which Kate and Geoff describe Ellie’s story. Kate remembered Ellie as a baby, watching television with her dad, never thinking for a moment that something could be wrong with her (IK: 12-17). Then her realization that Ellie did not startle
at sounds began the whole process towards diagnosis, which Kate describes as something akin to Homer Simpson falling off a cliff and hitting the cliff on the other side and trees all the way down, never getting a break (IK: 813). Geoff further explained that every step along the way was just another level of bad news (IG: 15). Hopelessness truly did ensue for this family after diagnosis; Geoff described it as floating in the middle of a giant vast unknown ocean with nothing on the horizon (IG: 430-433). Kate expressed that it was a year and a half of despair (IK: 1349). Finally, the fairy-tale ending for this family occurred after Ellie began to communicate with sign language. Geoff explained that they now joke that Ellie is deaf so that she will not take over the world and allow the rest of them to keep up with her brilliance (IG: 41-43). Other fairy tale metaphors used by the parents in this study included the idea of the fairy changeling and the alien baby, as well as the reference to the wizard of Oz in Kate’s interview where she compared their oral therapy to wishing and clicking their heels three times saying “There’s no place like hearing” (IK: 95-7). The way that the parents in the present study expressed their experiences support Mastergeorge’s (1999) findings of how parents use metaphor, and the types of metaphors they use, to describe their experiences of their child’s diagnoses and disorders. Additionally, the metaphors that both parents used in their storytelling were powerful images and points of understanding for me, the listener. Without having personal experience of having a deaf child, I was still able to experience through their metaphors some of the intense emotions that they felt before and after Ellie’s diagnosis.

Despite the congruency between the parents’ stories, including their use of metaphors, dyadic analysis also revealed some discrepancies between the two. One of these discrepancies is the timeline at which they remembered events occurring. Sometimes
differing by a few months, it was helpful to have the third source of triangulation, which was their child’s health record information, to validate their stories. At points of discrepancy, the correct time of the event was gleaned from the health record and information about each parent’s perspective emerged from comparing the differing versions. For example, when the parents reported the age of their child at the time of diagnosis, both reported an age that was higher than the age recorded in the health record. From that it was supposed that the parents keenly felt the length of the diagnostic process and to them, it felt like a longer time period than was actually the case.

This study incorporated multiple sources of data in order to increase the trustworthiness of the results; nevertheless, there are limitations to this study in relation to the sources that were consulted. On one hand, the professional reports from Ellie’s health record served as an important source of data triangulation. On the other hand, it must be noted that the actual voices of the professionals involved with this child—the audiologists, surgeon, doctors, and therapists—are absent in the presentation of these data. Their reports are informative, but static, and only reveal what was written down, not the dynamic voices of each involved individual. Therefore, although triangulation was possible with the health record to compare parent accounts with specific moments or appointments in their story, it was not possible to confirm what was actually said to the parents by the professionals as opposed to what the parents understood. This is meaningful for the case at hand because of the uncertainty of probable outcomes for Ellie. Regardless of what was communicated exactly by professionals, the parents interpreted this uncertainty in a particular way. In Kate’s case, her interpretation led to a questioning of professionals motivations in their offering of the implant to Ellie. Geoff did not appear to question their motivations, but he did describe
that the surgeon said “there was essentially a fifty fifty chance that it would work” (IG: 26-27). Future research that incorporates interviews with involved professionals will be useful to illuminate how what is said to parents is interpreted in the moment, and later on in the process, as they reflect back on what was said to them.

Overall, this study contributes to the existing literature in both the process of data collection and analysis, and in the content of the results. In terms of data collection and analysis, this study shows the merit of conducting separate interviews with each parent, but analyzing them individually and together as a dyad. When both parents, or two caregivers, are involved in the life of a particular child or children, dyadic analysis allows the investigation of each person’s experiences, but also lends itself to the analysis of overlaps and contrasts between them. This method is an appropriate option for any case study intending to explore or further understand parents’ experiences in relation to their child, especially for the fields of speech-language pathology and audiology.

In terms of content, this study adds to existing literature on CIs for children with CND and other abnormal neurophysiological conditions, as well as parent experiences related to their child with hearing loss. As detailed in the literature review, a few studies do exist that discuss outcomes for implanted children with CND. Unlike any study published in the literature so far, however, this research presents the outcomes of a child with CND and a CI from the parents’ perspectives rather than from the position of medical professionals looking at speech perception and production outcomes. As such it provides a rich and valuable account to consider when reflecting upon clinical practices and interactions with parents of children with hearing loss.
A number of clinical implications emerge from these data, especially in regards to service providers who counsel families of children with hearing loss. As described in the literature review, best practice guidelines for professionals in the field specify the provision of family-centred care, evidence-based intervention, and the promotion of informed choice. From the perspective of the parents in this study, none of these mandates appear to have been met. Kate specifically felt that the service approach they received was much more focused on intervention options than on the specific needs of their family or bringing their child with hearing loss into the existing family unit. She subsequently described a need for service that is more family-centred. Kate’s understanding of “family-centred,” however, is actually quite different than what is meant by “family-centred” in the British Columbia Early Hearing Program best practice guidelines. The BCEHP guidelines specify that family-centred care means the family is made an equal partner in the service provision, that their competence is acknowledged, that family strengths are used as a resource and that the family is enabled to make choices for their child. In Kate’s view, family-centred practice means one where the parents are encouraged to bring the child into the family. Additionally, the evidence regarding outcomes of various therapeutic approaches for children with CND is limited or nonexistent; therefore, both parents did not feel that there was enough information available to guide their decision-making. Related to this lack of evidence, they did not feel retrospectively that they were able to make an informed choice based on research, but instead, trusted the odds that they understood from the surgeon. Again, it is unclear what was said exactly by the professionals to these parents, but what they understood reveals that what is said may not always be equivalent to what is heard. Professionals in the field must therefore engage in reciprocal dialogue with the parents in order to find out what the parents
actually understood from what was said. When discussing the option of a cochlear implant, in particular with families for whom the outcome of implantation is uncertain, professionals should spend adequate time not only exploring what the future may look like if the implant does work, but also what the future may look like if it does not. Furthermore, professionals should ensure that parents do not feel pressured to choose a type of intervention program and mode of communication immediately, but to take the time they need to integrate the baby into their family first. Parents need to be encouraged in their ability to cope even if their child’s outcomes are uncertain. According to both parents, one meeting with a particular social worker relieved them of an incredible amount of pressure and stress simply because she affirmed their ability to cope, she alerted them to the technologies that will be available to their child, and she assured them that they did not have to know everything or teach their daughter everything. It is therefore very important that health professionals investigate the ideas that parents believe or feel about their future, and help to allay some of their fears that may be unfounded.

5.1 Conclusion

In conclusion, the case presented in this qualitative study contributes to research literature on the topic of CIs for children with abnormal inner ear physiology, specifically CND. Rather than presenting outcomes from a medical perspective, the current study describes the process of diagnosis, implantation, follow-up and outcomes from the perspective of two parents of a child with CND. By presenting their story in the form of a qualitative description, their voices are relayed and given just as much importance as the voices of medical professionals found in the existing literature. Both of the participants in this study mentioned that when they were trying to decide what to do for their child, they
researched but could not find any information, nor could they find any other parents in a similar situation. This study changes that fact, adding a valuable case to the limited number of published outcome studies available. Furthermore, because there are so few children with CIs and CND, every case acts as a helpful resource for both parents and involved professionals. The parents’ experiences presented here are rich in perspective and contribute to our understanding of the process and outcomes of implantation for children with CND. In addition, many of the parents’ experiences and the implications for clinical practice that emerge from these results are also relevant for other situations in which the outcomes for a particular intervention are uncertain, but parents must make decisions regarding their child’s health and intervention despite the lack of research-based evidence to guide them.
References


Appendices

Appendix A  Interview Guide

1. Would you tell me the story of your experiences in relation to your child’s cochlear nerve deficiency? Start in time wherever you want and take all the time you need. I’ll listen first; I won’t interrupt. I’ll just take some notes for after you are done telling it.

2. What were the different decisions that you needed to make regarding your child’s condition during that time?

3. Were there any pivotal moments or events that influenced you or your experiences during that time?
   a. If so, what were these and how did they influence you?

4. Can you describe some of the high/low points in this journey?

5. How has your child’s condition impacted or not impacted you, your daily life and those around you?

6. How do you feel about the journey that you have been on since first learning about your child’s cochlear nerve deficiency, the process of cochlear implantation, and now, given where your child is today?

7. Looking back, what are your reflections on your experiences given where your child is today in terms of his or her speech, language and overall development?
   a. What are the primary thoughts or things that stand out in your mind when you look back from where you are today?
   b. Is there anything you regret, or anything negative in your mind looking back?
   c. Anything that you are very thankful for or very glad about?

Further Prompt Questions:
   a. How did you feel?/What were your emotions in response to that?
   b. How have you coped or not coped with that?
   c. Can you tell me a little bit more about ______?
   d. What was going through your mind at that point? What about now looking back at that?
   e. What influenced your decision at that time?
   f. What external and internal factors played or didn’t play a role in that experience?
## Appendix B Transcription Conventions

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<thead>
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<tbody>
<tr>
<td>IK:</td>
<td>Interview with Kate</td>
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<td>IG:</td>
<td>Interview with Geoff</td>
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<tr>
<td></td>
<td>Natural pause</td>
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<tr>
<td>{}</td>
<td>Indicates an action by the individual speaking eg. {laughing}</td>
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<tr>
<td>[]</td>
<td>Text within the square brackets are characterized by the action within the inner curly brackets eg. <a href="laughing"></a> you know?] shows that the speaker is laughing while saying the words “you know?”</td>
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<tr>
<td>()</td>
<td>Text within parentheses when appearing in a direct quote are the researcher explanations pertaining to the quote</td>
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<td>…</td>
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