This copy has been supplied by the Library of the University of Otago on the understanding that the following conditions will be observed:

1. To comply with s56 of the Copyright Act 1994 [NZ], this thesis copy must only be used for the purposes of research or private study.

2. The author's permission must be obtained before any material in the thesis is reproduced, unless such reproduction falls within the fair dealing guidelines of the Copyright Act 1994. Due acknowledgement must be made to the author in any citation.

3. No further copies may be made without the permission of the Librarian of the University of Otago.
LISTENING THROUGH DEAF EARS

PARENTAL EXPERIENCES OF THE WIRED WORLD

Dr. Nina Sawicki

A Thesis submitted for the degree of

MASTER OF GENERAL PRACTICE

at the University of Otago
Dunedin

New Zealand

September 2008
ABSTRACT

Sensorineural hearing loss affects 1 to 3 of every 1000 children born. In most cases the child is non-syndromic (meaning that it is not associated with any congenital features) and the child is well. Sensorineural loss in childhood limits the development of spoken language but with amplification (hearing aids) or cochlear implantation and intensive habilitation these children may develop spoken language.

This Master’s thesis details a qualitative research study which aimed to examine the experiences of parents throughout New Zealand prior to, and in the years following their child’s cochlear implant.

The Research Question

What are the experiences of parents whose child(ren) undergo cochlear implantation in New Zealand?

Method

The decision to use qualitative research methods was deemed to be the most appropriate given that the aims of the study were based on exploring the experiences of the parents. A constructivist methodology was used to explore the meaning of these parents’ experiences. The study was carried out throughout New Zealand in 2007, and fourteen parents (seven parent pairs) participated in the study. Data for the study were sought through open-ended in-depth interviews. The analysis was iterative, therefore subsequent interviews incorporated issues raised by previous participants. The data from the interviews were analysed using a general inductive approach.
Results

Several prominent themes were found. Parents reported experiences of profound shock after their child’s initial diagnosis, a sense of isolation, and ongoing emotional distress which they did not perceive as being appreciated by the many health and service providers involved in the ongoing management of their child(ren). Many parents found the referral process erratic and the hearing aid trial a source of stress and frustration, with little benefit. Despite the stress of the surgery and the considerable habilitation work involved in the post-implantation period, the parents were overwhelmingly positive about the benefits noted after surgery. All parents described their implanted child as a “normal” child. There was low use of sign language and there was limited contact with the Deaf community. Many parents spoke of the need for sign language but reported a range of difficulties accessing tuition. These issues were more apparent for families in remote communities.

Conclusions

The implications arising from this study suggest that the management of implanted children by health and education providers needs to emanate from a definitive family-oriented paradigm. The needs of siblings and other extended family members also need consideration. Cochlear implantation provides a management tool, not a cure, for childhood deafness and implanted children will continue to face significant challenges in the world of hearing persons. The low use of sign language suggests that these children may not be receiving a holistic and pluralistic approach to their language development. As a consequence of limited contact with the Deaf community, minimal use of sign language, low modelling of its value by parents and increasing demands placed on implanted children to function as "hearing", these children may face
additional challenges as they mature.

Author and son eight hours post-implant surgery
ACKNOWLEDGEMENTS

I thank the parents who participated in this study and for the trust they placed in me to represent their experiences authentically. I would also like to thank them for the time they generously gave me to share their stories of their child(ren). It provided the data for this study, and deepened my appreciation of the resilience and commitment parents have for their children.

I thank all the staff of the Donald Beasley Institute who supported me through the thesis and always made me welcome during my trips to Dunedin. I would like to especially thank Dr. Anne Bray, who sadly died before I completed my thesis. Dr. Brigit Mirfin-Veitch quickly assumed responsibility for Anne’s role adding to her own work and I would like to thank her for her professionalism and ongoing support and interest. I would also like to thank Dr. Susan Dovey, Associate Professor of General Practice at the University of Otago, who provided sound and sustained academic support for this, my first piece of research, and encouraged me to aspire to excellence. Neil Heslop, manager of the Southern Cochlear Implant Programme, was especially supportive in facilitating the research and was always helpful in answering my queries. Fellow recipients of HRC scholarships provided valuable critique during our monthly study meetings through 2007 and 2008.

Finally, and perhaps most importantly, I thank also my husband who bore an extra parenting load during this period.
LIST OF TABLES AND FIGURES

Diagram of the ear showing outer, middle and inner ear, including the cochlear
Source: (Christiansen and Lee, 2002).................................................................6

Diagram showing the benefit of hearing aids as a function of hearing loss
Source Mc McCormick, B., Archbold, S., (Eds) “Cochlear Implants in Young
Children” .............................................................................................................8

TABLE 3.7.1: Final Study Group ........................................................................52

TABLE 3.9.1: The Coding Process In Inductive Analysis .................................54
ABBREVIATIONS AND EXPLANATION OF MEDICAL TERMINOLOGY

Adviser on deaf children (AODC): A hearing professional funded by the Ministry of Education to advise parents.

Aided thresholds: This is represented by the symbol “A” on an Audiogram. They are the softest tones that a person can hear while wearing hearing aids.

Amplification: To make sounds louder; may also refer to the piece of equipment used to make sounds louder, such as a hearing aid.

Audiogram: A graph of a person’s peripheral hearing sensitivity with frequency (pitch) on one axis and intensity (loudness) on the other.

Audiologist: An individual who holds a graduate degree and professional certification for the assessment and management of hearing loss.

Auditory-Verbal-Therapist (AVT): Teachers of children with hearing impairments who have obtained additional training and have specialist qualifications of Auditory-Verbal International, Inc (AVI).

Bilateral: A disorder or hearing loss that involves both ears.

Binaural: Hearing with both ears: wearing a separate device on both ears.

Cochlear: The inner ear where the reception of sound actually occurs. The organ of Corti (end organ for hearing) and hair cells (sensory receptor for sound) are located in the cochlea.

Cochlear implant: A biomedical device that delivers electrical stimulation to the V111th cranial nerve (auditory nerve) via an electrode array surgically implanted in the cochlea.

Conductive hearing impairment: Hearing impairment caused by damage or disease (pathology) located in the outer or middle ear that interferes with the efficient transmission of sound into the inner ear where sound reception occurs.
Congenital hearing impairment: A hearing impairment that occurs prior to the development of speech and language, usually before birth.

Deaf: Deaf used with a capital D refers to culturally “Deaf” as opposed to deaf which is framed in audiological terms. “Deaf” and deaf may be used interchangeably depending on the writer.

Decibel (db): The logarithmic unit of sound intensity or sound pressure; $1/10^{th}$ of a Bel.

DHB (District Health Board): A geographical health area which has governance over local health initiatives and is responsible for contracting out the screening process.

Food and Drug Authority (FDA): An independent body in the United States of America which has jurisdiction on new drugs and medical technologies.

Frequency modulation (FM): The frequency of transmitted waves is altered in accordance with the sound being sent.

General Practitioner (GP): a physician who practices in the community and is the first point of call for referral and access to secondary care services.

Habilitation: the therapy involved in supporting deaf children to acquire spoken language and develop alongside their hearing peers. It is occasionally referred to as rehabilitation.

Hearing Aids: Miniature public address system that amplify and shape incoming sounds to make them audible to an ear that would not otherwise detect them, the first step in an aural habilitative procedure.

Health and Disability Commissioner: An independent commissioner who passes jurisdiction on breaches of the Health and Disability Code of Consumer Rights.
**Hearing aid fitting:** Trying a hearing aid and ear mold on a person, using specific procedures, until it is suitable for the person acoustically, physically, and cosmetically.

**Hertz (Hz):** A unit of frequency measurement equal to 1 cycle per second.

**HFA (Health Funding Authority):** The division of the Ministry of Health which funds travel for publicly funded medical treatment.

**IEP (Individualised Educational Plan):** A legal written contract developed by a team (school and parents) that specifies instructional and related services needed for the child to obtain an appropriate education: includes short and long-term objectives.

**Intelligibility:** The ability to detect differences among speech sounds (e.g. to hear distinct words such as “vacation” and “invitation” as separate and distinct words).

**Itinerant teacher of the deaf (ITOD):** A specialist teacher of the deaf who has additional training, and visits the school with the aim of supporting the classroom teacher.

**Mapping:** The ongoing audiological assessment and adjustment of internal implant function.

**Microphone/Transmitter:** An electro acoustic transducer that changes a sound stimulus to electrical energy.

**Multi-Regional Ethics Committee (MREC):** The Committee that approves research conducted throughout New Zealand.

**New Zealand Federation of Deaf Children (NZFDC):** A voluntary organisation which aims to support parents of deaf children.

**New Zealand Sign Language (NZSL):** A unique signed language of New Zealand with its own syntax and grammar and local dialect. This is the third official language of New Zealand legislated in 2006.
National Screening Unit: The unit within the Ministry of Health designated to implement and manage the Universal Newborn Screening Programme (this is currently being rolled out in New Zealand).

Ngai Tahu Research Consultation Committee (Te Komiti Rakahu ki Kai Tahu): The committee which oversees the University of Otago’s responsibility to Māori under the Treaty of Waitangi.

Ongoing reviewable resource support (ORRS): A source of funding for children who need support in a mainstream classroom. It is funded by GSE (Group Special Education) within the Ministry of Education.

Otolaryngologist (ORL or ENT): A doctor who specialises in diseases of the ear and performs the cochlear implant surgery.

Plunket nurse: A paediatric nurse who specialises in infant development.

Residual hearing: The hearing that remains after damage or disease in the auditory mechanism. There is almost always some residual hearing, even with the most profound hearing impairments. Residual hearing can be accessed through the use of amplification technology.

Sensorineural hearing impairment: Often called “nerve impairment”, a sensorineural hearing impairment which results from disease or damage in the inner ear and is usually permanent.

Speech intelligibility: The percentage of speech of the talker that is understood by listeners.

Universal Newborn Hearing Screening Early Intervention Programme (UNHEISP): The screening programme being out rolled currently in New Zealand to detect hearing loss in newborn babies.
CONTENTS

Abstract.......................................................................................................................... i
Acknowledgements ..................................................................................................... iv
List of tables and figures ............................................................................................ v
Abbreviations and explanation of medical terminology.......................................... ix
Contents ........................................................................................................................ x

CHAPTER ONE: INTRODUCTION ........................................................................... 1
1.1 Significant Issues in Childhood Deafness............................................................ 1
1.2 Early Intervention Services in New Zealand ....................................................... 2
1.3 Anatomy of the Ear and Types of Hearing Loss.................................................. 5
1.4 Candidacy for Cochlear Implantation................................................................. 7
1.5 How a Cochlear Implant Functions ................................................................... 10
1.6 Issues Raised by Cochlear Implantation: Expectations and Outcomes ............. 11
1.7: The Deaf Community and Parents.................................................................... 18
1.8 Ethical Dilemmas for Parents and Providers ..................................................... 22
1.9 An Anthropological Perspective....................................................................... 30
1.10 Future Considerations .................................................................................... 33
Summary .................................................................................................................. 36

CHAPTER 2: METHODOLOGY............................................................................ 37
2.1 Introduction ........................................................................................................ 37
2.2 Theoretical Framework and Underlying Assumptions ...................................... 37
2.3 Naturalistic Inquiry ............................................................................................ 38
2.4 Social Constructivism ...................................................................................... 38
2.5 Design of the Study ........................................................................................... 39
2.6 Use of Open-Ended Interviews ....................................................................... 40
2.7 Interview Guide ................................................................................................ 40
2.8 Social Constructivism within the Discipline of General Practice...................... 41
2.9 Reflexivity ......................................................................................................... 43
2.10 Reciprocity ..................................................................................................... 45

CHAPTER 3: METHOD AND ANALYSIS ........................................................... 46
3.1 Introduction....................................................................................................... 46
3.2 Multi-Regional Ethics Committee Application and Ethical Concerns .............. 46
3.3 The Participants and the Location of the Research .......................................... 48
3.4 The Research Phase ........................................................................................ 49
3.5 Recruitment ...................................................................................................... 50
3.6 Sampling Strategy ............................................................................................ 50
3.7 Final Study Group ............................................................................................ 51
3.8 Analysis............................................................................................................. 52
3.9 The Process of Inductive Coding and Analytic Strategy ................................... 53
CHAPTER FOUR: RESULTS ................................................................. 56
4.1 General Introduction ......................................................................... 56
4.2 Experiences with Health and Education Providers from Diagnosis to Pre-
Implantation and Beyond ................................................................. 56
  4.2.1 The Complexity of the Parent-Health and Education Interface ...... 56
  4.2.2 The Initial Diagnosis and Use of Terminology ......................... 58
  4.2.3. The Referral Process for Implant Candidacy .............................. 62
  4.2.4 The Pre-Implant Hearing Aid Trial ............................................. 65
  4.2.5 Cochlear Implant Surgery and the Post Surgical Habilitation Process...... 69
  4.2.6 Technological Challenges ......................................................... 73
4.3 The Implanted Child and their Family .............................................. 75
  4.3.1 Introduction .............................................................................. 75
  4.3.2 Concerns of Child Safety ............................................................ 76
  4.3.3 Ease of Communication .............................................................. 78
  4.3.4 Issues for Siblings ..................................................................... 79
  4.3.5 Further Pregnancies ................................................................. 82
  4.3.6 Work and Finances ................................................................. 84
4.4 Experiences of New Zealand Sign Language (NZSL) and the Deaf Community ... 87
  4.4.1 Introduction .............................................................................. 87
  4.4.2 The Use of and Advice Regarding NZSL .................................... 87
  4.4.3 Experiences with the Deaf Community ...................................... 93
4.5 Experiences and Perceptions of a “Normal” Child .............................. 98
  4.5.1 Introduction .............................................................................. 98
  4.5.2 Choice and Desire for a “Normal” Child ...................................... 98
  4.5.3 Experiences of a “Normal” Child .............................................. 102
  4.5.4 Future Aspirations for Their Child ............................................ 105
4.6 Experiences and Information Regarding Bilateral Implants ................. 107

CHAPTER FIVE: DISCUSSION ................................................................ 111
5.1 Introduction ..................................................................................... 111
5.2 The Initial Diagnosis ....................................................................... 112
5.3 The Referral and Assessment Process for Cochlear Implant Candidacy ...... 114
5.4 Engagement with Health and Education Providers ............................. 116
5.5 The Implanted Child’s Family ........................................................ 118
5.5 Contact with the Deaf Community and the use of NZSL ..................... 121
5.6 Perception of a Normal Child .......................................................... 124
5.7 Bilateral Implants and Future Technology ........................................ 127
5.8 Summary ...................................................................................... 128

CHAPTER SIX: CONCLUSION ............................................................. 131
6.1 Introduction ..................................................................................... 131
6.2. Strengths of the Study .................................................................... 132
6.3. Limitations of the Study ................................................................. 133
6.4 Implications of the Study ................................................................. 135
  6.4.1 Implications for Health and Education Providers ....................... 135
  6.4.2 Implications for Health and Disability Policy ............................... 136
  6.4.3 Implications for Further Research .............................................. 138
6.5 Conclusion ...................................................................................... 139
REFERENCES ..................................................................................................... 141

APPENDICES .......................................................................................... 150

APPENDIX 1 ............................................................................................... 151
APPENDIX 2 ............................................................................................... 152
APPENDIX 3 ............................................................................................... 154
APPENDIX 4 ............................................................................................... 156
APPENDIX 5 ............................................................................................... 158
APPENDIX 6 ............................................................................................... 160
APPENDIX 7 ............................................................................................... 164
APPENDIX 8 ............................................................................................... 167
APPENDIX 9 ............................................................................................... 168
APPENDIX 10 ............................................................................................. 170
CHAPTER ONE
INTRODUCTION

1.1 Significant Issues in Childhood Deafness

Early access to language, and hence the ability to communicate, is fundamental for any deaf child's development (McNally, Rose, & Quigley, 1987; Spencer & Marschark, 2003). Nadel showed in his work on infant development that a child is socially active from the first minutes of life, and that learning takes place in interaction with others in meaningful contexts (cited in Komesaroff, 2007). With language, children gain the ability to participate in the world around them, enabling them to learn, create memories and develop an understanding of themselves (Hoff & Schatz, 2007). MacDonald and Carrol (cited in Komesaroff, 2007) suggest that to learn to communicate, a child must be engaged in repeated and habitual social exchanges where the child and the caregiver are intimately involved in constructing reality through finely tuned relationships. Families are generally the first context and community in which a child acquires language. Older members of this community draw on their own childhoods to facilitate a child's development of spoken language. In encounters with these others (caregivers and members of the family and, later on, peers and other adults) the child gradually develops a sense of self in relation to the physical world and also the psychosocial world (Stern, 2000). Depending on how effective these language encounters are, the child will create an inner image of self with others.

Traditional developmental psychology has been formed on the idea of the child as an individual constructor of meaning and knowledge. In contrast, interdisciplinary research has clearly shown that developmental processes such as the learning of language and interpersonal communication involve both the caregiver and the child in active roles during
the interaction (Stern, 2000). As the child grows this interactive circle naturally widens because parents form part of a wider cultural context. The dilemma for the 95% of deaf children who are born to hearing parents is that this natural process of language and socialisation may be disrupted (Luterman, 1989, 1999; Richter, Eissele, Laszig, & Lohle, 2002). As with parents of any child, the way parents of a child with a sensory impairment interact with their child depends on a variety of factors. The delivery and underlying philosophy of support systems and habilitation for parents are important variables for the future well-being of the child and family. Societal attitudes towards children with sensory impairments can influence the way parents appraise their child’s potential to develop. The debate regarding delayed language as an inevitable consequence of deafness has ensued, with good evidence suggesting responses to deafness and the lack of appropriate support services may influence the poorer outcomes (Strong, 1988).

1.2 Early Intervention Services in New Zealand

The diagnosis of hearing loss is the initial point of contact with support services for the deaf child and family. The New Zealand health sector is currently introducing universal newborn screening for hearing loss. A family-centred approach to early intervention with deaf children is seen as best practice in New Zealand, but evidence of its widespread acceptance and effectiveness is yet to be evaluated (Douglas & Robinson, 2006). Early intervention with deaf children tends to focus on the earliest period: from birth to 3 years. Early education development theorists suggest that attending to a child’s psychological, emotional and physical needs during these early years promotes the development of secure attachments. This in turn supports a sense of value in self, and trust in others. This period has also been identified as critical for optimal language acquisition. Language mediates interactions between child and parent, family and community. Papoušek and Papoušek (1997) suggest many parenting techniques are intuitive, involving parental adjustment of language and
communication to encourage certain behaviours and maintain attention. The rationale underpinning an early intervention practice assumes that without experience of deaf children, most hearing parents of deaf children cannot draw on this intuitive knowledge and interventions at this point in the child’s development may provide opportunities for these parents to develop the necessary skills and information to deal with their child’s hearing loss (Sass-Lehrer & Bodner-Johnson, 2003).

Many disciplines have contributed to the concept of early intervention for deaf children. These include early education and intervention, child development, medical, special and specialist deaf education services (Sass-Lehrer & Bodner-Johnson, 2003). This diversity, and thus competing paradigms, creates complexity when models of early intervention for deaf children are examined. The term intervention does not transcend all disciplines. Within a medical framework (HEIDI (Project HEIDI), 2004) deafness is framed as a biological deficit requiring correction. Deaf academics and social theorists propose that deafness can be construed as a naturally occurring human state that does not require intervention (Lane, Hoffmeister, & Bahan, 1996). Educationalists use the term intervention to encompass medical interventions, communicative choices and educational adjustments, such as the use of sign language for the wider circle of the deaf child (Mertens, Delk, & Weiderkemp, 2003).

Currently, New Zealand is in the process of introducing universal newborn screening for hearing loss (UNHSEIP). An audiologist is generally the first professional contact for deaf children and their families. After diagnosis, the child is referred to an Adviser on Deaf Children (AODC), a trained hearing professional who provides information on the deaf child’s development and is usually the main contact person between families and their involvement with subsequent hearing professionals and support services (Deaf Education Aotearoa /New Zealand and National Audiology Centre, 2004). The delivery of government-funded services is provided through both the medical and educational sectors. Medical
support includes the diagnosis and assessment of hearing loss, aural health and hearing aid trials, as well as assessment for, and habilitation after, cochlear implantation.

Educational support focuses on supporting language and cognitive development via:

- pre-school services within the two deaf education centres (Kelston and Van Asch)
- ancillary support in mainstream (hearing) early childhood centres
- home based support (focused on parents and siblings)

As deaf children transition to school, resources become managed under the Ministry of Education’s ‘ongoing and reviewable resourcing schemes’ (ORRS funding). In this system, the Ministry’s Group Special Education (GSE) sector coordinates reviews for children who require intervention from specialist services to access the curriculum. This review assesses the level of need, which is usually categorised as very high or high for deaf children. Other support services from the voluntary sector include the New Zealand Federation of Deaf Children Incorporated (NZFDC) and New Zealand Deaf community initiatives. The fragmentation of support services into the voluntary, medical and educational sectors may not promote a wholistic approach to deaf children and their families. In addition it increases the number of individual providers and services with which families need to establish and then maintain relationships. This fragmentation, in itself, may overwhelm some families’ ability to cope.

Government reviews have assessed the support services for deaf children and their families over the last ten years and these reviews have identified a number of “service gaps” (Douglas & Robinson, 2006). As a result, the health sector has responded by reducing the age of diagnosis (HEIDI (Project HEIDI), 2004) and facilitating access to cochlear implantation services. Strategies for resolving the service gaps within the education sector are not as
straightforward. Smiler (2007) has summarised some key areas of concern that have been identified. Concerns that are particularly pertinent to this study are:

- limited support for sign language development in the home and classroom around New Zealand (Laing, 2006; McKee, 2006)
- a shortage of appropriate opportunities for social contact for deaf children and their families with other deaf peers
- a need for improved support for deaf children placed within mainstream educational settings
- a lack of evidence of best practice from an international perspective (Douglas & Robinson, 2006)
- inequitable information, access and co-ordination of services throughout New Zealand (Douglas & Robinson, 2006).

Smiler (2007) notes that this period of review has highlighted the issue of language development and a family-centred approach as being common goals shared by all the support services.

1.3 Anatomy of the Ear and Types of Hearing Loss

Hearing impairment can be addressed in a variety of ways, depending on the type, nature and severity of the hearing loss. The ear comprises the outer, middle and inner ear or cochlear. Dysfunction of the middle ear results in conductive hearing loss, which is generally temporary and may be treatable. Sensorineural hearing loss is caused by damage or malformation to the delicate structures within the cochlear. This hearing loss is permanent and usually in the severe to profound range, that is, greater than ninety decibels in hearing level (dB HL).
Parents may choose to use sign language for communication. However, if the goal for their child is spoken language, there are techno-audiological tools, including hearing aids and/or cochlear implantation. Cochlear implantation has been offered since 1989 in New Zealand and approximately 200 children have received a cochlear implant and remain under the ongoing auditory management of the Southern and Northern Cochlear Implant Programmes. These services provide government-funded audiological and auditory rehabilitation services for implanted children.
1.4 Candidacy for Cochlear Implantation

Sensorineural hearing loss cannot be rectified surgically but can be assisted with conventional hearing aids which deliver an amplified signal into the ear canal. If there is little residual hearing, acoustic amplification will give little benefit. It is for these profoundly deaf children, with minimal if any residual hearing, that cochlear implantation may provide further access to audition (Archbold & Thoutenethoofd, 2005). The major difference between cochlear implants and conventional hearing aids is that the former involve an invasive, irreversible surgical operation on a young child who is not unwell. The operation is performed with the expectation that the child’s life will have increased quality of life as a result of better audition and improved speech perception and production. The benefits of such surgery can be demonstrated only if there is extensive and on-going auditory habilitation for these children (Simser, 1999; Spencer, Gantz, & Knutson, 2004; Tobey, Geers, Brenner, Altuna, & Gabbert). This extensive and sustained aural habilitation work is done primarily by parents.

Decisions about cochlear implantation are generally made after a trial of amplification with hearing aids, and so the decision is not generally “acute” in the traditional medical meaning (Niparko, Kirk, & McConkey, 2000). However there is some urgency because of the reduced neural plasticity of the auditory cortex with increasing age (Cooper & Craddock, 2006; Flexer, 1999; Osberger, Zimmerman-Phillips, & Koch, 2002). If the child receives no benefit from hearing aids, it is urgent to stimulate the auditory nerve. The duration of deafness prior to implantation is important because it affects the progress children will subsequently make (Tobey et al., 2003).

The use of cochlear implants among children with hearing loss has increased substantially in recent years, principally because the criteria for age and degree of hearing loss continue to change. Today, even children younger than 1 year of age are eligible for cochlear
implantation (Lenarz, Bertram, & Battmer, 2000; Niparko et al., 2000; Spencer & Marschark, 2003).

Potential cochlear implant candidates undergo a thorough and extensive assessment protocol to determine suitability, assess chances of success and establish realistic expectations. To be considered a candidate for a cochlear implant, the child must have a severe to profound hearing loss, receive little or no benefit from hearing aids in understanding speech by audition alone, and present no medical reasons that would negatively interfere with surgery and habilitation. Parents must be motivated to provide their child with spoken language as the preferred means of communication. They must also be willing and able to partake in extensive post-implant habilitation and auditory-verbal therapy (Spencer et al., 2004; Tobey et al., 2003).

The following diagram shows the benefit of hearing aids as a function of hearing loss.

![Diagram showing the benefit of hearing aids as a function of hearing loss](image)

*Figure 2. Aided threshold prediction of hearing aid benefit. Aided threshold response patterns obtained from the files of children attending the Children's Hearing Assessment Centre, Nottingham*

Source: McCormick, B., Archbold, S., (Eds) "Cochlear Implants in Young Children"
On the x axis, the hearing loss in decibels is mapped against the y axis showing the frequency in kilohertz. Hearing aids are very efficient with hearing loss of 30-40 decibels but become increasingly ineffective with increasing degrees of hearing loss (severe-to-profound hearing loss is from 80 decibels upwards).
1.5 How a Cochlear Implant Functions

A cochlear implant is an implanted electronic device aimed at providing severely to profoundly deaf individuals with a sensation of hearing (O'Donaghue, 1996). It is a prosthesis that bypasses the sense organ of the cochlear by using electrodes surgically implanted in the cochlea to stimulate the auditory nerve, reintroducing the signals to be carried by the nerve fibres to the central auditory system for processing.

The cochlear implant system comprises both internal and external components.

The external components comprise:

- a microphone
- a speech processor, which analyses, filters and digitises acoustic events into electric signals
- a transmitting coil which sends coded radio signals across the skin to the implant

The internal component comprises:

- an implant with a receiver/stimulator and an electrode array placed into the cochlea.

The microphone picks up sound in the environment, and sends it to the speech processor. The microphone signals are converted into electrical stimuli, then digitised and coded from high to low frequencies to match the frequency representation from base to apex of the basilar membrane. These coded signals are sent from the speech processor to the transmitter, which relays the signals across the skin, via a radiofrequency link, to the implanted receiver/stimulator. The stimulator then delivers the electrical stimulation to the electrodes to activate the auditory nerve fibres in the cochlea. The resulting electrical stimulation is transmitted as neural impulses along the auditory cochlear nerve to the central nervous system.
### 1.6 Issues Raised by Cochlear Implantation: Expectations and Outcomes

Technological advances in medicine often bring new expectations in treating previously untreatable conditions and for improved disease management and treatment outcomes (Li, Bain, & Steinberg, 2004). However, the use of new technology may have ethical and economic challenges, especially if the technology is still evolving and if long-term outcomes are unclear. Patients and families desire involvement in decisions involving health care (Marshall & Swerrisen, 1999), which means decision-making becomes more complex and cannot be guided by scientific facts alone.

Cochlear implantation for young children illustrates this issue well. In 1990 in the United States of America (USA), the Food and Drug Agency (FDA) approved the use of cochlear implants for children on the basis that hearing parents with deaf children can raise them as hearing because this device provides sufficient auditory stimulation for the development of spoken language (Nicholas & Geers, 2006; Niparko, Pulsifier, & Salorio, 2003).

The lengthy cochlear implantation process includes potentially stressful decision making, irreversible surgery and a demanding habilitation process. First, parents must decide whether the cochlear implant should be the sensory aid choice for their child. This decision is based on variable research outcomes (Tobey et al., 2003). Later, parents must deal with anxiety and fear prior to and during surgery (Burger, Eissele, & Spahn, 2005; Perold, 2001). Finally, parents must decide on their child’s educational placement and mode of communication while continuing involvement in the extensive and sustained habilitation process.

Cochlear implantation arouses hopes and expectations for parents that are not always realistic (Zaidman-Zait & Most, 2005). The child may have improved auditory response soon after activation of the device, but acquisition of intelligible speech is normally only accomplished after a lengthy process of habilitation (Stacey, Fortnum, Barton, & Summerfield, 2006).
Speech intelligibility may not improve significantly in the first few years following implantation and demonstrable gains may extend beyond five years of device experience (Tobey et al., 2003).

Cochlear implantation requires professionals to inform, guide, support and collaborate with parents constantly because of the irreversible nature of the surgery (Li et al., 2004). Parents should be considered not only as partners, as they would in many current intervention programmes, but also as direct clients themselves owing to the potentially stressful impact of the process on their own crucial needs and interests when dealing with this challenge (Burger et al., 2006).

Definitions of realistic expectations for a particular child may be challenging because while the literature documents that use of cochlear implants can significantly improve speech and language skills among children (Nicholas & Geers, 2006; Tobey et al., 2003), it also indicates great variability in individual outcomes (Archbold, Lutman, Gregory, Nikolopoulos, & O'Neill, 2002; Spencer & Marschark, 2003). As stated by (Marschark, Lang, & Albertini, 2002): “Unfortunately for both users and investigators, outcome variability is so great that it is difficult to make any good generalizations at this point” (p. 55). However, based on the large body of literature examining factors that impact on outcomes of cochlear implantation, clinicians and researchers are beginning to be able make some generalisations about these outcomes (Nikolopoulos, Lloyd, O'Donaghue, & Archbold 2001).

They still cannot however, predict the exact outcome that an individual child will achieve or predict which families will adapt to the complex habilitation process (Marschark et al., 2002). In addition, the widely used term expectations may encompass diverse areas beyond communication abilities, such as social and academic aspirations. Thus, it is even more
difficult to define realistic expectations in areas that have not been fully explored in research. Theorists have suggested that the parents’ stage in the process of grieving over their child’s deafness may influence their reasons for wanting the cochlear implant in addition to their expectations concerning their outcomes (Kampfe, Tambry, Ludington, McDonald-Bell, & Pillsbury, 1993; Kluwin & Stewart, 2000). For example, Kampfe and colleagues proposed that parents who are in a state of denial may be seeking a miracle cure that will completely remove deafness from their lives. It is possible that unrealistic expectations may impair parents’ ability to internalise information that does not support their expectations. This complex relationship between parents’ grief, individual coping processes and expectations for cochlear implantation has not yet been studied comprehensively.

Bruce & Schultz (2001) note that there has been a tendency in the literature and in practice to rely on the theoretical paradigms specific to death and dying to explain grief responses in general. This position is based on the assumption that these paradigms are not only relevant to parents who have children with disabilities, but can also be used to interpret a range of personal experiences of loss. Adoption of this theoretical perspective could lead to stereotyping and the placing of unreasonable expectations on those who experience losses other than death. Irrespective of the non-finite nature of loss, these individuals are expected to resolve their grief and accept their loss (Apicella, 1993). Family-centred intervention programmes have become common in the education of children with hearing loss. The underlying philosophy of these programmes is facilitation of collaborative partnerships to develop parental competence and involvement in their child’s education and development (Meadow-Orlans, Mertens, & Scott-Olson, 1997).

Despite early concerns and criticisms about the experimental nature of implanting children, concerns about possible psychosocial challenges and stress for parents of implanted children
(Burger et al., 2005), the risk of bacterial meningitis (Biernath et al.) and the lack of definitive evidence of patient characteristics that predict superior outcomes, candidacy criteria for cochlear implants have consistently widened since the release of the Nucleus 22 in 1985 (Osberger et al., 2002). This was the first cochlear implant device to gain FDA approval. Early guidelines for cochlear implants restricted use to post-lingually deafened adults with profound hearing loss (equal to or greater than 90 decibels of hearing loss) who exhibited no open-set speech recognition skills and did not benefit from hearing aids. Even though adults demonstrated high levels of performance, many hearing professionals were apprehensive about perceived benefits for children. Unlike post-lingually deafened adults who use the signal from cochlear implants to compare with previous auditory memory, a pre-lingually deafened child must use this signal to differentiate auditory events and organise and store these data for later access and meaningful use. This is a formidable task given the temporal and frequency resolving powers of the human ear. However, young children have the advantage of greater neural plasticity, particularly if implanted at a young age. Research has also shown that speech perception and production develop over a relatively long time in a pre-lingually deafened child (Osberger et al., 2002).

The research in the area of parental experiences to date has focused on limited evaluation of parents’ anxieties, responses, perceptions, expectations and adjustments related to their children’s cochlear implantation. Perold (2000), who studied eight parents with implanted children, reported increased anxiety during “activation” as well as disappointment during the “despondency period”, which lasted many months after surgery. This was likely, the authors concluded, because parents unrealistically expected an immediate change in their child’s communication skills. Likewise, Quittner (Quittner, Steck, & Rouiller, 1991) found that stress among parents did not necessarily decrease post-operatively and may even have increased. These authors also attributed this psychological stress to unrealised expectations,
the necessity of intense parental involvement in habilitation and possible restriction of parents' own lives. Beadle's study of 17 sets of parents also revealed parental reports of stress, but none at extremely high levels (Beadle, Shores, & Wood, 2000). Parents also reported receiving more support from formal sources like the cochlear implant team than from informal sources like family and friends. Parents who reported higher social support reported higher outcomes for their children and possibly an improved quality of life (Hintermair, 2006; Spahn, Burger, Loschmann, & Richter, 2004). Beadle also compared current parental expectations with parents' expectations prior to surgery. Beadles' results suggest that parents may change their expectations over time according to their experience with their own child. Spahn, in her study on quality of life and psychological distress in parents (Spahn et al., 2004), showed that parental quality of life was moderately reduced for both parents. She found that the level of distress was greater in fathers than mothers, but this may have been confounded by other sources of distress. The information given by fathers may be important in assisting parents of cochlear-implanted children in clinical practice. The fact that fathers are often less present than mothers in the child's therapy is not necessarily because of lack of interest or motivation. Paternal distress should be noted and "care should be taken to organize treatment in a way so that professionally active fathers are able to be involved in their child's therapy" (p. 24).

Spahn also felt it was important to investigate further the relationship between the duration of auditory habilitation of the child and the parents' psychosocial distress. While psychosocial distress seems to rise with the child's increasing age, parental quality of life seems to improve with duration of implant use. Hintermair's (2004, 2006) results suggested that relationships between parents become strained with the child's increasing age, which he argued, could lead to heightened parental distress. Reasons could be that, in accordance with normal development psychology, the parents' unconditional affection subsides with the increasing
age of the child, so that the more problematic side of the hearing impairment becomes more obvious to the parents. Spahn (Spahn et al., 2004) did not find any positive relationship between the speech ability of cochlear-implanted children and the extent of parental distress and loss of quality of life. One plausible explanation is that the ability of parents to cope positively with their child’s hearing impairment relates more closely with parents’ own psychological state than to the child’s actual hearing and speech impediment.

Anecdotal evidence (Archbold et al., 2002; Chute & Nevins, 2002) provided by parents described a range of parental observations following cochlear implantation, such as ease of acquiring speech and language, improved quality of life, greater social success, and more opportunities for the child. Parental expectations are also reflected in parents’ motivation for having the cochlear implant for their child. In Christiansen and Leigh’s 2002 study, 52% of participating parents reported that “ease of development of spoken language is their main motivation for cochlear implant”. In another study, 37% of parents mentioned the “desire to have a child who functions as a hearing person” as their main reason for choosing a cochlear implant (Kluwin & Stewart, 2000).

Parents’ satisfaction with the cochlear implant depends on their prior expectations (Meadow-Orlans, Mertens, & Sass-Lehrer, 2003). In a parental survey in 2003, 67% of the parents reported that they were very satisfied with the cochlear implant results (Meadow-Orlans et al., 2003). Similarly, in another survey, 67% of the parents reported that they were very satisfied with their child’s cochlear implant progress, and 39% were very satisfied with their child’s spoken language skills (Christiansen & Leigh, 2002).

The importance of examining different aspects of parental experience stems from policies developed in early intervention programmes, which aim to improve service delivery both for
children and their families (Simser, 1999). Family-focused intervention programmes have become a common practice in the education of children with hearing loss. The underlying philosophy proposes that professionals’ provision of information, guidance and support will empower parents to build collaborative partnerships for competence and involvement in their child’s education and development (Meadow-Orlans et al., 1997; Minke & Scott, 1995).

Satisfactory relationships between families and professionals in early intervention may be crucial for improved parental coping and involvement in habilitation as well as better child outcomes (Hadadian & Merbler, 1995; Minke & Scott, 1995). Perold (2001) noted the crucial importance of support for parents in the “despondency” period after implant surgery to help parents negotiate realistic expectations for their child’s slow progress.

In summary, cochlear implantation has become a preferred method for treating children either born deaf or pre-lingually deafened, whose parents choose a spoken language for their child. In terms of safety, effective device placement and ongoing audiological support, the provision of cochlear implants for children has attained an internationally high standard (Archbold & Thoutenethoofd, 2005; NIH Consensus conference, 1995; Niparko et al., 2003; Richter et al., 2002) With this surgery and technology, sensorineural hearing loss can be managed within a biomedical paradigm for some children. However, the majority of studies to date have focused on closed-format questionnaires devised by professionals to investigate perceptions of parents regarding outcomes for their child (Archbold et al., 2002; Nikolopoulos et al., 2001) even though they may have used the interview style of data collection. Such questionnaires may limit the responses that can be made, and hence may influence the measured outcomes. In general these data are analysed using quantitative methods, as they examine fixed variables and parameters, rather than trying to understand the meaning of these experiences for parents and how they are incorporated into their lives. Little
systematic published research has been based on the unrestricted reports and experiences of parents after their child receives a diagnosis of deafness or the journey from hearing aids to the decision about implantation. There is also little information about how parents adapt to changes as their child becomes a cochlear implant candidate, undergoes surgery and then begins the intense and ongoing phase of mapping and auditory habilitation.

1.7: The Deaf Community and Parents

Until recently the hearing parents of 95% of profoundly deaf children have needed to consider the use of sign language to allow their child to develop a language because gains with hearing aids do not permit auditory access in many environments. The use of listening skills alone would lead to significant gaps in communication and, in an educational setting, compromise learning.

Parents and their children live in a societal context that may influence the decision-making process. The Deaf community has made some strong statements since the inception of cochlear implantation and at times provided a barrage of publicity of intense negative reactions (Christiansen & Leigh, 2002).

Despite enthusiasm in some quarters about the use of cochlear implants in children, their use remains controversial for some groups and not all children are guaranteed of a successful outcome (Nikopololous, O'Donaghue, & Archbold, 1999; O'Donaghue, 1996; Spencer et al., 2004; Spencer & Marsckark, 2003). However, despite the publicity about intense negative reactions by many in the Deaf community to cochlear implants, paediatric implantation has continued to increase exponentially. Internationally, well over 40,000 persons have now received an implant (Christiansen & Leigh, 2002).
The process of adapting to life as a deaf person has often encouraged connections based on shared experiences, a feeling of difference from the majority hearing community and proximity to other deaf people. Those who identify as Deaf usually have a severe or profound hearing loss. For many in the Deaf community, being Deaf is as much about life and culture as it is about the audiological results which define the severity of the hearing loss (Brueggemann, 1999; Lane et al., 1996). Individuals who identify as culturally Deaf (in contrast to audiologically deaf) perceive themselves as a linguistic minority because of their use of sign language, a visual language with its own grammar and syntax. This visual orientation, which differs from reliance on sound by those who use amplification devices, has facilitated shared ways of being that reinforce the bond with the Deaf community (Padden, 1980). Many in this group do not value speech and hearing aids, and do not see themselves with characteristics of “disability” in relation to deafness. Such characteristics may include linguistic deprivation, powerlessness, incompetence, and deviation from a norm that focuses on “hearing” as an essential characteristic (Davis, 1995; Olkin, 1999). These individuals identify themselves as a normal part of human diversity. Their objection to the use of the phrase hearing impaired is that it emphasises disabled functioning in the guise of “broken ears” that need repairing (Christiansen & Leigh, 2002). It is often said that the Deaf community is not homogeneous but reflects social, political, linguistic, religious, and communicative variations (Christiansen & Leigh, 2002; Padden, 1980). Even the notion of a Deaf culture is not sacrosanct. In 1992 in the United States of America, Larry Stewart (a deaf professional well known for his outspoken advocacy for deaf children, their parents, and the Deaf community) wrote that the phrase “Deaf culture” was developed for political purposes and to deny deafness as a disability was nonsensical (Stewart, 1992).
Another perspective is demonstrated in the following quote by a successful young American student who won a prize for a documentary *Listen*: an exploration of what it means to be profoundly deaf:

I want to help people understand the distinction between being culturally Deaf and being a person who is profoundly deaf and living in the mainstream. Although I am deaf and sometimes have difficulties interacting in the hearing world, I am not culturally Deaf. In my experience, I have found that many people who are not familiar with hearing loss automatically assume that I am culturally Deaf (Newton, 2006).

The existence of these differences within the Deaf community may be at odds with the typical assumption made by many writers that the Deaf community has one “collective” voice (Chute & Nevins, 2002) and therefore one stance on the issue of cochlear implantation.

Some authors have explained this phenomenon of a “collective voice” as arising out of the frustrations of being dominated by a hearing society (Humphries, 1993) and being thus marginalised. At Gallaudet University in the US, the 1998 “Deaf President Now Movement”, culminated in the appointment of the first deaf president and reflected a reaction to this negative perception of deaf persons (Christiansen & Leigh, 2002). This “voice” of the Deaf community has come to symbolise the struggle by deaf people to control the direction of their lives and how they are portrayed in the media and to have more influence over the education of deaf children. The emergence of cochlear implantation presents a challenge to this “voice”, as it offers a medical intervention that can allow profoundly deaf children the opportunity to be educated in a hearing world. Now that numerous studies have documented the efficacy of this procedure (Cooper & Craddock, 2006; Niparko et al., 2003; O'Donaghue, 1996; O'Donaghue, Nikolopoulos, Archbold, & Tait, 1998) there is considerable controversy because of the challenge to deaf people's empowerment. Parents of children with implants
and the Deaf community have had an uneasy co-existence since the advent of cochlear implantation. For example, Larry Fleischer, a prominent deaf community activist and professor of Deaf Studies at California State University states, “Somehow, the idea must be conveyed that human rights for deaf children, based on the wealth of the Deaf experience, must supersede the notion of birthrights for deaf children born to hearing parents” whom he considered “ill-informed, ill-prepared, ill-advised and ill-fated” (Fleischer & Holliday, 1993).

A view from a parent countered by saying:

The hearing parent is bypassed, dismissed as an insignificant factor in his child’s own growth and development. To blindly proclaim that cochlear implants are universally wrong for all children and that parents are incapable or unable to make that decision for their children demonstrates a total lack of understanding of the parent-child relationship (Apicella, 1993).

Hampton’s survey on current perspectives on cochlear implants reported in Christiansen and Leigh (2002) concludes: “that it is possible to have a cochlear implant and still retains one’s identity as a culturally Deaf person”. This statement suggests that the Deaf community has begun to recognize that individuals with cochlear implants can still be affiliated with the Deaf community and that they are still deaf. Christiansen and Leigh (2002) conclude by stating:

More and more members of the Deaf community are considering implants and are beginning to adapt to the reality that children with implants are still perceived as deaf. Their task is to communicate this to parents of deaf children with cochlear implants.

Corker (1998), who has written extensively on the validity of the construct of deafness as a separate culture, argues that:

Being “like” someone or something is a matter of degree and that this is critical in the social stratification of deaf and disabled communities. We can be compelled to conform to a particular
identity because we are under pressure to fit, or we may have been rejected from an alternative frame-
work that we might have chosen had we been given the choice. For many deaf people, choosing be-
tween Deaf or hearing does not represent a real choice of social identification at all.

1.8 Ethical Dilemmas for Parents and Providers

The issues of parents’ right to implant their child by proxy consent or to wait until the child is old enough to be involved in the decision-making process is the crux of the ethical debate for paediatric cochlear implantation (Christiansen & Leigh, 2002).

Ethics are moral principles adopted by an individual, group or culture to provide rules for appropriate conduct. Morality in general refers to social conventions about what is perceived as right or wrongs (an expectation about human conduct as shared by a group religion or community). Morality involves some analysis of actions on the basis of a broader cultural context or value system (Clark, 1997; Jonsen, Siegler, & Winslade, 1998). Therefore, behaviour perceived as ethical by one group may be seen as unethical by another, depending on the paradigm. Paediatric cochlear implantation is a case in point. Experts viewing the same research results often come to diametrically opposed conclusions regarding the ethics of the procedure (Christiansen & Leigh, 2002). Those who identify with the culturally Deaf have commented that the cochlear implantation procedure is unethical, whereas those who do not share this perspective are likely to see cochlear implantation as ethical because it offers the family and child more educational choices. Given that most parents of deaf children are hearing, failing to restore some form of hearing could be considered as denying these children the cultural heritage of their hearing parents. Intentions of parents who wish to have some mechanism of providing their children with audition deserve equal respect with the contrasting wishes of the culturally Deaf community. There is however, a lack of clear research on educational and long-term employment outcomes for implanted children.
(Archbold & Thoutenethoofd, 2005). It may be argued that cochlear implantation is meeting the needs of parents to raise their child in the hearing world, but not necessarily equipping these children to function ultimately as "hearing" adults despite their cochlear implants.

Others see cochlear implantation as a medical solution to the problem of "deafness". This medical model of deafness as something to be remedied is far removed from the linguistic or sociological model of deafness. The use of technology involving an expensive surgical procedure and lifelong maintenance by an unusually wide range of professionals creates a dilemma if the measurement of outcomes derives primarily from a scientific and medical context with little measurement of quality of life outcomes for these children and their families. Blume (1994) noted that the medical profession has tended to equate "best practice" with the use of modern technology and the notion of a "cure". While undoubtedly ever-improving technology has had a positive effect on the lives of many people, including the Deaf, ongoing debate about the effectiveness of cochlear implants will contribute to the controversy. In addition, there is an implicit assumption that technology will facilitate "normalisation" into a hearing world for children who would otherwise become useful contributors to the deaf community (Stewart-Muirhead, 1998). Medical decisions should consider the extent to which expected benefits outweigh the risks, and if the new technology is an accepted clinical procedure and not a subject of research (Blume, 1994; Clark, 1997). These decisions are generally based on the principles of beneficence, non-malificence and respect for autonomy (Jonsen et al., 1998). Beneficence means the duty of physicians to do good. This duty is closely tied with their ability to fulfill the goals of medicine in conjunction with the patient's wishes for their own life. It involves judgment about how much benefit individuals receive. The corollary to beneficence is non-malificence, which is the duty to refrain from causing harm in the interest of maintaining well-being. Surgical risks and technological failure need to be considered as well as psychological and social issues of the
surgery. The balance is a judgment based on the available research on degrees of benefit weighed against degrees of harm. *Respect for autonomy* is based on the principle that individuals are capable of making decisions for themselves.

Informed consent to medical interventions is defined as the *"willing acceptance of a medical intervention by a patient after adequate disclosure by the physician of the nature of the intervention, its risks and benefits, as well as of alternatives with their risks and benefits"* (Jonsen et al., 1998). Informed consent for cochlear implantation depends on the comprehensiveness, accuracy and intelligibility of the specific information disclosed to an adult or a child’s lawful surrogate. It also depends on the value judgment of the person providing the information. Professionals need to be confident that the recipients of the information understand and interpret this information. Shannon (1997) considers informed consent to be one of the most crucial problems in bioethics. Ethical decisions for cochlear implantation are not clear-cut since both sides of the debate can evoke ethical principles depending on their paradigm. Both sides of the debate could argue they have the deaf child’s interest at heart. Ultimately, there will be a process weighing up the available research, the wishes of the parents and the medical and educational support services offered in that particular community. This process will ideally be interactive, individualised and non-prescriptive (Wegener, 1996).

**Beneficence**

The principle of beneficence comes into play with the consideration that by providing communicative benefit, increased audition and probably safety, “one is doing good for the child” (Balkany, Hodges, & Goodman, 1996). The hope is that after implantation the profoundly deaf child will benefit by improved spoken language and interaction with hearing peers. The assumption is that these skills will facilitate educational and employment
opportunities. The child's life will not be constrained by limited spoken communication resulting, had that child been educated primarily within the Deaf community. Proponents of this position also argue that cochlear implantation does not remove freedom of choice because the child can still decide as an adult to become part of the Deaf community or to straddle both communities. Implanted children still retain the “right to be deaf” as well as the “right to choose”.

The medical profession no longer considers this surgical procedure experimental and medical complications occur infrequently (Cohen, 1995). Cochlear implantation for children has become an acceptable clinical practice only after extensive work with deaf adults, based on ethically accepted practices for research (Clark, 1997). The literature to date has focused on specific outcomes measured by speech language tests (Niparko et al., 2003). Long-term research outcomes covering linguistic, communicative, and psychosocial factors will be critical to address the issue of benefit versus risk. Some supporters of cochlear implantation argue that they already have sufficient objective evidence, both medical and linguistic, to frame the procedure as clinically acceptable. However, cochlear implantation, like any other clinical procedure is ethically acceptable only for appropriate candidates, for whom benefits are likely to outweigh risks.

Conversely, culturally Deaf people often do not see themselves as being condemned to an inferior world of silence. They see their lives as linguistically rich and fulfilling, and believe that in opening the deaf child’s world to sign language parents will facilitate a transition to this cultural heritage (Lane, 1999; Stewart-Muirhead, 1998). They argue that this is a form of beneficence. Lane and Bahan (1996) describe prelingually deaf children as visual, and thereby part of Deaf culture even if their parents are hearing. Within this paradigm, the medical construction of deafness as a disability is jettisoned for a social construction of
deafness as a way of life. They argue that with cochlear implantation, the focus is on the child's impairment and not on the child. The surgery may influence the child to move away from a more natural signed method of language and communication toward an artificial hearing status that still does not guarantee acceptance into the hearing world. They also argue that allowing the child the right to be deaf does not necessarily jeopardise connections with the hearing world. Supporting to this stance, the executive director of the National Association of the Deaf in the USA writes about the reality of many deaf children and adults functioning in both the deaf and hearing communities (Bloch, 1999). To opponents of paediatric implants, reducing access to the Deaf community and signing world by promoting audition, when clear alternative and established mechanisms of communication already exist, means that harm is being done. The child is being denied access to visual language development, the right to be Deaf and the right to become part of the Deaf community. Some members of the Deaf community do not agree that cochlear implant surgery poses minimal risk. Although the increased safety of the procedure has been acknowledged, the procedure is still seen as invasive and applied to healthy people (Lane et al., 1996).

While risks are infrequent, technological failure is a possibility. The value of the surgery, with its major goal of increased and superior interaction with hearing society, is challenged as a worthy goal. Lane (1998) contends that the surgery continues to be innovative and does not meet the criteria of beneficence. This issue requires careful consideration because the path to oralism is arduous, with no guarantee of fluency in the hearing society. Archbold et al (2005) conclude from their review of outcomes of cochlear implantation that long-term outcomes showing evidence of benefit remain unclear.
Non-Malificence

Surgical techniques for cochlear implantation have evolved over the past 15 years. Incisions have become smaller and minimally invasive surgery is now a reality. Surgical complications, although relatively rare and frequently minor, are still a matter of concern as they may cause serious morbidity, even mortality in the case of meningitis. Therefore, several studies in the literature have reported surgical outcomes. Large centres report between 3 and 4% complications in implanted children. However, most of these studies have a relatively short follow-up, an important shortcoming, as it may be that long-term complications are underestimated (Archbold & Thoutenethoofd, 2005).

For parents the decision to implant is not an easy one, with age of implantation now 12 months or younger. While parents are counselled by cochlear implant teams that the device is not a cure for deafness, there are media and professionals who present it as a key for success in the “hearing world”. Parents may suspend grief when there is the possibility that their child may develop “normally” and the family may again become “normal”. The grief process may be put aside when highly specialised therapists and devices offer parents the hope that their child will talk and attend mainstream schools. Parents may focus their energies on treatments that assure their child’s chances of becoming like a hearing child. Parents may never deal directly with their feelings because the technology does not “cure” the deafness or the child’s difference. For some parents, the search for the normal child they were supposed to have never ceases. This could be seen as a failure of counselling. If parents do not learn to accept their child, both the child and the parent can never integrate the deafness into their lives in a way that permits acceptance (Luterman & Kurtzer-White, 2003). The work of Feher-Pout (1996) indicates there are clear links between family competence and adjustment, and adjustment and achievement in both preschool and school-age children. Therefore a potential consequence of not accepting their child as deaf is of concern. If a medical intervention has
the potential to interrupt a pattern of grieving and thereby prolong distress, it may be regarded as potentially maleficent.

**Respect for Autonomy**

The third principle, *respect for autonomy*, means that the patient (or parent in the case of a minor) is respected as a decision-maker and as an agent of self-determination. The National Institutes of Health Consensus Development Conference Statement (NIH Consensus conference, 1995) is explicit in supporting parental responsibility for decision-making. Balkany (1996) states that parents act in support of the rights of their children, including freedom of choice, respect for the individual and informed consent, to make decisions on behalf of their child. Unbiased information covering reasonable expectations and risk as well as evidence of benefit must be provided (Chute & Nevins, 2002). This process of deciding in favour of cochlear implantation is also occurring at a time of heightened stress for parents (Burger et al., 2005; Hintermair, 2006; Quittner et al., 1991) and thus their capacity for processing information about cochlear implantation needs to be carefully considered. To facilitate informed choice for parents, cochlear implant professionals must inform parents that cochlear implants do not restore normal hearing, outcomes remain variable and long-term commitment to habilitation is required.

To minimise the danger of unrealistic expectations, Pollard (1996) recommends that professionals provide sufficient information for parents to give informed consent with regard to technology and the lengthy habilitation process. However, he also recommends providing parents with the opportunity to appreciate a phenomenological awareness of deafness (the lived experience). This means providing an opportunity to have an unbiased appreciation of what life with hearing loss is like, whether implanted or non-implanted. Parents should understand that deaf children can have satisfying lives with or without an implant. He
suggests that there should be an independent person on a cochlear implant team to ask some questions of the parent and child (if old enough) to assess expectations and minimise any unacknowledged pressure from those who stand to benefit from the parents' decisions (Clark, 1997). Opponents of paediatric implants have raised the issue of biased information being presented to parents by cochlear implant teams (Bienenstock, 1998/1999). The medical community could take a lead role in their assessment process by providing a more holistic approach to cochlear implantation by offering unbiased information about the lives of deaf people. Opponents of implants question parents' ability to make decision about implants because of their relative ignorance about the rich lives of many deaf adults. However despite this stance, Lane (1999) reiterates the rights of parents to make informed decisions on the part of their child, but acknowledges that funding bodies are responsible for providing evidence of effectiveness.

The role of children and adolescents in the decision-making process is complex, but it is an important role given the intensive post-surgical habilitation that is necessary. Legally a child or adolescent under sixteen need not play a role in decision-making or consent for treatment, but ethically, most professionals believe children should be involved where possible (Deaton, 1996). However with the increasing uptake of newborn screening, and earlier age of implantation, the right for older children to be involved is becoming less of an issue because the decision is being made for children who are clearly too young to be involved themselves (Christiansen & Leigh, 2002).

Justice

While beneficence, non-malificence and autonomy relate specifically to the individual child and family, equally important is the principle of justice as it relates to the wider community. This is unlikely to be foremost in parents' minds at the time of the option of implantation. It
is, however, an issue for professionals who must decide on the wise and ethical use of national health resources (Cohen, 1995; Shannon, 1997). The reality of under-representation of racial and ethnic groups as implant candidates is a serious ethical concern (Christiansen & Leigh, 2002). The number of languages children hear may affect outcomes and ethnicity may affect pre-implantation processes such as candidacy evaluation and test performance. Ethnicity may also affect the initial referral to implant centres, as accessing the services and information may be more difficult for ethnic minority families (Archbold & Thoutenelhoofd, 2005). If research indicates improved academic performance by deaf children with cochlear implants then education and development of children without access to implants and those who are geographically isolated from habilitation services could be jeopardised.

1.9 An Anthropological Perspective

Traditionally, culture has been broadly defined as the "way of life" of a people, which includes norms, values, mores, language and other characteristics. "Deaf culture" therefore incorporates sign language, educational services for deaf children, deaf clubs, deaf sport and mores guiding interactions between deaf and hearing persons. The concept of a "hearing culture" is proposed as a contrast as if it too has distinguishing values and norms. Mention has already been made of some of the complexities inherent in viewing "hearing persons" or "deaf persons" each as belonging to a homogenous culture (Christiansen & Leigh, 2002; Padden, 1980; Stewart, 1992).

Laing (2006), who is a parent of a deaf child and trained as an anthropologist, writes of her experiences. Knowledge of migration theory assisted her process of straddling the deaf and hearing worlds with her daughter. This migration model is based on an understanding that
deafness can be considered as a cultural-linguistic paradigm rather than the more traditional medical paradigm. In terms of outcomes for children, much has been written of the dangers of treating a deaf child as disabled from the medical deficit paradigm, without this broader cultural perspective of deafness (Holcomb.T.K., 1997; Luterman, 1989; McKee, 2001). Laing (Laing, 2006) wrote:

Hearing parents of deaf children fall somewhere between refugees forced to move and migrants with a vision of a better world. (p.83)

One of the problems with this traditional definition of culture is that it does not readily provide tools to analyse the behaviours of individuals. The sociologist Anne Swidler (Swidler, 1986) suggests that it may be helpful to see culture as a “tool kit” from which individuals are able to select various pieces to construct “strategies in action” to deal with varying situations.

This view of culture focuses more on the means by which challenges are solved, rather than seeing culture as the ends or values, that are learned via an unconscious process of socialisation. This view permits insight of individuals' understanding of their situations and their behaviours. In her discussion of culture in action, Swidler focuses on two situations. In one, she refers to “settled” lives in which a tool kit of skills and knowledge suffice. “Settled” lives permit use of previous experiences. The corollary is of course “unsettled” lives, which can be seen in the more traditional context of culture but can equally be applied to a family undergoing change. (Laing, 2006) suggests these families may undergo cultural change. Parenting newly diagnosed deaf infants will severely challenge the 95% of parents, who are hearing. Their knowledge of deafness is limited and the grieving process is likely to delay their ability to absorb complex information.
Swidler argues that even during these “unsettled” periods, people are reluctant to abandon strategies with which they feel confident and familiar. Therefore it is predictable that hearing parents wish their child to hear (Christiansen & Leigh, 2002; Kluwin & Stewart, 2000). Unfortunately, this is not always possible as it depends on success with hearing aids and criteria for cochlear implantation. As a result, parents may have to adapt to alternatives. At this point they may become overwhelmed and vulnerable (Burger et al., 2005; Hintermair, 2006). Luterman (1989) has written extensively about this process that families face. He views deafness in the family as a challenge to family homeostasis and of the family paradigm.

Reiss (1981) adapted the notion of paradigmatic shift to families. His theory is that each individual develops a personal paradigm with his or her own constructs and expectations. When two or more people develop an intimate relationship, personal paradigms are reconciled to form a family paradigm. Growth for families could be seen as a series of challenges to a prevailing paradigm, and change results from a shift in this paradigm. This concept may be useful when examining families under stress with a deaf child. The most significant period of stress for the family appears to be at diagnosis and in the subsequent months when much new knowledge needs to be assimilated (Burger et al., 2005; Burger et al., 2006; Quittner et al., 1991; Simser, 1999; Spahn et al., 2004). During this time a new paradigm has to be established as they are now a “deaf family”. Within Swidlers’ framework, this is an “unsettled” period when families are operating with an inappropriate tool kit.

Of all the personnel involved in the implant process, it is the parents who remain the strongest source of support for their child, and levels of parental responsibility need to be sustained for successful speech and language development (Archbold & Thoutenethoofd, 2005; O’Donaghue, 1996; Simser, 1999). Results indicating improved outcomes from an
earlier age of implantation can add stress because parents feel pressured. This time pressure may detract from a more uninterrupted and natural process of decision making (Nicholas & Geers, 2006; Spencer et al., 2004).

1.10 Future Considerations

So far the discussion has centred on the issues involving a unilateral cochlear implant. Increasing (but still small) numbers of parents are considering bilateral implants. In New Zealand only one implant is currently funded per child so parents must pay the cost of the second implant themselves at a cost of $40,000-45,000. Bilateral implants may offer the possibility of binaural hearing. Binaural hearing permits the ability to process temporal, level and spectral information to both ears. One advantage of binaural hearing is having the opportunity to choose which ear to attend. To accomplish this, the brain receives input from both ears, locks on to the side with the better signal-to-noise ratio and inhibits the input from the side with the poorer ratio (Cooper & Craddock, 2006). This task is accomplished by a brain mechanism that attends to one ear while, in the background, monitoring the less clear side in case the optimal ear changes. When information is the same at both ears there is binaural advantage, often referred to as binaural summation. It occurs owing to a brain mechanism that combines or sums the information from each ear to provide an overall increase in loudness of the signal. Binaural summation typically refers to either an improvement in threshold, or a similar increase in loudness. Another way to think about the advantage of listening when the information is the same at both ears is that there are two versions of the same signal. Even though the information may be redundant, having redundant information can be useful in sub-optimal listening situations. In addition the brain can combine different information from both ears to improve performance which results in improved understanding over monaural listening. The term “squelching” describes the
boosting of the effective signal-to-noise ratio under binaural listening conditions (Cooper & Craddock, 2006).

A bilateral cochlear implant offers the potential advantages of localisation of sound, perception of speech and an improvement in the qualitative dimension of sound. The latter may include a more natural, balanced sound and improved “ease of listening” (Byrne, 1980).

Van Hoesel has examined the benefits of bilateral implants (Gantz & Tyler, 2002; R. van Hoesel, Ramsden, & Odriscoll, 2002; R. J. M. van Hoesel, 2004; R. J. M. van Hoesel & Tyler, 2003) and concludes that the results now leave little doubt that recipients stand to gain substantially from using both ears rather than just one, particularly for understanding speech in the presence of noise from another direction, and for localisation of sounds in the horizontal plane. The main benefits seem to derive from level cues at the two ears. However, benefits from binaural summation and squelch are not present in all patients.

There are more serious risks with bilateral implantation. In addition, the destruction of cochlear tissue in both ears may limit the individual’s ability to take advantage of future implant designs, molecular and genetic treatments. Many of the surgical risks involved in receiving two implants are similar to, or greater than those involved in receiving one implant (Gantz & Tyler, 2002).

Cooper and Craddock (2006) document growing interest in potential benefits of bilateral implants but also note concerns regarding increased costs. They frame some general principles that have received consensus. These principles suggest that two implants almost always create better hearing than one implant. However if a choice needs to be made, it is
better to offer two people one implant each than one person two implants on the basis of cost, risk, increased fitting time, maintenance and battery replacement.

The option of bilateral implants raise an issue about the value placed on monaural versus binaural hearing. This evaluation will involve some subjective decision making about the deaf child's quality of life.

At the time of writing this thesis, information provided to parents in New Zealand on the risks, benefits and optimal timing of bilateral implants is generally only provided on request.
Summary

Cochlear implantation is now an accepted management for deaf children, with the major goal to provide sufficient hearing to support the development of spoken language. Outcomes in terms of speech perception and production are published (Archbold & Thoutenethoofd, 2005), with age at implantation being a major factor in outcomes (Nikopoloulos et al., 1999). With newborn hearing screening and early diagnosis now being an important objective for New Zealand, very early implantation is much more likely, with the consequent expectation of greater benefit. This chapter has reviewed the literature regarding the medical, social and ethical issues that arise for parents at a time of high stress, non-finite grief and vulnerability. Significant decisions need to be made which may have long-lasting outcomes for the educational and social development of their child.

The ways in which parents experience these challenges, decisions and ethical considerations while navigating their way through this period of change in their lives are addressed with this research.
CHAPTER 2
METHODOLOGY

2.1 Introduction

This chapter explains the underlying methodological assumptions of the current study. The constructivist paradigm (Guba & Lincoln, 1985) informed the research approach. The terms used within the study are consistent with those of Lincoln and Guba (1985). The constructivist paradigm assumes there are multiple social realities, and that the researcher and participant create understanding through methods of naturalistic inquiry. This chapter outlines this constructivist paradigm, identifies the influence of the ontological and methodological assumptions and discusses the concepts of reflexivity and reciprocity as they may relate to this study. It also examines the use of narrative within the discipline of General Practice and explains the complex interaction between the disease/impairment with which the patient is diagnosed, and the patient who shapes understanding of how these present as human experiences. The work of Greenhalgh (1999), who has written extensively on the subject of narrative in medicine, has also informed this research approach.

2.2 Theoretical Framework and Underlying Assumptions

The aim of the current study was to examine the lived experiences of parents with profoundly deaf children who undergo cochlear implantation. The study aims to increase knowledge of the issues faced by parents from the time of diagnosis through to the post-implantation period. The goal of the researcher using an interpretative/constructivist approach is to examine the meanings that particular situations have for individual participants (Schwandt, 1994). The actual construction or discovery of new knowledge is created in the interaction between the researcher and the participants. The researcher therefore, influences the
interview, the manner in which it is conducted and the meanings that emanate from this interaction. Consistent with the aim of this study, the guiding paradigm is constructivism. Guba’s (1990) definition of a paradigm is a “basic set of beliefs that guide action” (p. 17). Therefore this study was not looking for a single truth that could be verified but rather, the exploration of several experiences of childhood implantation within different life contexts. There was an assumption that the meaning of their experiences would vary.

2.3 Naturalistic Inquiry

In naturalistic inquiry the researcher does not attempt to manipulate the setting. The purpose of qualitative methods is to examine naturally occurring experiences. Guba (Guba & Lincoln, 1981) identified two dimensions along which scientific inquiry can be described: firstly the extent to which scientists manipulate a phenomenon for the purposes of study and secondly, the extent to which output measures are constrained by predetermined variables. In contrast, naturalistic inquiry can be seen as discovery-oriented, therefore minimising manipulation of the study setting and having no constraints on outcomes. This contrasts with experimental research, in which the investigator tries to control the study by manipulating or holding constant external influences and in which a limited set of outcome variables are measured. Naturalistic inquiry replaces this emphasis with a discovery-oriented approach.

2.4 Social Constructivism

Constructivism, according to (Schwandt, 1994) is an approach used to understand human experiences. Constructivists are concerned with the meaning of lived experiences. They challenge the notion of objectivism which suggests that there is a single truth. In this study the parents’ experiences of cochlear implantation was assumed to be influenced by a number of factors, which may be yet unknown. A constructivist position permits contribution from all
perspectives and does not seek to justify one truth but seeks connection (Guba & Lincoln, 1985) as a means to move towards greater understanding. Originally the approach was known as naturalistic enquiry, but Guba and Lincoln (1989) have since used the term constructivism to characterise their methodology and proposed that it replaces a positivistic paradigm of enquiry where there is an implicit assumption about the truth. *Ontology which is defined as the nature of reality* is seen to be relativist and socially constructed. “Truth” is defined as the best informed construction on which there is consensus. Constructions arise because of “this interaction between observer and the observed that is created from the enquiry” (Guba & Lincoln, 1989) (p. 44). *Epistemology which is defined as the relationship between the enquirer and what can be known*, assumes that access to this knowledge is subjective, and that understanding is created through the research process and is influenced by both the researcher and its participants. The verification of the researcher’s construction by the participants is therefore an important component of the interpretative research process. Miles and Huberman (1994) have developed this thinking further, and refer to the concept of “critical realism” which acknowledges the presence of multiple truths but that some interpretations may more compelling on the grounds of internal consistency.

### 2.5 Design of the Study

The current study was designed to explore the experiences of parents and examine their meanings so an open-ended interview format was selected. Qualitative methods may consist of three kinds of data collection: interviews, direct observations and reviews of written documents. This study was based on data collected by open-ended interviews.
2.6 Use of Open-Ended Interviews

This was chosen as the most appropriate method of data collection because the study question has not yet been examined in New Zealand, and results generated through this study may identify further questions that may be answered with quantitative methods. Interviews permit researchers to examine those perspectives that cannot be observed. Interviewing for qualitative research begins with the assumption that the perspective of others is meaningful, knowable and can be made explicit (Patton, 1990). The quality of the information obtained during an interview is dependent on the skill of the interviewer. My extensive experience as General Practitioner (GP) was seen to be adequate for collecting this data.

A general interview guide was selected, outlining a set of issues that was to be explored with each participant. This outline was posted to the participants several weeks prior to the interview, so that they had a chance reflect on the questions. The participant information sheet (Appendix 6) was explicit about permitting other issues to be considered. Some issues were incorporated into subsequent interviews in accordance with the iterative nature of the study. The interview guide, however, served as a basic checklist during every interview to ensure all relevant topics from the literature review were covered. The wording and sequence could be adapted to specific participants during the interview. Data gained from informal open-ended interviews are more difficult to analyse but provide more flexibility. This choice of interview method may reduce generalisability but has the strength of permitting greater flexibility and individualisation (Patton, 1990).

2.7 Interview Guide

The interview guide is a list of questions to be covered during the course of an interview. It is prepared to ensure consistency with a variety of participants. It allows the interviewer to
decide how to best use the limited time available in an interview situation. In this study, there was only one opportunity to conduct the interview. The interview guide (Appendix 7) was modelled on a postal questionnaire used to examine the perspectives of parents (Archbold et al., 2002; Nikolopoulos et al., 2001). This study was also guided by the work of Lofland (Lofland, 1971) who has used many interview guides that have been used in sociological research.

The questions were designed with the aim of obtaining responses along the lines of:

- background family and demography questions
- experience questions about the diagnosis of deafness and referral process for a cochlear implant
- opinion questions about the diagnosis of deafness and referral process for a cochlear implant
- knowledge questions about the diagnosis of deafness and referral process for a cochlear implant
- feeling questions about the above experiences

2.8 Social Constructivism within the Discipline of General Practice

In the age of evidence-based medicine, objectivity is seen to be the gold standard of sound clinical practice. The drive to eliminate uncertainty and establish irrefutable truths in clinical settings is not without challenges. The contribution of science in medicine has afforded significant gains in the delivery of effective health care but it has also the potential to marginalise the patient’s experience of ill health, replacing it with experts, whose knowledge is presumed to be of a superior kind to that of patients. There is debate about the most appropriate place for patients’ experiences to be incorporated within the knowledge of
evidence-based facts. The scientific method is concerned with the formulation of hypotheses using reproducible methods that allow the construction of generalisable statements about how the universe behaves. Conventional medical training derives from this positivist paradigm and teaches students to view medicine as a science with doctors as impartial investigators, who build differential diagnoses like scientific theories (Greenhalgh, 1999). Greenhalgh (1999) writes of the tension within medicine between the “science” of objective measurement and the “art” of clinical proficiency and judgment. The evidence approach in clinical settings often incorrectly rests on assumptions that the clinical observation is totally objective and should, like all scientific measurement be reproducible. Tannenbaum quoted in (Greenhalgh, 1999) summarised this view in 1995:

Evidence based medicine argues for the fundamental separability of expertise from expert, and of knowledge from knower, and the distillation of medical truth outside the clinical encounter would seem to allow both buyers and sellers in the health care market to act independently and rationally (p.322).

While many disciples of the evidence-based medicine movement might support this positivist stance, Sackett, the founding father of evidence-based medicine made no such claim to the objectivity of the clinical method. Indeed, it was Sackett who argued we should acknowledge and measure the amount of disagreement in different circumstances rather than dismiss or attribute it to inexperience or incompetence (Sackett et al, 1996). Clinicians know that clinical judgment can be different from the analysis of measurable facts. In the language of empiricism such an observation could be interpreted as observer bias. However a constructivist perspective supports these multiple perspectives in clinical settings.

This narrative perspective, articulated by Greenhalgh, supports a social constructivist paradigm in medicine and my choice of this methodology for examining the experiences of the participants in this study. The discipline of General Practice, in which one cares for
patients and families over a lengthy period of time, provides many opportunities to observe and support patients as they come to understand their experiences of illness. For the families in this study, there were multiple ongoing interactions with health providers. This paradigm is well positioned to enable health care providers to understand the context of these parents’ experiences.

In summary there are multiple world views influenced by different social realities. Constructionist theory suggests that the author’s own experiences, beliefs and values influence the study and therefore the results.

2.9 Reflexivity

It is vital for researchers to find ways to analyse how subjective elements influence their research in order to create confidence about data integrity. Rice and Ezzy (Rice & Ezzy, 1999) define reflexivity as: “An acknowledgement of the role and influence of the researcher on the research subject”. The researcher can engage in an explicit self-awareness of the research process. The researcher is the instrument of the research. Reflexivity suggests that the researcher should take stock of their actions and role in the research process, and subject these to the same scrutiny as the rest of the “data”. Validity in qualitative methods therefore, hinges to a great degree on the skill, competence and rigour of the person doing the fieldwork. As a GP, and also a parent of a child with bilateral cochlear implants, it is important that I acknowledged this in the research process. My personal situation may have influenced the data gathered from the interviews as I was perceived as someone who may be knowledgeable about health issues both by profession and personal experience as a parent. Rigorous qualitative research is honest about the role of the researcher in the research (Liamputtong & Ezzy, 2005). A hermeneutic approach to the methodology meant that I reflected on how personally held biases and construction may have influenced the data.
gathering and the data analysis (Patton, 1990) (p. 85). The strategies used were a personal diary during the research, dialogue with a mentor during the period of the study and access to a counsellor. Finlay (2006) acknowledges that the process of engaging in reflexive analysis is difficult and its ambiguous nature is contested.

In summary reflexivity relates to the impact of researchers on the data gathering and the critical analysis of that role. The notion of researcher impact is gaining acknowledgement in qualitative research (Rice & Ezzy, 1999). It is now commonly held that that qualitative research involves interaction between the researcher and the data, although there appears to be little consensus on the role of researcher impact and conflicting views of the researcher’s previous knowledge and experience (Rice & Ezzy, 1999). Morse (1991) stated that qualitative research has been plagued with such doubts, some barely acknowledging the influence of personal beliefs while others suggest the researcher is part of the data. There appears to be a growing body of knowledge supporting the notion that research is socially constructed and therefore the researcher’s values may affect the method and the interpretation of the results (Mulhall et al 1999). Detachment and lack of personal involvement has been presumed to add to objectivity and reduce bias. Many qualitative researchers question the necessity of detachment, assuming that without empathy and subjective introspection the observer cannot fully understand human behaviour. Hertz (1997) suggests that an acknowledgement of self and scrutiny of one’s own values is essential to understand reflexivity.

A concern of misrepresenting data and its analysis is not uncommon for qualitative researchers. Contemporary thought in post-positivist research suggests that all research emanates from a particular ideological viewpoint which, once acknowledged, should present
no difficulty to the credibility of the results. General criticism of positivism has, according to Alvesson & Skoldberg (2000), lent emphasis to the value of the researcher’s whole person.

2.10 Reciprocity

Reciprocity has been defined as the “practice of exchanging things with others for mutual benefit”. Mutual trust, respect, and co-operation are dependent on the emergence of an exchange relationship, or reciprocity (Patton 1990), in which the researcher gains data and the participant gains something useful that makes their co-operation worthwhile. Gaining the trust of the participants is of paramount importance in yielding high quality rich descriptive data (Patton 1990). He postulated that some reason can be found for the participants to cooperate in the research with the potential of mutual exchange and he also suggested that interactive interviewing is an appropriate means for reaching an in-depth and intimate understanding of people’s experiences with sensitive topics. Alvesson and Skoldberg (2000) concur with this notion of intimacy and reciprocity, stressing the necessity of “establishing close personal rapport and mutual relationship” as paramount to the interview process. In the current study, questions were asked of me because of both my roles (as a doctor and as a parent) and I was seen therefore as being knowledgeable about cochlear implants.

In summary, this chapter has examined and justified the underlying methodological basis of social constructivism as the guiding paradigm for this study. The concepts of reflexivity and reciprocity in qualitative research have been discussed in order to increase the rigour in qualitative research. Social constructivism within the discipline of General Practice has been examined, with a potential to enhance the emerging trend in medicine of using knowledge gained from evidence-based research.
CHAPTER 3

METHOD AND ANALYSIS

3.1 Introduction

This chapter will summarise the methods used in the design, recruitment, research and analysis of the study. Initial consultation began with the managers both service provider teams in New Zealand, the Northern and Southern Cochlear Implant Programmes, in September 2006. The database of all children in New Zealand with cochlear implants is held by these two providers. Both managers were supportive of the study and did not perceive conflict with other research, after ethical approval had been granted from the relevant ethics committee.

3.2 Multi-Regional Ethics Committee Application and Ethical Concerns

Because the study involves children from around New Zealand, an application for ethics approval was submitted to the Multi Regional Ethics Committee in April 2007 (MREC see Appendices 1, 2 and 3). Initial consent was given provisional to two further conditions being fulfilled. One related to the issue of adequate Māori Consultation and the other issue related to the concerns raised by internal confidentiality (Tolich, 2004).

Despite extensive attempts, it was not possible to find any one with whom I could consult specifically regarding the perspective of Māori about the significance of this study. Neither of the cochlear implant teams had a person to whom this role is specifically delegated. The research proposal was however submitted to the University Of Otago Māori Ethics Ngai Tahu Research Consultation Committee (Te Komiti Rakahu Ki Kia Tahu) who requested any feedback on any issues that appeared to be relevant to Māori (Appendix 4). This is discussed in Chapter 6.
While confidentiality concerns protect participants in research from providers and other interested parties in the topic, internal confidentiality relates to inherent difficulties in participants identifying each other within the study, that is, one parent from another, and one parent pair from another. This is a particular challenge because of the small population of implanted children in New Zealand (approximately 200). Parents of children with cochlear implants may be connected by parents’ support groups and concurrent visits to the service providers. Ensuring that parents who participated in the study were unable to identify each other was important, but anonymity was difficult to guarantee and this was made clear in the consent form prior to the interview (Appendix 9). Internal confidentiality relating to couples meant that parents may have disclosed information unknown to the other. Therefore some results were not presented in this study.

I responded to the MREC and discussed the possibility of using indirect statements. However, as I proceeded with the research I decided it would reduce credibility not to use direct quotations. The participants all read the preliminary results and gave permission to present direct quotes. A concern was also raised by the MREC about bias, because of my own perspective as parent of a child with a cochlear implant, and this is addressed in the section on reflexivity (Chapter 2).

All research carries a risk of harm. To not conduct research also carries a risk of harm: health services will not benefit from research which may impact positively on health care policies. Research in small populations poses ethical challenges, as anonymity can be difficult to preserve. Participants were reassured that their interview would be kept confidential from their partner, and reassured that the results of the study would not interfere with their child’s ongoing treatment. These points were re-iterated prior to the interview and stated in the consent form. The interview was taped and participants were reassured they could request
that the tape be stopped and they could choose not to answer questions. The tape was transcribed by staff of the Donald Beasley Institute who were bound by a confidentiality agreement as part of their employment. Participants were also warned that their quotations may identify them. When the results were compiled into chapters, these were posted to all the participants to confirm they were comfortable with use of their individual quotes. No names have been used, and the age of the child has been withheld. All participants were informed that they would have access to the final report of the study.

3.3 The Participants and the Location of the Research

Data collection was carried out throughout New Zealand in 2007. The initial invitation to participate was sent to all parents in New Zealand with children who had been implanted for over six months, but less than five years and who had no additional disabilities. The study included children from both cochlear implant service providers so no potential participants were excluded. Children who had been implanted for less than six months were excluded because this period is intense with assessments and many parents report significant stress (Burger et al., 2005; Burger et al., 2006; Most & Zaidman-Zait, 2004). In-depth interviews would have been inappropriate for families at this time. In addition, benefits from cochlear implantation are not generally apparent in the immediate months following surgery and this may have created bias (Nikopoloulos et al., 1999; Niparko et al., 2000; Niparko et al., 2003; Osberger et al., 2002). Parents whose children had been implanted up to five years were included, as research has indicated evidence of increasing benefit up to five years post-implantation (Archbold & Thoutenethoofd, 2005; Christiansen & Leigh, 2002; Niparko et al., 2003).
3.4 The Research Phase

The interview guide was prepared at the start of the research (Appendix 7) but adapted in accordance with the iterative nature of qualitative research (Rubin & Rubin, 1995). Two issues not originally considered were: thoughts about bilateral implants and contact with the Deaf community. In the first three interviews it became apparent that little mention was made of the contact these children had with the Deaf community so I felt it was important to examine this issue further because existing literature refers to the challenges implanted children face straddling the hearing and Deaf world. In the four subsequent interviews, I raised these issues and new data emerged.

Each interview was conducted separately. The majority took place in the parents’ own home. One set of interviews took place in a quiet location in the parents’ work setting. The interview setting was always chosen by the parents, and they all chose the order of the interviews. Some parents assumed the other parent had already covered a topic in the previous interview and I needed to remind parents that I was examining experiences from their perspective. All parents spoke English, but for one parent pair for whom English was a second language. No parent was deaf. It is probable that deaf parents were less likely to consider a cochlear implant but I was unable to find any definitive data reported on this in the literature. The individual interviews varied from 50 minutes to 2 hours in length. In one of the interviews, I myself experienced a mild hearing loss having alighted from a plane with a cold. This meant the interview was very tiring for me, but a useful process to reflect upon.
3.5 Recruitment

In accordance with data protection protocols all families were initially approached via their respective service providers in writing. A copy of the ethical approval was posted to both service managers. They provided a letter of invitation to all parents who fulfilled the study criteria. Enclosed with this letter were the study information sheet and consent form. In total parents of (23 children from the northern regional cochlear implant team and 25 children from the southern team) fulfilled the study criteria and were invited to participate. Interested parents returned a participant interest form if they were interested in taking part in the study (see Appendix 8). This form allowed confirmation of age of the deaf child, years since implantation, sex, location and ethnicity. A total of nineteen responses from parents were received over the next month. When the forms were re-checked, two of the participants did not fulfill the study criteria: One child had been deafened by meningitis and another was five years post-implantation, reducing the potential participants to 17.

3.6 Sampling Strategy

Seven parent-pairs were finally chosen for interviewing (a total of 14 interviews). The original ethics application indicated five but after the fourth set of interviews new data was still emerging so permission was sought to MREC to interview two more parent pairs.

Qualitative inquiry typically focuses in-depth on relatively small samples selected purposefully (Patton, 1990). This assists in illuminating the question under study. Purposeful sampling aims to obtain information-rich cases from which one can learn a great deal about issues of central importance to the research question. For small populations such as this study, a great deal of heterogeneity could be a problem as individual cases are so different from each other. The maximum variation sampling strategy turns this apparent weakness into
strength. Common patterns that emerge from variation are of particular interest to the core experiences and central to shared aspects of the experiences of these participants (Patton, 1990). By using a maximum variation sampling strategy the purpose was not to generalise, but to gather information which may increase understanding of common patterns. Maximum variation in the sample group began with searching for parents whose children provided a range of ages, time post-implantation, gender, ethnicity and geographical location. Geographical considerations were important, as these parents may be some distance from service and support providers. The eventual parent pairs were biased in favour of the southern service provider because of fewer responses from the northern provider. Parents who did volunteer from the northern provider were difficult to access geographically at a time that was mutually convenient within the time-frame of the study.

In summary, with selecting a small sample of maximum diversity it was anticipated that the data collection and analysis would:

- yield high quality detailed descriptions of each case
- yield important shared patterns that cut across cases and derive their significance from having emerged from heterogeneity.

### 3.7 Final Study Group

Because of the small population from which this sample is drawn the descriptions shown in Table 3.7.1 will be restricted to maximise anonymity.
TABLE 3.7.1: FINAL STUDY GROUP

<table>
<thead>
<tr>
<th>Children of Parent Pairs</th>
<th>Age range: pre-schooler to mid-teen</th>
</tr>
</thead>
<tbody>
<tr>
<td>Ethnicity of Parents</td>
<td>11 European</td>
</tr>
<tr>
<td></td>
<td>1 Māori</td>
</tr>
<tr>
<td></td>
<td>2 Asian</td>
</tr>
<tr>
<td>Sex of Child</td>
<td>3 male and 5 female (one parent pair had two children with implants)</td>
</tr>
<tr>
<td>Location of Parents</td>
<td>5 urban</td>
</tr>
<tr>
<td></td>
<td>3 remote</td>
</tr>
<tr>
<td>Children with Bilateral Implants</td>
<td>4 had bilateral implants</td>
</tr>
<tr>
<td></td>
<td>4 unilateral implants</td>
</tr>
<tr>
<td>Birth Order of Child</td>
<td>5 deaf children first born</td>
</tr>
<tr>
<td></td>
<td>3 second or third</td>
</tr>
<tr>
<td></td>
<td>1 only child</td>
</tr>
<tr>
<td>Parents Age and Marital Status</td>
<td>All parent pairs were living together at the time if the interview</td>
</tr>
<tr>
<td></td>
<td>Age: late 20s to mid 40s</td>
</tr>
</tbody>
</table>

3.8 Analysis

The methodology used for the analysis was a “general inductive approach”. The inductive approach is a systematic procedure for analysing qualitative data in which the analysis is guided by a specific evaluation objectives or a research question (Thomas, 2006). Inductive analysis refers to approaches that primarily use detailed readings of raw data to derive
concepts, themes, or a model through interpretations made from the raw data by a researcher. This understanding of inductive analysis is consistent with Strauss and Corbin’s description (Corbin & Strauss, 1998): “The researcher begins with an area of study and allows the theory to emerge from the data” (p.12). Deductive analysis refers to data analysis that sets out to test whether data are consistent with prior assumptions, theories, or hypotheses identified or constructed by an investigator. The primary purpose of the inductive approach is to allow research results to emerge from the frequent, dominant or significant themes inherent in raw data, without the restraints imposed by structured methodologies. In deductive analyses, such as those used in experimental and hypothesis testing research, key themes are often obscured, reframed or unacknowledged because of preconceptions imposed by the data collection and analyses (Thomas, 2006).

The general inductive approach can be located within other qualitative methods and is most similar to grounded theory but does not specifically separate the codes into open and axial coding. Thomas (2006) noted that researchers who use the general inductive approach typically limit theory building to presentation of the most important categories. The use of a general inductive approach is common in several types of qualitative data analyses especially grounded theory (Corbin & Strauss, 1998). It is also consistent with the general pattern of qualitative data analysis described other authors (Huberman & Miles, 1994).

3.9 The Process of Inductive Coding and Analytic Strategy

The interviews were taped and later transcribed by another researcher. No written notes were made during the interview. The transcribed interviews were reviewed by hand. On receipt of the transcribed interviews, inductive coding began with multiple close reading(s) of the transcribed text from the interviews and consideration of the multiple meanings inherent within text segments. Text segments were identified that contained meaningful units and a
A label was created for a new category to which the text segment was ascribed. Additional text segments were added to the categories for which they were relevant. Initial descriptions of each category and subsequent associations, links and implications for other categories were marked. These were coded manually and checked by a researcher peer and supervisor for internal validity. Among the commonly assumed rules that guide qualitative coding, two differ from the rules typically used in quantitative coding. One segment text may be coded into more than one category, and a considerable amount of text may not be assigned to any category as it may not be relevant to the researcher’s question (Thomas, 2006). The following table shows the general approach to coding used in the current research.

### TABLE 3.9.1: THE CODING PROCESS IN INDUCTIVE ANALYSIS

<table>
<thead>
<tr>
<th>Initial reading of the text data</th>
<th>Identify text segments related to objectives</th>
<th>Label the segment of text to create categories</th>
<th>Reduce overlap and redundancy among the categories</th>
<th>Create a model incorporating most important categories</th>
</tr>
</thead>
<tbody>
<tr>
<td>Many pages of text</td>
<td>Many segments of text</td>
<td>30-40 categories</td>
<td>15-20 categories</td>
<td>3-8 categories</td>
</tr>
</tbody>
</table>

Source: Adapted from Creswell (2002, p. 266. Figure 9.4)

The following are some of the purposes underlying the development of the general inductive approach:

- to condense extensive and raw data text into a brief summary format
- to establish clear links between the research objective and the summary results and to ensure these links are both transparent (able to be demonstrated to others) and defensible (justifiable given the objective of the research)
• to develop a model or theory about the underlying structure of the experiences that are evident in the data.

After completing this process there were a small number of categories that summarised the most important themes of the research:

1. Experiences and relationships with health and education providers
2. Experiences of the implanted child’s family
3. Attitudes to the Deaf culture and experiences and use of Sign Language
4. Experiences of and perceptions of an implanted child as “normal”
5. Experiences and decision making about bilateral implants

In summary, data analysis was guided by the research question which was to identify the domains of experiences of parents of cochlear implanted deaf children. The text was read many times to gain meaning and to interpret the raw data. The results were influenced by the questions in the interview guideline. The results arose directly from the analysis of the raw data and not with a set expectation about specific results. The primary mode of analysis was the development of categories from the raw data into a framework. This framework contained key themes identified during the coding process. The results arose from multiple interpretations of the raw data. Inevitably, these results were shaped by the writer’s assumptions and experiences (see Chapter 2. 9 and 2.10 on Reflexivity and Reciprocity). Reflections on the journal dairy and de-briefings with the mentor were incorporated into this process and conscious choices were made about the results that were considered to be more important (Miles & Huberman, 1984). It is possible that another researcher may have produced different results.
CHAPTER FOUR

RESULTS

4.1 General Introduction

This chapter summarises the results that were identified using general inductive approach outlined Chapter 3. The five key themes will be presented in the following order: experiences with health and education providers, experiences and contact with Deaf culture, experiences of the implanted child family, experiences and perception of a “normal child”, and finally experiences and knowledge regarding bilateral implants.

4.2 Experiences with Health and Education Providers from Diagnosis to Pre-Implantation and Beyond

4.2.1 The Complexity of the Parent-Health and Education Interface

The process from initial diagnosis to successful implantation encompasses many health and education providers. While profound hearing loss is diagnosed within the health sector and initially framed within a bio-medical paradigm, the consequences of hearing loss are manifested primarily in educational and language outcomes. This health-education interface is something parents continually have to negotiate. This study involved interviews prior to the implementation of the Universal Newborn Screening Programme, although one of study parent’s children had been screened because an older sibling was deaf. For the other participants in the study, the diagnoses were initiated by parental concern, expressed initially to a GP or Plunket nurse. When parents first suspect the possibility of hearing loss, they are required to deal with many professionals (initially from the health sector) but then from a variety of education service providers. These professionals may use different terminologies, operate from different paradigms, have differing philosophies and offer conflicting advice. To illustrate the complexities of these communication interfaces, parents may liaise with
some or all of the following: a Plunket nurse, a GP, an audiologist (not cochlear implant trained), an otolaryngologist (not cochlear implant-trained), an early intervention service provider, an audiologist (cochlear implant-trained), an otolaryngologist (cochlear implant-trained), an auditory-verbal therapist, a speech therapist, an adviser on deaf children (AODC), a NZSL tutor, an itinerant teacher of the deaf (ITOD) and a teacher aide. In addition, there is usually input from voluntary agencies, some of whom are from the Deaf culture and who also bring their own perspectives and agendas. If their child had any other health or disability issues, these relationships may become even more complex.

The funding streams for supporting deaf children are also split between health and education. For example, an FM\(^1\) system may be funded through education sector. However the management of the implants is funded by health and contracted out to cochlear implant service providers which are located in Christchurch and Auckland. Many families have to travel to these centres necessitating liaison with the Health Funding Authority (HFA). Not surprisingly, many concerns emerged from the interviews about communication both from and between health and education providers. The lack of counselling support at the initial diagnosis and during the subsequent confirmatory testing period was of particular concern. During this period, parents reported feeling overwhelmed with the volume of information they received while struggling with distressing emotions. In addition, there was confusion regarding the use of terminology, the questionable value of the hearing aid trial, use of the hearing aid in the contra lateral ear post implantation, and inconsistent information about the value of a bilateral implant. Many parents described a feeling of abandonment as they were transferred between services. There was little evidence of a family-centred approach to intervention.

\(^1\)AN FM system increases the noise to signal ratio in a noisy environment. It is attached to the speech processor and receives the signal from either the lapel or head set microphone worn by the teacher. It needs to be specifically tuned.
The majority of parents became knowledgeable about the technology through the internet and from other parents. As a consequence, there was some tension as parents challenged the professionals with knowledge about developing areas of implant audiology and best practice overseas. The themes that emerge about relationships with service providers will be presented in chronological order, from initial diagnosis through to the post-implantation period.

4.2.2 The Initial Diagnosis and Use of Terminology

Following initial diagnosis, the dominant theme was shock, at times described by parents as a physical sensation. Some parents also reported shame and embarrassment. Two of the seven families had previous personal experience of deafness, yet even these parents described such feelings. To illustrate this, a mother with an older deaf daughter described her feelings when given the initial diagnosis for her baby:

I didn't believe it. I thought, no way can I have two deaf daughters. She was only tested as routine at six months because of (older deaf child). Oh, no, it wouldn't happen twice, my children are perfect. I still didn't believe it and thought it would get better and (deaf child) was too young for the test. I didn't want to tell anyone and I felt embarrassed having two deaf children.

Another mother reported a more physical sensation when presented with the news of her (deaf child's) diagnosis:

The initial shock was quite difficult really gut wrenching.... it was like a blow.

Of note were the comments of some fathers that suggested they experienced less initial emotional distress than the mothers. I did not explore this issue further as it was not the focus of my study, but it warrants further examination because gender may influence the receipt
and processing of distressing news. In contrast to his wife's comments reported previously, this father appeared less distressed in response to this news:

The feeling was. Ah...It didn't blow me over or anything like that. I think it was ok. On the farm, you know, you get exposed to different kinds of things. Deafness is not too bad in the scheme of things. It is not a life and death challenge.

The majority of participants in this study described the initial engagement with health providers unfavourably. It is possible that, with the delivery of distressing news, separation of content from process may be difficult, with the possibility of transference. However, despite this, comments shared by the participants in this study indicated a lack of awareness and empathy by providers. In some cases, this person was the audiologist, the ENT (Ear Nose and Throat) specialist or another audiologist at a later stage in the diagnostic process. Other parents reported a lack of awareness and knowledge of deafness on the part of the initial primary care provider (GP or Plunket nurse). The diagnosis of childhood hearing loss has been described as a medical and educational emergency (Flexer, 1999; Gilbertson & Bramlett, 1998; Sharpe, 1994) but many participants in this study sensed complacency on the part of health and education services.

One father commented about the complacency of the GP, both in regard to his lack of response, and his failure to acknowledge his wife's worries about possible hearing loss:

But just the fact; the local GPs did not have a clue. You know we had at least two that didn't detect anything. They did not take the mother's hunch seriously. That was one thing then that held the (deaf children) back.
Another father also referred to this complacency:

First, Plunket said the hearing was ok at 3 and 6 months. But I still worried. Then the GP kind of did a clap or something when (wife) said she was worried about her hearing at nine months. They (audiologists) did a couple of tests with her. They made clapping sounds and said, “Oh, don’t worry about it” sort of thing. Then once we found out, I was pretty gutted. I thought maybe she had glue ear but I never thought she would be deaf.

Another father who appeared less distressed drew a connection with his cousin who was deaf and with whom he shared childhood memories. It may have enabled him to absorb the news with more equanimity:

Initially when I first suspected (deaf son) was deaf, I didn’t have as big a reaction as I thought I would, actually. It was just oh, okay, it is a medical problem that we will have to deal with. I think the detail of what that meant was not fully apparent or we didn’t have enough information to comprehend what sort of issues there might be. But, having said that, I actually have a cousin who is deaf.

A mother who had concerns from birth described unsatisfactory contacts with both the GP and the audiologist:

From the word go, I was suspicious, so when (deaf child) was 5 months old she (GP) did distraction testing, where she (deaf child) sat on my knee and they stood behind. They thought it was all right but said (deaf child) was a bit young for that type to test so to come back at 9 months. At 9 months we went to the hospital for distraction tests and they (audiologists) said (deaf child) passed with flying colours.
This child was eventually diagnosed at 13 months, some 9 months after her mother raised concerns. An ENT surgeon eventually made the diagnosis after an ABR (Acoustic Brain Stem Reflex). This same mother continued:

The ENT surgeon said, “Yes, she is definitely profoundly deaf. There is no fluid”. I was in shock. He was so blunt, no bedside manner. He had none.

Another mother, although she had seen the audiologist and been told her child had some hearing loss was confused by the terminology used by different professionals:

Oh, I remember (audiologist) saying she had hearing loss; it’s nothing we can’t manage. Nothing we can’t fix. You know, don’t worry about it. I knew he wasn’t sure but he knew that it was not good. Oh, God; I didn’t get it. I just didn’t understand what he meant. He referred (daughter) to (adviser on deaf children). Then I got a phone call at work from (adviser on deaf children) and she said “I am the Adviser on Deaf Children” or whatever she calls herself. I went “Who”? Because (audiologist) never used the word deaf.

A mother whose child had some other health issues was told that her child may be deaf by a Plunket nurse who arranged further assessment. When she finally had the ABR after six further audiology appointments, she commented on the terminology used to describe the diagnosis and the incongruous behaviour of the audiologists:

“For this ABR we can conclusively say (deaf child) is deaf, we think profoundly deaf”. And they didn’t show me a chart to say this is what mildly deaf is, this is what severely deaf is, this is what profoundly deaf is. And I am like, what is profoundly deaf? They were very clinical. I think they could be more human. Yet, when we had (deaf child) in a sound-proof room one night when (deaf child) was asleep, everyone was whispering and I said, Why are we whispering, my child is deaf, isn’t she?”

61
Another mother also reported confusion with use of terminology, and also referred to distressing emotions that were not acknowledged when she heard the news:

I was thinking, ok, he may need hearing aids. But when the guy came out and told us he was profoundly deaf, I said” Pardon what is that? What are you trying to say? He’s like right, “Your kid can’t hear anything. It is the worse scenario to have”. Well, I was a wreck by then; I couldn’t handle much more. I hated it. I said, Oh, my God, my baby. It blew me out the window.

When parents did experience engagement from health providers, the benefits were reported favourably, illustrated by comments and experiences that were more positive. This mother described her initial contact with her GP after she and her husband realised hearing loss was a possibility:

When I said to my husband, “Oh my God this child cannot hear at all, I said ring (GP) immediately, take him immediately. We need the doctor to see him”. He saw him on the eve of a public holiday. God was working that day, and (GP) was incredible. He immediately listened to us, clapped his hands behind (deaf son) and said “I am going to immediately send a fax to the hospital today”, and it was his wish that the hospital would respond very quickly.

4.2.3. The Referral Process for Implant Candidacy

Parents had variable experiences of the referral process. Some parents described a smooth and well-organised process, while others struggled to access services. Others perceived obstruction by initial audiologists and local services to the cochlear implant centre. A mother whose child straddled two service providers prior to surgery talked of her distress when the confirmatory paper work for her child’s surgery became caught up in bureaucracy. This child had made little progress with hearing aids:
I was caught up with (service provider) because half-way through my child was transferred. When I rang (service provider), I was very angry after many times of them putting me off, and I said to them, “Look, do you have a deaf child? Do you know what it is feels like to be a mother of a deaf child waiting for surgery? Do you need me to go to (service provider) to photocopy the papers so I can get a surgery date. For you it is an admin task; for me it is my child’s hearing. The (admin person) was so rude and cold. She kept pushing it off, and saying “I will get back to you”. I said “It is not an admin task it is an urgent matter”. I rang and begged the hospital to do it. And then we found the funding had not kicked in yet, another delay.

Other parents described complacency on the part of audiological services and lack of awareness of the trauma that parents were experiencing after diagnosis and while considering options for language acquisition. Some parents indicated that services were focused on a medical diagnosis and until they had a confirmed medical diagnosis of deafness, services were not receptive to their needs and distress. While appropriate treatment and management is critically dependent on accurate diagnosis, health providers are not precluded from engaging at some level even if only by acknowledging parental anxiety and distress. A mother whose GP referred the child urgently for audiological assessment, found the delay at her local clinic extremely distressing. It took 3 ½ months for her son’s hearing loss to be confirmed. She described her distress about this:

I am still angry as they are still offering the same piss-poor service at (service provider). I would ring them every day and say, “When am I getting an appointment”? And they would say “We will send you a letter”. I would say, “Why can’t you give me an appointment over the phone”? When we finally went to the appointment, the audiologists were quite young and they told me there didn’t appear to be a problem with his (deaf son’s) hearing. Part of me was relieved; the other part thought: “This is a crock of shit”. 
The mother challenged their statement. Despite acknowledgment by the audiologists that this was only preliminary test and the child will need further assessment she felt there was no impetus to move the process forward. She also noted the lack of a family-centred approach:

They were focused on a clinical diagnosis of the child, whereas what they were dealing with was a family. So they completely struggled and they didn't see we needed support and the major players in my (deaf son's) life were not the diagnoses and equipment, it was the family. They completely lacked empathy for what they were dealing with. The thing that I put to them, where they let us down mostly, is they didn't refer us to the cochlear implant programme.

Because of the unacceptable delay, this mother initiated her own referral to another service provider. She described the new service providers' response to her request for help:

So in February I made contact with (service provider), and this was the first service that I'd accessed so far that understood this was an emergency and were responsive, and they basically said “Can you come up tomorrow”? They were happy to accept my judgment and start therapy straightaway, even almost before he got his hearing aids. What I very quickly realised was the therapist will teach the parent who will teach the child. I love them. They have been wonderful, and this is the positive for us in the whole story.

In hindsight, the mother realised that, not only was the initial information provided to her incorrect but that the first provider had lacked an awareness of a family-centred model of care. She also realised that her subsequent referral to the cochlear implant service had been unnecessarily delayed.

Another father spoke of the lack of a consistency in the referral process and discussed the issue of equity:
Having been on the good side of the fence (referring to his child’s outcome), in my experience there is a certain lethargy within parts of the system. And one of the things that has occurred to me through the cochlear implant side of things is that they are happy to help those parents who will help themselves. Putting on my socialist hat, that is a pity, less than ideal as those that are less aware will need most help. The squeaky wheel gets the oil, without doubt. It is not what you know; it is who you know.

Many parents of the younger children in the study described relief that their child was profoundly deaf, as opposed to severely deaf, as they realised that this increased confidence in cochlear implant candidacy. Once their child was accepted into the cochlear implant programme itself, parents reported being taken more seriously, describing feelings of relief that their concerns were going to be acknowledged. A mother whose referral process had progressed more smoothly discussed her experience of rapid engagement by health providers and how this impacted on her emotions. In addition, she refers to the consensus of management between providers:

The specialists at (service provider) were brilliant, and he pointed us fairly early on in the direction of the cochlear implant with her (deaf daughter) not having any other issues. It happened really fast for us, and we were told by another (service provider) she would be an ideal candidate, and we were really excited as that is what we wanted to happen because the first (specialist) told us it was the right step.

4.2.4 The Pre-Implant Hearing Aid Trial

In accordance with current guidelines, children who are potential candidates for cochlear implantation must undergo a trial of hearing aids prior to consideration for implantation (see appendices). All of the younger children in this study had undergone a short trial of hearing
aids, most with little benefit. Some parents had been advised that their child’s audiogram had improved with hearing aids but commented that this improvement had not improved listening for day-to-day life. The pervasive theme regarding the hearing aid trial was frustration, anxiety and distress. Parents wanted their child to have access to technology that was of proven benefit as soon as possible. Many parents considered the hearing aid trial not only a waste of time but also very stressful. The majority of parents in this study had access to the internet and sourced information from other parents. This meant they were well aware of the superior audiological outcomes of cochlear implants over hearing aids. Should the child not be deemed sufficiently deaf for a cochlear implant, the high cost of a non-funded implant placed the providers in a perceived position of considerable power. During the assessment process parents reported vulnerability and loss of control. A mother described her distress with her first contact with a service provider, and her concern at the enforced sharing of accommodation:

I didn’t like the trip to (service provider) . We had to share with another family and it was so inappropriate. The other child had another syndrome as well as being deaf. The mother rolled out her life story, which dominated the conversation for three whole days, and she had four children, all of whom had problems. I mean, how could we talk about our child who just had hearing loss?

One mother compared her own deaf child to other deaf children who did not qualify for an implant:

Those kids (other non-implanted deaf children), obviously through the hearing aid track aren’t anywhere near as speech proficient. And I have said that to so many people so often. It is horrible to say but I am pleased that she is so deaf, because, honestly, I see these kids and they talk totally differently. They are monotone, they I mean their language, their learning,
everything is so impaired. Those kids are going to need help for so much longer than (deaf daughter).

Another mother expressed her feelings about implants versus hearing aids:

How could one actually say it is a blessing she is so deaf because she is not formed perfectly. I don’t know which is worse, hearing aids or implants. But I am glad she wasn’t just moderately severely deaf: whatever it is where she is not getting a lot of benefit from hearing aids. I am sure there are a lot of children that just fall below qualifying.

This mother describes low benefit and frustration with the hearing aid trial:

A waste of time (hearing aid trial) to be honest, I think. At the moment we are going through painful rehabilitation. Every day we could cut off from the beginning to speed up the implant process the rehabilitation would be a lot easier because that is precious time and it is like life. A day of a deaf child’s hearing could be two months of rehabilitation. For crying out loud, just do the implant if she qualifies. They gave her three hearing aids. One didn’t work. The second one wouldn’t work. They gave her what they called the super aid and it had feedback all the time because it was turned up so loud. It was even more annoying to me because she didn’t hear it but whole family could hear it. It was a waste of time.

Another mother spoke of her distress and low benefit with the hearing aid trial:

It was absolutely diabolical, like (husband) and I had to hold her (deaf daughter) down and put them in. The part of it that was really hard was the minimal benefit that she was getting out of them for all that stress and physical pain I suppose. Again it was gut-wrenching: just the whole process, physically having to put in that much sort of physical strength. She pulled them out straight away. I think we got them in for a maximum of half an hour. They did tests on her and she got up to 55 decibels or something and she may have heard a dog bark.
Another mother continued this theme:

I could not even get him to wear them. I tore my hair out and got all the suggestions about getting them on him. And you know, there were days when we got him to wear them for an hour and just went hallelujah. He wore it for an hour and then, a week would go by, and he would not wear them. It was a bit of a joke because he wore them for 7 or 8 hours the whole 3 months.

The older children of the parents in this study had successfully used hearing aids for many years prior to implantation. These children were older at the time of surgery (aged from 9 to 13 years) and so knowledge about superior audiological outcomes was not available when their children were younger. Their thoughts regarding implantation were quite different from those of parents of the younger children. This sense of “wasted time” from parents of younger children contrasts starkly with the parents of the older children who had persevered with hearing aids for several years before considering and being considered, as implant candidates. A mother whose child was diagnosed shortly after birth but wore hearing aids successfully till late childhood comments:

But it took me a lot of time to consider the cochlear implant. I was not receptive. I thought it was an invasive type of solution, like a last resort. Her (audiologist) kept on feeding me information, and then when I was ready, I thought: It has helped others so it could be a possibility for (deaf daughter).

A father of two older children who were implanted in later childhood talked more positively of hearing aids:
I think we could have had implants earlier but we chose not to pursue that earlier. They made really good progress with hearing aids and we were unsure of the cochlear; it was still relatively new. We wanted to see how we could push the boundaries with hearing aids.

In summary, the use of hearing aids prior to surgery appeared to have been a positive experience for the parents of the older children while they prepared themselves for the possibility of surgery. In contrast, for the younger children in the study, the use of hearing aids appeared frustrating as an unnecessary prior to surgery. Once the child was considered a probable candidate, the parents felt a sense of urgency for the surgery to take place. Of concern was a perception that their child's needs were taken more seriously once they had been accepted into the cochlear implant programme. There may be a link between this theme of urgency to the results in part 5 of this Chapter (about the “normal” child). The desire for a “normal” child, the proven benefits of early implantation and the possibility of intelligible speech and age-appropriate language may influence this sense of urgency.

4.2.5 Cochlear Implant Surgery and the Post Surgical Habilitation Process

The surgery was universally considered a period of high stress, and this is well supported in the literature. This stress was offset, though, by a relief that the surgery had finally taken place, and hope regarding the possible outcomes. Many parents talked very favourably of immediate obvious gains while acknowledging the demanding nature of the habilitation process. One mother commented about the stress:

Well, I am a wreck from the time I walked into the hospital until the time I walked out. I was a mess, so I cried from the day I walked in to the day I came out. It was awful. What am I doing? Oh my God. Like 3 and half hours of surgery!

She continued on with the implant activation:
Oh, it was awesome. It was fantastic and we bought him a noisy toy as it was Christmas. He did the work. He has accepted the maps, and he is a kid that wants to learn.

A father discussed the stress his wife experienced with the birth of a baby at the time of surgery:

Well he (new baby) went downhill because (wife) was so stressed about everything. Jesus, yes she was affected as he wasn't feeding properly. So I basically had to look after him and I pumped formula into (new baby).

Yet he talked with confidence of the journey ahead and the decision they had made, even while acknowledging the uncertainties:

I knew they were capable. I was confident about what they had told me. Everything was positive in their attitude. I guess they were feeding me the positive side although there was the small print so as to speak.

In response to a query about the intense post-surgery habilitation and stress of the surgery this mother commented:

I think that, despite the short-to-medium term work that we have got to go through, it is totally worth it when I think of quality of life and the rest of their lives and ability to learn and communicate. I mean, I don't consider (deaf daughter) to be deaf.

Another mother of a child who was implanted in late childhood commented about the demanding nature of the habilitation process but the hope she had:
It was very hard initially, frustrating as we were told to take the hearing aids off the other ear. It was much harder than we anticipated, and the mapping was traumatic. At one point she threw it off her head. We knew it would get better as they advised us.

Many parents lacked of knowledge about the carer relief funding scheme. It appeared that assessors lacked knowledge about auditory-verbal therapy and the demanding language support needed. Carer relief provides funded respite days for parents of a child with additional needs, and is not means tested. Deaf children, particularly if they produce intelligible speech, may not present obvious clues about the demands on parents for language support. In response to a question about access to carer relief services this mother commented:

They said no to us. I think it was because I had my interview at my work premises, which are quite smart. And she could see I had a good job. I fully believe she sized me up in less than a minute. She wasn’t interested in what I had to say. She never saw (deaf daughter).

A mother who was eventually granted the maximum number of days discussed the initial judgment she received, and how it was reversed once the assessor appreciated the safety issues of parenting a deaf child:

When the woman came in, I think she was thinking there is not much wrong with this kid. Like (deaf daughter) seemed quite normal. Like she didn’t look like a special needs-type of kid. It is an invisible disability some of the time. We had just finished and when she gets up to go we couldn’t find (deaf daughter). She just disappeared and I had this gut feeling she (deaf daughter) was out on the road, and we both panicked because she couldn’t hear us. Then the woman gave me 28 days straight away.
Several parents had never heard about carer relief or of their entitlement. A mother of older children commented:

Not that I can remember. That would have been a big help when the children were younger. It was quite hard work when the children were little.

Another father remarked in response to the availability of carer relief:

Any what? No, never heard of it.

Support from advisers on deaf children (AODC), auditory verbal therapist (AVT) and teachers of the deaf (ITODS) was variable and there was no apparent consistency between parents. Parents had to adapt the rhythm of their work and life to provide language support. This adaptation was more apparent for parents who lived some distance from services. A mother who was located in an urban centre commented on the ease she experienced:

The support has been amazing. Yes, (Auditory verbal therapist) and (Itinerant teacher) and (adviser of deaf children) have been very good about the whole goal of this therapy, and this is leading your child toward independence and the parent toward independence of the support team. It is another step that (deaf daughter) will be fully independent and we will be free of this support. I have really benefited from (teacher of deaf) coming every week. I have loved the weekly visits and I will miss them.

Another mother who also lived in an urban centre described a less helpful experience:

Our advisor has not started the process for ORSS (Ongoing Resource Support Service) funding. She is as useless as tits on a bull. We have had no support and she is not pro-active in the slightest.
One mother frustrated by the limited service her daughter was receiving, commented:

Well, she only has 2 hours of support allocated week. It is not enough. Why are we paying the unemployment benefit, and not channelling money into medical issues, children with autism, and children with hearing problems, whatever.

4.2.6 Technological Challenges

For children at school, frustrations with FM receivers were common and caused parents stress in the school setting. Many parents described tension with their classroom (or pre-school) teachers which may also have been caused by the ongoing problems of the FM system and difficulty in finding satisfactory solutions from both implant clinics and the manufacturers themselves. The technology is evolving quickly and problems are surfacing that are not easily solved. Other parents described managing the school-home interface as a management job in its own right, and this experience is supported by the literature (Neuss, 2007).

This father’s comment illustrates some of the difficulties in relation to his concerns that his child’s behaviour was being misinterpreted:

We have times when (older hearing child) comes home and says “Miss ‘so and so’ told (deaf son) off and made him sit on his own again today”. (Deaf son) does not understand why he is being told off. There is dobbing in, for him making gestures. One of the teachers said he had been making the fingers to this child. But it wasn’t two; it was one finger and that is what he used to do. I mean I can’t be down at the school to watch to see what happens. My biggest fear is seeing him fail. No-one in (town) knows about cochlear implants or FM equipment.

Another mother commented in response to the problems with the FM and challenges with the relieving staff in the school setting:
Well, we are lucky that (deaf son) knows how to work it. He kind of has to because if he had relievers and stuff, they have no clue. We had one reliever who said “I know deaf kids, and he is just trying me out”. They don’t understand they need to look at him face on and don’t talk to his back. If you are face on he gets more out of it.

A father who had some proficiency in technology had taken some initiative in liaising with the manufacturers and shared his frustrations in regard to FM systems:

It has been a nightmare. We have had feedback and disturbance. I made a visit to (service provider) and I got a bit shitty. (Hearing professional) understood my frustration but said, “Well, if you are not happy with our service”. He was a bit defensive. I got frustrated everyone was trying to prove it was not their problem rather than fixing the problem. Like, “This is not my department. It’s not my problem”. So, (deaf child) was without her FM for almost a year. It is a long time in (deaf child’s) life.

The mother of this child observed the anger resulting from her husband’s frustrations about FM systems:

(Husband) finds he know more about the FM systems than (deaf professional). (Husband) got angry. It is not my job to work these things out. We were supplied with a piece of equipment that did not work. It is just not good enough, and that is when we got stuck into (another deaf professional).

In summary, this section has reviewed the major themes emerging from relationships with health and education service providers. Concerns about the deficient practice of a psychosocial model of care surfaced from the very first point of diagnosis through to the referral process. The experience of hearing aids prior to implantation proved a significant
point of stress for families with babies and toddlers. Many parents did not experience a family-centred paradigm of care and experienced significant difficulties managing relationships with multiple professionals. At times social and technological support for parents appeared deficient.

4.3 The Implanted Child and their Family

4.3.1 Introduction

This section will present the results relating to the implanted child’s family. The overwhelming experience of parents following surgery was of easier communication within the family and a reduction in the frustrations of daily living, with many parents reporting that their day-to-day lives were returning to “normality”. On reflection, many parents became mindful of restrictions that the sole reliance on hearing aids had imposed on their family life. Some parents discussed issues that surfaced for the sibling(s) of the implanted child. Other parents felt that parenting a deaf child had altered their feelings about further pregnancies. Several parents reported that auditory verbal therapy (AVT) practice had changed their relationships with their partners. Most parents felt the implant had improved their child’s safety and described how this influenced their parenting post-implantation. The parents of the older deaf children discussed the child’s increased social confidence within the school setting, at home and with peer relationships. They spoke of feeling more relaxed and this allowed their child to be more autonomous. This response is consistent with the results in Chapter 4.5 (The experience and perception of a “normal” child). Their child’s relationships with hearing peers were seen to develop like a hearing child. Parents altered the rhythm of their work and life, especially for parents who lived at some distance from specialist services. Many parents discussed changes within the couple relationship. However, owing to the small sample and the internal confidentially requirement using direct quotes to illustrate this result was inappropriate.
4.3.2 Concerns of Child Safety

It would be hard to overstate the relief the parents expressed regarding the increased physical safety of their child following implantation, especially of the younger children in the study. Safety around motor vehicles featured particularly. Every parent in this study referred to the increased confidence and relaxation that they experienced regarding their child’s safety. This increased confidence relates partly to the ease of communication that parents reported, but nonetheless they all made specific reference to safety and how this increased confidence impacted on their parenting style and reduced stress. The implant presents some safety issues in that direct trauma to the head must be avoided. Parents therefore needed to take extra caution when the child was involved in physical play. As the device cannot be exposed to water or moisture, safety in water remained a challenge.

A mother commented about her increased confidence:

Everyday things even are easier. Just getting out of the car and going to cross the road. You know there is a car coming or you can’t get down there quick enough and you just say: “Stop” and (deaf child) stops, you know.

This comment was made by the same mother whose carer relief was promptly reviewed after her child disappeared during the needs assessment visit (and was thought to be out on the road). Another mother also commented about safety regarding vehicles:

Like, it is a big world and we can hear everything. Like, you have to kind of think. Like, we hear the car coming down the road, whereas he (deaf son) wouldn’t hear the car coming down the road. I used to have to check on him all the time, and find out where he was, I used to think, my God, if I hadn’t seen him for ten minutes. You always thought safety. It was always
in the back of your mind. Now he can hear me say “Stop”. And he does stop. It is brilliant. He won’t cross the road. I don’t have to be three steps ahead.

Another mother talked about the challenges of water and the implant:

I don’t like going, the sea the beach and the pool. Just that is me, but I don’t show it. But it is the whole hearing thing. In saying that, I do take her. I would probably take the device off in a boat. I just would not let (deaf child’s) device get saturated.

And in response to communication in the water without an implant:

I would just gesture and keep (deaf child’s) attention. Yes, (deaf child) she is a good lip reader but you have to get (deaf child’s) attention. I do worry about the logistics of the swimming situation.

This particular mother enjoyed a hobby she wished to share with her child, but because of the risk for falls with this hobby she was reconsidering it:

I have to say I worry. (Deaf child) already fallen once and I got such a fright. So it’s an additional worry. So I’m already putting on mental brakes.

To conclude with this issue of safety, a father of older implanted children commented:

The implant has changed ease of communication particularly from a safety perspective and urgency of communication. Before (cochlear implantation surgery) the safety thing was always an issue. I probably let them go a little bit more now.
4.3.3 Ease of Communication

To illustrate the increased ease of communication and the reduced frustration in the family, a mother of an older child previously reliant on hearing aids commented:

Frustration is taken out of your life basically. Frustration of non-communication is just about totally gone. I mean I can talk to (deaf child) in the car. Not always, but a lot of the time. (Deaf child) does not get so frustrated, so the whole family is not as affected by that because (deaf child) she used to get up every morning with tears at breakfast time. The communication is 100% improved. It has improved the communication in our house incredibly.

Another father of older implanted children also previously reliant on hearings aids commented:

It is a life-changing thing, generally speaking. It’s certainly made things easier for the children and easier for us as family, and communication is considerably better. Both the children now talk on the telephone.

Another mother reflected on her parenting since surgery:

I don’t run after him (deaf son) like I used to because he can go and get things for himself. We are not saying to him, Go and get your bag; we don’t need to be so stressed with him. Going, oh my God, what is he doing? Where is he? Go and get and your school bag; come on, you are going to school. Before you had to stop what you were doing. I am not stopping and starting so much. You do not have to check on him and find out where he was. I don’t stress as much, I think we are laid back. Like, it is probably quite good. Like, he is a normal child.
Another mother of a child who was a toddler at the time of implantation commented:

Her whole level of understanding has changed. You know, every day asking her to do something for me, just behavioural stuff. Everything is so much easier, so much better. Playing with her baby brother is easier. Careful, or don’t pick him up or whatever. Stop. No, all those things are just so basic. Yes, there is that whole level of understanding we just didn’t see with hearing aids.

4.3.4 Issues for Siblings

While the topic of the study is *Parental Experiences of Cochlear Implantation*, many parents’ experiences and feelings were influenced by the needs of other siblings in the family. Other childrens’ experiences impacted on parents’ feelings. Many parents expressed concern that the pre-occupation with their deaf child had reduced their time and availability for the hearing child, and so many parents spoke of the extra attention they felt they owed to their hearing child. However, other parents felt that the hearing child benefited from the intense language input. Several parents also indicated that their hearing children were generally very patient suggesting some degree of accommodation on the part of the hearing children.

One father talked about an older hearing child, indicating that he had made significant accommodation:

He has been so good with his brother, but I think *(hearing brother)* has been ripped off quite a lot, He hasn’t had all the things that *(deaf son)* had. Everything we did with going here and there. He stayed behind with his Nana and all that sort of thing. Just lately he seems to me “I’m quite a sad sort of trip”. Looking back, it has been unfair; it has been unfair compared with what *(deaf son)* had. I guess down the track we will find out what the implications are, but I would say, yeah, no, we haven’t spent as much time and as much input into *(hearing child)*.
The mother of this child concurred with these sentiments also:

(Hearing brother) has been a good teacher and has a lot of patience for (deaf son). You know it must be frustrating for him. He looks at (deaf brother) and says “Try this”, and (deaf brother) will look at you and go “What”? Then he said “I wish he (deaf brother) could just hear”. With homework, it will take a good hour with (deaf son) and with his brother well it’s over in two minutes. We put the time in, as we want him to catch up with his peers.

Another mother commented about her older hearing son’s patience:

Well, he is incredibly patient. He has been wonderful. I feel like (hearing son) is missing out.

The father of this child also shared these sentiments:

We have had to develop a closer relationship with (deaf children) and we actually haven’t done that with (hearing child). He often makes the comments that (deaf siblings) get all this attention or whatever.

Many parents expressed concerns that their pre-occupation their deaf child had reduced the time and availability for hearing siblings, and so many parents spoke of the extra attention they felt they needed to give to the hearing siblings. This father commented:

Oh, I just think I have got to spend more time with (hearing child). You have just got to be aware of it. They miss out.

In contrast, to this theme of “missing out,” some parents believed that hearing siblings had benefited. In response to a question about siblings, this mother commented about the language development of a younger hearing sibling:

80
Oh, totally, I mean I think that his level of understanding and language is well advanced from what little kid of his age would be. The fact that we are more aware of that whole language, you know, and spending time with her, he gets it anyway and he wants to sit up here with (auditory verbal therapist).

Parents with two deaf implanted children did not raise concerns about competition between the children, and did not appear to be concerned about treating the children differently. The following comment from this father illustrated this point well:

Yes, I could imagine some families would make allowances for this one because he is deaf and the other one (hearing child) would be saying "(deaf child) always get this", or "You always let him do that" or whoever, whatever, and we don't even have to think about that.

Another parent of two deaf children commented about her sense that parenting was easier with two deaf children:

So, yes, extra work, I always think that one deaf and one hearing, because you would probably always feel like you wanted to do too much with the deaf child and make the hearing child miss out. And if you are the hearing child it would be awful.

In another family with two deaf children, issues arose around from perceived differences between the child who was using hearing aids and the implanted deaf child (only one of the children fulfilled the criteria for cochlear implantation). The father suggested that the implanted child was more socially aware, and the unimplanted child's life more socially constrained. He explained:
(Unimplanted deaf daughter) is aware that (implanted) daughter can hear more and know more. I think she feels disappointed, I don’t think jealous. She understands there is a difference. She often asks (unimplanted daughter) how to spell this and how do you spell that and I think (implanted daughter) is more socially aware and socially adjusted than (unimplanted daughter). I feel for her (unimplanted daughter), and she lives in a more sheltered world.

The mother of these children also commented:

Now we have (implanted child) who is hearing better than (unimplanted). That did take some getting used to with (implanted child) getting further ahead in language and probably for most things. She was correcting her. It’s academically easier for (implanted child).

4.3.5 Further Pregnancies

For some parents, their deaf child was their first. The experience of parenting a deaf child appears to have impacted on their feelings about further pregnancies. Two mothers were already pregnant at the time of the deaf child’s formal diagnosis. In response to her feelings about a future pregnancy, this mother (whose baby was subsequently born hearing) commented:

There’s no way we’d have another child now. There’s no way in hell we would roll the dice again.

And in response to the possibility of another pregnancy had her first child been hearing she commented:

Yes, absolutely. Yes. But I do long for another child sometimes. But, no, not with hearing loss. No, I do not want another child at all.
This mother talked of the feelings she experienced when her subsequent child underwent newborn screening at birth:

I sent her (screening tester) away twice so that my husband was there at the time of the test. Reflecting back, it’s the one thing that makes me cry even now, finding out that my second child was not deaf. It was so meaningful to me. That was the best news I had all year. Amongst all that awful bits of patchy, ill-guided, misrepresented information we had.

A father whose first-born child was deaf commented in regards to a further pregnancy:

I am not sure if I could go through all that again. Such a rough ride.

One mother commented that while open to another pregnancy, she was influenced by her partner’s feelings:

I really would have loved another child but (partner) didn’t want to largely because of the deafness. I would have been prepared to have another child, deaf or not deaf, but it did make me pause. But (partner) was pause and stop.

Another mother reconsidered having more children:

I was already pregnant when I found out about (first baby’s) deafness and we had no inklings (first deaf child) was deaf when I conceived. So I mean at that stage I always wanted a big family. I said I wanted four kids, and when those sorts of thing happen. It’s like, far out. You know, breeding children that are not a hundred percent. When I found out I thought Oh my God, I don’t want any more kids, but being pregnant and all. So (deaf child) has been a lot more work and some days you think, My God, have I got it?

She continued about future pregnancies:
So I would probably wait at least another year if I have any more at all, so whereas before I would have liked to have them closer together.

In contrast, another parent considered a further pregnancy could benefit the deaf child:

I am just thinking it would be nice to have another child. But it doesn't bother me. Yes, I was actually very selfish having (subsequent child) for (deaf child's) benefit. I never prayed for the other two (hearing children), but I prayed this time. So (deaf child) is getting benefit from having the lovely baby talk. So when you have the older child, you bring them in and with a baby you go Oh come here, you little baby.

4.3.6 Work and Finances

Many parents spoke of the impact on their finances. They spoke of the adaptation they had made to cope with intensive therapy away from home with multiple assessments. Most parents had to travel some distance to appointments, necessitating time away from work and other children. Some parents felt that the service providers failed to consider the needs of other children, especially pre-schoolers. Several parents felt that the funding authority for subsidised travel (HFA) was inflexible, and they suggested that the HFA (and contracted air carriers) could be more flexible with bookings when parents and children were travelling to necessary medical treatments. Several parents were self-employed which appeared to give them more flexibility. Parents who were employees had reduced their hours to adjust to additional parenting needs. A mother talked of the adaptation she had made:

I always had this sort of feeling that I would probably go back to work more than what I have. At this stage or after (deaf child) I went back two days a week, but that was before I found out (deaf child) was as deaf. It has limited, probably, my expectations in terms of how much I wanted to have a career.
Another mother commented about reduced career aspirations while acknowledging being at home was also important:

I think I would, but I was a stay-at-home mum.

Another mother had continued to work full-time but experienced judgment from health providers:

I am a very busy mother. I love being busy. I thrive on it and would be miserable if I didn’t have anything to do. But a lot of times I feel bad. These people (health providers) say I should be with my child more, but with a mother who is tight and angry and upset?

A father who was self-employed commented the changes he made to the therapy:

We knew it was not going to be easy. The work (auditory verbal therapy), well I just adapt myself around it. I mean everything is an opportunity for it (language). It (audio verbal therapy) gets natural. I take her out in my work place all the time. There are lots of language opportunities there.

Another family experienced considerable stress because the development of a new business had to be delayed during the assessment period. The father explained:

I mean the business was put on hold when we discovered (child) was deaf. It was tough. The delay in running the business was due to (deaf child). I could only do little bits of work as we were traveling to (service provider) twice a month and (wife) could not get any sick leave as she had not been there long enough. Before, (in old job) all the time she was taking off at that stage, she wasn’t getting paid for it.
Linking his adaptation to the more intensive parenting of auditory verbal therapy along with the family business, this father commented:

I don’t do a 40 hour week so I get to spend more time with the kids sort of thing, and it is still not a huge income at the moment.

He continued to discuss the stresses of travelling to assessments:

We couldn’t take (hearing child) to (service provider) with us as there was no one there to look after (hearing child) while we were at the audiologist. It started out that we were allowed to bring support people. It was going to be the big announcement. We were going to get an implant and had all these final tests, but when I said to (service provider) that (family support people) they were coming, they said “Oh well they (family) can stay in a motel”. There is no funding for support of the other sibling, and he is missing school staying with Grandma in (another town).

In summary, this section presents the common issues that parents discussed as impacting on their family life. In the period immediately following the implantation, auditory verbal therapy and mapping placed significant demands on the family’s time. However there are themes of relaxation about their child’s safety and easier communication in daily living, even allowing for the intensive time commitment of therapy and device maintenance. Most parents were aware of the hearing siblings’ needs, but had not yet developed any strategies to attend to those needs. Many parents changed work patterns and absorbed these changes in their lives. Others experienced a disruption to their work life, the care of other siblings and earning potential.
4.4 Experiences of New Zealand Sign Language (NZSL) and the Deaf Community

4.4.1 Introduction

This section explores parents’ experiences of and attitudes towards NZSL, including the advice received from professionals. It will also examine their relationships and contact that parents have with the Deaf community. The first part of this chapter will review the results associated with the use of NZSL by both the parents and the implanted children and advice that was given to parents from various health providers on the use of NZSL. The second part of the section will review this study’s results in relation to contact with, perceptions of and experiences of, the Deaf community. Because cochlear implantation offers the possibility of understanding and producing spoken language, I was interested in gaining some insight into how this group of implanted children and their families were using NZSL.

4.4.2 The Use of and Advice Regarding NZSL

Until recently, the dominant advice from cochlear implant service providers was a focus on spoken language: the underlying rationale being the critical stimulation of the auditory nerve. Firstly, this advice was probably influenced by the older age of children at the time of implantation: some of the parents had needed (or chosen) to develop proficiency in the use of NZSL prior to implantation as gains with amplification were still limited. Secondly, there was little research giving confidence that spoken language would develop while sign language was retained. However, there is now evidence pointing favourably to the ongoing use of sign language in combination with auditory skills training (Komesaroff, 2007). Thirdly, the age of implantation is reducing with earlier diagnosis and greater parental awareness. Therefore as children are presenting for implantation earlier, it is less likely they will have established signed patterns of communication prior to surgery.
professionals and, in particular, auditory verbal therapists perhaps do not need to be concerned with competition from pre-existing language patterns.

No families in this study used sign language meaningfully. Their reasons were: lack of opportunity to become proficient, embarrassment, advice from hearing professionals, and no perceived benefit. Other parents cited a preference for their children to be more independent in communicating with others (meaning using the spoken language of the majority). Some parents recognised a need for sign language but had not yet been able to initiate lessons, citing fatigue and a sense of overload.

One father clearly showed a reluctance to encourage the use of NZSL:

We talked to people who were really negative about cochlear implants, but I don't like sign language; we do not want to use it. There is no comparison. I mean, I understand people and the need for sign language, but it just seems. I would rather have her more independent.

However, when his child was unable to use the implant at the pool or bath time, alternative communication strategies were clearly necessary.

Although, we do sign to her for things. But, it is her own sort of little language.

A mother with a (non-European) background reported that the need to use NZSL carried shame or stigma:

They don't even bother teaching signing back in (home country) because it is seen as poor, signing is. You know the Caucasian culture, the European culture should be proud of their education. They want to help their child and help their children, whereas in (home country) if you have got any defect you are an outcast. People don't want to spend time with you.
The same mother continued to discuss the stigma yet acknowledged affirmation for the value of NZSL, as this mother was competent in many languages:

I had seen deaf people but I don’t think about signing, I think, Wow it is cool that she should sign but not that same reason why people use it. We are an (another ethnicity) background; it is almost like a stigma if you know what I mean.

In contrast, another mother wished to learn sign language but she was isolated geographically and there were no opportunities for tuition:

I would quite like to learn a bit more signing and we were given a folder with basic gestures like good boy and naughty boy and stuff like that. Yes, I wouldn’t mind learning a wee bit more because there are times that you have to, well, he can’t hear and he has got no implant like in the bath and swimming.

When asked about opportunities to learn language locally, she replied:

No, not that I have found here.

The father of this same child commented about his limited use of sign language and expressed a wish to learn more. However, he also referred to the limitations of travelling with NZSL as the only means of communication:

I mean we don’t sign. We just do some gestures, but I mean that is becoming less and less because he is getting so good at speaking. I always thought signing is something I would like to learn. Yes, it is a universal language, New Zealand Sign Language, but if you go overseas you have the same problem trying to speak British Sign. So signing was never an option. We never had to discuss it. We are a hearing speaking family.
He also parented an older hearing child and referred to time constraints and limited opportunities as reasons for not incorporating signing into his family’s communication:

I don’t think there is anyone over here who teaches NZSL. I have looked at diagrams in books but I think it is better to be taught by someone and it is also a time thing, you know. Well, I am working and looking after the kids at the moment. We both work and we are both pretty sort of full on.

Another mother acknowledged a need to sign, but had not started lessons despite availability. She also raised an important issue for parents who are attempting to learn NZSL while trying to build language competency:

One expands a child’s language by virtue of the parents’ inherent superior language base. To do this for your deaf child while learning sign language as a beginner presents some challenges, the least of which is time and exposure if you have been a hearing person all your life.

She continued with this concern about building competence in NZSL:

I feel it would add depth, I think sign language would be of benefit to him and I could respond more immediately to his needs (referring to the bath) so we signed up to classes to learn. I went to one but have not made it to any others. I’ve just got questions about how am I going to become good enough at sign language to teach my child. Because there is no point in me thinking that he can learn it. We’ve all got to learn it. So I have questions about how to make it happen because there are plenty of times when he’s not wearing his ear and I want to have those same conversations with him.
Another mother continued this theme of parental competence and was also concerned that her child would be excluded if she used sign language as her principal form of communication:

> Any language is not easy to learn, and so is the time of getting up to speed with sign language too, and in communication with other people too. It is exclusive. It excludes people.

She continued this theme of exclusion and of the commitment needed in learning sign language, and referred to the effect it would have on communication with extended family:

> Yes I would have gone to all the appropriate places to get that. But I mean this is obviously a lot of work and for me personally, and for everybody, we who wanted to communicate with her (deaf daughter). And I mean at the end of the day I wanted her (deaf daughter) to communicate with everybody. (Grandfather) is in his seventies now so learning a new sign language at that age is not easy, and (grandmother), well, she is Irish and she has got a language of her own sometimes too. I know sign language is now considered an official language in New Zealand but it is still not spoken by many people.

These comments reflect a fear of exclusion and a comparison to her own sense of exclusion due to lack of fluency in her own native language:

> I mean I hear Māori on TV and I just wish I could speak Māori. But it’s exclusive, it excludes people. It makes me think if I had the time I would learn Māori as a language. You feel left out when other people speak in other languages, so I can imagine she would feel the same. If you are ever left out it is a horrible feeling.

Most parents interviewed received confusing messages about the place of sign language, and no parent was encouraged to continue the use of it. Neither was it considered an adjunct to
general language competence. It was not encouraged as a contingency in emergencies such as in moisture, where the implant may not work.

A father (another ethnicity) commented on the advice he was given on sign language:

Just at the beginning we learned about sign language but they (hearing professionals) didn’t encourage it. She (deaf child) knows how to communicate with us in sign language but now we try to avoid signing.

Despite acting on the advice of the service provider, he talked of difficulties without access to NZSL. He also referred to lip-reading, a practice which was not encouraged by the underlying philosophy of auditory-verbal therapy:

At the swimming pool, I have to be very close to her and have to go and pat her or something like that, and she tries to lip-read as well.

Another mother discussed the daily challenges of the auditory verbal philosophy:

Well, we bought into the whole spoken language approach as advised. Don’t go down the sign language route at the same time, even though, intellectually some part of me thought my child is capable of learning both. But I thought I’ll throw myself one hundred percent into this auditory verbal approach and the signing will come later. But then there are times like in the bath when he asks “Mum why has this bubble got a rainbow on it”? So I can’t answer the question, and I can’t even say, “Wait till you are out of the bath”.

The father of this child also recognised he had naturally learned to lip-read despite the commitment to auditory verbal therapy:
When the children are in the bath and I am speaking to (hearing child) and turned away from (deaf son), he will reach out to me, turn and watch to see what I have been saying. So I am absolutely aware that he’s lip reading.

The comments of another mother also reflect this ambiguity:

We were advised not to sign. Oh, hang on. Actually when down at (service provider) they have changed the philosophy, and so we were not advised either way

In response to how she would communicate in a situation like this:

I would just gesture and, yes, she is a good lip-reader. I don’t like going to the beach or the sea. I have this anxiety around water but I will go in a boat but would take the device off.

She relied on the tendency to gesture and the child’s established competence in lip-reading. However, many parents who have implemented the auditory verbal philosophy have not been encouraged to gesture or lip-reading. These skills have developed naturally and unconsciously. Gesturing and lip-reading strategies had a place, even if not acknowledged, in the lives of the children and parents in this study.

4.4.3 Experiences with the Deaf Community

No parent interviewed described any meaningful or regular contact with the Deaf community. It is unclear how much the lack of engagement with, and/or exposure to the Deaf community after the initial diagnosis influenced this low use of NZSL. At the time of this study there was no formal obligation for the implant panel to have a Deaf adult advocate. NZSL is an official language of New Zealand so this merits further exploration. Some parents spoke of a desire to avoid contact with the Deaf Community, having had distressing experiences in the early
months following diagnosis. Others felt that Deaf advocates had a confrontational approach about the education of deaf children. There may be understandable reasons for Deaf advocates taking a confrontational stance, but this was difficult for parents to deal with in the period directly following diagnosis. Another theme that emerged was fear of losing a child to the Deaf community. Some parents had limited opportunity and no advice about initiating contact with the Deaf community. Other parents did not believe that contact with the Deaf community had any relevance to their child’s development.

A mother spoke of her feelings about her initial contact with the Deaf community:

I found the trip to (service provider) for the first big meeting of 3 to 4 days confrontational and I didn’t get on with (signing person). (Signing person) got angry with me in sign language, can you believe it? And (signing person) continued signing away to me as if I understood, I think because I asked naive questions and (signing person) was offended by me. I didn’t mean to offend.

In response to questions about ongoing contact with the Deaf community she commented:

Why revisit something stressful? You are meeting because you have something troublesome and distressing in your life. It’s is not because you share a love or passion of something that you are meeting up.

She continued about the Deaf community:

I don’t need to go. I don’t need to be part of the Deaf community. I might change as years go by but I don’t know. But I find it very confronting.

Her husband was not so daunted but still made reference to this confrontational style. He recognised a need to engage more but he also referred to time-constraints, work commitments
and parenting demands of a deaf child, as factors influencing low contact with the Deaf community:

Our contact is minimalist. It is a concern. It is something we need to address. But in the initial stages we were just focusing on spoken language as advised, which meant we would delay that whole integration into the Deaf community. And now I guess we have come to the point where we should do more. We have had a very busy time with (daughter). We planned to do a course but it didn’t happen. The KIT days (Keeping in touch), well, they are a bit intense, to be honest with those people who are Deaf advocates. And they don’t believe in cochlear implants, so there is quite a bit of tension.

A mother also referred to confrontation by Deaf advocates:

I felt like we would be disapproved of by deaf adults in the community because I’ve heard of this disapproval from adults that people like me are eroding their culture. So I can understand their perspective. I just felt I didn’t need to put myself in the firing line, so I went out of my way to avoid any events with (service provider).

She also spoke of a fear of losing her child after discussions with other parents whose child chose to use NZSL, and to live within the Deaf culture:

Like for me, I thought, I don’t want my child saying I’m not really part of your family. That was the clincher for me. I didn’t want my son to be fully immersed in the Deaf culture because there was no way I was ever going to be fully immersed and we would be worlds apart. I actually would lose him and I just didn’t want to lose him.

Her husband drew parallels with his own cultural heritage. He spoke of limited fluency in his own language and compared it to their child’s low use of NZSL. He mentioned that the
success of the implant fostered some complacency but that his child was still fundamentally
deaf and would therefore always need some access to NZSL:

He is not a fully hearing child in the same way as I am not fully (ethnicity) and they (parents
with cochlear implanted children) are not involved in the Deaf community. For certain other
ways I am not fully Kiwi. So I think there is an issue. Some full blooded (own ethnicity)
would call me a banana, yellow on the outside but white inside.

Drawing on the theme of “overload” with so much to manage in parenting a deaf child, he
was clear that it was not lack of opportunity that had prevented him from contacting the Deaf
community but fatigue:

We have had to get over the focus of the surgery in terms of being on the auditory verbal
approach. It has really all taken up all our time. It is almost like we have to take a breather for
a minute, and then the next thing is sign language.

He continued in relation to contact with the Deaf community:

No. Almost not at all. Non-existent. Apart from knowing a few other children with cochlear
implants. I don’t have a strong need to meet them. It will be something for (deaf child) to take
on and decide about rather than ourselves.

Several parents made quite clear reference to the lack of need, and low desire, for contact
with the Deaf community. This father put it succinctly:

Why force them to be with kids that they don’t necessarily have a lot in common with other
than the fact they have a hearing impairment? Deaf culture with a capital D is possibly never
going to be part of their lives. They want to be regular kids, part of the hearing world. And
they are accepted into the hearing world.
A mother made reference to the cochlear implant as a cure and used these terms to explain the technology to her parents. She saw that the problem of deafness would be resolved. Understandably, if the implant led to a cure other communication options were not relevant:

He (grandfather) knew that she would be cured, and his meaning was that this problem would go away. Anybody from his generation who was deaf would have been a social outcast and would have the stigma. I was adamant that she (deaf daughter) was not going to be in the deaf culture.

Another couple who lived in a remote community spoke of no opportunities to engage with the Deaf culture and community. Looking ahead though, the father was open to his child exercising a choice:

I don’t want to get involved. At this stage he has nothing to do with Deaf people. I guess that has got to be his choice as he gets older.

Several parents spoke of this choice. However, as there is low contact in childhood and a lack of modelling by parents, the children may perceive that the language and culture are not valued (or seen as relevant). It may be difficult for these children to develop confidence to exercise a choice. In order to exercise a choice, one needs to know that alternatives not only exist but are also valued. There may be a case for suggesting that there is a greater need to have NZSL modelled for them in a pro-active and positive manner.

The implanted children in this study appeared to be functioning on a day-to-day basis in the hearing world and were described by their parents as “normal” (Section 4.5). However, they remain dependent on electronic equipment (and batteries). Therefore, these children may
challenge the perceptions of firstly their hearing parents because they remain deaf and
secondly, the Deaf community because of the ease with which they seem to be developing as
hearing children.

4.5 Experiences and Perceptions of a “Normal” Child

4.5.1 Introduction
This section will review the results relating to the theme of normality. The use and reference
to the word normal was one of the recurring and pervasive themes in the interviews with
parents in this study. I chose not to examine parents’ understanding of the word normal, and,
conversely did not explore its corollary: what is not normal, as doing so was not the focus of
my study. In addition, I felt that an exploration of the meaning of the word normal could be
perceived as confrontational. I began each interview with a question that aimed to explore
each parent’s current experiences of their child. The use of, and reference to, the word normal
and the parent’s description of it as it pertained to their day-to-day lives followed naturally
and spontaneously.

Three main themes emerged from the data that relate to the use of, and reference to, the word
normal and are described by the following: choice and desire for a normal child, current
experiences of a normal child and future parental aspirations for their child.

4.5.2 Choice and Desire for a “Normal” Child
Many parents perceived cochlear implantation as giving them the choice for their child to
have a normal life, develop intelligible speech and develop normal friendships.

One father talked of the choices cochlear implantation offered his son:
I think it was a device that could provide him with a much more normal life in the sense that he would be able to operate within the normal community as opposed to being in the Deaf community. Thus, I saw the cochlear implant as almost allowing him to be domiciled within the hearing community and he could go back to the deaf community if he so wished.

With reference to the development of intelligible speech, several parents talked of the possible options they perceived cochlear implants offering their child. Many parents saw the choice for the possibility of intelligible speech as being so obvious that there was in fact no choice. One mother commented:

I think having the first one was a no-brainer, and absolute no-brainer.

Continuing this theme of opportunity and the development intelligible speech, another mother explained her reasons for cochlear implantation as the preferred management:

So I had a tiny bit of guilt about cochlear implant being the right choice but 99 percent of me was screaming, just get him a cochlear implant. And a lot of friends would say to me 'Actually how can any parent see there is a choice'? And I said, well, there is a choice. And I could clearly see because I'd done all this reading and I understood about the Deaf culture, and I could understand why some deaf people believe that parents shouldn't implant their children, but I didn't agree with it.
She continued:

I felt good about the fact of my decision, and I appreciated those while I was making the decision and realised that I did actually have a choice, but it was a screamingly obvious choice to me.

While reflecting on his decision-making, one father made reference to the use of the word “happy”. He was of a non-European background and had talked previously of the shame associated with having a profoundly deaf child. His beliefs reflected a fear that his daughter may not be able to have a happy life while living with the restraints that profound deafness places on a person in a hearing world dominated by spoken language:

It was an easy choice and decision for me because I am really looking for her to be happy.

The mother of the same child commented in reference to her child being hearing, despite the obvious equipment:

I don’t want people to stare at her thinking, Gee, what has she got on her head? It doesn’t look like a hearing aid, and I would always say, I have said I have a deaf child but she is now a hearing child thanks to cochlear implants. I was adamant she was not going to be in the deaf culture. I would love to be able to sign but not because I want to sign with my child but because I speak five other languages.

This mother values the challenge and sense of accomplishment in learning sign language, but does not perceive sign language to be the preferred basis of daily communication. She also made reference to choice when responding to a question about how much contact she would like with the Deaf community and sign language:
What do you mean Deaf culture, and not accepted into the hearing culture? Does she have to be in the Deaf culture because she is deaf, and can she be accepted in my culture, the hearing culture?

Another father of children implanted later in childhood discussed his choice of cochlear implantation rather than ongoing use of hearing aids. His decision was influenced by his daughter’s social development as she approached her teenage years. He shared awareness with his wife that their child was “missing out” as a growing teenager which appears to have influenced his choice in favour of implantation. He explained the dominant factor shaping his decision in the following way:

A realisation that the children would not go much further with hearing aids; we were as far as we could possibly go. There was better technology.

He continued to elaborate on his perception of his daughter’s social development:

There is the social side for my daughter. I won’t use the word outcast, but she now has more confidence and can go and chat with anyone about anything.

A mother of an older child suggested that increased age influenced her decision, as her daughter discussed her awareness of “missing out”. Until the time of implantation two years earlier, this girl had been using hearing aids. She commented:

She really felt as if she was missing out. She was very aware she was missing out on stuff in the family and at school. So how can we deprive a child of not being able to hear better even if we have got some sort of misgivings and she was getting virtually zilch with her hearing aids anyway?
The father of the same child also commented on this issue:

We realized. Well I was aware that she was definitely missing out on things as was (older deaf daughter) as well. Um, so, yes, well, I was aware that was going to have an effect on her development, mostly social stuff. But now she picks up the cues and innuendoes with her friends at school. That's a biggie. You know maturing up as a young lady and all the rest of it that goes along with all of that.

This mother discussed the potential to converse “normally” and about spoken language being an important factor in shaping their decision:

But (husband) and I kind of made up our mind. If we had the choice of getting the cochlear implants we were going to do that and, like, later on he can decide for himself if he wants to take it off and go with the deaf and sign, or he can carry on with how he is. Like now we have the choice to have a normal conversation with him.

4.5.3 Experiences of a “Normal” Child

One of the overwhelming themes that emerged from talking with parents is their perception that their daily life with their deaf child was not qualitatively different from that of their hearing children or other hearing children. A mother referred to her child’s normal behaviour while still making a reference to the obvious appearance of the equipment. The following quote illustrates this theme, and notes the comparison with her hearing peers:

I mean, I know, sure they got the coils on and stuff, but because they look normal and they sound normal and they do normal things these kids are accepted by their peers. She sounds like a normal kid.

A father of two older children spoke of forgetting they were deaf, despite the reference to batteries and the equipment:
Every day or so, although you are reminded of it, always conscious of the cochlear implant and the batteries, it is always there but do we think of them as deaf? Day to day not really, no, no, just normal, as normal as we know anyway. We don’t make special allowances.

He discussed his children’s behaviour and his expectations of the education system:

I don’t make special allowances for them. They are just like, yes, you may need to clarify things for them for the communication as you do but they get treated just like anyone else. At (school) report time I have lined a couple of them (teachers) up over the years in a nice way, and said, Look, are you telling me like it is. Because, and I have honestly over the years pretty much looked all of them in the eye look, and they say ‘Look, these are the results, just like little Johnny, or whoever’.

This same father continued with a very clear statement about his children’s experiences of themselves:

They don’t like to be different. They just want to be regular kids, and they are accepted in the hearing world apart from the odd comment. I don’t think they consider themselves as deaf.

Parents generally received advice about challenges with acquisition of another language or proficiency with music. The speech-processing software is programmed for human speech, not music, and enjoyment of music is not guaranteed. Similarly, other accents and use of different vowel combinations from other languages can be challenging. Despite this advice, several of the parents discussed their child’s positive experiences of foreign languages and enthusiasm in learning musical instruments. This same father continues:

Well, music, she is fantastic. When we travelled 2 years ago they had to learn basic words (of other languages) and the kids would play a game in Italian and French, changing languages and counting, in the back of the car.
I am not musical and I felt, well, if they get some benefit out of music that is great but if they don’t that’s life a small price to pay. But as it turns out they have as much enjoyment of music as their peers so I have been probably been a bit slack. They know all the words to the pop songs like a hearing child would so music has become a big thing.

Continuing this theme of comparison with hearing peers, and of equal opportunities, a mother of an older child commented in relation to her son:

Well, it was his choice to learn the violin after having heard a friend play at a concert. Why would you not to give the kid a go at it? Plenty of hearing children learn instruments but never make careers out of it.

Another father also commented on his son’s enjoyment of, and exposure to music, with comparison to hearing peers:

He loves music. There are songs when he sings along. He is starting to pick up words and he is singing in tune. I have heard children singing a lot worse. He is no more out of tune than (hearing brother).

References to normal intermingle with the notion of happiness. This mother described her child:

She is fortunately very happy, well adjusted, extroverted, normal as normal can be child. She is persistent, strong-willed, and I think this is an advantage being in the situation she is (meaning deaf).

Continuing this theme of happiness another father commented:

He is cheeky, happy, and always happy. He likes having you on with things. He is no problem; he is good, and there are no problems there at all.
This same father also reported how he had felt compelled to correct a teacher’s perception based on her previous experience with deaf non-implanted children. He felt it was necessary to tell her that an implanted child should not be treated like a deaf child:

I said, well, he is not deaf. He hears through a cochlear implant. So I say it will be a little bit different strategy from what you (teacher) are used to. I really bit my tongue and I came out there with big welts on my tongue. But, anyway, he (son) had been intimidated by the teacher.

Parents also had been advised about the risks with contact sport of trauma to the magnet. This father discussed his wish for his son to play sport like his friends while acknowledging these concerns:

I mean, we had him (deaf son) play rugby this year. It is only touch at this stage. I mean, he runs along and does flips. I mean, I am happy for him to play rugby, but he won’t tackle until he is 8 or 9 years old. He may have to take the magnet off, but they do touch, and ripper rugby.

4.5.4 Future Aspirations for Their Child

Many parents did not perceive deafness defining their child’s future for educational and work opportunities. Deafness, for many parents, was seen very much in the scheme of the differences and restrictions that all children face throughout their life. The deafness appears to have been placed within the range of normal challenges that are faced by all children.

A mother, typical of many, referred to her son’s future, and while acknowledging some of the real limitations deafness and cochlear implant, saw it as comparable to the limitations all people to some degree contend with:
If he wants to go to university, if he turns up at twenty and says I have applied for a scholarship at Harvard or whatever I'll be like ok. If he says he wants to go and work on an oil rig, he should be able to do the things like any other kid. He can do anything he wanted. I mean he will be limited. I'm sure he wouldn't be able to fly into space because he's deaf and it has its limitations. But to be honest in every single being in the world has the knowledge they all have limitations.

Another mother also referred to an open-ended future for her child. In the following statement, she indicated that it was her child's personality determining her future, unhindered as it were, by her deafness.

She can do whatever she wants. Yes, there's nothing that is going to stop her from having a normal life, normal success, normal. It's basically her personality of what she wants to do. She's got it all there and she's a good kid.

A father of two older implanted children also elaborated on his expansive view of his child's futures:

The sky is the limit. They can do. They are both very intelligent kids and I am sure everyone says that, but they really are. Gosh, they are quite exceptional at school.

A mother also spoke of her high aspirations. This mother expected no less from her implanted child. In fact, she inferred she held higher expectations of her. The mother had a professional background which may have influenced her aspirations for her daughter's future:

I have very high expectations she will do good things. She will be well educated with a fine career academically and professionally and the same for (other two hearing children). Yes, I am thinking she is going to be a doctor or a lawyer. She could be an audiologist. Tell them she can do this.
A non-professional father also did not perceive deafness as being a determinant of his son’s future. His comments suggest that his aspirations are no different from those of the older hearing son:

I mean, obviously, he can do what he wants and be whatever he wants. I have got no idea of what that is yet, but, in saying that, neither do I know what his brother wants to do.

Reference to the future aspirations of the implanted deaf children in this study as not being qualitatively different from those of their hearing siblings, reinforces a notion that their child’s development will follow a normal path. Statements like these from parents may suggest a normalisation of the presence of deafness among children, and within the wider human experience. Whether it suggests we are moving towards a more pluralistic approach to children with impairments, or whether it represents the subtle, hegemonic removal of the obvious speech and language obstacles deafness presents within educational and parenting perspectives is still unclear. These parents’ comments could mean a more inclusive approach to all children. However, a worry is that cochlear implantation may be subtly impeding this process of inclusiveness by this reference to wanting “normality”.

4.6 Experiences and Information Regarding Bilateral Implants

Many parents raised this issue. For the children with bilateral implants all were sequential with no consistent factors underpinning the decisions. Many parents had researched the issue themselves. Some had seen the benefit in other children, and one mother indicated it was fairly obvious that two implants were better than one. None of the parents in this study described a systematic approach with acquiring information from service providers. In addition, the available literature was not presented to them in language they understood. The issue of bilateral implantation as superior option is unclear, because the evidence is still
emerging. If parents choose a second implant they incur financial cost (approximately $40,000 to $60,000). When this is added to unfunded auditory habilitation parents are presented with ongoing costs ($3000.00 per year). Despite this, several parents indicated they would seriously consider bilateral implants if evidence of benefit was presented to them.

A father discussed his experiences about the confusing information he received:

Our (hearing professional) advised it briefly about two years ago and I was skeptical as obviously it was in (service provider’s) own interest. And we looked at it briefly and realised there were hardly any kids in NZ and our (hearing professional) advised us to be cautious because (service provider) wanted more kids to have them, so (service provider’s) research is good. Then (wife) met someone else’s (deaf child) in (service provider facility) who had bilateral implants, and she saw the testing and how much of a difference it made, in terms of real life and background noise.

Another father shared his lack of knowledge on this topic:

I don’t know how much extra benefit it would be? I really don’t know.

Another father discussed the moral dilemma, when he realised there was a possibility that his daughter may benefit:

It was a big commitment but I wouldn’t be able to live with myself if we didn’t do it. I felt a moral obligation. Once we had the knowledge that even if it just made her life just a little bit easier, and in the classroom. The surgeon was great, quite candid.
A parent whose child received her second implant shortly after her first, commented on this lack of information. More information about the availability of a bilateral implant may have resulted in her child just having one operation:

I just figured if you could have one, you could have two. *(Deaf child)* is not hearing in both; why not give her hearing in both. They *(service provider)* didn’t offer it to me. These people *(service providers)* did not have the foresight to think maybe we could afford the second, and maybe the parent wants better for the child. He *(hearing professional)* said, “Yeah”. And I said, when? And he *(hearing professional)* said “Well, if you have the funds, I would do it immediately” and I said what! Why didn’t you guys tell me this? Why wasn’t this information given to me?

When advised about the significant cost, it was obviously not a deterrent for this mother:

I could max out on my credit card, take a loan. Let’s do it. I will do it.

Other parents who had not yet considered a second implant indicated it was an option. This view is illustrated in the following comment:

The cost would not be barrier, not that I am saying that I can afford it. But we would find a way tomorrow.

Other parents were clearly not able to pay, but were concerned about justice and the additional safety benefits of bilateral implants. This father commented:

If I had the funds, I would definitely go for another implant. I think that for him to hear bilaterally it has got to be better. To get direction, and for *(deaf son)*, busy, noisy roads are a concern. He doesn’t know which way to jump. I think the whole system is wrong. This is a child that can do wonders with one implant, and he has a hell of lot of work to do to get where
he is now and he has got a hell of a lot more to do, and he is challenged more. So any device
that they can give him, I mean, at the end of the day, they wouldn't give a person one false
leg, they would give him two, wouldn't they?

This father's comments do raise issues of justice about the availability of bilateral
implantation for children. There is no research addressing the cost-benefit ratio of unilateral
versus bilateral implantation in terms of educational and employment outcomes. However,
we do know that children with two hearing aids perform better academically than children
with one (Bergeron, 2006). Children whose parents are able to fund a second implant may be
advantaged socio-economically confounding the potential benefit of the second implant.
There may be understandable reasons why service providers are reluctant to discuss unfunded
treatment options. However, parents need this information in order to make informed choices
for their child. The available evidence suggests that a second implant is best done as soon as
possible following the first (Scherf, 2006).

In summary, while parents appear to be receptive to appraisal of all information on bilateral
implants, service providers have not delivered this information in a systematic manner.
CHAPTER FIVE

DISCUSSION

5.1 Introduction

Some of the results of this study support other research presented in Chapter 1 and highlight areas where further research is needed. This study was successful in generating results that have not been previously documented: specifically the stress associated with the pre-implantation hearing aid trial.

The initial diagnosis of hearing loss and associated support and educational services was a crucial starting point for parents. It is also their first point of contact with hearing-related health and education providers. The referral process for cochlear implantation and the associated pre-implant hearing aid trial are two areas that created high levels of distress, owing to both the inherent uncertainty during this period and an inconsistent approach to information and services offered by health and education providers. Results pertaining to the family of the implanted child will be discussed as they impact on other siblings and parents’ work and career choices. Then the results of low use of New Zealand Sign Language (NZSL) among parents in this study and the perceived lack of value of engagement with the Deaf culture will be discussed. The results indicating a wish for a “normal” child will then be discussed. This wish for “normality” may have influenced the decision-making process for a cochlear implantation. The “normal” child was a pervasive theme, and appears to be related to the perception that cochlear implantation offers parents an opportunity to “treat” the deafness and thereby create the possibility of raising a “normal” child. The concepts of non-finite grief and loss (Bruce & Schultz, 2001) and parental grief (Luterman, 1989; Luterman & Kurtzer-White, 2003; Luterman & Maxon, 2002) offer insight in understanding these
experiences of parents. Finally, results that surfaced in regard to bilateral implants will be presented as this study raised concerns about the way non-funded treatments are presented to parents.

5.2 The Initial Diagnosis

The initial diagnosis of hearing loss and the associated support and educational services offered to parents prior to implantation appeared to be problematic, creating stress for parents that continued through the post-implantation period. Other researchers in New Zealand (Purdy, Chard, Moran, & Hodgson, 1995), Turkey (Incesulu, Vural, & Erkam, 2003), Europe (Burger et al., 2005; Hintermair, 2006; Spahn et al., 2004) and the United States (Feher-Prout, 1996) and have reported similar results. Regardless of the intervention that parents may later choose, they were initially overwhelmed with grief at diagnosis and required support during this period. This result is supported in the literature (Graham, Anagnostou, & Crocker, 2007; Luterman, 1999; Luterman & Maxon, 2002). Graham (2007) indicated that grief was the strongest emotion condition that parents experienced (p. 78). Bruce and Schultz (2001) caution the use of grief models based on death and dying (Kubler-Ross, 1969) to explain grief responses in parents of deaf children because of potential stereotyping and expectations placed on those experiencing losses other than death. Professionals who look to the Kubler-Ross model to explain parents' grief for a child with hearing loss may be initially supportive, but anticipate that parents will resolve their grief as if it were time-limited. Bruce and Schultz (2001) describe cycles involved in adapting to non-finite grief. Many parents in this study felt they received inadequate emotional support from service providers. It is not clear whether this perceived lack of support relates to lack of funding or whether services are expected to provide this more comprehensive psychosocial support for families.
The element of uncertainty regarding communication strategies prior to confirmation of the diagnosis was a prominent feature in the lives of most families in this study. Parents were given conflicting information and experienced variable waiting times for confirmatory testing and diagnosis. Furthermore, the parents’ experience of receiving the “bad news” was described in many instances as a profound physical sensation. This experience of shock has been reported in the literature (Hintermair, 2006; Incesulu et al., 2003; Quittner et al., 1991; Spahn et al., 2004). Parents are the essential partner in therapy (Bodner-Johnson, 1986; Minke & Scott, 1995; Simser, 1999), so one could argue there is a clear case for health professionals to be equally concerned with the parents and children. Research indicates that competence, achievement and adjustment in school-age children is related to successful family adjustment (Bodner-Johnson, 1986). There is a reasonable body of literature describing parents’ stories of encounters with health professionals (Baruch, 1981). Baruch noted that parents acknowledge their inexperience at dealing with the medical aspects of their child’s welfare, but he also maintained that health professionals expect them to be accomplished in this sphere (p. 291). He concluded that, when parents are properly informed about unfamiliar medical interventions or diagnoses and when anxieties are acknowledged, they show improved coping skills. This study suggests that many service providers were not treating families within this broader psychosocial context, and many parents were not receiving the ongoing counselling and support that the literature recommends (Graham et al., 2007; Hintermair, 2006; Luckner & Velaski, 2004; Luterman, 1989; Luterman & Kurtzer-White, 2003). Graham (2007) concluded with this recommendation “The skills of a psychology professional in working with these feelings are therefore a necessary part of all paediatric cochlear implant teams (p. 82)".
5.3 The Referral and Assessment Process for Cochlear Implant Candidacy

In the previous section, many of the issues discussed for parents around the initial diagnosis continued during the referral process. Uncertainty regarding terminology, inconsistent information about cochlear implant candidacy, and stressful decision-making impacted on many of the families in this study. This result is well supported in the literature (Most & Zaidman-Zait, 2004). The acceptance of a child into a cochlear implant programme also marks the beginning of a “medically deaf career” with life-long medical and audiological surveillance. This uncertainty and confusion about the process experienced by some parents was in stark contrast, however, to other parents who spoke of a more streamlined process, where their queries were addressed in a candid manner and in language they could easily understand. These parents were given appropriate and timely information and felt more empowered to make the right choice for their child.

The ability to provide appropriate information at the right time, in an empathic manner, and not couched in medical “jargon” is an important skill. Aristotle’s concept of phronesis in his work *Nichomachean Ethics* is relevant here. Phronesis is the virtue of moral thought, usually translated as “practical wisdom” and sometimes called prudence. Phronesis is the capability to consider the mode of action in order to deliver change, especially to enhance the quality of life. Aristotle says that *phronesis* is not simply a skill as it involves the ability both to decide how to achieve a certain end and to reflect upon and determine that end (Klosko, 2007).

This skill may involve an awareness of how grief can impact on the decision-making process, and so involves the ability to judge how much information is appropriate to share with parents at any particular time. It is possible that some of the variation in parental experiences may relate to varying abilities to process the complex and extensive information about their child. It is therefore important to provide this information in a way that does not overwhelm...
parents, potentially increasing anxiety. The process a family experiences with the diagnosis of a child with hearing loss very soon takes a departure from a more traditional “medical model” of treatment as there is no cure for deafness, only several management options. It is critical that parents understand that there is no cure for deafness and that this understanding is checked regularly by professionals prior to implantation.

Many parents considered the hearing aid trial a negative experience, with high levels of stress, frustration and limited success. Their accounts contrasted with those provided by families where older children had been successful hearing aid users prior to implantation. The parents of the older children in the study had not known about superior outcomes for cochlear implantation (Nicholas & Geers, 2006; Niparko et al., 2003; Richter et al., 2002) and had considered cochlear implants experimental. With this historical knowledge, the only option available to them for achieve spoken language as an outcome was persistence with hearing aids (amplification).

One possibility for this previous tolerance of hearing aids is that, with limited choices, families may have felt unable to express their frustration about this low benefit, but rather felt that they should “get on with it”. It is only with the luxury of additional and more effective choices that parents can afford to be dismissive of perceived “inferior” options. In contrast, the parents of the younger children in this study appeared to go through a due process with hearing aids as a matter of duty as they awaited the confirmation of implantation candidacy, but there was a lack of commitment to hearing aids as a viable long-term option.

Many parents spoke of relief that their child was sufficiently deaf to be considered for an implant. Spahn (2005) also referred to this, observing that parents of children “who are borderline cases for implantation are under greater pressure” (p. 9). Even with the
inevitability of a major surgical procedure, there was still a sense of relief that their child was accepted as a candidate for a cochlear implant, and that they were able finally to progress to this more effective intervention. This study found similar results to Spahn (2005), who noted “the marked relief experienced by the cochlear implant parents after initial fitting” (p. 9). If amplification with hearing aids is to remain an ongoing requirement of the referral protocol for cochlear implantation this study suggests that parents need more support and guidance during this period. This support would need to specifically address problems relating to the distressing sound feedback from the hearing aids and to offer strategies to support parents to maximise the use and wearing of hearing aids by babies and toddlers.

5.4 Engagement with Health and Education Providers

The success of deaf children is crucially influenced by parents’ reactions, acceptance, and advocacy for their child (DesGeorges, 2003). It is imperative for professionals who create systems for early detection and intervention to understand what families are asking for and need. Cochlear implant recipients require intensive therapy to attain maximum auditory, speech and language benefits (Simser, 1999), and parental involvement is critical in determining outcomes (Bodner-Johnson, 1986; Cohen, 1996). A family-centred approach from health and education service providers is acknowledged as best practice (Luckner & Velaski, 2004; Luterman & Maxon, 2002; Simser, 1999). The evidence of such practice in this study of parents is lacking. Many parents reported feeling isolated and of struggling with many providers with different terminologies, bureaucratic processes and service requirements. Some parents reported conflict over their child’s management which created some anxiety and distress about their child’s access to services and candidacy for cochlear implantation.
One intervention method offered to parents was auditory-verbal therapy (AVT), an approach that develops the child’s spoken language following normal developmental patterns using the access to hearing provided by a hearing aid and/or cochlear implants (Dornan, 1999). It requires intensive long-term parental participation and has been described as a “way of life” (Goldberg & Flexer, 1993) whereby parents become so familiar with the techniques learned in therapy that they use them with their children daily. Moeller (2000) reported that active family involvement in childrens’ speech and language development, paired with early intervention, leads to higher linguistic attainment. In addition, Seligman (Seligman & Darling, 1997) reported that meanings attributed to situations by participants will influence their response. Despite the importance of parental commitment and positive attitudes, very little is known about the experiences of transitioning to AVT from parents’ perspectives (Neuss, 2007). The present study indicates that hearing professionals lacked understanding of parents’ perspectives, as many parents reported confusion and others, a distinct lack of support and guidance from hearing professionals. In addition the parents in this study found that they assumed new roles following the detection of hearing loss including increased advocacy for their child and becoming teachers and facilitators of social interaction (Duquette et al., 2002).

For implanted children using FM systems in educational settings, poor access to specialised knowledge and readily available support meant that several children in this study, despite owning such equipment, were not able to access this technology for lengthy periods of time. Consequently, the parents of those children also felt that they had become equipment managers and general administrators but without adequate technical support from implant service providers and audiologists.
5.5 The Implanted Child’s Family

In this study some of the families underwent major changes in their work patterns, career aspirations and financial demands. The fathers’ role as supporters of mothers has been noted by Meadow-Orlans and Steinberg (1993), who emphasised the importance of spousal support in addition to that of extended family and friends. Of interest, Baruch (1981) also noted in his paper that emotional responses are largely attributed to mothers rather than fathers, and suggests this relates to the discomfort with which emotions are located in the male world. In this study fathers were given the opportunity to talk independently of their wives, enabling a male perspective to emerge supporting the results of (Baruch, 1981; Graham et al., 2007; Spahn et al., 2004). The majority of parents in this study reported excellent spousal support, but there may be some inherent bias because the study design required the participation of both parents so parents who were experiencing some degree of estrangement or difficulty within their relationship may have declined to participate.

Parents in this study reported that many extended family members lacked the confidence to support them. The low incidence of profound hearing loss and lack of knowledge of in the population may explain this lack of confidence. Grandparents may also be dealing with their own grief, a theme which is supported in the literature (Nyobo, Scherman, & Freeman, 1998). There are specific implications in regard to extended family members’ lack of confidence in handling the equipment, feelings of inadequacy with communication strategies, lack of knowledge of sign language and concerns about their grandchild’s safety while in their care. Owing to the constraints of the study, I was unable to examine this in greater depth. One participant did specifically note the lack of engagement with grandparents by an implant service provider, and this may be an area of support that implant service providers could consider reviewing.
Many parents spoke of the challenges they faced with the siblings of their deaf child. The hearing children of these parents were not interviewed as part of this study, but parents talked of their feelings of guilt and their experiences with their hearing children, and reinterpreted comments from the hearing siblings. Bat-Chava and Martin (2002) postulated that when a child with hearing loss is born first into a family, the family may have normalised deafness, and so when a hearing child arrives, he or she accepts this as part of family culture. In four out of the seven of the families interviewed, the deaf child was first-born, and three of these families had subsequent hearing children. Parents in this group, in speaking of sibling issues did not refer to the demands of the deaf child as a stressor for the hearing child, suggesting that the subsequent hearing child may have made this adaptation to “normalised deafness”. When the deaf child was born subsequent to hearing children, parents spoke of concerns that the hearing child’s needs were neglected, suggesting that this “normalised” deafness had not occurred. Reiss (1981), in his work on the family examined the concept of “crisis” and the development of a family paradigm. He refers in his work to sustained disability or illness in a young child as a family stressor. While some argue that deafness is not a disability, the parents in this study suggest that it is perceived, at least initially, as such. He notes that children with a disability may produce a family crisis, because they disrupt usual family routines and make it difficult for families to function on an implicit level. Families are not homogenous and differ in their long-term responses to these stressors. In time, some families become more confident and effective whereas others do not develop the skills to adapt. Reiss (1981) has posited that strong involvement with open and supportive health professionals has a major effect on how families deal with a crisis (p. 195). He also notes that a family’s emotional capacities were built up over weeks and months of experiencing, questioning, and learning.
Drawing on this insight and the concepts of non-finite grief and loss (see the section on initial diagnosis) in which Bruce and Schultz (2002) suggest that grieving continues and is affected by external and internal triggers. Health and education providers may need to be reminded of the necessity of an enduring open dialogue with parents that may go well beyond the post-implantation period.

Many parents had adapted or reduced their work patterns to accommodate the work involved in raising a deaf child. Archbold et al (2005) noted that “Time and family costs can be quite substantial especially for those in the first years of the programme and/or living further from the implant programme” (p. 934). Parents reported that carer relief support assessors lacked knowledge of childhood deafness, and as a result, some parents perceived an element of judgment. Thus, many parents in my study did not receive the benefit of this funded support, which is not means tested. The conclusion from Archbold (2005) was that there was a need to offer greater support during the first few years following implantation especially for families living furthest from the implant centre.

The necessity for ongoing support raises issues for New Zealand with two service providers and its unique geography. However, Archbold et al (2005) did not confine their conclusions to issues of financial costs but indicated that counselling was also still required for parents, years after implantation, supporting the work of Bruce and Schultz (2001) and concept of non-finite grief and loss.

In summary, examination of the reciprocal influences between deaf children and their families, available and sustainable support services, and increased awareness on the part of education and health care providers of these multiple factors will improve understanding of the complex processes involved in family adaptation to childhood hearing loss. Ultimately,
this understanding will lead to more effective interventions for deaf children and their families.

5.5 Contact with the Deaf Community and the use of NZSL

No parents identified a positive role model of a signed language option from health and education service providers, although, most indicated that sign language had been mentioned. No parents were using sign language on a daily basis with their deaf child. The parents in this study gave a multitude of reasons for not using sign language including fatigue and overload, lack of available tuition, and lack of perceived value. The low use of sign language among deaf children in this study supports the work of McKee (McKee, 2008; McKee & Biederman, 2003). However, despite this reported non-use, several parents were using gesturing, some unconsciously, as a communication means in environments where use of the implant was not possible.

Advice on the use of NZSL given to parents of newly implanted children may reflect a dominant model of spoken language from service providers in New Zealand who are predominantly hearing. Preisler (as cited in Komesaroff, 2007), refers to the low contact with, and experience of deaf children by implant teams in Sweden. This is of concern, as surgeons (and perhaps audiologists, to a lesser degree) are generally the first professionals to give parents detailed information about what it means for a child to have a cochlear implant. Furthermore, no parents of the children in this study had an experience of their child being signed to by an implant team professional. While the professionals may have mentioned sign language as a viable language option, this lack of use reflects ambiguity on the part of these hearing professionals.
Societal attitudes toward children with functional disabilities can influence the way parents view their children's potential to develop, and this lack of use of sign language by health and education providers within the implant services does not demonstrate an implicit value to parents. While many parents talked of their child having a choice to use sign language in later life, their lack of daily use during their child's early development also does not model this inherent value.

In 2000, the Swedish National Board of Health and Welfare formulated a policy that sign language communication should be established between the child and his or her family before cochlear implantation was performed (Komesaroff, 2007). Preisler (as cited in Komesaroff, 2007), noted in her study of parent-child interactions in the home setting, that children with the most developed oral language also had well-developed sign language. Rather than a binary model of oral versus sign language, another model could incorporate both into the emerging language of the implanted deaf child. Many parents in this study, while not consciously using sign language, were in fact doing so by developing their own gestures. When communication strategies in challenging environments were raised with parents, many acknowledged that they defaulted to the use of gesturing. Given the evidence that the use of an implant does not resolve the difficulties of social interaction (Spencer & Marschark, 2003), these children will be presented with greater demands on their language and communication skills. The auditory capabilities of the implant may not suffice in higher education, cultural and social activities, without the adjunct of a signed language option.

In a study by Wald and Knutson in 2000 (as cited in Komesaroff, 2007, p. 132), deaf adolescents with and without implants completed the Deaf Identity Developmental Scale. The study found that both groups gave the highest ratings to a “bicultural identity”; that is, adolescents wanted to be deaf but also part of the hearing society. This study is more than
eight years old so current emerging implant users will have been implanted at even younger ages than the adolescents in that study, thereby perhaps reducing early strong association with the Deaf community. However, its results of higher ratings to “biculturalism” need to be acknowledged.

To summarise, if there is merit in consideration of a more pluralistic approach, service providers need to demonstrate behaviour that values and encourages the use of sign language. Greater consideration must be given to funded tuition that is accessible to all implanted children and their families, especially for those in isolated communities. The requirement for this language support needs to be sustained as the child’s language matures. In addition, implant providers must demonstrate confidence that sign language is valued by hearing professionals by using it. It is likely that the mapping process would be less stressful for the child and audiologist if the audiologist could sign with the deaf child while he/she is “unwired”. Most deaf children live in hearing families, where they are exposed to speech daily. This current study suggests more attention must be given to providing families with sign language if we are to allow deaf children a choice to develop a bicultural identity. This study suggests that the low use of sign language and its low perceived value have not been adequately addressed.
5.6 Perception of a Normal Child

Modern societies appear to exert an influence on members to treat the body as an unfinished project that should be maintained in a healthy and attractive state. Although cochlear implants are not cosmetic, they could be seen as part of the current trend to use technical aids to adapt and “improve” the natural body (Alderson & Montgomery, 1996). This trend appears to confirm the dominant view that deafness is impairment and therefore requires treatment to confer “normality”. In contrast, a Deaf perspective argues that deafness can be part of the range of human experiences, and that surgery is not only unnecessary and potentially harmful, it is also potentially maleficent by its implicit acceptance of impairment. This assumption may prevent critical thinking and wise choices.

Through extensive use of body improvers, notions of an authentic self blur into concepts of expression and fulfillment of a self through adopting changing fashions. Adults are able to exert some choice, but young children may not be capable of, or offered choices about preserving their identity. Preservation of identity may seem irrelevant for very young children as they are not seen to have an identity till later. History, however, indicates that adults have been concerned with shaping children emotionally, physically, and psychologically. The task of parenting is inevitably associated with a degree of paternalistic benevolence. However, with the benefit of current knowledge in child psychology, previous historic child-rearing practices have been criticised (Cooter, 1992), and it would be useful to reflect wisely on current practice as it pertains to interventions for children (Alderson & Montgomery, 1996). Such interventions may not only powerfully shape childrens’ sense of themselves, but may give an implicit message about their parents’ perception of them as needing an intervention. The child may perceive that what underlies the choice and the parents’ wish for their child to be “normal” is a rejection of that child’s real persona. In (Komesaroff, 2007), Alderson identified this tension within society at large with a quest for an authentic personal identity...
and yet a need to be accepted. Kittay (2006) reflects on this paradox of a desire to be both different and normal. Given that one of the results in this study was of a parental desire for a “normal” child with the majority of parents describing their implanted child as “just like a normal kid”, this study suggests that a need to see their child as “normal” may have influenced the decision-making for cochlear implantation. Therefore, it is critical that the information presented to parents regarding outcomes for cochlear implantation is clear and that professionals check this understanding prior to surgery.

While the literature reports very favourable outcomes of cochlear implantation in terms of audition, speech perception and speech production for children, the literature on the experiences of parents is less well reported. Closed-format questionnaires derived from a professional’s perspective have largely been used to investigate parents’ perceptions. Archbold (Archbold et al., 2002) used an open-set format to examine the issue of parental perceptions 3 years post-implantation but this was based on a written questionnaire, not an interview. In Archbold’s study parents did not use the word normal to describe their children. However, there were numerous references to themes of social activity, assertiveness, confidence, independence, general adjustment and increased communicative options. Because the intervention of cochlear implantation provides an opportunity for parents to raise their child within a hearing world, this may explain the often-used word “normal” in this study. The word “normal” may also apply to these descriptions in Archbold’s study. However I did not specifically seek to elicit perceptions of “normality” as it was not the focus of my study.

Drawing on the work of Bruce and Schultz (2001), it is important to re-iterate that the grief models based on the death experience, usually employed to describe parental reactions, may be inappropriate. There is a paucity of evidence on the long-term effects of grief and how it
impacts on maternal-child bonding (Luterman & Kurtzer-White, 2003). Parental grief may be chronic. This study suggested the intervention of cochlear implantation may impact on this grief process by offering a surgical treatment that parents may perceive as restoring “normality”. Ethically, therefore, it is critical that both expectations and outcomes are clearly examined and unambiguously stated by the cochlear implant teams. Cochlear implant teams need to reiterate that cochlear implantation does not address the fundamental issue that profound deafness in childhood has no cure and is permanent.

The results of this study suggest that some parents may not have clearly understood the permanence of deafness. Although cochlear implantation offers the possibility of normal spoken language, it also marks the beginning of a “medically deaf career” and dependence on life-long medical and audiological surveillance. The possibility of a signed language communication option was discussed with all parents, but results suggest that it lacked meaningful engagement and that the medical perspective of providing an intervention has been the dominant influence in this study. This is not surprising as one could argue that hearing parents see themselves as “culturally different from their children”. Another explanation could be that signed language is not being presented by health and education providers as a viable communication choice and as one capable of creating success in educational and employment opportunities.

In summary, cochlear implantation may be seen against a background of societal forces shaping our ability to adapt and improve our physical body. This perception, in combination with successful auditory outcomes for their children, and the improved safety of the procedure, provides parents of deaf children with the option of a spoken language for their child. Their desire for a "normal" child and the inadequate presentation of a signed language...
to these parents as a valuable option are likely to add impetus to the increased uptake of cochlear implantation.

5.7 Bilateral Implants and Future Technology

Three of the children in this study had bilateral implants, but no parents in the study had indicated that they had experienced a systematic process for receiving information about bilateral implants.

A challenge for providers is the non-funding of the second implant (and it is unlikely to be so in the foreseeable future). Discussing potential non-funded treatments for which the research is still unclear, creates an understandable discomfort for health care providers. However, both the Medical Council of New Zealand (MCNZ, 2008) and the Health and Disability Commissioner (HDC, 1996) in its code of consumer rights state unambiguously that information about available treatment options needs to be provided to consumers. The NHS National Institute for Clinical Excellence (NICE) released its second draft in March 2008 on the issue of bilateral implants, which backtracked from its first draft, in which it recommended simultaneous bilateral CIS for pre-lingually deaf babies and children. Instead, it now recommends bilateral cochlear implants “in the context of research designed to generate robust evidence about the benefits to functional hearing and health–related quality of life of simultaneous or sequential cochlear implantation compared with unilateral cochlear implantation” (NICE 2008).

In addition to a recommendation for timely systematic provision of information about bilateral implants, the other concern is the optimum timing when it is already known to be a time of high stress for parents. To present an expensive unfunded treatment option at a time of high stress but which may confer benefit, may overwhelm parents (See Chapter 1
Introduction). However, as in the case of one of the parent participants in the study, significant stress can be created by failure to provide this information earlier rather than later. Other parents indicated that they would consider bilateral implants, if the research indicating increased benefit was presented. Without this information, there is a risk that paternalism could override autonomy. Providing this information inappropriately may have the potential for malificence. The results of this study suggest consideration should be given to investigating strategies that support health care providers managing this complex relationship between beneficence, paternalism and autonomy as it relates to bilateral implantation.

5.8 Summary

In this chapter, the results relating to the initial diagnosis, the referral process for cochlear implantation, and the experiences of the implanted child’s family have been discussed in relation to the available literature. The key themes to emerge are firstly, the need for sustained and ongoing counselling as parents come to terms with the communication options open to them. This need appears to extend beyond the immediate years post-implantation. Secondly, there appears to be a need for health and education providers to provide care using a family-centred paradigm, for both the immediate and extended family. Thirdly, parents need more support and guidance during the hearing aid trial and in managing complex equipment. Finally, the need to address the lack of support for sign language was discussed. I have posited that the value of sign language needs to be reflected in its use by health and education providers, especially within implant teams. Parents, in describing their implanted child, made continual reference to the word “normal” and the concept of non-finite grief may influence their decision to choose a cochlear implant and thus, to parent a “normal” child. In terms of the impairment paradigm, deaf children are not seen as “normal”, and making them potentially “normal” by the intervention of a cochlear implantation to function as hearing
children could take precedence over a more pluralistic process to facilitate their learning and language development.

There is widespread consensus that neutrality in counselling is the paradigm of good clinical practice (Nunes, 2001). Physicians and other professionals should not impose their own values, although in specific circumstances those values might be exposed so that an informed decision can be reached. In the consent process, the existence of the Deaf world, its values, and the richness of its sign languages need to be clearly explained. Corker (1998) writes of this pluralistic perspective:

In terms of self-definition, deaf people are caught at different points in a linguistic and cultural web made up of spoken languages, sign languages, deafness and hearingness. Different locations on the web therefore become associated with different meanings (p.5).

Corker continues this theme when she suggests that frameworks and theories are meant to assist and develop thinking, not restrict it. Several parents in the present study alluded to this concept themselves. The lack of comfort described by parents within the Deaf community alongside the ongoing challenges surfacing for implanted children among the hearing community suggest these children and families have yet to create their own space on this “cultural web”. Many parents talked of the need to connect their children with other children with cochlear implants. Implanted deaf children will inevitably forge a new place for themselves in this “cultural web”. One parent in the study put this need very succinctly:

I wish that a new community would spring up that is about children like my child.
Given the small numbers of implanted children in New Zealand, combined with the physical geography of the country, supporting the development of this “new community” will present some logistical and financial challenges.

This research has questioned paradigms and ideologies that represent world-views belonging to a particular time or culture. They could be used to create socially constructed realities that may constitute hegemony in certain circumstances. As implanted children and those who follow them grow and mature into adolescents, it may be necessary to appraise their needs as they will be challenging this cultural web that Corker aptly describes. Sound clinical practice suggests that services will not be unconsciously maleficent by obstructing this process, but will, at the very least support these children in redefining “their own linguistic and cultural web”.

The following quote by McNay raises a concern about the potential for domination of paternalism and beneficence over autonomy:

“As deaf and disabled people, we have been accustomed to the indignity and misguidedness of speaking for others” (McNay, as cited in Corker, 1998, p. 3).
6.1 Introduction

This study aimed to examine the experiences of parents whose child(ren) had undergone cochlear implantation. The study was limited to parents whose children had been implanted for over 6 months but under 5 years. It involved interviewing both parents so that the perspective of fathers could also be heard; much previous disability literature has focused on mothers. Results emerged suggesting a gendered perspective. While the results of cochlear implantation are gaining clarity for defined auditory and speech intelligibility outcomes, the experiences of parents remain a poorly researched area. This study has therefore examined these experiences hoping it will increase understanding of the complex relationship between the health and education interface, the manner in which health services engage with parents of recently diagnosed deaf children and the manner in which choices regarding communication strategies is presented. These results may enable services to provide more effective interventions for this group of families.

Understanding the nature of the impairment versus culture paradigm for parents of profoundly deaf children has been a central tenet is this interpretative study. An assumption of a need to correct hearing loss and educate children with spoken language has been a major driver in the choices in this study. All parents spoke overwhelmingly of a wish to have a "normal" child, and this was the endemic description of their child once implanted. The literature on paediatric cochlear implantation is yet to demonstrate clear outcomes for improved employment and educational opportunities for implanted children (Archbold & Thouten ethoofd, 2005) and so the evidence of these improved auditory and speech
intelligibility outcomes has yet to be shown in the lives of these children as they develop. The study of this group of parents has shown low use of NZSL. Parents gave a wide range of reasons for this low use, some of which could be remedied if proficiency in both languages indicates potential benefit to the child’s overall language and social development.

This chapter is organised into two sections. The first section addresses the strengths and weaknesses of the study, examining them in terms of specific methodology. The second section presents the implications of the results for the myriad of health and education professionals who work with profoundly deaf children and their families and implications for health policy, including the Universal Newborn Hearing Screening Early Intervention Programme (UNHSEIP), which is being rolled out across New Zealand over the next two years (2008-2009). The second section of the chapter concludes with implications for further research.

6.2. Strengths of the Study

One of the strengths of the study was its design. An important aspect of the study was that the open-ended interview format did not limit parents to prescribed topics or themes, and allowed parents sufficient time to describe a range of experiences that they felt to be relevant or important for them. The study was iterative and so the interview guide for later participants could incorporate emerging themes from previous participants. The participants were drawn from both implant service providers and so included all parents throughout New Zealand. The maximum variation sampling technique was aimed to include a wide range of families. All eligible parents in New Zealand who fulfilled the study criteria in New Zealand were invited to participate. Both parents were interviewed separately, giving space to the unique perspectives of mothers and fathers. An important aspect of the study was to understand the lived experiences of these parents; therefore, a type of naturalistic inquiry was chosen to
investigate the research question, specifically the constructivist paradigm. The need for health and education providers to gain an in-depth understanding of the experiences of this group of parents is important as parents are, in effect, the essential partners in therapy (Simser, 1999; Simser & Steacie, 1993).

The data were credible. The accuracy of the transcripts was checked by direct feedback from the participants. In addition the participants read the preliminary results. One of the reasons was to ensure that participants were comfortable with the use of potentially identifiable information owing to the small sample population of implanted children in New Zealand. The data were also checked by three supervisors who were experienced in qualitative methodology, at different points in the study.

My professional role as a doctor and my own experience as a parent appeared to have a positive effect generating greater disclosure. There is a large body of literature regarding reciprocity in qualitative research, and it is believed to promote interactive interviewing and increased trust (Alvesson & Skoldberg, 2000; Patton, 1990). I needed to be careful to bracket my own experiences during the interview, as I was at times asked to share them. I dealt with this request by means of an informal discussion once the interview had been completed. Being asked to share one’s own personal views in professional settings is a boundary issue doctors are skilled in recognising and managing.

6.3. Limitations of the Study

Financial considerations (travel costs to visit participants) and the time constraints of a Master’s thesis limited the study size (N=14). Although this study size was appropriate for implementing an initial interpretive study, a larger study may have provided greater transferability. For parents whose child’s experience with a cochlear implant was negative, or
for whom expected benefits were not forthcoming, may have been unwilling to participate in the study. The literature demonstrates that outcomes are variable so it would have added strength to the study if parents whose child had an unfavourable outcome had been included. This study was unable to identify factors associated with unfavourable outcomes for cochlear implantation. It may be necessary to specifically seek such parents as “critical cases”. This may necessitate a different research question and therefore study design. As noted previously, parents in relationships that were experiencing difficulty may have elected not to participate. Therefore, the experiences of some families may not be represented in this study.

All of the results of the study are not necessarily transferable to other countries as the provision of implant services, and the associated health and educational supports to deaf children depend on the level of funding and relative weighting given to policies which may reflect a dominant model of care. Other researchers should be careful not to draw conclusions unless the context is similar. By context, I refer to the local context (health and education professionals) as well as the sociopolitical and economic context of a country. Differing paradigms of care will in turn affect support for signed languages and engagement with the family from a broader psychosocial perspective. In addition, both Europe and Australia have already implemented universal newborn screening, so families in those countries will be presenting with issues generated from a provider-initiated screening tool. It will be similar in New Zealand within a few years. However, the results about the desire for a “normal” child, and the stress of the pre-implant hearing aid trial may be transferable to other countries.
6.4 Implications of the Study

A number of important implications can be drawn from the study. They are discussed under “Implications for health and education providers”, “Implications for health and disability policy specifically as it relates to UNHSEIP”, and “Implications for further research”.

6.4.1 Implications for Health and Education Providers

This study aligns with the work of Corker (1998), in which she refers to a “cultural and linguistic web of deafness, signed languages spoken languages and hearingness” and that different adults, adolescents, and children (Deaf and deaf) will find or create their place within this web. This pluralistic theme is one that has perhaps been eclipsed by the new technology of cochlear implantation which provides an effective and safe intervention for profoundly deaf children to enable them to develop spoken language and relate to the hearing world of their parents. The parents in this study spoke of the overwhelmingly positive benefits for their child post-implantation. These benefits need to be acknowledged.

However Corker’s theme reflects some current concerns in medicine about the limitations of the bio-medical paradigm. The study also aligns with Toombs (1995), who suggests that if a bio-medical paradigm of disease is taken to be the only complete truly scientific paradigm, attempts to redefine the goals of medicine and humanise medical care will have only limited success. For deafness, the impairment paradigm seems to reflect the bio-medical paradigm. The results from this study suggest that both health and educational providers need to consider the child and their family within a broader psychosocial paradigm. Acknowledging the pivotal role of the family in providing ongoing language support and training is an important aspect of the paradigm of family-centred care. I would posit that whenever professionals consider the child, they need to be thinking of the child and family as one unit, and the implications of such. Results from this study also indicate that the needs and
resources of both siblings and the extended family are important. The New Zealand Medical Council statement on best practice for Māori and their whānau (MCNZ, 2006) notes the importance of the “ability to include the patient’s family in their health care when appropriate”.

Research that includes an interpretative, social constructivist paradigm needs to inform clinical practice and education. Greater interdisciplinary communication, particularly with use of terminology may reduce parental confusion. While individual providers may have their own unique perspective, the vulnerability of these parents suggests that they should not be charged with the task of synthesising complex information from multiple providers. The availability of counselling services for the family needs to be sustained well beyond initial diagnosis and the years immediately post-implantation. Research suggests that the ideal practice for the newly diagnosed child and family unit is the provision of information in a tailored and timely manner, and that it is linked with both counselling and changing communication needs. It will be particularly important as the benefits and risks of bilateral implantation clarify. Professionals may be guiding parents about expensive unfunded treatment options, potentially raising anxieties about finances and concerns that a unilateral implantation may be perceived as an inferior treatment.

6.4.2 Implications for Health and Disability Policy

This study was completed prior to the roll-out of Universal Newborn Hearing Screening (UNHSEIP) in New Zealand. At the time of writing, it appeared likely that 9 District Health Boards (DHB) will be joining the programme during the 2008/2009 financial year (Ministry of Health, 2008). All screening has the potential to cause harm but this harm needs to be seen in the context of greater benefit with established screening tools and effective timely interventions (Gray & Raffle, 2007). Individuals anticipate timely and appropriate
intervention following screening. Two of the children in this study had been screened because they had a deaf older sibling. Yet one child did not receive the benefit of early amplification because of parental grief, unrecognised by the professionals supporting the child. The other parent's grief was not mitigated by her prior experience; it was still experienced as a profound shock. In both cases, the family and child unit did not receive appropriate support.

To maximise the expected benefits from screening newborn babies, it is essential that the NSU (National Screening Unit) ensures that the DHBs' newborn screeners have appropriate training in using this family-centred paradigm. At the time of writing this thesis, the NSU was contracting this training to an external organisation (Ministry of Health, 2008).

The Tooke Report (Tooke, 2008) which concerns itself with new directions for the future education of doctors, refers to the concept of "a pluri-potent practitioner with a broad-based skill set". This concept may assist the model for early intervention practitioners of deaf children because the broad-based skills involved in working with the child and family unit are needed by the many hearing professionals who work with this group of children.

Results from this study suggest that improved support in managing complex technical equipment is an area needing urgent attention and resources. Providers of audiological equipment need to consider how to work more effectively and collaboratively with audiologists, advisers and parents. This recommendation could perhaps be incorporated into service contracts.

The results of this study also suggest that policies regarding support for sign language need to be reconsidered. Specifically this study indicates that while this group of parents were not using sign language, there was some support for it as an additional communicative option. Many of the reasons cited for non-use by parents in this study could be rectified with
appropriate support and modelling of its value. Many parents had not been encouraged to think about the long-term benefits of an additional communication tool, not only for themselves for but also for their child in later life.

If referral guidelines for cochlear implant candidacy (see Appendix 10) continue to require a trial of hearing aids, the results suggest parents need greater support and guidance during this period. Low use of the hearing aids during this period means both that it is an inadequate trial of benefit and these children received minimal auditory stimulation. With non-use of sign language this negates the benefit of early intervention during this period.

6.4.3 Implications for Further Research

This is the first study that I am aware of that has examined the experiences of parents in depth in New Zealand. In Purdy’s study (1995), the results were drawn from measures that focused on pre-determined outcomes. Furthermore, I have been unable to find a study overseas that has interviewed parents separately using qualitative methodology therefore allowing an examination of a gendered perspective.

Ideally, doctors strive to draw their information from evidence-based medicine focusing on randomized controlled trials (RCTs): the “gold standard” and an internally rigorous research method for testing whether treatments are helpful, harmful, or ineffective. It is easier, however, to test the clinical effects of a treatment than the social effects, and it is easier to develop evidence that cochlear implantation provides superior auditory outcomes than to demonstrate that these children will have happier or more fulfilled lives with a cochlear implant. Influenced by the medical model of disability, clinical RCTs may be limited in how they can design and compare social interventions with medical ones, for example how they
can compare the effects of providing cochlear implant surgery with educational, psychosocially oriented, and inclusive policies for deaf children.

The children in this study were estranged from a Deaf perspective. As adolescents they will not have had a childhood experience of Deaf culture. Therefore, further research is needed to examine the experiences of their education and their psychosocial development. This is not only because of the low input of a Deaf perspective, but additionally to examine the effectiveness of the implant in higher educational and social settings.

6.5 Conclusion

Doctors who conduct trials need equipoise: a belief that the two or more treatment options available have an equal chance of benefit and risk of harm. Yet it may be hard to find doctors who believe that it is ethical not to provide cochlear implants. For these reasons one could posit that doctors cannot fully inform parents with neutrality about the risks and benefits of cochlear implants. Questions about the ethics of such procedures may best be framed from the Socratic perspective “as to what constitutes a good life” (Frank, 2006) rather than a protectionist bio-ethics stance, which, while useful, may be more concerned with informed and voluntary consent and protecting practitioners from blame. In addition, such questions may lead parents to consider the potential collective effects of personal decisions. These more general issues are likely to affect the child’s future by taking this debate into a more societal context.

This chapter closes a question posed by Winkler (1998) to assist persons who are reflecting upon treatment options.
Does it enhance the whole person, or offer only a palliative substitute for wholeness? Does it serve our desire for completeness and connection, or pander to our anxieties about our short-sighted demands for control?
REFERENCES


143


Best practice when providing care to Maori patients and their whanau, (2006).


APPENDICES
Health
and
Disability
Ethics
Committees

30 April 2007

Dr Nina Sawicki
6 Aylesbury Way
Karori
WELLINGTON

Dear Nina

MEC/07/04/053
A Qualitative Research Project to explore the Experiences of Parents whose child has Undergone Cochlear Implantation (CI) within the last five years.
Dr Nina Sawicki
Donald Beasley Institute

Thank you for the above application which was considered by the Multi-region Ethics Committee at its meeting on 24 April 2007 and approved subject to the following conditions.

Requirements:

<table>
<thead>
<tr>
<th>Requirement</th>
<th>Details</th>
</tr>
</thead>
<tbody>
<tr>
<td>Participant Information Sheet</td>
<td>Page 2: Clarify who will transcribe the taped interviews.</td>
</tr>
<tr>
<td>Maori consultation</td>
<td>Provide evidence of consultation with an appropriate Maori group at Greenlane Hospital</td>
</tr>
</tbody>
</table>
| Confidentiality   | • Explain in more detail how the confidentiality of the five pairs will be secured.  
|                   | • Explain how the two persons interviewed will not recognise each other.         |

Please forward three copies of your response in letter format with amended information sheet/consent form to the Committee administrator. Your response will be reviewed by a committee member and if the above points have been addressed to their satisfaction, final ethical approval will be given by the Chairperson under delegated authority.

If you have any queries, please contact me.

Yours sincerely

Rebecca Graham
Multi-region Administrator

Email: rebecca_graham@moh.govt.nz

Administered by the Ministry of Health
Approved by the Health Research Council
http://www.newhealth.govt.nz/ethicscommittees
APPENDIX 2: Response to queries raised by MREC (May 2007)

Sue Fish
The Multi Regional Ethics Committee Administrator
Ministry of Health
PO Box 5013 the Terrace
Wellington
16/05/07

Dear Sue

RE: MEC/07/04/053:A Qualitative Research project to explore the Experiences of parents whose child has undergone Cochlear Implantation (CI) within the last five years.

Thank you for the opportunity to respond to my Ethics proposal and I include details relating to the amended conditions as requested.

1. Clarification of Transcribing on participant Information Sheet:

Transcribing will be done by one of the staff members of the Donald Beasley Institute who automatically sign a confidentiality agreement as part of their employment contract.

2. Maori Consultation:

I perhaps did not clarify in my original application that while the Northern Regional Implant Programme is housed within Greenlane Hospital this is purely a rental agreement only. I had clarified this point prior to my original application, and did not pursue the issue of Maori Consultation with Greenlane hospital because of advice that I would not be able to use any guidance with another independent service. The Northern Regional Implant Programme is a separate charitable trust which stands (and is funded) independently in its own right. Greenlane Hospital has no clinical governance over the Northern Programme and no legal/clinical/ethical mandate to input into its service delivery. Thus Maori Consultation within Greenlane Hospital will not be able to provide me any advice which I can use in my relationship as researcher with the Northern Programme.

3. Internal Confidentiality of the Five Pairs and within the Couple Dyad

Due to the small population of parents of implanted children in NZ there is possibility for recognition of individual families by personal details. The age, sex and geographical location of the child may be sufficient to identify a particular family. For example, were I to be a participant in such a study my profession as doctor and mother to a 9 year boy with a double implant would identify me as Dr. Nina Sawicki of Wellington.

All research carries risks in terms of confidentiality and it is the responsibility of the researcher to make such risks transparent and to minimize potential breaches of confidentiality. The corollary of course is that not do research also carries risk. The group in question would not have the benefit of
talking about their experiences. We are not then in a position to assist such groups with the policy benefits that stem from good research.

While many parents may be quite comfortable identifying information and may even talk amongst themselves via parent support networks this internal confidentiality as couple participants in the research must be preserved as far as is possible by the researcher.

I propose:

**A. Consideration of possible identifying details**:

- **Delete specific occupation.** A parent's occupation is not relevant to the findings of the research although the effect on that parent's occupation may be.

- **Maintain rural/urban information.** I would however like to include this information option as I think this may be critical in regard to the accessibility of services.

- **Delete age of child.** Because the focus of the research is the experiences of the parents, the exact age of the child can be omitted in the research findings. The children can simply be identified as either pre-school or school age. It is unlikely (but not impossible) there will be parents with adolescent children because of the age at which implantation takes place (almost never over the age of 5). The characteristics of individuals in the research sample will not be presented in a Table format which could lead to easy identification of families. Information can be presented with minimal identification (mother/father of school age child/pre-school child).

- **Implant Programme.** Do not link individual parents with specific Southern or Northern Programme. This reduces the risk of geographical information enabling recognition by location of an individual parent couple. This also eliminates the risk of a clinician (surgeon, audiologist, speech language therapist, itinerant teacher) identifying their own particular client.

- **Participants.** Participants already have the opportunity to read the transcripts and comment if they feel any of the specific data may identify them. This will be reiterated and should this be the case then some of the data can be withheld from the analysis. In particular individual participants will be encouraged to consider the possibility of the shared information affecting the other parent. Should some of the raw data be withheld I do not believe this will alter the scientific rigour of the report as long as this process is transparent and described in the method. Methodological analysis of the final raw data will not be altered or compromised.

**B. Caution with the Use of Quotations:**

Dyads present challenges in research due to the needs of internal confidentiality. In this research, the dyads to be considered are the parents (mother and father). They may no longer be in a relationship other than as parents. We cannot make any assumptions about the nature of their relationship. Because of the design of my study, and my wish to capture the perspective of both parents individually, without influence from the other, this means information may be disclosed to me as researcher which was previously hidden or unknown from the other parent. Thus, this type of
research has the potential for malificence and distress if one member of this dyad finds information incongruent with their own personal experience and knowledge of the other parent.

To totally eliminate this risk I could interview both parents together but this would not allow me to capture the unique and individual perspectives of both parents and therefore I would believe alter my research question and the nature of the data I am likely to capture.

The use of quotations (raw data) provides evidence of a researcher's conclusion in qualitative research. However as noted by Dr. Tolich (Tolich 2004), this may allow one member of the dyad to be recognizable to another. I propose to use quotations sparingly and judiciously in the dissertation and in any articles/seminars arising from the research. Indirect statements can be used to convey the same theme. For example in discussing parenting challenges of deaf children one parent commented (Meadow-Orlans, Mertens et al. 2003) p.53

Parent 211 “She has a younger brother and two younger sisters. She does have some rough times when she can be pretty mean, but I think that comes out of frustration. But other than that, we treat her just like the rest of them, and we don’t make her hearing a priority as far as treating her differently because she can’t hear...”

Were this family in my study we could identify this family as parents to four children, the eldest of whom is a girl with an implant. They were in addition facing behavioural challenges with her younger siblings.

An indirect statement could be:

One parent “indicated that hearing loss created frustrations in communication with younger siblings affecting their child’s behaviour. However despite this the parents did not want to make any allowances for the child’s behaviour.”

Despite the safeguards, it is still possible participant pairs may recognize one another. I will inform participants in advance about this possibility. The information sheet and consent form will reiterate this commitment to preserve their anonymity along with an explanation that a small risk still exists. This will again be explained before the interview begins and reassurance given that they can choose not to answer any questions. This will give more confidence that consent remains truly informed.

Relevant Excerpt from Participant information sheet (full copy enclosed)

The Information given by you may disclose experiences, thoughts and feelings that you may not have shared with your partner/the other parent. In addition, because of the relatively small number of families in New Zealand you may feel that the study identifies you as a family. The information from your interview will be pooled with information from other interviews. It will be analysed before the final report is presented. The full interview will not be presented in the report but some quotations may be used to illustrate some of the key themes emerging from the research. You may wish to request some information be omitted from your interview after review of your transcript. You also may like to consider me what/if any safeguards you need as:

1. As couple (so that other families cannot identify you.)

2. As an individual (parent) so that you or your partner/other parent are not upset or distressed by information that you may learn about the other parent in the final report.
Relevant excerpt from Formal Consent form (full copy enclosed)

I understand that I will receive a full written transcript from the taped interview. Information from this will be aggregated with the other interviews and discussed anonymously in the written report. Every attempt will be made to ensure any quotations used will not identify me to my partner or us (as a couple) to other participants. However there will still be a small risk that I may recognize some information about myself and/or my partner.

Yours sincerely

Dr. Nina Sawicki

References:


APPENDIX 3: Final letter of approval from MREC (June 2007)

Health
and
Disability
Ethics
Committees

Multi-Region Ethics Committee
Ministry of Health
Level 2, 1-3 The Terrace
PO Box 5013
Wellington
Phone (04) 470 0655
(04) 470 0646
Fax (04) 496 2191

7 June 2007

Dr Nina Sawicki
6 Aylesbury Way
Karori
WELLINGTON

Dear Nina

A Qualitative Research Project to explore the Experiences of Parents whose child has Undergone Cochlear Implantation (CI) within the last five years.

Lead Investigator: Dr Nina Sawicki
Approved site: Donald Beasley Institute
MEC/07/04/053

The above study has been given ethical approval by the Multi-region Ethics Committee. Thank you for a thorough and considered answer to the ethical dilemma posed by “internal confidentiality”. The chairperson urges you to keep detailed notes on how this issue is addressed by participants in the recruitment, data collection and presentation phases of the research, with a view to writing up this aspect of the research.

Approved Documents
- Appendix 2: Study Information Sheet, Version 2 dated 2 June 2007
- Appendix 3: Participant Interest Form, Version 1 dated 29 March 2007
- Appendix 4: Consent Form, Version 2 dated 2 June 2007

Accreditation
The Committee involved in the approval of this study is accredited by the Health Research Council and is constituted and operates in accordance with the Operational Standard for Ethics Committees, April 2006.

Final Report
The study is approved until 30 June 2008. A final report is required at the end of the study and a form to assist with this is available from the website, http://www.newhealth.govt.nz/ethicscommittees under “Information for researchers”. If the study will not be completed as advised, please forward a progress report and an application for extension of ethical approval one month before the above date.

Amendments
It is also a condition of approval that the Committee is advised of any adverse events, if the study does not commence, or the study is altered in any way, including all documentation eg advertisements, letters to prospective participants.

Please quote the above ethics committee reference number in all correspondence.

It should be noted that Ethics Committee approval does not imply any resource commitment or administrative facilitation by any healthcare provider within whose facility the research is to be carried out. Where applicable, authority for this must be obtained separately from the appropriate manager within the organisation.
Yours sincerely

Sue Fish
Multi-region Ethics Committee Administrator
Email: sue_fish@moh.govt.nz
APPENDIX 4: Letter from Ngai Tahu Research Consultation Committee (March 2007)

Ngai Tahu Research Consultation Committee
Te Kohi Reihana ki Kai Tauri

06/03/2007 - 31
Wednesday, 07 March 2007

Dr Nina (Christine) CM Sawicki
General Practice
Dunedin

Tēnā ioe Dr Sawicki

Title: The Experiences of Parents whose Child undergoes Cochlear Implantation

The Ngāi Tahu Research Consultation Committee (NTRCC) met on Tuesday, 06 March 2007 to discuss your research proposition.

The NTRCC considers the research to be of importance to Māori health.

The Committee strongly encourage that researchers collect ethnicity data as part of the project and recommend the use of the Census question on ethnicity.

The Committee acknowledges that the researchers have identified Māori as being over-represented in “Acquired Deafness”.

The Committee acknowledges that the researchers have identified Māori as potentially underrepresented in some statistics due to accessibility issues.

The Committee suggests dissemination of the research findings to relevant Māori health organisations and the Committee would also value a copy of the research findings.

Nīhaku noa, nā

Mark Brunton
Kaitakawaenga Rangahau Māori
Facilitator Research Māori
Research Division
Te Whare Wānanga o Otago
Ph: +64 3 479 8738
email: mark.brunton@otago.ac.nz
Web: www.otago.ac.nz
APPENDIX 5: Letter of invitation from the Southern Cochlear Implant Team (also provided by the Northern Team)

[Date]

Parent of [First Name Last Name]
[Address 1]
[Address 2]
[Address 3]

Dear Parent,

Re: Cochlear Implant Research Project

Dr. Nina Sawicki, a Master of General Practice Student at the University of Otago and The Donald Beasley Institute in Dunedin, is undertaking a research project involving parents of children with cochlear implants. Details of the research project are enclosed.

We have been asked to invite parents whose children are part of the Southern Cochlear Implant Programme to take part. In forwarding details of the research project to you, we have not disclosed you or your child's personal details to the researchers or anyone else. We will not know of your decision to take part or otherwise.

We have reviewed the proposed project and are satisfied that the study meets the necessary ethical standards.

You are under no obligation to participate. If you are interested in taking part please complete and post the pink "Participant Interest Form" to Dr. Sawicki in the enclosed free-post envelope within 2 weeks.

If you have any other questions or concerns please feel free to contact us at any time.

Kind regards

Neil Heslop, MNZAS-CCC
Audiologist/Manager (Paediatric)
Southern Cochlear Implant Programme

Copy: File

van Asch Deaf Education Centre, Truro Street, Sumner, Christchurch, 8.
Ph/TTY 03 326 6009, Fax 03 326 5346, Email: info@vanasch.school.nz

159
APPENDIX 6: Participant Information Sheet

MAY 07

STUDY INFORMATION SHEET FOR PARTICIPANTS
THE EXPERIENCES OF PARENTS WHOSE CHILD HAS UNDERGONE A
COCHLEAR IMPLANTATION
RESEARCH PROJECT FUNDED BY THE HEALTH RESEARCH COUNCIL
NEW ZEALAND

Principal Investigator: Dr Nina Sawicki
Master of General Practice Student
University of Otago and
Donald Beasley Institute
Dunedin

As a parent of a profoundly deaf child who has undergone Cochlear Implantation, you are invited to take part in a study regarding your personal experiences as a parent. The following information is designed to help you decide if you would like to participate in this study.

What is this Study about?

This study is about the personal and day to day experiences and possible challenges you face parenting a child who is profoundly deaf and has undergone Cochlear Implantation.

There is much published information on the outcomes or these children on a variety of tests. However, we lack crucial information about how this treatment option and auditory rehabilitation impacts on the day to day lives of you and your family.

Through this study I hope to learn more about such areas as

- Issues surrounding initial diagnosis and the referral process from diagnosis and how this information was presented to you
- The quality of support offered post-implantation
- Your relationships with the professionals at the Cochlear Implantation Team
- How your concerns and worries were addressed
- Stresses you may have encountered as family or a couple during this process and following surgery.
- Issues you may face with your child’s teachers, itinerant teacher of the deaf and teacher aide issues
- Work and family issues. If your child has siblings this may have impacted on them
You may have had to alter or modify career plans. You may have had to review your financial choices.

- The benefits you have may discovered since your child’s surgery for yourself, and your wider family as a whole

The results of this study will be presented as a Master’s Thesis in General Practice.

**Who can be included in this study?**

You have been invited to take part in this study because you are the parent of a child with a Cochlear Implantation. Your child will have undergone a Cochlear Implantation within the last 5 years but not within the last six months.

I wish to interview parents **only** if both parents are willing to be interviewed, as both the mother and the father may have a different and unique set of experiences. It is important to hear as many of these experiences as is possible. I will interview each parent separately. This means that if the other parent is not willing to participate I will be unable to interview you but you **will** be provided with a copy of the findings.

Some parents do not live together and this does not matter as long as both the mother and father are willing to be interviewed.

**What will taking part in the study involve?**

If you take part in the study I will interview you by yourself in place of your choice where we have privacy and quiet. I can interview you at home, at your place of work or another venue of your choice.

The interview will probably last between one and two hours.

I will undertake all the interviews myself. I am a GP and a mother of a child with a Cochlear Implant. I have a Disability Research Scholarship from the Health Research Council to undertake this study.

Because of time constraints and the scope of the study I am **only** able to interview **10 parents** and so it may not be possible to interview every one who has expressed an interest in the study. However everyone who has expressed an interest will receive a copy of the research findings.

**Will the Information be kept private?**

The information that you give to me will me used for the purposes of this study only. Only I and my supervisors Associate Professor Anne Bray (of the Donald Beasley Institute in Dunedin) and Associate Professor Susan Dovey (of the department of General Practice Otago School of Medicine) will see the information that you give during the interviews.

When I write about the study or discuss the study with researchers I will not use your name or any data that could identify you.

You may choose to tell people you are taking part in the study if you wish.

Transcripts of the interviews will be kept in a locked cupboard for 10 years and then destroyed. Access to any computer files will be by confidential password only.
Internal Confidentiality

The Information given by you may disclose experiences, thoughts and feelings that you may not have shared with your partner/ the other parent. In addition, because of the relatively small number of families in New Zealand you may feel that the study identifies you as a family. The information from your interview will be pooled with information from other interviews. It will be analysed before the final report is presented. The full interview will not be presented in the report but some quotations may be used to illustrate some of the key themes emerging from the research. You may wish to request some information be omitted from your interview after review of your transcript. You also may like to consider what/if any safeguards you need as:

1. As couple, so that other families cannot identify you.

2. As an individual (parent) such that you or your partner/other parent are not upset or distressed by information that you may learn about the other parent in the final report.

**What happens if I don’t want to be part of the study?**

It is your choice whether you take part in the study. If you do not wish to be part of the study you do not need to do anything. You are still able to receive a report of the findings. Your information will not be linked directly to your Implant Team so your clinicians will not be able to identify you as their client.

None of the services you receive from your Cochlear Implant Team will be in any way affected by your participation in this study. None of the team members will know if you have elected to be part of the study. However you are welcome to tell them if you wish.

**What happens if I would like to know more about the study and am interested in taking part?**

If you would like to know more about the study or are interested in taking part please fill out the Participant Interest Form and post it using the free post Envelope.

If you would like more information then you are free to contact me through any of these contact addresses.

Email csawicki@actrix.co.nz
Phone 04 4767886- you can reverse charges
Fax 04 4767866
Cell/Txt 0272305808

You can also ring my supervisors:
Associate Professor Anne Bray,
Donald Beasley Institute
Freephone 0800878839

Associate Professor Susan Dovey
Dunedin School of Medicine
Phone 03-479-4135
If you would like advice about your rights as a participant in this study then you may wish to contact a Health and Disability Consumer Services Advocate. The telephone number is **0800 377766**

This study has been approved by the Multi Regional Ethics Committee and by Your Local Implant Team.
APPENDIX 7: Interview Guide

INTERVIEW GUIDE FOR IN DEPTH INTERVIEWS: OPEN-FORMAT SCHEDULE USED TO ELICIT RESPONSES

INTRODUCTION:

1. Confirm the name and age of the child
2. Date of implantation
3. Time elapsed since implantation
4. Number of implants (a small number of children in NZ have paid for a second non-funded CI)
5. Family details - number of siblings, birth order
6. Ethnicity

REITERATE PURPOSE OF THE RESEARCH AND THE CONFIDENTIALITY

1. Can you tell me a little about when your child was diagnosed, how old they were and what happened at the time of diagnosis? Prompt- /who made the initial diagnosis/Hearing aids offered/info given/counselling offered/immediate support post diagnosis.
2. What were your initial worries and concerns when your child was diagnosed?
3. How would you describe your child before implantation?
4. Can you tell me how your child was referred for a CI and how this process felt/proceeded for you?
5. How was this information presented to you?
6. What assisted you with the decision making process for the CI? What sources of information did you use- prompt professionals, other parents, the internet, wider family.
7. What were other people’s reactions to your decision and how did this affect you?
8. Depending (on age of child) how was your child involved in this process?
9. How do/did you feel about the process of “activation”/ tuning of the device and how well were your queries and concerns were dealt with?
10. How well does the CI Team communicate with your child? Prompt - e.g. has your child felt frightened or hesitant to attend appointments? Have any concerns of the child been adequately addressed?

11. What area of development has shown the most changes? e.g. communication, behaviour, confidence, independence, language, speech

12. Do you feel your parenting style has changed since surgery, and if so you can tell me about this?

13. How would you describe your child now?

14. Do you feel that having the implant has changed your relationship with your child? Can you describe this?

15. Do you feel that having the implant has changed the amount of help you need to give to your child? If so, in what ways?

16. What do you feel the implant has enabled your child to do - things that would have been perhaps impossible without it? (thinking of schooling, independence, family relationships, friendships etc)

17. Are there any changes which you regret since the surgery?/prompt- lost friendships, activities, health concerns with your child

18. Has there been any effect on other members of the family from the implantation?

19. If relevant - what/ if any difficulties have you experienced attending appointments (only two centres in NZ?)

20. What areas of concern do you have for the future?

21. What sort of aspirations do you have for your child? If you have other children, does this differ in any way from your other children

22. What has (have) been the most important element(s) in ensuring your child has made as full use of the implant as possible?

23. Tell me about some of the more encouraging moments for you and your child since surgery.

24. What advice would you give to other parents thinking about an implantation?

25. Are there areas of support you felt were lacking from the professionals dealing with you and your child?
26. What are some of the day to day challenges you face with your child - prompts

- head being knocked
- concerns in swimming pools and moist wet environments/outdoor activities
- lost equipment
- problems with FM system in the classroom
- taking the device off at night
- battery reliability issues
- safety issues
- static electricity on slides
- issues with airport scanners
- pain or discomfort from the device.
- activities your child is excluded from and how others deal with this especially at school
- access to funded carer relief and how informed these agencies are regarding the nature of hearing loss/CI rehabilitation following surgery.
- bullying
APPENDIX 8: Participant Interest Form

PARTICIPANT INTEREST FORM
PARENTAL EXPERIENCES OF COCHLEAR IMPLANTATION

If you are interested in taking part in the study of Parental Experiences of Cochlear Implantation please answer the questions on this sheet and post to Dr. Nina Sawicki in the Freepost Envelope provided.

NAME: (please indicate if you are mother or Father)

NAME OF OTHER PARENT:

CONTACT ADDRESS:

TELEPHONE NUMBER/CELL PHONE:

EMAIL ADDRESS:

WHICH ETHNIC GROUP DO YOU BELONG TO: PLEASE CIRCLE
- NZ EUROPEAN
- MAORI
- SAMOAN
- COOK ISLAND MAORI
- TONGAN
- INDIAN
- OTHER-please state

WHICH IMPLANT TEAM CARES FOR YOUR CHILD: please Circle
Northern
Southern

MY CHILD IS CURRENTLY....... YRS.... and..... MONTHS of age
SEX of child...please circle.... F M

YEARS SINCE IMPLANTATION....YRS... and ... MONTHS
APPENDIX 9: Participant Consent Form

CONSENT FORM FOR PARENT PARTICIPANT

If you wish to take part in this study please read this form very carefully. It outlines your rights as a study participant. Please sign the form if you wish to participate.

1. I have read or have had read to me the information sheet about the "THE EXPERIENCES OF PARENTS WHOSE CHILD HAS HAD A COCHLEAR IMPLANTATION."

2. I understand the information I have been given and have had an opportunity to talk about the study with Dr. Nina Sawicki.

3. I have been able to ask questions and am happy with the answers I have been given.

4. I understand that taking part in this study is voluntary and I can stop at any time.

5. If I do stop my involvement in the study this will in no way affect my child’s treatment from the Implant Service and none of my child’s treatment providers will query me about my involvement.

6. I understand that for my interview to be used for analysis the other parent of my child will also need to take part in the study.

7. I understand that my participation in this study is confidential and that no information that could identify me will be used in the report.

8. I understand that the Researcher (and Supervisor) will not talk to any other person about me or the information I give unless they are legally bound to do so.

9. I have had time to decide if I wish to partake in the study.

10. I understand that my involvement in the study will involve me being interviewed and that this will be taped.

11. I understand that I can have the tape recorder turned off at any point in the interview.

12. I understand that the discussion we have during the interview will be used as information for the study.

13. I know that the researcher may take notes during the study.
14. I know I will have the chance to check what I have said during the interview and that I can make changes at any time.

15. If I give written answers to the interview questions then these answers can be used as information for the study.

16. I understand that I will receive a copy of a report on the findings and that there will be a delay between my taking part in the study and receiving the final report.

17. I understand that if I take part there will be a delay between my interview and receiving the final report.

18. I know that if I have any questions or concerns about taking part in this study that I can contact the Health and Disability Services Consumer Advocate. The telephone number is 0800377766.

19. I know that at any point I can contact Dr. Nina Sawicki by email: csawicki@actrix.co.nz or by phone by ringing collect 04 4767886.

Alternatively I can ring Associate Professor Anne Bray at the Donald Beasley Institute Free phone 0800878839 or Associate Professor Susan Dovey 03 479-4135

Date

Signature
APPENDIX 10: Referral Criteria for Children

- Bilateral moderate to profound sensorineural hearing loss (i.e. ≥ 90dBHL at 2000Hz and above for better ear) also ski slope or reverse losses
- Referrals accepted up to three years of age for children with no language.
- Children older than three should have oral language developing.
- Children with additional needs will be accepted for assessment
- Limited or no useful benefit from hearing aids:
  - Aided thresholds fall outside the speech range.
  - Children who have developed speech: a score of 60% or less open-set sentence discrimination or <30% on word score.

Acknowledgements to Marinda Beukes, RNTNE Hospital, London, for original document

If in doubt, contact the Cochlear Implant Programme to discuss.