KA PUĀWAI NGĀ KŌHUNGAHUNGA TURI
A STUDY OF THE NATURE AND IMPACTS OF EARLY INTERVENTION FOR
MĀORI DEAF CHILDREN AND THEIR WHĀNAU

BY

KIRSTEN SMILER

Te Aitanga-a-Māhaki, Rongowhakaata, Whakatōhea

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Abstract

This research investigates the early experiences of Māori deaf children, documenting whānau (family) perspectives on interactions with early intervention professionals and environmental sources of information, the effects of these on whānau perceptions of deafness, how decisions around communication and language use are arrived at, and how these affect a sense of parental competence. The features of a whānau-centred model of intervention are explored by whānau participants and the researcher in order to provide an understanding of how early intervention services could be more effective from Māori perspectives.

Developing age appropriate language, communication skills and social acculturation is a synchronous process which typically occurs within the context of families. The majority of deaf children, however, are born to hearing parents and families with little experience of deaf people from which to develop a subconscious repertoire of skills with which to engage, facilitate and teach language to a deaf child. Early intervention services seek to support deaf children and their families in this process. In New Zealand a family-centred model of early intervention is accepted practice. Māori children are over-represented in deafness diagnostic statistics and their early language and social development takes place within a social context that is configured differently to the prototypical non-Māori family, that is, the whānau. Little is known or documented about the characteristics and efficacy of a family-centred model in relation to Māori deaf children and their whānau.

The Māori metaphor of transformative praxis was used to frame a kaupapa Māori approach to case study research. Kete mātauranga (woven baskets of knowledge) were co-constructed between whānau participants, early intervention professionals, and the researcher, using Māori methods of qualitative data collection: kōrero-a-tinana (observations of action and behaviour), kōrero-a-waha (spoken language), kōrero-a-ringaringa (signed language), kōrero-a-tuhituhi (written language).

Analysis of the data suggests that whānau perceptions of their deaf child evolve as the child moves through developmental stages and as the whānau encounters different sources of information and experiences relating to deafness. The study shows how the

relevance of information, spoken, written, and signed, from early intervention professionals and observational knowledge gained from others with lived experience of deafness, deaf people and their whānau, was interpreted and weighed by participants as they interacted with their own deaf child in everyday social contexts. Participants' aspirations for their deaf children centred on a holistic perspective of wellbeing and development, the whānau providing the foundational context from which this developed. Recognising that their deaf child was situated at the borders of multiple cultural and linguistic groups, through either familial or social connection, whānau aspirations centred on the child's active social and linguistic participation within these groups.

Initial encounters with professionals focused on medical perspectives of hearing loss, positing deafness as a medical concern remedied through routine technical and medical interventions. However, as the child entered developmental stages, whereby language acquisition and the social acculturation process began, whānau started to relate to their deaf child in more social terms, and required more social and linguistic support to ensure participation in various home and educational contexts. Early intervention services were seen by some participants to constrain, or conflict with, their social-cultural aspirations for the child, through a focus on acquisition of spoken English and facilitating participation in mainstream educational contexts. Whānau expressed frustration at the compromise they endured as a consequence and wished for a model of support that engaged with whānau aspirations and relational styles more effectively. Potential features of a whānau-centred model of early intervention were composed by the researcher and whānau participants during a *wānanga* (forum) held as a part of the research. The features identified utilised the tradition of *raranga* (weaving) as a metaphor with which to frame relational and participatory components of a whānau-centred early intervention model for Māori deaf children.

He mihi aroha

This work is dedicated to my Nana Hazel, Grandad Bob and my Mum, Heather.

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The saying ‘it takes a village to raise a child’ was pertinent to this study and was one of the principal findings of this research, intergenerational support and expertise best supports whānau to raise a deaf child. The same could be said about creating a PhD. I have been supported by literally hundreds of people during the course of this research, thank you to all who contributed to the creation of this work; it would not have been achieved without you!

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Glossary

AODC	Advisor on Deaf Children, specialist professional
Auditory Brainstem Response (ABR)	Test for hearing impairment
auditory verbal therapy	Type of therapy for hearing impairment
autism	Encompassing term for the spectrum of autistic conditions
AV Therapy	Auditory Verbal Therapy
BEACON	Parent mentor programme
bilingual education	Bilingual in English and New Zealand Sign Language
borstal	Correctional facility usually for young offenders (term no longer used)
CI	Cochlear implant
CODA	Child/ren of deaf adults
cochlear implant	Surgically implanted medical device which usually enables some hearing in deaf patients
DANZ	Deaf Aotearoa New Zealand
Deaf	Capital D indicates identification as a cultural minority
DHB	District Health Board
District Health Board	District Health Board (19 across New Zealand)
Early Intervention	Programmes for disabled children younger than school age, usually soon after diagnosis
EI	Early Intervention
GP	General Practitioner (primary health doctor)
GSE	Ministry of Education, Group Special Education (now just Ministry of Education, Special Education)
Habilitation	Habilitation in the context of early intervention refers to a ‘habilitative approach’ to supports, whereby supports aim to reduce the potential of developmental delays subsequent to having a hearing loss. This is differing to rehabilitation which aims to restore or reestablish skills which may have been lost as a result of disability or injury.
Hearing House	Auckland-based organisation supporting children with cochlear implants
impairment	A specific condition
intermediate school	State school common in NZ for Years 7 and 8, usually 11 and 12 years olds
Kelston Deaf Education Centre	Auckland-based centre where services and professionals are situated to support deaf children

kindergarten	Public preschool education centres for under 5 year olds
KIT	Keep In Touch days for parents of deaf children
mainstream school	Public/state school for all local children
Makaton	Communication programme for those with learning difficulties
medical model	Individual, deficit based model of disability
MoE	Ministry of Education
MoH	Ministry of Health
Mongrel Mob	A New Zealand gang
NCIT	Northern Cochlear Implant Trust (all regions north of Taupo)
Newborn Hearing Screening Programme	See Universal Newborn Hearing Screening Programme
New Zealand Sign Language	An official language of New Zealand
NFD	National Foundation for the Deaf
NGO	Non-government organisation
NICU	Neo-natal intensive care unit (of a public hospital)
NSU	National Screening Unit (of the Ministry of Health)
NZDS	New Zealand Disability Strategy
NZFDC	New Zealand Federation for Deaf Children Inc (national group of parent groups)
NZSL	New Zealand Sign Language
oralism	Oralism is the education of deaf students through oral language by using lip-reading, speech, and mimicking the mouth shapes and breathing patterns of speech.
ORS/ORRS	Ongoing Resourcing Scheme; previously Ongoing Reviewable Resourcing Scheme/
Palagi	Pasifika word for white/non-Pasifika person
Pasifika	People from Pacific Island communities living in NZ
Picture Exchange Communications System (PECS)	Visual communication tool
Plunket nurse	Well-child public nurse for babies and young children employed by the NZ Plunket Society
Project HIEDI	Project Hearing Impairment: Early Intervention and Detection
RTD	Resource Teacher of the Deaf
SES	Special Education Services (later GSE)
Sign Supported English	Signing of English rather than NZSL
social model of disability	Sees disability as socially constructed by a society which creates barriers
Southern Cochlear Implant Programme	Covers New Zealand south of Taupo

Special Education Services	Earlier name for Ministry of Education Special Education
Strengthening families	Holistic NZ model for support of family or young person involving all agencies working together
teacher aide	Educational support worker
Total Communication	Method of signing spoken English to use with speech
Treaty of Waitangi	New Zealand's 1840 founding constitutional document between indigenous Māori and British Crown
UNHSEIP	Universal Newborn Hearing Screening and Early Intervention Programme
Universal Newborn Hearing Screening Programme	Government-funded programme for all newborn babies
van Asch Deaf Education Centre	In Christchurch – one of two main centres for deaf education expertise

Glossary of Māori words

ako	Study/learn
Aotearoa	New Zealand
Aro Hā Mamaku	2010 meeting for families of deaf children, literally ‘the Loving embrace of the tree fern’
Aroha	love/ respect
Awhi/awhinatanga	assistance, support
Hapine	flax strips that have been softened
Hapū	sub-tribe, clan
Harakeke	Flax
Hui	Meeting
Hui Whakawhanaungatanga	Meeting facilitated by the researcher where all the participants and their families shared and discussed aspects of the research
Iwi	tribal grouping
Kai	Food
Kaitakawaenga	Māori liaison coordinator employed by the Ministry of Education
Kete	Basket
Kete kōrero	basket which tells a story
Kete mātauranga	woven baskets of knowledge
Kaimoana	Seafood
Kaitiaki	guardian, caretaker/s
Kaiāwhina	support people/assistant
Kaiwhakahaere	leader, manager
Kanohi-kitea	to meet in person
Kapa haka	Māori performing arts
Karakia	Prayer, chant, religious or spiritual incantation
Kaumātua	Older male, elder/s
Kaupapa	the way things are done, philosophy, agenda
Kaupapa Māori	Māori philosophy, principles, language and culture
Kawa	Protocol
Kete	woven basket
Kete whakairo	woven basket with intricate detail
Kia tūpato	watching out/being careful/politically astute
Koha	gift, contribution
Kōhanga reo	Māori language pre-school
Kōkā	term of respect for maternal figure or female role model
Kōrero	Talk
Kōrero-ā-ringaringa	sign language
Kōrero-ā-tinana	observations of action and behaviour/ body language

Kōrero-ā-tuhi/kōrero-ā-tuhituhi	written language/writing
Kōrero-ā-waha	spoken language/talking
Koroua	male elder
Kuia	older woman
Kura kaupapa Māori	Māori immersion school
Māhaki	humility, showing respect
Mahi	work, occupation
Mana	integrity, prestige, status
Manaakitanga	care for, nurturing, according respect and dignity
Manuhiri	Visitors
Māori	indigenous people of Aotearoa/New Zealand
Māoritanga	Māori culture, way of life
Marae	meeting area of whānau or iwi
Mātauranga Māori	Māori knowledge
Mihi/mihimihi	greetings, introductions, speeches
Mokopuna	grandchild/ren
Pā harakeke	flax plantation
Pākehā	non indigenous person, usually of European origin
Pepeha	sayings, quotes
Puawai	blossom/blossoming
Raranga	Weaving
Rau	Leaf
Ta moko	facial tattoo
Tamariki	Children
Tāngata whenua	Indigenous inhabitants, or hosts
Tangihanga/tangi	Funeral
Tapu	condition of sacredness
Teina	younger sibling
Te reo Māori	the Māori language
Te rito	central shoot of the flax plant
Tikanga	customs, protocol, obligations and conditions
Tikanga Māori	Māori customs, protocol and values
Tino rangitiratanga	self determination/ governance
Tipuna	ancestor or forebear see also tupuna
Titiro	Looking
Tuakana	older (usually) sibling
Tupuna	ancestor or forebear see also tipuna
Urupā	Cemetery
Wānanga	forum for learning, can also refer to a specific tertiary educational institution
Whakapapa	genealogy, cultural identity
Whakarongo	To listen/listening
Whakawhanaungatanga	The process of establishing or creating relationships
Whānaunga	Relative
Whānaungatanga	to establish relationships
Whānau	A fluid concept applying to family/ extended family
Whānau-centred	centred around the unique needs of the whānau

Whānau Ora	Applying Māori principles and philosophy to enhance wellbeing; also the name of a programme of holistic support for family or person having difficulties
Whāngai	the raising of a child by non-biological parents
Whāngai mokopuna	children raised by grandparents by agreement with birth parents
Whare	house/s
Whenu	strands of flax used in raranga

Table of Contents

Abstract.....	i
Acknowledgements	iv
Glossary	v
Glossary of Māori words	viii
Chapter 1. Introduction to the research	1
1.1. Introduction.....	1
1.2. Aims of the research.....	2
1.3. Research questions	3
Chapter 2. Literature review	5
2.1. The impact of childhood deafness.....	5
2.2. Pathways to language for deaf children	6
2.3. Early intervention with deaf children: theories, models and practices	8
2.4. Constructions of deafness in early intervention.....	14
2.5. Support for deaf children and their families in New Zealand	17
2.6. Deaf children with multiple disabilities: development and service provision	20
2.7. Signposting the principles of the Treaty of Waitangi in public policy to promote Māori development	21
2.8. Māori experiences of deafness and early intervention in New Zealand	26
Chapter 3. Ngā kete matauranga: constructing knowledge	29
3.1. Introduction/Overview	30
3.2. Theoretical considerations: the challenge of context	32
3.2.1. Unpicking threads: the history of research about Māori and deaf people	32
3.3. Reweaving a research approach.....	36
3.3.1. Research paradigms	37

3.3.2.	Paradigms influencing this research.....	38
3.4.	Raranga kete: a case study approach.....	41
3.4.1.	Case study research: description from the Western academy	42
3.4.2.	He kete korero, he kete wānanga, he kete ako: the contextual case	43
3.4.3.	Defining the boundary of the case: What to weave and why?	44
3.5.	Whakawhanaungatanga: a kaupapa Māori approach to research relationships	45
3.5.1.	Aro Hā Mamaku	47
3.6.	Te pā harakeke: sampling and sourcing participants	49
3.6.1.	First encounters with research participants	52
3.7.	Preparing whenu to weave into kete: co-constructing data between researcher and whānau participants.....	54
3.7.1.	Interviews with key informants	57
3.7.2.	Data management.....	58
3.8.	Raranga korero-ā-waha, ā-tuhi, ā-tinana: data analysis	59
3.8.1.	Hui Whakawhanaungatanga/wānanga: reflecting participant feedback on findings and interpretation.....	62
3.9.	Ethical considerations.....	64
3.10.	Research challenges: reconciling relationships, responsibilities and expectations of the western academy and of indigenous and marginalized communities	65
Chapter 4.	Reflective practice: The weaver's hands, heart and intellect	69
4.1.	Introduction.....	69
4.2.	Ka pū te ruha, ka hao te rangatahi: (<i>The new net goes fishing while the old one is cast aside</i>)	70
4.3.	My industrious maternal grandparents: raising deaf children in New Zealand	74
4.4.	Deaf-Mum: Deaf-Hands, Deaf-Mind, Deaf-Heart.....	76

4.4.1.	Navigating motherhood and medical interventions	78
Chapter 5.	Early intervention service delivery in New Zealand: context to the case study	81
5.1.	Introduction.....	81
5.2.	Universal Newborn Hearing Screening and Early Intervention Programme (UNHSEIP) in New Zealand.....	81
5.2.1.	The genesis of UNHS in New Zealand	81
5.2.2.	Transitioning from screening to support	84
5.3.	Early intervention: Delivering services at the interface of sectors	86
5.3.1.	AODC (Advisors on deaf children): Navigators of the UNHSEIP	88
5.3.2.	Early Intervention support from Deaf Education Centres in New Zealand	89
5.3.3.	Cochlear implant programmes	93
5.3.4.	Support for early acquisition of New Zealand Sign Language.....	96
Chapter 6.	Tiana.....	99
6.1.	Overview	100
6.2.	The shaping of whānau perceptions of deafness.....	102
6.2.1.	Identification of deafness	102
6.2.2.	The evolving context of whānau.....	103
6.2.3.	Constructing deafness through experience	106
6.3.	Experiences of early intervention: language and communication	110
6.4.	Experiences of Early Intervention: Decisions and Opportunities	115
Chapter 7.	Brooklyn	119
7.1.	Overview	120
7.2.	The shaping of whānau perceptions of deafness.....	123
7.2.1.	Identification of deafness	123
7.2.2.	The evolving context of whānau.....	124
7.2.3.	Constructing deafness through experience	126

7.3.	Experiences of early intervention: language and communication	128
7.4.	Experiences of early intervention: decisions and opportunities	132
Chapter 8.	Jay	137
8.1.	Overview	138
8.2.	The shaping of whānau perceptions of deafness.....	140
8.2.1.	Identification of deafness	140
8.2.2.	The evolving context of whānau.....	141
8.2.3.	Construction of deafness through experience.....	144
8.3.	Experiences of early intervention: language and communication	144
8.4.	Experiences of early intervention: decisions and opportunities	152
Chapter 9.	Sian.....	154
9.1.	Overview	155
9.2.	The shaping of whānau perceptions of deafness.....	158
9.2.1.	Identification of deafness	158
9.2.2.	The evolving context of whānau.....	164
9.2.3.	Constructing deafness through experience	165
9.3.	Experiences of early intervention: Language and communication	171
9.4.	Experiences of early intervention: decisions and opportunities	178
Chapter 10.	Starr.....	184
10.1.	Overview	185
10.2.	The shaping of whānau perceptions of deafness	186
10.2.1.	Identification of deafness	186
10.2.2.	The evolving context of whānau	188
10.2.3.	Constructing deafness through experience	191
10.3.	Experiences of early intervention: language and communication.....	194
10.3.1.	Experiences of early intervention: decisions and opportunities.....	200
Chapter 11.	Whānau perceptions of the deaf child	205

11.1.	Introduction	205
11.2.	Perspectives on deafness within the whānau	205
11.2.1.	The meaning of deafness: whānau constructions of deafness.....	207
11.2.2.	Mentoring relationships within whānau: raising children from collective experience	211
11.2.3.	Envisioning life pathways and outcomes for deaf children: the impact of deaf adults.....	214
11.3.	The effect of EI experiences on shaping whānau perceptions of the deaf child	216
Chapter 12.	Refocusing early intervention services for Māori: Ngā Kōhungahunga Turi	219
12.1.	Introduction	219
12.2.	Reaching for equity across the UNHSEIP?	220
12.2.1.	Refocusing the lens on the problem of inequity.....	222
12.2.2.	Delivering services to Māori deaf children and their whānau across the UNHSEIP: key provider perspectives	223
12.2.3.	Participatory and relational components of family-centred practice: whānau participant experiences	226
12.3.	A Kaupapa Māori approach to support for Māori deaf children and their whānau	231
Chapter 13.	Conclusions	238
13.1.	Consideration of the research questions	238
13.1.1.	What shapes whānau perceptions of deafness in the early years? ...	238
13.1.2.	What are the early intervention experiences of whānau	239
13.1.3.	Do the design and delivery of early intervention services and support systems for deaf children need to be adapted to be more effective for Māori? And if so, how?	240

13.1.4. Recommendations: How do the design and delivery of early intervention services and support systems for deaf children need to be adapted to be more effective for Māori?	240
13.2. Ka puāwai ngā kōhungahunga turi	240
References.....	242
Appendices.....	253
Appendix A	253
Appendix B	256
Appendix C	258
Appendix D	261
Appendix E.....	263
Appendix F.....	264

Chapter 1. Introduction to the research

1.1. Introduction

Māori children are historically over-represented in hearing-loss statistics; Māori are also disproportionately represented (approximately 25.1%) in the New Zealand Sign Language (NZSL) community (Statistics New Zealand 2006:14).¹ While medical and educational data have repeatedly identified deafness amongst Māori quantitatively as an issue of concern, relatively little is documented about the lived Māori experience of deafness, from either the perspective of deaf Māori themselves, or from the perspective of whānau² raising Māori deaf children. ‘Whānau’ is what Māori recognise as their familial arrangements (Walker 2013). The life experiences of Māori Deaf people, as for many other Deaf ethnic minority groups, tend to culminate in a life characterised by social, ethnic and linguistic disadvantage, challenging their development of a secure identity in, and participation with, deaf and ethnic communities (AKO Ltd. 1995; Dugdale c2001; Hairston and Smith 1983; Lane et al. 1996; McKay-Cody 1998/1999; Paris and Wood 2002; Smiler 2004). In addition to Māori deaf children’s experience in the special education system, the nature of whānau interaction, engagement or

¹ In 2006, Statistic New Zealand stated 24,090 people reported ability in New Zealand Sign Language, of this 6,057 people were able to communicate in English, te reo Māori and New Zealand Sign Language. It is highly likely that the majority of these users are Māori deaf people and their whānau members. The 2013 census reported Māori comprise 14.9% of the national population.

² The term whānau is often translated into English as simply meaning family, families or an extended family network which can encompass several generations. Although this is the simplest way to describe whānau to non-Māori, the reality is that the concept of whānau is something that is fluid to Māori communities and generally complements a holistic worldview. Māori most commonly use the term to describe inter-generational groups of people with common whakapapa (ancestry). However, Māori often intuitively resist placing boundaries on the parameters of who comprises whānau and the term is often used loosely to include non-related peoples such as in-laws and friends. Another aspect of whānau which is commonly understood by Māori is the issue of shared values. Whānau are not only recognised for the individuals comprising them, but also by the values and cultural norms that bind and characterise whānau members. This research purposefully uses the term whānau as opposed to family/families/extended-family, and chooses not to provide a translation of whānau within the text. Whānau stands as it is, accepting that ‘whānau’ may be interpreted and understood by Māori communities as they see fit. This research also invited participants to self-define the parameters of their whānau (Ihimaera 1998; Metge 1995).

otherwise, with available forms of support and resources during the pre-school years is a key factor in shaping identity and opportunity into adulthood. This factor is acknowledged, but has not been substantiated by empirical research conducted with whānau of Māori deaf children.

A family-centred approach to early intervention with deaf children is accepted practice in New Zealand, although evidence of its application or effectiveness in general has not been systematically evaluated (Douglas and Robinson 2006: 8), let alone specifically in relation to Māori. Anecdotally, a cultural mismatch may be noted between the delivery of deaf education-related services and the needs of whānau of Māori deaf children. This is evidenced in poor rates of hearing loss identification amongst Māori (J. Digby et al. 2013; Greville Consulting 2007), lower educational achievement for Māori (Fitzgerald & Associates 2000), few Māori staff working with whānau of deaf Māori children, limited understanding of tikanga Māori and te reo Māori amongst non-Māori staff, an absence of Māori models of intervention, and weak formal links with Māori communities and organisations (DEANZ Undated).

Bodner-Johnson and Sass-Lehrer suggest that for family-centred approaches to be effective, deaf children and their families must be understood from an ecological perspective. They propose that to understand the life of a deaf child “...we must come to understand the individual child and the individual family. What are the various sub-systems? How do they interact with one another? What are the relationships that occur among them?” (Bodner-Johnson and Sass-Lehrer 2003: 7-8). The ecologies of Māori whānau differ from other population groups within New Zealand and indigenous populations internationally (M Durie 1997; M Durie et al. 2002; Haig 1997; A. H. Macfarlane 2000; Metge 1995; Pere 1991). Accordingly, there is a need to identify and describe those dynamics which impact on Māori deaf children and their whānau, and to understand how these interact with the effectiveness of current early intervention practices.

1.2. Aims of the research

The focus of this research follows on from a key issue that emerged from the researcher’s MA which studied Māori deaf adults’ accounts of their construction of cultural-linguistic identity (Smiler 2004). That study revealed that whānau perceptions

of deafness and their relationships with the deaf education system impacted directly upon whānau decision-making, as well as on their ability to support a deaf child's participation and personal development within whānau and educational contexts.

The proposed research has two chief aims: (1) To document how whānau of Māori deaf children experience the early intervention system, with a focus on how these interactions, in combination with other sources of knowledge, affect their construction of deafness, their decisions about language use and other early educational interventions, and their sense of competence in raising a Māori deaf child; (2) To investigate how the design and delivery of early intervention services for deaf children could be more effective from the perspective of Māori deaf children and their whānau. Parallels can be drawn between Māori frameworks of holistic wellbeing and family-centred interventions, most obviously the principle of making the family, or whānau in the case of Māori, the central reference point for organising support of an individual with specific needs. The features of a 'whānau-centred' model of intervention and the philosophies that would inform this are not yet articulated in the context of deaf education. Therefore, the two aims of the study are complementary in contributing to an understanding of whānau experiences of early intervention as it currently exists, and identifying the characteristics of a 'whānau-centred' intervention approach that would promote good educational outcomes for Māori deaf children.

1.3. Research questions

1. What shapes whānau perceptions of deafness in the early years?
2. What are the early intervention experiences of whānau of deaf children?
 - a. *how do these experiences inform communication, language and relationships between Māori deaf children and their whānau?*
 - b. *how do these experiences shape whānau decisions and opportunities for the child in the early years?*
3. Do the design and delivery of early intervention services and support systems for deaf children need to be adapted to be more effective for Māori, and if so, how?
 - a. *How do early intervention professionals describe their role and approach to providing early intervention services to whānau of Māori deaf children?*

- b. *How can Māori experiences of raising a deaf child, and early intervention inform a 'whānau-centred' approach to early intervention that would promote better outcomes for Māori deaf children?*

These questions are explored in this thesis in the following chapters.

Chapter Two reviews the literature on deaf children and the impact of childhood deafness on the development of the child and their language acquisition.

Chapter Three outlines the methodology. Using the metaphor of raranga, the Māori art form of weaving and plaiting fibres from the harakeke (flax) plant the way in which the research was undertaken and the rationale for it is described.

Chapter Four provides a reflection that focuses on the formative nature of my childhood social and linguistic experiences, the intergenerational impact of deafness, and the complex and evolving nature of Māori whānau in a modern context, providing a conceptual lens for the research.

In Chapter Five a context for the case studies is provided, describing the situation of early intervention in New Zealand.

In Chapters Six to Ten the five case studies are presented. These discuss the situation of each of the children and their whānau. It explores their experiences with early childhood education and health professions, and the acquisition of language - Māori, English, and or NZ Sign Language (NZSL).

In Chapter Eleven the way in which whānau has conceptualised the deaf child is reviewed.

Chapter Twelve provides an overview of how EI services and supports describe their role in relation to Māori. In this chapter I argue that the current system of EI supports does not work toward Māori aspirations for their deaf child. A metaphor of the pā harakeke is proposed as basis for organising support.

Chapter Thirteen summarises major findings from this research and explores the implications of these.

Chapter 2. Literature review

2.1. The impact of childhood deafness

Early access to language and communication is an essential prerequisite to a deaf child's development (Clarke and Siraj-Blatchford 2000; Erting 2003; Gee et al. 2003; Marschark et al. 2002; Rose et al. 1987; P. E. Spencer and Marschark 2006). Language allows children to engage and participate with the wider world to which they belong. It enables children to learn, form memories, and develop understandings of themselves and of others (Brown and Nott 2006; Hoff and Shatz 2007). Developing age appropriate language and communication skills and social acculturation are synchronous processes. Families are conventionally the first contexts in which children acquire language and usually provide a child with its first language community – older family members intuitively draw on skills they have subconsciously acquired during their own childhoods in order to engage, teach and facilitate spoken language development and communication (Papoušek and Papoušek 1987). Ultimately, families provide the very foundation we use to make sense of our world as Bodner-Johnson writes:

Families generally provide a foundation for everything we are or do. ... We believe if we can fit into our families, we can fit into our friendships, the community and the world (Bodner-Johnson 2003:4).

For the 96% of deaf children who are born to hearing parents (Mitchell and Karchmer 2004) the socialisation process is typically disrupted by communication issues. Strategies subconsciously applied by family members to facilitate language and social development may be ineffective. Consequently, deaf children in hearing families often experience significant delays in language and communication development, which impedes social, emotional, cultural and cognitive developmental milestones (Mayberry et al. 2002; Richter et al. 2002). Traditionally, this has led people to believe that language and communication deprivation is a natural consequence of deafness (Meadow 1980). However, it is not the physical state of deafness itself which impedes language and communication; rather it is people's responses, typically those in charge of socialising the deaf child, which contributes to language deprivation. A deaf child's

development is highly dependent on a range of factors such as: how families respond to their child's deafness, what types of support and experiences families are able to access, whether supports correspond with the family's views on deafness, how a family responds to these supports, and ultimately how a child responds.

The following sections of this chapter provide background to this research. The literature review begins with the ways in which deaf children can acquire language, followed by an introduction of key EI theories, models and practices and the underlying influence of constructions of deafness on these. EI supports currently provided in New Zealand and the implications of multiple disabilities for service providers are identified as context for the study. Finally the implications of the Treaty of Waitangi (as the country's founding document) are considered in relation to service provision for Māori.

2.2. Pathways to language for deaf children

Although families are usually the most natural language environments whereby children typically acquire language, this is not the case for the majority of deaf children. (Marschark and Spencer 2006:14) note a clear distinction between *language development* and *language learning*, the former being a natural process, and the latter being the result of an intentional and structured activity of language teaching and learning from an intervening source – as is the case with EI supports for deaf children. They write:

“Although this distinction is rarely important in studies of hearing children (viz. only when those children have special learning needs), it is not one that can be viewed lightly in studies of language used by deaf children. Language appears to develop relatively naturally among deaf and hearing children of deaf parents (given the above caveats) and among hearing children of hearing parents. Deaf children of hearing parents, meanwhile, typically have been taught language from the time they enter early intervention programming through to their college careers.” Marschark, Schick and Spencer (2006: 14)

Various studies have explored the language development of deaf (and hearing) children who have been socialized within families who use sign language as primary language (M. Bishop 2008a; Cramér-Wolrath 2013; Dettman and Dowell 2010; Gaustad 1988; Koester et al. 2004; Mayberry 2007, 2010; E. Spencer 2004). Due to the visual accessibility of language in these contexts, early language development tends to occur

along a normal trajectory – with the exception of those with an additional disability, which may affect this learning pathway the majority of deaf children however, a purposeful decision must be made regarding which language/s the family and professionals will foster. Early Interventionists argue that action on language choices must be made within the ‘critical period’ from birth to around three years, during which language acquisition is most efficient (Dettman and Dowell 2010; Mayberry et al. 2002; Mayberry 2007, 2010)

There are various ways in which a child can understand, process and express language through the senses – the primary being visual, auditory and tactile (the latter mainly used by deaf people with vision loss and not a focus of this research). Spoken and a signed language are natural examples of languages processed in these modalities and the advent of cochlear implantation and sophisticated hearing aid technology now means that deaf children may be able to access language via either mode. Stredler-Brown (2010:292-298) categorizes the various approaches to language teaching and learning according to modality as follows. **Auditory** mode approaches include *Auditory-Verbal* (a unisensory approach whereby the child is isolated from visual information to language and encouraged to utilise and develop listening skills) and *Auditory-Oral* (a multi-sensory approach which encourages listening but with the support of visual and environmental cues). **Visual** mode approaches include: a *Bilingual* approach whereby children are expected to learn a natural sign language as a first language that provides a foundation for learning of the local spoken and/or written language as a distinct language. Other visual mode approaches make use of artificial signed systems to produce signs or other visual cues in the same word order as the spoken language, either with or without simultaneous speech; these are collectively referred to as *Manually Coded English (MCE)* and *Cued Speech*. Multimodality approaches have commonly been adopted within education systems, such as *Total Communication* (in New Zealand and elsewhere), which involves the use of a Manually Coded English system, in conjunction with spoken and written language (Marschark and Spencer 2006).

Stredler-Brown (2010:308) who writes on the relationship between communication choices and outcomes during the early years proposes a model for selecting a communication approach for a very young child. In this approach, both parents and

professionals undertake an informed decision-making process, followed by ongoing formal and informal observations of the child's developmental profile and the modalities used by the child in spontaneous language and communication. These are then analyzed and shared between families and professionals. Families are asked to periodically review the approach used and are encouraged to examine whether the appropriate developmental gains have been made. Where developmental gains have been unsatisfactory, data will support identification of gaps and the approach is reviewed by both families and professionals. In order to serve the best interests of the child decisions around language choices cannot be viewed as static; contextual circumstances may demand changes, and empirical evidence should form the basis to "recommend, choose, maintain or change and approach" Stredler-Brown (2010:308-309).

2.3. Early intervention with deaf children: theories, models and practices

Early intervention with deaf children tends to focus on the earliest period of deaf children's lives – that is, from birth to three years of age. Child development theorists conclude that attending to a child's psychological, emotional and physical needs during early childhood is crucial to ensuring that they develop secure attachments which support a sense of trust in others, and feelings of being valued and loved. Early childhood experiences support a child's development of long-term relationships with others as children, and in adulthood (Erikson 1963). The early childhood age bracket has also been identified by child language development theorists as a "critical period" for optimal language acquisition (Beattie 2006; Bochner and Albertini 1988; Rose et al. 1987; Ruben 1997). Language mediates interaction between child, parent, family and community. It is suggested (Papoušek and Papoušek 1987, 1997) that many parenting techniques used to promote child development are intuitive and unconscious, often involving parental adjustment of language and communication styles to encourage behaviour and maintain attention. The rationale for early intervention for deaf children and their families assumes that without prior experience, most hearing parents of deaf children cannot rely on the intuitive and unconscious parenting techniques that they would customarily use with hearing children (Traci and Koester 2003). Early intervention is therefore required to ensure that new information and skills

are provided to account for their unique circumstances (Sass-Lehrer and Bodner-Johnson 2003).

Principles and practice in early intervention with deaf children have evolved from multiple fields, such as early childhood education, child development, medicine, special education and deaf education, (Sass-Lehrer and Bodner-Johnson 2003), all of which have their respective traditions and theories.³ This diversity makes the task of exploring the area of early intervention with deaf children particularly complex. Even the term ‘intervention’ has several connotations that do not transcend disciplines. Typically the term is used in medical circles (HIEDI 2004), which frames deafness as an individual physiological problem to be corrected medically, for example, through cochlear implantation (Clark 2003). A social model of disability (Oliver 1996), and Deaf academics (Ladd 2007; Lane 1984) posit disability or deafness as a natural human state that does not require ‘intervention’, in contrast to the medical sense that assumes the physical state of deafness is problematic, unnatural and requires remediation (Oliver 1996). In educational discourses the term intervention can encompass medical interventions, educational approaches as adopted by educationalists, and communication changes, for example, learning sign language, in the communities surrounding a deaf child (M. Mertens et al. 2003). The variable use of the term intervention amongst professionals and within academia complicates the task of evaluating and discussing the literature. This research acknowledges this complexity, yet continues the use of the term intervention based on two factors: (1) deafness is a point of difference that alters conventional routes to language learning, communication and socialisation and hence some form of intervention to alter the behaviour of the child and their families are required; and (2) the literature on deaf children and their families is firmly couched in this terminology and thus a digression from this term may be confusing. Instead, I assume that the term can apply to individuals and groups, while the politics surrounding usage of the term will be contextualised within the text of this thesis.

Studies of parental experiences of early intervention programmes show that the nature of the relationship between parents, families and intervention professionals directly

³ See section 2.4 *Constructions of deafness in early intervention*.

shapes families' responses to their deaf child, is a powerful contributor to how well the deaf child integrates into families and communities, and how successfully the deaf child is in achieving developmental, linguistic and educational outcomes (Sass-Lehrer and Bodner-Johnson 2003). The role of the professional as expert, whereby the status and competence of parents and families in child rearing situations are demoted, is commonly reported (C. Dunst et al. 2002). Beazley and Moore (1995) speculate that professionals' uncritical approach to professionalism may contribute to a sense of dependence and vulnerability amongst parents. A recent shift in philosophy from the professional-parent dichotomy to one that emphasises the role of families can, however, now be seen in the early intervention sector. Sass-Lehrer and Bodner-Johnson (2003) attribute this shift in focus to literature which discusses individual behaviors in terms of ecological systems (Bronfenbrenner 1979) and family social systems (Minuchin 1974). Such an approach moves from a teacher-child or parent-child dichotomy, in which knowledge transfer is linear from adult to child (or professional to parent), to an approach which encourages a collaborative approach between professionals and families as holistic units. In this model, families are empowered to claim a role as the goal setters, enhancers, and facilitators of the learning, development, and wellbeing of the child. This approach claims to be sensitive to the ecological dynamics of children and their families and frames the family-centred approach to intervention as Bodner-Johnson (2003) outlines:

The ecological perspective rests on the idea that development relies on the child's capacity to understand and shape the world that he or she experiences; the ability of children to communicate effectively with those in that environment has a critical influence on that capacity (Bodner-Johnson 2003: 7).

According to Dunst (2002:147) family-centred practices can be conceptualised in terms of relational and participatory components:

1. *The relational component includes practices associated with (a) good clinical skills (active listening, compassion, empathy, respect, being non-judgmental and (b) professional beliefs and attitudes toward families, especially around parenting capabilities and competencies.*

2. *The participatory component relates to practices which are (a) individualised, flexible, and responsive to family concerns and priorities, and (b) provide families with opportunities to be actively involved in decision making, family-professional collaboration, and family actions to achieve desired goals and outcomes.*

Dunst (2002) concludes that the simultaneous use of both the relational and participatory components is what sets the family-centred approach apart from others. In New Zealand the parameters of the relational and participatory components of family-centred practice have yet to be specifically documented as such in research, policy or practice guidelines (DEANZ 2003). In her review of special education services in New Zealand, Barwick (1998) notes the ambiguity with which the ‘family-centred’ approach has been applied in New Zealand:

Family-centred services have rapidly become seen as very valuable, and ‘best practice’ within early intervention. However, commentators note that there is not yet any real consensus on what constitutes family-centred services, and that is important to distinguish between services which range from family-allied services to family-empowerment services (Barwick 1998:4).

Dunst also questions whether the family-centred approach actually does a better job of engaging families than other approaches, and to what extent the philosophy of a family-centred approach manifests in practice:

Professionals in education, health, human services, and other fields typically claim that ‘we’ve worked with families for 25 years, and we’ve always been family centred’. Both research and experience tells us that this claim, for the most part, is not borne out of the ways that families are treated and the ways that families are involved in helping relationships with professionals. We need better research to substantiate or refute claims about family centeredness, with an eye toward increasing specificity regarding the characteristics and consequences of family-centred and other family-orientated approaches to working with families (C. J. Dunst 2002:145).

In response to widespread concern over the uneven and inconsistent application of family-centred principles internationally, a diverse panel of international experts with expertise in working with families of deaf children (including parents, deaf professionals, early intervention program leaders, early intervention specialists, and researchers from across the world) convened at the inaugural 2012 International Congress on Family-Centred Early Intervention for Children who are Deaf or Hard of Hearing, and develop international consensus statement, *Best Practices in Family-Centered Early Intervention for Children Who Are Deaf or Hard of Hearing: An International Consensus Statement* (Moeller et al. 2013). A set of agreed-upon guidelines, 10 evidence-based principles and associated provide/programme behaviours, were developed to promote the wider implementation of validated, evidence-based principles for family-centred EI. The key principles and associated practices are reproduced in Table 1:

Table 1: Best Practices in Family-Centered Early Intervention for Children Who Are Deaf or Hard of Hearing: An International Consensus Statement principles (Moeller 2013:430-444)

Principles	Principle description
Early, Timely, & Equitable Access to Services	Screening and confirmation that a child is D/HH will be effective to the degree that they are linked with immediate, timely, and equitable access to appropriate interventions.
Informed Choice and Decision Making	Professionals promote the process wherein families gain the necessary knowledge, information, and experiences to make fully informed decisions. This includes educating families regarding special education laws and their rights as defined by these laws. Decision making is seen as a fluid, ongoing process. Families may adapt or change decisions in response to the child's and families' changing abilities, needs, progress, and emotional well-being.
Family Social & Emotional Support	Families are connected to support systems so they can accrue the necessary knowledge and experiences that can enable them to function effectively on behalf of their D/HH children.
Family Infant Interaction	Service providers support families to Families and providers work together to create optimal environments for language learning
Use of Assistive Technologies and Supporting Means of Communication.	Providers must be skilled in the tools, assistive devices, and mechanisms necessary to optimally support the child's language and communication development.
Qualified Providers	Providers are well trained and have specialized knowledge and skills related to working with children who are D/HH and their families. Providers possess the core competencies to support families in optimizing the child's development and child-family well-being
Collaborative Teamwork Early intervention teams	An optimal FCEI team focuses on the family and includes professionals with experience in promoting early development of children who are D/HH. Ongoing support is provided to families and children through transdisciplinary teamwork, whereby professionals with the requisite skills are matched to the needs of the child and family.
Progress Monitoring	Service providers work in partnership with families to FCEI is guided by regular monitoring/assessment of child and family outcomes.
Program Monitoring	FCEI programs evaluate provider adherence to best practices and include quality assurance monitors for all program elements.

The consensus statement requests a 'call for action' on an international scale, urging that the principles form the basis of legislation, guidelines, consensus papers, and position papers regarding early intervention services and models. The implications of the consensus statement has yet to be tested and evaluated in New Zealand in relation to EI.

2.4. Constructions of deafness in early intervention

How families are supported to respond to childhood deafness in New Zealand and internationally has been directly influenced by societal beliefs about deafness, in particular, the historical debate over whether spoken or signed language is best for deaf people (Branson and Miller 2002; Jankowski 1997; Lane 1984; Monaghan 1996).

Advocates for spoken language generally accept a medical perspective on deafness which classifies deafness and the relative severity of its impact on spoken language acquisition according to degrees of hearing loss (HIEDI 2004). The medical response to deafness works toward the restoration of hearing through hearing-aids, cochlear-implant technology⁴ and aural-oral therapy methods that encourage the use of residual hearing and spoken language. This approach aims to enable deaf children to access language aurally and to move through linguistic milestones as hearing children might (Richter et al. 2002). The pedagogical approach associated with this is known as oralism.

Oralism has been linked with social Darwinist beliefs that sign languages are primitive gesture systems as opposed to actual languages (Branson and Miller 2002), a view that has had a profound impact in shaping language practices in deaf education internationally. It is argued that a pathological model of deafness has resulted in the stigmatisation of signed language and negative social outcomes for the Deaf communities who use them (Branson and Miller 2002; Forman 2000; Jankowski 1997; Lane 1984; Lane et al. 1996; Monaghan 1996; Townshend 1993).

In 1880, an international congress on education of deaf children, held in Milan, decreed the “incontestable superiority of speech over signs” (Lane et al. 1996) which led to the

⁴Cochlear implants are prosthetic hearing devices that consist of both internal and external components. The internal component is described as a “series of wires or electrodes ... surgically placed in the lower channel of the cochlear of the recipient”; the “cochlear implant sends electrically transformed sound information to the sound analysis system of the transplant ... a minicomputer ... usually called the sound analysis ‘speech (or sound) processor’” (Christiansen and Leigh 2002:54).

promotion of oralism as a teaching method. This approach aimed to integrate deaf children into hearing society by encouraging the use of residual hearing and communication via lip-reading and speech. Despite deaf people's known historical use of sign languages elsewhere, oralist pedagogy was adopted in New Zealand in 1880 with the establishment of the first state-funded deaf school (Collins-Ahlgren 1989; Monaghan 1996; Townshend 1993) and continued as the main pedagogy within deaf education until the late 1970's (Aspden et al. 1992; Monaghan 1996; Townshend 1993). The advent of improved hearing aid technology and cochlear implantation has changed the dynamic of the "oralist agenda" (Ladd 2003; Lane 1984). Historically this agenda sought to educate and normalise deaf children who could clearly not hear via concentrated training in speech and lip-reading. The cochlear implant alters this dynamic by providing children with 'artificial hearing' (Christiansen and Leigh 2002; Clark 2003; Waltzman and Cohen 2000) and is seen by many parents (Chute and Nevins 2002; Purdy et al. 1995; Richter et al. 2002; Zaidman-Zait 2007), educators (Nevins and Chute 1996; Richter et al. 2002) and medical professionals (Summerfield and Marshall 1995; Waltzman and Cohen 2000) as an attractive option that offers more access to the development of spoken language. As a consequence, cochlear implantation in young children has become very popular internationally and is a corollary of the relatively well-resourced universal newborn hearing screening programme in New Zealand (M. Cullen 2006) and other countries with socialised healthcare. Nevertheless, with only three generations of deaf children having experienced cochlear implantation internationally and two generations within New Zealand, the long-term impact of cochlear implantation is only just being explored (Paludneviene and Leigh 2011).

Another construction of "deafness as a linguistic and cultural identity" challenges the medical paradigm that underlies most educational responses to deaf children. Deaf writers (Padden and Humphries 1988) describe the cultural meaning of being deaf as having 'a different centre'. This perspective asserts that deaf children are naturally visual people who acquire language visually through the use of a sign language, such as NZSL (New Zealand Sign Language) (Collins-Ahlgren 1989; Monaghan 1996; Townshend 1993). This perspective also posits that as visual people, deaf people tend to share common characteristics that shape their orientation to sensory, cognitive and social experience. These common traits and behaviours are identified as 'Deaf culture

‘within communities of deaf people (Higgins 1983; Lane et al. 1996; Padden 1980). Since most professionals in the field of deaf education are not themselves deaf, this perspective is not readily available to hearing families (McKee 2006). Instead, such professionals’ beliefs about deaf people tend to mimic the beliefs of the wider hearing majority, that their children must speak and act socially and cognitively as hearing persons. These expectations are known to have caused emotional, social and linguistic rifts between deaf children and their families that can continue into adulthood (Corker 1996; Higgins 1983; Holcomb 1997; Ladd 2003; Schein 1989).

The stigmatisation of sign languages has meant that NZSL has never been readily accepted nor resourced within deaf education in New Zealand. Initial attempts to introduce ‘visual communication’ were prompted by a small group of advocates including parents, deaf people and educators in the 1970s who were frustrated by the unsatisfactory outcomes of the oralist approach (Collins-Ahlgren 1989; Dugdale 2000; Monaghan 1996; Townshend 1993). As a result, ‘Total Communication’, also known as TC, was introduced in 1979. In this method, children were taught to use Australasian Signed English in English word order, with speech, to encourage the understanding and development of spoken English (Department of Education 1979). Although TC greatly increased the visual accessibility of communication in school, the method proved unnatural and cumbersome for many deaf children who often unconsciously switched to a different style of signing (NZSL) outside the classroom (Collins-Ahlgren 1989; Dugdale 2000; McKee and Connew 2001). From 1993, NZSL began to gain some acceptance for classroom use, including the introduction of a bilingual approach, English and NZSL, in the residential deaf schools (McKee and Biederman 2003; Nuthall 1997; Pivac and Smith 1996). While international research supported the linguistic and social merits of bilingual programmes at the time (Ahlgren and Hyltenstam 1994; Strong 1988), and New Zealand deaf education policies and strategies acknowledge the benefits of NZSL to deaf children (DEANZ 2003), the reality is that bilingual education is still difficult to access in New Zealand. Research suggests this can be attributed to the geographical isolation of many deaf children in mainstream schools and the limited and intermittent access to bilingual education resources, especially human resources such as the NZSL language models, and teachers and bilingual peers to act as a language community (McKee and Smith 2003c, 2003a, 2003b; McKee 2008). Weaknesses in implementing bilingual education are

exacerbated by the government sector's lack of commitment toward developing the workforce and resources required to service the bilingual education needs of deaf children and their families (DEANZ 2003; Fitzgerald & Associates 2000; Mckee 2008).

Philosophical constructions of deafness have always underpinned the types of support made available for deaf children and their families in New Zealand. Although a recent review (Douglas and Robinson 2006) suggests a family-centred approach is currently employed by professionals working with deaf children, which in theory enables families to drive the selection of educational goals and support, history has shown that societal constructions of deafness inform which types of support are funded by government. As a consequence, underlying societal values can shape how families of deaf children respond to their deaf children and how they support them acquire language and social competence.

2.5. Support for deaf children and their families in New Zealand

Securing a diagnosis of hearing loss for a deaf child is the first step for them and their family entering the world of support services for deafness. During the course of this research, the New Zealand universal newborn screening for hearing loss (in which all newborn babies are screened at birth with a monitoring system being implemented for children at risk of developing hearing loss at a later stage (Universal Newborn Hearing Screening Advisory Group 2006)⁵. In this context, a screener and audiologist are often the first professional contact for deaf children and their families. The audiologist then refers families to an Advisor on Deaf Children (AODC), a trained professional who becomes the main contact person between families and professionals, provides information on deaf children's development, helps families understand the implications

⁵ Since the 1980's identifying hearing loss has involved an 'at risk factor' approach or a 'targeted hearing screening' approach whereby only babies who exhibited key risk factors, i.e. family history of hearing loss, jaundice requiring exchange transfusion, craniofacial abnormalities, ototoxic drugs, mechanical ventilation lasting five or more days, low apgar scores, birth weight less than 1500 grams, bacterial meningitis, infections such as rubella, herpes, toxoplasmosis and those associated with hearing loss, were screened. However, with the recommended age for identification of hearing loss being three months, and the average age of identification in New Zealand in 2004 and 2005 being 45.3 and 33 months respectively, a targeted system of screening for hearing loss amongst all newborns was introduced in New Zealand in 2006. (National Screening Unit, 2006).

of deafness, and coordinates the various services available for their children (DEANZ and National Audiology Centre (NZ) 2005).

In New Zealand, the delivery of government funded support services is organised under medical and educational sectors. Medical supports include diagnosis and testing of hearing loss, ongoing ear health and hearing aid support, as well as support for cochlear implantation. Many of these services involve short-term visitation with local hospitals and audiology units attached to hospital systems. The education sector on the other hand, focuses on supporting language acquisition and cognitive development via various pathways. Options for early childhood education support include two government funded pre-school centres, the van Asch Deaf Education Early intervention centre based in Christchurch and the pre-school attached to the Kelston Deaf Education Centre in Auckland, placement and ancillary support in mainstream (hearing) early childhood centres, receiving support within the home, or receiving no support at all. However, as deaf children enter the ‘transition-to-school-period’, from 4 years and 8 months onwards, resources become managed and funded under the Ministry of Education’s ongoing resourcing schemes (ORS funding). Under this system, the Ministry’s Group Special Education (GSE) sector coordinates reviews for children who require interventionist support from specialists or a specialist teacher to access the curriculum. Children who are eligible for ORS funding are assessed according to a ‘level of need’, which is categorised in terms of several verification levels. Depending on the outcome of the ORS assessment, support staff⁶ may be allocated to support the child in the early childhood education setting or within the home (Ministry of Education 2012). Supports for early childhood deafness from the wider community include the following:

- *New Zealand Federation for Deaf Children Incorporated (NZFDC)* – a national organisation (representing regional parents of deaf children groups) who provide a network for parent to parent support and advice

⁶ Key professional supports include Advisors on Deaf Children (AODC), Resource Teachers of the Deaf (RTOD), Speech Language Therapists (SLT), Teacher Aides (TA) and Deaf Resource Persons. These are explained further in Chapter 5.

<http://www.deafchildren.org.nz/>, and run *BEACON* – a parent mentor programme <http://www.deafchildren.org.nz/parent-mentors.php>.

- *New Zealand Deaf community initiatives* – such as Deaf Aotearoa NZ, local Deaf clubs, and Magnet Youth, all of which provide information and social events for deaf people of all ages <http://www.deaf.co.nz/>;

Over the last decade, services for deaf children and their families have been the subject of review and critique, identified gaps prompted the implementation of new services and restructuring of old services (Barwick 1998; DEANZ 2003; Douglas and Robinson 2006; Fitzgerald & Associates 2000; HIEDI 2004; McKee 2005; Noble 2006; Stockwell 2000). This process has resulted in placing some existing medical and educational services under the umbrella of the Universal Newborn Hearing Screening and Early Intervention Programme (UNHSEIP). Resourcing for cochlear implantation has now increased and the education sector is identifying clear service ‘gaps’ for deaf children and their families. Addressing these gaps is ongoing. Key areas of concern identified by reviews and critiques include the following:

- a dearth of social contact for deaf children and their families with deaf peers and other NZSL users (McKee 2005; Noble 2006; E. Smith 2003);
- limited support for sign language development within the home and the classroom (Laing 2006; McKee 2005, 2006);
- the need for improved communication support for deaf children placed within mainstream classroom settings (McKee and Smith 2003c, 2003a, 2003b; Sameshima 1999);
- a lack of understanding surrounding whether current practices used to assess the educational development of deaf children in New Zealand are reflective of international best practice (Barwick 1998; DEANZ 2003; DEANZ and National Audiology Centre (NZ) 2005; Douglas and Robinson 2006; Hafer and Stredler-Brown 2003; Ministry of Education 2006);
- information, advice and coordination of services for families are not consistent nor equitably available across New Zealand (Douglas and Robinson 2006; Fitzgerald & Associates 2000; HIEDI 2004; Noble 2006);
- the deaf education sector requires extensive workforce development, in particular: further professional development for current staff and recruitment

and training for specialised staff, particularly in regard to NZSL proficiency (Douglas and Robinson 2006; Human Rights Commission 2013; McKee and Smith 2003c, 2003a, 2003b; Noble 2006; Stockwell 2000);

- although Māori children are well over represented in deafness statistics, and while educational policy agrees that Māori perspectives should be reflected in educational practice, it is not clear how services plan to implement this (DEANZ 2003; J. Digby et al. 2013; Douglas and Robinson 2006; Fitzgerald & Associates 2000; Greville Consulting 2007; Smiler 2004).

Traditionally the structure of support services has fallen into three sectors, medical support, educational support and voluntary support, each of which tended to focus within its own discipline and/or framework, and generally avoid, albeit not necessarily deliberately, the holistic impact that deafness can have on children and their families. The advent of this review period however, has brought the issue of ‘working collaboratively’ to the fore, with each sector being forced to review their current practice in relation to the ‘bigger picture’ of holistic development. In addition to identifying gaps in service delivery, this review period has illuminated language development and working with families, as with the family-centred approach, as common goals shared across all support sectors.

2.6. Deaf children with multiple disabilities: development and service provision

The impact of deafness for children who are deaf and have additional or multiple disabilities is dependent on the nature of the disabilities and the ways they influence one another (Jones and Jones 2003; Van Dijk et al. 2010). Piecing together an understanding of the relationships between multiple disabilities, their etiologies, influence on one another, and how they shape a child’s development is often a streamlined process for neither families nor professionals. Firstly, the disabilities must be recognized either by families or identification and diagnostic services – a potentially lengthy process. Multiple disabilities may be difficult to compartmentalize from one another; they may influence one another in ways which may mask one another, or make diagnostic tools difficult to apply. The disabilities may be caused by illness or injury – the impact of which may not be immediately apparent as focus may be placed on

critical life saving measures and/or the impact of which unfolds as a child moves through developmental milestones in an atypical fashion. Disabilities may also not emerge concurrently and thus may influence the way the disabilities emerge and appear to outside observers (Beals 2004; Jones and Jones 2003; Van Dijk et al. 2010).

While little is known of the developmental trajectories of deaf children with multiple disabilities, Van Dijk et al. (2010:173) argue that the etiologies of deafness and concurrent disabilities must be considered by families and EI professionals. These etiologies provide insights into how the multiple disabilities intersect and help inform the drafting of a potential developmental trajectory (in holistic terms). This trajectory can provide both families and services with a structure from which to base expectations and support. Jones and Jones (2003:316) note that each instance is a unique context-dependent challenge – whereby piecing together an understanding of how the disabilities relate to one another must be considered within the context of the primary socialisation unit (typically the family).

Both Van Dijk et al. (2010) and Jones and Jones (2003:298) note children with multiple disabilities provide service providers with a ‘conundrum’. A highly specialised and individualized programme of support relying on a multidisciplinary team of professionals is required to undertake a process of identification, diagnosis, assessment and EI. In New Zealand a collaborative approach (typically across medical and educational sectors) is endorsed, however reaching a course of intervention on a potential developmental trajectory for a deaf child with multiple disabilities in this context is complex as professionals and families are likely to undertake an analysis from differing conceptual lenses to disabilities and children’s development as well as approaches to working with families (Alliston 2007). In New Zealand resourcing for supports are compartmentalized as either a health or education delegation. Consequently – a developmental need must be categorized as either a health or educational responsibility.

2.7. Signposting the principles of the Treaty of Waitangi in public policy to promote Māori development

In New Zealand, the macro-context for service provision and social outcomes for Māori people is framed by guiding principles about partnership between Māori and the state,

as formalised in the Treaty of Waitangi, signed between Māori and the British Crown on February 6th 1840. Initiated by the British Crown, who claimed an interest in the lands of New Zealand and exhibited concern over the potential impact of unmanaged colonization (since the late 1700's) on indigenous occupants Orange (1987:12), the British drafted the document with three broad objectives: the cessation of Māori sovereignty to the British Crown, for the British Crown to have absolute control over land matters and the equal application of a British legal system to both Māori and colonial occupants (Orange 1987). Māori however, have long debated that a poor translation of text from English to te reo Māori (where legal terms were poorly translated and not conceptually equivalent) have led to differing understandings of what was negotiated (E. T. J. Durie 1991). When and Hayward (2012:6) describe the Treaty as *“an essential ‘exchange’ between the partners” whereby the Crown:*

... ceded the right to establish civil government (‘kawanatanga’ in article 1) in exchange for guaranteeing to Māori the continued ‘chieftanship’ of their lands, estates, and treasures (‘rangatiratanga o ratou wenu, o ratou kainga, me o ratou taonga katoa’ in article 2). In article 3 of the treaty, Māori were given the rights and privileges of British subjects. Māori had, therefore, the same rights as settlers in addition to the continued right to exercise ‘chieftanship.’ Unlike the Crown’s treaties with other Indigenous peoples in other parts of the world, the Treaty of Waitangi did not extinguish, but rather guaranteed, the rights of Māori in addition to recognizing their place in settler society.

The Māori text clearly places differing parameters around the notion of cessation and has led to multiple interpretations and debates over the significance of the document. The Treaty of Waitangi is nevertheless acknowledged as the main mechanism which facilitated British colonization, implementation of British systems of governance, land tenure, law and social development (Orange 1987). After 1840 however, the Crown failed to uphold the nature of this agreement and post 1840 brought rapid British colonisation and a dramatic decline of the Māori population (Orange 1987). The burgeoning settler population led to tensions over access to and control of land (a primary economic resource), fuelling conflict between Māori and settler communities.

The consequences were long-term; displacement and/or alienation from tribal territories, the introduction of unknown diseases and the erosion of traditional social structures which promoted health and wellbeing – all of which compounded and led to a decline in the Māori population and an altered health profile (Lange 1999). Initially, Māori leaders and communities responded to this situation using various Māori-led initiatives (Lange 1999). In recent years, Māori scholars reflecting on the original intent of the Treaty of Waitangi have noted that it was drafted (in part) as a means of managing the potentially negative impacts of unmanaged colonisation, and obliges (a reference made by various Māori scholars based on interpretations of both English and Māori language versions of the document) the Crown to ensure Māori enjoy equity in all spheres of life including the same health and wellbeing profile as non-Māori (M Durie 2004:81-97).

Dismissed as inconsequential to legal issues by governments and judges for almost a century following its signing (E. T. J. Durie 1991) the Treaty of Waitangi is now recognised as New Zealand's founding document (Te Puni Kōkiri 2001) and is considered a primary platform from which Māori development can be framed (M Durie 2001). Operationalizing the intent of a Treaty which was composed in two languages, using conceptually disparate terms is complex. It is for this reason that the Waitangi Tribunal was established as an independent Commission of Inquiry in 1975 to consider and provide recommendations on Māori claims against the Crown, emphasising the 'principles' and 'spirit' of the Treaty as opposed to the actual text. In 1988 the Royal Commission on Social Policy Royal Commission on Social Policy (1988) also adopted this approach to clarify the application of the Treaty of Waitangi to health and social policy, based on three principles: partnership, protection, and participation. These guiding principles have directly informed the development of health, education and social policy and are an attempt to operationalize the intent of the Treaty of Waitangi in these areas of government service.

The Treaty of Waitangi bears mention in a number of key health and education policies directed at redressing inequities experienced by Māori and supporting Māori development. Mentioning The Treaty of Waitangi at the outset of policies and strategies invokes the context of the relationship between the Crown and Māori (as a partnership) and provides guidance on how the principles of partnership, protection

and participation can support Māori development. In the education sector, the Treaty is mentioned in numerous documents. Those perhaps most directly influencing Māori deaf children and their whānau include the early childhood curriculum for preschool children, *Te Whāriki: He Whāriki Mātauranga mō ngā Mokopuna o Aotearoa: Early Childhood Education*, (Ministry of Education 1996:3), and The Ministry of Education's *Special Education Specialist Service Standards*. Te Whāriki acknowledges that 'all children [in early childhood settings] should be given the opportunity to develop knowledge and an understanding of the cultural heritages of both partners to Te Tiriti o Waitangi' and suggests curriculum text and structure 'reflects this partnership'. The Ministry of Education's *Special Education Specialist Service Standards* was also developed using a process which 'reflects the principles partnership, participation and protection' (Ministry of Education 2006:6). Other high level policies and strategies influencing education sector more broadly (from primary to secondary education) include the Ministry of Education's *Ka Hikitia: Accelerating for Success. The Māori Education Strategy 2013–2017* (Ministry of Education 2013:14) and the New Zealand Curriculum (Ministry of Education 2007:3). Ka Hikitia asserts Māori success is a 'joint responsibility of the Crown (represented by the Ministry of Education and other education sector agencies/departments) and iwi, hapū and whānau' which hinges on the collaborative efforts between the sector and Māori. It is envisioned that whānau, hapū, iwi, Māori organisations and communities can "contribute to what and how Māori students learn, as well as working together to provide support for Māori students' learning". The New Zealand Curriculum (Ministry of Education 2007:3) also supports this approach and states "The New Zealand Curriculum ... will help schools give effect to the partnership that is at the core of our nation's founding document, Te Tiriti o Waitangi/The Treaty of Waitangi".

Mention of the principles of The Treaty of Waitangi within the health sector can be first found from the (New Zealand Public Health and Disability Act (NZPHDA) 91 2000) which provided the basis for a series of wide ranging health reforms which altered the structure of the health sector as well as how services were resourced (Tenbensel et al. 2011). Whether 'mainstream' health services best addressed the health needs of Māori was questioned in these reforms and the potential of 'positive discrimination' was examined as an approach to addressing health inequities for Māori and supporting Māori health development (Boulton et al. 2013). Consequently, a

number of key policies and strategies in the health sector now reference the principles of The Treaty of Waitangi. *He Korowai Oranga: the Māori health strategy* (Ministry of Health 2002:2) notes the Government is “committed to fulfilling the special relationship between iwi and the Crown under the Treaty of Waitangi. The principles of partnership, participation and protection (derived from the 1988 Royal Commission on Social Policy) will continue to underpin that relationship”. *Whaia Te Ao Marama: The Māori Disability Action Plan for Disability Support Services 2012 to 2017* (Ministry of Health 2012) also references the three principles: “Māori participation at all levels, partnership in service delivery, and protection and improvement of Māori wellbeing” (Ministry of Health 2012).

Finally, one of the most recent policy initiatives that aims to address inequities for Māori and to promote Māori wellbeing is the *Whānau Ora* policy (Taskforce on whānau centred initiatives 2010). Māori scholars have argued that Māori view health and human development in a holistic sense (M Durie 2004); addressing inequities and to promoting Māori development requires a move from compartmentalized service delivery (e.g. under either health or education sectors) to one which supports holistic development and wellbeing. It is from this basis (and the ongoing emphasis placed on the Treaty principles of partnership, protection and participation) that the policy of *Whānau Ora* can be contextualized (Taskforce on whānau centred initiatives 2010:6). *Whānau Ora*, which once referred to a long-term health goal, now refers to “a philosophy (which focuses on the health of the whole whānau, not just the health of the individual), a distinct model of practice (embracing the health and social service sectors), and an outcome of holistic wellbeing” (Boulton et al. 2013:24-25).

Specifically the policy outlines a series of *whānau outcome goal reproduced below*: (Taskforce on whānau centred initiatives 2010:22)

“Whānau are: self-managing, living healthy lifestyles, participating fully in society, confidently participating in te ao Māori [Māori world], economically secure and successfully involved in wealth creation, cohesive, resilient and nurturing. In order to facilitate these goals whānau-centred interventions should be characterised by six key operational elements: whānau-centred methodologies

shaped by the values, protocols and knowledge contained within te ao Māori, commitment across government, the establishment of an independent Trust with a dedicated government appropriation, a primary focus on best outcomes for whānau, through integrated and comprehensive delivery, strong regional direction, building on existing provider capabilities. A framework comprising seven principles that support the achievement of whānau ora (in philosophical terms) is introduced and can be seen to both inform and drive whānau-centred service delivery, they include: Ngā kaupapa tuku iho (the presence of Māori values, beliefs, obligations and responsibilities, to guide whānau in their day- to- day lives); Whānau opportunity (the chances in life that enable whānau to engage with their communities and foster whanaungatanga or connectedness); Best whānau outcomes (increases in capacities to undertake those functions that are necessary for healthy living and the wellbeing of whānau members); Coherent service delivery (the unification of interventions so distinctions between service sectors do not overshadow whānau needs); Whānau integrity (the acknowledgement of whānau accountability, innovation and dignity); Effective resourcing (that resourcing should be adequate to the size of the task and tied to results); and competent and innovative provision (recognising the need for skilled practitioners able to contribute to whānau empowerment and positive outcomes)’’.

2.8. Māori experiences of deafness and early intervention in New Zealand

Māori children are over-represented in early hearing-loss diagnostic figures. Māori comprise 24% of the New Zealand child population aged under 15 (Statistics New Zealand 2002)⁷ yet they comprised 34% of the 2012 deafness notifications (J. Digby et

⁷ The census results outlining the ethnic composition of the New Zealand child population from the 2013 census had yet to be compiled when this work was undertaken.

al. 2013). Māori over-representation in childhood hearing-loss has been noted for several decades (M Durie et al. 1989).

Research on deafness amongst Māori has described this in terms of health inequity, and explores ways to prevent factors leading to poor ear health (J. Digby et al. 2013; M Durie et al. 1989; Universal Newborn Hearing Screening Advisory Group 2006). While this approach has the potential to reduce Māori deafness statistics, there is little qualitative investigation of Māori-specific experiences of childhood hearing-loss or intervention beyond diagnosis. Internationally, studies of professional, parent, child and community perspectives on deafness and early intervention have included ethnic minority and indigenous groups within their samples. However, most of these studies' findings have also tended to identify experiences and responses to hearing-loss common to most deaf people without identifying or providing a context to those aspects which are unique to the ethnic minority or indigenous population (Bodner-Johnson and Sass-Lehrer 2003; Marschark et al. 2002; Sass-Lehrer and Bodner-Johnson 2003; Scott-Olson 2003; Walsh 2003; Yoshinaga-Itano 2003). The New Zealand literature follows a similar pattern. The experiences and perspectives of professional, parent, child, community and ethnic groups are noted as important, yet support services remain dominated by non-deaf and non-Māori providers (DEANZ 2003; HIEDI 2004; Ministry of Education 2003; Universal Newborn Hearing Screening Advisory Group 2006).

The introduction of universal newborn screening however, may provide an opportunity to address this issue. In an attempt to provide some perspective on Māori experiences of disability and early intervention, the Ministry of Education's recent review of best practice in early intervention (Douglas and Robinson 2006), has drawn on Jill Bevan-Brown's Māori-led research (J. Cullen and Bevan-Brown 2000) in its review of best practice in early intervention, which recommends that services:

- are 'whānau-based';
- include Māori workers;
- utilise culturally appropriate and relevant assessment measures;
- include resources developed by Māori for Māori;
- are based in Māori concepts of special needs;
- use culturally appropriate teaching strategies;

- include Māori content and practices;
- are supportive of Māori people and culture.

It could be argued that placing the family, or whānau in the case of Māori, as the central focus for early interventionists, complements Māori perspectives on child development and worldviews which value holistic and ecological realities (M Durie 1994; Edwards 1990; Haig 1997; Henare 1988; Pere 1991). This approach has been endorsed by Māori researchers working in the field of special education and early intervention (J. Cullen and Bevan-Brown 2000), case studies of whānau with disabled children (Bevan-Brown 1994, 2004; Tihi H. and Gerzon 1994; Timutimu-Thorpe 1994) and Māori Deaf adult's reflections of childhood (Smiler 2004). Douglas and Robinson (2006) nevertheless note lower levels of educational achievement, the small number of Māori staff working with whānau, poor access to trilingual interpreters (te reo Māori, NZSL and English), limited understanding of tikanga Māori and te reo Māori amongst non-Māori staff, lack of provision for Māori models of intervention, and limited links with Māori communities and organisations as evidence that Māori deaf children and their whānau are poorly served. This is consistent with Brown and Nott's (2006:139) suggestion that the notion of a family-centred intervention is 'elusive' because of the diverse responses to parenting across cultures. They argue that professionals must first gain an understanding of the family activities and routines as an avenue to knowing how to interact with the family and approach interactions with their child. M Durie, Fitzgerald, Kingi, McKinley, and Stevenson (2002) remind us that Māori life experiences are diverse and distinct from other population groups within New Zealand, and indigenous populations internationally. For the early intervention sector to deliver family-centred interventions, or whānau-centred intervention as it could be more aptly named in a Māori context, serious consideration needs to be paid to identifying and describing those specifically Māori ecologies that impact on whānau with Māori deaf children.

This chapter has reviewed literature on the impact of deafness for children, concepts and models underlying service provision, and introduced the macro-context for social policy aimed at improving outcomes for Māori in New Zealand. The next chapter describes the way in which the research was undertaken and the rationale behind using the tradition of raranga (traditional Māori weaving) to situate the research approach.

Chapter 3. Ngā kete matauranga: constructing knowledge

Hutia te rito o te harakeke

Kei whea te, Komāko e kō?

Ka rere ki uta, ka rere ki tai

Kī mai koe ki au,

he aha te mea nui i te ao?

Māku e kī atu

He tangata, he tangata, he tangata!

If you pluck out the centre shoot of the flax

Where will the bellbird sing?

It will fly inland, it will fly seawards

If you ask me,

What is the most important thing in the world?

I will reply

People, people, people!

3.1. Introduction/Overview

Raranga, the Māori art form of weaving and plaiting fibres from the harakeke (flax) plant, is an indigenous tradition through which generations of Māori women have expressed themselves in practical, intellectual, spiritual and creative ways. My approach to the research is influenced by this tradition. This chapter explains the theoretical framework and methodological approach to the research, using the practice of raranga as a metaphor for the research process. The first phase of this research was spent studying the literature on contrasting research paradigms and the history of their development, applications and impacts. This work paralleled another pursuit, which also challenged my practical, intellectual, spiritual and creative abilities; I was learning raranga from my partner's whānaunga (relative), Veranoa Puketapu-Hetet (Te Ati Awa, Tuwharetoa, and Ngāti Maniapoto) at a whānau studio at Waiwhetu Marae in Wellington. The late Erenora Puketapu-Hetet, (Veranoa's mother, who was a respected and accomplished weaver, teacher and revivalist of this art form) reminds us that "Māori weaving is full of symbolism and hidden meanings, embodied within the spiritual values and beliefs of the Māori people" (Puketapu-Hetet 1989: 41b). The metaphors of pā harakeke (the harakeke plantation) and raranga are well known amongst Māori: the metaphor of the tender, vulnerable young shoots central to the plant, protected and nourished by the embrace of the elders or outer leaves is commonly invoked in Māori oratory. The language used in the art form of raranga extends from this concept. These metaphors emphasise the interconnectedness of whānau members with one another, and with other whānau. It was this tradition which (unconsciously, at first) has given shape to my thinking about research paradigms and an approach appropriate to this study.

As an emerging researcher I could have simply adopted other researchers' rationalisations for a particular approach. I was however, drawn to several paradigms, methodologies and debates. When I referenced this information with my own self-knowledge (heightened through learning raranga), I was compelled to use aspects of other people's ideas, as opposed to accepting any in their entirety. This is perhaps not surprising. Guba and Lincoln (2008:256) who write on Gertz's (1988) prophecy of the 'blurring of genres' conclude that the various research paradigms are indeed

“beginning to ‘interbreed’”. Crotty describes the process an emergent researcher must undertake when attempting to settle on their approach to research:

Attending to recognised research designs and their various theoretical underpinnings exercises a formative influence upon us. It awakens us to the ways of research we could have never otherwise conceived. It makes us more aware of what is possible. Even so, it is by no means a matter of plucking a methodology off the shelf. We acquaint ourselves with the various methodologies. We evaluate their presuppositions. We weigh all their strengths and weaknesses. Having done all that and more besides, we still have to forge our own methodology that will meet our particular purposes in this research (Crotty 1998: 14).

Accordingly, this chapter describes the process of designing this study. The initial sections consider the relevance of epistemology, ontology and axiology. This begins with the contextual considerations as mapped in 3.2 *Theoretical considerations: the challenge of context*. Section 3.3 *Reweaving a research approach* outlines research paradigms as well as the rationale for framing the research within the worldview exercised in the tradition of raranga. The metaphor of a kete (a woven basket) – and the practical, intellectual, spiritual and creative process of constructing the kete – is used to frame a case study approach described in sections 3.4 *Raranga kete: a case study approach* and 3.5 *Whakawhanaungatanga: a kaupapa Māori approach to research relationships*. The final sections of this chapter are structured accordingly through a two stage process employed by weavers: (1) preparation of material in 3.6 *Te pā harakeke: sampling and sourcing*, 3.7 *Preparing whenu to weave with into kete: co-constructing data between researcher and participant*, 3.8: *co-constructing data with participants*; and (2) weaving material together to create an object in the section describing analysis – 3.9 *Raranga korero ā-waha, ā-tuhi, ā-tinana: data analysis*. Section 3.10 *Ethical considerations* outlines the ethical consideration undertaken as a part of the research process and section 3.11 *Research challenges: mediating relationships, responsibilities and expectations of the western academy and of indigenous and marginalized communities* canvasses the tensions experienced in trying to meet ethical expectations of both the western academic institution and of research

communities. Overarching the weaver's efforts is an unobserved, internal process whereby the weaver references herself to the material as a natural resource and to its original environment. This element is included in the description of the research process.

3.2. Theoretical considerations: the challenge of context

Settling upon an approach and methodology for this research was an iterative process of review and reflection. Silverman (2006:16-18) recommends that researchers generate a holistic approach to their research and adopt a historical, political and contextual sensitivity. The focal participants in this study, the whānau of Māori deaf tamariki (children), have diverse backgrounds and are positioned at an intersection of cultures. During early intervention in relation to their deaf child, Māori whānau need to reconcile their knowledge of Māori, D/deaf, medical, and educational worlds with information given to them by medical and educational professionals, using this to make decisions about various choices and how to tailor their parenting approach to their deaf child. It is also likely however, that many will have never had occasion to consider the paradigms and histories surrounding deaf and Māori people, nor how these inform the ways in which information is constructed and presented to them in the process of early intervention. Negotiating the intersection of Māori, deaf and special education worlds is challenging for families, as is undertaking research with people navigating this experience. As this research emphasises a collaborative relationship between researcher and participants, which potentially influences their ideas and course of action, it is necessary for the researcher to fully appreciate their context in designing the research.

3.2.1. Unpicking threads: the history of research about Māori and deaf people

Research concerning Māori and deaf people has been predominantly undertaken in the guise of positivist objectivity (Crotty 1998: 27) to justify a normative biological hierarchy and reinforce the status quo of the powerful and elite (Branson and Miller 2002; L. T. Smith 1999). Messages of inferiority have seeped into the collective subconscious over generations, endorsed by research, and framed as facts (Lane 1992; L. T. Smith 1999). Russell Bishop describes this process and its impact on Māori:

Researchers in Aotearoa/New Zealand have developed a tradition of research that has perpetuated colonial power imbalance, thereby undervaluing and belittling Māori knowledge and learning practices and processes in order to enhance those of the colonizers and the adherents of colonial paradigms. A social pathology research approach has developed in Aotearoa/New Zealand that has become implied in all phases of the research process: the “inability” of Māori culture to cope with human problems and propositions that Māori culture was and is inferior to that of the colonizers in human terms. Furthermore, such practices have perpetuated an ideology of cultural superiority that precludes the development of power-sharing processes and the legitimization of diverse cultural epistemologies and cosmologies (R. Bishop 2005: 110).

Historically, research on deaf people has been overwhelmingly informed by a medical, pathological paradigm of deafness. Research questions and findings have focused on the supposed audiological, educational, psychological, social, and linguistic deficits of deaf people and their communities (Lane 1992). In this tradition, deaf people were generally treated as objects of research – mainly about audition and speech deficits – rather than consulted as expert participants on their own experiences, shared culture, language, and history (Baker-Shenk and Kyle 1990; Ladd 2003: 65). Māori too have been objects of inquiry within the realm of ‘cross cultural research’ – “that is, when the researcher and the person or community who are the object of research are culturally different” (Spoonley 1999: 51). Scientific texts written about Māori during the initial colonisation period in New Zealand constructed Māori as a deviant ‘other’ (L. T. Smith 1999: 82). Te Awekotuku (1991: 5) asserts that “... their [the colonist researchers’] published works became standard texts through which Māori students of Māori [studies] more often than not had their history, their culture, their myths and their customary concepts fed back to them – after some questionable processing.” In a deaf context, it has been argued that ethnocentric research acts as a form of social control since the knowledge produced by this form of research has informed popular perceptions of deaf people (Lane 1992). A deaf scholar, (Ladd 2003: 13), claims that society is ‘brainwashed’ by the medical model of deafness, and as a result many people “cannot easily grasp that deaf are ‘dual category members’ – that is, that some of their

issues might relate to issues of non-hearing whilst others relate to language and culture.”

Both deaf and Māori communities have become suspicious of the motives of cross-cultural research, as evident in critical discourses in deaf and Māori studies (Baker-Shenk and Kyle 1990; R. Bishop 1996; Padden 1980; L. T. Smith 1999). The advent of deaf consciousness and Tino Rangatiratanga (Māori self-determination) movements has prompted the assertion of self-defined cultural and linguistic identity amongst Māori and deaf communities. This extends to research in which Māori and deaf⁸ people have sought to claim control of their knowledge and hence their destinies, through research that reflects their worldviews and is conducted by the people, of the people, for the people (Ladd 2003: 19; L. T. Smith 1999). Expressions such as Deaf-Way, Deaf-World (Lane et al. 1996), Deaf-Power (Jankowski 1997), Deafnicity (Eckert 2010) and Deafhood (Ladd 2003), Mana Motuhake (independence and autonomy) Tino Rangatiratanga (absolute sovereignty), and the reassertion of kaupapa Māori (a body of ancient knowledge accumulated by Māori people) (Pihama 2001; G.H. Smith 1997) evidence a paradigm shift.

The notion of Deafhood introduced by the British Deaf academic Paddy Ladd (Ladd 2003: 3) resists a scientific, pathological definition of deaf people’s identity and experience. Deafhood affirms the diversity of deaf people’s experiences as contributing to a collective understanding of what it means to be deaf; regardless of the degree of hearing loss, language or communication preference, their participation in a hearing society is compromised, and they are therefore culturally different. Ladd posits that the idea of Deafhood expresses the reality that each deaf person negotiates their social position and sense of identity in relation to hearing and deaf cultural contexts. He writes:

Deafhood is not, however, a ‘static’ medical condition like ‘deafness’. Instead, it represents a process – the struggle by each Deaf child, Deaf family, and Deaf adult to explain themselves and each other their own existence in this world. In sharing their lives with each other as a community, and enacting those explanations

⁸This refers mainly to deaf people overseas; as yet, deaf people in New Zealand remain under-represented in academia as a result of educational barriers.

rather than writing a book about them, Deaf people are engaged in a daily praxis, a continuing internal and external dialogue. This dialogue not only acknowledges that existence of a Deaf person is actually a process of becoming and maintaining 'Deaf', but also reflects different interpretations of Deafhood, of what being a Deaf person in a Deaf community might mean (Ladd 2003: 3).

Parallel discourses about identity exist in Māori communities. Colonial processes have impacted every facet of life, from food choices to language use. Our identity does not hinge on static markers – such as language or biology – and identifying Māori people based on such markers proves problematic. The late Irihapeti Ramsden (Ramsden 1993: 243) argued that while all the traditional markers of cultural identity should be upheld at all costs, young people's identity must also be situated and affirmed in their contemporary context.

The future of our people [Māori] cannot be stereotyped by our current view of Māori-ness. Major cultural markers such as the language of our ancestors, the marae and tangihanga must be retained at all costs, but, under pressure of changing time, many more adjustments are likely. These choices are for Māori to make, they are a matter of mana.... how each of us expresses our Māoritanga is the product of a variety of experiences. None of us is today what our ancestors were, and our descendants will not be like us. With aroha, knowledge, strength, commitment and politicisation our descendants will be Māori, their way ... Our work as today's version of Māori is the same as that of our tipuna: to continue our story, to strengthen it according to our times and to add to the next chapter. That will be done (Ramsden 1993:243).

There is a danger in ignoring the reality of research participants' historical contexts. Said (1978), cited in (L. T. Smith 2008: 113) reminds us how research has the potential to write our histories and identities: "... research can also be described as "a corporate institution" that has made statements about indigenous peoples 'authorising views' of us, 'describing [us] teaching about [us] and ruling over [us]". Without acknowledging the researched history of Māori and deaf people and participants' contemporary reality,

researchers risk repeating patterns of imposition, of corporatising versions of truths to serve unspoken agendas. Naming the epistemological foundations from which research springs enables a decolonising approach to this study.

Māori and deaf scholars have challenged researchers to commit to social-justice orientated research that commits to unveil inequity, oppression, and evidences a commitment to transformation or tangible change. At the 2010 International Leaders' Summit of Educators of the Deaf⁹, Dr Roslyn Rosen, Director for the National Center on Deafness at California State University, argued that those involved in deaf education “need to shift from a pathological view to a humanistic view. The reframing of ideologies allows us to pursue anything and everything for the child”. This research situates deaf children's experiences within their families in social, linguistic and cultural terms. It also acknowledges discourses of self-affirmation amongst Māori and deaf communities, expressed in terms such as Tino Rangatiratanga (M Durie 2001), Deaf Empowerment (Jankowski 1997), Deafhood (Ladd 2003) the social model of disability (Oliver 1996), and research paradigms stemming from these discourses such as kaupapa Māori (R. Bishop 2008b) or Māori-centred research (M Durie 2004), and deaf-centred approaches (Baker-Shenk and Kyle 1990). These paradigms advocate research that values these communities' ways of knowing and being, thus framing research within the realities of these communities.

3.3. Reweaving a research approach

Given the contextual considerations of the research aims and collective participant histories, this research draws upon several broad theoretical research paradigms: the constructivist paradigm, social constructionism, transformative paradigm, and Kaupapa Māori research. The following section outlines these paradigms and their influence on this research.

⁹ This was held on July 18th 2010 at the Center for Dialogue, Simon Fraser University in Vancouver, Canada. One hundred and twenty world leaders attended the Summit from thirty two countries. Information presented comes from my notes from debates and discussions.

3.3.1. **Research paradigms**

Patton (1980:37) writes that a research paradigm is a ‘worldview’, which provides a researcher with “a way of breaking down the complexity of the real world”. In this sense, the researcher is a key component in the research process, perhaps even the fundamental instrument, for it is via their ‘worldview’ or articulated research paradigm that the research is processed. Denzin and Lincoln (2000:22) compare the concept of a paradigm to a ‘net’ comprising the researcher’s assumptions with regard to four basic principles: axiology, epistemology, ontology, and methodology. Axiology (or ethics) requires the researcher to reveal their assumptions about how they will be a ‘moral or ethical person’ in the world. Epistemology is described as the philosophy of knowledge, where researchers ask themselves: “What is the nature of knowledge? How do I know the world? What is the relationship between the enquirer and the known?” (Denzin and Lincoln 2008:245) The principle of ontology challenges the researcher to question “the nature of reality and the nature of the human being in the world” (Denzin and Lincoln 2008:245). Finally, methodology is where the researcher “focuses on the best means for acquiring knowledge about the world” (Denzin and Lincoln 2008: 245); methodology, then, is the strategy, design, or plan of action by which the research questions are investigated, whereas the method is the procedure and techniques used to gather and analyse data (Crotty 1998: 3).

Social scientists have long debated two principal paradigms of inquiry: logical positivism, and phenomenological inquiry (Patton 1990: 37). Positivism is closely associated with the notion of objectivity, and maintains that knowledge is not arrived at by speculation or abstract reasoning, but rather, is grounded firmly in something that is posited (Crotty 1998: 20). Positivism emphasises the direct experience of scientific observation, and has a close relationship with quantitative, empirical research methods.

Phenomenological inquiry, on the other hand, emphasises the subjective nature of human experience, and views research as a value bounded process. This approach primarily uses qualitative and naturalistic approaches to inductively and holistically understand human experience in real world settings (Patton 2002: 39). This approach entails an intimacy between the researcher and the researched; the researcher is a prime instrument in the research process and must work closely with the researched in order to gain insight into the context of their reality, as Flick writes:

Qualitative research is a situated activity that locates the observer in the world. It consists of a set of interpretive material practices that make the world visible. These practices transform the world into a series of representations including field notes, interviews, conversations, photographs, recordings and memos to the self. This means qualitative researchers study things in their natural setting, attempting to make sense of, or interpret, phenomena in terms of the meanings people bring to them (Flick 2002: 227).

Researchers often assume that the positivist inquiry paradigm and quantitative methods are synonymous, as are phenomenological inquiry and qualitative methods. Crotty (1998: 41) argues, however, that this is misleading and that the way in which findings are interpreted and presented is more indicative of a paradigm.

Lincoln and Guba (2000: 165-66) describe four major interpretive inquiry paradigms in social science: positivism, post positivism, constructivism and participatory action frameworks. They note that a series of perspectives, feminism (in its various forms), ethical race theory, queer theory and cultural studies, sit alongside these paradigms. Patton distinguishes between a paradigm and perspective thus:

... paradigms deal with first principles or ultimates – they are human constructions. They define the worldview of the researcher as interpretive-bricoleur. These beliefs can never be established in terms of their ultimate truthfulness. Perspectives, in contrast are not solidified, nor as well unified, as paradigms, although a perspective may share many elements with a paradigm – for example, a common set of methodological assumptions or a particular epistemology (Patton 1990: 37).

3.3.2. Paradigms influencing this research

According to Denzin and Lincoln (2005: 24) the constructivist paradigm assumes a relativist ontology (there are multiple realities); a subjectivist epistemology (knower and respondent co-create understandings); and a naturalistic (in the natural world) set of methodological procedures are employed. Findings are “usually presented in terms

of the criteria of grounded theory or pattern theory, terms such as credibility, transferability, dependability and conformability replace the usual positivist criteria of external validity, reliability and objectivity”.

Social constructionism also makes the ontological assumption that reality is socially constructed by people active in the research process, and that it is the researcher’s role to contextualise the multiple constructions of meaning and knowledge (Burr 2003). Crotty (1998) explains that a key difference between constructivism and social constructionism is that the latter entails social critique that the constructivist paradigm constrains;

Constructivism ... points to the unique experience in all of us, it suggests that each one’s way of making sense of the world is valid and worthy of respect as any other, thereby tending to scotch any hint of critical spirit. On the other hand social constructionism emphasizes the hold our culture has on us: it shapes the way which we see things (even the way we feel things) and gives us a definite view of the world (...) there are social constructionists aplenty who recognize that it is limiting as well as liberating and warn that while welcome; it must also be called into question. On these terms, it can be said that constructivism tends to resist critical spirit, while constructionism tends to foster it (Crotty 1998: 58).

The transformative paradigm extends the premise that reality is socially constructed, including the processes by which certain individuals and groups maintain positions of power and privilege. The ontological assumption of this paradigm questions: How is social reality defined? By whom? Whose reality is given privilege? What are the social injustice implications of accepting that reality that has not been subjected to a critical analysis on the basis of power differential? Mertens (2007: 216) prioritises the axiological assumption of the transformative paradigm, which insists that research must demonstrate respect, beneficence and justice. Emphasis is placed on developing and maintaining respectful working relationships with communities. Beneficence is defined in terms of the promotion of human rights and increase in social justice. The epistemological stance of the transformative paradigm posits that knowledge is socially and historically located in a complex cultural context and that the methodology must

demonstrate an active relationship between the researcher and participants in generating this knowledge. Questions should emerge from a consultative process between the two. Methods must be cognizant of cultural complexity and power relations, and issues of discrimination and oppression recognised.

Significantly, Mertens' description of the transformative paradigm draws heavily on her experience as a Professor at Gallaudet University, an American university for deaf and hard-of-hearing students, and on Māori scholars' accounts of a kaupapa Māori approach (Mertens 2007).

Since the colonial period, Māori have actively resisted the process of colonisation by employing multiple strategies to engage with it and the effects of social inequity. One contemporary conceptual strategy – kaupapa Māori – has its genesis in a collective struggle for Māori-controlled, Māori language-medium schooling. The kaupapa Māori approach to education is a proactive, resiliency focused response to an education system, which was actively used as a colonising agent for over a century and failed generations of Māori children (G.H. Smith 1997). The kaupapa Māori response to education acted as an intervention that simultaneously stimulated a renaissance of te reo Māori and tikanga Māori while normalising and affirming the younger generation's experience of 'being Māori' in a modern context. Since the conceptualising of a kaupapa Māori approach to education (G.H. Smith 1997), a number of Māori scholars have also contributed to and helped develop the theory and its principles of kaupapa Māori and appropriated these within the realm of research (R. Bishop 2005; Pihama 2001; Pohatu 2003; L. T. Smith 1999). As the theorising evolves, one point made by Smith (G.H. Smith 1997: 65) centres this theorising activity of kaupapa Māori, that is: "The transformative praxis of kaupapa Māori as an intervention strategy, in the western theoretical sense, critiques and re-constitutes the resistance notions of conscientisation, resistance and transformative praxis in different configurations". As a Māori researcher, I interpret this to imply that the locus of control regarding research about Māori should be placed in Māori hands, minds and hearts. Pihama, Cram and Walker 2002: 33) affirm this transformative intent of a kaupapa Māori approach:

Kaupapa Māori theory has had the dual effect of both providing the theoretical 'space' to support the academic writing of Māori

scholars and to be the subject of critical interrogation, analysis and application (Pihama et al. 2002: 33).

Despite agreement on the transformative principle of kaupapa Māori research, it is perhaps not surprising that there is little consensus on defining what the approach entails. Analogous to feminist approaches to research, where Crotty (1998) observes that there are ‘many feminisms’, any approach requires a researcher to draw upon their own worldview. Māori are as diverse as any another group of people, and cannot and should not, be expected to reduce their reality to a homogenous definition or description of experience. We can say however, that kaupapa Māori research encapsulates Māori worldviews, affirms Māori knowledge and ways of knowing, privileges Māori processes of developing and maintaining relationships with community, is guided by the axiology (tikanga or ethics) of Māori communities, and insists on those communities contributing to determining the ‘validity’ or trustworthiness of the data and findings.

3.4. Raranga kete: a case study approach

Writing on the transformative potential that indigenous-led research can have, L.T. Smith (2008: 119), notes that if we take the lead from indigenous researchers and their communities, we will find new conceptual ways of thinking, and learning. She notes the stories of indigenous peoples are rich with metaphors and can act as motivational drivers that “inspire a transformative praxis that many indigenous researchers identify as a powerful agent for resistance and change”. Framing the approach to this research through the metaphor of raranga positions the research in a transformative paradigm, using Māori imagery to describe process and method, in language that encompasses indigenous and Western theory, academics and non-academics.

In 2002, I began a research journey by undertaking my Master’s thesis on social and linguistic identity of Māori members of the New Zealand Deaf community. That same year I also started to learn raranga. In the beginning, these were two separate activities: I researched, read, and wrote during the week, prepared harakeke during the evenings, and in the weekends, went to a whānau studio at Waiwhetu Marae to weave with a small group of women. We pottered around the studio all weekend, learning various techniques: finding and preparing harakeke to weave, and learning the technical skills

to weave material together. Our pottering was occasionally guided by small comments, glances or subtle cues from body language in reaction to our activity, from our teacher Veranoa Puketapu-Hetet, and occasionally her mother, Erenora Puketapu-Hetet, ('Aunty El'), pointing out something we should notice, and often relating it to a philosophical observation about life and whānau. Sometimes, our activity was interrupted by a quiet epiphany, achieved after toiling several hours trying to achieve a particular skill. Often the epiphany had a parallel message that related to life as well as to the skill achieved. While weaving, our spirits, intellect, endurance and patience were often tested and shared with one another. The weaving terms and techniques we learned during our work were doorways to teachings about our interconnectedness to all life, and to how nature can provide us with insights and metaphors by which we live.

During this initial creative journey, I was attempting to familiarise myself with academic literature on research methodology; it was through relating this literature to the practice of weaving that it made sense to me. Becoming a weaver gave me an analogy for the role of the weaver/researcher as a creator, collaborator, student and self-reflective investigator who has a relationship with the medium in which she works. Although I did not articulate my research practice in those terms at the time, in hindsight that is how I intuitively conceived it in my mind, heart and hands (in action). It is for this reason I have chosen to couch my methodology in relation to the metaphor of raranga, as observed and interpreted by me.

3.4.1. Case study research: description from the Western academy

According to Stake (2008) a case study is not a methodological choice, but a choice of what is to be studied – what we choose to put a boundary around and call a case. Stake (2005) identifies three types of case study approaches: intrinsic, where the intrinsic interest is in the case itself; instrumental, where a case is chosen to explore an issue or research question determined on some other ground in order to gain insight into something else; and a collective or multiple case study, which is an instrumental case study extended to several cases. Stake (2005: 443-46) suggests this approach utilises the several cases to “gain a better insight, and perhaps better theorizing about a larger

collection of cases”. This research includes various methods of investigation all of which feed into a collective case study.

3.4.2. He kete korero, he kete wānanga, he kete ako: the contextual case

The case can be likened to a kete. Every kete, whether plain and simple or detailed and intricate in construction, has some story underlying its production and its appearance. Weavers, as a matter of practice, often study kete of others as well as our own, for what they can teach us: perhaps we could explore how to weave with a new medium using traditional methods, explore the qualities of particular type of tension, uncover the algorithm behind a complicated pattern, delight in the effect of colour and how it was obtained, or ponder an abstract concept communicated through the pattern, form, tension, colour or material. Each kete studied provides new detail for reflection, consideration and sometimes example. We examine whenu (strands) for their physical quality (width, strength, colour), the overall shape of the construction, the tension and skill with which it was woven. We smile at errors in pattern, acknowledging the uniqueness of the kete and the humanity and humility of the weaver. We almost always ask, “does it fit an intended purpose?” For example, it hardly seems sensible to weave a kete whakairo (intricately woven kete with a detailed pattern) to carry potatoes (as it would not support the weight of the object well and the detail in the design is easily ruined). Through the process of examining others’ kete we learn about context, that is, we may question the weaver about their raranga process in order to build our knowledge of context; we also may use knowledge gained from others’ weaving to enact new knowledge, or to provide an example from which we reinforce or practice specific skills.

This process is not unlike the description provided by case study literature from the Western academy. The process and skills required are similar but, the material is different. Instead of weaving harakeke, the case study researcher is weaving people and perspectives, and in this situation using qualitative techniques such as kōrero-ā-waha (talking), kōrero-ā-tuhi (writing), kōrero-ā-tinana (body language), wānanga (learning together), hui (meeting together), and whakawhanaungatanga (creating relationships).

Through the particular and contextual-rich description of the case we arrive to an understanding of the universal – this is a paradox and strength identified by various scholars (Simons 2009; Stake 2008; Yin 2002). Flyvbjerg (2011: 302-03) contends that although case study is perhaps one of the oldest research methods evident across all disciplines, it is still held in “low regard, or simply ignored, as a methodology across the academy”. This is a concern for myself. Literature on early intervention for deaf children shows that much research centres on providing a quantitative evidence base about concerns such as, language learning, parental bonding, and normative measurement of educational success in comparison to non-deaf and hearing-impaired peers. In a sense, the focus on quantitative evidence stems from the political context underpinning the sector; those resourcing initiatives to support early intervention initiatives (either through government or philanthropical resources) prefer to do so based on quantitative evidence, believing that such evidence verifies the validity of need. Flyvbjerg however, emphasises that case study knowledge (including case studies drawing from solely qualitative methods) should not be discredited, as he concludes that all ‘experts’ operate on “intimate knowledge of several thousand concrete cases” and that “context-dependent knowledge and experience are at the very heart of expert activity” (Flyvbjerg 2011: 303). This is the practice of weavers; we study many individual kete in order to develop our expertise. Kete kōrero, kete wānanga, kete ako: a kete speaks a thousand words, and effectively operates as a contextual instrument of learning and teaching.

3.4.3. Defining the boundary of the case: What to weave and why?

Simons (2009: 23) summarises the various strengths of a case study approach, and considers the factors to consider when determining the boundaries of the case in relation to given research questions. Simons concludes that case studies allow for the complexity of programmes and policies to be studied in depth within the context within which they are enacted; allows for the documentation of perspectives and the exploration of contested view points; and can demonstrate the influence of key actors and interactions between them in telling the story of a policy or programme in action.

Given the dearth of research regarding Māori deaf and hearing-impaired children and their interaction with family and the education system, a case study approach provides a close view of these realities, which may inform further research. This study seeks to gain insight into how whānau think about ‘deafness’ in their child and what informs that perception; to gain insight into whānau experiences of early intervention services; and to explore whether those services and support systems require adaptation in order to become more effective for Māori. Underlying these research questions is the knowledge that while services articulate a ‘family-centred’ model of intervention, the contextual realities that would inform this approach in relation to educational or medical interventions for Māori deaf children are not well documented or articulated. Taking a collective case study approach, the participating whānau, as the natural unit of study, will form multiple intrinsic cases from which the research questions may be answered and theorised. As described in the literature review, a close relationship exists between family¹⁰ responses to their child’s deafness, societal attitudes to deafness, and the types of support services offered to deaf children and their families. By exploring the cases of specific whānau experiencing early intervention services, it is hoped this research will illuminate some of the common contextual issues for this population in the early intervention sector.

3.5. Whakawhanaungatanga: a kaupapa Māori approach to research relationships

Fiona Cram (1999: 35) writes about the internal dialogue that occurs within Māori researchers who grapple with what it means to be an ethical researcher. She notes that she is guided by what she “knows is right, with that knowing coming from many sources”, including her relations and research colleagues, and with overlap between these two communities. The notion of ‘tika’ or ‘ethicalness’ introduced to Cram by Moana Jackson also guides my research processes. Whakawhanaungatanga expresses an implicit value found in Māori and deaf communities of developing and maintaining relationships within relevant social networks (Lane et al. 1996; L. T. Smith 1999). As a member of these communities, I too, by virtue of socialisation, ascribe to this value.

¹⁰ The use of family in this context is reflective of the fact that whānau-based research has not been undertaken, and thus to date all literature discusses early intervention in terms of the family as opposed to the whānau.

Bishop (2008b: 157-58) writes on whakawhanaungatanga as a kaupapa Māori research approach, as follows:

Whakawhanaungatanga is the process of establishing whānau (extended family) relationships, literally by means of identifying, through culturally appropriate means, your bodily linkage, your engagement, your connectedness, and, therefore an unspoken but implicit commitment to other people. ... Establishing and maintaining whānau relationships, which can either be literal or metaphoric within the discursive process that is Kaupapa Māori, is an integral and ongoing constitutive element of a Kaupapa Māori approach to research. Establishing a research group as if it was an extended family is one form of embodying the process of whakawhanaungatanga as a research strategy.

It is within the context of whānau – bound by whakapapa (ancestry) or by kaupapa (shared affiliation or agenda) – that a researcher may seek guidance from kaumātua and kuia. Cram (1999: 43) writes that kaumātua – kuia and koroua (female and male elders) – are an essential component to research: “they know how people are connected together through whakapapa, and they advise on the proper Māori processes in other situations. Kaumātua are the receptacles of mātauranga Māori [Māori knowledge] and are kaitiaki [guardians/receptacles] of te reo Māori me ona tikanga [Māori language and customs]”. Kaumātua advise us on how to proceed ethically in communities. This principle can also be applied to deaf people and their communities. Older members with insight into the life span and values of deaf people are able to provide guidance on how to proceed ethically, and are well networked; they understand the history of networks on an institutional level as well as a community level. They too are the repositories of knowledge about social norms and customs, and draw from the lived experience of being a deaf person in hearing families and society. The construct of whānau has transformative potential. It is within this relational context that intergenerational groups are able to support one another to enact transformative changes at personal and collective levels.

3.5.1. **Aro Hā Mamaku**

At the outset of this research process I sought to develop relationships with relevant communities before attempting to identify specific research participants. I had established relationships within the adult deaf community (founded on my childhood experiences in the deaf community, and with Māori deaf community leaders), and with parents and whānau with deaf and hearing impaired children (a mixture of deaf and hearing parents – Māori and non-Māori). These people initially supported me through the process of identifying a research agenda and questions, and in applying for ethical approval from the Health and Disability Multi-regional Ethics Committee (see Appendix F). However, I felt uneasy with the fact that I had not identified a collective of Māori whānau with deaf children. There were a small number of Māori parents involved in the national advocacy organisation, the New Zealand Federation of deaf children (NZFDC). I asked myself whether I was networked with the wrong group of people. I also had to question my assumption that Māori whānau of deaf and hearing-impaired children would be, or would even want to be, networked in some way. This was an impasse that I was unable to move past for quite some time in forging working relationships with the relevant communities of interest, and planning data collection.

When an invitation was (indirectly) received for interested parties to attend an event for Māori families of deaf children at Te Papa o te Aroha Marae in Tokoroa in 2010. I was both excited and relieved. *Aro Hā Mamaku: Whakawhanaungatanga Hui 2010* was the first event of its kind, the initiative of a Māori parent, Charlotte Cassidy who had four children, two of whom are deaf/hearing-impaired. Charlotte's vision was to have deaf/hearing impaired Māori children playing together around the marae, while whānau collaborated and strategised a pathway for a better future. Speakers from professional services were invited to speak on their services, and workshop sessions with themes such as: "Identifying issues and priorities for whānau with hearing-impaired children"; and "building our power: diverse experiences in the community". An agenda of whakawhanaungatanga was set. The nature of the hui is described below, as it was an important milestone in the research process for this study.

My initial intention was to attend the hui to make my face seen and known (kanohi kitea), amongst whānau, but the experience of attending Aro Hā Mamaku challenged me on how to proceed. A strong contingent of professionals and whānau with deaf

children were invited, and after initial contact with Charlotte (who had limited networks with deaf adults) the invitation was extended to include Māori deaf adults in an effort to make a connection with this community of interest.

In spite of the statistical profile of high numbers of Māori deaf children, only a small number of local whānau attended the hui. Attendees, including myself, undertook a process of wānanga, (collaborative debate and discussion over identified kaupapa /themes) with the intention of summarising our conclusions to present on the final day of the hui to the Hon. Tariana Turia, co-leader of the Māori (political) Party, and then Minister of Disability Issues. In the presentation to the Minister, Charlotte Cassidy explained that the name for the hui, *Aro Hā Mamaku*, references the mamaku, (also known as the black ponga or tree fern). The mamaku is endemic in New Zealand, growing twenty metres high with leaves two to three metres long. Standing beneath the mamaku one feels as if one is standing under a large umbrella, a protective shelter under which younger life can thrive. Charlotte Cassidy used this imagery to conceptualise the connectedness of attendees with one another, forming an intergenerational 'kaupapa whānau' with transformative potential. The plea for improved services was put to Tariana Turia, who emotively endorsed the struggle of whānau, yet was unable to provide examples of the Government's concrete support to enact improvements. After the Minister left, participants suggested the establishment of on-going annual hui. This has yet to eventuate, no doubt due to a lack of resources.

Over the years I have observed parents active in advocacy for deaf children. Many become battle-weary from responding to changing health and education policies and strategising action to gain resources and improved access to education and the community for their children. As their children grow older, they often quietly exit advocacy roles and newer parents replace them, losing the collective knowledge of previous struggles. Newer parents and whānau contend with issues specific to the generation of their child such as policies, funding formulas, and political dynamics of the day. As newer parents enter the advocacy journey, they often do so with little intergenerational wisdom from other families, and are usually un-informed by the deaf community's own history, causing them to tackle issues reactively rather than in a visionary and proactive way. It is hardly surprising that a collective has yet to be

formed for Māori whānau with deaf tamariki. Other than the one-off hui in 2010, I have yet to hear of a consumer forum focused on Māori whānau with deaf children.

From the Aro Hā Mamaku hui, I was able to move past the impasse of assuming that I should find an established collective representing the ‘participant community’ with whom to consult. From this experience I summarised a series of points from which I could work: (1) At the point of this research there was no collective bound by the common kaupapa of supporting Māori whānau with deaf and hearing-impaired Tamariki; (2) There is interest amongst whānau with deaf and hearing impaired tamariki to engage in whakawhanaungatanga: It is a concept they are familiar with, having seen it modelled elsewhere (for example, in kōhanga reo, kura kaupapa and whare kura, that is, Māori-medium education initiatives); (3) whānau are dispersed by geography, a lack of knowledge of one another, and by the false belief that the choice of communication modality for their child– i.e. sign language or spoken language – categorises them and determines which groups and individuals are relevant to associate with. This is a division promulgated by some professionals and supported by a wider societal impression that languages exist in a hierarchy, whereby sign language is less desirable than speech.

3.6. Te pā harakeke: sampling and sourcing participants

Considering Māori deaf children and their tamariki are born and raised in the context of whānau, and early intervention services engage with families in service delivery, the context of whānau is the natural unit for analysis. Stake (2008: 30) suggests that while researchers in many research traditions seek representativeness in their sampling, case study researchers should choose cases that exhibit some typicality, yet also provide an opportunity to learn. Stake argues that at times the opportunity to learn is a more important criterion than representativeness.

The process of choosing cases (whānau) for this research is compared to the process a weaver will undertake when selecting a harakeke plant to cut rau from which to prepare whenu (strands of flax, sized into sections and softened accordingly) that will form the kete (the case). A weaver considers several factors when choosing a harakeke plant:

the environmental conditions the plant endures, the individual quality of the plant (for example, its colour or strength), and the weather conditions in which it was cut, all of which potentially affect the final appearance of the kete. Some are chosen for their unusual or unique qualities, others for their more typical characteristics. I have undertaken a similar approach in this research, and regarded each whānau as if they were an individual harakeke plant; all were sought because of their particular qualities. Woven together with the strands (whenu) from other plants (whānau), they tell a collective story that provides an opportunity to learn. Five whānau with pre-school deaf children form the collective case.

In selecting cases for the study, diversity in the following key characteristics of the wider population of Māori deaf children was sought with the view this would provide an opportunity to learn:

- Location – the sample included participants from:
 - rural, urban and provincial locations;
 - locations which have high and low concentrations of Māori and deaf populations; and
 - locations which offer high and low levels of early intervention support.
- child with/without cochlear implants or a child with/without hearing aids;
- a child who used either NZSL, home signs, English, or te reo Māori;
- deaf child with an additional disability.

Whānau selected also varied in terms of educational status, whānau structure and types of social networks. The following table outlines a basic profile of whānau participants and their deaf child/ren according to this criterion.

Table 2: Profile of whānau participants

Whānau	Location	Cochlear implant and/or hearing aids	Degree of hearing loss	Language	Additional disabilities	Family history of deafness
1.	Provincial/Urban Invercargill	Unilateral cochlear implant	Severe to profound bilateral hearing loss	NZSL Home signs Spoken English		No
2.	Rural/provincial Waiouru	Unilateral cochlear implant and hearing aid	Severe to profound hearing loss in left ear and profound in the right	Home signs Spoken English (emerging)		Yes: maternal great aunt
3.	Provincial Wairarapa	Hearing aids	Mild bilateral hearing loss	English Te Reo Māori		Yes: biological mother, maternal uncle, three first cousins (maternal).
4.	Urban Auckland	Bilateral implant (non-responsive)	Profound hearing loss	Picture Exchange System (PECS) Makaton Small number of NZSL signs	Undiagnosed: suspected brain damage due to Meningitis C: Described by diagnostic professionals as displaying Autistic-like traits, or possibly having global developmental delay.	Yes: great uncle (paternal) and mother's first cousin.
5.	Rural/provincial Hawkes Bay	Hearing aids	Moderate to severe	NZSL English Te Reo Māori		Yes: relationship unknown – extended whānau members.

To source their working material, weavers keep an eye out for environments and places where harakeke plants with various qualities tend to grow, and exchange this information within their networks. A similar approach was used for this research. At the beginning of the research process I interviewed several key informants who worked in early intervention, some of whom who had knowledge of numerous Māori whānau, and helped to identify potential case study participants. Three whānau were quickly identified in this way. The other ‘method’ used was ‘keeping a watchful eye out’, which although not particularly scientific, was effective in identifying whānau who proved to be appropriate research participants. In one case, I had just interviewed a professional informant and was waiting for a flight at an airport when a Māori mother sat in front of me with her two children, an infant and a four-year-old child with a cochlear implant. I approached her and introduced myself and the research. I cautiously waded through a ‘first encounter’, exchanged contact information, and began to build a relationship from there. Contact followed through phone conversations, e-mails and text messages, and a process of ‘checking-one-another-out’ ensued. The whānau ended up agreeing to participate. Another whānau with a deaf child were introduced to me at a party in a rural town, and also eventually agreed to participate in the study.

The decision to approach whānau and request their participation was never taken lightly. Characteristics of the whānau identified by professional informants were carefully discussed prior to making contact. In some instances I decided against contacting whānau who did not quite fit the parameters of the study; for example, the deaf child was already of school age, or the whānau was already over-researched. The professionals who suggested suitable families for this research also brokered initial contact and introductions. When whānau indicated willingness to speak to me, I contacted them and arranged a visit to introduce myself and the research.

3.6.1. First encounters with research participants

The data collection process began with a phone call and an initial introductory visit. Each whānau responded to this process differently. Phone calls were often brief and focused on scheduling a time for an introductory visit. Here, the purpose was outlined by way of an introduction to myself, the research aims, and a description of what to expect in terms of participation. In some cases, I travelled some distance for a brief introductory visit, then returned home and waited for their response. In all cases they agreed to participate.

Two whānau undertook this introductory process primarily via phone, email and text. One of the mothers I had already met in person at an airport, however, I did not meet the other mother until my first visit to interview. Interestingly, these were the younger mothers in the research, and seemed more comfortable using technology as a medium for communication. I was conscious that these mothers had not yet had an opportunity to consider fully what it meant to be involved in the study – that is, research in which they would be a part of a small sample and which required an intense period of participation. Consequently, when I traveled to meet these whānau in person, I tried to treat the visit as an introductory meeting. They were however satisfied with the introduction and keen to proceed with a semi-formal interview on the same day. In one whānau, grandparents were the primary guardians of the children, and thus I was conscious of following the conventions of that generation. We arranged a meeting time over the phone, and I traveled to their home for an introductory visit. I took some food for morning tea, and over morning tea I introduced myself and the research. I was not surprised when much of the conversation focused on identifying family and personal links to one another. I left them with the instruction that they could let me know if they were interested. They were, and we scheduled another visit the following week. I used the same process with another whānau, and a similar experience ensued, except that in one case, when I was expecting to leave and wait for them to get back to me, they decided that I should stay and begin a formal interview immediately.

The final whānau recruited for this research was found by ‘fluke’ at a party in a rural town. I was introduced to the mother of a deaf child by her relative. I spent time with this mother, her children, parents, cousins, aunties and uncles over the weekend of the birthday party. They were curious about my interaction with their deaf child, questioning my interest in him. I tried to explain myself ‘in layers’, worried that they would have no reference point, or a negative reference point for the world of research. First I explained that my interest came from my personal experience of having a deaf mother, I then explained that I was doing some research in the area of early intervention. Questions flowed through the weekend. When I asked the mother if she would like to participate in the research, I sensed both interest and hesitation, and decided to leave it. After a series of conversations with other whānau members however, she decided she would agree to me coming to stay and ‘hang-out’ with her whānau. My first visit to this whānau began with visits with the aunties, uncles and grandparents of the deaf child, and eventually, the mother and father of the child. They were apparently still unsure about participating. I visited their home and they interviewed me. I started the process by identifying

their concerns, and asked them if they wanted to ask me some questions. They asked how participation in the research would benefit their child. I felt the question was fair and sensible. I myself would have asked the same question. I spent half an hour talking about the role of research, the design of this research, the transformative intent of the research, as well as the emphasis on whakawhanaungatanga. I also explained the control they would have in terms of process: that they could withdraw their information and exit from the research at any stage for any reason. They agreed to take part. The benefit of participation in the research as perceived by the whānau of this child is later described in *Chapter 10. Starr*. In this description the participants suggest the research process heightened their awareness of the experience of deafness (as perceived by a deaf child) supported the process of construction understandings of the child's behavior, language and development. These constructions provided a platform from which relevance of support services for their child were critically (as opposed to passively received) explored.

3.7. Preparing whenu to weave into kete: co-constructing data between researcher and whānau participants

Once the outer rau are cut from the harakeke plant, a weaver constructing a kete undertakes a laborious task of preparing whenu. The process begins with stripping the rau – sizing whenu, trimming off parts that are damaged or unweavable, and softening them using a method called hapine. A weaver must carefully consider her objectives when preparing whenu, she is purposive in the way she prepares whenu; she maintains the vision of what her kete is going to look like, but must be resigned to the fact that the rau will not always comply – some whenu will not turn out as expected. Either way, she must consider how she will weave those whenu she has prepared to achieve the kete she planned.

In my mind, the process of data-collection is like these steps of making a kete. Weavers may work on the preparation phase alone or alongside others. The data for this study was generated with participants, using qualitative, contextualised methods including kōrero-ā-waha (recording spoken interviews and conversations – formal and informal) kōrero-ā- ringa (signed conversations – formal and informal), kōrero-ā-tinana (observations of one another's body language), kōrero-ā-tuhi (written medical and educational documents, and personal written anecdotes from whānau), hui (gathering and meeting of whānau involved in the research), and wānanga (collaborative debate and discussion over identified kaupapa /themes).

In encounters between people, we are ultimately presenting ‘constructions’ of ourselves through forms of language and action. These are sources of qualitative data. Saratakos (1993) writes of the strength of a qualitative approach, in allowing for research to occur in natural settings, whereby participants are able to explore and frame their world as they wish to construct it. A qualitative approach stresses interpretations and meaning, and has the potential to raise the role of the researched. Influenced by the paradigms of social constructionism, and transformative and kaupapa Māori research, data in this study was considered to be constructed collaboratively between researcher and participants, within the embracing ethic of whakawhanaungatanga.

When planning data collection, I initially intended to undertake three semi-structured interviews (see Appendix C) during a series of three visits. However, I was required to reexamine my approach during the moment of data collection. I found that although my questions were sensible (we began initial meetings using the semistructured interview schedule), whānau members did not always organize responses according to this linear structure. Rather, whānau participants prioritized establishing a respectful relationship: once trust and respect was established, they preferred to narrate and construct their stories with reference to the wider research objectives with as little interruption as possible. It was my role to engage as an active listener, listening for threads which related to the research objectives. The setting for our meetings varied. Often discussions took place over a cup of tea at dining room tables, or lounge areas in homes. However, the needs of children also had to be accounted for and ‘sitting about home talking’ was difficult to manage at times with young children requiring attention during play. Thus the practical needs of children had to be accounted for and many discussions took place during scheduled and impromptu outings with children in tow, for example, at McDonalds, or while playing at Lollipop Land (an indoor children’s play area).

The unintended consequence of this was that the constructed narratives of adult whānau members tended to include spontaneous commentary of the children’s activity which was woven into their narrations on the research objectives. These observations (and later reflection of) formed an important data set and were included (with participant permission) as a part of the research process. The observation of this kōrero-ā-tinana occurred throughout the data collection process and was not quantitative, behaviours were neither itemized nor examined in terms of frequency or presentation of; rather, they provided contextual insights into the

contextual social and linguistic dynamics of the whānau. A. B. Smith and Ballard (2004) writes that this type of naturalistic observation is subjective and aims to “get to the essence of the material, rather than measuring behavior”. For example, I was interested in impressions of a hierarchy of responsibility between siblings, or evidence of practical support provided by wider whānau in terms of raising the child. These may be things not spoken about, but taken for granted and exhibited in action. Such observations helped build a picture of the whānau context.

Whānau were also asked to reflect on their own observations of their deaf child. A. B. Smith and Ballard (2004) notes that often mothers in particular, through their role as main carers, often have significant insight into their children, and should not be discredited, especially given that their observations are based on ongoing reflection over time. These were often discussed in great detail. Often mothers and other main carers in this research were perplexed over the child’s behaviour and we spent time pondering potential reasons and meanings. I was an active participant in this process. Participant constructions did not occur in isolation, they occurred in reaction to a context, a context that included me as a researcher. Often I took my own pre-school aged son to visits with whānau and our children played together. We spent times observing and commenting on our children’s interactions, as parents do. We often put forward our observations for response and reflection. I was conscious not to make comments of comparison between children, instead asking questions around what behaviour was like prior to my visit. For example, one child was in the process of toilet training when I was collecting data. My question was not “Is your child going to the toilet yet?” but rather “How’s the toilet training going?”

The last form of data included written forms of data such as folders of written educational and medical correspondence collected by whānau, and some personal written material.

Due to the need to prioritize the principle of whakawhanaungatanga I was forced to reevaluate initial expectations that I would undertake three interviews in three visits to produce the necessary data. I became less concerned with the number of visits and staged discussions (interviews) and I began to use whakawhanaungatanga as the principal driver. Timeframes for visits became less important. It wasn’t until we reached a mutual consensus that we ended the visit. Often we spoke for several hours, had a break, spent some time with children with an activity, and returned back to discussion later that day. As I trusted in the approach of whakawhanaungatanga, trust and rapport ensued and korero flowed more freely, not

necessarily in the form of conversations, but in various forms – spoken, signed (primarily with the deaf children involved in the research), action, and in the sharing of written and photographic information.

3.7.1. Interviews with key informants

While this research prioritised the need to voice the experiences of whānau experiences, placing these at the fore of the research, these experiences cannot be divorced from context that is the UNSHEIP (*see, Chapter 5. Early intervention service delivery in New Zealand: context to the case study*). Therefore, a series of semi-structured interviews were also undertaken with 29 professional informants employed in both the government and private sectors. Twelve professionals involved in designing and implementing services to deaf children and their families (senior government Ministry staff within relevant Ministries and staff in senior and management positions from main service providers) were interviewed to gain descriptions of services and support systems as they existed at the time of collecting data, while 17 professionals working directly with whānau (advisors on deaf children, resource teachers of the deaf, audiologists, pre-school staff, habilitationists; speech language therapists, early interventionist specialists, sign language mentors, kohanga reo kaiako, kuia and koroua) were interviewed to gain insight into the context of the individual whānau cases. Deciding upon whom to interview to support the direct contextualizing of a whānau case study was negotiated with whānau participants. Whānau tended to choose professionals who either had regular contact with them and their child, offered a critical form of support, or had positive relationships with a deaf child and/or whānau. The schedules used during these interviews were developed from the literature review and research questions, attached as an appendix to this thesis (Appendix D).

Interviews with these key informants were undertaken within a differing frame. Interviews tended to be more structured (as opposed to whānau discussions) following the format of the semi-structured interview schedule more directly. While rapport and relationships between researcher and participant are essential parts to undertaking qualitative interviews, rapport and relationships were framed in a differing way with professionals than they were with whānau. The social conduct framing interviews with professionals was largely determined by the social expectations of their professional settings: interviews were conducted sitting down, in workplaces (only one was conducted in a professional's home at their request) at agreed locations and time-frames. Social norms employed in Māori settings, such as mihimihi, were

received in differing ways by key informants and did not necessarily work toward rapport building as they typically do in Māori settings. Underpinning this differing frame of interaction was the mutual understanding that I was attempting to gain an understanding of context to describe the structure and nature of the UNSHEIP and the way in which the whānau participants were receiving supports. I was not attempting a co-construction of a case (as I was with whānau) and thus these interviews were perceived as less ‘personally risky’ and related to individuals in their professional capacity. During the term of the research, a series of significant changes were made in regards to early intervention services and documentation of these changes was at times difficult to source. Therefore, the discussion in the interviews tended to focus on the evolving nature of the UNSHEIP during the course of the research, provided key information on how early intervention professionals describe their role in terms of Māori deaf children and their whānau and supported the contextualizing of case study descriptions.

3.7.2. **Data management**

Discussions with both whānau and professionals were audiotaped and/or filmed. Recordings were later transcribed and returned to participants so they might have copies of the original data set. A number of conversations with whānau members were informal and not recorded as either the setting or the impromptu nature of interactions did not allow for a recording (for example, discussions undertaken while driving). In these instances notes were taken as a part of my field journal when practically possible, usually within a week of the event. Interestingly filmed conversations usually included the sponetaneous activity of children in the background. This was included in the data set with the permission of whānau participants who participated in co-constructing a reflective observation on these activities.

Transcripts of discussions were provided to participants so they might re-orientate themselves with previous conversations and served as the basis from which whānau participants were able to collaborate in the writing of chapters regarding their specific child. Transcripts belonging to professionals were returned as a matter of courtesy and for checking. During the Hui Whakawhanaungatanga/wānanga held as part of this research¹¹ a significant number of children attended the hui and were often filmed or photographed during moments of play (with

¹¹ See section 3.8.1 *Hui Whakawhanaungatanga/wānanga: reflecting participant feedback on findings and interpretation.*

whānau permission) and returned to whānau. This data was especially useful in that it captured aspects of the children's social and language capacity in a context that was wider than their whānau. These images also served in the interests of whakawhanaungatanga, they were static images which whānau cherished as memoirs of their time with one another. These were also returned to whānau. All data sources were entered into NVivo, which was able to cope with cross analysis of the various forms of data: audio, film, photos, written transcripts and field notes.

3.8. Raranga korero-ā-waha, ā-tuhi, ā-tinana: data analysis

The process of analysing data to construct a story is an iterative process, again akin to the final stage of construction of a kete, which involves the weaving of prepared material into 'he kete kōrero', a 'kete which tells a story'. The weaver/researcher continuously references her main objective – the intended purpose of the kete kōrero/the answering of research questions – during the preparation phase. Yet post preparation phase, the weaver/researcher will have to accept the character of the data as it stands to construct the story of the case (kete kōrero). The way a kete tells a story will vary, and is largely driven by the creative and holistic insight the weaver has into her prepared material. She will convey the message through shape, texture, pattern, colour, and tension. The kete is holistic and context-specific, yet its form and meaning is open to several interpretations. The story told through the kete is a construction. It is time bound yet timeless – the story stands as it is, yet is also potentially incomplete as the weaver is always able to unpick, reweave and reconstruct another interpretation of the same medium.

Links can be made between the approach inspired by the methodological process of analysis used in raranga and that articulated by Frank's description of dialogical narrative analysis (DNA) (Frank 2012: 33-52). According to Frank, undertaking a DNA assumes that stories are understood as "artful representations of people's lives; stories reshape the past and imaginatively project the future" and acknowledges that "stories are always told within dialogue: Storytelling always responds to others – whether actually present or imagined – and anticipates future responses, including the retelling of the story, with variations." While utilising a DNA approach, the researcher should ask themselves a number of critical questions: (1) 'What multiple voices can be heard in any single speaker's voice, how do they merge and how do they contest one another?' that is, what conceptual tools and dialogues has the speaker used to cobble their narrative together? (2) What makes stories distinct from other forms of narratives? What counts as story, what does not? (3) Why is someone choosing to tell a story?

(4) What stakes does the storyteller have riding on telling this story? In particular, what facets of self and/or group identity does the storyteller aim to portray and/or maintain? These were critical considerations as part of the process of transforming stories into case narratives alongside whānau participants.

Patton, who writes on how to transform data to case narratives, also supports this process and describes this practice in terms of producing fine weaving:

The case study should take the reader into the case situation and experience – a person's life, a group's life, or a program's life. Each case study in a report stands alone, allowing the reader to understand the case as a unique, holistic entity. At a latter point in analysis, it is possible to compare and contrast cases, but initially each case must be represented as an idiosyncratic manifestation of the phenomenon of interest. A case study should be sufficiently detailed and comprehensive to illuminate the focus of the inquiry without becoming boring or laden with trivia. A skillfully crafted case reads like fine weaving. And that, of course is the trick, how to do the weaving? How to tell the story? How to tell what stays in the final case presentation and what gets deleted along the way (Patton 2002: 450).

The analysis process for this research entailed moving between inductive and deductive approaches – on the one hand allowing findings to develop as themes arise from the data, yet also making sense of the data in relation to an existing framework of research questions (Patton 2002: 453).

As highlighted by case study theorists, this is the paradox of the case study approach. It is through the detailed context-specific example of the case (which draws on an inductive approach) that universal truths or storylines can be found (deducted from knowledge of multiple cases). The analysis process in this research reflects this point. The first stage of analysis used as a part of this research, involved an inductive process of sourcing emerging themes and storylines from individual whānau, while the second phase involved exploring points of convergence and divergence between these cases in order to produce a meta-level of analysis whereby these experiences were discussed in terms of the specific research questions. C. Robson (2011: 474) supports this process of thematic analysis whereby he identifies how the process can include two types of thematic coding analysis as a “realist method, which

reports the experiences, meanings and reality of participants” and “as a constructionist method which examines the ways in which events, realities, meanings and experiences are the effects of discourses operating in society”. In Robson’s view, qualitative analysis enacts a process involving “codes and themes occurring from the data determined inductively from reviewing data, relevance to research questions, previous research and theoretical considerations” (C. Robson 2011: 476). It is through the immersion in the data that meanings and patterns are identified, initial codes are generated, themes are identified and networked with one another, and an iterative process of integration and interpretation is made.

The first process which involved weaving the storylines of individual cases supported the meanings and realities of each whānau. They were actively co-constructed alongside whānau. The first stage of this process of forming a sense of story for individual whānau began with a search for the key thread or the core story specific to them. Initial formal interviews began with a semi-structured interview schedule to collect information around specific research questions. In relating their own account of their experiences, it became apparent that participants constructed their narrative around the key messages they had to tell to inform the research aims. Key threads were quickly identified by participants themselves in their initial narratives and formed the first stage of analysis, undertaken jointly during the data collection process. These themes were revisited in subsequent meetings, whereby whānau were asked to look at their initial accounts for affirmation and/or extrapolation. This method worked towards defining a finer understanding of context as understood by whānau participants. Once key storylines from each whānau had been identified, a draft case study describing each whānau was written and presented to each of them for their feedback.

There were risks and unpredictability in this collaborative approach. The principle of whakawhanaungatanga in the research process took precedence at times with respect to how the story could be told in its final form. For example, observational notes written independently by me, and quotes taken from interview transcripts were reviewed by whānau. At times, my construction of an event, the interpretation of quotes, or my inclusion of certain observed details was critiqued by participants whose construction of events varied from my own. In these instances, we mediated a consensus through debate and discussion. This process of negotiation between researcher and participants about how to represent their case was ongoing throughout the whole research process. Each case (as presented in the following chapters) is organised

around key research questions, yet also reflects and highlights the storylines and themes most salient for each whānau in creating their kete kōrero.

The second phase of analysis (which again involved an iterative process of data collection and analysis) sought to explore the way in which experiences and perceptions from the viewpoints of whānau and professional participants were constructed by discourses operating in wider society and within the early intervention sector. In this phase, points of convergence and difference across the cases were identified to form a meta-level analysis of the collective storyline. Managing this process collaboratively with a large number of participants in different locations was logistically difficult.

3.8.1. **Hui Whakawhanaungatanga/wānanga: reflecting participant feedback on findings and interpretation**

Toward the end of the data collection process, I approached whānau and proposed that we have a Hui Whakawhanaungatanga. The hui was held at Te Kura Kaupapa Māori o Ngā Mokopuna (a Māori language immersion school) in Seatoun Wellington, held over a weekend period in October 2010. It was attended by 36 whānau members and 15 support people including kaumātua (male and female) who were Māori and deaf/hearing-impaired, ringawera (volunteer workers) from whānau associated with Te Kura Kaupapa Māori o Ngā Mokopuna, and other Māori whānau with experience of deafness who cared for the children while the adults were occupied. The hui had five specific purposes:

(1) **Wānanga:** to undertake a collective reflection and debate about themes arising from their kete kōrero in relation to the research questions. In this discursive process, data and interpretation were extended, contributing to the credibility of findings and conclusions;

(2) **Whakawhanaungatanga:** to maintain and develop relationships with one another, in keeping with the transformative principles of the methodology. Most of the whānau in the research had little or no connection with other whānau with deaf children. Time was set aside for whānau to develop relationships with one another, with other deaf people (adults and children) and their whānau, and with myself the researcher;

(3) **Rolling consent:** All participants had formally consented to participating in the research by reviewing the information sheet and signing the consent forms at the outset of the research (see Appendix E). However, due to the candid and emotive way in which participants responded to

the research questions, objectives and the process of whakawhanaungatanga the notion of *rolling-consent* was quickly introduced. In this approach we undertook a process of on-going negotiation of consent throughout the research process. Participants were deeply involved in the co-construction of case descriptions and thus could not definitively decide at the outset whether the final case description would be one which they would happily consent to. Whānau were also not able to anticipate at the outset how these constructions would influence their deaf child (who at a pre-school age and with limited language abilities were unable to consent themselves). Whānau members were continuously asked to reflect on the long-term implications of the presentation of cases on multiple whānau members including their children. Therefore, the deaf children's participation (as the centre of case descriptions) was agreed to on behalf of their parent and/or legal guardian. While signed consent forms satisfied the ethical responsibilities as identified by an ethics committee, they do not address the research relationships and responsibilities facing Māori researchers who enter communities or create a community through a research process. The process of *rolling consent* acted as an ongoing reminder of my accountability to the relevant communities, allowed the whānau participants space and time to reflect on the implications of their participation on the wellbeing of the deaf child and the collective entity of the whānau and placed the locus of control with participants who made the final decision on the presentation of cases.

(4) Pseudonyms: *Following presentation and discussion of findings*, whānau were invited to debate and discuss their feelings about whether or not to use pseudonyms in the final thesis. As a part of the process, examples of written research where pseudonyms had and had not been used (and the potential ramifications of these decisions) formed the basis of a wānanga.

A collective decision was reached by participants that, despite their vulnerability in exposing intimate aspects of their lives, they opted to use their real names, as they wanted to own the stories and use the research as a platform for future advocacy. We agreed that a final decision regarding pseudonyms should be made after each whānau had read their draft case study. Interestingly, as drafts of participants' chapters were shared, whānau felt less secure about using real identities and were concerned about potential repercussions from any critical comment on experiences with EI service providers. Whānau were not confident that EI professionals would regard the cases as points of learning, and perceived that their children (who would deal with professionals for at least ten more years) might be discriminated against. Many believed a number of professionals in the EI sector were powerful and motivated to

maintain the perception that they were collaborative experts, contrary to the feeling of some whānau. Consequently, one whānau opted for the use of pseudonyms. While the potential ramifications of using real identities in this research had been actively discussed with participants in a thorough process, final decisions rested (with respect) with whānau participants.

(5) *Future research directions:* to discuss potential future directions for research. Naturally, research inspires future research questions. However it wasn't until after the data collection process was complete that I realised I had not raised this possibility with participants. I decided the hui was the appropriate forum to ask them about future research topics and priorities.

3.9. Ethical considerations

As outlined in section 3.3 *Reweaving a research approach*, a transformative paradigm elevates the importance of axiological or ethical principles of respect, benefice, justice, and relationships within research methodology (Mertens 2007: 216). In a kaupapa Māori paradigm, researchers are led by axiological assumptions embedded in tikanga Māori. Cram (1999: 42-49) collaborated with Linda Smith (drawing from her PhD work in Māori education (L. T. Mead 1997) to compile a set of guidelines for researchers working with the parameters of tikanga Māori (within Māori moral principles): mana (power, dignity and respect), manaakitanga (sharing, hosting and generosity), aroha (respect), māhaki (humility, that is, acknowledging the power of expertise and experience belonging to participants), titiro, whakarongo (listening and observing situations, and developing a platform of contextual understanding from which to speak), and kia tūpato (to be politically astute and reflective of your status as an insider/outsider). As I was undertaking research with Māori deaf children and their whānau and service providers, these were the ethical principles, which governed my interactions and processes. Most of the participants had no other reference point for the social conduct of researchers and expected our social interactions to be governed by these principles; they appeared to be intuitively understood.

Various professionals were however somewhat perplexed by this approach. They understood a less personalised approach to research, whereby those acts, which worked toward whakawhanaungatanga with whānau, were not consistently recognised by professionals as contributing to an ethical process. For example, some were personally overwhelmed by a koha as social acknowledgement for their time and contribution, or unsure about the type of detail

to provide in introductions, especially following my own mihimihi where I described my own personal background in Māori and deaf communities as an entry point to the research. Some were aware of these social formulae and recognised them as distinctively Māori, while some appeared slightly uncomfortable and preferred to remain within social formulae which focused on their role as a professional rather than emphasising an aspect of their own personal identity. Interestingly, this was in direct contrast to the experience of whānau. Most professionals saw their participation as an extension of their professional role, and saw their contribution as a responsibility to provide specified information regarding their service or work experience. In these instances, an attempt was made to match social formulae to the participant being interviewed.

An application to the Multi-Regional Health and Disability Ethics Committee for ethical consent for the research was approved. A copy of this approval is attached as Appendix E.

3.10. Research challenges: reconciling relationships, responsibilities and expectations of the western academy and of indigenous and marginalized communities

Apprentice researchers (including PhD students) are often encouraged to engage with literature and mentoring relationships with more experienced researchers to help them assume skills required to undertake research within academic contexts. Initial steps for PhD students typically include penning an academic proposal to gain entry into an academic programme as well as constructing a methodological approach in an application to an ethics committee to approve the instigation of data collection. The adage ‘you don't know what you don't know’ is one that can dawn on an apprentice researcher during the term of a research project. For me, this included the realisation that my apprenticeship had begun long ago prior to my PhD enrolment and included my socialisation in Māori and Deaf communities, learning through lived experience the axiological assumptions which underpin these communities and determine how people move within them (*see Chapter Four. Reflective practice: the weaver's hands, heart and intellect*). This was a powerful reflection which drew me to shaping my research approach within the knowledge of raranga and affirmed that while satisfying the ethical requirements of a western academic institution I still was required to satisfy the axiological assumptions of relevant research communities.

This latter responsibility was emphasized as most important due to the knowledge that I was seen by whānau participants as a member of multiple communities. As membership to these communities are life-long, exiting them is not possible, and thus, the nature my membership required reflection. To a large extent the nature of my membership was determined by other members of the research community, who in the framework of whakawhanaungatanga and the notion of kaupapa whānau, appointed kinship type roles to me. During the course of the research I was referred to by participants as ‘aunty’, ‘cuzzy’, ‘cousin’, ‘sista’, ‘sister’ and ‘whaea’ (an older woman within a kinship group) and sometimes by my name. Whether I approved of such titles was irrelevant to participants, who, based on my socialization in both Māori and Deaf communities, language abilities, and genealogical links, gave me titles which affirmed a kin-like association and acknowledged my experience of community.

L.T. Smith (2007:128-129) writes that research ethics for indigenous and marginalized communities “is at a very basic level about establishing, maintaining, and nurturing respectful relationships, not just among people as individuals but also with people as individuals as collectives, and as members of communities, and with humans who live with and other entities within the environment” Entering “preexisting relationships, building, maintaining and nurturing relationships, strengthening connectivity” are in her view “important research skills which require critical sensitivity and reciprocity of spirit by a researcher”. In this sense I was entirely comfortable with the attribution of kinship identities as it served the development and maintenance of relationships while simultaneously flagging the responsibility they placed on my shoulders. The appointment of this responsibility was not a role I was entirely uncomfortable with either as I understood this from their cultural lens, yet, it did provide challenges on how to rationalize processes considering the academic exercise was to immediately fulfill the requirements of a PhD – one which had to be approved of from perspective of the ethics committee operating from a Western research paradigm. Within the framework of whakawhanaungatanga, I was framed at times by whānau participants as more ‘knowledgeable’ thus asked to advocate or support whānau in some interactions with professionals, in active and passive ways. This illustrated that the role as PhD researcher was not necessarily acknowledged nor accepted within the framework of whakawhanaungatanga, and instead, whānau participants often preferred to frame my role and identity within their own cultural lens. From a qualitative perspective, this type of relationship supported the collaboration in a case study and provided a depth and richness of description which otherwise may have not been achieved. Such depth of description supports the transformative intent of

this research as it is these types of insights which are less understood by service providers and programmes – most of whom appear to maintain very superficial relationships with whānau (from the perspective of whānau members.) This dynamic adds to the ethical robustness of research and argueably satisfies the ethical responsibilities of both the Western academy and of the relevant research communities.

L.T Smith (2007:113) also writes that researcher's undertaking research with those from indigenous or marginalized communities must be mindful that the lives of these individuals are often characterised by complex life-circumstances related to the experience of being marginalized. Investigating within these social landscapes is described by (L.T. Smith 2007:113) as being on 'tricky ground', understanding of how groups have been marginalized and how this characterizes experiences and discourses within supports a researcher's movement within these communities and deduct meaning from research data.

Indeed, this useful metaphor captures some of the challenges faced by me through the research process. Whānau with deaf children are placed socially and linguistically at the intersection of Māori and Deaf communities. This research provided a context for whānau participants (who were just emerging into this experience having only had young children) to explore how these two experiences influence one another and manifest, fused in the individual and influencing the dynamic of a whānau, (see *Chapter Two: Literature Review*). Due to the research focus and approach I was effectively supporting this iterative exploration, where whānau participants explained their experiences within well known discourses, yet also contested them at later stages, or revised their views and position within. L.T.Smith (2007) reminds researchers that cultural homogeneity and community consensus and/or isolation are myths tagged to indigenous and minority communities, arguing that internal relations of power exist within these communities (as they do any other) and work towards marginalization, silencing and empowering groups and individuals within. Interestingly, this dynamic was not one I was neither unfamiliar nor uncomfortable with, through my socialization experiences (see, *Chapter Four: reflective practice; the weavers hand, heart and intellect*). I had come to see the cultural 'trickiness', characterising these cultural terrains. Significantly, whānau participants were also to a large degree comfortable with describing the complexities of their lives and considered this when they made an important decision of whether to have their real identities used in the reporting of this research. The concept of rolling consent (see section 3.8.1 *Hui Whakawhanaungatanga/wānanga: reflecting participant feedback on findings and*

interpretation) describes how this process was introduced to gain consent to co-construct the case descriptions as a part of this research and whether at the end of the co-construction period they would use real identities, or not. This approach allowed whānau participants to reflect on how the tricky terrain of their lives influenced their case descriptions and encouraged them to reflect on what implications using real identities may have on them and others. After careful consideration, four out of five whānau opted for the use of real identities. There were multiple drivers behind these decisions, however most important was the desire to have their stories heard by others: by deaf people and their whānau members and those who influence the nature and structure of supports for whānau with deaf children. Whānau participants discussed the potential of contesting and/or revising their presented constructions and decisions at a later date, yet accepted that the ‘tricky ground’ was inevitable and ‘a part of life’. In response to this, some requested if the research could continue in a longitudinal exploration of the issues. These comments influenced the decision to undertake an application to the Health Research Council for Post-Doctoral study with the view to continue the same relationships into further research (see *Chapter 13. Conclusions, section 13.2 implications of these conclusions*).

This chapter explained how and why the research was undertaken using a case study approach conceptualised within a Māori tradition of raranga (weaving) as a framework for the research process. Ethical aspects were justified in terms of Māori relational principles and values, of which whakawhanaungatanga (connectedness) is central to the conduct of respectful and transformative research relationships. In Chapter 4 I position myself as the researcher and explain my research journey.

Chapter 4. Reflective practice: The weaver's hands, heart and intellect

4.1. Introduction

To an educated eye the identity of a weaver can sometimes be surmised from identifying signature features found within their work. When fellow weavers undertake a period of 'study', often in the form of mentorship, they are encouraged to study others' work and examine it for intentional and unintentional information. Superficially, information is coded in pattern, technique, colour, form, composition and texture, all of which communicate messages. It is also understood that through the weavers' hands the heart and intellect also manifests and thus an object of creation also reveals complex aspects of the creator. The same could be said about researchers working within the qualitative tradition. As the researcher is framed as the primary instrument of data collection, it is via them that the research question or problem is defined, the rationale for methods is decided and data sources such as interviews and observations are co-constructed with participants and then funneled through the conceptual lens of the researcher.

It is for this reason that many qualitative researchers encourage reflective practice. Reflexivity encourages the researcher to 'engage with oneself' and the process of reflexivity (Patton 2002: 65) "reminds the qualitative inquirer to be attentive to and conscious of the cultural, political, social and linguistic and ideological origins of one's own perspective and voice, as well as the voices of those one interviews and one reports." Mertens (2009: 71) also stresses the importance reflective practice in transformative approach; she writes:

... Self-knowledge is an essential part of establishing effective partnerships and relationships, as well as for clarifying worldviews. Self-knowledge alone is not sufficient, however; personal transformation is a necessary part of social transformation. Combining self-knowledge with cultural knowledge and skills in effective partnering facilitates (1) the development of the research or evaluation focus and identification of questions (2) the development of interventions; and (3) making decisions about design, measures, samples, analysis and interpretation and use that are in keeping with the transformative paradigm (Mertens 2009: 71).

In Māori and deaf community social practice, reflexivity is commonplace. In Māori communities, it is embedded in the act of reciting whakapapa, often in the form of mihimihi or pepeha, or identifying a common social connection between yourself and others. In deaf communities, introductions follow a similar format whereby connections to a deaf person, or networks of deaf people, are made to sign-post your social and linguistic backgrounds. Reflexivity requires identifying connections either identifying a connection to a common social network or common idea or theme of interest, in an attempt to foster a relationship with an individual and/or group of people. This piece of research also presents a mihimihi, effectively a reflection, as a preface to the whānau cases presented in this work. This reflection focuses on the formative nature of my childhood social and linguistic experiences, the intergenerational impact of deafness, and the complex and evolving nature of Māori whānau in a modern context. It is envisioned that this construction will position the readership for the conceptual lens from which whānau involved in this research were viewed.

4.2. Ka pū te ruha, ka hao te rangatahi: (*The new net goes fishing while the old one is cast aside*)¹²

Okahuaitu te maunga

Waikakariki te awa

Repongaere te roto

Rongopai te marae

Whānau a Kai te hapū

Te Aitanga-a-Māhaki te iwi

On my father's side, our whakapapa (genealogy) connects us to several hapu and marae from Te Aitanga a Mahaki, Rongowhakaata, Whakatohea and Ngāti Kahungunu. Some of my kaumatua and kuia may be able to identify the web of connections between myself and various tupuna through their intricate knowledge of whakapapa. Most of these connections I am not able to name as the skill to do so requires a lifetime of socialisation within specific networks, something I did not have the privilege of experiencing. I have chosen to begin this section with

¹² This is a proverbial saying used amongst Māori whereby fishing nets are likened to the generations old and young. The latter taking up an active role as the older retires. The use of this whakatauki as section heading reflects the content of this section whereby I describe my social and linguistic experiences in Māori communities during my childhood and discuss the later impact these had on the conceptual lens from which this research is examined.

one connection in particular as it was through this whānau connection that I have identified myself to participants involved in this research. The stories of my childhood, of past personalities, lifestyles lived, habits shared and traditions practiced belong to whānau members who also shared this whakapapa. These informed the schema of who I feel I am as one of the new personalities and the latest thread in the weave.

My father, the second-born child of seven children was a whāngai¹³ (a gift of aroha) child raised by his father's older sister who was unable to conceive her own children. These siblings raised their respective children in proximity to one another in both Gisborne and Wellington. As my father entered his early years at school during the 1960s, my father's whāngai mother, separated from her husband and resettled in Wellington. Believing strongly in hard work, decorum and homemaking, she secured work in manual occupations, and her social life, which once revolved around the activity of whānau working and farming whānau-owned land, now centered on a small network of Māori migrants to the city and whānau who came to stay when they visited the city. My biological grandparents also migrated to Wellington after a physical injury restricted my grandfather's ability to undertake ongoing physical work. Thus my father and his siblings saw one another frequently.

The significant majority of the following cohort of children, 'the cousins', were born and socialised in urban contexts. My siblings and I grew up in Porirua, a satellite city north of Wellington, New Zealand's capital city, which was heavily populated by migrants from all over the world. Here, we occupied a space as 'in between people'; ironically identified as 'Māori' by school teachers who taught us kapa haka in an attempt to affirm our sense of 'Māoriness' yet having limited socialisation experience with the land we came from and those whose marae we affiliated with. Our lives were not determined by the rhythms associated with forging survival from land and sea. Adults 'got jobs' which usually involved working for others for a fixed income and our lives were determined by what this resource could afford us. Those living in our geographical proximity usually shared a similar resource base and thus our lives were

¹³Whāngai is the customary practice of what is loosely translated in English as adoption or foster care. More specifically, whāngai mokopuna is an agreement made between birth parents and grandparents whereby a child is raised by grandparents. Māori however, make a clear distinction between the institution of whāngai and adoption/foster care. Research shows (Mcrae and Nikora 2006:1-18), that while adoption and foster care tends to focus on the immediate interests of the child, the practice of whāngai works toward multiple ends including the immediate welfare of the child, and establishing nurturing relationships between individuals, families and broader relational networks. This is evidenced in the nature of the agreements between birth parents and whāngai relations, and in the openness of relationships which are fostered as a consequence.

indirectly shared. Our behavior was determined by this constraint. We built similar houses, shared similar routines. The nine-to-five work routine for some, and shift-work for others, could afford the same types of food, and took part in similar social activities and the children shared childhoods through attending local schools.

Our socialisation experiences were thus perhaps more like those from within our wider geographical community, almost like migrants. The process of cultural, social and linguistic transmission, usually experienced in intergenerational communities, was disrupted by grandparents who were either living elsewhere or had passed away too soon which for my grandparents this was due to poor health associated with unhealthy lifestyles, lifestyles perpetuated through modern 'convenience'. However, like all young people we created with what we had. My brother and male cousins did not learn of the great physical feats of our ancestors. Instead, they aspired to mimic the masculine prowess of cartoon heroes, Transformers and Ninja Turtles, and play sport, hockey and tennis in the case of our whānau, like their fathers and uncles. My cultural activity was 'doing marching' (kiwi-style) which involved performing intricate military-like marching drills with steely composure across burnt summer grass. With these strangers we also shared sites of cultural significance: the corner-dairy, fish-and-chip shop, Chinese-takeaway shop, the 'spacies' parlour, bakery, butcher, supermarket, mall, school swimming pool, local beaches and parks, and of course, movie theatres, then called picture theatres. Seasonal traditions that once were dictated by the observation of ancient natural cycles were replaced with the celebration of European histories and characters, for example, at Guy Fawkes and Christmas. Due to the wider trend of commercialisation these celebrations did however evolve during our childhood to resemble a mixture of old and new traditions. Christmas had nothing to do with honouring the life and spiritual teachings of Jesus Christ; rather, we called it Xmas and it marked the beginning of the 'holiday period', where we celebrated whakawhanaungatanga, cementing a sense of family connectedness through actions and the year's hard work. Adults took the accumulated annual leave so they might spend summer weather with children. Children no longer observed adults in their work or daily-lives. Adults worked and children were placed into care or school and thus this was the only opportunity to spend natural periods of time together. Annual savings were spent to buy gifts for loved ones, and the excesses of the summer harvest were enjoyed.

Migrant children also tend to teeter between old and new worlds, the culture of their families origin and the new destination of relocation. Those children who develop bilingual or

multilingual abilities tend to find a firmer footing in the culture of the old and new and are able to code switch, socially and linguistically, between the two more effectively. As young people, my siblings and I had learnt NZSL as a first language from our mother, so we had a sense of this dual footing. We did not however, have the same sense in terms of our identity as Māori, principally because of the intergenerational disconnection from our land, elders and language. Given her own personal struggle to use NZSL openly, often in defiance of the daily discrimination she endured, and to connect socially with those with a similar history, my mother affirmed the importance of being able to ‘use your own language’. It was her quiet assumption that encouraged me to actively seek language and I quietly placed myself in situations where I would be exposed: a bilingual classroom at Intermediate school, studying te reo Māori as an elective subject at college and as a part of an undergraduate degree at University.

In many ways these courses and institutions served as an intervention and I was one of the few cousins raised in the urban context to decide to learn te reo Māori. It is not possible to say however, that the language has since thrived amongst us. I have learned that the pathway to language learning cannot be divorced from the whānau. This has been a somewhat quiet and sad epiphany. Educational initiatives which targeted young people and older people at times, for example, through wānanga education, targeted individuals with the intention to keep the language ‘alive’. In this individualistic approach the intervention was flawed and language remained stagnant in the individual. For those who have acquired te reo Māori, this has broadened the depth of our social experiences and lives. We are able to participate in traditional contexts with greater clarity and inclusion and are no longer relegated to quietly waiting-out traditional ceremonies in the periphery, but participating with a greater depth of appreciation and understanding. For the majority however, te reo Māori does not often serve them in the context of their daily lives and routines. To try and use the language with whānau members who are not able to respond is often seen as pretentious and exclusionary. However, it is accepted that a Māori worldview is embedded, as if in an encrypted code, in the idiosyncrasies of te reo Māori. In this sense, te reo Māori is acknowledged and respected even when it is not used in daily life.

We were also like migrants in many other ways. Migrants often undertake a process of revisiting the ‘homeland’. This could present through food choices, language use, and clothing and on occasions, actually returning to the land. In our case, this was most often for obligatory

cultural activities, such as tangihanga, birthdays, and summer holidays where we found our connection to our past through activity. This included the annual summer tidy-up of our grandmother's home and property, spending still hot summer days listening to elders reminiscing of past personalities and making sure we were up to date with who had been born and who had died. Social reprieve was found by stilling oneself at the urupā, sitting with dead people and pulling weeds from their graves, being thrown about by the waves on the East Coast beaches or being satisfied by their fruits. In the latter post-millennium years the region was promoted as the 'first place to see the sun', marathon music festivals became trendy and jovial young people returned to grace the land with their presence. We had accumulated our annual leave, as our parents had once done to spend time with young people, to spend time with the old and the dead, land and the sea, and to bring with us traditions of the New Year celebration.

4.3. My industrious maternal grandparents: raising deaf children in New Zealand

My maternal grandparents emigrated to New Zealand from Scotland during the 1950s. Initially they settled in Paraparaumu, north of Wellington, where three of their eight children were born, the eldest hearing, my aunt, and two profoundly deaf, my uncle and mum. My grandparents then settled in what was the burgeoning settlement of Porirua during the era of a major state housing boom, which eventually characterised the area, and had five more children. They were an industrious couple, my nana having eight children in quick succession, with no family support to raise her children, and my granddad working as a builder to provide for his family. My grandparents called New Zealand their home. It is the place where their children were born and raised, and where my granddad was eventually buried in 2003. There is no doubt however, that they both retained a strong sense of Scots identity which was reflected in their reverence for family and in more measurable aspects of their lives such as their accents, language use which drew from the Scots songs, poems and other forms of oral history, visual memorabilia of Scots heritage placed around their home, and of course in their children's names.

During the late 1950s when both my uncle and mother were born, there was little support for families with deaf children. The diagnosis and early intervention experiences for nana and granddad were marked as a distressing time during which they were not well supported. Nana had suspected that two of her three children, who were all aged under five at the time, my mother under two and my uncle a little older, were in fact deaf, and sought a diagnosis from

professionals at Wellington hospital. At diagnosis, she was instructed, not advised but instructed, to place her hands behind her back and to engage her children with 'oral communication'. That is, to expect her profoundly deaf children to acquire language based on observing arbitrary lip-patterns produced on her mouth. Shocked and distressed at the diagnosis, and she notes she was never offered support from professionals, she sat at a bus stop outside the hospital with three children in tow and sobbed. Despite her desire 'to do right' by her children, following the instruction given to her was almost impossible. Out of necessity she opted for intuitive parenting, that is, she engaged her children with 'whatever worked'. My mum and uncle used idiosyncratic home-signs and actively sought to create visual language. As siblings were born, and life unfolded, all the older children were expected to undertake their fair share of household chores, and communication developed between siblings as they naturally occur in large families.

During the 1950s the majority of deaf children were sent to residential schools for deaf children, van Asch and KDEC. My mum and uncle however, attended a deaf-unit classroom, a recent initiative aimed to keep children in proximity to families and in mainstream schools, which was based at Te Aro School, Wellington. Despite being able to maintain closeness to family, my grandparents noted that without being able to instruct in NZSL, the teachers were unable to deliver a curriculum or teach basic skills in core subjects. As older children of a large family with hard working and pragmatic parents, they did however learn many 'manual skills' and were not afraid to 'give things a go'. Benefits of this schooling approach noted by our family include the socialisation experience it provided, namely regular contact with other deaf peers. Through ongoing contact, the children explored the visual parameters of their own idiosyncratic home signs, which gave them access to the network of adult users of an underground language, NZSL. These friendships were important relationships influencing the nature of socialisation experiences during their formative years. In many ways, these connections are as important to my mum and uncle as are the bonds they have with their own biological family members.

The communication ability of my mum's family has been limited largely to the home-sign system they adapted as children. My mum and uncle met other deaf children during their childhood years and adapted their home-sign system to the more advanced approach of NZSL. Through their role as older siblings, where they also supported the raising of their siblings, their nieces and nephews, their own home-sign system and basic NZSL was well used and

known across several generations. In addition, my siblings and I and my uncle's two hearing children are fluent in NZSL. However, I have always felt my mum's and uncle's participation in family-life has been limited by the restrictions of home-signs, while the depth of knowledge in NZSL amongst family members was too superficial to conduct an in-depth conversation. An interpreter who recently attended a family member's wedding reminded me however, that the openness of most family members across generations, to use visual communication with little inhibition, was rare and should be appreciated as such.

4.4. Deaf-Mum: Deaf-Hands, Deaf-Mind, Deaf-Heart

My mum has three children, two daughters and a son. When we were little she was a very 'hands-on' mum, patient and knowing. Her language, sign language, was our mother language and we accessed spoken English through other family members, particular from my mother's family. Both languages were used in our household when we were growing up. As a young child I did not know my mum was unable to hear, associating her deaf-related behaviour and sign language as a part of our family culture, our way of life. I was about seven years old when I realised it was also a physical condition. As children age they move through a developmental milestone, realising they are beings separate from their mothers, or the person acting in that role. As I was moving through this developmental milestone, a number of factors contributed to affirming a sense of difference between myself, as a hearing person, and my mother and other deaf people, as deaf people. In this categorising process, hearing people, typically non-family, advised me that my mother and all those like her, belonged to a new category, 'deaf', which was interchangeably used with the terms 'deaf and dumb', 'hearing-impaired' (when trying to be polite), 'hard-of-hearing', and 'mute'. Being deaf, my mother was not privy to these conversations and was unable to interject or educate. It was at this point that society took my mother's language away from me, telling me that what we were doing was a little bit embarrassing and that we should probably try keep signing to a minimum in public, and preferably small and close to our bodies to make ourselves unnoticeable. As children, our signing was combined with a mimic of those guttural noises deaf people make when signing. We naturally assumed that the noises deaf people made were a necessary part of the language. We were then told we weren't really 'talking' and according to some boys in my school playground, we were "acting like a mental". I would cringe when my Mum began to 'discipline' me in public with a lecture. It wasn't what she said that stopped the behaviour, rather a desire to stop the stares that drew so much attention.

As small children we were embraced into deaf circles, and other deaf adults delighted in our use of sign language, praising and encouraging our use of NZSL. The deaf people we knew came from all walks to life, from the well-educated to hardened criminals. We knew deaf people who spoke with an exaggerated guttural speech punctuated with over-dramatised gestures, to those you couldn't tell were deaf, those who could use the phone, and those who made no noise whatsoever, just signed. During my childhood there were no dictionaries or grammar books to govern our language use, and there were few inhibitions around 'signing correctly'. It didn't really matter what you did as communication was achieved and all appeared to be accepted. Difficult communication attempts were waded through with great patience until the two parties found a middle ground of mutual understanding and respect. There was admiration for those who were able to walk in both worlds, hearing and deaf, yet emphasis was placed on belonging to one another.

During the 1990s a deaf academic, Pat Dugdale, was filming a group of local deaf people signing, which my mum participated in, as a part of the research process for the production of an NZSL dictionary. As children we watched a gradual shift in our mother. She signed 'differently', more purposively, and began insisting on expanding our vocabulary. These sessions led to the eventual publication of the NZSL dictionary, one of the initial stepping stones toward the passing of the New Zealand Sign Language Act in 2006. When passed, the weight of the demoralising categorisation process endured by us over the years, individually and collectively, was lifted and we quietly celebrated in the knowledge that what we knew had always been right, and it was society that had been wrong.

Much has been written about children of deaf adults (CODA), affirming the complexities of their life experiences. Personally, I am reluctant to refer to myself as a CODA, principally because it acts as a label and because we never used the term in childhood. It was first brought to my attention as I became involved in research with deaf people. Usually when I meet others who are either deaf or have some form of connection with other deaf people, I prefer to describe my connection in terms of the types of relationships I have had with the deaf-world, that is, I have a deaf mother and uncle, and I learnt NZSL as a child. I take an interest in recent explorations in categorisation where deaf people are again being relabeled according to their modality of communication, signing or speech, and/or according to which technological device they use, hearing-aid, cochlear implant. I hold fast to my conclusions, decided at about four

years of age – that it pays to do what works, so long as communication, language and belonging are achieved.

4.4.1. **Navigating motherhood and medical interventions**

Three months following my PhD enrolment I become pregnant with my eldest son. Six months before I was to complete the writing phase I fell pregnant with my youngest son. Consequently, the journey of becoming a mother has run parallel to undertaking this research and has provided me some insight into participants' lives. In particular I have gained a better appreciation of the interface between professionals and families, insights into children's behaviour, children and adult relationships, as well as meeting the insurmountable expectations of 'modern motherhood'. I am now startled at my arrogance, that I attempted to undertake this research with no knowledge of being a mother or having a family. I smile at my ignorance and am relieved that I decided to have children alongside the PhD journey as they have taught me lessons no textbook could have imparted.

Perhaps one of the invaluable lessons that supported my gaining an understanding of the context of this research, and perhaps the significance, was when my eldest son was born. His birth was complicated, and we stayed in hospital for the week following his birth for reasons related to his and my recovery. I had spent the previous year writing a research proposal about early intervention, yet this was my real introduction to the world of intervention, medical intervention in particular. This was the first time I had navigated the interface of family and professional worlds in support of a child, though I had extensive experience undertaking this for adult family members. In hindsight I can see that gaining perspective on information on your child's point of difference while in the fog of post-birth trauma is daunting. This was also the first occasion where the significance of early identification and access to support became more pertinent as I waited tentatively for the results of both my sons' newborn screens. My eldest son presented with several risk factors. As UNHS had yet to be implemented in the DHB in which he was born (*see page 85 for a further explanation*), we attended a later appointment post-discharge. I was not impressed. I found the relational skills of the audiologist were poor, information was vague, and after having great difficulty settling my baby to sleep, the equipment did not work properly and we were asked to 'come back' for another appointment. Exasperated, I told the audiologist "not to worry about it" and I would "let them know if I thought there was a problem". I had lost all confidence in the system and had become 'on paper' the stereotypical neglectful Māori mother who doesn't take her baby to important

medical appointments. The reality was that I had more confidence in my ability to identify deaf behaviours and respond accordingly due to my own childhood experience, than I had with the medical system. Thankfully, when my second son was born the UNHS programme was running in the DHB and we had a less stressful experience. A screener attended our room the day following his birth, gave clear and concise information and conducted a screen. I wondered whether I would have felt the same way had I been referred. The experience was a motivator to continue with the research and illustrated the shades of grey when it comes to individual experience.

My second introduction to intervention began when, from a young age, my eldest son was admitted to hospital regularly for unmanaged asthma. After numerous admissions, almost fortnightly during the winter, the pediatricians decided it probably was asthma rather than ongoing bouts of bronchiolitis. Like many children with asthma, he also developed allergies to major food groups, eggs, dairy, wheat and nuts, and to insect bites. This time the intervention required lifestyle changes and renewed approaches to parenting. I had to learn how to cook all over again: how to shop and stock the pantry; how to convince my child to eat food no other child was eating, in the wider whānau and in his childcare centre, while not encouraging a fearful approach to food; how to include my child in celebrations which required the partaking of food to which he was allergic, for example, Easter eggs, and how to tactfully educate other whānau members who were used to giving food to children as a gesture of love, around safe food choices. The latter was the most difficult as most surmised that as he didn't experience anaphylaxis, the food didn't cause any problems. They did not however witness the late nights spent consoling a distressed child reacting to food eaten during the day. In the end, my son learnt to advocate for himself, refusing these types of food when offered and informing well-intentioned adults that these were his 'itchy-kai', food which makes his skin itchy. For his asthma, I had to teach my son how to communicate his needs. Often he would continue playing despite wheezing excessively and it wasn't until he was literally having an asthma attack that he would start panicking and frantically try to gain my or his preschool teacher's attention. Fortunately one of his preschool teachers also had severe asthma and supported him and me with learning self-monitoring.

Although these diet changes and facilitating self-awareness of breathing were the most significant changes required, there was no support for these activities from medical professionals; rather they were undertaken through my own initiative. The support provided

post-diagnosis comprised of medication and an occasional visit to a pediatrician who monitored my son's weight gain and general health. I tried to grapple with how to make the lifestyle changes necessary to support my son's wellbeing. When I asked professionals for advice, approaches varied. Some were battle fatigued, negligent and unsympathetic and others caring and committed. At times I was made to feel small and neurotic and at other times professionals were supportive. Most used language I did not understand and they all focused on explaining what was happening to his body. My plan to have a working routine went out the window as I was required to drop everything in moments of frequent illness. At times it felt as if I was expected to run while being forced to stand still, which is impossible.

In hindsight, the best support provided to help me enact the lifestyle changes required, which were in reality the major part of the intervention, came from others with similar experiences. I learnt how to restock my pantry, cook family meals during a work week that we could all eat, bake with no egg, dairy, wheat or nuts, decipher his asthma triggers, and support and educate my son on how to take responsibility for his own wellbeing as I knew I couldn't always be there to say no to biscuits and notice the onset of wheeze. Thankfully he has grown out of the food allergies and eczema, however he still suffers from asthma, albeit this is now manageable. Asthma is a fairly common illness in New Zealand, and its impact is considered by most to be less severe than deafness. And yet, through my experience of adjusting to my son's allergies and asthma, I gained a newfound appreciation for the hard work and dedication whānau must undertake to raise a deaf child, and how challenging the plethora of labels, advice and contradictions must be. This experience allowed me a greater sympathy, especially with those main carers involved in this research.

Having provided a personal context for this research, the next chapter sets out the Aotearoa/New Zealand context for the case studies and the way in which the early intervention services have developed.

Chapter 5. Early intervention service delivery in New Zealand: context to the case study

5.1. Introduction

The introduction of a Government supported Universal Newborn Hearing Screening and Early Intervention Programme (UNHSEIP) from 2006 paralleled the beginnings of this research. A system of audiological and educational support services existed prior to this introduction yet concern over the late age at which many deaf children were being diagnosed led to a programme of Universal Newborn Hearing Screening (UNHS) within the public health system and the coordination of supports within a government supported UNHSEIP. The objective was to ensure prompt diagnosis and timely access to EI supports. The deaf children of whānau involved in this research were all aged under five and were in the first cohort of children to have participated in the UNHSEIP (as it is currently framed) and therefore provide example cases of how the UNHSEIP is experienced from the perspective of deaf children and their whānau.

This chapter describes the structure of the UNHSEIP, beginning with an overview of its development and proposed structure and an introduction to the structure and nature of key support services (which existed prior to their reframing under the UNHSEIP) at the time of this research. This chapter draws from data collected from 29 key informants at various levels (*see section, 3.7.1 Interviews with key informants*) of the UNHSEIP, including those involved in policy development and implementation, those delivering both government and privately funded services and deaf people and their whānau (principally those whānau involved in this research). Description of the current EI structure for deaf children forms part of the wider context for this study.

5.2. Universal Newborn Hearing Screening and Early Intervention Programme (UNHSEIP) in New Zealand

5.2.1. The genesis of UNHS in New Zealand

In 2001, the prevalence of significant bilateral or unilateral hearing loss in /New Zealand had been estimated at three per 1000 births, typical of the international range. The average age for

detection for children whose hearing loss was greater than moderate, was 46 months or older (National Audiology Centre 2002, 2003, 2004) dropping to 33 months in 2005 (Greville Consulting 2007). This age of diagnosis, considered poor by international standards, put many children well beyond the critical period in which deaf children are most likely to benefit from intensive support for language development. Professional and consumer concern over the implications of the late identification and untimely commencement of support and intervention led to cross-sector advocacy to Government, insisting on the need for a UNHSEIP. In 2001, a number of key stakeholder attendees from a National Foundation for the Deaf (NFD) conference, resolved to lobby Government. In 2002, a cross-sector lobby group, Project HEIDI (Hearing Impairment: Early detection and intervention), developed a report presented in 2004, Project HEIDI: Hearing Impairment: Early Detection and Intervention, aimed at improving outcomes for children with permanent congenital hearing impairment (HEIDI 2004: 9). In August 2005, the Government announced a commitment to introducing UNHSEIP, and in May 2006, the Government earmarked 16 million dollars in the 2006 Budget to fund the UNHS segment of that commitment (M. Cullen 2006: 28). According to two key informants from the NSU (National Screening Unit in the Ministry of Health), political and health sector leaders at the time of the announcement of UNHS valued consultation with consumers, especially the disability sector as the government had recently formulated a national Disability Strategy.

Following the government's announcement of their commitment to the UNHS section of the UNHSEIP had been cemented with an allocation of a significant budget, the NSU was charged with leading the implementation and monitoring of a staged introduction of screening over a three-year-period from 2007 to 2010. According to key informants from the NSU, implementation began with District Health Boards (DHBs) which ran existing programmes (Waikato, Tairāwhiti and Hawkes Bay) and a phased stage of implementation undertaken with the remaining DHBs. The commitment to implementing UNBHS led to the development of a national training and qualification programme for newborn screeners to work in regional DHBs, while audiologists were already established within the private and public sectors.

Positioning the implementation of the NBHS initiatives within the NSU aligned deafness with a medicalised paradigm of disability. The genesis of the NSU stems from the implementation of cancer screening programmes. Within this model, screening was synonymous with identifying disease associated with morbidity. UNHS has however recognised and challenged

this pathological orientation, advocating policies more in line with a social model of disability. Two key informants within the health sector commented as follows:

[Newborn Hearing Screening] challenged the National Screening Unit's philosophy ... because it was set up based on the cancer screening programmes: breast screening and cervical screening is about finding disease and fixing it, whereas antenatal and newborn screening is a whole lot different. Newborn hearing screening was the first one to really come along and challenge that perception that you 'Screen for something because it's bad and you need to fix it' ... [this] perspective is quite challenging sometimes for the National Screening Unit because it's not within the medical model and [the National Screening Unit] was very much medical model: okay you find something, you fix it, you have an operation and you're fixed.

... If [newborn hearing screening got] underway [that's] sixty four thousand parents [that need] talking to about making sure that their children's hearing loss is identified and also portraying deafness not as a tragedy ... But to say, you are still intelligent, you're a person, you can accomplish and reach goals just like anyone else – you have a life to live. [I] always challenge language: I challenged somebody fairly high up as she referred to deafness as 'morbidity'.

UNHS is now offered across all twenty District Health Boards (DHB) and individual DHBs offer screening services to all babies born within their region, including hospital and home births. Screening services are directed by a framework of nationally consistent policies, standards and guidelines as supported through the NSU (Ministry of Health 2011). The NSU make a clear distinction between screening and diagnosis; screening categorises babies as those with an 'increased chance' or 'high risk', and those with a decreased or 'low risk' of hearing loss. Those in the first category are referred for assessment via audiology services to ascertain a diagnosis of hearing status. DHBs often work within and across their geographical boundaries, collaborating at times to optimise local capacity to provide audiology assessments. One key informant from the NSU identified this as a pragmatic response to the structure of the audiology sector, in which a number of audiologists worked within the private sector prior to the introduction of NBHS, and because pediatric audiology is a highly specialised field. For

babies who pass newborn screening yet display one or more risk factors (a family history of hearing loss, cranio-facial anomalies of the head, neck and ears, in-utero infections, an association with genetic syndromes that are linked with progressive hearing loss, neurodegenerative disorders and postnatal factors such as admission to neonatal intensive care for 48 hours or more) a protocol has been established for timely targeted follow up. NBHS is now monitored and evaluated by the NSU who monitor the quality of the screening programmes and work with expert groups and consumers to ensure their service reflects the latest evidence surrounding newborn screening (Ministry of Health 2011).

5.2.2. Transitioning from screening to support

The core goals of the UNHSEIP emphasise the need for timely intervention, and are ultimately geared toward ensuring infants with congenital hearing loss receive intervention by the age of six months. Framed as the ‘1-3-6 rule’, the programme aims to: have babies screened by one month; undertake an audiology assessment to ascertain a diagnosis by three months, and finally to initiate appropriate medical, audiological and early intervention services, by the age of six months.

The latest diagnostic data provided by National Notification Database (NND) (J. E. Digby et al. 2012: 31) demonstrate the average age of diagnosis (across all degrees of hearing loss) is improving (from 68 months in 2010 to 57 months in 2011) since implementation of the UNHSEIP. The average age of diagnosis for Māori, across hearing statuses, was 54 months compared with 52 months for those of European descent. The authors of the report suggest a further analysis of the age of notification in relation to hearing statuses, as Māori are more inclined to experience more milder and moderate forms of deafness, would provide more contextual meaning to this data. Key government agencies responsible for supporting deaf children and their families, through what is described as the ‘UNHSEIP screening pathway’, include the Ministry of Health (MOH), whose responsibilities include screening, diagnosis, and implementation of medical interventions, and the Ministry of Education, (MOE), whose key responsibilities include providing support with EI services with an educational focus.

A number of non-governmental organisations (NGOs) also provide various support services for deaf children and their families. In some instances, these organisations have dual capacity as aspects of their service are government funded while other aspects are resourced through fundraising efforts or from private resources. Many of these supports emerged prior to the

announcement of a UNHSEIP and were driven by the ongoing concern held by deaf people, their families, and professionals over the lack of specific support available. The UNHSEIP proposes timely and seamless access from screening to early intervention support and since its introduction the government has allocated resources to some NGO services, while aspects, usually those activities which support social and holistic wellbeing, such as access to family support networks and mentoring, remain funded through private fundraising efforts. An overview of the UNHSEIP screening pathway as envisioned by current Government is featured below.

Figure 1: Overview of the UNHSEIP screening pathway (Ministry of Health 2011:3)

This programme focuses on identification of newborns with moderate to profound hearing losses, resulting in an estimated 80 to 120 babies annually who will be eligible for early intervention support. Children with hearing loss, regardless of status, acquired progressively or through illness and/or accident will be identified through a targeted risk factor approach. It was noted by a number of key informants in this study that such an approach may create gaps in service for Māori. They noted that diagnostic data indicates Māori are more likely to experience varying degrees of hearing loss through illness, accident, progressive and conductive loss, and as a result of 'at-risk' neonatal factors, thus entering services through a different pathway than the UNHSEIP. Key informants noted that intervention for Māori children often occurred once a child had entered early childhood education. In their experience, deafness, especially deafness

associated with late onset and progressive hearing loss, was commonly identified by families' and educators' lay observations of children within home and early childhood education settings. These observations formed the basis for self-referral to audiology services for confirmation and diagnosis. Encouraging Māori participation in early childhood education and monitoring their health through this avenue was seen as a significant way of capturing a cohort of children who may experience late onset of deafness (of varying degrees and for diverse reasons), and those missed via other health check interventions, such as those by General Practitioners and Plunket Nurses.

While initial efforts focused on establishing an infrastructure to support the newborn screening programme, criticisms have been made regarding the simplicity of a '1-3-6' pathway, especially when a significant amount of work still needs to be undertaken across sectors to ensure appropriate transitioning between screening and early intervention.

A number of key informants, involved in policy development and those at the interface of service provision, conceded that ultimately political will drove the instigation of newborn screening in a reactive (albeit necessary) process, and that aspects of the UNHSEIP pathway are still being developed. Consequently, a number of participants noted the robustness and range of supports offered in the early intervention sector, but concluded that reflection and review was required to improve the UNSHEIP pathway. One key informant from the NSU reflected on the need to explore these issues further and considered that at the time of implementation of the screening initiative, the wider sector needed to be cognisant of international best practice, to diversify choices, and to co-ordinate itself to ensure timely and smooth transition between services resourced and delivered across sectors.

5.3. Early intervention: Delivering services at the interface of sectors

The UNHSEIP currently sits within a network of services and supports which historically have existed independently from one another. They involve a multitude of professionals and community groups whose practice and expertise draws from varying perspectives on health, wellbeing, language, education and deaf people. The introduction of the UNHSEIP, which demands a unified and timely approach to EI within the '1-3-6' timeframe, has called for improved integration of services from these groups despite variance in frames of reference. This process forced the beginnings of a closer examination, from the various key players

delivering and receiving EI support, of how ‘best outcomes’ for deaf children and their families are identified and framed, and how various supports can best work with one other, given the varying positions and worldviews around deafness amongst professionals and families.

Despite attempts to develop an integrated approach through the UNHSEIP, a number of key informants supporting the delivery of services and whānau participants of this research still experienced the UNHSEIP as fragmented and untimely. In part, they attributed this to the diverse ways in which deafness was conceived by various professional groups and Government’s need to delegate funding appropriations to either health or education sectors. In this context, services are required to frame themselves as meeting either a health or an education need. Whānau and key informants involved in this research noted that dividing supports from the UNHSEIP into health and education pathways, in order to rationalise resourcing, undermined the holistic impact of deafness on the child and their whānau. Various supports struggled to fit exclusively into health or education criteria. For example, Hearing House offer post cochlear implant support in the form of AV Therapy, a specialist preschool and a parent support network. Several key informants suggested that such constraints caused an onerous justification and decision-making process across government departments, whereby various departments negotiated funding responsibilities, and/or working protocols to ensure a ‘smoother’ experience from a consumer’s perspective. Key informants delivering support at the interface of service and families also noted that while government funding appropriation had been allocated to supports, many supports remained under-resourced. For example, bilateral cochlear implants are not universally fully-funded, and deaf children’s and parents’ acquisition of NZSL is inhibited by the unavailability of learning resources. Post introduction of the UNHSEIP, many supports remain reliant on private and/or voluntary means, as with deaf and/or parent mentor schemes and additional social supports provided for those with cochlear implantation.

During the time of this research, Specialist Education Services (within the MOE) had prioritised raising achievement levels for Māori and Pasifika children with special needs. Their approach included increased resourcing to these populations and the implementation of a holistic approach to early support and intervention. According to one MOE key informant, a focus on identifying learning needs and supporting active participation (inclusivity) in home and community life supports the child’s development in the most holistic sense and works towards shifting academic performance:

So in terms of 'Special Education' [the MOE's] role is to obviously make a difference to children with special needs. In particular, making sure that they're able to be present at either their early childhood centre or school and able to participate in what's happening in both the social and the academic context of school and the wider community and then learn and achieve. ... [The Ministry of Education is] not just looking at the disability but looking at 'What are the learning needs?' and [asks] 'How can that child's performance [be shifted] in terms of learning?' ... learning in the global holistic sense ... being an active member of the school, their local community, etc.

Community in this context is synonymous with connection to those living within geographical proximity to one another and connection with a familial group. Deaf and Māori experiences have shown us, however, that community may be defined differently. Internationally, deaf people have formed communities spreading across geographical boundaries, bound by languages and common social experiences that frame their identity and culture. Māori use of the term 'whānau' may be as a descriptor of a familial group but may also be used to identify intergenerational groups of people bound not by biological connection but rather common identifying features or commitments. It is not clear whether the MOE's commitment to facilitating inclusivity within communities extends to a community which is framed by neither geographical nor familial connection.

5.3.1. AODC (Advisors on deaf children): Navigators of the UNHSEIP

Following diagnosis, an Advisor on Deaf Children (AODC) will make contact with the child's family within two days of an audiology referral. The AODC provides specialist support to families by providing information and advice about their child's development, with a fundamental focus on language and communication. The AODC guides the development of a family-centred EI plan and liaises with other professionals and organisations to support the plan. AODCs are employed by the MOE, and provide a critical role in navigating support provided locally and nationally, including those within the medical and educational sectors, with NGOs, such as the parent mentor programme BEACON and Hearing House, and with

consumer and stakeholder groups such as New Zealand Federation of Deaf children, Deaf Aotearoa New Zealand, National Foundation for the Deaf.

The Advisor will typically provide support in home settings, and across the various settings in which early intervention experiences may occur. An Advisor will usually have experience as a teacher of deaf children and hold a post-graduate qualification (either a post-graduate diploma, or a recently introduced Masters qualification) through which they will have extended audiology-based knowledge, understanding of deaf children's behaviour and development, and experience of working with service providers in education and medical settings, NGOs, and community groups. Although Advisors have worked with deaf children and their families across a wide range of ages and hearing statuses since the 1960's, when their role was first introduced, the advent of the UNHS and the UNHSEIP has altered the parameters of their role, especially given the '1-3-6' targets. Several key-informants involved in policy development note that Advisors have numerous professional development opportunities to support their work in this evolving context, in particular, helping them to become 'reflective practitioners', able to critically review the interplay between their personal views on deafness, deaf people, language and communication, how these can shape interactions and information shared with families, and frame their decision-making.

5.3.2. Early Intervention support from Deaf Education Centres in New Zealand

In the historical provision of deaf education, van Asch Deaf education Centre (van Asch) and Kelston Deaf Education Centre (KDEC) were core sources of educational support for deaf children, from preschool to secondary school aged children, and their families from 1880 until the 1970's (Allen 1980; Aspden et al. 1992). As the majority of deaf children are now educated in local schools in proximity to their families. The role of these institutions has changed and they now offer a 'centre of specialist support' whereby specialist staff provide regional support to deaf children in mainstream classroom settings. Enrolment in day or residential education has been greatly scaled down in both centres. After a review of deaf education undertaken in conjunction with a review of special education services in New Zealand (Ministry of Education 2010b, 2010a) the role of the deaf schools shifted once again and in November 2012, administration of the two centres merged under a joint governance structure.

Both van Asch and KDEC employ specialist staff to provide EI support to deaf children and their families within the boundaries of what is identified by the MOE as the northern (KDEC) and southern (van Asch) regions¹⁴, and also coordinate itinerant and advisory support at primary and secondary levels to deaf students with high and very high needs. The school grounds, which historically hosted residential facilities for deaf children, now provide the premises for a 'spoke-and-wheel' type service where specialist staff, such as Resource Teachers of the Deaf (RTD) base themselves. Audiological assessments, technical support with listening devices, the opportunity for residential schooling, and support for learning NZSL are typically provided. Both centres have preschools within their grounds, albeit functioning under differing structures and approaches to supporting deaf children and their families.

The van Asch preschool service has recently shifted focus, from providing a local preschool programme, attended by a small number of local deaf children, to a two pronged EI programme comprising weekly EI sessions for local deaf children and ten week intensive short-term residential EI sessions for families of deaf children who reside in the wider southern region. This approach envisions that family-centred support can be provided to the geographically dispersed population that they serve. The approach employed in these EI sessions emphasises supporting families, typically parents, to observe their children's behaviour and *help parents tune into their child* according to the principal of van Asch. Developing a holistic sense of the child's development and preferences around communication and language use is encouraged. The centre emphasises parental choice, encouraging parents to make choices based on their observations, especially in regards to language use and communication. As the principal describes:

[The programme has] got a very strong focus on family. The parents or caregivers (whoever are the key people in that child's life), are expected to stay and be a part of the sessions because the sessions aren't just for the children, they're for the family. [The programme's] focus around that is parent-to-parent contact and [the programme] sees that as an important part of the programme: that they just have the opportunities to support each other, learn from each other. Often other parents have answers [the programme doesn't] have because they're living it. ... So parent-to-parent contact is very

¹⁴ Northern is defined as covering the upper to central part of the North Island, and Southern covers the whole of the South Island and southern half of the North Island to Taupo.

important in the programme and [the programme] also works with the family and the child, one-on-one around communication, and development.

Previously, the centre had designated times for different communication modes, for example, separate spoken language morning sessions and sign language morning sessions. However, leaders of the programme felt that this approach isolated parents and families from one another and the holistic benefits of exposure to other approaches. In the most recent approach, Sign Supported English was integrated into the programme, with the view that this would diversify the language experiences of children and their families.

KDEC offers a specialist preschool for local deaf children and their families. Due to its structure and funding as a preschool, deaf children and their families access the preschool from the age of two years onwards. This timing falls towards the end of what is typically considered as the early intervention period (age 0 - 3 years). The KDEC preschool therefore saw a differing catchment of deaf children and families to those at van Asch which caters for children who are approaching the end period in which EI services typically target, who may have already accessed other forms of support within the local region, and who may use a range of communication methods.

The KDCE preschool provides the country's only bimodal, bilingual preschool setting in which deaf children have the opportunity to acquire spoken English and NZSL from natural language models. Several key informants and whānau participants in this research noted societal prejudices toward sign languages, prejudices which were, in their opinions, perpetuated by professionals who shared this low-regard for NZSL. This meant some families were fearful of sending their children to this preschool. It was suggested that these families and professionals felt early exposure to NZSL was an inhibitor to the use of speech and listening skills, a desired outcome for most families with deaf children. A number of professionals noted that NZSL was viewed, by both families and professionals, as an option to be employed 'when all else failed' or as an interim strategy to be employed until speech and listening skills had developed. Several key informants and whānau participants in this research noted that the bilingual approach was misunderstood and feared by many families and professionals who erroneously believed the preschool focused on NZSL alone.

The nature of relationships and engagement between the preschool and families differ to those at van Asch. A collaborative approach to building relationships and working with families, as

described by key informants and whānau participants in this research, was valued by the preschool. However, the structure of the preschool meant it had less capacity to deliver a full mentoring-type experience than the van Asch EI programme, whereby EI staff would support carers', typically parents, development of self-knowledge of their children, based on observational experience. Contact time between staff and families typically centred around 'drop off' times, either at the beginning or end of preschool sessions and other necessary meeting times such as IEP meetings. While the preschool aimed to facilitate 'open-interactions' with families, it was reported that interactions were constrained in these settings and by daily-life constraints, such as parents' need to pick up siblings from nearby schools. Such constraints were amplified for those families whose children were transported from home to preschool via taxi or shuttle bus, thus limiting family contact time even more. Despite these constraints, the preschool encouraged regular contact and attempted to facilitate relationships between school and families outside preschool sessions. It was intended that this social exposure would support the development of a reference point from which carers could evaluate their developing knowledge of their own child. A senior teacher involved in the preschool noted these social experiences formed the basis from which a social identity as deaf, as opposed to a medical and/or linguistic based identity, could be formed. As the teacher explained:

[There are] family nights ...they've been running eight or nine years ... you don't get all the families but the option is there ... [there is] help with transport ... But it's that ... seeing your child interact with other children, it's seeing them interact with deaf adults, it's seeing deaf adults, deaf parents interacting with each other ...

... deaf children knowing each other [is] one of the bonuses of this particular centre. The GSE [Group Special Education] ... their goal is for the children to be part of their local community because of their Mum and Dad ... One of the outcomes here is that these children start to form relationships with each other, they are around other children that they can identify with – even if, at the beginning it's only that we've both got a hearing aid or we're starting to use sign language. To be interacting with the adults there, to go into the wider school events, like we've got Christmas assembly next week, KDEC sports day. That is a big outcome.

Ruamoko, a school-based marae, which is associated with a network of Māori deaf and hearing people, supports those within the KDEC region and is sited adjacent to the preschool. The preschool children regularly make short visits and interact in this setting with Māori adults, deaf and hearing. Again, this provided children and families with socialisation experiences, and an added dimension to a contextual repertoire from which to place their own observations of their child.

5.3.3. Cochlear implant programmes

The New Zealand Cochlear Implant Programme was originally established in 1986 with funding provided by the Deafness Research Foundation Inc. as a part of a research project situated at the Auckland DHB and with a satellite clinic in Christchurch (as of 1988) (NZ Audiological Society 2011). While both sites were initially privately funded and established through the efforts of professionals concerned at the dearth of support for cochlear implantation in New Zealand (Gunn 2010), the government has since earmarked significant funding to support unilateral implantation for a fixed number of deaf children and adults through New Zealand's public health system. In specific circumstances, for example, children whose hearing loss resulted from meningitis, funding is now provided for bilateral implantation (Ministry of Health 2013). This has been a point of public interest at the time of writing, and advocacy from professionals and families is being undertaken to encourage full government funding for bilateral implantation as an option. (Gunn 2010: 9; Radio New Zealand National).

The cochlear implant service is now delivered through two major providers, which, through their independent histories of development, had originally established themselves as independent trusts, contracted to the Ministry of Health. The *Northern Cochlear Implant Trust* (NCIT), services the Northland, Auckland, Waikato, BOP, Rotorua and Taupo regions, and the *Southern Cochlear Implant Programme* (SCIP), services the rest of New Zealand, from south of Taupo in the central North Island. Both Northern and Southern Cochlear Programmes provide adult and paediatric assessment, surgery, MaPping, and habilitation support towards the development of audition and speech. This includes actively assisting parents to facilitate their child's spoken language development. When asked to describe their overall focus, key informants from the services indicated that:

The wider goals are hearing and spoken language. So, for every child that comes through, the expectation is that by providing them a CI this is going

to give them access to hearing and that in turn gives them access to spoken language. So, the ideal outcome is that a child with a hearing loss ... by the time they reach school age they [will] have age-appropriate spoken language [and] attend their local mainstream school with minimum support. That would be the ideal goal.

Obviously language, oral language. I don't know if this is the way to put it or not but to provide a full oral language service to all children whose parents have made that choice and regardless of where they live, what their cultural or ethnic background is and what difficulties that they might have in their own home.

Key informants from both organisations emphasised that the outcomes experienced by implanted children are highly dependent on the timeliness of the implant and the suitability of tailored specialist support received post implant.

While both CI centres receive government funding to provide their service, they also fundraise to support the surgery sections of their programmes and various specialists supports such as auditory-verbal (AV) therapy, habilitation, audiology, family support, counseling, transition to school programmes, and preschool support, either a specialist preschool in proximity to the programme's centre or a mainstream preschool attended in the child's locality. Both programmes commended the government's decision to increase resourcing in this area, yet still rely on privately raised funds to implement their services. One provider, Hearing House, employs two full time professionals to lead their fundraising efforts. At the time of this research, 75% of their budget is from privately raised funds. A key informant from the SCIP programme, which is also governed by a charitable trust, noted the struggle they faced to deliver necessary post-implant supports with the current resources.

... We are governed by a charitable trust ... The majority of their funding is through the MOH and MOE. One of the things they are looking at is to make the programme more sustainable, so that as such alternative sources of income, other charitable organisations, private funders, ... looking at other sources of revenue to do what we do. If you look for example at children using speech processors, we don't have enough funding for... replacement processors. So a speech processor has a fixed life, so a lot of the children are

at the point where their speech processors will need replacing, so some children are not able to take advantage of the technology that is available.

Key informant A: If we had more numbers ... we could do more visits [within the] region as well. Key informant B: So, it's all those... travelling to children to do habilitation, providing training to them, it's all those things we have talked about. The consequence often for children is if they have problems with equipment or habilitation programmes in the regions and if we don't have the time or resources to follow them up, then they may visit us and we find that they need that support in their local centre. If they were properly supported and resourced we would be able to do it.

At the time of this research the SCIP was located within the grounds of van Asch close to their EI programme. Both the SCIP and EI programmes support deaf children, yet the SCIP focuses specifically on the development of speech and audition. Deaf children and the families who live locally can access these services on the van Asch site regularly. Those within the wider Southern region may either visit the van Asch site for a period of time to access intensive sessions focusing on cochlear implantation habilitation or EI supports, or professionals from the SCIP and EI centre may travel within the region to provide support to deaf children and their families in their homes and/or a mainstream preschool in their home region.

In the Northern region, the implant programme has a relationship with Hearing House (which also relies on significant private fundraising efforts), an Auckland-based provider of post-implant specialist support to deaf children in mainstream preschool settings, locally and in the wider northern region, and an onsite specialist preschool which supports spoken language outcomes. This preschool is attended by a mixture of deaf and hearing children, with hearing children acting as language role models, and is pitched to parents as a context that supports deaf children to develop speaking and listening skills so they might transition to a local preschool near their homes. At the time of this research, Hearing House was developing its service further to include counseling support, a parent-support network, and outreach post-implant support to the wider northern catchment area that the NCIP serves. The NCIP also has a working relationship with the preschool based at KDEC, which provides post-implant support to children in the bilingual, bimodal environment described above.

5.3.4. **Support for early acquisition of New Zealand Sign Language**

At diagnosis, an AODC will typically discuss language and communication options with families of deaf children. Depending on a child's responsiveness to modes of communication, and the views of whānau on language and communication options, an AODC can attempt to support the child and their family using NZSL in the home. Assuming that families will have little or no independent access to NZSL users, support and resources would be typically sought from the AODC, as a potential language model if they have fluency in NZSL, specialist staff and programmes based at van Asch and KDEC. An AODC may also provide support by seeking a local resource i.e. identify local users of NZSL or create a local resource, for example, network families interested in learning NZSL in a playgroup situation. Support is also gained through local and national parent-led support networks. In this context, those who have opted to use NZSL with their deaf child are able to network with others using NZSL on local and national levels.

A small number of deaf and hearing NZSL users are employed within the UNHSEIP in a professional capacity to support deaf children with NZSL acquisition, working, for example, as Deaf mentors, NZSL language assistants, resource teachers of the deaf (RTD), Advisors on Deaf Children, or as communicators and interpreters. These personnel, and the conditions in which they work, do not necessarily provide deaf children and their whānau with a natural language context which is regular, intimate and meaningful. Mostly these professionals work to facilitate deaf children's participation in mainstream educational settings and/or in one-to-one situations, whereby they support the deaf child's acquisition of NZSL from them as the individual language model. The AODC may be able to facilitate connections with a natural community of NZSL users, i.e., a community that exists based on natural need within the locality of the whānau. This assumes however, that the local communities of users have the time, skills and willingness to engage with and mentor local deaf children and their families.

Despite being recognised as one of the official languages of New Zealand through the New Zealand Sign Language Act 2006, support for deaf children's natural acquisition of NZSL during the critical period of language development through the UNHSEIP is, according to whānau participants of this research and key informants involved in this research, poorly supported. Several participants commented on the lack of local resources supporting language

development into fluency citing both small populations of NZSL users in the region where the deaf child lived making ongoing contact with fluent language models difficult to support, and that NZSL was poorly supported in the education system. Given the dearth of support at primary, secondary and tertiary levels of education for those using NZSL as a first language, the option of NZSL was prefaced by many professionals as an interim language support which could support ‘early communication efforts’, at best, until the child had acquired spoken language with the support of hearing aids, cochlear implants and therapy options supporting the development of spoken language. NZSL was posited to most whānau in this research as an unrealistic language option due to the poor support for acquiring fluency through the education system, and because as an NZSL user, the child would encounter compromised opportunities to access education and socialisation in NZSL. It was in this context that NZSL was equated to a language leading to limited educational options and obstacles to participating in mainstream society. According to the whānau participants of this research, becoming bimodal, having fluency in spoken and signed languages, was not posited as an option with whānau, nor were the social and emotional benefits of becoming an NZSL user and networking with other deaf NZSL users discussed. One key informant, a professional involved in supporting cochlear implantation, noted that families’ decision-making is influenced by the structure of services, their accessibility, and how well resourced they are. In their view, parental choices were constrained by the reality of poor services and access to NZSL, which naturally steered families to the well-supported and resourced option of spoken language.

Ethically anybody within our organisation, and outside, believes parental choice is the way to go. But if you’re a family living in a rural area then you know you do not have a choice of learning New Zealand Sign Language, if you don’t have a family member that can sign you cannot make that choice. You have to make the oral choice. I’m not saying that you should or shouldn’t. It’s not a value judgement, it’s just an observation, but you know that is not free choice.

Another key informant, also involved in providing service support to those post-implant, suggested that the parameters of their support limits the support they can offer to families. They are funded and resourced to provide access to spoken language, consequently other language options must be explored at the initiation of the family.

If people then want to pursue (separately) deaf culture and New Zealand Sign Language for their child (separate to what we do) then they can do that. We don't say to people you must not sign with your child, what we would say is 'We are focused on spoken language and this is what you need to achieve... this is what you need to do to achieve spoken language' Anything else they want to (if they want to elect to choose) go down a bilingual path, they can do that on their own.

Underpinning communication modality choices made by parents during the EI period is a tension between families' desire to maintain a close and spontaneous connection with their deaf children, to educate their child in proximity to their home, and often to their siblings, and within the language and culture of their home and communities. Deaf people and languages associated with deaf people (i.e. NZSL in the case of New Zealand) were rarely identified as a language indigenous to the deaf child by their whānau and were viewed as secondary to spoken languages by both whānau and key informant participants.

This chapter has completed the contextual understandings for the research. In the next five chapters I present the case studies of the young Māori deaf children and how they have fared. Each chapter presents a description and discussion of the deaf child and their whānau in relation to the key research questions. The main section headings include: *The shaping of whānau perceptions of deafness* which canvasses the contributing influences shaping whānau perceptions of deafness; *Experiences of Early Intervention: language and communication* describes the early intervention (EI) experiences of whānau in relation to language and communication and finally *Experiences of Early Intervention: Decisions and Opportunities* which describes the consequential link between EI experiences and the shaping of decisions and opportunities for whānau.

Chapter 6. Tiana

It is difficult not to form an immediate impression of Tiana. She is a vivacious and joyful child with a strong sense of self. Though petite and short in stature, Tiana is strong, athletic, and physically competent, moving with a sense of purpose and conviction. Assertive and definitely not self-conscious, she explores life through her body in what seems to be non-stop physical play, dance, and general movement. With a strongly defined independence and social agency, Tiana confidently interacts with others. Her spoken language is clearly comprehensible, socially appropriate, and often punctuated with facial expressions and gestures to express emotional intent. Tiana appears to realise the 'world is her oyster'. She relishes discovery in all its forms, and loves hands-on learning, thriving on the social company of others.

6.1. Overview

Tiana celebrated her fifth birthday when she and her mum, Rebecca (who is Pākehā), became involved in this research. Born prematurely at 27 weeks, Tiana suffered several health complications associated with gastroschisis¹⁵ and premature birth, of which deafness was one consequence. Diagnosed as deaf shortly after her birth, Tiana, an only child, has been raised in Invercargill by Rebecca, a sole parent, with regular support from her Mum and a group of close friends. Tiana's father is Māori. His iwi affiliation known to Rebecca is Ngāti Kahungunu. While Rebecca had been in a relationship with Tiana's father at the time of Tiana's birth, they separated when Tiana was approximately five months old and no longer maintain contact with one another. In an effort to provide Tiana with a context, Rebecca initially kept brief and amicable contact with various members within Tiana's paternal whānau. Eventually, however, she decided to limit this contact due to stress endured within what had been a difficult relationship. Neither Rebecca nor Tiana had seen or heard from Tiana's father since Tiana's first birthday. During the time of this research Tiana was living with her mother and grandmother in Rebecca's family home, and had begun settling into a local Catholic primary school. Toward the end of the research, Rebecca was living with Tiana in her own house in proximity to her mother, close friends, Tiana's school, and Rebecca's work places.

Rebecca reported that to a large extent she was relatively pleased with Tiana's developmental progress. She was participating actively in family life; progressing well socially and academically at school with the assistance of support staff; and her spoken language was comprehensive and developing at age appropriate levels. In October 2010 Tiana was identified as 'very high needs' via the Reviewable Resourcing Scheme (RRS) assessment. Correspondence from the Ministry of Education indicated their expectation that, as a child with a cochlear implant, Tiana would eventually function in the same capacity as a hearing child and would require a lesser level of support. In January 2011 however, correspondence between the Ministry of Education and Rebecca indicated the introduction of the "Success for All – Every School, Every Child" meant Tiana would be shifted to the ORS (On-going Resourcing Scheme) and verified as 'high needs' for her remaining school years.

¹⁵ Gastroschisis is where the abdomen is not sealed and the bowels protrude externally from the body at birth.

The process of participation in this research¹⁶ provided Rebecca with an opportunity to reflect on how she processed the trauma associated Tiana's premature birth, how she managed to cope with Tiana's evolving health complications associated with premature birth, and how she eventually ended the difficult relationship with Tiana's father. Reflecting on the first few months after Tiana's birth, she said:

I think it was "yes I am a first time mum and then this has happened and it's totally not what you expect". You want your baby to be healthy or whatever, but yeah she's not ... so therefore I was just probably more like asking "Is she going to die?" "Like is she going to die?" "Oh my God - is she going to die?" I guess I kind of thought like that but then also because of all my crap that was at home I guess I never really registered anything anyway. Everything was just way above my head, it was crazy. Like crazy, intense and I don't know it's really hard to explain, it's like nothing I've experienced before. I still look at her to this day and just go 'Wow, I've got this five year old'. What the hell, five years of all this crazy trauma! I guess in some ways it's a traumatic part of my life that was just blocked out. I dunno, I've never just broken it down and never really gone into too much depth because she's okay. (Rebecca)

Rebecca also reflected on the meaning of her recent experiences of EI support, how information had been presented to her, and how this informed her decision-making processes. As a sole parent with a small and close support network, Rebecca attempted to deal with adversity with a pragmatic 'get on with it' attitude. However the challenge of being a Pākehā mother raising a deaf and Māori child in Invercargill presented unique challenges. Rebecca expressed her concerns as to how best to socialise Tiana as Māori in the absence of her paternal whānau. Fortunately Rebecca had a close network of Māori friends. Meeting with other deaf people and their whānau through the Hui Whakawhanaungatanga heightened Rebecca's awareness of the complexities underlying deaf people's social and linguistic realities and fostered a greater

¹⁶ Rebecca and Tiana were introduced to me via the Southern Cochlear Implant Programme (SCIP), who acted as an intermediary contact during the recruitment phase of this research. During the course of the research Rebecca and I met several times over weekend periods; I flew to Invercargill and spent time with Rebecca and Tiana (and those in their social sphere) in home, community and school contexts.

understanding of the history of deaf people within wider society. Both Rebecca and Tiana enjoyed their contact with other deaf people and their whānau, as it provided a social context of support comprising those who identified as both Māori and deaf, something previously lacking in Tiana's life.

This chapter provides a description and discussion of Tiana and her whānau in relation to the key research questions.

6.2. The shaping of whānau perceptions of deafness

6.2.1. Identification of deafness

At her twenty-week scan Tiana was identified as having gastroschisis. Her abdomen was not sealed and her bowels were hanging externally from her body. Tiana was born shortly after at 27 weeks gestation, weighing 1044 grams, and was admitted to Wellington Hospital's New-born Intensive Care Unit (NICU). A series of immediate medical interventions were undertaken to resettle Tiana's bowels and close stoma formations¹⁷ and her abdominal wall. Tiana was incubated and ventilated from birth, and required on-going ventilatory support and treatment for neonatal jaundice. Rebecca resided at Wellington's Ronald Mac Donald House¹⁸ while Tiana remained in hospital for a five-month period; Rebecca's days were spent at Tiana's side with four-hourly visits in the evenings though she was often unable to touch or feed Tiana due to the child's fragile condition. When Tiana was aged 30 weeks Rebecca was finally able to hold her daughter. Faced with the gruesome reality of her health complications and Tiana's fragility, Rebecca anchored herself with points of certainty, choosing to focus on small achievements and feeling incredibly grateful for her daughter's life. Deafness was however, not a consequence that Rebecca had considered or prepared for. Discharged from hospital with no formal diagnosis of hearing-loss, Tiana was referred to audiology for further testing having been screened for hearing loss twice while in hospital. After several attempts at diagnosis Tiana was eventually diagnosed with a severe bilateral hearing loss.

All the nurses just used to love her because she was real 'cruisey', she was real quiet, always a good sleeper. I thought 'Why is she so quiet?' I didn't

¹⁷ A stoma is an opening (either natural or surgically created) connecting a portion of the body cavity to the outside environment.

¹⁸ Ronald MacDonald House is a charitable organisation that provides residential support in proximity to hospitals for families of hospitalised children.

think at the time she may have a hearing loss. ... They actually did warn me about the whole big picture, like cerebral palsy and blindness or 'you could have hearing-loss' but I never really thought that would happen. (Rebecca)

6.2.2. The evolving context of whānau

Tiana's premature birth and the health complications stemming from both the premature birth and gastroschisis – including deafness – was, for Rebecca, an overwhelming experience. Rebecca had recently moved to reside in proximity to Tiana's paternal whānau. She found managing the difficult relationship with Tiana's father while isolated from her own support networks to be overwhelming at times and was deeply concerned she had lost the support and confidence of her family. Approximately four months after returning home with Tiana, Rebecca was disheartened by the lack of practical and moral support from Tiana's father, and decided to end the relationship. She returned to her hometown to raise Tiana in proximity to her own family. Despite her difficult relationship with Tiana's father, Tiana's paternal whānau were affectionate and loving with Tiana and provided practical support. Tiana knows her father's name, where he lives, and has photos of him. However, he is an enigma at this stage in her life. Consequently Tiana has had very little experience of her paternal whānau from which to assist her understanding of her Māori heritage. Rebecca's network of support however comprises a group of close friends who are a mixture of ethnicities including Māori. People within this group know Tiana intimately and some speak te reo Māori to Tiana, and socialise her in contexts which operate under Māori social norms.

Duane used to speak to her in Māori and I'd speak to her in English. I know some Māori words and I would use them. And like her Kōkā¹⁹ Tray who was talking to me [in te reo Māori] and Aunty Tamai they were with me in Wellington. I know Tray is fluent in Māori and so every time we'd go to her in Christchurch she'd teach her. ... I wanted her to go to a school where they had a strong kapahaka and were into cultural things. (Rebecca)

I really want Tiana to know she has this unique heritage, and I want her to learn it. I know that I won't be able to teach her like she should be taught. That's why it was important for me to send her to a school where it is whānau

¹⁹ Kōkā is a term used to refer to a maternal figure; mother, aunt and/or a female role model to children and others. This term is used as a sign of respect.

based. [I ask: “Would you say the school’s whānau based?”]. Oh yeah definitely, that’s why it’s probably why I picked that school because they’re big with kapahaka, they’re really whānau based, everybody knows everybody. (Rebecca)

It is within this new configuration of support that Tiana has been raised during the early period of her life. Rebecca acknowledged the limitations of parenting alone and noted the significant contribution her family, friends and EI professionals made to raising Tiana. This network provided a diversity of social experience which Tiana was able to draw from, and a network of parenting advice and support for Rebecca.

Tiana is my wee village child. From ‘day-dot’ there have always been heaps and heaps of people caring for her. That’s why I think she copes really well with lots of people because it’s always been like that. And I like that. I like that she can experience everything if she can. Why not? Because I don’t know everything [implies she has no experience from which to inform her decision making]. (Rebecca)

To date however, the majority of Tiana’s day-to-day life has been lived in proximity to her mother, maternal grandmother, and Rebecca’s small group of close friends. Rebecca has raised Tiana in households with either her friends or her mother in a childhood home. Working in various part-time jobs (hairdressing, labouring, and painting) in order to support Tiana and herself, her efforts have focused on providing a stable home-life with emphasis on maintaining child-centred routines. At the beginning of the research Rebecca and Tiana were living with Tiana’s maternal grandmother, following is a description of our first meeting in her home.

I meet Rebecca at her home. A meandering footpath down the side of a 1940’s style Bungalow leads to a front door and is littered with boys and girls bikes (I note they have no training-wheels). I wonder if Tiana has siblings. It is later confirmed that Tiana is physically accomplished and can ride bikes without training wheels and is ‘a bit of a tom-boy’. An established garden surrounds the property and given the planting choices I wonder if this is a family home or owned by an older person. The front porch and stairs are spacious with a small arrangement of shoes out front. I knock and Rebecca, a Mum aged in her 20’s, greets me warmly and affectionately. I am led down

the hallway. Family photos cover the wall, some of which include family sporting photos spanning several generations. We enter the open plan kitchen and dining room area where I am introduced to Tiana and her grandmother. Tiana is excited. She wiggles, shuffles, giggles and beams an extended smile, unable to bring together some words to greet me with. She immediately comments on my hairclips and jewellery, trying to touch them. We giggle and she exclaims 'sparkly'. She introduces her 'ears', her cochlear implant, it is a statement: "I have ears". She is desperate to touch me and so I give her a little cuddle. She knows this visitor is just for her and appears to relish in the attention. Adult conversation ensues, and we undertake a mutual assessment of one another. An assessment of my intent is made by Rebecca's mother, who appears supportive of Rebecca and her decision-making. Rebecca, Tiana and I are left alone. Rebecca and I have a cup of coffee and chat. I suggest given the time, it is 5pm, we go out to get a bite to eat and we agree on MacDonald's. Tiana cannot keep physically still. She races down the path outside, sidestepping bikes and other toys covering the footpath. Every third step or so she springs up like a little lamb. I cannot help but giggle as she is so sweet. While in the MacDonald's car park Tiana announces her father's name, excited to share this piece of information. I smile, affirming I have noted what she has said.

Over the years Rebecca has collected a series of photo and memorabilia connected to Tiana's birth and early childhood. As a part of the research process, Rebecca, Tiana and I spend a morning reviewing photographs. We are led by Tiana, who chooses photos of significance to herself and introductions and explanations of the significance are given. Various members of Tiana's maternal family and friends from school, community, and family networks feature heavily in descriptions and intricate detail is given as background to events. Tiana was able to identify her father in photos and labelled factual information known to her, such as his name and place of residence. It was obvious Tiana held those in her social sphere in high regard and invested considerable effort in maintaining relationships with peers from kindergarten, school, and family networks.

6.2.3. **Constructing deafness through experience**

Rebecca absorbed the implication of having a deaf child over time. As deafness was a non-life-threatening condition the meaning of deafness and the experience of parenting a deaf child was not something that Rebecca had given specific thought to until this research asked her to describe her experiences. In Rebecca's view, their lives were a journey travelled alongside one another, and through living life they learned about one another. Rebecca did however share her angst that she would never be able to fully understand life from the perspective of a deaf person and that she lacked a life experience of deafness to parent from. Nevertheless, it was a task she was clearly prepared to work through.

A number of visual diaries, profile books, and family albums have been produced by Rebecca, kindergarten teachers and EI Specialists to document Tiana's early life, her developmental progress, and to support Tiana in making sense of her experiences while at home. During one of our informal meetings Rebecca and Tiana began to shuffle through the items and decided to construct stories attached to them. Their narrative began with items associated with Tiana's birth and the early months during which she was hospitalised in the NICU. The discussion then shifted to her early years at preschool and touched on the interactions with professionals providing EI support. Tiana appeared to be aware of her difficult start to life. She understood innately that she had endured pain, and now accepts she is now safe, healthy, and happy. The following excerpt is an observational note describing part of this informal meeting.

Tiana wrestles with the lid of a small circular box. She manages to jiggle the lid off, springs to her feet and stands ready to individually present the contents. Inside are objects from her time in NICU, memoirs from her past. I invite her to sit and explain the meaning of the individual objects. The first object presented is a cut-out of her name with a butterfly on it. This is followed by the various medical paraphernalia she is unable to name, such as the velcro fasteners used to fasten cords in place. She then presents a small angel doll a gift from her Nana, tiny pink booties, a knitted bonnet, which she attempts to try on, and tiny nappies. She smiles at them fondly, almost as if they belong to a distant memory. Tiana pulls out a rubber band and wraps it around her arm, asking her mother "what's this for"? Rebecca replies "It's for your blood pressure". Tiana becomes unusually quiet and announces, "I get hurt". We go through her photos from the days when she was in NICU,

Tiana comments on a newborn photo of herself “Oh, oh – it was sore!” her eyebrows inverted. Tiana flicks through this album with a mixture of smiles and inverted eyebrows, indicating joy at seeing her newborn photos and displeasure at seeing her fragility and pain. She places the album on the floor and remembering the presence of a camera, stares at it and smiles.

After we browse through various family photos with introductions to her various friends, family members and memories of events being made, Rebecca shows me a montage of photos and images pasted onto a large piece of fluorescent green card. The objective of the montage was to explain Tiana’s deafness to teachers and children at kindergarten. It provided an insight into how Rebecca had constructed or made meaning of Tiana’s deafness at the time. Handwritten messages surrounding the images provide a guide and interpretation to the arrangement.

The story begins at the left of the page – photocopied images of the ear with a cochlear implant, names for the various parts of the ear and hearing aids are taped to the side. “My name is Tiana, I am profoundly deaf” sits along these images. Central to the montage are images of Tiana eating her Weet-Bix while in hospital, post-surgery, for her cochlear implant (her head is heavily bandaged). There are images too of the members of the Southern Cochlear Implant Programme, the house made available to Tiana and Rebecca while visiting at the Van Asch premises, and a photo of a mural at Van Asch which reads:

Deafness

Is a Miracle

Of Nature and Heaven

With a Language of Beauty

New Zealand Sign Language

Toward the right of the montage are images of facial expressions and images of NZSL signs from the New Zealand Sign Language Dictionary; the text reads, “I can learn lots from facial expressions and New Zealand Sign

Language”. At the bottom left of the Montage are more recent photos of Tiana with the text “This is me on the day of my surgery – 19 July 2007 at St George’s Hospital, Christchurch. I got a cochlear implant. I can hear now thanks to the Southern Cochlear Implant Programme”. Tiana is in the other room putting her shoes on, she returns to the room. I point to the montage and ask, “What’s this?” Tiana squats down to the floor with her face close to the paper. She taps the images of the ears and whispers as if addressing the paper “I don’t know? ... I don’t know? ...” Tiana traces the images of the ears with her fingers and pauses, she then recognises her photos of herself and replies, “It’s for me, it’s for me!”. Tiana sits quietly for a minute with a distant, reflective expression, then shuffles across the carpet and fiddles with the small hearing-aids taped to the left edge of the montage. Tiana announces, “Those are my ears – they’re for little girls, aye?” Rebecca and I giggle.

During Tiana’s early years, Rebecca was presented with the usual plethora of information provided to families of deaf children. She also had the opportunity to meet two deaf children with cochlear implants, and their mothers, as well as two deaf adults, one who had a cochlear implant and used spoken English and the other who was a fluent user of NZSL. The meeting with the adult with a cochlear implant was an accidental encounter at a local shop. Rebecca did not feel it appropriate to question the person about her cochlear implant or her way of life within this context, and their contact was restricted to an exchange of pleasantries only. Meeting the fluent user of NZSL was organised by staff at van Asch to provide a social contact or a potential network of localised support intended to provide, through the sharing of their stories, a context to the meaning of deafness and the potential life trajectories of deaf people. This was not immediately obvious to Rebecca. Meeting with a fluent user of NZSL included a presentation in a lecture format. Although the information was informative, practical, and delivered in an engaging manner, Rebecca was only passively engaged and information received was taken at face value. Though Rebecca valued the person and the idiosyncrasy of their experience she did not have enough life experience with Tiana at that point to ask critical questions or critique the information given. She was unable to apply the deaf person’s narrative to her own child’s experience of a cochlear implant. Contact with parents at the KIT (Keep in

Touch)²⁰ days with deaf children for example, was largely superficial. Meetings were pleasant and friendly yet they were also restrained, principally due to mutual unfamiliarity. Again, Rebecca did not have enough of a bearing on Tiana's own situation to know how to ask for specific support, to form questions about the meanings of deafness, or to compare others' experience to her own. When Tiana's AODC organised a meeting between Rebecca and another mother whose son also had a cochlear implant, Rebecca described the meeting as a 'try before you buy' meeting. She wanted to know what the outcomes of the cochlear implant were in real terms, i.e. could the child hear, and was their spoken language intelligible and comprehensible. In hindsight, Rebecca viewed this meeting as somewhat misleading, comparing it to 'trying on jeans'.

I met a lady here – when I moved home – with her son who had a cochlear implant and she came to see me and that was good too, meeting another mother ... but because I think I met her at the time when I didn't really know what was going on and I couldn't ask her the right questions. She would really only answer what I would ask. (Rebecca)

It's not like buying a pair of jeans, they might look really good when someone else puts them on, but you might not fit them and look ridiculous and they don't work for you. (Rebecca)

Rebecca was encouraged to connect with another parent whose child was deaf and also had a cochlear implant as an informal mentor. To some extent Rebecca assumed Tiana would automatically connect with this child as they attended the same preschool, but this did not eventuate. The two children enjoyed one another's company as children naturally do in preschool settings. However, due to differing abilities in language and social skills, Tiana preferred to socialise and bond primarily with other hearing children.

From Tiana's birth onwards Rebecca was required to focus on the immediate medical attention her daughter required. Deafness in this setting was initially framed as another physical consequence of Tiana's premature birth, essentially as a condition requiring medical intervention. Tiana's responsiveness to the cochlear implant and success with acquiring age-appropriate spoken language was reassuring for Rebecca whose aspirations were for Tiana to

²⁰ KIT (Keep in Touch) days are organised by Teachers of the Deaf and supported by regional family support groups around the country. They involve social activities and outings to allow families with deaf children to meet, exchange information and offer friendship.

be actively involved in the social life of family and community. Rebecca however, also embraced the idea of exposing her to other social experiences which validated Tiana's difference as deaf. Structured attempts – such as parent-to-parent meetings, and meetings with sole deaf adults provided, to a limited extent, the context of 'a single version of deaf experience' which left Rebecca dissatisfied and Tiana disinterested. Social contact at KIT days partially addressed Rebecca and Tiana's need for social contact with others with similar social experience, yet Rebecca admitted her preference for interactions with a focus on Māori children and their whānau, and a context which operated on Māori social norms.

The Hui Whakawhanaungatanga held toward the end of the research phase filled this gap in social experience for Tiana and Rebecca. Within safe proximity to her mother, Tiana relished the social environment which allowed her to spend time with both hearing and deaf children and their whānau, attempting communication using spoken and signed modes even though her knowledge of sign language was limited. She especially enjoyed spending time with two teenage deaf women who attended as kaiawhina (support people and helpers). One of them had a cochlear implant, spoke both English and te reo Māori, and was a user of NZSL while the other, used primarily NZSL. During our last meeting, Rebecca reflected on the hui, concluding the event 'opened her eyes' to the multiple experiences and perspectives of deaf people and their whānau throughout different stages of life. Myths, such as, for instance, that deaf people with cochlear implants don't use NZSL, were debunked as Rebecca was exposed to this social situation during which spoken languages (English and te reo Māori) and NZSL were used with ease by both deaf people, with and without cochlear implants, and hearing people. Rebecca was also affirmed in her decision to implant Tiana, suggesting that in her context, and with the resources available to her, 'she would have been lost without it'. Rebecca's angst around not knowing what 'life as a deaf person' was like was partially alleviated as a part of this research process. Becoming aware of the historical context of deaf people in society and other's experiences of deafness provided a fuller context to her own experiences of parenting Tiana.

6.3. Experiences of early intervention: language and communication

Post discharge from the NICU, Tiana was referred to audiologists for testing in the Hawkes Bay to ascertain her diagnosis. She was diagnosed as having severe-to-profound bilateral hearing loss and was fitted with hearing aids around September/October 2006. This fitting and

meeting with an AODC coincided with Rebecca relocating to her hometown, almost a year after Tiana was born. It was also during this time that Tiana was hospitalised for on-going bouts of bronchiolitis, later diagnosed and managed as asthma, and ear infections treated with grommets. Rebecca reported Tiana did not tolerate hearing aids well. She could only wear them for approximately an hour per day, regularly attempting to pull them off and chewing on them. Audiology reports suggested Tiana's hearing aids were of little benefit in terms of allowing her to access spoken language. Tiana's AODC encouraged Rebecca to consider a cochlear implant and began the assessment process in April 2007. In the interim the AODC supported Rebecca to use a basic vocabulary of NZSL signs with Tiana for early communication and language development and advised her to be assertive in making Tiana's hearing-aids a part of her routine.

Basically she, she didn't really tolerate the hearing aid, she was pulling them out, didn't really like them, they were uncomfortable. I didn't really see a humongous change in anything. If anything, she was more irritated by the whole experience. So, I guess she, it must have been the AODC that said, you know, 'this is the type of thing that's available [referring to a cochlear implant] we could possibly see what we can do with that?' So I sort of just went along with it, I was thinking – okay?" (Rebecca)

Rebecca found the introduction to NZSL an exciting process as she was finally able to connect everyday life experiences to language. Language was used in a relevant and engaging manner and Rebecca made an effort to extend her own learning of NZSL. Tiana was receptive to NZSL, responding appropriately and depending heavily on facial expressions for cues of emotional behaviour and responses, a behaviour which Tiana still maintains. Rebecca could see the practical benefits of NZSL in a home context, yet she privately held fears that Tiana might experience prejudice and limited social participation if she relied solely on NZSL. When the option for cochlear implantation was proposed, Rebecca continued to use NZSL with the intention of using it as an 'interim communication strategy' that would support Tiana's acquisition of spoken language post-implantation. During this time Rebecca relied heavily on professional advice, and was also advised to focus on supporting spoken English as a primary language.

I did sign with her when she was a baby and it was very exciting. After I got to grips with it, I'd stick up wee posters that I'd been given, cut outs, I'd stick

them up all over the place ... just after she had her hearing aids. I must have moved into the house with my friend ... I used to stick them up around the house and we'd do wee signs. We were quite into it, it was something new. Everybody that would talk to me would ask 'Does your daughter sign?' and I would say, 'Well you know, just baby-signs – just simple'. You know she'd ask me for a drink or something to eat and she really liked signing 'plane' because we used to go on planes heaps and she'd sign 'Are we going on the plane, Mum?' My AODC advised me not to do the sign, because she said, 'She needs to start listening'. I was advised to encourage her to listen and use her speech. I thought about putting her into a wee kōhanga down here and I was advised in a 'nice way': 'because she is 'like this' [using spoken English] and 'because she needs to start doing this [use spoken English]', 'what is your first language going to be?' 'I wouldn't advise you to do that [use another language] because she might get ... confused. (Rebecca)

Tiana received her cochlear implant on the 19th of July 2007 under the Southern Cochlear Implant Programme when she was almost two years old. Post-surgery treatment was timely and regular. Support included switching on the implant, Mapping (the setting of the electrical stimulation limits necessary for the cochlear implant user to perceive soft and comfortably loud sound) and Habilitational support (support with developing listening and spoken language). Shortly following her implant, Tiana started attending afternoon sessions at her local kindergarten. Initially she attended kindergarten three days a week, and later five. Reports from Tiana's AODC, Resource Teacher of the Deaf (RTD), and Rebecca, suggest Tiana found kindergarten an enjoyable experience, where the social context contributed to her progress towards developmental milestones and acquiring spoken language. Kindergarten was not, however, Rebecca's first choice of preschool. Conscious of Tiana's identity as Māori, and concerned that her ability to provide Tiana with access to te reo Māori and tikanga Māori within her own home environment was limited as she was not a speaker of te reo Māori Rebecca considered sending Tiana to kōhanga reo. Knowing she was ill-equipped to support Tiana in affirming a sense of positive cultural and linguistic identity as Māori, she considered kōhanga reo to be a type of intervention, a means of supporting her in Tiana's development as a Māori child.

[I ask Rebecca – Why would you have sent Tiana to kōhanga reo? She replied]. “I thought it would be good for her because I was never going to be able to teach her the language and I think that should be important to her. I want her to embrace her culture and I want her to know about it. I wasn’t going to be the one that’s going to be able to do that for her. I just like the whole whānau-type aspects of it. Like they were very, you know, family-orientated. (Rebecca)

Rebecca was, however, encouraged by various professionals to focus on spoken English as a first language for Tiana, primarily as it was her household language. Tiana remained in kindergarten for the entire preschool period. While Rebecca did not argue against the rationale of focusing on her home language, she privately regretted that Tiana did not have access to Māori-language environments to support her development in ‘other ways’, in particular, to support a positive self-image as Māori.

Tiana primarily communicates in spoken English. Her ability to speak clearly and be understood is more or less comparable to a hearing child in social situations. However, Rebecca reports that at times Tiana still has difficulties in understanding instructions and questions. Rebecca uses several strategies, such as repeating herself, speaking clearly to her face, using visual information or tangible examples, or leading Tiana through examples to support her processing of information. Many aspects of Tiana’s body language, her tone of voice, and her communication strategies suggest she is deaf and has used sign language. Signs used in infancy, such as ‘plane’, have been retained and she still prefers to use some of these signs instead of their spoken equivalents. She also uses facial expressions to communicate emotional intent or to mark questions, for instance, inverting or raising her eyebrows. Overall, Tiana has exceeded Rebecca’s expectations for her language development and communication.

Rebecca believes Tiana’s confidence is testimony to her on-going success in social life. The following excerpts are observational notes based on two outings with Rebecca and Tiana, intended to depict how Tiana fares in social contexts and how she uses languages in these environments.

Tiana is racing between the MacDonald’s playground and her table, she picks intermittently at her chips and a few cold chicken nuggets. After fossicking in her ‘Happy-Meal’ bag, Tiana realises she was given a ‘boy toy’ and

protests loudly using her body and spoken language simultaneously; “No, no, I want the girl one, the girl one!” She stamps her feet and shakes her head and hands. Rebecca searches her wallet for change; I offer her a coin, which she accepts. Rebecca speaks clearly and toward Tiana’s face. Tiana watches as she is instructed: “Go to the counter and ask for a girl toy”. Tiana hesitates briefly, searching her mother’s face for further information. Rebecca repeats herself. Tiana quickly turns on her toes and weaves between the adult legs to the back of the busy Friday night queue – completely confident in her ability. Tiana quickly returns with her toy, presents it to her Mum proudly and announces, “I got a girl one, I got a girl one”. I notice Tiana rolls her ‘r’ with a southern accent.

The weather is wet and cold, but it seems there’s quite a crowd already. We park across the road from the park where the circus is being held. It’s called the “Aotearoa Circus” and is animal-free. As soon as we park, Tiana spots some friends known to her from kindergarten; she points and announces their presence to Rebecca. Rebecca catches up with them. We purchase tickets to the circus and potter around the front waiting to be ushered in. The tent canvas is predominantly red and yellow. The light shines through and everything inside the tent is given a red tinge. I find it visually overwhelming and distracting and I wonder how Tiana experiences this. We settle down to plastic seats. They are front row and Tiana has direct visual access to the centre ring. As soon as the circus music starts Tiana is immediately disturbed by the noise and covers her ears. She is absorbed by the performances although I can’t really tell if she can follow the auditory information, (she doesn’t respond to their calls for crowd participation). But she follows the visual humour in the acts well. I’m not sure if that’s due to the grown-up nature of the content or if she simply can’t process the instructions. Tiana sees me taking photos and asks to take some as well. I let her play with my camera, she enjoys taking photos, and I think it makes her feel an adult. At halftime it’s cold, wet and raining. People congregate under the ‘circus shop’, a tent filled with traditional sweets such as popcorn, homemade fudge, and fruit juice in paper cups. There are no pre-packaged factory sweets or treats here. Rebecca buys Tiana some popcorn in a paper cup. When Tiana wants

to go to the toilet, Rebecca takes her to the queue of children holding on to their mothers' hands, their little bodies jiggling up-and-down in earnest at the make-shift portable toilets. After halftime Tiana decides to sit with her little group of friends, three or four other children, on the metal stairs. Rebecca gives her space and sits further away by the plastic chairs; Tiana and her friends giggle away and point at everything! Rebecca and I giggle. It appears Tiana is having a great time with her friends, and seems to follow their conversation generally although it's hard to hear what they're saying with all the noise. I wonder if they're all just saying things like "look at this" "look at that" rather than having a detailed conversation?

6.4. Experiences of Early Intervention: Decisions and Opportunities

I suppose I'm learning everything with her ... these people are professionals so they ... they know best ... I guess. [I ask Rebecca: "Do you think they know best?"] Well I don't know any different ... so I don't know ... yeah?
(Rebecca)

Since Tiana's birth Rebecca has had a sense of having very little control over her situation. Initially, she had not come to terms with falling pregnant, and Tiana, premature with severe health complications, was not what she expected. During this early period Rebecca relied heavily on her maternal instinct and decided to focus solely on Tiana, filtering out peripheral distractions such as relationship pressures, aiming to bond with her daughter. Attempting this while her future was uncertain intensified the bonding process. Bonding, despite adversity gave Rebecca the strength and conviction to make difficult decisions, celebrate all achievements (big and small), observe her child's innate 'free-will', and appreciate that maintaining an open mind helps to live through life's unexpected 'curve-balls'. This mind set has framed the way Rebecca approaches her decision-making since Tiana's birth.

Initially, information on Tiana's prognosis was short-term focusing on the need for major medical interventions such as surgery. In these instances Rebecca felt she was ill equipped to make decisions. Information was provided to her in verbal and written form, but Rebecca felt

that it was presented merely as a set of directions, and she was not, at that time, able to evaluate or provide context to these. The terminology baffled her, as did the complex explanations of the functions of the body and the impact of direct intervention. Given her situation, however, Rebecca was unable to find any alternatives and hence she trusted in the professionals' expertise despite her concern for the consequences. As a result, Rebecca focused on those aspects she was able to control, in particular her role in providing maternal support to Tiana.

They talked to me as if I was to understand all of these big medical terms, but didn't necessarily break it down "like this is what she's got". All I wanted to know was that she was going to be okay and today she's okay, today she's eating, today she's pooing. Okay we've got through today and then we'll go to the next day. You know I'm pretty simple like that, like just keep it simple and then I'll cope alright. (Rebecca)

By the time Rebecca was beginning to meet with professionals associated with Tiana's deafness she became more familiar with the processes by which medical professionals operate. Her first interaction was with diagnostic and audiology professionals who presented much of the information in a clinical manner. Key messages she gained at that point were: 'Tiana was deaf'; 'she could hear very little if at all'; and 'hearing aids would provide access to spoken language'. These messages took a while to process. It was also a message Tiana's father found difficult to accept and Rebecca found herself in the role of mediator, trying to temper his reaction to professionals. There was also no support for them as parents to help process this information. They had little understanding of the implications of what life as a deaf person entailed.

Shortly after diagnosis Rebecca shifted to Invercargill and met with a very different type of professional. The relationship Rebecca had with Tiana's AODC was founded on frequent contact and discussions of Tiana's development and progress within a preschool and home context. This was in contrast to contact with medical professionals which had been characterised by infrequent and brief contact in medical settings during which factual information pertaining to Tiana's health and a list of potential medical intervention pathways were imparted. The AODC provided a relationship and channel of communication that supported Rebecca and Tiana in various ways. Sources of information, written, auditory, visual and kinaesthetic, were provided, and 'real world' contexts to factual information such as introductions to networks of those with lived experience relevant to Tiana's situation, were

facilitated. Despite this support, Rebecca admitted she still had little sense of the long term impact of deafness that could help her to evaluate or critique information, and was, to a large extent, entrusting decision-making to professionals.

Then they said 'this is what happens'. So I guess I didn't really grasp the whole hearing aids, cochlear implant thing. Why is it so miraculous and these kids can talk all of a sudden? And how do you actually do that in the first place? And run the risk also of doing it and completely ruining all or if any hearing she had anyway!?' (Rebecca)

The decision to implant Tiana was perhaps the most significant decision made in Tiana's early life, and in hindsight Rebecca was pleased with this decision, especially given that the predicted outcome, that the implant would support Tiana with spoken language and enable active participation in family and community life, was clearly achieved. Rebecca perceived her role in this process to be somewhat passive as even up to the point of this research, she had not understand the technology of the implant, only the real-world implications of being implanted, that Tiana was using spoken language confidently in social contexts.

Tiana is deaf, she is profoundly deaf, she has a cochlear implant, I do need to understand it, I do need to know it. I think 'I do know it' 'but I don't'. It's only because I don't fully understand the technology, the biology". Why don't I understand it? I don't know? Maybe it's because I'm just more like 'hello, she is implanted now and she can talk – so we're okay'. But I know I shouldn't be like that ... I don't tend to think like that ... but I do. (Rebecca)

As Tiana aged, Rebecca also observed a wider consequence to her decisions, lamenting her lack of understanding of the social consequences of being a deaf person with an implant. During one of our last discussions Rebecca confided her concerns around how Tiana might cope socially as she grew older, what types of challenges she might face in society, and how could she foster Tiana's resilience to work through those life challenges. The following excerpt is a summary of our last discussion as a part of this research. It illustrates the sense of uncertainty she experienced despite feeling satisfied with Tiana's developmental progress, Rebecca was also curious about Tiana's potential life path.

Tiana and my son play tag on Rebecca's front lawn, the sun is setting. As we say our extended goodbyes, Rebecca confesses she wonders what life might

be like for Tiana as she gets older and how she will fare socially and academically in her teen years with a cochlear implant. We discuss potential sources of information to help Rebecca explore the issues young people with cochlear implantation face socially and academically. Rebecca is bewildered at how much she will need to explore and wonders where she might get support to deal with what she predicts will be issues unique to Tiana as a young person with a cochlear implant. Rebecca asks some basic questions around deaf history and is dismayed at the little she knows of this history. She suggests support and encouragement for parents to access this information is necessary so they can contextualise their child's situation and to provide a platform for resiliency. The setting sun and mosquitoes biting our children's ankles are cues for our final goodbyes. We promise to maintain contact.

Chapter 7. Brooklyn

Brooklyn is an observant child. Listening actively with her eyes, she engages with people and environments. You can see Brooklyn's thinking in her eyes. Petite in frame, Brooklyn's strong physique is detailed by her fine bone structure – her limbs, feet and hands are long, narrow and slim. Dark curly hair, skin, and expressive brown eyes dominate her face. Brooklyn's language was emerging during the research period. While playing, she focused on action orientated aspects of play with other children. Confident in her 'internal voice' however, Brooklyn uses her physical prowess and competence with grace and skill, rendering her a well-liked play companion with other children. Identifying strongly as a 'girl', Brooklyn likes pretty yet practical clothing. Her mum, Ngairé, often dresses her with splashes of 'girl colours' such as pink and purple. Sweet and kind natured, Brooklyn's quiet demeanour belies her inner sense of physical competence, resilience and knowing who she is.

7.1. Overview

Living in the quiet semi-rural settlement of Waiouru Military Camp, Brooklyn was living with her mum, Ngaire Taitimu-Swainson, her ‘dad’, Riki Taura, and her baby brother, Kyrin (aged three months at the outset of the research). Riki is not Brooklyn’s biological father, but is considered by all (including Brooklyn) to be Brooklyn’s dad, their bond founded on an early attachment with her. Through her mother, Brooklyn’s whakapapa connects her to her iwi, Te Āti Awa (Taranaki), Te Aupōuri, and Ngāti Toa. Through her biological father she connects to the Cook Islands and Tauranga Moana. Through Riki, Brooklyn connects to the Tainui iwi and the hapū, Ati Haunui a Paparangi. The settlement in Waiouru provided the intimacy of a small community situated within one of the country’s most pristine natural environments. Until recently, the lives of many generations of Ngaire’s whānau had been centred on this little settlement. Ngaire was the last of her whānau remaining in the settlement as most had relocated to Australia for improved employment and lifestyle opportunities. Ngaire and Riki were also questioning residency in Waiouru, evaluating its suitability in terms of accessing specialised support and specialists for Brooklyn. Ngaire was working part-time at the military pub and Riki, who had recently moved to Waiouru, was working in the forestry industry. However, during our last meeting, held in Taupo which is on the other side of the Tongariro National park and Lake Taupo, Ngaire and Riki were considering relocating and visited local schools there. They were considering the move in order to provide their family with a different lifestyle and more direct access to medical and educational support.

Brooklyn was four years old when she and her whānau became involved in this research. Her progressive hearing loss was newly diagnosed, meaning she had only recently received a cochlear implant and begun accessing EI support. Brooklyn’s parents were unsure if her deafness was congenital or the result of otitis media. At the outset of this research, Brooklyn did not have a strong first language. She was still learning to use her cochlear implant and beginning to explore the use of spoken language. Midway through the research, EI professionals were concentrating their efforts in supporting Brooklyn to learn and use fifty spoken words in anticipation of her transition to primary school. Toward the end of the research, Brooklyn transitioned to a local primary school where Ngaire reported her spoken language had greatly improved in what was a challenging social environment. Ngaire, Riki and Brooklyn still use a number of visual communication strategies and home signs which they

called 'Brooky's signs' to support Brooklyn's communication and to bridge efforts in increased spoken language.

I initially met Ngaire and her children serendipitously at an airport waiting area. I arrived after completing an interview with another research participant and Ngaire was returning home after visiting an EI professionals.

Ngaire walks through the security sensor with three-month-old Kyrin in a front pack and Brooklyn holding her hand. I notice her briefly. She sits in front of me on the plastic seats in the waiting area, lays Kyrin on a blanket on the floor and begins organising her baby and bag. I notice Brooklyn's cochlear implant and Ngaire's attempt at communication. I immediately identify Ngaire as a young Māori mother aged in her early 20s and wonder if she would be interested in participating in the research. I decide to introduce myself and not knowing what type of response I will receive, prepare myself for a difficult 'cold-call conversation'. I start by acknowledging that my introduction was an awkward thing to do, I explain who I am, what my role is professionally, and provide a very brief lay version of the research. We talk a bit about Brooklyn and she tells me Brooklyn had only just been implanted, approximately six weeks earlier, and that she was returning after visiting an EI professional. Ngaire appears to have a general understanding of the process but perhaps lacks knowledge of technical terms. Ngaire uses language like, "they're just turning it on and checking what sounds she can hear". I ask her how the implant was coming along, albeit distracted by Brooklyn's rummaging through her bag. Brooklyn looks at her mum and signs 'drink', beginning a negotiation via home sign, gesture and facial, she signs 'drink' and asks with questioning eyebrows and points. Ngaire shakes her head and hands, "No, Brooklyn" she says. Brooklyn persists with repetition and seems to be trying to produce some words, although they make no clear form. Ngaire allows Brooklyn to have a drink. There is little fuss and minimal frustration between them. Ngaire turns back to me to continue our discussion. I am impressed by her relaxed way with her children, and she appears to have a strong intuition about her children. We talk a bit about her baby, Kyrin. She seems to be 'in love' and bonded with him. We talk briefly

about whether she might want to participate in the research. I tell her I can email her the information and also suggest that she ‘google’ me so that she knows my interest is legitimate, that I am actually interested in the research. Ngaire laughs and we exchange contact details. Her flight is announced and she gracefully bundles up her children with no protests from them. They walk out to the tarmac to board their flight. Brooklyn holds her mum’s hand, turns and looks through the glass as they leave and waves to me “bye”. I wave back “bye”.

As my first encounter with Brooklyn and her whānau was somewhat serendipitous and opportunistic, I tried to ease into visits tentatively. Emphasising whakawhanaungatanga, a relationship with mutual benefits was a paramount objective. Ngaire and Riki were young Māori parents, aged 23 and 26 respectively. They had been given neither time nor space to consider my intentions, the implications of their involvement in this research, or the potential impact that participating would have on their view of Brooklyn and their whānau. Communication to initiate face-to-face contact was initially managed via email and phone and arranging times to meet was difficult. At the beginning of the research, a care and work arrangement was shared between Ngaire and Riki: Ngaire cared for her children during the day while Riki worked a 45-minute drive away as a forestry worker. In the early evenings, roles were reversed, Riki caring for the children while Ngaire worked in bar service at a military pub. Waipoua is a transit town some distance from airports which ruled out short ‘day-visits’. An invitation was extended by Ngaire and Riki to meet at a middle-point in Palmerston North where I was invited to an audiology appointment and an informal discussion afterwards. After our first meeting I acknowledged the whakapapa shared between my own partner and son with Ngaire and Brooklyn as a part of the process of whakawhanaungatanga. My partner and son both attended further meetings between us. Sharing whakapapa benefited the research and the process of whakawhanaungatanga. In all, our contact comprised three formal interviews during separate visits, two meetings with the various professionals working with Brooklyn and her whānau, participation at the hui whakawhanaungatanga, and a weekend visit in Taupo, again a mutually agreed middle-point with an airport nearby.

7.2. The shaping of whānau perceptions of deafness

7.2.1. Identification of deafness

The UNHS initiative was not available in the region where Brooklyn was born. When Brooklyn was six months old, Ngaire noticed her child was not responding to environmental noises or spoken language. Dubious about a local GP's assessment of Brooklyn as hearing, Ngaire and her whānau sought second opinions via the military doctor and private audiologists. Identified as having otitis media with effusion, bilateral ventilation tubes were inserted when Brooklyn was 16 months old and removed 18 months later. Ongoing concerns with Brooklyn's language and speech development prompted Ngaire to seek further assessments. When Brooklyn was three-and-a-half years old she was eventually diagnosed as having a progressive hearing loss, a severe-to-profound hearing loss in her left ear and profound in her right. Ngaire was disheartened with the public health system and frustrated with delays in receiving support and advice. The following excerpt is Ngaire's summary of her experiences, as shared with other whānau participants at the Hui Whakawhanaungatanga. This narrative illustrates the angst she endured as a young mother as she tried to navigate the health system in order to address what was initially a health concern and that ended in her learning of Brooklyn's permanent and profound hearing loss.

When I was pregnant with Brooklyn I actually hid my pregnancy from my family for eight months. Riki isn't her biological father, but he's her dad. Her biological father has no idea about her hearing loss ... Before she was one, I noticed she wasn't responding to loud sounds or anything, so my sister-in-law took me and Brooklyn to the doctor (about 20 minutes away) and he said her ears were fine. So, we went to another doctor for a second opinion and he said she had a real bad ear infection and that we should get it checked out at the hospital by a specialist. So we took her to a specialist in Palmerston [North], but were told we'd have to wait about half a year. So my mum and dad paid for her to go to a private hospital, she got those [grommets] done, but they didn't do much help. She ended up getting hearing aids. When she was about ... just over three years old, they did a hearing test ... an ABR? They found that she was profoundly deaf in her right ear and severe-to-profound in her left ear. It was last October when she got her cochlear implants, so she

hasn't been wearing it for that long. Brooklyn started school last month and she's doing good so far. It's good living in a small town cos everyone knows her and everyone is learning from her – well everyone who knows her anyway.

Despite having some basic medical intervention, the grommets, and receiving hearing aids prior to her identification as affected by deafness at aged three-and-a-half, Brooklyn's behaviour, as placid and unresponsive to environmental noise and spoken language, indicated deafness to her mother long before diagnosis. Ngaire received no formal EI support for Brooklyn's language development prior to her cochlear implant and spent much of this early period with a pragmatic attitude. After the birth of Kyrin, Ngaire attempted to parent her hearing child Kyrin as she had Brooklyn, and this brought unexpected results.

“Kyrin is different from Brooklyn, when Brooklyn was a baby she never really made sounds. Like talking back, you know those cooing sounds. When Kyrin started communicating, I'd say ‘look, look’ [Ngaire acts the scenario as she holds Kyrin, attempting to command his visual attention by encouraging him to look in the direction of her pointed index finger]. I was really amazed, like wow, he was different. Brooklyn just lay there all the time, she was such a quiet baby. My sister-in-law always just thought she was a ‘good baby’ and compared her to my niece who is one month younger. My niece just screamed and was a loud baby. Brooklyn would just lie on her play mat and was just quiet. [I ask: ‘Did she respond to visual things like the TV turned on?’] Yep, once she noticed the TV she would just stare at it. But by sound she didn't look up. I said to my sister-in-law (my brother's partner) ‘I'm sure she can't hear’ and she goes ‘Why’? ‘Because all the loud banging – she doesn't even flinch.”

7.2.2. The evolving context of whānau

Brooklyn was conceived when Ngaire was in her late teens, her pregnancy concealed from her family until the eighth month. She did not have a long-term relationship with Brooklyn's biological father who now has no contact with Brooklyn. Ngaire met Riki when Brooklyn was two years old and fell pregnant with their youngest child, Kyrin. Brooklyn and Kyrin are well bonded as a consequence of regular and stable child-centred routines at home and their parents'

stable relationship. The formation of this unit occurred as Brooklyn's deafness was being identified and they began their pathway into EI supports.

Ngaire and Riki viewed Brooklyn as capable, encouraging her to take up those roles appropriate to her status as tuakana, older sister. The following excerpt is an observational note from my first meeting with Ngaire and Riki at Lollipops Land, an indoor playground in Palmerston North, and describes the sense of responsibility and care Brooklyn has for her younger brother.

Brooklyn has spent the best part of an hour dashing about Lollipops Land, calling out to her dad at five minute intervals, commanding his attention to rate or observe her physical prowess during play. He always returns her gaze and affirms her constantly by raising his eyebrows and smiling. Ngaire is focused on Kyrin, who is either being breastfed or seated on her lap sucking on a lukewarm potato chip. During our discussion Brooklyn regularly attends to Kyrin, she strokes his face and kisses him. Kyrin is sitting in a well-padded area of Lollipops Land, she picks him up, he is three-quarters the size of her. Brooklyn is confident, she holds Kyrin under his armpits and waddles across to the small children's area. Her parents giggle at her attempts at being a big sister. Brooklyn brings Kyrin into a cushioned hollow wheel where children lie inside and are spun around. She places Kyrin inside the wheel. Ngaire looks nervous and inches herself closer to her children in preparation for an intervention, although she tries not to hover. Brooklyn rocks the wheel gently and Kyrin giggles, enjoying the sensation. Ngaire smiles and Brooklyn looks at her as if to say "look mum", smiling at her mother. Unfortunately this takes her concentration from the rhythm of her rocking and she moves the wheel just a little bit too forcefully. Ngaire warns her with her expression, "eyebrows-down". Brooklyn registers her mother's warning, successfully takes Kyrin out, and with her hands under his armpits, shuffles across the padded mat area to return Kyrin to their mother, only to drop him inches from their mother. Kyrin falls on his face, banging his teeth and screams with fright. Ngaire scoops him up to check him. He has a small bit of blood on his mouth but is otherwise fine. Ngaire places him back on the breast to soothe him. Riki is very relaxed and he visually checks on his boy and decides it's a little knock. Ngaire shows her crossness with him through her expression, he

smiles to himself, knowing he is being told off. He warns Brooklyn with stern words and looks to be careful. Brooklyn is unsure and upset, she looks around for some way to ground herself. Riki offers to take Kyrin for a walk to distract him. Ngaire wants to hold him. I sign, gesture and talk with Brooklyn, “What happened?” She looks upset and accidentally tips her chips over. I try to reassure her with smiles and kind words. We have a little laugh and reassure Brooklyn.

Many of Ngaire’s whānau were involved in Brooklyn’s life as a new-born, her mother intimately coaching Ngaire on managing the practicalities and routines of caring for a new baby, while her father provided moral support. When I first met Ngaire, Ngaire’s parents had just left for Australia and she was caring for two young children independently in her own home. Her key support was now centred on her friends and Brooklyn’s aunt Ariana, one of Riki’s sisters. All have had hands-on involvement in her upbringing, helping Ngaire navigate the EI system during those early years prior to Brooklyn’s diagnosis. As diagnosis was late, making sense of Brooklyn’s deafness was a collective process in which professionals have only begun to play a part.

7.2.3. Constructing deafness through experience

Ngaire and Riki are relaxed, warm, attentive and intuitive parents. They tend to observe their children before making conclusions, reflecting regularly on their parenting approach and work collaboratively in parenting. As a consequence they seem to understand their children intimately. Because Brooklyn’s diagnosis was late, Ngaire and Riki had spent most of the critical period during which children are thought most likely to benefit from EI with no specialist support. They did not know what to do, where to go for support, nor how to ask for this. Ngaire acknowledged Brooklyn’s deafness defined many of her social interactions, yet because Ngaire and Riki tended to focus on understanding Brooklyn holistically, their energy was put toward understanding their daughter as she was. Deafness was considered an integral part of Brooklyn’s identity and they sought to identify with and understand these aspects of her and live with it. As Riki aptly put it “You just take it on your shoulders and carry on”.

Ngaire’s maternal aunt is also deaf, although not profoundly. When asked what impact having a deaf member in her whānau had on her perceptions of Brooklyn, Ngaire reminisced about some of the communication difficulties her aunt had experienced with her whānau, in particular

that of being misunderstood and mocked by the younger cohort of children. Ngaire was saddened at times by some of the failed communication attempts Brooklyn experienced during play with other children, which brought her thoughts back to her aunt. Nevertheless, Ngaire and Riki admired Brooklyn's innate resilience in play and attempted to focus on her strengths, hoping to support and foster her resilience.

Sometimes I feel sad with some things. Like when other kids don't understand her, she's trying to play with them and they try to talk to her and she'll talk back, and how she's talking and they don't understand her ... Yeah but then she's pretty happy; she doesn't care. She's like 'Oh you don't want to play with me?' and she carries on.

Ngaire had not seen her deaf aunt since Brooklyn's birth and she had not considered her as source of support or advice, principally because she lived some distance away and was unable to communicate effectively with her. Interestingly, Brooklyn's parents expressed the importance of valuing the knowledge of those with lived experience of deafness and were especially interested in meeting with deaf people and whānau with deaf children, particularly those who were Māori and/or with cochlear implants. Neither could remember being told of the NZFDC and when I advised them of the group, they were intrigued about the NZFDC objectives. Ngaire was privately assessing the suitability of a local woman with a profoundly deaf mother-in-law as a Teacher Aide for Brooklyn during her transition to primary school. Both Ngaire and Riki had, on various occasions, come across children and adults with cochlear implants in public and made conscientious efforts to introduce themselves and ask questions. As Riki tells us:

*I seen this boy he's, I think he was about 16, I just finished work and gone to get my pie and I noticed he had, it wasn't a cochlear implant, it was the same as that but it wasn't a cochlear implant. So I went over and I knocked on his window and he didn't look at me, and I was like, I didn't know obviously ... so I had to really bang on the window. He turns round and he winds his window down a bit cautious of me eh. I just asked him about it and that's awesome, whereas before I wouldn't have done that. **Ngaire says:** We wouldn't even have noticed them before. **Riki:** Yeah.*

Midway through this research Ngaire and Riki attended a whānau member's wedding where they were introduced to a young woman who also had a cochlear implant. Intrigued, Ngaire questioned her about the implant. The woman denied she had one and self-consciously arranged her hair to visually conceal her implant. Ngaire pushed further by introducing her to Brooklyn and showing her Brooklyn's cochlear implant. The young woman was immediately more forthcoming, showing her the cochlear implant and offering advice from her experience and networking with Ngaire and Riki through Facebook. Ngaire was grateful to gain a perspective from a young woman who had had an implant and intended to use her as a source of ongoing advice and information.

7.3. Experiences of early intervention: language and communication

It's about language, building on language, but also too it's about us all working together as a whole whānau. So it's a whole village that we need on board for Brooklyn's education. Not one person can do it. (Brooklyn's Kindergarten Teacher).

Prior to Brooklyn's cochlear implant, Brooklyn and her whānau received very little EI support for communication and language development. Although Ngaire had known Brooklyn had a hearing loss from nine months of age, she did not know how severe her hearing loss would become and the implications this would have on her language and communication development. Ngaire's and Riki's efforts to support Brooklyn while at home were often guided by their parental instincts. Riki commented that before Brooklyn received an implant they had "figured out to talk to her left side" and they used visual communication strategies and home signs. It was evident during the various occasions I met with Brooklyn and her parents that these signs and the visual communication strategies were still an innate part of their social interaction. When asked how they came up with 'Brooky's signs', Riki said: "She comes up with the signs and we just learn what she's talking about and then we tell her the word; everything she does is gesture." An initial assessment report from the Van Asch Deaf Education Centre's preschool's residential course, written when Brooklyn was three years and nine months, described and praised the language and visual communication strategies Brooklyn's parents had been using.

The family uses spoken English with the addition of visual cues to communicate with Brooklyn. Facial expression, body language and gestures are already fundamental components of communication between Brooklyn and her parents. The extension of these visual strategies to support what Brooklyn is hearing will assist her to better understand the message being conveyed. Ngaire and Riki are also aware of a variety of ways to get Brooklyn's attention.

Brooklyn was accepted for cochlear implantation by the SCIP in the week of her first assessment, when she had just turned four. The decision to focus on spoken language was relatively straightforward for Brooklyn's parents, who felt she needed to be able to use the language of her household and wider community in order to participate more fully in these social contexts. This decision required a drastic shift in their approach to communication. Until this point, they had been relying principally on simple signs and visual communication. The implant process went relatively smoothly and professional input into Brooklyn's spoken language development was now more forthcoming, organised, and structured. The types of specialists involved changed from being mainly medical specialists and audiologists to educators promoting a structured approach to developing Brooklyn's spoken English. This included staff at the SCIP, a speech language therapist, a teacher aide, an AODC and kindergarten staff. Ngaire found the SCIP habilitationist particularly supportive in this process, that she was reliable and committed with structured objectives. Her methods were clearly explained and understood by Ngaire. Visits were made to Ngaire's home and Brooklyn's kindergarten where she explained her methods so they might be applied in various settings in her absence.

Brooklyn's initial reaction to being implanted was a mixture of intrigue and confusion. Her parents observed her reaction with interest and accepted that they needed to work through initial difficulties to support Brooklyn as she learned to process sound and spoken language. Ngaire and Riki explained.

Ngaire: "It's funny too because when she got, when they put it, turned the cochlear on we walked under the trees and she was just looking up because she could hear birds, she was crying a lot. She used to sit there clicking a pen for ages just listening to it. ... She cried a lot in some parts especially at cartoons. She'd watch cartoons and once she heard them yeah she would just

sit there and cry. Riki affirms Ngaire: Yeah and she'd go, "No, no" Ngaire: Yep and when I was talking she would just look at me and started crying every time I talked, like she would be thinking 'What is that coming from your mouth?'

Towards the end of the research the various EI professionals were conscious of Brooklyn's approaching fifth birthday and transition to school and their support was focussed on her acquisition of fifty spoken words and developing her ability to cope in a classroom environment. The cochlear implant habilitationist worked actively with kindergarten staff and Brooklyn's teacher aide. The aide was a local woman whose extensive professional experience included working with another implanted child in a Kōhanga reo environment where three languages, Māori, English and NZSL, were actively used. This teacher aide was working with resources from van Asch and applying them in the context of Brooklyn's kindergarten. They often required adapting to ensure they were practical and relevant. A speech language therapist visited Brooklyn's home regularly, but Ngaire doubted these visits were of any benefit, feeling they lacked focus.

She'll just sit there and be, and she'll just say "So how is she?" [I ask Ngaire and Riki if they think she might be attempting some observations before working more directly with Brooklyn]. Oh she's done that both times but she doesn't, she doesn't talk to Brooklyn or anything.

After a group discussion with Ngaire and the teaching staff at Brooklyn's kindergarten, it became apparent that all efforts were focussed on supporting Brooklyn's spoken language, especially given that she was about to start school. It could not be denied, however, that Brooklyn still had a strong preference for visual communication strategies in home, whānau, community and preschool contexts. She relied on gestures and home signs to bridge communication to spoken language, especially when her spoken language was not understood. As Brooklyn persevered with these strategies Ngaire and Riki considered a bimodal approach. Advice from professionals supporting Brooklyn's spoken English however discouraged the use of Brooklyn's signs, finding them 'distracting'. Ngaire reported:

Her deaf advisor from Van Ash said they don't want her to learn signing, they want her to use her ears. [I ask Ngaire if they positioned this as an 'either/or option']. No. they just say it's better for her since she's got 'the ears' she

should use them They just asked us if we wanted her to have a cochlear and we said 'yep'. I was telling them that her speech therapist wanted to teach her sign language and they said she shouldn't be doing that because she can hear now. She should be teaching her to listen, to learn to listen and to speak; they just thought it was better for her.

Riki had mixed feelings about dropping 'Brooky's signs', his intuition told him to validate Brooklyn's attempts at communication, to 'meet her halfway'. In his view, communication should be meaningful to Brooklyn. They had taken Brooklyn's lead in communication efforts thus far, efforts which were meaningful to Brooklyn and responses to real-life situations. He saw the process as a natural and reciprocal learning process.

Instead of trying to discourage her [from using her preferred communication strategies and signs], better to get her to come off it and learn [spoken language], you know meet her halfway. She'll make her language [her signs], then we'll have to learn that, and then we'll teach her ours sort of thing. So I don't know, it's still learning, trying to learn.

Ngaire wanted to support Brooklyn's acquisition of spoken language although she also felt sign language was still relevant. It was Brooklyn's first mode of communication and so she was still actively using those strategies and signs in daily life. Ngaire could see the social benefit of belonging to a sign language community. Both parents were despondent at the lack of formal support for learning NZSL, especially in their small semi-rural community.

I want her to know sign language, learn it. Because before the spoken language came it was the sign language, and I was speaking to her about you know ... like with how Māori – a lot of it is we speak with our gestures. It's like gestures.

There are a lot of people who want to learn signing there because of her, but no one knows where to get it from, cos it's just a small town. Coming here and seeing all this, conversation in signing is just really cool to see. And then Brooklyn saw people signing to her and we saw her face and she kind of looked confused. ... We'd like her to know what people are saying to her and be able to respond back to them using sign. Because we're in a small town and there's nothing close to us like that, it's kind of hard.

During my last visit with Brooklyn's parents we discussed the issue of Brooklyn's language development. She was still using a mixture of spoken language, gesture, and home signs, although spoken language was now beginning to dominate her communication attempts. Ngaire and Riki were constantly entertained by Brooklyn's spontaneous use of spoken language and her enthusiasm in communication was praised. There was use of spontaneous language, for example, she pointed to a power station while driving to Taupo and exclaimed "Wow, that's amazing!" This was an encouraging indicator that Brooklyn was listening to her environmental language and producing spontaneous spoken language in appropriate contexts. Brooklyn was also using her visual communication and language, despite having no support for it, while at home. She regularly told stories (especially when excited) about her day at school using gesture, home signs, and visual communication strategies. Brooklyn also understood the significance of her implant and the impact it had in terms of access to communication and language, as this observation note shows:

We are in the foyer of a hotel, Brooklyn is swinging the door of her hotel room, and she is teasing Kyrin who wants to exit the room. She holds the door open suggestively and as Kyrin tries to exit she attempts to shut the door. Riki scolds her. Brooklyn stands still but defiantly scrapes the side of her head on the door so her cochlear headpieces detaches. In her act of rebellion she decides she doesn't want to listen. Riki and Ngaire giggle.

7.4. Experiences of early intervention: decisions and opportunities

EI support for Brooklyn before she reached three years of age had focused on addressing her chronic ear infections and on the fitting of hearing aids. It was assumed hearing aids would suffice as a primary support for developing language in the home. In reality, hearing aids were ineffective and Brooklyn's whānau, in the absence of EI support typically offered at early stages of diagnosis, were left to support Brooklyn's development, relying principally on parental intuition. As Brooklyn's access to spoken language was significantly limited during this phase, Brooklyn was largely led by her need to communicate in a visual mode. Keen to communicate with their daughter, Ngaire and Riki developed a series of home signs, using gestures and visual communication strategies that achieved communication. Without NZSL,

both language role models and community, both parents and child were using idiosyncratic signs at a rudimentary level of communication.

Brooklyn's eventual late diagnosis produced a shift in her parents' approach. Communicating in the visual mode was evaluated during an intense period of professional support for spoken language development. The resulting decision to shift modality was largely influenced by her parents' desire that Brooklyn use spoken language within her community and due to the absence of support for sign language. From the point of her implantation, support for Brooklyn became more forthcoming and structured. However, a sense of urgency overshadowed the decision-making process as Brooklyn's approaching fifth birthday signalled her coming transition from kindergarten to primary school. Information was provided in verbal and written forms, from the AODC and staff from the SCIP, and Ngaire began the process of getting to know the key EI professionals from the organisation. Surgery and initial follow up visits were relatively straightforward and Ngaire and Riki found support from the SCIP structured and forthcoming, a relief given the dearth of EI information and support prior to the implant. Ngaire and Riki were also cognisant that Brooklyn's spoken language would develop differently from those implanted at a younger age. Therefore their expectation was to work diligently at supporting her in everyday settings and provide regular one-to-one attention to improve her language. The structured approach, clear explanation of process, and centrality of the SCIP service fostered a sense of trust between whānau and the service.

However, Ngaire and Riki were uncertain about some aspects of service provided by EI professionals across medical and educational settings. Some of the relational skills of EI professionals were not understood or approved of, and while frustrating, it was expected that this was a natural consequence of building relationships with non-Māori professionals whose way of relating was founded on different social norms and value systems. From Brooklyn's parents' perspective, EI professionals tended to assume their profession's social formulae was the norm. At times, their inability to read Ngaire's and Riki's verbal and non-verbal social cues reinforced a sense of powerlessness for these parents. This was often indicated by feelings of discomfort during interactions, yet as they frequently felt disempowered by the nature of the interaction it was difficult to challenge midway through.

The following excerpt is an observational note I wrote after an audiologist's appointment attended by Ngaire, Riki, Brooklyn, Kyrin and myself. The appointment illustrates how the

social formulae assumed by an audiologist during a routine check-up dictated the nature of the interaction, the type of information shared, and an eventual outcome.

Ngaire, Riki, their children and I wait in a hospital waiting area skimming women's magazines and chatting about children and family life. We are eventually called to meet with the audiologist who quickly ushers us down a corridor and into a very small consultation room. A bed sits to the side of the room, the audiologist's desk and chair dominate the rest of the space, posters, and chairs are strewn in an ad hoc fashion around the room which is lit with an incandescent light. There is barely enough room for us and we shuffle about arranging chairs so we can all fit. I decide to sit at the back. The door is open and there is little privacy from others in the hallway. I ask if they want me to close the door, Riki says "Yes please". This creates the illusion of increased space. I take no notes, and just observe. I consider introducing myself to the audiologist, he doesn't seem to care who I am, and it appears he thinks I'm just a family member. Obviously time pressured, we are not welcomed by greetings, and we subconsciously shuffle our chairs in arrangement around him, as if to prepare ourselves as his audience. Brooklyn is sitting on Riki's knee, Kyrin is squirming on his mother's lap, the audiologist shuffles and arranges piles of papers. Brooklyn notices a poster on the wall, a poster of a child with a hearing aid. She points to it, inviting her Dad to look as well, points to herself and says "Brooky". Riki seems to understand Brooklyn's intended communication, responding using gestures, home signs and words simultaneously to say "Yes Brooky has got one of those". The audiologist begins the 'examination'. He holds Brooklyn's head and manipulates her body in a matter-of-fact manner, so he can examine her ears, hearing aids and cochlear implant. Brooklyn doesn't seem to mind and seems very familiar with this process. The audiologist starts talking simultaneously with Ngaire and Riki about Brooklyn's ear moulds, suggesting she will need new ones. He prepares an 'ear-putty' to make an impression in her ear. The audiologist asks Brooklyn's parents what colour he should order for Brooklyn's ear-moulds. Ngaire suggests that they ask Brooklyn. Riki starts to gesture, using home sign and talking simultaneously about what colour she wants. Riki uses the poster on the wall to point at the

ear mould, then at Brooklyn, and in her ear. They then provide Brooklyn a chart of colours to choose from. She chooses the same colour as the 'ear-putty'. From my perspective, Brooklyn thought she was being asked to identify the colour of the ear putty (which she did correctly of course) rather than what colour she wanted her ear mould to be. The audiologist then busies himself with paper work and we quickly leave his office. I ask Ngaire and Riki why they chose that colour, and I put forward my interpretation of what I thought Brooklyn may have meant. Ngaire and Riki laugh, and see how I might have been correct. Riki confirms that was his interpretation as well. Ngaire says she hopes she'll wear it now that it's been ordered!

After implantation, Brooklyn's parents developed an interest in developing networks with deaf people. Ideally this would help provide a social context to support them in their decision-making processes, and help them to envisage a potential developmental trajectory. They acknowledged Brooklyn's uniqueness as a deaf person and did not expect her development to parallel that of a hearing child. Such a network would also support them in their parenting efforts. There was however, little information to support the whānau in building a contextual understanding of implanted children. There was no introduction to the NZFDC or the parent mentor programme. Ngaire and Riki commented that, had they known, they would have actively engaged with these groups during Brooklyn's earlier years in order to provide a wider social network of support for themselves and for Brooklyn.

To date, most of Ngaire's and Riki's meetings with deaf people had been accidental; lamenting the limited contact with others similarly placed, they were concerned that their geographical isolation would hinder such contact even further. Through the Hui Whakawhanaungatanga, the opportunity to meet with deaf adults, who communicated in spoken and signed modes, was made, and they had since met with deaf people from the wider community. This experience supported the development of a contextual understanding of deaf people's social and linguistic realities, and helped them provide a context for Brooklyn and her abilities. For example, meeting with deaf people who used sign language in social contexts affirmed their earlier decision to use a visual mode of language during Brooklyn's early years, and although their main focus at the time of the research was to support spoken language, meeting those with fluency in NZSL fostered their respect for 'Brooky's signs'. As an awareness of deaf people's social and linguistic realities broadened, Ngaire and Riki also reflected on their earlier process

of negotiation, whereby they had tried to scaffold spoken language from 'Brooky's signs'. They felt it important to affirm all Brooklyn's communication efforts to help her build self-esteem. This was difficult to reconcile with the active discouragement of professionals who advised against attempts at sign, framing them as 'distracting' from the objective of spoken language. While Brooklyn's parents were keen for her to use spoken language, they were equally accepting of visual communication and NZSL. Information and support for Brooklyn to become bimodal was neither provided nor discussed.

Overall, the status of professionals and their insights into Brooklyn's development were always respected and considered by Ngaire and Riki. However, they also privately evaluated this advice and knowledge against their own intimate knowledge of Brooklyn within the context of their whānau. Ngaire and Riki were not always outspoken about their own assessments, which were often revealed to me during our own discussions. Toward the end of the research, new knowledge gained from discussions with other deaf people and their whānau had begun to influence their views of potential life trajectories and opportunities for Brooklyn, forming a platform from which to evaluate information and make their own decisions.

Chapter 8. Jay

Jay's face is dominated by the serene gaze of his dark eyes and framed by his long sunburnt brown hair which is lovingly combed and plaited daily by his maternal grandmother. In new contexts or in the company of new people Jay is an even-tempered and quietly unobtrusive child, blending inconspicuously into social environments. Jay holds a special status in his whānau: as the youngest whāngai mokopuna he has, over the years, been the recipient of the type of devotional love and attention fostered by grandparents. As a consequence Jay's demeanour in the whānau context is confident, assured, assertive and direct, especially in interactions with his cousins and peers at kōhanga reo. Jay is being raised in his maternal grandparents' home alongside two other older cousins Mason and Cassandra who have also been identified as deaf; Mason's deafness being moderate-to-severe, Cassandra's mild-to-moderate and Jay's mild. Jay is a bilingual child and was using spoken te reo Māori (at kōhanga reo and with some whānau members) and English (within his home) at the time of this research.

8.1. Overview

I think he's had a lot of awhi – love? He's just had that all his life, he's had a lifetime of it and he reflects that. (Jay's ITOD.)

Jay was four years old when his grandparents agreed to participate in this research. Jay is the whāngai mokopuna of his maternal grandparents, Arthur and Mary Totara, who have raised him from the time he was three days old. Prior to Jay's birth, an arrangement had been made between Mary and her daughter (Jay's birth mother) whereby Arthur and Mary would raise Jay as their whāngai child. This arrangement alleviated resource pressure on Jay's birth mother, as well as providing Jay with the privilege of being raised by grandparents who were better equipped to meet his needs in the most holistic sense. Under this arrangement, Jay's whakapapa to his biological parents, siblings, and cousins was open knowledge, yet his primary bond was with his maternal grandparents who led the parenting role in his day-to-day care. Through his grandfather, Jay's whakapapa connects him to Ngāti Porou, and through his grandmother to Rangitāne. While this research was being undertaken, Jay was living in his maternal grandparents' home in the Wairarapa with two of his cousins Mason (aged 9) and Cassandra (aged 7). All three children are deaf but to varying degrees from moderate-to-severe, to mild-to-moderate and mild respectively. Deafness is common within the whānau; Arthur and Mary have two children who are deaf and four mokopuna, albeit to varying degrees. Jay was diagnosed when he was approximately two years old (his biological mother had a hearing loss cause by injury); Mary believes his hearing loss was likely to be progressive and he was eventually fitted with hearing aids at approximately two years of age.

Amongst the whānau, English predominates as the principal language in their various households. Most of Arthur and Mary's children live in close proximity to one another. Te reo Māori is spoken as a second language by some of Arthur and Mary's children and a number of their mokopuna have acquired basic conversational ability in te reo Māori through attending kōhanga reo and through paternal grandparents. Use of te reo Māori is limited to specific domains, such as kōhanga reo or in response to other speakers, and, according to Arthur and Mary, the older children's ability in te reo Māori has stagnated in the absence of on-going exposure to the language in mainstream primary school. The deaf children in the whānau have exhibited an interest in NZSL when exposed to it, yet none of the whānau had learned or used it due to a lack of opportunity to access or acquire the language in the home setting, and

Arthur's view that NZSL was unnecessary for deaf children who had developed capacity in speech.

From the outset, Jay was cherished by his grandparents. The diagnosis of deafness did not alter Arthur and Mary's response to Jay; being accustomed to deafness amongst their own children and other mokopuna, Jay's diagnosis was not perceived as a tragedy, but rather was accepted as a part of their reality. Through raising deaf children (although none profoundly so) prior to raising Jay, Arthur and Mary had already formed their own opinions of what to expect in terms of a deaf child's development. Their views were not always informed by professionals' advice, but based on their own observations of deaf people and expectations of deaf people's capacities in a hearing society. At times, Arthur and Mary's views and what was perceived by professionals as their casual attitude were at odds with EI professionals' views. Participating in this research gave Arthur and Mary an opportunity to air their concerns regarding the mismatch between the beliefs of whānau and the aspirations of EI staff, and the on-going frustration of trying to align themselves with a system which did not value their aspirations.

Arthur and Mary were introduced to me via their AODC who suggested their case would be of particular interest to me given the incidence of intergenerational deafness and the whānau commitment to Kōhanga reo. Arthur and Mary were initially contacted via phone and I suggested we start with an introductory visit to kanohi-kitea for mutual assessment of intent. As grandparents acting as primary carers, the only such case in this study, I was cognisant of the generational differences between us which might frame their expectations of the nature of research and the conduct of researchers. Consequently, many of our initial meetings were based in their home over cups of coffee, exchanging traditional pleasantries. We moved through the interviews at a relatively slow and formal pace, often spending time making connections of whakapapa and common networks. I did not get the opportunity to meet with Jay until my third scheduled visit when I took my own child, who was the same age, to spend the day with him at kōhanga reo. Toward the end of the research, Mary and her daughter Karen (Jay's aunt) attended the Hui Whakawhanaungatanga along with Mason, Cassandra and Jay. While the Hui Whakawhanaungatanga was the first time some other whānau participants from this research had spent time with other Māori deaf people and their whānau, Jay's whānau had an intergenerational experience of deafness and the social experience was not so new. Unfortunately Arthur was chronically ill during this time and unable to attend. Sadly his health

deteriorated while this research was being written and in January 2012 Arthur passed away – moe mai ra e te koroua ma te atua koe e tiaki.

While this research acknowledges the incidence of intergenerational deafness in Jay's whānau, this case description purposefully focuses on Jay as the youngest deaf child receiving EI support during the research period. The experience of intergenerational deafness is described as a contextual contributor to Jay's experience. This chapter provides a description and discussion of Jay and his whānau in relation to the key research questions.

8.2. The shaping of whānau perceptions of deafness

8.2.1. Identification of deafness

Jay was identified as having normal hearing through the UNHSP and routine preschool checks undertaken by health professionals visiting Jay's kōhanga reo. As parents and grandparents of deaf children, Arthur and Mary identified some aspects of deaf behaviour, already noticing in Jay a heavy reliance on visual information, a tendency to miss subtle auditory information, and the unusual pronunciation of particular words. Arthur and Mary requested further testing through the audiology department of the Hutt Valley DHB, finally securing appointments when Jay was almost two years old. The testing process was somewhat tedious and difficult for Mary to manage. The audiology department was a two-hour drive away from their home, and little consideration was given to how the whānau would be able to manage transport and testing logistics with Jay's feeding and sleeping needs. As Jay's hearing was identified to be normal in some tests and impaired in later tests, Mary concluded his loss was likely to be progressive.

As he got older we sent him to kōhanga reo and he was passing their test (or whatever they do) but when we took him back to the Hutt and they found 'Oh no – he's got a hearing loss!' I said 'Well how can you pass one lot [of tests] and he doesn't pass the other lot?' And then they give him the test they have to do at the hospital and he'd get bored or they take too long. I used to say 'Oh you have to hurry up because he gets bored too quick'. He was only maybe one, nearly two years old. Then they started learning that they had to do their tests quicker. He fell asleep in most of them because we used to have to wake him up. And they said 'Oh don't try and put him to sleep'. Well you can't tell a baby not to go to sleep, especially driving from here [Masterton]

to over there [Lower Hutt] and it was always an early hours' appointment. We would try and keep him awake. By the time we got there he was either tired or bored. He couldn't do half the tests they were trying to do. [I ask how they delivered the diagnosis]. They just measured up his ear and put a hearing aid on, but the biggest problem was that he wouldn't wear them. [I ask if they provided any information about deafness or contact details for various supports]. Not really. They just said 'He's deaf and he's got to wear hearing aids'. Then we found his hearing loss was similar to Mason and Cassandra's. (Mary)

8.2.2. The evolving context of whānau

Arthur and Mary were parents to five children (two of whom were deaf) and grandparents to 14 grandchildren (four of whom were deaf). Jay has been with Arthur and Mary since he was three days old. However, his cousins Mason and Cassandra were initially under their mother's care until an intervention from CYFPS (Children Young Persons and their Families) saw them placed first under a paternal aunt and uncles' care and later, Arthur and Mary's care when Mason was aged five and Cassandra aged three. The lives of Arthur, Mary, their children, and mokopuna were deeply intertwined through daily routines and regular contact. Houses did not demarcate this whānau; rather the children and mokopuna lived in close proximity to one another and moved frequently and casually between houses in their day-to-day interactions with Arthur and Mary's house serving as a whānau centre point. Arthur and Mary's children often appeared during my visits, involving themselves in our discussions on their own terms and adding information, humour, clarification, or at times simply a quiet presence. The following are observational notes taken during my first meeting with Arthur and Mary in which they illustrated the slower pace of life offered as grandparents living in a relatively quiet provincial town.

I arrive at Arthur and Mary's home after a two-hour drive from the Hutt Valley over the Rimutaka ranges ('the hill') to the Wairarapa. The rain hasn't stopped since early morning and it is now noon. I note the provincial characteristics of this part of Masterton, the streets named after native trees; the wide roads with little traffic or cars parallel parked along the sides; and the houses that were built in either the colonial era or during the 1950s' state-housing boom. Arthur and Mary live in a 1950s style state home. Their

section is long, the house at the midway point, with a section of grassy lawn framing the front and the back of the house. I note the lawns are freshly mown. The air is still cold at noon. A small pile of shoes are strewn around the front entrance to the home and I gather they are a 'shoes off' house. I knock on the glass-paned door and wait for an answer. Arthur greets me promptly and frankly "Hello, hello, come in". I quickly flick my shoes off and Arthur ushers me down the hallway bypassing the adjacent rooms (kitchen, bedrooms etc) and down the end to the lounge area which is heated by a fire. A collection of children's mismatched socks sit in front of the fire, obviously being dried on this wet-weather day. Mary comes in and we exchange greetings (a kiss on the cheek and hello). The home has a 'lived in' feel to it. The small room is occupied by the couches, a large television, a computer, a book case and a coffee table. The lounge periphery is trimmed around the top-edge with a tidy row of baby photos. I'm invited to sit and we exchange pleasantries and humour over a cup of coffee and the pastries I had bought. After introductions to the research and an agreement to participate, whakapapa connections are made. We begin our korero with the photos of Arthur and Mary's 14 mokopuna. I am introduced to them by photo, including Jay as he is at kōhanga reo. Although Arthur and Mary are well aware of the focus of my research, they only briefly mention Jay. We eventually discuss Jay in more detail during subsequent meetings; however he receives very little individual attention in initial discussions, instead throughout our first meeting we focus on outlining connections between people and the whānau as a whole.

Up until recently Arthur had been employed as a truck driver for approximately 20 years. Due to his chronic and worsening heart condition however, Arthur had retired at the time of this research and spent much of his time as a primary carer for various mokopuna. Mary is employed part-time as a domestic cleaner and also spends much of her time raising her mokopuna and running the household. During visits, Mary is often occupied with cooking, dishes, washing and other domestic chores. According to Mary their home is frequently used by her other children who live in close proximity. She regularly cooks large meals 'just in case' as whānau members often appear at meal times, sometimes with their mokopuna. Arthur is the

constant presence. He is home for sick children, fields appointments, runs errands, helps around the home and welcomes visitors.

In discussions of how they believed Jay perceived his whānau, Arthur and Mary were clear that Jay was primarily bonded to them as parental figures and affectionately referred to them as ‘mum and dad’. Jay’s whānau was structured hierarchically. As grandparents, and the elders of the unit, Arthur and Mary were the anchor to which several generations of adults and children were connected. In this context, an ethic of mutual care and respect for one another, mana and manaakitanga, was emphasised and through this, they were obligated to one another as exhibited through their whānaungatanga. Knowledge of whakapapa was considered important for the children to acquire though it was expected, given the complexity of their whānau dynamic, that this would unfold in natural course, when Jay had the maturity to ask questions, which were always accurately answered. In the meantime, Jay was free to choose from the number of children, half-brothers/sisters and cousins, as well as aunts and uncles to whom he felt most bonded. Western terms of demarcating kin relationships, such as brother, sister, mother, father, were not necessarily significant to this whānau. Often those who offered him regular aroha and manaaki, and who had the most frequent contact with Jay in daily-life were favoured, yet all were acknowledged as a part of the unit.

Arthur He’ll come and ask me ‘Is that my cousin?’ Mary He doesn’t know who his real siblings are, according to him they’re all his cousins. His aunty’s two boys are like brothers to him, not his cousins. Arthur He calls his aunty ‘mum’ and his biological mother by her first name. Even when he goes down there he goes ‘Can I go to ‘Brianna’s’ [his biological mother] for a weekend, dad? Like I say, he sees his Aunty Karen more than he sees his mother and he calls his two cousins his brothers. They’re his brothers as far as he’s concerned. He just calls his real father by his real name.

Arthur and Mary had very strong bonds with the kōhanga reo Jay attended. This was not so much because they were staunch proponents of the language revitalisation aims of the kōhanga reo, but because they felt that Jay would be exposed to the experience of whānaungatanga fostered in the kōhanga reo context. Despite its struggles in recent times to remain open, Arthur and Mary continued to be staunch supporters, sending Jay regularly and attempting to facilitate close relationships with kaiako and kaumātua. The ethic of whānaungatanga as enacted

between his grandparents and the kōhanga reo sent clear messages to Jay regarding the importance of relationships and cemented his bond to it.

8.2.3. **Construction of deafness through experience**

We don't think of him as deaf or being handicapped. (Arthur)

As the youngest deaf mokopuna in their whānau Jay is less of an enigma to his whānau than deaf children typically are in hearing families. He was not framed as unusual, or in terms of his deafness, as deafness is familiar to those in his household. Household routines are structured around the social norms of the three deaf children. Although all three rely on their hearing aids in public and educational contexts they tended not to wear them consistently in their home, where they relied on their own visual communication strategies such as exaggerated speech, and facial expressions. In the home they are able to predict activities due to consistent and well-organised daily routines. Arthur and Mary did not strictly enforce the wearing of hearing aids in the home for several reasons. Principally, this was a strategy to avoid losing or misplacing the equipment and to reserve their use for educational contexts. The natural state of deafness was considered a normal aspect of the children's identities and their idiosyncratic communication strategies accepted as normal. Ironically, Jay's grandparents disliked describing the children as 'deaf'. They believed the children's ability to use spoken English in the home and Māori in other domains meant participation in family life and routines were barely affected. In their view the term 'deafness' evoked language deprivation, communication difficulties, and interestingly, the use of sign language; in their view, non-signers were not 'really' deaf.

8.3. **Experiences of early intervention: language and communication**

Children are bit like little gardens in some ways. You're nurturing them and encouraging them to grow. (Jay's ITOD)

Up until the age of three, Jay was principally exposed to English in his home context and te reo Māori while at kōhanga reo. Arthur and Mary had opposing views on the relevance of NZSL for their mokopuna. From Arthur's perspective, hearing aids had maximised the children's

ability to be receptive and to process spoken language and auditory information and sign language was for those who relied solely on visual communication and language. Conversely, Mary was somewhat intrigued by NZSL and its potential usefulness, especially when it came to introducing communication strategies for the children in complex social contexts.

I was so amazed at what the teacher was doing with the students that were down there [van Asch Deaf Education Centre] and then when I come back I thought 'What a pity they haven't got it here' because I'd like to learn. I mean some things ... like with Mason and Cassandra it is best if you know a bit of sign language because sometimes they interrupt you when you're talking. And you've got to learn to teach them how not to interrupt you. When I got back from there [from van Asch Deaf Education Centre] I thought I wouldn't mind learning that. (Mary)

Mary attempted to teach Mason and Cassandra some basic signs after visiting the van Asch Deaf Education Centre and to convince Arthur into attending visits. In her view, the social experiences of observing her deaf mokopuna using NZSL with other deaf adults affirmed the naturalness of the language for deaf people, and its usefulness for communication. Arthur however, remained firm in his belief that it was unnecessary given the children's ability to use spoken language. Not knowing how to learn NZSL in their region, and given Arthur did not support the children learning NZSL, they had not pursued this further.

Arthur and Mary chose to focus on spoken language and ensuring Jay wore hearing aids consistently to optimise exposure to spoken language became more important. In practice, Jay's hearing aids were not worn consistently either at home or kōhanga reo contexts, though for differing reasons. The kōhanga reo had recently undergone a number of changes following its near closure due to issues with teaching and mismanagement. Almost a year prior to this research, when Jay was three years old, unqualified and untrained staff did not ensure Jay wore his hearing aids impeding his language development and interactions with peers during play. With support from whānau affiliated to Jay's kōhanga reo and the National Kōhanga Reo Trust, the organisation reconfigured their staffing and new leadership to redress issues stemming from inadequate teaching practices, including supporting Jay with consistent hearing aid use and using communication strategies to support his social inclusion with staff and peers. The restructuring heightened Mary's need to monitor the staff's role in overseeing Jay's hearing aid use. Although their vigilance improved significantly, correct and consistent usage

was not always ensured by staff. Mary had observed however, that her insistence resulted in an improvement in Jay's ability to comprehend and produce spoken Māori, and his participation in collaborative play with other children increased.

If he didn't want to do it they didn't care and he just took them off and threw them away. They didn't care to go and get it and look for it. It's only since I brought the hearing aids home that I put them on and make sure he comes home with them. Like the other day I got him out of the van and the teacher was there. And I said 'Where's his hearing aids. 'Oh I don't know?' she says. I says to him 'Baby, where's your hearing aid?' 'Oh in my bag' he says. I said to him 'You're supposed to keep them on.' Yeah it's them not checking up to make sure he's got them on. (Mary)

So even though his hearing loss is not that severe in terms of, you know, on a scale of one to ten of actually being really deaf he's not that bad. [I ask if he's having difficulty with language and communication]. When he first started wearing the hearing aids at kōhanga he would not wear them. He was just pleasing himself and just now in the last two years he's starting to wear them all the time. It's only because I'm putting them on. Because they used to have the hearing aids there and they're supposed to put them on and they'd only let him wear it if he wanted to wear it. And of course he had to wear them! Now he's catching up – that's only by wearing the hearing aids all the time. Before I think he was behind, he used to play by himself. And also I think because the kōhanga has changed – it's starting pick up what it should be. (Mary)

As a part of this research I observed Jay within the context of his kōhanga reo and met with kaumātua and kaiako (teachers) to discuss his participation within the kōhanga reo context. I was most curious about the nature of the relationship between whānau and kōhanga reo, Jay's participation, and the approach used to support the acquisition of te reo Māori. Prior to my visit Arthur and Mary had provided me with a candid brief of the difficulties the kōhanga reo had previously faced with its restructure following mismanagement issues. Jay's grandparents were confident in the new leadership and reported the positive relationship with the kaumātua, affectionately referred to as Koro Rob. It was difficult to describe Jay's participation in the kōhanga reo as an individual, as much of the activity involved the collective action of the whole

group of children. While there were moments of ‘free-play’ these observational notes describe the nature of Jay’s participation in one group activity, describing some of the strategies used to facilitate language acquisition by Koro Rob, the most experienced staff member.

It is almost lunchtime and Koro Rob has spent part of the morning working in the office; his entry into the room appears to have altered the dynamic in the room of children who were having a free-play session. As lunchtime nears they appear to be getting restless and perhaps hungry. Koro Rob arranges a small child’s chair next to me in amongst the children. He sits and we begin to discuss the background to this particular kōhanga reo. Despite his quiet and humble physical demeanour, the children notice him and their activity settles in his presence. While many continue with their play on the outer periphery of the mat area some congregate near him, some attempt to converse about their play and activity using a mixture of te reo Māori and English. Based on the nature of their use of te reo Māori, it appears likely that many of the children come from English-speaking households and that for them – as for Jay – te reo Māori is a second and emerging language. Koro Rob is a native speaker of te reo Māori and is a repository of language for the children and for some kaiako (teachers) whose command of te reo Māori indicates they are also second language learners. Koro Rob responds in te reo Māori, scaffolding from the language offered by various children. I note a pattern. The child is affirmed through the repetition of language they have used and errors are subtly corrected through the demonstration of the correct form. Sometimes Koro Rob offers an open-ended question as a method of encouraging spontaneous language use. His voice has an impressive boom, which fills the room without dominating the children. They sense his authority but do not appear fearful. Jay is one child who approaches Koro Rob. Hovering he watches him to see his action. Koro Robs sits and as we begin to talk Jay watches with his head tilted to the side, eyes assessing our actions. Koro Rob acknowledges Jay through his body language and eye contact, just briefly. Jay shyly registers the acknowledgement, his head tilting down further while maintaining eye contact for a brief moment longer. He suddenly disengages and resumes his play.

Arthur and Mary knew some basic te reo Māori however, were not conversant. Some of their adult children had basic conversational ability. Arthur reported they did not always use te reo Māori consistently, but when used, it was well understood by Jay. Whānau members who were speakers of te reo Māori were encouraging Mary to learn te reo Māori, posing it as ‘her duty’ to support Jay’s use of it in the home.

[I ask if Jay can speak te reo Māori]. Oh he does, but he won’t speak it at home because we don’t speak at home. I can’t understand it eh. Karen and Missy, they know a fair bit so sometimes he’ll talk to them and I’ll go ‘What’s he on about?’ And they’ll go ‘Mum you want to learn because that’s what he’s speaking’. But we can’t understand it so we have to ask the girls what he’s talking about. (Arthur)

I am thinking about learning [te reo Māori] this year. I got the hard word from my cousin; she went along to the kōhanga reo. She told me it was my duty to learn. So I’m thinking about doing that this year. (Mary)

As I was unable to observe Jay socialising within his home context (our scheduled visits were always at midday, while Jay was at kōhanga reo) I was unable to observe his use of language and communication within this context. According to reports from Arthur and Mary, his AODC and ITOD, and observations while at the Hui Whakawhanaungatanga, Jay predominately uses spoken English within his home context – mostly with the support of hearing aids, though this was not strictly enforced. This was a point of contention between Arthur, Mary and professionals. The decision to not wear hearing aids consistently in the home was, from Arthur and Mary’s view, a purely pragmatic decision based on the reality that the hearing aids of all three children had in the past become frequently lost or damaged. Monitoring hearing aid whereabouts and usage in their home environment was somewhat challenging given the large number of whānau members frequently using the house, and the robust nature of the three deaf children’s play in amongst the various other hearing children who also visited. Arthur and Mary were concerned about the potential expenses and reprimand from professionals incurred as a result of lost, misplaced, or damaged hearing aids.

Arthur and Mary’s decision-making here sat at odds with professionals’ advice to consistently use hearing aids to optimise Jay’s exposure to spoken language. Further, Arthur and Mary’s home behaviour apparently contradicted their insistence to school and kōhanga reo staff that

Jay wear his hearing aids consistently in those environments. Balancing the various needs of the whānau, which included the perceived responsibility for maintaining hearing aids, was a significant reality for Arthur and Mary. It was reasoned that the whānau knowledge of the deaf children's preferences and social cues coupled with their predictable routines enabled the children to predict the movements of those in the household and for whānau to respond appropriately. The intimate relationships within whānau meant all were expected to be mindful of using other strategies to support communication with and around the deaf children. Arthur and Mary reported the children had not developed nor used home signs.

The separate, respective drivers for Jay to achieve bilingual ability in te reo Māori and English were distinct. English was recognised as a language of necessity being the language of the household, wider New Zealand society, and the economy. Arthur and Mary believed however, that spoken Māori was a marker of identity, would support his socialisation into Māori cultural norms and values, and provided an entry into Māori social networks. Socialising Jay with other Māori children, and with those he was connected to via whakapapa, and speaking te reo Māori were imperative to helping him develop a sense of identity as Māori.

We talked about kōhanga reo or kindergarten, I say why not put him with all the rest of the Māori kids at kōhanga reo, they'll all learn together. At this kōhanga reo everybody is related – everybody, even the teachers were related or a friend! (Arthur)

Arthur and Mary reported that from the age of three, the primary professional engaging with Jay on a frequent basis was his AODC and ITOD whose role included supporting Jay with spoken English and pre-literacy. Jay's ITOD had extensive experience teaching deaf children and had also worked with his deaf siblings during their preschool and primary school years and thus she had some contextual understanding of the whānau. As this ITOD had no experience or capacity to speak te reo Māori however, difficulties arose when she was appointed to work with Jay one-on-one within the kōhanga reo context. While Arthur and Mary agreed with Jay gaining support to develop his spoken English, the ITOD undertook this work within a te reo Māori domain, the kōhanga reo. Koro Rob, Arthur and Mary felt the use of spoken English in this setting breached their commitment to providing a haven for te reo Māori. This was a frustrating experience for all involved. Arthur and Mary believed they required support for bilingual capacity and would have liked specialist support through the Ministry of Education to do so. However, Special Education Services (MOE) were only able to provide a skilled deaf

education professional to support Jay in the development of spoken English, while the kaitakawaenga²¹ was only able to act as an intermediary point, supporting relationships between Ministry of Education staff, whānau, and the kōhanga reo rather than language and pre-literacy development in te reo Māori for the deaf child.

As Jay's fifth birthday neared, Arthur and Mary began discussions over the suitability of local primary schools. This process forced them to revisit their aspiration for Jay to develop bilingual capacity in spoken English and te reo Māori. Arthur and Mary relied heavily on the kōhanga reo for Jay's development in te reo Māori and saw its initiatives as an intervention, supporting the child in areas where they were unable to, or where their skills were still developing. If Jay's ability in spoken and written te reo Māori was to advance, Arthur and Mary would require the on-going support of a school teaching in an immersion environment. Jaded by their difficulties in trying to gain support for both English (at home) and te reo Māori (at kōhanga reo), Jay's grandparents were not convinced that Special Education Services would be able to support their broader desire for bilingualism. The aspiration for on-going development in both spoken and written English was maintained however, and they saw benefits in sending Jay to a school which would focus on development in this language. The way the supports were structured created a scenario where it appeared to Arthur and Mary that they would have to choose between the two languages. In this context, their decision making hinged on feelings of guilt. They felt had they not chosen to support a mainstream school setting where English predominated, they would be tagged as 'bad parents' and would have to bear the consequences if Jay's language did not progress adequately. Given the dearth of specialist support for Jay's development in te reo Māori, they felt this was a very likely consequence and they were frustrated with the lack of flexibility. Eventually Arthur and Mary decided to send Jay to a mainstream, English speaking school, their decision influenced by a professional concern that as a deaf child Jay needed to acquire strong skills in at least one first language, usually the language of the home which in this case was English. Consequently, Jay's ITOD reported she felt her role was critical given the decision to transition Jay to an English medium school, and she was working diligently on strengthening his English proficiency prior to starting school.

²¹ A Kaitakawaenga works alongside other Special Education Services staff to inform practice related to Māori specific interventions and provide culturally responsive special education services to Māori in accordance with the goals, objectives and policies of the Ministry of Education.

The ITOD also reported that basic te reo Māori and cultural activities such as kapahaka would be taught at school by a Māori resource teacher.

The family have made it known that Jay will be going to Longbridge School so therefore I suspect my role with him is quite important in that I get some of his English well on board. [I ask if there is anyone who can help him with his te reo Māori]. There's a very strong kapahaka group, a high Māori population in the school and there is a kapahaka group, as they get older. [I ask if there is anyone employed from the Ministry to support Jay with te reo Māori.] Oh yes, yes somebody yes, yes, yes. Yes, yes they come; yeah there is someone who comes into all the classes I think he does a programme right round the school. It would mean that the Māori is on-going. This teacher that Cassandra had she would do a lot of her directions in Māori, like going to wash their hands and sitting on the mat and so she would be getting a lot of that follow-up. [I ask if this teacher was affirming prior knowledge of te reo Māori]. Well I think the way she used directions would have done that. [I ask after the title or the job description of the person who would be supporting Jay's te reo Māori]. Oh just probably it would be the resource teacher but they would be Māori. (Jay's ITOD)

Facilitating and supporting Jay's development in bilingual competence was complex. Jay's two primary social contexts – home and kōhanga reo (which enacted the principles of whānaungatanga recognised by Jay's grandparents) – were using different languages. Further, hearing aids were not being used consistently in both environments thus limiting his access to spoken language acquisition. Formal EI supports were limited by the brief of a professional's role, a brief which does not demand that individual EI professionals develop capacity to support multilingual or bimodal aspirations. Although Arthur and Mary were well aware of the dearth of support for bilingual development, having experienced similar frustration when organising support for their older mokopuna, they were frustrated that their aspirations were not able to be supported.

8.4. Experiences of early intervention: decisions and opportunities

He's the baby ... after all we've been through with the others; we just copy on (Mary)

Oh we're the sort of people that don't like asking for help anyway, we just struggle along, try and work it out for ourselves (Arthur)

Arthur and Mary's whānau dynamic is complex, having three whāngai deaf children living with them. The children were placed in their grandparents' care for varying reasons, and at different times. This created a dynamic whereby the children had bonded intimately with their grandparents at different points in their lives and for different reasons. Arthur and Mary had had some involvement with the EI services for the older children, yet as they did not take the principal role in their day-to-day care or take the lead in terms of EI support, there were aspects of Jay's experience with which they were more familiar. Both grandparents believed they had learnt a great deal from the older deaf children. In particular, they had come to accept the uniqueness of each child, recognising their individual temperaments and abilities, and concluding variances resulted from a mixture of personal traits and the consequences of individual life circumstances. Arthur and Mary drew their aspirations for each of the children based on their knowledge of them as individuals.

As the youngest whāngai mokopuna, Jay had bonded with Arthur and Mary from birth and his grandparents had been more influential than with the two other mokopuna in terms of decision-making and defining aspirations. Two of their primary aspirations for Jay at the outset were to develop a bilingual ability in spoken English and te reo Māori, and to socialise Jay in Māori contexts which operated according to tikanga Māori (a traditional value base). Hearing aids were considered the primary intervention at the point of Jay's diagnosis. It was assumed that the ability to access spoken language and auditory information would suffice for his development and he would, as hearing children naturally do, acquire spoken language in context. Decisions made at the outset included sending Jay to kōhanga reo where he would access spoken te reo Māori as a language intervention, and be exposed to a value system which his grandparents believed mirrored their own. Complications arose however when Jay did not wear his hearing aids consistently and the kōhanga reo faced near closure due to teaching and mismanagement issues. As these issues appeared to be resolving themselves and Jay was

beginning to show advances in spoken te reo Māori, his grandparents had to decide which primary school would best support their aspirations. This decision represented perhaps one of the most contentious issues for Arthur and Mary during the research period. During discussions they openly discussed their decision-making process as they evaluated the pros and cons of various schools, considered how deaf education professionals might be able to work in various environments, and lamented the lack of Māori professionals with knowledge of deaf children who had an ability to support their bilingual aspirations.

Arthur and Mary eventually decided to send Jay to the same school as his cousin, who, they reported, was doing well, as they felt the mainstream school would support him well in English and help him develop a strong language base. Acquiring spoken capacity and literacy in written English was a goal which Arthur and Mary felt, would be well-supported. Their final decision, they believed, rested on a compromise as they did not have the skills to foster knowledge of te reo Māori in their own home and relied heavily on immersion language settings such as kōhanga reo and kura kaupapa to provide the necessary language environment for the development of fluency. Arthur acknowledged the consequences of these decisions, knowing that mainstream education environments offered only superficial exposure to te reo Māori and cultural activities. Belonging to an older cohort of Māori who were either punished for using te reo Māori in educational settings and/or were never exposed and taught te reo Māori within home settings by whānau, Arthur and Mary were well aware of the missed social opportunities incurred as a consequence. Arthur was saddened by his inability to speak te reo Māori, speaking frankly about the limits placed on him when trying to socialise with other native speakers, kaumātua in particular, or when trying to take leadership initiatives in social occasions which often required oratory skill in te reo Māori. These were experiences they did not want for their mokopuna. They wanted to diversify their grandchildren's social experiences, enabling them to take a participatory role in domains which used te reo Māori as well as English.

Chapter 9. Sian

Upon first meeting Sian I recognised that she was unlike any other child I have ever met; I also found it difficult to pinpoint why. Physically, Sian is an averaged sized four-year-old girl with dark blond hair, her facial features are soft and feminine; her light skinned complexion is gently warmed by her rosy pink cheeks. The undertone of her skin and the softness of her features are indicators of her Māori, Samoan and Pākehā heritage. Sian constantly moves, and is driven to stimulate her senses in ways which are unique to her. She loves to climb and feel her body thud and vibrate while running (apparently directionlessly), and squeals and laughs joyously for arcane reasons. She enjoys the rhythm of repetitively undertaking specific tasks, and grounds herself through pedantic ‘chinning’ (applying direct pressure to her chin as a sensory soother) and arm-flapping. While Sian does not typically engage with social cues or language (auditory or visual), paradoxically she enjoys the social company of her whānau. Often she gazes to an imaginary horizon when suddenly her eyes will momentarily flit towards people to assess whether their potential activity is of interest to her. Sian contracted meningitis when she was 16 months old, the impact of this illness being profound hearing loss and what has been loosely diagnosed as Autistic-like traits. It is this combination of states which contributes to Sian’s unique way of being in the world. To most, Sian is an enigma, yet to her whānau, Sian possesses a rich internal life and inner dialogue which can be understood through careful observation of her actions.

9.1. Overview

That's the thing with Sian, she's just so different. (Sharlene)

Sian was born in 2007, the fourth and youngest child to her Auckland-based parents, Sharlene (Samoan/Palagi) an early childhood teacher, and Jarrod (Māori/Pākehā), a primary school teacher. Sian's maternal whakapapa links her to Samoa and Ireland and her paternal whakapapa links her to Ngā Puhi and Ngāti Wai. At the outset of this research Sian was living with her parents, her three older siblings, and her paternal grandfather. Towards the end of the research however, Sian's parents had separated and entered into a shared care arrangement for Sian and her siblings.

Sian was born hearing, but identified as deaf after she contracted Meningococcal Meningitis C in June 2008 when she was 16 months old. Sian's illness caused severe-to-profound bilateral sensorineural hearing loss and what was described, at the time this research was conducted, as autistic-like traits. This loose description was not a definitive diagnosis and Sian's parents were working with various professionals to gain an understanding into the nature of her behaviour and the interface between these two states. As an initial and primary intervention, Sian was implanted with what her parents were told were the first fully funded bilateral cochlear implants in August 2008²² and began receiving intensive AVT (auditory verbal therapy) through a team of local specialists.

Approximately one year post-implant it became evident Sian was in fact unreceptive to this method. Further ABR (auditory brainstem response) testing (when Sian was two years and eight months old) found no recordable brainstem response to sound, and a paediatric neurologist acknowledged Sian's developmental differences. Since then, Sian and her whānau have been trying to understand these differences, exploring the relationship between these and her deafness and working with these understandings to inform their decisions around EI.

Sharlene and Jarrod were introduced to me by the manager of the Kelston Deaf Education Centre (KDEC) preschool. After an initial agreement for me to make contact, a series of phone

²² Meningococcal meningitis C can cause ossification (the hardening or transformation of cartilage into bone) of the cochlear, resulting in a bony growth. An ossified cochlea makes the process of cochlear implantation difficult, as the bone can interfere with inserting electrodes into the cochlea, affecting either the insertion depth or the placement. If ossification is present or likely (for example, in the case of deafness caused by meningitis) prompt implantation is encouraged. In New Zealand funding is usually provided for a single implant. Sian received fully funded bilateral implants due to the possible risks stemming from potential ossification.

calls and emails were made and I offered to visit their home to discuss the research and allow an opportunity for mutual assessment. Although I had not anticipated immediate consent (especially given the intense attention they had already received from media and given the complexity of their case), Sharlene and Jarrod agreed to participate in the research within the first half hour of meeting and were keen to begin discussions. Upon first meeting Sian, I immediately recognised her difference. She was not a typical deaf child. The following excerpt is an observational note written after our first meeting in her home in Auckland.

I walk up a long driveway unsure which house is Sian's home. The driveway begins at the end of a cul-de-sac, which spreads out in a fan direction to several 1970's-styled homes with semi-mature gardens and trees. I spot a Māori man mowing his lawns and smile, asking 'Hi, are you Jarrod?' He smiles and we acknowledge one another, we greet with air kisses to the cheek, and he quickly ushers me to the front door and directs me to a stairwell, which ends in a hallway. 'Sharlene is just up there,' he says and waves his hand, directing me up the stairs. I gather he needs to pack away the lawnmower as it is nearing sunset. I take the initiative and make my way up the stairwell where I'm greeted by Sian. I smile at her, attempting to engage her eyes and she doesn't respond. I wave my hand gently to indicate 'hello' and touch her shoulder. Sian remains very still, her eyes averted to the side, head tilted down. Unsure of where the rest of the family are, I look around the hallway. Sian suddenly grabs my arm and forcefully drags me through the dining room and into the lounge. She arranges my body so that I will sit on the floor; she places herself next to me and attempts to unzip my bag. I unzip my bag and give her several pieces of paper and pencils to see what she does; she continues to rummage through my bag. I take out a packet of fluorescent pink and orange post-its and stick them to paper in random order – Sian joins in on the activity. We create post-it 'lists' arranging post-its in various patterns which utilise aspects of colours and composition. Sian then climbs onto my lap and puts her head under my poncho. The poncho is knitted and when held to the light looks like a fishing net. I take it off and give it to her. She arranges herself on the mat and starts to use the poncho as a 'blankie'. Smoothing it repetitively, she appears to enjoy placing the poncho over her face and staring through the holes. We use no spoken or signed

language. Sharlene walks into the room, giggling and smiling at Sian. ‘Hi, I’m Sharlene,’ she says to me. I get off the floor and greet Sharlene with air kisses to the cheek and greetings; I tell her about the game we have been playing. Sharlene confirms Sian enjoys those games often playing them at home. Jarrod quickly joins us and Sian remains very interested in the poncho, arranging herself in various positions alone and alongside people (her parents, myself, and her siblings) pedantically smoothing ‘blankies’. In between discussions she tries to kiss me. Sharlene quickly goes to the kitchen to fetch a sandwich and says to me, ‘Oh she does that when she wants something from someone, it’s a form of communication, and she’s probably hungry’. Sian spends the evening pottering around the rooms with her siblings. Sian’s behaviour is different to that of any other child I have ever met. She constantly moves, seeming to enjoy running aimlessly and squealing. Sharlene and I discuss how she seems to enjoy feeling her body vibrate as we feel her thudding her feet to make the floor shake. She deftly climbs up high on furniture; she watches her favourite DVD (*Ice Age*) with her face literally inches from the large wide screen TV squealing and smiling at the images. She flaps her arms regularly and removes her pants as she doesn’t like the sensation. Regularly she runs to Sharlene and applies direct pressure to her mum’s body using her chin (which Sharlene calls ‘chinning’). She doesn’t appear to make eye contact with anyone but certainly has an understanding of her own movements and those of the household. She watches from a distance assessing their potential movement or activity. Sharlene also reports Sian sleeps very little and has bouts of wakeful periods in the middle of the night. Sian is an extremely active child and it is easy to see how her parents believed she was autistic based on her behaviour. I leave late, at around 11pm, and Sian shows no signs of tiring, although her parents certainly do.

Sian’s parents agreed to several more meetings and expressed interest in attending the proposed hui at the end of the research. Sharlene, Jarrod and I met on several occasions, in and out of the home. Given the coexistence of autism and deafness is relatively rare, Sharlene and I accompanied Sian’s key worker and her language therapist to a day seminar given by Professor Rita Jordon addressing how to manage autism and challenging behaviour. At the end of the

session we discussed the points made in the seminar and the implications for Sian. While it was obvious Sharlene and Jarrod had endured a very difficult and emotional journey, trying to do the best by their child, they were also bitterly frustrated with the unknown aspect of Sian's diagnosis and the lack of examples from which they could envision a potential life trajectory for Sian. Finding a natural support network was a significant challenge for this whānau who found membership in such networks often hinged on categorising themselves in established groupings based on either 'mode of language use' or 'diagnosis of disability-type'.

This chapter provides a description and discussion of Sian and her whānau in relation to the key research questions.

9.2. The shaping of whānau perceptions of deafness

9.2.1. Identification of deafness

In June 2008, Sian contracted meningococcal meningitis C, her illness causing severe-to-profound bilateral sensorineural hearing loss. Sian was admitted to Auckland's Starship Children's Hospital where her pathway into EI services began. Sian was aged 16 months. The initial period of identification and EI was framed within the medical system. Her illness, a life threatening medical emergency, was treated with the support from teams of various medical specialists who also monitored Sian for the potential impact. As Sian slowly recovered, Sharlene and Jarrod observed a difference in their daughter, who appeared to be socially displaced and distant, was disinterested in maintaining eye contact; and unresponsive to familiar voices and general noise. Prior to her illness, Sian had been meeting developmental milestones typical of her age, beginning to use spoken language and becoming well-socialised in a whānau with close intergenerational relationships. Sharlene, an experienced early childhood teacher, and Jarrod, an experienced primary school teacher with insights into children's behaviour, suspected Sian's hearing had been affected by the illness and shared their suspicions with medical staff.

She'd lost all of her motor skills and I said to them in hospital, 'I don't think she's hearing'. I'd go to the toilet in the same room and she could see me leaving and she'd start crying. I wasn't worried about her falling off the bed because she couldn't move, but I was like 'It's ok Sian I'll just be two seconds, all right? Mummy will be back', but she just kept screaming, nothing I would

say in that ten seconds would work ... and when I went back she would be like calm right down. My aunty gave me a musical toy that jiggles and makes a noise. I put it behind her ear and I was like 'she's not hearing' and no one would believe me. They just said 'Oh it's just the Meningitis, it will heal'. Then they said we needed to get a standard audiology test in six weeks' time and that was ok, but I just kept saying 'I don't think she's hearing, I really don't think she's hearing'. I clapped my hands and all that sort of jazz and because she still had a few words. 'Hello' and 'Mama'. They sent us home. They discharged us and said 'Don't worry, you'll be in the system, don't worry. The audiology test will come up and then you can get her eyes tested, standardised testing – da, de, da'. I was like "Yeah, I don't think you're listening, I don't think she can hear". I don't know how many times I said it. (Sharlene)

After a series of persistent requests from Sharlene, testing was undertaken and Sian's deafness was later confirmed via an ABR (auditory brainstem response) test. Sharlene and Jarrod were immediately taken to meet the ENT (ear, nose and throat) specialist who introduced the possibility of a cochlear implant within minutes of identifying Sian's deafness.

I don't know how many times I've said 'I wish I had someone there'. I wouldn't have cared if they were Māori, Pacific Island, just if they knew the system and knew what was happening. We were like 'Okay, so she's a great candidate'. I can't remember if it was at that meeting if they talked about bilateral, I blocked a lot of that out really. We didn't have an advisor or anything. It was sort of 'Would you like to have? Are you interested in this type of thing?' That's when I burst into tears, I was like, 'So my child's deaf and you want to talk about an operation that might enable to her to hear, but not hear? (Sharlene)

A CT scan identified bilateral ossification of Sian's cochlear and fully funded bilateral implants were offered. Upset and confused, Sharlene and Jarrod returned home unsure of the function of the cochlear implant and how to proceed. An advisor and counsellor visited Sharlene and Jarrod's home and explained that to be accepted as a candidate for a cochlear implant they had to undertake a process which involved more meetings and information sharing. Surgery was eventually undertaken on the 1st of August 2008. As Sian received the country's first fully

funded bilateral implant, she and her parents received intense attention from medical professionals and media who watched Sian with great interest. Sian's story rode on the crest of a very public and active campaign which aimed to heighten awareness of the seriousness of meningococcal meningitis, to promote immunisation against the disease, and encourage families to seek prompt medical advice at the presentation of symptoms. At risk populations, including Māori and Pasifika (those of Pacific descent), were specifically targeted. As a child of Māori, Samoan and Pākehā heritage, Sian was a prime 'poster-child', the survivor miracle child with prompt, diligent parents, grateful for the medical intervention and fully funded bilateral implants, the success of which was expected to provide her with much needed access to spoken language. Reflecting on the media attention, Sharlene and Jarrod had mixed feelings. The overwhelming sense of gratitude for their daughter's life was, and still is, paramount. They appreciated the medical intervention and support which had saved her life and felt privileged to receive fully funded bilateral implants when others' had not. Sharlene and Jarrod were convinced prompt intervention and providing full funding for bilateral implantation where needed were significant messages worthy of advocacy. The complexity of the post-implant experience, however, set them on a journey they could never have anticipated.

Initial switch on and Mapping sessions held in August 2008, were undertaken by audiologists and AV therapists from Hearing House, an Auckland-based organisation supporting children with cochlear implants. Reports by staff noted Sian's initial response to wearing the device was fairly typical of those in the introductory phase of the cochlear implant.

Sian accepted the devices as long as she was distracted. However, keeping them on is a bit difficult at the moment because she does try to rub them off as soon as the coil is placed on her head. I expect this difficulty to ease as she becomes more used to the sound. (Audiologist, August 2008)

Initially Sian would only tolerate the implants for a short period of time. However, for the last two months she has been wearing her implants all waking hours and is enjoying the sound. She is able to indicate that the coil needs to be returned to her head when it falls off either side. Sian detects the 6 Ling sounds consistently and conditioned response is emerging at an age appropriate level. She turns to her name being called in a quiet room both near and at a distance of 1 metre. Sian turns to locate the speaker, stills when spoken to, and stops her own vocalisations to listen. She is beginning to

demonstrate vocal turn taking when listening attentively (AV therapist, November 2008)

During this period Sian had been attending a mainstream preschool. The noisy environment and lack of specialist support prompted Sharlene to request a position for Sian at the Hearing House preschool. Sian started when she was approximately three years old and stayed until she was approximately four. During this time she was immersed in spoken English with deaf children with cochlear implants and hearing children who used spoken English and she received specialist support from onsite AV therapists who focused on her receptiveness to auditory information and encouraged the use of spoken English. Although Sian's progress reports from Hearing House indicated a promising response and receptiveness to the cochlear implant, privately Sharlene doubted the optimism of the assessments. In her observation, Sian had not significantly advanced beyond the level of her language development prior to the implant. Sian's social behaviour also remained unusual. She was becoming increasingly introverted; was disinterested in holding eye gaze (a significant communicative skill required by deaf children), made fleeting and momentary eye contact from the periphery of social groups, and was generally disinterested in social activity with people. At Sharlene's instigation, Sian was assessed by a paediatric neurologist in October 2009 (Sian was then aged two years and eight months), who acknowledged her developmental differences. However, the paediatric neurologist refrained from giving a definite diagnosis of autism, indicating that such a diagnosis was difficult to determine.

Whilst Sian has mild delays in all developmental arena other than language which remains severely delayed, she is making progress in a forward direction. Her expressive language remains significantly abnormal and out of context with other developmental domains. I do not feel strongly that Sian has cognitive or other causes impairing her progress in language development. In particular I did not feel strongly that she was demonstrating features highly suggestive of autistic spectrum disorder or significant cognitive delay. Previous imaging does not show any damage to cortical language areas. Acknowledging though that autism and cognitive delay, particular in the setting of hearing impairment can be difficult to test for such a young age, close follow up is required. (Paediatric neurologist, September 2009)

This assessment paralleled an updated ABR test which found no recordable brainstem response to sound following the cochlear implant, proving Sian's deafness and explaining her limited progress in spoken language. The coil and the processor were removed immediately, but the internal cochlear implant remains awaiting approval to be removed despite Sian's parents' earlier request to have it removed. Medical specialists suggested that the removal of the cochlear implant was a difficult procedure and perhaps worth revisiting when Sian was aged seven. Sian's parents accepted this rationale, however, would have preferred that the magnets resting on the side of her head be removed earlier. Given that the specialist services provided by Hearing House were focused on supporting those with cochlear implants their service no longer met Sian's needs. Sharlene and Jarrod enrolled Sian with the KDEC preschool in Auckland in February 2010 where she attended half-day sessions during week days. In this setting, a team of skilled specialist staff worked in a bimodal setting (using spoken and signed modes). Deaf children, with and without cochlear implants, and hearing children, able to use either or both spoken language and NZSL, were exposed to signing and speaking deaf and hearing adults. Children were encouraged to follow their natural language preferences and, where willing and interested, were supported in bimodal awareness and capacity. As Sian was unable to use spoken language and demonstrated little interest in signed language, a language therapist who specialised in working with children with language delays was appointed to work with Sian. Later specialist support people included an experienced key teacher and an early interventionist appointed by the Ministry of Education. As Sian had no definitive diagnosis that explained her behaviour or added insights into her lack of language and communication, intense observation and recording of Sian's behaviour ensued. This was a collaborative process with Sian's parents whose expertise and insights into Sian's behaviour were included. The data was later used to support Sharlene and Jarrod in attaining a fuller diagnosis for Sian from the paediatric neurologist. Even after augmenting the data with a series of on-going assessments from the paediatric neurologist the reluctance to diagnose Sian as autistic persisted. Alternative possibilities offered included potential autistic-like traits and global developmental delay. Sian was then referred to general paediatrics where she was monitored regularly. During these on-going assessments, diagnosis was again avoided, yet her behaviours, which were becoming more noticeable and more aligned to behaviour presenting in autistic children, were more often acknowledged as such. Given the coexistence of autistic-like traits and deafness it was difficult to apply diagnostic tools.

I had a long discussion with Sian's parents and Jo today. I have stated that it is obvious she has social and communication difficulties, however teasing this out from the result of her deafness following meningococcal meningitis versus a possible diagnosis of ASD, is quite difficult. It certainly does not sound as if prior to 16 months there had been any concerns in regards to these issues, although again I advised that autism is not often diagnosed until two or three years of age anyway, as it takes time for the symptoms to become apparent. It sounds as if they [AV Therapists] are making some progress with her communication with intensive speech language therapy and at present I would be most comfortable reviewing her again in six months' time to assess how things are going (Paediatrician, June 2010)

During the consultation we tried using the Checklist for Autism in Toddlers (CHAT). This showed a fairly high risk of autism according to the answers given. I have reservations about the accuracy of the autism checklist because of Sian's previous problems with meningococcal meningitis. We did try looking at an Asperger's Syndrome rating scale for older children, but this was not appropriate for a child Sian's age. ... My impression is that Sian may well have features of autism. It is difficult to know if this is due to the meningococcal meningitis, or if it is a separate problem. I have given Sharlene some contact information from Autism NZ and also for Rainbow House, so that she can get some more information and resources to help with dealing with behaviour. I have not been able to find other behavioural rating scales that are for children in Sian's situation. The overlap between meningitis, hearing loss and behaviour is really quite unique. (Paediatrician, June 2010)

As it was likely that Sian was not born with autism, professionals provided a tentative explanation rather than a diagnosis. It was likely that her brain had been damaged through the meningitis and now presented in a way that an autistic child's brain might present. Her behaviour, then, mirrored an autistic child's behaviour due to her brain functioning in a similar way. With this knowledge, Sian's key worker, language therapist, and early interventionist actively combined their skills and knowledge alongside Sharlene and Jarrod to support Sian's

development. Sian was beginning to use the picture exchange communication system (PECS)²³ with varying degrees of success and was monitored carefully to help understand her behaviour.

Since starting at KDEC preschool, photographs have also been used to support Sian's understanding of what activity is happening next e.g. mat-time, home-time. Sian looks at these photos and often looks at the one of her mum (which signals home-time). The [picture exchange system] PECS is currently being trialled with Sian. This is in its early stages. She has learnt that exchanging a picture results in her getting an item of food (raisins). This system is being developed with Sian at preschool and will be introduced at home when appropriate as a way of her being able to ask for things."
(Language therapist, June 2010)

9.2.2. The evolving context of whānau

At the outset of this research Sian was being raised in an intergenerational household with her paternal grandfather, parents and her three older siblings, the eldest aged 14 and Sian was the youngest aged four. A number of Sharlene and Jarrod's siblings and their children also lived in close proximity to their household and offered Sian's parents support with raising their children, as well as a wider network of cousins, aunts and uncles within which the children were raised. Sharlene's own mother Nana Fale and her husband Papa Rod also lived close by and were in regular contact with the children and offered support. Toward the end of the research period, Sharlene and Jarrod decided to separate and relocated in two separate houses in close proximity to one another. They have a shared care 'week about' arrangement whereby the children spend a week with each parent. Unfortunately Jarrod's father's health deteriorated rapidly during the separation and requires intensive hospital care. He is now living nearby Jarrod's home in a residential home which offers specialised hospital support. Sian and her siblings see their grandfather regularly. Despite the parental separation, Sharlene and Jarrod remain in regular contact and they support one another actively in the raising of their children, which they still see as a joint responsibility. The parental decision to separate has not effectively altered the key network of support involved in raising Sian.

²³PECS is a form of augmentative and alternative communication. PECS is often used as a communication method for children with autism and provides an alternative to speech, sign and writing. Within PECS a number of picture symbols are used as the modality; children are encouraged to use picture symbols spontaneously within home, school, and community settings.

9.2.3. **Constructing deafness through experience**

Sian's our quirky child. (Jarrod and Sharlene)

Both of Sian's parents had experienced close relationships with deaf family members prior to Sian's birth, Jarrod with his uncle, affectionately referred to as 'Uncle Dave', and Sharlene, with her younger cousin Daniel. Uncle Dave and Daniel were born in different eras in which societal responses to deafness and the resulting ideologies informing the education system differed from one another. The reflections, insights, and knowledge gained from this intergenerational experience of deafness added to the montage of information which shaped perceptions of deafness amongst Sian's whānau. Yet Sian's parents struggled in the midst of their own experience to clearly see how the historical contexts of Uncle Dave and Daniel had contributed to the era of the EI system under which Sian was born and raised. The coexistence of Sian's deafness with her autistic-like traits made it even more difficult to apply these experiences to their situation. During the research period Sian's parents articulated their observations of Sian's situation in light of the historical contexts of Uncle Dave and Daniel. The research reconciled past knowledge with new knowledge and supported Sian's parents as they formed their own perception of deafness in relation to Sian.

Jarrod's Uncle Dave had died tragically in a fishing accident in 2002. Had he been alive he would have been aged in his early 60's at the time of the research. Born in the era of residential education and oralism, Uncle Dave also lost his hearing through contracting meningococcal meningitis as a young child and was sent to board, at what was then called the Kelston School for the Deaf and the Dumb to attend primary school. Jarrod believed he would have been aged approximately five years. This was a typical experience for deaf children of this era. According to Jarrod, the early and enforced long-term separation of child from whānau at such a young and formative age traumatised his grandmother and the rest of the whānau who grieved during periods of long term separation. At the time however, they also felt they did not have any alternatives. During those short times they were able to spend with him, they attempted to facilitate Uncle Dave's participation in whānau life and developed their own idiosyncratic communication system based on home signs and gesture. As the majority of his time was spent in a residential setting with other deaf children, Uncle Dave formed strong family-like bonds with his deaf peers at residential school, acquired the underground language of the playground (sign language) and was socially active as an adult with the deaf community. Typical of the era, many of Uncle Dave's whānau developed pet names for one another, endearing and

humorous names based on an amusing aspect of their personality or physical characteristics. Uncle Dave's pet name amongst his whānau was 'Dummy', assigned because of the common societal phrase 'Deaf and Dumb' being used at the time to describe deaf people. According to Jarrod and his father, the term was not used in a derogatory way but was a common epithet used in the English speaking world for deaf people. They felt this perhaps reflected their acceptance of general terms used in society without question.

Jarrod. Everyone in our whānau used to refer to Uncle Dave as deaf and dumb; it just seemed to be normal and that's what it was like. [Sharlene comments, incensed with the use of a derogatory term]. Jarrod: That's what everyone referred to it as, 'being dumb' meaning he couldn't speak. 'Dummy' was his nickname, that's what everyone used to call him. It wasn't because he was 'thick'; it was because he couldn't speak. That's what his brothers used to call him, he was 'Dummy', and they never saw it as derogatory. It was never like that – that was just his name.” (Jarrod)

During interviews Jarrod fondly reminisced about his late Uncle. He admired his innate resiliency and ability to forge what he described as a 'fulfilling and colourful' life in spite of his limited educational experiences, childhood separation from whānau, and enforced institutionalisation. Jarrod was struck by the profound and intimate bonds formed between Uncle Dave and his deaf peers, as demonstrated at his Uncle's recent tangi, and was heartened to know his uncle was well known to the Māori deaf community.

Sharlene's cousin, Daniel, was raised in an era where sign language was becoming more readily accepted in the education system in Aotearoa/New Zealand, and negative social attitudes toward deaf people were being challenged. Daniel is also a fluent user of NZSL and a qualified teacher teaching deaf children. Sharlene held memories of her family actively questioning attitudes underlying the misconceptions about deafness in society. Having her own deaf daughter forced Sharlene to revisit these conversations, and she felt that such reflection had somewhat politicised her understanding of the impact of language discrimination and the on-going discrimination experienced by deaf people in wider society.

I feel the angst of them [deaf people] – historically you can see why [there is a lot of angst felt by deaf people]. You've been beaten because you use a different language and people call you 'deaf and dumb'. I hate that. I can

remember relatives arguing about my deaf cousin, his mother said he wasn't to be called 'deaf and dumb' or 'mute'. That was the terminology they used back then. I'll never forget that. (Sharlene)

[Daniel's] got an uncle who is deaf and they were fine, perfectly functioning and normal. I hate that people struggle with words whenever they talk about deaf people. (Sharlene)

Making links with deaf adults and with the local deaf community was not as challenging for Sian's parents as it had been for other participants in this research. They lived in Auckland, where the deaf community is the most numerous and diverse in Aotearoa/New Zealand. They had access to this community through their own whānau connections. Sian was attending a preschool with deaf teachers and to which deaf adults sent their hearing children. As Sian had a bilateral cochlear implant however, Sharlene and Jarrod were apprehensive of the potential response they and Sian would receive from older deaf people. In some instances, they were the recipients of hostile accusations that they had inflicted 'child abuse' on their daughter having allowed her to be implanted. Support from staff at preschool (deaf and hearing) and associated families (with deaf and hearing members, some of whom were also implanted) alleviated these negative responses by consistently encouraging their connection to one another and to deaf adults. As Sian was not going to be responsive to spoken language and her parents were exploring her receptiveness to NZSL, the relevance of deaf people and the local NZSL community became more salient. Taking initial steps to learn NZSL and socialise with other deaf people however, took a great deal of courage. Acquiring a basic ability in NZSL and regular socialising with deaf adults through Sian's preschool cemented a sense of community awareness and eased social awkwardness.

There's the Deaf Society but I've sort of worked out that it's for older deaf people? They have Christmas parties and picnic days and annual picnics ... I don't know if this is my misconception because I'm hearing ... that we don't go to those ones. It's just for deaf adults with deaf children or with hearing children (which doesn't matter). I have seen it, I did like what I'd seen, but I kept forgetting to join up. (Sharlene)

Sharlene and Jarrod found that while Sian was generally acknowledged and accepted by other deaf adults amongst the deaf community, those within the community found it hard to make

sense of Sian's behaviour because of the coexisting nature of her deafness and her autistic-like traits. Sian's parents also struggled to find a natural niche amongst that community. As hearing parents, they were socially constrained by their basic command of NZSL, had limited social experiences within the community, and were regarded cautiously at times by other deaf adults. Sharlene and Jarrod found that as they persisted, despite social awkwardness, their acceptance into the social fold was eased. The introduction of a name sign for Sharlene by deaf people at the preschool, indicated her regular presence and attempts at NZSL had been noted, acting as a gentle welcome into their social fold.

Every time I would walk in [to the preschool] they would be like, 'Hi Sian's mum,' and they said, 'You will always be associated with Sian, that's her name sign (air flick of hair out of face with the right hand). She always flicks her hair out of her face, and that's her name sign. They said, 'So your name sign will be 'Sian's mum' (hair flick and then signs Mum) – you will always be associated with her'. I said, 'That's fine.' That's how I got my name. (Sharlene)

Unsure how to enter the social fold himself, Jarrod was encouraged by the fact that his Uncle Dave was well known amongst the local deaf community, including several Māori members. When I mentioned it was acceptable to network within the community based on this familial connection as one would within Māori social networks, Jarrod was intrigued but equally apprehensive of beginning conversations due to his limited ability in NZSL.

In an effort to gain insight and support from families with similar experience to their own, support was sought from others. Various methods of introduction followed, comprising formal introductions via service providers, informal introductions made through their existing social networks (such as the deaf community), and chance meetings with individuals. As well-educated professionals experienced in working with children and diverse families, Sharlene and Jarrod found making meaningful social contact with various sources of support relatively straightforward. Finding the relevance of these supports was another challenge; networks were often lacking in contextual perspective and were often conceived of in relation to either autism or deafness as opposed to a coexisting relationship between these.

Those with experience of autism were often able to offer a particular view of parenting a child on the ASD spectrum. However, as Sian had not been diagnosed as classically autistic but

merely displayed traits akin to those associated with autism, the relevance of others' experiences and advice was often confusing. Strategies offered by other parents often hinged on the use of language as a tool to mediate behaviour, which was not applicable to Sian who was unable to develop spoken language and appeared only vaguely interested in using either sign language or visual communication strategies. Similarly, Sharlene's attempts to gain social support from parents of deaf children and deaf adults were also overshadowed by the lack of knowledge as to the coexistent nature of Sian's deafness and autistic traits. Sian's preference to observe social groups from the periphery, her avoidance of intimate eye contact, and her lack of communication (spoken or signed) signalled disinterest and delayed social skills. The question, 'What's wrong with Sian?' was often used as an initial conversation starter between Sharlene and others with whom she sought social connection. During these conversations she was disheartened by the prejudice inherent in these labels. As Sharlene was coming into contact with various views held by groups in society, the use of labels was not always apparent to her; for example, during one of our discussions Sharlene asked me to clarify the meaning of conversations she had had earlier with deaf adults.

Sharlene seeks to clarify a previous conversation she had with a number of deaf adults. During this conversation she had asked a deaf mother how to sign 'hyperactive'. Sharlene signs 'MENTAL/SILLY' in NZSL and asks me to confirm its meaning. I reluctantly confirm that I understand its meaning. She insists on knowing and I tentatively suggest it is associated with mental illness. I then decide to be frank with her and suggest that the use of the sign is somewhat derogatory. Sharlene considers my proposition stoically and confesses the location of the hand movement may have been somewhat different, she says 'It wasn't exactly like that, but it was around the brain'. I suggest an alternative NZSL sign 'BRAIN DAMAGE' which I have seen older deaf people use to indicate delays in mental or cognitive development. This sign is less derogatory and would have been an attempt to be polite using a limited repertoire of NZSL terms for such characteristics. Sharlene agrees my suggestion was another likely possibility. I suggest that she would still have had a right to be upset about the use of that sign as it too comes with a negative stigma attached. Sharlene then asks for the meaning of another sign, which she reconstructs from memory. The reproduction lacks a definite direction – there is neither a definite start nor end. I resign the movement to

suggest what I think she is signing and ask her if my reproduction is correct. She confirms it is. I report the sign is AUTISM. Sharlene is excited by the reproduction and practices it as we continue talking. This is a sign she had seen another deaf mother use on another occasion. We discuss the different reference point that the sign AUTISM offers as opposed to BRAIN DAMAGE and MENTAL/SILLY – older signs couched in a tradition of derogatory associations. We explore the connotations of the movement; the emphasis the sign places on the inward nature typical of those on the ASD spectrum and the preference for limited eye contact. We discuss its usefulness when Sharlene attempts an initial ‘What’s wrong Sian?’ conversation with those in the signing community.

As experienced Māori and Samoan education professionals working within the education system, Sharlene and Jarrod were familiar with the use of politically correct terms. Having a deaf daughter, the politics informing labels, as well as the stigmatising potential of these, to describe children who were different became more emotive and salient. They were most concerned with the potential impact of labels on whānau as used in educational policies and ideologies. While they had always known about the complexities of these from their perspective as educators, their understanding was now based on first-hand experience. Jarrod and Sharlene understood from the perspective of the educator that diagnoses and labels provide a potential developmental trajectory as well as an entry point into a system which provides resources to support development. Now, as Sian’s parents, they were frustrated and resentful over the way labels were used to identify resource supports for Sian’s development, such as the ORRS funding system, while simultaneously painting a deficit picture of their daughter’s development.

***Sharlene:** Well at first I was like ‘I don’t know if I want her to get a diagnosis’. **Jarrod:** They have to put her in a box you see. **Sharlene:** I’m familiar with the process of getting forms; she needs a diagnosis to get what she needs. If she doesn’t, that’s okay, I don’t want to be all ‘woolly, woolly’ going to the paediatrician and they just keep calling her unique. Then we leave there and then that [the lack of diagnosis] hinders her getting an EI teacher or funding or whatever it is she needs.*

I'm still struggling with calling her 'special needs' ... they're just different.
(Sharlene)

Having a deaf child was not, in Jarrod and Sharlene's view, a tragedy. Their experience of deaf people gave them some idea of the challenges they might face and they felt somewhat equipped with skills to work through these challenges. The complexity of deafness coexistent with autistic-like traits however, and the impact this had on Sian's language development, presented a very new challenge of which Sian's parents and professionals had little experience. Experience of deaf people and communities provided Sian's parents with a sense of potential life trajectories; however, as Sian was unlike any other deaf child that her whānau and most professionals had ever encountered, it was difficult to develop a sense of future direction.

9.3. Experiences of early intervention: Language and communication

Sian's parents' primary expectation was that Sian would have an opportunity to develop a strong first language and participate actively in the daily life of the whānau. When first diagnosed, Sharlene expected Sian would be bimodal, using NZSL as a first language, already being familiar with the language through the deaf within their whānau, while simultaneously acquiring, with the support of a cochlear implant, the spoken languages of their household (English and te reo Māori). These they assumed, would be acquired naturally, just as their other children had acquired language. Jarrod, a fluent speaker of te reo Māori as a second language learner, taught in a te reo Māori immersion classroom at a local school, and all three of their hearing children were proficient bilingual speakers of English and te reo Māori. Sharlene spoke primarily English, although she knew some basic Samoan and te reo Māori. Both Sian's parents understood the commitment required to acquire and teach a language to proficiency levels. In their experience of raising bilingual children, and as second language learners, Jarrod and Sharlene believed good language role models were essential. Hence they expected they themselves would also be learning NZSL and would have deaf people as their language models.

Within weeks of implantation, Sian was receiving AV therapy from specialist staff based at Hearing House. Sharlene and Jarrod were generally optimistic with Sian's initial progress. They understood extensive support for Sian's language learning would need to occur in their home as well as at pre-school. Activities suggested by the AV therapists were implemented in the home, and Sian was exposed to a language-rich household where both English and te reo

Māori were spoken amongst three generations. Reports from initial sessions indicated Sian spent most of the first two months acquainting herself with her cochlear implant and the sensation of sound, and observations of her progress indicated she was progressing well. During Sian's first session with the AV therapist, the following observations were noted, indicating her receptiveness to sound and spoken language. Sian was aged one year and nine months, however due to her recent implant her hearing age was recorded as three months.

Sian is listening attentively in sessions and mum reports she is happy to sit and listen to stories at home now. She is moving to music and using a singing voice and is able to identify two of the songs by rhythm. Sian is able to detect all six Ling sounds and imitate three. Mum reports she appears to understand some early phases that she knew prior to her illness.

Sian is using her voice with appropriate inflection and intonation. She is blowing raspberries as a vehicle sound, which her mum reports she did previously. A few of her early words have now returned – 'no', 'duck', 'down', 'hello' – and she is using 'mum' consistently. She is using performatives for a range of animal sounds. Sian is mainly producing three consonants in her babble interspersed with vowels. As her oral motor skills develop, she will begin producing a wider range of consonants. The development of her vowels and consonants, as well as her ability to imitate, indicates she is listening well, making sense of the new signal and on her way to spoken language through audition.

Sian has developed some positive pragmatic skills, many of which were present prior to the implant. She has good eye contact and shared gaze. She looks to others when wanting a response to something to gauge their reactions to a situation. Sian expresses her needs and wants with a combination of voice and gesture. She is beginning to understand turn taking and her family is encouraging her to share. She responds well to praise and loves to be in control of activities and demonstrate her skills. (AV therapist, November 2008)

Specialist staff praised Sian's parents' initial efforts and commitment levels, reminding them to persist with expectations around listening and encouraging them to create a home context

conducive to Sian's receptiveness to speaking and listening to spoken language. Balancing these expectations with the reality of necessary work commitments and the demanding routines associated with an intergenerational household was challenging. Providing Sian with long-term one-to-one attention in a quiet household was an unrealistic goal and had to be mediated against raising and meeting the individual needs of four children, providing support to an elderly parent, and negotiating the logistics of living in the busy city of Auckland. When Sian was initially implanted she attended the preschool where her mother worked for long periods of the day.

Sian is now wearing both devices all waking hours. This is due to the family's perseverance and consistent expectation that she do so. Sian's family are committed to her being a speaking, listening child and provide good language models for Sian and interact with her appropriately. However due to work commitments it is difficult for mum to provide Sian with quiet one-to-one time regularly. There are concerns around the noisy environment of her present pre-school; its lack of language focus, lack of sound field equipment and low staff ratio. This is adversely affecting both Sian's behaviour and ability to listen. The staff of the preschool are not trained to target language development for a hearing-impaired child and numbers do not permit them to do so. Sian is currently establishing her behaviour boundaries, which are typical for a two-year-old child. It is important therefore that the family continue consistent expectations that Sian listens when she is spoken to. (AV therapist, November 2008)

Sharlene recognised however that while it was convenient to have Sian attend the preschool, as her primary daytime environment it did not provide an ideal learning environment for a child with a cochlear implant. Sian's parents enrolled Sian at the Hearing House preschool, an environment conducive to auditory language learning and that provided ready access to specialist AV therapists and audiology staff.

After initial interactions with medical and educational professionals progressed, Sharlene and Jarrod enquired about the use of NZSL. They were however, discouraged from this, given Sian was to receive a bilateral implant. The option to use NZSL, although stated at the outset as a desired outcome by Sian's whānau, was actively discouraged, and despite living less than a ten minute drive from the KDEC preschool (where NZSL lessons are provided to families with

deaf children) professionals informed them that as Sian had a bilateral implant she would receive AV therapy via Hearing House. This was confusing for Sharlene and Jarrod who had a lived understanding of the diversity of deaf people's life experiences. They appreciated the significance of sign language, and that sign language was a natural language and an avenue to deaf culture and community.

I was so naïve. He [the Advisor] said 'Well what do you want to do?' And, I was like 'Can't we do everything, I just want to learn sign language because she is deaf, da, de, da, and then we'll go to Hearing House – it will be great – won't it, isn't that how it works?' And he just kind of looked at me and gave me the strangest look, like 'She has no idea'. In hindsight they didn't let us know, I didn't know that in AV therapy you didn't sign, that you weren't encouraged to sign, that really it was a 'no-no' to sign. (Sharlene)

I was told at Hearing House there is no place in Auckland or New Zealand that does the whole 'total communication' that she might sign, speak, do this, do that. I did ask. (Sharlene)

The decision to give Sian a cochlear implant hinged on her parents' belief that it would give her the opportunity to actively participate in the everyday life of their whānau and wider society. Post-implant, they discovered, however, that their decisions were critiqued from various angles. During AV therapy sessions, the AV therapist's responses to Sharlene's attempts at sign language, gesture, and visual communication strategies indicated such behaviour was a social faux pas. Relatives connected to Sharlene's cousin Daniel knew Sian was not learning NZSL and were hurt and confused by Sian's parents' decisions.

My aunty said to me, 'Why aren't you at KDEC, you should be signing!' I was like, 'We can't sign, we've been told no.' 'Well that was just rubbish!' she said. My reply was, 'Well, that's the Hearing House advice'. (Sharlene)

After a period of one year, Sian's spoken language, in particular her expressive language, was still significantly delayed. This, coupled with Sian's socially introverted behaviour led to parental concern. Raising the issue initially with specialist staff, Sian's parents were, in response, asked to consider how they themselves might be contributing to Sian's lack of progress. Sharlene and Jarrod felt they were regarded as neurotic and neglectful and that aspects of their lives were cross-examined, causing self-blame and confusion.

After the implant, that was great ... she's a perfect candidate for it. They asked us, 'Yes, you're committed?' and we were, 'Yes, we know what the commitment level is'. Then pretty much a whole year passed with intensive therapy and it wasn't working. They started to blame us, we got the major guilt trips from them. 'Maybe you've got too many people in your family, in your household, maybe you're too noisy, you're not paying her enough attention, she shouldn't be at work with you, maybe you should be at a quiet environment ...' They were basically saying 'You should stop working, it doesn't matter about all your bills ... [the bills] don't matter?' It caused friction between us, because I was like, 'Why aren't I a stay-at-home mum? And the reality was we had three other children and all our focus had been going into Sian. (Sharlene)

We were at therapy every week without fail, doing stuff at home with her, the cochlear implants – she hated them. I just felt like I was torturing her every time we had to put them on, and they'd say, 'You're not doing enough, you're not doing it right.' I was about to go insane because I was thinking what are we doing wrong? Finally they did the test and were kind of like, 'It's not working, it hasn't been working for a year.' I thought – why didn't anyone know! They hadn't been working because her nerve endings had too much damage. Then two people came to see us from the hospital, two audiologists; I just cried and said 'Why didn't you know?' They were very sorry, but we had no word from Hearing House. (Sharlene)

After a series of investigations it was discovered Sian's nerve endings were permanently damaged and she was not receptive to the cochlear implant during this period. Bitter disappointment and frustration ensued as Sian's parents questioned why they were discouraged from using NZSL simultaneously with AV therapy. As AV therapy was no longer applicable, Sian's parents were asked by Hearing House to find a more suitable preschool placement for Sian. While it was accepted that AV therapy was no longer relevant to Sian, her parents were incensed over the deterioration of the relationship between specialists from Hearing House and their whānau. From Sharlene and Jarrod's perspective, the organisation lacked processes to indicate a gracious and culturally appropriate exit from their service, leaving them feeling angry, bewildered, and devalued.

That was pretty hideous, she was at kindy at Hearing House and they were like, 'There's nothing we can do for her'. I was like 'Okay, where to next?' (Sharlene)²⁴

In their quest for alternative support for Sian, Jarrod and Sharlene were directed to KDEC. Prior to attending KDEC, the medical and educational professionals they had dealt with indicated, through subtle social cues, that KDEC was an institution of poor quality and a point of last resort. They were surprised and confused to find this reputation unjustified and the multidisciplinary team at KDEC skilled and open to various communication and language options. As NZSL was used in the preschool, Sian's parents felt the centre's poor reputation may have reflected the societal prejudices against NZSL as well as the limited resources the preschool was working with.

***Jarrod:** Hearing House told us, 'You can't sign to her because that gives her an 'out'. Kelston was the worst alternative that they saw. It was like they were the poor cousin and they were 'Richie Rich'. When I go to Kelston I feel the aroha, 'paku te utu, nui te aroha' [they had little resource but a lot of compassion and love] – you know. I'm looking at Kelston and in the preschool and they look like the public kindys. **Sharlene:** Yep, under-funded, under-resourced.*

As Sian's parents were also struggling to find a definitive diagnosis on whether Sian was autistic or not, it was affirming to know that while KDEC staff reported frank observations of Sian's language, which affirmed little (if any) progress at times, they were committed to a collaborative relationship with Sian's parents to make sense of these observations. The relationship was thus described by Sharlene and Jarrod as collaborative, and hinged on a strong respect for the collective expertise of whānau and professionals.

[Sian's Language Therapist based at KDEC] was like 'We'll do the best we can for her while she's in our care, we'll try the PECS, sign, and we know she's not looking to pick up sign, but we can try this and that – it's not 'Sorry

²⁴ Representatives from Hearing House were interviewed as key informants as a part of this research. They acknowledged they were perceived by some families as a culturally 'Pākehā organisation' and were thus undertaking an evaluation of their service in order to identify ways they could make their service more culturally appropriate and responsive to Māori.

we can't help you, she's deaf but she's not signing, so you can't stay here.'
(Sharlene)

The first thing the manager at KDEC said was 'If sign doesn't work for you, Sharlene, we won't just send you away.' (Sharlene)

Communicating daily observations between specialist staff and involved whānau was a collaborative process. Sian was not maintaining eye contact and only one incident had been recorded where she used signs to ask a staff member to unwrap her sandwich for her. The PECS was being introduced, and staff were considering whether photo-based images or abstract symbols were most effective with Sian. Sian was also using 'kisses' and 'waves' to communicate either requests for something or to indicate a person leaving. Sian was engaging other children through mimicking their behaviour and staff were encouraging her to play social games with other children. After attending the seminar given by Rita Jordon, I asked Sharlene, Sian's key teacher, and her language therapist if this seminar had brought any new conclusions to light about Sian, especially in regards to her language development. Based on the collaborative knowledge of whānau and professionals, they concluded they would continue to focus on the PECS, and on exploring how her autistic-like traits influenced her communication ability, especially in regards to Sian's ability to reproduce signs with intent.

I think photos are easier to understand than symbols. She [Rita Jordon] was saying photos are more complex sometimes because they're very specific – which you can understand – but Sian has shown us that symbols are more abstract to her, she will understand a photo much easier than a symbol – which suggests photos are easier for her. A symbol is kind of more general but it can be perceived to be more difficult to understand as well. Regardless of what she [Rita Jordon] is saying Sian has shown us that photographs are the easiest form of visual representation for her. That's my feeling. She is able to use symbols, she is responding to some basic signs if we can get her attention, she hasn't shown us any willingness to produce signs – not willing – but able to. (Sian's language therapist)

I've been trying to get her to do key signs for every activity. So we're doing a 'Mr Potato Head' activity. I think in the moment of the activity, for her, communication is about her asking for a piece of potato head. So, if it was a

hearing child we would be modelling the word. So, where possible we will model the sign that goes with the piece but often she's so focused on the piece she's not necessarily getting that input. I guess with a child, not that Sian has autism, but a child with autism you would be modelling the word. Some of those kids don't hear the word anyway because they don't use that sound or they're not that interested. The piece is more important to them. (Sian's key teacher)

Although Sian was not using NZSL at the time of the research, and professionals suggested she may not use sign language, Sharlene was keen for Sian to be exposed to NZSL regardless. In Sharlene's view, Sian was unable to access spoken language and little was known about her possible diagnosis as autistic, so she felt there was a possibility Sian would benefit from exposure to a rich language environment regardless of whether she was producing signs.

She will mimic, she will copy kids, she will sign – I know she can do this, that's why at the latest IDP ... they [the professionals] said, 'Well she's not really signing so we're going with text, key signs'. I said, 'Yeah I just still want her to have that input which is why I'm learning NZSL'. It's a long and slow process. I just want that input around her because I don't know ... if she is like an autistic child, her brain is four at the level of two. So, when she's six she will be like four and all the things we have been putting in, she might grasp – you just don't know. (Sharlene)

9.4. Experiences of early intervention: decisions and opportunities

***Jarrod:** If I gave advice to other parents I'd say 'It's not a big deal. There are still lots of opportunities and there's going to be challenges – but there are still opportunities for them. **Sharlene:** I'd say 'Get informed,' but you know, there's the question of 'How do you get informed?'*

Sian's accessing EI services and supports was characterised by the initial, unknown nature of her diagnosis and the lack of understanding around the coexisting relationship between her deafness and possible autism. Initial major decisions to have Sian implanted with a bilateral implant was a decision Sian parents' had made based on their knowledge of deaf people and

what they knew to be the significant relationship between early access to language and early childhood development. This knowledge was founded on years of study undertaken as a part of their own professional training as educators and experience as professionals working with whānau and their children in the education system. Providing Sian access to spoken language was, in their opinion, an opening of opportunity, allowing Sian to access the intricacies of daily life and foster intimate relationships within her whānau.

[I ask Sian's parents what their initial feelings about the cochlear implant were.] Sharlene: I thought it was fantastic, they made it sound like she would be a speaking child, and I said 'Fantastic! [I ask about when advice around the cochlear implant came through?]. It was at the very beginning, but it was a useless meeting anyway, it was really random.

In hindsight, Sian's parents felt the process by which professionals informed them of the cochlear implant, the process of implantation, and AV therapy was rushed and based on a medical perspective; Sharlene and Jarrod were ushered immediately from an audiologist who delivered a diagnosis to another professional offering a cochlear implant, leaving them overwhelmed and confused. The focus of these contacts appeared to be, in Sharlene's experience, presenting the grounds for medical intervention and assuring Sian's parents of the benefits of this, rather than considering fundamentally what it meant to have a deaf child and offering potential sources of information to help her form a context within which decisions could be based. A later meeting was organised by an AODC to discuss information and Sian's candidacy for cochlear implants. On reflection, Sharlene and Jarrod felt the process used in this setting was more balanced. Information was sourced from more diverse sources, yet it was also tokenistic. The status and view of medical professionals was accentuated and the process of information sharing was described by Sharlene and Jarrod as 'going through the motions'. Despite feeling unease with the decision-making process, Sian's parents decided for cochlear implantation because it would support Sian in developing spoken language.

The use of NZSL was an option Jarrod and Sharlene had anticipated positively, although they were quickly steered from this by professionals who advised, directly and indirectly, to avoid sign language in light of their daughter's status as a bilateral implantee. As well as directly advising against the use of NZSL, indirect measures included negative responses to their questions about NZSL such as 'stony silences', 'pursed lips', and non-affirming body language and facial expressions. Direct methods of communication from highly qualified professionals

were not always read in terms of their content, but rested on the qualification and status of the professional. Often information was stated directly, with Jarrod and Sharlene told that a decision to pursue NZSL would distract from the objective of spoken language. Information was at times difficult to contest. For example, for a significant period of time, Sharlene had believed Sian to be unresponsive to her cochlear implant during AV therapy sessions. Her parental instinct was negated by professionals who encouraged her to be responsive based on crude testing methods such as looking for Sian's responses to spontaneous foot-stomping and clapping. Some information hinged on affirming parental guilt, questions such as, "Are you committed to a hearing and speaking child?", were interpreted as accusative, questioning Jarrod and Sharlene's actions (or lack of) and insinuating these were contributing to Sian's lack of progress. Contesting information in this context was on par with contesting the professionals' expertise and authority.

As a bilateral implantee living in relative proximity to one of the country's major specialist centres offering AV therapy, Jarrod and Sharlene were encouraged by medical and education professionals to access this service. Sian's parents acknowledged Hearing House was a well-established specialist centre, perceived to be well resourced in relation to other services, placed in an affluent part of Auckland, perceived subconsciously as an indicator of high quality by Sian's parents, and staffed by highly-skilled and qualified staff whose professional opinions were respected. Decision-making in this context was difficult for Jarrod and Sharlene to manage. The information and knowledge they had gained through their own observation as parents and educators was at times actively contested by professionals with specified expertise and status. This, alongside the lack of culturally appropriate processes used to foster and maintain a positive relationship, created feelings of *whakamā* (embarrassment and subservience) and fuelled a deterioration in the relationship. Tests soon confirmed Sian's nerve endings were damaged and Sian's parents were informed the AV therapy would not benefit Sian. Sharlene, without support during testing, was presented with vague and specialised commentary around Sian's damaged nerves. Sharlene had no knowledge of specialist terminology to process the content of information and was distressed and demoralised at her lack of understanding.

I was with some specialist; she was doing the testing and said, 'Oh that wasn't good', but didn't tell me exactly what wasn't good. So I thought, 'Okay,' went into the lift and burst into tears in front of all these people. I

just couldn't get enough information from people that made sense to me, it was all technical and I was thinking, 'Okay, whatever – it didn't work? What didn't work?' I still don't know what works, even up until now. It wasn't until recently it was, 'Oh it's the nerve endings ... I still couldn't tell people seriously what happened.' [I ask is it important to know the details?]. I think now it's more important, so that I can explain it, because you do have to justify what you put her through – what we did. Obviously it didn't work, I just kept holding onto hope that there was some other reason why something else might work, but when the nerve endings are dead and it flat-lines – you know. (Sharlene)

Deciding to have Sian implanted was a well-supported decision. Professionals were eager to provide detailed information around the medical procedure of implantation and steps toward AV therapy. As Sian's nerve endings were damaged and the cochlear implant rendered obsolete, Sian's parents decided they wanted the implant removed. Interestingly, support to remove the implant was less forthcoming and they were advised they would have to wait. Sian had turned five by the end of this research and still the implant had not been removed. Sharlene was, again, incensed at the irony of an immediate denial to have the implants removed accompanied by an immediate offer of a brainstem operation.

Well, I want her to have them taken out but they said to wait, but then they offered me the brainstem operation! I said, 'No!' I'm not putting her through that. I don't even know what it is – but I just said, 'No'. (Sharlene)

Overall, Sian's parents were frustrated by the absence of consistent or recognisable social processes used by various professionals to inform and support their decision-making. The negative attitudes encountered from professionals (medical and educational) regarding the use of NZSL were especially confusing given Sian's later diagnosis of damaged nerve endings. Sian's parents had initially decided they would like Sian to access NZSL, even as an interim measure, as one form of language and communication, yet were actively discouraged from doing so. During this research, Sian's receptiveness to NZSL was also explored, but the coexistence of deafness and autistic-like traits was not well understood and so decisions around support for language development were difficult to make. The approach used by a group of specialist staff associated with KDEC was appreciated by Sian's parents. KDEC's focus was to explore a pedagogy which suited the child and whānau and that would foster language and

communication rather than a specific modality. A collaborative relationship between professionals and whānau was fostered from the outset, with great respect given to the feelings of trauma and despair experienced thus far. It had been asserted by staff at KDEC that they would work in collaboration to explore Sian's communication and language development in order to support decision-making.

As Sian had only begun using the PECS and was observed to be peripherally interested in visual communication, Sian's parents were especially anxious about the best primary school placement. Sharlene's preference was to keep Sian at KDEC until her language and communication progressed further, and until more was definitively understood about how her deafness related to possible autism. Jarrod and Sharlene also preferred that Sian remain with other deaf children for cultural reasons. As educators and parents of three hearing children educated in bilingual units, Jarrod and Sharlene valued the provision of a context in which children could both develop competency in te reo Māori and foster a Māori social identity. Sian's parents saw parallels to this experience and the experiences of deaf people in deaf education settings. Sian's parents lamented the diaspora of deaf children from KDEC and believed there was academic and cultural value in teaching deaf children in shared social and educational contexts.

I suppose she'll go to Arohanui Special School. It's a base school. Other than that I have no idea – no concept of how she will be at school. Arohanui is purely special needs kids. When she turned four I freaked out: 'She's not leaving, she's not leaving until she turns six, legally she's allowed to stay here.' She [the Manager of KDEC] just looked at me and went, 'It's okay, Sharlene, she can stay'. And then secretly I was like, 'I'll be okay, I'll be okay.' (Sharlene)

It's kind of sad because you can see it's a school, it's just that no one is there. ... I just want her to be with people who are the same, it's like with the bilingual units – being together, seeing each other's strengths. My children have all been in bilingual units, it gives them empowerment of who they are. I think they need to have a unit, like a school. (Sharlene)

At the end of the research Sian turned five and her parents sent her to Oakland School, a school which offers specialised support for children with autism. How the interface of Sian's deafness

and autistic-like traits shape her experiences of language and communication was still unclear; professionals were still undertaking a reflective process of observation, implementation of support methods to support with language development and reflection for effectiveness. During our last meeting for this research Sharlene and Jarrod reported Sian was now producing NZSL signs spontaneously and was becoming more socially aware. Within her new school setting, Sian was being introduced to Makaton signs. Neither Sharlene nor Jarrod had strong views on this. They were willing to attempt various methods for communication, yet Sharlene remained firm in her view that full exposure to NZSL would be beneficial to Sian, regardless of whether she produced signs with fluency or not. Sharlene believed Sian to be an observant child who would benefit from access to a full language, and her own intuition, based on parental knowledge and professional expertise, told her Sian was responding to this mode of communication.

Chapter 10. Starr

Starr is an engaging and commanding little boy with a strong and wilful character. Short and stocky in stature, his face and facial features are set with gentle eyes and his long wispy brown hair plaited and fashioned in 'corn rows' daily. During this research, Starr was aged between two-and-half and three years and transitioning between toddlerhood and boyhood as a youngest child of an intergenerational household. In this household, Starr and his five older siblings were being raised by whāngai parents Leslie and Hemi (alongside their own five children) as their mother Awhina sadly passed away approximately six months previously. Starr's status as youngest child in this large intergenerational household accounts for much of his assertiveness, a strategy devised to cope with keeping up with the daily demands of play with older children. Despite being able to access spoken language with the support of hearing aids, Starr endured a number of health complications, which rendered these obsolete for significant periods of time during his early life. Consequently, at the time of this research, Starr held a strong preference for visual communication and sign language. His new whāngai parents, Leslie and Hemi and his blended set of siblings were acquainting themselves with Starr and all his communication idiosyncrasies. In response, Starr was trying to show them 'the way' through his insistence on particular routines and wilful communication attempts.

10.1. Overview

Starr was born September 2008 and was identified with a bilateral severe-to-profound hearing loss, (later revised to moderate-to-severe in mid-2009) through the Newborn Hearing Screening Programme within the Hawkes Bay District Health Board. Sadly, Starr's mother, Awhina Phillips, suddenly passed away in June 2010 when Starr was aged 20 months. Starr was the youngest child of five siblings and aged between two-and-a-half to three years during the research period. Immediately following Starr's mother's passing, her second cousin and partner – who are now Starr's current whāngai parents – Leslie Cooksley-Pekepo (a stay-at-home mum for ten children) and Hemi Renata (who has worked as a truck driver for 21 years) took the role of carers for Awhina's children from the time of the tangihanga onwards. In addition to assuming responsibility for Awhina's children, Leslie and Hemi also parent five of their own biological children aged between 9 to 19 years. Awhina's sudden death was traumatic for the whānau. However, as experienced parents who were emotionally bonded with Awhina's children, Leslie and Hemi quickly decided to apply for legal guardianship/custody of Awhina's children and established a day-to-day routine, with the intention of providing Starr and his siblings with a sense of stability and daily rhythm. Leslie and Hemi reported they knew of Starr's biological father (who is Pākehā) yet they confirmed he has not had any involvement in Starr's life, even prior to Awhina passing away.

Starr was identified as a participant in this study through a mutual whānau connection. We met while at his aunt Crystal's 30th birthday. Crystal is married to my partner's cousin and is Leslie's sister. My first impression of Starr was that he was a lively two-and-a half year old boy who, despite having an elementary command of NZSL and little spoken language, had a commanding influence on his nine older siblings. His communication methods during play ranged from screeches of warning, gestures, home signs, squeals of glee and a powerful side-to-side (indicating don't or no-no) 'finger-wag' – pulled out for communication 'emphasis'. As a part of the delicate dance of getting to know and understand one another during the research process, it became apparent that Starr's new whānau (who had only recently begun taking sole charge of Starr's care) were coming to terms with having a deaf child and what that meant to them.

Leslie, Starr's whāngai mother, was charged with the day-to-day care of Starr, and was beginning to explore her own feelings about having a deaf child and her parenting approach, while simultaneously managing both her own, and the children's grief over the loss of Awhina.

It was also clear that Leslie had little information about Awhina and Starr's interaction with EI professionals prior to her death, the services and resources that could be made available to her, or how she might gain support to process her own emotional responses to having a deaf child. As a part of the kaupapa Māori research approach of whakawhanaungatanga used in this research, Leslie and Hemi were encouraged to actively take part in discussions with EI professionals and the wānanga held for this research. Through meeting with Starr's AODC, Leslie and Hemi learned about the early experiences of Starr and Awhina during those first twenty months of his life, and gained access to information on potential sources of support for raising him. One outcome of the research process was to facilitate relationships (whakawhanaungatanga) with those EI professionals currently involved in Starr's life and to introduce Starr's whānau to the perspectives of those with lived experiences of deafness (deaf people and their whānau). Leslie and Hemi reported that this process was rewarding and provided them with time and space to explore their own emotional responses to having a deaf child in their whānau, and encouraged them to think critically about various sources of information and how it may relate to their experience. Uncovering the reality of Starr's early years was at times emotionally challenging, especially for Leslie, who heard for the first time from professionals an intimate description of Starr's early life with Awhina. The process was both painful and healing.

This chapter provides a description and discussion of Starr and his whānau in relation to the key research questions.

10.2. The shaping of whānau perceptions of deafness

10.2.1. Identification of deafness

Starr was identified as having a bilateral severe-to-profound hearing loss through the Newborn Hearing Screening Programme within the Hawkes Bay District Health Board. Starr's mother, Awhina, was contacted by an Advisor on Deaf children (AODC) shortly after identification. Awhina was given information about cochlear implantation following his diagnosis, however, Leslie and Starr's AODC both reported that Awhina was staunchly against cochlear implantation. According to Leslie, Awhina held the view that surgery should not be performed on the head as she considered the head to be highly tapu and surgery to the head could

potentially have compromised the holistic wellbeing of the child.²⁵ Starr was fitted with hearing aids at the age of ten weeks while his mother began using baby signs for early language development and communication. Progress reports from his AODC showed the use of hearing aids were of initial benefit, but his progress in using them was not straightforward. Five days after having them fitted they were misplaced, and as Starr become more mobile, he repeatedly pulled them off and chewed on them. The AODC reported that Awhina was a forthright and assertive person. She had bonded with Starr and understood the nuances of his idiosyncratic behaviour and communication strategies, reflected in her interactions with him. In April 2009 Starr's AODC reported the following observation in her notes:

Your mum (Awhina) is a lovely singer; you loved looking at a book and let us know that you'd like some board books, especially one with rough or soft things to touch. Your clever mummy is a natural; she makes lots of lovely interesting noises and chats away at just the right level for you to hear her clearly. (Starr's AODC)

At this point in his life, Starr was meeting his developmental milestones, he was a social and inquisitive child, and Awhina was engaged and using a mixture of spoken and signed language. It was at this point that two pieces of new information affected the communication approach used for Starr. Initially his audiogram indicated that he was not able to hear sounds within the frequency of spoken language, and professionals were considering whether he was a suitable candidate for cochlear implant, although Leslie reports Awhina did not support this. Audiograms in mid-2009 however, indicated that Starr was hearing within the frequency range of speech, and his hearing loss was now assessed as moderate-to-severe, and thus he was no longer a candidate for a cochlear implant. Professionals advised Awhina that with the support of hearing-aids, Starr was better positioned to acquire some spoken language. During this time Starr also had recurring middle-ear infections. Correspondence between the AODC, medical professionals and audiologists in April 2009 indicated there was a poor relationship and

²⁵ In traditional Māori society the concept of tapu was used to describe a state or condition of restriction and/or sacredness. Tapu was, and remains still in modern Māori society, used as a form of social management and stems from a Polynesian tradition whereby a series of restriction and prohibitions worked towards the maintenance of what was considered a spiritual equilibrium of all life, and social order amongst communities. In relation to the human body, the head was (and still is according to many) considered tapu with strong rules of prohibition attached to activity associated with the head. These rules worked toward the wellbeing, dignity and sacredness of the individual and community. In this instance surgery upon the head may have been seen to compromise the holistic wellbeing of the child and whānau.

communication between Awhina and medical professionals over the issue of surgery to insert grommets and the removal of adenoids. Awhina was reluctant for Starr to have any surgery, unclear of its purpose and concerned that the removal of adenoids was associated with cancer. After some support and clarification from her AODC, Awhina rescheduled missed surgery appointments, which occurred at the beginning of June 2010. Leslie and Starr's AODC reported that during this time Awhina was still using a mixture of baby signs and simple spoken language with a mixture of results. Starr however relied consistently on visual communication, something which was also well received by his siblings. Sadly, Awhina passed away just weeks after Starr's surgery.

10.2.2. The evolving context of whānau

Prior to her passing, Starr's mother Awhina was the sole parent to her five children. Networked to others through shared whakapapa (including Leslie and Hemi and their children) and social networks, Starr and his siblings have lived in busy households with regular contact with those within this network. Leslie and Awhina were connected through whakapapa as their respective grandfathers were brothers. This was highlighted when Leslie's eldest daughter and Awhina's eldest son began dating, causing Awhina and Leslie to develop a more intimate bond solidified through frequent contact in day-to-day life, and the development of relationships between their respective children.

Immediately following Starr's mother's passing, Leslie and Hemi felt strongly about supporting Awhina's children through her tangihanga and taking the lead on their care. Hemi had experienced institutionalisation as a young person (having been placed in a borstal during his youth) and Leslie's whānau had a strong tradition of whāngai. In their view, the children needed to remain connected with one another and return to a regular child-centred routine in order to process the grief of losing a mother and to help them achieve a form of stability. Between them, Leslie and Hemi had an intimate understanding of the commitment required to care for another five children and of the reality of a large family. Leslie's own mother Joy Pekepo (nee Pere) (Ngāti Kahungunu/Ngāti Ruanui) came from a family of 21 children (seven brothers and sisters and 14 half brothers and sisters from her mother and father's respective second marriages). Her husband, Ngavii'iti (of Cook Island Māori descent) came from a family of 14 siblings. In Pakeha terms, Ngavii'iti and Joy's whānau unit might be described as a blended family with Joy and Ngavii'iti raising three children (Leslie and Jason being Joy's biological children, and Crystal, a whāngai child from Ngavii'iti's biological sister) as brother

and sisters. In Māori terms however, they consider themselves whānau, a whānau committed and obliged to one another through a common need and ethic of care rather than through obligation by biological connection. This ethic was reinforced through the histories of Ngavii'iti and Joy's respective whānau – the Pekepo and Pere whānau. Both these whānau formed strong relationships with one another over several generations within the region of the Hawke's Bay, relationships founded through intimate bonds formed through common links to shearing, sourcing and providing kaimoana to the local community, shared interest in rugby league, and to some extent, affiliation to a local chapter of the Mongrel Mob²⁶ with Ngavii'iti having been a chapter president in his youth. Hemi also spent part of his youth as a patched member within this chapter prior to having children, though retired prior to the birth of his eldest child to focus on the raising of his family. It is evident upon meeting Hemi and Leslie that while they have moved on from active participation in gang activities, there are however, indicators of previous connections, demonstrated through language use, clothing choices, humour, values and lifestyle. This background is a facet of the history of this whānau as well as for Awhina who was also networked to a similar group of people. This was the context in which Starr was raised for the first twenty months of his life and continues to be raised within since becoming the whāngai child of Hemi and Leslie.

Starr's whānau now comprises a web of people bound by various complex circumstances and realities. I would imagine that upon first engagement with Starr's whānau it would be difficult for a non-Māori professional to form an understanding of its membership and structure. Starr lives in a lower-socio economic area of Camberley, Hastings, in a whānau home owned by Leslie's aunt. A large group of ten children and young people dominate Hemi and Leslie's household. However, as Hemi and Leslie welcome and host whānau regularly, young and old whānau come and go from their house. The whānau is not limited to those who live within the household and the daily lives and routines of grandparents, aunties, uncles, cousins and 'other' relatives are intertwined. Children are resident across a series of households. The raising of children is regarded as a collective and intergenerational responsibility and guidance is sought from elders including relatives and others identified as having expertise in areas, for example the kaumatua at kōhanga reo. Whānau, in this instance, is not so much defined by biological

²⁶ The Mongrel Mob is a New Zealand gang formed during the 1960s and early 1970s. Traditionally, the Mongrel Mob has offered young men (many of whom were often alienated from their own families) a surrogate familial-type network.

connections between one another but rather emphasis is placed on a commitment and ethic to belonging and caring for one another, expressed as whakawhanaungatanga.

The manifestation of whanaungatanga was highlighted at Leslie's sister's 30th birthday party in 2011 (Starr was aged two-and-a half). Over a weekend period, I was able to observe Starr in this new whānau context, and through ongoing discussions with Leslie, her sister Crystal, and the wider whānau, Leslie and Hemi allowed me to introduce the research to them. The following excerpt originates from my observational notes of this event in which Starr participated. It illustrates the principle of whanaungatanga in practice, how a complex web of people worked collectively to facilitate the event, an event which celebrated their connectedness and unity. The extract also describes the place and role of children within this group.

The day is spent in preparation mode. The whānau are well versed in 'teamwork'. Breakfasts are made, dishes are washed, beds tidied and packed away, washing organised and the house vacuumed. Women hover around the bathroom door, calculating the best time to 'catch' a shower. People arrive, introductions are made between people, and connections are made as we undertake the party preparation duties: preparing kai, the setting up of marquee and band equipment. It is hard to estimate the number of whānau helpers present as people come and go, however a visual estimate of around twenty-five people (including children) and the party hasn't started. The children play around the house, under the marquee, at the park across the road, at the local school and watch TV during moments of rest. Ngatainui, the eldest and six-year-old son of Crystal and Tautoko (Leslie's younger sister and her husband) takes me on the grand tour of Otane School (where we play races and hide-and-go-seek), the local kōhanga reo (where his Mum Crystal works), a very old feijoa tree which produces a prolific amount of large ripe feijoas, and the local dairy. The children have the physical freedom to explore this community – people know them and their whānau.

There was much contextual information gained during this event, including an insight into the social dynamics of the whānau, the nature of Starr's participation in the whānau as a deaf child, and how his deafness impacted, and how he was received and understood by the wider group. Interestingly, various whānau members admitted they had given Starr's deafness little

consideration and were still coming to understand the intricacies of what they perceived to be unique behaviour.

10.2.3. **Constructing deafness through experience**

I just didn't want him to be treated as different because he's not disabled or anything. He's really clever and just has this thing about him; he just has this thing, which touches everybody – everyone who meets Starr. (Leslie)

As I did not have the opportunity to meet Awhina, it is difficult to report on how her perspectives on deafness were shaped. Through discussions with Leslie, Hemi and Starr's AODC (who reported to me her clear memories of interactions between Awhina and Starr), it became apparent that Awhina had formed an intimate bond with her baby and had spent time enacting the delicate dance mothers of new children undertake to become acquainted with one another during the yearly phases of their lives: observation of child, responding to child and making meaning of these efforts. Although an experienced mother, Awhina had no experience of deaf babies prior to having Starr and also had to balance her parenting efforts with meeting the needs to her four other children. Leslie and Hemi reported Awhina also hosted and provided practical support for various transient whānau members in her home and thus had to employ several strategies to meet the needs of the group. Starr's siblings were often required to exhibit a certain level of independence in their self-care and work collectively to maintain household routines. Older children were often expected to provide support to younger siblings including Starr. While they were aware of Starr's difference, Starr's deafness was not a defining feature of their whānau life. Rather, focus was placed on maintaining daily family routines that promoted unity and cohesion. Starr's siblings had reported no firm thoughts about Starr and his deafness to Leslie and Hemi. They were however, simultaneously protective yet frustrated with communication breakdowns. Leslie and Hemi concluded this was a consequence of no support being provided to the children and wider whānau on how to communicate with Starr and how to interact with him.

Leslie, who assumed the role of primary caregiver of Starr at 20 months, had up until that point, given the issue of his deafness little consideration. She was 'at sea' in terms of her views of deaf people, their capabilities and potential life trajectories. Through initial informal conversations Leslie affirmed that she recognised Starr to be 'just like a normal child' recognising his great potential, intelligence, innate love of play and learning yet she also felt

there were aspects of Starr which puzzled her. Leslie had a strong desire to learn more about Starr, especially how to support him in his language acquisition. During the research period, Leslie sought an assessment of Starr's development from his AODC. In simplistic terms, she was seeking an understanding of what to expect from a deaf child, the reasons for his behaviour, and whether he had met the typical developmental milestones for a deaf child. As an experienced mother she had developed a strong intuition around children's behaviour and developmental progress, yet this knowledge of hearing children was not always applicable to Starr. Although Leslie was in contact with EI professionals in order to gain an assessment of Starr's development, she was also reluctant to allow professionals to take the lead on how her thinking should be framed. In discussion with other whānau members, the question was raised around why EI professionals might be regarded with suspicion. Leslie's sister Crystal concluded that Māori experiences of colonisation tends to imbue a sense of mistrust for those who are a part of what was described as 'the establishment'. Leslie and Hemi were innately wary of professionals, (and even of me as a university affiliated researcher). In their experience, professionals wield authority, yet know little of the complexity of their day-to-day reality. They certainly are not associated with assistance, support and positive personal transformation.

I'm like the opposite, whereas I told my professional 'Oh nah I don't really need you either'. They weren't telling me what I wanted to hear; they weren't really answering my questions. Like, I have not met another deaf child in the Hawke's Bay since I've had Starr and I've had him for one year now. I have never been to any deaf association, apart from the aid I got. (Leslie)

This research process provided Starr's whānau with a catalyst for reflection and discussion. These discussions continued beyond the research, amongst the wider whānau, and were to some extent solidified at the Hui Whakawhaungatanga. Initially reluctant to attend the hui, Leslie sought counsel from her parents and wider whānau who encouraged her to go. She accepted the challenge of participating in the hui in the hope that she could develop an improved network of social support and learn from other deaf people and whānau raising deaf children.

Awesome, thanks Kirsten for inviting us. I don't like getting involved in things like this; I'm not really a sociable person – but yeah for Starr, that's what my parents say. Cos I don't do marae, and I didn't want to listen to them 'da, da, da,' But like I said, it's about Starr and not me [Group Laughter] and about him meeting everybody, he's awesome, and we're all

here... I got a ... like I said my aunty is deaf but you sort of don't notice those things until you got Starr and then you sort of realise "Oh my aunty is deaf, my cousin is deaf and then you wonder why they're so ..." but they never went through schooling or nothing. And we've never done sign language. We've never been told where to go. (Leslie)

Prior to participation at the hui, Leslie and Hemi's social experience of deaf people included deaf people in a hearing whānau context where spoken language predominated. Communication was often brief and directive and deaf people in Starr's whānau were perceived or accepted as handicapped. As a part of the hui, we used the school hall and grounds as our marae, and whānau occupied classrooms as whare moe (sleeping areas). Starr's whānau – the largest whānau involved in the research – assumed a whole classroom as their whare moe. Starr and his siblings inevitably approached the various deaf adults inquisitively. Accustomed to queries from curious children, their questions and interactions were entertained. Sometimes questions such as "Is that man deaf?" and statements such as "I know signs too" were directed to speaking bystanders. Demonstrations of their home-signs were displayed in breaks in their play. Starr spent the majority of his time playing with his siblings who were his safe reference point, and he rarely strayed far from Leslie, as she was the only one who understood his innate need for very-particular routines, without which, he becomes distressed. After the first day at the hui Starr began interacting with others, including other deaf adults, practicing those signs he knew (for example asking for a drink). These were entertained by deaf adults with great patience. What was considered hoha (annoying and/or attention seeking) behaviour by his hearing whānau, was considered a normal part of Starr's development by the deaf adults. Patrick Thompson, a Māori deaf kaumātua involved in deaf education and Ngāti Turi advocacy, had observed this behaviour as well. In his view, affirming communication success fosters communication confidence and encourages further communication attempts.

The question of what does deafness mean and how our views are shaped was debated and discussed extensively at the hui. At the beginning of the research Starr and his whānau had little experience of other deaf people yet through the research process Starr's whānau paused to reflect on those deaf people they knew (including a kuia at Starr's kōhanga reo) as well as incremental exposure to a diverse group of deaf people (across various life stages) in their

whānau. When posed with the question of ‘If there were other deaf people in their whānau, and if that impacted on their perception of Starr’, Hemi and Leslie began talking about deaf people within their wider whānau network with fondness and humour, realising that they had accepted these people into the whānau-fold without considering what life was like from their perspective, nor that they might have insights into Starr and what life was like for him. What was once the cause of in-group humour, i.e. their attempts at communication with these deaf people, was now the source of knowledge about how deaf people fare in hearing families. Toward the end of the process Hemi and Leslie reiterated deaf people and their whānau as important teachers of ‘deaf world-view’ as a rich resource and as natural allies, allies who could support them in developing their parenting intuition with Starr. Leslie and Hemi lamented the dearth of deaf people who were made available to them through the EI system.

10.3. Experiences of early intervention: language and communication

Leslie knew very little about Starr’s and Awhina’s early experiences with EI professionals in regards to language and communication support and it was Starr’s AODC who held the most intimate details of Awhina’s journey with Starr. During a discussion between Starr’s AODC, Leslie and myself, I asked Starr’s AODC to describe the period prior to Awhina passing, to provide us with a context:

The family was faced with decisions about what kind of intervention, what kind of future they wanted for him, and his communication mode. Cochlear implants were talked about and a little letter went down to the Southern Cochlear implant team, just letting them know there was a little boy up here who seemed to have a profound hearing loss. Awhina was reluctant to go down that path because in her view the head was tapu and she didn’t want anything to happen to his head. She opted for powerful hearing aids and spoken English, spoken language, English it was. And we also talked about some sign language, but at the start she wanted to go with powerful hearing aids and spoken English only. After a while she found they just naturally used gesture, which is something Leslie, you said happened with you [Leslie agrees]. Awhina went through a stage of saying ‘Well he can’t hear me, I’m not going to talk’. She didn’t consciously say that, but she did go quiet. And

so we did a lot of work with her encouraging her to just keep communicating. I'd turn up with toys and we'd play and sing and do board books. Yeah, we'd just get on the floor and have lots of floor time, just playing. She was great; she just really grabbed it and ran. (Starr's AODC)

Leslie began this research journey with a disdain for sign language, believing it 'made Starr look like an invalid' and was simplistic gesturing. In her view, spoken language was the *modus operandi* of their world and thus he should be encouraged to speak and act as a hearing person to best facilitate his participation. However, much of the foundational language and communication support provided to Starr while Awhina was alive was based on sign language, gesture and visual communication strategies alongside spoken language. On-going ear infections, which rendered hearing aids ineffective for significant periods of time, meant that Starr was unable to access spoken language and sound, thus reinforcing his need for sign language and gesture. At the beginning of the research Leslie and Hemi had given deafness little consideration, and difficulties around language and communication was a dominating feature of their relationship with Starr. The following excerpt has been taken from my observational notes. It describes what was intended as a gentle introduction between Starr and myself from his aunt Crystal. This was the first interaction I had ever had with Starr and Leslie and it illustrated the basic nature of Starr's communication and language at that point, his strong preference for particular routines, which were being used as a basic form of communication, and how the wider whānau were still becoming accustomed to these routines and their meanings.

I am sitting in a bedroom floor on a mattress prepared for me by Crystal, the light from the hallway shines into the room; Crystal brings Starr who is two-and-a-half to meet me. Crystal sits in the hallway and places him on her lap, he wriggles, his eyes absorbing images of his surroundings, trying to gather and make sense of this new hallway context. Starr has 'deaf-eyes'. He appears to be relying wholly on visual information. Crystal speaks my name to him and points to me, Starr however sits on her lap with his face looking outwards, Crystal's face is not in his line of sight; his face tells me he is not interested, I am a stranger, his eyes seeking something familiar. Crystal tries to remove his shoes from his feet, as shoes are not worn in the house. Starr wriggles away from her lap screaming and squealing – he is overwhelmed.

Leslie enters the hallway and advises Crystal not to take Starrs' shoes off. Crystal asserts that shoes are not worn in the house. Leslie explains if Starr's shoes are taken off he understands this to be a cue for bedtime. With little spoken or signed language two-year old Starr squeals in confusion as the sisters disagree.

The communication strategies used by Starr while at this whānau event were visually orientated. He used a mixture of facial expressions, actions, basic signs, gestures alongside simple vocalisations (usually for emotional emphasis) to communicate and they were also often misunderstood. Communication efforts were limited to his understanding of 'cues', and those few communication attempts he was successful at, for example asking for a drink in sign, were brushed off. The repetitive nature of the requests was not tolerated and was seen at time to be 'hōhā' (annoying) attention seeking behaviours.

Starr spends much of his time at home in play amongst older children (primarily his cousins and siblings), who attempt to facilitate his participation and communication with varying levels of success. At times, the effort was draining on the children, who either exclude or become irate with Starr. The siblings are obviously bonded as demonstrated in their play. Strong relationships between Starr and the older cohort of children within the whānau were evident throughout the event, in particular with his older sister. Leslie and Hemi reported that Starr's older sister had a close relationship with him and was expected to assume responsibility for Starr, both before and after their mother's passing. The children are given physical freedom to explore their environment and were at times both unsupervised and uninterrupted, and are expected to manage their own social play, including conflicts and discrepancies. The following two observations illustrate how the children negotiate communication with one another during play.

It is the mid-morning, the night after Crystal's 30th birthday party. Adults are waking and milling around in a large double-sized carport while the morning meal is being prepared on a barbeque. A park sits in between the house, main train line, and train intersection (there are barrier arms). Cars in this semi-rural community do not frequently use the road between the house and park and thus the children potter about and regularly skitter across the road to play at the park. I follow them with my own child in tow; I place some younger children in the baby swings. Starr prefers to follow his siblings to the see-

saw. They are all trying to climb up on each end, and the see-saw sways in exaggerated fashion as children climb up and jump off, often ricocheting children off the edges. Starr climbs up the middle of the ramp squealing. Starr's older sister yells, her intonation rising in annoyance, an instruction to get off which he doesn't hear. He keeps climbing up the ramp toward his sister. I walk across and suggest to Starr's older sister that she seat Starr in front of her, while she sits at the back so he won't fall off so he can have a turn safely. Starr complies. Starr appears to love physical play, he tolerates bumps, knocks and falls with very little lament. He appears to be a physically tough and resilient child. However, Starr is regularly misunderstood and dismissed, resulting in screams of frustration, all for want of a better communication strategy.

Starr plays with some toys on the deck in the mid-afternoon sun. A cousin of a similar age sits with Starr. When seated carefully the child places his face in Starr's line of sight, staring him straight in the eye while simultaneously taking Starr's toy from his hands and altering his body posture so his back is turned to Starr, to exclude Starr from seeing the toy. Starr stares back momentarily appears vacant and despondent. The cousin holds the toys for a brief time and places the toys out of Starr's reach, all the while maintaining a stern eye gaze with inverted 'cross' eyebrows. The prolonged stare seems to have halted Starr and affirmed the other child's social dominance. The child walks away and Starr sits quietly staring at the toy. Starr references his gaze between the toy and his cousin repeatedly. Finally Starr decides not to play with the toy and he walks away.

Strategies for communicating or managing conflict, i.e. using language for self-expression, naturally bypassed Starr. Starr's squeals and screams irritate the whānau, who tend to interpret this behaviour as naughtiness and defiance. I understood this behaviour as an expression of rage. In my observation that weekend, Starr appeared to be a frustrated little boy whose attempts at communication amongst his peers regularly failed, resulting in constant confusion and rejection. During my visit, I engaged with Starr in a different way from the whānau. Some of the whānau commented on this, at times curious or confused as to why I would take an interest in this child.

The following excerpt is an observational note of my interaction with Starr and his siblings while at this event. This scenario illustrates the nature of Starr's communication and how it dictated the nature of his participation in the whānau as well as the children's' keen interest in developing skills to communicate with Starr.

It is the evening of Starr's aunt's 30th birthday and friends and whānau are arriving to the marquee set up in the adjacent paddock to her house. The open plan kitchen and lounge area is converted into a space for the children of party-goers. The children have just been ceremonially washed and in dressed in flannelette and polar fleece PJs, they are hopping on mattresses, pottering around one another; they have sensed this is a 'special occasion'. Supervised by Ngavii'iti (their grandfather) who is jumped on, cuddled and kissed, they watch the cartoon Toy Story 3. Crystal comes in for short periods to arrange the incoming tide of birthday presents. She displays them on the dining room table, announcing to her dad what had been given to her and by whom. Starr stays with the rest of his siblings and cousins in the lounge with his grandparents. I try to get to know Starr a little bit better and I attempt to 'play' to explore what strategies he employs for communication. We play peek-a-boo around the door and the couch. Starr's hearing aids have just been removed and he doesn't use any words rather, sounds for emphasis of intent (i.e. excitement, frustration, and warning). Starr begins to understand my communication intent as we play 'boo'. As he has no hearing aids on I quickly teach him signs associated with our play and scaffold on concepts. Playing Boo using the door leads to using the signs: DOOR, OPEN THE DOOR, CLOSE THE DOOR, COME HIDE BEHIND THE DOOR, WHERE? WHERE ARE YOU? WHERE AM I? Starr's preference for visual communication is evident. He promptly memorises signs and visual communication strategies quickly putting them to creative use. I am impressed by Starr's intelligence and innate joy. Starr's siblings are propped on mattresses around him and he props himself on the couch with his blanket and settles himself, falling asleep while watching Toy Story 3.

It is early in the morning, the morning after the 'big-party'; the children potter around the lounge and kitchen in their PJs, the older children eye-ball

birthday presents on the dining room table, announcing who gave what to whom. I instruct the older siblings to clear the bench. They all work collectively preparing the bench for breakfast, clearing washing and sorting dishes and mess. Starr is perched on the edge of a chair watching intently. I lined up the breakfast cereal boxes individually presenting each box while simultaneously demonstrating the signs for each. The older children are intrigued and begin asking questions. One sister announces her knowledge of the alphabet in NZSL, which she learnt at school. She confidently begins her demonstration, and three others watch and begin to unconsciously move their fingers in similar fashions. It appears the movement interests them. I ask them if they want to know some more. I show them the various signs for the cereal types, and signs associated with breakfast routine: BREAKFAST, HUNGRY, BOWL, SPOON, CUP, DRINK AND FINISHED. Starr enjoys his communication successes with me and repeats the signs correctly and in context. He starts using his new knowledge with his older sister signing his favourite cereal WEETBIX. She smiles, and tells me, that's his favourite. For the rest of the day I am followed by Starr who repeatedly asks for a drink of water, slices of cheese and crackers!

When Leslie assumed the role of primary carer of Starr and his siblings, she immediately sought schools for the older children and a kindergarten for Starr. Overwhelmed by the paperwork required for enrolment and the lack of support in navigating this process, Leslie felt unwelcome at a local kindergarten and decided to follow the recommendation of her sister and enrolled Starr with a kōhanga reo, Te Kōhanga Reo Wānanga Whare Tapere o Takitimu based in Hastings. Despite having no experience of deaf children and having had negative experiences with Specialist Education Services already, the kaumātua at the kōhanga reo was enthusiastic about including Starr and his whānau. Leslie had a positive relationship with staff at the kōhanga reo as she was able to relate to them on a personal level and they actively supported her in seeking support for Starr and his needs. One whaea²⁷ was hearing-impaired, and staff had learnt some basic NZSL so some used a mixture of spoken Māori and some NZSL signs with Starr. Starr's AODC organised a local playgroup for children and parents to use NZSL.

²⁷The term whaea is typically used to mean mother or aunt. In Māori education settings, older Māori women are often referred to as whaea, as a term of respect and endearment. Using this term within these settings allows for the acknowledgement of the familial-like bonds formed between teachers and students and the hierarchical division between young and old.

However at the time of the research Leslie was reluctant to use NZSL despite Awhina's decision to do so and Starr's inclination toward sign language. Leslie stated that she didn't want him to appear as an 'invalid', wanting him to fit in and 'be normal'. She found the image of Starr using sign language unpalatable.

Toward the end of the research process Leslie and Hemi gained further exposure to NZSL, NZSL users (hearing and deaf) and their attitude toward NZSL softened. They realised the choices around language do not necessarily have to be fixed, they could respond in a fluid nature in response to the child (as they realised it is sometimes the child who ultimately decides) and whānau context. They saw the potential for Starr to be bimodal (using a signed and spoken language), and trilingual, with potential proficiency in NZSL, spoken English and te reo Māori. The lack of regional support to achieve this however was a real issue, and they were concerned toward the end of the research that it would require initiative, ingenuity and hard work on their part. There was very little support for their large intergenerational whānau to acquire NZSL. They were concerned that the majority of support from specialist staff (such as a speech language therapists and teachers of the deaf) was principally focused on spoken and written English, and the kōhanga reo staff were unable to support them with supporting Starr in spoken Māori. Leslie and Hemi were very concerned that Starr would come away from his early childhood with no strong first language.

10.3.1. Experiences of early intervention: decisions and opportunities

Upon entering this research, Leslie and Hemi were in contact with some EI professionals, principally an AODC, audiologists, and a kaitakawaenga²⁸. They were however, somewhat confused over the role these various supports were supposed to play, and what exactly it was that they were supporting them with. In part, this confusion was due to the fact that Leslie and Hemi had been at the periphery of Starr's life until he was twenty months of age, and had missed the intense period of engagement following Starr's diagnosis. They were also generally

²⁸A Kaitakawaenga works alongside other Special Education staff to inform practice related to Māori specific interventions and provide culturally responsive special education services to Māori in accordance with the goals, objectives and policies of the Ministry of Education.

apprehensive about engaging with specialists and professionals, the majority of whom they perceived to be either difficult to relate to socially, or impersonal.

At the time of this research a number of important decisions in relation to supporting Starr's language development were pending. Leslie and Hemi had only begun to start engaging with EI professionals, partly due to encouragement given through this research process, and because they had been focusing on trying to bond with Starr and his siblings and establish new routines. Immediately following Awhina's passing, Starr's AODC attempts to meet with Leslie on several occasions were not always well received. After a shared discussion between the two it was decided that this was partly because Leslie was overwhelmed with the adjustment to parenting five extra children, attempting to establish a new routine for the children and because the role of the AODC was not clear. In respect for Leslie's request for space and for time alone to bond with Starr and his siblings, the AODC purposefully attempted to maintain distance while regularly making brief contact to check and see when Leslie might be ready. This period of 'space' created a period of awkwardness whereby Starr's AODC had repeatedly announced her availability yet the distance made Leslie feel uneasy about responding or being proactive about making contacts.

During my first formal interview with Leslie and Hemi it became apparent that both, and Hemi in particular, had little to do with Starr's AODC and had not developed a strong relationship with any EI specialists. Leslie however, developed strong and warm relationships with staff at Starr's kōhanga reo. This Leslie attributed to their relational style and approaches. They were socially recognisable and respected by Leslie who was able to read these interactions as indicators of support and encouragement. Consequently, questions around future directions for Starr were difficult for Leslie and Hemi to answer. They openly didn't know what to expect from Starr in terms of his development as their expectations were informed by what they had expected from the other children in their whānau. Leslie had identified Starr as an intelligent and sociable child. However, Leslie and Hemi found the issue of communication perplexing, their initial aspirations were to have an English-speaking child, yet Starr obviously had a strong preference for sign language and visual communication strategies. To add to the complexity, the kōhanga reo (which acted as an intervention to support the acquisition of spoken te reo Māori) provided the social context in which they could gain parenting and social support in ways they understood and respected, yet did not provide them with the language context to support their initial goal of supporting Starr with spoken English as a first language. Decision

making under these circumstances was difficult. Leslie requested an assessment of Starr's development. She wanted to know if his behaviour and language development was what one would expect from a deaf child. She wanted to know if he was comparatively 'normal' and wanted a picture of a potential developmental trajectory to help guide her expectations and decision making.

During our formal interview with Star's AODC, the assessment process was patiently discussed with Leslie using the assessment folder to illustrate the assessment criteria, and it was discussed in length how Leslie would be involved in this process. Leslie and the AODC discussed potential dates for assessment. Leslie reported at a later interview that while the process was well explained, and information (the folder) provided, she still found it difficult to relate to the assessment process. The language used was unfamiliar to her and she still wanted to observe a point of comparison, i.e. have contact with other deaf children and people. Concerned that Leslie would disengage with her AODC or withdraw from professional support due to not feeling confident about the assessment process, I encouraged Leslie to continue with her requests for an assessment, although by the time of the hui whakawhanaungatanga she reported she was still waiting for the assessment to be undertaken.

Hemi and Leslie admitted that up until their participation in this research, their decision making had been limited by the lack of social exposure to a diverse group of deaf people at various life stages, to living examples of the impact of interventions and their resulting outcomes. Again this research process provided Leslie and Hemi with a view of a diverse range of deaf people (at various life stages) and their whānau, providing them with insight into various perspectives and dispelling myths around language and developmental expectations, in particular, myths around the limits of deaf people. In fact with the right support and language environments deaf people are capable of acquiring several languages in various modes (spoken and signed). Hemi and Leslie were now articulating their admiration for those deaf people at the hui who were bimodal, and multilingual. Sadly, they could not see how they would be able to foster this within their own home, especially given their own limited knowledge of NZSL, te reo Māori and lack of knowledge around how to bridge language acquisition between signed and spoken languages. In their local home context NZSL was being offered as a part of a small playgroup, however Leslie was reluctant to attend. It clashed with her daily-routine with her children and was a social context she could not relate to or feel comfortable in. In her opinion it would have been more useful to help foster NZSL in home and kōhanga reo contexts. Leslie and Hemi

suggested that with the large numbers of people in their whānau, it would have been more useful to provide a language intervention to the wider whānau group, i.e. NZSL classes targeted at the whānau, and on-going support with spoken languages in the home. It was for similar reasons that they were not comfortable about approaching organisations such as the New Zealand Federation for Deaf Children, or a local deaf club.

Similarly, the description of engagement with professionals from Leslie and Hemi suggest medical and educational professionals may have not fully understood aspects of their identity as a whānau, and in many instances have not even recognised them. Hemi reported that professionals engaged solely with Leslie (as she was available to field appointments during working hours) and no consideration was given to the involvement of other whānau members. Hemi suggested professionals would be intimidated by his physical appearance as he has a large physique and has facial ta moko.²⁹ Hemi and Leslie commented on how Starrs' mother Awhina was perceived by professionals, and the impact this may have had with engagement:

Hemi: "You, you can't compare us with Awh ... I mean she [the AODC] would have been really intimidated by Awh ... You know Awhi would be really intimidating. We're more the passive, more the passive ... Leslie: I know what Awhina was like, if she didn't want anyone there she'd just let you know, she was a busy person".

The inability to 'relate' to professionals was a significant barrier to engagement for Leslie and Hemi who felt disconnected from the EI system, patronised by the status of professionals as experts, and generally anxious about having to interact with them. In the short time they have had Starr, Leslie, Hemi and their whānau engaged with professionals in an ad hoc fashion and opted instead to principally draw from their significant collective experience and knowledge of raising children. Usually Hemi and Leslie experience life at the periphery of society. They are constrained by the pressures of raising ten children with limited economic resources and find it difficult to find the time to explore or attend scheduled activities (for example a night class in NZSL) outside their daily routines.

²⁹ In contemporary contexts, ta moko (facial tattoo) is given for various reasons ranging from an acknowledgement of genealogical connections (whakapapa), as an artistic expression of identity as Māori, and at times, to indicate connection and affiliation to gang groups. The uneducated eye may not be able to differentiate between the various types of ta moko; those with gang affiliated ta moko may be discriminated against or feared by those who are inexperienced in socialising with these communities.

Ironically, Leslie and Hemi actively participated in the hui and met with other whānau participants in this research. When asked how this was different from engaging with other organisations, they attributed this to the approach I had used in building a relationship with them. In this research process, their time was valued, their lifestyle accepted as an inherent part of their reality and the number of people associated with their whānau was unquestionably welcomed and their views accepted and validated. This was an experience they had rarely had with those who affiliated with what was described by one whānau member as the ‘establishment’.

Chapter 11. Whānau perceptions of the deaf child

11.1. Introduction

As demonstrated in the case studies, individual whānau members' perceptions of the deaf child came from a highly contextualised experience dependant on a variety of factors. This was an evolutionary process. The apt description of “a life-long journey” given by Tiana’s mother, best encompasses the view that as the child moved through developmental and life milestones, whānau members would grow in understanding, based on experience of the child in the natural course of events. Underscoring this expectation was the assumption that the deaf child’s sensory experience as a deaf person determined interactions with their environment and thus was an innate part of their identity. In this chapter sections *11.2 Perspectives on deafness within the whānau*; *11.2.1 The meaning of deafness: whānau constructions of deafness*; *11.2.2 Mentoring relationships within whānau: raising children from collective experience* identify the contextual experiences contributing to whānau participants’ perceptions of the child, including the impacts of the intergenerational and hierarchal nature of whānau on how the child and deafness are perceived. Section *11.2.3 Envisioning life pathways and outcomes for deaf children: the impact of deaf adults* outlines how observations of deaf whānau members (and other deaf adults) informed main carers and decision makers’ views of potential life pathways and outcomes. In the last section *11.3 The effect of EI experiences on shaping whānau perceptions of the deaf child* discusses how, through early interactions with professionals working within the UNHSEIP, whānau members’ attention was drawn to medical perspectives of hearing loss, positing deafness as a medical concern remedied through routine technical and medical interventions. As the child entered developmental stages, where language acquisition and the social acculturation process began, however, whānau started to relate to their deaf child in more social terms. Support to understand the holistic impact of deafness was less forthcoming.

11.2. Perspectives on deafness within the whānau

This chapter addresses the question, *What shapes whānau perceptions of their deaf child?* As illustrated in the case studies, the nature of whānau is often intergenerational and multifaceted. Membership is often self-defined by a group who may use a variety of factors to frame themselves. Whānau may describe a group of people living within a same household and

sharing the same whakapapa but can also refer to several groups of people living across several households or simply a sole-parent living alone with a small social network. In some cases, it may comprise non-related persons bound by social experience, as in the case of deaf adults who shared childhoods in residential deaf schools or through a shared philosophical approach to life or lifestyle for example, through church or gang membership. As described in the case studies, all children involved in this research were raised by an intergenerational group. Although each child formally lived in one house, in their daily-life and routines, additional whānau members both related and non-related were significant.

The position and primary relationships of each deaf child within their particular whānau structure differed, and whānau members' perceptions of each child differed accordingly. Tiana was raised by her sole mother, who was supported in turn by her own mother in daily routines. Jay was raised by his grandparents and had daily contact with his aunts, uncles and cousins who lived in close proximity to one another. Brooklyn was initially raised by her mother with support from her maternal grandparents, but when this research began the grandparents moved to Australia and Brooklyn's parents were re-establishing a new network of support which included friends and some of her father's whānau. Sian lived with her parents, siblings and grandfather, and had regular contact with whānau on both maternal and paternal sides. Starr was raised by whāngai parents in a large group of siblings and cousins who had regular contact with their maternal grandparents.

In most whānau, the social division between younger and older generations was marked. In the whānau with large numbers of children, they were managed as a group. While adults managed daily routines, most of the deaf child's social and linguistic interaction was with similar-aged children through play rather than directly with adults. Children were often given freedom to explore and develop their abilities through imaginative play. The deaf child was positioned within a hierarchy of the child cohort, in which they developed relationships with siblings, cousins and in some cases the general peer group at kōhanga reo. The birth order of the deaf child within their cohort also played an important role in determining the nature of interactions within this group. In several whānau, the adults expected the older children to meet the roles and responsibilities of tuakana (older child). Tuakana are expected to role model adult-endorsed behaviour, provide social support to younger members, and demonstrate leadership while children were playing alone or with other social groups. In many ways, such delegation worked as a form of social control and a means of managing behaviour in large groups. Sian,

Starr and Jay as youngest (teina) children, who incidentally happened to be deaf as well, meant the tuakana children in their whānau were heavily involved in socialising them. Brooklyn and Tiana were raised in different conditions. Brooklyn was an eldest child, and, with most of her maternal whānau having moved to Australia, she was expected as tuakana to support her younger brother during play situations. Tiana's whānau, on the other hand, was smaller, and hence the majority of her social and linguistic contact occurred with adults, her mother and grandmother. In this situation Tiana's mother appreciated the social and linguistic benefits of regular contact with a peer group, and developed social networks to ensure that Tiana had friendships with her preschool and primary school peers, and with the children of friends. It was however, difficult to tease out whether perceptions of Tiana as a deaf child were related to the child's identity as tuakana, teina, a deaf child or a combination of these factors.

11.2.1. The meaning of deafness: whānau constructions of deafness

Children naturally learn about the world through physical, sensory and language experience. Deafness hence shapes the sensory, social, and linguistic experiences of a deaf child and how they construct meaning from these (Marschark and Hauser 2012). Whānau involved in this research intuitively understood this premise and tended to construct understandings of their children based on a series of observations and reflections drawn from the way in which they saw their children interact with the world. These reflections were based on the child's social interaction, primarily within the whānau setting, but also within the context of experimental play in various settings. Through getting to know one another, individual whānau members reached their own understanding of deafness in their child. Most often this was framed in terms of the child's behaviours, abilities, preferences, and what whānau members viewed as their potential. Each whānau case illustrates the uniqueness of context and how the interplay of various factors determined the nature of interactions with the deaf child, interactions which influenced how the deaf child was eventually perceived by whānau members.

Tiana's deafness was identified promptly following a series of medical interventions following her birth. She accessed medical and early intervention support, a cochlear implant, AV Therapy and on-going early intervention support within home and early childhood settings, and, as a consequence, her language and social development approximately paralleled that of a hearing child. As Tiana managed to integrate herself into her hearing community with relative ease,

her deafness was not identified by hearing people as a defining feature of her identity, nor did it frame her social experience in a marked way. Her mother tended to frame Tiana in terms of her temperament, as a vivacious child with a strong will to live life. Tiana's mother identified that both she and Tiana were 'sporty types.' A strong sporting ability and competence ran through women of her maternal line and both preferred interacting and learning through a kinaesthetic approach. Consequently, Rebecca tended to focus on fostering Tiana's social abilities and oral language in practical and visual ways. She used key signs to bridge action and speech, yet once spoken language was established, there were only a few features of her behaviour which indicated Tiana's difference. One of the most obvious was Tiana's cochlear implant and hearing aid, which she fondly referred to as her 'ears', while the quality of her speech was an observable difference only to one with a trained ear. Her ability to read facial expressions for communication cues was also notable. Tiana's consistently positive socialisation experiences with other hearing children meant there was very little to differentiate her socially from her peer group.

Due to all of these factors, Rebecca (and those within her general social sphere) engaged with Tiana as a hearing person. In private moments, however, Tiana was instigating her own personal inquiry of what it meant to be deaf, observed and reflected upon by her mother. In her daily 'wind-down to bed-time' routine, Tiana would not fall asleep without wearing her cochlear implant, becoming disorientated and distressed by the sensation of deafness. This emerging awareness of the physicality of deafness proved uncomfortable for her. While Tiana was occasionally drawn to other deaf people and on occasions she identified those who wore hearing aids and cochlear implants as being similar to her, she did not yet understand that deafness was a trait that she shared with others who were deaf. Rebecca had not evaluated Tiana's reactions but she did indicate she would have appreciated some insights into how to support Tiana during this process.

Brooklyn's deafness was progressive and diagnosed relatively late at three-and-a-half years of age. Consequently, during the early years of Brooklyn's life, interactions with her whānau, particularly with her mother, were not referenced to the fact she was deaf. Instead, her mother focused on establishing a strong bond with her daughter and responding to all communication efforts. In these early interactions, a set of home signs emerged between Brooklyn and her whānau, termed "Brooky's signs", and were used as an effective communication strategy. Up until Brooklyn's younger brother was born, her parents accepted her behaviour,

communication, and social efforts without judgement. A first child often presents a major learning curve to new parents in establishing how to respond to their children's needs and how to 'tune' into them. As Brooklyn's younger brother moved through developmental milestones their parents noticed differences in behaviour between them. Ngaire noticed the visual approaches to communication, language and social interaction she had used with Brooklyn worked with Kyrin, yet she found herself using more auditory information as well. It was at this point that Ngaire realised she had responded instinctively to Brooklyn's visual preferences. Brooklyn was, in Ngaire's mind, a very visual child and this was her reference point for Brooklyn until she was diagnosed with a progressive hearing loss, from which time the frame posited by professionals was deafness. Once supports had been established and focus on spoken language begun when Brooklyn was four years old, Ngaire and Riki began encouraging Brooklyn to notice, respond to, and read auditory information. Brooklyn was initially unsure about auditory information with her responses ranging from intrigue, to awe, confusion and sometimes fear. During the course of this research Brooklyn quickly came to familiarise herself with the sensation of listening offered to her by her cochlear implant, yet still demonstrated a strong preference for visual communication and language. Throughout this process, Ngaire and Riki held aspirations for Brooklyn to participate linguistically and socially within their whānau and wider community, and thus were following professional guidance to support her with aural-oral skills. Underscoring this, however, was the deep respect they held for Brooklyn's need to decide the way she would express herself. Based on their early interactions with her, Brooklyn's parents framed her as a visual person, whom they hoped would acquire spoken language for practical reasons.

As the youngest deaf child of several deaf children being raised by experienced grandparents, Jay's language, communication and behaviour were not identified as unusual or different, but rather as the types of behaviour that could be found in a child. Jay's grandparents were uncomfortable using the term 'deaf' and instead they identified Jay and the deaf members of their whānau as 'hearing-impaired'. When asked why they had chosen this descriptor, Jay's grandparents reasoned that as Jay and the other deaf children in their whānau, could access spoken language and socialise within a hearing context therefore they were not deaf with that label being reserved for profoundly deaf people or those who used sign language. In his whānau context however, Jay and his cousins interacted using a mixture of spoken language and visual communication strategies. Jay often wore hearing aids in educational settings, marking his

hearing status, but not at home, and thus perceptions of his identity varied between these two settings.

Sian's whānau had prior exposure to deaf whānau members with Sian's maternal great uncle and her mother's first cousin. As such, the whānau were accustomed to deaf people's preference for sign language and communication and how these shaped the nature of interactions in whānau contexts. As Sian's deafness was coupled with 'autistic-like-traits', identified as such during the course of this research, her whānau were unable to apply their experience of deaf people to interactions with Sian. Instead, her whānau moved through a process of discovery, where they spent significant periods of time observing and reflecting on Sian's behaviour, language and communication both at home and in educational contexts, in order to construct a holistic understanding of her. As educationalists and experienced parents themselves, Sian's parents were well-versed in children's development. This helped them see Sian as a child whose sensory experience framed her responses. Sian's parents tended not to compartmentalise her behaviours as being caused by her deafness or her 'autistic-like traits', rather, they described her behaviour and accepted that the two states merged influencing each other. For example, Sian did not exhibit the concentrated eye contact typically displayed by deaf children. Intense stares and facial expressions were not responded to. Instead, Sian would observe people from social peripheries and make eye contact using side-long glances. In this sense Sian was a visual child though she generally preferred to maintain a social distance. On occasion she did enjoy interactions she initiated, for example cuddles with her parents or siblings. In this sense, her deaf and autistic characteristics merged and influenced how her whānau reacted to her.

The configuration of Starr's whānau evolved drastically during the early years of his life. His mother passed away in his second year, and his four siblings and he were taken under the care of whāngai parents. His mother Awhina had spent the early years of his life observing, responding and bonding with Starr, but Lesley, his whāngai mother, was only beginning this process. The two mothers held different understandings about appropriate language and communication for a deaf child. Starr's hearing aids were ineffective during his early years due to on-going problems with the health of his ear. In response, Awhina with the support of her AODC began using visual language and communication strategies. Starr had thus developed a basic repertoire of NZSL and, as the youngest child of five, had experience in practising his visual communication strategies. Through the context of play and daily-life settings, Starr and

his siblings had forged a close understanding of one another using this mode of communication. Their bond was perhaps reinforced by their mother's death as they moved through a difficult process of transitioning to another household and whānau configuration.

When Lesley took over Starr's care, there were a large number of children within the household and strict routines were established in order to manage the needs of the various children. Lesley observed that Starr responded well to this structure as it provided some stability which helped communication. During the early days of transition between households these routines apparently supported Starr's sense of belonging and participation in the new whānau situation. Starr had also become more responsive to his hearing aids, observing and responding to auditory information more readily than he had in the past. Lesley focused on facilitating spoken language during the initial transition period as she believed the long term goal of spoken language acquisition would support Starr's general integration and participation in the daily routines of the whānau. However, the shift from visual language to spoken language was abrupt and poorly supported rendering this a difficult transition. Starr continued to use visual communication with varying degrees of success. During play, aspects of Starr's communication attempts were understood but due to the older siblings' limited knowledge of sign language, communication tended to be reactive to Starr's initiation of communication and was not always successful. A series of idiosyncratic home signs and gestures emerged as an aid to understanding spoken language. At times Starr would use his voice, for want of a better strategy, to gain a reaction, often attracting negative attention. Starr's whānau framed him as an intelligent child with perceptive ability to visually read people. His strong will to participate in whānau life was recognised, yet as their modes of communication were mismatched his deafness was at this stage of his life, seen as a limitation which caused frustration.

11.2.2. Mentoring relationships within whānau: raising children from collective experience

One of the potential benefits of raising children within an intergenerational group that whānau identified, was the depth and richness of experience it could possibly offer. Older and more experienced whānau members, often grandparents, were recognised for their status. They played a critical role in raising children in various forms, ranging from occupying primary care roles to providing encouragement and practical support to main carers. Members of the parents' generation tended to offer similar forms of support and also provided a peer group where

parents could share experiences. The youngest cohort of the whānau, the ‘child group’, offered a context for play and learning. In all cases there was one primary carer who had taken the lead role and was thus identified as knowing the child best, typically a mother or grandmother or someone acting in that role. Primary carers typically had close daily contact with the deaf child, as did children in the younger child cohort.

For the whānau involved in this research there were various internal resources to help main carers gain skills in ‘tuning into children’ and insights into their development. Getting to know a child is an intimate process between adult and child and main carers had varying experiences of this. Tiana’s mother raised her daughter as a sole parent, her mother offering general encouragement and practical support, affirming Rebecca’s belief that she was an independent and competent mother, and providing practical support when she worked. Tiana’s mother also drew heavily on a close-knit network of friends who would encourage her and offer practical support. Jay was raised from birth by his maternal grandparents, who took a lead role in his care while younger whānau members offered pragmatic forms of support. Jay’s grandparents had faced numerous challenges in raising their own children which were alluded to but never described. They admitted these life lessons provided a platform from which to raise the youngest generation. Further, they respected the forms of advice and support provided by kaumātua and kuia based at Jay’s kōhanga reo. Brooklyn’s young mother received practical support from her parents immediately following Brooklyn’s birth. As Sian was the youngest of four children, Sian’s parents were well-versed in raising children, and as experienced educators, working in both early childhood and primary school sectors, they understood how children developed and parented from this viewpoint. Sian’s paternal grandfather was living with Sian’s parents during the course of this research, and while he was too frail to offer practical support as he had done in previous years with other children, he was a central figure in family life. Sian’s parents also drew from the wider whānau network, and had a lot of involvement in the lives of their nieces and nephews. Starr’s whāngai parents, Hemi and Lesley, had extensive experience raising children and their lives were intertwined with Lesley’s parents who were recognised as providing support.

Through mentoring arrangements main carers were supported in various ways. Most whānau members offered a unique contribution to the raising of children and roles were often negotiated within the network. The nature of the whānau hierarchy and relationships between members directly influenced how roles were assumed. This negotiation process was complex.

Biological parents, or primary carers, were not necessarily the ultimate decision-makers. Often main carers were supported by elders from the periphery in decision-making. The dynamics of this support could vary and was not necessarily discernible to outsiders. For example, Ngaire's parents and other whānau members endorsed Ngaire's intuition regarding Brooklyn's ear health when health professionals' views conflicted with her observations. These affirmations were critical as it was via their insistence and encouragement that Brooklyn finally gained a diagnosis. Ngaire recognised herself as a young parent and sought this support from her parents. Lesley's parents provided an 'extra set of hands' to help raise the large number of children within Lesley and Hemi's household. Lesley's parents' views drew from a lifetime of rich experience of whānau and people in general. Thus their guidance was sought on a multitude of matters especially on raising children. When Lesley expressed doubts over attending the Hui Whakawhanaungatanga held as a part of this research, her parents acknowledged experience of deaf people within the whānau was limited. They encouraged Lesley and Hemi to attend so they might gain better insights into deaf people's experiences and potential as a reference point from which to parent, and to whakawhanaungatanga (build relationships) with others who had lived experiences of deafness, again, to support their parenting efforts. Rebecca sought support from her mother in mostly practical ways. She provided the practical care for Tiana so Rebecca's time could be freed up to undertake paid employment. In this relationship, Rebecca was recognised as being independent, in terms of decision-making and in managing daily parenting, while as a sole parent she needed support with childcare so she could work. Due to this regular contact, Tiana had a strong bond with her grandmother. As the elder of the household, Sian's grandfather provided the spiritual leadership for the household. In Jay's whānau, his care and that of his two deaf cousins was the responsibility of Jay's grandparents who were recognised as the heads of the whānau unit.

The nature of relationships between those within whānau hierarchy and whether the mentoring arrangements in place suited all parties was not readily spoken of during the course of this research. The position of 'experience' was generally respected by younger and/or inexperienced whānau members who were less likely to openly critique the types of mentoring offered by older whānau members due to the tradition of not speaking ill of elders and maintaining a united public face for the whānau. It was apparent that elders worked toward fostering main carers' competency and independence as carers, yet they did not do this with an insight in to how deaf children develop.

11.2.3. Envisioning life pathways and outcomes for deaf children: the impact of deaf adults

International literature argues parents typically apply, most often subconsciously, those positive and negative parenting approaches used by their own parents or main carers, when raising their children (Papoušek and Papoušek 1987). The case studies in this research demonstrate, as does other research exploring the experiences of whānau (Ihimaera 1998; Metge 1995; Walker 2013), that Māori children are often raised within a wider intergenerational network of people than is experienced in the western construct of family, and thus their children's social and linguistic experiences are determined by the nature of this structure. Consequently it could be argued that, given the intergenerational experiences of deafness in four out of five of the whānau involved in this research, the deaf adults in each had some bearing on the nature of the deaf child's socialisation in the whānau context despite not being directly involved as primary carers. Most whānau participants in this research were not new to deafness as such, and had at least one example of a deaf person's life trajectory, with both the positive and negative aspects, in their whānau.

The main carers of the deaf child and decision-makers within the whānau participating in this research, potentially two separate people and/or groups, had also assumed this knowledge to inform, often subconsciously, an approach to raising the latest deaf child. This was perhaps most clearly displayed in the case of Jay, whose whānau had a high incidence of intergenerational deafness. The approach employed by Jay's grandparents in raising the latest deaf child drew directly from experience with others, as his grandmother Mary noted: "He's the baby ... after all we've been through with the others, we just copy on".

Poor educational experiences of deaf people are a prime contributor to poor outcomes for numerous generations of deaf people in New Zealand and characterise the complex social experiences of deaf people in hearing families (McKee 2002). Not all deaf people affiliated with whānau participants had poor educational outcomes, yet they described their educational experiences as challenging. Whānau participants were able to observe the intergenerational impact of these challenging educational experiences, mainly relating to language and miscommunication in learning environments, which fuelled their decision-making and aspirations for their own children. The complex aspects of life-paths of older deaf whānau members were observed by those raising the deaf children and in some instances informed the

complexity of main carers' responses to the deaf child. Brooklyn's mother reflected on her own childhood observations of her adult aunt's experiences of social isolation and resolved to facilitate a more inclusive experience for Brooklyn. Brooklyn was implanted with a cochlear implant and while she had adapted her own home signs which were still respected by her parents, they parents hoped she would develop an ability in spoken language to support her inclusion in whānau life. Starr's whānau expressed similar sentiments. They also had seen deaf whānau members' restricted social participation which influenced their desire for Starr to move from using NZSL to spoken English, believing this would increase his participation and belonging to their whānau. In the case of Sian and her parents, this research provided a space to explore how knowledge of two very different deaf people in their whānau, both paternal and maternal lines, had informed their decisions. They concluded that Sian would be given a bilateral implant, yet they also held aspirations for her to become bimodal and perhaps even trilingual with English/NZSL and te reo Māori. These decisions were influenced by knowledge that both deaf people in their whānau were fluent in NZSL and English, and because Sian's siblings were already bilingual in te reo Māori and English. Sian's parents were disappointed by both the fact that Sian was unresponsive to her bilateral implant and by the fact that were actively discouraged from using NZSL. Toward the end of this research, Sian's parents reflected that while both these deaf relatives played an important role in shaping their decision-making and parenting approaches, Sian's experience was complex and unique, and that it was important to accept each deaf person's circumstances as unique.

Observation of deaf whānau members provided some perspective on a single deaf person's life outcomes, with the exception of Jay where there were several deaf people in the whānau. However, the primary carers of deaf children also sought knowledge of a wider range of deaf children and adults in order to give context to their own specific circumstances, and to support a vision of their own child's potential trajectory. This was clearly articulated by Lesley who sought a report of Starr's developmental progress in relation to other deaf children, and as a result, she and her AODC worked through a standardised assessment noting Starr's developmental achievements. Witnessing Starr interact with other deaf adults and children from various social and linguistic backgrounds at the Hui Whakawhanaungatanga held for this research provided Lesley and Hemi, and other whānau, with examples of developmental potential in a natural setting. Behaviours that were initially seen as idiosyncratic were recontextualised as 'deaf behaviours', those shared by a cohort of known deaf people, and deafness was framed as a potential social identity. The need to find diverse examples of deaf

people's life trajectories was not necessarily a priority for Mary and Arthur, who felt that with the support of hearing aids, Jay was not too different from hearing children. They also noted that the experience of having deaf children and grandchildren had equipped them well with the knowledge of his potential. Tiana and Brooklyn's whānau were very interested in networking with other Māori with cochlear implants. Since cochlear implantation is a relatively new technology the whānau in this study were most interested in exploring the potential long term outcomes of having an implant, in a holistic sense, exposing their children to positive role models, and developing a network for whānau support.

11.3. The effect of EI experiences on shaping whānau perceptions of the deaf child

Whilst immersed in the EI period, whānau members found it difficult to identify the impacts of the structure of the UNHSEIP and how their interactions with EI professionals impacted on the way they framed and responded to their deaf children. Through constructing a record of their experiences for the purposes of this research, whānau participants divorced themselves from the thick of experience and were motivated to reflect, review and draw conclusions. From the position of retrospective insight, whānau participants concluded through interactions with the UNHSEIP system and interactions with individual EI professionals that they had co-constructed a view of their deaf child, identifying a position from which they made had decisions and parented during the early intervention period.

The first stage of the UNHSEIP involves the identification and diagnosis of deafness and provides an entry point into this system. Screening and diagnostic services are typically undertaken and situated within medical settings. Participants' reflections on these screening and diagnostic processes indicate that deafness was initially presented as a medical concern, a position reinforced as diagnosis was essential to gaining access to support services, and because medical professionals were acknowledged for their authority and expertise. For those children with a late diagnosis, whānau had already identified, and to some degree accepted that their children had a hearing loss but still required a diagnosis in order to access supports.

The UNHSEIP protocol is that an AODC is introduced to the family immediately following diagnosis to provide information about deafness and to offer informed support with decision-making and accessing EI supports. It is at this point that an AODC theoretically supports the family's move into the second early intervention phase of the UNHSEIP. For the most part

however, whānau participants did not know they were about to enter into a programme of EI as this was not made explicit to them. The line between diagnosis and EI was often blurred by the rapid introduction of intervention options prior to introducing information on deafness and before a relationship was developed between whānau and the AODC. For four of the five children in this research, intervention options of hearing-aids and cochlear implants were introduced by specialists before whānau had the opportunity to meet an AODC to discuss the wider implications of deafness for their child and whānau. The relevance of the AODC role as a navigator to the world of deafness and EI supports was inadvertently undermined by these processes as whānau assumed that an intervention phase had begun with the introduction of technological supports. The eventual introduction of an AODC was confusing for most whānau who initially could not place where the AODC's expertise lay or what the AODC's role was in relation to the wider UNHSEIP. Principally as they did not understand that they were involved in neither the UNSHEIP nor what the wider objectives were. Whānau typically did not understand that AODCs were involved in the UNSHEIP, nor what the wider objectives of the programme were. It was difficult for an AODC to provide information on the wider impact of deafness in this context as whānau had already embarked on a process of identification, diagnosis, and introduction of technological support (cochlear implant/hearing aid) which acted as a default reference point for information. Case studies demonstrated that this linear progression does not prepare whānau for the complexity of the holistic impact of deafness as most whānau eventually experienced it. Not until the child began exploring their own social and linguistic capacity in the whānau context did their whānau participants' perspectives branch out from this structured frame. As the previous section (*11.2 Perspectives of deafness within the whānau*) illustrated, deafness and the deaf child were synonymous, and the child and their whānau were interconnected. When whānau had arrived at this point of experience, or while whānau were in the moment of experience, they began to integrate new information with their experience of their child. Often the deaf child was already of school age by the time whānau had arrived at this position and thus such processing was retrospective. Contextualising information on deafness, deaf children's development, and the type of EI supports available was complex and often confusing for whānau because of the authority of the linear frame of a process set by UNHSEIP implementing identification, diagnosis, and introduction of technological support. This was reinforced in various settings by the status of multiple professionals.

This chapter has reviewed the way in which whānau conceptualised the deaf child in context. Chapter Twelve provides an overview of how EI services and supports describe their role in relation to Māori. In this chapter I argue that the current system of EI supports does not work toward Māori aspirations for their deaf child. A metaphor of the pā harakeke is proposed as basis for organising support.

Chapter 12. Refocusing early intervention services for Māori: Ngā Kōhungahunga Turi

12.1. Introduction

This chapter addresses the question *Can the design of EI services and support systems for deaf children be adapted to be more effective for Māori, and if so, how?*

Over the last two decades a number of Māori scholars have examined the issue of inequities for Māori in health and educational sectors, concluding that inequities arise when the vision, i.e. the identification of potential outcomes identified by whānau, and the supports provided to meet that vision are mismatched (Penetito 2010; Reid and Robson 2007; G.H. Smith 1990). Māori scholars have long argued for holistic models of wellbeing and healthy development that align with Māori worldviews, models which are only now being recognised by the health sector (M. Durie 1985; Penetito 2010; Pere 1991; G.H. Smith 1990). This chapter moves from this premise and argues that a conceptual shift is required if the UNHSEIP are to meet whānau aspirations for their deaf children and for their healthy development and wellbeing.

The first section of this chapter, *12.2. Reaching for equity across the UNHSEIP*, argues that while a number of key strategies and policies within the educational and health sectors aim to reduce inequity for Māori and those with disabilities, Māori goals and aspirations for deaf children are not well supported by the professional sector, principally because their holistic perspectives of wellbeing and healthy development are not endorsed within the types of supports made available. The second section *12.2.1. Delivering services to Māori across the UNHSEIP: key provider perspectives*, provides a description of the approaches key providers have employed to deliver services to Māori. Section *12.2.2. Participatory and relational approaches with Māori: whānau participant experiences*, describes both the nature and impact of interactions at the interface of professionals and whānau participants. The final section of this chapter *12.3.A Kaupapa Māori approach to support for the Māori deaf child and their whānau* proposes a conceptual shift from the rhetoric of EI and ‘family-centricity’, or even ‘whānau-centricity’, is required if the UNHSEIP is to meet the holistic aspirations of whānau for their Māori deaf child. The metaphor of the pā harakeke, flax plantation forms the basis of a Kaupapa Māori way of theorising way of conceptualising a system of support.

12.2. Reaching for equity across the UNHSEIP?

Ethnic inequity³⁰ which is unnecessary, avoidable and unjust in health and education has been consistently noted as an issue for concern by Māori academics (B Robson and Harris 2007a; Bridget Robson and Harris 2007b; G.H. Smith 1990). Reid and Robson, examining the issue of inequity in Māori health, define health equity as “the absence of systematic disparities in health, or in the determinants of health, between two different social groups who have different levels of underlying social advantage/disadvantage, that is, different positions in social hierarchy. In this approach attention is not given to the individual, but instead “monitor[s] how resources (including health service) [are] distributed across the community. Including the processes that determine how resources are shared and the underlying values of society” (Reid and Robson 2007:4). In the quest for reaching equity, a number of government strategies and policies directed at Māori in the arena of health and education have been introduced over the past decade with the view of reducing disparities. Those most specifically relevant to this research are discussed and outlined in the literature review (see sections 2.7. *Signposting the principles of the Treaty of Waitangi in public policy to promote Māori development*; 2.8. *Māori experiences of deafness and early intervention in New Zealand*). Embedded in these policies are the Treaty of Waitangi principles of **partnership**, **protection** and **participation** as introduced in the 1988 Royal Commission on Social Policy (Policy 1988). These principles provide a conceptual platform, from which programmes can structure an approach to working with Māori deaf children and their whānau. Numerous Māori scholars reference these principles as providing a key structure from which programmes and services can respond to Māori in the areas in health and education.

The introduction of the UNHSEIP, as outlined in (*Chapter Five: Early intervention service delivery in New Zealand: context to the case study*), responds to historical data indicating key inequities for deaf children – specifically, the unacceptable (by international standards) average ages of diagnosis and introduction to supports. The example of ongoing over representation of Māori in diagnostic data, where Māori are more likely to experience mild and moderate forms of hearing loss, is often used to flag the existence of inequities for Māori (J. E. Digby et al. 2012; J. Digby et al. 2013; M Durie et al. 1989). A number of key informants hypothesized

³⁰ Reid and Robson (2007:4) prefer to use the term inequity as opposed to inequality. They propose inequalities can be at times expected. They provide the example of illness which can only be gender specific (such as prostate and cervical cancers). Equality in this sense is an elusive goal.

differential access to determinants of health and wellbeing, framed in their words as ‘illness related to poverty’, differential access to primary health care, and differential quality of care received, as underlying causes for this over representation³¹. This inequity may be reduced (sensibly so) if clearer links were made between how differential access to the determinants of health and wellbeing, primary health care, and quality of care received and the prevalence in Māori were better understood. This is a large-scale issue and requires an integrated approach across multiple sectors; a number of policies (*as described in section, 2.7. Signposting the principles of the Treaty of Waitangi in public policy to promote Māori development*) have been developed to raise the general health profile of Māori and thus work indirectly toward reducing this inequity.

Importantly, the case studies presented demonstrate early identification and introduction to supports alone does not necessarily consistently occur. In instances where this identification and introduction to supports was achieved, it did not necessarily result in a deaf child’s access to language during the ‘critical period’, in which children are most receptive to language learning. The targeted approaches to capture ‘at risk’ groups may be more significant for Māori who are presenting with hearing losses due to factors to do with their differing health profile. Accordingly, a differing approach to target ‘at-risk’ populations must account for this differing health profile of Māori. (Reid and Robson 2007) conclude that in an attempt to reach equity different resourcing is often required for distinct and separate groups, they write:

Equity, like fairness, is an ethical concept based in a model of justice where distribution of resources ensures everyone has at least their minimum requirements. It does not necessarily mean that resources are equally shared; rather, it acknowledges that sometimes different resourcing is needed in order that different groups enjoy equitable health outcomes (Reid and Robson 2007:4).

The case studies presented in this research provide some contextual insights into the nature of how differential access to these factors lead to a higher prevalence in hearing loss for Māori. When questioned about the provision of service for Māori, key informants involved in the

³¹ This summary draws from Reid and Robson’s citation of Jones (2001:&7) who suggested there are three main pathways that contribute to ethnic inequalities in health: differential access to the determinants of health or exposures leading to differences in disease incidence; differential access to health care; and differences in the quality of care received.

design and implementation of services acknowledged this as a primary inequity requiring attention. The development of relationships with Māori communities was seen as a starting point for understanding the nature of differential access to determinants of health and wellbeing, differential access to primary health care, and differential quality of care received for Māori. For example, the key informants from the NSU noted that UNHSEIP providers are specifically obliged to consult with Māori (and Pacific populations); develop relationships with organisations and providers who can assist with raising awareness of the UNHSEIP amongst Māori (and Pacific populations).³² Further comments suggest that if undertaken, this relationship building experience may lead to improved communication between providers and Māori communities. The NSU also noted the UNHSEIP can be monitored (although what was being monitored was unclear) by ethnicity and socioeconomic status to maintain a ‘reducing inequalities focus’.

12.2.1. **Refocusing the lens on the problem of inequity**

The cases presented in this research suggest that while efforts supporting the reduction in rates of diagnosis, especially when they are an unnecessary consequence of illness and/or disease, are sensible; they also raise various questions around how to frame the problem of inequity. Māori academics have long argued that Māori have framed health and wellbeing in holistic terms, emphasizing the interconnectedness between the determinants of health and wellbeing and immediate health outcomes. Embedded in this assumption is the view that immediate health outcomes are as important as other holistic outcomes associated with general wellbeing (M. Durie 1985; Pere 1991; Te Whaiti et al. 1997). Recent government policies are now beginning to reflect these assumptions in both health and education sectors at policy level (*see section, 2.7 Signposting the principles of the Treaty of Waitangi in public policy to promote Māori development*).

The cases presented in this research support these views, and suggest whānau members were most interested in the development of their child in holistic terms and felt the primary inequity was (in accordance with international literature) was when linguistic and social competence in familial and societal domains was delayed or not achieved and when their child’s passage

³² These comments indicated an awareness of inequities facing Māori and Pasifika populations (as being overrepresented in the social determinants of health) yet, it was unclear whether key informants (including providers) were able to articulate how a relationship might differ with Māori as Tangata Whenua and Treaty partners with the Crown.

through holistic developmental milestones was affected as a consequence. In this point of comparison, whānau were using an imaginary trajectory of the ‘typical developmental for a deaf child’ (not the trajectory of a hearing child – as the pathway of development is recognised is differing due the experience of deafness) and wanted to support their child to move along this ‘typical’ pathway. This was further complicated as whānau participants felt they either lacked or had a limited sense of this trajectory due to a lack of exposure to information, deaf people and their families (as a platform for processing information and decision making). Creating an aspirational vision for their child’s future was therefore compromised. Importantly, this concerns not only Māori but also non-Māori families with deaf children within New Zealand and internationally (Moeller et al. 2013). However, in the case of Māori, the view of healthy development is influenced by Māori holistic frameworks of health and wellbeing which are unique.

This research demonstrates that the UNSHEIP and whānau participants had framed the ‘problem’ of deafness in differing ways. Therefore a conceptual shift would be required (which could potentially result in a different resourcing structure as well) if the sector is to meet whānau aspirations for their Māori deaf children and to facilitate a whānau-centred approach to early intervention. The following sections outline the health and education sectors’ uncertainty in terms of identifying, understanding and meeting Māori specific aspirations, describes a disjuncture between professionals and whānau during critical interactions that supposedly form the basis of a successful family-centred approach to EI

12.2.2. Delivering services to Māori deaf children and their whānau across the UNHSEIP: key provider perspectives

As a part of this research a number of key informants involved in the design and implementation of services across the UNHSEIP³³ were interviewed to gain a description of service provision and general understanding of the wider goals and intended outcomes of services. Organisations were asked to describe policies, practice protocols and training relating to the provision of service for Māori as well as identify potential barriers to access to services

³³ Interviews were undertaken with representatives in senior positions from government departments, those involved in the design of services, as well as those in management positions of key service providers. Contextual knowledge gained from interviews with those EI specialist staff working directly with whānau participants provides a background context to these interviews as well.

from the perspective of both whānau and provider. Diagnostic inequities for Māori were identified as a concern by the majority of key informants involved in service design and delivery while several noted how participatory and relational differences between providers and whānau with Māori deaf children could contribute to an intervention's ineffectiveness. Several key informants agreed these factors were indicators of a larger problem – one which was difficult to profile. A concerted effort had been made at provider level, through research approaches such as survey, investigating diagnostic and participation in service data, and/or through directly questioning individual whānau members as a part of a service evaluation, to gain a fuller perspective on these issues.

Steps undertaken to address inequity at provider level were diverse, perhaps appropriately so, as they delivered services to whānau whose unique social experiences determined the nature of barriers they faced in accessing services. The two cochlear implant providers, NCIP and SCIP, described differing approaches to service delivery for Māori. Senior staff from within the Northern programme had employed an independent researcher to survey whānau within their service and analysis of diagnostic data, in order to investigate the context of inequity for Māori. They had identified that while their service was recognised as 'culturally-Pakeha' (by both consumers of their service and by staff), they acknowledged that they were servicing an ethnically diverse population and thus they ought to seek a better understanding of this context. As summarised by their researcher:

People say, 'I bet it's only Pakeha families that go to the Hearing House and 'middle-class families' that go to the Hearing House. So I was really interested in finding out about what types of families come here and how do they compare to the general population ... What we found was that Māori families seemed to be accessing the service very well in numbers, in line with their general population ... So, okay [that means] they are attending, but what does that mean? Are they really engaged with the services here? ... We've been talking to families and asking them how they engage with the services and how comfortable they feel about attending and [asking them to identify] what barriers are, in the way, to having full you know full engagement with the service here? And [asking them] what [would] a service look like if they could design a service? We're [asking ourselves as we're] a Pakeha

organization and what does that mean for cultural responsiveness and cultural competence and cultural confidence and how things might develop?

The population dynamics of the SCIP differ from the northern region, with lower numbers of Māori, and ethnic minorities, participating in their service. Within the service agreement between the SCIP trust and the MOE, a clause refers to ‘honouring the Treaty of Waitangi’. In the first instance a key informant from the programme felt it important to develop relationships with Māori, yet indicated confusion over this loose instruction. It was unclear whose role this might be and with whom they might consult, whether it be local hapu and iwi or the whānau they directly serve, in which case, they would potentially be consulting with hapu and iwi outside the geographical boundary of their service. In either case, the organisation was interested in developing positive relationships with relevant groups, yet required guidance on how to do so.

The preschool and EI programme held at KDEC and van Asch respectively, also expressed uncertainty about how to address inequities, how to support whānau aspirations, and where to seek guidance. Adjacent to the KDEC preschool sits Ruamoko, a school-based marae developed and built from the efforts of Māori (hearing and deaf) with the support of school leadership at the time. Management from the KDEC preschool noted this proximity meant that Māori, both hearing and deaf, adults and young people were visible to deaf children and their families, and that children were able to participate in a marae where the kawa (social protocols) involved a fusion of Māori and deaf cultural norms. The preschool also emphasised relationships with whānau outside of preschool sessions through facilitating meetings and informal ‘get-togethers’ to encourage a sense of community between all families. Management noted that fostering a sense of community works toward holistic outcomes, wherein the child and family are exposed to a social context and place where being deaf is normalised, and the network provided families with support. The van Asch EI programme recognised potential areas for improvement. The programme found that guidance on how to facilitate this was lacking, as the principal of the school explained:

I would love Māori to feel more welcome in our programmes and I think we need guidance with that. We don't really have the skill and knowledge of ... how to go about it. So, I think it is something that we have always got to keep looking at, and yes, we can improve – but that would be my philosophy about everything.

As an initial response, the principal noted staff had undertaken training to heighten their awareness of tikanga Māori and te reo Māori to improve their relational approaches used with whānau. As a part of this process, the programme leadership asked themselves what critical factors underscored their service and concluded that their family-centred approach to EI was consistent with Māori frameworks of wellbeing. The lack of Māori specialist staff was also recognised as problematic and as an interim measure the principal encouraged whānau to include their own whānau resources, for example, grandparent attendance to support EI sessions. Connections were made with the school-based marae, a recent initiative, yet the school had faced challenges as to who would support the marae and had yet to find a permanent staff member to fill the role.

Across government departments and providers within the UNSHEIP, inequities for Māori were recognized, yet profiling and addressing the problem was challenging – especially at provider level. Key informants noted attempts to construct a deeper understanding of the problem could be found across UNSHEIP, yet overall, providers were not entirely confident that they understood the nature of inequity as experienced by Māori.

12.2.3. Participatory and relational components of family-centred practice: whānau participant experiences

Returning to Dunst's (2002:147) framing of family-centred practice in terms of relational³⁴ and participatory³⁵ practices (*See section 2.3. Early intervention with deaf children: theories, models and practices, p12*) the experiences of whānau participants support Dunst's (2002:145) hypothesis, that despite family-centred practice being endorsed across professional sectors, this tends not to be the experience of families – as was the perception of whānau participants. (C. Dunst et al. 2002:223) suggest family-oriented models tend to occur on a continuum ranging

³⁴ The relational component includes practices associated with (a) good clinical skills (active listening, compassion, empathy, respect, being non-judgmental and (b) professional beliefs and attitudes toward families, especially around parenting capabilities and competencies.

³⁵ The participatory component relates to practices which are (a) individualised, flexible, and responsive to family concerns and priorities, and (b) provide families with opportunities to be actively involved in decision making, family-professional collaboration, and family actions to achieve desired goals and outcomes.

from professionally-centred, family-allied³⁶, family-focused³⁷ and family-centred. Services which are family-allied and family-focused in orientation tend to fare well in the relational aspects of their approach, while family-centred practice adds to this by building family capacity. (C. Dunst et al. 2002:223) note professionally-centred practice emphasize professionals' expertise and abilities to define families' needs. Families tend to act as passive recipients in the intervention process whereby services and programmes are driven by the goals and outputs identified by professionals. These cases suggest that while a family-centred approach is endorsed in policy this is not how it is perceived by whānau with Māori deaf children. In particular the overall structure of the UNHSEIP controlled the way whānau members framed and responded (the participatory component of family-centred practice) to the 'issue' of their child's deafness. The programme identifies what steps are necessary upon an identification and or diagnosis, which professional groups are relevant, what types of supports will be resourced (an indicator of who and what is deemed important enough to engage with), what outputs are significant (for example, the 1-3-6 priority which emphasizes diagnosis and access to EI supports by 6 months) and the rationale behind a categorization and assessment processes which determine who participates in the programme – and why. These experiences provided the foundation for engagement with professionals (the relational component) and influenced how information was processed and evaluated and decisions around support options made.

The initial stages of engagement with the UNHSEIP involve moving through stages of identification and diagnosis. These stages were seen by whānau participants as an important and necessary 'categorization' process; marking a decision-point and was a powerful precursor to accessing information about a potential developmental trajectory of their child and necessary supports required to raise their child. This experience tended to set the scene for engagement (the participatory component) with the programme. The 'deciding-power' associated with these professionals, reinforced their authority as 'expert' on the child and demoted whānau members' expertise. For example, in the cases of Brooklyn, Jay and Sian, whānau members had already identified their child's deafness using their expert knowledge of their child – prior

³⁶ Families are seen as minimally capable of independently effecting changes in their lives. Families are viewed as agents of professionals for carrying out professionally prescribed recommendations and courses of action. Professionals enlist families to implement intervention under the guidance and tutelage of the professionals.

³⁷ Families are seen as capable of making choices among options professionals deem important for healthy functioning. Professionals provide advice and encouragement to families on the basis of their choices and decisions. Interventions focus on monitoring family use of professionally valued services.

to an audiological assessment. These judgments were primarily dismissed by professionals until whānau members insisted on repeat assessments to validate their concerns. Although this is a common account from parent's discovering deafness in their child, these case studies raise a possibility that Māori are potentially being discriminated against in health settings when seeking referrals and diagnosis. Assessment occurred primarily within hospital settings (flagging to whānau members that deafness should be framed as a medical concern) and was both initiated and scheduled by hospital staff who determined the parameters of interaction, i.e. the time, place, duration and content of discussion. Interactions in these settings were thus characterized by professionals' need (determined by DHB protocols) to complete a series of steps, measurement, diagnosis, information-sharing and agreement or not to an intervention or procedure. In the cases of Tiana and Sian, a professionally-centred approach to supporting the child and whānau through a serious (life threatening) health condition, of which deafness was identified as a later consequence, was seen by whānau participants as both necessary and appropriate. Professional leadership in these settings was appreciated as whānau participants felt they had neither the expertise nor energy to lead decision-making at that time. Difficulties arose however when professionals were unable to identify where and when this 'leadership' approach should have been phased out and a more collaborative approach be applied in relation to deafness (as a non life-threatening condition). As there was no marker to shift whānau participants focus from the life-threatening event to the non life-threatening consequence (deafness), deafness was seen on a continuum of an 'event'. Contact with professionals was in hospital contexts and thus created a sense of tragedy with the child's deafness and feelings of powerlessness for whānau members.

Typically cued in at the point of identification and diagnosis, an AODC is the theoretical interface between families and the UNSHEIP and the professionals working within it. While other professionals within the UNHSEIP usually provide a specific type of support and/or service, an AODC takes an advisory and coordinating role in assisting whānau to navigate services, to interpret information and experiences, and theoretically to support families to determine goals for their child and whānau. Due to the definition of their role an AODC has potentially the greatest influence on facilitating the participatory aspect of a family-centred approach however the AODC still had similar systemic constraints as medical professionals working within the DHB context and as employees of the Ministry of Education. Caseloads must be managed within a given structure and timeframe providing pressures on facilitating this approach. The significance and role of the AODC was also obscured by the fact that

whānau members had already been introduced to information about or begun medical /technological intervention options i.e. cochlear implants and the use of hearing-aids prior to the introduction to an AODC. The introduction of technological supports prior to an AODC (who is more likely to discuss the consequences of deafness in developmental terms and then provide information from this point) reinforced the view that deafness was a medical concern, which was easily ‘remedied’ by a technological response. The fuller implications of deafness became apparent as the child moved through developmental stages. Often observing their child as they met a stage of development (or not), acted as a trigger for whānau members which consolidated information from an AODC and it was at these stages that information became more pertinent to whānau. The sequence of introductions to professionals, support options and information was significant – each stage acting as a platform for response and directly influenced the participatory experience of whānau members.

Interactions with professionals (the relational component) varied across the continuum (professionally-centred, family-allied, family-focused and family-centred) depending on the personal awareness and skill set of the various professionals. The highly structured context involving identification and diagnosis left little space for professionals to facilitate relationships and for whānau members to establish the wider context of their situation. In all clinical cases, interactions were professionally-centred. The relational skills of diagnostic professionals are critical; diagnosis is typically a point of emotional response and has the potential to compound a sense of trauma. Whānau participants noted the clinical setting and the relational abilities of specialists generally did not allow for relationship-building nor account for whānau members’ emotional response to interactions. To some extent, whānau members were well-versed in the nature of interactions with clinical specialists and while the relational approaches encountered were often ill-matched to those that whānau were accustomed to using, some participants were resigned to interacting with professionals in this way.

In all cases, professionals tended to engage closely with one whānau member (typically the mother or someone acting in that role) and were not able to experience the whānau as a whole and thus grasp the potential influence of the whānau in shaping the early years of the deaf child’s life. Due to the logistical constraints professionals faced, it was not necessarily feasible to spend the time needed to meet the relational expectations of the wider whānau and some

whānau identified professionals as lacking in skills, or perhaps sufficient time, to undertake a 'scoping exercise' investigating the whānau dynamics.

A Kaitakawaenga, a Māori cultural advisor, employed by the Ministry of Education, works toward facilitating relationships between service and whānau. Several whānau involved in this research were introduced to a Kaitakawaenga to support the relationship between the two groups. It is assumed that Kaitakawaenga are skilled in working with whānau, and due to their social experiences with Māori communities, are able to employ various relational approaches recognisable by Māori whānau. Key informants working within the MOE acknowledged the historical experiences of disconnect between whānau and professionals and that the introduction of this cultural liaison role was an effort to support relationship-building between the two.

Going back to the other side, [to] Māori whānau experiences of our service. I think it can be very hard to access our service. It's not a familiar place. You know many families don't have a great experience of government departments and this is like interacting with a government department. I think that's why we've really tried to make that first bridge [connecting families with an AODC and Kaitakawaenga] happen at audiology so that you know you're already there.

Interestingly, whānau members' comments on this experience indicated that the prompt introduction of the AODC and Kaitakawaenga at the point of diagnosis was not a guaranteed fix for addressing relational issues in engaging with EI services. Whānau participants found it difficult to see where the Kaitakawaenga fit within the structure of EI support as they did not have any observable expertise in relation to deafness, e.g. as an audiologist might have, they were often introduced at later stages of engagement with professionals and thus their status and authority in relation to other professionals was difficult to gauge. In some cases they added to the whānau's burden of engagement with yet more professionals, or their relational approach was mismatched with whānau members. Alluding to the role that kuia, older women, or 'aunties', often play in managing relationships within a whānau, Hemi, Starr's whangai father, dismissed the role of the Kaitakawaenga as tokenistic in his comment: "*What – are they gonna send in one of the 'Aunties' or something?!*" While whānau overall appreciated the theoretical objectives of the Kaitakawaenga, they also appreciated the personal integrity of various professionals, the genuine attempts at rapport and direct relationships with those specialists

who would have the most to do with their child and whānau. Whānau members tended to bond best with professionals who were able to both meet their relational needs as well as provide some form of critical support and expertise.

12.3. A Kaupapa Māori approach to support for Māori deaf children and their whānau

Case study experiences reveal that the wider, long-term aspirations of Māori deaf children and their whānau will not be supported within the current system of EI for two reasons. Firstly, from the perspective of whānau participants, the UNHSEIP appears to support a very narrow purpose: engaging families promptly to ensure deaf children and their families are able to access supports within the critical period in which a deaf child is most receptive to language supports. Underscoring this premise is that if a deaf child's language skills develop in an age-appropriate sequence this minimizes the potential negative impact of deafness (see sections, *2.1. Impact of childhood deafness; 2.2. Pathways to language*) The vision expressed by whānau however, mirrors Māori models of holistic wellbeing and healthy development outlined by Māori academics (M. Durie 1985; Pere 1991); deafness is acknowledged as a life-long state which will characterise life experiences beyond the early years of a child's early experiences. Embedded in this vision is the assumption that the experience of deafness (as a sensory experience and as a social identity) is inseparable from an identity as Māori (or any ethnic identity for that matter) – through linguistic and social experience they are fused within the individual. The identity of individual whānau members is also shaped by the experience of deafness; they too, live with the holistic implications of deafness, the experience having life-long bearing on how they express an identity as individuals and as a whānau collective. These insights crystallized for whānau members when they were asked to reflect on the experiences of raising a deaf child. Secondly, the theoretical approach of engagement indicated by the UNHSEIP, 'family-centricity', is not applied consistently across professional groups – the professional-centred approach dominates on participatory and relational levels. Case experiences challenge the appropriateness of family-centred approach to intervention as well. The cultural construct of whānau is conceptually different to family (Ihimaera 1998; Metge 1995; Walker 2013) (*see Chapter One: Introduction p1*) and the concept of intervention flags several negative associations which do not sit well with Māori perspectives on health and wellbeing nor does it inspire whānau competence in raising a deaf child.

It is for these reasons that this thesis proposes a conceptual shift is required to support Māori deaf children and their whānau to reach their aspirations for wellbeing and healthy development. Sass-Leher and Bodner-Johnson (2003:161) writes that programme design for early intervention for deaf children should begin with ‘a development of a program’s philosophy and purpose’ and ‘addresses the roles and relationships of families and professionals, the nature of learning in young children who are deaf and hard of hearing and their families, and the intended outcomes for both children and families’. The core goals of the UNHSEIP are described as ‘1-3-6’ goals: babies to be screened by 1 month of age, audiology assessment completed by 3 months of age, initiation of appropriate medical and audiological services, and early intervention education services, by 6 months of age (Ministry of Health 2013:2). The case studies presented in this research suggest this is too narrow a focus for an overarching programme goal and recommends the UNSHEIP review the programme and specify a programme philosophy and purpose for Māori deaf which is directly informed by the Treaty of Waitangi principles of *partnership, protection and participation* (Royal commission on social policy 1988) (*see section, 2.7 Sanctioning equity: the significance of the Treaty of Waitangi for EI provision in New Zealand*) as well as the evidence-based principles identified in the *international consensus statement of best practices in family-centred early intervention for children who are deaf or hard of hearing* (Moeller et al. 2013) (*see section, 2.3. Early intervention with deaf children: theories, models and practices, pp13 - 14*).

In keeping with the metaphor adapted for the research approach described in *Chapter Three Ngā kete matauranga: constructing knowledge*), this research extends from the metaphor of raranga and proposes that the wider metaphor of the pā harakeke (flax plantation) offers a kaupapa (conceptual basis) for a programme philosophy. The proposed kaupapa was co-constructed through wānanga with whānau participants, kaumatua and kuia who provided mentorship to the researcher during the course of this research. It is a concept recognisable to Māori and utilises and affirms Māori ways of organising and thinking. Kōhungahunga are the fine silky fibres found within harakeke leaves; the metaphorical use of the term by Māori orators to refer to young children offers a paradox – the vulnerable silky threads (the kōhungahunga) of the harakeke plant (metaphorical whānau) are the internal substance which provide it’s strength and resilience. *Te puawaitanga o ngā kōhungahunga turi* translates loosely as ‘the blossoming’ of young deaf Māori people’ within the context of their whānau; it emphasizes the healthy holistic development of the deaf child based on Māori and deaf perspectives of healthy development (*see section, 2.8. Māori experiences of deafness and early*

intervention in New Zealand p 30), within the interdependent context of whānau. Te puawaitanga o te ngā kōhungahunga, the wellbeing and healthy development of the deaf child, encompasses a holistic kaupapa (the philosophy and purpose) to inform the nature of supports for Māori deaf children and their whānau.

This thesis also proposes supports and services related to deafness also be arranged within the concept of pā harakeke. Imagery of the tender young shoot at the centre of the plant, te rito, protected and nourished by the embrace of the outer leaves, provides a visual conceptual base for ideals around intergenerational kin relationships. The centre is likened to the youngest child, the immediate outer leaves the parents, while the successive outer leaves, fanning outwardly from the centre shoot, represent the numerous generations before the child, all protecting and investing in the latest shoot, the centre and life of the plant. As with whānau, all ‘members’, the leaves, are interdependent; they cannot exist without one another. Although one harakeke plant will begin as a single shoot protected by two outer leaves, these quickly multiply with the plant often growing to contain numerous shoots protected by outer leaves, growing outwards in a fan-like formation. In this sense the plant is likened to the concept of whānau, whereby numerous rito, referred to here as the *kōhungahunga* turi or young deaf person, are cared for and protected by outer leaves, generations of related adults. The single plant often exists within a cluster of harakeke plants, a collection or community which shelter and are connected to one another through context and proximity. Māori oratory regularly borrows from this imagery to describe cultural ideals around children, whānau, wellbeing and relationships.

There is a transformative synergy inherent in the concept of pā harakeke as it promotes the competence of whānau to raise a child while simultaneously acknowledging the need to create a specialised community of support to do so. In a literature review commissioned by the Ministry of Health to identify the principles and practices of EI the reviewers Alliston (2007:42-43) note (Turnbull et al. 1999:168) comments on the significance of providing the necessary ecological environments around and within families and children in order to foster healthy development, they write:

“the major emphasis becomes ‘fixing the multiple ecological environments, rather than fixing the child, so that key people in the environments value the child with a disability and eagerly create accommodations and supports so that the child gets the implicit message from the earliest years that he or she belongs in an authentic inclusive community’”.

This research recommends pā harakeke be adapted as a kaupapa Māori approach towards supporting Māori deaf children and their whānau reach a programme philosophy – *Te puawaitanga o ngā kōhungahunga turi*. In this sense, a pā harakeke approach to *Te puawaitanga o ngā kōhungahunga turi* works from this premise: whānau collaborate with a transdisciplinary community with multiple expertise to co-construct an approach to raising their child with a focus on supporting whānau to provide the optimal ecological environments to facilitate healthy development. This broad focus allows for the inclusion of professionals (groups already employed within health and education sectors) to work with deaf children (*see Chapter Five: Early Intervention service delivery in New Zealand: context to the case study*) as well as supports’ which address healthy whānau function (for example those seen within the policy and practice of whānau ora) and those with language and socialization expertise of relevant language communities. As a generalisation English is the language of the household for most whānau with Māori deaf children yet we can also assume that te reo Māori and New Zealand Sign Language (NZSL) are also key language communities for whānau as the participation in these communities support the holistic development of the Māori deaf child. The pathway to language learning for a deaf child requires specialist supports as well as natural exposure to and participation within relevant language communities. The inclusion of whānau into the language communities of their children is important; language is acquired through a functional and naturalistic context for both the deaf child and their whānau. The case studies presented in this research demonstrate that the inclusion of deaf children and their whānau within Māori and NZSL language communities is poorly facilitated, and in some instances actively discouraged, albeit for differing reasons. Underscoring whānau members’ final decisions to veer away from pursuing te reo Māori and NZSL options was the lack of first language users from these communities trained to work in professional roles which would support language acquisition. The potential contribution of members from these communities is two-fold: support with contextualizing and naturalizing language as well as offering mentoring support (to child and adult whānau members) to enhance the mana (self concept, competence and personal esteem) of the child through modelling deaf and/or Māori-centred communicative and social resiliency strategies. Within these language communities are multiple intergenerational experiences, knowledge of these experiences provide whānau with longitudinal insights into the child’s development and potential life trajectory. This, alongside contributions from professionals who facilitate the navigation of services and specialist forms of support (for example, and AODC or whānau ora provider), provides whānau with a sound

base for decision-making, and a base from which decisions can regularly be evaluated by whānau and professionals.

A *pā harakeke* approach to support also shares the basic tenets articulated in the evidence-based principles identified in the *international consensus statement of best practices in family-centred early intervention for children who are deaf or hard of hearing* Moeller et al. (2013:430) summarise a FCEI as “... based on explicit principles, validated practices and best available research while being respectful of family differences, choices and ways of doing things”. They also suggest FCEI is a “flexible, holistic process that recognizes families’ strengths and natural skills and supports development while promoting the following: (a) joyful, playful communicative interactions and overall enjoyment of parenting roles (b) family wellbeing (e.g. enjoyment of child, stable family relations, emotional availability, optimism about the child’s future), (c) engagement (active participation in program, informed choice, decision making, advocacy for child) and (d) self efficacy (competent and confident in parenting and promoting child’s development)”.

Returning to R. Bishop’s (2008b:157-158) employment of *whakawhanaungatanga* as a kaupapa Māori research approach, the concept of *whakawhanaungatanga* also underpins the nature of relationships between relevant groups within a *pā harakeke* approach. In the following explanation of the approach, he notes the connectedness of the groups is cemented through a long term commitment towards a shared purpose and direction. The process is discursive and emphasizes the mentorship of intergenerational expertise and knowledge – in this instance, this knowledge and expertise gained through research, and collective knowledge (community knowledge) gained through life experience. Both threads provide the evidence base for action and mentorship to whānau.

Whakawhanaungatanga is the process of establishing whānau (extended family) relationships, literally by means of identifying, through culturally appropriate means, your bodily linkage, your engagement, your connectedness, and, therefore an unspoken but implicit commitment to other people. ... Establishing and maintaining whānau relationships, which can either be literal or metaphoric within the discursive process that is Kaupapa Māori ...”

The social norms, in this thesis described as relational approaches, employed to facilitate whakawhanaungatanga have traditionally been founded on tikanga Māori (traditional values system unique to Māori) (H. M. Mead 2003). The case study examples showed that while whānau participants had foundational understanding of tikanga, the application of tikanga in everyday life was variable and context dependant – reflecting the social complexities facing Māori in modern-day contexts. Deciding upon a relational approach to establish relationships is a necessary skill for those wishing to partner with whānau yet this research demonstrates a scripted approach to building relationships may not necessarily have the desired effect due to the diversity of relational expectations amongst Māori. Macfarlane (2009:46) argues an understanding of how power is shared and balanced as well as an understanding of the principles of the Treaty of Waitangi (partnership, protection and participation) is essential to effective partnering and relational approaches. Dunst (2002:147) more specifically recommends practices associated with (a) good clinical skills (active listening, compassion, empathy, respect, being non-judgmental and (b) professional beliefs and attitudes toward families, especially around parenting capabilities and competencies. The cases presented in this research suggest that those working within these broad principles tend to employ relational approaches which lead to effective relationships and collaborative partnerships – perceived by whānau as whakawhanaungatanga. The approach used to identifying whānau expectations about relational approaches as a part of research process provides insights into the assessment required to develop an understanding of the contextual parameters of the whānau and how these may influence relational expectations, these include: Who are its members? Is there a hierarchy? How is the hierarchy structured and what is the nature of the relationships within? Where are the whānau members located geographically – does this have some bearing on the nature of relationships within the whānau? What are the roles of individuals and how do these shape their interactions? What are the educational and social experiences of the members and do these have some bearing on how they respond to information? What communities have the whānau been socialised in? How do the social and linguistic backgrounds of the membership influence relational expectations?

The proposed kaupapa Māori programme philosophy, *Te puawaitanga o ngā kōhungahunga tūri*, and approach to arrangement of supports and relationships within, *pā harakeke*, promotes the Treaty of Waitangi principles of *partnership, protection and participation* (Royal Commission on Social Policy 1988), the relational and participatory components of Dunst's (2002:147) recommended approach to family-centred early intervention, as well as the tenets

of the evidence-based principles identified in the *international consensus statement of best practices in family-centred early intervention for children who are deaf or hard of hearing* (Moeller et al. 2013) offer a differing lens to approaching the UNSHEIP.

Chapter 13. Conclusions

13.1. Consideration of the research questions

13.1.1. What shapes whānau perceptions of deafness in the early years?

Deafness and the deaf child were considered by whānau to be synonymous; the sensory experience of deafness accepted by whānau participants as a natural aspect of the deaf child's being, the lens from which their environment was perceived. This visual preference was a strengths-based view of the deaf child that remained post-introduction of EI supports and despite the various approaches employed to facilitate language learning. The onset of language learning (or lack of in some cases) prompted whānau members to perceive deafness in social terms. Whānau could see that through the experience of isolation from social and linguistic experiences, their child's development would be inhibited. Full participation in the life of the whānau, which hinged on the synchronous process of language learning and socialisation, was a critical aspiration held by whānau members who recognised that participation cemented a sense of belonging and identity to the whānau unit. It was for these reasons that all whānau wanted their child to access and acquire at least the spoken language of the household, typically English and/or te reo Māori. Visual language (NZSL) and communication strategies were recognised by whānau (to varying degrees) as being a natural approach to language learning for a deaf child, as it engages the innate visual orientation of the child, yet there were numerous challenges to facilitating this: the dearth of support for learning NZSL for the deaf child and wider whānau.

Experiences of engagement with professionals and supports within the EI sector were highly variable, yet in all instances these provided powerful frames of reference from which to shape a perspective on deafness. Four out of five cases presented in this research had intergenerational experiences of deaf people within the whānau. Observations of a deaf relative provided a single example which also influenced decision making during the EI period. Social disadvantages resulting from poor educational experiences and limited social participation in whānau settings fuelled whānau desire for improved educational experiences and socialisation experiences for their child in the whānau context. Professionals' opinions and perspectives were respected as

‘specialist views’ on deafness yet these were always mediated with personal knowledge of the deaf child that whānau members had gained through experience.

13.1.2. What are the early intervention experiences of whānau

This thesis presents a series of rich contextually situated cases to outline the early intervention experiences of five whānau, presented in chapters six to ten, exploring how these (1) Inform communication, language and relationships for the deaf child within the whānau and (2) How these shape whānau decision-making and opportunities.

As is the universal challenge, trying to support a deaf child’s language development was perhaps the most frustrating and complex aspect of raising a deaf child across the cases. As a general rule, whānau had a limited understanding of how deaf children develop and acquire language from which to make decisions and thus relied heavily on professional’s information and advice in this area. Though four of the whānau cases had known of intergenerational experiences of deafness, decision makers involved in raising the deaf child were not able to articulate a clear understanding of how deaf children developed and acquired language. Some merely observed previous generations of deaf people as having ongoing social barriers associated with language and communication. Due to the imperative of facilitating a strong first language during the early years of development, choices around language were often presented almost as static decisions. The case experiences show however that decisions around language need to be fluid and responsive to context. This was demonstrated across the cases, not necessarily because professionals did not support whānau aspirations around language, although in some cases this was clearly the situation, but because the pathway to reaching aspirations was not linear. For example, most whānau aspired for their child to acquire spoken Māori, yet given the dearth of support in this area, and the fact that most did not have a language model within the whānau context, they had to rely on an intervention such as kohanga reo and concluded this was not a sensible choice. Instead spoken English was decided upon as a first language, as it was the language of the household, endorsed by professionals as a sensible choice. What was not apparent to whānau however was that the route to language learning can take multiple paths, and aspirations for bilingualism, while currently poorly supported, were achievable if creative solutions and commitment were applied to reach this goal. Although all whānau involved in this research indicated a desire to support multilingualism they had no understanding of how to facilitate this in relation to neither NZSL nor te reo Māori.

13.1.3. Do the design and delivery of early intervention services and support systems for deaf children need to be adapted to be more effective for Māori? And if so, how?

This research suggests Māori goals and aspirations for their deaf child were not well supported by EI services and support systems, principally because their holistic perspectives of wellbeing and healthy development were not endorsed within the types of supports made available within the UNSHEIP and because the parent-professional model, which demotes the status of whānau and endorses professionals as experts, was most common, particularly in clinical settings. The policy endorsed family-centred approach, which is more collaborative in nature, was applied by a small number of professionals, yet in these instances this was applied to the context of whānau, a differing construct to family.

13.1.4. Recommendations: How do the design and delivery of early intervention services and support systems for deaf children need to be adapted to be more effective for Māori?

This research suggests a conceptual shift is required from the UNSHEIP to meet whānau aspirations for Māori deaf children. Chapter Twelve, Refocusing early intervention services for Māori: Ngā Kōhungahunga Turi offers the metaphor of the Pā harakeke to describe an alternative – more collaborative – way of organising supports around the deaf child and the whānau. In this approach the role of whānau with a deaf child, other deaf people (adults, children and wider whānau) and professionals within the UNHSEIP work collaboratively to meet the support the healthy development and wellbeing of the deaf child within the context of whānau. While a parent/family support network currently exists within New Zealand, the New Zealand Federation for deaf children, this group is structured as a parent support network and advocacy group, who works independently from the professional sector.

13.2. Ka puāwai ngā kōhungahunga turi

These conclusions formed the basis of the development of a post-doctoral research project, titled '*Ka puāwai ngā kōhungahunga turi*', funded by the Health Research Council. The overarching aim of the project is to contribute to an understanding of a whānau ora (a whānau-

centred approach to support which promotes holistic outcomes for deaf children and their whānau) approach to early intervention service for Māori deaf and hearing-impaired tamariki and their whānau. The research aims to undertake an examination of how exemplary EI programmes for deaf children within the United States of America, South Africa and Australia support indigenous populations and explore what implications their practice has for Māori in New Zealand. The study will employ whakawhanaungatanga as a kaupapa Māori approach to research, and thus will network Māori whānau with deaf children to develop Ngā Kōhungahunga Turi, a kaupapa whānau network of Māori with deaf children, professionals, providers and people with lived experience of deafness (including deaf adults). This network would actively participate in the research process (from consultation to advocacy) at all levels, in the interests of developing whānau expertise, capacity and advocacy.

Establishing Ngā Kōhungahunga Turi as a part of this post-doctoral research supports the operationalization of the pā harakeke model of organising supports. Most importantly, the networking activity identifies and networks whānau (an activity which has never been undertaken before) and invites them to participate in collaborative examination of how international practice in EI can inform approaches for Māori.

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Appendices

Appendix A

Māori deaf children and their whānau: A study of the nature and impacts of early intervention

• The Research

Māori children are over represented in the number of children diagnosed with hearing loss, and are often diagnosed at a later age than other children. The recent introduction of newborn screening for hearing loss in Aotearoa has now started in the hope that children (including Māori children) will be identified earlier and access early intervention services during the early years of their development. This PhD research aims to look at the nature and impact of early intervention services for Māori deaf children and their whānau how they can be most effective are for Māori.

• About the Researcher

Ko Maungahaumi te maunga
Ko Waipaoa te awa
Ko Repongaere te roto
Ko Te Whānau a Kai te hapu
Ko Te Aitanga a Mahaki te iwi
Ko Kirsten Smiler ahau

Tena koe, my name is Kirsten Smiler and I am a PhD student at the School of Linguistics and Applied Language Studies at Victoria University of Wellington. My interest in this area of research stems from personal and professional experiences. I am hearing, however both my mother and uncle are profoundly deaf and so I have been surrounded by deaf people all my life and used New Zealand Sign Language as a home language during my childhood. I also work as a Māori health researcher at Health Services Research Centre (also based at Victoria University of Wellington) where I have been involved in projects that examine how health services can contribute to an improvement in Māori health. This PhD will be supervised by Dr. Rachel McKee, Dr. David McKee and Associate Professor Jackie Cumming based at Victoria University of Wellington.

• Who will be involved?

A small number of whānau with Māori deaf children will also be asked to participate in the research process; their experiences will be the focus of final research report. I am interested in finding out about their experience of having a deaf pre-school child and hope to meet with these whānau several times over a one-year period to discuss how the early intervention process is going for them and their child.

Interviews will be also undertaken with 10 to 15 key professionals involved in the delivery of early intervention services. Professionals will be asked questions about how early intervention services are

currently being delivered in Aotearoa, what things are being done well, and what they think could be improved.

What to expect?

I will contact you to discuss whether you are interested in taking part in the study. I can meet with you to discuss and explain the research face-to-face if that is best for you.

Meetings with whānau of a Māori deaf child will be negotiated between myself and whānau. I will meet with whānau to gather information on their experiences; some discussions will be formal (interviews) and other meetings informal (for example, informal phone conversations, discussion over a cup of tea). The format of all meetings will be discussed and negotiated with whānau.

Professionals will be asked to participate in an interview with me. Interviews are fairly informal and will take approximately one to two hours of your time.

I will arrange to come and meet you at a place and time that best suits you.

You can choose to use te reo Māori, English or New Zealand Sign Language during interviews. We can use whatever language best suits you. If you do require or prefer to have a professional interpreter, I will organise and fund this.

You will be asked to show that you agree to being interviewed for the research. You will be asked to sign a form showing you agree to being interviewed (a consent form). This document provides evidence that you have agreed to participate in the research. For those who prefer to use New Zealand Sign language during interviews you can also show you have agreed by signing a statement on video camera. This will provide a record that you have agreed.

With your permission, our discussion could be recorded using either an audio recorder or video camera (for example, for users of New Zealand Sign Language). This is to help the researcher remember what you have said.

Your participation is entirely your choice. You do not have to answer all the questions I ask you and you may stop the interview at any time. You are also free to withdraw from the study at any time without having to give a reason and without repercussions.

You may bring a support person or people of your choice to the interview.

• What happens to the information I give?

I will analyse the information and this will form the basis of my PhD thesis (a written report).

The recordings (audio and video) will be transcribed (written up) and held in a secure location (at the Health Services Research Centre at Victoria University of Wellington). After five years, this information will be destroyed. The only people who will see this information will be myself, and my supervisors. If you choose I can send you copies of transcripts from recorded interviews.

Many people who participate in research like to have what they say remain anonymous (unidentifiable). These people often like to use a Pseudonym (a fake name) instead of their real name in the research report so they can't be identified. Others prefer to be more open and don't mind have their identity revealed in research reports. You can choose what best suits you and we can discuss these options.

- **What happens after the study is finished?**

You will be invited to come to an open hui where I will present the findings of the research. It is likely that whānau, professionals and people within Māori and Deaf communities will attend this hui. It will provide an opportunity for you to ask questions and make comments about the findings of the research.

Findings will also be made available to relevant agencies (government and Non Government Organisations) involved in early intervention services for deaf children.

The Research team

Kirsten Smiler

Māori Research Fellow, Health Services Research Centre, School of Government, Victoria University of Wellington.

Dr. Rachel McKee

Senior Lecturer, Deaf Studies Research Unit, School of Linguistics and Applied Language Studies, Victoria University of Wellington

Dr. David McKee

Senior Lecturer and Director, Deaf Studies Research Unit, School of Linguistics and Applied Language Studies, Victoria University of Wellington

Assoc Professor Jackie Cumming

Director Health Services Research Centre, School of Government, Victoria University of Wellington

Contacts

- **Kirsten Smiler**

Health Services Research Centre
School of Government
Victoria University of Wellington
PO Box 600
Wellington 6140
Email: kirsten.smiler@vuw.ac.nz
Phone (04) 463 6522

- **Rachel McKee**

Deaf Studies Research Unit
School of Linguistics and Applied Language Studies
Victoria University of Wellington
PO Box 600
Wellington 6140
Email: rachel.mckee@vuw.ac.nz
Phone: (04) 463 5640

Participant Information

This project has been approved by Multi-region Ethics Committee, which reviews national and Multi-regional studies; Ethics Reference MEC/10/01/011

If you have any concerns or unanswered questions regarding your rights as a participant in this project, you may want to contact an independent Health and Disability Advocate: free phone 0800 555 050; free fax 08002SUPPORT (0800 27877678).

Appendix B

Whakawhānauanga 2010
Whakawhānauanga 2010

Aro Ha Mamaku

WHAKAWHANAUNGATANGA 2010

ARO HA MAMAKU
he pāpā, he pāpā, he pāpā

Aro Ha Mamaku is made up of parents and individuals who share a common theme: they have children or have members in their family who are hearing impaired.

They have come together out of a need and desire to help others navigate through the multitude of organisations and agencies to manage the care of their hearing impaired child or other whānau member, while managing a stable home life and ensuring that other members of their whānau do not miss out on the care and attention.

ARO HA MAMAKU
Charlotte Cassidy, Edinburgh Street, TŌKOROA 3420
Tel: 07 556 5915 Mob: 027 752 8940

Papa o Te Aroha Marae,
Mossops Road
Tōkoros
6-7 May 2010

Whakawhānauanga 2010
Whakawhānauanga 2010

KAUPAPA / OBJECTIVE

We've all experienced the frustration of dealing with a number of agencies to get the basic services provided for our tamariki. It's even harder when one, some, or all of our tamariki are hearing impaired.

Aro Ha Mamaku Whakawhānauanga (Gathering) 2010 is an opportunity to meet other parents who are in the same boat, learning practical ways to help ourselves in the home and introducing our children to other children with the same learning and socialising issues.

This is not an opportunity to moan! It is an opportunity to meet others who have had the same experiences, and perhaps get a few tips on where or how we can find further support, particularly if we live in a rural area and do not have immediate access to these services.

We hope that Gathering 2010 will allow families to network with each other, meet representatives from relevant agencies for whānau with hearing impaired children, and support and enable each other to navigate through a system heavily weighed down with form filling, phone calls and emails!

COSTS

To attend Gathering 2010, there is no cost for whānau. However, if you wish to give a koha on behalf of your whānau, that would be appreciated.

ACCOMMODATION / MEALS

Accommodation and meals at Papa o Te Aroha Marae. Please bring your own blankets and towels. Other bed linen will be provided. If you have special dietary needs, please inform when registering, or to be safe, bring your own requirements.

If you wish to stay off site, this cost will need to be met by you at your own cost.

T-SHIRTS

All tamariki attending will receive a free t-shirt as part of their participation. Please ensure you list their correct size when registering.

REGISTRATION (main contact person)

NAME	
POSTAL ADDRESS	
CONTACT PHONE	
CONTACT EMAIL	
NUMBER ATTENDING	

NAME	ADULT / CHILD	T-SHIRT SIZE

PLEASE NOTE: Registrations closed 28 April 2010. You must register by this time to ensure a place in the workshops and accommodation at the marae.

Whakawhānau Tangata (Gathering) 2010 is an opportunity for parents and families of hearing impaired children to find out more about services available to them and for their tamariki to meet others with the same diagnosis.

TIME	DAY 1 Thursday 6 May 2010
9.30am	Gather outside front gate, Papa Te Arahi Marae, Moscop Road, Tokoroa
10.00am	Official welcome to Aro Ha Marama Gathering 2010
11.00am	Light refreshments
11.15am	Settling in, bedding. All tamariki attending depart by bus for Nature Walk. Packed lunches will be provided. This will free up time for workshops for parent.
11.30am	KEYNOTE SPEAKER Noeline Kuru and Estelle Barlow
12.15pm	LUNCH
1.00pm	WORKSHOP 1 Identifying and prioritising key issues for hearing impaired children. Facilitated by Te Raranga Eian
	WORKSHOP 2 Building our power - diverse experiences in the community. Facilitated by Dolly Flude
	WORKSHOP 3 Whānau and Action! Facilitated by Sharon Clair
2.00pm	Workshop feedback and discussions
3.00pm	AFTERNOON TEA

TIME	DAY 1 CONTINUED
3.30pm	Spare time - by this time your tamariki would have returned from their action packed activities
6.00pm	KAI A TE PO / DINNER
8.30pm	Settling in for the evening. KEYNOTE SPEAKER Kingi Biddle Karaoke for the night

TIME	DAY 2 Friday 7 May 2010
6.30am	Karaoke
7.30am	BREAKFAST
8.30am	Gather for photos at the front of the Marae
9.30am	Organised activities for Tamariki at sports ground across the road Pack up bedding and clean up
10.00am	KEYNOTE SPEAKER Hon. Tariana Turia
10.30am	Parent discussion time around services, issues arising, networking.
12.30pm	LUNCH
2.00pm	Karaoke and final farewells

SPEAKERS AND FACILITATORS

Noeline Kuru

In 2008 Noeline completed a diploma in Maori Mental Health. She currently works for Tūwharetoa Health Services in Taupo, is a strong advocate for Like Minds Like Mine and has three children.

Estelle Barlow

Programme Manager and Auditory-Verbal Therapist
Cert. A.V.T. B.Ed (Hons), Adv. Post Grad Dip HI, Adv. Post Grad Dip SpEd, Post Grad Dip Mgmt of Specialist Centre
Estelle qualified as a teacher in 1974. Her teaching experience has been in the UK, Germany and Hong Kong. Following the births of her three children, one of whom is profoundly deaf, she returned to teaching with a post graduate qualification in Hearing Impairment. Estelle is currently a Certified Auditory-Verbal Therapist and the Programme Manager at The Hearing House in Auckland.

Sharon Clair (Ngāti Raukawa, Ngāti Rangihū, Scottish)

Sharon Clair has a background in nursing and health. She was the very first Maori woman to speak to the plenary of the United Nations International Labour Organisation (ILO) conference, at its 95th session in 2006. As a union activist, political commentator

and advocate on Maori worker interests Sharon runs her own consultancy, Whakatoa Limited in Wellington.

Kingi Biddle (Ngāti Whakaue, Te Arawa)

Kingi has an extensive background in broadcasting starting at Radio Te Arawa OF. He has worked at Māi FM, Aotearoa Radio, Raukawa FM, Pūrenawa FM and Rūa Māi. And presented Māori Television's inaugural quiz show 'Mind Your Mohio and Kai Time'.

Charlotte Cassidy (Ngāti Raukawa, Ngāti Te Rangi, Maniapoto)

Charlotte started Aro Ha Marama as a parent who uses many services in the Education and Health Systems in Aotearoa today. Charlotte lives in Tokoroa with her husband and four beautiful children, two of whom have a hearing disability.

Hon Tariana Turia

The Hon Tariana Turia has had a long and active history on Māori iwi Development, especially in the areas of health, employment and education. She is currently Co-Leader of the Māori Party. She is married to Hori and has six children and many mokopuna.

SPONSORS AND SPECIAL THANKS

Thank you to the following organisations and individuals for your support of this event.

And a special thanks to:

Ernie Nkoro

Te Hihiko Des Forges

Te Raranga Eian

Dolly Flude

Kelston Deaf Education Centre

Papa o Te Arahi Marae

Te Whānau Moko o Aotearoa

The MANY volunteers who helped with the event

Appendix C

Māori deaf children and their whānau: a study of the nature and impact of early intervention

Semi structured interview guide for whānau of Māori deaf children

First interview

Section one: Whakawhanaungatanga, nga mihimihi

Start with wider background context: whānau, whakapapa, common interests etc, like 'tell me about your family – how many kids, which is the deaf child, family roles (who works? Who is primary caregiver?), any other deaf people in the family?

Diagnosis

Can you describe your experiences with how your child was diagnosed with deafness/hearing loss?

PROBES (use non-technical language: “tell me about how and when you found out your child was deaf/had a hearing problem”)

- *How old where they*
- *Where were they diagnosed? How were they diagnosed?*
- *What was your initial response and feelings?*
- *How do you feel about your child being deaf?*
- *What professionals were involved? How was this experience for you?*
- *What types of information were you given?*
- *How useful was this information?*
- *What types of initial support did you receive? How did you find the support?*

Access to intervention services?

Can you describe your child's and whānau experiences of early intervention services so far?

PROBES:

- *How did you find out about early intervention services?*
- *What do you know about what types of early intervention services are available to your child and whānau?*
- *What types of services have you been able to access so far?*
- *How have you found these services?*
- *Can these services make any improvements?*
- *What types of professionals have you found work well and not so well with you and your whānau? Why?*
- *What has been the biggest challenge so far in having a deaf child?*
- *What/who has been the main source of information & support so far?*

Second Interview

This interview has a dual purpose. Firstly, the interview will begin with asking for an update on whānau experiences of early interventions services since the first interview, to recap what they told the first time, to give them opportunity to reflect on that, possibly enrich or affirm their account (after thinking about it in the interim). Secondly, it focuses on identifying what outcomes parents are seeking for their child. The researcher will use both a semi-structured interview technique and another ‘projection technique’ where participants will be asked to reflect on what they believe makes a happy and well deaf child. Participants might be asked visually map these ideas.

Section one of interview #2 Update on experiences of early intervention services

- *Have you found out anything new about early intervention services since the last interview?*
- *What sorts of changes have you seen in your child since (diagnosis/last interview)?*
- *Have you had any engagement with professionals or services since the last interview? How have you found these? Specific/concrete descriptions of interactions. “Tell me about your last visit with the Advisor/ Audiologist/Pre-school. What did you talk about, how did it go?*
- *Can these services make any improvements?*
- *What types of professionals have you found work well and not so well with you and your whānau? Why?*
- *Contact with other families of deaf children – how much? How? Value?*
- *Had you met deaf/HI people before you had a deaf child? What was that experience like?*
- *Have you made the type of progress you had hoped for your child?*

Section two of interview # 2 Questions about what a happy and well deaf child looks like at age 5

- *Visual mapping (or brainstorming) of what they visualise a well and happy child to be like.*

Third Interview

This interview focuses on collecting an update of experiences of the early intervention services so far, and questions surrounding how parents’ confidence and competence in raising a deaf child.

Update on experiences of early intervention services

PROBES:

- *Have you found out anything new about early intervention services since the last interview?*
- *What sorts of changes have you seen in your child since the last interview?*
- *Have you had any engagement with professionals or services since the last interview? How have you found these?*

- *Can these services make any improvements?*
- *What types of professionals have you found work well and not so well with you and your whānau? Why?*
- *Have you made the type of progress you had hoped for your child?*

Questions about whānau confidence and competence in parenting?

PROBES:

- *Now that it has been one year since the first year, how confident are you feeling about parenting your child?*
- *What are some of the things that you are doing well/not so well?*
- *How do you think early intervention services can help support you to develop and maintain confidence in parenting?*
- *Do you think the services available to you will help you support you to confidently parent? Why/Why not?*
- *Have you had contact with deaf/HI people since having a deaf child? What was that like, how did it affect you? If no, would you like to?*
- *How do you feel about your child being deaf after his pone year period? Has your thinking changed? Why?/Why not?*
- *What future goals does your whānau have for your child? How do you think your will achieve them?*
- *What do you see for the child's future education – kind of schooling, what support do you think they might need?*

Projection/reflection question? *Can you describe what you think is a good way of informing and supporting whānau during this process?*

Appendix D

Māori deaf children and their whānau: A study of the nature and impact of early intervention

Semi-structured interview guide for key informants

Whakawhanaungatanga, nga mihimihi

Information about key informant's professional background

- *Can you describe the role you play in the service/organisation you work for?*
- *How did you become involved in this role?*
- *What qualifications and/or experience led you to this role?*
- *Would you like to develop your career further within this organization or area of service? Why?*

Processes around the implementation of services

- *What are the wider goals of the organisation/service?*
- *What are the intended outcomes of the organisation/service?*
- *What are the unintended outcomes organisation/service?*
- *What are the procedures/description of services carried out by the organisation/service?*
- *What resources does the organisation use to implement their services?*
- *Are these resources sufficient?*

What is the context in which services are being implemented?

1. Can you tell us about the population you serve? Who are they? How are they identified? Have there been any changes in local demographics which have influenced how you deliver services?

- *What is the **local context** with which you deliver your services?*

2. Can you describe how services are delivered within your organisation?

- *What is the **operational context** in which services are being implemented?*

3. What are some of the key policies influencing the way your services are being implemented? (For example, SE 2000, the passing of New Zealand Sign Language ACT 2006, implementation of newborn screening, NZ Disability Strategy, He Korowai Organa, Whānau Ora, Special Education Review, deaf discussion document.

- *What is the **political context** in which services are being implemented?*

4. What are some of the organisations key strategies? What are the key strategies (for example government, NGO strategies) that influence (directly or indirectly) the way services are being implemented? What are some of the organisations key strategies?

- *What is the **strategic context** in which services are being implemented?*

4. What are some of the underlying values and philosophies that underpin your organisation?

➤ What is the **cultural context** in which services are being implemented?

5. What are some of wider economic influences that have impacted on your service? (*For example, what is the impact of the recession?*)

➤ What is the **economic context** in which services are being implemented?

Focus on Māori

1. Does your organisation have any specific policy, practice protocols, training relating to provision of service to/interaction with Māori?

2. What are the risks and barriers does your organisation experience in trying to deliver support to Māori deaf children and their whānau?

3. What are the risks and barriers for Māori deaf children and their whānau for receiving support from your organisation?

4. What type of impact does your organisation have on deaf Māori children and their whānau? How does your organisation measure or evaluate impacts?

5. What direction do you think your organisation should take into the future? Why? Generally speaking and in relation to Māori?

6. Do you think your organisation could make any improvements?

7. Do you have any further comments regarding the delivery of services to Māori deaf children and their whānau?

Appendix E

Māori deaf children and their whānau: A study of the nature and impacts of early intervention

Consent form for interview

I agree to take part in an interview, and:

- I understand the information material supplied explaining the project;
- I have had the research explained to me in a language I understand (for example, New Zealand Sign Language or te reo Māori)
- I am providing consent on behalf of my child/ren;
- I can withdraw from the interview at any time;
- I can withdraw my information at any time;
- The interview will be recorded, and written up;
- The recording, notes and transcript will be kept in a locked file, which will be seen, by Kirsten Smiler and her supervisors. The notes and recording will be destroyed five years after the conclusion of the research;
- If I want, I will be sent a copy of my transcript or notes and asked to return them with any corrections or changes I wish to make;
- I have had a chance to ask questions about the research and the interview, and these have been answered to my satisfaction.

Please indicate if you would like to remain anonymous in the PhD and in any presentations done reporting the research findings:

I would like to remain anonymous - (I do not want to use my real name)
Yes / No

OR

I would like to use my real name in the PhD and in any presentations reporting the research findings
Yes/No

I know that if I have any further questions at any stage I can contact Kirsten Smiler on 463 6522 or email her at kirsten.smiler@vuw.ac.nz

Signature.....

Name (please print)

Date

Address.....

Email.....

Phone/fax/mobile.....

Appendix F

Multi-region Ethics Committee

Ministry of Health
133 Molesworth Street
PO Box 5013
Wellington 6145
Phone (04) 470 0655
(04) 470 0646
Fax (04) 496 2340
Email: multiregion_ethicscommittee@moh.govt.nz

23 February 2010

Kirsten Smiler
Health Services Research Centre
Victoria University of Wellington
PO Box 600
Wellington

Dear Kirsten

Ethics ref: **MEC/10/01/011**
Study title: Māori deaf children and their whānau: A study of the nature and impacts of early intervention
Investigators: Kirsten Smiler, Rachel McKee, Dr Jackie Cumming
Localities: Victoria University of Wellington

The above study has been given ethical approval by the Multi-region Ethics Committee.

Approved Documents:

- Semi-structured interview guide for Whanau of Maori Deaf Children
- Semi-structured interview guide for Key Informants
- Consent Form for Interview
- Information Sheet

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.

Progress Reports

The study is approved until **23 February 2014**. The Committee will review the approved application annually and notify the Principal Investigator if it withdraws approval. It is the Principal Investigator's responsibility to forward a progress report covering all sites prior to ethical review of the project in **February 2011**. The report form is available at <http://www.ethicscommittees.health.govt.nz>. Please note that failure to provide a progress report may result in the withdrawal of ethical approval. A final report is also required at the conclusion of the study.

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.

We wish you well with your study.

Yours sincerely

A handwritten signature in black ink, consisting of several loops and a long horizontal stroke extending to the right.

Annisha Vasutavan
Administrator
Multi-region

Email: annisha_vasutavan@moh.govt.nz