He Kiteka Hauā i Murihiku

Perspectives of disability and wellness of hauā Māori living in Murihiku

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ABSTRACT

Disability is of considerable concern for Māori as they are over represented in this area and have more severe disabilities than the non-Māori population in Aotearoa/New Zealand. Whilst many initiatives have been put forward to facilitate access to disability services, utilisation of services remains proportionately low for hauā Māori (Māori living with disability) despite their experiencing a higher incidence of multiple disabilities. This poor uptake of services indicates the need for targeted research to assess Māori experiences and viewpoints of disability, in order to better understand how to deliver relevant services for hauā Māori and their whānau (families). Given the prevalence of disability within the Māori population, it is also interesting to note the concept of ‘disability’ is largely non-existent within Te Ao Māori (Māori world-views) and in recent literature. Investigating the impact of disability for Māori and their whānau, more specifically Māori perceptions of ‘disability’ (MOH, 2011), has been identified as a research priority by Māori whānau living with disability.

In 2012, a collaborative study, Hauā Mana Māori, was conducted to explore, accessibility issues for hauā Māori and their whānau. This thesis reviews the qualitative component within this project that explicitly explored hauā Māori perspectives of disability and health and also aims to present the effective data collection techniques developed to perform disability research within this community. This study was guided by Kaupapa Māori Research (KMR) methodology, using philosophies steeped in tikaka Māori (Māori culture), Whānau Ora (community wellbeing) and hauora Māori (Māori health) ideologies. This process was largely informed by a group of hauā Māori living in Murihiku, Rōpū Kaiārahi (leadership group), to ensure the methods used were relevant and empowering to hauā Māori. Thirty hauā Māori living in Southern Aotearoa/New Zealand were interviewed using the data collection instrument, the Whakāro Pōkare Visual Tool, and the findings from thematic analysis are presented within.
Common themes of wellness for *hauā Māori* interviewed included feeling valued, being connected to community, having a strong sense of self and self-worth, having access to determinants of health and having a positive approach towards physical health. Conversely, frequently referred to themes within perspectives of disability comprised of being undervalued, feeling disconnected, a low self-esteem, limited access to resources and poor physical health.

A noteworthy finding was that many *hauā Māori* do not consider a physical limitation a disability, and are therefore not *whakamā* (embarrassed) to openly discuss issues that non-\(^{Māori}\) tend to avoid. This attitude revealed a cultural dissonance, between \(^{Māori}\) and non-\(^{Māori}\) views on disability and pointed to a preference of \(^{Māori}\) perspectives of acceptance for the *hauā Māori* interviewed.

Lastly, being guided by KMR principles allowed for relevant research process to be established leading to the development of an appropriate qualitative data collection instrument, the *Whakāro Pōkare* Visual tool. This tool enabled the qualitative research to successfully collect voices of *hauā Māori*. Participants reported beneficial outcomes from being interviewed using the data collection tool. Future research investigating the potential for utilisation within the clinical setting is suggested.
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I would especially like to acknowledge members of my whānau who have been incredibly patient and my best advocates including; my loving partner, Malcolm Dacker, and my children William, Kate and Ariana, my Mother and Father; Marg and Bob Bryant, and Ro Todd, Erica Todd, Bill Dacker, Winsome Aroha.

Next I would like to acknowledge the people that were close to me throughout this research journey including: Kelly Tikao (my dear friend), members of the Rōpū Kaiārahi, and all of the participants from Murihiku, Awarua Rūnaka, Waihōpai Rūnaka, Hōkonui Rūnaka, and Īraka Aparima Rūnaka, Ngā Kete Mātauranga Pounamu Charitable Trust, Tracey Wright-Tawha, Melanie Reed, Donald Beasley, Brigit Mirfin-Veitch, Tōmairangi Marae, Awarua Whānau Services, Professor Steve Milosalvjevic.

I would like to extend my sincere thanks and appreciation to my supervisors, Professor Leigh Hale and Dr Jim Williams for their enthusiasm, encouragement, and guidance of the research and towards the completion of this thesis.

I also wish to acknowledge the New Zealand Ministry of Health (MOH) and Health Research Council (HRC) for funding the Hauā Mana Māori project, University of Otago School of Physiotherapy for their continued support, and University of Otago Scholarships for office for accepting to support me with a Māori Post graduate study scholarship, all which have assisted me immensely through my Masters journey.

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He iti, he Pounamu.
CHAPTER 1- INTRODUCTION

I begin this chapter by explaining the background to my Masters thesis, a thesis that was embedded in a larger project funded by the HRC and the MOH of New Zealand. In this background section I introduce the larger research group members and the individuals with whom we consulted. This background provides the basis for the aims of my thesis. I then review the philosophies and concepts underpinning my work. I begin by introducing some Māori paradigms of health and traditional Māori views of disability. From there I review present day qualitative data and demonstrate that disparities for hauā Māori are considerable in spite of founding documents and key strategies. Research priorities to address these disparities are highlighted. Amongst these significances is to explore how Māori view disability and wellness, which concerns with the principle aim of this thesis.

Kāi Tahu dialect of Te Reo Māori/ Māori language is used throughout this thesis and is italicised. The reader is advised to refer to the glossary of Māori words at the end of this thesis for reference if requiring simple translations. Commonly Kāi Tahu dialect defers from other Māori dialects in that where many kupu/ words, ‘ng’ is replaced by a soft ‘k’. For example the kupu ‘rangitira’ for many Kāi Tahu descendants would be ‘rakitira’. I wish to acknowledge that providing brief translation of Māori terms and ideologies, can lead to a superficial understanding of concepts integral in Māori world-views. I recognise also that these terms and ideas are more fully understood by experience, which provides the deeper context than is allowed within the confines of this thesis, especially when relating to fundamental foundations of how Māori view the world.

HAUĀ MANA MĀORI

In 2009, a Māori health provider based in Murihiku/Southland, Ngā Kete Mātauranga Pounamu Charitable Trust (NKMPCT), contacted the University of Otago School of Physiotherapy, (where the author and supervisors are employed). Ngā Kete Mātauranga Pounamu Charitable Trust stated the organisation wanted to broaden their understanding of the needs of Māori in their catchment. The Whānau Ora collective called Te Pōhā Oranga (Ngā Kete
Mātauranga Pounamu Charitable Trust and Te Rūnaka of Awarua were, at that time, running community consultation *hui* (meetings) in the Murihiku area. They were eager to find out what the community felt about access to health services and health concerns currently facing the community and were interested in developing their research capacity.

This coincided with the New Zealand MOH and HRC promoting a joint research Request for Proposal (RFP), *Māori Health Joint Venture: Māori living with disability and their whānau*, to investigate accessibility to disability services by Māori living with disability and their whānau.

The School of Physiotherapy in conjunction with the Donald Beasley Institute and Ngā Kete Mātauranga Pounamu Charitable Trust responded to this RFP, and were granted approval for funding from the MOH and HRC to complete a project, titled *Hauā Mana Māori*, addressing Māori living with disability and their whānau and their use of disability services.

Principal organisations and members of the *Hauā Mana Māori* research team included:

1. *Ngā Kete Mātauranga Pounamu* Charitable Trust is a not-for-profit, *mana whenua* (local Māori authority status), *kaupapa Māori* (Māori centred) health and social service provider, serving the Murihiku/Southland community for 11 years. Their service includes; providing disability information and advocacy, *Māori* led health promotion, smoking cessation, *Māori* mobile nursing, *Whānau ora* (healthy families) services, and amongst much more. Forty-eight staff are employed, and a majority (98%) are *Māori*, and they provide services to a client base of more than 3,000 clients. The NKMPCT have offices based in Invercargill and Queenstown and extend a *Whānau Ora* inspired service delivery within the Southern District Health Board boundaries. NKMPCT mission is to ‘Connect Whānau to resources, Ideas and Energy for Wellbeing and Independence’. Values that personify the agency are upheld in a phrase *Aroha ki te Takata* – having the highest regard for the wellbeing and welfare of mankind.

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1 “Rūnaka” is a Kāi Tahu word for the governing council or administrative group of a Māori Hapū (sub tribe) or *Iwi* (Tribe).
Tracey Wright-Tawha (CEO), Melanie Reed (General Manager), and Sandra Stiles (Disability Advocate) were all central links and the connections and input from NKMPCT proved to be imperative to this research. Murihiku is the community and population that NKMPCT operate within, and NKMPCT has a relationship with Oraka Aparima Rūnaka who provides a manawhenua mandate over NKMPCT. It was important to the whānau involved to have familiar, safe, local faces connected to the research, and therefore NKMPCT were integrally involved throughout the entire research process and the project relied heavily on the guidance of the NKMPCT around kawa and tikaka for their community.

2. **Donald Beasley Institute, Dunedin** is a non-profit organisation whose main function is conducting quality disability research to advance the health and wellbeing of those living with disabilities. Dr Brigit Mirfin-Veitch (Director) has been involved in research and education in the area of Intellectual Disability (ID) for 18 years and is recognised internationally as having expertise in health and health education for people with ID. She is an experienced qualitative researcher and has a strong commitment to ensuring that disabled people, their families/whānau and supporters, and the disability service sector all have a voice within and through research. Brigit was one of the principal investigators of the *Hauā Mana Māori* project.

Kelly Tikao, (*Kairakihau Māori / Māori Researcher*) of Kā Tahu iwi (tribe) descent, is a registered nurse and was employed by the Donald Beasley Institute, and was primarily involved in informing and leading *Kaupapa Māori* qualitative research. She is presently studying for her doctoral degree, exploring traditional Māori child birthing practices.

3. **University of Otago School of Physiotherapy/Te Wananga o Otago Kura o Komiri Pai.** A core team was identified, namely Professor Leigh Hale, Professor Stephen Milosaljevic (two principal investigators of *Hauā Mana Māori* project), and Katrina Anne Pōtiki Bryant (*Kaiārahi Māori* and Master’s student).

Professor Leigh Hale (Dean, *School of Physiotherapy/Kura o Komiri Pai*) is an internationally recognised physiotherapy disability and rehabilitation
researcher who has successfully led many studies and all her peer-reviewed publications are linked with disability and rehabilitation. Leigh has a close working relationship with the disability community in Otago and Southland.

Professor Stephan Milosavljevic, presently Director at University of Saskatchewan School of Physical Therapy, Saskatoon, Canada, was at the time of this project, an Associate Professor in the University of Otago School of Physiotherapy / Kura o Komiri Pai. Stephan is an experienced researcher in clinical and community-based research focusing on identification of injury risk and prevention, effective rehabilitation strategies, rural ergonomics, and occupational biomechanics. Stephan has close relationships with local rural communities and is highly regarded in Otago and Southland communities; in particular Stephan has undertaken extensive research with sheep shearers, many of whom are Māori.

4. **Kairakahau Māori (and author of this thesis).** Katrina Anne Potiki Bryant, (Waitaha, Kati Mamoe, Kai Tahu, Kaiarahi Māori, BPhty).

Ko Pukekura te mauka

Ko Taieri te awa

Ko Takitimu te waka

Ko Waitaha, Kāti Mamoe, Kāi Tahu kā iwi

Ko Kāi Te Ruahikihiki, Kāti Taoka kā hapū

Ko Ōtākou te Marae

Ko Wiremu Potiki te tupuna

Ko Katrina Potiki Bryant tōku ikoa

Katrina is of Kāi Tahu iwi descent with strong affiliations to Ōtākou Rūnaka. She is a Physiotherapist with special interest in providing relevant physiotherapy services to Māori and cultural competency and has worked at the School of Physiotherapy as Kaiarahi Māori since 2005. This Masters thesis is intended to be the beginning of a research career addressing participation of Māori in physiotherapy and health.
5. **Research Advisory Group** This group comprised people who were approached to be part of an advisory group given their expertise in research areas specific to this research:

- Dr Sue Crengle (descendant of Waitaha, Kāti Mamoe, Kāi Tahu, Senior Lecturer and Director of Tōmaiora Māori Health Research Centre, Te Kupenga Hauora Māori, Faculty of Medical and Health Sciences, the University of Auckland) holds specialty qualifications in general practice and public health medicine. She has worked as a Senior Advisor in the MOH for 12 months and is presently working as a senior Māori health researcher who has undertaken *Kaupapa Māori Research* (KMR) using both qualitative and quantitative methods. Dr Crengle is from the Oraka-Aparima Rūnaka in the Murihiku area. Sue was an advisor on the *Hauā Mana Māori* project.

- Donna-Rose McKay (Director of Disability Information and Support Services, University of Otago) was asked to guide this research at multiple points throughout, given her expert advice on issues pertaining to disability.

- Dr Jim Williams (Senior lecturer, Māori researcher, University of Otago Te Tumu/Department of Māori Pacific and Indigenous Studies), has a great knowledge of Kai Tahu iwi whakapapa and history, and is also one of the supervisors for this thesis.

Others that were consulted throughout the research process and contributed valuable advice and knowledge, informing the research, included:

- Jo Kingi (Public Health South) who has performed research looking at Māori concepts of disability.

- Dr Emma Wyeth (Director of Te Rōpū Rangahau Hauora Māori o Ngāi Tahu (Ngāi Tahu Māori Health Research Unit) who is a senior Lecturer in Māori Health, Department of Preventive and Social Medicine. Emma has a range of research interests within the field of *hauora Māori* (Māori health) and is also from the Murihiku area.

- Maui Hudson (Whakatohea, Nga Ruahine, Te Mahurehure, Research Developer, University of Waikato) has an interest in developing and promoting *Te Ao Māori* perspectives within ethical considerations in research.
- Associate Professor Joanne Baxter (Associate Dean Māori Dunedin School of Medicine, Associate Dean Māori Division of Health Sciences, Director of the Māori Health Workforce Development Unit, University of Otago).
- Edward Ellison, Chairman of Kai Tahu ki Otago (KTKO), Kaumātua o Ōtākou (elder leader of Ōtākou).
- Mark Brunton/ Ngāi Tahu Research Consultation, (Kaitakawaenga Rangahau Māori/Facilitator Research Māori, Office of Māori Development, University of Otago.)
- Dr Tom Shakespeare (Senior Lecturer, Norwich Medical School, Norwich England, Disability researcher). Research has included exploration of conceptualisations of disability.

6. **Rōpū Kaiārahi (Participant Advisory Group):** Incorporating KMR methodologies, in order to best guide Māori disability research it is essential to include members of the hauā Māori population that are involved as participants, who identify interest in informing and directing the research process, with the intention of the research being meaningful and relevant to the research population. This is further described later.

The named researchers were chosen for this study for their expertise in disability, Kaupapa Māori, rural, qualitative, and participatory action research. Ngā Kete Mātauranga Pounamu Charitable Trust and Kairakahau Māori provided advice and guidance to ensure the research was embedded in a hauora Māori world-views. The Rōpū Kaiārahi input allowed this research to be relevant, specific, and responsible to the research participant population.

A central theme was agreed upon for the project; providing a deeper understanding of what enhances hauā Māori access to support, wellbeing, and living their enriched lives. “Hauā Mana Māori - living unique and enriched lives” was the descriptive phrase developed by the research team to incorporate the main theme and it was established that this would be an appropriate title for the research project as a whole.

The project had a three-pronged approach-

- **Study 1:** Organisational postal survey of accessibility using a structured questionnaire
Study 3: Qualitative investigation, interviewing Māori living with disability and their whānau, underpinned by the principles of a kaupapa Māori research approach.

Whilst the larger research project was addressing disability service accessibility issues for Māori living with disability it was felt important, to gain awareness of particular needs of service provision successfully, to look specifically at how hauā Māori view ‘disability’. This was performed in the qualitative research element of the broader study, Study 3.

Before we could commence the collection of data it was identified that we required development of an appropriate tool that was capable of accurately collecting perspectives within a Southern Māori context.

I was intimately involved in framing the research project, developing the research questions, methods, tool for data collection used, and the undertaking of the in-depth interviews, alongside the greater research team, of special note is the other Kairakahau Māori, Kelly Tikao. I primarily conducted the analysis, results and discussion sections around the qualitative section of the Hauā Mana Māori research project, and this work is presented within this Masters thesis; He Kiteka Hauā i Murihiku- Perspectives of disability of hauā Māori living in Murihiku.

AIMS OF THE MASTERS THESIS

My Masters thesis therefore had two aims:

1. The primary aim was to present hauā Māori perspectives of wellness and disability within a southern Māori context.
2. A secondary aim was to develop an appropriate research framework to collect data relevant to perspectives of wellness and disability for Māori living with disability and their whānau.
MĀORI CONCEPTS OF HEALTH AND DISABILITY

To provide reference for perspectives incorporated within this thesis it was felt imperative to first present Māori world-views attached to both health and disability.

Hauora Māori (Māori Health) Paradigms

Māori philosophies of health are often described as a more holistic approach to that of the non-Māori, mainstream population (Ratima K and Ratima M, 2007). Traditionally health (and illness) was viewed as largely influenced by the delicate balance of ‘tapu’ and ‘noa’, an involved Māori society order (or law) system maintained by principles rather than rules, which is central and intertwined throughout te Ao Māori (the Māori world view) (Sachdev, 1989; Cram, Smith and Johnstone, 2003). Tapu has commonly been translated as ‘sacred’ inferring a relationship to the atua (gods), and refers to balancing order between the physical and supernatural realms, but this translation only partially describes this term. The concepts embraced by tapu and noa also give reference to a traditional ‘health and safety’ system that identifies risks and consequences of unsafe practices. The nature of tapu covers multiple aspects, including a much deeper understanding of identifying the something to be ‘special’ or warning ‘to be wary of’. In this respect, the idea of noa denotes something that is ‘safe’. An object, place, person, event, or practice may carry a sense of tapu, which may fluctuate, and be added or removed given certain situations. A thing considered to be noa, may ‘remove’ the tapu nature of something else by coming into contact with it (Salmond, 1978).

“Wellness” to many Māori is also often perceived to be linked more to an individual’s ability to contribute to their whānau (extended family), hapū (sub tribe) and iwi (tribe) thus based not just on personal level, but rather perceived as performance within a wider community setting (Cram et al, 2003). Whānau is central to Māori and the term whānau ora (healthy families) is a commonly used phrase to express health.

Sir Mason Durie, (Rangitane, Ngāti Kauwhata, Ngāti Raukawa, former Deputy Vice Chancellor, Massey University, leader in Māori Health) is renowned for his work
in the forefront of Māori health promotion, research, education, and conceptualisation framing Māori health concepts to embrace these wider aspects of health for many Māori. The popular depiction of hauora Māori: Te Whare Tapa Whā, was proposed following a hui with Māori mental health workers in 1982 (Rochford, 2004), anchored on a study performed by the Māori Women’s Welfare League in 1982 (Murchie, 1984), and further defined by Durie (1994). In an attempt to express and provide validity to how many Māori experience health within the mainstream health industry and to empower Māori themselves, Durie (2005) stated “...by reconfiguring health in terms that made sense to Māori, it was possible for Māori communities to experience a sense of ownership and to balance medical and professional dominance with community involvement and local leadership” (Durie, 2005, p. 10). Te Whare Tapa Whā model is steeped in tradition, and likens Māori wellbeing to the main pillars of a wharenui (main house). Wharenui are the embodiment of a specific chiefly tupuna (ancestor). The Te Whare Tapa Whā model described the four pillars of the whare tūpuna (house of our ancestors), referring to four cornerstones of health, encompassing te taha tinana (physical realm), te taha wairua (spiritual realm), te taha whānau (social realm), and te taha hinengaro (mental realm). This model identifies the worldview many Māori have where mauri (vital life force) is the binding force for all realms, and when all are balanced, this contributes to a state of mauri ora (wellbeing), where the mauri looks to the wairua for direction, hinekaro for construction, tinana for action and the whānau for support (Matenga-Kohu and Roberts, 2003). This acknowledges the interrelatedness of each realm, and their effect on the overall health of an individual suggesting if one of the pillars becomes weak and unwell then the others will suffer or be placed at risk of also becoming ill. The whare will be unstable unless consideration and health planning is put in place to not only strengthen the pillar or dimension that is presenting as unwell but to be mindful of the other pillars that may need to be supported alongside the healing of the primary concern. For example, if a person’s relationships with their support systems were compromised this may have consequences for their mental, physical, and spiritual wellbeing. Likewise if someone were to sustain a physical health injury this in turn may place stress on relationships and mental health, and so on.
More recently Durie has developed and modified a model for Māori health promotion, acknowledging other considerations in Te Ao Māori, which encapsulate broader Māori world-views of hauora (Durie, 2004), Te Pae Mahutonga (Southern Cross Star Constellation). This model brings forward the idea of four tasks of health promotion, represented by the four central stars in the Southern Cross constellation. They are: mauri ora (cultural identity), waiora (physical environmental protection), toiora (healthy lifestyles), and te oranga (participation in society). Te Pae Māhutonga also includes two other concepts, characterised by the two pointer stars in the Southern Cross, ngā manukura (community leaders), and te mana whakahaere (autonomy). Durie (2004) describes this model as follows:

...One way to bring together the threads of health promotion...to signpost the strategic directions that might be pursued by States, the health and education sectors and Indigenous peoples themselves. Most important, Indigenous health issues cannot be seriously addressed unless they are part of a wider agenda that includes cultural identity, the natural environment, constitutional arrangements, socio-economic realities and Indigenous leadership. (Durie, 2004, p. 184)

Another interpretation of Māori perspectives of wellness, Te Wheke Kamātu (The Octopus of Great Wisdom), is described by Dr Rangimarie Turuki Rose Pere. This model was developed to depict the health realities of whānau (family), hapū (sub tribe) or iwi (tribe), all represented as an octopus, and identified eight tentacles or dimensions of wellbeing including: wairua (spiritual dimension); taha tinana (physical world); hā taoka tukuīho (breath, treasures that have come down); mana (divine vested authority); whānaukataka (kinship ties that move in four directions across the universe); hinengaro (“the Hidden Mother” who is intellectual, mental dimension within us); ranga whatumanawa (emotions and senses) and; mauri (life principle, ethos, psyche). The copious suckers on each tentacle depict the multiple aspects within each dimension that further contribute to hauora. This model emphasises that many Māori view their individual health as inseparable from the health of whānau, whānau health indivisible from the health of hapū, and wellbeing of hapū integrally intertwined with that of the iwi (Love, 2004).

Within the design of this study, reference was predominantly made to Te Whare Tapa Whā model, as this is a commonly used depiction of hauora Māori (Māori health), identifiable by many. This was further confirmed when the Whare Tapa
Whā model was chosen to embody this research by the Rōpū Kaiārahi discussed in chapter 3. Elements involved in Te Wheke, such as mauri, mana and whānaukataka, are also embodied within the methodology used in this project, discussed in chapter 2. Importantly acknowledged is the interconnectedness of the wellbeing of the individual, whānau, hapū, and iwi. Notably, aspects mentioned embedded in Te Pae Māhutonga, the model for Māori health promotion (specifically connection to a cultural identity, healthy lifestyles, involvement within society, leadership and autonomy) come through as strong themes within the results of this thesis, following interviews with hauā Māori.

**Māori concepts of Disability**

Within te Ao Māori (Māori world-views), there is often a lack of distinction between health and disability and thus no clear definition of ‘disability’ as it is perceived in a te Ao Pākehā. The holistic view of hauora Māori (as discussed above) includes multiple elements, emphasising and recognising the interdependence on whānau, wellness within a community context, and the determinants of health. This balance of multiple, interrelated aspects, contrasts the generalised te Ao Pākehā medical model of disability, which conceptualises disability with respect to physical, sensory, psychological and psychiatric, learning and intellectual impairments, focusing on independence (Ratima & Ratima, 2007). Some even suggest that there is no Māori word for disability (Ryan, 1995), however the term ‘hauā’, according to Williams (2000), is historically translated as ‘crippled’ or ‘lame’. Hauā is used in present day by some as a translation into English, as a person with a disability, but the concept remains different (as for many concepts translated into other languages) to that which it represents in English, the latter often used in a negative sense (like the term Māori which means ‘normal’ but was used to collectively describe the aboriginal tribes of Aotearoa/New Zealand). Hickory (2004) suggests hauā refers to a person affected in some manner that is ‘uniquely different’ to the norm.

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2 “Pākehā” refers to the British and European settlers arriving to Aotearoa/New Zealand in the early 1800’s and their descendants. “Te Ao” translates to “the world” therefore “te Ao Pākehā” refers to the world-views or perspectives of the current dominant ethnic group of Aotearoa/New Zealand.
Traditional Perspectives

Limited knowledge exists on how hauā were perceived in traditional society and historic research on this topic is greatly needed (Nikora, Karapu, Hickey & Te Awekotuku, 2004). James Watkins (Watkins, 1842), on April 4 1842, infers within his diary log, notes on his take of Māori views of disability as the following:

...Their traditions as well as language show them to have origin in common with the Polynesian. They appear to regard cripples, etc., among the superior class as sacred persons, who, were they to approach a common fire, would produce an instant death.

This comment identifies that the general view of Māori towards hauā was that of a special and revered one. There are accounts of those with deformities being respected and being imbued with a sense of sacrosanct, or ‘tapu’ (Fortune, 2013) where disability is caused by ‘external forces’ which fits the religious model of disability (Nikora et al, 2004). This is further supported by the following:

...Certainly [hauā] were seen as special, touched by ka atua (the gods). Even six toes, a common feature in the South (and still occurring today: my son was born with a sixth toe on the tip of his tomtoe, leading the doctor to ask us "Which of you has Māori blood?) and was seen as special. Tuhawaiiki told Shortland that his son had six toes on each foot and would be a great man. (Personal communication Dr Jim Williams, 26 Nov 2015)

Tuhawaiiki from Murihiku, purportedly had a son with six toes, and in Shortland’s account on meeting him (Shortland, 1852, p. 81.) Tuhawaiiki told Shortland he believed this to be a good omen. This was considered a transmission of tapu because it is coming down from the ariki (chief) line, as Tuhawaiiki’s uncle, Te Wakataupunga was the ariki of the Southern hapū until his death about 1836. For the Tainui iwi, they refer to their tupuna (ancestor), Hape, as a rakatira (great chief), and he was considered one of the pou (founders) of the Tainui tribe, despite his talipes equinovarus or ‘club foot’. Other notable chiefs, such as Te Rangihaeata of Ngāti Toa iwi, had clubfoot but little focus has been on the disability, more a prognostication of greatness. Talipes equinovarus, or ‘hape’ in Te Reo Māori in honour of this rakitira (chief), and is a congenital deformity of the foot, which has a higher prevalence within Māori (6-7 per 1000) when compared to the white population (2-3 per 1000) (Chapman, Stott & Nicol, 2000). Hape (the ancestor) has been described as a tohunga (specialist or expert, revered person who is considered the holder of knowledge). Some suggest he was even regarded...
as a demi-god, as stories tell that he was not chosen to come over to Aotearoa secondary to his club foot, but when his *iwi* arrived they were purportedly and mysteriously greeted by Hape. Reports suggest there were villages where those with deformities would be placed and looked after by the *hapū*, an example of one such township was north of Moeraki in the mid 19\textsuperscript{th} century (Bill Dacker personal communication, October 25, 2015). Nikora et al (2004) acknowledged accounts depicting both embracing and segregation outlooks towards *hauā* in traditional Māori society, explaining the following:

...*When communities were peaceful, food bountiful, and leadership stable the impaired were probably well-supported and valued within groups provided they themselves did not pose an uncontrollable or unpalatable threat to others. Of the later, if sickness or impairment were seen to be caused by an infringement of tapu or an atua affliction, or makutu, then isolation or banishment of the individual and perhaps their family was not out of the question (for example, see Best, 1924). Indeed, during periods of unrest, war, in-group competition for food shortage, the need for individuals and the broader group to survive may well be prioritised over the needs of impaired persons.* (Nikora et al, 2004, p. 8).

Anyone who threatened the fabric of society was likely to be banished, but this was not a general practice for how *hauā* were treated.

**Modern day**

*Hauā Māori* population is diverse and similarly as *Māori* philosophies of health are broad, so are *Māori* concepts of disability (Ratima and Ratima, 2007). Disability within *te Ao Māori* generally demonstrates elements of medical and social models of disability (Nikora, 2004), but also remains largely unclear and undefined. Accounts from *Māori* disability research support the notion of a ‘disability’ being vague within the *Māori* world-views or different to that of non-*Māori*. For example:

*When conducting research with Māori with disabilities and their whānau, not one of them used the terminology ‘disabled’ and I was very aware of this language being something not often used to describe the impairments their whānau member lives with.* (a researcher as quoted in Nikora et al, 2004, p. 16).

*Those who were mentally disabled, physically disabled and mongoloids-nobody seemed to treat them differently to the rest. They were just accepted as whānau- oh that was back in the 40’s.* (a participant as quoted in Kingi and Bray, 2000, p. 10).
Although obscure in its definition within *te Ao Māori*, disability is a substantial issue for modern day *Māori*, and inequalities exist in the way *Māori* experience disability both quantitatively and qualitatively (Ratima and Ratima, 2007). Many of those disabled who identify as *Māori* often suffer marginalisation effects of living with a disability, however these impacts are compounded by marginalisation effects of being *Māori* (Collins, Hickey, Higgins and Phillips, 2009; Mikaere, 1994; Pihama, 2008).

The Disability Survey 2013 conducted by Statistics New Zealand, provided examples of health disparities with *hauā Māori* and non-*Māori* with disability (Statistics New Zealand, 2013). These included:

- Higher disability rates than non-*Māori*. *Māori* adults were more likely to have a disability, disability rate of 32%, compared with 27% for non-*Māori* adults. For children there was a similar trend. *Māori* children had a disability rate of 15%, 9% for non-*Māori* children.
- Significantly higher disability rates for *Māori* than non-*Māori* in the areas of psychological/psychiatric impairments, difficulty with learning, and difficulty with speaking and intellectual disability.
- Slightly higher rates of vision impairment and slightly lower rates of mobility impairment than non-*Māori*.
- Higher likelihood of living in more deprived areas of New Zealand, being unemployed, earning less, and having fewer or no qualifications.

Data from the above disability survey were further analysed, specifically comparing social and economic outcomes for *hauā Māori* and non-disabled *Māori* and led to the publication *He hauā Māori: Findings from the 2013 Disability Survey* (Statistics New Zealand, 2015). Key points from within this report acknowledge that, compared with the non-disabled *Māori* population, *hauā Māori* demonstrate:

- Almost double the rates of experiencing discrimination; (23%) than non-disabled *Māori* (13%), suggesting that disability is a factor in discrimination afflicted upon *hauā Māori*. The national average of those with disability that suffer discrimination, irrespective of ethnicity, is 14%, therefore being *Māori* is also a factor in being discriminated against *hauā Māori*. 

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- Lower incomes and lower employment rates than other Māori, over 65% had annual incomes of $30,000 or less. Notably 25% of hauā Māori stated their household income was not sufficient to meet their everyday needs.
- More perceived problems with housing than non-disabled Māori, particularly issues with cold and damp houses.
- 40% with no formal educational qualifications, almost double the number of adults of non-disabled Māori.
- Higher rate of contact with family and friends than the non-disabled Māori; however, a lower rate of satisfaction with the amount of contact with family and friends. This possibly indicates that Māori living with disability have a higher dependence on whānau. Interestingly hauā Māori are slightly less likely to feel lonely than those living with a disability, overall.
- 48% rated their life satisfaction 8+ out of 10 highly; however not as high as their non-disabled Māori (72%) (Statistics New Zealand, 2015).

These reports reflect the “double whammy” effect that many hauā Māori suffer from the marginalisation and discriminatory factors associated with being both Māori and living with disability.

Ratima and Ratima (2007) state Māori demonstrated higher rates of single and multiple disabilities across all age groups and more severe impairments for children and overall. In 2004, the MOH released a report (MOH, 2004) showing that Māori were more likely to have a severe, functional disability requiring assistance that was twice the rate for non-Māori. This report also indicated that hauā Māori were considerably less likely to live in residential care. This may represent the role whānau support has in preventing the need for residential care and also highlights an increased load on whānau members to provide care, given the propensity for more severe disabilities requiring assistance (MOH, 2004).

**RATIONALE OF THE STUDY**

The rationale for this study was guided by the Treaty of Waitangi, current health policies and research undertaken in this field, as described in the next section. The reason for its Southern focus is also explained.
Te Tiriti o Waitangi/ The Treaty of Waitangi

Te Tiriti o Waitangi/Treaty of Waitangi, written in 1840, offers a framework recognising certain similar and special rights of the indigenous peoples of Aotearoa/New Zealand, collectively referred to as Māori, relative to the settlers to New Zealand governed by the British Crown (Orange, 2011). Notably, this agreement plays an important role in emphasising expected equity in health outcomes for Māori and settlers and should be acknowledged when discussing health issues for Māori. Although controversy surrounds interpretations and translations between the English and Māori versions, this document clearly stated in the English version the Crown was “…anxious to protect their (Māori) just Rights and Property and to secure to them the enjoyment of Peace and Good Order…” and that the Crown “...extends to the Natives of New Zealand Her royal protection and imparts to them all the Rights and Privileges of British Subjects.” In relation to hauora (health), these two statements plainly indicate the Crown was promising to ensure that Māori experience the same health ‘privileges’ as those of their non-Māori co-inhabitants. The Māori version of the Treaty confers rakatiratanga (autonomy) for Māori to manage their own affairs, and tinorakatira (unqualified exercise of their chieftainship) over, amongst other things, taoka (treasures). It has been discussed that these references are also implicit when considering hauora Māori (Māori health) issues, as Māori considered health as being taoka, or something revered (Barnett and Stone, 1998; Kingi, 2007). In 1987 the New Zealand Board of Health acknowledged the relevance of the Treaty of Waitangi to health and supported iwi as agents of health, thus stimulating a “…new era of health policy...”(Durie, 2005). It follows that, according to the Treaty, Māori should be entitled to be involved and at the helm in all levels of governance over hauora Māori related policy, provision of services and research.

The undesirable health and disability disparities of Māori compared to non-Māori living in Aotearoa falls short of the Tiriti o Waitangi commitments. Te Tiriti acknowledges that the wellbeing of Māori as the Tākata Whenua or indigenous people of New Zealand, be protected alongside all New Zealand residents. In particular, Article 3 ‘oritetanga’ (equity) guarantees that Māori share equally in the benefits of modern society including equal standards of health care, equality of access to health care, and a general equality of health outcomes (Waitangi Tribunal, 2001). Social, cultural, economic, and political factors cannot be
overlooked in terms of their contribution to the health status of this group (Waitangi Tribunal, 2001).

Poor health outcomes have been linked with de-culturisation, alternatively acculturation has been correlated to improved health (Isajiw, 1998.) In 2002, the New Zealand MOH acknowledged that Māori accessed disability support services less frequently than other ethnic groups in Aotearoa, and suggested that these service providers may lack provision for cultural needs or expectations of Māori (MOH, 2002). Escalating the impact on Māori living with disability is the acknowledgement that the disability sector has lacked strong advocacy, and lagged in regards to Māori development initiatives applied to other health-related areas such as child health or mental health (Ratima and Ratima, 2007).

Health Policies

Many health initiatives and policies have acknowledged the need to address disparities in health and disability outcomes for Māori. For example in 1995, He Ānga Whakamana (Ratima, Durie, Allan, Morrison, and Waldon, 1995) was developed to provide a model for disability services for Māori, acknowledging barriers and citing six principles for service provision: enablement; safety; participation; effectiveness; accessibility; and integration. Evaluation indicators for these principles are also discussed. The New Zealand Disability Strategy, 2001, Making a World of Difference/Whakanui Oranga (MOH, 2001) demonstrated a shift towards a more social perspective of disability, making a distinction between impairments (what individuals have) and disability (which lies in their experience of barriers to participation in society). This document outlined the main objectives for an all-embracing society, where someone with an impairment could feel valued, included, and able to fully participate within communities, with opportunities for employment, economic development, and leadership. Of note, two key intentions of this strategy were: (1) to promote participation of disabled Māori within their communities and access disability services, and; (2) value families, whānau and people providing ongoing support. He Korowai Oranga, New Zealand MOH’s Māori Health Strategy (translated as ‘The Cloak of Wellness’) (MOH, 2002) followed on from the New Zealand Disability Strategy goals and aimed to support Māori whānau to achieve optimal health and wellbeing. Specifically, the objectives of He Korowai Oranga included:
(1) whānau experience physical, spiritual, mental, and emotional health and have control over their own destinies; (2) whānau members live longer and enjoy a better quality of life and; (3) whānau members, including those with disabilities, participate in te Ao Māori and the wider New Zealand society. ‘Whānau Ora’ was an inclusive approach launched by Te Puni Kōkiri (New Zealand’s Ministry of Māori Development) and the Ministries of Social Development and Health in 2011 (MOH, 2011). The vision of Whānau Ora includes providing services and opportunities to all whānau in need across Aotearoa/New Zealand and acknowledges the need for collaboration of agencies, working with whānau to empower them, focusing on the needs of whānau as a whole, rather than working with individual family members. Whānau Ora provides whānau autonomy for access to health care and health education, connecting whānau to services and promoting whānaunaukataka (relationships) placing roles and responsibilities within the whānau to maintain their wellness. Whānau may also look for support from Whānau Ora “navigators”, who are advocates within the Whānau Ora services and who assist whānau to access health services if they are unsure or identify barriers to doing so (Te Puni Kōkiri, 2012).

Despite the introduction of these strategies Māori health statistics for Māori living with disability and morbidity rates are disparately poor compared to non-Māori (Ratima and Ratima, 2007) and there remains disparities for Māori with access and utilisation of rehabilitation and disability support services (Harwood, 2010). Quantitative indicators suggest higher prevalence of disability in Māori population compared with non-Māori, however only 16% of those who access MOH-funded disability services identified as hauā Māori (MOH, 2012). The National Advisory Committee on Health and Disability report “To have an Ordinary Life” stated:

It is reasonable to assume that Māori adults with an intellectual disability will have poorer access to primary health care and secondary health care than non-Māori adults with an intellectual disability. There is a paucity of health promotion materials for adults with an intellectual disability and even more scarce are health promotion for Māori adults with an intellectual disability. (National Health Committee, 2003, p.153-154).

Another possible explanation for inequitable use of disability services by Māori is that Māori may think of and perceive ‘disability’ differently, therefore have
unique needs compared to what is generally provided for within the mainstream disability services.

**Research relating to Māori perspectives of health and disability**

There is much evidence validating health services should be responsive to the needs of *hauā Māori*, to achieve improved access to health and disability services for *Māori* living with disability and their *whānau*. Jones, Crengle and McCleanor (2006) suggest that health services in the past have largely failed to acknowledge Treaty obligations, ignoring cultural differences, and "*assumed that the Pākehā way of doing things is a norm*" (Jones et al, 2006, p.1).

Cram et al (2003) state the "*practices and cultural concepts that are imperative to Māori health and wellbeing have often been undermined by dominant Pākehā views on health.*" Cram et al (2003) conducted qualitative research, through interviewing twenty-eight *Māori*, that aimed to look at how *Māori* talk about health and their interactions with mainstream and *Māori* health providers.

Twelve themes emerged from this research; importantly, identifying the need for integrating traditional *Māori* concepts remained a focus in health for *Māori*, noting particularly the holistic, relational nature link to health. The interconnectedness that participants mentioned referred to many other themes related to *Māori* health including *whānau, wairua* (spirit linked to both religious beliefs and relationship to the environment), mental and physical health being dependent on each other. Also identified were the ideas of rapport with health professionals, promotion of *Māori* health and use of *Māori* settings for health service delivery. To better understand enablers and limitations to access of health services for those living with disability, it is paramount to investigate *hauā Māori* experiences of disability, incorporating perceptions of elements necessary for their wellness, and those that contribute to disabling them (Nikora et al, 2004).

Research priorities of *whānau* living with disabilities were identified by Collins et al (2009) and included addressing the impact of disability on *Māori* and their *whānau*, specifically investigating *Māori* perceptions of ‘disability’. *Uia Tonutia - Māori* Disability Research Agenda (MOH, 2011) published co-jointly by the MOH and HRC in 2011 further identified fundamental areas to be addressed within
hauā Māori research and states that hauā Māori research should “enable the voices of Māori with a disability and their whānau to be heard” (MOH, 2011, p. 1). Fortune (2013), on reviewing literature related to the impact of policies on Māori children with special needs, stated:

...to identify appropriate provisions for Māori who are disabled and their whānau then the differing views and perceptions Māori possess in regards to disability need to be taken into account to ensure that future provisions are appropriate to the individual needs and aspirations of Māori. (Fortune, 2013, p. 42.)

Although indicators have suggested strongly that there needs to be research done to gauge Māori perceptions of disability to better provide disability services to Māori, there remains very little research in this area.

The Māori Disability Information (MDI) framework (Potaka, Durie, Ratima and Waldon, 1994), addressed the means to enhance quality of service for Māori people with disabilities by sampling a group of Māori people with disabilities and their advocates to ascertain their perspectives on disability service provision. Findings from this study included specific consideration to certain social and economic pressures faced predominantly by Māori more than non-Māori. Accordingly the report recommended that information with respect to whānau support, economic position and other social indicators is important to service provision for hauā Māori. Whilst this study looked at service provision needs for hauā Māori, detailed perspectives of disability and health were not examined. In another similar qualitative study, He Anga Whakamana: A Framework for the Delivery of Disability Support Services for Māori, Ratima et al (1995) studied thirty hauā Māori, a sample group of people with a range of disabilities or, where appropriate, their primary caregiver, to ascertain client perspectives as to the delivery of disability support services. Participants identified Māori-specific assessment criteria, access to cultural expertise, and input to assessments as highly valued. These findings reinforce the view that acknowledging Māori knowledge and world-views in the delivery of disability support services to Māori is important, and may help to bridge the existing inequality gaps in service between Māori and non-Māori. Further cultural barriers identified included limited number of Māori health staff, inadequate use of tikaka Māori and Te Reo Māori, and lack of whānau involvement, difficulty with access to culturally appropriate information and general communication issues, which together led
to services largely being used at points of desperation. This study led to the development of a framework for disability services provision, which included six main principles: whakapikipiki (enablement); whai wahi (Participation); whakaruruhau (safety); Totika (effectiveness); puteka (accessibility) and; whakakataka (integration). Significantly again, whilst this research investigated views specific to disability services, it did not address specifically haua Māori views of disability. Ratima and colleagues (1995) do however acknowledge, “...An understanding of Māori perspectives should be evident in all aspects of the daily processes of disability support services” (Ratima et al, 1995, p. 41).

Physiotherapy research (White, Mavoa and Bassett, 1999) explored the perceptions of a small sample of 19 participants from the Ngāti Tama iwi, aged between 14-60 years, recruited by the snowball method of sampling. This study addressed the participants’ perceptions of health and illness, but did not look at disability per se. Being haua Māori also was not an inclusion criteria and it was not clear whether any of the participants themselves were haua. Interestingly, however, it was acknowledged that:

...the western influence was apparent in the illness beliefs, with the majority of participants conceptualising illness as the opposite to health...Whereas the traditional Māori concepts of health were more strongly represented in the health beliefs. (White et al, 1995, p. 11).

This supports the general understanding that illness or disability is not a strong concept for Māori, rather the focus is on health. Health was seen by some as being fit and well balance between physical, spiritual, mental, emotional, also; harmony with the community and environment, and some believed health was absence of illness. In terms of illness, some believed separate Māori and Pākehā (dominant ethnic group illnesses, stating use of rongoā Māori (Māori medicine), for general health and wellbeing, indicating medical pluralism. In regards to perceptions of physiotherapy, there was a strong feeling that physiotherapy and traditional Māori methods of healing are linked, in that manual techniques are used and the non-invasive nature of the techniques and their effects are seen to be the same. Participants saw physiotherapists as experts in treatment of movement problems although they did acknowledge deficiencies in the physiotherapists’ cultural awareness. Participants also suggested that physiotherapy services could be improved by delivering these services in a more culturally sensitive manner;
further marae based services would make those interviewed more comfortable, as would having a Māori physiotherapist.

Bray and Kingi (2000) performed research specifically addressing Māori concepts of disability. This study aimed to explore Māori world-views of disability, and to identify provision of support services to Māori with disabilities and their whānau. These authors interviewed 15 participants who identified as Māori, aged between 22-65 years but it was again unclear whether any of the participants themselves were hauā Māori. This study found that those interviewed generally answered the question, “What does disability mean to you?” from a social model perspective (which views disability as a consequence of environmental, social and societal barriers) and this study reiterates a resounding theme within research in this area that Māori perspectives of disability do not fit the medical model stating:

...Everybody interviewed was aware of impairment on a physical, psychiatric and sensory level. However, they did not equate or necessarily connect this with their view of the term “disability”, or being “disabled”. (Bray and Kingi, 2000, p. 12).

Participants made reference to poverty, alcohol and drug abuse, tobacco use, barriers to accessing food sources, decreased use of Te Reo Māori, and issues with identity and self worth being, leading Bray and Kingi to conclude that “colonisation, as stated by most participants, as the primary disability.” This study identified the varied experiences of Māori stating:

Takata Whenua are diverse in biological, social and cultural terms and more research is needed to unbundle the multiple associations and affiliation within which their realities are lived. (Bray and Kingi, 2000, p. 20).

Acknowledging, with emphasis, the need for accessible research of experiences of disability and disability services by Māori living with disability themselves, the University of Waikato Māori and Psychology Research Unit conducted a qualitative study interviewing 50 hauā Māori and their care givers living in the Midland area (Nikora et al, 2004). In summary, these authors noted that most interviewed were largely dissatisfied with mainstream services, preferred Māori disability service providers, and that greater financial assistance was required. This research used the MOH’s definition for disability for the inclusion criteria, and, again, did not investigate how Māori with disabilities define the concept of ‘disability’. The authors did, however, acknowledge that more research was
needed to explore how Māori living with disability identify themselves, intimating that the way someone perceives ‘disability’ can influence the uptake of disability services.

**SOUTHERN PERSPECTIVE**

I have whakapapa (ancestral) affiliations to Waitaha, Kati Mamoe, and Kāi Tahu iwi (tribes), all related to Southern New Zealand areas, and I am connected to Ōtākou and Puketeraki/Karitāne and linked to areas in the Murihiku including, Hokonui, Ōraka Aparima/Riverton, and Kaka Point. Because of my associations I feel authorised and obliged to perform research within a Southern rohe (area). I have observed the differences in our experiences of history, our reo Māori, our kawa (policies) and tikaka (procedures) to those of Northern iwi. I was, therefore also interested to investigate a Southern hauā Māori perspective, as I believed there may be differences to those from Northern based Māori, which might translate to differing needs than those proposed following Northern based hauā Māori research in relation to disability service provision.

**Māori in Murihiki**

The Murihiku/Southland district of New Zealand is a well-bounded region. Historically Murihiku was the area of land south of the Waitaki River and extended as far East to the Waiau River, according to Shortland’s key informant Tiramorehu, who was based at Moeraki. Therefore the original boundaries were both more Northern and less Eastern than the province of Southland is known by today (Stevens, 2011). In fact it is thought that Murihiku was the pre-European South Land, rather than Southland (Dacker, 2006). Kāi Tahu Whānui, who are descendants of the Kāi Tahu, Ngāti Māmoe, and Waitaha tribes is the iwi authority in Murihiku and many Kāi Tahu have considered Murihiku as a synonym for Southland for several generations (Stevens, 2011).

Kāi Tahu is made up of 18 Rūnaka Papatipu (subtribal authorities), and hold Mana Whenua status for both Otago and Southland regions. The Murihiku/Southland district has four mana whenua rōpū (local authority groups): Awarua Rūnaka (Bluff), Waihōpai Rūnaka (Invercargill), Hokonui Rūnaka (Gore), and Ōraka Aparima Rūnaka (Colac Bay).
Murihiku area has the largest Māori population of district health boards in the South Island, a larger Māori population than the Otago region (7.1% larger). Māori comprise 12.4% (11,607) of the people in the Southland Region, compared with 14.1% for all of New Zealand (Statistics New Zealand, 2015). Kāi Tahu is the most common iwi affiliation of Māori living in Murihiku/Southland (35%). Matāwaka (Māori originating from other rohe) also represent Māori in Murihiku, and include those who identify as Ngā Puhi, Ngāti Porou, and Ngāti Kahungunu (Southern District Health Board, 2011). The concept of whānau for some Māori in the Murihiku area is one of an extended whānau basis, including new and often unrelated whānau as their blood relatives are frequently distantly located. The Māori profile in Murihiku is that of a younger population than the non-Māori population. Close to 50% of Māori in Southland are aged under 20 years compared with 25% of non-Māori aged under 20, however of those in 65 plus age bracket, 15% are non-Māori and 4% are Māori (Southern District Health Board, 2011).

Although Southland has a disability rate of 26% (high compared with the national disability average rate of 23%) (Statistics NZ, 2014), statistical data and information around disability for Māori is limited in the Southern DHB Māori Health Action Plan 2011/12 (Southern District Health Board, 2011). This document acknowledges only 74% of Māori living in the Southland area are enrolled in the Southern PHO, in comparison to 94% non-Māori, and thus accessibility for Māori needs to be addressed. This report highlights engaging more Māori to access health services and emphasises that health priorities for Māori include access to care, child health, cardiovascular disease, cancer, smoking, immunisation, rheumatic fever, respiratory conditions, diabetes, and ethnicity data collection. Interestingly, Southland disability data per se were not available so no summary is presented for this section, however it was implied amongst several of these priorities, and supports the need for development and utilisation of Māori health research in this region.

**SUMMARY**

In summary, few studies have addressed Māori perspectives of disability in a historic or current environment and, although Māori disability research agendas suggest this is important, no studies have specifically addressed Māori living with
disability and their whānau perspectives of disability. This is the primary aim of this thesis. Limited disability data in the South warrants more research performed in this area and given I have whakapapa links to the South motivates and allows me to perform this research in for my whānau, hapū, and iwi.

The next two chapters review the methodologies used, and protocols for the qualitative investigation are introduced and discussed. These chapters explain the philosophies and processes underpinning the secondary aim of this research, which is to develop a useful method for collecting data on perspectives of disability within this community, and are, accordingly, explained in some detail.
CHAPTER 2-METHODOLOGY

This chapter provides a platform for this study outlining the backgrounds, theories and philosophies behind the fundamental methodologies used. Importantly reviewed are the incorporated relevant Māori world-view concepts, which underpin the methods used, as further discussed in chapter 3. Also reviewed in this chapter are relevant qualitative research methodologies and these are compared to Māori ideals, to demonstrate the usefulness of qualitative research within this project.

KAUPAPA MĀORI RESEARCH (KMR)

Traditionally Māori were great researchers and scientists (Berkes, 2009). Evidence of this includes rongoā Māori, mahika kai (traditional Māori food preparation and cultivation sites) and how, following migration, Māori adapted ancient knowledge to the resources available in new environments (Beattie, 1994; Best, 1934, 2005). Māori were avid astronomers and navigated the seas proficiently using this knowledge. Toa Waaka, Vice President of the Society for Astronomy Research and Traditions, explains that astronomy and physics became the basis of Te Reo Māori and states Māori ancestors were scientists. He stated that:

They understood the processes of nature. Their scientific observation was seen in a much more, I suppose, holistic way. But today we can now look at their knowledge and say, 'Hey actually what they were saying is quite right. (Toa Waaka, 2015)

When contemplating Māori as scientists it is also helpful to have an understanding of Māori epistemologies or Mātauraka Māori (Durie, 2004). Māori traditionally maintained their history and information largely through oral means. For example:

People remember stories; they forget facts and figures so our ancestors put their knowledge into the reo, into stories so that we would not forget. (Moana Wesley, personal communication 1.12.15)

Misrepresentation potentially alters the account drastically and therefore many Māori view transfer of knowledge and the recipient with much consternation. Manihera (1992) describes why Kaumātua often have difficulties in handing down of knowledge.
Importantly Māori systems of knowledge collection and transmission are considered tapu (subject to restrictions) (King and Goff, 2010). The person receiving information must be capable and be able to be trusted with it. To hold knowledge is a privilege that is only gifted to those that have the right or show the ability to understand it and the tools to be responsible for the information. Tōhuka or expert authorities in Māori society were the holders of special Māori knowledge, sometimes exclusively (King, 2008). This carried phenomenal responsibility and was a vital role in regards to the retention and application of old knowledge handed down from generations of learning. It therefore is not surprising that the impacts of colonisation such as the decline of use of Te Reo Māori (Māori language) and movements such as the Tōhunga Suppression Act, 1907 (Stephens, 2001) that legislated against tōhunga practicing and replaced them with modern medicine practitioners, have led to substantial damaging and disparaging consequences for Māori knowledge transference.

Compounding to this diminishing effect, non-Māori research has a history of discouraging indigenous people from being involved, secondary to the sensitivities of theft and misrepresentation of indigenous knowledge, invasive and disrespectful methodology, and disregard for unique beliefs and practices or world-views that indigenous people hold (Bishop, 1999). Outcomes from such research hold little meaning for Māori, increase impact of marginalisation and often lead to a ‘focus on negative aspects of Māori realities’ (Jones et al, 2006). This sentiment is also expressed by Smith (1999) who stated “The word itself, ‘research’, is probably one of the dirtiest words in the indigenous world’s vocabulary.” (Smith, 1999, p.1).

Hokowhitu (2009) reminded those writing about Māori perspectives to avoid limiting perceptions of who we are by relying on unsubstantiated portrayals of the past and suggests that we must look at current views and the lessons of our tupuna, to be able to demonstrate who we are:

Everyday culture and traditional culture must form a composite of an Indigenous sense of self if a healthy Indigenous epistemology is to take hold. (Hokowhitu, 2009, p. 107-108).
It will be seen in chapter 5 that contemporary research needs to reflect on the traditional approaches outlined above. Kaupapa Māori Research (KMR) evolved, in part, from a reaction to questionable research conducted on and with Māori since the arrival of Europeans to Aotearoa/New Zealand, that was not demonstrating the same positive outcomes for Māori (Pihama et al, 2002).

There were concerns around the treatment of Māori participants and the general disinterest to consider Māori perspectives within the research design or analysis, leading to inaccurate portrayal of information provided by participants. Taking the opportunity during the 1980-90’s amongst the resurgence of Te Reo Māori and Māori health initiatives, leaders in Māori research such as Graham Smith, Linda Smith, Leonie Pihama and Taina Pohatu, worked tirelessly to forge the way to provide a platform for contemporary researchers today to confidently plan, conduct, evaluate and disseminate research in a culturally responsive ‘space’ (Smith, 1999). Smith (2000) continues to explain why considering kaupapa Māori in depth is relevant in research with Maori:

... there is more to kaupapa Māori than our history under colonialism or our desires to restore rangatiratanga. We have a different epistemological tradition that frames the way we see the world, the way we organise ourselves in it, the questions we ask, and the solutions we seek. (L. Smith, 2000, p. 23)

The word ‘kaupapa’ literally means ‘stage’ and refers to a ‘platform’ for agendas, practices, and ideologies to be presented. Kaupapa Māori infers Māori approaches, and principles – “a philosophical doctrine, incorporating the knowledge, skills, attitudes and values of Māori society” (Māori dictionary, 2016). KMR therefore provides a theoretical framework, based on philosophical values that reflect Māori world-views and customs reflected in a tikaka or Māori “code of conduct” (Pipi, Cram, Hawke, Huriwai, Matakī and Milne, 2004). Tikaka Māori has been described as ‘the set of beliefs associated with practices and procedures to be followed in conducting the affairs of a group or individual’ (Mead, 2003, p. 12) and when used in research provides a safeguard for the research process (Jones et al, 2006). Hudson, Milne, Reynolds, Russell, and Smith (2010) described traditional, guiding tikaka as:

...locally specific practices that aim to enhance these relationships and ensure the preservation of mana (justice and equity, reflected through power and authority)......Tikanga also provides a framework through which Māori can
actively engage with ethical issues and consider the effect research may have on their values or relationships. (Hudson et al, 2010, p. 2)

A KMR epistemological approach was born, steeped in kaupapa, tikaka, kawa (lores), the lessons from tupuna following generations of learning through critical observation that safely guide Māori as they navigate life in te Ao Māori (Māori world) to enhance the preservation and perpetuation of whānau, hapū, iwi (Bishop, 1996). As a repository of knowledge, KMR is “the philosophy and practice of being Māori” (Smith, 1992, p. 1) and creates a place in which Māori voices can flourish.

In 1993, incorporating Māori world-views within health research was boosted with funding from HRC, which assisted in establishing two Māori health research units, whose key objectives entailed “to increase the Māori research capacity and world views to encourage the development of methodologies that reflect Māori world views and intellectual traditions” (Durie, 2005, p. 15).

KMR should not be singular, permanent or prescriptive (Lee, 2005) but responsive to the diverse nature of being Māori. Smith (1999) identified key principles to provide some reference for conducting research with Māori in a safe and respectful way and acknowledges these are not all encompassing, stating “these sayings reflect just some of the values that are placed on the way we behave” (Smith, 1999, p. 120). KMR operates in a manner where tikaka Māori is considered the ‘norm’ rather than the ‘other’ (Eketone, 2008). Being directed by these principles ensures that the way research is conducted is tika/carried out correctly, protecting both researchers and participants when studying issues pertaining to Māori (Cram, 2001). Delineating an outline also assists Māori researchers in overcoming barriers presented to kaupapa Māori researchers by non-Māori, for example, mainstream research processes which fail to acknowledge, understand, respect or see validity of Māori world views and epistemologies.
Principles of Kaupapa Māori Research

Following is an outline of Smith’s Kaupapa Māori Research framework (Smith, 1999) that was applied to the research presented in this thesis. Further detail of how these principles were specifically applied to this qualitative study is contained in the Chapter 6.

1. Aroha ki te takata—respect for people

Aroha (caring love) is a concept that incorporates rakimarie (peace), compassion and empathy. Researchers should endeavour to identify and respect Māori aspirations for research. This principle relates to allowing people to define their own safe space to meet and talk about research, on the participants’ terms, not necessarily the researchers (Pipi et al, 2004). Tino Rakatirataka, the principle of self-determination applies here and entails meeting with whānau, hapū, and iwi on their conditions, allowing them to define what issues they determine important and how they foresee the investigation should be undertaken. Consulting local rūnaka to identify Kaumātua or respected representatives of the local people, who can competently steer the research, is often an essential starting point. Kaumātua (elders) are often experts of local knowledge, geography and politics (Pipi et al, 2004), and are essentially connected to the community. This person or group should be allowed to prioritise health research endeavors, determine how the research process is best to be initiated and be involved integrally as mediators throughout the research process (Houston, 1992). Involvement and approval in the initial stages of research, by respected delegates, demonstrates understanding of protocol, respects the mana of the people and enables appropriate engagement to occur.

If the research question does not originate from the community but rather from external researchers with an area of interest or concept they wish to examine with Māori, presentation or laying down of that idea to the people can be compared to the offering of a koha (contribution/gift). It is the option of the people whether they choose to accept that ‘koha’, agree to be involved and engage in that relationship or not. This allows the mana (empowerment) of the people to remain with the people. There is an understanding that if they do choose to participate it was through no coercion and they deem kaupapa (agenda) as being relevant and helpful. This was the case with the Hauā Mana Māori project, as the
question did not come from the community itself, however when presented to them the idea was taken up with much enthusiasm.

2. *He kanohi kitea- face to face*

*He kanohi kitea* literally translates as ‘a face seen’ (Mead, 2003) and refers to the importance to many Māori, of meeting with each other in person. It suggests that the researcher should be prepared to “show ones face and share of oneself” (Barnes, 2006) which may appear quite exposing, however demonstrates respect and a commitment to the relationship. This is imperative in research for building a level of trust, developing essential relationships and allows for the intent of the researcher to be determined by a Māori community.

*Kanohi ki te kanohi* (face-to-face) is regarded within Māori communities as critical when one has an important ‘take’ or purpose. This form of consultation allows the people in the community to use all their senses as complementary sources of information for assessing and evaluating the advantages and disadvantages of becoming involved (Pipi et al, 2004, p. 146.).

A personal approach is often the preferred method of collecting information as opposed to questionnaires sent out to participants and using technology such as mail, telephone, email or SMS text. ‘Face to face’ may not always be considered the best means of collecting the data, however, and should not be imposed. The most desirable method should be determined with consultation with the participants or community.

3. *Titiro, whakaroko...korero- look, listen...speak.*

As opposed to the researcher dominating, this principle honours the *mana* of the participant as the central, most important voice. It alludes to allowing time to share information, demonstrating empathy and building trusting relationships with participants and communities, which was essential within the qualitative study in *Hauā Mana Māori* and refers to the *kaupapa Māori* concept of ‘atu *whakarongo*’ or vigilantly, patiently listening. The concept of ‘*a te wā*’ or ‘when the time is right’ is encompassed here also, suggesting things may occur at their own pace, warning to be observant, sensitive to when it is appropriate to speak, captured in the ‘*koru*’ element of our interviews discussed later. Often research conclusions suggest that, in retrospect, the process or methodologies used could
have been different to provide more effective or significant solutions. This KMR concept aims to avoid these limitations by entering research without preconceived ideas or attempting to force the process, and rather allowing for a more ‘organic’ course of action. The concept proposes time is ‘given’ as opposed ‘adhered to’. KMR frequently entails a more lengthy process that may not always fit notions of ‘timeframes’ or ‘deadlines’, however attempts to avoid insufficient and futile endeavors.

4. Manaaki ki te takata—look after people

*Manaakitaka* (hospitality), is a central concept to creating a safe environment for research participants, so they feel comfortable and able to fully participate (Tipene-Matua, Phillips, Cram, Parsons, and Taupon, 2009). For Māori it is a means to measure themselves’, using a value system based on how well guests are cared for. Mead (2003) writes that “all tikanga are underpinned by the high value placed on manaakitanga – nurturing relationships, looking after people, and being very careful about how others are treated” (Mead, 2003, p. 29 as cited in Tipene-Matua et al, 2009). This principle also reminds us that KMR should be inherently transformational and result in mana-enhancing, beneficial outcomes for the research population. The responsibility and commitment of the researcher engaging in effective research with Māori is to ensure the people from the community are not maltreated or misrepresented and ultimately experience positive change. Employing research methodologies that simply extract information without demonstrating consequential benefits for participants’ is considered futile and a discourteous manner of executing research. It is this nature of conduct that contributes to the undesirable view of research being an appropriation of knowledge, which functions solely to advance the researcher.

Many suggest that KMR should be undertaken by Māori who *whakapapa* (have origins) to the communities (Smith, 1999), those with relationships that are accountable and ongoing, thus increasing the probability of constructive outcomes. This may not always be possible where Māori population is not high, limiting research potential and placing undue pressure on those who *whakapapa* to the area. It emphasises, however, the expectation and responsibility to form and maintain relationships when entering research Māori and supports developing Māori research capacity within *whānau hapū/iwi* (Wilson, 2008). Employing Māori from the communities within which you are working, who have
little or no research experience is one way to contribute back to the population involved (Jones et al, 2006; Pipi et al, 2004).

Conceptualising ‘ownership’ of the knowledge comes under this category. Data is often only offered following a level of trust gained that the researchers are going to treat the information wisely and respectfully. The mainstream practice where the researcher feels entitled to the information collected as “theirs” to do with what they choose is challenged here. Respecting KMR philosophies, control of the research should remain with the whānau/hapū/iwi and they should feel empowered to dictate how it should be disseminated. Generally participants are agreeable with researchers proposed avenues for dissemination and publication given the research process has been favourable and they remain in control.

5. Kia tūpato- take caution.

Researchers are reminded to be vigilant around respecting kawa and tikaka, or protocols and procedures, which govern how many Māori view the world and engage in day-to-day life. It is essential to have an appreciation for tikaka as a lack of understanding or adherence may be considered largely offensive and impertinent and can lead to deleterious consequences. For the researcher, harm may occur in the form of public humiliation, personal attack, disrepute or discrediting of the research. Misrepresentation, mishandling of information, exploitation, degradation, and depletion of mana are among the ill effects for participants if tikaka is disregarded in the investigative process. Understanding tikaka practices such as pōwhiri (engagement ceremony), karakia (prayers), waiata (supporting songs), also lifts the mana of the research (Jones et al, 2006). Observing tikaka processes of powhiri (first encounter) has been described as “...a way of reducing the space, or any perceived status hierarchy based on academic training, between researchers and research participants...” (Tipene-Matua et al, 2009).

Acquiring awareness of the politics existing within the hapū, iwi or rūnaka, is also recommended and the research team developed their familiarity of this with initial hui (meeting) and communication throughout the research process. A lack of understanding of political status within these groups may lead to poor acceptance of the research process and reduced participation.
6. Kaua takahia te mana o te takata- do not trample on the mana of people.

The term ‘participant’ has stronger connotations within KMR with respect to the level of involvement that may be expected. With this in mind, and understanding that Māori involved in research (whether as participants or researchers) often have fervent sense of responsibility to their people, therefore to simply extract information with no sense of reciprocity of input, participation, gifting back of outcomes, or maintenance of the relationships created would be considered akin to trampling on the mana of those involved. Essentially, the data should be analysed using frameworks that encompass Māori world-views and epistemologies. A website designed to assist whānau, hapū, and iwi understand KMR (www.rangahau.co.nz) illustrates how to best interpret data, and explain the phenomenon being researched using kaupapa Māori methodology and states that this requires researchers to have a “conscious awareness of Māori systems, knowledge, people and processes,” and further, “the key to analysis under kaupapa Māori is to be able to appropriately interpret and understand information that has been intertwined with tikanga Māori, Māori knowledge and understandings.” Whether data are drawn from interviews, hui, surveys or other methods, it is important that the researcher be able to view the wider cultural and societal context that is shaping the research material (www.rangahau.co.nz).

In the Hauā Mana Māori project, the Kairakahau Māori analysed the interviews, and this process is explained later.

Bishop and Glynn (1999) presented a diagrammatic representation (see appendix A) that highlights the position of the researcher in KMR along with pertinent questions the researcher should ask themselves with regards to approaches to research. These questions provided a helpful resource in framing the current research to reflect KMR principles, and were instrumental in guiding analysis, processes alongside Western guidelines available in Braun and Clarke (2006), discussed in the Qualitative Research section following. As mentioned earlier, as the researcher, care must also prevent inadvertently depleting the mana of the research population, denying acknowledgement and ownership by assuming all the accolades from the research as ‘your’ work.
7. *Kia kakau mahaki* - be humble, don’t flaunt your knowledge

This principle acknowledges that knowledge and information held by both researchers and communities is of equal validity and importance. Māori are often confronted with the view that Māori knowledge is not seen as legitimate and has to be proven to be so by ‘experts’ (Bishop, 1999). Understandably, undermining or intimidating participants leads to poor engagement. The idea of ‘letting your attributes speak for themselves’ or humility of the researcher is implied in this principle. It is key to establish respect for the information and knowledge held by the participant, that the research team is genuine and values the participant’s input. This principle also suggests utilising your credentials to advance communities rather than projecting them upon the people, and simply benefiting yourself as a researcher. The primary investigators of the Hauā Mana Māori project, in spite of being experienced researchers, were humbled by their experience within a KMR environment.

8. *Whakawhānaukataka,* - making connections

This refers to the principle of extending whānau structure or making connections is a kaupapa Māori ideal fundamental when researching Māori. The importance of establishing strong relationships between participants and researchers; maintaining them is especially key to performing meaningful KMR, promoting all involved.

*Te Ara Tika* - a Māori Ethical Framework

Hudson et al, (2010) developed a Māori Ethical - *Te Ara Tika* (the correct pathway). It aims to attain an ethical, more constructive approach towards hauora Māori research and following this pathway further consolidated the KMR approach taken within this research. Emphasis was placed on the need to effectively identify: potential risks; specific roles, relationships and responsibilities of those involved in research; concepts of justice and reciprocity allowing positive outcomes for whānau, hapū and iwi; perceptible outcomes for all involved in research, supporting more equitable benefit sharing. Principles for this model, as for KMR principles, are largely drawn from tikaka Māori, mātauranga Māori (traditional knowledge), the Treaty of Waitangi, indigenous
values and Western ethical principles, and include: (1) Whakapapa (relationships); (2) tika (research design); (3) manaakitanga (cultural and social responsibility) and; (4) mana (justice and equity). Other concepts embedded within this framework include the Māori values of whakapono (faith);  tūmanako (aspirations); aroha (awareness); tapu (special) and; noa (mundane). This framework was also incorporated to guide the study of Southern hauā Māori. Of benefit, Hudson et al (2010) designed a visual representation of this framework (see Appendix B.). The framework is represented as a circle and segmentalised into quarters denoting the four main principles. Each of the principles in turn is divided into three parts, and signifies progressive expectations of ethical behaviour; the closer to the core, the more essential to ethical research process. Most central are considered 'best practice' research which embodies Te Ao Māori. ‘Good practice’ presents as responsive to things Māori and is represented by the middle section. Researchers are required to address the outermost part of each sections, which express ‘minimum standards’, to achieve ethics. This process both directed the current research’s safety mechanisms and influenced the diagrammatic depiction of the qualitative study, as discussed later when reviewing the development of a research tool used within this study.

Guidelines provided in KMR principles and the Māori Ethical framework have informed all processes throughout the research and this thesis sought to meet the aspirations of both these frameworks. Employing these values is not only an effective model for working Māori but, furthermore, a respectful and successful method to conduct research in general.

QUALITATIVE RESEARCH GUIDELINES

Given that the primary aim of this study involved exploring ‘perspectives’, qualitative research was considered to be the most appropriate method of approach. Qualitative research “is based on an interpretative epistemology, meaning that knowledge is generated and shaped through interaction between those involved in the research process” (Carpenter, 2004, p. 9). Many assumptions and characteristics of qualitative research, as described by Carpenter (2004), match KMR ideals as can be seen in table 1. (See Table 1.)
Table 1: Relationship between qualitative research characteristics (defined by Carpenter and Whalley, 2004 p. 10.) and KMR principles, (as described by Smith, 2000).

<table>
<thead>
<tr>
<th>Qualitative Research Principles</th>
<th>KMR Principles</th>
</tr>
</thead>
<tbody>
<tr>
<td>Research is grounded in peoples everyday lives and in exploration of how people experience and make sense of dimensions (e.g. Interventions, events, relationships) of their lives</td>
<td>KMR is founded on observing tikaka practices, which provide framework for life in Te Ao Māori. The principle of tino rangiririrakata (self-determination) applies here.</td>
</tr>
<tr>
<td>Human behaviour can only be understood in context</td>
<td>Researchers are reminded “kia tupato”- proceed with care and to be vigilant around respecting kawa and tikaka, or protocols and procedures, which govern how many Māori view the world and engage in day to day life. The data should essentially be analysed using frameworks that encompass Māori world-views and epistemologies.</td>
</tr>
<tr>
<td>People, including the researcher, perceive and interpret reality differently, there are multiple realities rather than an objective truth to be discovered.</td>
<td>Whole premise of KMR is providing research framework that acknowledges the Te Ao Māori lens is different from that of Te Ao Pākehā or mainstream approaches to research and also Māori are a diverse population. This also acknowledges that within the Te Ao Māori there are multiple realities, perspectives and experiences of being Māori.</td>
</tr>
<tr>
<td>Research is conducted in a natural setting (as opposed to controlled or laboratory settings).</td>
<td>KMR requires allowing people to define their own space and to be able to meet and talk about research on their terms, not necessarily the researcher’s. Manaakitanga (hospitality), is a central concept to creating a safe environment for research participants, so they feel comfortable and able to fully participate.</td>
</tr>
<tr>
<td>The research process is initiated by ‘problems’ or irritants arising from the experience of everyday life or the ‘realities’ of clinical practice</td>
<td>Researchers should endeavour to identify and respect Māori aspirations for research, allowing whānau, hapū, and iwi to define what issues they determine important and this should lead to positive transformative outcomes for their community. KMR does not always come from a problematic or deficit outlook.</td>
</tr>
</tbody>
</table>
The researcher is an integral part of the research process. The issue is not one of minimising the researchers role but describing and explaining it thoroughly.

| SAME | Kia kakau mahaki- be humble, don’t flaunt your knowledge. This principle acknowledges that knowledge and information held by both researchers and communities is of equal validity and importance. Manāki ki te Takata: emphasises, the expectation and responsibility to form and maintain relationships when entering research Māori and supports developing Māori research capacity within whānau/hapū/iwi. Because the researcher is so intimately involved in the qualitative research (and not a blinded objective outsider), it is important that who they are is and where they come from is described so there is an understanding of the perspective they might overlay the project with and why they might do what they do. A reflective statement or whakapapa is helpful to provide reference of where the researcher is from and their background. He kanohi ki te kanohi- face to face, demonstrates respect and a commitment to the relationship. This is imperative for building a level of trust, developing essential relationships and allows for intent of the researcher to be determined by a Māori community.  
DIFFERENT: Kia ngakau mahaki- be humble, don’t flaunt your knowledge, the researcher, care must also prevent inadvertently depleting the mana of the research population, denying acknowledgement and ownership by assuming all the accolades from the research as ‘your’ work. |
Data analysis is inductive and interpretive.

“Kia āta-whakaaro’ (precise analysis) and ‘kia āta-korero’ (robust discussion) of the practical/ethical/spiritual dimensions of any project is necessary to provide a foundation to ‘kia āta-whiriwhiri’ (consciously determine) the conditions which allow the project to ‘kia āta-haere’ (proceed with understanding).”

Data are presented in narrative form with the aim of preserving and representing the participant’s voices.

Manaaki ki te takata-establishes the responsibility and commitment of the researcher engaging in research with Māori is to ensure the people from the community are not misrepresented. A well-known whakatauki (proverb) states: Te kai a te rakatira, he kōrero – (the food of chiefs is talk), and refers to the importance to many Māori of the use of spoken language, and is demonstrated in the predominant use of whakatauki, waiata (songs), pepeha (stories), karaka (incantations), whaikorero (ceremonious discussions), and karakia (prayer).

Qualitative methods of gathering data including the collection of stories, discussion, art, and other forms of expression have been identified as appropriate for KMR research (Rautaki Ltd and Nga Pae o te Maramatanga, n.d).

For Māori, qualitative methods have enabled us to ‘give voice’ and provided an opportunity to explain phenomenon from our own perspective. It allows for a Māori perspective to be heard, and allows for more equal empowerment of the participant. The level to which this occurs differs in each research project, within each method (and is not limited to qualitative methods), and across different researchers (Rautaki Ltd and Nga Pae o te Maramatanga, n.d)

Thematic analysis approach of analysing qualitative data has been used in similar research looking at Māori perspectives. Bothio and Huntington (2006, p. 24) explain the rationale for choosing a qualitative design using interviews.
suggesting it was “…consistent with being a traditionally narrative group who taught culture, Te Reo (language), values and beliefs to each other by way of story, in a place that is deemed safe and appropriate to them…”.

Clear descriptions and guidelines for thematic analysis are set out in depth by Braun and Clarke (2006), in a useable method for the emerging researchers. This framework largely guided the analysis process employed for this qualitative study and thesis, *He Kiteka Hauā i Murihiku*. Table 2 represents an overview of the Braun and Clarke’s (2006) detailed 6-phase guide how to best perform thematic analysis, and directions on how to achieve ‘good’ thematic analysis.

**Table 2 Guidelines for effective thematic analysis technique as described by Braun and Clarke (2006).**

<table>
<thead>
<tr>
<th>Phase</th>
<th>Description of how to effectively perform phase of thematic analysis</th>
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</table>
| 1. Transcription and familiarising yourself with the data. | Transcribe data to an appropriate level of detail.  
Read and re-read the data, noting down initial ideas.  
Check transcripts against the tapes for “accuracy”. |  
| 2. Coding and generating initial themes.   | Code interesting features of the data in a systematic fashion across the entire data set,  
Collate data relevant to each code, giving each data item equal attention in the coding process.  
Coding process should be thorough, inclusive and comprehensive, to ensure themes have not been generated from a few vivid examples. |  
| 3. Searching for themes, analysis         | Collate all codes into potential themes, gathering all relevant data extracts to each potential theme.  
Check themes are internally coherent, consistent, and distinctive.  
Analyse data by interpreting and, making sense of what is being said rather than just paraphrasing or describing. |
| 4. Reviewing themes, | Check the themes work in relation to the coded extracts and the entire data set. Generate a “thematic map” of the analysis. |
| 5. Defining and naming themes | Continue with ongoing analysis to refine the specifics of each theme and the overall story the analysis tells. Generate clear definitions and names for each theme. |
| 6. Producing the report | The final opportunity for analysis. Clearly explain specific approach to thematic analysis. Select vivid, compelling extract examples, final analysis of selected extracts, relating back of the analysis to the research question and literature, producing a scholarly report of the analysis. Use language and concepts in the report that are consistent with the epistemological position of the analysis. Ensure analysis tells a convincing and well-organised story about the data and topic with a good balance between analytic narrative and illustrative extracts provided. Ensure there is a good fit between what the researcher claims to do, and what they have shown to have done – i.e., described method and reported analysis are consistent. Researcher is positioned as active in the research process; themes do not just “emerge”. |

Although the guidelines provided are thorough, the authors acknowledge their desire to provide some framework whilst avoiding limiting the flexibility of using this approach. It is noted that this type of analysis is not expected to be linear, rather a process where there is movement back and forwards throughout the phases as required. Time should be allowed for all phases of the analysis to be completed adequately, without rushing a phase (Braun and Clarke, 2006).
Personal reflective statement

Importantly the background, world-views, and experiences that contribute to the ‘lens’ of researchers performing the analysis phase of qualitative research also needs to be taken into account as this may present certain biases in how the data is interpreted and represented. As discussed, it is imperative that the researchers responsible for the analysis phase in KMR to have a close understanding of the tikaka and practices of the rohe (region), to effectively and accurately represent the themes, views and perspectives that arise from the qualitative data. Therefore presented below is my reflective statement to provide a sense of my world-view.

I am primarily a mother to three tamariki/children, a practicing physiotherapist (with over 18 years experience) with my own physiotherapy clinic in Dunedin and I am the Kaiarahi Māori at the University of Otago School of Physiotherapy, working on the Ethics committee, teaching things Māori and supporting the physiotherapy students throughout their undergraduate journey. I am also an active member of Ōtākou Rūnaka and I am a member of the whānau committee. I was born in Dunedin/Otepoti, grew up here and returned to Dunedin where I live presently, 10 years ago following living in North America for 8 years. I have long had an interest in Te Ao Māori, being drawn into the Dunedin Māori community as a young child under the caring wings of my great Aunt Emma Grooby, who was one of the founding members of the Māori Women’s Welfare league. I have been especially interested in hauora Māori and have entered this project as emerging researcher or Kairakahau Māori, hoping this to be the start of my research career chasing the goal of enhancing Māori experiences of health and wellbeing. It is important to highlight that I am of Kāi Tahu ancestry, and although I feel strongly connected to Ōtākou, my whakapapa does extend to mana whenua status in the research project defined location of Murihiku rohe as I also have connections to Ōraka Aparima Rūnaka and Kaka Point. I also have Scottish and English ancestry, with four generations of links to Dunedin and the Taieri behind me on my Mother’s side. Therefore I live my life in both Te Ao Māori (Māori world) and Te Ao Pākehā (non-Māori world), acknowledging both as important to contributing to my world lens. I also feel privileged to be able to practice physiotherapy as I find it is a health profession, which requires me to be open to many cultural perspectives.
The following two chapters discuss the engagement process with the hauā community in Murihiku, the design of a data collection tool and the methods that were used in this research and demonstrate how these were largely informed by principles and philosophies covered within this chapter.
CHAPTER 3- DEVELOPMENT OF THE PROTOCOL

DEVELOPMENT OF THE PROTOCOL

To more fully understand the barriers and facilitators experienced by hauā Māori and their whānau interviewed when accessing disability services and support, (one of the main aims of the Hauā Mana Māori project), we first wanted to investigate hauā Maori perspectives on health and disability (one of the main aims of this thesis). As mentioned in Chapter 1, this was also identified as an important approach to assessing issues relating to access to healthcare by Nikora et al. (2004). It was essential to first develop a clear framework for the research that reflected interpretation of the study and direction from the Murihiku hauā Māori population and their whānau, as per KMR principles, before effective data collection would be possible. As developing an appropriate research framework to collect data relevant to Māori with disability and their whānau was one of the aims of this thesis, it is imperative to discuss this process in some detail. The research team developed a structure for the research and this was conceptualised into a model to facilitate introducing and explaining the research to the Murihiku community. Following further consultation this model was adapted to be used as an actual data collection tool. The steps taken to develop the framework and models used within this research are detailed in the next section. The development of the protocol was fundamental to the Hauā Mana Māori project, and whilst the whole research team was involved in the basic structure of the research, it was the Kairakahau Māori (myself and Kelly Tikao) who developed and worked intimately with the framework and models. These formed the basis for the data collected and analysed for my thesis, and are thus described in detail.

FORMULATION OF AN IDEA – RIPPLE EFFECT (WHAKĀRO PÕKARE).

It was recognised as valuable to embody a metaphor for Whānau Ora within this project, as Whānau Ora is intertwined within hauora Māori issues and in keeping with tikaka Māori, as metaphors are used prominently in Māori whakatauki (proverbs) to enhance transference of information and understanding of concepts (Jacob, 2014).

As a starting point, and in the spirit of being relevant to the research population, specific care was taken to match the foundations of the research to Ngā Kete
Mātauranga Pounamu Charitable Trust philosophies of whānau ora. This concept was then broadened to guide the project as follows:

_Whānau Ora is about our walk with whānau in weaving wellbeing outcomes that enhance knowledge, attitude and behaviour towards the pursuit, attainment and maintenance of whānau goals and aspirations....our setting or contribution is in the health and social service arena whereby we wrap holistic flax roots driven service provision around individual or whanau plans promoting a no wrong door/service area point of access.. _ (Personal communication with Tracey Wright-Tawha, March, 2012).

This definition further consolidated foundations of the research and the importance of being guided by the individual ideas and aspirations of wellness for whānau, to enhance knowledge towards perspectives of disability.

To ensure participants were respected as central to this project, they were likened to the concept of a kōhatu (a stone or pebble) being dropped into the centre of a puna (pool of water) and the pōkarekare (ripple) that ensues, represented how hauā Māori create an affect or ripple within their community, be that a displacement of thinking, of services, of needs, of discomfort, of challenge. Their energy creates ripples, and how those ripples are perceived by hauā Māori, their whānau and their community could indicate perspectives of their needs and how to best cater for these from a disability service angle.

From this, stemmed the Ripple Theory or the Whakāro Pōkare for this study that embraced the idea of hauā Māori creating a ripple effect in their communities, and symbolised how they impact and are impacted upon within their environment. Using visual imagery has also been identified as a useful way to relay information within Māori populations (Cram et al, 2003). Accordingly a visual representation of the Whakāro Pōkare was developed as follows. The research pool or puna was designated by a porowhita (circle) and another two porowhita were placed inside these porowhita. The inner porowhita represented the participant, those hauā Māori living in Murihiku, and were characterised by the kōhatu that remained at the centre of this research project at all times. The next circle contained those close to the participant from iwi, hapū, whānau, whoever they determined were to be within this arena. The last porowhita included values associated with kaupapa Māori that the Kairakahau Māori
believed were strongly connected to the topic of the research, therefore aligning the research with *Te Ao Tawhito* (the ancient world of our tūpuna), connecting the tool to something of the past. These were as follows: *Te Ao Hurihuri* (changing world); *Tikaka* (customs); *Te Reo Māori* (Māori language); *Rakimarie* (peace, humility); *Kōrero* (communication); *Titiro* (to view, perceive, vista, perspective); *Āta whakaroko* (to carefully listen, to hear what is being said); *Mana* (pride); *Kaha* (strength); *Aroha* (love); *Manāki* (care for) and; *Tohatoha* (distribute, share out). These were also added, on the outer layer to acknowledge the creation of a ‘safe space’ for the research to take place, guided by *kaupapa Māori* philosophies. To highlight the research was addressing the wellbeing of *whānau, Whānau Ora* was placed on every *porowhita* or *pōkarekare* (ripple).

A visual depiction of the *Whakāro Pōkare* (see figure 1), representing the research project, was developed and prepared to introduce the research and the research team to the Murihiki community at the initial engaging meeting (or *hui*). This was also used as a governing research framework.

![Whakāro Pōkare Diagram](image-url)

**Figure 1**: The Whakāro Pōkare Model representation of the research prepared to present to the Murihiku community at the initial hui at Tomairangi Marae.
This pictorial representation encapsulates the importance of the centrality of hauā Māori within this research, by placing hauā Māori in the middle. The research is represented in the visual depiction as a puna or ‘spring of knowledge’ and implied the hauā Māori are gently placed within research that is safely governed by Whānau Ora and kaupapa Māori principles.

CONSULTATION WITH THE MURIHIKU COMMUNITY

Having a broad research framework and “whakāro pōkare” model prepared to present to the hauā Māori community, consultation with the community was set to take place.

A pānui (notice) inviting hauā Māori to articulate their realities on living with was disability (see Appendix C) was distributed widely in the Southland region through various networks in Murihiku, including by the Ngā Kete Mātauranga Charitable Trust, the Pānui Rūnaka, Kai Tahu newsletter, and the Southland rūnaka (Waihōpai Rūnaka, Te Runanga o Awarua, Te Runanga o Oraka Aparima, Hokonui Rūnaka).

An initial hui (meeting) to present the research ideas was held at Tōmairangi Marae, Invercargill, 30th of March 2012. This marae was suggested, as it is convenient to Invercargill city and is considered significant by the local members of the research team as many hauā Māori settled in Murihiku were originally from other tribal affiliated areas of New Zealand.

The initial hui was well supported by the community with approximately thirty attendees. A mihiwhakatau (opening ceremony), guided by the manawhenua (local tribal members of Murihiki), opened the hui (meeting) and mihimihi (introductions) followed. It was suggested by members of Ngā Kete Mātauranga Pounamu Charitable Trust that introductions include a description of what each person considered their disability to be, with attendees choosing if they wished to and how much they wished to disclose.

Many of those who attended used Te Reo Māori, waiata and haka to express themselves and whakapapa, forgiveness, humour, sadness, and stories of overcoming were also included within the community’s korero (discussion).
A power point presentation was delivered by the Kairakahau Māori, which introduced members of the research team and encompassed photos and images of whānau, research ideas and framework, using the Whakāro Pōkare imagery.

Following the presentation, the community was asked to provide feedback on the proposed research and the framework. Comments from the community included:

- Enthusiasm and appreciation regarding the opportunity for this community to voice their experiences of disability and acknowledgement of the need for this research to occur.
- The general acceptance and approval of the aims of the research and the framework by the attending hauā Māori community.
- The importance of acknowledging tikanga Māori within research processes. It was suggested that tikanga Māori provided the tika/correct framework to inform, guide and navigate the research process to allow good connections to be made, trust to be gained and acceptance of research by the community. Many of those who attended used te reo (Māori language), waiata, haka (challenge performance) to express themselves.
- Importantly, the valuing of kaumātua was brought to the attention of the group. The kaumātua from the University of Otago who supported the research was not available to attend this hui and the research team continued to present the research without kaumātua support. It was suggested by a prominent tāua (Kāi Tahu word for Grandmother) of the community, to give mana to this research there needed to be kaumātua representation at all hui. She suggested this also removed the responsibility from the Pākehā principle investigators, neither of whom were fluent in Te Reo Māori or tikaka, and this reflected diminished mana or integrity of the research to the kaumātua present.

Completed Participant Interest Forms with contact information (see Appendix D) from attending hauā Māori and their whānau who were interested in being involved in a steering group or Rōpū Kaiārahi for this project, were collected. Signed University of Otago “talent release forms”, were also collected for the use of photos taken during this hui in future presentations of this project.
FORMATION AND FEEDBACK FROM PARTICIPANT ADVISORY GROUP (RŌPŪ KAIĀRAHI).

This project was guided by Uia Tonutia - Māori Disability Research Agenda, (MOH, 2011) which recognised was the need to reduce the “double whammy” effect within the disability research sector research that creates “marginalisation of disability issues in the health sector and the marginalisation of Māori in the disability sector” when not directly involving hauā Māori to inform research priorities, ethics, methodology, evaluation. It was decided pertinent to form a Rōpū Kaiārahi. From those who attended the hui at Tōmairangi Marae, sixteen people completed the contact information form and volunteered to be part of our Rōpū Kaiārahi. They comprised hauā Māori, whānau of hauā Māori, and hauora Māori workers, all living in the Murihiku area. Those who agreed to be involved were contacted, via self-identified best means. They were asked if they wished to be involved with a research advisory group, Rōpū Kaiārahi, to assist in framing the questions and methods to be used in the project. Also not only was this in accordance with a KMR philosophy which suggests the community being researched should be integrally involved in defining research questions, methodologies, and processes, it also assisted to develop research capacity within the community.

Ethical approval from the University of Otago Human Ethics Committee was gained to form the Rōpū Kaiārahi (University of Otago Human Ethics Committee’s reference code: 12/028).

Those who identified as being interested in being part of the Rōpū Kaiārahi were invited to a second hui in Invercargill, on May 11th 2012, at the Ngā Kete Mātauranga Pounamu Charitable Trust clinic in Invercargill. Eight members participated in a three-hour hui (meeting), with kai provided, discussing the questions that had been identified in the literature and by the Kairakahau Māori as important questions in the current study. The rōpū (group) was interviewed on the primary questions around hauora/wellness and hauā/disability and their thoughts on the most effective methodologies to be used. Other potential questions were also discussed. This hui was audio-recorded and the recording later transcribed verbatim to assist the research development.
DESIGN OF THE RESEARCH FRAMEWORK.

Main themes stemming from the feedback of the Rōpū Kaiarahi informed the design of the research and are discussed in this section, illustrated by quotes arising from the dialogue at the hui:

1. **Māori relate to Sir Mason Durie’s Model, Te Whare Tapa Whā.**

When discussing Māori perspectives of health, the members of the rōpū suggested *te whare tapa whā* offers a valid representation of hauora Māori:

   P1: I think when you look at the Te whare tapa whā from the model side of things, Māori can really relate to it.

   P2: For me, actually I agree with it. I mean there’s 4 sides to a house and if anyone of those sides is out, I mean, things are out of kilter then not level. But for me, personally, I think there is one there that determines how strong the other 3 walls are and that’s mental. Because depending on where your mindset is, it will either build you up or tear you down ...

   P3: That’s why I also would like to call (Sir Mason Durie) a rakatira, tohu rakatira. He is just so in-blended with everything and if you’re not Māori, you still understand.

2. **Te Whare Tapa Rima**

From this discussion participants continued to suggest that the *Te Whare Tapa whā* representation should include *rakatira* or *Atua* aspect, providing a guidance element to the model.

   P3: To just go in with the blend of mauri ora I reckon you put your top line, up there, Rakatira, what the other one Atua and tino rangatiratanga if they believe in sovereignty through our maunga, through our waka...Tupuna and atua they are on that (white) board we see today.

To incorporate this, a *te whare tapa rima* model was designed, which depicts the element of leadership and guidance. This was expressed by members of the rōpū as being a separate element from ‘whānau’ or even ‘wairua’, which is more of an individual spiritualism, or sense of self. ‘Rakatira’ represented guidance provided by inspiring leaders and also other influences that present values or beliefs for which Māori connect to and practice within their daily lives. These values and how connected or disconnected Māori are to them, may impact on the status of hauora.
3. **Importance of valuing and honouring tikanga Māori**

Acknowledging aspects of things Māori was deemed as an important factor to incorporate within the study to the Rōpū Kaiārahi. Members of the rōpū stated that the use of karakia, waiata, and haka were appreciated and required to provide a safe environment for this project to continue. Discussed also was the importance in ensuring support from kaumātua throughout the process.

P2 ....Karakia, coming back to this point, is really important because it links us with our tipuna and our atua with the blessing of those kaumātua,... karakia gives us structure and that’s where it comes into the Kaupapa (of this study), if you understand structures of karakia, it’s also the same as understanding the structure of where we need to go, and the structure of life.

P3 .... We go to our Pōua and our Tāua our Koro and our Wahine and our Kuia to seek some guidance and some reassurance.

A member of the Rōpū Kaiarahi highlighted the importance of having a kaumātua to provide tikanga guidance and awhi (cultural support) to the research, was asked if she would take on the role of kaumātua within this research. She was already a prominent kaumātua in the Murihiku community and thankfully she agreed to accept this responsibility. The research team was extremely fortunate to have guidance from such a knowledgeable and respected kaumātua, and this did indeed contribute towards the mana of this project.

4. **Environment and effect on hauora needs to be acknowledged within research framework.**

The environment in which we live can have an effect on our hauora and was therefore acknowledged as an important aspect to be taken into account within the research, by one of the senior Māori health researchers advising this research. A suggestion was made to reference the Pōhā Titi model (see Appendix E). At the time the research was being conducted this model was in the midst of being developed by Ngā Kete Mātauranga Pounamu Charitable Trust and the local community “to assist and enhance whānau resilience” and to encapsulate a notion for healthcare provision within the environment of the Murihiku area.

3 “Pōua” is the Kāi Tahu word Grandfather.

4 “Koro” is the generic Māori word for Grandfather.
Pōhā Tītī is the traditional Kāi Tahu method of preserving manu tītī (muttonbirds), a Kāi Tahu delicacy, using natural fibres. The Pōhā Tītī/ Pōhā Oranga model alludes to part of the local landscape, the southernmost islands of Aotearoa/New Zealand called the Muttonbird Islands. The model reflects that the migration of whānau to the isolated Titī/Muttonbird Island is an important way that southern Māori continue practice and hand down the traditional tikaka (ways) and matauraka (knowledge). The model explains how the environment on the islands is and draws on how this strengthens whānau ora (health of whānau):

The Titī/Muttonbird Island is one place where whānau by virtue of their whakapapa, come together...to work, to share, to learn and teach, to play, to laugh, to enjoy each other without the distractions of the outside world. It is an opportunity to reconnect with our whakapapa (genealogy), our whenua (home land), Te Ao Wairua (spiritual realm), Te Ao Kohatu (ancient world). The islands draw you back each year and embrace you as soon as you arrive...It is our whakāro that those values and behaviours that have sustained us as a people for hundreds of years can be utilised by and for whānau development.

The model also refers to the resourceful and flexible nature of natural fibres found in harakeke (flax) and to the resilient character of people in regards to being able to learn, heal, adapt and sustain themselves.

5. **Questions around perceptions of disability and wellness were appropriate questions.**

The following research questions to be used in the project were put forward to the Rōpū Kaiarahi for comment:

a. Wellness - What does wellness mean to you? What makes you well? What helps you achieve it? What makes it hard for you to achieve this?

b. Disability – What does disability mean to you? Tell us about your disability.

This stimulated much enthusiastic discussion and there was a general acceptance that the above questions were applicable and valuable as potential questions to be used. The Rōpū Kaiarahi confirmed the importance of considering perceptions of wellness and disability within the research and expressed excitement that hauā Māori were being provided the opportunity to have their voices heard, their realities of living with disability and what that meant for them and their whānau recorded.
6. **Suggested methods to recruit participants**

The following were suggestions from the *Rōpū Kaiārahi*, as people or organisations to contact to recruit participants:

- Community groups, e.g. Intellectual Disability Empowerment in Action (IDEA) Services.
- Southern District Health Board contacts
- *Māori* Health providers such as Ngā Kete Mātauranga Charitable Trust and Awarua Health and Safety Services, Te Korowai Hauora – Māori Mental Health unit
- Local *rūnaka*
- Local *Kōhunga Reo* and *Kura Kaupapa*
- *Kaumātua* – Those identified in the community as Tāua (Grandmothers) and Pōua (Grandfathers)
- Members of *Māori* groups such as *Kapa Haka* (performance groups)
- Organisations who provide *mirimiri* (massage) and alternate healing therapies to clients with a disability.

7. **Suggested methods of data collection**

Following is an overview of the points made by the *Rōpū Kaiārahi* reflecting their recommendations for approaches to gathering information.

- In-depth, *kanohi ki te kanohi* (face to face) interviews with *Māori* living with a disability and their *whānau*; interviews to be either audio-recorded or video-recorded. It was proposed the interviewer could be a member of the research team or a *Māori* person living with a disability or one of their *whānau*.

- Different participant groupings might be considered, given different styles of communication. Individual interviews were suggested for older participants as it was felt they might work better within this population. Focus groups were suggested for interviewing with younger groups as it was also thought this might facilitate more in depth discussion within groups of younger people. The following grouping of participants was put forward:

  1. 16-25 years old/*Rakatahi* - focus groups up to 7 participants
2. 26-49 years old/ Kaimahi- focus groups and individual follow up if identified as necessary up to 7 participants

3. 50+ and kaumātua- kanohi ki te kanohi, with focus group if identified as necessary by the participant

4. Whānau and caregivers of Māori living with a disability- focus groups and individual follow up if identified as necessary by the participant

- Allow participants to choose the venue for the interviews to take place, permitting them to be define a comfortable and safe environment. Participants may wish to conduct the interview in their homes for convenience and familiarity. It was also recommended that an optional venue be offered, as researchers coming to the home may be considered too intrusive for some. Members of the Rōpū Kaiārahi from Ngā Kete Mātauranga Pounamu Charitable Trust suggested that their rooms would be made available to those who preferred to meet away from their homes.

- The use of multi media to collect data was suggested as ideal within this research. Using photos (or a “photo-voice” type methodology), where participants take digital photographs with provided cameras of items they consider represent contributing factors to being disabled and being well, was perceived to be a good idea.

- Following from this, it was also acknowledged many of the Rōpū Kaiārahi enjoyed creating different forms of art to express themselves. It was therefore recommended the participants provided examples of art (for example, using waiata (songs), drawing, sculpture, poetry) identified by the participant that expressed their realities of living with a disability.

- The use of the Whakāro Pōkare model was put forward as visual means to collect information from within the semi-structured interviews, to facilitate the interview. One of the members of the Rōpū Kaiārahi stated he understood it was well known that Māori respond well to use of visual techniques for learning and communication. There was also discussion about how this technique could be used to provide a graphic recording of discussion.
Subsequent to this *hui* with the *Rōpū Kaiārahi*, members from Ngā Kete Mātauranga Pounamu Charitable Trust gently reminded the research team the importance of staying in touch with this *rōpū* to continue a good relationship.

Inspired by this, the research team was invited the *Rōpu Kaiarahi* to Dunedin from Murihiku, to visit the work environments of the research team, gaining further insight as to who the research team were and where the knowledge would be stored and looked after. A van was organised by Ngā Kete Mātauranga Pounamu Charitable Trust and seven members of the *Rōpū Kaiārahi* came to Dunedin.

There was a *mihi whakatau* (welcoming ceremony) at the University of Otago School of Physiotherapy, led by Dr Jim Williams who was the *Kaumātua* representative for the research team in Dunedin, followed by a guided tour of the School of Physiotherapy, offices of the Primary investigators and the different classrooms, biomechanics and balance labs. A walk through the university campus led to a visit to the *Te Huka Mautauraka* (the Māori Centre), support network for Māori students studying at the university, which also served to introduce one of the participants from Murihiku, as he was thinking about coming to Dunedin and studying in the future. The day finished at Donald Beasley Institute rooms, familiarising the *rōpū* with the offices and resources available there. This interaction between service, participants and the research team provided an opportunity for knowledge exchange, strengthening rapport and trust, and provided greater context of the project for both the Dunedin based research team and the Murihiku *rōpū*.

**DEVELOPMENT OF THE VISUAL TOOL**

Mourie (2012), Data collected data in physiotherapy and disability research in the Cook Islands using a similar model diagrammatic representation to facilitate in depth interviews (see Appendix F). This model placed comments from the interview which related to seven identified areas (rehabilitation, social relations, communicating, work around the house, daily living, attitudes and feelings, public spaces) within a heptagon, allowing for a plan of action to be developed to address attitudes, needs and priorities and barriers for participants living with disability in the Cook Islands. Informed by the above approach, and guided by the feedback from the *Rōpū Kaiārahi*, a visual model to aid data collection was constructed. In order to enable honest and clear expression of participants in
kanohi ki te kanohi/ face to face interviews, an overlap of the whakāro pōkare /ripple effect and whare tapa rima was used, and incorporated the following:

1. The initial visual whakāro pōkare model was used, representing the KMR principles surrounding the puna, or research pool, providing a safe forum for the research to be conducted. A puna/pool of water was represented, using a water motif within the model. The participants, hāua Māori, are placed in the middle of the model, symbolising their centrality within the research.
Ripples, designated by enlarging circles, would allow participants to represent priority to the elements that disabled them and made them well by placing these elements on the model (either by placing word cards or writing directly onto the model) closer or further to the centre on the diagram.

2. *Te Whare Tapa Rima* model.
This model was an adaptation of the Sir Mason Durie’s depiction of hauora Māori, *te Whare Tapa Whā*, and included an additional component in response to a suggestion from the Rōpū Kaiārahi. “Rakatira” was added as another dimension of hauora, which refers to leadership and also embraces the notions of tupuna, tuakana (older ones), and Kaiārahi (leaders). Therefore the five components of hauora in the *Whare Tapa Rima* model included Rakatira; Hinengaro; Tinana; Wairua and; Whānau, giving five tapa (walls) to the “Whare”. A pentagonal shape, in essence the shape of a house, was used to represent *te Whare Tapa Rima* model and the house of the participant, replacing the central circle formerly used to depict the participant. This shape was used to perpetuate a holistic approach around the broad question of disability and wellness and permitted the acknowledgement of *te Ao Māori* to continue to be present and fundamental to the research.

3. Physical environment.
In order to incorporate an element of landscape and natural environment, a central pentagon that represented the *whare* (house) formed by the five walls in *Te Whare Tapa Rima* was incorporated. This also depicted the participants, placed in the middle of the puna, representing the research. Context was placed on the idea that some Ngāi Tahu traditional Pā (fortified village) sites that were built on top of water such as on estuaries,
headlands surrounded by water and on Islands (for example, Pukekura and Māpoutahi.) The placement of these Pā sites was strategic to protect the wellbeing of the hapū, by having an expansive view over the waters and approaching waka (canoes). Further rationale became aligned with the notion of ancient whare, which were made from a number of natural resources depending on plants growing in close proximity to the kaika (village) such as: toetoe, pātītī (tussock), wīwi (rushes), raupō (bulrush), harakeke (flax), muka (flax fibre), kōrari (flax flower stalks) and nikau leaves. These whare were thatched together, low to the ground and small (Beatties, 1994). They were waterproof and sturdy but as they were constructed entirely with fibrous materials, they were also porous. This concept is portrayed within the Whakāro Pōkare Visual Tool by interrupting straight lines of the pentagon with gaps. The thinking here was the walls of Te Whare Tapa Rima are porous and allow for movement of thoughts to and around other components of the framework and reflects commitment to reduce the barriers and provide flexibility in the research approach, utilising this breathable porous whare to highlight flexibility, change, adaption and flow of thoughts on seeking of balance and hauora. This also represented a component of permeability, acknowledging the disabling and enabling factors identified by the interviewee have direct effect on them. Figure 2. shows the original version of the Whakāro Pōkare Visual Tool.
Figure 2: The original version of the Whakāro Pōkare Visual Tool

Once this original version was completed it became apparent the model was too wordy and crowded, and it was recognised the graphic for the poster needed to be simplified to create a clear tool for data collection. It was decided to remove all words, except “Hauā Mana Māori” in the middle, continuing to highlight the centrality of participants to this research. The final graphic representation of Whakāro Pōkare Visual Tool, shown in figure 3, was produced with the words removed. As well as creating simplicity, eliminating the writing from the original graphic, allowed for an open discussion where only the words of the participants, depicting their ideas, were recorded on the tool.

The visual model was laminated to enable white board markers to be used to record participants’ ideas that could be photographed and wiped away at the conclusion of the interview so that the laminated tool could be reused for another interview. Having the printed model laminated also provided an effective method for encapsulating a clear, visual depiction of the information from the participant,
allowing the participant to manipulate and alter the written information accordingly. Two copies of the final visual tool were printed, one large A1 poster to use in potentially larger group settings and one smaller A3 size one to be used with individuals and their whānau for ease of bringing into people’s homes. Cue cards were created using the removed words from the original Whakāro Pōkare design, with the idea that they could be used if the participants needed prompting or inspiration as they were words encompassing hauora Māori and te Ao Māori. These cue cards were also laminated and could be placed on the model using blue tack on the back of the card.

Figure 3: The final version of Whakāro Pōkare Visual Tool used within the in-depth interviews.
DEVELOPMENT OF QUESTIONS

Following meeting with the Rōpū Kaiārahi, a framework for interviewing hāua Māori participants was developed.

Koru element in the Interviewing

It was identified, following reviewing the Rōpū Kaiārahi hui audio recording, that the discussion often appeared to digress but would eventually return to be closely relevant to the core of the discussion. Stopping this seemingly irrelevant meandering discourse may have led to key information being overlooked. Although often time consuming, it was perceived important to value streams of discussion which may move outwards away from principle questions and allow return to the central discussion.

The Koru symbolises freedom of expression that spirals outwards but then returns back on itself, in a continuum. Māori, traditionally viewed knowledge itself, as manifesting itself in the form of a spiral such as the koru as it may “reveal and conceal itself instantaneously” (Mika, 2007). This imagery is also used in te Ao Māori as a metaphor of time as a continuum, that occurs and folds back onto itself, moving outwards and inwards relative to the centre. “If whakapapa measured time, the spiral representation of whakapapa reflects a Māori notion of time as cyclic” (Stewart, 2014, p. 1231). The idea of the Koru was thus used in the question framework to remind the interviewer to permit conversation to spiral outwards to some degree to allow knowledge transmission and collection of important information that may have otherwise gone undiscovered if the conversation was steered short because of time constraints or not seeming pertinent at that time.

The research questions were categorised into three core areas:

1. **Puna** (the pool of water that the framework sits within): the broad questions to be asked: wellness, disability, organisations, access, and whānau.

2. **Taparima**: Once a question had been asked from the Puna section, the researchers would cue the participant to address the question in relation to their experience of te Ao Māori: Hinengaro, Tinana, Rakatira, Wairua, and Whānau.
Koru: Participants were then asked to reflect more deeply on their answers. The koru allowed for participants to express widely and then like a koru come back to the centre or heart of the kōrero.

A cue card for the interviewer was developed to assist with guiding the interviews, providing a consistent framework for the interview process and is represented in table 3.

Table 3: The framework for interviewing participants including the elements of Puna (research questions), te Whare Tapa Rima (Te Ao Maori cues), and Koru (allowing for conversational exploration).

<table>
<thead>
<tr>
<th>Themes</th>
<th>PUNA/Broad</th>
<th>TAPARIMA/cues</th>
<th>KORU/self express</th>
</tr>
</thead>
<tbody>
<tr>
<td>HAUORA/wellness</td>
<td>What does wellness mean to you?</td>
<td>- What makes you well in respect to your hinengaro, tinana, whānau, wairua, atua/rakatira?</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>- What helps you achieve this?</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>- What makes it hard to achieve this?</td>
<td></td>
</tr>
<tr>
<td>HAUĀ/disability</td>
<td>What does disability mean to you?</td>
<td>- Tell us about your disability in terms of hinengaro, tinana, whānau, wairua, atua/rakatira</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>- What Disables You?</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>- Do you think that that living in te Ao Māori makes you see/interpret disability differently than others? If so, how?</td>
<td></td>
</tr>
</tbody>
</table>

The Kairakahau Māori performed trials using the Whakāro Pōkare Visual Tool on each other to modify and improve interviewing technique. This provided opportunity also for the interviewers to become more cohesive and consistent in their interviewing approaches and allowed them to experience being an interviewee.
Having finalised the study protocol and methods following *Kaupapa Māori* Research methodologies the research project was ready to commence collecting data. The research team again approached the University of Otago Human Ethics Committee and attained ethical approval to undertake the study (University of Otago Human Ethics Committee's reference code: 12/175).

In the next chapter the actual research methods used within this project will be discussed.
CHAPTER 4- METHODS

This chapter reviews how the methods used for data collection in this study were determined. Processes for the data analysis and dissemination of the results are also discussed in this chapter.

METHODS USED FOR DATA COLLECTION:

Participant Recruitment:

Based on the recommendations of the Rōpū Kaiārahi and guided by Ngā Kete Mātauranga Pounamu Charitable Trust, Kaumātua support from local rūnaka (Waihōpai Rūnaka, Te Runanga o Awarua, Te Runanga o Oraka Aparima, Hokonui Rūnaka) and the Rōpū Kaiārahi, it was agreed recruitment would be achieved through the following avenues.

Māori Health organisations in Murihiku, namely Ngā Kete Mātauranga Pounamu Charitable Trust and Awarua Social Services, promoted the recruitment of participants through their networks, via newsletters and by directly contacting patients who were considered potentially eligible, to inform them of the research and ascertain their interest to participate.

1. Māori organisations in Murihiku, including local Rūnaka and all Kōhanga Reo in Murihiku were sent a panui (notice) about the research either electronically or by mail. Participant Interest Forms were also sent to these organisations with self-addressed return envelopes. Those interested were requested to complete and return the Participants Interest Form to the researcher in the provided envelopes (see Appendix G and H).

2. Fifty disability services in Murihiku/Southland were contacted via phone and email about the research. Information packs were sent including information about the project, Participant Interest Forms with self-addressed, return envelopes for patients of these services that potentially met the inclusion criteria and were interested in volunteering (see Appendix I).

3. A pānui/notice appeared in the monthly edition of “Pānui,” a Kāi Tahu newsletter that goes out to all registered members of Kāi Tahu īwi.
Inclusion Criteria

Hauā Māori and their whānau were accepted into the study if they:

- were of Māori descent;
- were aged over 16;
- resided in Murihiku area; and
- self-identified as living with disability.

“Disability” was open to a broad interpretation, and allowed participants to self-identify their disability, acknowledging the absence of distinction between wellness and disability, with lack of definition of disability in te Ao Māori. As reported by Harwood (2010) it is up to each whānau to define for themselves who their whānau are (which may include traditional Māori definitions or more contemporary models), thus a broad perspective was taken within this research, and the terms “disability” or “whānau” were not predetermined.

There were no specific exclusion criteria. Considerations were taken on how to accommodate for a variety of impairments or communication barriers, so that no form of disability would be discriminated. For example, research into accessibility of a signer fluent in Te Reo Māori was undertaken, and two signers in the North Island were located in case a potential participant required this service. This was not required by any of the potential participants. If the hauā Māori had difficulty with communication, the whānau or care-giver would be asked to assist with the korero (interview). The research team was prepared to also interview in Te Reo Māori and English, as one of the Kairakiha Māori was competent at a high level of Te Reo Māori.

For this study I aimed to recruit thirty participants. This sample size was based on similar research exploring Māori concepts of disability which recruited fifteen participants (Kingi and Bray, 2000), investigating how Māori talk about health which had a sample size of 28 participants (Cram et al, 2003; MOH 2004, 2012) and another that looked at indigenous perceptions of health that had 14 participants (Stamler, 2010). I therefore considered that a sample size of 30 should be more than sufficient to reach data saturation.
Data Collection

Although it was intended that 3-4 focus groups of 6-8 participants be interviewed with the aim of achieving data saturation with these numbers, this did not occur. Only one focus group discussion occurred and was audio-recorded. Upon reflection following the first focus group interview in which the discussion became convoluted and confusing it was decided that this type of data collection did not fit well using the Whakāro Pōkare Visual Tool. Further it was felt that the participants’ responses were influenced by the other participants and it was difficult to ascertain clear responses. The six participants involved in this focus group were all individually interviewed later.

In-depth interviews for data collection purposes were conducted by the Kairakahau Māori, with each participant at a location determined by the participant and their whānau to ensure participants were interviewed in a place where they felt comfortable and safe. The initial five interviews were conducted by both of the Kairakahau Māori together to develop common interviewing techniques for increased consistency, and the remaining interviews were divided and conducted separately by the two Kairakahau Māori for effective use of time. The Kairakahau Māori also met on a regular basis to share field notes on feedback from interviews and what was going well or not in order to modify and improve the interviewing process.

At onset, the procedures of the interview processes were explained to participants and their whānau and their right to withdraw at any time without prejudice was made clear. A consent form was signed before data collection took place.

All interviews and the focus group were audio-recorded, as data from interviews that have been audio-recorded and then transcribed allows for reliable process of analysing data (Morse, 1995). The Whakāro Pōkare Visual Tool was used to facilitate the interviews. Both the participants and the interviewers (directed by the participants) wrote on the tool with whiteboard pens or placed cue cards on the tool. At the end of the interview the Kairakahau Māori would go over the finished Whakāro Pōkare tool with their participant as an overview of what was discussed in the interview to ensure what had been captured was indeed what
the participant was trying to share. To clarify elements of the interview that were not clear on audio recording (for example, reference to where words were placed on the laminated Whakāro Pōkare tool), the finished, written upon Whakāro Pōkare tool was photographed at the end of the interview. Figure 4, shows an example of a finished Whakāro Pōkare Visual tool following an interview with one of the participants.

Figure 4: An example of a completed Whakāro Pōkare Visual Tool following being interviewed.
METHODS USED FOR DATA ANALYSIS

Imperative to this research was that data were analysed with a Māori lens, by those with an understanding of the te Ao Māori perspective. Te Ara Tika Māori ethical framework guides researchers with appropriate steps necessary throughout the research analysis process: "Kia āta-whakaaro’ (precise analysis) and ‘kia āta-korero’ (robust discussion) of the practical /ethical / spiritual dimensions of any project is necessary to provide a foundation to ‘kia āta-whiriwhiri’ (consciously determine) the conditions which allow the project to ‘kia āta-haere’ (proceed with understanding)” (Hudson et al, 2010 p. 5). I initially led the analysis, aided by the other Kairakahau Māori. Further ongoing analysis was aided in interpretation by discussion with the kaumatua, principal investigators of the Hauā Mana Māori project, the Māori research advisors, the Rōpū Kaiārahi, and the Ngā Kete Mātauranga Pounamu Charitable Trust. For this thesis the data were further reanalysed by myself at a deeper level, revisiting themes to understand them further in relation to my Master’s research questions, adding that additional lens to the analysis.

A thematic analysis was used as a qualitative analytic method to evaluate data, as it had been identified as an appropriate method to be used with KMR (Bothio and Huntington, 2006). This methodology allowed a kaupapa Māori approach, permitting the Kairakahau Māori to apply a Māori lens whilst teasing out important themes within the data. Notably it was a compatible method for the emerging Kairakahau Māori performing the analysis, who were relatively new to qualitative analysis. Initial approaches to analysing the data using this technique confirmed this system indeed fitted well with the qualitative approach of this research.
### Table 4: Description of how phases of thematic analysis method as outlined by Braun and Clarke (2006) was applied to *He Kiteka Hauā i Murihiku* data analysis.

<table>
<thead>
<tr>
<th>Phases of thematic analysis as per Braun and Clarke (2006).</th>
<th>Description of analysis of data performed in this qualitative study, <em>He Kiteka Hauā i Murihiku</em>.</th>
</tr>
</thead>
</table>
| 1. Transcription and familiarising yourself with the data. | The audiotapes from the interviews were transcribed word for word by a transcription service and checked for accuracy by the *Kairakahau Māori*. As the transcriber was not fluent in *Te Reo Māori* a glossary of Māori words were provided to assist with *Te Reo Māori* used by both *Kairakahau Māori* and participants.  

*Kairakahau Māori* transcribed one interview she had conducted largely in *Te Reo Māori* as it contained more *Te Reo Māori* than the transcription service felt capable to transcribe to a desired standard of quality.  

The transcripts were placed into a format with a blank strip to the right for summary notes by the researcher to assist with identifying themes.  

The *kairakahau Māori* read the transcripts multiple times, listened to the audio-recordings, scrutinised the photographs taken of the developed visual tools and referred to their field notes and summary notes in the transcripts, searching for key ideas and perceptions. |
| 2. Coding and generating initial themes. | The use of data identification coding approach, code and retrieve system, and labelling themes as they emerged, contributed to the thematic approach to analysis. Common threads appearing within the interviews were identified relating to issues described by participants leading to either their wellness or disability. The threads were labelled and given a colour code. All comments within the transcripts that demonstrated commonalities were highlighted with the same colour. As new ideas came out of the discussions with all concerned, new colour codes were developed. |

The final colour-coding framework was used to code the interview transcripts allowing the predominant themes and sub-themes to emerge. The quotes from the transcripts with the same colour coding were placed together accordingly.

Processes involving thematic maps to see relationships within various codes were used to assist this process as per Braun and Clarke (2006). (see Appendix J). Broader themes became apparent and within the themes, sub-themes also emerged, combining different colour codes to form these themes.

4. Reviewing themes.

After 25 participants transcripts had been analysed, data saturation was reached as no new themes were appearing, with further analysis. The last five interviews were reviewed and confirmed this was in fact the case.

5. Defining and naming themes.

The emerging themes were presented and discussed in a second hui with members of the Rōpū Kaārahi and the Ngā Kete Mātauranga Pounamu Charitable Trust to ensure that the emerging themes were correct, relevant, and accurately reflected a picture of their community. The findings at this stage were largely confirmed and verified by the community as being a clear and valid depiction of their realities, and there was a request by the group that the research group prepare the representation in a manner, which could be used by this community. Feedback from this hui was used to further analyse and finalise the findings.

6. Producing the report.

Report was submitted to MOH and HRC on the Hauā Mana Māori, part of which included results from the qualitative study referenced in this thesis.

Final thesis for Masters Degree prepared. Further reanalysis of data at an in-depth manner was performed for this thesis and a more thorough review of the themes achieved.
METHODS USED FOR DISSEMINATION

Following the initial analysis by the Kairakahau Māori, to ensure that the analysis was a true representation of realities of disability for hauā Māori, a hui with the Rōpū Kaiārahi and members of Ngā Kete Mātauranga Pounamu Charitable Trust involved in this project was held in the Ngā Kete Mātauranga Pounamu Charitable Trust rooms in Invercargill. It was very important to the Kairakihau Māori that the sensitive information provided was treated carefully, respected and it was an actual depiction of their experiences. A simple representation of the themes was prepared to present a preliminary analysis and written on a whiteboard (see figure 5).

![Figure 5: Representation of emerging themes presented to the Rōpū Kaiārahi](image)

There was an overwhelming consensus that these findings accurately depicted what life was like for them in the Murihiku community and they affirmed that the visual diagrams presented to them were a good representation of this. This justified that Kairakihau Māori had heard information the participants had
shared, and through the analytical process, had managed to capture the key themes that resonated well with the Rōpu Kaiarahi. Feedback from the Rōpū Kaiārahi is further presented and discussed in the results section (chapter 5), and in the discussion section (chapter 6).

As per the participants’ requests, following being inspired by the presentation, the information was made into handout format and laminated for them to be able to use (see figure 6).

Figure 6: Hand out prepared for dissemination to participants.
The *Kairakahau Māori* noted many of the study participants had interests in creating art and crafts as a means to express themselves and keep them active within their communities. Some studied art, some had been producing a wide range of mixed medium artworks over their life time and others considered themselves hobbyists. Many used art as a way to structure their day, to network into other community groups and ultimately to enhance their *hauora, wairua* and *mauri ora*. Whilst constructing a dissemination plan it seemed appropriate to combine the creative talents of the participants with a public feedback of the *Hauā Mana Māori* research project. Participants and Ngā Kete Mātauranga Pounamu Charitable Trust were consulted about the concept of an art exhibition as a way to communicate their realities of being *hauā Māori* to the community they live in as a way of disseminating the research findings and the idea was met with excitement and support from all. Plans were made to hold an exhibition at a local art gallery, invitations sent to all the participants, and follow up phone calls made to ascertain interest and answer any questions. Participants were invited to make creative pieces that they either had produced in the past or made specifically for the exhibition, that they enjoyed making or that they felt helped express what it was like to live as *hauā Māori*.

A two-day art exhibition was held in Invercargill and acted to serve many functions. This was a community-wide event honouring those who took part in this project and those they represented within the disability community. It also highlighted the mutual respect and learning that occurred between the research team and the local *Māori* community. The opening of the art exhibition provided a means to first collect together again with everyone involved in the research, to present the findings to them and obtain constructive feedback from the participants as to whether the researchers were presenting their views correctly, and to allow the participants to relay their feelings of being involved with the project. Laminated cards with schematic representation of the findings were given to all the participants as they requested, to empower them with their own words and to give them the opportunity to correct the researchers where they saw it necessary. The event was extremely well received by both participants and the public and provided an innovative way for participants in this community to further express their realities in a creative form from music to bag making, jewellery, painting, collage and poetry. It was quite an emotional evening with the art gallery filled with participants, family/whānau, and health care providers.
exhibition concluded with a *karakia whakamūtunga* (closing blessing) on the Sunday afternoon, this provided an opportunity to use *tikaka* to formally and spiritually close the *Hauā Māori* research project.

Other means of dissemination of the larger project (incorporating information from this thesis’ findings) to date have included:

(1) Report to the MOH and HRC to contribute to policy development as per the joint tender research project, March 2013.

(2) Plain language brochures both in *Te Reo Māori* and English were developed and distributed to disability services for their clients.

(3) Presentation to *Māori* disability service workers at Te Piringa seventh hui Taumata, Huria Marae, Tauranga Moana, March 2013.

(4) Presentations to health professionals at the University of Otago School of Physiotherapy Centennial Symposium, April 2013.

(5) Media releases in local newspaper, Southland Express, August 8 2013, p. 44.


(7) Publications in the international peer reviewed *Journal of Humanities in Rehabilitation*, “Art as a tool for disseminating research outcomes: The *Hauā Māori* Project and Participatory Action Research in New Zealand.” (in press)
CHAPTER 5- RESULTS

This chapter includes a description of the participants interviewed, common themes of wellness and disability as expressed by the participants and lastly an overview of the participants’ general impressions of the research process and use of the Whakāro Pōkare Visual Tool.

CHARACTERISTICS OF PARTICIPANTS

Given the recruitment strategy, it was not known how many people received the information about the study. Of the thirty-eight participant interest forms that were returned, thirty-seven fulfilled the inclusion criteria. One individual did not meet the inclusion criteria because they were not of Māori descent.

Thirty people (10 males and 20 females) aged between 17-74 were interviewed. Seven participants were not interviewed secondary to health issues and/or urgent appointments at scheduled interview times, pressing whānau responsibilities, tangi, and limited resources of the researcher and the participants. All participants lived in the community (Invercargill = 26; Winton, Queenstown, Riverton = 4). All 30 participants underwent in-depth interviews lasting between one to two and half hours long. Of the 30 interviews, 21 interviews occurred at the homes of the participants, six occurred at the rooms of Ngā Kete Mātauranga Pounamu Charitable Trust, two at Southern Institute of Technology, and one at a church where the participant worshipped. Table 5. presents the characteristics of the participants.
### Table 5: Characteristics of participants.

<table>
<thead>
<tr>
<th>Characteristics</th>
<th>Category</th>
<th>n = 30</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age</td>
<td>16 - 19 years</td>
<td>2</td>
</tr>
<tr>
<td></td>
<td>20 – 29 years</td>
<td>2</td>
</tr>
<tr>
<td></td>
<td>30 – 39 years</td>
<td>2</td>
</tr>
<tr>
<td></td>
<td>40 – 49 years</td>
<td>8</td>
</tr>
<tr>
<td></td>
<td>50 – 59 years</td>
<td>7</td>
</tr>
<tr>
<td></td>
<td>60 – 69 years</td>
<td>7</td>
</tr>
<tr>
<td></td>
<td>&gt; 70 years</td>
<td>2</td>
</tr>
<tr>
<td>Iwi (*some participants reported multiple iwi)</td>
<td>Ngāi Tahu</td>
<td>17</td>
</tr>
<tr>
<td></td>
<td>Ngā Puhi</td>
<td>6</td>
</tr>
<tr>
<td></td>
<td>Waitaha</td>
<td>3</td>
</tr>
<tr>
<td></td>
<td>Kāti Māmoe</td>
<td>2</td>
</tr>
<tr>
<td></td>
<td>Tainui</td>
<td>2</td>
</tr>
<tr>
<td></td>
<td>Maniopoto</td>
<td>3</td>
</tr>
<tr>
<td></td>
<td>Ngāti Kuri; Rakiura; Ngāti Porou; Ngāti Kahungunu; Te Atiawa, Waikato</td>
<td>1 (in each iwi)</td>
</tr>
<tr>
<td></td>
<td>Solely Maata Waka (not Mana Whenua)</td>
<td>11</td>
</tr>
<tr>
<td>Disability reported on consent form. (*some participants reported multiple disabilities)</td>
<td>Hearing impairment</td>
<td>4</td>
</tr>
<tr>
<td></td>
<td>Diabetes</td>
<td>4</td>
</tr>
<tr>
<td></td>
<td>Arthritis</td>
<td>3</td>
</tr>
<tr>
<td></td>
<td>Heart</td>
<td>3</td>
</tr>
<tr>
<td></td>
<td>Visual impairment</td>
<td>2</td>
</tr>
<tr>
<td></td>
<td>Stroke</td>
<td>3</td>
</tr>
<tr>
<td></td>
<td>Multiple Sclerosis</td>
<td>2</td>
</tr>
<tr>
<td></td>
<td>Epilepsy</td>
<td>2</td>
</tr>
<tr>
<td></td>
<td>Sarcoidosis</td>
<td>2</td>
</tr>
<tr>
<td></td>
<td>Schizophrenia</td>
<td>2</td>
</tr>
<tr>
<td></td>
<td>Severe depression</td>
<td>2</td>
</tr>
<tr>
<td></td>
<td>Autism spectrum disorder</td>
<td>2</td>
</tr>
<tr>
<td></td>
<td>Recovering from cancerous tumour removal</td>
<td>2</td>
</tr>
<tr>
<td></td>
<td>Blood clotting problem</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td>Chronic pain</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td>Asthma</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td>Anxiety</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td>Meningitis</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td>Dialysis</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td>Dyspraxia</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td>Fractured femur</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td>Alzheimer's disease</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td>Alcohol foetal syndrome</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td>Chronic Obstructive Pulmonary Disease (COPD)</td>
<td>1</td>
</tr>
</tbody>
</table>

In the following section I present the main themes that emerged from the data analysis process. It should be noted the objective in this section is to represent wellness and disability in this chapter as perceived in *te Ao Māori* (as described in Chapter 1) where disability is not considered in an undesirable sense or not being well. It is not the intent to polarise the two ideas of disability and wellness, rather the results are presented reflecting upon what enables the participants and what disempowers them.
In terms of wellness, the main themes were: (1) Whakamana - Being valued; (2) Whānaukataka - Relationships, keeping in touch and connected; (3) Healthy sense of self-identity and self-worth; and (4) Good access to resources. (5) Physical elements of disability.

Conversely in respect to our participants’ perspectives of disability, the main themes were: (1) Not being valued; (2) Negative impacts of discrimination, colonisation, and disconnection; (3) Lack of self-worth; (4) Poor access to resources; and (5) Physical limitations of disability.

Given that perspectives and voices of the hauā Māori are being presented, it was felt necessary to include many quotes within the results section, as viewpoints in actuality are often best articulated by the way the participants put it in their own style. To maintain anonymity and to avoid monotonous use of ‘one participant said…’ the participants have been provided pseudonyms when presenting these quotes.

**COMMON THEMES OF WELLNESS**

*Hauā Māori Mauri Ora - What Makes Me Well?*

Common themes of perspectives of the hauā Māori in regards to factors that lead to a sense of wellness are presented in this segment.

1. **Whakamana** - Being Valued.

Feeling a sense of being valued was identified by the hauā Māori and their whānau as one of the most contributing factors involved in being well. Many aspects adding to this concept appeared within the dialogues and are presented below.

**Having an active role in the community**

Being actively involved within the community was a strong theme that was highlighted within the interviews as a factor that leads to feeling well. Many participants stated that “giving back” to the community within which they live,

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5 *Whakamana* means to uplift and acknowledge or give *mana* to a person.
was satisfying, rewarding, and provided a sense of uplifting their mana (their self-worth). Wellness, for one Tauā, was having the role of kaumātua acknowledged and Māoritaka being valued. Jane suggested that her position was slowly being more recognised at the Kōhanga Reo and her disability was becoming less of an issue:

... people at the Kōhanga are flattered. And I went over a couple of times, and they said to me, we want you as a Nanny. And I'm now being given the right to just get on my scooter and go over whenever I want. And we are going out... and they’ve asked me to go as the Nanny with them, and I’ll go. You see? So slowly it’s happening.

This comment illustrates how the participant feels the community is beginning to understand how to engage her in leadership activities, taking into account her disability but not limiting her involvement because of it, and exemplifies how important having a purposeful role within society is for those living with disability.

**Having Tikaka Māori being valued by community**

Having the importance of Tikaka Māori acknowledged in everyday life to many participants led to a general sense of wellbeing. In some instances this appeared to be directly related to whether participants continued to access health services. Joan suggested he was impressed with a physiotherapist who showed acknowledgement of the tapu nature of the head and asked specifically for permission to touch the participant’s head. Many participants described positive experiences of being able to support others in the community to learn more about tikaka, often within volunteer work and paid employment, and also within community groups such as church groups, children with special needs support groups, and school groups. This provided a sense of recognition of the value of tikaka, and a feeling of pride to be able to contribute to an understanding tikaka within the community.

**Being a leader**

There were several participants who found that having leadership roles within their communities gave them a greater sense of being valued and supported their sense of wellbeing. Leadership roles included being a leader in Kapa Haka group, prefect at school, Māori Worship group for men at Church, a Kaumātua at
kohunga reo, a Māori female Minister and involved in Ngati Kapo NZ, Māori services for Foundation for the blind. This seemed to also provide a feeling of purpose, uplifted mana and responsibility.

**Being employed**

A number of participants were not in paid employment as their disability prevented them from attending work consistently. Many participants were, however, volunteers for various organisations and community groups, such as Māori wardens, church ministries, and disability and health services. Participants felt employment or volunteering provided a sense of responsibility, social contribution, value, and improved self-esteem. This contradicts a widely held perception that the Invalid’s Benefit is a “hand out” for those who are lazy; an attitude that many participants remarked was in fact disabling.

One couple discussed the volunteer work they undertook to support Māori youth.

*Mary (Wife)*: *(The doctors) encouraged [name] was to get involved with voluntary work where he’s not tied, contractually tied... The positive thing about him not working is that if he’s not well, there’s not contractual obligation to an employer. His language of love is service. So he does, he does live a good life, but every now and again he feels like it would be nice to have gone back to work ....*

*Hoani (Husband):* I’m not indestructible. Because with our youth programme, I’m doing things that I actually enjoy doing. Eeling, and floundering, and diving... I think it keeps me alive, you know?

Tahu explained the value he finds in volunteering and assuming a leadership role within a Māori ministry at his church: “It’s not just for Māori, eh? It’s for everyone, your karakia.” He suggested being involved with the ministry has assisted him to get out of the gangs and using drugs, and has led to an enabling effect on his life.

Some participants worked within disability services. Samantha explained she found this to be an empowering experience for her, providing her both with a sense of being appreciated and being supported, and open access to helpful information. She also cherished the ability to help other hauā Māori and their whānau.
Respect and positive attitudes from the community - someone believing

For most, being able to participate and have responsibility within the community was empowering and an enabler of wellness, facilitated further by positive attitudes from the community. Tahu, who had been involved in heavy drug use and sometimes violent behaviour, talked about how he was asked to become an integral member of a community group supporting Māori men and how this invitation, that having “someone believing in me” had helped turn his life around. Tarapi said that he thought there was an improvement in community perception of disabilities that facilitated his wellness.

Like the kids these days respect me, respect me. Where the grown up adults would point their noses up, and point their fingers at me. Yeah ...... Because they’ve learnt more about disability people, and they have disabled people in the class now. Because when I was at school, we were all put in special classes.

Being there for whānau

A strong theme contributing to a sense of wellness described by many participants was reaching the potential to contribute and gift time to whānau life. This was quintessential for many participants, articulated simply by a whānau member, Mary, explaining her partners drive to be well following a work related incident which led to his disability. He said:

It was a process. It was for [name] to find his place in himself. That I’ve survived, I’m alive, I’ve got little people to take care of now.

2. Whakawhānaukataka6 - Being connected

Experiencing a feeling of belonging and maintaining relationships was identified as a compelling factor that made participants feel well. There were a number of relationships that hauā Māori participants identified as critical to them.

Being connected with Whānau and Whenua

The role of the whānau was integral to the wellbeing of many hauā Māori interviewed. Whānau were often their primary kaiāwhina (carers), their

6 Whakawhanaukataka is to make connections and form relationships.
kaitautoko (support people), their eyes, their ears, their communicators, their nurses and their advocates. Many participants identified the value of being connected with their whānau, and having whānau to awhi (support) them in times of need and in daily life. Being able to reciprocate this awhi was also empowering and strengthened bonds within whānau. Tahu stated:

*Keeping in touch with your family, your friends, and...Yeah. Just sometimes I think you just, knowing that you’re keeping in touch with others, and you know, they help you, you help them. I think that’s all important too. Because it makes you feel good.*

In discussing the basis of wellness, Fred stated he found strength from his connection to whānau, saying “...as we look at our, our whānau and what that means, you always have like ah, towers....always having that strength of whānau, everywhere you go.”

As many Māori move further from their origins or whenua7 (home land), a phenomenon common in Southland, whānau become more dispersed. Eleven of those interviewed did not identify with local iwi and were of Maata Waka status. Maintaining relationships with whānau that were not close was an important aspect that kept many participants sound and well. Tarapi said returning to his whenua (place of origin), where his whānau are, is a strong element to enhancing his life.

*Interviewer: What else makes you happy and enjoy life?*

*Tarapi: Going home*

*Interviewer: Going home? And home’s...*

*Tarapi: To my whānau. Seeing the whānau. Seeing my mokopuna’s.*

Maintaining relationships and keeping connected with whānau, despite the fact some whānau relationships were under stress, was still considered by some hauā Māori as valuable and an important part of being well:

*Henare: Oh. I’m still healing in this area*

*Interviewer: So in your relationships with your Whānau, are still healing?*

*Henare: Yeah*  

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Interviewer: And what does that mean to you?

Henare: Just letting them know what’s out there for me, and I...sometimes my mind takes me to places where I want to be, and sometimes I don’t want to be there

This comment inferred that the participant found maintaining a relationship with his whānau was important to him for a sense of wellness. In order for this to occur, Henare felt it critical to relay his realities of living with mental illness; a process he felt was difficult but was occurring slowly.

**Friends and community as whānau**

There were no restrictions placed around who could be considered whānau in this research and we noted that along with close friends, animals and health service workers such as nurses and doctors were included into whānau descriptions. A sense of being connected at many levels was identified:

“I think (being well) is also a sense of belonging because in the absence of identity you’re lost. So whether it be a club, a society, at that level. Or at whānau level. Or maybe it’s just your friends, but you need to have some kind of connectedness.”

Extended whānau often includes friends. As discussed in Southland, many Māori are Maata Waka, or from out of the Southland area, away from their whenua and many do not have whānau close. Friends therefore were also seen as integral to participants’ support systems. Community whānau are important as well. Tahu, who was mātawaka (originally from another tribal area), talked about his feelings of community being whānau:

...very important, because I want to be out there showing them; hey I’m part of this community. You’re not the only people who’s part of this community. I’m here too.

Helen suggested that “knowing in what way I can help with the Māori community ... would make me feel 100% better.”

Jane describes overcoming being away from her whenua, and then returning. She was assisted by a health provider who understood the role of relationships within the community was an important factor towards re-establishing a sense of wellness:
When I came back to Invercargill, from Balclutha I’d been away ten years, but when I came back I got a big shock, because where I was once valued, I wasn’t wanted. So I had to rely on the (Māori health provider) service, to start making connections... ...and by doing that I found whānau, right and that made me well. Now I’m a nanny at the kohunga. I’m going into the church now.

Relationship with health care provider

Having a positive connection with health care providers was a resounding theme within the interviews and was perceived as contributing to participants’ sense of wellness, and facilitated their access to healthcare services. There were many quotes to support this, and Hoani exemplified this simply when talking about what facilitates access to good health care.

“I think it’s important for me to have connection, or some sort of emotional, or not attachment, but some sort of emotional understanding with the person...cause I mean for me, if I don’t have some sort of emotional attachment to a service, or a person, well ok, well that’s at an end for me.”

Being treated with respect regardless of ethnicity or disability was also apparent within the interviews in relation to contributors to wellness. Tom explained his relationship with his general practitioner, who demonstrated an open door policy and understood the importance of whānau, recognising that were both beneficial to his sense of being well:

And I still get a wee bit healing with the GP... cause he understands our korero. Cause whānau are really (important). ...Just every time he says, I’m open, just book a day, and might only need five minutes, but he says, even a lunch break for a couple of minutes, and you get out of there. And feeling good. Yeah, he’s open... he listens, eh? He listens and then he’ll say tell me more? You know, pushing a wee boundary.

Joseph comments on his positive relationship with his surgeon who was Māori, with whom he felt connected, made him feel understood and valued. Joseph described a positive experience whilst at an appointment with a surgeon, and made specific reference to not feeling discriminated against because of being Māori, where in the past he felt he had not been treated seriously or heard:

That surgeon’s top dollar man...focussed on the job, you know? Not focussing on the social things, focussing on the, like how can we help that person. Yeah, and to prove a point, the surgeon was Māori... I reckon it made a big difference. He gave it to me like no other health services provider has ever related to me. You know? ... No internal barriers with him.
Tahu simply articulated one of the most common themes for wellness as “being heard” by a health professional. This theme was expressed by Daphne, as she described important elements for good health and disability service provision:

...that they listen, they are not negative and they...sometimes they go beyond to help. It makes you feel that you’re, somebody thinks that you’re worth helping.

3. Whakatū tika\(^8\) - A strong sense of identity and self-worth

Developing and upholding a sense of self-worth and identity was another factor that participants saw as contributing to wellness. This was different to relationships with others and being valued in the sense it related to finding value from within. It encompassed giving worth to allowing time for yourself to find calm and quietness, relinquishing responsibility to a greater power, self-respect and mana, reflecting on elements of Te Whare Tapa Rima and what contributed to one’s own mauri ora, being involved in hobbies, or art to express individual world view and realities, whilst also providing a meditative aspect and identifying with tikaka Māori and other cultural affiliations.

Having faith

Many participants found a connection to a church and Christianity provided a clear sense of direction and strong identity that they found integral, often primary, in respect to a sense of wellness. Mindy suggested that being a Christian was “something that defines me...points me in the right direction,” and “takes number one priority focus.” Often having faith in a greater power, and being able to relinquish responsibility in some areas of life provided the individual with relief and calmness.

Karakia

Recitation of karakia, waiata, and haka allowed many interviewees a space for a state of calm, routine, and safety, as well as a daily ritual, as Joan explains: “When I get up in the morning, do a karakia. When I do breakfast, I do a karakia. When I know that I’m in danger, I do it really quickly.” Most participants differentiated karakia as

\(^8\) Tū tika translates as self esteem (Ryan, 1995)
separate to religion and Christianity, but a few did not. *Karakia* highlighted an aspect of identifying with and valuing things *Māori*. Daphne stated it was vital for her sense of wellbeing: “Oh yes, *karakia’s most important to me. Uh, karakia, I te morena, I te ata, I te pō* (Uh, *karakia in the morning, in the day and at night*).”

**Rakimārie - finding calm from within**

Many participants spoke of the importance of claiming their own space and time to find peace and rest. It was essential for the health of many to find moments of quiet space in the day. Some found this through a variety of activities such as making sculptures, knitting, making cards, doing puzzles and gardening.

Combating fatigue was a major issue shared by many and therefore timeout to recoup and recover was deemed essential as described by a *whānau* member, Mary, as follows:

> The busy-ness in our home, that’s life. And having peacefulness...that’s the most important because of the illnesses that (he) has suffered, he needs calm.

**Aroha and Mana**

To care for one-self featured as a seminal aspect of wellness for some. *Aroha* (giving and receiving affection) was a focal element for many *hauā*. Moana noted the relatedness of the *Māori* concepts of *aroha* and *mana*, or the desire of the *wairua* to be acknowledged for its worth, (Matenga-Kohu, 2003) was also articulated as important in terms of self-worth.

> Moana: I think anybody who has a disability, needs to have the inner strength to deal with his or her disabilities. Yeah. *Aroha*, which could be in that inner circle. Being with mana

> Interviewer: Mana? Why do you talk about mana? What’s mana to you?

> Moana: Pride in who you are.

**Connectedness of elements in te Whare Rima**

When considering *hauora Māori*, the *Whare Tapa Rima* model resonated with most participants as explaining a true, encompassing and functional idea of their individual pictures of *hauora* or wellness, as Adam explained: “*all make me, they make who I am. They make my essence*.” Pania stated the elements contributed to “*...the Mauri, the inner self*”. Most interviewees differed in the aspects that
featured strongly for them, and some identified that at different points of time their *Whakāro Pōkare* diagram would look different. Most of those interviewed agreed, however, on the connected nature of the elements within Te Whare Tapa Rima. Henare states:

*Without one, there’s, it’s just, it just doesn’t look right. It’s like a map, isn’t it. You know? Pull one thread out, and it’s all up the huha... It’s like the stuff of our tipuna, they have wai, and sacred waters too.*

The above comment makes reference to *wairua* as the ‘sacred waters’ and again a vital part of self-esteem.

**Guided by Tūpuna**

As the last comment signaled, many referred to an important element to feeling well was acknowledging ancestors as being past and present, being guided by them and the lessons handed down from them provides a sense of strength. Lois encapsulated this idea in the following quote:

*...yeah, because without our tipuna, our Kaumātua it’s the one that keeps us really strong, and so kaha (strength) would be another one that goes right around us.*

**Sense of Māori Identity**

Most participants felt that having a strong, positive sense of being *Māori* was essential for them establishing a healthy state, although the degree of affiliation to Māoridom did vary within the group, as did the means by which they had acquired this connectedness to *te Ao Māori*. Some were born into a *whānau* with strong *tikaka*, whilst others had come to finding this link later in life. Joseph explained how he gained a positive sense of being *Māori* whilst in prison. He described he had been subjected to cultural discrimination for many years and harboured a deep anger which he could not understand or control. Connecting with *tikaka Māori* led to a more affirmative sense of self and a better coping mechanisms to deal with being discriminated against, and thus an improved sense of wellness. Tarapi had found healing and wellness in his life-long practice of *tikaka Māori*. He claimed his connectedness to *te Ao Māori* was “everything” to him but mostly, it had contributed to his ability to have a positive and affirmative outlook on his life.
Whakaahu whakamua

Pressing forward and being positive

Having a positive mind-set was acknowledged as a feature that would keep participants well. This positivity extended to being acknowledged as a human first, rather than being defined by their disability. Being accepted and respected as a human being with a disability was considered essential when establishing a healthy relationship between client and practitioner. This attitude was illustrated by Tom:

I knew it was a struggle, physically, emotionally, spiritually, mentally, coming to terms with this new thing. Again, it’s a time factor, because I had to go through that process of grieving and then once that happened, I mean that’s when I could move forward. I mean it’s all a journey, and it hasn’t ended. Yeah, like if I want to present this certain mind-set, which indicates to others that you have a disability then so be it. But then I don’t have that mindset. (I’m) not governed by that. Because at that point, once you then have that ability to embrace yourself in that particular disability, it’s no longer a disability.

This idea that the haua Māori did not feel defined by their disability was a common thread within most of the discussions, nor did they wish to have sympathy. There was a certain determination for not being ‘owned’ by disability but pressing forward through life, acknowledging fluctuations in life’s ups and downs. Mindy said:

I could blame everybody, but in the long run, it’s my life, even though I have MS, it doesn’t have me. And I’m not going to walk around with this tattoo saying ‘feel sorry for me’ and all I could say really is, if it sucks for you today, tomorrow’s going to be a good day. You know, have a good sleep tonight. Go and have a cup of coffee, or a cup of milo, or a cream cake. You know, because nobody, nobody can do for you, unless you do it yourself.

As is characteristic of many Māori, those interviewed held a healthy view of death, in that they did not perseverate on their current situation but acknowledged their disabilities and continued to be very grateful for their life:

Jack: I just accept that I will die sometime that is a given. So I should have died 43 years ago, so I figure I have had it good to live this long. In life this is always my impression, kua mate tātou no matter how and why it is just when. So I enjoy it while you can. I’ve had a good innings.
Interviewer:  So how do you perceive your future?

Jack: Well, I don’t know about a long life, but it’s like... what will be will be. I live every day, I get up and say thank you very much for another day. You know, I’m much more of a believer than I used to be. You know, you play, lip service, and now I’m a, more a believer, and, cause I wake up every day. And say thank you.

Drug free

Being free from smoke, alcohol and drug addictions was expressed as a major part of being well for many participants. This freedom was attributed to establishing a stronger sense of self-worth and clearer self-identity by several of those interviewed. Tahu who now used Te Reo Māori, waiata, and tikaka Māori in everyday life, acknowledged how pivotal exploring a Māori identity was within his drug rehabilitation process, and this had allowed him to be drug free now for 20 years.

4. Whakahaere Matatiki – Access to Resources

Having access to adequate resources was vital for participants to live healthily, to stay connected, to support a strong self-esteem, and maintain their independence, whilst also enabling them to contribute better to whānau. Resources include pūtea (money), information, education, transport/mobility, financial support, ability to buy food and supplies of their choice at the supermarket and advocacy to assist in receiving good healthcare that was responsive to their needs.

Pūtea- finances

Generally within the participant population financial resources were not ample and this proved to be an obstacle to good health, as discussed later. Many, however, had a healthy approach to their financial status. Pania commented on how she lost most of her money following redundancy and found this was a “big learning curve” and she now refused to worry about money. Hoani described having access to pūtea was not a major drive in his life, rather he saw it as simply an enabler to support his whānau.
Education

Formal education amongst the participant population was reported by a few as an important element providing a sense of health, and many had goals for continuing education and courses. Joseph was presently studying at Southern Institute of Technology (SIT), and a few participants were studying Papa Ako courses, and one worked at SIT, supporting Māori students. Joseph felt that achieving education contributed to his wellbeing, and identified his main driving force was building a knowledge base for him and his whānau to battle against discrimination. He felt that studying law might enable breaking a cycle which he saw was undermining the movement forward of his whānau, and he wished to acquire knowledge on how to establish a ‘new’ pattern of living in this world without fear and anger.

Access to Health and Disability Services and Information

Many acknowledged having access to relevant information about the health and disability services available, was helpful towards being well. Many of the participants were actively receiving health care through Ngā Kete Mātauranga Pounamu Charitable Trust and many did rate having good access to information about health care options in the area and also information about health and disability given to them. Some were fine with written material but most preferred receiving information in the form of face-to-face consultation.

Transport/ Mobility - being able to get around

Being mobile signified independence and freedom, and this definitely contributed to a sense of wellbeing for almost all the participants. Enablers of mobility included having mobility scooters, walking frames, pick up services, and guide dogs, and on the whole, those that needed such support had it. Jane explained how a mobility scooter now enabled her to attend hui and work at the kōhanga reo. Tarapi was able to enjoy his hobbies following the prescription of a sturdy mobility scooter:

*I sometimes go on my mobility scooter, cause I love using my mobility scooter. My mobility scooter used to get me to Bluff. But not this one. Yeah. To go fishing.*
Enabling supermarket shopping was a clear common theme with almost all participants, as important within their daily life. For some this contributed to getting out of the house, being social, and also being able to provide sufficiently towards whānau. Samantha described disability service provision that assists with getting to the supermarket was vital for whānau life and provided a sense of interaction within the community:

...was what we woke up for...to be able to feed our whānau. So shopping to me, from a service delivery point of view...is something that we should be able to get support with. It’s a big part of community...

Helen said that having someone pick her up and drive her to the various supermarkets encouraged a sense of value and allowed flexibility on options for items she wished to purchase. Prior to using this service she had to use one supermarket which had a limited range of products. Again, Hannah explained how supermarket shopping specifically led to a sense of independence:

It’s about... as a person holding onto your independence to...just get out among, you know the shop, rather than rely on someone to, buy it in, you know... ...it’s, it’s supporting their independence.

Advocacy

Having someone to awhi (support) and assist you to access health care services came strongly through the interviews as an enabler of wellness. Supportive whānau were important, and this concept could extend to a health care worker who had health knowledge, a good relationship with the participant and an understanding of their individual needs. This was identified by Joan who noted when attending visits to specialists with support has been beneficial in having her questions answered:

But it’s funny how when you take an advocate with you, like some of the ones I’ve dealt with, that they’ve been there and they’ve asked these questions before, then they got me to come along... ...those questions are actually getting answered because, you’re sitting there.

Another example was Jane who was nervous about going into surgery; she found solace from an offering of support by a Māori health care provider to attend an appointment with her and the surgeon. She also talked about a Māori health care provider who advocated for her and how this made her ‘well’:
I had to fight and fight and fight to get (care) staff, fight for the right... But I’ve gotta say it all came from Ngā Kete. Not, not the outside people they were no help at all, because at their, in their little boxes, right, didn’t understand what I really needed, right. It was Ngā Kete that did it, they got me to the shop, and got me there, got me, and got me mobile, and it got me a scooter.

5. *Whakahauora taha Tinana*\(^{10}\) - Physical elements of impairment

This theme incorporates the physicality elements that are incorporated within disability, which did not come through as strongly within this project as the other themes but it was still nonetheless acknowledged. Some felt more enriched for their experiences living with a disability, some mentioned the importance of physical exercise on the other elements of *hauora*, and others discussed healthy nutrition as part of their concept of wellness.

**Not viewing physical impairment as disability**

One major expression amongst the *hauā Māori* voices was that the physical impairments were not seen as disability. One participant describes how he believes having his below knee amputation has offered more opportunities than it has taken away, and he feels his life has improved from going through the process:

> It’s like a sense of arrogance on my behalf but I don’t consider myself as having a disability because to me my type of disability, to me physical disability is governed by what I think...And I mean like, it doesn’t make you perfect, all it does is see the difference between, actually understand the value of a parent and wife. I’ve gained more from this process than I’ve lost.

Supporting this, a youth talked about her disability not being physical, even although she was blind. She continued to state “I know I have a disability but I don’t think about it. I just can’t see, that’s all.”

**Physical elements of disability made them stronger**

In some cases rather than feeling the physical aspects of disability were disempowering, the view was that being disabled enabled some participants to feel ‘better’ than not having a disability. Helen had a progressive disorder which

\(^{10}\) *Whakahauora taha Tinana* means to create sense of “physical wellbeing” (Ryan, 1995).
led to her now permanent physical disability and explains how she now feels more at ease:

I think actually (having this disability) has made me louder. Yeah, more vocal because I was shy...So I felt really uncomfortable. And now I can just (think), so oh well...that’s made me feel comfortable.

Physical Exercise

Keeping physically strong, through work and exercise, was acknowledged by many as part of being healthy. Manawa talks about how her work on the Tītī (mutton bird) Islands and her art practice helps keep her fit and well. Walking was the most common form of exercise. Aside from the obvious physical benefits of exercise for the tinana, most references made around positive aspects of performing exercise were on the other elements of te Whare Tapa Rima. Several participants talked about the advantageous impacts of being active had on their wairua. For example, when asked how he kept his wairua healthy, Tarapi stated:

I exercise, I swim, I go to a gym, I do walking to the park, I try and do, tai chi. I’ve been taught tai chi, so I, know how to do it. It is (nice in the park) especially on a day like this, yeah. Karakia, karakia comes with everything that you, before you do anything, it’s important that you do that. I do that anyway.

Some participants talked about how exercise had been part of assisting them to stop using drugs and alcohol, achieve anger control, and fight depression. Others expressed they used exercise as a means to address diabetes, which was more prevalent within the interviewed population than the four participants who first identified in the consent forms. Six other participants acknowledged they also suffered from diabetes in the interviews, leading to ten participants, or one third of our participants, living with diabetes.

Healthy Food for Health Body

Nutrition was also an important consideration when dealing with diabetes, as Anaru states, “some of the illness that kiss our people is diabetes....I try to have good kai.” Nathan had type-one diabetes and talked about how it had changed his life as a young person, especially when it came to drinking alcohol and eating food like most of his peers took for granted. He acknowledged he just had to “step it up and take control of it".
COMMON THEMES OF DISABILITY

Whakahauā - What makes me disabled?

Following interviewing the participants there were many factors identified that contributed to the participants feeling disabled, and the main themes that arose are presented below.

1. Whakaiti\textsuperscript{11} - not being valued

A fundamental disabling factor, as perceived by many participants was being undervalued and disrespected within their own community. Participants described a range of ways in which they experienced a sense of not being appreciated.

Not being actively included in the community

Community perceptions of disability were mentioned as limiting, by many participants, who often found themselves excluded from responsible roles within their community, when they wanted to be involved. Jane states:

\[I\textsuperscript{h}ave\textsuperscript{t}\text{to}\text{badger\textsuperscript{p}eople\text{to}pick\text{me}\text{up}.We're\text{undervalued}....\textit{it's\text{a\young\
society\and\we're\inder\road}.Even\though\text{when\they\see\us\they\make\a\huge\
fuss\and\they\do\look\after\us\when\they\see\us}.\textit{Mana\is\the\things\that\they're\not\doing}.\textit{Like\leaving\us\at\home\and\what\not}.\textit{But\not\recognising,}
\textit{but\mana\to\me\is\when\people\awhi\me,\and\they\care\whether\I'm\there\or\not,\or\care\what\I\know\or\what\I\don't}....\textit{So\yeah,\see\I'm\stuck\at\the\moment,\I'm\a\victim\of\being\sort\of\ignored.}\]

This quote illustrates one of the disabling factors identified by this population, being unrecognised and not involved by the community largely due to their disability, despite participants themselves feeling that they have much to offer the community.

\textsuperscript{11}Whakaiti\text{is\a\broad\concept,\defined\in\http://Māoridictionary.co.nz\as\1.(verb)\(-a,-hia,-ngia)\to\belittle, disdain,\look\down\on,\disparage,\denigrate,\make\small,\lessen,\decrease,\reduce,\diminish,\turn\down\(sound),\cheapen.}
Not being actively included on Marae

It is well established that Māori have much respect for their kaumātua or elders. One Tāua talked about how she wished to be involved with the marae and she pointed out that she had kaumātua status, however she felt that because she was “too slow” she was being disregarded because of her disabilities. This contributed to a sense of isolation. She called to iwi leaders to acknowledge disabled Kaumātua and not just able bodied ones:

And one of the things that made me very sad is what I see is the role of the Kaumātua on the Marae has shifted. The kaumātua are now executives so when they go to go out anywhere, “oh don’t bother with her she’s too slow”. We now sit and we hope somebody will remember us. So what I had to do, is go back into the kohunga where I started, and there I’m valued, as a nanny, but on the Marae forget it. The church is starting to fulfil the role of the Marae. What I see, is the able bodied younger Kaumātua are the business people, so you’re left with, the likes of me, being lost.

Not being able to contribute

Not being able to contribute actively within the whānau, secondary to limitations in mobility, fatigue or other issues related to impairment was almost more frustrating to those interviewed than the limitations on a personal level. Kayla was restricted considerably by having to be on dialysis every day, for up to five hours a day and had a hospital bed set up in her living room so that she could continue her role within her whānau as an active mother of five children, all with disabilities themselves, and a carer for others. She expressed her struggles and frustration at not being able to participate in whānau activities as she would like to as the central figure in her whānau:

Well I feel like I am the pole that holds up the tent. Because I carried my beautiful, I carried them all. I’m trying to keep everything together, because my uncle is IHC and I have him once, twice a month, and that’s very hard. I couldn’t do this, but I have to do this, because I have to teach my children, I have to teach them so many things that you can overcome. This is just, this is all they know.

Two tāua stated that they wanted to take care of their mokopuna (grandchildren) who were, at the time, living in distressed families. The tāua however both felt this was impossible secondary to their impairments to take their grandchildren under their wings, and this was incredibly frustrating for them not to fulfil a role in their whānau that they strongly desired to perform. For many participants the
inability to contribute to whānau as they would like to, led to frustration and whakamā. When asked what disability meant to Hoani, he described his disappointment and ensuing financial hardships for his whānau related to not being able to work as he did before becoming disabled:

> It’s a pain in the butt to be honest. For me, it’s a restriction. And it’s gotta be there. Because it’s part of my life now and I just find it a real nuisance, because, like I said earlier, you can plan a day and it doesn’t come to fruition. Sometimes you get a lot of fruition from it, but we don’t, because I’m not working, and I don’t have the money like normal people who are working have, we can’t get out and pick and choose what we want to do. We’ve got to budget.

Financial and budgetary constraints on whānau were common experiences expressed by the participants.

**Ill-informed attitudes of the community to disability**

Negative attitudes of the community towards disability had a stronger disabling effect than the actual diagnosed disability for many. General low level of understanding disabilities was identified by many, Moana stating:

> Friends and the community, it just frustrates me sometimes, their lack in knowledge can be annoying...yeah...lack of knowledge around disability. It’s the attitudes of your community really.... affects your mental health.

Tarapi talked about the poor attitudes from those in public transport: “Some of the bus drivers are that grumpy to people with disabilities. You don’t know what to say. Yeah, put off by their grumpiness.”

A mother of two children with disabilities, talked about how misunderstanding of her whānau’s situation within the community had adversely affected her and her whānau:

> ...just understanding what we’re going through is complex. But you know like, we do need to get on with our day just like everybody else and being inclusive in the community. That’s why they’re with me because they think that you have a disability, they think you don’t have a mind as well.

Many talked of the stigma within the general community around having a mental health diagnosis. Many of those interviewed felt disassociated from their communities more because of the diagnosis rather than the mental health issue itself:
And of course once you’ve got a mental health stigma, it really is, it really can be used as a weapon, right? And the society still uses that as a weapon. Yeah…. Now I’m discharged from the mental health team, but the stigma is still there. I’m the loony.

Helen explained how she did not appreciate how she was treated by the wider community stating she was regarded “…like a blindy, really, like someone with a disability, yeah you want to be treated like a human.”

**Worrying about what others think**

Perseverating on societal attitudes towards disability led to additional grief for some *haua Māori* interviewed. Irene expressed this view that was similar to that of some other participants:

> I’m thinking about what they’re thinking of me, and I get real like… I’m like oh stop thinking about that. I see it really bad when I was walking through into high school, I’d feel like butterflies in my stomach and I used to feel like, oh what’s going to happen today.

**Discrimination secondary to Māori ethnicity**

Being discriminated against had major, direct destructive influences on the health of an individual and their *whānau*. Failing to receive appropriate healthcare because of a sense of discrimination against being *Māori* within health care provision was a theme within the interviews. Henare describes his experience of this:

> Yeah, it makes you avoid the services, but you wanna avoid conflict, because it’s too hurtful, too painful. ..There’s also, many levels of this too. It’s not just the one word, or one way of doing it. It impacts on ones outlook of themselves. You feel it, you live it, you, you know...

Gladys talked about feeling discriminated against, following being incorrectly labelled by a healthcare provider as receiving a “*hand-out*”, when in fact she was working and not receiving a benefit she was entitled to. The participant and her *whānau* had the impression this assumption occurred because she was *Māori*.

Joseph reflected on how he felt discriminated against when he visited a health care provider secondary to the fact that he is Māori. He made reference to the lack of understanding of *Tikaka Māori* and cultural competency that the health care provider demonstrated that deterred him from seeking further health service from this specific provider:
Just, like, it’s gutting. Because that person’s trained to sit in that seat and help another human being regardless of what ethnicity, what age or gender they may be, yet that person there discriminated (against) them, (their patients).

He continued to speak about developing coping mechanisms to assist him to navigate discrimination he experienced due to his Māori ethnicity within the health system and that he wanted to share these strategies with his whānau back at his home in the far North. “You’ve got to realise that you can’t stop discrimination. Instead of struggling over it, just step over it.”

**Devaluing and lack of understanding of Māoritaka**

The marginalisation of Māori and their world view within society was a common theme that was identified by participants as having a disabling effect. Many participants claimed that karakia and waiata are important to be acknowledged as valid avenues for health and sense of wellness. This, however, was not always clearly understood within Te Ao Pākehā and Māori patients therefore may be misunderstood, misdiagnosed, and mistreated. This was demonstrated in the following discussion with Tahu who often used Te Reo Māori, waiata and haka as a grounding technique when he had episodes of severe depression:

>Like sometimes, my mind slips. It doesn’t really happen much, but when it does, it feels like you’re in Te Pō. You know, and when you feel that, you need to come and bring yourself out of there….with Waiata… I used to get into trouble when people couldn’t understand my illness, and they wouldn’t take me serious, I went on a smashing spree. .. I don’t like calling it names, or..you know? Like I had this illness quite a while, and then, get a name like schizophrenia. I says, I don’t wanna be tagged. So I used to just karakia, and they can’t understand me... why I do haka, and they thought it was offensive, and I says it’s part of my language, and it’s part of my wairua. And your haka, and I love haka, waiata. I haka every day to somebody.

This young man describes te Pō, the realm of darkness, nothingness to symbolise his deepest depression. Te Pō also has connotations of potentiality, hope and potential. To bring him into the realm of the living, the light or Te Ao Marama, he performs a passionate haka, to establish some grounding back in the world. Tahu also expressed his sense of frustration at being “diagnosed or labelled” and being largely misunderstood. This frustration with being diagnosed without consideration of using a Māori lens was expressed by other participants, including Jane who continued to state: “There are no such things as manic depressiveness or schizophrenic in Māoridom...”
2. Whakatūhāhā\(^{12}\)- Disconnected from whānau and wider community.

People interviewed talked about not being connected and feeling isolated as disabling effects, especially given the regular nature of whānau to provide primary care for many Māori.

**Not wanting to burden whānau**

A central concept for many Māori is whānau, and for hauā Māori whānau is often their primary care giver. Many hauā Māori interviewed expressed this was their reality however some identified they felt distressed about the extra responsibilities whānau took on secondary to their disabilities. Lana says, “I see it a lot. Because my view on it, is, I don’t like to impose my disability on people”

Hoani said that since he had an injury that required his family to take care of him at times, he feels “anger, frustration, anxiety, you name it, it’s all there. I do (take an antidepressant). Yeah well I have to though. I have to, otherwise, it, my family suffer unnecessarily otherwise.” Jane talked about missing out on activities as she did not want to further burden whānau, by asking them to pick her up.

**Physically disconnected with whānau, hapū, iwi.**

When the significance of whānau is a highlight for most Māori, not being connected to or being isolated from whānau, can be a disabling issue. Within this population 11 participants were Maata Waka (from another area, not mana whenua). Many had moved to Southland secondary to relocating for work, within industries such as meat processing (“freezing works”) and wool harvesting industries (Paringatai, 2013), and were geographically far from their whānau and support. A few had moved to the “deep South” to remove themselves from whānau rifts, and had relocated as far away from a break down in whānau dynamics and disruptive relationships. Others followed their partners to settle in Murihiku. All maata waka stated this situation lead to a feeling of isolation, and all felt they suffered in some way, missing the lack of care normally provided for by whānau.

\(^{12}\) Tūhāhā, according to http://Māoridictionary.co.nz, means to “…be standing alone, isolated, unique, separate, independent”. Therefore with the prefix whaka-, which is used to indicate “to cause something to happen, cause to be” (http://Māoridictionary.co.nz) this word suggests to cause to be isolated.
Poor relationship with health provider

Participants in this research felt that their relationship and being able to communicate with health care providers was essential, if not the most important aspect, in determining whether they accessed quality health care or not. This was one of the strongest themes and indicated the importance in establishing strong connections with hauā Māori, most feeling the nature of the provider strongly determines whether they continue to use the provider or perceive benefits from receiving treatment. This had major implications in regards to treatment accessibility, more than the treatment itself in many cases. Some participants described experiencing a lack of understanding tikaka Māori by health care providers which contributed to hauā not being heard or “missing the big picture”, as described by Leila, who continued to explain if a health care professional “…blocks out certain parts of someone’s values or beliefs … it’s choosing what you want to hear” it deters her from using that service again.

Health provider not understanding whānau as central

A lack of understanding how integral whānau is to many participants, was perceived by participants as a barrier to receiving relevant health care, exacerbating her feeling of disability. For example, Lana, reacted to a situation where a support worker made her feel distressed about having whānau living with her. Although the support worker's attitude was unacceptable to the participant, she said she did not wish to cause conflict by complaining, a response also described by many of our participants:

I had my brother living here for a while, and I just felt my carer really intrusive, because she just didn’t have a really good understanding of it. I just felt she just didn’t really understand whānau, like whānau will come and go. You know, and I don’t think she really got that… It was just annoying. Just didn’t find her accommodating.

Pākehā perception of disability versus Māori whakāro

Many of the hauā Māori interviewed had both Pākehā and Māori whānau affiliations and several acknowledged a difference in respect to attitudes towards disability. Acknowledged amongst the group, was an awkwardness in the Pākehā community towards disability whereas the Māori community seemed more
accepting. One participant talked about his experience of becoming an amputee and the different reactions within his Māori and Pākehā whānau:

Yeah so attitudes can differ. I think that if I look at it in a cultural context my Māori cousins were just like “so what?” And it was all good and they’d make fun of it but um in a compassionate way. You know I’ve got a (Māori) cousin, and he lost his leg through a motor bike accident and I was ringing him up saying oh look Bro, I’ve just been told I’ve got to get this amputation he talked my through it and then his final statement was “don’t bloody ring me up crying either” click (laughs). And when I went up North it was all good. I mean you know it was just cool, yeah. I still had to do the dishes you know. And Mums (Pākehā) side of the family were quite different, was distant and very... yeah don’t even look there, talk there and that was a different dynamic at the time. ... like some, on the Mum’s side. That awkwardness, or makes that... reminds you in a sense that... that I’m disabled... so that’s more disabling than anything else.

Joan viewed Pākehā attitudes towards disability difficult to manage and how they had to manage the environment to make the non-disabled feel more at ease:

Like (Pākehā are) just uncomfortable. Like they want to be helping you, but at the same time they want to be getting as far away from you as possible because they don’t know how to talk to you. Yeah, because they’re uncomfortable. Yeah. So the person with the disability has to work extra harder to make the non-disabled person feel comfortable.


A low self-worth was often linked to whether participants felt they were able to access healthcare. This low self-esteem appeared to affect hauora at many levels. The compounding negative effects of colonisation or being disconnected to their whenua, shame around disability and an imbalance of connections between the elements of te whare tapa rima, were contributing factors to this low self-worth.

Negative impacts of Colonisation - the “bottom of the pile”

Some participants identified issues relating to post colonisation for Māori as having a negative effect on health. Jane talked about the outcomes of colonisation and how she perceived it had affected the health of Māori:

...our young people are getting caught up with gambling, marijuana and all those things. In my opinion, because of colonisation, we’re at the bottom of
the pile so we’ve got to do something to get ourselves out of it, so what do we do? We turn to the easiest thing that’s here, and the cheapest thing, or what we believe to be cheap. But in the old days it was booze and it still is part of booze. And nowadays it’s drugs. And then if it’s not drugs it’s gambling. To make more money, because we’re in such a depressed state, right.

Generational abuse secondary to negative impact of colonisation

A number of comments made by participants implied they were exposed to generational substance and child abuse and some mental health and physical disabilities suffered were directly linked to this abuse. As Manawa suggested, low self-esteem within her whānau had a generational affect leading to abuse:

...So what happened in my opinion is that the parents are depressed, and they’ve hardly got any food. They’re trying to find ways to get the food, and then to block it all out they’re either drinking or smoking or gambling or whatever and then the violence erupts right?

Alcohol and drug abuse appeared frequently to be linked and used as “fillers” for the hole left by the mamae (hurt) and low self-esteem following violent or sexual abuse. For example, Trudy suggested her disability, severe depression, had stemmed from a long history of child and sexual abuse and subsequently her four children had all suffered child abuse. She dealt with her mental ill health by self-harming, which “releases all the poison that was in there when I was a kid” and chronic substance abuse. She had found little respite from her mental torment, even though she had received treatment or as she puts it “counselling coming out of my ears.” This severely impacted her self-esteem:

I feel like I just come from one screwed up world, and I am ashamed of it? Or ashamed of them ... Spiritually I feel broken all the time. But I don’t feel worthy. I’m forever apologising to everyone. But anyway, that’s where I am today. Stuck.

Complex whānau.

Many of those interviewed experienced multifaceted whānau issues, and often had multiple health and social services involved with their whānau. Notably, a significant number of whānau interviewed reported having several whānau members living with disabilities which added more stress, both financially and emotionally. Some participants reported that substance abuse was frequently used to deal with complex whānau situations and relationships. Irene spoke of how she used alcohol to deal with death amongst her whānau. That said,
resilience of whānau was apparent within this community in that many whānau demonstrated the ability to deal with extreme situations of financial difficulty, isolation, and highly stressful situations involving agencies such as Child Youth and Family Services (CYFS), Accident Compensation Corporation (ACC) and Work and Income New Zealand (WINZ). There was little said about positive experiences in dealing with these agencies, however many descriptions on the difficulties experienced, where the agencies showed little understanding of hauā Māori realities. Problems keeping on top of filling forms and communicating with various agencies were often amplified whilst also having to deal with impairments. Manawa talked about how she had complicated issues with her whānau in relation to her mokopuna living in a disruptive household with CYFS involved. Even though she was living with a difficult disability herself, she was the primary whānau member trying to deal with agencies around the support for the children, and she expressed a state of hopelessness around dealing with CYFS, and this contributed to her fatigue.

Whakamā

Some participants expressed feeling shame in relation to their disability, and they had to work through this to deal with their disabilities. Gladys explains:

I guess for me, (disability) is something that can enslave you until you actually work through particular issues. Like I had to look at grief. I had to look at, oh my gosh, the shame factor of having (a disability). Shame, shame, shame. You know cry that stuff out.

Imbalance within Te Whare Tapa Rima

Using Te Whare Tapa Rima model to talk about health and disability emerged as a highly self-reflective practice, a technique for expressing a sense of self. A disturbed balance within the foundations of this whare appeared to lead to a low self-esteem. Joan explains the disparaging affect stemming from a shift within Te Whare Tapa Rima:

If the hinengaro is no good, you know your mental status... that will imbalance your tinana because you will become unwell. And if you don’t have the support

14 Whakama is another broad concept which, simply put, means to be shy, without mana, embarrassed, feeling shamed.
from your rakātira, from the whānau or whom you call whānau, your kapa haka group or whatever, then your wairua will become iti. You will feel belittled. So to be a whole, which is mauri ora, if any of those are unbalanced, then that will lessen your thing for purpose.

This exemplifies the views of many participants who spoke about the relationship of foundations of their individual idea of Te Whare Rima. It was a commonly reflected perception that if one area of their “whare” was negatively impacted, this had further detrimental effects in other areas, representing a general lowering of the holistic view of self. Mindy states:

*My headaches, and fatigue, affect everything. So tinana, wairua, yeah, yeah and Whānau, hinengaro, really affects everything...*

4. *Whakahōtaetae*\(^{15}\) - Poor access to resources

Closely related to negative impacts of discrimination are the *hauā Māori* perceptions of disabling impacts secondary to having limited access to the various determinants of health as discussed in the following section.

**Limited Pūtea**

As mentioned, not being able to provide for *whānau* was a major issue for most participants. Furthermore, reliance on benefits was considered disabling. Even for those with paid employment, their disability frequently meant they earned very little. Many volunteered, as previously reported, and therefore earned little. Although many participants stated that a value system based on money was not what they ascribed to, all participants recognised the need for financial resources, and many were struggling with their finances. Adding to this hardship was also the cost of specialist appointments and transport requirements. Pania explained: “When you are disabled the costs (of health care) go up at least a third.”

Being unable to afford healthcare was another concern and disabling factor for many participants and their *whānau*, with some suggesting that they had not accessed health care they knew they needed because of the perceived cost associated with receiving treatment.

\(^{15}\) *Whakahōtaetae* is described in [http://Māoridictionary.co.nz](http://Māoridictionary.co.nz) “to prevent, obstruct, bar, block, impede, stop, thwart.”
Kate explained the difficulties faced when being expected to survive on a disability benefit:

\[(After)\] everything goes out, just normally (left with) around $40 a week. They expect that to pay for food, petrol, and you can’t go and buy a pair of socks, or you can’t even buy a pack of chocolate biscuits. And they say you should be on health stuff. I’d like to see what they can buy with $30, I really would.

**Education**

As discussed above, many *hauā Māori* have not received the benefit of a formal education. Disregard for learning styles and pedagogies more aligned with things *Māori* were identified by some of our participants as limitation to accessing relevant and quality education. For example, Irene felt she had been wrongly labelled with a learning difficulty as a child, and suggests that her particular learning styles had not been identified until later in life following studying as an adult student:

*If I was to ever have Māori people, if I was teaching some how, I’d like, I’d find like they learn maybe differently, and I could help that... I’ve just been learning about people learning in different styles, and I’m like that would have helped so much at school.*

Not knowing how to access the educational institutions teaching *Te Reo Māori* and other related courses was also noted as a barrier to Tahu who had desires of extending his study in these areas.

**Not receiving quality healthcare**

There were some references to feeling limited and further disabled by not having access to quality healthcare, not being offered specialist services early enough or at all. Kayla explained her experience of not being offered assistance with placement of fistula and needles into her arm, a specialised technique which requires a high level of sterilisation. She relies heavily on her husband and *whānau* to assist with this daily process which can take up to ninety minutes, adding to the hours required for dialysis. Her husband has to juggle work to assist her and to support their five children. Kayla was distraught and overwhelmed by the lack of specialised assistance for her and her *whānau*, even though they had been battling to have this service in place to support the rural community who needed it:
The saddest thing is I know myself personally of three Māori women who died, because they never gave them people to put their needles in and the support that they needed. And their family begged them. And they just had enough. Begged. That is so sickening. (crying) It is sickening. I’m sorry Katrina, it is sickening. It should not happen. In any shape or form, when it’s money. It’s because of money.

**Limited information**

Lack of information on what health services were available, when and how to access them, was a frequent complaint throughout the interviews with respect to accessing healthcare. This appeared as a major difficulty to receiving appropriate services. This was expressed in the following quote from a whānau member following a participant being diagnosed with meningitis and not being referred for rehabilitation:

The disappointment for us has been that we were not given enough support and information. The process never happened the way it should have. We fell through the gaps. It’s changed our family’s life. There was no follow up. We didn’t have social workers on board, we didn’t have help. We never had help. We had no idea what to expect. It was the most life changing. We didn’t know what the implications were.

Lana talked about limited assistance when she suffered physical abuse and stated: “There were no resources, you know? Even when we got older. There was nothing. We just had to deal with those things….I don’t know where else to go anymore.”

Furthermore it was felt that better health promotion and education were required. One participant talked about being totally dissatisfied and confused following instructions from a specialist to research on Google™ information around a new symptom secondary to her spina bifida. Health information delivery was also identified as being problematic. Although visual media was identified as being desirable, participants especially valued when health professionals took time to discuss information about their health and disability issues. *Kanohi ki te kanohi* rang true for most participants as the preferred means of health information delivery, and a barrier identified to receiving effective health care was the lack of time given to discuss health issues with health care professionals. One participant articulated her frustration in the lack of information given by her healthcare provider: “I get quite confused about that
because I’m not too sure who I’d ask for help. They actually just gave me some pamphlets.”

**Limited advocacy – having to fight for yourself**

Participants commonly identified that they had to constantly battle to receive health care or resources that would enable health care. Kayla spoke of her struggle over her case of medical misadventure that had led to her impairment. She had five children, all with various disabilities themselves, two with severe disabilities, and her partner (who is her full time carer) and she had to constantly justify receiving a benefit. She stated: “I’ve had to fight. I feel like that’s all I’m doing.”

Many participants talked about copious amounts of paperwork and red tape required to be regularly filled out and sent to WINZ and ACC to verify their disability status, the difficulty compounded often by their various states of inability to complete forms. Trudy stated her frustrations:

...continually having to justify, your disability or your whānau’s disability... Telling your story over and over and over again. It’s probably more important that we have really good advocates who can help that process of what makes me well...

Joan talked about missing the additional support to reinforce whānau participation into consultations:

*I think the missing link for me is having an advocate that will say, “but you didn’t ask that question” or to say to the specialist or whatever, my whānau wants me to stay in the room, ‘cause then I go phew. If the services are good, quality and can meet my need I’ll go wherever I need to go to get that, but in doing that sometimes what’s missing, is having that support...*

**Transport**

Limited transport options for those with disability often constrained their sense of independence. Being able to participate autonomously within the community was highly dependent on access to transport and consequently deficits in transport options presented barriers. Being limited in terms of her mobility, one participant talked about feeling like ‘a nuisance,’ leaving her feeling undervalued and solitary. Transport for grocery shopping came up as a main concern for
almost all of the participants interviewed and signified loss of freedom to choose and purchase food and supplies of their choice.

5. Whakaiwikore16- Physical limitations secondary to disability

Many interviewed acknowledged that physical impairment was what they were diagnosed with and what contributed to them being labeled as living with a disability (see the Table 3. which lists identified disabilities from the Participant Interest Form which asked, ‘Can you tell us what disability you have?’). However, following analysis of the interviews, it became apparent participants perceived other issues, discussed above, contributed more strongly to their perceptions of what disability is to them. Having said that, there were many that stated the physical element to their impairment primarily led to them feeling disabled, and there were many simple quotes demonstrating this. When asked “What is disability?”, some answered referring to physical ailments, as exemplified below:

I had a heart attack on the Marae at a Tangi. Yes, and like we all do, I thought oh well we’ll go to the hospital and get fixed, but that’s not the case. The case is your health’s ruined from then on. And it dictates what you can do and what you can’t do.

I have really bad arthritis, and it gets really sore. It’s really sore today, so I’ve been warming it up a bit. I had diabetes (too).

Most acknowledged the multifaceted elements of personal limitations and also limitations placed on hauā Māori by others contributing to perspectives of disability, as exemplified by Joan in the following quote:

My disabilities are that I have had several heart operations, and my heart is very bad, and also I have a personality disorder, so I spend a lot of time in and out of the mental health unit. I’ve actually been discharged from the mental health unit, but that stigma is staying with me. And as I say my health is pretty poor.

Multiple disabilities within whānau

Some couples were interviewed, and predominantly these relationships involved one partner looking after the other, but for some couples disability affected them

16 Whakaiwikore means to “cause to grow weak, weaken, enfeeble” (http://Maoridictionary.co.nz) and often refers to the tinana/body.
both, this made life very challenging. Also as identified there were hauā Māori who also had children and other whānau members living with disabilities, some who were being cared for primarily by the hauā Māori participants. This placed obvious extra responsibilities and loads on these participants, as exemplified by a previous quote from Kayla who struggled to navigate life on dialysis and caring for five children all of whom also had disabilities.

**Fatigue**

Being fatigued was a considerably, incapacitating consequence of living with a disability for many hauā interviewed. It was a serious matter that had to be consistently taken into consideration for many of those interviewed in order to function on a daily basis. Hoani stated:

> My neurogenic fatigue is huge (problem). I can try and organise things, for my day, and because of fatigue, it just doesn’t happen. I get hoha (bored) with it, because I think I spend most of my life sleeping.

**THE EFFECTIVENESS OF THE WHAKĀRO PŌKARE VISUAL TOOL:**

The secondary aim of this thesis was to develop research data collection method that was relevant to the hauā Māori and their whānau in Murihiku. Firstly, as already discussed many of the participant identified strongly with the Whare Tapa Whā model and Sir Mason Durie’s work as an ambassador for hauora Māori. The additional element of Rakatira or leadership led to the creation of te Whare Tapa Rima and this addendum was well accepted firstly by the Rōpū Kaiārahi, who developed the idea, and also by the other participants interviewed. No one challenged the extra element and many viewed it as a valid component within the health and disability discussion. Utilising a holistic approach with the Whakāro Pōkare Visual Tool and the inclusion of an adapted version of Mason Durie’s Tapa Whā Model, we were able to approach the qualitative interviews with a wide lens, taking in many aspects of the participants’ lives. The initial interviews went well, with participants not afraid to offer advise on how to improve the questions and interview techniques as they saw would be helpful. As an example, Tarapi made comments that assisted to modify the way we asked the questions:

> More so, how does your disability affect you would be a better question. So definitely you’ll get more out of people if you say how does it affect you? Yeah. Hope I’m helping with your research I just think with.. your dealing with a lot of different levels of people as well. And it think with some things you need to
be more simple and more specific. Yeah, to cater to the needs of different people, with different, levels of smartness or cleverness.

We received positive feedback, encouraging the continued use of the Whakāro Pōkare Visual Tool for the remaining qualitative interviews. People found the graphic nature of the tool helpful, appreciating the space on the tool that gave them a sense that they had freedom to speak their thoughts. Irene talked compared the research process to an unsatisfactory experience she had with a medical practitioner:

Irene:  yeah, you’re telling me I’m going to have an operation on my back, and I’m just like, I’ve got this piece of paper (from) her, and you tell me to go look it up on the internet.

Interviewer: Right ok, for you, you needed to have more of a discussion? Or, more..

Irene: Always remember I’m very visual...like this (the Whakāro Pōkare Visual Tool) thing’s very, very helpful, yeah. See if you hadn’t have had this, and tried to explain to me what we’re doing, I wouldn’t have known what’s going on.

Interviewer: Ok so you’re finding this model really helpful?

Irene: Yes, definitely.

Others liked the water element and said it looked like paua with the blue, this appealed to them. Some acknowledged they connected with visible element of using the tool and this aided in the interview for them:

Tahu: ...always remember I’m very visual. Like this thing’s very, very helpful, yeah. See if you hadn’t have had this, and tried to explain to me what we’re doing, I wouldn’t have known what’s going on.

Interviewer: Ok, so you’re finding this model really helpful?

Tahu : Yes, definitely.

Most importantly it facilitated the conversations around health and disability well for the hauā Māori. Participants largely felt that the tool encapsulated a full picture on their perspectives of health and disability, Tom states simply:

It’s all amongst here anyway. It’s all in this lovely korero here.

There was a sense of pride and ownership over the finished Whakāro Pōkare Visual Tool following the interviews, and many even stated they felt 'healing' benefits from the process. Comments supporting affirmative views on the use of the tool and the research included:
Tahu: Yep. So that all joins up, like I don’t like boxes. I like round circles and crosses, cause you might wanna just sit on that porch for a while, and listen to...oh, wairua ...(singing) And I want to put my name in there. Hope you’re going to draw all this up. Yeah, it’s looking healing, yeah. Like you’ve got to put that somewhere.

Joan: So I think it’s been a useful exercise.

Tarapi: Ah, yeah it was able to allow me to go back into, back into my whānau, way back...

Tom: There’s a lot of feelings come out. Yep um, and it worked in right round, you know all round the whole process. There is almost like a journey. And it was, the different areas that you can go, work in whether it’s important, really important and sort of work it all back in, yeah.”

Tarapi identified that he did similar exercises with health care providers followed up with extra processes offering coping strategies:

..... we basically did similar projects to this. Not only did we do this part, but they also built within it a strategy to cope with it.

It was explained clearly to the participants that they could end the interview at any time if they felt they needed to or if they felt uncomfortable. No one took this option and there were no comments suggesting the process was detrimental. A few participants did become upset during their interview when the discussion touched on a distressing issue for them, however the interviewers ensured that all interviews were ended on a positive note. Follow up calls were made to some participants to ensure they had not remained distressed and none were. One comment talked to how this tool facilitated honest conversation including things that are not generally openly discussed with others but also a gentle reminder that this is sensitive information given with the expectation that it will be treated with respect. Tom stated:

We’re actually, as much as we’re telling you this stuff, we’re actually quite private people.

The research process as a whole was largely a positive process for all involved. This is discussed further within the strengths of the study. Feedback at the dissemination hui, about the experiences of the hauā Māori on being involved in the research process included:
Feedback from the Rōpū Kaiārahi at the hui where the preliminary findings were presented overwhelmingly confirmed the results encapsulated the lived realities and perspectives of health and disability of hauā Māori in Murihiku. Some comments supporting this included:

Tom: ...as a thing, you know as...that’s a really good way of showing it, so that’s really to me it’s very educational ... it’s a really good kind of template to work on, through you own life as well. .....instead of having a whole lot of information and funny, it’s right there so....So you can visualise it. It kind of shows you a wee journey.

Trudy: ...oh well I’m empowered from this you know, and I can move on.

Tarapi: ...you’re not just giving detailed amounts... ..you’re actually, this is the guts of the story...

Tahu: Of our heads, of our heart. Mana, mana!

Kayla: Oh well, good work. Can I have a picture of that cause it’s just so motivating.

Participants expressed coming to Dunedin, to visit University of Otago and Donald Beasley Institute, was another highlight in the research process for them. Kayla suggested:

...going to Donald Beasley...been amazing. Sometimes get a bit of advocacy from (them now), I can pass that onto all the whānau so that, that’s empowering, yeah.
CHAPTER 6- DISCUSSION

SUMMARY OF MAIN FINDINGS

Research Framework

A secondary aim of this research was to develop an appropriate research framework to collect data relevant to perspectives of wellness and disability for Māori living with disability and their whānau. This is presented first as the research structure’s effectiveness determines the accuracy and authenticity of the results presented on hauā Māori perceptions of wellness and disability.

As presented above in Chapter 5, many participants found the Whakāro Pōkare Visual Tool within the research valuable assisting the interview process. Tom expressed the views of many, when asked if his version of the Whakāro Pōkare Visual Tool was a good representation of his experience of being hauā Māori, saying:

*I do, I think this has been really helpful actually. Yeah, it’s put a lot out there, actually. Like I’ve never really thought of all the different things, and how it affects, like the ripple, and yeah, it’s been really good.*

Also as explained in chapter 5, the feedback from the Rōpu Kaiārahi demonstrated a high level of affirmation that data collected and primarily analysed, did indeed represent accurate depictions of experiences and perspectives on health and disability for hauā Māori and their whānau in Murihiku.

Central to KMR is the idea that research needs to be transformative. The process for many participants has been transformative; it has been taken back to informants/participants, and disseminated in the community. Being involved as a participant in the research was beneficial, and helpful for many of the participants. Some expressed they felt more clarity and they felt enlightened around how certain elements of their life affected others, one commenting at the end of the interview. Kayla said:

*The more I go through that process, the more understanding I have of myself, and it’s ok, cool. These are things that I only need to change. You know, and I get that through, reading the word, engaging with others. Things that are providing support. But going through it, and articulating is, is a serious thing. I*
think it’s, it’s been really useful for me, it’s good, you know? It’s given me a bit of spark, I really appreciate it, and thanks for sharing this with me, this has been good.

In order to have a more meaningful impact on the hauā Māori community, enhancing disability service provision and disability research by collecting perspectives in a meaningful way will further continue to assist this community. Ngā Kete Mātauranga Pounamu Charitable Trust claim it has been transformative. When asked how she found being involved with the research and what impact if any has the research, the CEO of this Trust, Tracey Wright-Tawha, stated:

It was a great learning process for us and impressed on me that anyone could play a role in research. It made us a better provider in that we became even more whānau centred and people powered in our thinking, planning and delivery approach. I personally felt that being involved was leading and that we could genuinely say we thought more deeply about our clients journey. Would love to do more!!

Dr Brigit Mirfin-Veitch commented on behalf of the Donald Beasley Institute:

As an institute specialising in disability research and qualitative methods, we were very excited to be able to extend our knowledge of how both topics are perceived, and can most appropriately be pursued from a Māori perspective. There is a dearth of information about the way in which Māori view the construct of disability. This research has addressed this gap. Furthermore, there is still much to be discovered about how to be responsive to Māori within the context of qualitative research. This research has facilitated the development of an important framework for guiding qualitative research with Māori, and specifically extends the Kaupapa Māori Research tradition within the field of disability research.

Given the plethora of rich information that was collected, the enthusiasm for being involved in the research process and the indication that the analysis of the data was validated by the Rōpū Kaiārahi and the participants at the dissemination hui, it can be concluded that the Whakāro Pōkare Visual Tool efficiency and usefulness to collect hauā Māori perspectives of health and disability within the Murihiku community has been affirmed. As discussed above this positive affirmation of the Whakāro Pōkare Visual Tool supports the accuracy of the results as summarised below.
Summary of findings on hauā Māori perspectives of wellness and disability

This study aimed, primarily, to present hauā Māori perspectives of wellness and disability within a Southern Māori context. The findings from this qualitative study fulfilled this aim, highlighting the factors that hauā Māori considered contributed to their experience of disability and also elements critical to attaining wellness. These important data, confirmed to be accurate by our Rōpū Kaiārahi and participants at the dissemination hui, should better inform health and disability services and their wider community how to enhance enriched and unique lives for hauā Māori and their whānau living in Murihiku.

Five main themes related to components of wellness and of disability emerged from this study and these key points related to hauā Māori experiences of being valued, self-esteem and sense of identity, sense of connectedness, access to resources and finally to the strengths and limitations allowed by disability.

Māori perspectives of disability and health generally embrace a broad approach, with multiple factors involved, as reviewed in chapter 1, and often considered strongly connected. Ratima and Ratima (2007) predict that:

*Māori concepts of disability and disability services ...will emphasise the creation of environments conducive to attainment of balance, spiritual and emotional wellbeing, maximum functioning, strengthening positive interdependence (whānau will be central), and maintaining and reinforcing a secure cultural identity.* (Ratima and Ratima, 2007, p. 190).

The findings from this study also reinforced the interrelatedness of the constituents of te whare tapa rima and, appropriately, the Whakāro Pōkare Visual Tool has been used to illustrate this (see figure 7).
Figure 7: Summary of findings demonstrating the interrelatedness of points made by hauā Māori on their perspectives of wellness and disability placed in the Whakāro Pōkare Visual Tool.

Placing the ideas that arose from the research, back into the data collection tool, permits illustration that these points are interlinked to sections of *te whare tapa rima*. The closer the subthemes are placed to the *tapa rima* element in the diagram, the more frequently they were referred to by the participants, and the importance placed on these subthemes within the interviews. By inserting them back into the *puna* (or spring of knowledge), also acknowledged the fluidity and buoyancy of these concepts, representing the interconnected and flexible nature of elements of hauā Māori realities of health and disability. For example, having a healthy relationship with a health provider comes strongly under being connected or *whānaukataka* but also relates to *rakatira* (leadership). The movement and connection of points amongst elements of *te whare tapa rima* often appeared whilst interviewing the participants and was useful to view how
healthy and disabling factors in one area of life affected other areas. Further teasing out the concepts and connectivity of elements of *te whare tapa rima* in relation to the *hauā* perspectives of health and disability, as discussed next, demonstrated how elements flow between each other, and are strongly intertwined.

**Tinana/Physical Health**

Some *hauā* acknowledged their impairment was physical, however most did not view the physical element the major focus, encapsulating their perspectives of disability. When talking about the physical limitations of their disability, more often the emphasis remained on the ability of *hauā Māori* to contribute and participate in *whānau, iwi* and community. This was contrary to focusing on the deficits of someone living with a disability, referring to them as ‘dis-abled’ or ‘un-abled’. Treating impairment as ‘taboo’ can contribute to it becoming ‘disability’, as some interviews highlighted. Many of the *hauā Māori* had both *Māori* and *Pākehā* whakapapa, and some identified feeling more comfortable, as a person with a disability, amongst their *Māori whānau*. Some stated they had to work harder in *te Ao Pākehā* to make others feel less awkward around their disability.

Almost all participants were in the workforce, many of them involved in voluntary work, demonstrating their drive to be involved in the community. Whilst participants largely did not identify physical barriers as disabling, being mobile was extremely important, as alluded to numerous times within the interviews, and seemed to be directly related to a sense of independence. Being able to get to the supermarket was specifically mentioned often.

Their ability to be employed in paid work was another consideration within the physical element of disability and wellness. Paid work was often limited because of the physical constraints secondary to their impairment, and this in turn was obviously related to their ability to provide financially for their *whānau*.

As supported by the disability service provider survey within the larger *Hauā Mana Māori* project (Centre for Health, Activity, and Rehabilitation Research, 2014), most services in Invercargill had well addressed the physical accessibility issues within their facilities. Poor uptake of the disability services, nonetheless, remained for *hauā Māori* within Southland (Southern District Health board,
The perceived quality of relationship or connection with the health provider was largely acknowledged as a strong determinant, for the hauā Māori interviewed, to accessing disability health care or not.

It follows that physical dimensions of wellness and disability for the hauā Māori interviewed related directly to ability to contribute to whānau and also dependent on relationships with wider community including health professionals.

**Whānau/Healthy Relationships**

As discussed in chapter 1, it is well established that whānau is a central for many Māori. This was also evident for hauā Māori population in this project and the concept of whānau within this research was found to be broad. A feeling of connectedness and being valued within this greater whānau were two very common themes identified as key contributing factors to perspectives of wellness and disability for the hauā Māori interviewed.

Relationships within community were integrally perceived as influencing a state of health or disability, including relationships with the health care providers. This was one of the strongest determining factors within the interviews, leading to continued access to disability services. Durie (2009) stresses the importance within hauora Māori services of ensuring every patient should leave an appointment with a health professional feeling ‘engaged, enlightened and empowered’. Feedback from participants confirms this. Communication is crucial, providing a feeling of being treated with respect, valued and being listened to. Valuing a person encompasses a number of facets, as highlighted in our findings. Active engagement with hauā, enhances their mana and creates a space where services can be offered in a way that values the client and is more relevant (Drury and Munroe, 2008). Research supports alliance with health professionals (Asay and Lambert, 1999) and how a patient perceives treatment is delivered (Wampold, 2001; Blow, Sprenkle, and Davis, 2007) are more important to many patients than the treatment received. Valuing hauā Māori, upholding their Māori identity and empowering their self-esteem are imperative to successful access of services. Providing health information face-to-face and allowing time for discussion, were examples given by participants of positive approaches towards effective disability service provision. Importantly valuing tikaka Māori within
service provision was fundamental for some participants as it demonstrated empathy, a sense of caring and an understanding of their cultural makeup, which all contributed to a mana-enhancing effect.

Attitudes of the wider community towards hauā Māori were described as influential upon the perceived value and ability to interact within the community, self-esteem and overall wellbeing of hauā Māori. These attitudes were acknowledged as being somewhat disabling rather than enabling, although some provided favourable accounts of their experiences with community interactions. Poor attitudes of the community were cited by participants as stemming from lack of insight or information provided to the community around living with disabilities. Hauā Māori mentioned the need for leaders in the community to better inform the general public around issues relating to disability, to facilitate participation within the wider community and lessen the extra burden for hauā Māori to have to do this.

Having an active role within the whānau, hapū and iwi and the wider community was acknowledged as a fundamental aspect towards wellness. For example, being able to be involved in marae functions came up on several occasions as an issue. Māori generally acknowledge and engage elders or kaumātua into active roles on the marae, however some hauā stated disappointment that they were not involved more within the marae activities. Being actively involved within the Māori community was a point that some hauā Māori suggested would contribute largely towards a feeling of being valued and belonging.

A large proportion of participants in this study originated from areas outside of Murihiku and many were not physically close to their whānau. The role of whānau for many Māori is generally well known, and as reinforced by the literature, whānau have been shown to be the main care provider for hauā Māori. The expectation that whānau will pick up the caring responsibilities may leave a gap in support if wrongly assumed to be present. The need for strong advocacy was highlighted by hauā Māori involved in this project, especially for those who did not have whānau close that they could rely on to fulfil the prominent responsibility whānau play. Some interviewed did not wish to burden whānau who were already stretched, and there were some participants who were also the
main care givers of the whanau. These points further emphasise the need for quality advocacy.

Related to the importance of relationships, within hauā Māori perspectives of disability, was another theme involving the disconnecting and disenfranchising impacts of colonisation. Participants described their perspectives of post colonisation, including separation from whānau, hapū, iwi and marae secondary to urbanisation and chasing jobs, and complex whānau issues (including issues relating to poverty, imprisonment, housing, child custody). Colonisation was a disabling element for many Māori living with disability, as also identified in Kingi and Bray’s research findings (Kingi and Bray, 2000). These impacts were highlighted in the disability survey (Statistics NZ, 2015) as discussed in chapter 1, including lower levels of education, income, employment, and higher impact of poverty and poor housing. This qualitative study also supported these impacts of colonisation on hauā Māori, including statements on health care services that do not acknowledge tikaka Māori, and poor access to determinants of health such as education, employment, money. These issues all reflected back on the ability of hauā to contribute to whānau at the level as desired by the hauā Māori in the study. Colonisation has led to Māori view of health not being considered the ‘norm’, and often not openly accepted valid in respect to health care management for Māori, hence devaluing of things Māori. This further contributed to difficulties in connecting with and receiving treatment that is responsive to the needs of hauā Māori.

Many hauā Māori described looking to the leaders in health advocacy, governmental agencies and iwi leaders to address these barriers, provided by disconnection and discrimination, to promote accessibility to the determinants of health.

Rakatira / Healthy Leadership.

As discussed above, hauā Māori called for leadership to facilitate avenues towards health including iwi groups to support them, health policies and health care providers that were responsive to their needs, and community leaders educating community around things Māori and disability.
Most participants actively sought to be in the workforce, many were involved in volunteering positions if they were unable to find paid employment. Being reliant on disability allowances was acknowledged as being distressing, many frustrated by having to constantly fill forms for governmental agencies. Added issues involved the perceived experience of discrimination, being made to feel like they were there for a ‘hand out.’ The hauā Māori interviewed acknowledged that leadership within these agencies supporting a non-discriminatory ethos, would contribute greatly to their wellbeing.

A service that facilitates connecting hauā Māori with health care providers who have been identified as working well with Māori, was acknowledged as something that would facilitate access to quality health care for hauā Māori. This would further address the communication element that frequently appeared within the interviews as being important to accessing disability services. These services are currently available in the form of Māori community nurses, who are capable in terms of health literacy, needs of their community and who generally have an understanding of the health specialists that work well with Māori. This role was acknowledged by many participants as fulfilling in many ways, including assistance with attaining mobility aids, and transportation to appointments and within the community. There was a sense captured in the participants’ korero that the potential within this role to assist them was limited by funding. Allowing focus and providing resources to support this type of advocacy was seen as valid and warranted in the case of supporting hauā Māori within this population to receive quality health care. Autonomy in regards to the right to be informed and choose appropriate healthcare is acknowledged also. Participants acknowledged they wished to be better informed and able to make health care choices, aimed to achieve the goals identified by the whānau themselves. Some also acknowledged they preferred to have someone come with them to appointments to assist them navigate their way through the health care system, whilst still allowing autonomy to sit with the hauā and their whānau. This is discussed in further depth within the implications of this study.

Many of those interviewed acknowledged being led by the lessons handed down from their tupuna and looked to them for inspiration, knowledge and wisdom, to help with everyday living, governed largely for some, by tikaka Māori. Hauā Māori interviewed in this project also made reference to rūnaka and iwi.
representatives to take a leadership responsibility, further supporting hauā Māori within te Ao Māori, adding to an elevated sense of being valued and connected to whānau. As discussed in the whānau section, participants also made reference to seeking support from leaders within iwi and Rūnaka groups in respect to promoting hauā Māori roles and equitable participation in Māori events and functions on the Marae.

The origins of having ‘Rakatira’ as an element in te Whare Tapa Rima of the Whakāro Pōkare Visual Tool stemmed from the acknowledgement by hauā Māori in the study of Sir Mason Durie’s leadership qualities within the realm of hauora Māori advancement. Most participants expressed that being integrally involved within the research project, and seeing the results from the project was enlightening and contributed to a sense of wellness. There was an overall tautoko/support for the Kairakahau Māori for the way they led the research to be conducted in a way that hauā Māori connected with and found valuable. The expression voiced was a desire for Māori leadership within Māori health and Māori health research. One participant voiced her excitement for seeing so many Māori on the University of Otago campus during her visit to the research teams environment, acknowledging that, “Maybe they will become a Māori doctor to help me.”

Hinekaro/Mental Health:

There were two main areas of themes appearing from participants’ discussion relevant to hinekaro or mental health. Firstly, was the area of stress related elements leading to distraction or unhealthy foundations from which to apply context to Te Ao Māramatanga, the world in which we live. The second area was that of psychological, psychiatric, intellectual and learning impairments.

Impacts of colonisation placed stress on many whānau and this continues to have implications on self-esteem and mental health and the effects of this stress can be passed on through generations of whānau. To achieve equity for hauā Māori, calls are out for a structural level approach to reduce socioeconomic inequalities that cause and replicate disparities (Ratima and Ratima, 2007). It is my observation that the longer the generational repeat of patterns of stress occur within whānau, and the further away from the origins it gets, the harder it is to understand the cause and therefore the more difficult it becomes to rectify. Addressing these
impacts, for example by valuing tikaka Māori practices as valid or by applying a non-discriminatory approach, reportedly had a positive effect on mental wellbeing on the participants in our study, and therefore improved ability to function as an incorporated member of whānau, hapū iwi and the greater community.

Hinekaro is the framework to be able to comprehend, define, communicate and provide reference, to the other elements in te whare tapa rima; the physical world, the wairua, leadership and support systems. Depending on the connection to te Ao Māori, many of the hauā Māori interpreted these elements through a Māori lens. Participants whose impairments stem from an abnormality in ability to perceive or put elements into context, recognised it should be diagnosed using a Māori lens. The lack of respect to te Ao Māori when diagnosing and treating ailments affecting hinekaro, was described as disabling by participants in the study, who voiced experiencing stigmatisation of ‘labelling’, of note to hauā Māori, in a manner that is not relevant to Māori world views. Many Māori find barriers to health care removed when Te Ao Māori / Māori lens is considered and treated respectfully. Having health professionals who have a healthy respect of te Ao Māori (and in many cases in terms of psychology require an understanding, at least that of the patient, of te Ao Māori) is suggested as a valid way to provide relevant diagnosis and treatment.

Wairua/Spiritual Health

Matenga-Kohu and Roberts (2003) provide their understanding of te Ao Māori concepts relating to some views on ill health and health of the wairua. They explain that the desire of the wairua is to “produce evidence of its existence” or be valued by others and also encompasses a strong sense of self. This is expressed as mana, which can be measured by the energy present within the mauri or vital life force within an individual. As referred to in chapter 1, mauri is considered to be the binding element of all aspects of health and the level of mauri an individual contains, and depicts the level of wellness one experiences (or Mauri ora). Matenga and Roberts (2003) continue to describe that when the energies involved with producing a sense of Mauri Ora, become depleted, one moves into a state of koretake (with no purpose or reason), which can move deeper into oho (overwhelmed), and further into mauri rere (panic stricken), and the end result if
this continues is total depletion of \textit{mana}. According to Matenga and Roberts (2003), another cause of poor health of the \textit{wairua} can occur when the \textit{wairua} is restricted to a state of \textit{noa} or within the physical domain, where it is considered \textit{kāpō} (spiritually blind), stripped of \textit{tapu}.

These concepts were endorsed by many of the participants interviewed in this study. For example, some discussed how experiences of discrimination, drug abuse and sex abuse had led to gross depletion of their \textit{mauri}, leaving them feeling in a state of “\textit{te Pō}” (the nothingness), “stuck”, “lost” and totally overwhelmed with very low self-esteem. Low self-esteem was identified as an outcome of the breakdown of the elements of health, secondary to poor physical, mental health and poor relationships. A lack of self-worth led to a sense of not being worthy of receiving healthcare by some participants, which of course presents as a barrier to access of health care services.

Facilitators of healthy \textit{wairua} were identified by participants included valuing \textit{tikaka Māori} practices such as \textit{karakia}, \textit{waiata}, \textit{haka}, \textit{Te Reo Māori} within daily \textit{whānau} life, community life, supporting \textit{Māori} identity by respecting of \textit{te Ao Māori} and to uphold important \textit{Māori} concepts including \textit{rakimarie}, \textit{aroha} and \textit{mana}. These practices were mentioned often as important for a sense of safety and a healthy environment for health care provision, also to transition back into everyday life following consultation. Upholding the concept of \textit{mana} brings the focus back to valuing. These concepts were reiterated within the results of this study, as participants rated the sense of being valued and a sense of self-identity being important aspects towards health. Valuing a person, from the perspectives of the participants, includes effective communication, ensuring their voices are “heard”, and also avoiding discriminatory actions and attitudes towards them. All this takes time. Gifting time is more relevant to many \textit{Māori}, who often relate more closely to being ‘in’ time as opposed to being ‘on’ time. Providing services that build confidence and self-worth may also enhance community participation, furthering self-esteem.

Durie (2005) explains that \textit{te taha wairua} is of significance to \textit{Māori} as it incorporates the idea of a connection to the environment and relationship to \textit{te Ao Māori}. The disconnectedness described by the participants to things \textit{Māori} and to their \textit{whenua} (ancestral lands) following post colonisation of Aotearoa is
directly related to the health of the wairua. Participants did acknowledge a part of their perspective of disability was due to lack of self-worth attributed to colonisation. These involved interrelated effects of postcolonisation affecting their wellbeing such as limited access to determinants of health, which lead to complicated whānau issues involving multiple agencies and services interactions, history of substance abuse and violence within whānau. Addressing these impacts of colonisation (as reflected in discussion around leadership) may lead to positive outcomes, that break the cycle of harmful practices to fill voids in life such as alcohol and substance abuse or self-harming.

Lastly, finding rakimarie (calm and time for yourself) was also identified by many participants as necessary for achieving a sense of wellness by ‘feeding’ the wairua. Many involved themselves in arts and crafts practice, others in the form of hobbies, as a way to find calm and to express themselves. Recitation of karakia also served this function for some to find a quiet and safe calm. Being connected to the Atua (Gods) and a Christian faith allowed many hauā in the study to find calm and wellness through connectedness with a church and the congregation, and a sense of being valued.

Some of the themes are similar to the perspectives of non-Māori living with disability, such as attitudes of others towards impairment, knowledge about disability, access to recreation and cultural opportunities, need for leadership (MOH, 2001) and poverty (Nikora et al, 2004; Statistics NZ 2013). This may be expected given the shared encounters of attitudes, stigmatisation and marginalisation endured by those with impairments (Thornicroft, Rose, Kassam, Sartorius, 2007). Also many of the hauā Māori did acknowledge both a Māori and Pākehā whakapapa, being influenced by both worlds, and therefore have increased the chance of experiencing commonalities with regards to non-Māori concepts of disability. However the themes identified were specific to Māori perspectives as discussed below. Many hauā voiced contributing factors to perspectives of health and disability were linked to themes not too dissimilar to non-Māori and acknowledged in NZ Disability Strategy such as: being valued; not being marginalised for being ‘disabled’; and attitudes of the wider community.
The New Zealand Disability Strategy states:

Disability is not something individuals have. What individuals have are impairments. They may be physical, sensory, neurological, psychiatric, intellectual or other impairments... Disability is a process which happens when one group of people create barriers by designing a world only for their way living, taking no account of the impairments other people have... (MOH, 2001).

This definition, whilst acknowledging the social model of disability also encompassed within the findings of this study, misses perspectives and specific elements, acknowledged by hauā Māori interviewed, and presented in this thesis. Major points of difference experienced by hauā Māori interviewed, to the perspectives of the general disability population, included the following: experiences of discrimination for being Māori, therefore being privy to the “double whammy” effect of discrimination; the value for hauā Māori of having tikaka Māori recognised within community (specifically by health care professionals); the strong focus on whānau as central and in many cases primary care givers; the added impacts of decolonisation that can lead to generational abuse; complex whānau with multiple issues and multiple governmental agencies involved; not wishing to burdening whānau who may be already stretched; the desire to be active within the Māori community; and that some did acknowledge Māori views and attitudes towards disability were different to those demonstrated by non-Māori.

STRENGTHS OF THE STUDY

Given that Māori participants and whānau were involved in this research, the use of methodology informed by KMR principles was tika (appropriate). Being guided by KMR principles, that are steeped in tikaka Māori and reflective of the world-views of the participants, led to the research findings being respectful. It also directed the research team and participants to navigate throughout the research process safely, enabling all members to feel included and not excluded. Of note, the following KMR concepts were especially acknowledged with significant importance, guiding this research to achieve the affirmative results addressing both aims of this thesis. The following reviews how the principles of KMR were successfully applied to the research with beneficial outcomes and highlight many of the strengths within this research, which is hoped to be useful for future research in this area.
1. *Aroha ki te takata* (respect for people): This was achieved in this study by consultation with Ngā Kete Mātauranga Pounamu Charitable Trust, local *rūnuka*, developing a *Rōpū Kaiārahi* and identifying leading *Kaumātua*. Ngā Kete Mātauranga Pounamu Charitable Trust were interested in collecting better understanding of their community and the research team was able to assist this. Establishing a close relationship with Ngā Kete Mātauranga Pounamu Charitable Trust was fundamental, as they were directly and intimately involved with this community, and exhibited a clear sense of responsibility to it. Ngā Kete Mātauranga Pounamu Charitable Trust is a *Māori* Health Provider and *Whānau Ora* partner, alongside Awarua Social Services in Murihiku. The *kaiwhakahaere* (CEO) Tracey Wright-Tawha and her colleague Melanie Reed kept the research grounded in Murihiku by being the conduit between the research, the participants and the research team. In many ways they advocated for the participants, held their collective voice in research meetings and reminded the researchers of the importance of the communication with participants and being kept in the loop with the research process. The *hauā Māori* will likely benefit from Ngā Kete Mātauranga Pounamu Charitable Trust having a better understanding of their perspectives, and dissemination into the wider health provider network also extends these benefits to the *hauā Māori* in Murihiku.

The development of *te Rōpū Kaiārahi*, acknowledging the need for *hauā Māori* from the area to guide the research to be relevant, was a direct and purposeful method of also achieving incorporation of this concept of *‘aroha ki te takata’* into the study. Embedding *hauā* within the research processes empowered them, not only with a voice on their perspectives, but the *mana* of ownership of the project, controlling the way in which the research was conducted in a manner which they could relate to and was theirs. Consultation with the *rūnaka* and leaders in community was also important and continues to be. Acquiring an idea of the political nature surrounding *hauā Māori* health provision, and general issues in Murihiku allowed for safe navigation for the research team to not offend anyone along the way.

2. *He Kanohi kitea* (to be seen to be open, honest, providing clear intentions and transparent process): Having an open process was acknowledged by the research team as imperative throughout the research, to ensure the work done by the research team accurately depicted the perspectives of the participants, with as
little as possible incorrect portrayal through interpretation of the researchers. Regular hui with the research team, Ngā Kete Mātauranga Pounamu Charitable Trust and the Rōpū Kaiārahi throughout, encouraged feedback, affirming and constructive in order to be responsive. For example, a hui was conducted to confirm we were analysing the data appropriately, and another for the dissemination to the participants, allowing further feedback.

The structured face-to-face interview method, conducted in spaces largely dictated by participants as most comfortable, was identified in by this community as optimal for research within their Murihiku population. This was a successful means of collecting relevant, qualitative information. This also gave those being interviewed the ability to gauge the researcher’s intentions as interpreted by the participants and how much information they were willing to provide to the interviewer.

3. Titiro, whakarongo,...korero (Observe, listen and then speak):

The primary aim of this thesis fitted well with this principle; the whole purpose being to provide a platform for hauā Māori voices to flourish. Being receptive and responsive to the participants’ advice along the research path, and adapting the research methods accordingly led to a more relevant and accepted procedure. The development of the Whakāro Pōkare Visual tool was largely informed by the Rōpū Kaiārahi and provided a very acceptable method of data collection within this population. The research team was always interested in what participants had to say and were constantly concerned with conveying an honest depiction of their perspectives. This KMR principle was incorporated in the interview questions, by identifying a koru element, allowing participants space and time to say what they wanted to.

Ata whakarongo (hearing the viewpoints with fresh, open ears) was another element related to this principle used in the research. Although the interviewers were aware of past research done in this area, they made a concerted effort to not let this information influence the way they conducted the interviews or analysed the data.

The primary investigators acknowledged that the emphasis on establishing relationships and allowing the participants to determine research processes led
to the project taking more time than they were accustomed to, but provided a
deeper understanding for them into Te Ao Māori and therefore to the subject at
hand.

4. **Manāki** (demonstrating love and respect for people): Again this concept is
embraced within the central goal of the research team, to provide the most safe
research processes leading to research results truly reflecting hauā Māori
experiences. This in turn has led to many of the participants feeling empowered
and had a sense of ownership over the research. This was evident within
feedback from the participants.

Hosting the participants in Dunedin, allowed them to share the environment of
the research team, further allowing a deeper relationship to be developed. This
corresponded well with the notion of manākitaka.

It is advisable to avoid deficit type thinking such as solely investigating the
negative elements of an issue (Reid and Robson, 2007). By addressing both
perspectives of wellness and disability in this study, allowed a much more
thorough approach, providing valuable information for relevant provision of
services that may have been missed if only addressing one or the other. This was
another advantage of this research.

Maintaining relationships within this community is expected and necessary to
inform further dissemination, continuing to acknowledge autonomy and
ownership of the project with the hauā Māori community. It is important to
continue to gauge how comfortable they are with their information being
disseminated and that they are involved with this.

Accountability of the researchers to demonstrate the concept of manāki, was
amplified for the Māori members of the research team with whakapapa
connections to the South, whose responsibilities to the community do not stop at
the end of the research. This is exemplified by a quote from a participant from
dissemination hui in Murihiku. She stated:

> I count yous (Kairakahau Māori) as whānau now because we’re all on the
same lining and we know that all those things…we know why we’re here, we
know what the next part is and how to make ourselves well, but where do we
go from there...
One of Ngā Kete Mātauranga Pounamu Charitable Trust key aims in being integrally involved in this research process was to develop their own research capacity within their community, and leaders from Ngā Kete Mātauranga Pounamu Charitable Trust have acknowledged this was achieved following performing this research.

5. Kia tupato (be careful): Incorporating tikaka Māori allowed safe and appropriate cultural practices that are inclusive of all, and the use of tikaka, Te Reo Māori and Mātauraka Māori (Māori knowledge) was encouraged to be expressed by all involved with the project.

Being responsive to advice on tikaka from the hauā Māori was important. For example one of the Tauā involved as a participant suggested the research team must ensure at all times in larger presentations, they were supported by kaumātua. It was given and received as a "kia tūpato" kōrero (be careful warning) rather than to belittle us. The Tauā was rightfully speaking out, informing the Kairakahau Māori of the need to manāki our ‘manuhiri’ (referring to our Pākehā colleagues we worked alongside) and not potentially placing them in a position of risk. As per her advice, this was to be achieved by having a kaumātua aligned with the project, which also gave the project mana within the Māori community. The research team agreed and realised the hui could have been postponed to a time that suited our kaumātua and not allowed planning logistics to get in the way of tikaka. Kaumātua presence was ensured at future hui and wānaka (workshops), and specifically we asked this Tauā (she was also part of our Rōpu Kaiarahi) to be our kaumātua, representing the project in Murihiku. She graciously accepted and the project was enriched by their presence and their wisdom throughout all phases of this study.

This is also where in the Hauā Mana Māori project, the Kairakahau Māori and advise from senior Māori researchers played an important role: guiding the research and, by observing tikaka, ensured all researchers, participants and communities involved were protected from unnecessary harm. Kairakahau Māori prepared with karakia, waiata and read previous Māori research by disabled Māori academics and service workers, which provided guidance on how to better conduct ourselves in this research project. A ‘give way rule’ was established early in the research process, following consultation with Dr Sue Crengle, a prominent...
Kai Tahu hauora Māori researcher originally from Murihiku. She recommended this rule should be applied where KMR principles and Western research philosophies clashed, where non-Māori techniques would ‘give way’ to prevailing tikaka Māori practices. This responsibility also became a strong role of the Māori members of the research team. Understanding the political environment within this community was also helpful, as discussed above.

6. Kaua takahia te mana o te takata (do not trample on people):

Local community were promoted to be part, or participants, of the research as opposed to being the subjects or objects of the study, as demonstrated with the establishment and importance of the Rōpū Kaiārahi. Imperative is the idea mana, and being careful not to belittle. Again, constantly referring to the Rōpū Kaiārahi at each step to ensure we are performing appropriately to whakamana or uplift those involved, in a way not to whakaiti or belittle.

Referring to other experienced Kairakahau Māori on ways to ensure this did not happen was beneficial and also demonstrated the respect we had for the mana of these experienced leaders. The data was analysed through a Māori lens, by the Kairakahau Māori and this was vital to stay true to this principle. Understanding tikaka Māori allowed the nuances expressed by Māori within the interviews to be correctly interpreted, therefore not misrepresenting important information within Māori perspectives. Consultation occurred with whānau involved, to determine whether the results depicted an accurate picture. This confirmed that the research answered the research question with rectitude, avoiding misinterpretation of data collected.

Seeking advice from Associate Dean Māori, Dr Jo Baxter, was helpful around preventing inaccurate focus of research results in media portrayals, which can lead to a misrepresentation of Māori realities negatively impacting on Māori and further discouraging engagement in research.

7. Kia kākau mahaki (be humble): Care was taken not to present ourselves as the experts and information given by the participants was acknowledged as the main focus. There was no right or wrong, all that mattered was their view. Having our offices at the University of Otago and the Donald Beasley Institute critiqued by the Rōpū Kaiārahi, some offices being untidy, demystified the idea of the research team being in an inaccessible position.

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The Rōpū Kaiārahi agreed to the research being presented at Te Piringa hui by the kairakau Māori and a member of the Rōpū Kaiārahi. Having a participant alongside to deliver the presentation, provided accountability to the Rōpū Kaiārahi. This also acknowledged that the research contained the voices of the community, it was owned by this community, and it was up to them to determine how it best benefitted them. The research team was humbled by the work within this community and hoped this sense of kia kākau mahaki (humility) was evident, further empowering the hauā Māori.

Being guided by KMR methodology successfully directed the research to be performed in a meaningful manner for participants as discussed above. The development of a relevant data collection tool, the Whakāro Pōkare Visual Tool, also aligned closely with these principles, and was verified by the Rōpū Kaiārahi and participants as a useful and acceptable instrument for data collection. The expectation of research to be transformative is embedded in KMR philosophies. On seeing the results of the research, the Rōpū Kaiārahi confirmed that this did reflect their perspectives of living with disability and were excited that their voices were being expressed in this way. An additional and unexpected advantage, acknowledged by the participants, was the provision of an insightful and ‘healing’ benefit experienced by some following the interview using the tool. It was described as very helpful to have a patient, interested, listening ear and a visual instrument that hauā Māori could conceive a mental picture of the many aspects of their lives contributing towards health and disability. This was a huge, favourable asset of this research. Honouring our hauā Māori participants, the development of the tool and the interview process was largely guided by KMR principles. This provided the extra advantage by having tikaka Māori understood, valued and uplifted.

8. Whakawhānaukataka (making and maintaining strong connections with whānau, hapū, iwi and wider community): This was a strong benefit towards this research being appurtenant. This principle was applied at many levels in the Hauā Mana Māori study processes, including initial consultation with iwi groups, Ngā Kete Mātauranga Pounamu Charitable Trust and the community around recruitment of Māori coordinators and participants, conducting interviews with participants, and analysis and dissemination of research results.
Working with Māori community proved to be engaging and rewarding from the research perspective, in that it allowed more relevant findings to be determined, and on a personal level in terms of broadening my whānau and connections in the ‘deep South’. Consulting with the community in the initial stages of research design was important in establishing healthy relationships within the community. Creating these relationships continually reinforced the concept that driving factors, goals and motivations for the research was to achieve beneficial outcomes for that community and strengthened the commitment from the researcher to ensure this happened.

Early in the planning phase of the broader project, Hauā Mana Māori, it was decided to first perform the qualitative study (that this thesis is based on) so that data from the hauā Māori voice could inform the service providers. This was helpful when performing the on-site interviews with service providers, the second part of the three-pronged project, as it enabled an opportunity to discuss and disseminate the findings on hauā Māori views. In turn, it was hoped, this could lead to improved accessibility for hauā Māori to health and disability services. For instance, many services were interested in the idea of cultural training for their service and considered connecting with a Māori health provider for consultation when needed.

Further dissemination within the health and disability workforce and research, the results from this qualitative research were delivered to MOH in a report in 2013, delivered in physiotherapy conferences, and applied to physiotherapy curriculum at University of Otago School of Physiotherapy. The research team was invited in 2013 to present the findings of the Hauā Mana Māori at a Te Piringa hui, in Tauranga Moana. Te Piringa is an organisation made up of Māori Health providers from around the country who deliver services in the area of disabilities. One of their aims is to lead many research opportunities for Māori disability, and have a working relationship with leaders in health policy development at a governmental level. Alongside a participant who travelled with me to awhi the presentation, we presented our findings at the hui. The Te Piringa hui was also attended by the Honourable Tariana Turia, who at the time was the New Zealand Government Associate Minister of Health, and a remarkable advocate for promoting and uplifting hauora Māori. Notably she is known for her instrumental part in establishing ‘Whānau Ora’ as part of the New Zealand MOH
policies, largely driven by her leadership. Many others also attended this hui including those who worked directly with hauā, hospital board members and health and disability policy leaders. It was significant to be able to present a Southern hauā perspective, a demographic whose voice has been underrepresented in recent hauā Māori research. It was also an opportunity to encourage others to perform similar research using methods deemed to be successful within this population. Others were advised to modify the process and the tool to be specific to the needs of the rohe (area) and hauā being interviewed. Further dissemination of this research to the wider hauā Māori health and disability support networks, including influential members of parliament who can affect major changes at a governmental level, was a beneficial outcome of this study.

**LIMITATIONS OF THE STUDY**

There were a number of limitations identified with this research project, and identifying these should assist with future research in this area.

The need to collect more demographic information was identified when comparing the results to statistical information in the Disability Survey (Statistics NZ, 2015). Initially it was not seen as important to collect information such as employment, educational qualifications, income, whether hauā felt they had enough money for day-to-day living, or whether they felt housing was sufficient. This was not the aim of the thesis and the research team did not want to deter participants from engaging by asking these specific questions. These are valid reasons however in reflection, if done respectfully, it would have been insightful to have this information, to be comparable to the statistical survey. Qualitative and quantitative research is useful in providing valid information for improving health (with special emphasis on determinants of health in this case). Multi-methods including both qualitative and quantitative approaches may be adopted in KMR (Barnes, 2000) and Māori experience of disability may be characterised by both quantitative and qualitative wide inequalities relative to non-Māori (Ratima and Ratima, 2007). This requires being very conscientious, in that techniques engaged for such research all closely align with KMR philosophies.

Time frames are important to provide structure and motivation to achieve research outcomes in timely fashion, and need to be clearly outlined. However,
establishing and maintaining connections with research populations when conducting KMR is very time consuming and often does not fit within timeframes set by Western research practices. Some of this research was pressed in order to meet the funding body time constraints, given the priorities and extra responsibilities to be connected to the hauā Māori in Murihiku. For instance, some of the willing participants were not interviewed, secondary to tight time frames to have a deliverable report for the MOH and HRC. Being provided with more flexibility around some timeframes would have contributed to being able to conduct this research in an even more meaningful way for the community involved.

Participants in this study were recruited largely through a Māori health provider, Ngā Kete Mātauranga Pounamu Charitable Trust who was interested in the perspectives of the clients. This could be seen as a limitation, as many of the participants were receiving relevant and empathetic care from a Māori provider, and we may have missed perspectives of those who were more vulnerable and not receiving effective care. Presenting these data may have provided more insight as to why some hauā Māori do not access health care and thus information about how to improve accessibility for hauā Māori to useful and efficient health care.

No one on the research team identified as living with a disability and although the research team had members with experience in the disability research sector, a hauā Māori representative on the team would have been optimal as identified by in Uia Tonita- Māori disability Research Agenda 2011 (MOH, 2011), preferably from the Murihiku area. The now late Donna-Rose McKay, who was Head of the University of Otago Disability Information and Support Service, was approached as a consultant early in the research process, and she gladly helped. She suggested that it may be more relevant to involve someone from the community to make sure research is useful, effective and reflective of changes needed to happen for Māori with disability in Murihiku, and was enthusiastic that a Rōpū Kaiārahi was established.

Further our research question did not emanate from hauā Māori community in Murihiku, but instead in response to an HRC request for proposal of research around Māori living with disability and their whānau. It was a research project
placed upon this community and we acknowledge that this could be perceived as a denial of self-determination. However throughout the rest of the project, given the establishment of the Rōpū Kaiārahi and the working relationship between the research team and both the Māori health providers in Murihiku, (Ngā Kete Mātauranga Pounamu Charitable Trust and Awarua Social and Health Services), and by considering research priorities already identified Māori who are living with a disability (MOH, 2011) we were able to address self-determination. The kairakihau Māori were cognisant that due to the research question not originating from the community that this did not fit within the pure definition of KMR. Instead it was accepted that this research was comfortably deemed as being guided and informed by KMR principles, an approach suggested by Dr Emma Wyeth, another prominent Kairakahau Kai Tahu (Kai Tahu researcher) experienced within the hauora Māori field.

The principal investigators on the research team were not Māori. Often, issues pertinent to things Māori are seen by some to be insufficiently addressed by non-Māori researchers. Some suggest that past research around Māori realities, performed by non-Māori, have failed to address issues other than cause of disease and impact on the individual (Murchie, 1984; Barnes, 2000). The Hauā Mana Māori research team’s approach however was entirely collaborative; being mindful of the tensions that can develop between the Kairakahau Māori and the senior non-Māori researchers (Selby and Moore, 2007). The emerging Kairakahau Māori were enabled to take the lead and initiative, guided and mentored by the more senior researchers on the team in regular meetings. Ensuring the ‘give way’ rule (as discussed above) was applied became an extra responsibility of the Kairakahau Māori, and expressing to the primary investigators tikaka Māori processes did take some time and energy. Although championed by impressive senior researchers with wisdom and experience in the disability field, the Kairakahau Māori were research assistants and did not lead the project. Therefore, it felt tika (correct) to acknowledge that this research project was guided by KMR theory and principles and was not a pure KMR project in the eyes of some. With this in mind, we endeavoured to approach the research with “cultural humility” (Ahuriri-Driscoll, Hudson, Foote, Hepi, Rogers-Koroheke, Taimona, Tipa, North, Lea, Tipene-Matua and Symes, 2007; Gifford and Boulton, 2007), to develop meaningful relationships within the community and with Māori health providers as discussed above. The issues of non-Māori
leadership were somewhat mitigated, as the recruitment of participants, data collection, and dissemination to the participants for the qualitative study were largely undertaken by the Kairakahau Māori. Also the analysis, coding and thematic representation was performed largely by myself, providing a Māori lens and interpretation. Eventually, as more Māori get involved in performing research competently and confidently and valuable outcomes from KMR are recognised, hopefully we will arrive at a place where tikaka practices and KMR principles will not have to be defined and justified, and KMR becomes validated, normalised and utilised. I would like to go further to suggest that KMR principles are valuable, ethical guidelines to conduct research in many areas, not just for Māori.

Most contemporary Māori navigate both Te Ao Māori and Te Ao Pākehā, therefore many hauā Māori understand and are influenced by Pākehā (non-Māori) world-views. In this respect any research seeking Māori perspectives of disability may not avoid including elements from te Ao Pākehā. However those participants interviewed mostly strongly identified with being Māori and therefore it can be considered Māori perspectives that were collected.

**COMPARISON OF RESEARCH TO OTHER PROJECTS**

This study supported findings in previous research, there were similarities and differences with other studies:

Results from the research reinforced a number of highlights in the most recent disability survey (MOH, 2013) including statistical information regarding quality of life. In-depth demographic information was not recorded, as at the time of collecting, this was not felt necessary and also was felt that we wanted to encourage those to be involved and not feel like being part of a negative statistic. Perspectives of hauā Māori was the primary aim and what was being collected rather than comparative statistical information. Although statistically, it cannot be compared, it can be noted that data from the interviews in Murihiku support the statistical information collected around experiences of discrimination being common and frequent among disabled Māori adults, supporting the “double whammy” effect, of being both disabled and Māori (Collins et al, 2009; Ratima and Ratima, 2007). The interviews supported this experience of discrimination where many of the participants spoke of the disabling impact of being
marginalised, feeling like being at the “bottom of the pile”, “little people get left behind. Us little ones...”, being exposed to discrimination for being hauā Māori amongst health providers, governmental offices, public transport, law enforcement, hospital and classroom. Combatting the disabling impacts entails the things that make the hauā Māori feel well such as being valued, being connected, employed, heard, having tikaka Māori respected and integrated, and being actively involved in Māori functions and activities on the Marae.

Specific information about employment, income, housing, or education, was not collected in the Hauā Mana Māori study. However, as mentioned within the interviews, almost all participants were in the work force and only a few worked in full time positions. Many were reliant on benefits and several hauā talked about the stress and difficulty this placed on them financially and their self-esteem. Having to deal with paper work and bureaucracy was noted as problematic. There were many that discussed that the lack of putea was a major issue. Some mentioned housing as a limitation to wellness. Some also acknowledged that further education would be helpful, and three of those interviewed were presently students. Of importance, it was noted within the Statistics New Zealand Disability Survey (Statistics NZ, 2015) one quarter of hauā Māori stated their household income was not sufficient to meet their everyday needs. This was brought up within some of the interviews, however it is difficult to compare without accurate data. The impression was many participants may have been struggling financially, and this was definitely highlighted in the interviews. It has to be said, however, that secondary to the resilience, resourcefulness and support demonstrated amongst the hauā Māori and whānau interviewed, the experience of financial struggle may have been minimised within the interviews. On the whole, within the Statistics New Zealand Disability survey, more hauā Māori perceived problems with housing than non-disabled Māori, particularly issues with cold and damp houses (Statistics New Zealand, 2015). This was also identified on several occasions with the hauā Māori participants interviewed in Hauā Mana Māori project.

Cram et al’s (2003), looked at themes that appear when Māori talk about health. This project involved a generalised cohort of 28 Māori, who were not necessarily hauā Māori, living with disability. Their findings supported similar findings to this thesis’s interviews, in that they identified the most important facilitator to
health care was the rapport with health care professionals. Also, similar contributors to ill health were identified and expressed by Cram et al into three categories: (1) those affecting the individual included drugs and alcohol; (2) poor health of the whānau stemmed from factors undermining foundations of whānau, such as stress and poverty and; (3) at the societal level included targeted advertising of unhealthy behaviours, generalisation of low expectations for Māori, and an inability to afford health care. The last category was not strongly highlighted within the interviews of our participants, neither were further findings in a study conducted by Cram et al, including integrating traditional Māori concepts and practices (rongoā) into health care or the delivery for Māori Marae-based health care.

The aim of the MOH research, Whāia Te Ao Mārama: The Māori Disability Action Plan for Disability Support Services 2012 to 2017, (MOH, 2012) was to establish priority areas of the aspirations of hauā Māori, in order to reduce barriers that may impede hauā Māori and their whānau from achieving improved outcomes. The Whāia Te Ao Mārama study was conducted approximately concurrently with this the Hauā Mana Māori project and although totally relevant to this project (and almost similar in its findings), it is not mentioned in chapter 1 as it was not influential to the research processes used in the Hauā Mana Māori project. Two hundred Māori participated in the Whāia Te Ao Mārama study. The research participants were listed as Hauā Māori, their whānau, and those working in the disability support sector, organisations such as Te Piringa, Needs Assessment Service Coordination Association (NASCA). All named contributed to this study over an 18-month period. Secondary to little information provided within the report on the inclusion criteria and demographics, it was unclear how many hauā Māori were involved and interviewed. The report was also unclear on methods or methodology utilised. The report did acknowledge hauā Māori aspirations on contributing factors towards positive difference in their lives and these were as follows: (1) Having autonomy and leadership over their own lives; (2) Being supported as both disabled and Māori; (3) Being able to participate in te Ao Māori; (4) Having whānau valued as primary support system; (5) Being connected to support networks including Māori and disability communities and; (6) Taking a holistic approach to their disability. These were also all identified within the current thesis. Whaia te Ao Marama provides a five-year plan, between 2012-2017, with proposed actions to address aspirations of hauā Māori. A tōrino
double spiral diagram incorporated in the plan has similarities to Whakaro Pōkare Visual Tool and illustrates four interconnected core elements identified as needed for effective service provision for hauā Māori.

1. *Te Ao Māori*: representing the ability to participate in their own whānau, hapū, iwi, drawing support through te reo, whakapapa, whānaukataaka, manaaki, and wairua.

2. *Te Ao Hurihuri* (new world): political economic, social and environmental trends

3. *Te Rangatira*: whakamana of hauā Māori, to take up their roles as they have a right to do within whānau, society and *Te Ao Māori*, controlling their own sense of destiny

4. *Tūhonohono*: Relationships with whānau, hapū, iwi and caregivers

These elements captured the same themes reiterated in the *te whare tapa rima* model, identified by Rōpū Kaiārahi, but are framed in a different manner. Guiding principles of the five year plan included: (1) enabling hauā Māori (greater leadership, choice and control over disability supports, acceptance of diversity of Māori, respect for tikaka Māori); (2) respecting hauā Māori roles in whānau and community); (3) valuing whānau (as primary support, supporting whānau, socioeconomic solution); (4) respecting community (good partnerships with whānau, hapū, iwi, full participation of Māori in planning disability services, change of attitude of whānau, hapū, iwi to support vision for Hauā Māori); and (5) delivering high quality, effective disability services (culturally safe, improving hauā outcomes, better knowledge and access to disability services for Māori, equitable resource allocation for Māori-focused disability services). Of note this report incorporates work to inform Enhanced Individualised Funding (EIF) and Choice in Community living, governmental funding and housing options available for those living with disability. Evaluation for eligibility to access these resources is done by the Needs Assessor and Service Coordinator. This is relevant to the findings of my thesis in regards to informing access to much needed financial assistance for many of the participants within the *Hauā Mana Māori* study.

As discussed in chapter 1, physiotherapy research was performed by White et al (1999) exploring perceptions of health and illness. This study demonstrated KMR methodology which was established by a kaumātua of the Ngati Tama iwi, used semi-structured interviews, open ended questions, similar to *Hauā Mana Māori*,
however it did not investigate perspectives of disability and did not specify recruiting hauā Māori. The White et al results, however, did confirm that health was perceived as a balance of the elements in te whare tapa whā, as described by the participants in the Hauā Mana Māori study. ‘Māori illness’, as identified within the Ngāti Tama people, was not a strong theme in my study.

Nikora et al (2004) aimed to provide information to enhance the development and implementation of an effective model of disability support service provision to Māori with disabilities and achieved this, in part, by identifying and documenting needs expressed by disabled Māori and their carers living in the Midland area. The research involved interviews with 49 hauā Māori, aged 10-60+ years. This report focused on health and disability service provision as opposed to perspectives of health and disability, and acknowledged the hauā Māori interviewed particularly accessed whānau as their primary health care support. Of note, however, this study specifically recruited those who had not accessed disability support services and purposefully avoided recruitment through any of the known disability or health service providers. Results, therefore, may have been influenced by this recruiting technique, although it is considered good in theory that it captures the perspective of those not accessing health care services, providing insight as to improving accessibility. The main provider was identified as a whānau member, but many also received care from other sources on an as-needed basis, accessed both mainstream and Māori services. Findings similar to my study were: mainstream services could improve cultural sensitivity; more financial support for is needed for Māori living with disabilities and whānau; further financial help for whānau members who are carers is also required; more Māori workforce would make positive difference to hauā Māori and whānau as the key support is integral. Additional advice within this report included that the GP is the person most likely to be contacted for advice about accessing disability services, and at times of crisis, more practical assistance around home and time out for carers is needed, additional financial support was called for a social worker or liaison person for whānau carers to talk to and greater support networks for whānau were identified.

Again, as discussed in chapter 1, the Bray and Kingi (2000) research, like this thesis, aimed to explore Māori world-views of disability. This was a small study of 15 Māori, aged 22-65 years, and no reference was made as to whether any of the
participants identified as having a disability. It was interesting to compare the latter study’s findings of Māori perspectives to the hauā Māori perspectives captured in this thesis. Bray and Kingi summarised the main idea contributing to disability was the impact of colonisation which was also a strong reality for hauā Māori in this thesis. These similarities expressed around disabling elements secondary to colonisation included being disconnected from whenua, different ways of doing things, not knowing who you are, where you are from, not having skills or autonomy over destiny, being forced into Pākehā politically controlled systems, urbanisation that led to loss of manaaki, awhi, loss of connection to Marae and knowledge, to not be able to use Te Reo Māori, and the loss identity and associated low self esteem of Māori. Many attributed directly self-destructive behaviour and high use of cannabis, alcohol and tobacco, being deficient in the ability to function adequately as apparent and with whānau, to dispossession of land and language. Poverty was noted as a disabler in Kingi and Bray’s (2000) research, and was viewed by the Māori interviewed as “being more disabling than any physical, psychiatric or sensory impairment.”

Other similar trends demonstrated in both the Kingi and Bray’s (2000) research and this thesis included highlights acknowledging differences between Māori and Pākehā perceptions of disability, where Māori embraced a more holistic, more ‘accepting of everybody’ philosophy. One of their participants was quoted as saying “we are disabled in the Pākehā world- in our own world we’re not.”

Also identified was the uneasiness experienced by many Māori with regards to non-Māori labels of psychological diagnosis for Māori. As expressed by the hauā Māori participants, more focus was called for towards use of a Māori lens in the solving of Māori mental health issues.

As explained within the results section, one of the participants went on a “smashing spree” because he felt misunderstood, was frustrated by being labelled using Pākehā terms, and used haka to bring him back to a safe space, or Te Ao Marama, from Te Pō. To a health professional who does not understand this concept of Te Pō/Te Ao Mārama and the use of Te Reo Māori, karakia and haka, and the impact on his wairua, this may seem threatening and a very unusual thing to do, that might require medication to suppress it. Someone with understanding
of Te Ao Māori however, might embrace this use of tikaka Māori as a coping mechanism and as a method of healing.

It was also noted in Kingi and Bray (2000), as in this thesis, that whānau were caregivers and it was perceived that Māori whānau were lessening some load on the New Zealand health care system by looking after hauā Māori, yet this role of whānau was largely undervalued by governmental agencies. The need for Māori-based disability services within the community was also further acknowledged.

Additional findings in Kingi and Bray (2000) that were also identified in the current thesis included: the acknowledgement of change from traditional food and resources, with specific reference to those with diabetes\(^\text{17}\); and also being limited in gathering kai like they used to and not having access to kai they used to have access to, for example, kai moana (seafood) and the bush food.

However Kingi and Bray (2000) did not capture aspects of the disabling effects for the hauā Māori participants in the Hauā Mana Māori such as: the negative attitudes of others towards disability; not being valued; and not being able to contribute to whānau. These are all experiences that may be only truly understood by those with a disability and important when informing best disability service provision.

Ratima et al (1995) studied hauā Māori views, service providers those interested in Māori disability services, to produce a report for the Core Services Committee. Similarities identified within this latter research to the current thesis included the following: (1) The importance for hauā to be well because they have whānau to look after themselves; (2) a preference for Māori based services; (3) a lack of Māori people in the health workforce; (4) some felt that predominantly Pākehā service made them feel uncomfortable (no Māori to talk to, need more Māori there, feel the system is unfriendly to Māori); and (5) an undercurrent of poor communication skills, with one participant stating: “If you are into tikanga then yes you will feel uncomfortable.”

\(^{17}\) Diabetes is proportionately high within the Māori population (Baxter, 2002) and these findings were supported by the high rate, or one third, of the research population in He Kiteka Hauā e Murīhiku being diagnosed with diabetes.
Having tikaka Māori part of disability support services also was generally supported in Ratima et al (1995), acknowledging use of Te Reo Māori, waiata, and karakia. In terms of whānau involvement, most identified they wished to have whānau participation, and the authors quote the Māori concept ‘you never go alone’. Whānau participation is noted as important as it shows services are caring and aware of your culture and helps whānau understand disability, provides further support after treatment, if something went wrong, participants said they felt better knowing the whānau was involved, whānau support is key. In the current thesis, poor communication between providers and clients was highlighted as a major barrier to use of disability services. Culturally qualified health professionals were suggested the best way to address communication issues, and disability services were advised to incorporate a holistic definition and approach improving wellbeing of Māori whānau community iwi groups, and should involve consultation with these whānau and hapū groups. Ratima and Ratima (2007) recognised that this would take time and suggest that in the interim ‘Māori Liaison’ positions were high priority, who would develop a primary relationship with the patient and would relay information and act to refer to specialists. This supports the finding of the research performed in Murihiku, where advocacy services was strongly indicated.

Ratima and Ratima (2007) additionally found that hauā Māori interviewed identified miscommunication and lack of Māori services was linked to the use of services only in times of extreme need rather than onset of symptoms, some only engaged with a General Practitioner (GP) in times of crisis. A lack of knowledge of what services were available, was also acknowledged, and Marae based services were suggested but as mentioned this was not a strong need.

There were some themes that did not appear in any of the other similar research that did appear within the current study. Looking at the demographics there is a higher proportion of the Māori population in Murihiku that identified as Maata Waka, or did not carry mana whenua status, than in other areas of New Zealand. As discussed this can be attributed to many moving to the south for work opportunities such as in the meat works and wool harvesting industries (Paringatai, 2013). This demographic trend is similar for hauā Māori, as seen in the results where one third of the participants had whakapapa ties to Northern iwi. Some participants identified that whānau were not always available to be the
key carer, and some identified isolation from their *whenua* as being disabling. This emphasises the need even more for funding to support advocacy positions to support these *hauā Māori* in a manner that are ‘Māori friendly’. *Marae*-based services, as noted several times, did not come through the interviews as a strong theme. I predict that this may have been influenced by the large number of participants that were referred through Ngā Kete Mātauranga Pounamu Charitable Trust and these clients were already accessing a *Māori* based service, who had strong *tikaka* throughout their service and almost served as a *marae* for many participants. This service also readily uses *marae* for many their functions. Having said that, another theme that came out of the study not noted within other studies, is the acknowledgement of the need for improved *marae* strategies and policies to support *hauā Māori* participate and have an active role in *marae* proceedings.

**IMPLICATIONS OF FINDINGS**

Leading from the results addressing the primary aim exploring the perspectives of wellness and disability of *hauā Māori* in Murihiku and their *whānau*, the following recommendations are presented.

As a health care service provider/advocate/carer/policy maker/leader/governmental agency/ *rūnaka*/*iwi* researcher the following steps should be taken to enhance the unique and enriched lives of *hauā Māori* in Murihiku:

1. **Value *hauā Māori* and their *whānau*.** This is empowering and can be achieved by:
   - allowing *hauā Māori* to be heard, and signal that they have been heard
   - following up patients, especially those missing appointments
   - encouraging active roles in *whānau*
   - encouraging active roles in community
   - involving *hauā Māori* in *Marae* operations and events
   - valuing and respecting *tikaka Māori* within your service
   - inform community about being *hauā Māori*
   - inform *Māori* community about disability
   - inform disability community about being *Māori*
   - conveying positive messages and encouraging positive attitudes of the wider Murihiku community
- engaging employment services, and facilitating employment or active position in the workforce
- employing hauā Māori in roles to achieve the all of the above

2. Facilitate hauā Māori to be connected. Being connected enables many hauā Māori to achieve their goals and can be made possible by:
- spending time to establish a healthy relationship with hauā Māori
- using communication skills that acknowledge value of tikaka Māori and of disability
- encouraging face to face interactions with hauā Māori
- embracing whānau within your service, acknowledging the broad term of whānau
- understanding some Māori in Murihiku are Maata Waka and are isolated from whānau, and disconnected from their whenua
- understanding you may become considered whānau
- endeavouring to be more “whānau-centred” and “whānau-led”; for example, facilitating and being responsive to feedback from the hauā Māori community
- ensuring a ‘no tolerance’ policy, actively discourage and educate staff around discrimination
- connecting with Māori community
- establishing a relationship with Māori health and disability providers
- employing Māori staff
- communicating with and informing agencies such as Housing New Zealand, Work and Income New Zealand (WINZ), Accident Compensation Corporation (ACC), Child, Youth and Family Service (CYFS) as advocate for hauā Māori
- assisting hauā Māori with form filling
- applying funding towards developing advocacy services as a conduit to quality health care and applicable services

3. Encourage developing a strong self-identity and positive self-worth for hauā Māori by:
- recording quality ethnicity data
- acknowledging the interconnectedness of te whare tapa rima elements of hauora Māori to achieve Mauri Ora
- knowing the Māori community
- respecting and valuing tikaka Māori within your practice
- respecting mana kaumātua and responsibility
- being accountable to service policies and strategies that incorporate the Treaty of Waitangi, updating cultural training of staff routinely, and ensuring this can be actioned in a practical, usable, and productive way.
- embracing the use karakia and te reo within your practice
- enabling participation in hobbies, arts and crafts
- encouraging positive attitudes towards disability
- embracing concepts such as aroha, manaaki, and rangimarie
- respecting and valuing role of religious faith (as appropriate)
- promoting services to free hauā Māori from addictions and harmful behaviour (drug, alcohol, tobacco, gambling, violence, child abuse)
- using the Whakāro Pōkare Visual Tool within your service

4. Facilitate access to resources and determinants of health (such as funding, affordable housing, education, healthcare, transport, employment, food, social networks) by:
- educating those who work for agencies connected to provision of determinants of health about the realities faced by hauā Māori in Murihiku
- providing affordable health and disability services, understanding and facilitating access to funding available to contribute to more affordable services for hauā Māori
- connecting with financial assistance and housing agencies to facilitate access to funding (eg. EIF and Choice in Community Living options for hauā Māori) as an advocate for hauā Māori
- encourage use of budgeting services
- providing relevant and accessible information to hauā Māori on quality healthcare services available. This may entail the use of te reo and consider alternative marketing media tools such as Facebook, Ngāi Tahu publications such as Te Karaka magazine or Panui, and the ‘Māori grapevine’ (networking through Māori organisations such as Kohunga Reo,
- encouraging hauā Māori to access affordable education and learning activities in Murihiku (eg Southern Institute of Technology)
- facilitating accessible transport to and from your service
- facilitating legal support (as appropriate)
- facilitate assistance to enhance independent supermarket shopping
- informing public transport and supermarket vendors on the realities of *hauā Māori* and act as advocates for *hauā Māori*
- advocating for *hauā Māori* to be employed within the workforce
- offering child and *whānau* caring options within your service

5. Enable rather than dis-able *hauā Māori* by:
   - focusing on strengths, uniqueness and diversity of *hauā Māori*
   - encouraging activities and means through which *hauā Māori* can continue to contribute to *whānau*, *hapū*, *iwi* and the wider community (rather than deficits secondary to having a disability)
   - encouraging healthy lifestyles (e.g. healthy eating options, cooking classes, community exercise classes and individualised exercise options)
   - understanding fatigue can be a big issue for *hauā Māori*, therefore knowing signs and being mindful to take fatigue into consideration when dealing with *hauā Māori*
   - educating *hauā Māori* on ways of combatting fatigue (e.g. with appropriate rest when needed, good sleep patterns, adequate nutrition and appropriate levels of exercise)

Further discussion of some main features within the implications from this qualitative study is presented below.

**Marae Policies**

Some discussions were made around improved self-worth, self-esteem, sense of connectedness and being valued by facilitating active involvement of *hauā Māori* within Marae operations. It was noted by some participants that whilst Māori tended to respect the needs of their *kaumātua* or elderly, considerations for the diverse needs of hauā in enabling them in participating fully on the Marae may require some work, identifying accessibility issues as one area needed to be addressed. Establishing a role on rūnaka for a *hauā Māori* representative that can advocate for *hauā* participation, may be a good start, and this will be conveyed to the rūnaka in Murihiku. This position on the rūnaka could inform awareness of disability and provide clearer policies or *kawa* (for instance how to deal with
issues of hauā not being able to handle people singing too loud and having to remove themselves, how to accommodate for those with diabetes possibly having to eat earlier). Further discussion on marae may involve acknowledging when to engage hauā Māori when they are well. This may necessitate identifying when they are not well, understanding not to engage them at these times so hauā are not put at risk. Having extra information for disability for mana whenua and manuhiri on the website, may also be entailed. Suggestions therefore include that rūnaka have a hauā representative that can advocate for the needs of hauā. Further investigation into how whānau, hapū and iwi groups currently address engaging hauā Māori is required, and rūnaka are encouraged to represent and incorporate policies for hauā Māori within activities on the marae, and in general.

Advocacy Services

One of the primary recommendations arising from the results, that would assist hauā Māori to access health and disability services is the establishment of an Advocacy Service in Murihiku, as discussed above. Many hauā Māori depend on whānau to awhi them in times of need. Whānau, however, are not always close or available, especially for those who are Maata Waka, as many Māori in Murihiku are. Maata waka are often away from their whānau, and do not have whānau, hapū, iwi support and do not necessarily benefit from the additional support received from those with whānau as primary carers. Having acknowledged this, however, many are married or have been ‘adopted’ into a Kai Tahu whānau or are involved in the wider Māori community. Mana whenua do take Maata Waka under their wing and end up providing a role that whānau might otherwise carry out. Still, having an advocate supporting hauā Māori to access organisations that are responsive to needs of hauā Māori is vital to facilitating access to health and disability organisations in Murihiku. This would be best suited to be a person who is:

- familiar with the hauā Māori population and various service providers that are ‘Māori friendly’,
- knowledgeable in tikaka Māori practices ,
- with connections within the Māori community and organisations,
- aware of funding and funders to be able to access resources and pūtea,
- trained as a health professional or worked in a health promotion, delivery or research.

Roles might include reminding of appointments and if unable to attend, notifying the service and rescheduling, accompanying the *hauā Māori* to the specialist, ensuring the *hauā Māori* is satisfied his or her questions have been answered, and following up with the *hauā Māori* in between appointments. Advocates could also assist with transport and with accessing other support that the *hauā Māori* may require, for example, filling prescriptions. As mentioned it is not intended that this role remove autonomy of *hauā Māori* over health decisions but rather that focus is on facilitating access to relevant and quality health care and information as determined important by *hauā Māori* and their *whānau*. These roles already exist in the form of *Māori* Community Nurses, and the recommendations from this research is to recognise the value of this role, allowing more funding to develop relationships with the *Māori* community, with the health professionals who work well with *hauā Māori*, with governmental agencies, and the *hauā Māori* population itself, for the position to meet desired outcomes.

**Establishing Relationships with *Hauā Māori* and the *Māori* Community**

One of the most important determinants of access to services identified by the *hauā Māori* interviewed was the quality of the relationships formed between the health care service providers and *hauā Māori* and their *whānau*. Physical barriers to access of services, notably, were not mentioned within the interviews. Communication skills, empathy, support of *whānau* involvement, time spent and an understanding of tikaka *Māori* with regards to that of the health care provider were all viewed as more important in relation to whether the participants rated the healthcare received and whether they would access that service again. Therefore it cannot be stated strongly enough that establishing a healthy relationship with *hauā Māori*, is vital to facilitating use of health care services. Work needs to be done within the health and disability service provision to ensure discrimination is not occurring, and this starts with recording ethnicity data accurately. Continuing up skilling in the area of cultural safety is important and may be facilitated by connecting with the *Māori* community and *Māori* health care providers, who will probably be more than enthusiastic that you contacted them.
Using *Whakāro Pōkare* Visual Tool as a Clinical Tool

Whilst this tool proved to be valuable as a research data collection tool, it could also be used to assist organisations to understand their *Māori* clients more fully. One of the surprising, yet rewarding outcomes of using the *Whakāro Pōkare* Visual Tool to facilitate the korero in the interviews, was that many participants stated they had some considerable benefits from the process of the interviews. This was attributed to being able to identify elements that contributed to health and disability and then visualise how these aspects were connected offered an engaging, enlightening and empowering experience. This secondary response to the model that had not been predicted by the research team were the benefits expressed by participants in not only taking the participant through this process of expression about their lives and their wellbeing but the end result was that participants were able to see their own *hauora*, lives, challenges, supports, strengths, and weaknesses placed before them. It not only provided a visual tool for the research but one for the participants also. This enriched the research experience for both the *Kairakahau Māori* and the *hauā Māori* participants.

Several participants stated that they were interested in performing the process again at a later date to be able to compare where they were in relation to changes that they had established themselves they needed to make. One participant specifically attended the dissemination *hui* in order to tell us how much her life had improved since being interviewed. During the research process she realised she was unaware why she had been taking antidepressants for many years. She had contacted her doctor to discuss this, and it was decided to cease medication. This participant attributed her refreshed energy levels, which enabled her and her husband to go swimming daily, to being part of this research and she stated she had considerably higher sense of ‘feeling well’. One participant stated at the end of his interview:

*I’ve so much substance out of this. Just a couple of things on that little mini chart, you showed me, yeah I was just like, oh yeah, so there, there’s the gap, yeah that’s where I needed to go yeah, so...so kia ora for that.*

The use of this model within initial and follow up assessments may also encourage beneficial engagement between patients and health professionals. It opposes the practice of writing ‘secret’ clinical notes while taking subjective examination and allows for a picture of wellness and disability to emerge. It
requires interaction with the client and permits the patient to modify the picture accordingly as they see necessary. To do this necessitates sitting down face-to-face with the patient, gifting them time, and actively listening to what they feel is important to them, all factors our hauā Māori consider important for well-being.

**FURTHER RESEARCH DIRECTIONS**

Future research is required to:

- Identify facilitators and barriers for hauā Māori and their whānau of health and disability services living in other regions of Aotearoa, New Zealand.
- Investigate the acceptability, feasibility, and effectiveness of the recommendations and strategies to facilitate service access for hauā Māori and their whānau proposed by this research.
- Investigate Southern District Health Board and other Southern Māori health providers’ practices, and support implementation of findings from this project, especially in regards to supporting advocacy workers within this area.
- Investigate and inform Southern Rūnaka Disability policy and procedures
- Validate the Pōkare Whakāro Visual Tool developed in this research in other regions of Aotearoa, New Zealand as research tool as well as a tool potentially useful to organisations to find out more about their clients and to build relationships with them.
- Performing similar research in Otago.
- Investigate hauā Māori realities of mental health with respect to diagnosis, treatment and relevance to te Ao Māori.
- Investigate traditional disability perspectives.
- Look at hauā Māori demographics more closely to compare quantitative indicators within statistical data.
- Investigate if the research framework and Pōkare Whakāro Visual Tool will be useful in Northern areas. Northern researchers may wish to adapt to suit their specific needs.
- Work with Te Piringa to disseminate findings from this research.
SUMMARY

Whilst all participants self-identified as hauā Māori with impairments, when addressing perspectives of ‘disability’ most veered from being described as ‘disabled’. This confirmed the lack of direct connection of disability to their impairment but rather focused on the disabling affects of lack of being valued and limitations in the ability to contribute to their whānau because of their impairment as more disabling than the impairment. In te Ao Māori where there is largely a void of the concept of ‘disability’ it is recognised that this has positive and negative implications. Affirmatively it offers a more accepting environment where hauā Māori feel normalised and not marginalised in daily life. However when it comes to having a voice on rūnaka, Marae and in Māori settings, the lack of consideration, practices and policies to address issues arising secondary to disabilities has led to many Marae missing out on having hauā Māori engage appropriately with Marae, whānau, hapū, and iwi activities where hauā Māori can offer considerable contributions. Feeding this back to the rūnaka is therefore an important step to this research.

The research team were thankful that so many Māori living with disabilities and their whānau agreed to participate in the project. It appeared the topic under study was important to them and they wanted to give voice to their realities as hauā Māori. It was truly humbling listening to and being entrusted with the stories the hauā Mana related to us. I sincerely hope that in this thesis, I have faithfully captured these stories and presented them with the respect they deserve, and in so doing, identified how access to health and disability services can be enhanced for hauā Māori and their whānau.

Murihiku is blessed with a very rich base of diversity within its Māori population. One thing that stood out for me was the resilience, resourcefulness, unique and distinct natures demonstrated by the hauā Māori interviewed. I feel very privileged to have worked with this community and have been humbled by their honesty and their clear desire to have their true voices heard. I only hope that I have done a good job for this community. The aspiration to provide an authentic platform for which their voices can flourish and for the results to be transformative in a positive manner, has been what I kept coming back to and was my driving force to complete this thesis.
The development of the Whakāro Pōkare Visual Tool is a significant product of this research, and may be useful in future Māori health research and in subjective health care interviews with affirmative engagement and health care outcomes for Māori. This research process was transformative and endorsed the methodology and methods used as a sound, legitimate means of conducting research within this population. The hope is that research guided by KMR principles will continue to become more normalised and less energy will need to be spent on defining why we (Māori) do the things we do, and more focus on attaining affirmative research outcomes for our communities. Again I support the use of KMR processes not only as an appropriate model for research within Māori populations but actually an ethical way to approach research in general.

More work needs to be done investigating hauā Māori perspectives of disability and wellness, to allow insight into this population leading to relevant disability service provision. This study has just scratched the surface, but in doing so a valid tool has been developed which can be used within future research. It is recommended that it be adapted for suitability within other rohe (areas) through consultation with local hauā Māori and their whānau.
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APPENDIX A: Diagrammatic representation, demonstrating the position of the researcher in Kaupapa Māori Research.

(reproduced from Bishop and Glynn, 1999, p. 129)
**APPENDIX B: Te Ara Tika - a Māori Ethical Framework**

Kia ora Whānau

Wan to hav e you r

say on living with a disability?
Nau mai haere mai whānau

Hauā Mana

Māori

Living enriched lives

Friday 30 March 12

Tomairangi Marae

Commencing 10am, refreshments provided

Ngā Kete Mātauranga Pounamu is working with the University of Otago School of Physiotherapy and would like to introduce to you & your whānau a study that aims to gather information on the health and wellbeing needs of Māori whānau and or individuals living in Murihiku with disability.

A disability could be physical, mental, whānau or spiritual disability; anything that you feel contributes to you living to your full potential. Feel free to bring whānau with you.

Everyone is welcome.

RSVP Sandra Stiles, Kaiāwhina Disability, Ngā Kete, ph xxxxxxxxxx
APPENDIX D: Participant Interest Form

Hauā Mana Māori

Living unique and enriched lives

Participant Interest Form

Please fill this out if you think you may be interested in being a participant of the Hauā Mana Māori research project.

Name:

Address:

Home Phone:

Mobile Phone:

Email address:

Date of Birth:

Ethnicity: ☐ NZ European ☐ NZ

☐ Other. Please state:

Iwi:

Alternative Contact for you (Name, Phone, email)

Please tick one of the following:
☐ I am Māori and living with a disability. Can you tell us what disability you have?

☐ I am whānau/carer to Māori who live with a disability.

☐ I support Māori who live with a disability.

Best way to contact me is: ☐ email ☐ text ☐ phone

☐ visit me ☐ letter

☐ other ________________

Needs: ☐ visual ☐ wheelchair accessibility

☐ deaf interpreter ☐ dietary

☐ Te Reo Māori ☐ other

Please send us your form in the stamped addressed envelope or email your Participant Interest Form to Katrina

katrina.bryant@otago.ac.nz
APPENDIX E: Proposed Pōhā Tītī model being designed by Ngā Kete Mātauranga Pounamu Charitable Trust and the Murihiku community.

1. PROPOSED MODEL - POHA TITI:

The following is the basis for the proposed implementation model of Whanau Ora by Nga Kete Matauranga Pounamu Trust and Awerna Social & Health Services.

The model is based on our Ngai Tahu tradition of Hopu-Titī (Mutton binding). This practice has endured for generations and is one of the longest surviving mahinga kai traditions that continues to sustain whanau.

Hopu titi involves the annual migration of whanau to the southernmost islands adjacent to Rakia for a period of up to two months. There, whanau return to harvest the titi chicks, preserve them and bring them home for winter kai, for trade and sale.

The Titi/Mutton-bird Island is one place where whanau by virtue of their whakapapa, come together from all corners of the motu and the globe, to work, to share, to learn and teach, to play, to laugh, to enjoy each other without the distractions of the outside world.

It is an opportunity to reconnect with our whakapapa, our whenua, Te Ao Wairua, Te Ao Kohatu. The islands draw you back each year and embrace you as soon as you arrive. The tikanga and matauranga is handed down from one generation to the next. Each member of the whanau has a role to play and responsibility and is equally valued no matter how large or small their role may be.

The islands are governed by a set of regulations based on tikanga and whenua each have a responsibility to look after the island environment ensuring that the “manu” (binding grounds) are not compromised. As with Marama, each island has its own way of doing and managing things (kawa), that has endured for generations. It is in effect, the exercise of te Tino Rangatiratanga.

The Poha is the receptacle in which titi were preserved and stored. It is constructed using rimu-rapa (bull Kelp). The poha is placed in a kete made of harakeke. The kete is sometimes lined with “Tetaki” tataki grass and then kiri tōtara is placed around the poha to prevent it from being holed, and its contents spoiled. The method used to hold everything in place is called “taa te poha”, where strips of harakeke are tied giving a net effect. The titi are carefully placed in the poha and when full, it is fastened off to ensure it is air tight.

This “poha” concept involves a range of processes in order to achieve the end goal. It is a whanau activity. E.g.; The gathering, processing and weaving together of strips of harakeke; Gathering and preparation of kelp; gathering and preparation of kiri-tōtara etc....

We intend to develop this further into a working model to assist and enhance whanau resilience. It is our whakairo that those values and behaviours that have sustained us as a people for hundreds of years can be utilized by and for whanau development.

Whakapapa, Whenua, Whanau, Tiakitanga, Tikanga, Matauranga, Manakitanga, Wairua
2. Poha Titi

In addition to preserving food, Poha were used to carry fresh water, seeding new coastal areas with shell fish, starfish and paua. Special slits in the poha would open up as the poha were plunged into the moana and allow the shellfish to escape.

Ngai Tahu used the Poha as a flotation device which allowed them to paddle out to sea and come back over the breakers like a bird, a sport known as kaukau.

Poha also were used to protect the body when gathering seafood on the open coast, worn over the torso like a wetsuit or made into sandals to be worn on the rocks while fishing or gathering kamoana.

Poha Oranga Model - Resilience, Cultural Pride, Sustainable Best Practise.

Whakatauki - Proverb

Te Poha Oranga  Ma wai e whakakii i te poha?  The Poha of Well-Being  Who will help fill the poha?
Ma kau, mau, ma tatou katoa.  I will, you will, we will together.
3. Poha Oranga Model
DNA of Wellbeing ki Murihiku

Whakapapa - The principle of kinship, genealogy, lineage, relationships.

Tikanga - Culture, custom, ethic, etiquette, lore, manner, methods - that which is Maori.

Matauranga - Tradition, environmental knowledge, traditional practice, Rongoe, Mahika kai.

Whanau - Birth, building block of Maori society, extended whanau.

Wairua - Spirit, soul, quintessence, Wairua resides in the heart or mind whilst others don’t limit wairua.

Kai:
- Whakapapa
- Tikanga
- Kava
- Sustainable
- Resource

Rimu Rapa
- Kelp:
  - Organic
  - Durable
  - Resilient

Whanaungatanga - a relationship through shared experience, belonging, kinship and connection

Whakauka - to be lasting, sustained, preserve, conserve and enduring

Totara:
- Strong
- Steadfast
- Diversity
- Prevails

Whakitipu - to grow, cherish, rear, bring up, raise

Harakeke:
- Unity
- Binds
- Whanau
- Flexibility
- Resourceful

Wehikore - to be fearless, in safety, unafraid, intrepid

Aroha - love for the wellbeing of mankind, to consider beyond the benefit of oneself whilst caring for thyself

Methodology:
The poha has held the tili and sustained our people for generations. The Poha Oranga model will strengthen and enable our whanau to determine their own Rangatiratanga and Wellbeing outcomes. Poha production is only successful when the whanau work together.
APPENDIX F: An example of the data collection tool used by Mourie

Hauā Mana Māori

Living unique and enriched lives

Tēnā Koe,

Thank you for your interest in the Hauā Mana Māori research project looking at Māori living with disability and their whānau in the Southland area.

We are hoping that this will give Māori living with a disability and their whānau, a voice to inform us and others as providers, how to best offer services to this community.

We have enclosed an Information Sheet and a Participant Interest Form. If you would like to take part in the Hauā Mana Māori study can you please fill in the Participant Interest Form and send it back to us in the self addressed, stamped envelope enclosed.

If you have any queries about this project or what we are asking of you please do not hesitate to contact Katrina Bryant (03) 4794034 or katrina.bryant@otago.ac.nz

Once again we are grateful for your assistance with this.

Nāku noa,

Katrina Bryant (Kai Tahu, Physiotherapist)
Kaiarahi and Masters Student
University of Otago School of Physiotherapy
PO Box 56, Dunedin 9054
APPENDIX H: Information Sheet for Hauā Māori

Hauā Mana Māori

Living unique and enriched lives.

A research project involving Māori whānau living with disability in the Southland area.

Tēnā Koe,

You are invited to take part in a research project looking at which health and support services disabled Māori and their whānau in Murihiku area need and use, what helps whānau get these services and what may prevent whānau from getting these services.

We are interested in getting your perspective on wellness and disability and whether being Māori has an impact on living with a disability in your community.

Disability can come in many forms and we are interested in all forms of disability: tinana/physical, hinengaro/mental, whānau/relationships, wairua/spiritual and rangatiratanga/leadership and guidance.

Who will be doing the study?

The research project is a collaboration between the University of Otago School of Physiotherapy and Donald Beasley Institute in Dunedin, a disability research institute based in Dunedin. This project is strongly guided by our research partners, Ngā Kete Mātauranga Pounamu Charitable Trust and Rōpu Kaiarahi (Reference Group), Māori living with a disability and their whānau who are working alongside our study's researchers and are engaged in the research process.

Who will be doing the interviews?
Katrina Potiki Bryant and Kelly Tikao are two Māori researchers of Ngāi Tahu descent. They are both based in Dunedin and will be conducting all the interviews.

**Who can be in this study?**

If you are Māori over the age of 16 years of age living with a disability in the Southland region you can take part in this study.

**What will happen if I choose to take part?**

If you agree to take part in this project Katrina or Kelly will contact you to arrange a time to do a one-to-one interview or a small group interview (known as a focus group). You can choose which type of interview you would prefer and you are welcome to bring a support person(s) along if you wish.

You will be asked questions about your life, your disability/whānau member’s disability, disability of the person you care for, what helps you to use services in your community, what makes you feel part of your community, what does disability mean to you as a Māori person, as a whānau member to someone who has a disability or as a carer of a Māori person with a disability.

The interviews will be audio taped to help us remember exactly what was said so we can fully understand the information you tell us. These recordings will only be used for this project.

It may be, because of your disability, that you are unable to talk to us. We will then find another way to communicate with you so that you can share your information with us. It may also help, with your permission, for us to talk to a whānau member who knows you well.

We may like to check some of your information at a later stage so we will phone you or email you, as you prefer, for this information.

The researcher will also be writing some key points from the interview onto a larger laminated piece of paper during the interview. This will help the researcher write key ideas you have expressed in your interview onto something you can also see and for you to have a say on whether the researcher has recorded your thoughts accurately.
What will happen with the information I share with you?

The information that we gather from you will be used for this study only. Only the researchers will see this information.

Your name or any other information that might identify you will not be used in reports about this research. However, if you would like to be identified and/or your iwi affiliations acknowledged you can discuss this with either Katrina or Kelly.

All information will be kept in locked cabinets at the School of Physiotherapy, University of Otago for five years.

What do I do if the interview causes me distress or raises worries for me?

Let the person interviewing you know if the interview causes worries for you or raises issues. They will talk to you about what you might be able to do about this. We do not want you to become distressed and can stop the interview if this happens.

What do I do if I want to take part in this study?

If you want to be part of the Hauā Mana Māori study you can do any of the following:

- fill out the Participant Interest Form and send it to us in the stamped addressed envelope provided.

- Email Katrina on: katrina.bryant@otago.ac.nz

- Phone Katrina on: (03) 479 4034

- Email Kelly on: ktikao@donaldbeasley.org.nz

- Phone or text Kelly on: 027 4792026 or call Kelly on the Donald Beasley Institute toll free number 0800 878 839.

After you have filled out the Participant Interest Form Katrina or Kelly will contact you and answer any questions you may have about the research and then will arrange a time to do the interview with you.

What will happen if I don’t want to be part of the study?
Nothing will happen. You do not have to accept this invitation. If you do accept this invitation you can withdraw at any point of the study without having to give a reason.

**Is it safe for me to be part of this study?**

This study has been approved by the University of Otago Human Ethics Committee. This means that a special group of people have made sure that the study is safe and that we will work with people in a kind and respectful way.

**If you have any questions?**

If you have any questions about our project please feel free to contact either:

- Associate Prof Leigh Hale, School of Physiotherapy, University of Otago, Dunedin. Tel: (03) 479 5425, leigh.hale@otago.ac.nz
- Katrina Bryant, School of Physiotherapy, University of Otago, Dunedin. Tel: (03) 479 4034, Katrina.bryant@otago.ac.nz
- Kelly Tikao, Donald Beasley Institute, Dunedin. Toll free number: 0800 878 839, ktikao@donaldbasley.org.nz
APPENDIX I: Cover letter for email to services

Hauā Mana Māori-Living unique and enriched lives

Tēnā Koe,

Thank you for helping us with recruiting people to participate in a research project looking at Māori living with disability and their whānau in the Southland area.

We are looking to meet with Māori between the ages of 16 upwards who may be living with a disability, be it mental, physical, spiritual, dysfunctional whānau/relationships or influences.

We are hoping that this will give Māori living with a disability a voice to inform us, and others as providers how to best offer services to this community.

Attached is an electronic notice with information about our research. Could you please send this out to you networks and to those you think may fit our research criteria.

If you have any queries about this project or what we are asking of you please do not hesitate to contact Katrina Bryant (03) 4794034 or katrina.bryant@otago.ac.nz

Once again we are grateful for your assistance with this.

Kind regards,

Katrina Bryant (Kai Tahu, Physiotherapist)

Kaiarahi Māori and Masters Student

University of Otago School of Physiotherapy

PO Box 56, Dunedin 9054
APPENDIX J: Example of mapping themes.
The following simple descriptions may assist readers in interpreting the use of Māori terms in this thesis. Please note Kai Tahu dialect has been predominantly used (where a soft ‘k’ is often used in place of ‘ng’ used in other dialects).

<table>
<thead>
<tr>
<th>Glossary Item</th>
<th>Description</th>
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<td>Ara</td>
<td>Pathway, direction</td>
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<td>Ariki</td>
<td>Chief</td>
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<tr>
<td>Aroha</td>
<td>Love</td>
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<td>Aroha ki te Takata</td>
<td>Respect for people</td>
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<td>Atua</td>
<td>Gods</td>
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<td>Awa</td>
<td>River</td>
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<td>Awhi</td>
<td>Care/support</td>
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<td>Hā</td>
<td>Breath</td>
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<td>Hapū</td>
<td>Subtribe</td>
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<td>Hauora</td>
<td>Wellness</td>
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<td>Hinekaro</td>
<td>Mental Health</td>
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<td>Hui</td>
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<td>Iwi</td>
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<td>Kaha</td>
<td>Strength</td>
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<td>Kai Moana</td>
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<td>Kaiai</td>
<td>Village</td>
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<td>Kaitakawaenga</td>
<td>Mediator/arbitrator</td>
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<td>Kapa Haka</td>
<td>Haka group</td>
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<td>Kapō</td>
<td>Blind</td>
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<td>Karakia</td>
<td>Prayer</td>
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<td>Kaupapa Māori</td>
<td>Māori centred agenda</td>
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<tr>
<td>Kawa</td>
<td>Marae protocol</td>
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<td>Kiteka</td>
<td>Perception</td>
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<td>Kia tupato</td>
<td>Be careful</td>
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<td>Koha</td>
<td>Gift</td>
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<td>Kōhatu</td>
<td>Stone</td>
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<td>Kōhunga/kōhaka Reo</td>
<td>Māori language school</td>
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<td>Kōrero</td>
<td>Discussion</td>
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<td>Maata waka</td>
<td>From another area</td>
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<td>Mahika kai</td>
<td>Food gathering place</td>
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<td>Mākutu</td>
<td>Curse</td>
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<td>Māmæ</td>
<td>Pain/hurt</td>
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<td>Mana</td>
<td>Prestige</td>
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<td>Mana Whenua</td>
<td>Territorial rights</td>
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<td>Manakitaka</td>
<td>Hospitality</td>
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<td>Manuhiri</td>
<td>Visitors</td>
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<td>Manukura</td>
<td>Leader</td>
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<td>Māori people of New Zealand</td>
<td>Normal/indigenous</td>
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<td>Marae</td>
<td>Meeting house</td>
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<td>Mātauraka</td>
<td>Knowledge</td>
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<td>Mauka</td>
<td>Mountain</td>
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<td>Mauri</td>
<td>Vital essence</td>
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<td>Mauri ora</td>
<td>Holistic Wellness</td>
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<td>Mauri rere</td>
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<td>Mihimihi</td>
<td>Greeting</td>
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<td>Mihiwakatau</td>
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<td>Mirimiri</td>
<td>Massage</td>
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<td>Mokopuna</td>
<td>Grandchildren</td>
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<tr>
<td>Noa</td>
<td>Every day, safe</td>
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<td>Pā</td>
<td>Fortified village</td>
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<td>Pākeha</td>
<td>European Person</td>
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<td>Ripple</td>
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<td>Pou</td>
<td>Upright support</td>
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<td>Pōwhiri</td>
<td>Rituals of encounter</td>
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<td>Puna</td>
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<td>Putea</td>
<td>Money</td>
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<td>Rakatira</td>
<td>Revered person</td>
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<td>Rakimarie</td>
<td>Peace</td>
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<td>Five</td>
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<td>Rohe</td>
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<td>Te Ao Pākehā</td>
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<td>Te Ao Tawhito</td>
<td>Old world view</td>
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<td>Te Pae Mahutonga</td>
<td>Southern Cross</td>
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<td>Te Pō</td>
<td>Place of underworld</td>
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<td>Te Reo Māori</td>
<td>Māori language</td>
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<td>Tika</td>
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<td>Tinana</td>
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<td>Titiro</td>
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<td>Tūmanako</td>
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<td>Listen</td>
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<td>Connections</td>
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