

Hauā Mana Māori

Living unique and enriched lives

A report for the Health Research Council and the Ministry of Health

Beauty in everything



*Mā te rongo, ka mōhio; Mā te mōhio, ka mārama; Mā te mārama, ka mātau;
Mā te mātau, ka ora.*

(Through resonance comes cognisance; through cognisance comes understanding; through understanding comes knowledge; through knowledge comes life and wellbeing.)



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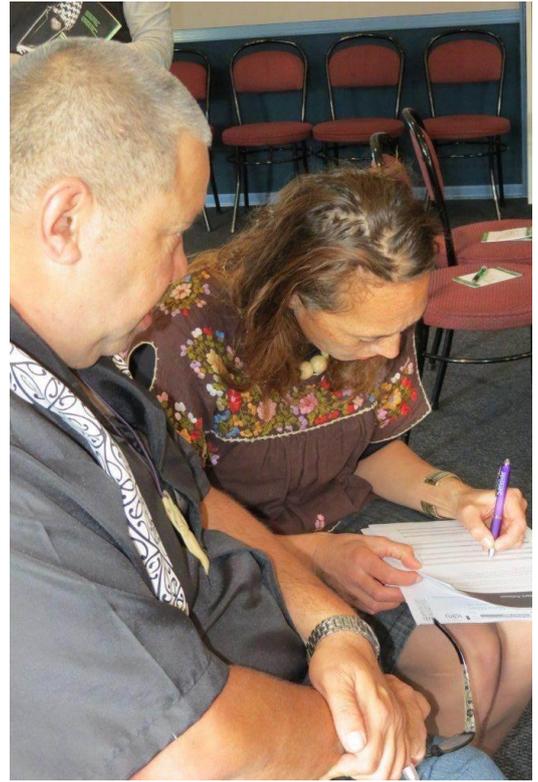
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Executive Summary

Introduction

This report presents the findings of research undertaken to explore the accessibility of health and disability support organisations for disabled Māori and their whānau in the Murihiku / Southland region. The research arises from a 2011 Request for Proposal (RFP), Māori living with disability and their whānau, which was jointly funded by the Ministry of Health (MoH) and the Health Research Council of New Zealand (HRC). This joint initiative sought an innovative project to improve knowledge of the barriers to, and facilitators of, access to health and disability services and supports by Māori with a disability and their whānau.

Specifically the primary aims of this research were to:

1. Explore how accessible health and disability organisations are for Māori living with a disability and their whānau; identifying both the barriers and the facilitators to accessibility.
2. Make recommendations for improving accessibility of service delivery for Māori living with a disability and their whānau in order to inform Ministry of Health and Disability policies.

Design and Methods

Design

A mixed methods case study design, underpinned by the principles of kaupapa Māori research, was used. In a case study, an entity or a phenomenon is studied in-depth. Data can be collected by a variety of methods and collated to provide a rich description of the case, the narrative of which can be used to drive theory development. In this research, we collected data from a number of sources to explore accessibility of health and disability support organisations for Māori living with disability and their whānau in the Murihiku (Southland) region.

In Māori concepts of health there is no clear distinction between health and disability and thus no clear definition of disability. Therefore, in the current research, we did not

predetermine the term “disability” and were open to a broad interpretation of it and allowed participants to self-identify their disability. This broad conceptualisation and self-determination of disability therefore did not allow us to categorise hauā Māori participants into levels of severity of disability. Similarly we used a broad definition in identifying organisations that provide a health or disability service. Our study thus had broad representation across “types” of disability and organisations, as well as covering city, small town, and rural areas.

Methods

The research comprised three phases:

Phase 1: a participatory action research (PAR) phase with disabled Māori living with a disability and their whānau.

Phase 2: comprised a structured literature review to inform the development of a questionnaire. This questionnaire was then administered to organisations providing a health or disability service in the Murihiku region.

Phase 3: an onsite visit of a purposive sample of service organisations.

In Phase One, comprehensive community consultation resulted in the formation of a Rōpu Kaiarahi (research advisory group). Guided by participatory action research principles the researchers working alongside the Rōpu Kaiarahi developed a visual tool, the Pōkare Whakāro Visual Tool, which was then used to facilitate data collection during in-depth interviews with disabled Māori and their whānau living in Murihiku. This collaborative group formulated the questions for the interviews. It was considered important in the first instance to establish what participants perceived as either facilitating or impeding their health and wellness, as this would then determine issues pertaining to accessibility. Data were analysed thematically and verified by the Rōpu Kaiarahi.

In Phase Two, a structured review of relevant literature provided the evidence base from which a questionnaire was developed to survey health and disability service organisations regarding accessibility of their service for disabled Māori. The questionnaire contained approximately three questions on each of the following five categories of primary interest: (1) analysis of workforce competencies, (2) quality standards, (3) service effectiveness, (4) physical access and promotion of services, and (5) health literacy and information needs.

Community consultation identified 66 health and disability organisations presently providing support for people living with disability in the Murihiku region. On invitation, 50 organisations agreed to complete the postal survey.

In Phase Three, a purposive sample of organisations participating in the postal survey consented for an onsite visit during which their answers to the survey were explored to provide deeper insight.

Results

In Phase One, 34 Māori living with disability volunteered to be interviewed in the PAR project, and 29 were interviewed. Five volunteers were not interviewed due to subsequent personal circumstances. Four themes relating to what made participants feel well and healthy emerged: 1) *Feeling valued*, (2) *Being connected/keeping in touch*, (3) *Having a strong sense of self identity and self-worth*, and (4) *Being able to access appropriate resources*. Conversely, factors that disabled the hauā Māori were: (1) *Not being valued*; (2) *Negative impacts of discrimination, colonisation, and disconnection*; (3) *Lack of self-worth*; and (4) *Poor access to resources*. These themes are comprehensively discussed in chapter four of this report.

There was a 59% (n=28) response rate to the survey in Phase Two. Fifteen of these organisations were subsequently visited in Phase Three. The findings of Phases Two and Three are summarised below:

Analysis of workforce competencies:

- 83% of organisations were providing, or planning to provide, staff with cultural training to ensure cultural competency.
- 79% of organisations said they knew how to access expertise to provide education to staff on Tikaka Māori relevant to their service.
- 93% of organisations reported 'good' to 'excellent' accessibility for disabled Māori and whānau.
- Many organisations appeared not to fully understand their Treaty of Waitangi obligations: There appeared to be a misunderstanding between a non-racial, human

rights approach of respect for all people, no matter the ethnicity, and the concept of the importance of tikaka Māori practice for services provided for Māori.

- Māori attendance at most organisations was generally less than 5% and 72% of organisations employed less than 5% Māori staff (although 8 (28%) organisations were sole practices).
- Although most organisations said they would ask their clients what approach to health care they preferred, it was not clear they could actually accommodate a client's wish for a more holistic, Māori-focussed approach to health. Many described offering to refer the client to a local Māori health provider if necessary.
- One organisation was clearly proactive, regularly meeting with a cultural advisor to discuss issues relevant to Māori and to ensure their clients were being assisted appropriately.
- For both Māori and government organisations interviewed, tikaka Māori practice was explicit. These values were integral to practice and the concept of Whānau Ora was well understood and observed by these organisations.
- The understanding of the concept of "Whānau Ora" amongst other organisations was poor; few of these organisations were able to fully articulate its meaning.

(2) Quality standards:

- 11 (38%) organisations said they included Māori in the development of services or policy – provided in the form of Māori wardens, having Māori representation at a governance level of the organisation, or having an advisory group.
- Some organisations were part of national organisations, and said that the development of services or policy was undertaken at a national level, and this information did not always overtly reach the regional or branch level.
- For some organisations, quality assurance of cultural competence was mandatory and was a formal part of their accreditation process.
- Although feedback was sought from clients by many organisations (59%), a failure to routinely include an ethnicity question in this process meant they were unable to determine data specifically pertaining to Māori.

(3) Service effectiveness:

- Many organisations (79%) were able to provide a service to clients within one day and most (90%) were able to provide a home service if necessary.

- Only 5 (17%) organisations identified that they were a registered provider of health care for Māori.
- Although most organisations said they collected ethnicity data in some format, a number said they were reluctant to ask this information directly but rather made assumptions based on appearance or name. This practice could lead to over- or under-estimation of Māori clients.

(4) Access and promotion of services:

- All organisations reported good physical access.
- Most organisations (93%) thought that their service had 'good' to 'excellent' overall accessibility for disabled Māori and their whānau.
- When asked to comment on what they did well in this regards, these organisations identified many examples of good accessibility and promotional practices; these are detailed later in the report.
- To improve accessibility of service uptake, most organisations reported the need to promote their services further to Māori communities and Māori healthcare providers.
- Funding for transport for people to access the service was identified as an issue and it was suggested that information regarding the availability of ACC and PHO taxi vouchers and the St John's ambulance transport service (in some areas) should be promoted.

(4) Health literacy and information needs:

- Information provided in organisations was mostly in the written format, and some organisations offered this information in a number of languages, including Te Reo Māori.
- Many organisations reported that they would have face-to-face meetings with clients to ensure that the person had understood the information provided.
- Alternative sources of information such as audio-recorded information or information in braille did not appear to be available.
- Organisations did however, access appropriate assistance when required, such as from the Blind Foundation, Deaf Aotearoa, and interpreters.

Recommendations

Based on the suggestions and issues described by these participants and organisations, the following are recommended strategies to facilitate disabled Māori and whānau access of health and disability support organisations:

- *Value clients:* Participants in this research consistently identified that feeling valued as people facilitated their access of health and disability services. There were a range of ways suggested for this to occur, including:
 - Being valued as an active contributing member of the community
 - Receiving respect and a positive attitude from the community
 - Being listened to
 - Not being discriminated against
 - Being provided with choice
 - Being provided with a flexible approach

- *Being connected / keeping in touch:* feeling connected was important to our participants; organisations could assist with this by:
 - Facilitating connection with whānau
 - Understanding the importance of whānau
 - Understanding that friends and community are also whānau
 - Endeavouring to be more “whānau-centred” and “whānau-led”; for example, facilitating and being responsive to feedback from the disabled community
 - Being culturally inviting, for example, in greetings and hospitality
 - Consulting with a cultural advisor

- *Enhance a strong sense of self identity and self-worth:* organisations could foster this by:

- Specifically asking about ethnicity and never assuming
 - Acknowledging and making the most of a strong belief in a religious faith (as appropriate)
 - Offering karakia
 - Allowing time and space for rakimarie
 - Facilitating aroha and mana; spend time building relationships with their clients
 - Endorsing Māori health models such as te Whare Tapa Wha
 - Encouraging a sense of Māori identity
 - Being positive - whakamana
 - Discouraging drug and alcohol use
 - Being accountable to service policies and strategies that incorporate the Treaty of Waitangi, and workshop with staff what that means for the service and how this can be actioned in a practical, usable, and productive way.
- *Resources* Organisations could:
 - Be a strong advocate for their clients
 - Assist clients to access:
 - Pūtea
 - Education
 - Employment
 - Transport/ Mobility
 - Better advertise and market their services to the Māori community and Māori organisations
 - Better network with other organisations, especially with the Māori health providers
 - Provide appropriate information in a wide range of formats (such as plain language, different languages, audio-recordings) and reinforce this information face-to-face with the client
 - Consider service accreditation regarding cultural competency

The primary recommendation arising from this research to assist hauā Māori to access health and disability services is the establishment of an Advocacy Service in Murihiku. Many Māori rely on whānau to awahi them in times of need. Whānau, however, are not always close or available. Having an advocate to awahi or support hauā Māori access organisations and who are responsive to their needs is critical to improving access to health

and disability organisations in Murihiku. This advocate could take on a range of roles, for example, accompanying the hauā Māori to the specialist, assisting them to identify and to ask pertinent questions and ensure the hauā Māori is satisfied his or her questions have been answered. On a more practical level advocates could assist with transport and with accessing other support that the hauā Māori may require.

Chapter One: Background / Whakapapa

1.1 Introduction

This report arises from a 2011 Request for Proposal (RFP), Māori living with disability and their whānau, which was jointly funded by the Ministry of Health (MoH) and the Health Research Council of New Zealand (HRC). This joint initiative sought an innovative project to improve knowledge of the barriers to, and facilitators of, access to health and disability services and supports by Māori with a disability and their whānau. Specifically, the proposal required:

- Quality evidence: building the evidence-base through the production of quality research and evaluation.
- Capability development: participation of Māori with disability and their whānau in research that will help Māori meet their health needs.
- Knowledge transfer: to facilitate the contribution of evidence to improved outcomes for Māori with a disability and their whānau.

The resulting contract, which specified a start date of 1 February, 2012, and a final report date of 31 January, 2013, used a case study design to explore, in the Murihiku / Southland region, the access for Māori living with disability and their whānau to health and disability services and supports to identify the barriers and facilitators to access.

The specific aims of our research were to:

1. Identify the health and disability community services and supports presently available for people living with disability within the Murihiku/Southland region.
2. Explore how accessible these identified services are for Māori living with a disability and their whānau; identifying both the barriers and the facilitators to accessibility.
3. Make recommendations for improving accessibility of service delivery for Māori living with a disability and their whānau; recommendations to inform Ministry of Health and Disability policies.
4. Develop an appropriate research framework to collect data relevant to Māori with disability and their whānau.
5. Build research capacity and capability for Māori and Māori with disability within the Murihiku region.

To achieve these objectives we undertook three phases of research, underpinned by kaupapa Māori research principles that utilised a case study design:

Phase 1: a participatory action research project with hauā Māori and their whānau.

Phase 2: a survey of organisations providing a health or disability service in the Murihiku region.

Phase 3: an onsite visit of a purposive sample of service organisations.

This report details each phase of the research and the research findings. The report begins with a summary of the knowledge that underpinned our research and concludes by making recommendations, arising from the findings, for improving accessibility of service delivery for Māori living with a disability and their whānau.

The research team comprised Assoc Prof Leigh Hale (Associate Dean of Research, School of Physiotherapy, University of Otago); Assoc Prof Stephan Milosavljevic (Senior Lecturer, School of Physiotherapy, University of Otago); Dr Brigit Mirfin-Veitch (Director, Donald Beasley Institute); Kelly Tikao (Ko te Ōteauheke te mauka, Ko te Awaiti te awa, Ko Takitimu te waka, Ko Kāi Tahu te iwi, Ko Kāti Irakehu, Kāti Tārewa kā hapū, Ko Ōnuku te marae ki te Pātaka o Rākaihautu, Ko Kelly Tikao tōku ikoa, Mihi atu rā); and Katrina Potiki Bryant (Ko Pukekura te mauka, Taieri te awa, Ko Takitimu te waka, Ko Waitaha, Kāti Māmoe, Kāti Tahu kā iwi, Ko Kai Te Ruahikihiki, Kāti Taoka kā hapū, Ko Ōtākou te Marae, Ko Wiremu Potiki te tupuna, Ko Katrina Potiki Bryant tōku ikoa).

Both Kairakahau Māori are health professionals. Katrina is a practicing physiotherapist (with over 18 years of experience) with her own clinic in Dunedin and is the Kaiarahi Māori at the University of Otago School of Physiotherapy. Kelly is a registered nurse and Kairakahau Māori with the Donald Beasley Institute (promoting research and education in the field of intellectual disability).

In our report we have utilised the Kāi Tahu dialect. It was felt by the research team that this dialect was the most appropriate to use, given the research location and the many participants who identified with the Kāi Tahu, Kāti Māmoe and Waitaha iwi. Therefore a “k” replaces the “ng” in all Māori words and preference is given to Kāi Tahu terms.

1.2 Background

Disability is a substantial concern for Māori. Approximately 17% of New Zealand's population identify with having some form of disability that impacts on their life (Statistics New Zealand 2007). The age-standardised disability rate for Māori was 19% (95,700 people) in the 2006 census (Office for Disability Issues and Statistics New Zealand 2010). About half (49%) of Māori living with disability are under the age of 25 years (Ministry of Health 2012). Several factors contribute to this age-related difference, including a higher mortality in earlier age groups resulting in lower life expectancy (Cunningham et al 2002), earlier onset of age-related illness and disease (Ajwani et al 2003), and a high birth rate (Statistics New Zealand 2010). Mobility disability (11%) and agility disability (9%) are the most common types of disability experienced by Māori adults (Ministry of Health 2004).

The Treaty of Waitangi acknowledges Māori as Tāngata Whenua, indigenous people of New Zealand, and reinforces the importance of protecting the wellbeing of Māori, Māori participation in determining processes for best practice, and partnership with non-Māori with these aspirations in mind (Kingi 2007). He Korowai Oranga, New Zealand Ministry of Health's Māori Health Strategy (translated as 'The Cloak of Wellness') (Ministry of Health 2002) has as its intent the support of Māori whānau to optimise health and wellbeing. The outcomes specified by He Korowai Oranga are:

1. That whānau experience physical, spiritual, mental, and emotional health and have control over their own destinies;
2. That whānau members live longer and enjoy a better quality of life (than they currently do);
3. That whānau members, including those with disabilities, participate in te ao Māori (Māori Society) and the wider New Zealand society.

He Korowai Oranga is reinforced by the New Zealand Disability Strategy (Making a World of Difference / Whakanui Oranga) (Ministry of Health 2001). Underpinning the New Zealand Disability Strategy is a vision of a fully inclusive society: "*New Zealand will be inclusive when people with impairments can say they live in a society that highly values our lives and continually enhances our full participation.*" Two key objectives of this strategy are (1) to

promote participation of disabled Māori and (2) value families, whānau and people providing ongoing support.

Whānau is central to Māori. Acknowledging this, Te Puni Kōkiri (New Zealand's Ministry of Māori Development) and the Ministries of Social Development and Health jointly initiated Whānau Ora in 2011 (MOH 2011). Whānau Ora is an inclusive approach to providing services and opportunities to all whānau in need across Aotearoa / New Zealand. This approach requires interagency collaboration to work together with families to empower the whānau, to focus on the family's needs as opposed to working separately with individual family members.

In spite of these fundamental documents and initiatives, Māori health statistics and morbidity rates are disparately poor compared to non-Māori (Robson and Harris 2007). These disparities extend to Māori living with disability and to their access and utilisation of rehabilitation and disability support services (Harwood 2010). For example, Māori were more likely than non-Māori to have a functional disability requiring assistance (14% of all Māori living in households compared with 9% of all non-Māori living in households). Disease and/or illness are the most common cause of disability reported by Māori (with an age-standardised rate of 8400 per 100,000 people living in households) and by non-Māori, but for the latter the age-standardised rate is lower (5500 per 100,000) (Ministry of Health 2004). Furthermore, Māori with disability are more likely to: live in more deprived areas of New Zealand, be unemployed, earn less, and have fewer qualifications. The importance of whānau support for Māori with disability is emphasised by the fact that Māori with disability are less likely than non-Māori with disability to live in residential care facilities (in 2001 only 700 Māori with disability lived in residential care facilities) (Ministry of Health 2004), despite Māori having an age-standardised rate of severe disability (requiring continuous or daily assistance) that was twice the rate for non-Māori (4100 per 100,000 population compared with 1900 per 100,000 respectively) (Ministry of Health 2004a). This may highlight the role whānau support has in preventing the need for residential care, but may also increase burden on whānau members if it is expected they will be there to provide care. This supports a continuing trend noted in a 1999 Ministry of Health report that described 13% of Māori living with disabilities and needing assistance compared with 10% of non-Māori. This is consistent with a higher risk for disabling chronic disease and injury experienced by Māori (MoH 1999a). Furthermore, 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 ID and even more scarce are health promotion for Māori adults with an intellectual disability*” (National Health Committee 2003:153-154). Arguably, this information extrapolates to Māori with other forms of disability.

Resolving the poor health status of Māori has been identified as being of the highest priority to the Ministry of Health. The undesirable health and disability disparities of Māori compared to non-Māori falls short of the Treaty of Waitangi commitments. The Treaty acknowledges that the wellbeing of Māori as the Tāngata 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).

To improve access to disability services and supports for Māori living with disability and their whānau, we first need to explore and understand current access. This was the core objective of our research. Jones et al (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’ (p 1). In a qualitative study, Māori living with disability identified that Māori-specific assessment criteria, access to cultural expertise, and input to assessments were highly valued (Ratima et al 1995), reinforcing 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. Recently, the Ministry of Health launched an action plan for disability support services (Whāia Te Ao Mārama: 2012 to 2017) to guide actions to address the needs and priorities of Māori who are disabled. The action plan reiterates that if services do not acknowledge the significance of culture in the assessment and support of Māori living with disabled, there is a greater chance that the outcomes will be poorer health (Ministry of Health 2012).

Of pertinence to our research is that in Māori concepts of health there is no distinction between health and disability and thus no clear definition of disability. The concept of “wellness” is better understood, and is perceived to be more linked to an individual's ability to contribute to their iwi and whānau, thus based not on personal performance *per se*, but performance within a wider community setting (Ministry of Health 2004, 2012). Whānau Ora reinforces this viewpoint. Therefore, our research viewed both Māori living with disability and their whānau as entwined and not separate entities. Further, 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 our research, and the terms “disability” or “whānau” were not predetermined.

The primary aims of this research were to identify the barriers and facilitators for Māori living with disability accessing health and disability support organisations in the Murihiku / Southland region, and to make recommendations for improving the accessibility of these organisations. Based on kaupapa Māori research principles, we used a case study design to achieve these aims. In a case study project, data are collected from a variety of sources to build a holistic picture of the phenomenon under exploration. In our case study we collected data from hauā Māori and their whānau and from organisations providing health and disability services in Murihiku / Southland. Conscious that people with disabilities should control all aspects of their lives including research that focuses on issues of importance to them (Seekins and White 2013), we used participatory action research to listen to the voices of the hauā Māori. Secondary aims were to develop an appropriate research framework to collect data relevant to Māori with disability and their whānau, and to build research capacity and capability for Māori and Māori with disability.

This study strove to address one of the key principles detailed in the Uia Tonutia - Māori Disability Research Agenda, published co-jointly by the MOH and HRC in 2011 that research should enable the voices of Māori living with a disability and their whānau to be heard.

The following chapter describes the methodological approach to this research.

Chapter Two: Methodology

Our research was guided by the principles of Kaupapa Māori research, and underpinned by a transformative research paradigm (Mertens 2009). These approaches were taken to ensure the research was conducted in a manner that respected Māori ideologies and world-views, would result in quality research of significance to Māori, and had the potential to bring about beneficial change.

2.1 Kaupapa Māori Research

2.1.1 The name of this research: “Hauā Mana Māori: Living unique and enriched lives”

Important in the initial stages of our research was to develop the research’s guiding kaupapa or philosophy that would underpin what we did. From an early brainstorming kōrero by the research team, the research name of “Hauā Mana Māori: Living unique and enriched lives” emerged, a name the team felt encompassed what this research was about.

Our research was guided by Kaupapa Māori Research. To align this project with the principles of this research methodology it was considered important that the Kairakahau Māori describe Kaupapa Māori Research in general and how the philosophies have been interpreted for this study, this they have done briefly in the next two sections (2.1.2 and 2.1.3) (For a more in-depth elucidation on this topic please see Appendix 4).

2.1.2 Kairakahau Māori (Māori Researchers)

In the reclaiming of knowledge comes a reclaiming of knowledge perception. As Kairakahau Māori it was important that we took the time to hear, see, and feel the kōrero (talk) that had been gifted to us by all of those involved in the Hauā Mana Māori research project. We honoured the opportunity to sit with our people and learn about their lives. We have a responsibility to our Māori communities, as Kairakahau Māori; to facilitate positive change and mediate action as directed by the needs and the dreams of the hauā Māori and their whānau within this project.

2.1.3 Kaupapa Māori Research

Kaupapa Māori research evolved from a reaction to questionable research conducted on and with Māori since the arrival of Europeans to Aotearoa. Missionaries, ethnographers, artists, property investors, and historians all wrote what they saw and furthered their interests and intrigue with the natives of this whenua (land).

Māori over the years have been studied in the main with awareness that they were involved with a research project. However, some practices in the earlier times did breach all ethical boundaries by placing Māori in research projects unknowingly. It could be argued that the research was to improve the wellbeing of Māori, but would often just raise the credentials of those facilitating the research and appeared to have minimal impact on improving the wellbeing and development of te Iwi Māori. According to Rangimarie Mahuika, research about Māori can be written in a way that is “alien to our (Māori) understanding” (Mahuika 2008). A great deal of research in the past told Māori how they lived their lives, often exclusive and often out of context. These research results then became published and formally accepted as a true record on how Māori were – often far from the reality experienced by the Māori participants.

The discussion about the inclusion of Māori into the research process as the researcher was fueled in the 1980's with Māori education leaders and writers instigating the establishment and support for Māori immersive education such as the: Kohanga Reo (preschool language nests), Kura Kaupapa (primary immersion Māori schools), and Whare Kura (Tertiary Immersion Education). These schools of learning about te Ao Māori whilst immersed in te reo Māori provided a huge surge of passion for cultural revitalization and strength in the mana of te iwi Māori.

Graham Smith said this further defined and expanded the concept of kaupapa Māori and Mahuika and Smith described it as a “theory of liberation” for Māori. Many Māori academics have addressed kaupapa Māori theory, it has been debated, discussed, pulled apart, put back together, disliked, and liked. Kaupapa Māori as a repository of knowledge is “the philosophy and practice of being Māori” (Smith 1992 p1). It is not a new concept developed purely to sit alongside the academic speak according to Nepe; it can be dated back to the early Creation stories (Nepe 1991). Māori have been practical researchers

since the beginning of their existence. Working on a whakāro (concept), practicing that whakāro, evaluating it and adjusting the methodology. Eventually early Māori produced a result that would then be incorporated into improving their way of life.

Anuru Eketone (2008) suggests that the academic debate about what kaupapa Māori theory and research is, is not important, as long as the voice of the Māori community representing whānau and Māori health and education providers is also being heard and valued (Mahuika 2008). Collectively these voices are forging a new style of research approach, driven by a need, conducted collectively utilising Māori values and philosophies and producing recommendations that can be employed across community and government services to better meet the needs of te Iwi Māori. Research is a valuable tool, it is power, it is knowledge and it can be a way forward for Māori and Aotearoa (G. Smith 1997, 2003; L. Smith 1999).

In our research we endeavoured to apply the following tikaka Māori protocols to guide the way we conducted our communication amongst the research team, community services, kaumātua, Rōpu Kaiarahi, and participants:

1. *Aroha ki te tākata - respect for people*: we developed a close working relationship with our research partners in Invercargill, the Ngā Kete Mātauranga Pounamu Charitable Trust (called from here onwards as the Ngā Kete Trust). We formed a Rōpu Kaiarahi (Research Advisory Group) comprising people with disability and their whānau and kaumātua (elders) living in our research community of Murihiku. We ensured that during the process of consultation and research planning that the empowerment/mana of the people remained with the people and there was an understanding that if they did choose to participate they deemed the kaupapa (agenda) as important.
2. *He kanohi kitea - face to face* ('a face seen') (Pipi 2004, Mead 2003): to the best of our ability, consultation, planning, and research methods were conducted face-to-face to demonstrate respect and a commitment to the research relationship.
3. *Titiro, whakaroko ... kōrero - look, listen ... speak*: within the confines of the research contract, we allowed time to share experiences with all those involved in the research; to allow for the research to occur within comfortable and acceptable time frames.
4. *Manāki ki te tākata - look after people*: we used a transformative research paradigm (Mertens 2009); thus the research findings were transparent and relevant to the

community, and aimed to achieve beneficial change. The research methodology was underpinned by the key concept of *koru* allowing people living with disability and their whānau to tell their stories, and then together with the researchers, analyse, interpret and make sense of these stories. It was planned that the findings would result in beneficial action for those from whence it came. Additionally, where ever possible, individuals from the community were trained in research skills, thereby perpetuating research beyond the life of this study.

5. *Kia tūpato - caution*: the study endeavoured to observe tikaka, ensuring mutual respect and understanding of all concerned.
6. *Kaua takahia te mana o te tākata - do not trample on the mana of people*: in this study we adopted a transformative, action research paradigm (Mertens 2009), in which the “participants” were fully involved and guided all aspects of the research, assisted by the researchers, to ensure the research led to outcomes the “participants” wished for.
7. *Kia manawa mahaki - be humble, don't flaunt your knowledge*: our research paradigm and methodologies ensured that Māori knowledge was valued and respected, and that the researchers' knowledge was used to assist and guide the advancement of the community.
8. *Whakawhānaukataka - weaving people together/making connections*: our participatory methodology established strong sustained relationships between the researchers and the community (Hodgson 2001).

2.2 Research Team Reflexivity

As stated, our research was guided by kaupapa Māori research principles. Our first phase of our research used a Participatory Action Research design. Both these research approaches are grounded on research questions generated by the participating community; the answers to which should be emancipatory and result in change (Kemmis and McTaggart 2000, Mahuika 2008). However, although we, as researchers, strongly endorsed and espoused community involvement and ownership in all aspects of our project, we were conscious from the outset that the community we were to work in, the Murihiku / Southland community had not initiated this research. The Murihiku community did not request or generate the project; rather, the request for this research had come from the New Zealand Ministry of Health and we, the research team, chose the Murihiku community as the location for our case study, in response to the Health Research Council's Request for

Proposal (RFP). This request was, however, most likely informed by the Uia Tonutia Māori Disability Research Agenda (Ministry of Health and the Health Research Council 2011). This Agenda was informed by 304 participants comprising Māori living with disability, unpaid whānau carers, kaumātua and others at 11 regional wananga and 13 hui (Collins et al 2009) and thus was driven by the community.

Furthermore, it is strongly advocated that kaupapa Māori research be undertaken by Māori researchers who whakapapa (have origins) to the community in which the research will occur (Mahuika 2008). In this project we were very conscious that our principal investigators were neither Māori nor from the Southland community and nor did our emerging Kairakahau Māori whakapapa to the region. However, the research team had previously developed a close relationship with our Southland research partners, Ngā Kete Trust, who in turn had strong links to the community. The principal investigators had extensive experience in disability research, and were able to support, in terms of basic research principles, the emerging Kairakahau Māori working on the project. The emerging Kairakahau Māori on our research team were guided in the process of kaupapa Māori research by consulting extensively with experienced Māori researchers and our research advisor, Dr Sue Crengle. Although only four of the five members of the research team had health professional backgrounds, all five had expertise and experience in disability and in qualitative research.

Everyone involved in this research were committed to the kaupapa Māori principles underpinning this study and fully recognised that the knowledge transfer in this study would be a four-way exchange; principal investigators, our research partners (the Ngā Kete Trust and our Rōpu Kaiarahi), research participants, and the emerging Kairakahau Māori would all be developing new research and cultural understandings and skills interactively with each other. Figure 1 is an organisational chart that shows the equal explanatory and decision-making powers that our Rōpu Kaiarahi, the Nga Kete Trust, and the research team had in this study. We endeavoured at all times to work with the community and to uphold Kaupapa Māori and Tikaka Māori.

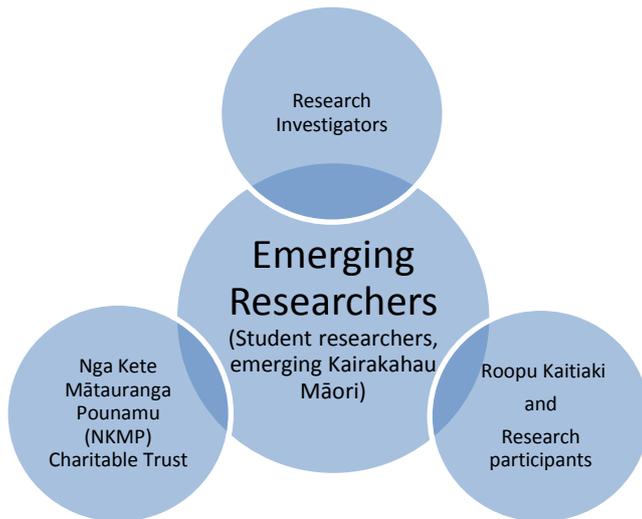


Figure 1: Organisational chart for the Hauā Mana Māori Research

In keeping with kaupapa principles, it was appropriate that the Māori members of the research team would lead the data collection and analysis process. To this end the Kairakahau Māori not only consulted with other members of the research team and experienced Māori researchers; they also met together on numerous occasions to discuss their own thoughts and perceptions (a process known in qualitative research as ‘bracketing’; in Māori terms it is known as wānanga, kit e whakawhiti ngā whakāro (an exchange of thoughts and views)). Both Kairakahau Māori interviewed each other and interviewed together in the initial interviews with participants to peer review, assess, and modify their interviewing styles.

Chapter Three: Methods and Sample

The method of research chosen was that of an exploratory case study. Although case studies cannot be used to estimate prevalence or causal relationships, their strength is in their contextual in-depth exploration and understanding of a problem (Gilgun 1994).

3.1 Case Study Research

In a case study an entity or a phenomenon is studied in-depth. Data can be collected by a variety of methods and collated to provide a rich description of the case, the narrative of which can be used to drive theory development (Merriam 1998). In the current research the “case” was that of Māori living with disability and their whānau living in the Murihiku / Southland district of New Zealand.

The Murihiku / Southland district of New Zealand is a well-bounded region that represents a fairly typical example of rural and small-town New Zealand. It is a diverse region with an assorted mix of people and land. It has:

- A mix of urban, rural, and remote rural areas: 23% of the land being intensively farmed and 60% taken up by National Parks and conservation reserves.
- A mix of people: of the New Zealand population, 2.3% (90,000 people) live in Murihiku / Southland; 50,000 of whom live in the city of Invercargill.
- A good representation of Māori: Māori have lived in the Southland region for over 800 years. Murihiku, the Māori name for Southland, originates from Māori legends and means “the last joint in the tail of the fish that is the South Island”. Māori comprise 11.8% (10,442) of the people in the Southland Region compared with 14.6% for all of New Zealand (Statistics New Zealand 2010).
- Ngāi Tahu/Kāi Tahu is the most common affiliation in Murihiku / Southland – 35% of people of Māori descent indicate an affiliation with this Iwi. Ngāpuhi (9.3% of Māori in Murihiku / Southland) and Ngāti Porou (8.5% of Māori in Murihiku / Southland) are the next most common Iwi affiliations. In the Murihiku / Southland region 21% of Māori did not know or did not want to comment on Iwi affiliation (Statistics New Zealand 2007).
- Te Rūnaka o Ngai Tahu is the Iwi authority and overall representative governing body of Ngai Tahu Whānui, who are descendants of the Ngai Tahu, Ngāti Māmoë, and Waitaha tribes. Te Rūnaka o Ngai Tahu is made up of 18 Rūnaka Papatipu, and hold Mana

Whenua status for both Otago and Southland regions. The Murihiku / Southland district has four mana whenua Rōpu: Awarua Rūnaka (Bluff), Waihōpai Rūnaka (Invercargill), Hokonui Rūnaka (Gore), and Ōraka Aparima Rūnaka (Colac Bay).

Murikihu / Southland is fairly representative of rural New Zealand. This area has the largest Māori population of district health boards in the South Island; with a younger age Māori profile than the non-Māori population (about 50% of Māori in Southland are aged under 20 years, 25% of non-Māori are aged under 20. Of those aged 65 plus, 15% are non-Māori and 4% are Māori). Furthermore, Māori are over-represented relative to the non-Māori population in lower socioeconomic areas according to the NZDep01 decile scale. An itinerant work force in the wool and meat packing industry has resulted in many Māori from other New Zealand regions moving into the Murihiku region. These statistics are consistent with other (rural/small town Māori) samples (Statistics New Zealand 2012). See Table 1.

Table 1: Regional statistics of interest

Region	Population	Population % Māori	City (Population)	City % Māori	Median Income	No. of Farm Holdings
Southland	94,200	11.8%	Invercargill (48,700)	14%	23,200	3,660
Hawkes Bay	154,800	23.5%	Napier (58,600)	18%	22,600	3,129
Tasman/Marlborough	138,100	8.8%	Nelson (59,800)	18%	22,450	3,543
Taranaki	109,100	15.8%	New Plymouth (52,200)	13%	23,200	3,318
Northland	157,400	31.7%	Whangarei (79,000)	25%	20,900	4,899

(Statistics New Zealand)

3.2 Methods

We collected data from a range of relevant sources to inform our case study. Our primary data were collected from Māori living with disability and their whānau in Murihiku. Data were also collected from the organisations that were currently providing health or disability services and support in Murihiku. Other data sources included printed information we

collected along our research journey (for example, health information brochures) and the published literature.

We used three phases to collect these data:

Phase One comprised a Participatory Action Research (PAR) project with people living with disability and their whānau.

Phase Two was a postal survey of organisations providing a health or disability service or support in Southland.

Phase Three was an onsite interview with staff of a purposive sample of the above organisations.

3.2.1 Phase One - PAR Project: Method and Sampling

Phase One was a Participatory Action Research (PAR) project. In PAR, the researchers and the community work collaboratively to undertake the research; as co-participants they take collaborative ownership of the project and in a cyclic process reflect, plan, act and observe. In this project, our community were people living with disability and their whānau. We requested volunteers from this community to form a Rōpu Kaiarahi (Research Advisory Group). The researcher team then worked closely with the Rōpu Kaiarahi to explore ways in which we could:

1. Decide on an appropriate research framework to collect relevant data.
2. Identify the barriers and facilitators to accessibility of the service organisations disabled Māori utilise or would like to utilise.
3. Suggest ways in which such organisations could be made more accessible.

3.2.1.1 Establishing the Rōpu Kaiarahi (Research Advisory Group)

We gained ethical approval from the University of Otago Human Ethics Committee to form the Rōpu Kaiarahi (Ethics Committee's reference code: 12/028). To introduce our research and to establish our Rōpu Kaiarahi, we held a hui at the Toimarangi Marae in Invercargill in March 2012. This marae was suggested for its location convenience and as it caters for multiple iwi. A pānui (see Appendix 1) inviting people to have a say on living with disability

was distributed widely in the Southland region by the Ngā Kete Trust, the Pānui Rūnaka / Kai Thu newsletter, and the Southland rūnaka.

Approximately 30 people attended the hui and sixteen people volunteered to be part of our Rōpu Kaiarahi.



Figure 2: Hui at the Toimarangi Marae in Invercargill in March 2012

3.2.1.2 Establishing the PAR methods and procedures

In keeping with the principles of PAR, we invited our Rōpu Kaiarahi to a second hui held in May 2012, the aim of which was to consult with them on how best to conduct the project. At this hui we explained what we would like to explore in our project, and ways we thought we could do this. We invited discussion, comments, and suggestions around three questions: i) What questions should we ask, ii) Who should we talk to in this study to collect data, and iii) How should we collect these data? The ensuing discussion was audio-recorded.



Figure 3: Hui with the Roopu Kaiarahi held in May 2012

i) *Questions to be asked of research participants*

Five main areas of importance within our research were identified in this hui: perceptions of wellness, perceptions of disability, organisations, accessibility and whānau; from these the PAR research questions were developed. Our Rōpu Kaiarahi considered it extremely important that perceptions of wellness and disability be first established, before the issues and context of accessibility of organisations could be understood. The PAR research questions were categorised into four 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: Hinengaro, Tinana, Tipuna, Wairua, and Whānau.
- 3 *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.
- 4 *Rating of organisations*: As participants mentioned organisations they accessed or wished to access, they would be asked to rate, from their perspective, how the organisation catered for them on a scale 0 to 10 as (a) a person living with a disability and (b) as a Māori. Participants would then be prompted to elaborate why they rated an organisation well or poorly.

The questions can be seen in Table 2.

Table 2: Question framework for use in the PAR project

Topics	PUNA / Broad	TAPARIMA / cues / prompts	KORU / self-express
HAUORA/wellness	What does wellness mean to you?	<ul style="list-style-type: none"> • What makes you well in respect to your hinengaro, tinana, whānau, wairua, atua/rakatira? • What helps you achieve this? • What makes it hard to achieve this? 	
HAUĀ/disability	What does disability mean to you?	<ul style="list-style-type: none"> • Tell us about your disability in terms of hinengaro, tinana, whānau, wairua, atua/rakatira • Do you think that Māori have a perception of disability • Do you think that Māori see/interpret disability differently than others? 	
WHAKARITENGA MAHI/services	What services do you use? (Have you used any in the past 3 years?)	<ul style="list-style-type: none"> • How do services cater for hinengaro, tinana, whānau, wairua, atua/rakatira? • What is done well? • What could be better? • Are there other services you would like/want/need to be using? 	
PUTANGA/Access/needs	What enables and what stops you from getting the health care/services you would need.	<ul style="list-style-type: none"> • Do you feel your needs as Māori are being met in terms of hinengaro, tinana, whānau, wairua, atua/rakatira? • How do you think your needs, as someone living with a disability, are best be met? 	
IWI WHĀNUI/Community	Who is your whānau or what does it mean for you?	<ul style="list-style-type: none"> • How does your whānau stay well in terms of hinengaro, tinana, whānau, wairua, atua/rakatira? • How does this affect you? • What does whānau ora mean to you? • What is done well to achieve Whānau ora? • What could be done better? • Do you feel respected and loved by your whānau and community? • How do people perceive you? • How do you perceive yourself in this community? • How do you think you fit into the community? • How does this affect you, and your everyday life? 	

ii) Suggested ways to recruit participants

The following were suggested by our Rōpu Kaiarahi as people or organisations from which to recruit participants for the PAR project:

- Community groups, e.g. IDEA Services
- Southern District Health Board contacts
- Ngā Kete Matuaranga
- Awarua Health and Safety Services
- Te Korowai Hauora – Māori Mental Health S
- Local runaka
- Kohunga Reo
- Kura Kaupapa
- Kaumātua – Taua and poua
- Members of Māori groups such as Kappa Haka groups
- Organisations who provide mirimiri and alternate healing therapies to clients with a disability.

iii) Methods for collecting data:

Our Rōpu Kaiarahi suggested the following methods that would be appropriate for collecting data:

- Use different approaches for different age groups, for example, individual interviews for older adults, focus groups for middle aged adults, and face book or a blog discussion for the younger generation. Groups/forums for kaumātua.
- Use art as a method of gaining the perspectives of children. Creating some piece of art, story, or waiata to add to the kōrero that contributes to the picture of being Māori living with a disability.
- The idea of using multi-media.
- Through waiata in English and Māori.
- Photo voice or an image (e.g. via the internet) - photographs or images that depict the reality of living with a disability.

From the kōrero with our Rōpu Kaiarahi we decided to keep the study focussed on adults and an age inclusion criteria of 16 years and older. Although using social media, such as face book or blogs were potentially enticing as helpful tools for recruitment and data collection, due to time limitations and the complex ethical issues of using such tools, we did not pursue these methods. We decided to use two methods of data collection: (i) focus groups and (ii) individual interviews; the method to be used would depend on individual participant wishes. Art work was one method favoured by our Rōpu Kaiarahi as a way to collect meaningful data but we agreed that there would not be time to hold a hui to create art. Instead our Kairakahau Māori suggested using a visual method to assist data

collection in the focus groups and individual interviews to facilitate data collection (described below).

3.2.1.3 Ko te Pōkare Whakāro Visual Tool

The initial concept facilitating the approach to the qualitative interviews originated from natural processes and wisdom of our tūpuna Māori. We looked to the past in order to find a method and a visual tool that would gently guide the kōrero with our participants.

Our thinking became aligned to the ancient whare, made from a number of natural resources depending on what was growing in close proximity to the kaika (village) such as: toetoe, patiti (tussock), wiwi (rushes) raupo (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 constructed entirely with fibrous materials, they were also porous and this concept is portrayed within the Pōkare Whakāro Visual Tool.

We placed the whare inside a puna (pool of water/pond) to represent the participant, the embodiment of them. This then allowed the Kairakahau Māori to utilise this breathable porous whare to highlight: flexibility, change, adaption and flow of thoughts and the seeking of balance and hauora.

We also likened the concept of a kōhatu (a stone or pebble) being dropped into a pool of water (puna) and when this occurs the ripple (pōkarekare) affect that takes place is not only a beautiful phenomenon but it also represented for the Kairakahau Māori how Māori with a disability create an affect or ripple in their community. Hauā Māori can create a displacement: of thinking, of services, of needs, of discomfort, of challenge, of excitement, of raw energy, and of love. Their energy does appear to create ripples and we felt that it was how whānau and services perceived those ripples that could indicate where the facilitators and barriers were for our participants.

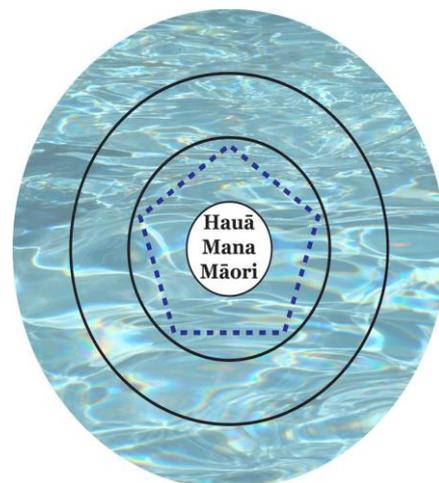
A puna using water imagery was placed inside a porowhita (circle) and another two porowhita were placed inside these porowhita. The inner porowhita represented the participant living with a disability in the Murihiku area. They were the kōhatu (stone or pebble) that guided and remained at the centre 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 borders of the porowhita represented Whānau Ora and this reminded us to keep the whānau close in order to ensure we were not just looking at the participant's wellbeing but what aided their wellbeing and the wellbeing of their whānau. Thus Whānau Ora was placed on every porowhita or pōkarekare (ripple). The last porowhita included principles of kaupapa Māori research as mentioned above. These were values that we believed not only guided the participant but also guided the Kairakahau Māori with communication amongst the research team, services, advisors, Rōpu Kaiarahi, and Hauā Māori and their whānau (see Figure 4a).

Once we had completed this version of the Pōkare Whakāro Visual Tool and could see the principles and how it could potentially work, we were able to see that at this stage of shaping, the tool was too wordy, too crowded, and needed some space and light. We wanted to remove the words so that the only words that came to be on this tool were those of our participants (see Figure 4b). Hence, a new visual tool was developed and laminated. One large A1 poster and one smaller A3 poster allowed us to use the visual tool in potentially larger group settings or for the individual and their whānau. Having the visual tool laminated allowed white board markers to be used upon them, with the writing wiped away at the conclusion of the interview. A photo was taken of the visual tool prior to wiping away the contents and this photo was used in the data analysis process (see Figure 5).



4 a. Draft Tool



4b. Completed Tool

Figure 4: Pōkare Whakāro Visual Tool



Figure 5: Example of the Pōkare Whakāro Visual Tool in use

The Pōkare Whakāro Visual Tool was piloted in three individual interviews and one focus group meeting with members of the Rōpu Kaiarahi. Whilst the tool worked well in the individual interviews, it was found not to be useful in a focus group situation. In the group setting, it was difficult to capture individual journeys of wellbeing as well as get an overall group feeling, and not everyone felt comfortable to share their thoughts or “place” their thoughts on the tool. The more vocal people in the room tended to overwhelm those less vocal. One participant did not know what the Māori words on the cue cards meant and we realised we would need to write the English meanings on the back of the card so all participants felt included and could engage with the model and the study.

Participants in the individual interviews said they liked the tool and found it helpful in facilitating conversation around hauora. They liked the imagery on the tool and the simplicity of it. There was little hesitation to use the cue cards and place them on the model, relative to the centre, to indicate their personal feeling of importance to hauora. Participants liked the size of the tool and that it allowed wide discussion, “to go out of the puna”, rather than be restricted by boundaries.

One participant with visual impairment said that although they could not “see” the tool, the description of it facilitated discussion and the participant endorsed it. When asked if raised lines should be used to enhance the tool for those with visual impairment, the answer was “no”; that the verbal description was enough.

3.2.1.4 Procedure of the PAR project

Recruitment and inclusion criteria

Ethical approval for the PAR project was obtained from the University of Otago Human Ethics Committee (Ethics Committee's reference code: 12/175). We sought to recruit 30 adult (16 years and over) Māori who identify as living with a disability and whānau or care giver/support person of Māori who identify as living with a disability, residing in Murihiku. Whānau or care givers/support person could identify as Māori or not. Although, we were to recruit and interview until we considered we had reached a point of data saturation, it was decided to initially target 30 participants and sample for diversity in age, type of disability, and gender.

Informed by our consultation with our Rōpu Kaiarahi, we recruited participants using the following strategies:

- Our research partners, the Ngā Kete Trust and the Donald Beasley Institute, promoted our call for participants through their networks.
- A pānui was sent to the local Murihiku Rūnaka (Hokonui Rūnaka, Waihōpai Rūnaka, Ōraka Aparima Rūnaka, Awarua Rūnaka), introducing the project and requesting for Kaumātua support from the rūnaka.
- A pānui was distributed through the Māori, Iwi, Hapū and Whānau organisations in Murihiku, e.g., Te Pānui Te Karaka, Karaka, Marae (Murihiki, Ngā Hau e Wha, O Te Ika Rana, Te Akau (Matāwaka), Te Whānau a Hokonui, Te Rau Aroha, Ōraka Aparima), Rūnaka hui, Kura Kaupapa (Te Arawa Whenua), Kohunga Reo, and Kapa Haka groups.
- Pānui / flyers were sent to main disability organisations in Murihiku, e.g., Awarua Social Service, CCS, PACT.
- Key public noticeboards identified by the Rōpu Kaiarahi.
- Promotion at local Whānau Ora Consultation Hui.

Procedure

We chose two data collection methods: (1) semi-structured interviews and (2) focus groups, both of which were audio recorded. As noted by our Rōpu Kaiarahi, given the different styles of communication likely to be used by participants and the anticipated wide age range, we proposed to use a variety of participant groupings and approaches for data collection:

1. 16- 25 years old/ Rangatahi: focus groups (n= ± 7).
2. 26-49 years old/ Kaimahi: focus groups and individual telephone or face-to-face follow up if identified as necessary (n= ± 7).
3. 50+ and Kaumātua-kanohi ki te kanohi: focus group and individual telephone or face-to-face follow up if identified as necessary (n= ± 7).
4. Whānau and caregivers of Māori living with a disability: focus groups and individual telephone or face-to-face follow up as necessary (n= ± 7).

If a participant did not wish to be part of a focus group (for example, preferred a one-on-one dialogue) or had a communication style not conducive to focus group discussion, we used individual semi-structured interviews. We were flexible in these interviews to ensure the optimal method of communication was used, depending on the individual's requirements, for example, we were prepared, for those unable to verbally respond, to use written, computer-based, or diagrammatic replies, a sign interpreter for those participants hard of hearing, and plain language interview questions for those participants with an intellectual disability. All participants were asked if they wished whānau / a support person to accompany them.

In the semi-structured interviews, we used the Pōkare Whakāro Visual Tool to facilitate discussion and interpretation of data. Participants could write on the laminated visual aid and / or stick on pre-made word cue cards (in both Māori and English) whilst they talked, using the laminated model to facilitate and illustrate their thoughts. At the end of each interview a photograph of the visual aid with participant's thoughts written or cue-carded on, was taken.

Interviews and focus groups were conducted by the Kairakahau Māori. At the completion of each interview or focus group, the researchers made field notes of topics that appeared to be important within the kōrero. The interview questions were developed and informed by our Rōpu Kaiarahi as described previously, and can be seen in Table 2 on page 26.

Participants were given the option to bring to the interview, or focus group, photos or images, make sculptures and other art pieces, recite haka, waiata or whakatauki, or write a story which assisted in expressing their perceptions of Hauora, Hauā, Whakaritenga Mahi, Putanga, or Whānau.

Data analysis

The audiotapes from the interviews and focus groups were transcribed word for word and checked for accuracy. The te reo Māori used by both Kairakahau Māori and participants meant that the transcriber had to work hard at writing the language heard. A glossary of Māori words were provided to the transcriber and this was useful but still each transcript took longer than initially planned to transcribe to ensure the reo Māori component in each transcript was right and spelt correctly. One interview had to be transcribed by the Kairakahau Māori as it contained a greater amount of te reo Māori than the others.

A thematic analysis was conducted according to the guidelines of Braun and Clarke (2006). It was important in this project that data were analysed with a Māori lens, by those with an understanding of the Te Ao Māori perspective. So initially, the Kairakahau Māori analysed the data, guided in the process by the other members of the Research Team, but aided in interpretation of the data by the Kaumātua, the Māori research advisors, the Rōpu Kaiarahi, and the Ngā Kete Trust. A constant comparative method was used, in that interviews were briefly analysed after they had occurred, and this analysis then informed future interviews and analysis. In the fuller analysis process the Kairakahau Māori individually read the transcripts multiple times, listened to the audio-recordings, scrutinised the photographs taken of the developed visual aids, and referred to their field notes, searching for key ideas and perceptions. The key ideas were labelled, colour coded and comments referring to the idea made. All codes that demonstrated commonalities were highlighted with the same colour. As new ideas emerged from the transcripts, new colour codes were developed. Once the transcripts were all colour coded, the various comments with same colour coding were then collated. The two researchers then combined their analyses, and discussed and debated their findings to develop and refine the coding frameworks. Overarching themes developed, combining different codes to form these. Processes involving thematic maps to see relationships within various codes were used to assist this process as per Braun and Clarke (2006). Broader themes became apparent and within the themes, subthemes also emerged. The coding framework was then discussed with the wider research team until a final coding scheme was agreed upon.

Members of the research team then used the final coding framework to code the interview transcripts allowing the predominant themes and sub-themes to emerge. The emerging themes were presented and discussed in hui with members of the Rōpu Kaiarahi and the Ngā Kete Trust to ensure that the emerging themes were correct, relevant, and accurately

reflected a picture of their community (see Figure 6). 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.



Figure 6: Discussion of emerging findings with members of the Rōpu Kaiarachi and Ngā Kete Mātauranga Pounamu Charitable Trust

Rigour

Verification of the themes was achieved by comparing multiple sources of information (visual artefacts, audio-tapes, field notes) and multiple researchers' perspectives and by deferring to the Rōpu Kaiarahi. Reflexivity or potential bias impact of researchers' perspective/world view was discussed and considered.

Further, we were invited to present this research at Invercargill, hosted by Ngā Kete Trust and Te Piringa (a national collective of Māori health providers of disability services). We invited our participants to attend, and 20 attended on the day. One of our Rōpu Kaiarahi assisted us in presenting the results at this hui. Our participants strongly affirmed our findings. Members from Te Piringa were impressed with the research in the sense that it represented “grass roots” research, capturing voices of Māori living with disability, and provided a Southern perspective. We received the following feedback from Donovan Clarke, Kaiwhakahaere, Executive Director Māori Health, Southern District Health Board and a member of the board of Te Piringa (personal communication 2013):

Thank you for the fantastic work you are doing to support Māori living a disability. I really enjoyed the presentation; it was informative and provided a good understanding of Māori health models and their application to today. Te Piringa looks forward to further engagement with Otago University and your team.

Given these factors the research team was asked to present this research at Hui Taumata 2013, March 20th 2013, Huria Marae, Tauranga, again supported by Te Piringa.

3.2.2 Phase Two - Organisational Survey: Methods and Sampling

The first step in this second phase was to develop a questionnaire with which to conduct the survey. As no appropriate questionnaire for this survey could be sourced, we had to develop one. To underpin the development of the questionnaire, we systematically reviewed pertinent literature. In keeping with our desire to build research capacity and capability for Māori, two Māori under-graduate physiotherapy students undertook this structured literature review as a summer research project, under the direct supervision of one of the Kairakahau Māori, who in turn was mentored by the rest of the research team.

3.2.2.1 Structured literature review

The research question for this structured literature review was: What are the most appropriate questionnaires / questions to assess both disability and indigenous cultural accessibility of health and disability services?

A comprehensive review of published literature in CINAHL, Medline, Embase, Pubmed, Google Scholar, Web of Science, and Scopus electronic databases was conducted from January 1st 2000 to 31st October 2011. The search strategy involved using keywords 'questionnaire' or 'survey' and 'indigenous' in combination with disability, Māori, health literacy, service effectiveness, quality standards, workforce competence, health promotion, and accessibility (terms truncated where possible). Limits applied were that articles were available in English or Te Reo Māori and published after January 1st 2000.

Titles and abstracts of all articles found were independently screened by the two student researchers according to predetermined inclusion / exclusion criteria to elicit studies that had questionnaires or key findings relating to our research. These would be used to formulate questions to be included in our questionnaire to assess both disability and Māori cultural accessibility of health and disability organisations.

The inclusion criteria required articles to have an indigenous or disability element, be written in English or te Reo Māori, and have a qualitative component or questionnaire included in the study. The authors of articles who did not attach their questionnaire in the

relevant article were contacted to request the questionnaire or question layout that was used. Opinion pieces and narrative studies were excluded.

Full text articles of the studies that met the inclusion criteria were appraised by the two student researchers using a qualitative research assessment tool developed by the Critical Appraisal Skills Programme (CASP) (Arlidge 2009, Wiley 2009). This assessment tool includes ten questions which are designed to systematically appraise qualitative reports. Quantitative studies were not assessed as we were interested in the questionnaire / questions used by the study as opposed to the study findings. Qualitative articles were quality assessed to appraise how rigorous the findings were if these findings were to be used as the basis of questions in a questionnaire. Relevant data, either specific questions or key findings from the included qualitative studies, were extracted by five members of the research team, and used to form the final questionnaire.

Of specific interest to our questionnaire were questions relating to five key areas: (1) Analysis of workforce competencies, (2) Quality standards, (3) Service effectiveness (reduction of disparities and facilitation of wellness), (4) Access and promotion of services, and (5) Health literacy and information needs.

3.2.2.2 The questionnaire

Based on the findings of the structured review outlined above, a questionnaire was developed to assess accessibility aspects in relation to:

1. Workforce competencies.
2. Quality standards.
3. Service effectiveness.
4. Access and promotion of services.
5. Health literacy and information needs.

The time frames of the research contract did not permit time for pilot testing of the questionnaire. The questionnaire however was discussed with our research partners and our Rōpu Kaiarahi and refined accordingly. We also delayed the survey until we had preliminary findings from our PAR study to ensure that what our participants were telling us was reflected in the questionnaire. The questionnaire can be seen in Appendix 2.

3.2.2.3 *Survey procedure*

Ethical approval was gained from the University of Otago Human Ethics Committee to undertake this survey (Ethics Committee's reference code: 12/028). To ensure a good response rate to our survey we followed the strategies described in the Modified Dillman approach (Dillman1991).

Sample

We used a broad definition of "organisations" to include in this survey, namely, any organisation in the Murihiku region that provided a health or disability service of any nature for disabled people. As no data base listing such a broad spectrum of organisations existed, we consulted with our research partners, the Ngā Kete Trust, and with appropriate stakeholders (such as the Southland district and city councils, known health and disability services, appropriate websites, Māori networks, and local people by "word of mouth") to identify appropriate organisations. We identified 66 organisations. Please see the list overleaf.

Procedure

One of our Kairakahau Māori telephoned all organisations on our list explaining the survey and obtained their consent to mail the questionnaire to them. Consent was obtained from 50 organisations and the questionnaire was posted to, along with an information sheet, a consent form, and a stamped, addressed envelope for return of the completed questionnaire to these 50 organisations. Follow-up telephone calls reminding organisations to complete the survey were made one week after the submission deadline had expired. If organisations so wished, we completed the survey during these telephone follow-up phone calls. Twenty-nine organisations completed the survey.

Data analysis

The frequency distributions of the quantitative data were calculated and qualitative data from the questionnaires reported verbatim.

List of health and disability services identified in Murihiku / Southland

FIORDLAND	Health and Disability Consumer Advocacy Service (Southland)	RIVERTON
Health Centre Community Worker	Health Care NZ	District Nurse
GORE	IDEA Services	Riverton Medical Centre
Asthma New Zealand	Invercargill and Gore chiropractic Clinic	TUATAPERE
Gore Community Mental Health Team	Ngā Kete Mātauranga Pounamu Trust	Community Worker
Gore Health Centre Ltd (Dr Park)	PACT Group Southland	Home Help
HealthCare NZ, Gore	Plunket	Tuatapere Surgery
Mataura Medical Centre	Prohealth Physiotherapy Ltd	WAKATIPU
Resthaven Retirement Village	Ruru School	Community Mental Health
Southland Multiple Sclerosis Society, Gore	Southern Mobility	Disabilities Resource Centre
INVERCARGILL	Southland Hospital Mental Health Services	Frankton Medical Centre
Access Home Health	Southland Branch Heart Foundation	PACT
Bester McKay Family Doctors	Southland Multiple Sclerosis Society	Queenstown Medical Centre
Bluff Medical Centre	Southland Stroke Foundation	Supporting Families
Diabetes Society	Southern Health	Surgery Remarkables
Disability Resource	Stephenson Murray Physiotherapists	WINTON
Dr AM Johri	Stroke Club Southland	Community Worker
Dr Martin Tooke	The Lung Association	Central Physiotherapy
Dr McKerchar	Te Rūnaka o Awarua	Medical Centre
Dr Terpstra	Total Mobility Scheme	WYNDHAM
Dr Finlayson	Winsor Street Physiotherapy	Wyndham Health Centre
Eastern Physiotherapy	LUMSDEN	RIVERTON
Eastern midwifery	Lumsden Medical Centre	District Nurse
Glenda Graham: Counselling Service	NIGHTCAPS	Riverton Medical Centre
Glengarry Medical Centre	Medical Centre	TUATAPERE
Head Injury Society	Practice Nurse	Community Worker

3.2.3 Phase Three - Onsite Organisational Interview: Methods and Sampling

Originally we planned to undertake an onsite assessment of accessibility, from both a cultural and a disability perspective, with a purposive sample from our list of identified organisations who agreed to participate. Six to eight organisations were to be assessed. This assessment was to be guided by the processes described by the New Zealand Ministry of Health (Guidelines for Cultural Assessment – Māori Under the Intellectual Disability (Compulsory Care and Rehabilitation) Act 2003, August 2004) and those developed for mental health disability (Mental Health Commission 2004). Based on these guidelines, we proposed to develop a checklist in consultation with our Rōpu Kaiarahi and the Ngā Kete Trust, as we acknowledged that as a research team, we did not have the time or the expertise to develop such a tool. However, the outcome of our initial consultations and subsequent discussions was uneasiness about visiting service organisations and administering such a checklist. We considered that it may be perceived as punitive by the organisations concerned, and not as a constructive process. We therefore decided, as a more affirming, positive step, to visit consenting organisations and use our survey in a kanohi ki te kanohi / face-to-face interview to probe more deeply their responses to the survey questions.

3.2.3.1 *Onsite interview procedure*

Sample

From the organisations that had responded to our questionnaire-based survey (n=29) we gained consent to visit them to discuss their completed surveys in more depth; 15 organisations agreed.

Procedure

The organisations were visited by one of three members of our research team. The person in the organisation who had completed the survey was interviewed. Using the completed questionnaires as a prompt, we probed their responses to the survey questions. These interviews were audio-recorded and the recordings then transcribed.

Data analysis

Using the survey questions as guidelines, we analysed these data using a thematic analysis (according to the guidelines of Braun and Clarke (2006) as described above) to explore: (1) how good the organisations perceived their accessibility to be; (2) what they thought was being done well with regards to accessibility, to identify what they thought good accessibility practices were, and what issues might be preventing them from doing “good practice”; and (3) to find out what organisations suggested as ways accessibility could be improved.

The next chapter reports the results of the three phases of our research.

Chapter Four: Results

4.1 Phase One - PAR Project

4.1.1 Participants

Of the 34 Māori living with disability who volunteered for the PAR project; 29 were interviewed (18 males and 10 females). All participants lived in the community (Invercargill = 26; Winton, Queenstown, Riverton = 3). Five volunteers were not interviewed: two interviews were cancelled as a result of tangi and three as a result of whānau commitments. All 29 participants chose individual interviews for the method of data collection and thus no focus groups were conducted. Table 3 presents the characteristics of the participants.

Table 3: Characteristics of participants in PAR project

Characteristics	Category	n = 29
Age Range: 17-74 years	16 - 19 years	1
	20 – 29 years	2
	30 – 39 years	2
	40 – 49 years	8
	50 – 59 years	7
	60 – 69 years	7
	> 70 years	2
Iwi (*some participants reported multiple iwi)	Ngāi Tahu	17
	Ngā Puhi	6
	Waitaha	3
	Tainui	2
	Kāti Māmoe	2
	Ngāti Kuri; Rakiura; Maniopoto; Ngāti Porou;	1
	Ngāti Kahungunu; Te Atiawa	
Disability (*some participants reported multiple disabilities)	Hearing impairment	4
	Diabetes	4
	Arthritis	3
	Heart	3
	Visual impairment	2
	Stroke	3
	Multiple Sclerosis	2
	Epilepsy	2
	Blood clotting problem	1
	Chronic pain	1
	Sarcoidosis	2
	Recovering from cancerous tumour removal	1
	Asthma	1
	Anxiety	1
	Meningitis	1
	Dialysis	1
	Dyspraxia	1
	Fractured femur	1
	Alzheimer's disease	1
	Alcohol foetal syndrome	1
Schizophrenia	1	

4.1.2 Findings of the PAR project

To more fully understand the barriers and facilitators that research participants experienced when accessing disability services and support, we first needed to appreciate their perspectives on health and disability. The main themes that emerged with respect to our participants' perspective of *good health* 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. Conversely in terms of *disability* the main themes were: (1) Not being valued; (2) Negative impacts of discrimination, colonisation, and disconnection; (3) Lack of self-worth; and (4) Poor access to resources.

These themes are expanded below.

Findings

To more fully understand the barriers and facilitators that research participants experienced when accessing disability services and support, we first needed to appreciate their perspectives on health and disability. The main themes that emerged in respect to our participants' perspective of *good health* 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. Conversely in terms of *disability* the main themes were: (1) Not being valued; (2) Negative impacts of discrimination, colonisation, and disconnection; (3) Lack of self-worth; and (4) Poor access to resources.

These themes are expanded below.

Hauā Māori Mauri Ora - What Makes Me Well?

1. Whakamana - Being Valued

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. This relates to having a sense of active responsibility within society and of having reciprocal relationships. These notions of

active citizenship and reciprocity can also be found in the disability literature. Many participants stated that “giving back” to the community within which they live, was satisfying, rewarding, and provided a sense of uplifting their Mana (their self-worth). Wellness, for one Taua, was having role of Kaumātua acknowledged and Māoritanga being valued. She 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 the participant 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.

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 which many participants remarked was in fact disabling.

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

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

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?

Another participant 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. One participant 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 Māori.

Respect and positive attitudes from the community

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. One participant 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 *“someone believing in me”* had helped change his life around.

Another participant said that he thought there was an improvement in community perception of disabilities which 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 heard and not discriminated against

When asked what factors encouraged them to use a particular service, and to feel like the service received was right for them as Hauā Māori, one participant simply articulated one of the most common themes for accessibility as *“being heard.”* This theme was expressed by another participant as she describes what is important 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

A common theme within the interviews in relation to contributors to wellness, was being treated with respect regardless of ethnicity or disability. One participant explains his relationship with his general practitioner, who demonstrates an open door policy and understands the importance of whānau, recognising that both are 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.

One participant 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.

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. One participant 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 recognition of the value of tikaka, and a feeling of pride to be able to contribute to an understanding tikaka within the community.

2. Whānaukataka - 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.

Whakawhānaukataka - Being connected with Whānau

Many participants identified the value of being connected with their whānau, and having whānau to awhi/support them in times of need and on-going. Being able to reciprocate this awhi was also empowering and strengthened bonds within whānau.

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.

As many Māori move further from their whenua, a phenomenon common in Southland, whānau become more dispersed. Maintaining relationships with whānau that are not close was an important aspect that kept many participants sound and well. One participant said that home is where his whānau are, rather than reference to a place.

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

RESPONDENT: *Going home*

INTERVIEWER: *Going home? And home's...*

RESPONDENT: *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, were still considered valuable.

RESPONDENT: *Oh. I'm still healing in this area*

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

RESPONDENT: *Yeah*

INTERVIEWER: *And what does that mean to you?*

RESPONDENT: *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 infers the participant finds maintaining a relationship with his whānau is important to him for a sense of wellness. In order for this to occur, he feels it critical to

relay his realities of living with mental illness; a process he feels is difficult but occurring slowly.

Being there for whānau

Having the potential to contribute and gift time to whānau life was quintessential for many participants, articulated simply: *“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...”* One participant suggested that *“knowing in what way I can help with the Māori community ... would make me feel 100% better.”*

Friends and community as whānau

Extended whānau often includes friends. In Southland, many Māori are matā waka, or from out of the Southland area, and many do not have whānau close. Friends therefore were also seen as integral to participant’s support systems. Community whānau are also important: *“..... 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.*

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.

Relationship with health care provider

Having a positive connection with health care providers was a resounding, strong theme within the interviews and was perceived as contributing to participants’ sense of wellness, and as facilitating their access to healthcare services. There were many quotes to support this, however one participant exemplifies 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

Another participant comments on why he highly rates his doctor as a health care provider: *“He raised his eyebrows, you know, it was like he knew how to communicate with you? Just that bit, even just that facial, you know, cool.”*

3. A strong sense of self 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. One participant 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. Most participants differentiated karakia as separate to religion and Christianity, but some did not. Karakia highlighted an aspect of identifying with and valuing things Māori: *“Oh yes, karakia’s most important to me. Uh, karakia, I te morena, I te ata, I te po.”*

Rakimarie - finding calm from within

Many participants spoke of the importance of claiming their own space and time to find peace and rest. Fatigue was a shared issue by many and therefore timeout to recoup and recover was deemed essential as described by one whānau member: *“The busy-ness in*

our home, that's life. ...And about having....peacefulness....that's the most important because of the illnesses that (he) has suffered, he needs calm."

Aroha and Mana

To care and respect one-self featured as a seminal aspect of wellness for some. Mana, or the desire of the wairua to let it be known and excel, was also articulated as important in terms of self-worth.

RESPONDENT: *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?*

RESPONDENT: *Pride in who you are.*

Reflecting on the connectedness of 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 one participant explained: "*all make me, they make who I am. They make my essence.*" Most interviewees differed in the aspects that featured strongly for them, and some identified that at different points of time their Pōkare Whakāro diagram would look different. Most of those interviewed agreed, however, on the connected nature of the elements within Te Whare Tapa Rima:

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 huu ha." "It's like the stuff of our tipuna, they have wai, and sacred waters too, and like our, like coming here, from Awa, or Tahiti, Rarotonga ..".

Sense of Māori Identity

Most participants felt that having a strong, positive sense of being Māori was essential to establishing a healthy state, although the degree of affiliation to Māoridom did vary within the group. One person explained how he gained a positive sense of being Māori whilst in prison. He described how 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 understanding of his coping mechanisms to deal with being discriminated and thus improved wellness.

Whakamana - 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 the following two quotes:

Its 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. Yeah, like if I want to present this certain mindset which indicates to others that you have a disability then so be it. But then I don't have that mindset. Hey, look if I'm going to get disability parking wicked! Bring it on. If you want to fund me to be disabled and give me some money then, hell yeah. I'll take it but at the end of the day, for me, its 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.

Another participant 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.

RESPONDENT: *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?*

RESPONDENT: *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.

+77

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 often attributed to establishing a stronger sense of self-worth and clearer self-identity. One participant who now used te reo Māori, waiata, and tikaka 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. Resources/Matatiki

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. Resources include pūtea, information, education, transport/mobility, financial support and advocacy to assist in receiving good healthcare that was responsive to their needs.

Pūtea

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. One participant 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. Another participant 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 did not feature strongly as an element considered important for a sense of health, although many had goals for continuing education and courses. One participant was presently studying at Southern Institute of Technology, and a few participants were studying Papa Ako courses. One participant felt

that achieving education contributed to him being well in the sense he was building knowledge for him and his whānau to battle against discrimination.

Transport/ Mobility - being able to get around

Being mobile signified independence and freedom, and this definitely contributed to a sense of wellbeing. 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. One Tāua explained how a mobility scooter now enabled her to attend hui and work at the kōhanga reo. Another participant was able to enjoy his hobbies following the prescription of a sturdy mobility scooter:

RESPONDENT: *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.*

INTERVIEWER: *To Bluff!?! You're kidding me. Would you just head along the motorway to Bluff?*

RESPONDENT: *Yeah. To go fishing.*

INTERVIEWER: *Do people laugh on the way when they see you on your mobility scooter with your fishing rod out the back?*

One participant said that having someone pick her up and drive her to the various supermarkets encouraged a sense of value and is as it allowed flexibility and options on items she wished to purchase. Prior to using this service she had to use one supermarket which had a limited range of products.

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. One specific example was a kuia 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.

WHAKAHAUĀ - What makes me disabled?

The perception of disability within this research population was important to consider when focussing on providing valid services for Māori living with disabilities in Southland. As outlined in Chapter 1 the Māori worldview of health can differ from the Western medical model ideologies and concepts of disability. Therefore in order to assess accessibility issues related to healthcare services for the Southland Māori population, we explored our participants' views of disability. The following themes were identified during analysis of the interviews and offer much insight into barriers to accessibility of health services within this population.

1. Not being valued

Being undervalued and disrespected in your own community was perceived by participants as a fundamental disabling factor. Participants described a range of ways in which they experienced a sense of not being valued.

Not being actively included in the community

Community perceptions of disability can be limiting and participants often found themselves excluded from responsible roles within their community. One Tāua talked about how she wished to be involved with the Marae and be respected as a Kaumātua and how principles had changed and that the important roles of kaumātua are being devalued.

I have to badger people to pick me up. We're undervalued.... it's a young society and we're in the road. Even though when they see us they make a huge fuss and they do look after us when they see us. Mana is the things that they're not doing. Like leaving us at home and what not. But not recognising, 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.... 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 undervalued and not involved by the community largely due to their disability, despite the participants themselves feeling that they have much to offer the community. In the above quote the kuia who has kaumātua status, felt as though she was being disregarded

because of her disabilities. This contributes to a sense of isolation and is closely linked to the next point.

Not being able to contribute

For many participants the inability to contribute to society as they would like to, led to frustration and whakamā. When asked what disability meant to the following participant he described his disappointment and ensuing hardships 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.

Attitudes of the community

Negative attitudes of the community towards disability had a stronger disabling effect than the actual diagnosed disability. A mother with disabled children talked about how misunderstanding of her whānau's situation within the community had adversely affected her and her whānau.

It's a health and safety issue that we just get from a to b and 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 around having a mental health diagnosis:

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 within my family is still there. I'm the loony.

Pākehā perception of disability versus Māori whakaaro

Many acknowledged a difference in respect to how Pākehā viewed disability. There was a general consensus amongst the group that there was awkwardness in the Pākehā

community towards disability and 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.

One participant viewed Pākehā attitudes towards disability difficult to manage:

“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.”

2. Discrimination, negative impact of colonisation, being disconnected.

Discrimination

Participants in this research felt that discrimination was apparent in how carefully people listened to you. If health providers, for example, did not listen it could result in them missing important pieces of information, “*missing the big picture*”, as described by one participant: “*...blocks out certain parts of someone’s values or beliefs ... it’s choosing what you want to hear.*”

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. One participant 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....

One participant 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.

Another participant reflected on how he felt discriminated against when he visited a health care provider secondary to his five and half years in prison and 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).

Another participant suggested he had developed coping mechanisms to assist him to navigate discrimination he experienced due to his Māori ethnicity within the health system and that as a result he had a desire to teach his whānau these skills. “*You've got to realise that you can't stop discrimination. Instead of struggling over it, just step over it.*”

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

Some participants identified issues relating to post colonisation for Māori as having negative effect on health. One participant 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 now days it's drugs. And then if it's not drugs its gambling. To make more money, because we're in such a depressed state, right

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 can then be misunderstood, misdiagnosed, and mistreated. This was demonstrated in the following discussion with a participant who often used te reo, 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 Po. 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.

Not understanding whānau as central

Understanding the importance of whānau was important to many participants and a lack of understanding of this concept was perceived by participants as a barrier to receiving good health care. The participant below 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 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.

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 multiple 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. One participant 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 ACC and WINZ

Disconnect with whānau, hapū, iwi

Not being connected to or being isolated from whānau, was another issue identified as having a disabling effect. Many participants explained they were matā waka in Southland and were geographically far from their whānau and support. This situation led to a breakdown in whānau dynamics, lack of communication, disruptive relationships, and a feeling of isolation, all disabling factors.

Us little ones being left behind

Being disabled and Māori living in Southland, felt for some like they were being discarded and isolated in terms of receiving healthcare. This sense of not being listened to was strikingly apparent in that participants were very eager to meet with the researchers and to express their stories and realities. One participant commented:

...I feel like the little people get left behind. Us little ones, you know, you feel like, well they're never going to know, or help my family.

3. Lack of self-worth/self-esteem

A low self-worth was directly linked to whether participants felt they were able to access healthcare. This low self-esteem appeared to affect hauora at many levels. The compounding effects of whakama, whakaiti, or being humble, a strong emphasis of whānau first, being a product of colonisation in Southland, and having a disability, may, in the opinion of our participants, be contributing factors to this low self-worth.

Whakamā

It was common for participants to feel shame in relation to their disability, and they had to work through this to deal with their disabilities. One participant 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 had cancer. Shame that I am now an amputee. Shame, shame, shame. You know cry that stuff out, you know, I had to get in touch with that and let it out because if I didn't do that then I would still be a slave to it. Now and then you go through those processes of being able to shed that shame, shed that whatever it is which then enables you to move forward.

Generational abuse

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. For example, one participant 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 had “*counselling coming out of my ears.*” This affected 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.

As one participant 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* (pain) and low self-esteem following violent or sexual abuse.

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. One

respondent 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 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 commonly reflected that the perception that if one area of their “whare” was negatively impacted, this had further detrimental effects in other areas, representing a holistic view of self and health and disability.

4. Poor access to resources

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. One participant 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.*”

Transport for grocery shopping came up as a main concern for many participants and signified loss of freedom to choose and purchase food and supplies of their choice. Being limited in terms of her mobility, one participant talked about feeling like “*a nuisance,*” leaving her feeling undervalued and solitary.

Limited Pūtea

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. One participant explained: *“When you are disabled the costs (of health care) go up at least a third.”*

Another participant explained the difficulties faced when being expected to survive on an invalid’s 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.

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.

Education

As discussed above, many participants had not received the benefit of a formal education. Disregard for learning styles and pedagogies more aligned with things Māori were identified by some participants as causes of limited access to good education. For example, one participant 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 one participant who had desires of extending his study in these areas.

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 is 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."

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. One participant talked about limited assistance when she suffered 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."*

Another participant spoke of her struggle over her case of medical misadventure that had led to her being on daily dialysis. 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 paper work 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.

4.2 Phase Two - Organisational Survey

4.2.1 Structured review

The literature database search resulted in 763 articles, 234 were duplicated, and 442 were deemed irrelevant after screening the titles and abstracts and excluded. The remaining 87 articles were assessed using the inclusion / exclusion criteria. Twelve studies were finally included in the review, eight of which were qualitative studies and these were appraised for study quality using the CASP qualitative research assessment tool. A summary of the main findings of each included article and relevance to the current study is detailed in Appendix 3. The structured review, as described above, informed the development of the organisational survey questionnaire.

4.2.2 Organisational Survey

Of the 50 questionnaires distributed, 29 (58%) questionnaires were completed. One service organisation replied to say that they did not complete the questionnaire as it was considered not applicable to the service they offered. The reasons for the other 20 organisations not completing a questionnaire were not provided. Table 4 below presents the characteristics of the organisations in terms of type of service provided and geographical location.

Table 4: Characteristics of organisations (n=29) (Questions 1 and 2)

Type of service provided		Location
Medical centre	(n=2)	Town
Medical centre	(n=5)	Small town, rural
Community worker	(n=1)	Town
District nurse	(n=1)	Small town
Nurse service	(n=2)	Small town, rural
Physiotherapist	(n=3)	Town
Physiotherapist	(n=1)	Rural
Psychological services	(n=2)	Town
Advocacy service	(n=1)	Town
Disability equipment	(n=1)	Town
Specific Disability support service	(n=2)	Town
Disability service provider	(n=2)	Small town, rural
Community support	(n=1)	Rural
Māori health provider	(n=4)	Town
Special needs school	(n=1)	Town

Table 5 shows the answers to the “yes/no” questions asked in the survey and a collation of the comments written in relation to these questions.

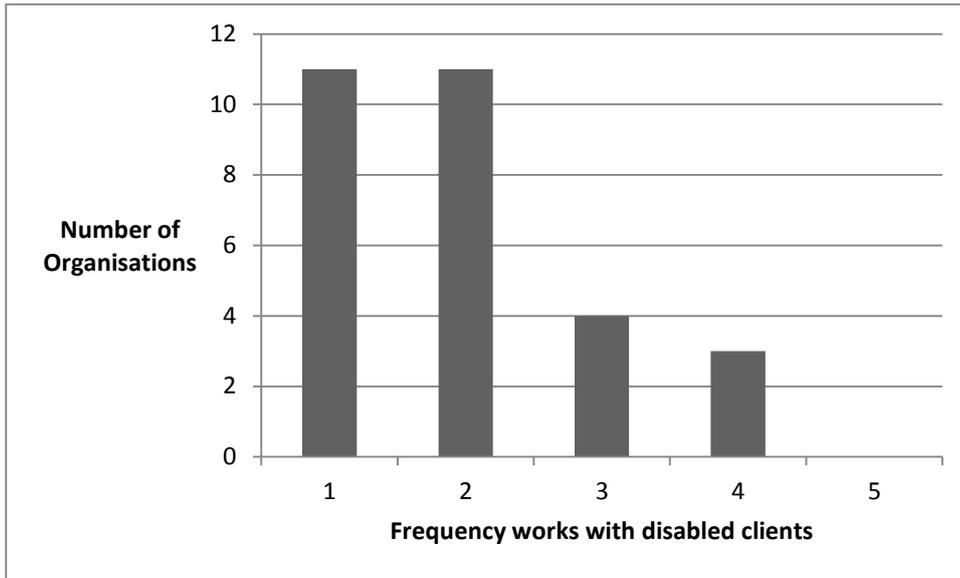
Figures 7 and 8, respectively, displays the data relating to how often the organisation worked with disabled people and how quickly an organisation was able to see a referred client.

Table 5: Answers to the ‘Yes / No’ questions with comments (Questions 3, 10, 11, 12, 13, 14, 19) (n=29)

Questions	Yes	No	No Response
3. Does your organisation make home visits?	26 (90%)	3 (10%)	0
10. Has your organisation ever included Māori in the development of services and/or policy review regarding Māori with disabilities?	11 (38%)	14 (48%)	4 (14%)
Amalgamated Specific Comments Made: <ul style="list-style-type: none"> - Not specifically at this level, as this is done at a national / central level. - Have attempted to attract Māori on to the organisation’s Trust but with little success. - Our founding nurse specialist was Māori. - I receive cultural supervision regularly whereby I discuss all Māori clients and the work I do with them. - Have had advisory group in the past and a presently have a board member who is Māori. - Room for improvement, pockets of resistance / lack of understanding, stigma of institutional racism. - Intend to. Have been thinking about it; it has been mentioned to the new Board. - Doing "cornerstones accreditation" therefore will have to. - Not to a great extent. The rural education process is co-ordinated with the Māori warden process. 			
11. Do you ask clients to provide feedback regarding the services you provide?	17 (59%)	8 (27%)	4 (14%)
Amalgamated Specific Comments Made: <ul style="list-style-type: none"> - Comments/complaints form available, online and hard copy. - All seem to be happy with level of service. - Not specifically at this level, as this is done at a national / central level. - Complaints mostly a lack of understanding from patients, worries around privacy (community told). - Asked about transport vouchers. - Difficulty with whānau acceptance, gaining trust, letting Māori clients know that you care. - Thinking of developing Māori specific physiotherapy questionnaire - General comments via reception. 			
12. Does your organisation have someone who specifically addresses issues regarding Māori with?	12 (41%)	13 (45%)	4 (14%)
Amalgamated Specific Comments Made: <ul style="list-style-type: none"> - Not specifically at this level, as this is done at a national / central level. - We have a Māori representative who we can consult with. 			

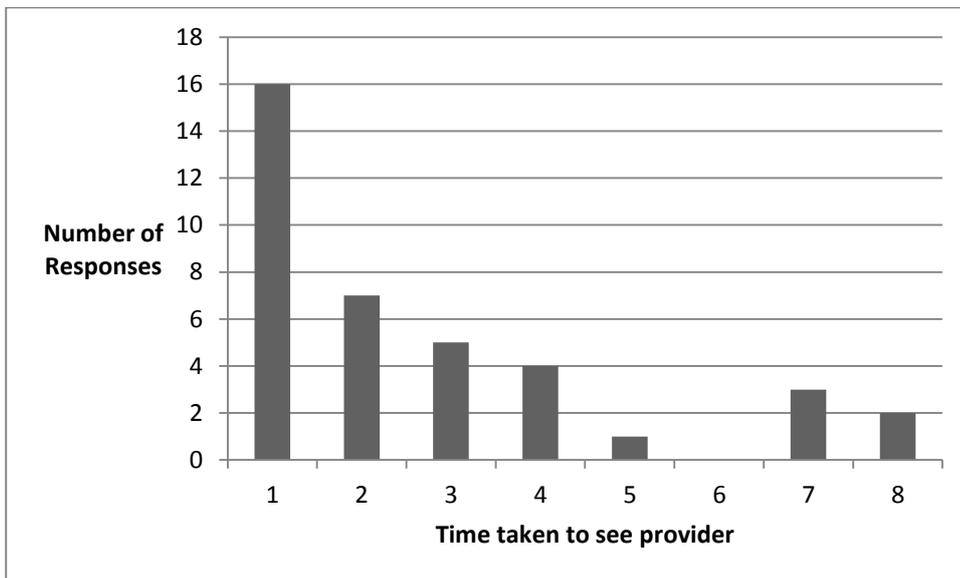
<ul style="list-style-type: none"> - Māori health service. - Number of Māori advocates. - We ask someone to external to our organisation to come in. - A staff member whose husband is Māori. - A cultural supervisor. 			
<p>13. Does your organisation provide education to build understanding, awareness, Tikaka Māori and cultural sensitivity among staff to improve services to Māori with disabilities?</p> <p>**No, but we plan to provide training during the next 12 months = 2</p> <p>**No, we do not plan to provide training during the next 12 months = 7</p> <p>Specific Comments Made:</p> <ul style="list-style-type: none"> - Cultural study days a requirement. - Organisation does not provide but encourage staff to attend training sessions organised by DHB, PHOs or professional societies. - I receive training in cultural awareness periodically when it is available. - Part of training - all new workers. - Bring in Māori liaison officer -about once a year or as required. 	15 (52%)	9** (31%)	5 (17%)
<p>14. Does your organisation know how to access expertise to provide education to staff on Tikaka Māori / things Māori relevant to your service?</p>	23 (79%)	2 (7%)	4 (14%)
<p>19. Are you a "Māori provider"? (i.e. eligible for Māori provider funding)</p>	5 (17%)	1 (3%)	No response = 3 (10%) Not Sure = 8 (28%)

Figure 7: How often does your organisation work with disabled people? (Question 4)



(1 = very often; 2 = often; 3 = sometimes; 4 = rarely; 5 = never)

Figure 8: If a person wishes to see a particular health professional/provider within your service, please estimate how quickly are they usually able to see that provider? (Question 5)

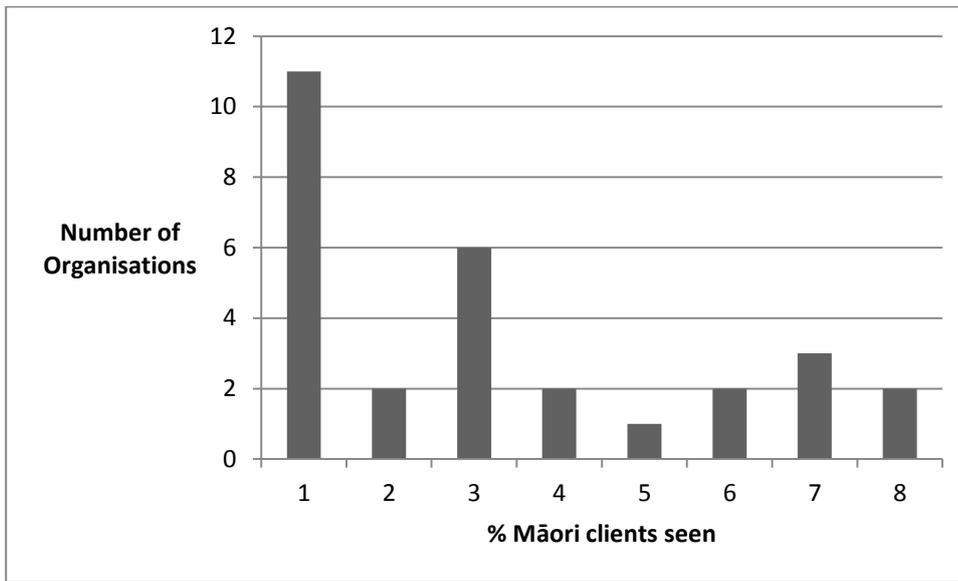


(1 = same day; 2 = next working day; 3 = within 2 working days; 4 = within 3 working days; 5 = within 4 working days; 6 = within 5 or more days; 7 = does not apply; 8 = depends on nature of problem).

Note: some organisations gave more than one response to this question

Apart from the Māori specific organisations, most organisations had less than 5% clients and staff who identified as Māori. See Figures 9 and 10 below. Some organisations, which were not Māori specific, had greater percentages of Māori clients (11 organisations) and staff (4 organisations).

Figure 9: What percentage of your consumer population are Māori? (Question 7)



(1 = less than 5%; 2 = 6-10%; 3 = 11-25%; 4 = 26-50%; 5 = 51-75%; 6 = 76-100%; 7 = unsure; 8 = no response)

Figure 10: What percentage of your staff are Māori? (Question 8)



(1 = less than 5%; 2 = 6-10%; 3 = 11-25%; 4 = 26-50%; 5 = 51-75%; 6 = 76-100%; 7 = no response)

All organisations responded to question 6 saying that their organisation was fully physically accessible. When asked how well an organisation perceived their service accessibility was for Māori with disabilities, 13 (45%) organisations rated their access as “excellent”, 10 (34%) as “very good”, 4 (14%) as “good” and there were 2 (7%) no responses. Table 6

reports what services thought they were doing well or how they could improve regarding their accessibility for Māori with disabilities and whānau.

Table 7 presents the written responses, from those organisations that answered the question, for Question 15 (*How does your organisation ensure that all information provided to clients is easily understandable?*), Question 16 (*Please describe how your organisation caters for clients who have disabilities affecting their communication or whose first language is not English?*), Question 17 (*When treating Māori clients, how do you integrate their cultural beliefs and whānau into the treatment?*), and Question 18 (*What does “Whānau Ora” mean to your organisation?*).

Table 6: Organisation's service accessibility was for Māori with disabilities and whānau (Question 9)

Organisation	Please describe what is done well	Please describe what needs improvement
1	If our service is needed anyone can access it.	No response
2	No response	No response
3	Our community tries to reach all ages of all races.	Get government departments to travel out to our area
4	Good relationship with Ngā Kete.	No response
5	If need to be referred, no hesitation in doing so.	No response
7	We have excellent relationships with all patients.	Better systems identifying Māori
8	Very accessible during clinic hours. Range of services and medications on standing orders.	Workload does not support extended hours. Community needs assessment could identify if further services are required.
9	My office is within walking distance of bus routes, has easy parking. I will use texting to communication.	Home visits would not be usual practice - only under special circumstances
10	Good relationship with Ngā Kete and Awarua.	Getting out to community and get to know Māori whānau. Knowing where and how to contact Māori and whānau, privacy act is a barrier in accessing information.
11	Doesn't matter who they are or what you provide. Manager is now Māori. Increasing awareness of all Marae in Southland area about this service.	Could market services more to Māori community. Informing the younger generation what services.
12	Friendly to all cultures, needs-based, if not will ask.	Letting Māori community know of services, networking with Māori providers could be better (e.g. Ngā Kete), knowing what services Māori providers provide
13	No response	Employ a clinical mental health nurse / clinician, sustain employment, culture of service is not conducive to having clinician work here.
14	Engagement with whānau, making sure that they're seen, respect their wishes. Governed by tikaka, Māori values of Te Ao Māori manakitanga whanaungatanga aroha.	No access for the unit to community providers and no clinical space in community, have collaborative approach within this (hospital-based) space.
15	Non-discriminatory, no steps, car parking available, pamphlets for advocates, inviting family / whānau.	Better advertising / marketing to Māori community and Māori organisations, e.g. Ngā Kete
16	Accept Ngā Kete vouchers, communicate with Māori provider, fax through scripts if can't get here, afford appointments,	More accessible through PHO funding for free smears.

	discuss payment of account if problematic.	
17	Employed Māori health providers, have a Māori liaison officer.	Visit to Māori provider, connect with Māori health practitioner.
18	Liaise with other services (e.g. Ngā Kete). Treated like every other person, all staff encouraged to be culturally sensitive. Provide services on Ohai Marae. Free service on Marae.	Funding to provide service to the community, sharing with other providers specifically Māori health provider. Gap for this community. Improve access to community.
19	Work in conjunction with community health worker, with [Name] Community Health Trust, Southern PHO with Māori initiatives, provide sexual health and pap smears.	Transport can be used (travel vouchers, St Johns), improve communicate with clients. Education is big but can only do so much. Wish could target those who do not come in.
20	Would like to think they would treat everyone the same. Physical environment, variety of staff, good recall, follow-up. Māori often do not value themselves first - whānau come first, so try and promote individual health so person good for whānau health.	Having different hours for working e.g. hours suiting dairy, shearers and other rural workers. Know local Māori – need to earn trust of other Māori.
21	Accept texting, offer text reminders, difficulties getting secondary disability, don't charge for 'no shows', try to see people quickly, aware of shearing work.	Tend not to follow-up those who 'do not attend', drop-in service, want to refer to Māori services, do not think there are barriers, flexible time concept, set up Māori specific services.
22	Well educated cultural competencies, know community well, they know us, especially shearing community, medical Māori wardens available.	Spread word, make more know, talk to shearing gangs, get to know general Māori population more, give out information re. transport to get to provider. Need guidance around how to address / think of things Māori which would improve inclination to seek provider.
23	Time, flexible, communication styles, good at building relations.	Improve services for people living with disability.
24	All the same across the board, no issues	No response.
25	Accessible to all, advertising / communicating / networking	Consult / hui - feedback from whānau
26	See few Māori.	Better marketing of services.
27	No discrimination. Do ask ethnicity. Recognise different funding available. Do good job of following up, diabetes, keeping in regular job.	Improve cultural awareness
28	Open door policy, Māori support person, onsite services, whānau orientated, talk "parent talk", plain language. Teach haka, Karanga, weaving, poi making, kapa haka, PolyFest, visit to Maraes, include Māori culture in staff development	Next term will be focussing on "all about me" module – will look at whakapapa – we are "one".
29	No response	No response

Table 7: Responses from organisations that answered questions 15, 16, 17, and 18 (n=25)

How does your organisation ensure that all information provided to clients is easily understandable?	Please describe how your organisation caters for clients who have disabilities affecting their communication or whose first language is not English?	When treating Māori clients, how do you integrate their cultural beliefs and whānau into the treatment?	What does “Whānau Ora” mean to your organisation?
No response.	Interpreter.	Acknowledgement and referral to te Korowai Hou Ora service at Southland Hospital.	Have inter-agency approach with local Māori provider.
Speaking with client and ensure understanding.	We do not have any client in this area.	We deal with each client on a personal level.	Understanding compassion for all family members.
By asking patients, some material available in Māori.	Interpreter.	Ask if they want a support person.	Family and Health.
Notes kept in home. Able to have family present.	Interpreter.	Asking - what / how etc they want treatment done.	Working with the family to find best health practice.
Nurses ensure understanding by questioning client understands.	All speak English - if needed we would contact local Marae for assistance.	Talking with them, asking what they want, do they want whānau involved.	Integrated approach to health and social services empowering whānau to work together.
Some Māori leaflets. Not aware of any Māori who are not English speakers, would contact DHB Māori support staff if necessary / as appropriate.	Some educational leaflets in Māori and Samoan. Access to language-line through hospital contacts.	Always when giving advice / information ask for feedback re. suitability for their beliefs / lifestyle.	Literally - All or Whole family. Health services are provided in a family context, appropriate to beliefs and lifestyles.
Yes.	I do the best I can to understand, would invite them to bring a support person who could assist.	I am aware of some cultural issues, would seek help if sense that there is something I don't understand.	I associate this with the programme initiated by the Māori party but also understand the term meaning the betterment of the family.
Team of deaf advocates and for migrants and refugees.	Sign language training, networks in Southland (e.g. deaf advocates).	Ensure say their name correctly.	Large part of how we do things, centre of all get togethers.
Booklets, nurses, if needed access to Māori interpreter.	Interpreter.	Ask.	Try to incorporate Whānau as much as possible on first visit.
Written, large print available, access translator if require.	Use support people or translators, and Deaf Aotearoa.	Ask client what they need.	Everything Māori that need to know, understand and bring into service.

Yes, one-on-one, about 5% use Te Reo.	Māori speakers, none of staff are fluent, Kaumātua.	Yes.	Community / institute / SDHB / hospital / organisations - we are all whānau.
Getting patients to demonstrate / or repeat in own words.	Interpreter, involve whānau, provide sign language interpreter.	Form relationship, find common ground, courtesy, different pillows for head/feet, comfortable with practice.	Mind, body, whānau, spirit. Try to take into account / holistic approach.
Not really.	Client brings interpreter, someone who can communicate for them.	Personally up to Doctor.	Respect needs of Māori.
English pamphlets, discuss with clients.	Not as such.	Māori physiotherapist, Māori receptionist, support person invited.	Soon to be discussed within organisation.
Written and oral information.	Not well, often depending.	Reminders, contracting, dialogue, opportunistic - with whānau.	Not given enough focus, new contracts.
Doctors diagnose, nurse makes an appointment with client to discuss. Care Plus - patients with 2+ conditions, consultation with nurse every 3 months.	Speaker slower.	Māori elder will be contacted around death, ask.	Whole family, not just immediate family.
Interpreter.	Bring family with.	Non- specific, respect their wishes.	Not sure.
Ensure client can understand.	Interpreter. Speak slower and repeat.	Areas of improvement, understanding Wairua and whānau/iwi/tribal.	No response.
Brochures, signage, ask questions, open to all, client focussed. Communication.	Interpreter, can ask Citizen's advice bureau.	Respect cultural differences, consent to touch head/face, different pillows for heads.	Māori word – abstract meaning.
Face-to-face explanation, along with a brochure.	Learn to do one-on-one, listen harder, get to know person.	Not really.	Never heard of it.
Call Māori specific services.	Discuss with patient and ask them to recall back. Demonstrations. Brochures in waiting room.	Hasn't had to - most patients speak English - take time / be respectful. Hospital has translators, speech and language therapist comes occasionally or can be referred to.	If need more help required by patient - try to get in domestic help as Māori not keen on going into a rest home - trying to increase quality of life in a respectful manner.
No response.	Interpreter. Engage a family/whānau member to be present.	Would engage the Te whare tapa wha model.	To work collaboratively and collectively with agencies working with a family.

4.3 Phase Three - Onsite Organisational Interview

Fifteen organisations were interviewed onsite. The findings of these interviews are presented below: Presented in turn are the findings related to: (1) general insights, (2) what organisations are doing well, (3) what some of the “issues” were, and (4) methods suggested by organisations of improving access.

4.3.1. General insights

The onsite interviews with service organisations allowed for greater insight into how organisations perceived their accessibility for Māori living with disability and their whānau. Some organisations focussed more on the ‘Māori accessibility’ perspective of the questions, as opposed to ‘disability accessibility’. A frequent first response to our question was that the organisation did not specifically do much for Māori as they “*treated everyone equally*” and “*did not discriminate*”; they were “*colour blind*” “*Um, well I mean I guess that they are treated like every other patient.*” So then, when they were asked how accessible they thought their service was for disabled Māori, the general response was: “*I’d probably say good or very good because I don’t think we discriminate.*”

When asked if someone in the organisation specifically addressed issues regarding Māori, unless they were a Māori health provider or were part of a governmental department, the answer was usually negative. One common response was that local Māori were not particularly involved in their culture: “*...so although I may see you know Māori, um in terms of how they live, they’re probably not very Māori and they don’t tend to have, you know they’re not strongly involved in Marae or any of that ...*”

Whānau involvement was considered, and some organisations had pamphlets that advocated for and invited whānau to accompany the person receiving the service. This was largely taken up by whānau accompanying young people.

The process of going through the survey with organisations in an interview format did make some people actually think more about their Treaty of Waitangi obligations and ways in which accessibility could be improved for Hauā Māori. Responses such as “*You’re right, it is thought provoking*” and “*Yes well, look, it’s certainly awakened my ideas to actually go out there seeking ...*”

4.3.2 What were organisations doing well?

4.3.2.1. Physical access of organisation

All organisations had adequate to good physical access; their premises were wheelchair accessible and disabled toilets were available. Most organisations were on the ground floor with good parking facilities and access via ramps. Those on the first or second floor had accessible lifts or facilities they could use on the ground floor for disabled clients. Signage, for some organisations, could be improved to promote accessibility, in that it was not easily seen and/or was only in English.

4.3.2.2. Home visits

All organisations said that they did, or could, provide home visits as they considered that home visits increased accessibility, albeit frequently from the perspective that the person was too ill or incapacitated to come in, as opposed to the person's cultural choice to be seen in their home environment. For some organisations, doing home visits was not cost effective.

4.3.2.3. Time taken for first visit from health professional

Most people who required a health professional were seen quickly, within a day or two, but it did depend on the nature of their complaint or their location. Rurally-based people may have to wait a little longer to see a health professional.

4.3.3 What were some of the "Issues"?

4.3.3.1 Ethnicity Data

Most organisations said they collected ethnicity data. Some organisations asked clients on their first visit about their ethnicity: *"They are generally asked, you know how they identify, you know whether they identify as Māori or not, and we don't, you know, like, presume"*

Some organisations felt awkward asking this question and so assumed ethnicity based on appearance or name:

I don't always, um simply because it just doesn't feel right to ask, but sometimes I'm very aware perhaps when I get to know them a bit further that they are quite a lot, yeah they do show their Māori heritage but I just don't, I just see people as people...

4.3.3.2 Percentage of Māori Attending / Staff

Generally, unless the organisation was specifically a Māori health provider, the percentage of Māori clients seen was low (about 5%), as were the number of Māori staff employed (0 - 2 staff members). This said, a number of organisations only had one or two staff in total. The reasons why so few Māori accessed their service had either not been thought about by the organisation or was unknown: “*Well I don’t think they access as much as, as the general population.*” For example, one reason for why it was thought the shearing gangs were not accessing health services was their ‘tough’ nature, their resilience:

I know there’s a lot of percentage of Māoris down here ... I don’t know the [reason], it’s a real community and a lot of the Māoris that work in rural communities’, just tough shearers and tough people that don’t, don’t wanna to come to treatment I suppose.

4.3.3.3 Whānau Ora?

‘Whānau Ora’ did not mean much to anyone interviewed except the Māori health providers and some of the governmental organisations. From the Māori health service perspective, Whānau Ora was about a holistic approach to strengthening families:

You come to a kaupapa Māori provider who’s working in a Whānau Ora way, and we say this is our menu of services. How could we best tailor them to fit your needs? So there is a difference of approach.

The Māori health providers said that this approach was all about empowering whānau, allowing families to make meaningful decisions, and thinking about health from all its aspects. One provider said surprisingly what whānau often wanted was not big or complex; it was often focussed on simple things to improve their health, such as doing things that would encourage the family to have dinner together each night or to attend a school event to support their tamariki. It was the provider’s role to acknowledge all the good things that happen in whānau, to facilitate community participation; trying to see what they could do to help families achieve what they had decided upon.

One provider took the concept further, expanding the support to all members of the health care team, so they felt empowered to assist whānau:

To be well, we need to make sure we’re looking after each other, as a whānau would do. From that, we look after as leaders...we look after our teams...our respective teams...make sure that they feel part and parcel of the decisions that are

made...that they are an integral member of that team...because if we don't get it right within ourselves, we're not going to be able to look after our patients.

4.3.3.4 Funding is an issue to provide really good access

Lack of funding to provide a good accessible service was raised on a number of occasions: *“a lot of things that we could do, we can't 'cos we haven't got the resources, the people working on it.”*

Services said they were underfunded and this made them feel undervalued, and yet they were expected to do things differently, and have training to do this, with no extra financial compensation. The expectation was that they would *“work smarter”* and reduce duplication of services, for example, providing services for whānau themselves as an agency instead of working in partnership alongside a Māori health provider.

Access to funding for transport for disabled people to access service providers was still problematic, especially in the rural areas, even though some funding, in the form of taxi vouchers was available via ACC and PHOs: *“you know, like the transport, which has been an issue for like 30 years that I've been around, anyway.”* In one rural area, St John's Ambulance service provided transport for a donation, mostly funded by a charitable organisation. Although considered a valuable service, the financial model for it was felt to be not really viable in the long-term.

4.3.3.5 Disability focussed issues

One issue raised in small-town Southland, was the over-familiarity of people in the community with each other, and that this could result in people not thinking about accessing services when they probably should:

Gore I suppose, is probably, well in my opinion anyway, you know, quite self-sufficient really within its sort of community, it is a fairly tolerant community with all the disabilities which can be good and bad at the same time, good in fact that you know everybody can just sort of get around their business no matter what sort of disability now but um, being in the way that it can take quite a while for somebody to notify services if they sort of see something, because it is just like, “oh that is so and so .. they have always been like that.

A disability advocate also referred to the *“over-familiarity”* issue:

.... particularly with those that are, have been, their whole lives have been managed by others and they haven't had much say in their own life and what's going on, it's an empowerment thing for them too to be able to actually say "hey I don't want to be doing this anymore, I would like to be doing this instead

Some organisations were doing an excellent job of being accessible for Māori and whānau, but had not really considered their accessibility (other than physical factors) for those living with disability, or even considered that they served people who had a disability:

Definitely our ability to articulate disability issues more fluidly. We never know whether we're talking with a person who has a disability or a disabled person who's blind, or, so our language needs to improve and probably the scope of the services. You know, where, from ... someone who has, they're living with a disability, where do we need to improve our services from their perspective?

4.3.4 Suggested ways to improve accessibility

Although many organisations appeared on discussion to be not fully accessible to Māori living with disability and their whānau, many were inadvertently undertaking good practices without consciously realising it, or during the course of the interview came up with ways in which they could improve their access. Some organisations, as stated earlier, were doing an excellent job. As we can learn from such good practices, these “good practices” are presented below as ways in which accessibility can potentially be improved (Table 8). These strategies or practices are not discussed in any particular order of importance.

Table 8: Small “good” practices or strategies known to enhance accessibility reported by organisations

“no hesitation in referring client on”	“don't charge for 'no' shows”
“very accessible during clinic hours”	“try to see people quickly”
“offer a range of services”	“onsite services”
“within walking distance of bus routes”	“advertising / communicating / networking”
“easy parking; no steps”	“open door policy”
“use texting messaging to communication”	“time, flexible, communication styles, good at building relations”
“fax through scripts if client cannot get here”	
“discuss payment of account if problematic”	

One provider summarised eloquently what was important to make their service accessible for Māori:

Well bricks and mortar aside, I think it's time, I think it's about having the time and taking the time. I think it's also about being flexible and nimble in your approach. I think it's about having very strong communication skills orally. Written and perhaps in a non-audio way as well But I think overall it's about taking time to build relationships.

4.3.4.1 The all-importance of whānau: being “whānau-centred” and “whānau-led”

To Māori, whānau is all-important, and for a service to be accessible it is fundamental that this be acknowledged: *“It is, it's just whānau always comes first.”* Being “*whānau-centred*” and “*whānau-led*” ensures good accessibility.

Because a lot of whānau would say that they've never had an opportunity to do that necessarily in other agencies. We're very committed to taking our whānau with us. They help shape our services. For example, we would not be extending Mirimiri massage services, without whānau having told us that's what they wanted.

Further, to enhance accessibility, knowing how to contact whānau is important: *“The thing that could help you provide, be more accessible to Māori living with disability would be to know where and how to contact Māori whānau?”* However, some providers expressed frustration with misunderstandings with the privacy act and accessing patients and whānau. Some organisations said that contacting whānau can be an issue in Southland, where due to the past itinerant-nature of many Māori living in Southland, there is often a lack of whānau for the older generation.

4.3.4.2 Relationship building

According to the organisations interviewed, a good place to start improving access for Māori was to build relationships with the Māori community:

She told us that we need to form a relationship first, and she said you know find out about the person and get them to, tell them a little bit about themselves then tell them about yourself...

Living in a small rural community was considered advantageous to building relationships:

I think probably our best asset is that we know our community really well, and we know our Māori patients and they know us, so that they're accepting of us as treatment providers.

Developing links with the local Rūnaka was also thought to be a good practice:

We have got the local Rūnaka that we sort of link in with and the team long ago were welcomed on to the marae so we were considered family if you want to sort of call it that.

Interviewees felt it was difficult to maintain relationships with communities if you were not directly in them; a physical presence was considered important.

4.3.4.3 Asking the disabled community what they want

Some of interviewees said that to inclusively improve accessibility for Māori living with disability and their whānau, an important strategy would be to ask the community (those living with disability) what they wanted and saw as important: *"Yeah...asking the community what do they want...or need."*

It was felt that consultation hui to get feedback from disabled whānau as to what they see should be happening; having consumer advisory groups and gaining direct feedback from stakeholders was the best way to get information to improve access: *"Heard excellent things from whānau – as it is what they want – solution and responses are often a lot simpler than what the organisations think they should be."*

4.3.4.4 Better advertising/marketing of services to the Māori community and organisations

The most frequently cited suggestion by people interviewed was that service organisations should market what they offered to both the Māori community and Māori health providers: *"I suppose it's getting out in the community and really letting families know who we are, what we are..."*

I don't know whether it would be um, more awareness around our services. Because a lot of people think you know if you go to any of the societies not just [Name] but all those ones that it is all about support groups and we need to get away from the image because that is just, you know a side line of what we do.

4.3.4.5 Better networking between services, especially with the Māori health providers

Interviewees felt that networking between organisations should be improved so that clients were appropriately referred and resources shared, especially in rural areas where resources were limited. Some providers had developed memoranda of understanding with each other to facilitate this process. Although many organisations did this, it was felt by some of those interviewed that improved communication would further assist the process:

Communication is always one that can be better, I mean um, we have these memorandums of understanding and we do liaise quite a lot but of course being rural services too we are short in resources and you know it [communication] is the last thing you know down on the priority list you know until it, something happens so to speak, so yeah so we are always really talking.

4.3.4.6 Providing choice

Some interviewees stated that fundamental to ensuring accessibility was to provide clients with choice, in particular choice about where they would like to be seen

All about connecting whānau to resources, ideas, energy, the energy being staff, for wellbeing and independence, and with a philosophy like that, it's presumptuous to think that people then would have to come into your agency to do that. It's more about, for Māori, kaupapa driven Māori, is being where our people are, or where they say that they would like to receive the support. So it's kind of, needs must. But with addiction work, problem gambling related work, we have to have the first face to face and full assessment done here on site to determine risk. But after that we can do service in a home environment, or a community setting of a person's choice. I'm a great believer that the best therapy that you may have in terms of a session with someone, could be a walk along the beach.

There were ambiguous responses to providing services on local marae in Southland. One provider said that:

And we find that probably about 95% of our clients would prefer either to come here or we go to them, to their home, which shows that there is a lot of disconnect between Māori and Marae based service delivery. And that's for lots of reasons. People have come here, moved to Invercargill, they're disconnected from their own manawhenua, or you know, grass roots if you like, flax roots. And so urban Māori are less likely, particularly if they're not from here, to be involved with a marae.

However, another Māori service provider thought that the Marae was important to Māori; this provider suggested that although Māori in Murihiku had come from diverse areas and Iwi, and although there might be slight differences, many of the processes, the tikaka, were similar on most Marae and this made whānau feel at home. The Marae can be a central point of wellness, even though the person may not come from the area. This organisation was keen to encourage more activities at the Marae, for example, health clinics and programmes for young people, and this may be more optimal than a home visit for some. This provider did acknowledge that it depended on individual preference, and that some Māori did not want to go to the Marae.

4.3.4.7 Flexibility

According to many of those interviewed, the key to working with disabled Māori and whānau was flexibility, especially with regards to time: *“but I think there are some things about accessibility that are for some um, that are around time and concepts of time...”* *“Yes I think you’re right and so the way that we run our schedules, which is important because we need to, but unfortunately that doesn’t work within a different cultural value...”*

That a cultural value was given to time: *“Cultural aspect of time which is a gift, when you’re here gifting your time so time is about quality of time rather than being on time, yeah.”*

Cultural concepts of time lead to a discussion around being flexible / tolerant with regards to appointment times: *“I mean sometimes people have difficulty coming because of their disability.....or their life is sort of in chaos...”* The provider with whom this discussion was held said that she used a number of strategies in attempt to be flexible, for example, being understanding, using texting to confirm appointments, not charging for ‘no shows’, and trying to see people after hours if necessary

As another provider summarised: *“I think it’s more important for our Māori whānau that we can be where they want us to be Because a number of our whānau who say they have a disability usually want more of our time than, I mean there is no way we would do 15 minute time slots on anything they require more of our time and listening ear which is fine. It’s absolutely fine.”*

4.3.4.8 Showing people you really care – valuing them – building esteem

Organisations said that important to improving accessibility is showing that the service really cares for their clients. One respondent told the following story to illustrate this point:

I think another thing that I, and I should've perhaps become more aware earlier, is that I think that sometimes I really need to show those Māori clients that I do care and I want them to come I had one woman I was actually talking with someone and waiting for her to come and I didn't realise she'd come and she could hear that I was talking with someone, well she just left. Now this is a woman, was in her 50s um with very, you know she'd worked but she was just, really just struck with her worthlessness and she left and said oh that's alright you know, and I think that sort of, I learnt from that that perhaps with those Māori clients, I have to go a little bit further so that perhaps if they don't turn up, then I do, I follow them up because otherwise they think they're just not important enough and they will just sign themselves out.

It was felt, by some, that some of the unfortunate home environments, linked with racism, had left many disabled Māori feeling disempowered. This was elaborated at length by one interviewee:

But I guess when you're abused and as children, you just grow up believing, and but absolutely they'll say, you know I'm nobody, I'm worthless, I'm not important ... and that really gets in the way of them accessing services for them and that's where they need to, I think if they're treated by someone who is sunny, well I think you're important, I don't care what you think but I think you're important and I think you should be here...

And I think the thing I'm sort of learning from a case is that yeah that keeping in, keeping there, letting them know that you do really care... ..'cause I don't think people necessarily expect you to care and in a way you have to really go, you have to go the extra mile to let them know that you do actually care... and if you care, you will hang in there or you will continue to make a follow-up And if you don't do that, then you're just another Pākehā who doesn't care about me or about Māori.

4.3.4.9 Providing information to clients

Many felt that the providing of information to clients could be improved. Whilst brochures were readily available in most services, and often in a number of languages, most of the information was provided in a written format. Most organisations however said they would

prefer to use the brochures in a one-to-one session with the client, rather than just let the client take the brochure home to read, as this allowed the opportunity for questions to be asked and to ensure understanding of information provided.

There appeared to be a need for more diverse forms of information, other than written forms. Some of the ways suggested by the interviewees were:

- Demonstrating information (e.g. teaching of exercises).
- Ask clients to repeat the information provided to check understanding.
- Having large print brochures available.
- Use of interpreters. Most organisations had access to a list of interpreters or would contact the citizen's advice bureau or the local hospital for more information.
- Contact other services organisations, such as the Blind Foundation or Deaf Aotearoa as necessary.
- Asking the caregiver or their family member to be an advocate.
- In-house training on sign language and interactive drawing techniques ("so people can draw their thoughts down if they can't talk them out loud").
- Ensure information is provided in plain language.
- Web-based information.
- Text messaging.
- Face book.

Although having brochures in different languages was considered a good idea, it was problematic when the person providing the information could not read the language of the brochure: *"I think we have brochures in about 25 different languages in a folder that we can access, I mean we can't read them but we can access them."*

4.3.4.10 Client feedback

Many organisations asked clients for written feedback but this was usually submitted anonymously and did not include ethnicity data, so no organisation could really recall receiving any Māori specific feedback or identify such feedback. They did get feedback from clients but they did not necessarily ask for ethnicity on the feedback forms. One suggestion made was to develop and use with clients a Māori specific health feedback of services questionnaire.

However, one organisation felt that it would be hard for Māori clients to give negative feedback and she would rather raise the issue directly with a client if she perceived there to be a problem: *“I think that’s really, you know it would be really hard for them to give me negative feedback.” ... “...and so if I perceive it as an issue yeah I’d raise it there.”*

4.3.4.11 Safe cultural practice: *“It is more a case of asking, yeah. It’s not assuming anything.”*

Many of those interviewed referred to cultural competency. Most people did undertake some form of continuing education, and this had included sessions in cultural competence. A number of private practices (General Practices, Physiotherapists, Nurses) had in-service cultural training sessions and invited people in to provide these sessions, or they attended the local district health board, health trust, or their professional society training sessions. With regards to cultural competence training, people mostly referred to specific culturally acceptable protocols, for example, using different pillows under heads and feet in physiotherapy practice or asking permission to touch:

I used to always think, oh Māori culture, here we go again, you know but when they talk about you know the Māori sensitivities, nobody really actually said what they were And you are thinking right well what would be insensitive to them, nobody, you know all the workshops we went to nobody ever said or what the protocol is you know around, around funerals or being a patient in hospital, nobody had ever said you know.

This focussed approach was different to the more encompassing approach taken by Māori service providers, summarised by one provider as:

No, very much...really around...our values...our Māori values. It’s not just about tikaka...you know, tikaka’s based on our values that were based around te Reo Māori...so you know, whether it’s whanaungatanga...manaakitanga...all of those good things...the principles ...yeah...and aroha.

In general, when asking about being culturally competent, those interviewed said it was about asking the client what they would like: *“we do try and suss out any needs or if we’re not sure, we ask.” “Ah, basically if you just say what you’re doing, is that OK, with you, and you give them the option.”* Some organisations were more specific about this:

.... because everybody is still individual, and so we ask them. You know, are you open to Māori models of practice? Would you like to know more about Te Wheke,

or Whare Tapa Wha ... Checking how they want to be responded to, or engaged with, so, you know, but we are Māori. So you know, if they want karakia, we'll do karakia, if they don't, we don't. If they want hello instead of kia ora, well that's fine. We're not about pushing something on somebody, but we do have assessment tools that are Māori flavoured, and you know, meet, greet, seek is all about whanangatanga, it's about making sure people feel comfortable. A lot of people are surprised that they get offered a hot drink or a cold drink, or, we just say that's part of our process, so yeah.

One organisation had taken their Treaty of Waitangi obligations seriously. They had moved premises into an ex-funeral parlour ...

.... in the beginning it was you know a bit sort of iffy for people. We did get the Māori services you know, the local Iwi, the Kaumātua and everything to come through and bless it we had to destruct the building in a certain way ... sort out the cultural sensitivities so our filing room [as opposed to the consultation rooms] is in the area that you know, where bodies were processed so to speak.

One school, catering for the needs of disabled children, included Māori culture in staff development, and had had a whole term of study groups devoted to this. One member of staff went on one of Sir Mason Durie's course and what they had learnt was now displayed on classroom walls. Students were taught basic te Reo Māori or went to the Southern Technical Institute's te Reo Māori courses. The school incorporated a number of culturally related activities into their curriculum, such as kapa haka, trips to the PolyFest, visits to maraes, taught haka and karanga, weaving, and poi making. The theme for the next term was: "All about me"- a module that would look at whakapapa – "we are one".

4.3.4.12 Using a cultural advisor

One suggestion made was for organisations to have a local cultural advisor, with whom they can regularly discuss and review Māori clients with. The interviewee went on to say that a local cultural advisor would have local Māori knowledge, of whakapapa, which would help build relationships and trust with Māori, and this could be difficult for those who do not have such knowledge:

I think that the areas where I am perhaps not, you know is that sort of involvement of, or that awareness of whānau and spiritual things, I think that's where I would be inadequate and I probably wouldn't know of the sort of, have a sense of where

people's history of their Iwi and that might be 'cos that doesn't, and I sort of, I don't, I guess in some ways I can't see the relevance of that, but that's because I'm not making those cultural links and I'm probably never going to...

4.3.4.13 Culturally inviting

Although all organisations were disability accessible in the physical sense, interviewees felt that much could still be done to make the accessibly inviting from a cultural perspective. One provider summarised the important aspects of this:

What people say they like about coming here, is the meet, greet and seek process. Is, often you know, the accessibility to myself, because I have my doors open, most of the time and I like to mingle with our.. our whānau that come in and the things that I listen for, they say oh it's really warm here, and I go are we talking about the heating? And they go no we're not, we're talking about something else. That I think is more important than a flyer on the wall. But the flyer on the wall needs to be there too. But moreover, more overly important is the relationships and taking the time and ensuring that we're understanding and having you know, a proper exchange of information. And that we are meeting their needs.

The school that catered for disabled Māori, reiterated the above factors, such as an open door policy, having a Māori support person, whānau orientated, talk “parent talk”/plain language. Also important were to have Māori values upheld in official documents.

4.3.4.14 Accreditation

Health and disability accreditation of a service was considered to be one way of ensuring organisations took their Treaty obligations seriously and were accessible to those living with disability. For those organisations subject to accreditation, cultural competency was compulsory for all staff. Appointing a quality assurance person to assist in disability access was also suggested.

The next chapter discusses the findings of our research.

Chapter Five: Discussion

5.1 Phase One – PAR Project

The findings from Phase One highlighted the factors that hauā Māori consider critical to health and wellness. This was important information, as asserted by our Rōpu Kaiarahi, as from these factors strategies that may facilitate improved access to health and disability services for disabled Māori and their whānau could be identified.

The strategy that was identified as having the most potential to would facilitate Māori access to organisations is to value the person. Drury and Munroe (2008) eloquently write of Manākitaka, the skill of hospitality, of interactions and encounters during which the mana of all is uplifted. These authors also write about active engagement with clients to acknowledge and enhance their mana so that services can be offered more meaningfully and in a way that values the client. Valuing a person encompasses a number of facets, as highlighted in our findings. First, services need to have a positive attitude towards disabled Māori and be respectful of them. This requires that a positive relationship is developed. In order to achieve this, the service first needs to identify that the person affiliates with their Māori culture. Thus the first information required is to ask the person about their ethnicity and iwi affiliations. Our participants described how Māori are more comfortable with disability, whereas Pākehā (in the opinion of participants in the current study) are less comfortable with the concept. It is possible that this discomfort or guarded approach may also extend to enquiring about ethnicity. Services should be direct when asking about ethnicity. This is the first step in forming a meaningful relationship with Māori clients and showing clients that tikaka Māori is important to the organisation. There is nothing new in this finding; establishing cultural identity is crucial to the good health of indigenous people (Durie 2003b, Elder 2008); however from our study findings it appears that it is not yet embedded in everyday practice.

Furthermore, by identifying that a client is indeed Māori means that the service can then facilitate the person's self-identity and self-worth. Research participants considered the enhancement of self-identify/self-worth/self-esteem to be very closely linked with health and wellness. A starting point to enhancing these attributes for hauā Māori is to acknowledge and support their Māori identity.

To support Māori identity requires an understanding of Māori models of health care (Rochford 2009), such as the Te Whare Tapa Wha model and to uphold important Māori concepts and customs such as karakia, rakimarie, aroha, and mana (Kingi 2007). Small gestures such as offering time for karakia at the beginning of a session or being understanding of haka is affirming for clients. Although not specifically mentioned by our participants, the use of te reo Māori can be powerful in valuing a person, even if only to pronounce the person's name correctly, although use of te reo Māori should not be assumed but in response to the person's use of the language (Pitama et al 2011). These are small steps that build towards a trusting relationship and the potential that disabled people will start including the service into their conception of their extended whānau. To Māori, whānau is all important, whānau come first. Again, appreciation of this will facilitate wellness for hauā Māori who use services.

Upholding the concept of mana brings the discourse back to valuing. Valuing a person, from the viewpoint of our participants, means to listen to them and ensure you "hear" what they are saying, making sure you are not discriminatory in your actions and attitudes towards them, and that you do not make assumptions. All this takes time. Gifting time is precious to Māori.

Valuing a person may lead to positive outcomes; they no longer feel the need to turn to harmful practices such as alcohol and substance abuse or self-harming to fill voids in their life. Providing services that build confidence and self-worth may also enhance community participation, furthering self-esteem.

It was extremely interesting to note that participants did not identify physical barriers as disabling. However access to affordable and flexible transport was considered important. Service organisations need to assist participants to access appropriate transport and financial services that might be available to them, and also to ensure that no shame was attached to this process. Providing information and education empower people, but for our participants they would prefer this information to be given to them face-to-face. Information about what services are available and what they can access is essential. Thus one of the main services participants require is one of advocacy. Increasing advocacy services for disabled Māori and their whānau is one of the primary recommendations from this project.

Many hauā Māori were struggling financially and unable to find employment. Jansen et al (2008) reported four main classifications for barriers to health care for Māori for disability. Under 'cost barriers' they identified direct costs such as consultation costs, prescription charges, and indirect costs related to travel expenses or childcare. Māori with disability were also the most likely to report an unmet need for health services (23%) in the previous 12 months, as were adults with severe disability (22%) of which Māori are over-represented in that category (MoH 2004a). These findings are reinforced by Shoen and Doty (2004) who reported Māori were almost twice as likely as non-Māori to go without health care in the previous year because of cost, 34% and 18% respectively. Likewise, the most common reason for having an unmet need for medication was affordability (estimated 32,900 adults) (MoH 2004a).

Research suggests that 54% of successful outcomes are due to a positive therapeutic alliance (Wampold 2001); Asay and Lambert (1999) attribute 40% success to the client attributes and coincidental events. Both sets of authors argue that only about 15% of successful therapeutic outcome is due to the actual intervention delivered. As highlighted by Blow et al (2007), how a treatment is delivered is much more important than what is delivered. Although the above research pertains to psychotherapy research; the findings can arguably be extended to health and disability services per se. This then makes how services are accessed and delivered extremely important. Valuing hauā Māori, upholding their Māori identity and empowering their self-esteem is imperative to successful access of services.

5.2 Phases Two and Three - Organisational Survey and Interviews

We developed a questionnaire specific for our organisational survey that was based on a structured review of literature reporting on access to health and disability services from the perceptions of both Māori and people living with disability. Using our developed questionnaire we surveyed 50 organisations in Southland providing a health or disability service. We had a good response rate of 58%, given that a study which investigated study response rates to surveys used in organisational research (n=1607 studies) reported that the average response rate was 35.7% (SD18.8%) (Baruch and Brooks 2008).

Furthermore, as seen in Table 4, we had responses from a diverse range of organisations and locations (town, small town and rural).

One of the objectives of the current study was to undertake onsite accessibility assessments of a purposeful sample of organisations. This objective led us and our research partners to think, why are we doing this, what would be the importance of it, and who should be doing it? To do such an assessment correctly, the cultural assessors should not only have expertise in Māoritaka but also have experience and knowledge in the disability sector, and this would require a number of people, for example, Kaumātua, people with a disability, and personnel with clinical skills. Further, we thought that this exercise might be deemed as punitive by the organisations assessed. We decided to turn the assessment on its head and explore with organisations the good accessibility practices they were doing, what they felt could be done better, and the reasons for what they did or did not do.

Our questionnaire contained approximately three questions on each of the following five categories of primary interest: (1) analysis of workforce competencies, (2) quality standards, (3) service effectiveness, (4) physical access and promotion of services, and (5) health literacy and information needs. We discuss below our organisational survey and interview findings in relation to each of these key categories.

5.2.1 Analysis of workforce competencies

In our survey, we found that organisations were attempting to ensure cultural competency amongst their workforce by encouraging staff to have cultural training. Most organisations (79%) said they knew how to access expertise to provide education to staff on Tikaka Māori relevant to their service. For some staff this was mandatory to maintain their professional registration under the Health Practitioners Competence Assurance Act (2003). Cultural training appeared to be most frequently offered by the Southern District Health Board, Primary Health Care Organisations, or professional societies. Two Southland Māori health professionals' names came up repeatedly in the interviews as being the people providing cultural training; a question to ask would be how burdensome this task is for these two professionals if they appear to be the only ones in Southland providing training.

Such cultural training did not necessarily mean that these organisations were particularly accessible to Māori, as although they reported 'good' to 'excellent' accessibility to disabled Māori and whānau (93%), none reported receiving Māori specific feedback on their

service, so the question remains largely unanswered. These findings are similar to those commented upon by Wiley (2009) and Watson (2008). A qualitative study by Wiley (2009) conducted semi-structured interviews with ministry officials, service providers, Māori consumers of health care and their caregivers. A key finding from these interviews was the discrepancies found between staff and consumer perceptions regarding the quality of culturally appropriate health care given. Every organisation in Wiley's study reported providing some form of training to improve the cultural awareness and sensitivity of staff. Eight out of the nine organisations interviewed reported their service accessibility to indigenous peoples with disability as being 'good' or higher. However, not one respondent reported accessing a service provider who acknowledged and was aware of their cultural needs. Wilson (2008) suggests measuring cultural competency by requiring client input, as self-reports from health providers is open to manipulation for a favourable outcome.

Regular patient satisfaction surveys and staff reflections on their own practice may aid to reduce the discrepancies between staff and consumer perceptions on the quality of culturally appropriate health care given (Durie 2008, Wilson 2009). This said; many organisations in our survey appeared to not fully understand their Treaty of Waitangi obligations. There was a misunderstanding between a non-racial, human rights approach of respect for all people, no matter the ethnicity, and the concept of the importance tikaka Māori practice for services provided for Māori. "We treat everyone who walks through the door the same" was frequently the policy applied. Yet the statistics of Māori attending most organisations was generally very low (5% or less). Southland has an 11.8% Māori population, and the health disparities between Māori and non-Māori are well known, yet organisations did not appear to ask the central question – why are Māori not attending my organisation and receiving services? These findings suggest that health professionals should, as Drury and Munro (2008) propose, think about cultural competence as not just having knowledge of another culture, but rather to allow and acknowledge "these ways of being into our ways of being" (p.319). As we probed during the interviews, we frequently saw 'light bulb' moments when our questions made the interviewee think, perhaps we could improve our accessibility, make our services welcoming to all? All organisations did however express interest in our study findings so they could learn how to better improve access for Māori.

In our survey we found that 21 organisations (72%) employed less than 5% Māori staff. This is low given Southland's Māori population, although it must be noted however, that 8

(28%) organisations surveyed were sole practices. These findings are however not uncommon. Major disparities in the health workforce in New Zealand have been previously reported; Harwood (2010) reported that despite Māori representing 15% of the total population, only 3.2% of doctors, 2% of nurses, and less than 2% of therapists are Māori. Jansen et al (2008) documented Māori experience of health and identified from their research with Māori whom attended ten *hui* or meetings, a frequently unfulfilled preference for Māori clinicians or providers, leading Jansen et al (2008) to classify the under-representation of Māori in the health professions under 'organisational level barriers'. In a qualitative study conducted by Cram et al (2003), Māori were asked questions regarding their views on Māori health and their own health care. The general consensus reported was that Māori were more likely to access a health service from a Māori health provider compared to a non-Māori health provider as they felt that Māori health providers treated them holistically and integrated their cultural beliefs and *whānau* into the treatment.

We sought to find out how the organisations we surveyed integrated their Māori client's beliefs and *whānau* into the service delivered. The most frequent reply from organisations was that they would ask their clients what approach to health care they would prefer. What we did not ascertain was if the client then wanted a more holistic or Māori-focussed approach to health, for example, along the lines of the *Te Whare Tapa Wha* model, whether these organisations could actually accommodate the client's wish. Many organisations did say that they would refer the client to one of the local Māori health providers if necessary. One organisation was proactive and met with a cultural advisor regularly to discuss Māori clients in order to ensure these clients were appropriately provided for. A more holistic approach to health can be understood through the Māori health concept of *Te Whare Tapa Wha* of which there are four cornerstones. The most widely mentioned cornerstone is *taha wairua* (spiritual) as it incorporates the whole person (mapping themes of Māori health). The other three dimensions are *taha hinengaro* (mental), *taha tinana* (physical) and *taha whānau* (family) (Harwood 2010). This holistic approach to health care is fundamental to many Māori health practitioners, whereas non-Māori practitioners were seen as less likely to understand it (Cram et al 2003, Durie 1999). Misunderstanding the value placed on *taha wairua* and *Te Whare Tapa Wha* is one of the reasons that Māori are less likely to access mainstream health services compared to non-Māori and are more willing to access services provided by Māori practitioners (Cram et al 2003).

For the Māori and governmental organisations interviewed, tikaka Māori practice was explicit. These values were integral to practice and the concept of Whānau Ora was well understood and observed by these organisations. Many of these organisations were, however, grappling more with disability accessibility per se. How could they make their services more accessible for disabled whānau, not in the physical sense, but accessible more holistically?

The survey found the understanding of the concept of 'Whānau Ora' to be poor amongst most respondents; few organisations were able to fully articulate what it meant. Whānau Ora was jointly implemented by the Ministry of Māori Development, Te Puni Kōkiri, and the Ministries of Social Development and Health in 2010 (Te Puni Kōkiri / the Ministry for Māori Development 2012). It is seen as an inclusive approach to providing services and opportunities to all whānau / families in need across New Zealand, empowering whānau as a whole as opposed to focussing on the individual. This approach would be highly applicable to disabled whānau, and would greatly assist meeting their diverse needs. However, given Whānau Ora's inter-agency nature, it was interesting that only a few providers had any concept of it. Nationally, 25 Whānau Ora collectives, made up of health and social service providers, were selected to develop whānau-centred services. In Southland the only collective is the Te Poha Oranga Collective comprising Ngā Kete Mātuaranga Pounamu Charitable Trust and Te Rūnaka o Awarua (Te Puni Kōkiri / the Ministry for Māori Development 2012).

5.2.2 Quality standards

Quality standards in terms of health care providers assessing their own services with a view to improving these through policies and training are important. There are a number of ways in which this can be achieved regarding quality access of the organisations for disabled Māori. Having Māori representation at a policy level is one way. Eleven (38%) organisations said they had included Māori in the development of services or policy for Māori with disabilities. Some organisations talked of having Māori representation at a governance level of the organisation, having an advisory group, or using Māori wardens. The Māori Wardens Project was a Government initiative, administered by Te Puni Kōkiri, in which volunteer Māori skills were developed to assist Māori youth, safer communities, and community reassurance. It is a voluntary service, and whilst Māori Wardens are not

police they do have work guidelines outlined in the Māori Community Development Act 1962 (Te Puni Kōkiri / the Ministry for Māori Development, 2012).

Some organisations were part of national organisations, and said that the development of services or policy were undertaken at a national level, and this information did not necessary filter down overtly to the regional or branch level.

One general practice in our survey said that quality assurance of cultural competency was mandatory as part of the “Cornerstones” accreditation process, an accreditation programme designed by the Royal New Zealand College of General Practitioners for general practices in New Zealand. Embedded within this accreditation programme are criteria and indicators to ensure the General Practitioners’ (GP) commitment to Te Tiriti o Waitangi / the Treaty of Waitangi (Royal New Zealand College of General Practitioners 2012). Such an accreditation process would be another way of ensuring quality standards are met.

Regular patient satisfaction surveys should be part of ensuring quality standards (Durie 2008; Wilson 2009) but, although feedback was sought from clients by most organisations surveyed, by not including an ethnicity question in this process, they were unable to dissect out information pertaining to Māori.

5.2.3 Service effectiveness

Many accessibility practices considered important to Māori, such as the option to be seen at home and to be seen promptly by a health professional, were offered by the services we interviewed. According to He Ritenga Whakaaro-Māori experiences of Health Services, the timing and availability of services and appointment systems were identified as organisational barriers for Māori to access health care (Jansen et al 2008). In the General Practitioner Assessment Questionnaire (GPAQ) (Mead et al 2008), 60% of respondents identified the ability to get an urgent (same day) appointment with a General Practitioner (GP) as one of the four highest priorities with regards to accessibility. Further, in the report of results from the National Primary Medical Care Survey, a nationally representative, multistage study that collected data on the content of patient visits to various health providers (MoH 2004b), Māori were less likely than non-Māori to report being offered a choice of appointment times. Being referred for surgical care and specialist services was

also identified by our structured literature review as important for reducing the disparities in health care (Malcolm 1996; Mead et al 2008); and although we did not specifically ask about this issue, organisations said they would refer clients as appropriate

Service effectiveness can be also linked to funding. Durie (2003a) reported four main explanations for the indigenous differences in health status: genetic predisposition (although 85% of genetic variation is random and does not relate to race or ethnicity (Ellison-Loschmann and Pearce 2006)), socioeconomic disadvantage, resource alienation, and political oppression. Socioeconomic disadvantage was found to be partially responsible as Māori mortality rates have reportedly remained high even after controlling for social class (Sporle et al 2002). Māori health providers deliver health and disability services to predominantly Māori clients within a kaupapa Māori delivery framework. There are also health providers who are significant providers of health and disability services to Māori. Both these models have linked with specific government funding (Ministry of Health 2013). For this reason we asked the question: “Are you a Māori health care provider?” and only 5 (17%) of the organisations we surveyed identified that they were. One factor identified by organisations to providing a fully accessible service was inadequate funding. There appeared to be expectation that they would work smarter and reduce duplication of services, for example, providing services for whānau themselves as an agency instead of working in partnership alongside a Māori health provider.

5.2.4 Access and promotion of services

Most organisations (93%) thought that their service had ‘good’ to ‘excellent’ accessibility for disabled Māori and their whānau. When asked to comment on what they did well in this regards, these organisations identified many examples of good accessibility and promotional practices; such as: With regards to client respect and staff education comments in the completed questionnaires were: “if a service is needed anyone can access it”; “treated like every other person”; “respect their wishes”; “non-discriminatory”; “excellent relationships with all patients”; “all staff are encouraged to be culturally sensitive”; and “well-educated in cultural competencies”.

Engagement with whānau was mentioned frequently in respondents’ comments (“whānau-orientated”) and many organisations reported that they had good relationships with the local Māori health providers (the Ngā Kete Trust and Awarua Social and Health Services).

Some organisations recognised that different funding was available for Māori and some accepted Ngā Kete Trust vouchers in this regard. Many organisations had Māori staff involvement, such as, a Māori Manager, a Māori liaison officer, and a Māori support person, and linking with local Marae was achieved by some organisations: “increasing awareness of all Marae in Southland area about this service” and “we provide free services on Ohai Marae”. Rural-based practices said they “knew their community well and they know us, especially the shearing community and the Māori wardens”.

When asked how they thought they could improve their organisation’s accessibility, most organisations reported the need to promote their services further to Māori communities and Māori healthcare providers. One organisation said that they should have better systems for identifying Māori. Organisations did collect ethnicity data, however many people said they were reluctant to ask this information, so assumed it, based on appearance or name. There was also an assumption by some that “local Māori” did not really identify with their cultural heritage.

All organisations considered that their premises were fully physically accessibility. The questions in our survey were based on Edwards and Merry (2002a, 2002b) audit of physical accessibility of dental practices, which included questions as to whether the practices were fully accessible on ground floor without steps, or on the second floor with a lift and adequate door width, adequate circulation and accessible toilets (i.e. on same floor); ground floor access with steps or first floor access without a lift.

Although the 2006 Disability Survey estimated that 28% of disabled adults indicated they needed to park close to their destination (Statistics New Zealand 2007), parking did not emerge as an accessibility issue in this survey of Southland organisations. Funding for transport for people to access services was identified as a potential barrier. It was suggested that information regarding the availability of ACC and PHO taxi vouchers and the St John’s ambulance service (in some areas) should be promoted. Distance to travel for care is classified under ‘organisational barriers’ according to Jansen et al (2008) and is seen as one of the greatest barriers to access for Māori with disability. Brabyn and Barnett (2004) investigated the extent to which different areas in New Zealand vary in their geographical access to GP’s and Māori participants reported higher travel times on average, explained by the rural nature of many Māori communities. Additionally, Cumming et al (2010) who studied determinants of GP visits in New Zealand found GP utilisation to be lower in rural areas.

5.2.5 Health literacy and information needs

Whilst all organisations were overtly physically accessible (for example, they had wheelchair access, disabled toilets), there was some lack of attention to other disability accessible practices, for example, information. Whilst brochures were available in plain language, different languages, and sometimes in large print, people interviewed did not talk of alternative sources of information such as audio-recorded information or information in braille. They did however, speak of accessing appropriate assistance when required, such as from the Blind Foundation, Deaf Aotearoa, and interpreters. One organisation had some basic training in interactive drawing techniques and signing. Texting was frequently mentioned as one way of improving communication with clients. Interestingly, website and Facebook communication was only mentioned by one organisation.

Information provided in organisations was mostly in the written format, and some places offered this information in many languages, including Te Reo Māori. Many organisations reported that they would have face-to-face meetings with clients to ensure that the person had understood the information provided. If the client was unable to speak English they would access an interpreter or ask that a family member accompany the client.

Health literacy can be defined as ‘the degree to which individuals have the capacity to obtain, process and understand basic health information and services needed to make appropriate health decisions’ (Kickbusch et al 2005). Results from the ‘2006 Adult Literacy and Life Skills Survey’ showed that on average, four out of five Māori males and three out of four Māori females have poor health literacy skills (MOH report 2006). Research suggests that people with poor literacy are less likely to access health services and have less knowledge of their illness, treatment, and medicines. Qualitative data has shown several reports from patients complaining that they do not understand the information that is given to them by their health providers; both oral and written (Cram et al 2008, Wiley 2009, Wilson 2009).

As well as health literacy in terms of the actual information presented to patients, it is also important to consider the impact disability including hearing, visual, and intellectual impairments can have on the ability to understand information. For example, many Māori prefer face-to-face interaction (*kanohi ki te kanohi*), yet in the 15-24 year age group, of

whom 79% had consulted a GP or family doctor at least once in the previous 12 months, hearing disability was the most common type of disability for Māori (MoH 2004a). A common finding by Edwards et al (2002b) following audits of dental practices in England was that many practices often played background music in reception and surgery areas, making it difficult for patients with hearing impairments to differentiate speech. They also identified that practice information for the visually impaired was typically inaccessible and it was unusual for the information to be available in alternative formats. Edwards et al (2002b) reported providing information in form of audiotape very useful.

In the next chapter we integrate and discuss the findings from our two key sources: (1) people living with disability and their whānau, and (2) services organisations.

Chapter Six: Summary

In our research, using case study methodology, we explored, in the Murihiku / Southland region, the access for Māori living with disability and their whānau of health and disability services and supports, to identify the barriers and facilitators to access. This general discussion firstly addresses the specific aims of our research sequentially and then finishes with recommendations for improving access based on our findings.

6.1 Aim 1: Identify the health and disability community services and supports presently available for people living with disability within the Murihiku/Southland region.

It would appear that people living with disability in the Murihiku region are well catered for with regards to health and disability services; we identified 66 such organisations and we acknowledge that this is not an exhaustive list. There will be organisations that we missed. Four organisations were specifically Māori focused, with two organisations being identified as Māori health providers (Ngā Kete Mātauranga Pounamu Charitable Trust and Te Rūnaka o Awarua), which together form the only Southland Whānau Ora collective, the Te Poha Oranga Collective. Organisations in Southland frequently referred to these two Māori health providers and expressed a desire to build better relationships with them.

6.2 Aim 2: Explore how accessible these identified services are for Māori living with a disability and their whānau; identifying both the barriers and the facilitators to accessibility.

Aim 3: Make recommendations for improving accessibility of service delivery for Māori living with a disability and their whānau; recommendations which will inform Ministry of Health disability policies.

Our PAR study identified what factors made our hauā Māori feel well and what disabled them. These findings were corroborated by what organisations told us in the survey and onsite visits; together they allowed us to understand the facilitators and barriers to services that could potentially assist hauā Māori and thus to make the following recommendations to enhance accessibility:

6.2.1 Advocacy Service

The primary recommendation arising from this research to assist hauā Māori to access health and disability services is the establishment of an Advocacy Service in Murihiku. Many Māori rely on whānau to awhi them in times of need. Whānau, however, are not always close or available. Having an advocate to awhi or support hauā Māori to access organisations and who are responsive to their needs is critical to improving access to health and disability organisations in Murihiku. This advocate could take on a range of roles, for example, accompanying the hauā Māori to the specialist, assisting them to identify and to ask pertinent questions and ensure the hauā Māori is satisfied his or her questions have been answered. On a more practical level, advocates could assist with transport and with accessing other support that the hauā Māori may require.

Secondary to the time involved when establishing important relationships, an advocate with health knowledge, to bridge or mediate between health care providers, could be a good solution. This role would include establishing relationships with clients and providers in the community to assist with communication between services such as ACC and WINZ, finding appropriate healthcare professionals, and ensuring clients are given sufficient time, and appropriate funding and resources.

Recommended beneficial attributes for this role include:

- Someone who understands the hauā Māori population and the service providers to be able to facilitate hauā Māori to receive health care.
- A familiarity with the local Māori community.
- Knowledge of funding and funders to be able to access resources and pūtea.
- Health knowledge - trained as a health professional or worked in health promotion, delivery or research.

6.2.2 Establishing relationships with Hauā Māori

Hauā Māori viewed relationships formed between the health care service providers and hauā Māori and their whānau one of the most important determinants of access to services. Of note is that physical barriers to access of services were not mentioned at all in the interviews. Establishing a healthy relationship with hauā Māori, on the other hand was viewed vital to facilitating use of health care services.

6.2.3 Flexibility – knowing your clients

Although we acknowledge that this is not an easy recommendation to incorporate in to a busy health service with a large client base, nevertheless, it is a strategy that might, in the long term, be beneficial to all.

A common complaint from services and hauā Māori were the number of missed appointments. It can give the impression that hauā Māori do not think they need their appointment, respect the need to go to an appointment, or respect the need to contact the service and let the service know they will not be attending. Sometimes this impression may be correct but for many of those we spoke to in this study, other factors came into this equation. Many of the hauā Māori discussed their constant fatigue, in part this was due to the condition they have and for some, tiredness was due to a medication side effect. Fatigue can also lead to a decline in motivation and a “losing track of time” scenario. If services could have some flexibility around appointment times or a tracking system that texted or rang the clients due for appointments then this could (a) keep the communication and relationship up with hauā Māori and (b) potentially reduce the missed appointments and increase their access to care.

Another element to be considered is that Māori often have a perspective of time where “time given” is more valuable than a more European ideal of “being on time.” “Time given” refers to the idea that the quality of the interaction during a period of time or being fully present for that period of time. Unfortunately there is often a mismatch when combining this idea of quality time and a health professional’s busy appointment schedule.

Low self-esteem within this population is one other point to take into account. The lack of self-worth can lead to a barrier to access services due to a sense of not being worthy of receiving healthcare.

An advocate, as suggested in the point above, could stay in touch with the hauā Māori and their whānau and assist the person to be prepared and ready for their appointment, to remind the person of their appointment and if unable to attend to notify the service and rebook another appointment time. Another valid comment made by some participants was an awareness of clients who suffer poor mental health and whom may struggle to get out of bed in the mornings. Appointments in the morning are very difficult for some to attend

and perhaps having an awareness that perhaps afternoon clinics or appointment schedules may work much better for some hauā Māori.

6.2.4 Recording Ethnicity Data

It appeared very important to the Hauā Māori we interviewed that they want their service to know they are Māori and what iwi they affiliate to. Collecting ethnicity data is not only good practice but it also make a difference to people in the awareness their service has about what contributes to the overall wellness of their clients. Ethnicity data must also be collected when seeking feedback from clients.

6.2.5 Funding

Some of the reasons hauā Māori are unable to attend appointments or take part in any health promotion activity/programme was because they may not have the funds to pay for a taxi/bus to get them to and from the appointment or event or to pay for the treatment/prescription or entry fee. Having an advocate to assist hauā Māori to work through some personal budgeting that allows for medical costs to be covered or to seek any available funding to subsidise treatment and medication costs could be helpful.

Participants spoke of the multiple times they were expected to complete official documents for organisations like WINZ or ACC, and that their impairments often made it hard to complete such documents. They felt they had to continually fight to obtain the resources they are entitled too, which further minimised their well-being. Agencies should explore ways of making it easier for these processes to be undertaken.

6.2.6 Suggestion Strategies

Based on the suggestions and issues described by participants and organisations in the current study, the following are suggested strategies to facilitate disabled Māori and whānau access of health and disability support organisations:

- *Value clients:* Participants in this research consistently identified that feeling valued as people facilitated their access of health and disability services. There were a range of ways suggested for this to occur, including:
 - Being valued as an active contributing member of the community
 - Receiving respect and a positive attitude from the community
 - Being listened to
 - Not being discriminated against
 - Being provided with choice

- Being provided with a flexible approach

- *Being connected / keeping in touch*: feeling connected was important to our participants; organisations could assist with this by:
 - Facilitating connection with whānau
 - Understanding the importance of whānau
 - Understanding that friends and community are also whānau
 - Endeavouring to be more “whānau-centred” and “whānau-led”; for example, facilitating and being responsive to feedback from the disabled community
 - Being culturally inviting, for example, in greetings and hospitality
 - Consulting with a cultural advisor

- *Enhance a strong sense of self identity and self-worth*: organisations could foster this by:
 - Specifically asking about ethnicity and never assume
 - Acknowledging and making the most of a strong belief in a religious faith (as appropriate)
 - Offering Karakia
 - Allowing time and space for Rakimarie
 - Facilitating Aroha and Mana; spend time building relationships with their clients
 - Endorsing Māori health models such as Te Whare Tapa Wha
 - Encouraging a sense of Māori Identity
 - Being positive - whakamana
 - Discouraging drug and alcohol use
 - Being accountable to service policies and strategies that incorporate the Treaty of Waitangi, and workshop with staff what that means for the service and how this can be actioned on a practical, usable, and productive way.

- *Resources* Organisations could:
 - Be a strong advocate for their clients
 - Assist clients to access:
 - Pūtea
 - Education
 - Employment
 - Transport/ Mobility

- Better advertise and market their services to the Māori community and Māori organisations
- Better network with other organisations, especially with the Māori health providers
- Provide appropriate information in a wide range of formats (such as plain language, different languages, audio-recordings) and reinforce this information face-to-face with the client
- Consider service accreditation regarding cultural competency

6.3 Aim 4: Develop an appropriate research framework to collect data relevant to Māori with disability and their whānau.

Our Kaupapa Māori research approach to the Action Participatory Research project, informed by our Rōpu Kaiarahi, assisted us to develop a novel, simple, visual tool to collect data in Māori-focussed in-depth individual interviews. The research team members who were intimately involved in the development of this tool, and thus should be credited for its development, were our Kairakahau Māori, Katrina Potiki Bryant and Kelly Tikao.

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. 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).

Many Māori respond to visual media, and the model used in this research proved to be beneficial to aid discussion around health and disability with hauā Māori. Upon further trials and refining, the model need not be restricted to hauā Māori and could be a useful assessment tool for others. The tool requires validation in other regions in New Zealand / Aotearoa.

6.4 Aim 5: Build research capacity and capability for Māori and Māori with disability within the Murihiku/Southland region.

This project built research capacity and capability for Māori and Māori with disability. At an overt level the skills of our Kairakahau Māori, Katrina Potiki Bryant, a Masters level student, and Kelly Tikao, a researcher with the Donald Beasley Institute; and Amy Russell and Aroha Montgomery, two under-graduate physiotherapy summer students, were clearly developed. Nested within this work Katrina Potiki Bryant is undertaking her Master's degree thesis, the aim of which is to explore and understand the concept of disability, health, and wellness, and how these concepts influence the provision and uptake of service for disabled Māori and their whānau. The emerging Kairakahau Māori spent time reflecting on the PAR study. This reflection can be seen in Appendix 4.

The research team's approach to this study was entirely collaborative; 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. Our research partner, the Ngā Kete Trust, attended and informed all meetings and was thus intimately involved in the research as it evolved, learning about the research process, and gaining research skills along the journey. So too did our Rōpu Kaiarahi, for many it was their first exposure to research, and they expressed enjoyment in this process. In the spirit of Whakawhanaukataka (weaving people together / making connections), the Ngā Kete Trust suggested that the research team should be mindful to not only come to the community with questions, but also to invite the community to come to the research team with questions. It was also suggested that there were young members of this Rōpu who may be interested in studying in Dunedin and that the project provided a good opportunity to offer an introduction to the University of Otago campus and support available for Māori students. With this in mind the Rōpu Kaiarahi visited the research team in Dunedin on two occasions (see Figure 11).



Figure 11: The Rōpu Kaiarahi visit the University of Otago

We acknowledge that our research has not yet brought about overt change. We are aware of this, and thus know that we have not yet fully met our Kaupapa Māori research or Action Participatory Research obligations. Change takes time, and this is a work in progress. It is planned that this research will continue beyond the time-span of the research contract as hopefully a Doctor of Philosophy thesis. We hope that we can attract a Māori PhD candidate to, within the framework of a kaupapa Māori approach, take the ideas and recommendations suggested by our work and implement some of the suggested changes, evaluate the outcomes, and make further recommendations.

6.4 Research Limitations

Our research was a case study located in Murihiku, our findings thus relate to this region of New Zealand and to those who participated in the study. Although we argued that Murihiku was fairly representative of rural Aotearoa / New Zealand, we cannot fully

extrapolate our findings to other regions of Aotearoa. Further this research used a mixed methods design which provided a rich description of hauā Māori living in Murihiku, what made them feel well, what disabled them, and what could potentially facilitate their access to the many health and disability services potentially available for them. We are cognisant that we cannot from this research, make causative links.

In our research we used a broad definition of disability and allowed participants to self-identify their disability. This broad conceptualisation and self-determination of disability therefore does not allow us to categorise hauā Māori participants into levels of severity of disability. Similarly we used a broad definition in identifying organisations that provide a health or disability service. Our study thus had broad representation across “types” of disability and organisations, as well as covering city, small town, and rural areas.

We were further cognisant of the fact that the principle investigators on the study were not Māori, nor did our Kairakahau Māori originate from the Murihiku region. Further, our research questions did not emanate from the disability community of Murihiku. We therefore appreciate that our research could only be guided by kaupapa Māori principles as it did not meet fully the requirements of this methodology. Our close association with our Murihiku research partners, Ngā Kete Trust and our Rōpu Kaiarahi went some way towards mitigating for this. With this in mind, we endeavoured to approach the research with “cultural humility”, to develop meaningful relationships and Whakawhanaungatanga (Ahuriri-Driscoll et al 2007, Gifford and Boulton 2007)

6.5 Future research

Future research is required to:

- Identify facilitators and barriers for hauā Māori and their whānua 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 whānua proposed by this research
- 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.

6.6 Dissemination of findings to participants and the wider community

The Kairakahau Māori learnt that many of the study participants had a passion for the arts. Some were studying art, some have been producing a wide range of mixed medium artworks over their life times and others would consider themselves hobbyists. All use art as a way to structure their day, to network into other community groups and ultimately to enhance their: hauora, wairua and mauriora. Whilst working through a dissemination plan it seemed it would be both appropriate and exciting to combine the creative talents of the participants with the 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 of disseminating the research findings and the idea was met with excitement and support from all. A two-day art exhibition was held in Invercargill from 9th-11th August 2013. 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 event was extremely well received by both participants and the public and some wonderful art works were developed and displayed. The 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 Mana Māori research project.

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APPENDIX 1: Pānui for first hui



**NGA KETE MATAURANGA POUNAMU
CHARITABLE TRUST**

Oraka Aparima Health & Social Services

Kia ora Whanau

Want to have your say on living with a disability?

Nau mai haere mai whanau



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, Kaiawhina Disability, Ngā Kete, ph 03
2145123**

APPENDIX 2: Hauā Mana Māori Organisational Questionnaire



**NGA KETE MATAURANGA POUNAMU
CHARITABLE TRUST**
Oraka Aparima Health & Social Services

Donald
Beasley
Institute

Disability research
and education

100 YEARS OF EDUCATION,
RESEARCH AND PRACTICE
100
SCHOOL OF PHYSIOTHERAPY
1913 - 2013



Hauā Mana Māori

Living unique and enriched lives

Please complete the following questionnaire by ticking the appropriate response or detailing your answer on the lines provided.

1. Please describe the type of services your organisation provides:

2. What is the geographical location of your organisation?

- Town (30-100k pop)
- Small town (<30k pop)
- Rural location

3. Does your organisation make home visits?

- Yes
- No

4. How often does your organisation work with disabled people?

- Very often
- Often
- Sometimes
- Rarely
- Never

5. If a person wishes to see a particular health professional/provider within your service, please estimate how quickly are they usually able to see that provider?

- same day
- next working day
- within 2 working days
- within 3 working days
- within 4 working days
- within 5 or more days
- does not apply

6. How physically accessible is your organisation?

- Fully accessible on ground floor without steps, or on the second floor with a lift and adequate door width, adequate circulation and accessible toilets (i.e. all on same floor)
- Ground floor access with steps
- First floor access without a lift
- Other (e.g. multi floor building)

7. What percentage of your consumer population are Māori?

- Less than 5%
- 6-10%
- 11 – 25%
- 26 – 50%
- 51 – 75%
- 76 – 100%
- Unsure

8. What percentage of your staff are Māori?

- Less than 5%
- 6-10%
- 11 – 25
- 26 – 50%
- 51 – 75%
- 76 – 100%

9. How would you describe your organisation's service accessibility to Māori with disabilities? (i.e., can clients easily access agency services when they're needed?)

- Excellent
- Very Good
- Good
- Fair
- Poor

Please describe what is done well: _____

Please describe what needs improvement: _____

10. Has your organisation ever included Māori in the development of services and/or policy review regarding Māori with disabilities? (*Please elaborate on your answer*)

Yes

No

11. Do you ask clients to provide feedback regarding the services you provide?

Yes

No

If yes, please describe the feedback provided by your Māori clients.

12. Does your organisation have someone who specifically addresses issues regarding Māori with disabilities (e.g. service staff, disability experts, etc.)? (*Please elaborate on your answer*)

Yes

No

13. Does your organisation provide education to build understanding, awareness, Tikaka Māori and cultural sensitivity among staff to improve services to Māori with disabilities? (*Please elaborate on your answer*)

Yes

No, but we plan to provide training during the next 12 months

No, we do not plan to provide training during the next 12 months

14. Does your organisation know how to access expertise to provide education to staff on Tikaka Māori/ things Māori relevant to your service?

Yes

No

15. How does your organisation ensure that all information provided to clients is easily understandable? (This includes both oral and written sources of information)

16. Please describe how your organisation caters for clients who have disabilities affecting their communication or whose first language is not English?

17. When treating Māori clients, how do you integrate their cultural beliefs and whānau into the treatment?

18. What does "Whānau Ora" mean to your organisation?

19. Are you a "Māori provider"? (i.e. eligible for Māori provider funding)

Yes

No

20. Are there any other comments you would like to add?

Thank you for completing this questionnaire

Appendix 3: Summary of studies included in Hauā Mana Māori structured review

Author and Article Title	Area looked at	Study Population	Study Type	Main Findings	Relevance to Questionnaire
<p>Wiley (2009)</p> <p><i>At a cultural crossroads: Lessons on culture and policy from the New Zealand Disability Strategy.</i></p>	<p>Analysis of workforce competencies</p>	<p>Mainstream Health services</p> <p>Four key areas: interviews conducted on Ministry officials, service providers, consumers and caregivers of health care</p>	<p>Qualitative</p>	<ul style="list-style-type: none"> • Discrepancies between staff and consumer perceptions on the quality of culturally appropriate health care given • Inter-service collaboration could aid in the distribution of knowledge about agency activities which could improve consumers access to health services • Financial concerns as families with disability often have higher health and living expenses • Not one Māori consumer felt that their cultural needs were addressed 	<p>Are client satisfaction surveys encouraged to gauge whether the staff cultural training that has been put in place is having a satisfactory and effective outcome on the recipients of the health care?</p>
<p>Cram et al (2003)</p> <p><i>Mapping the themes of Māori talk about health</i></p>	<p>Analysis of workforce competencies</p>	<p>Māori consumers of health care</p>	<p>Qualitative</p>	<ul style="list-style-type: none"> • <i>Wairua</i> (spiritual aspect) is the most widely mentioned aspect of Māori Health • Patients view <i>wairua</i> as the key to understanding health and illness as it gives access to the whole person • Important to integrate Māori beliefs into the treatment 	<p>Importance of Māori Health models such as Te Whare Tapa Wha and the influence it can have on patient-provider interaction and treatment</p>

<p>Nikora et al (2004)</p> <p><i>Disabled Māori and disability supports</i></p>	<p>Analysis of workforce competencies</p>	<p>Māori living with disability and/ or their whānau carers</p>	<p>Qualitative</p>	<ul style="list-style-type: none"> • Māori with a disability and their carers express a desire for Māori health providers • More culturally sensitive staff • Needing financial support as well as increased emotional support when very stressed 	<p>Need to identify percentage of Māori health providers</p> <p>Identify staff training</p>
<p>Bolitho & Huntington (2006)</p> <p><i>Experiences of Māori families accessing healthcare for their unwell children: a pilot study</i></p>	<p>Analysis of workforce competencies</p> <p>Health literacy and information needs</p> <p>Service Effectiveness</p>	<p>Māori consumers of health care</p>	<p>Qualitative</p>	<ul style="list-style-type: none"> • Limited research exploring individual experiences of Māori when accessing health care • Financial barriers, doctor's fees and cost of medications • Families feeling vulnerable, 'you don't want to question anything for fear that you may be waiting longer in the queue' • Families did not know whether they should be accessing health services - feel that they are a hassle, or over reacting. 'Is she sick enough to be admitted?' <p>Hesitated to access health services</p>	<p>Māori are influenced by previous visits to the GP</p> <p>Unsure of whether 'child is sick enough' to take them to health services; issue of health literacy. Knowing what needs to be seen to</p> <p>Financial barriers</p>

				because of previous experiences that made them vulnerable	
Wilson (2008) <i>The significance of appropriate health services for Indigenous Māori women</i>	Analysis of workforce competencies Service effectiveness	Māori Women	Qualitative	<ul style="list-style-type: none"> • Whānau, spirituality, traditional and contemporary knowledge is important for health and well being • Nurses must engage in self-reflection on their own practice to increase their effectiveness • Need to include the consumers of health care when measuring cultural competence • Integrate culture into clinical practice 	Key questions to optimise culturally competent practice include: how key beliefs of Māori women are determined, how trust is promoted in the service (seven questions) and building on existing strengths of the patient
Mead, Bower & Roland (2008) <i>The General Practice Assessment Questionnaire (GPAQ) – development and psychometric characteristics</i>	Quality standards	Data from GP practices throughout United Kingdom	Quantitative (postal questionnaire)	<ul style="list-style-type: none"> • Scales of the GPAQ are internally reliable and that the items demonstrate an interpretable factor structure 	Key questions asked: ability to get an urgent (same day) appointment with a GP and ability to get a referral to a specialist when the patient felt it was necessary were among four of the main priorities for patients
Crengle (2001) <i>The development of</i>	Access and promotion of services	Report on development of Māori primary care services over past	Qualitative	<ul style="list-style-type: none"> • Barriers to care in Māori care services: financial, geographical, transport, lack of knowledge of health issues and how to access information, barriers within 	Supports previous findings on barriers to access including inability to receive care

<i>Māori primary care services</i>		decade		the health care system and cultural barriers	at the time needed, limited follow-up and failure to provide information in a way that is appropriate for Māori
Ministry of Health (2004b) <i>Māori Providers: Primary health care delivered by doctors and nurses: the National Primary Medical Care Survey (NatMedCa):2001/2002 Report 3</i>	Access and promotion of services Service effectiveness	Nationally representative, multi-stage sample of private GP's in New Zealand (28 practitioners at 14 Māori provider practices)	Quantitative (survey)	<ul style="list-style-type: none"> Percentage of Māori patients was substantially higher in Māori providers (59%) compared with private GP's (12%) community governed non-profit (19%) Two thirds of patients possessed a Community Services card (CSC) 60% of visits involved writing of a prescription Three-month follow-up was recommended in 62% of visits, referrals made in 18% of visits and nearly 2% in an emergency referral Several key questions in the 'Practice Questionnaire' 	<p>Key questions:</p> <p>Percentage of Māori staff and patients</p> <p>Identifying health services provided</p> <p>Site information: geographical location including if located in rural area</p> <p>Financial: standard charge for patient including with CSC</p>
Edwards and Merry (2002a)	Access and promotion of services	157 general dentist practices in Merseyside, England (response rate	Quantitative Two-page	<ul style="list-style-type: none"> Although dentists were willing to treat disabled patients, few dental practices were accessible at the time of the survey - only one third of practices 	Physical accessibility of the health care facility

<p><i>Disability Part 2: Access to dental services for disabled people: a questionnaire survey of dental practices in Merseyside</i></p>		<p>81%)</p>	<p>postal questionnaire</p>	<p>reported having a fully accessible surgery</p> <ul style="list-style-type: none"> • Key issues: physical barriers, lack of time and lack of domiciliary equipment 	
<p>Edwards, Merry and Peeling (2002b)</p> <p><i>Disability Part 3: Improving access to dental practices in Merseyside.</i></p>	<p>Access and promotion of services</p>	<p>Follow-up to the previous postal survey – audit of 27 general dentist practices in Merseyside, England</p>	<p>Qualitative (audit)</p>	<ul style="list-style-type: none"> • Disability awareness training can help in understanding of disabled people’s needs and break down some barriers • Attitudes are just as important as physical premises in improving access • Provided simple changes for practices to improve access regarding attitudes of staff, health and safety issues, parking, ramps and handrails, reception, seating in the waiting room, hearing and visual impairment 	<p>Attitudes of practitioners</p> <p>Physical barriers: many practices had designated parking but did not have a disabled space, lack of ramps and handrails</p>
<p>Casamassimo, Seale & Ruehs (2004)</p> <p><i>General dentists’ perceptions of educational and treatment issues</i></p>	<p>Access and promotion of services</p> <p>Service effectiveness</p>	<p>National survey in America of general dentists to determine overall care of children with special health care needs (CSHCN) (n = 1251, response rate</p>	<p>Qualitative (survey)</p>	<ul style="list-style-type: none"> • Dentists with hands-on educational experiences in dental schools with CSHCN were less likely to consider such factors as level of disability and patient behaviour as obstacles to care and were more likely to desire additional education in care of 	<p>Need to ask providers if they provide care for disabled and if so, how often</p> <p>Barriers to willingness to treat also identified,</p>

<p><i>affecting access to care for children with special health care needs</i></p>		<p>24%)</p>		<p>CSHCN</p> <ul style="list-style-type: none"> • Postgraduate education in general practice or advanced general dentistry residency had no effect on willingness to care for CSHCN 	<p>e.g. level of disability, patient behaviour, funding</p>
<p>Ministry of Health (2010)</p> <p><i>Kōrero Mārama: Health Literacy and Māori – Results from the 2006 Adult Literacy and Life Skills Survey</i></p>	<p>Health literacy and information needs</p>	<p>Māori consumers of health care</p>	<p>Ministry of Health research report</p>	<ul style="list-style-type: none"> • 4/5 Māori males and ¾ Māori females have poor health literacy skills • People with poor health literacy are less likely to access health services and more likely to be hospitalised or attain chronic conditions • Building health literacy can be achieved through clearer communication from health professionals, providing plain language health information 	<p>How do you ensure that the information you provide to patients is clear and easy for patients with poor health literacy skills to understand?</p>

Appendix 4: Kairakahau Māori Whakāro



*Whaowhia te kete Mātauraka
Fill the basket of knowledge.*

In the reclaiming of knowledge comes a reclaiming of knowledge perception. As Kairakahau Māori it was important that we took the time to hear, see and feel the kōrero (talk) that had been gifted to us by all of those involved in the Hauā Mana Māori research project. We honoured the opportunity to sit with our people and learn about their lives. We have a responsibility to our Māori communities, as Kairakahau Māori; to facilitate positive change and mediate action as directed by the needs and the dreams of the hauā Māori and their whānau within this project.

This section of the report explains the *perception* we took in order to gather and summarise the kōrero contained within the qualitative interviews.

Kairakahau Māori – No hea māua?

Kairakahau Māori provide a positive and exciting step towards producing dynamic bicultural research that removes the past errors of Māori being over researched, misunderstood and alienated from the research outcomes; and only rarely given the

opportunity to be the *researcher*. Alongside the development and discussion of kaupapa Māori theory and research methodologies is the growth of the Kairakahau Māori workforce.

Ko te Ōteauheke te mauka
Ko te Awaiti te awa
Ko Takitimu te waka
Ko Kāi Tahu te iwi
Ko Kāti Irakehu, Kāti Tārewa kā hapū
Ko Ōnuku te marae ki te Pātaka o Rākaihautu
Ko Kelly Tikao tōku ikoa
Mihi atu rā

Ko Pukekura te mauka
Taieri te awa
Ko Takitimu te waka
Ko Waitaha, Kāti Māmoe, Kāti Tahu kā iwi
Ko Kai Te Ruahikihiki, Kāti Taoka kā hapū
Ko Ōtākou te Marae
Ko Wiremu Potiki te tupuna
Ko Katrina Potiki Bryant tōku ikoa

Both Kairakahau Māori are health professionals. Katrina is a practicing physiotherapist (with over 18 years of experience) with her own clinic in Dunedin and is the Kaiarahi Māori at the University of Otago School of Physiotherapy. Kelly is a registered nurse and Kairakahau Māori with the Donald Beasley Institute (promoting research and education in the field of intellectual disability). Katrina and Kelly have an extensive background in the arts and are actively involved with the Otepoti Māori community. Primarily they are hākui (mothers) to collectively seven tamariki and although they have entered this project as emerging researchers they feel comfortable with what they bring on another level to the study alongside the participants, services and senior researchers, and that is an energy and passion that is uniquely theirs.

It has always been important to highlight that although the Kairakahau Māori are indeed Māori and of Kāi Tahu ancestry they do not carry mana whenua status in the research

project defined location of Murihiku. This belongs to those of Awarua, Ōraka Aparima, Waihōpai and Hokonui Rūnaka. So with this in mind it was imperative that this be acknowledged with Ngā Kete Trust and the Rōpu Kaiarahi. We took the status of manuhiri (visitors) in their rohe (region) and thus it was vital for us during this project to assist where possible to create capacity for Māori to eventually conduct research such as this in their own rohe for their own community. It was also important that the methodology, analysis and research recommendations that emerged from the research were in context to this community. This was to ensure that the recommendations are relatable and practical to the Murihiku community.

Being manuhiri also placed the Kairakahau Māori in a position of adhering to a tikaka that was directed by our: participants, kaumātua, Marae and service or institute we were being housed within. This meant the timing, duration, nature of discussion and tikaka were in the hands of the haukaika (home people) – we were prepared and open to this approach to the research project.

The nature of whakapapa and the nomadic lifestyle of tūpuna Māori also meant that at times we found connections with those involved in the project and enjoyed the links between iwi and hapū, Māori and other shared ethnic backgrounds. Making these links allowed us to build a rapport with our participants and also allowed the interview process to take a level that we believe is arguably deeper than perhaps if this rapport had not been established.

It was also important to eat together, laugh together, get frustrated together, cry together and work together to ensure their concerns and successes were heard within their narratives for this study. The boundaries between rakahau Māori and participants often seem broader and more open than in mainstream health research, it is the nature of whanaukataka (relationships). Having regular debriefing sessions between the Kairakahau Māori and senior researchers allowed for some of the challenging issues to be discussed and worked through.

With this also in mind, after links have been established either through the course of conducting the research or blood connections, Kairakahau Māori unlike many non-Māori researchers remain in a distant sense within this community. These participants and their

whānau become part of our whakapapa and hence the rapport does not end at the point of dissemination but has really only just begun.

“I yeah, I think in my situation um, ‘cause this little duty here for one, for, for the year, has, has been amazing, ‘cause I, I only see parents you know so for me, I see yous in the community and yous is, we’re all, we’re all, I count yous as whānau now because we’re all on the same linear and we know that all those things that, you, 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...” (Hauā Māori Participant).

The Kairakahau Māori not only have a responsibility to the Primary Investigators and the funding body but also to the participants and their community. This is the glue and the solvent that creates the internal challenges for all Kairakahau Māori working in two different paradigms and having to walk neatly and safely between the two.

We viewed this project from our Kāi Tahu wāhine eyes, this was our Māori worldview at this time, who we are as Māori women and what we can share and learn throughout this project. We value te reo Māori, tikaka, manāki ki kā tākata (care towards others), wā (time, leniency around time), kōrero and kōrero ano (more talk), kaumātua, tamariki, rakatahi, pakeke, mātua, the art of listening/āta whakaroko, our presence in others home, karakia, mihi, waiata and kai.

We were guided and hosted by Ngā Kete Trust – a Māori Health Service provider and Whānau Ora partner alongside Awarua Social Services. The kaiwhakahaere (CEO) Tracey Wright-Tawha and her colleague Melanie Reed kept the home fires burning on this project 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 our research meetings and reminded us what was important for these people and more often this was communication and being kept in the loop with the research process.

Two examples of how Ngā Kete Trust reminded the research team to stay in touch was through the suggestion of a visit of the Rōpu Kaiarahi to Dunedin from Murihiku. To see us in our work environments to further understand who we were and where the knowledge would be stored and looked after. This exchange between service, participants and the research team provided knowledge exchange, rapport building, trust, visuals that meant

more than presenting who we are through PowerPoint presentations. This visit gave the project a context, we were getting to know the context in Murihiku and now some of the Murihiku people were able to experience the context of the research.

The second visit was prompted by another participant who wanted to bring her three children, her whānau and her carers to meet the research team and explore the resources with predominantly Donald Beasley Institute and the Anne Bray Library housed within, but it also gave the Kairakahau Māori an opportunity to meet in one visit the whole whānau and gain more knowledge around who they are and how they work together. It was also important that this whānau were able to share kai with the team, access library resources, make connections in regards to the carers being informed of the library and how the information officer can help them access information on many disability issues, what other research information is available to them and we were also able to learn of other services in Murihiku, this led to two meetings with this service and valuable knowledge gained each time.

It was also imperative that no differentiation existed between how we worked with participants and how we worked as a research team. We worked on the basis of honesty and manāki. This did mean at times the research team faced conflict and resolution, cultural discrepancies and cultural respect. Whānau needs always came first in regards to both the participant and a member of the research team. We were working in a real world where the research project although important, was never alleviated to a status that threatened to leave the original research pathway.

Kaupapa Māori Research

Kaupapa Māori research evolved from a reaction to questionable research conducted on and with Māori since the arrival of Europeans to Aotearoa. Missionaries, ethnographers, artists, property investors and historians all wrote what they saw and furthered their interests and intrigue with the natives of this whenua (land).

Māori over the years have been studied in the main with awareness that they were involved with a research project. However practices in the earlier times did breach all ethical boundaries by placing Māori in research projects unknowingly. This could be argued that the research was to improve the wellbeing of Māori, but would often just raise

the credentials of those facilitating the research and appeared to have minimal impact on improving the wellbeing and development of te Iwi Māori. According to Rangimarie Mahuika, research about Māori can be written in a way that is “alien to our (Māori) understanding,” (Mahuika 2008). A great deal of research in the past told Māori how they lived their lives, often exclusive and often out of context. These research results then became published and formally accepted as a true record on how Māori were – often far from the reality experienced by the Māori participants.

In the late 70’s pockets of Māori academics and educationalists began to assert their distaste for being treated like “guinea pigs” in numerous research projects run by non-Māori (Mahuika 2008 p1). This assertion commenced a ground swell for more contemplation over research projects. Some Māori academics became more critical and observant of research methodologies and analysis within research projects. The overarching concern being the wellbeing of the Māori participants within these research projects and the lack of ability and willingness of the researchers to portray the Māori perspective within the research to more truly reflect the data provided by the participants.

This prompted a challenge to all researchers in New Zealand and indeed the funding bodies to be more “accountable to their research ethics” not only with Māori research participants but to all who partake in human research (Bishop and Glynn 1992, Mahuika 2008, L Smith 2011, Walker 1990).

Over the years the discussion about the inclusion of Māori into the research process as the researcher, was fueled in the 1980’s with Māori education leaders and writers instigating the establishment and support for Māori immersive education such as the: Kohanga Reo (preschool language nests), Kura Kaupapa (primary immersion Māori schools) and Whare Kura (Tertiary Immersion Education). These schools of learning about te Ao Māori whilst immersed in te reo Māori provided a huge surge of passion for cultural revitalization and strength in the mana of te iwi Māori.

Graham Smith said this further defined and expanded the concept of kaupapa Māori and Mahuika and Smith described it as a “theory of liberation” for Māori. Many Māori academic have addressed kaupapa Māori theory, it has been debated, discussed pulled apart, put back together, disliked and liked. Kaupapa Māori as a repository of knowledge is “the philosophy and practice of being Māori” (Smith 1992 p1). It is not a new concept

developed purely to sit alongside the academic speak according to Nepe, it can be dated back to the early Creation stories (Nepe 1991). Māori have been practical researchers since the beginning of their existence. Working on a whakāro (concept), practicing that whakāro, evaluating it and adjusting the methodology. Eventually early Māori produced a result that can then be incorporated into improving their way of life. Examples of this are in the realm of rongoa Māori (Māori medicine), mahika kai (traditional Māori food preparation and cultivation sites) and how Māori adapted their knowledge stemming from their homelands in Hawaiki to the natural resources only available in this new terrain (Beattie 1994, Best 1934, Best 2005).

Anuru Eketone (2008) suggests that academic banter about what kaupapa Māori theory and research is, is not important, as long as the voice of the Māori community representing whānau and Māori health and education providers is also being heard on this “take” (subject) (Mahuika 2008). Collectively these voices are forging a new style of research approach, driven by a need, conducted collectively utilising Māori values and philosophies and producing recommendations that can be utilised across community and government services to better meet the needs of te Iwi Māori. Research is a valuable tool, it is power, it is knowledge and it can be a way forward for Māori and Aotearoa (G. Smith 1997, G. Smith 2003, L. Smith 1999).

... there is more to kaupapa Māori than our history under colonialism or our desires to restore raNgātiratanga. We have a different epistemological tradition that frames the way we see the world, the way we organize ourselves in it, the questions we ask, and the solutions we seek. (L. Smith 2000 p 230)

Kaupapa Māori theory is not only obvious in the way we approach research utilising Māori values, tikaka, te reo Māori, aroha, tribal knowledge and whakapapa, it sits in all components of a research project. It lives within the kākano (seed) of an idea, at the kōrero (talking/communicating/consulting) stage and is integrated throughout the whole research process.

Linda Smith (2000), surmising the essence of kaupapa Māori research not only looks at the knowledge gained and how Kairakahau Māori come to the knowledge, perceive the knowledge and then understand the knowledge. Smith says this does not appear to carry as much weight in mainstream methodologies as it does within kaupapa Māori research.

As Kairakahau Māori, we have learnt within the Hauā Mana Māori project that knowledge is shared and given in a reciprocal and repetitive nature. The boundaries of the research process appear less defined than perhaps those of mainstream and the teaching and sharing of knowledge occurs from the kākano (seed) stage. The dissemination of knowledge and recommendations are in place from first contact made between Kairakahau Māori and the participant. The sharing of information or knowledge occurs throughout the research process and is presented more formally at the end of the project timeline alongside the wider research results (L Smith 2011).

Kaupapa Māori in relation to the Hauā Mana Māori Research Project

Graham Smith (1990) identified six key elements of kaupapa Māori that can inform and assist the undertaking of research; other senior researchers such as Linda Smith, Leonie Pihama and Taina Pohatu further expanded these principals. The Kairakahau Māori incorporated these principals into all elements of the research project.

***Tino RaNgātiratanga* – The Principal of Self-determination**

The Hauā Mana Māori research project tried in most aspects to ensure that participants, their whānau and Ngā Kete Mātauraka Pounamu Charitable Trust had a sense of ownership over this project. It was imperative that the participants felt their contribution in the initial stages of this project, at our first presentation to the community at Toimairangi Marae, did get heard and was actioned. For example, one Taua suggested the research team ensure at all times in larger presentations requiring tikaka Māori (Māori customs) that we are supported by kaumātua. It was a suggestion given and received as a “kia tūpato” kōrero (be careful warning) rather than to belittle us. At this particular hui the kaumātua supporting the research team could not attend and we prepared one of our senior male colleagues to take his place on the paepae (formal speaking platform). The Taua was rightfully speaking out to say that we need to manāki (look after) our manuhiri (our Pākehā colleagues we work alongside and not put them potentially into this position), and to have a kaumātua aligned with the project gave the project mana. We agreed and realised we could have postponed the hui to a time that suited our kaumātua and not allowed our own planning logistics to get in the way of tikaka (custom). We made sure at all future hui and

wānaka (workshops) we had a kaumātua present representing the project in Ōtepoti (Dunedin), we also approached this particular Taua (she is also part of our Rōpu Kaiarahi) to be our kaumātua who represented the project in Murihiku. She graciously accepted and the project has been enriched by their presence and their wisdom throughout all phases of this study.

We have mentioned previously in this report that we were aware that the research question did not emerge from the Murihiku hauā Māori community or the disability services. It was a research project placed upon this community and we acknowledge that this could be perceived as a denial of self-determination. We hoped, however, that throughout the rest of the project and given the working relationship between the research team, Ngā Kete Mātauraka Pounamu Charitable Trust (will refer to as Ngā Kete Trust from now on) and Awarua Services we were able to address self-determination within the way we conducted the qualitative interviews, the way we communicated to all involved with this project and paid the utmost respect to tikaka processes that the participants and Ngā Kete Trust wanted to abide by.

Most interviews were conducted at the participant's home, some in a private office at Ngā Kete Trust (warm, refreshment facility, centrally located and physically accessible for all) and one interview took place in a church administration area (this was a special place to the participant and he felt most comfortable here). Some participants preferred to be outside of their home environment and this was easily accommodated due to the arrangement we had with Ngā Kete Trust.

Taonga Tuku Iho – The Principal of Cultural Aspiration

The Hauā Mana Māori project encouraged tikaka, te reo Māori and Mātauraka Māori (Māori knowledge) to be expressed by all involved with the project. We prepared ourselves as Kairakahau Māori with karakia (incantations), waiata (Māori songs) and read previous Māori research by disabled Māori academics and service workers that guided us to better conduct ourselves in this research project. That is not to know everything, but to know our limitations with our reo Māori and cultural knowledge and be able to articulate this with our participants and Ngā Kete Trust. In one of the interviews the kaumātua wanted to express predominantly in te reo Māori. This was encouraged, yet the Kairakahau Māori did ask if it was alright that if she needed to seek clarification could she

ask again in either te reo Māori or English to ensure she was following the conversation and not getting lost in translation. The participant happily agreed and the interview proceeded.

Utilising a holistic approach with the Pōkare Whakāro visual tool (discussed in more detail later in this section) 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. Two participants were confident and passionate to lead the interview process with *karakia* at the beginning and end, and one participant illustrated how singing *waiata* and performing *haka* helped his *wairua* (spirit) and *tinana* (body). He felt invigorated and empowered through the *waiata* process.

Ako Māori – The Principal of Culturally Preferred Pedagogy

Alongside the kaupapa Māori principals, the values that have been shared with us by the participants, *whānau* and Ngā Kete Trust's own health model, the Pōhā Model have influenced the research methodology and enriched the study. Throughout the analysis process we incorporated a few other pedagogies to guide us through this process, such as narrative and thematic analysis. The Kairakahau Māori had *wānaka* to discuss the analytical methodology and how we were individually and collectively interpreting the data. We were pleased that we agreed and felt similar with all themes that were presenting themselves in the data gathered. Our conclusions were later ratified when we presented the initial key themes to our Rōpu Kaiarahi in January 2013. They affirmed that the visual diagrams presented to them were a good representation of what life was like for them in the Murihiku community. This justified to us that we had **heard** the information the participants had shared, and through the analytical process, we had managed to capture the key themes that resonated well with the Rōpu Kaiarahi.

Kia Piki ake I ngā raruraru o te kainga – The Principal of Socio-Economic Mediation

Adelaide Collins is a social science researcher in Māori Development and the Director of MDRC – Māori Development Research Centre. Adelaide has worked alongside other research colleagues on numerous research projects that inform the Ministry of Health, non-government education and health service providers, *whānau* Māori and the research

community about priorities for research as directed by whānau with a disability. We utilised the summary Adelaide, Huhana Hickey, Nancy Higgins and Hazel Phillips wrote for the Health Research Council and the Ministry of Health in 2009. The outcome of their study highlighted the need to develop a research agenda on Māori Health as perceived important and necessary from whānau living with a disability. It was noted in this report that they made a clear distinction between “moving public perception away from treating disabled people as social outcasts to viewing societal structures critically”. This report also reminded us as Kairakahau Māori how difficult it can be for Māori and their whānau living with disability in Aotearoa because of the multiple barriers that are placed before them. This includes being Māori, being disabled, often being unemployed or unable to work to their full capacity and more so if they are all of the above and are wāhine Māori (Collins et al 2009, Mikaere 1994, Pihama 2008). The desire from the whānau interviewed for this particular report was to reduce the “marginalization of disability issues in the health sector and the marginalization of Māori in the disability sector”.

Performing a quantitative component to this research project addressing a collective of Murihiku services that worked specifically in the disability arena, allowed this research to be informed of what the services believed they were doing to improve their delivery to meet the needs of their Māori clients. Through the qualitative and quantitative processes also, Māori living with disability and clients of their service-determined details on improvements and how to make these changes.

The discussion around access to pūtea (funds) or employment was raised with most of our participants and will be discussed in the findings section of this report, but needless to say it was a prominent issue that we thought might be raised. We perhaps did not fully comprehend prior to commencement of this project just how much this issue is altering the wellbeing of the Murihiku disabled community.

The socio-economic concerns that hauā Māori express led us to think beyond the WINZ and ACC handouts and to think more strategically and long term that involved the services the participants utilised and how financial status did not dictate access to health care. Please see the recommendations in the findings section of this report for further elaboration on the above.

Whānau – The Principal of Extended Whānau Structure

The role of the whānau in the Hauā Mana Māori project is illustrated in the Pōkare Whakāro Visual Tool discussed in greater detail below. Whānau are placed in the inner circle surrounding the hauā Māori participant. The outer circles all embrace the concept of whānau ora, and address the health needs of the whole whānau. Whānau Ora gives whānau autonomy through access to resources such as health care and health education, connecting whānau to services and promoting whānaunaukataka (relationships) by the very nature of placing a role and responsibility with the whānau to maintain wellness. Whānau can also seek support from the Whānau Ora “navigators” key support workers within the Whānau Ora services that can assist whānau not confident or unable to access the support in the community (Te Puni Kōkiri 2011).

Whānau are integral to the wellbeing of hauā Māori because they are often their primary kaiāwhina (carers), their kaitautoko (support people), their eyes, their ears, their nurses, their communicators and their advocates. For the Hauā Mana Māori project we also interviewed couples, predominantly these relationships involved one partner looking after the other, but for some couples disability affected them both, this made life very challenging. There were no restrictions placed around who could be considered whānau in this research and we noted that close friends, animals and health service workers such as nurses and doctors were included into whānau descriptions.

Murihiku has a larger Māori population than the Otago region (6% larger) and given that Ngāi Tahu are the dominant Southern iwi it was not surprising that most Māori in Murihiku identified Ngāi Tahu as their iwi (35%). Given the geographical placement of Invercargill and the surrounding Southland townships that lie in the Murihiku borders the tribal representation of: Ngā Puhi, Ngāti Porou and Ngāti Kahungunu is impressive (24.7%) (Statistics New Zealand 2006). Often their whānau are in the North Island or overseas and yet they do not appear to want to live anywhere else; coming strongly through the narratives of the study participants was a desire to live in Murihiku until they die. So the concept for whānau for some Māori in the Murihiku area was of an extended whānau basis. They then have new and often unrelated whānau around them and have their blood relatives distantly located. This did not appear to be an issue for many of the participants of this study.

Whānau for a number of hauā Māori can be in the long-term relationship they have formed with their doctor or their nurse at their health service. Developing friendships with health professionals and seeing them as whānau is a relationship that the Hauā Mana Māori study investigated further with the service surveys and interviews.

Kaupapa - The Principal of Collective Philosophy

Although it has previously been mentioned that the kaupapa of finding out what facilitates and what stops hauā Māori using services was a research concept that originated outside of the community, what has been interesting to note in the Southern DHB Māori Health Action Plan 2011/12, is the national health priority 4.2. *To reduce the barriers for Māori to access care.* Only 74% of Māori living in the Southland area are enrolled in the Southern PHO, in comparison to 94% non-Māori. The Kaiwhakahaere Hauora Māori (General Manager for Māori Health, Southern PHO), Donovan Clarke, alongside his team of colleagues highlighted the goal to address the issue of access to care with the utilisation of research and development (Southern District Health Board 2011).

Whilst the Hauā Mana Māori project was in consultation mode with the hauā Māori community about the aims of this research project, the Whānau Ora collective called Te Poha Oranga (Ngā Kete Trust and Te Runanga of Awarua) were running community consultation hui 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.

Therefore with the accessibility issue already raised in the Southern District Māori Health Action Plan 2011/12 and within the Whānau Ora consultation Hui, we believed we could also add to this discussion and potentially provide some recommendations that contributed to the overall accessibility kaupapa.

Te Tiriti o Waitangi – The Principle of the Tiriti o Waitangi

Confirmed to Māori upon the signing of the 1840 Tiriti o Waitangi were the rights and privileges of British subjects, alongside the exclusive right for the Crown to buy land that Māori wanted to sell, and in return, the Crown guaranteed full rights to Māori as owners of their lands, forest, fisheries and other possessions. The English version described the

guaranteed full rights as “undisturbed possession” of all their properties, but in the Māori version of the Tiriti o Waitangi it used the words “tino raNgātiratanga” (sovereignty) over what Māori perceived as treasure (taoka). Given the many years of post Tiriti discrepancies, predominantly over land retribution and Tiriti breeches, the clauses in both the English and Māori version of the Tiriti that entitles Māori to have access to health services and to enjoy the benefits of wellness lies in the rights as British subjects and the autonomy to perceive the hauora (health) of Te Iwi Māori as a taoka. This taoka that we cherish and care about is not only a task for Māori alone but also a responsibility as Crown partners to provide equitable health access, services and treatment. The state of Māori health provides a somber picture in a country that on appearance does not equate. The expanding margins between Māori and non-Māori health and the increasing numbers of Māori contracting diseases or chronic illnesses that are not normally associated with Māori is a huge concern.

The Tiriti o Waitangi is an important document that is woven into all national Māori and Mainstream Health Plans to not only meet the Tiriti obligations, but to put effective research, policies, strategies and funding in place to reduce the health inequalities between Māori and non-Māori and address the problem now, before it becomes unmanageable tomorrow.

The Hauā Mana Māori project was a partnership between the University of Otago School of Physiotherapy, the Donald Beasley Institute, Ngā Kete Mātauranga Pounamu Charitable Trust, Kairakahau Māori and Hāua Māori and their whānau. There were numerous cultural and working partnerships within this research project. The Tiriti principals of partnership, participation and protection were worked at by all members of the team and challenged also at times. These challenges involved cultural practices verses mainstream processes and were mostly resolved. The research team and the way we approached the study became more in line with the principals of the Tiriti utilising the protection and participation values as we worked through the project (Orange 1987, Waitangi Tribunal).

Acknowledgement must be given for the above section to Rautaki Ltd for producing the website Rangahau – this is a fantastic resource for emerging and experienced Kairakahau Māori and mainstream researchers: www.rangahau.co.nz

Pōkare Whakāro Visual Tool

The initial concept that facilitated the way we wanted to approach the qualitative interviews originated in the traditional processes and wisdom of tūpuna Māori. We wanted to look to the past in order to help find a method, find a visual tool that would gently guide the kōrero of our participants.

We were attracted to Mason Durie's Te Tapa Whā Māori Health Model designed by Mason alongside some of his mental health colleagues in 1982 to address Māori mental health assessment and care planning as a holistic strategy to introduce the research project to the Rōpu Kaiarahi (Durie 1998).

Durie likens Māori wellbeing to the main pillars of a whareniui. Whareniui are the embodiment of a specific chiefly tupuna. The whareniui within this wellbeing model represents the body of the person being assessed. Durie described the four pillars of the whare tūpuna as the following:

Te Tapa Wairua – Spiritual Health

Te Tapa Hinengaro – Mental Health

Te Tapa Whānau – Extended Family Health

Te Tapa Tinana – Physical Health

The concept of the Tapa Whā Model is that if one of these pillars becomes unwell then the others will be sacrificed or placed at risk of also becoming ill. The whare will be unstable unless consideration and health planning is put in place to not only heal 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.

We found that the Tapa Whā Model allowed us initially to look at “access” to health and support services from a hauā Māori, whānau and service perspective. It was another insightful tool that allowed us to delve a little deeper into the participant's narratives to find some of the more intricate and intangible reasons for not attending health services or health support groups.

It was suggested by one of our Rōpu Kaiarahi members that another holistic concept to include in the development of a visual tool was the Tuakana/Senior and Rakatirataka

(Chieftainship) realms. For this member, these divisions or entities embraced a sense of a higher being, power generator or knowledge source that aided the participant.

The Kairakahau Māori further developed the visual tool to include some of the values associated with kaupapa Māori that were believed to be strongly connected to the topic of our research such as: 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). Parallel to the construction of the Pōkare Whakāro visual tool we wanted to keep aligning the visual tool and ourselves with Te Ao Tawhito (the ancient world of our tūpuna) to see what could connect the tool to something of the past. The Kairakahau Māori aligned the emerging Pōkare Whakāro Visual Tool to the ancient whare, made from a number of natural resources depending on what was growing in close proximity to the kaika (village) such as: toetoe, patiti (tussock), wiwi (rushes) raupo (bulrush), harakeke (flax), muka (flax fibre), kōrari (flax flower stalks) and nikau leaves. These whare were thatched together, low to the ground and small to keep heat in (Beatties 1994). They were waterproof and sturdy but constructed entirely with fibrous materials, they were also porous and this is the concept we wanted to portray with the Pōkare Whakāro visual tool.

We placed the whare inside the puna (pool of water/pond) to represent the participant, their embodiment of themselves. This then allowed the Kairakahau Māori to utilise this thinking – this breathable porous whare to be part of the tool. We used the short hyphenated lines around the whare to represent the movement between the whare and the elements inside and out of the whare on the visual representation.



Figure 12a: Pōkare Taparima Visual Tool

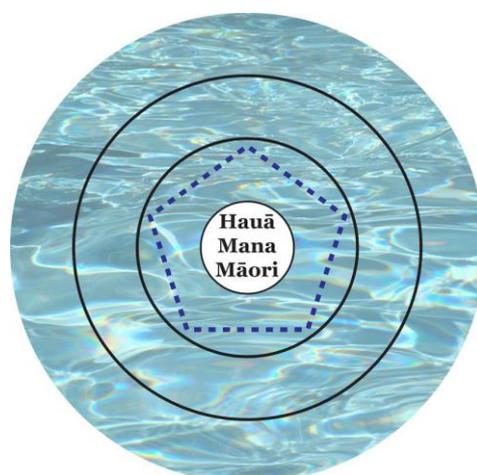


Figure 12b: Pōkare Whakāro Visual Tool

We also likened the concept of a kōhatu (a stone or pebble) being dropped into a pool of water (puna) and when this occurs the ripple (pōkarekare) affect that occurs is not only a beautiful phenomenon but it also represented for the Kairakahau Māori how Māori with a disability create an affect or ripple in their community. Hauā Māori can create a displacement of thinking, of services, of needs, of discomfort, of challenge, of excitement, of raw energy and of love. Their energy does appear to create ripples and we felt that it was how whānau and services perceived those ripples gave us a good indication where the facilitators and barriers were for our participants.

A puna using water imagery was placed inside a porowhita (circle) and another two porowhita were placed inside these porowhita. The inner porowhita represented the participant living with a disability in the Murihiku area. They were the kōhatu (stone or pebble) that guided and 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 borders of the porowhita represented Whānau Ora and this reminded us to keep the whānau close in order to ensure we were not just looking at the participant's wellbeing but what aided their wellbeing and the wellbeing of their whānau. Thus Whānau Ora was placed on every porowhita or pōkarekare (ripple). The last porowhita included principals of kaupapa Māori research as mentioned above. These were values that we believed not only guided the participant but also guided the Kairakahau Māori with communication amongst the research team, services, advisors, Rōpu Kaiarahi and Hauā Māori and their whānau.

Once we had completed this version of the visual tool and could see the values and how it could potentially work, we were able to see that at this stage of shaping, the visual tool was too wordy, too crowded and needed some space and light. We wanted to remove the words so that the only words that came to be on this visual tool were those of our participants. Hence, a new visual tool was developed and laminated. One large A1 poster and another A3, these allowed us to use the visual tool in potentially larger group settings or the smaller one for the individual and their whānau. Having the visual tool laminated allowed white board markers to be used upon them and wiped away at the conclusion of the interview. A photo was taken of the visual tool prior to wiping away the contents and this was also analysed to assist the Kairakahau Māori in the findings.

feedback and were able to improve on how we delivered the tool to individuals. We were also able to critique the tool for ourselves and conclude that the tool was not as effective as we hoped with the larger focus group due to a) the management of this wide range of people with their differing views b) their level of understanding of the research project and c) questions and the terms used and the dynamics in the group from those eager to share to those slightly intimidated by the group setting. We needed to sharpen our group management skills and ultimately the visual tool did not appear in this trial run to manage the multiple issues that were being shared so that what was left at the end of the session could still be effectively analysed in order to contribute to the findings.

The individual trials went well and we received great feedback to encourage us to continue with the Pōkare Whakāro visual tool with the rest of the qualitative interviews. People commented on liking the space on the tool, it gave them a sense that they had freedom to speak their thoughts. Others liked the water element and said it looked like paua with the blue, this appealed to them.

The interviews were also audio-recorded and hence the thoughts gathered on the visual tool were key themes that were being presented in their kōrero. At the end of the interview the Kairakahau Māori would go over the Pōkare Whakāro visual tool with their participant as an overview of what was discussed in the qualitative interview to ensure what we had captured was indeed what the participant was trying to share. A secondary response to the visual tool that had not been predicted by the research team were the benefits expressed by the participants in not only taking the participant through this process of expression about their lives and their wellbeing but the end result was that the participants were able to see their own ora (wellbeing), lives, challenges, supports, strengths, 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.

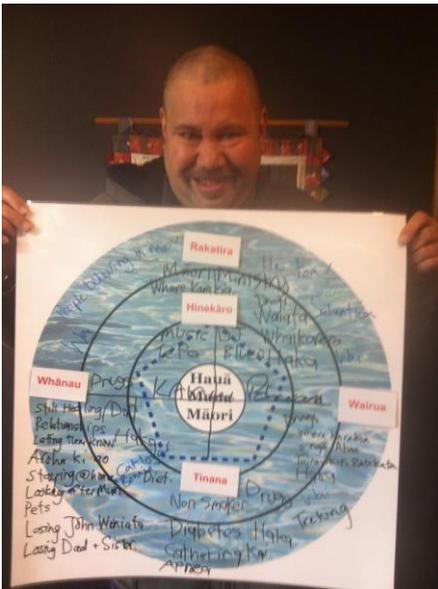


Figure 14: Kanui holding his Pōkare Whakāro Figure 15: Kairakahau’s Pōkare Whakāro

We also learnt during the trial run of the Pōkare Whakāro Visual Tool how to modify and improve on our questioning technique. We gained insight into what questions made sense for most and which questions were too confusing or too hard to answer for others. We were able to refine the questions and obtain a sense of whether the amount of questions we had were overwhelming, not enough or if we needed to formulate another genre of questions.

We decided it was also important to trial the tool on ourselves and put ourselves through what our participants may experience whilst taking part in the interview process. This again was another affective way to have empathy with our participants, to potentially see where the questions did not work so well or did, and to also test our own interviewing skills to ensure we were delivering the interviews in the same way.

Hearing the Kōrero (analysing the data)

We used thematic analysis as a qualitative analytic method. This analytical approach allowed us to identify patterns and standalone issues with the data. Thematic analysis also provided the sense of movement or flexibility as opposed to other analytical methods that appeared to place firm boundaries on where the data lies (Braun and Clarke 2006). As emerging Kairakahau Māori relatively new to analysing data and understanding the numerous global theories that can aid or restrict the analytical process, we felt that by not subscribing to any other theory other than kaupapa Māori we were able to reflect more

closely the themes that were presenting themselves in the narratives. What we did do however is learn from our senior researchers and through reading thematic analysis references on how to manage this process more effectively. Braun and Clark (2006) emphasized the need to know the data well, to read the transcripts a number of times to become very familiar with the content. We developed initial codes that enabled us to organise the data into groups. We then used a series of mapping techniques to seek themes and to re-organise the themes with sub themes.

With the key themes in draft form we returned to Murihiku to the Rōpu Kaiarahi to hear their thoughts to what we had been able to find within their kōrero from both service surveys and participant interviews. They were really interested in the findings and early presentations of the themes. They thought the interpretation of the research results did depict their kōrero well and they appreciated seeing it clearly mapped out. We were asked if we were would consider producing brochures that reflected what they were seeing.

So you just outlined clearly, like a wee template for us...I'm part of a few different places, that's a really good thing for me to show...as a thing, you know as, or even if they ask me for a talk that's a really good way of showing it, so that's really to me it's very educational ... (Rōpu Kaiarahi participant in response to our first draft of findings)

We returned to the Pōkare Whakāro Visual Tool to see if what we used in the approach to the research would work again in aiding the analysis. We found that when we placed the Pōkare Whakāro alongside the thematic maps we began to see an evolution process take place that reflected what we were seeing in the themes and also what was fed back to us at the Kaiarahi Rōpu session.

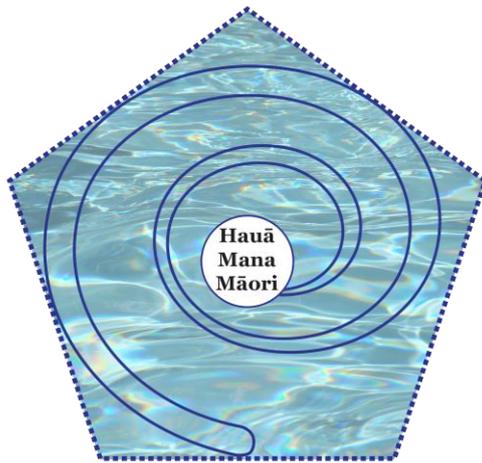


Figure 16: New image of Pōkare Whakāro Visual Tool

The image of the whare tupuna that sat within the puna (pool of water) in our first diagram became the porous walls at the edge of the puna, almost engulfing the water.

This transition of the whare tupuna from internal to the exterior of the puna reflects the journey many of the participants went through and many are still experiencing. For some being part of this research journey had aided them to see their strengths and weaknesses. They had seen where they needed to take responsibility for their internal barriers to accessing care for themselves, but to also see how services and the community can make changes to provide better for Hauā Māori.

The new image of the Pōkare Whakāro Visual Tool (as seen above) removed the porawhita (circles) and replaced these with a koru (spiral) that stems from the Hauā Māori in the centre and swirls around and away from the takata (person) and towards the edge of the whare tupuna. The Whānau Ora concept is now represented in the double lines of the koru. The movement around and out depicts the autonomy of the hauā Māori and their whānau, the energy flow that continues to go out and then back in a cyclic motion. This is another way of perceiving the pōkarekare (ripples) that hauā Māori produce within their community. This version of the visual tool shows strength, a readiness to address their health needs and an awareness of perhaps some of the services, advocates, whānau that perhaps can assist them live their lives not alone and powerless but empowered and enriched.



Figure 17: Tamati Ruru and Kanui Poharama (Members of the Rōpu Kaiarahi for the Hauā Mana Māori Project) - “Strength is Expression of Self”

APPENDIX 5: Glossary of Māori terms

The follow simple descriptions may assist readers in interpreting the use of Māori terms in this report.

Aroha	-	love
Hapū	-	collection of whānau who are related
Hauā Māori	-	Māori living with disability
Hinekarō	-	emotional, thought
Iwi	-	collection of hapu
Karakia	-	prayer
Kaumātua	-	older person (generally male of high status)
Kaupapa	-	philosophy
Kōrero	-	speak, talk
Ko te Pōkare Whakāro	-	The Ripple Visual Tool
Mana	-	Honour, control, influence, prestige, power,
Marae	-	meeting place
Mātauraka	-	knowledge
Mihi	-	statement/acknowledgement of welcome
Mihimihi	-	statement of identity (who a person is: their mountain, river and people)
Mihi mutuka	-	ceremony of farewell and leave-taking
Oraka	-	well-being, wellness
Pōwhiri	-	ceremony of welcome and greeting
Puna	-	pool of water
Tikaka	-	protocols
Te Reo Māori	-	Māori language
Wairua	-	spirituality
Whakapapa	-	genealogy
Whakatau	-	informal greeting ceremony
Whakawhānaukataka	-	to form relationships and networks
Whānau	-	collective of people who are related
Whanaukataka	-	linking through genealogy (whakapapa)
Whare	-	house
Wharenui	-	meeting house
Whenua	-	land