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Māori with Disabilities (Part Two):
Report Commissioned by the Waitangi
Tribunal for the Health Services and
Outcomes Inquiry (Wai 2575)

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Acknowledgements

He waka eke noa.

We are all in this together

This whakataukī has several meanings, one of which is “a waka we are all in together” – we are all in this together – we rise together, fall together, work together, keep going together.

Accordingly, we would like to thank the whānau, caregivers, providers, experts and disability professionals who graciously gave of their time to help guide and inform this research project, and in particular, those who agreed to be interviewed. Ngā mihi nui ki a koutou te whānau!

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Glossary

Aotearoa	New Zealand
Hapū	Subtribe
Hautupua	Remarkable, extraordinary
Hōhā	Fed up, bored, tiresome
Hui	Meeting, gathering, assembly
Iwi	Tribe, extended kinship group, nation, people
Ka pai	Good
Kaiārahi	Navigator, guide
Kainga	Home, village, settlement
Kanohi ki te kanohi	Face to face
Kāpō	Blind
Kaumātua	Elderly
Kaupapa	Purpose, topic, policy
Kaupapa Māori	Approach incorporating Māori knowledge, skills, attitudes, principles and values
Kaupapa whānau	Non-kin family
Kawa	Protocols, customs
Kōrero	Discussion, conversation, discourse
Kuia	Elderly woman, grandmother
Kura	School
Kura kaupapa	Primary school where children are taught mainly using Te Reo
Mākutu	Magic, sorcery, spell, curse
Mana	Prestige, authority, control, power, influence, spiritual power
Mana motuhake	Autonomy, self-government, self-determination, independence
Manaakitanga	Hospitality, generosity, kindness

Māoritanga	Māori culture, Māori practices and beliefs, Māoriness, Māori way of life.
Marae	Courtyard or open area in front of the meeting house (wharenuī) but also used to describe the complex of buildings around the marae
Marae atea	Courtyard/public forum, open area in front of the meeting house (wharenuī) where formal welcomes to visitors take place and issues are debated
Mātauranga Māori	Māori knowledge, originating from Māori ancestors, the Māori world view and perspectives
Maunga	Mountain, mount, peak
Moko	Grandchild, short for mokopuna
Motu	Land, country
Noa	To be free from the extensions of tapu, ordinary, unrestricted, void
Pākehā	Person of European descent
Parapara	Talents, gifts
Pūrākau	Story, myth, ancient legend
Pūtea	Money
Rangatahi	Young person
Rōpū	Group, party
Tāmaki Makaurau	Auckland
Tamariki	Child/children
Tangata/tāngata	Person/people
Tangata whaikaha	Person with a disability
Tangi	Funeral
Tapu	Sacred, prohibited, restricted, holy
Te Ao Māori	The Māori world
Te Reo Māori	The Māori language
Te Tiriti	The Treaty of Waitangi
Tikanga	Correct procedure or custom

Tikanga Māori	Māori procedure or custom
Tino rangatiratanga	Self-determination, sovereignty, autonomy
Tohunga	Expert practitioner of any skill or art
Tupuna/tupuna	Ancestor, grandparent/ancestors, grandparents
Whaikaha	Disability
Whakamā	Shy, embarrassed, ashamed, bashful
Whakapapa whānau	Kin family
Whakaoranga	Relief, redress, revival, recovery, restoration, rehabilitation, rescue
Whakaaro	Think, plan, consider, decide
Whānau	Family, extended family, friends, a familiar term to address a number of people
Whānau Hauā	Māori with a disability
Whānau Ora	Government whānau centred strategy to assist families to reach their aspirational goals
Whanaungatanga	Relationship, kinship ties, sense of family connection
Whāngai	Foster child, adoptive child
Whare	House
Whareniui	Meeting house

Abbreviations

ACC	Accident Compensation Corporation
CCS	Crippled Children Society
CYFS	Child Youth and Family (currently known as Oranga Tamariki – Ministry for Children)
DHB	District Health. Board
DPO	Disabled People’s Organisation
ICF	International Classification of Functioning, Disability and Health
IHC	Society for Intellectually Handicapped Children

IHCPA	Intellectually Handicapped Child and Parents Association
MoH	Ministry of Health
NASC	Needs Assessment and Service Coordination
ODI	Office for Disability Issues
UNCRD	United Nations Convention on the Rights of Persons with Disabilities
UNDRIP	United Nations Declaration on the Rights of Indigenous Peoples
RSA	Royal New Zealand Returned and Services Association Inc.
WHO	World Health Organisation

Introduction

This report is part of the Wai 2575 Health Services and Outcomes Kaupapa Inquiry, concerning alleged Treaty breaches by the Crown in regards to Māori health and wellbeing. In directions from the Chief Judge, this inquiry was organised into a three-staged approach:

1. priority themes that demonstrate systems issues (Stage One)
2. nationally significant system issues and themes that emerge (Stage Two)
3. remaining themes of national significance, including eligible historical claims (Stage Three).¹

For Stage Two, the inquiry was also further defined into three priority themes:

- Māori mental health (including suicide and self-harm)
- Māori with disabilities
- alcohol, tobacco and substance abuse.

This report has been produced to provide research evidence for the particular focus on 'Māori with disabilities' for the Wai 2575 priority theme.

Report Focus

In a direction from 28 June 2018, Judge S R Clark confirmed that the Waitangi Tribunal would prepare three separate research reports for stage two of the Wai 2575 Health Services and Outcomes Kaupapa Inquiry². Based on the recommendations from a pre-casebook discussion paper³, and the consideration of collected evidence and bibliographic material, an overview report concerning the stage two priority theme of Māori with Disabilities was commissioned, with the purpose of delivering an overview of government provision of disability services and their effectiveness for Māori.

On the 21 December, Judge S R Clark confirmed that the *Māori with Disabilities* report will be split into two separate parts⁴. Part One of the report is to focus on a review of available literature and documentation to provide an overview of the Crown role in:

- recognising, addressing and contributing to disparities (or inequity) in outcomes for Māori with disabilities.
- the provision of accessible disability services and programmes for disabled Māori, including the kind of barriers that Māori and their whānau might face in gaining adequate access to disability services such as physical, geographical, financial, educational; reluctance based on previous

¹ Wai 2575, #2.5.17, para 6.

² Wai 2575, #2.5.29

³ Wai 2575, #6.2.3 Pre Case-book Discussion Paper: Part 1, April 2018, Waitangi Tribunal Unit

⁴ Wai 2575, #2.3.4

poor experience or cultural barriers; and government policies and practices recognising and addressing or contributing to those barriers.

- the responsiveness of disability services for Māori, including how well Māori with disabilities are treated and cared for in the health system; how well specific requirements of Māori with disabilities are met by government agencies and health providers; clinical responsiveness to the needs of Māori with responsibilities; the adequacy of Māori focussed programmes for Māori with disabilities; Māori participation in the workforce caring for Māori with disabilities; and Māori participation in governance, decision making and policy development for disability services.
- the effectiveness of disability services for Māori, including evidence of how well Māori needs are addressed by the health system; the adequacy of monitoring the effectiveness of services for Māori with disabilities; the extent to which government disability services achieve desired health outcomes for Māori; the adequacy of decision making over what Māori disability information is collected by government agencies; and how well such information is used in developing, monitoring and implementing policy, legislation and practices in disability services.

Recognising the gap in current available literature or documentation of the lived experience of Māori with disabilities and their whānau, as well as of providers of services to Māori living with disabilities, the Waitangi Tribunal scoped Part Two of the *Māori with Disabilities* report. This report is to be based on gathering qualitative, primary evidence through oral interviews to explore key topics identified in the pre-casebook discussion paper:

- disparities in health outcomes and poor health outcomes for Māori with disabilities
- Māori access to disability services
- responsiveness of health services to Māori disability needs
- effectiveness of health services for Māori with disabilities.

The focus of this report is on the experiences of Māori with disabilities, whānau experiences of the provision of disability services, as well as expert and provider views on the provision of disability services and their effectiveness for the health and wellbeing of Māori with disabilities.

Moreover, the specific questions that this report addresses include:

- how the contemporary health system, including legislation, policies and practice recognise and provide for the needs of Māori with disabilities; and to what extent implementation may diverge from policy objectives.
- the extent to which disability policy and practice provide culturally appropriate disability services and treatment for those Māori who require it, or provide for Māori led and developed systems and methods of disability care/Kaupapa Māori.
- the extent to which Crown acts or omissions have contributed to disparities in disability service and outcomes between Māori and non-Māori, and whether/how these have been recognised and addressed.

- what barriers Māori experience in accessing disability services, and how existing Crown policies and practices have recognised or addressed such barriers.
- the efficiency of the current monitoring and data collection for identifying and addressing any disparities in disability services and outcomes for Māori.
- the extent to which Māori have had opportunities to contribute to relevant policy and legislative development.
- the key historical developments that have contributed to the current system of government disability services for Māori and to Māori experiences and attitudes to disability services.

Claimant issues around Māori and disability identified within Statements of Claim⁵ further informed the scoping for this project and the particular questions that are explored throughout the oral interviews and the contextualising review.

This report is organised into two specific sections:

- section one presents a historical overview of Māori and disability, including the development of relevant policies and resulting practices in regards to Māori and disability.
- section two looks at the thematic analysis of the qualitative interviews – which are the main sources of new data - and ends with the conclusion.

Themes

The second part of this report has been organised around themes that have emerged from primary interview data with Māori living with disabilities, their whānau, Māori disability service providers, Crown agents, and academic and professional experts working within the field of disability.

Theme 1 Terminology

The first theme concerns issues around ‘terminology’ and captures the various discussions that were held during interviews around the importance of terminology and the diversity of which ‘name’ adequately captures lived experience of disability for Māori. This theme also frames the report, in that it sets up important conversations around identity, which were contained throughout the interviews.

The following additional themes have not been organised in any order of perceived importance, but instead to capture a sense of flow of the interrelated nature of the themes.

Theme 2 Policies and Legislations

⁵ Summary of Claims Issues for the Māori with Disabilities Report, Riana Te Ngahue; Waitangi Tribunal, 2019

While part one of this report provided a context to how policies and legislations have strongly shaped aspects of service delivery for Whānau Hauā⁶, the theme around this impact was conveyed in interviews in less definable ways, where whānau and Whānau Hauā focused on the lived experience of policies that were often obtuse and un-relatable to the realities of their lives.

Theme 3 Systems, supports and services

- Engagement
- Diagnosis and treatment
- Workforce capability and capacity
- Access and accountability

All interviews became focused on systems, supports and services, which for the sake of clarity have been broken down in analysis to capture particular sub-themes that were highlighted throughout the interviews. The themes of ‘engagement’, ‘diagnosis and treatment’, ‘workforce capability and capacity’ and ‘access and accountability’ have been identified as central components of the interview data.

Theme 4 Participation and inclusion

The theme of ‘participation and inclusion’ in regards to decision making, came across strongly in the interviews, and has been broken down further into the areas of ‘advocacy’ and ‘representation’.

Theme 5 Crown funding and commissioning

A further theme that was reiterated throughout interviews concerns Crown funding and commissioning mechanisms, and the effect it has had on the lived experiences of Māori with disabilities.

Theme 6 Research, evaluation and data

The place of ‘research, evaluation and data’ was a theme that was identified in regards to service provision and planning, and in particular the impact of the current gaps in evidence on whānau experiences.

Theme 7 Aspirations

The final theme in the data analysis section is that of ‘aspiration’, which focuses on the voices of the interviewees in regards to their aims, goals and wishes for the future. The notion of focusing on aspirations in this theme represents where interviewees expressed the wish to move beyond the dominant ‘deficit’ thinking models.

⁶ This report uses the terms ‘Whānau Hauā’ and ‘Māori with disabilities’ to refer to Māori disabled. While the researchers acknowledge the different debates and preferences around terminology, the above terms are used here to be consistent with the terminology currently used in the Wai 2575 Tribunal documentation. See page 37 of this report for thematic discussions around terminology.

Methodology

This research report was designed to provide an outline of contemporary disability services relevant to Māori: how these are implemented; the impacts and outcomes for Māori, and Māori responses; along with Māori participation in legislation, governances and policy developments in respect to disability services.

This project focuses on four key topics which were identified and discussed in the pre-casebook discussion paper⁷ as these relate to disability services for Māori:

- disparities (or inequity) in outcomes for Māori with disabilities
- accessibility of disability services for Māori
- responsiveness of disability services to Māori
- effectiveness of disability services for Māori.

This research was carried out within a Kaupapa Māori framework. Kaupapa Māori research broadly refers to research that utilises mātauranga Māori and Māori 'norms'. It is underpinned by Māori philosophy and principles, resonating with a Māori world view. Specifically, this research focused on the principles of Whānau (relationships), Tino Rangatiratanga (self-determination) and Tikanga Māori (Māori cultural practices). These particular principles were a focus in the context of this research as they are relevant to the ethical and methodological approach which underpins this research. These principles guide the overall research process including the way in which the researchers engage with all participants, as explained below:

- *Whānau:*

Whānau represent the core unit of Māori society, encompassing how people connect with each other and to the environment. Within this research, the principle of whānau acknowledges the responsibility of the researcher to nurture those relationships and to consider the relationship and power dynamics between researchers and those being interviewed.

- *Tino Rangatiratanga:*

The principle of Tino Rangatiratanga reinforces one of the goals of kaupapa Māori research, allowing Māori to take control of their own lives, aspirations, culture and knowledge. Tino Rangatiratanga was a goal of this research, to support Whānau Hauā to have their say on matters that are meaningful to them.

- *Tikanga Māori:*

Tikanga Māori refers to the undertaking of research which reflects and supports the cultural realities of Māori communities. Māori custom and processes are incorporated within the design of research methods, matching the diverse cultural experiences and needs of Māori.

Both primary and secondary research was undertaken in order to achieve the research objectives, hence the report represents the approaches in two specific sections of the report, where section one of the

⁷ Wai 2575, #6.2.3 Pre Case-book Discussion Paper: Part 1, April 2018, Waitangi Tribunal Unit

report features a review of available literature to present a historical overview of Māori and disability, while section two looks at the thematic analysis of the new data/qualitative interviews and ends with the conclusion.

The historical overview was compiled to provide relevant historical context to aid understanding of current issues of Māori living with disabilities. A literature search was undertaken to identify material relevant to the historical context of state policy on Māori and disability in New Zealand. Bibliographic searches of the online database EBSCO and Google Scholar were done, using the combination of terms Maori/disability/history and disability/history/New Zealand. Additional material was identified from the footnotes and bibliographies of retrieved items. The online database of the *Appendices to the Journals of the House of Representatives* was searched, using the combination of search terms Maori/cripple(s)(d), native/cripple(s)(d) and rehabilitation/Maori. The National Archives online database, Archway, was also searched, using the terms Maori/disability Maori/disabled, Maori/cripple(s)(d), rehabilitation/Maori, Native/cripple(s)(d), and rehabilitation/Native.

The primary data research component of this report focused on undertaking semi-structured interviews with a range of stakeholders. The researchers carried out qualitative individual and group interviews with a range of different practitioners, service providers, whānau claimants, and other whānau members. There were 27 interviews in total with 37 different individuals, many of whom wore multiple hats in their interview and in the disability space, meaning that they had lived experiences as either Whānau Hauā, or whānau, as well as working within the disability field.

The breakdown of the participants included:

- 10 experts⁸ in the disability sector
- seven service providers
- four whānau claimants
- eight Whānau Hauā
- eight whānau members.

The participants were recruited through a range of avenues. The Waitangi Tribunal provided an initial list of key contacts in the disability field which provided a starting point for interviews. Alongside this list, an email invitation was sent to all claimants, counsel and others from the Waitangi Tribunal distribution list to participate in the research. Furthermore, as the interviews progressed, recommendations and suggestions resulted in further recruitment of participants. All relevant governmental ministries were informed of the research project and contacted for participation – however, not all chose to engage.

⁸ It is acknowledged that all Whānau Hauā interviewed for this report were the experts of their own lived experience as Māori with disabilities. However, for descriptive purposes the term ‘expert’ is here used to refer to interviewees who have an established track-record of working within the disability sector as academics, advocates or strategists, who have helped to shape the conversation around Māori and disability.

It is important to note that there was no specific disability type inclusion or exclusion criteria for the interview participants⁹. For the purpose of this report there was a focus on Māori who *identify* as disabled, rather than the researchers defining the range of disabilities to be included or not. Furthermore, there was no emphasis on recruiting or defining ‘mental disabilities’ versus ‘physical disabilities’, just as there was no differentiation between participants born with disabilities versus participants who had acquired disabilities as part of their life-course or life events. The majority of the participants identified as having ‘physical disabilities’, notwithstanding, it needs to be noted that the complexities of these lived experiences does not exclude mental health concerns.¹⁰ However, for the purpose of the secondary data review, exploration of key policy and practice developments around mental health and ‘intellectual disabilities’ was included, to provide a full context of the evolving health discourse in relation to Māori.

Participants were located from a wide variety of different regions from across New Zealand. Regions which participants were interviewed from include: Te Tai Tokerau, Te Tai Tonga, Ikaroa-Rawhiti, Tāmaki Makaurau, Te Tai Hauāuru, Hauraki-Waikato and Waiariki.

The majority of interviews were conducted kanohi ki te kanohi (face to face), with some, due to time restrictions, being conducted via phone or Skype. As part of the ethical process for this research, full consent was sought from each participant to be voice recorded during the interview. This consent allowed the interviews to be transcribed, for use by the research team in the write-up of the report. Furthermore, in order to ensure that the researchers were able to capture information and perspectives which was both useful and transparent, participants were assured that their anonymity would be maintained throughout the research process. This practice and assurance has been consistent throughout all our research investigations and is part of a desire to ensure that all participants feel safe. More broadly, this idea is consistent with kaupapa Māori research principles and in particular the principle of ‘Manaakitanga’, which is applicable to the idea that participants should be kept safe and free to express themselves without risk to mana or tikanga. In accordance with standard ethical guidelines (Health Research Council New Zealand) the resulting interview transcripts have been kept in secure data storage - with only the researchers being able to access the information - where it will be kept secure for 5 years.

The interview schedule (see Appendix 2) was semi-structured, with each interview being shaped as a result of the nature of the kōrero (discussion) with the interviewee. There were three different interview schedules: one for service providers and experts; one for Māori with disabilities; and another for whānau members. The interview schedule was designed to reflect the experiences of whānau and

⁹ See also the United Nations Convention on the Rights of Persons with Disabilities (CRPD): “Persons with disability include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others.” CRPD Article 1, 2006. <https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities/article-1-purpose.html>

¹⁰ It is envisaged that this will be picked up by the ‘Mental health and Addiction’ component of the Wai 2575 research inquiry.

Whānau Hauā as described by them through their lived experience, and was based on the questions that this report addresses.

In concord with the decision to have a self-defined and all-inclusive criteria of 'disabilities' the interview questionnaire did not focus on specific disabilities, nor was it designed to elicit analytic 'comparison' of disabilities. Instead, the questionnaire allowed for exploration across a range of experiences, and across instances of multiple or concomitant disabilities.

The interview transcripts were individually analysed by the research team to recognise and shape key themes and topics emerging from the interviews. From this, key themes and sub themes were arranged in a table, along with relevant secondary data for the report for a cross-evidence analysis of themes

To allow for further understanding of the emerging themes, a brief quantitative analysis was also conducted. To this end a search of available online sources - including governmental web pages (for example, Ministry of Health, District Health Boards, Office for Disability Issues and Statistics New Zealand) and academic databases (for example, Google Scholar) – provided a context of available statistical data on Māori and disability. An analysis was done of original data sources available through organisations such as Statistics New Zealand, alongside a snapshot review of reports/journal articles/web pages that interpreted the original data sources. Comparison of the literature against original data sources was undertaken to validate the interpretations of data. Moreover, an investigation was completed of the content of available surveys to identify quality data sources that can best define properties of disabled population in New Zealand.

The draft research report was peer reviewed by Emeritus Professor Sir Mason Durie, in accordance with the Waitangi Tribunal Chief Historian's Evidential Standard guidelines, and the authors made all changes suggested by Professor Durie for the final report. Furthermore, feedback was received from interested parties, including the Crown, Tribunal claimants and their legal representatives, which were also taken into account for the drafting of the final report.

Sources

Information for this report was gathered from a range of different primary and secondary data sources:

- the primary research component consisted of 27 qualitative interviews with 37 participants. These individuals included a range of service providers, experts in the Māori disability field, Whānau Hauā, whānau and claimants. Participants were from different areas across New Zealand with representation from both urban and rural areas. The majority (33) of participants interviewed were of Māori descent.

- the secondary research included literature that was sourced through academic journals, searches of grey literature and the Waitangi Tribunal bibliographical sources document¹¹. Literature was also retrieved through online databases EBSCO and Google Scholar, with additional material identified from footnotes and bibliographies of retrieved items. The online database of the *Appendices to the Journals of the House of Representatives* was also searched, as was the National Archives online database and Archway.

Limitations

A number of limitations have been identified around the findings of this report, foremost in regards to time and sample-size constraints. The project was committed to a fast, six-month completion, with only three months dedicated for participant recruitment, interviews, analysis, and write-up. This in turn imposed limitations on the number of participants – while more than the 30 individuals and whānau originally planned were interviewed, with more time that number could have been increased significantly, especially in light of the overwhelming response from claimants, whānau, service providers, advocates, and academics involved in the Māori and disability space who wanted to participate in the project.

The purpose of the secondary source review was to provide the context against which the new primary data could be cross-checked for strength, and in this sense ameliorate some of the obvious limitations of sample-size. To this end, the themes that have been identified converge across the data. The 37 individuals involved in this project provide a “snapshot” of experiences and voices that give substance to the data that is currently available, and should be treated as such.

The gaps within the available, government collected quantitative data - which has been identified as part of commissioning rationale for this report - raises some further questions around limitations, and highlight the priority for more extensive research studies to grow out of this overview project.

However important it is to raise the above issues, there is full confidence in the validity of the findings and the ability of the report to inform and contribute, not just to the Waitangi Tribunal proceedings, but to the wider discourse around Māori health, wellbeing, and disability.

¹¹ Wai 2575, #6.2.3 Pre Case-book Discussion Paper: Part 1, April 2018, Waitangi Tribunal Unit

Section One:

Māori and Disability Services: The Historical Context

‘Disability’ within Te Ao Māori

There is a paucity of evidence¹² about pre-contact attitudes to disability within Māori society. Life was harsh and physically demanding; the necessity of survival through food-gathering and cultivation; and the demands of warfare would have placed a premium on physical prowess.¹³ Nikora et al note that the inference could be drawn that those with physical impairments would have struggled to find a valued place within communities.¹⁴ However, they also note that the elderly had a respected status within the community, which suggests that there was still respect accorded those who were physically impaired. They also infer that the status of those with physical impairments may have fluctuated depending on the availability of resources: in times of plenty, they may have been regarded as welcome participants in society; in times of need, they could have been regarded as burdens to the community.

Mason Durie has noted the importance of communal understandings of wellness and sickness in Māori society.¹⁵ Illness was not regarded so much as an individual affliction, but as a matter of social, spiritual and environmental significance for the community. Illnesses were attributed to an infringement of tapu, either by the individual afflicted, or another member of the community. Physical afflictions were therefore regarded as signs of a more fundamental spiritual transgression. The focus of treatment was upon trying to identify the source of the infringement and restore balance between tapu and noa elements in the environment, as well as addressing and relieving the physical symptoms. Physical impairments may have resulted in the isolation of the afflicted individual, and possibly their wider whānau, as a way of addressing this imbalance. Nikora et al suggest that there is evidence such attitudes may remain in contemporary whānau, with attitudes of whakamā and secrecy surrounding whānau

¹² Due to the scarcity of historical research into disability in New Zealand, this review has been informed broadly by the works of Tennant and McClure. The review of their works (and others) has been included primarily to provide the overarching context to situate the analysis of the new primary data in section two of this report.

¹³ L.W. Nikora, R. Karapu, H. Hickey, & N. Te Awetokutu, *Disabled Māori and disability support options: Report for Ministry of Health*, Hamilton, 2004, [http://www.moh.govt.nz/NoteBook/nbbooks.nsf/0/E47418EA66705C62CC2572640002A83A/\\$file/disabled-Māori-disability-support-options.pdf](http://www.moh.govt.nz/NoteBook/nbbooks.nsf/0/E47418EA66705C62CC2572640002A83A/$file/disabled-Māori-disability-support-options.pdf), accessed 23/1/2019.

¹⁴ L.W. Nikora, R. Karapu, H. Hickey, & N. Te Awetokutu, *Disabled Māori and disability support options: Report for Ministry of Health*, Hamilton, 2004, [http://www.moh.govt.nz/NoteBook/nbbooks.nsf/0/E47418EA66705C62CC2572640002A83A/\\$file/disabled-Māori-disability-support-options.pdf](http://www.moh.govt.nz/NoteBook/nbbooks.nsf/0/E47418EA66705C62CC2572640002A83A/$file/disabled-Māori-disability-support-options.pdf), accessed 23/1/2019.

¹⁵ M. Durie, *Whaiora: Māori Health Development*, Auckland, 2nd ed. 1998, pp: 7-10.

members with disabilities.¹⁶ What is apparent is that the concept of ‘disability’, as it has been understood in the modern Western medical paradigm, had no equivalent within Te Ao Māori. As Hickey and Wilson note, colonising experiences created indigenous peoples’ disability.¹⁷

Colonial Models of Disability

With the arrival of European missionaries and settlers from the early nineteenth century, Māori systems of health and healing were disrupted by the advent of new belief systems. The settler society which was established in New Zealand in the nineteenth century placed a high premium on physical and mental fitness and self-sufficiency. Health and race were foundational concepts. New Zealand was a ‘racialized state’, a product of an Empire that was ‘increasingly ruled and organized through discourses and practices of race’.¹⁸ New Zealand was also ‘a healthy country’, supposedly the British colony with the healthiest climate and the most favourable living conditions.¹⁹ In the nineteenth century, immigration companies used mortality and morbidity statistics showing New Zealand to be healthier than any of the other British colonies to entice migrants.²⁰ New Zealand was the colony where the worst traits of the old society were abandoned and the very best stock of the British race was gathered, to create a new society and a new people – ‘Better Britons’.²¹ New Zealand’s burgeoning self-image was closely tied to health and racial values.

The poor, the sick, the elderly, decrepit and those unable to support themselves had no place within such a vision of society. In an age of *laissez-faire* government, there was strong resistance to the idea of public welfare for any groups of people. The political discourses of the time regarded such people as burdens and actively legislated to keep them out of the colony; the 1882 Imbecile Passengers Act required ship captains to take financial responsibility for bringing any passenger to New Zealand who

¹⁶ L.W. Nikora, R. Karapu, H. Hickey, & N. Te Awekotuku, *Disabled Māori and disability support options: Report for Ministry of Health*, Hamilton, 2004, [http://www.moh.govt.nz/NoteBook/nbbooks.nsf/0/E47418EA66705C62CC2572640002A83A/\\$file/disabled-Māori-disability-support-options.pdf](http://www.moh.govt.nz/NoteBook/nbbooks.nsf/0/E47418EA66705C62CC2572640002A83A/$file/disabled-Māori-disability-support-options.pdf), accessed 23/1/2019.

¹⁷ H. Hickey & D. Wilson, *Whānau Hauā. Reframing disability from an indigenous perspective*. Auckland, New Zealand, 2017.

¹⁸ D.I. Salesa, *Racial Crossings: Race, Intermarriage and the Victorian British Empire*, Oxford, 2011, p.17.

¹⁹ J. Belich, *Making Peoples: A History of the New Zealanders From Polynesian Settlement to the End of the Nineteenth Century*, Auckland, 1996, pp.289–300; M. Fairburn, *The Ideal Society and Its Enemies: The Foundations of Modern New Zealand Society 1850–1900*, Auckland, 1989; R. Grant, ‘New Zealand “Naturally”’: Ernst Dieffenbach, Environmental Determinism and the Mid Nineteenth-Century British Colonization of New Zealand’, *New Zealand Journal of History*, 37, 1, 2003, 22–37, 25–7; T. D. Selesa, ‘“The Power of the Physician”: Doctors and the “Dying Maori” in Early Colonial New Zealand’, *Health and History*, 2001, 3, 13–40, 26–30.

²⁰ L. Bryder, ‘Introduction’, in L. Bryder (ed.), *A Healthy Country: Essays on the Social History of Medicine in New Zealand*, Wellington, 1991, p.4; M. Nicolson, ‘Medicine and Racial Politics: Changing Images of the New Zealand Maori in the nineteenth century’, in Arnold, *Imperial Medicine*, p.83.

²¹ J. Belich, *Paradise Reforged: A History of the New Zealanders From the 1880s to the Year 2000*, Auckland: Allen Lane, 2001, Part 1.

was 'lunatic, idiotic, deaf, dumb, blind or infirm'.²² In the eyes of the state, the disabled were largely categorised as part of 'the poor' who should be supported by their families in the first instance.

By the end of the nineteenth century, following over a decade of economic depression and growing urban social problems, attitudes towards the idea of public support for the most vulnerable in society began to change. *Laissez-faire* approaches were replaced with the Liberal Government's programme of legislative intervention over the course of the 1890s and early 1900s, which was designed to deal with the Old World problems that the Liberals believed had begun to infect New Zealand's ideal society. The passage of the Old Age Pension Act in 1898 was the first instance in which the state was willing to embrace the idea that there were groups in society who were deserving of public financial assistance.²³ This basic principle was extended in the early twentieth century by the Miners' Phthisis Act in 1915, which was intended to support those workers who were disabled from pneumoconiosis, a chronic lung disease, and by a pension for the blind in 1924. The Workers' Compensation for Accidents Act 1900 also provided workers injured in work place accidents with a weekly allowance. However, many Māori were ineligible for these pensions, or received lower rates because their interest in customary land was regarded as a justification for reducing their pensions.²⁴ Disparities in Māori and Pākehā access to state pensions was a constant theme in early twentieth century social security provision.

The late nineteenth century saw the establishment of a range of institutions in which the physically and mentally disabled might be housed. The Lunatics Ordinance 1846 enabled the forcible detention of 'persons of unsound mind' in the interests of public safety and order, and increasingly by the late nineteenth century, people who would later be classified as intellectually disabled were kept in mental institutions. In 1880, a school for deaf children was established by the Education Department in Sumner, and the Jubilee institute for the Blind was opened in Auckland in 1890, which included a school for children as well as work training for adults. In 1907 Otekaieke Special School was opened for boys regarded as mentally defective, and in 1916 the female equivalent, the Richmond School for Girls, was established. This was part of a general push towards institutional care of those regarded as mentally defective. In its 1919 Annual Report, the Education Department noted that 'the ordinary community holds no place for the feeble-minded child.'²⁵

This trend towards the institutionalisation of the intellectually disabled should be understood in the context of early twentieth century concerns about racial fitness. Eugenic ideas were popular in Western intellectual circles in the early twentieth century, and eugenic thought linked both intellectual and physical disability with the fear of racial degeneracy. In New Zealand, these ideas found expression in widespread concerns about the quality of New Zealand's population and fears the physical superiority of New Zealand's settler stock was under threat. Several state inquiries in the first three decades of the twentieth century addressed these concerns, for example, the 1924–25 Committee of Inquiry into

²² Quoted in Margaret Tennant, 'Disability in New Zealand: A Historical Survey', *New Zealand Journal of Disability Studies*, 2, 1996, p.7.

²³ M. McClure, *A Civilised Community: A History of Social Security in New Zealand 1898-1998*, Auckland, 1998, pp.14-15.

²⁴ M. McClure, *A Civilised Community: A History of Social Security in New Zealand 1898-1998*, Auckland, 1998, p.19.

²⁵ Tennant, 'Disability', p.10.

Mental Defectives and Sexual Offenders concluded that ‘unless prompt and effective action is taken the multiplication of these degenerates will increase and the race will steadily deteriorate.’²⁶ Therefore, state provision for the congenitally disabled in the early twentieth century focused largely upon preventing them from tainting society, rather than ameliorating their situation.

However, the aftermath of WWI did result in some steps towards state provision of rehabilitation services for the disabled. The large number of servicemen returning from war with some form of physical or mental impairment meant that it was impossible to ignore them or expect families alone to bear the brunt of support. Unlike those with congenital disabilities, disabled servicemen were generally regarded as deserving of respect, although those wrestling with shell-shock and other forms of psychological trauma still struggled with the shame and stigma of mental illness. As Margaret Tennant notes, soldiers’ wounds were honourable scars denoting the sacrifices they had made, rather than signs of racial inferiority.²⁷ The state therefore accepted financial responsibility for the medical treatment of returned servicemen and paid out pensions according to the degree of their disability and rank. Nevertheless, the rehabilitation services offered by the state were still regarded as inadequate. Lobbying from the Returned Servicemen’s Association (RSA) led to the establishment of the Ex-Soldiers’ Rehabilitation Commission in 1930. The report of the Commission made several recommendations regarding the need for a Re-establishment League to help oversee the needs of disabled servicemen, which was eventually implemented by the RSA with support from the state. The report also commented on the suggestion that Māori soldiers might constitute a special category of need; they rejected this idea in terms that summed up early twentieth-century understanding of Māori welfare needs as no different from those of Pākehā:

We have, however, very little to say in relation to the Maori ex-soldiers as a separate class. In all the matters considered by us the law makes no distinction between the Maori and European and our Maori ex-soldiers are within the scope of all the foregoing recommendations. In many, perhaps the majority of cases, the life of the Maori is more or less closely woven with that of the European, socially and economically, and we have no more suggestions to make.²⁸

Along with WWI, the polio epidemics of the early to mid-twentieth century also had a profound impact upon wider perceptions of physical disability and state provisions for rehabilitation. The impact of polio was so public and affected such a wide section of society that it was impossible to ignore. Families with children who had gone from ‘normal’ to ‘disabled’ in a matter of weeks also had a different attitude to the disability of their children compared to those families with children born with congenital disabilities;

²⁶ Tennant, ‘Disability’, p. 14.

²⁷ M. Tennant, *The Fabric of Welfare: Voluntary Organisations, Government and Welfare in New Zealand, 1840-2005*, Wellington, 2007, p.99.

²⁸ Ex-Soldiers Rehabilitation Commission – Report of Commission Appointed to Inquire into and Report Upon the Position of Physically and Economically Incapacitated Soldiers, *Appendix to the Journal of the House of Representatives (AJHR)* 1930, H-39, Session I, p.26.

without a strong sense of stigma, they were more ready to demand attention and resources from the state.²⁹

The establishment of the Crippled Children's Society (CCS) in 1935 as a special lobby group was a key consequence of the polio epidemics. The CCS was one of the first disability organisations to make a deliberate attempt to reach out to Māori communities and extend its services to Māori children. In 1939 it was recommended at the CCS annual conference that all branches should have a separate account to cover the care of 'native children' and educational material was translated into Māori.³⁰ Officials declared that education was key; the belief was that once Māori parents were educated about their children's disabilities then they would become more willing to avail themselves of the Society's services. However, CCS reports indicate limited success in this. CCS officials decried the indifference of Māori to deformities 'which Europeans look upon with horror' and complained that Māori whānau were reluctant to bring their children into hospitals for treatment. Tennant has suggested that this indifference may reflect the gulf between Māori and Pākehā understandings of disability; while the latter increasingly focused upon disability as a medical problem to be fixed, the more holistic approach of the former may have looked at the whole person and not recognised a physical condition as requiring medical attention.³¹

The election of the first Labour Government in 1935 heralded some important changes in welfare and health provision that would impact the services available to disabled people in New Zealand society. One of the new Government's first pieces of legislations was the 1936 Pension Amendment Act which introduced an invalid's pension, available to those permanently unable to work through accident, illness or congenital conditions. This extended the previous concept of the eligibility of certain groups of people for state assistance. It also broadened Māori eligibility for state support, by removing consideration of Māori ownership of customary land in pension assessments. However, as Margaret McClure notes, in reality, the Pensions Department continued to administer pensions in a way that undermined the principle of equality and registrars were directed to take into account the living standards of Māori communities when carrying out assessments for pensions.³² The poverty of Māori communities was seen to imply acceptance of lower living standards, thereby justifying paying lower amounts. This continued to be the case until the Maori Social and Economic Advancement Act 1945 formally removed the possibility of discrimination in Māori benefit entitlements.³³ However, even after this, Māori continued to be subject to a greater degree of scrutiny from the state about how they were spending their social security payments. Among the complaints were concerns that the practice of sharing resources amongst whānau was a misuse of benefits that were intended only for the eligible individual; officials were suspicious of beneficiaries who might have 'impecunious natives' living with them who

29 J.C. Ross, 'A History of Poliomyelitis in New Zealand' Unpublished M.A. Thesis, Canterbury University, 1993, pp. 43-44.

30 H.E. Carey, *The History of the New Zealand Crippled Children Society's First Twenty-five Years 1935-1960*, New Plymouth, 1961, pp.29-30; Tennant, *Fabric*, pp.100-102.

31 Tennant, p.102.

32 McClure, pp.111-2.

33 McClure, p.121

would misuse the benefit.³⁴ This reflected the conflict between the communal basis of Māori society, versus the individualised conceptions that underlay social security entitlement. Nevertheless, the benefits introduced by the Labour Government were to make a huge difference to the income levels of whānau from the mid-twentieth century.³⁵

The 1938 Social Security Act, regarded as a landmark in the history of social welfare in New Zealand, is particularly significant for the history of disability because of the system of free public health which it introduced. This substantially reduced the costs of medical treatment, encouraged earlier attention to conditions that could result in disability, and allowed for the provision of drugs and other forms of treatment. However, as Tennant has noted, the increasing medical interest in treating disabilities could be a double-edged sword. While it no doubt resulted in growing research into many conditions and optimism about the life prospects of disabled people, the increasing application of the medical model of disability 'increased the likelihood that disabled persons would be viewed in terms of specific functional impairments – as parts of bodies that did not work, rather than as whole individuals.'³⁶ The increasing state provision for the prevention and treatment of disability also served to highlight the differences and disparities between the Māori and Pākehā experience of disability.

State Approaches to Māori Health

Within the settler paradigm of health and welfare, Māori occupied an ambivalent place. New Zealand's founding myths have been dependent upon a narrative of supposedly favourable race relations between Europeans and Māori from the mid-nineteenth century. The British Empire annexed New Zealand in 1840, during a period when paternalistic humanitarianism influenced the British Colonial Office.³⁷ There was a desire to avoid the previous mistakes and atrocities that occurred in dealings with indigenous peoples in other places, particularly in the Australian colonies. The popular opinion that the indigenous people of New Zealand were a 'superior type of native' supported these aims.³⁸ Some observers believed Māori demonstrated levels of intelligence and adaptability that would make it possible for them to become 'Brown Britons'.³⁹ Official discussions about the future of Māori in settler society were

³⁴ McClure, p.114.

³⁵ Tennant, *Fabric*, pp.165-6.

³⁶ Tennant, 'Disability', p.19.

³⁷ A. Lester, 'British Settler Discourse and the Circuits of Empire', *History Workshop Journal*, 54, 1, Autumn, 2002, 25–9; R. McGregor, 'Degrees of Fatalism: Discourses on Racial Extinction in Australia and New Zealand', in P. Grimshaw and R. McGregor (eds), *Collisions of Cultures and Identities: Settler and Indigenous People*, Melbourne, 2007, pp.246–7; Nicolson, 'Medicine and Racial Politics', pp.75–6; A. Ward, *A Show of Justice: Racial 'Amalgamation' in Nineteenth-Century New Zealand*, 2nd ed. Auckland: 1995, pp.34–6; Salesa, *Racial Crossings*, ch.1.

³⁸ Belich, *Paradise Reforged*, pp.206–7; Grant, 'New Zealand "Naturally"' p.26; R. Lange, *May the People Live: A History of Maori Health Development 1900–1920*, Auckland, 1999, p.60; Pat Moloney, 'Savagery and Civilization: Early Victorian Notions', *New Zealand Journal of History*, 35, 2, 2001, 153–76, 161–3; Nicolson, 'Medicine and Racial Politics', p.68.

³⁹ Belich, *Paradise Reforged*, pp.209–10.

framed by ideas about racial amalgamation, the eventual absorption of the Māori into the European population.⁴⁰

As was the case in other colonial settings, the arrival of Europeans precipitated a demographic decline for Māori.⁴¹ From around 1800, there were reports of waves of epidemics causing substantial loss of life. Influenza, measles, whooping cough, bacillary dysentery, typhoid, tuberculosis and syphilis were among the diseases that decimated Māori communities in the nineteenth century. Many of these infectious diseases, as well as causing loss of life, could leave survivors with serious physical impairments. Uncertainties about the Māori population at first contact with Europeans in the late eighteenth century, with estimates ranging from 86,000 to 175, 000, also make it difficult to assess the extent of depopulation. However, even the lower end of these estimates indicates that incorporation into global networks of microbial exchanges was a disaster for Māori. The Māori population dropped to around 42,000 in 1896 before beginning to recover.⁴²

Public officials and numerous self-appointed experts emphasised the unhealthy conditions of Māori life. Inappropriate clothing, poorly ventilated whare, bad diet, insistence on living in unhealthy localities, and lack of attention to cleanliness and basic sanitation were the main factors thought to explain Māori depopulation.⁴³ The gathering of people at hui and tangi also came in for particular criticism from European observers. In 1881, Major Gilbert Mair, Native Officer for the Auckland and Waikato region, claimed that the annual meetings of the Waikato tribes ‘generate disease from the over-crowding and over-feeding and poverty that follows’.⁴⁴ Another official in 1886 blamed ill-health in his district on the fact that locals were spending too much time and energy on ‘political meetings, discussions, and plottings’.⁴⁵ Officials rarely mentioned the social and economic devastation many Māori communities experienced due to war and land confiscation as reasons for ill-health. While some recognised a connection between Māori poverty and sickness, they usually attributed poverty to lack of industry, laziness and an inherent inability to plan for the future. Māori were therefore responsible for their own demise. After listing the numerous sanitary transgressions observed in the local Māori community, one

⁴⁰ M.P.K. Sorrenson, ‘Maori and Pakeha’, in G. Rice (ed.), *The Oxford History of New Zealand*, 2nd ed., Auckland, 1992, pp.142–3; Ward, *A Show of Justice*. For discussion of state policies of assimilation in the early twentieth century, see R. S. Hill, *State Authority, Indigenous Autonomy: Crown–Māori relations in New Zealand/Aotearoa 1900–1950*, Wellington, 2004.

⁴¹ I. Pool, *Te Iwi Māori: A New Zealand Population Past, Present and Projected*, Auckland, 1991, pp.42-6; A.W. Crosby, *Ecological Imperialism: The Biological Expansion of Europe, 900-1900*, 2nd ed. Cambridge, 2004, ch.10.

⁴² I. Pool, *Te Iwi Māori: A New Zealand Population Past, Present and Projected*, Auckland, 1991, p.78; A.W. Crosby, *Ecological Imperialism: The Biological Expansion of Europe, 900-1900*, 2nd ed. Cambridge, 2004, ch.5.

⁴³ See for example, the reports from Native Department officials, which repeated these criticisms year after year. Reports from Officers in Native Districts, AJHR, 1880, G-4, pp.2–3, 6; AJHR, 1881, G-3, pp.2, 6; AJHR, 1881, G-8, p.15; AJHR, 1883, G-1, 6–7; AJHR, 1883, G-1A, pp.5, 10; AJHR, 1884, G-1, pp.1–2, 4, 5, 6, 18, 20; AJHR, 1885, G-2, pp.1–2, 6, 7, 8–9, 12–13; AJHR, 1885, G-2A, pp.1–2, 3, 5, 8–9, 12–13; AJHR, 1886, G-1; AJHR, 1888, G-1, p.1; AJHR, 1892, G-3, p.1.

⁴⁴ Native Districts, AJHR, 1881, G-8, p.15.

⁴⁵ Native Districts, AJHR, 1886, G-1, p.3.

government official lamented in 1884: 'What can one hope to do with people who are so foolish as to persist in a course which can only be described as suicidal in the extreme?'⁴⁶

Others with an interest in Māori health believed that while the situation was dire, the cause was not hopeless. James Pope, Inspector of Native Schools, believed Māori could 'escape extermination' if they rejected the unhealthy aspects of their culture and emulated the healthy ways of Europeans.⁴⁷ This perspective formed the core of Pope's 1884 book, *Health for the Māori*, written for the instruction of Māori children in Native Schools. The provision of pure air and clean water were the most significant remedies needed to improve Māori health, reflecting the sanitarian approaches of British public health.⁴⁸ Pope's analysis combined these sanitary understandings with Victorian middle-class morality. He blamed drinking, improper dancing, and irregular lifestyles for Māori ill-health.⁴⁹ The substitution of tangi, hui and a communal, subsistence way of life with European-style funerals, picnics and tea parties, individualised land-holding and regular work was also said to be crucial to Māori health reform. Pope's ideas about Māori health had an important influence on a generation of reformers committed to saving the race through the modernisation of Māori communities.⁵⁰

The beginning of the twentieth century signalled a new era for public health in New Zealand.⁵¹ With the establishment of the Department of Public Health in 1901, public health officials sought to impress upon the public an awareness of the individual's duty in maintaining public health. This new model of preventative medicine provided impetus for the reform of sanitary conditions and hygienic behaviour in Māori communities. Māori health reform was a particular interest of Dr James Malcolm Mason, the Chief Health Officer.⁵² In 1901, Mason appointed Dr Maui Pomare to the position of Native Health Officer, with the task of transforming sanitary conditions in Māori communities. Pomare was an ex-pupil of Te Aute College, the elite Anglican Māori college, and had graduated from the American Medical Missionary College in Chicago in 1899, becoming the first qualified physician of Māori descent.⁵³ Pomare emphasised the need for Māori to engage with modern concepts of medicine if the race was to survive,

⁴⁶ Native Districts, AJHR, 1884, G-1, p.2.

⁴⁷ J. H. Pope, *Health for the Maori: A Manual For Use in Native Schools*, Wellington, 1884, p.4. The Native Schools system was set up 1877 with the aim of civilizing Māori, with a particular emphasis upon teaching children English and inculcating them with 'European' ideas of hygiene. Native Schools served Māori communities in remote areas, although the European children of settlers also attended if there was no other school in the area. Lange, pp.77-82; J. Simon and L.T. Smith, *A Civilising Mission? Perceptions and Representations of the New Zealand Native Schools System*, Auckland, 2001.

⁴⁸ Pope, *Health for the Maori*, pp.39-51.

⁴⁹ Pope, *Health for the Maori*, pp.76-80, 91-102.

⁵⁰ Lange, pp.78-9.

⁵¹ D.A. Dow, *Safeguarding the Public Health: A History of the New Zealand Department of Health*, Wellington, 1995, ch.2; K. Ford, 'The Tyranny of the Microbe: Microbial Mentalities in New Zealand, c.1880-1915', PhD Thesis, University of Auckland, 2013, ch.1.

⁵² Dow, *Māori Health*, p.93.

⁵³ Pomare was of European, Ngati Mutunga and Ngati Toa descent. See J.F. Cody, *Man of Two Worlds: Sir Maui Pomare*, Wellington, 1953; Graham Butterworth, 'Pomare, Maui Wiremu Piti Naera', from the Dictionary of New Zealand Biography, Te Ara - the Encyclopedia of New Zealand, updated 30-Oct-2012 URL: <http://www.TeAra.govt.nz/en/biographies/3p30/pomare-maui-wiremu-piti-naera> (accessed 25 November 2012).

and he criticised those aspects of Māori culture he believed were detrimental to health. Yet he also believed Māori could not be forced into changes that they did not understand or agree with. Therefore, the key to effecting transformation in Māori communities was to adapt modern methods of sanitation to Māori knowledge and traditions.⁵⁴ In 1905, Dr Peter Buck, also known as Te Rangi Hiroa, a graduate of Otago Medical School, joined Pomare in the Department. Like Pomare, Buck was of European and Māori ancestry, had been educated at Te Aute College and was a firm advocate of the need for Māori to engage with the Pākehā world to survive.⁵⁵ His approach to Māori health reform was also grounded in the belief that change could only be successful if Māori were themselves convinced of the principles of modern hygiene.⁵⁶ He embarked upon an intensive study of Māori language and traditions to make his arguments for sanitary reform more persuasive.⁵⁷

Pomare and Buck's emphasis upon Māori engagement with modern sanitary science was reflected in another development in Māori health reform in the early twentieth century, the Māori Councils Act of 1900.⁵⁸ This legislation was driven by James Carroll, a Liberal politician of mixed Māori and European descent, and the 'Young Māori Party', a new generation of Māori leadership, which included Pomare, Buck and Apirana Ngata.⁵⁹ The Māori Councils Act set up a system of Māori local bodies, with responsibility for limited governance in their communities. Village Committees, or Komiti Marae, were to oversee the administration of important health measures such as sanitation and water supplies in each kainga. Pomare worked closely with the Councils in his first years as Native Health Officer, trying to ensure his messages of health reform were understood and implemented.⁶⁰

The desire of the Public Health Department to exercise authority over Māori communities had its most obvious expression in the Tohunga Suppression Act 1907. This legislation was aimed at preventing the practice of tohunga, Māori healers, whose influence over Māori communities indicated the continuing relevance of Māori models of healing into the twentieth century.⁶¹ Both Pomare and Buck were caustic about the modern tohunga, and regarded them as dangerous charlatans, whose activities led Māori to delay seeking proper medical attention until it was too late. Lange has argued that concerns about the increasing influence of the prophet Rua Kenana were also behind the implementation of the legislation, although the Act was never used to prosecute Kenana.⁶² Whatever the main motivations behind it, the

⁵⁴ Lange, pp.157–9.

⁵⁵ Buck was of Ngati Mutunga descent. J.B. Condliffe, *Te Rangi Hiroa: the life of Sir Peter Buck*, Christchurch: Whitcombe and Tombs, 1971; M.P.K. Sorrenson, 'Buck, Peter Henry – Biography', from the Dictionary of New Zealand Biography. Te Ara - the Encyclopedia of New Zealand, updated 4-Jul-12
URL: <http://www.TeAra.govt.nz/en/biographies/3b54/1> (accessed 12 November 2012).

⁵⁶ Lange, pp.163–6.

⁵⁷ Condliffe, pp.92–3.

⁵⁸ Lange, pp.140–6; Dow, *Maori Health*, pp.99–102; See also Hill, pp.50–64.

⁵⁹ Belich, *Paradise Reforged*, pp.200–206; Hill, pp.43–47.

⁶⁰ Public Health, AJHR, 1903, H-31, pp.66–69.

⁶¹ Lange, pp.248–49; Derek Dow, 'Pruned of Its Dangers': The Tohunga Suppression Act 1907', *Health and History*, 3,1,2001, pp.41–64.

⁶² Lange, p.249.

Tohunga Suppression Act has become representative of the suppression of Mātauranga Māori by the state in the early twentieth century.

Despite an initially optimistic outlook regarding Māori health reform, public health officials demonstrated increasing frustration and impatience towards Māori by the second decade of the twentieth century. Pomare and Buck left the Public Health Department for political careers, and other officials lacked their understanding of the barriers to health reform in Māori communities.⁶³ The initial promise of the Māori Councils were stymied by a lack of adequate resources and many of them fell into abeyance by the end of the decade. The plan to train Māori health nurses for rural Māori districts from 1911 represented another attempt to address the health needs of Māori communities, but the vision of training young Māori women to serve as ambassadors for Western medicine in their communities was not met by the reality in the early twentieth century, as recruitment and retention proved difficult, partially due to the racial prejudice Māori women experienced during their training.⁶⁴

The Health Act of 1920 attempted to deal with the health problems in Māori communities by reintroducing a specific Māori health infrastructure. This was partially a response to the conditions in some communities that had been exposed by the terrible mortality during the 1918 influenza epidemic; the death rate for Māori was among the highest in the world. The legislation created a Māori Hygiene Division with the Department of Health, headed by Peter Buck. Buck's strategy was to revive the Māori Councils, which were granted the authority to operate as Health Councils and enforce by-laws relating to health and hygiene. As with earlier in the century, the vision of the Māori Councils was for a degree of self-sufficiency and autonomy for Māori communities in matters relating to health. Dealing with typhoid, tuberculosis and infant health in Māori communities were the main issues facing the Division. However, again as with the earlier iteration of the Māori Councils, efforts to enact reform were stymied by the lack of funding for the Councils to adequately tackle these issues.

During the 1930s, a community alternative to the state-based approaches to Māori health was established in the Rotorua region. In the Rotorua region, a District Nurse, Robina Cameron, sought to harness the energy and enthusiasm of women to address the problems of women's and children's health in Māori communities. Working with Te Arawa leaders, she organised health committees, mainly made up of women, to encourage health reform in Māori homes. These committees came together to form the Women's Health League in 1937, and support for the League spread throughout the North Island. Durie notes that although the influence of the League was to some extent superseded by the establishment of the Maori Women's Welfare League in the 1950s, it continued to be a strong influence in the Rotorua region throughout the twentieth century, and showed the potential for effective community health action.⁶⁵

⁶³ Buck became Member of the House of Representatives for Northern Māori in 1909, Pomare Member of the House of Representatives for Western Maori in 1911. Buck's political career was short-lived however.

⁶⁴ Dow, *Maori Health and Government Policy*, pp.133-6.

⁶⁵ Durie, pp.46-7

The impact of war, land confiscation and continued land alienation was devastating for Māori communities and had a detrimental impact on their health status. In a period when the state largely discouraged the full participation of disabled people in society, and when state commitment to Māori health and welfare provision was at best ambivalent, Whānau Hauā were largely invisible in terms of public health and welfare provision. When they do appear, underlying assimilationist discourses encouraged inadequate and paternalistic approaches. This would continue to be a theme in the second half of the twentieth century.

Post WWII Disability Policy Developments

The second half of the twentieth century was characterised by profound changes in the way the state interacted with disabled people. The 1938 Social Security Act had involved the state taking responsibility for the most needy and vulnerable in society, including those whose physical circumstances meant they were unable to provide for themselves and their families. Increasingly in post-war Western society, state support extended beyond just replacing lost income to providing a range of services that were intended to support those people with physical and intellectual disabilities to fully participate in society. However, these services continued to be overwhelmingly monocultural and largely failed to meet the specific needs of Māori whānau. Yet, for most politicians and organisations dealing with social services, the idea of separate service provision for Māori was an anathema, undermining the principles of integration and equality that were the basis of post-war racial policy. As the examples discussed below will show, within the context of mid-twentieth century social and racial policy there was no conception that Whānau Hauā might have specific social and cultural needs that could not be adequately met by services for the general population.

Initially, disability rehabilitation services were focussed upon providing support to returned servicemen. The Disabled Serviceman's Rehabilitation League was the main organisation responsible for supporting disabled servicemen to reintegrate into civilian life. This included training and employment programmes. From 1955, these services were made available to disabled civilians as well, and from 1969, the League, which was renamed the Rehabilitation League NZ, became the official government agency for providing disabled people with assistance and training.

This shift in attitude towards the disabled, their place in society and the state's responsibility to them, was in part encouraged by the rise of consumer advocate groups of disabled people and/or their families. One such group was the Intellectually Handicapped Children's Parent's Association (IHCPA) established in 1949. Tennant notes that the IHCPA (later the IHC) had a difficult relationship with the state at times, given that it was formed in opposition to prevailing state policies towards the treatment of children with intellectual disabilities.⁶⁶ The attitude of the state authorities in the immediate post-war period still advocated the care of people with intellectual disabilities in large-scale state institutions. The 1951 Consultative Committee on Children with Intellectually Disabilities (also known as the Aitken Committee, after its Chairman, Dr R S Aitken) recommended that large scale residential institutions

⁶⁶ Tennant, *Fabric*, pp.155-6

accommodating about 400-500 children were the best model of care and the parents of intellectually disabled children should be encouraged to place their children in these institutions from the age of five.⁶⁷ Thousands of children were admitted to psychopaedic hospitals such as Kimberley in Levin, Templeton in Christchurch and Mangere Hospital in Auckland from the 1950s until the 1970s; for many, these places became their permanent homes. Brookes has noted the range of justifications that were used by medical professionals to persuade parents that it was best to put their handicapped children into institutionalised care, from the idea that it was a waste of the mother's time and energy, to the argument that 'normal' children in a family would suffer if a disabled child was cared for at home.⁶⁸ The 1956 Annual Report of the Mental Hygiene Division of the Department of Health stated that:

By and large, it can be said that the intellectually handicapped are happier amongst their own. They enjoy a community life in which the competition and the striving is not too great for their intellectual capacity. This can be achieved by residence in colonies much larger in size than is often contended. After years of experience, this Division still holds the view that the colony of 750 gives a much wider scope for these 'children' and a much happier environment than the restrictions imposed by a smaller one.⁶⁹

Given what is now known about the abuse and deprivation experienced by children in these institutions, this policy constituted a major tragedy for these children and their families.⁷⁰ Many parents of children with intellectual disabilities vehemently opposed this model of care, which, as the 1973 Royal Commission on Services for the Mentally Handicapped noted, was even at the time at odds with prevailing policy in other parts of the world.⁷¹ A survey of families with intellectually handicapped children from the early 1970s found that Māori were much less likely to institutionalise their children, and instead looked to the care of the wider whānau, particularly grandparents, to care for children.⁷² However, the experience of Māori children who were institutionalised was particularly traumatic, as they found themselves in Pākehā institutions that were alien to their life experiences and unresponsive to their cultural and spiritual needs.⁷³ Institutionalisation often resulted in a disconnection from whānau and a complete loss of cultural identity for Māori children.

⁶⁷ Services for the Mentally Handicapped: Third Report of the Royal Commission of Inquiry into Hospital and Related Services, Wellington, 1973, p.13.

⁶⁸ B. Brookes, "Cherishing Hopes of the Impossible": Mothers, Fathers, and Disability at Birth in Mid-Twentieth-Century New Zealand', in T. Light, B. Brookes, and W. Mitchinson eds., *Bodily Subjects: Essay on Gender and Health, 1800-2000*, Montreal, 2014, pp.187-90.

⁶⁹ Quoted in Services for the Mentally Handicapped, p.15.

⁷⁰ See B. Mirfin-Veitch and J. Conder, "Institutions are places of abuse": The experiences of disabled children and adults in State care between 1950–1992, Dunedin, 2017.

⁷¹ Services for the Mentally Handicapped, p.14. Paul Gibson, New Zealand's Disability Commissioner from 2011-2017, has noted that New Zealand institutionalized its children at three times the rate of other similar countries. Paul Gibson, 'Foreward', in Mirfin-Veitch and Conder, pp. iv-v.

⁷² Brookes, p.191.

⁷³ Keri Ratima and Mihi Ratima, 'Māori Experience of Disability and Disability Support Services', *Hauora: Māori Standards of Health IV*, Wellington, 2007, p.192; Mirfin-Veitch and Conder, pp.34-5.

One of the main purposes of the IHCPA was to provide support for parents to care for their children at home, and to lobby the state over the following two decades to change its policy regarding the care of children with learning disabilities. The move to deinstitutionalise people with disabilities is one of the most significant features of disability policy in New Zealand from the 1970s. The 1973 Royal Commission Report on Services for the Mentally Handicapped was highly critical of the Aitken Committee Report and recommended a complete reversal of most of its recommendations. The 1973 Report concluded that ‘the disproportionate emphasis put on care in large psychopaedic and psychiatric hospitals in the past 20 years is wrong. The emphasis should be on the provision of facilities in the community to keep persons *out* of hospital and to provide the care they need in the community.’⁷⁴ The 1973 Royal Commission Report also challenged the medical view of disability, noting that hospitals were places for people who were sick, whereas the majority of the “mentally handicapped” were not sick; they required care rather than medical treatment.⁷⁵ For this reason, the report recommended that responsibility be taken away from the Department of Health and passed to the Department of Social Welfare; the care of the intellectually disabled was a matter of welfare rather than health.

Following many of these principles, the Disabled Person’s Community Welfare Act 1975 established the legislative basis for community care for people with disabilities:

- (a) to assist and encourage disabled persons to become socially and financially independent:
- (b) to promote schemes providing for the assessment, work experience, training, sheltered employment, and other suitable activities of disabled persons:
- (c) to promote the general wellbeing, recreational opportunities, and welfare in the community of disabled persons by assisting individuals, families, and sections of the community to overcome social problems associated with physical or mental handicap.⁷⁶

As Tennant has noted, the provisions of the Act were significant, because they were based on the principle of changing the social and cultural environment to suit the needs of disabled people, rather than forcing disabled people to fit in with their surroundings. These changes reflected a move away from the medical model of disability, which understood disability as the result of the person’s physical or mental limitations, to a social model of disability, which views disability as the consequence of environmental and social barriers that prevent people with impairments from full participation in society.⁷⁷

Along with community care for disabled people, ‘mainstreaming’ children with disabilities in state schools also became standard policy by the latter part of the twentieth century. The principle of inclusive education is enshrined in the Education Act 1989, which states that “People who have special education needs (whether because of disability or otherwise) have the same rights to enrol and receive

⁷⁴ Services for the Mentally Handicapped, p.15

⁷⁵ Services for the Mentally Handicapped, p.16

⁷⁶ Disabled Persons Community Welfare Act 1975

<http://legislation.govt.nz/act/public/1975/0122/latest/DLM436790.html>

⁷⁷ For further discussion of different models of disability, see Nikora et al, pp.5-6.

education at state schools as people who do not.”⁷⁸ However, the movement towards community care for disabled people and inclusive education for children with disabilities gained momentum at a time when the welfare state in New Zealand was undergoing profound changes during the welfare reforms of the 1980s and 1990s. This meant that many of the support services required for the care of disabled people in the community and the mainstreaming of disabled children in school were being curtailed at precisely the point when they were most needed.⁷⁹ Without adequate planning and resourcing, the move to community care from institutional settings could be traumatic rather than empowering for disabled people, and the communities into which they were placed were not always welcoming to them.⁸⁰

Another key piece of legislation relating to disability was the 1972 Accident Compensation Act. This legislation followed the 1966 Royal Commission on Compensation for Injury in New Zealand, which had found flaws in the existing model of compensation of injuries through accident based upon the 1900 Workers Compensation for Accident Act. The Accident Compensation Corporation (ACC) established a no-fault principle of financial relief based upon financial earnings and eliminated the need for litigation. Most significantly it applied to all people injured in accidents, not just those injured in the workplace. It included lump sum payments for those permanently disabled and provided support for costs associated with rehabilitation. However, the generosity of its provision created disparity between those who were injured in accidents and those whose disabilities stemmed from illness or congenital conditions.⁸¹

The late twentieth century also saw the development of more assertive self-advocacy groups that aimed to put the needs and intentions of disabled people themselves at the centre of disability policy. This reflected the emergence of identity politics in many Western countries, as various minority groups became more assertive about expressing their distinct identities and social and cultural needs.⁸² In 1983, the Disabled Persons Assembly was established, becoming an important support and advocacy group for people with disabilities. One of the issues the assembly focussed upon was discrimination against disabled people; this eventually resulted in the Human Rights Commission Act being amended in 1993 to include disability among the grounds upon which it was illegal to discriminate.⁸³ One of the challenges faced by the Assembly was the diversity of its membership, which was divided by the various experiences of race, gender, class, sexual orientation, age etc.⁸⁴ For Whānau Hauā, the increasing assertiveness of disability identity politics in the late twentieth century brought its own complexities, as

⁷⁸ <http://www.education.govt.nz/school/running-a-school/inclusive-education/>, accessed 7/4/2019.

⁷⁹ Tennant, *Disability*, p.28.

⁸⁰ Tennant, *Disability*, p.28. For research into the effects of the closure of the Kimberley Centre on former residents, see P. Milner, S. Gates, B. Mirfin-Veitch and C. Stewart, *An examination of the outcome of the resettlement of residents from the Kimberley Centre*, Dunedin, 2008, <https://www.health.govt.nz/system/files/documents/publications/resettlement-of-kimberley-residents.pdf>, accessed 9/4/2019.

⁸¹ Tennant, *Disability*, p.24.

⁸² Tennant, *Disability*, p.26; Hickey and Wilson, p.83.

⁸³ Tennant, *Disability* p.27.

⁸⁴ Tennant, *Fabric*, p.162.

they wrestled with their identity as both Māori and disabled. Issues of intersectionality⁸⁵, the compounding of oppression through the convergence of multiple identities and inequities, have been crucial for indigenous people with disabilities, as they have struggled to have their specific experiences acknowledged within the wider disability activism movement.⁸⁶

Post-War Māori Welfare Provision

While these developments in provision for disabled people in the general population had a major impact on the experience of Whānau Hauā, any form of social security provision for Māori needs to be understood in the context of post-war racial and social policy in New Zealand. Integration was the essence of these policies: Māori were to be integrated into Pākehā social and economic life so that they could become productive members of society. These policies are expressed in this statement by Peter Fraser, Minister of Maori Affairs, in 1949:

It is not necessary to emphasize the fact that the time has come when the Maori has realized the benefits to be gained from taking his place in the life of the community as a whole, and, as a result, the desire to be self-supporting and responsible members of the nation is evidenced by the movement on every hand to play a full part in all sections of national life. An independent, self-reliant, and satisfied Maori race working side by side with the pakeha and with equal incentives, advantages, and rewards for effort in all walks of life is the goal of the Government, and the realization of such a goal will be of inestimable advantage both to the community at large and also to the economy of the country in the field of production and in the general development of the country.⁸⁷

While Fraser's reference to an independent and self-reliant Maori race might indicate the potential for self-determination, in practice there was little room for awareness or recognition of the value of concepts of Te Ao Māori, or an approach which recognised that Māori social and cultural values might be different but equally valid to those of Pākehā. Development and progress for Māori in the post-war period was largely measured by the state in European terms; how well Māori adapted to modern Pākehā society.

The Maori Social and Economic Advancement Act 1945 was intended to achieve the goal of creating 'an independent, self-reliant, and satisfied Maori race'. The Act established the Maori Welfare Division and its Welfare Officers as the key points of contact between the state and whānau, bringing the Maori Affairs Department into the daily lives of Māori. Welfare officers employed by the Welfare Division were expected to work with local tribal committees, District Nurses and local GPs to ensure that Māori health

⁸⁵ The complex, cumulative way in which the effects of multiple forms of discrimination (such as racism, sexism, and classism) combine, overlap, or [intersect](https://www.merriam-webster.com/dictionary/intersectionality) especially in the experiences of marginalized individuals or groups. See <https://www.merriam-webster.com/dictionary/intersectionality>

⁸⁶ Hickey and Wilson, p.89.

⁸⁷ Department of Maori Affairs – Annual Report of the Board of Maori Affairs and of the Undersecretary, Department of Maori Affairs for the Year Ended 31st March, 1949, *AJHR*, G-09, 1949, p.2.

and welfare needs were attended to. Descriptions of the various duties of the Welfare Officers included supervising the welfare of ‘crippled children’.⁸⁸ The expansion of the Maori Affairs Department into welfare provision was in the context of the profound changes Māori communities were experiencing due to the post-war acceleration of urban migration, which created enormous challenges for many whānau in terms of whānau ora. The post-war relationship between Māori communities and the state was complex; some historians have argued that the Maori Welfare Division was essentially a tool of state hegemony which co-opted and tamed existing Māori institutions and removed the possibility for a truly autonomous approach to Māori social policy that could properly meet Māori needs.⁸⁹ However, Aroha Harris has noted the complicated and dynamic nature of the relationship between Māori communities and the Maori Affairs Department, in which various agendas sometimes diverged and sometimes merged.⁹⁰ The Maori Women’s Welfare League, established in 1951, also became a crucial point of negotiation and tension between the needs of Māori communities and the agendas of the Maori Affairs Department, and was particularly active in terms of health provisions for whānau.⁹¹

The Hunn Report of 1961 reinforced the importance of integration as the goal of racial policy in post-war New Zealand. Jack Hunn, the Secretary of Maori Affairs, believed integration between Māori and Pākehā to be a natural and inevitable consequence, stating that ‘Evolution is clearly integrating Maori and pakeha. Consequently ‘integration’ is said to be the official policy whenever the question is asked.’⁹² However, while integration had been the basis of racial policy since WWII, the Hunn report proposed a raft of policy initiatives to encourage and speed up the process. Hunn argued that Māori who resented the pressure to conform to ‘the pakeha mode of life’ needed to understand that this was an inevitable consequence of becoming modern: ‘It is not, in fact, a *pakeha* but a *modern* way of life, common to advanced people... not merely white people – in all parts of the world.’⁹³ At a time when urban migration was reaching its peak, Hunn regarded urbanisation as a positive force for successful integration, arguing that if Māori and Pākehā lived together as neighbours, they would better understand and appreciate each other than if they were living in separate communities.⁹⁴ Within this perspective, there was little room for the development of alternative models of Māori modernity. While Hunn gave lip service to the idea that the “fittest” aspects of Māori culture might be retained, the reality of the policy directives that came out of the report provided little space for this retention to occur – the improvement and modernisation of Māori was to be done on Pākehā terms. As Aroha Harris has noted, it was in this grey area, ‘where the things that were important to Māori – and yet somehow difficult to explain across the cultural divide – competed with the forces of integration for a secure position in

⁸⁸ Department of Maori Affairs – Annual Report of the Under-Secretary for the Year Ended 31st March, 1948, *AJHR*, G-09, 1949, p.12; Department of Maori Affairs *AJHR*, G-09, 1949, p.9.

⁸⁹ Tennant, *Fabric*, p.166.

⁹⁰ A. Harris, ‘Maori and ‘the Maori Affairs’, in B. Dalley, *Past Judgement: Social policy in New Zealand History*, Dunedin, 2004, pp.191-205.

⁹¹ Tennant, *Fabric*, pp.167-9.

⁹² J.K. Hunn, ‘Report – Department of Maori Affairs’, *AJHR*, G-09, 1960, p.15.

⁹³ J.K. Hunn, ‘Report – Department of Maori Affairs’, *AJHR*, G-09, 1960, p.16.

⁹⁴ J.K. Hunn, ‘Report – Department of Maori Affairs’, *AJHR*, G-09, 1960, p.14.

modern New Zealand', where tension and conflict was to occur in many areas of Māori social policy over the coming decades.⁹⁵

One of these areas was health policy. While claiming that Māori had an impressive record of health improvement in the twentieth century, the Hunn Report also highlighted the disparities between Māori and Pākehā mortality figures.⁹⁶ From the mid-twentieth century, these disparities were increasingly highlighted as a cause for concern in a country that prided itself on racial equality. From the 1950s, the Maori Women's Welfare League was particularly active in the health domain, through its focus upon the issue of improving substandard Māori housing which was widely recognised as contributing to ill health, and through its central role of the key point of contact between whānau, Māori welfare officers, district health nurses and health professionals. Māori infant mortality was a key issue in the mid-twentieth century, as it was observed that Māori rates in the 1960s were comparable to Pākehā rates in the 1920s.⁹⁷ For example, in 1965 the League supported a Health Department campaign to battle anaemia in Māori infants by helping public health nurses to administer iron tonic to babies.⁹⁸ Mason Durie also notes that from an early stage, the League advocated the establishment of health clinics that were accessible and 'culturally relevant'.⁹⁹ However, he also notes that the League's activities were circumscribed by a state which saw the League as a vehicle to advocate and support the state's vision of health provision, rather than Māori self-determination in health policy.¹⁰⁰

By the 1980s, this was beginning to change. The publication in 1980 of the Medical Research Council commissioned report *Maori Standards of Health* by Dr Eru Pōmare, highlighted the disparities between Māori and Pākehā mortality rates over the twenty-year period 1955–75. However, the response to these disparities was markedly different from previous decades. The emphasis was on the hope that 'Maori people themselves will consider these findings and provide the leadership which will be needed to enable the occurrence of many of these common diseases to fall in the Maori population.' In an article in the *New Zealand Health Review* in 1984 discussing the report, Pōmare noted that Māori people needed to be actively involved from the outset in the planning and implementation of any health initiatives that might affect them.¹⁰¹ He also noted that there were 'serious problems' in the delivery of health care to Māori and that Māori could consider developing their own health programmes in an endeavour to redress these deficiencies. Empowering Māori communities to address their own health needs was key feature of discussion at the first national health hui, Hui Whakaoranga, held at Hoani Waititi Marae in 1984. Durie notes that this national hui came out of a series of hui at marae around the country, at which health, and the recognition of the value of a Māori perspective on health and

⁹⁵ A. Harris with M. M. Williams, 'Maori Affairs, 1945-1970', in Atholl Anderson, Judith Binney and Aroha Harris, *Tangata Whenua: An Illustrated History*, Wellington, 2014, p.404.

⁹⁶ Hunn Report, pp.19-22.

⁹⁷ D. Dow, *Safeguarding the Public Health: A History of the New Zealand Department of Public Health*, Wellington, 1995, p.197.

⁹⁸ D. Dow, *Safeguarding the Public Health: A History of the New Zealand Department of Public Health*, Wellington, 1995, p.198.

⁹⁹ Durie, p.49

¹⁰⁰ Durie, p.49

¹⁰¹ E. Pōmare, A Historical Perspective: "The Changing World", *New Zealand Health Review*, 4,4, 1984, pp.6-7.

wellbeing, were debated and discussed.¹⁰² This Māori-led approach to health service delivery also extended to Māori health research itself: in the early 1980s, a dissatisfaction with the dependence of existing information about Māori women's health upon white male health professionals led the Maori Women's Welfare League to launch their own research project into Māori women's health and wellbeing. The Rapuora project established a new model for community-led, tikanga-based health research.¹⁰³ Community health initiatives, some of which were state sponsored, some of which were iwi or locally funded, were a key feature of a changing health landscape from the 1980s onwards.

Durie and Tennant explicitly connect the shift towards Māori self-determination in health and social policy with the passing of the Treaty of Waitangi Act 1975, which signalled a new form of cultural assertiveness for Māori and a new understanding of the relevance of Te Tiriti to contemporary social policy.¹⁰⁴ However, while the implications of Te Tiriti for social and health policy were being discussed and debated throughout the 1980s and 1990s, the translation of these discussions into explicit policy developments was not always clear. As Pōmare et al noted in the third edition of *Hauora*, published in 1995, 'while the significance of the Treaty is acknowledged by many, the principles are not protected by statute.'¹⁰⁵ Likewise, Durie has pointed out that the Treaty of Waitangi is only enforceable when it is incorporated into relevant legislation; he noted that several Acts refer to the importance of acknowledging Māori interests, but do not explicitly refer to the Treaty of Waitangi as an obligation on the Crown.¹⁰⁶ This includes the Health and Disability Services Act 1993, which while it noted that meeting the special needs of Māori was one of the Crown's special objectives, did not refer to any obligations under the Treaty of Waitangi. Durie described the Act as a disappointment to Māori in this regard, because several submissions had urged the Minister of Health to include a Treaty clause.¹⁰⁷

As well as the changing role of the Treaty in social policy, the political and economic context was also an important factor in these developments. The 1980s and 1990s were a time when the devolution and decentralisation of many functions of the state were an active goal of both Labour and National governments. Devolution could seem to provide an opportunity for greater Māori sovereignty over social policy, with the closure of the Māori Affairs Department in the early 1990s, and a shift to greater iwi control over the provision of some of the services previously supplied by the state.¹⁰⁸ The move to contract health and disability services out to independent providers was a key feature of the Health and Disability Services Act 1993 and thus provided an opportunity for alternative service providers to step into health and disability service provision. As Durie notes, many Māori groups, dissatisfied with the existing services for Māori, saw the new contracting environment as an opportunity for new approaches

¹⁰² Durie, pp.52-3

¹⁰³ Durie, pp.52-3; D. Dow, 'Driving Their Own Canoe: Māori and Health Research' in B. Dalley, *Past Judgement: Social policy in New Zealand History*, Dunedin, 2004, p.102.

¹⁰⁴ Durie, pp.52-53; Tennant, *Fabric*, p.171.

¹⁰⁵ E. Pōmare, V. Keefe-Ormsby, C. Ormsby, N. Pearce, P.Reid, B.Robson and N. Wātene-Haydon, *Hauora: Māori Standards of Health III. A study of the years 1970-1991*, Wellington, 1995, p.27.

¹⁰⁶ Durie, pp.90-1.

¹⁰⁷ Durie, pp92-3.

¹⁰⁸ A. Harris with M. M. Williams, 'Tangata Whenua, Tangata Ora, 1990-2014', in *Tangata Whenua*, pp.441-2, 449-50.

in delivering health care and disability services to whānau.¹⁰⁹ But at the same time, the results of the neoliberal economic reforms of the 1980s and 1990s were devastating for many whānau, who were among the most vulnerable in society, and relied heavily upon state support and services. As Harris has pointed out, Māori aspirations for greater sovereignty over welfare matters ‘saw Māori effectively assist in dismantling a state on which, arguably, they relied more than ever.’¹¹⁰

By 1984, the Department of Health was cautiously acknowledging the value of concepts of health rooted in Te Ao Māori, with the publication of ‘Health: a Maori View’ in *Health*, the official Department of Health publication.¹¹¹ The article noted that ‘It is important to recognise that in a multi-cultural community like New Zealand’s, there exist many different cultural beliefs, attitudes and practices that people have towards health and sickness.’ It explained the Māori perspective in the following terms: ‘Health from a Maori perspective embodies a holistic philosophy. It encompasses spiritual, mental, family and physical dimensions. Maori people believe that each one of these dimensions cannot be looked at separately but are inter-related to form a whole and are the foundations on which good health depends.’¹¹² However, acknowledgement of alternative perspectives on health was a long way from achieving institutional change; later editions of *Hauora: Māori Standards of Health* noted that public health services remained overwhelmingly monocultural.¹¹³

These late twentieth century developments in Māori social policy have had a profound impact upon how Māori disability has been conceptualised. As the reports of the Crippled Children’s Society from the mid-twentieth century indicated, there had long been the recognition that Māori did not access disability services at the same rate as Pākehā and that there was a high level of unmet needs amongst disabled Māori. But instead of continuing to attribute this to a lack of education or problematic attitude on the part of Māori, as had been the case in the mid-twentieth century, by the 1990s there was increasing recognition that Māori faced particular barriers to accessing disability services. Research since then has consistently identified the cost of disability services and the inappropriate cultural frameworks of the institutions that serve Whānau Hauā as key concerns.¹¹⁴ In 1995, *He anga whakamana: a framework for the delivery of disability support services for Māori*, a report to the National Advisory Committee on Core Health and Disability Support Services, noted that many Māori were made to feel alienated and uncomfortable by their engagement with disability services.¹¹⁵ Cultural barriers, such as inadequate use of Te Reo Māori, lack of encouragement of whānau involvement and lack of integration between the social services supposed to serve Māori were so significant in preventing Māori accessing disability services, that they result in Whānau Hauā only using them in times of extreme need. The report

¹⁰⁹ Durie, p.146.

¹¹⁰ Harris, p.441.

¹¹¹ P. Ngata and L. Dyal, ‘Health: a Maori view’, *Health*, 36, 2, Winter, 1982, pp.3-5.

¹¹² P. Ngata and L. Dyal, ‘Health: a Maori view’, *Health*, 36, 2, Winter, 1982, p.3.

¹¹³ E. Pōmare and G. de Boer, *Hauora: Māori Standards of Health: A Study of the years 1970-1984*, Wellington, 1988, p.8.

¹¹⁴ For examples of this research, see Nikora et al; Centre for Health, Activity and Rehabilitation Research, *Hauā Mana Māori – Living unique and enriched lives*, Dunedin, 2014.

¹¹⁵ M.M Ratima, M.H Durie, G.R. Allen, P.S. Morrison, A. Gillies, and J.A. Waldon, *He anga whakamana: a framework for the delivery of disability support services for Māori*, Palmerston North, 1995.

highlighted the need for culturally appropriate mainstream services, but also argued for Māori specific disability services that operate within a Māori cultural context.

He anga whakamana concluded with these words:

There is an added onus on providers of services to Māori, that not only shall clients be equipped to participate in mainstream New Zealand society, but they should have the opportunity to participate in Māori society, to belong to Māori institutions and importantly to remain Māori. The costs of disability are high; they should not include cultural alienation.¹¹⁶

This discussion of the historical context to current inequities in access to disability support services has shown that for most of the last 150 years, some degree of cultural alienation has been largely the norm for Whānau Hauā who have interacted with the state. As Ratima and Ratima have noted, ‘Historically, disability support services have not only been unresponsive to Māori – they have been destructive.’¹¹⁷ Recognising the destructive aspects of this history contextualises the new primary data contained in this report, and is part of the task of developing new frameworks that are responsive to Māori needs.

¹¹⁶ Ratima et al, p. 48.

¹¹⁷ Ratima and Ratima, p.192.

Section Two: Māori and Disabilities - Lived Experiences

1. Terminology

The term Whānau Hauā was provided as part of the Waitangi Tribunal commissioning process, therefore, for consistency, this is the term that is used throughout this report. However, the research team have endeavoured to honour the words and voices of those we interviewed by using, where possible, the terms and terminologies used by each interview participant.

Interview participants used a diverse range of terms and terminologies, perhaps reflecting the diverse identities, experiences, backgrounds, histories, opinions, and thoughts that exists within the Māori disability sector. Hickey (2019) adds that terminologies ‘can also differ region to region, iwi to iwi, hapū to hapū, and whānau to whānau, and as such [Māori should] be allowed to describe or define impairment for themselves as they see fit.’

Accordingly, the following section outlines various terminologies used and/or discussed by interview participants when referring to Whānau Hauā.

Disability

The term ‘disability’ has long been contentious in that Māori ‘do not easily relate to that term or even the concept behind it.’¹¹⁸

According to one interview, part of the contention can be traced to early European colonisation and settlement where terminologies and concepts were introduced that framed disability as a ‘curse’ and/or ‘abnormal’:

The term disability and its depiction of abnormality, people who are weak, sick, broken, disabled, was a term that a lot of colonising powers used to take over indigenous populations. So, there’s a... I don’t know what you would call it – a kind of an understanding across indigenous populations that that term was used to highlight their dysfunction and justify the whole process of colonisations. So, we’re really clear that the term disability, even as it’s used today, is not one that fits the whakaaro of our people. (Provider)

With colonisation came the loss of lives, land and culture, as well as Māori understandings of disability. Currently, there are attempts within the Māori disabilities sector to reclaim what it is to be Māori and disabled:

¹¹⁸ H. Hickey, *Whānau hauā: the experiences of accessing health and disability services for Māori with disabilities A Report funded by the Health Research Council and Auckland University of Technology*, 2019.

To understand disability from a Māori perspective, it is imperative that language around impairment be relevant for Māori... Māori need their own terminologies that they themselves identify. Not terms identified for them, but ones that come from their own understanding and experiences.¹¹⁹

According to the New Zealand Disability Strategy 2016 to 2026, most Māori with disability identify as Māori first which further emphasises the importance of Māori defined terminologies that reflect, strengthen, and validate their cultural identity, language, values, principles, practices, lineages, and linkages to the land.

Another common theme highlighted throughout interviews were issues around how disability was defined in the health system. According to Hickey and Wilson (2017), the International Classification of Functioning, Health and Disability (ICF) (endorsed by WHO) influences the way in which disabled persons are diagnosed and treated (Westby, 2013). This subsequently impacts on who and what services and supports were available for Whānau Hauā.

Furthermore, for this expert in the disability sector, physical and neurodevelopmental problems like Fetal Alcohol Spectrum Disorders (FASDs) are not currently recognised or supported as a disability in New Zealand:

... it doesn't get classed as a disability and that... I think it's also important to point out that mental health service is usually excluded as well because it's not a mental health problem. So, they're excluding it because it's a disability but then it's not accepted as belonging to the disability. Just sort of floats out there. (Expert)

Emerging research concurs, by considering the rising number of people who need high support as a result of cognitive disabilities, such as dementia, autism, and foetal alcohol spectrum disorders. Interviewees strongly expressed the current confusion and inadequacies around definitions of disabilities. New policies need to consider these changes especially as the aging population growth will have significant impact on the number of people with conditions such as dementia.¹²⁰

¹¹⁹ H. Hickey, *Whānau hauā: the experiences of accessing health and disability services for Māori with disabilities A Report funded by the Health Research Council and Auckland University of Technology*, 2019.

¹²⁰ Office for Disability Issues, 2017

Whānau Hauā

According to Hickey (2019) the term Whānau Hauā was an umbrella term designed to encapsulate the concept for Māori with disability. The term describes disability from a Māori perspective and is informed by Te Ao Māori. It was gifted to Te Roopu Waiora¹²¹ by the late Donny Rangiahau (Tūhoe). Hickey writes:

Whānau Hauā signifies the wind that propels whānau with member(s) who have a disability. Whānau differs from the commonly understood construction of the nuclear family, and can be made up of either whakapapa whānau or kaupapa whānau.

A similar description of the term Whānau Hauā was shared in a provider interview:

In the Māori dictionary I think [it] says something about [hauā] being disabled or broken. And we also align that thinking around the term hau, meaning wind. And how the wind sort of, can be a really strong gale or can be a gentle breeze. It has the ability to change the environment. And depending on the mood of Tāwhirimātea, if he's in a really bad mood he will change the environment. So, whānau who are trying to cope with their environment, it's made all the more difficult because of the environment. Which is very much attune to the social model of disability. (Provider)

Hickey also writes that, while other terms have been developed, 'they have not been done in consultation with Whānau Hauā and therefore have not been adapted by the disability community.'

Tangata Whaikaha/Tāngata Whaikaha

The term tangata whaikaha describes a Māori person with a disability. Tāngata whaikaha – with a macronised 'ā' – describes two or more Māori people with a disability. Whaikaha means to have strength, to have ability, to be 'otherly' abled, and to be enabled:

Tāngata Whaikaha means people who are determined to do well, or is certainly a goal that they reach for. It fits nicely with the goals and aims of people with disabilities who are determined in some way to do well and create opportunities for themselves as opposed to being labelled, as in the past. (Whānau)

Similarly, this whānau participant and expert who participated in the discussions around the formation of the term 'tangata/tāngata whaikaha' reiterated that it was a strength-based term, inclusive of all disabilities:

¹²¹ Te Roopu Waiora Trust is a Kaupapa Māori Organisation founded and governed by whānau with physical, sensory, and intellectual disabilities. More information about Te Roopu Waiora can be found at this link: <http://www.teroopuwaiora.nz/>

It's a strength based approach to describing all disabilities... rather than looking at people's 'disability', looking at people's 'ability' (Whānau/Expert)

The term Tāngata Whaikaha was introduced as part of the Ministry of Health *Whāia Te Ao Mārama 2018 to 2022: The Māori Disability Action Plan*, and was also included as part of *Te Reo Hāpai (The Language of Enrichment)*, a glossary of 'mana enhancing Māori world view', that is, a glossary of Te Reo Māori terms for use in the mental health, addictions, and disability sectors, and was used by some of the interviewees as their preferred term.

Hautupua

According to the *Dictionary of the Maori Language* (Williams, 1985), the term 'hautupua' means 'remarkable', and based on an interview with one provider, is a concept and term that best fits a Te Ao Māori informed understanding of Māori disability and impairment:

So, the term hautupua, which means 'extraordinary being' to some iwi, most iwi, is probably the closest thing we've come to, to describing someone that has an impairment. Because there's a distinct difference between impairment and disability. (Provider)

The concept of Māori with disability as 'remarkable' and/or 'extraordinary' are part of Māori cosmogony and held in the songs, art, histories, traditions, and origin stories of iwi:

I think for Ngā Puhī, one of the highlighted people... Tāngata Rongonui (famous people¹²²) – would be Hongi Hika's¹²³ second wife – Turi-ke-tuha... she was his war strategist, known as his favourite wife and was completely blind. We have the stories of... Pūkākī, well known rangatira (leader¹²⁴) of Te Arawa¹²⁵ – he too was blind, but a strategist, an amazing strategist for their abilities to look after the people of Te Arawa. Here in this area (Tāmaki Makaurau/Auckland) we have Hape¹²⁶ who's a well-known tupuna. And his case is really interesting because it talks about how the Tainui waka left him behind and then he found his way back... well he found his way here and stood on the Manukau shores in the harbour and as the waka arrived, he called to them. So, that saying, Te Kāaanga-a-Hape (The Welcoming Call of Hape¹²⁷), and all the milestones we have is actually a lesson to our people around their not wanting to take him because of his disability – leaving him in the islands as a result and then not realising just the awesome powers that he had to be able to bring himself to Aotearoa. And then settle himself as

¹²² Researcher's translation

¹²³ Ngā Puhī leader. (c. 1780–1828)

¹²⁴ Researcher's translation

¹²⁵ The traditional lands of the Te Arawa people are around the Rotorua lakes

¹²⁶ Hape (also known as Rakataura) was the senior priest on the Tainui canoe. He is also the progenitor of Auckland based tribe Te Kawerau-ā-Maki. According to the Ngata Dictionary website (<https://www.learningmedia.co.nz/ngata/>), the word 'hape' means 'clubfooted'

¹²⁷ Researcher's translation

a ‘tangata pūkenga (skilled person¹²⁸)’ I suppose – massive skills that he had. So, there are a lot of stories in our whakapapa (genealogies¹²⁹) and our pūrākau (stories¹³⁰) that yeah, they aren’t quite translating into publications.

Māori with disability were therefore vital members of their iwi, and played a pivotal role in iwi history. Reclaiming this history was also seen to contribute to Māori with disability reclaiming their rightful place in society:

So, we’ve got a lot of work to do as far as reintroducing or revisiting the whole term of parapara or giftedness and the way in which some of our tūpuna were positioned within their hapū and their iwi. Like, everyone had a role to play and certainly those with impairments did too.
(Provider)

Whānau

By far, the most commonly used term by interview participants to describe Māori living with disabilities was whānau.

They’re whānau and they’ve got the same needs as everybody else – housing, jobs, you know... budgeting issues, all of these things. They’re the same needs, the same things... jobs... [we shouldn’t] look and think in terms of their (Māori with disability) inabilities. Because then you’re restricting yourself... (Expert)

The term ‘whānau’ is often translated as ‘family’, but unlike Western definitions and meanings of family, which tend to emphasise the ‘nuclear family’, Māori meanings and definitions of whānau are more complex. According to the online resource ‘Māori Dictionary’ (www.maoridictionary.co.nz), whānau is defined as ‘extended family, family group, a familiar term of address to a number of people’, and as the ‘primary economic unit of traditional Māori society’. Some definitions also include kuia and kaumātua as being the head of a Māori whānau unit (Pere 1986). Metge (1995) defines two kinds of whānau: whakapapa-based whānau are based on genealogical connections, while kaupapa-based whānau are connected to ‘fulfil a common purpose or goal’. Similarly, Hohepa (1999) describes the various ways in which the term whānau has both traditional and more ‘evolved’ meanings: traditional in that the construct of whānau through whakapapa connections remains as a key definition, and more recently the co-option of the term whānau in the linking of groups of common interest, or common kaupapa.

Mason Durie (1994) also emphasises the diversity of whānau in contemporary Māori society, noting that the term whānau has undergone changes in line with changes that have occurred in Māori society more generally. Accordingly, Durie (1994) identifies three Māori sub-groups: one group consists of those who

¹²⁸ Researcher’s translation

¹²⁹ Researcher’s translation

¹³⁰ Researcher’s translation

are ‘culturally’ Māori in that they understand Māori whakapapa (genealogy) and are familiar with Te Reo Māori (Māori language) and tikanga Māori (Māori customs); another group are ‘bicultural’ and identify as Māori but also operate effectively among Pākehā; and a third group of Māori are described as ‘marginalised’ and not able to relate to Māori or Pākehā effectively. Thus, while the literature shows there is no universal definition of whānau, there is a broad consensus that genealogical relationships form the basis of whānau, and that these relationships are intergenerational, shaped by context, and given meaning through roles and responsibilities.

2. Policies and Legislation in everyday life

While the secondary literature reviewed in section one of this report shows how Crown policies and legislations have shaped the experiences of Māori with disability and their whānau, during interviews the subject of legislation and policy was expressed in less tangible ways. One issue that was raised by Whānau Hauā and other whānau members was that they were either not aware of many of the policies surrounding disability, or they were confused by the complexities of what this meant in regards to the subsequent support available to them. Whānau further expressed that they were unsure of disability legislation, and lacked clear guidance and information around this. For many whānau and Whānau Hauā the impact of this was noted not just in regards to navigating the system, but also in regards to navigating actual physical spaces, where there was a sense that policies should be in place to regulate better access to public places, including school and in community settings.

This meant that where legislation was referred to by interviewees it was most often in terms of what it is currently not addressing, such as the need for more legislation focusing on public places. This interviewee talked about wanting legislation to guide issues relating to equal access at places such as at marae:

See like we are trying to get all our marae around here set up for the disabled. That is something we are working on in our marae. It is very slow. It is very hard. (Whānau)

Whānau spoke of the difficulties they faced in understanding the current legislation and what it means for them:

It is the code of health and disability. A code for who? Is it a code for the Pākehā that can understand the legislation in here, but we can't as Māori? (Whānau)

Also expressed were feelings of uncertainty and a lack of stability due to regular changes in the government. Both providers and whānau mentioned that the development of disability policies and legislation in New Zealand is slow and that the processes in developing these needs to change to provide the best outcomes for Whānau Hauā:

One of the underlying issues that we have and probably why we need to be before the Tribunal, is the issue that when governments change government, all this, these good initiatives get taken

away. How do we ensure the sustainability and longevity of good, healthy policies that benefit and enhance the rights of Māori? And, in particular, Māori disabled? (Expert)

There's a lot of work to happen through legislation and regulation to turn those good policy spaces into things that can actually happen in work programmes. (Crown Agency)

Many of the experts interviewed stated that the current policies surrounding disability all focus on a westernised model of care, not taking into account Te Ao Māori and Kaupapa Māori approaches. It was expressed that Māori are too often not brought to the table on disability policy, or brought in either too late or are far under-represented when coming to decisions on disability policy – a recurring theme throughout the interviews.

This notion is reinforced by research conducted by Hickey and Wilson (2017) who state that there are current gaps that exist in knowledge related to Māori and disability, and that Māori exclusion from health and disability policy and service planning forums is further contributing to this issue.

It was suggested that Māori should have their own policies and legislation in place in order to fund and provide services/support for Māori that are deemed appropriate by Māori. The need for whānau-centred policy, as opposed to the current individualised funding and models, was also expressed:

How I look at it – I just believe we need a parallel government actually. A parallel parliament – similar to what they have in Canada. They have an indigenous parliament. They even have indigenous courts. So, if you were to do it that we could have a parallel government and what happens is that government would oversee... like, we're all under the mainstream laws – that parliament however would have the freedom, the responsibility and the mana to be able to advise on the Māori within those laws. (Whānau Hauā)

Suggestions were made from providers about future methods for working with Whānau Hauā, and the benefits of changing current policies to ones which focus on a whānau-centred approach, rather than an individualistic approach. Multiple providers referred to the need to recognise and resource how the current Whānau Ora approach¹³¹ can support whānau around disabilities:

If you're starting a policy how do you think of things in terms of whānau-centred first for that to then drop down into operations. And one of the things we've been finding as we've been talking with different departments is that often people will think of whānau centred as being a really good approach for service provision. But then when we kind of unpack they then go, wowsers, now we understand it's actually not just how we do our service provision but how we organise

¹³¹ Whānau Ora is an indigenous framework that puts whānau in control of the services that they need in order to flourish, working together to build on strengths and achieve aspirations. Whānau Ora focuses on a collective approach, rather than individual, wrapping support around the whole whānau. See: <https://www.tpk.govt.nz/en/whakamahia/whanau-ora/about-whanau-ora>

ourselves. And that's been, you know, in some ways a higher, a higher bar for people to kind of, for government departments to reach. It's to go, it's not just in how you contract stuff out. I mean, that absolutely makes a huge difference but there's also the more systemic stuff that needs to be dealt with that then makes how you contract provision of services out way better. (Crown Agency)

Whether it's called Whānau Ora or not, whether it's working with Māori whānau or not, the broader New Zealand community also wants government agencies to work together. So, that's both an issue in how we do that when the public finance act specifically links financial reporting to whānau and how we do it when the kaupapa or the vision of what we want for New Zealand as a nation actually requires us to cut across that. So, there's some public policy issues in there but also wonderful opportunities. (Crown Agency)

3. Systems, Supports and Services

The purpose of the 'Māori with Disabilities' report was to deliver an overview of government provision of disability services and their effectiveness for Māori, with a particular focus on disparities (or inequity) in outcomes for Māori with disabilities. Inequities within the systems were expressed by participants throughout the interviews, with a particular focus on the health system.

To contextualise what is meant by health system, the World Health Organisation defines 'health systems' as follows:

A health system consists of all organizations, people and actions whose primary intent is to promote, restore or maintain health. This includes efforts to influence determinants of health as well as more direct health-improving activities. A health system is therefore more than the pyramid of publicly owned facilities that deliver personal health services. It includes, for example, a mother caring for a sick child at home; private providers; behaviour change programmes; vector-control campaigns; health insurance organizations; occupational health and safety legislation. It includes inter-sectoral action by health staff, for example, encouraging the ministry of education to promote female education, a well known determinant of better health.¹³²

The need for more responsive systems, supports and services was seen by interview participants as essential to improving inequities and disparities in the health system for Whānau Hauā. In the following quote, this health expert states that the current struggles in the New Zealand

¹³² Rehfues, E. A., Bruce, N., & Bartram, J. K. (2009). More health for your buck: Health sector functions to secure environmental health. *Bulletin of the World Health Organization*, 87(11), 880–882. <https://doi.org/10.2471/BLT.08.059865>

health system to properly address inequalities for users of Whānau Hauā services will, result in both unnecessary financial costs to the health system in the long term, and lifelong consequences for Whānau Hauā and their whānau:

If people aren't assisted to live as optimally as they can, when you've got some sort of disability there are always consequences to it not being managed properly. And that affects parts of other people's health and wellbeing down the track. (Expert)

For this expert in the disability sector, what is required is the establishment of systems and structures that work for Māori:

It's called racism... It's about wanting to continue inequitable treatment of Māori, Pacific and people of colour here in this country. And it's extremely difficult to get past it... But my point really is, is that do we waste our time continuing to change the systems that don't work or do we get acknowledgement that they don't work and get on with establishing systems that will work? I mean, that's what bothers me most of all probably. Is that while we're all trying to change the world... You know, yeah. It's just hopeless and even for those who think that they're doing the right thing. The interesting thing for me is that they genuinely believe that they're making a big contribution. In a way they don't understand that whole issue of disempowerment and about when you're in the situation that a lot of our people are in the disability sector and not only in that sector but in other sectors as well, you don't, you can't find it within yourself to admit that the system that's operating isn't right. I mean really, in a way, we've got quite sick systems in this country. (Expert)

The following section explores qualitative themes around disparities and discrimination, models of service and care, workforce capability and capacity, access and availability, and cultural responsiveness.

Disparities and Discrimination

Whānau Hauā and their whānau shared a multitude of stories around the types and forms of racism, inequalities, and discrimination they encountered when trying to access government support and services.

This expert talks about how the pervasiveness of institutional racism means that Whānau Hauā have come to either 'normalise' and/or 'tolerate' discrimination and inequities in the support and services they receive:

I feel so sorry for our people who think they're getting a good deal, because some of them do so - they think they're alright because they're getting something, so used to getting nothing. So, that whole issue of the institutional racism that's gone on for years in Aotearoa – it doesn't matter what systems you're talking about, you go into any steel cage and see – and the kōrero is the same about how our people are treated. (Expert)

This participant tells of the discrimination she faced when applying for a home from Housing New Zealand:

So, we visited Housing New Zealand. She told me, 'do you know why you didn't get that house?' And I said, 'no I don't know why I haven't got a house'. 'It's that I've got your file here and it says in your file' - this woman was not meant to tell me this by the way - 'It says in your file "a deaf, dumb, mute". That's why they won't give you a house. You won't get a Housing New Zealand house'. (Whānau Hauā)

Lack of government support often meant that the whānau needed to 'pick up the slack', however, this resulted in increased pressure and strain on wider whānau resources (that is, money, time) and relationships.

This mother and caregiver talks about how her eldest son put his life on hold so he could help care for his disabled father, as well as the lack of government support to help deal with the mental trauma and distress that her husband's stroke has had on her and her children:

Before he [husband] had his stroke he [son] was at Uni. So when he [husband] had his stroke he just finished and came home. So he has never gone back to complete his degree. I want him to but he is not into it at the moment. Our little guy, he most probably suffered some kind of depression or something. He was a very unhappy young man and we are just seeing a kind of improvement this year. We want him to heal. His Dad has got to heal as well. No support. We were so ill-prepared for what was in store for us. They didn't tell us like how he would act. Because like his whole personality changed. We were in shock for a while. They have got no counselling for like our children, getting them in counselling or anything like that, or me. (Whānau)

This whānau caregiver talks about how the needs of his disabled child became so great, that he wasn't able to continue in his job:

I worked at the prison. I held a good job at the prison. That fell apart because I couldn't commit to the prison all the time, and it was something I liked doing, working in there. So that all fell away when I had to commit to him. As you know working at a prison you just can't leave. But that was a reality for me, which leaves them compromised, the prison. So the guilt bit more. So I finished. I resigned. I pushed to work. You have still got to live. It is not free. So I pushed for a long time to work [as caregiver for son]. Under the Ministry of Health [funding] that is not an option. (Whānau)

This same father and whānau caregiver speaks of the toll that caring for his son has had on his health and longevity:

So my son has Cerebral Palsy but I am 46. I would be lucky if I make it to 50. If I make it to 50 we are having a party. I know that for me and my health, I still lift my son. We are with ACC. They have provided us with the equipment but the equipment doesn't work in our house. Like thank you for giving it to us and the training and all that. Then what? I have still got to get him from A to B, through all this. (Whānau)

This whānau caregiver – who at one point had thoughts of suicide – also talks about the daily struggles that having a disabled child has had on his wider whānau, physically, psychologically and emotionally:

I don't think you can underestimate the impact it has on the wider family. That impact is massive and you can hear it in everybody's [the whānau] voices. For me I will say did I consider suicide? Not the actual suicide itself, but I thought about it. I thought 'oh, man this is hard'. In the early days I was thinking this is hard... It was all that... The impact on the family mentally, physically, is massive. It is absolutely huge. I mean your whole life changes and it is every day. It is daily. You will see the neighbours going off to rugby and my boy is still sitting there...he could have been there. It is all that, the what ifs and all that... I will just keep harping back to justice. That is all we seek, is justice. (Whānau)

To deal with the lack of government support and services, a lot of whānau and community-based groups and networks now fill an important gap and provide vital supports and services for the wider community:

Myself and three other parents helped to establish an after school and holiday programme and weekend programme for our rangatahi [young people¹³³] with specifically more intellectual disabilities. And these parents aren't all Māori but the governance structure, because I was there, made sure that we have a part, as much as we can, a partnership framework for how we do things. And what I've seen with our community who are Māori... the whānau that come to our service, come to our service because... they're already stretched. (Whānau)

The research team also interviewed a number of grandparents who had become the main caregivers for their disabled grandchildren, however, grandparents (as opposed to parents) were often not entitled to certain government assistance. The following quote shares one such story of a grandmother, and the struggles and frustration of getting the government support her moko was entitled to:

... the Ministry of Health, they only look at the main carer as to what they are going to give them. So [the] mother [of my grandchild] and my son... they are now separated... I said have you [mother] got a bigger bed for [grandchild] yet? She [mother] says I didn't know about that... I said you need to get the bathroom done and she [mother] said they [Ministry of Health] won't do it... This child has got a right to have [a bathroom]. We shouldn't have to beg. Why do we

¹³³ Researcher's translation

have to feel guilty and have to beg all the time? We shouldn't have to. Why are we guilty?
(Whānau)

Another whānau caregiver talks about the impacts that discrimination, and lack of government support for her grandchild, had on her and the passing of her husband:

The cost of petrol and everything. Taking her and putting her in the wheelchair and stuff like that. Go and do your shopping and you have got to make sure, you have to cover. I used to get a benefit, \$210 for [granddaughter] that had to cover all her special food. She couldn't eat normal food like you and I. Everything had to go through a whiz. I had to buy a whiz. I had to buy all this stuff that you needed to, you know. And these are the little things. And yes, don't want to go and tell anybody. Too shy...Especially Māori who accept what they are given and they shouldn't. They are humble... Yes. It is about everybody [i.e. the impacts on the whānau]. That is why I think my husband died early. (Whānau)

This interview participant talks about the inequity, racism, and discrimination she has observed as a caregiver for her grandchild:

Not being racist, but for us if you are Pākehā you get it just like this. If you are Māori you are questioned. You are whakamā. You are shy. You back off. Why? Why do we do that to ourselves? Then you have got an agency that sits up above you and goes – like I had CYFS and I wasn't allowed to take her for operations, I wasn't allowed, I didn't have the right to do that. Yet she lived in my home. I was her guardian but I didn't have the right to sign the paper for her to have an operation. Mind you, I had someone always lingering over the top of me. I couldn't be a grandmother... Oh, I need to get milk. It cost about \$300 and something a week for her milk that she has to drink because it was a milk that tops her up and fills her up. Even though you give her veggies and stuff she still needed it. It balanced out her body. Oh, well we need receipts. We need this. I said no, no. Here. They give the piece of paper to them, from the doctor to them. You sort it. If you want to be a part of this child's life you start sorting it. (Whānau)

Models of Service and Care

The term 'models' in this section is used to describe pathways to and through services; 'clinical decisions' about what treatments are offered; a way of conceptualising and organising services; and a high-level strategy for allocating service resources.

According to this provider, the dominant model in New Zealand is the medical and/or clinical model which medicalised and pathologised disability and disabled individuals¹³⁴:

134 The strengths model arose as an alternative to diagnostic-based social work approaches, which were often criticised as categorising people according to symptoms, ignoring critical environmental situations and ultimately blaming individuals for their disabilities. In contrast, the strengths perspective avoids blaming behaviour by focusing on identifying individual, family and community strengths (Russo 1998).

Whereas, you know, we're very aware that the dominant model in New Zealand, whether people admit it or not, is the medical model – where there's something wrong with an individual so they place that idea of disablement as the responsibility and the cause by an individual as opposed to anybody else. (Provider)

In order for this parent to receive funding and support for her disabled child, she felt pressured to treat and view her child as a deficit:

So, right from the start, the system wanted us to see him as a deficit and all the things he couldn't do so they could fund him. And we strongly came from the perspective of strength and empowerment and a feeling that there was nothing wrong with him. He just needed extra support and we have two sons and so each of them has had their own requirements. Each child is different, and each child needs different things and that's how we saw our youngest son, really. And to be able to... and the only reason why the whole sort of, deficit model¹³⁵ was there was to guide us into funding... (Whānau)

For this provider, there was still too much focus on overseas models, when there were already indigenous models here in New Zealand that worked and were producing better results:

Why don't we look at indigenous models that are actually legitimate and have actually worked? (Provider)

According to this expert in the disability sector, current 'models of care' in New Zealand lack compassion and empathy:

The other thing too is our frontline people in our services, and I want to say that there are some really good people because I've heard that, but by and large, and I talk to our whānau, our frontline people are judgemental, they lack empathy and compassion, they are gatekeepers and they're quite discriminatory and racist. So, there's a whole host of work that the government needs to do on the empathy and compassion and the relationships that their frontline staff have with people. Because I've interviewed people who say, you'd think it was their money that they were giving away. (Expert)

¹³⁵ A perspective which attributes failures such as lack of achievement, learning, or success in gaining employment to a personal lack of effort or deficiency in the individual, rather than to failures or limitations of the education and training system or to prevalent socio-economic trends. For example, the argument for the introduction of youth and adult training schemes in the 1981 White Paper *A New Training Initiative* included the suggestion that because people lacked skills there were no jobs for them, and that therefore this deficit must be addressed by appropriate training. The implication here was that unemployment arose from a deficiency in the unemployed themselves, rather than from economic trends. The deficit model of teaching, in which the teacher provides the learning to make good a deficit, stands in direct contrast to the belief that the teacher's role is to draw out learners' tacit knowledge and understanding through questioning and facilitation.

Workforce Capability and Capacity

The capacity and capability of the workforce was mentioned in many of the interviews, and often related back also to the context of whānau being supported to be carers and decision makers. While all whānau were supportive of having more say over their care and support, this caregiver believed that systems and processes that supported whānau capability to manage their care packages were needed as well:

And so, we're in a catch 22, I feel. Because I feel I have the ability and the brain power to try and figure out after high school what might be, you know, enabling a good life for my baby. And if you want to give me a package then ka pai. The challenge though, for a lot of our whānau is about, that's about yes, it's about tino rangatiratanga, but if you're talking about individuals, where is our capability to not only manage our own life but manage the life and employment of others to support our young person? So, that's, I think, is always going to be the tension and I know that for members of our community who have rangatahi Māori with challenging behavioural issues, they're burnt out. And so, they want those institutions to support them to support their young person to be independent. So, I think that services need to... absolutely, if we're thinking futuristically and that our communities are able, then I think tino rangatiratanga, self determination to do what they think is best for their rangatahi. There is also a catch 22 there as well – is that you only know what it is that you know. (Whānau)

According to another whānau caregiver, a more skilled and competent workforce for Whānau Hauā was needed:

But the major thing was, for me was like, you know, well if you have all these young nurses coming in and it was like the older ones had [better experience] but then they were going off, so we would be there to watch to make sure that they would be, they were doing it right. You know, and we, you know, we just have to get a rapport with all these nurses but man it was... I felt that we shouldn't have had to be telling their nurses what to do. (Whānau)

A skilled workforce here also meant that workers were able to deliver in a kaupapa Māori way.

According to this interview, more kaupapa Māori services were needed:

... one of the biggest difficulties is that often when people need, especially start to need specialist services is that there then aren't options for Kaupapa Māori provision. So, it means that often people and their whānau lose opportunities to be treated, and I mean treated in a way, and that respect their, their whakaaro. And I think often, we are maybe doing better at kind of primary health. But as soon as you need specialist services, the more difficult it is. (Crown Agency)

For this mother, the lack of available support in her community and being denied any sort of financial support from Work and Income New Zealand (WINZ) for seven years, due to an administrative error, made caring for her disabled daughter particularly challenging:

I had just finished having a baby... my baby was two weeks and I had a caesarean. So, I wasn't able to really lift or anything, but I had to in this case because of my daughter. I had to lift her to put her anywhere – take her to the toilet. There was no help out there. I got a hold of [a provider in my community] and they had no one available to come and help me in the area. And even, we applied for disability allowances through WINZ and got, for seven years we got declined. So, we weren't, you know, it was a bit of a struggle... and having other kids as well to run around after as well. So, yeah, it was... yeah. I just felt like there was no help out there. Just having to do everything. (Whānau)

Cultural Responsiveness

Poor engagement between Whānau Hauā, their whānau, and disability service providers was raised as an aspect of significant importance for all groups. According to this disabilities expert, many health services 'continue to deliver culturally inappropriate services and tend to neglect the worldviews of indigenous people, offering a service based on the dominant biomedical model.¹³⁶'

Interview participants often referred to negative experiences, particularly surrounding cultural safety, responsiveness and the cultural competency of some providers and practitioners.

According to this provider in the disability sector, cultural competency is an ongoing issue:

Because when we talked about Treaty training back in those days we had to decolonise how our staff were thinking and their perceptions of actually what Māori is, because their perceptions were way off, and that is still today. So every new staff that comes in, because that is our New Zealanders understanding of Māori, Te Ao Māori, the Treaty of Waitangi. Anything to do with Māori is way left field. They are not even close. Our decolonisation is about empowering our ancestry... but also speaking to that same philosophy, we are not here to disempower you. So this is actually, we are empowering them. (Provider)

Another expert in the disability sector also adds:

It is the government's responsibility to ensure that services are provided in a culturally responsible manner. If we have the proper mechanisms in place to ensure that providers are equipped to be culturally competent, that would benefit Māori. (Expert)

¹³⁶ D. Wilson, *The nurse's role in improving indigenous health*, Contemporary Nurse, 15:3, 232-240, DOI: 10.5172/conu.15.3.232, 2003.

More recently, iwi have played an increasingly important role in providing social services within their communities:

It is important that iwi appreciate the unique needs of kāpō Māori and the impact that social determinants have on the health outcomes and wellbeing of tāngata Whaikaha. (Whānau Hauā)

Providers also spoke of the importance of supporting the Whānau Hauā workforce to be able to confidently participate in Te Ao Māori:

So our marae are the centre and the heart of our Māori communities, and yet our people we have been spending time [with] were finding that staff around tikanga and kawa, that they didn't know any of the etiquette so they weren't supporting them in their community because they were scared. (Provider)

Ensuring that Te Ao Māori is accessible to Whānau Hauā was also a concern:

It even got to the point even with our own culture, Te Ao Māori, and our own tikanga can be inaccessible. (Whānau)

Access and Availability

Based on qualitative data, the main access and availability issues were usually in relation to transport, infrastructure, lack of resources, and lack of awareness around available services for Māori with disabilities and their whānau.

Lack of services and support were particularly pronounced for whānau in rural locations:

Finding people in those, and this is where our whānau miss out, you know – whānau out in those rural settings absolutely are cheated because just the fact of finding people. (Provider)

For this young mother with disabled children, being rurally based meant she was strongly reliant on whānau support:

Here in the north it is only our whānau. There is no support anywhere else. It is so hard. You have got to travel so far. It doesn't come easy travelling. (Whānau)

Interviewees talked about access to disability services and support required whānau to move to the city, resulting in social and cultural marginalisation:

Historically, many kāpō Māori and their whānau were required to migrate to Auckland to access kāpō services such as schooling. Once in Auckland it was not uncommon for them to become

marginalised and it became increasingly difficult for them to retain their culture and language. From this migration there has also been a loss of traditional whānau support for kāpō Māori and for many a disconnection from their iwi. (Whānau Hauā)

According to this interview participant, current assessment tools perpetuate the issue of whānau hauā having to move away from rural tribal areas in order to access services:

The problem is that the Pākehā assessment tools or needs-assessors – they capture this. In their view it's like 'move to this service, move to a better place', but this is my maunga, its part of my identity. (Provider)

The issue of inaccessibility – not just to support services, but to public and community spaces – was another topic that was highlighted by interviewees. Inaccessibility in this sense concerned practical matters of building access standards, as well as the sense of 'not being welcome', alongside the complexities around lack of finance, transport and support while out of the home:

It's an issue. You might be able to get out and about but if you're not welcome in the local supermarket or the local swimming pool there's no point going out. Or if you've got no money you might be able to get out but could you get home again? There's a whole lot of stuff that's interrelated and access is only one of the issues that need to be sorted out. (Whānau Hauā)

This caregiver believed that more needs to be done to ensure that all schools cater to the diverse needs of children with disabilities:

All schools should be set up to cater for all the different needs that we have, including disabled kids. That is what I was saying. It doesn't even make sense to me. I am, like, it is a public building you know. It should be compliant. (Whānau)

One of the recurring issues mentioned was that marae also needed to be supported to be more accessible for Māori with disability and kaumātua:

See like, we are trying to get all our marae around here set up for the disabled. That is something we are working on in our marae. It is very slow. It is very hard. We have just had our marae done up in *Marae DIY*. As far as we got there, we got a concrete pathway but we have got a disabled shower in now... We are just trying to get the other marae to follow. Because it is not just our children, it is our elderly. Our elderly are all getting old. Karen and I have set up exercise classes for our elderly in respect to balance in our marae. (Whānau)

This whānau caregiver felt that more needed to be done for whānau who are currently not accessing, but were entitled to, government support and services:

What does that mean when a lot of our whānau are already missing out on the services that they should be accessing? So, I mean, I know whānau up north who, you know, have physically and intellectually disabled rangatahi who didn't even know that there were services available for them. You know, so our system's failing those who are accessing services. (Expert)

Interviewees also talked about access and availability as being about systems offering clear navigation. This caregiver wanted to see the streamlining of services and pathways for Whānau Hauā:

Now they all [disabled whānau] go to the doctors and none of them have been channelled into something better. So I am blaming the hospitals at the moment. Because surely to goodness most of these kids get pneumonia or something that hospitalises them. But when they get into the hospital why haven't they been channelled to where they can get help from? (Whānau)

4. Service and Support Funding

In concord with issues around systems and services, the interviews revealed a widespread concern about funding gaps and inadequacies. Whānau Hauā that were interviewed accessed from the spectrum of services that are currently provided nationally^{137 138}, yet a multitude of issues around ineffective resourcing emerged throughout the interviews. While most of the interviewees were clear about the needs that they had, and what it would take to have them met, they spoke of their struggles to establish engagement from Government systems to support them:

Ngāti Kāpō needs to be adequately resourced by the Crown to work with iwi to address the health and wellbeing needs of kāpō Māori. For example, this could include the placement of kāpō Māori into programmes to help reconnect them with their whānau, hapū and marae. It could also include specific education regarding the use of guide dogs on marae and to dispel myths regarding guide dog use. For instance, many marae are unaware that guide dogs are trained to defecate and urinate upon command and therefore there is a low risk of spoiling occurring on the marae atea or in the wharenuī. (Whānau Hauā)

Some concerns were raised around the lack of accountability of mainstream organisations in terms of ensuring proper Māori representation at all levels of leadership and governance, and in acquiring government funding for Māori clients:

You find at a [Kaupapa Māori] organisation like mine – in order to get funding for example, from the Māori provider development scheme which the Ministry of Health runs, which is a fabulous scheme, you know, you have to have the majority on your board Māori, the majority in your

¹³⁷ Ministry of Health; District Health Boards; ACC; Ministry of Education; and Ministry of Social Development.

¹³⁸ The total funding for disability services from Vote Social Development in 2017/18 was \$3.716m (Office for Disability Issues, 2017. Briefing for incoming Minister: Disability Issues)

senior management team Māori, the majority of your staff Māori. Well, you know, I'm pretty sure mainstream providers who provide disability services to Māori don't have to do that. But I do – to get any funding. You know, so it's about how do you make it a more equitable process for actually getting funding for the clients you look after or that you support. (Provider)

For this interview participant, the issue of more equitable funding process was also reiterated:

You know, so it's about how do you make it a more equitable process for actually getting funding for the clients you look after or that you support. I think the other thing that would make a really big difference is if we could have many more health professionals and allied health professionals that are Māori. (Provider)

According to an interview with one Crown agency, 'ACC is an entitlement driven system' while 'MoH is a rationed system'. For whānau, this translated out into marked disparities in the quality and level of funding and support they received through the Ministry of Health when compared to whānau receiving ACC entitlements:

This is my biggest gripe. A drunk can get in a vehicle, drive down the road, flip through a paddock and he gets everything overnight, and it is local. We have got three or four of them in this county. We watch them while we struggle with our kids. We see them in their big flash vans. We see them get a house through ACC. We see them with all their gears. We are entitled to what? Twelve hours cares a week or 20 hours cares a week. You are only entitled to a certain amount of hours in the day for school. Even the education department; 25 hours. That is all you are allowed at school. Every other child can go for 30 hours. How come ours can only go for 25 hours? This house, my husband and I had a freehold when we came here and we lived next door. We are in our 50s. We built this house for my granddaughter. To be able to do that we went into debt... We had no funding for this house. We did it on our own. I fought for everything, a shower... I had to pay for the installing of it and that was dearer than the shower ... There are so many things and yet for us here we strive for everything that we need for our children. (Whānau)

As mentioned in a previous section, it was expected that Kaupapa Māori services for Whānau Hauā would come to have a profound impact on the disabilities landscape in Aotearoa New Zealand, yet virtually all the providers we spoke with ran their services on the 'smell of an oily rag':

Ngāti Kāpō has had to operate off minimal funding and struggles to survive. In my view, Ngāti Kāpō is the appropriate organisation to provide services to kāpō Māori and to advocate for kāpō Māori. Unfortunately, Ngāti Kāpō continues to receive very limited resources and does its best in often trying circumstances. I believe that provided Ngāti Kāpō is properly resourced that it can make a huge difference in addressing the health disparities and health challenges faced by kāpō Māori and their whānau. Although we were limited by our funding I am proud of the effort that Ngāti Kāpō has and continues to make to provide welfare and advocacy services to kāpō Māori

and their whānau throughout New Zealand. That said, much more can and should be done to ensure that kāpō Māori and their whānau enjoy the same health outcomes and quality of life as other full sighted New Zealanders. (Whānau Hauā/Provider/Expert)

Similarly, programmes like Whānau Ora – in comparison to mainstream programmes – continue to receive low levels of funding yet achieve high levels of success in meeting the disparate and diverse social and health needs of Māori:

... the Whānau Ora approach is saying actually, whānau make decisions about how they prioritise and what they want and when they want it. And therefore... so, it's a totally different approach and I can see how successful that has been particularly when there have been whānau who have had a whole raft of needs including those who are Whānau Hauā in terms of actually, you know, making decisions about that. What that looks like on the ground, you know, Whānau Ora is a small, a one level, you know, if you look at kind of government funding – it is a small amount of funding which is really why we're doing this work on whānau centred which is starting at the policy level. (Crown Agency)

This whānau caregiver believes more transparency is needed around how funding decisions are made:

So, I absolutely think there's a layer of complete unconscious bias in those decision makers and who are those decision makers working for? Are they ultimately working for the government? Then make that very clear to whānau. Or are they working to support whānau? And being transparent about the limitations of the pūtea. Because that's what it's about at the end of the day. How much money, so we can resource our young person to make sure that they have a great life knowing that our Māori with disabilities are the poorest of the poor. So, NASC and those funding organisations ultimately are our barriers. Because the services themselves are contracted to try and do their best but I wonder what the agenda is of our funders, or that mechanism for accessing funding. Absolutely know that it's not a continuous pot of money. There is a ceiling to it, I get that. But the process around how you distribute funding really needs critiquing. (Whānau)

For this interview participant, the criteria and language by which funding is determined is also debilitating:

So, that in my view, the criteria is supposed to try to keep people out... you've got to meet all these horrible, horrible definitions of yourself just to get services. And then when you do become eligible the contributions are contributions. So, it, they kind of, for me, the poverty mentality. So, you contribute to people's lives but you keep them where they can't move forward. It's like a holding pattern until people die and then new people come and you hold them there too... I know it could be more talk about the funding but you have to start with attitude. It has to start with the attitude that we've all got to... we've all got our whakapapa and that's the most important thing to me as a Māori. And then when it comes to getting support

and assistance, recognising that I'm more than a label that somebody's given me on that particular day. (Whānau Hauā)

Another topic that was raised was the current policies around daily disability rates and the criteria which determines this. Providers interviewed expressed concerns around the equitability of the current rates, particularly in relation to those with more complex, or multiple needs, stating that there didn't seem to be any policy or criteria around how daily rates are determined:

So, is it equitable? Well when you have no criteria for what daily rate people will get and you're a Māori organisation and the majority of your clients are Māori and the majority of them more higher complex, one would expect that I wasn't sitting at sixty percent, but I would be at the top. So, who's at the top? If I've got the most complex [service users], you know? (Provider)

5. Participation and Inclusion

Participation and inclusion of Whānau Hauā at all levels of decision making – from whānau, hapū and iwi to national governance and international representation – was seen by interview participants as imperative to advancing the rights of Whānau Hauā to lead, innovate, and control their destinies.

The following sections provides examples from interviews with claimants and others involved in advocacy work and services, around the issue of effective representation for Whānau Hauā.

Advocacy

Health advocacy involves promoting the needs and rights of people who use health services. Advocates may also support people who make complaints about their treatment.¹³⁹ In the New Zealand disabilities sector, this has traditionally been the role of non-profit organisations with some of the most well-known being: the Jubilee Institute for the Blind (established in 1890 – now the Royal New Zealand Foundation of the Blind); the Crippled Children Society (established in 1935 – now CCS Disability Action); and the Intellectually Handicapped Children's Parents' Association (established in 1949 – now IHC). In addition to advocacy work, many modern organisations offer their own 'in-house' suite of health and disability services.

Health advocacy has played a pivotal role in the Māori with disability sector, particularly in ensuring that Whānau Hauā and their whānau receive support and care that meets their social and cultural needs.

¹³⁹ R. Du Plessis & A. Scott, *Health advocacy and self-help*, Te Ara - the Encyclopedia of New Zealand, <http://www.TeAra.govt.nz/en/health-advocacy-and-self-help/print> (accessed 10 April 2019)

Ngāti Kāpō¹⁴⁰ o Aotearoa (also referred to in interviews as Ngāti Kāpō and/or Kāpō Māori) is a national Māori advocacy, health and disability service provider that is driven by and for Whānau Hauā consumers and their families:

The purpose of Ngāti Kāpō is to advocate and provide services that enable and promote kāpō Māori members' health and well-being and self-sustainability. Our vision is to illuminate the darkness with hope, self-determination, independence and individual and whānau well-being. Our mission includes offering specialist cultural support initiatives, solutions and advice.
(Whānau Hauā)

Ngāti Kāpō was founded in the early 1980s¹⁴¹ and began as a network for kāpō Māori (Māori blind):

It initially involved connecting with kāpō Māori living up north, as well as down to Wanganui and across to Gisborne. (Whānau Hauā)

Over the last three decades, Ngāti Kāpō o Aotearoa have been instrumental in providing advocacy, health, and disability services to kāpō Māori throughout the country.

A number of smaller and/or emerging organisations also exist including Tāmaki Ngāti Kāpō and Vision Pacific. According to their website, Tāmaki Ngāti Kāpō, established in 2003, was a 'breakaway group' who identified a need for whānau support around the uniqueness of being kāpō Māori in Tāmaki, and are an independent consumer group guided by a Board of kāpō 'whose kaupapa is generally determined by Māoritanga'. They currently assist kāpō Māori to navigate 'service providers that are available' or to get in contact with 'specialist disability agencies'. An advocacy service is also provided.

Vision Pacific (formerly called Akamarama Advocacy) was founded by Tewai Halatau and Latoa Halatau in 1998. According to the Vision Pacific website, their team, including the Board, is comprised entirely of people with disabilities of Māori and Pacific heritage who are committed to supporting family/whānau and people with disabilities to 'participate fully and independently in society':

¹⁴⁰ According to Higgins et al (2010), Ngāti Kāpō o Aotearoa adopted the term 'kāpō', which comes from Ngā Puhī dialect, and was brought to Ngāti Kāpō by Bill Rako. It was subsequently adapted by the kaumātua (respected elders) and kuia (respected older women) of Ngāti Kāpō after wide consultation with elders without, and with, sight, like Sir Kingi Ihaka. The word kāpō was used to holistically identify the state of being for people who are vision impaired blind, or deaf blind. Other terms that were considered by Ngāti Kāpō, which would identify the 'state of being blind' were 'matapō' (black) and 'pohe' (dim). Also, of importance is the fact that the meaning of 'kāpō' for Ngāti Kāpō is directly linked with the term, Ngāti and with the whakatauki (proverb) 'kā pō, kā pō, kā ao, kā awatea' (the forward journey from darkness into the light). This whakatauki is also used in whaikōrero (men's oratory) by most iwi. Further to this meaning, some have also indicated that the wairua (spirit) of a person may know before birth that their physical being will be kāpō but the onset of the physical impairment of blindness or vision impairment may occur sometime after birth (Russell, 2007).

¹⁴¹ According to Higgins et al (2010), Ngāti Kāpō o Aotearoa's inaugural hui was held in 1981 in Auckland, and soon after developed seven rōpū (support group). In 1991, it was registered as an incorporated society and by 1995 had eleven rōpū.

Moving into your first flat, the dignity that comes from having your own pay packet after a week's work, settling down with someone you love. They're all things most of us want. Disability need not prevent someone from achieving any and all of these goals. Based on our Māori and Pacific Island heritage, we know a holistic approach to social issues is highly beneficial, and not just to people with a Māori or Pacific Island background. All ethnicities can benefit from the holistic approach we offer.¹⁴²

More recently, Tū Tāngata Turi o Aotearoa, was established to support the Māori deaf community:

I decided to set up my own Māori deaf kinda community to try and see who wants to get involved and learn about Māori language and Māori concepts. And there's only a little bit of Māori sign [language] set up so far. It's not really a developed language at the moment, in sign language. So, yeah, I've been involved in that way. I'm a representative for the deaf Māori community for the last twenty years, yeah... I saw a lot of Māori, deaf Māori issues out there and a lot of barriers that people couldn't get through. Like, for example, lack of communication, don't know how to read for example. There's no access to interpreters or captioning, subtitles and a lack of communication. So, I was kind of interested in those areas. And so, a few... people really don't know their history, their Māori history and who they are. And they don't know how to do the research. So, I was really interested in when I did my research and I kind of want to share that with the rest of my Māori community, Māori deaf community, to kind of get to know who their iwi is and where their whānau is from for example. And so, after having conversations with those people they kind of started getting interested themselves and as Māori, oh Māori Land Court... so, I've kind of got that link with Māori Land Court and with the deaf Māori community and tried to link them up so that they could find their heritage as well. (Whānau Hauā)

Ngāti Turi o Aotearoa¹⁴³ and Ngā Rangatahi Turi Māori o Aotearoa¹⁴⁴ were also briefly mentioned by interview participants, however, due to time constraints, the research team were unable to include either of these groups in our interview sample.

¹⁴² <http://www.visionpacific.org.nz/>

¹⁴³ According to their Facebook page, Ngāti Turi supports the Māori Deaf community to achieve their aspirations in life. It places whānau at the centre of decision making and supports them to build a more prosperous future. Ngāti Turi was created in response to a recognition by Government that standard ways of delivering communication and socialisation needs of the Māori Deaf community. We ensure the strengths and abilities that exist within whānau and aim to support and develop opportunities that fulfil potential. Ngāti Turi recognises that Māori Deaf whānau have skills, knowledge and experiences that contribute to their own resilience, and can provide a platform for whānau and families to become more self-managing and independent.

¹⁴⁴ Ngā Rangatahi Turi Māori o Aotearoa is a group for deaf Māori youth. Besides a Facebook page and mention of a hui for deaf Māori youth being held in September 2019, there seems to be little written or publicly available information about the group.

Both CCS Disability Action¹⁴⁵ and IDEA-IHC¹⁴⁶ also offered disability advocacy services for whānau Māori. IHC support provide advice on the rights and entitlements of those with an intellectual disability; guidance on dealing with services and agencies such as schools, health professionals and government agencies; and guidance to people with intellectual disabilities to become self-advocates. CCS Disability have Kaiārahi who ‘work alongside the whānau’ in a holistic way to provide information and advocacy on disability issues:

A lot of work goes in behind the scenes to make sure support workers are matched up correctly with whānau and that the whānau, you know, the needs are taken into consideration across all of their, you know, different parts of their life. So, if they have a particular religion that they are, we always try and match them up with someone with the same faith... So, it's taking all those different aspects of a person. (Whānau Hauā)

Whānau advocacy or self-advocacy was mentioned by a number of interview participants, although this was often a skill that was developed over time and born from circumstance and frustration:

So, yeah, I had to have, at an early age I guess, start attempting to advocate for myself in terms of information, of access to information. Not that I knew that it was going to be a big thing because I just thought, oh what a hōhā (annoying¹⁴⁷). Can't even read the stupid things so I'd muck around. And I guess that was part of the lacking of where my education sort of fell away because I wasn't able to have the skills and the tools to really advocate strongly for what I needed in primary school. (Whānau Hauā)

Representation

According to Hickey¹⁴⁸, it is important for indigenous peoples with disabilities to know how to access their health and wellbeing without barriers, and that Māori are seriously under-represented in any decision-making roles that include people with disabilities in New Zealand. It is also important for the New Zealand disability community to understand why Māori are not participating, and why the health and wellbeing of Māori with disabilities is worse than others with disabilities.

Ensuring proper representation of Whānau Hauā (and Māori in general) in the decision-making process ‘at all levels’ was seen as an issue requiring greater attention by this interview participant:

¹⁴⁵ CCS is the acronym for the Crippled Children Society founded in 1935. CCS Disability Action has been the name of the organisation since 2007

¹⁴⁶ IDEA Services is the service arm of IHC. IHC New Zealand is a New Zealand organisation providing support and care for people of all ages with intellectual disabilities. It began as the Society for Intellectually Handicapped Children, hence the IHC acronym.

¹⁴⁷ Researcher's translation

¹⁴⁸ H. Hickey, *Whānau hauā: the experiences of accessing health and disability services for Māori with disabilities A Report funded by the Health Research Council and Auckland University of Technology*, 2019.

So, we're trying to do similar things around Māori disability. I suppose the thing that if we were looking at, you know, how could we be more responsive to Whānau Hauā, I suppose it's quite difficult to get a responsive service when the purchasers and the funders are not Māori... you know? And I don't think that that's anything new. You know, how many people are at the decision-making level and how...? Well, kind of, that's a given, you know, that I think you just need to have Māori at every level within government, within agencies. (Provider)

Another provider also added that there needed to be 'a separate Māori commissioner of health and disability to keep an eye on things'.

The lack of effective political representation for Māori disabled was of concern for this claimant:

We need an MP [Member of Parliament], we need MPs in parliament who are disabled and preferably who are Māori. We don't get any party supporting us high enough on the party list. We've only had one disabled MP through the entire hundred and whatever years in parliament. (Whānau Hauā)

The lack of a pan tribal, pan disability Disabled People's Organisations (DPO)¹⁴⁹ to represent Māori disability issues regionally, nationally, and internationally was concerning to this claimant:

It's ironic you know, that if the Pacific Island community have been supported and set up their own disabled persons organisation. We don't have a... pan tribal... pan disability Māori organisation that's a DPO [Disabled People's Organisation] in New Zealand. We've had no support. We've had no funding. We've got no representation of Māori at an international level.

The lack of government support in ensuring more diverse representation of Māori disabled at the international level was also an area of concern for this claimant:

UNDRIP¹⁵⁰ has two articles that specifically mention indigenous with disabilities – articles twenty-one and twenty-two. The UNCRPD only has preamble P. Now, with those and the Treaty

¹⁴⁹ The United Nations Convention on the Rights of Persons with Disabilities (the Convention), in Article 4(3), promotes the active involvement by government agencies of representative organisations of disabled people (referred to as Disabled People's Organisations), which are governed by disabled people. Over 2013/2014, the Disability Action Plan 2014-2018 was developed through a collaborative process involving government agencies and national Disabled People's Organisations. This work was coordinated by the Office for Disability Issues. Organisations that comprise the DPO Coalition have a history of working together under the Convention i.e. monitoring implementation of the Convention and working with government agencies. The Office for Disability Issues supports the DPO Coalition to meet together and lead thinking about working collaboratively with government agencies to implement and advance the Convention.

¹⁵⁰ The United Nations Declaration on the Rights of Indigenous Peoples (UNDRIP) is an international instrument adopted by the United Nations on September 13, 2007, to enshrine (according to Article 43) the rights that "constitute the minimum standards for the survival, dignity and well-being of the indigenous peoples of the world." The UNDRIP protects collective rights that may not be addressed in other human rights charters that emphasize individual rights, and it also safeguards the individual rights of Indigenous people.

of Waitangi, along with the UNDRIP, along with UNCRPD, tell me that by right we should have international representation at the UN [United Nations] meetings for indigenous disabled, at least. Now, those meetings exist a lot in Geneva. We have got no indigenous disabled person going and that upsets me... ODI have never ever supported that role. Even our human rights commissioners have never supported that role and yet, they send Pākehā off to the UN meetings but they don't send any indigenous disabled person. DPO has Māori blind there and they have Māori deaf there but we don't have any other impairment group there. And we really shouldn't be going by impairment... we should have impairments but we should be going by a Māori umbrella to the DPO – not by impairment. (Whānau Hauā)

The lack of a peak body for Māori disability and support services was of concern for this interview participant:

I think too that Māori disability services, support services, need a peak body of some kind. And there used to have one, it was called Te Piringa. When funding got cut in the sector, what you'll find, what you found is that the more rich, not that there's any such thing in the disability sector, but the more, the ones that had more pūtea (funding¹⁵¹) or more resource actually funded the get togethers. When Ngāti Hine was a lead there, when they lost their funding in a certain area, then Te Piri Na fell over because it's lots of little Māori organisations that literally are already working beyond their capacity anyway. (Provider)

6. Research, Evaluation and Data

One of the themes that became increasingly visible throughout the interviews was around data, evaluation, and research of Māori and disability.

Interviewees commented on these aspects from their own particular viewpoint; so for providers the lack of consistent and adequate data impeded their ability to deliver best services and have a robust overview of needs; while for thinkers and workers within government and academic spaces the lack of reliable quantitative data and qualitative representations of lived experience of being Māori and living with a disability was limiting and again, highlighted gaps within the ability to plan, purchase and develop theories or delivery approaches around Māori and disability. For whānau, the impact of inadequate data collection and/or management was expressed through the frustration that came from experiencing disconnects within service provision based on data not reaching across services, or data not reflecting what was important to whānau.

¹⁵¹ Researcher's translation

Data Quality, Availability and Linkage

The Appendix of this report presents a snapshot of currently available data on Māori and disability, with a provisory comment on the limitations of the data. While earlier thinking around data issues has been expressed in current literature and has also prompted the Disability Data and Evidence Working Group¹⁵², data – or the inadequacy of it – is something that has been picked up by claimants to the Waitangi Tribunal as an issue of significant effect on the lived experiences of Māori with disability, and echoed throughout the interviews:

Little research has been done in the disability sector, let alone Māori who are disabled. So, it's the sector as a whole. So, we don't know all sorts of things, like how Māori became, got into the service and what types of disabilities are prevalent and what supports are actually in place for the kinds of disabilities there are. And again, I feel really bad because I don't know if it's factually true. I only know anecdotally that a lot of the clients that I work with that are Māori, dual disability ... there's not much really done in terms of research about that. (Provider)

Feedback from whānau carers focused on the effect of the system not being linked up as providing barriers to receiving best care for their Whānau Hauā. This comment, about the education system, highlights the frustration that was expressed by many parents trying to coordinate school readiness for their tamariki:

There needs to be a database, at first. So that child is followed through. She hits five, she is off to school. What is in process for that child? She has got all this stuff up to five, well, what happens when she gets to school? Is the school ready to have her? Then, oh, off to college now. Is that college ready to have her? This is just not happening for our tamariki now. (Whānau)

¹⁵² In response to the concerns around data quality for disability, and to improve data collection and statistics on disabled people, in “2015, the Minister for Disability Issues announced the establishment of the Disability Data and Evidence Working Group, jointly facilitated by Stats NZ and the Office for Disability Issues” (Office for Disability Issues, 2018). The funding for the Disability Survey covered from 2004 to 2014, and the alternative for this survey is to be the Māori Social Survey, which was supposed to be done after 2018 Census (Office for Disability Issues, 2018). However, a report by Statistics New Zealand, in August 2015, claims that “disability-specific survey is scheduled to be run as a post-censal survey in 2023 and intended to be every 10 years thereafter.” (Statistics New Zealand, 2015). The Disability Data and Evidence working group has helped inclusion of disability questions in other household surveys. For instance, the Washington Group Short Set (WGSS) of questions is used to identify disabled people in the New Zealand General Social Survey (NZGSS) 2017. Therefore, the data released in 2016 from this survey should be considered cautiously as their purpose of data collection and the questions used is different from the Disability Survey in 2013. The Washington Group Short Set survey is designed ‘to identify individuals who are at greater risk than the general population of experiencing restricted social participation because of difficulties undertaking basic activities’ and it is not designed to estimate prevalence of disability (Office for Disability Issues, 2017). Moreover, the disability questions on NZ Census are not considered as a robust source of data about the disabled population and cannot identify them properly (Statistics New Zealand, 2015).

The lack of coordinated data and linkage across systems also increased the burden of whānau navigating on their own across multiple service providers, or even the same government provider, but for different specific services:

She [tamariki] could have gone to [multiple appointments] in a week, which she could have condensed to four in one day. None of that is ever taken into consideration. Obviously it is computer generated. The appointment flicks around on their calendar and then the paperwork goes out. Because when we were under the Ministry of Health [tamariki] would get three appointments, three different to do with health on the same day, but three different papers. So obviously there is not somebody there going “oh well this is going to the same person”. There is none of that. (Whānau)

I’m really tired of telling what I need and then having to justify it over and over again. Surely, we can move on and so, lots of people know what will actively get a difference in their lives. Because loads of people have that – lots of time to think about this stuff. (Whānau Hauā)

For interviewees who were involved in service provision and/or service design and thinking around best service provision for Māori with disability, the lack of adequate data highlighted the inability of analysis leading to robust, best practice decision making by Crown agencies.¹⁵³

I don’t think the people who are making decisions are asking ‘what’s wrong with this picture’. And it is having a structural analysis of it and why isn’t it. (Expert)

The missing piece is the lived experience – that [research] has to become the centre that we design our methodologies and services from. (Crown Agency)

Evaluation and Assessment of Services

Evaluation and assessment of services was mentioned by interviewees in a couple of ways: while some providers focused on the ‘over-auditing’ of services (in particular those delivered by Māori organisations), others mentioned the lack of evaluation of services – in particular evaluation of whether services were effective for Māori.

Examples where ‘over-auditing’ was seen as a barrier to effective service delivery focused on auditing as a process to ensure contract compliance, something that was not necessarily compatible with delivering best outcomes for Māori.

¹⁵³ It is important to note that data on disability is in the process of improving through inclusion of new disability questions in Statistics NZ surveys. This in turn could help improve/update policies especially the NZ Disability Strategy (Office for Disability Issues, 2017). These new sources of data are required to enable measuring progress.

There was also a call for appropriate assessment tools, which could take into account the holistic, Te Ao Māori approaches that were seen as appropriate for best outcomes for Māori with disability:

Such an approach would involve making an assessment that looks at all of kāpō Māori needs. This would include addressing key factors and issues impacting upon kāpō Māori and their whānau health and wellbeing arising, for instance, from factors including cultural disconnection, poverty, poor living conditions and overcrowding, substandard housing, educational underachievement, unemployment, access to health services and discrimination... Any assessment would include a plan of action to alleviate those issues. (Whānau Hauā)

The idea of assessment of services as focusing on the ‘wrong things’ was similarly expressed when looking at the dearth of evaluation of services – this was primarily mentioned in regards to where mainstream services were providing for Whānau Hauā, and where a mainstream approach was seen as potentially lacking in effectiveness for Māori and their whānau.

So, things like comes back to when a mainstream service, and I love my sister organisation spectrum and IHC and ideas – they’re all doing fabulous work. However, they are looking after and supporting Māori clients who might not know we exist. And who is actually evaluating what mainstream services are doing with Māori? It’s in their contracts. (Provider)

The interviews highlighted that the idea of measuring outcomes, and in particular outcomes determined by Whānau Hauā, is inexplicably linked to issues around data gathering, management, and assessment of services.

Research on Māori and Disability

The academics, experts, providers, and designers of services all reiterated that there is a distinct lack not just of data, but also of qualitative research on Māori and disability. For many, this was especially visible in regards to the voices of those with ‘lived experiences’ – so Māori with disability and their whānau, but also those who provide the services. While there is now a significant body of thinking and evidence around Māori health and wellbeing, the same cannot be said for Māori and disability, and for many of those interviewed this represented a significant barrier to developing a true, best service approach for disabled Māori:

They need to do a real analysis of, you know... What’s wrong with this picture? Who’s affected most by disability? Who’s accessing the services? And who importantly, isn’t and why aren’t they? So, you know, yeah... quite cynically, it’s in the government’s best interests – their purse strings, not to be identified with Māori but actually it’s costing us a lot of money in other ways because somewhere down the track, that’s going to cost the country a lot of money. (Expert)

So there's still a big research area to know what is it that works for Māori in regards to the disability sector. We know that our Māori aren't being met in regards to their needs as Māori. (Provider)

What this also meant for some interviewees, was that the Western narrative – not just around lived experience, but also around contemporary assumptions about Whānau Hauā – had not yet been superseded by the history, values and voices of Te Ao Māori. The debate around terminology over Māori with disability that is highlighted in a previous chapter of this report is one example of this; further research is required to explore not just what Māori and disability means in our contemporary world, but also in the history of Te Ao Māori:

We need to look at what our tūpuna considered this aspect of disabilities back in the day, prior to European arrival, because no-one has really done that. What I'm finding is a really distinct difference. There's a period where, after Pākehā first arrived that the idea of makutu or a curse, the curse syndrome we call it, where Māori started to consider a disability as a curse. We're not finding that kind of research, well, we're not finding that to be the same prior to European arrival. (Expert)

In summary, the theme around data, evaluation, assessment and research strongly resonated throughout the interviews. For providers, academics, government and whānau alike, there seems to be a barrier towards gaining an understanding of needs and aspirations, or the approaches that work or don't work. While this information deficit exists, the designing and delivery of services that work for Māori with disability and their whānau will not be able to truly capture best outcomes for Māori.

7. Aspirations

One of the recurring topics that emerged throughout the interviews was around defining and acknowledging Whānau Hauā aspirations. For everyone interviewed, from Māori with disabilities to providers, there was a focus on identifying 'overarching' as well as 'specific' needs of Māori living with disability, and acknowledging the diversities within lived experiences.

While Whānau Hauā needs were aligned with the type of disability experienced¹⁵⁴, some of the more 'general' needs that were mentioned consistently by Whānau Hauā, caregivers and whānau included:

- appropriate accommodation/housing
- transport
- medical support
- appropriate resources and equipment.

¹⁵⁴ Ministry of Health. (2012). *Whāia Te Ao Mārama: The Māori Disability Action Plan for Disability Support Services 2012 to 2017*.

For whānau looking after tamariki with disability, access to education – meaning appropriate, well-equipped and appropriately staffed schools – was cited as one of their biggest needs. Whānau also consistently reiterated the need for ongoing and adequate in-house support with care-giving, as well as respite care – problematic access to these was particularly mentioned by rural whānau.

Other essential services that were mentioned by whānau was the availability of a ‘navigational’ worker – meaning a person or service that helps whānau access and navigate across the multiple services that Māori with disability have to traverse. As mentioned in previous sections, for many whānau, the issue of having to coordinate knowledge about and access to multiple services, was seen as a real barrier to getting the best service for Māori living with disability.

What I would like to see put in place is that anyone with a disability, right from the beginning there is a case worker from day one to work alongside that person with disability and carer. All the information is compiled onto a database accessible for doctors and agencies that are involved in the wellbeing of the person with disabilities. There is nothing worse than having to repeat the same information over and over when you are dealing with different groups.
(Whānau)

Reframing Needs: Whānau Hauā and Aspirations

Many of the interviewees who talked about ‘needs’ also spoke about problematic definitions of how need is defined by services and systems, and that real system analysis and recognition of ‘need’ requires a new conversation that transcends imposed ‘tick-boxes’:

So when we’re asked ‘What help do you need?’, first is a tick box which is, you know, that’s bad. We should be moving more to a strength-based opportunity for conversation, where you have open ended conversation and whānau will be asked ‘How are you coping? Is there anything you need?’ (Whānau)

Reframing conversations about need means looking also at aspirations and goals of Whānau Hauā, and going beyond struggling to receive the basics. Even for interviewees who struggled everyday with the system around ‘the basics’ it was seen as important to talk about aspirational needs.

Many talked about struggling with how to move from ‘surviving to thriving’. For some this meant focusing on positive attainments that are in line with ‘what most people want’, and included education, employment, home-ownership, and relationships:

I want to get married, I want to have children and I want to get a job – just like you. (Whānau Hauā)

Where there was an expressed desire to move from deficit to aspirational thinking, there was a distinct message to define needs within a Te Ao Māori framework. This meant that Whānau Hauā wanted to feel and be ‘Māori’, and to live their lives according to Māori values. As mentioned in previous chapters of this report, the need to be Māori was expressed as paramount by many of the interviewees, who expressed that they wanted access to Maturanga Māori, Te Reo Māori, to have rangatiratanga over themselves and their experiences, and to retain their mana in all aspects of their life:

It has to start with the attitude that we’ve all got to... we’ve all got our whakapapa and that’s the most important thing to me as a Māori. And then when it comes to getting support and assistance, recognising that I’m more than a label that somebody’s given me on that particular day. (Whānau Hauā)

Tino rangatiratanga was an aspect that was consistently mentioned as a core value as well as a core aspiration, especially articulated by young Māori with disability:

Our rangatahi who are kind of very passionate about, one, being Māori, because our older Māori didn’t have that as well. But, two, the feeling of tino rangatiratanga within our young is just alive and kicking. (Provider)

Tied to the aspiration of ‘being Māori’ and tino rangatiratanga, was the underlying framework of mana motuhake – this was expressed again as a notion of identity, and, moreover, as something that was hard to hold onto in a system that defined disability and subsequent needs in a very limiting way:

No matter whatever, we’ve all got mana and that should be the underlying principle to everything that happens. If it takes so long to build up mana and somebody who doesn’t know you flicks it away just like that because they’ve got their own agenda or they’ve got their own needs to meet. (Whānau Hauā)

But as a whānau, we ultimately want to be able to make the decision and we want to clearly know what korowai we can put around our boy to make sure his needs are met. Because when you start talking about personal care for people with a disability, that’s intimate stuff. Yeah, that’s tapu, that’s mana. (Whānau)

So, it just highlights the ability of parents... it actually came, you know, for me it’s the ability of parents to decide their own mana motuhake over their own children, even children who have disabilities. (Whānau Hauā)

The ability to access and utilise Te Reo was another aspiration that was expressed throughout the interviews, often within the context of the immense challenge that these whānau have had in having Reo Māori as their primary means of communication:

So our boy is right into Te Reo Māori. If it was up to him he would only speak kōrero Te Reo... He actually told us he wanted to go to the Kura, the Kura Kaupapa which is just down the road here. So he tells us on his machine 'I want to go to Kura. Well that couldn't happen.' The Speech Language Therapist advised us that the reality of this world is it is in English. There was a real breakdown. We couldn't deliver for him but that was his aspiration, he specifically asked for it. (Whānau)

It was important for me to bring our children up to reclaim our language. But at that point, when he was first diagnosed, we were strongly recommended to only hold one language. And so, right from the start it put me on the back foot when we were trying to reclaim Te Reo Māori... And so the system yet again was settling us into a pathway of going... using Western frameworks. (Whānau)

I would really want to see that there is some redress because of the past to actually help Māori, disabled Māori to have the ability to strengthen their ties with whānau, to have easier access to being able to speak Te Reo Māori. You know, I think that those things are just largely ignored and that's, I think because Māori generally, we are bicultural. You know, we are, because we have to be. But it also means that it gets covered over all the things that are missing or could be better. (Provider)

Aspiration was also articulated in the sense of being within Te Ao Māori, and showing that the Whānau Hauā community has a wealth and knowledge to offer:

We're wanting to show that this is a community that has a massive contribution to make to Māori development. That we're beyond the 'feel sorry for me, come and fix us.' Because we've had a very long history of that kind of approach. We're now saying to our communities, we've got some unbelievable skills among this community and you need their help, as opposed to the other way around. (Whānau Hauā)

Best Outcomes and Aspirational Frameworks

The notion of 'outcomes' was expressed in interviews in various ways. Firstly, it was looked at in light of aspirational thinking, in that Māori values-based aspirations lead to 'best outcomes' in lived experiences of Whānau Hauā. Secondly, outcomes came up as a topic when looking at models of best practice, and in regards to how best practice is measured.

Outcomes were also talked about in regards to frameworks— discussions around current inadequacies of 'Pākehā frameworks', or 'Western discourse' in regards to Māori and disability was reiterated across the range of interviewees:

I just feel that the organisations are all Pākehā-fied systems and they are not Māori – that is my strong belief. They don't know the tikanga, they don't know how to treat. As far as I am concerned it is totally different with Māori and Pākehā. (Whānau)

Frameworks that presented barriers for best outcomes were also seen as based on deficit – and much like the viewpoints around 'aspirations'- this provided a barrier for Whānau Hauā to live to their fullest potential:

We don't fit the current model of disability whether it's the administrative model, whether it's the charitable model, whether it's the medical model or the social model. All of them are deficit models. Whether it's deficit against the environment, or deficit with the individual. (Whānau Hauā)

Outcomes were thereby intrinsically tied to transcending beyond mainstream framework, using an aspirational and non-deficit lens. The need for a holistic, and Kaupapa Māori approach, was reiterated and contained within the examples provided during the interviews, which included Mason Durie's *Te Whare Tapa Whā, Enabling Good Lives*¹⁵⁵, and the Whānau Ora approach.

However, the positive thing is that there's a thing happening in the sector called systems transformation with enabling good lives principles which when you talk to Māori they go, oh, tino rangatiratanga. We've had it all this time, you know? We aren't calling it enabling good lives and we're not calling it systems transformation. That has the potential to make a huge difference to Māori. (Provider)

Whānau Ora, as a model of holistic, Māori value-centred and whānau-inclusive framework, was especially emphasised as having the potential to achieve outcomes, and to shift attention – by government, government agencies and providers – to work towards outcomes determined by and important to Māori with disability and their whānau.

The difference between Whānau Ora and a lot of service provisions of the Whānau Ora model is about outcomes based. So, it's not saying 'you must do three visits and two of this and seven of this'. It's actually saying if this is the outcome we agreed to, how do you work to get that outcome? Which is a very different way of government procuring services. I think it's good for whānau and can... and is good for providers in that it allows, it gives them the ability to think and work more widely and holistically. But it does make it harder for us bureaucrats in Wellington to really kind of, count things. (Crown Agency)

¹⁵⁵ The Ministry of Health aims to transform the disability support system using Enabling Good Life principles. It uses a co-design approach to change the support services based on what disabled people and their whānau want, piloted in MidCentral DHB. It is supposed to help people plan their goals, provide personal budget, improve and monitor outcomes for whānau, and refer them to other required service providers (Office for Disability Issues, 2017).

When you define tipping points so that things will change and they can't go back. So, I said that Whānau Ora is a tipping point for Māori. Well, I hope it is. And I hope that EGL [Enabling Good Lives] is the tipping point for disabled people. (Whānau Hauā)

The interviews also revealed other, less publically know frameworks, which have been based on working towards best Māori outcomes, and which are closely aligned with service provision, and the wealth of experience of Māori service providers. One example of such model, the 'Whāngai' model, targets the importance of whanaungatanga and manaakitanga:

The way I approach how we work here, we're almost like it's a whāngai situation. You know, when you come here the family are still really important. But we really are taking on the role of whāngai, you know, a whāngai organisation. And I think that that's not really understood and so [are] a lot of the policies that support good safe care of Māori. (Provider)

For many of the participants in this project – and while there was a multitude of unmet needs, and deeply felt trauma around those needs – the message behind aspirations was also a message of hope. Hope that by working with some of these intrinsic Māori models, by receiving adequate funding, and by having their voices heard, Whānau Hauā would be able to achieve what they, and their whānau, envision for themselves.

Conclusion

The focus of this report was to capture and collect the stories and ‘lived experiences’ of whānau with disability services in Aotearoa New Zealand. It was also intended to explore expert and provider views on the provision of disability services and their effectiveness for the health and wellbeing of Māori with disabilities. The project - while including a contextualising historical review - was scoped in response to a lack of adequate data around Māori and disabilities. This has created an opportunity for new and unheard voices to emerge, and to analyse these within the wider context of the developments and history of the provision of health services by the Crown.

The historical review in section one of this report provided a context that highlighted how the roots of present inequities in Māori experiences of disability services in Aotearoa can be found in nearly two centuries of state health and welfare policies. This discussion of the historical context of disability services draws attention to the failure of state and voluntary agencies in the past to address the specific needs faced by Whānau Hauā, which has helped to explain current disparities, and which can be traced back to racial policies that underlay approaches to addressing Māori health and social issues. The colonial state’s commitment to policies of racial amalgamation, assimilation and integration meant that social policies, including policies towards Whānau Hauā, were based on the belief that ‘raising Māori up’ to accept Western ideas about health and wellness was the key to improving outcomes. As the review shows, it was not until the late twentieth century that the validity of approaches to identity, health, and disability centred in Te Ao Māori began to be appreciated by state agencies.

From the interviews analysed in section two of this report, a clear picture has emerged around the challenges and barriers that were encountered by Whānau Hauā in their everyday lives, and the gaps that were perceived not just by them, but their wider whānau and Māori service providers. In many ways the stories of whānau negotiating their way through what often looks like a minefield of systems, services and funding provisions, echoes some of what the historical review highlights. The imperative conclusions that can be drawn from this analysis sit alongside the ongoing debates around inequity, disparities and best practice for how the health sector as a whole addresses Māori needs, and the pressing urgency around providing an inclusive Māori health system.

Rewiring systems, services and funding mechanisms

Many of the issues raised around inequalities in the system, lack of participation and inclusion, gaps in services and support, differential treatment, and discrimination and racism weren’t new issues ‘per se’, in regards to Māori experiences of the wider health system, and perhaps reflects the progress that the Crown is yet to make in this area.

Furthermore, Whānau Hauā also spoke of the limited options in the kinds and types of services available, particularly the lack of culturally responsive and Kaupapa Māori services and support. Kaupapa Māori social, health and advocacy services have for many decades filled the gap left by mainstream services by providing vital advocacy and navigation services, culturally responsive support, and pathways for Whānau Hauā to connect with, and confidently and proudly participate in, Te Ao Māori. Yet these same service providers spoke of the challenge of delivering best practice, kaupapa Māori services, based on systemic barriers which included inadequate and insufficient funding from Crown funding allocations and mechanisms, restrictive contracting and misunderstanding of “kaupapa Māori services” by Crown agencies, as well as an under-developed and under-paid workforce.

While it was not within the scope of this report to undertake a comparative analysis of the experiences of Māori versus Pākehā with disabilities, the statistical data that was surveyed does capture some indicators of disparities in disability service and outcomes between Māori and non-Māori. The interviews further revealed that Whānau Hauā and their whānau felt that they were “treated differently”. Interview participants shared story after story about the daily challenges and barriers they faced, including being let down by mainstream disability services, the racism and discrimination they encountered, the daily physical, mental and emotional struggle and stress of caring for disabled whānau with limited or no government support, whānau members’ lives being turned upside down or put on hold, and in the most desperate of whānau situations, thoughts of suicide or premature death.

The stress that was experienced by Whānau Hauā and whānau around inadequate or inaccessible funding was a strong indicator that while the Crown has delineated lines of disability funding, for all whānau that participated in these interviews it was simply not enough to provide for appropriate care. The reality of already being on the poverty line that is dis-proportionally experienced by Māori throughout New Zealand¹⁵⁶ has a significant compounding effect when Māori are also living with disabilities.

Funding mechanisms were obtuse to many whānau, who had no help in understanding or accessing entitlements, and who were often excluded from funding based on criteria of disability. Restrictions and criteria placed on current service provision resulted in the exclusion of a range of disabilities and discounted a large range of Māori experiences. These restrictions were based on inappropriate and outdated definitions of disability that urgently need to be addressed. Furthermore, inequities in funding and service provision between those Whānau Hāua who were under the auspice of the Ministry of Health, as opposed to the Accident Compensation Corporation, impacted on whānau wellbeing in significant ways.

¹⁵⁶ Ministry of Social Development (2017). Household incomes in New Zealand: Trends in indicators of inequality and hardship 1982 to 2016. Prepared by Bryan Perry, Wellington, July 2017.

One commonly cited barrier was also that whānau were prevented from being paid to care for a disabled family member. There were no systemic mechanisms that supported Whānau Hauā in these situations, which again highlighted that within most mainstream approaches, Whānau Hauā were treated as individuals, rather than as part of a whānau system. Initiatives based on a Māori models of health and wellbeing that were being adopted by the Crown in certain areas, such as Whānau Ora, were seen as having significant potential to address these gaps, and interview participants were impatient to see more commitment by the Crown to develop policies and practices for disabled Māori based on holistic, Māori frameworks and conceptualisations of disability based in Te Ao Māori. Furthermore, providers that were already using holistic, whānau-centred frameworks that were based on achieving outcomes determined by whānau, were seen as needing more invested and considered support from the Crown.

Sovereignty and identity

Whānau Hauā spoke of the limited opportunities they had to contribute effectively and strategically to the types, and ways, disability services and supports are delivered in New Zealand, and decisions about their treatment and care. They spoke that in the wider picture, Crown legislation and practices did not consider or allow for a representational model that ensured Whānau Hauā were not only better supported to participate on platforms where they could make meaningful contributions, but that the diversity within the Māori disability community was recognised and acknowledged by the Crown.

Issues around identity were strongly tied into the notion of participation, in that all interviews highlighted the need for diverse voices to be in charge of how they self-identified, and what this meant in terms of the service and support provision they, themselves, determined. Decision-making around care was tied in with tino rangatiratanga and mana, which are concepts that need to be supported in future Governmental directions around service provision for Whānau Hauā. For the interviewees they always considered themselves Māori first and foremost, something that was often unable to be accommodated within mainstream services.

At a broader level, Whānau Hauā wanted sovereignty and autonomy in deciding what systems, supports and services worked best for them. This included having well-funded and resourced whānau, hapū, iwi and kaupapa Māori/Whānau Ora based systems, supports and services, as well as access to rongoa (traditional medicines).

The Treaty of Waitangi and disability

In the area of policy, the Principles of the Treaty of Waitangi¹⁵⁷ have gained increasing recognition in health and disability policy over the years, an example of this being the Mental Health Foundation

¹⁵⁷ According to Cochrane (2005), the Principles of the Treaty of Waitangi were partly an attempt to reconcile the different Te Reo Māori and English language versions of the [Treaty of Waitangi](#), and allow the application of the Treaty to a contemporary context. Principles include: The Kawanatanga Principle – The Principle of Government;

(MHF) who incorporated the Māori version of the treaty into its practice frameworks and the New Zealand Public Health and Disability Act 2000, which acknowledges Treaty principles.

While this move towards inclusion in a policy space is timely, the stories of the interviewees for this research project highlight that the ‘lived experience’ of Māori with disability is still a long way off true fulfilment of Treaty principles. In terms of the articles and principles of the Treaty, partnership, participation, sovereignty, autonomy, and equality are rights guaranteed to Whānau Hauā under the Treaty of Waitangi. However, many of the themes identified in this report appear contrary to the articles or principles. Lack of representation, participation and inclusion in the design, and types, of services and supports, as well as discrimination and racism were all prevalent themes throughout this report.

For Hickey (2008), sovereignty, autonomy, and equality are rights guaranteed to Whānau Hauā under the Treaty of Waitangi. This includes Article one, which guarantees Māori their right to their own tribal sovereignty, and is “the key issue for Māori with disabilities who can argue the same rights as Māori without disabilities”.

The Māori text of article two of the Treaty of Waitangi gives Māori their full sovereignty and chieftainship rights over their land, villages, property and treasures, which is consistent with article one, however, Māori with disabilities “clearly do not have autonomy or sovereignty of services, are not given broad inclusion throughout their tribal groups and do not have the ability to self-determine their needs in their own way”.¹⁵⁸

Article three promised Māori the full protection of the Crown, however, for Māori with disabilities, if articles one and two are not being complied with then article three may be compromised. Furthermore, Hickey (2008) also includes Article four, which gives Māori the right to practise *rongoa*, traditional spiritual practices, and exercise their customary law in areas impacting on them.

For the Treaty to provide a robust protective mechanism for Māori with disabilities, consideration also has to be given to how the full effect of other, international protection mechanisms, such as the Convention on the rights of Persons with Disability (CRPD) and the United Nations Declaration on the Rights of Indigenous Peoples (UNDRIP), can work in partnership with Treaty principles to allow for best outcomes for Whānau Hauā.

The Rangatiratanga Principle – The Principle of Self-Management; The Principle of Equality; The Principle of Cooperation; and The Principle of Redress. Further details can be found at the following link:

<https://www.waitangitribunal.govt.nz/treaty-of-waitangi/principles-of-the-treaty/>

¹⁵⁸ Hickey, S. J. (2008). *The Unmet Legal, Social and Cultural Needs of Māori with Disabilities* (Thesis, The University of Waikato). Retrieved from <https://researchcommons.waikato.ac.nz/handle/10289/2571>

Towards the future – ‘He waka eke noa’

For Whānau Hauā, and despite the barriers they spoke about, optimism remained in the stories and voices of the people and families were interviewed. The whakatauki ‘he waka eke noa (we are all in this together without exception)’ encapsulates the many stories of resilience, inspiration and strength that were shared by whānau. That is, whānau, whanaungatanga, whakapapa, aroha, mana and (mana)akitanga remained a source of hope, happiness and light during the dark times.

While the main focus of this report was to share the stories of Whānau Hauā, this project also afforded a rare opportunity to gather from interview participants some of the latest thought leadership, issues, challenges and concerns. In this sense, this report could be viewed as an update of the current state of affairs for Māori in the New Zealand disabilities sector. There was a definite sense of frustration that was expressed by Whānau Hauā - and providers and experts working in the disability field - about the inadequacies and confusing data around Māori and disability. The current monitoring and data collection activities by the Crown were seen to be inefficient, and as contributing to gaps and failures in identifying and addressing any disparities in disability services and outcomes for Māori. Apart from the lack of lived experience and whānau voices within current data, there was also a vast wealth of knowledge and best-practice examples used by Māori providers ‘on the ground’ that was not being captured, yet collecting this information would enable the Crown to make more informed decisions around policies and practices that concerned Māori with disabilities.

Certainly one of the key findings from this report would be the need for the development of a specific research agenda for Whānau Hauā and the disabilities sector, and it is hoped that this report will provide another platform for future discussions, and a platform to truly start listening to the many voices of all Māori whose lives have been affected by disabilities.

Appendix 1

Māori and Disability – A Quantitative Snapshot

This appendix provides a scan of current available quantitative data, which was considered as part of the thematic analysis of the primary data.

Disability and Its Prevalence

In the 2013 Disability Survey, disability is defined as long-term limitation (resulting from impairment) in a person’s ability to carry out daily activities: ‘A disabled person is someone with an impairment that has a long-term, limiting effect on their ability to carry out day-to-day activities. “Long-term” is defined as six months or longer. “Limiting effect” means a restriction or lack of ability to perform.’ Figure 1 below shows that the 2013 Disability Survey identified 24% of all New Zealanders and 26% of Māori were disabled. Table 1 below shows that the all age prevalence of disability varied between ethnic groups. Māori (26%) and Other ethnic groups (28%) had a highest all age prevalence rates of disabled people in their ethnic populations. Other findings from 2013 Disability Survey showed that in general, Māori are more likely to be disabled (26%) than non-Māori (24%), and Māori children are also more likely to be disabled (15%) in comparison with non-Māori children (9%).

Figure 1: Prevalence of disability in NZ, Source: (Statistics NZ, 2013)

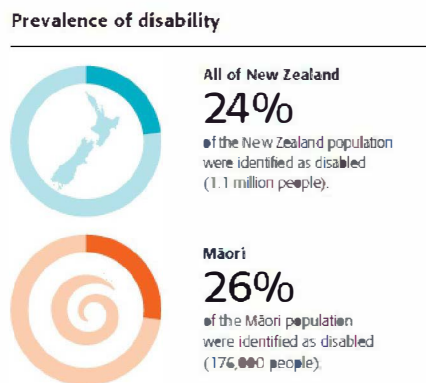


Table 1: Disability prevalence by ethnicity, for all age groups, Source: (Office for Disability Issues, 2016)

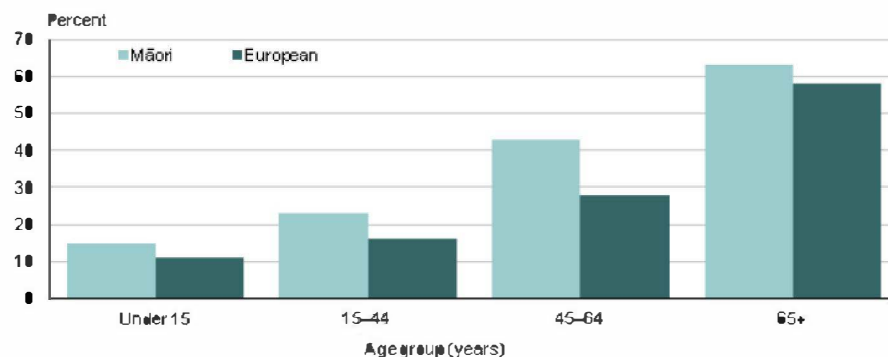
	Māori	European	Pacific	Asian	Other
Disability prevalence	26%	25%	19%	13%	28%

A study in 2017 found that socio-economic status of Māori and their health condition can predict post-injury disability. With 49% of Māori experiencing significant disability three months after injury.¹⁵⁹

As mentioned in the previous chapters, health inequalities have been seen between the Māori and non-Māori population for a long time.¹⁶⁰ Disability is one of the indicators of this inequality, for instance, Māori men aged 65 or above were almost 1.3 times more likely to be disabled than non-Māori.¹⁶¹

Furthermore, disability is more common among the younger Māori population, as more than half of all disabled Māori are aged under 45 years.¹⁶² On the other hand, looking at the disability rate in each age groups reveals more details. Figure 2 compares disability percentages between Māori and European in each age group. It indicates higher prevalence of disability among Māori than European in each age groups. It can be seen that the percentage of disability increases by age. Similarly, total disability rate is increasing, for instance from 16% for the 15–44-year-old age group to 59% for the 65 years and older age group (Auckland District Health Board, 2017; Statistics New Zealand, 2013).

Figure 2: Disability for Māori and European, by age groups, (Source: Statistics New Zealand, 2013)



The prevalence of disability in each region is shown in Figure 3. It can be seen that Auckland has the lowest prevalence with 19% of people in Auckland disabled (in 2013), while Taranaki has the highest with 30% of people in Taranaki are disabled).¹⁶³

¹⁵⁹ Wyeth, Samaranayaka, Davie, & Derrett, 2017

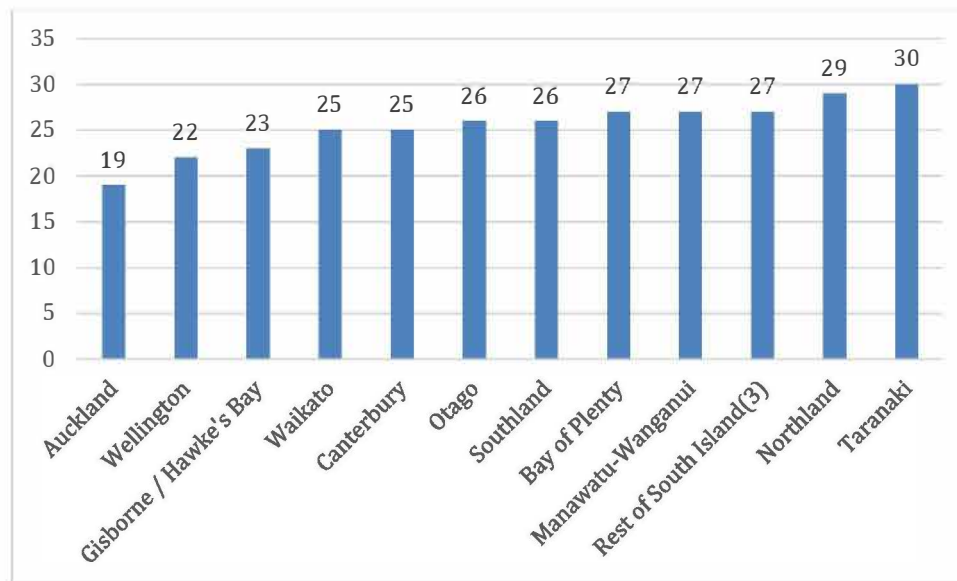
¹⁶⁰ Ajwani S, 2003; Reid P, 2007; Ministry of Health; University of Otago, 2006

¹⁶¹ Statistics New Zealand (NZ), 2013

¹⁶² Statistics NZ, 2013

¹⁶³ 'The distribution of MOH clients for disability services is skewed towards high-deprivation deciles. Māori and Pacific are over-represented in high-deprivation deciles, with 44% of Māori and 53% of Pacific clients in deciles 9 or 10. Asian and European clients are fairly evenly spread across all deprivation deciles.' Ministry of Health. 2015. Demographic Information of Clients Using the Ministry of Health's Disability Support Services as at September 2013. Wellington: Ministry of Health. Published in April 2015

Figure 3: Disability prevalence (%) by region, for people in private households, Source: (Statistics NZ, 2013)



The most common forms of disability for adults were limitations in physical activities and for children was difficulty in learning. The table below shows a broader categorisation of the impairment rates by ethnicity. The percentage is calculated based on the total population in each ethnic group with specific impairment type. It shows no significant difference among ethnicities in terms of their most common impairment types. However, we need to consider the population of each ethnic group as well.

Table 2: impairment rate¹⁶⁴ (broad), percentage¹⁶⁵, by ethnicity, Source: Disability Survey, 2013

	Total population	European	Māori	Pacific peoples	Asian	Other (MELAA ¹⁶⁶ and Other)
Sensory ¹⁶⁷	11	12	11	7	5	14
Physical ¹⁶⁸	14	15	13	10	7	15
Intellectual	2	2	3	3	1	5
Psychiatric/psychological	5	6	7	5	3	8
Other ¹⁶⁹	8	8	11	8	4	8
Total	24	25	26	19	13	28

In a more detailed categorisation (Table 3) the top three impairment types for adults were: mobility impairment, hearing impairment and agility impairment.¹⁷⁰ Similarly, most Māori with disability had mobility impairment (12%), hearing impairment (8%), or any of agility, psychiatric/psychological, or learning impairments (7% each).

¹⁶⁴ Any individual may appear in more than one impairment type

¹⁶⁵ The percentage of the total population, in each sex and ethnic group, who had the specified impairment type.

¹⁶⁶ MELAA refers to Middle Eastern/Latin American/African

¹⁶⁷ 'Sensory' includes both hearing and vision impairments.

¹⁶⁸ 'Physical' includes both mobility and agility impairments.

¹⁶⁹ 'Other' includes impaired speaking, learning, and developmental delay for children aged 0–14 years, and includes impaired speaking, learning, and remembering for adults aged 15+ years.

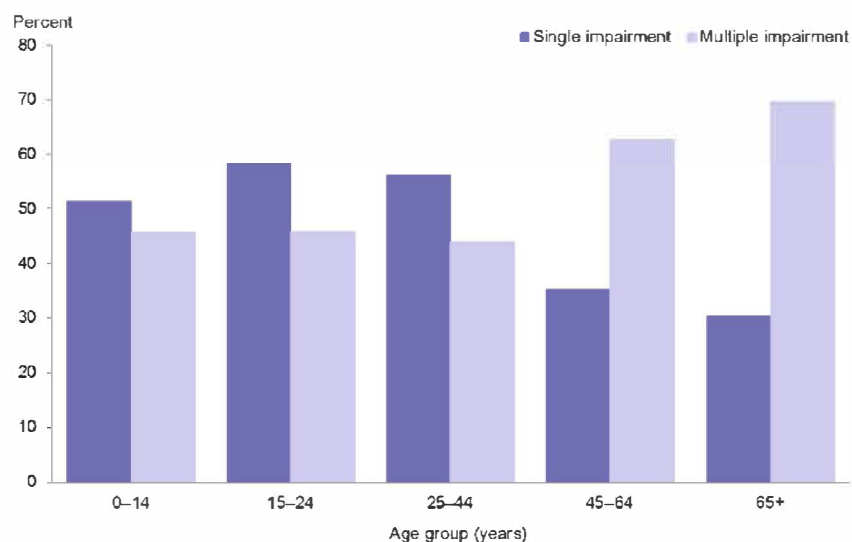
¹⁷⁰ Ministry of Health, 2018

Table 3: Impairment type, percentage of all adults and Māori, Source: the Disability Survey, 2013

Detailed impairment type ¹⁷¹	% of all adults	% of Māori
Hearing	10	8
Seeing	5	5
Mobility	16	12
Agility	9	7
Intellectual	2	3
Psychiatric/psychological	6	7
Speaking	3	5
Learning	5	7
Memory	5	4
Total	27	26

Figure 4 below shows how Māori experience single or multiple impairments and how it changes by age. Single impairment is more common for younger groups (under 45 years of age), while the rate of multiple impairment to single impairment increases significantly after 45 years of age.

Figure 4: Māori experience of single and multiple impairments, by age group, Source: (Ministry of Health, 2018)

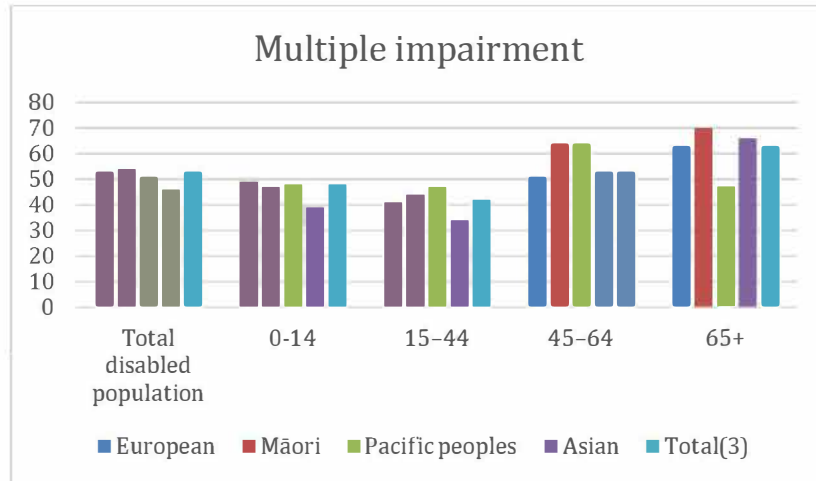


In general, most disabled people (53%) had multiple impairments, according to the Disability Survey in 2013 (Figure 5 below). The percentage of people with multiple impairments does not differ significantly

¹⁷¹ Any individual may appear in more than one detailed impairment type, and they were counted in each group of impairment type. Therefore, the total number showed in the table is not the sum of rows above.

by ethnicity, but disabled Māori aged 45 years and over might need more support, as more than 60% of them had multiple impairments.

Figure 5: Disabled population with multiple impairments, percentage, by ethnicity, by age group, Source: derived from Disability Survey, 2013



The disability surveys in 2013 and 2006 provide comparable data for ethnic groups, however previous surveys provide only Māori versus non-Māori data. Therefore, to provide glimpse of trends for number of disabled people in each ethnic group, Figure 6 is derived from the survey data in 2006 and 2013. Moreover, Figure 7 shows the how percentage of disabled Māori has increased from 1996 to 2013.

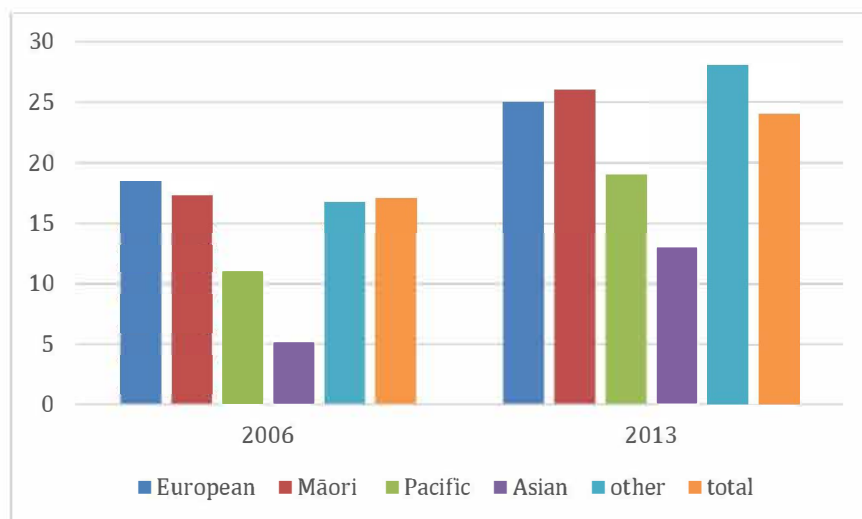


Figure 6: Comparing percentage of disability in each ethnic group between 2006 and 2013, Source: derived from Disability Surveys in 2006 and 2013

As can be seen in Figure 6, there was a slight difference between the percentage of Māori and European groups in these two years. In general, the total rate of disability has increased by 7% from 2006 to 2013.

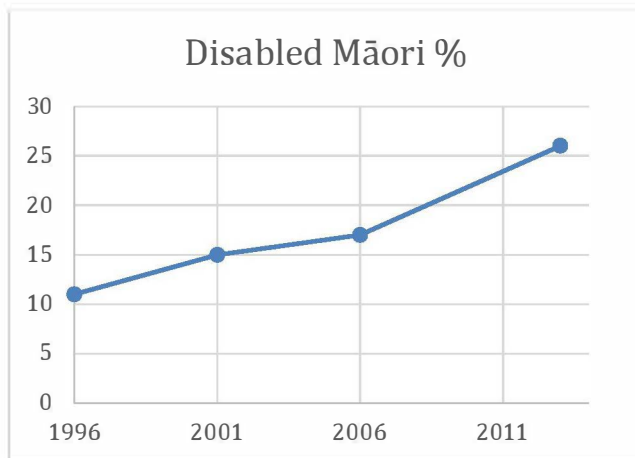


Figure 7: Disabled Māori (rate) from 1996 to 2013, Source: derived from Disability Surveys in 1996, 2001, 2006, & 2013

The number of Māori people who use Disability Support Services funded by Ministry of Health (MoH) is increasing; it was 5,030 (16.2 % of the total DSS clients) in 2013 and then it increased to 5,920 (17.5% of the total DSS clients) in 2016.¹⁷² Therefore, considering the absolute number of Māori who used this service, there is an 18% increase from 2013 to 2016.¹⁷³ Supported Living is a service by MoH to enable disabled people (aged over 17 years) to live independently by receiving the support they need (Ministry of Health, 2016). This service has also indicated an increase in the number of Māori accessing this service from 2014 to 2016. The number of Māori disabled using this service was 372 (out of 2797) in 2013 that increased to 512 (out of 3,438 of total clients) in 2016.

Employment and Education for Disabled People

Disability affects the likelihood of Māori being employed, according to the Disability Survey in 2013. The data showed that 44% of disabled Māori were employed in comparison with 68% of non-disabled Māori.¹⁷⁴ Accordingly, the unemployment rate is higher for disabled people. In 2017, the unemployment rate was 11.4% for disabled people comparing to 4.5% for non-disabled people. We note that the unemployment rate for disabled people has increased from 2013 to 2017 (from 9% to 11.4%). It is highly

¹⁷² Ministry of Health. 2017. Demographic Report on Clients Allocated the Ministry of Health's Disability Support Services as at September 2016; and Ministry of Health. 2015. Demographic Information of Clients Using the Ministry of Health's Disability Support Services as at September 2013.

¹⁷³ Ministry of Health, (2018). *Whāia Te Ao Mārama 2018-2022: The Māori Disability Action Plan*. Wellington: Ministry of Health.

¹⁷⁴ Office for Disability Issues, 2016

likely that the unemployment for Māori with a disability has also increased over that same period. The table below compares the unemployment rate between Māori and total population in 2013.

Table 4: Source: Disability Survey 2013

	Māori		All adults	
	Disabled	Non-disabled	Disabled	Non-disabled
Unemployment rate	17%	11%	9%	5%

Almost two-thirds of disabled people earn less than \$30,000, which increases the probability of having worst socio-economic outcomes. For instance, 25% of disabled Māori described the unaffordability of everyday expenses compared to 8% of non-disabled Māori.¹⁷⁵ Around 40% of disabled Māori live in the most socio-economically deprived areas. In 2016, about 60,000 people received a health and disability benefit (which accounts for an increase of \$5.5 billion from 2000).¹⁷⁶

Table 5: Total personal income of disabled and non-disabled people living in private households, Source: (Office for Disability Issues, 2016)

Income range	Disabled people	Non-disabled people
Total personal income in the last 12 months of \$30,000 or less	64%	45%
Total personal income in the last 12 months months of \$70,000+	8%	17%

Lower qualifications are more likely to be seen among disabled than non-disabled. People who had no qualification were more likely to be disabled (33%) compared to non-disabled (15%). Similarly, the rate of those with no qualification was 41% among Māori who were disabled compared to 24% of Māori who were non-disabled. Therefore, Māori health is affected by disability as not only do they have higher rates of disability, they are also more likely to have no qualifications and be unemployed, which adversely impacts on their social (whānau) health and socio-economic circumstances which directly impacts on their overall health and wellbeing. This has been reflected in how people rated their health status in the 2013 Disability Survey where disabled Māori were more than five times more likely to rate themselves as having fair or poor health status than non-disabled Māori.

¹⁷⁵ Office for Disability Issues, 2016

¹⁷⁶ Office for Disability Issues, 2017

Social Connectedness

Among disabled Māori who responded to the 2013 Disability Survey, 25% said they did not have enough contact with non-resident friends (someone who was living in another household) during the last four weeks. This satisfaction level was less than non-disabled Māori (23% of non-disabled Māori felt they did not have enough contact). Generally, disabled Māori were slightly less likely to have had contact with family and friends in the last four weeks than non-disabled Māori (Statistics New Zealand, 2015).

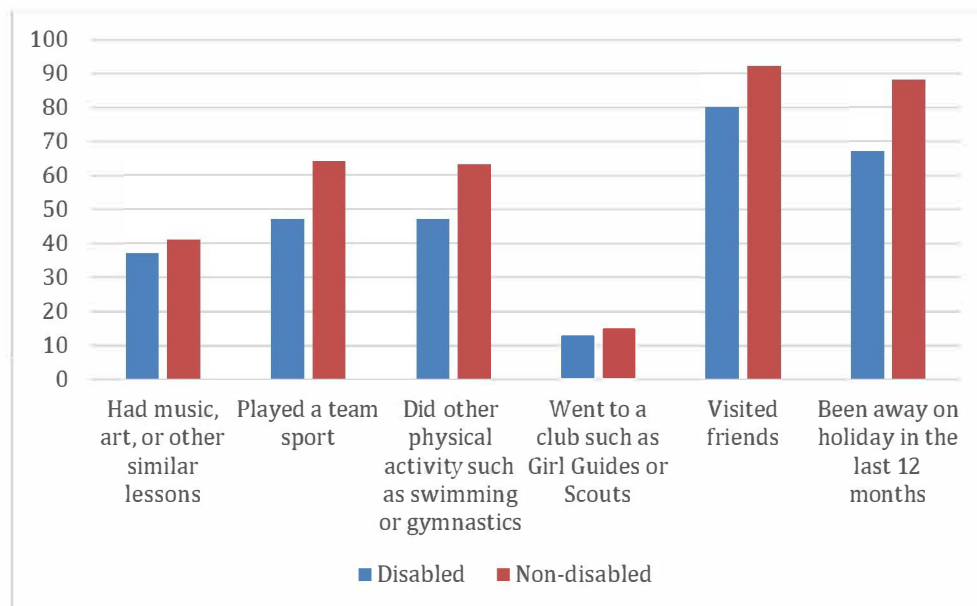
Moreover, disabled Māori were more likely to feel lonely in the last four weeks. Almost 41% of disabled Māori said that they had at least an occasional feeling of loneliness, compared to 30% of non-disabled Māori.

Another factor that describes social connections in the disability survey was leisure activities. Disabled Māori children were less likely than non-disabled Māori children to participate in leisure activities such as art lessons, physical activity, been to a clubs (such as Girl Guides or scouts), and/or had been away on holiday (Table 6 & Figure 8). For Māori children (aged 5–14) the biggest gap between disabled and non-disabled was in holidays, team sport and other physical activities.

Table 6: Māori children (aged 5-14) participation in leisure activities, 2013, Source: Disability Survey

Leisure activities	Disabled	Non-disabled
Had music, art, or other similar lessons	37	41
Played a team sport	47	64
Did other physical activity such as swimming or gymnastics	47	63
Went to a club such as Girl Guides or Scouts	13	15
Went out with family or friends	93	97
Visited friends	80	92
Been away on holiday in the last 12 months	67	88

Figure 8: Māori children (aged 5–14) participation in leisure activities, 2013, Source: Disability Survey

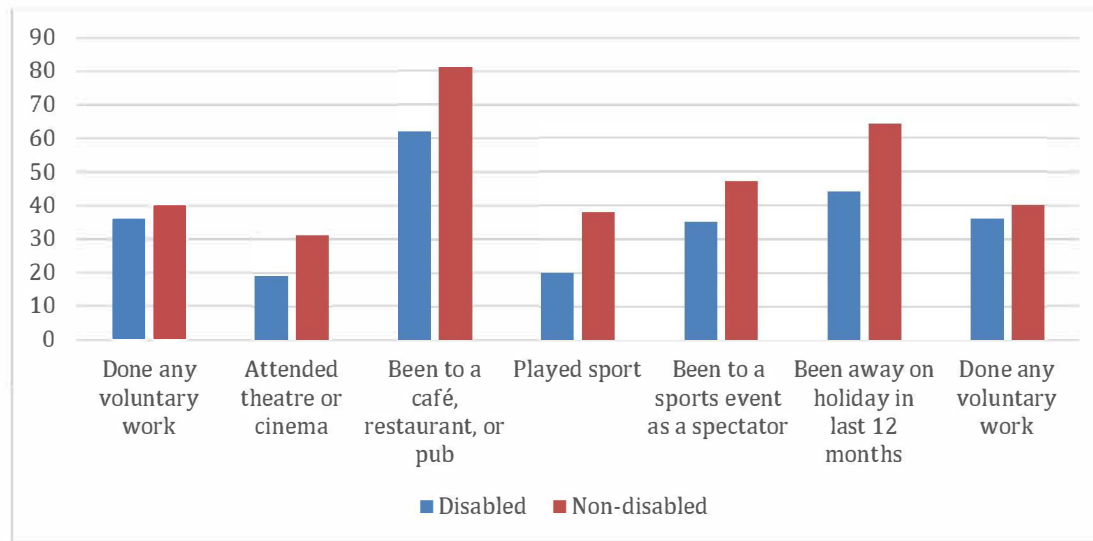


For Māori adults with disability, the biggest difference in leisure activities, compared to non-disabled Māori, was going on holidays, going to a café or restaurant, or pub and playing sport (see Table 7 and Figure 9).

Table 7: Māori adults (aged 15+) participation in leisure activities, percent, 2013

Leisure activities	Disabled	Non-disabled
Done any voluntary work	36	40
Attended theatre or cinema	19	31
Been to a café, restaurant, or pub	62	81
Played sport	20	38
Been to a sports event as a spectator	35	47
Been away on holiday in last 12 months	44	64
Done any voluntary work	36	40

Figure 9: Māori adults (aged 15+) participation in leisure activities, percent, 2013



Responding to Inequity

The leading cause of disability in the 2013 survey was disease for adults (42%) and a birth condition for children (49%) (Statistics NZ, 2013). Hospitalisation is also more likely to cause disability for Māori than non-Māori (Hickey & Wilson, 2017). For disabled Māori, the most common cause of impairment was also disease or illness (40%) (Table 8).¹⁷⁷ This raises questions around the response of the health system and healthcare professionals towards Māori with disabilities.

Table 8: Causes of impairment, percentage of total disabled population and disabled Māori, Source: the Disability Survey, 2013

Cause of impairment ¹⁷⁸	Total disabled population	Disabled Māori
Disease or illness	41	40
Accident or injury	31	28
Existed at birth	14	24
Ageing	28	18
Other	24	28
Total	100	100

¹⁷⁷ There are distinct issues of concern for older Māori. Māori experience an earlier onset of age-related disease and impairment. For example, Māori women aged 45 years and over have a significantly higher rate of impairment caused by disease/illness than non-Māori, similar to the profile expected for the non-Māori 65 and over age group. Ministry of Health. 2004. *Living with Disability in New Zealand*. Wellington: Ministry of Health.

¹⁷⁸ Any individual may appear in more than one cause of impairment. The percentage of adults with a specific cause of impairment has been calculated out of those who specified a cause of impairment.

Among the total disabled population, Māori adults aged 15-64 were around 9% more likely to have an unmet need to see a health professional than their non-Māori peers (Hickey & Wilson, 2017). The New Zealand Convention Coalition Monitoring Group reported that their qualitative data indicated concerns of disabled people about accessing health services and also the negative attitudes of health professionals (Office for Disability Issues , 2016). Lack of autonomy, discrimination and inequality were other themes coming out of their reports. Disabled people experienced difficulty in accessing health services such as not having alternative formats to read information, or inaccessible vehicles, for example, for mobile breast screening. They also mentioned that they received fragmented rehabilitation services from Ministry of Health, ACC and District Health Boards.

Appendix 2

Wai 2575 Interview Schedule

Whānau Hauā

1. What disability services are you currently using?
 - a. *Do you like the current services you are using?*
 - b. *Do you have any particular goals or aspirations?*
 - c. *Why did you choose those services?*
 - d. *What has been your overall experience with the current services?*
 - e. *Do you feel your current services are meeting your needs and supporting your aspirations?*

2. What have been your experiences of disability services in New Zealand?
 - a. *What services have you used in the past?*
 - b. *What were your experiences with those services?*
 - c. *What have been the main challenges and barriers in terms of getting the right services and supports?*

3. What do you think could help improve the health system and services for your whānau?
Explore: *particularly in terms of access and responsiveness of services?*

4. Is there anything else you would like to add?

Whānau

1. What disability services is your whānau currently using?
 - a. *Do you like these current services? Please explain.*
 - b. *Do you and your whānau have any particular goals or aspirations?*
 - c. *Why did your whānau choose these services?*
 - d. *What has been the overall experience for your whānau when using the current services?*
 - e. *Do you feel your current services are meeting your whānau needs and supporting your aspirations?*

2. What have been your experiences of disability services in New Zealand?
 - a. *What services have your whānau used in the past?*
 - b. *What were your experiences with those services?*
 - c. *What have been the main challenges and barriers in terms of getting the right services and supports?*

3. What do you think could help improve the health system and services for your whānau?
Explore: *Particularly in terms of access and responsiveness of services?*

4. Is there anything else you would like to add?

Disability Experts/Government/Services

1. What is the current state of the health system and disability services for Whānau Hauā?
 - a. *How responsive has the health system and disability services been for Whānau Hauā?*
 - b. *Are they meeting the needs of Whānau Hauā and/or achieving equitable outcomes?*

2. What are some of the factors (i.e. social, cultural, historical and systemic) that have contributed to the current state of disability services for Māori in New Zealand? What do you believe to be the main challenges and barriers for Whānau Hauā? How have these factors informed the design, delivery and commissioning of Whānau Hauā services
Explore: *for example, social factors may include attitudes, perceptions; cultural factors may include worldview (western vs. Māori/indigenous world views); historical may include the impacts of colonisation; political may include representation; systemic may include policy/regulation.*

3. What particular strategies, paradigms and models, have historically and/or currently, inform the design, development, delivery and implementation of the New Zealand health system and disability services for Māori?
Explore: *For example, Western (i.e. clinical models) vs Māori/indigenous models (i.e. Te Whare Tapa whā/Whānau Ora); any strategy documents (particularly those that make reference to the Treaty)?*

4. What do you think will help improve the overall health system and services for Whānau Hauā, particularly in terms of improving access and the responsiveness of services for Whānau Hauā, or achieving equitable outcomes?
Explore: *Where are the gaps? What are the barriers? What systemic changes need to happen that will improve access and responsiveness of services? What systems do we need in place to ensure equitable outcomes for Whānau Hauā? Do they know of any promising research, innovations, approaches, models? Can they provide any examples of services that are achieving good outcomes for Whānau Hauā?*

5. Is there anything else you would like to add?

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